THE UNIVERSITY OF BRITISH COLUMBIA

8th International Conference on Fetal Alcohol Spectrum Disorder

Research, Results and Relevance

Integrating Research, Policy and Promising Practice Around the World

March 6–9, 2019

The Westin Bayshore
Vancouver, BC, Canada

SYLLABUS

Presented by

THE UNIVERSITY OF BRITISH COLUMBIA
Interprofessional
Continuing
Education

8th International Conference on Fetal Alcohol Spectrum Disorder 2019

Fetal Alcohol Spectrum Disorder Research, Results and Relevance

Integrating Research, Policy and Promising Practice Around the World

THURSDAY, MARCH 7

CONCURRENT SESSION A

CONCURRENT SESSION B

FRIDAY, MARCH 8

CONCURRENT SESSION C

CONCURRENT SESSION D

SATURDAY, MARCH 9

CONCURRENT SESSION E

POSTER ABSTRACTS

Description

This advanced level conference/meeting continues to bring together global experts from multiple disciplines to share international research. From the pure science, to prevention, diagnosis and intervention across the lifespan, the conference will address the implications of this research and promote scientific/community collaboration. It provides an opportunity to enhance understanding of the relationships between knowledge and research and critical actions related to FASD. First held in 1987, the conference brings together people passionate about this work in a stimulating environment where they can learn and forge new partnerships.

Conference Objectives

During FASD 2019, participants can expect to:

- consider the implication and potential application of emerging evidence-based, and cutting edge research
- expand and challenge their knowledge and understanding of hard science
- explore different models of advanced practice from and across disciplines
- engage in knowledge exchange and focused dialogue through formal sessions, networking and onsite meetings
- develop connections and partnerships among global researchers, networks, governments, communities, service providers and families

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Tribute to Dr. Geoffrey Robinson:

"Our start in life has a profound and permanent effect on our final outcome!"

Tribute originally written by Dr. Robert Armstrong, 2001 & 2006, revised and expanded by:
Dr. Christine Loock, 2007, UBC Pediatrics, Vancouver, BC, Canada

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What Dr. Geoff Robinson did in a career that spanned over **half a century** was to transform the way we think of children and the role of the family, and their collective experience with the health care system. A few of us may still remember a <u>**not so**</u> "child and family friendly" health care system that separated the child from their family throughout their hospital encounter. Not until Geoff's work as one of Canada's first "population health" pioneers were services (much less words) like **"care by parent"** and **"daycare surgery"** ever invented.

Without his vision to take the lead and organize our 1st Fetal Alcohol Syndrome conference on FAS prevention in **October 1988**, held in Vancouver, we all would not be here today. Our own **BC FAS Resource Group (**also founded by Geoff) included Joanne Weinberg, Kwadwo Asante, Bob Armstrong, Dana Brynelsen, Basil Boulton, Heather Clarke, Bob and Julie Conry, Christine Loock, Art Steinmann, and Marilyn Van Bibber, who with international experts including Sterling Clarren, Ragnar Olegard, Bob Sokol, and Ann Streissguth, have continued to advance the FAS field to where we are today. It certainly marked the turning point in my career, with a new found focus on FASD prevention, and I am personally indebted to each of them, along with Geoff, for their vision, collegiality and mentorship.

Brief Biography: *"Geoff was a great communicator and a great teacher, but always listened to the opinions of others. As a result we all felt that his achievements were ours as well. He was an intellectual giant, with a warm inner side*."
– **Dr. Jim Jan, MD, FRCPC, UBC Professor Emeritus**

Geoff Robinson was one of those rare physicians of the 20th century actually born in British Columbia. He did his undergraduate training at the University of British Columbia, received his M.D. from Queen's University in Kingston, Ontario, and pediatric training at the Hospital for Sick Children in Toronto. He did continued training in the United States at the famous Harriett Lane Hospital at Johns Hopkins in Baltimore and subsequently in Boston at the Harvard teaching hospitals. These were very formative years and laid the groundwork for many of his major contributions. In 1954, Dr. John McCreary, founder of UBC Pediatrics, invited him to join the medical faculty in Vancouver. From 1954 to 1970 he served as the Paediatric Outpatient Department Medical Director at the Vancouver General Hospital, from 1970 to 1976 as Medical Director of the Diagnostic Centre for Children, and from 1976 to "retirement" in 1986 as the Head of UBC Division of Population Paediatrics.

He always had tremendous insight into <u>what was wrong</u>, and <u>what was possible</u>. He combined this with a scientific approach to study the problem and a sharpened capacity to convince others that the evidence pointed to the need for change, and that <u>they had better change!</u> And if you wanted to change something, he stressed that you had to get to know, engage and mentor the decision makers in Ottawa and Victoria to guide them into making the **right decisions**!

Academic Awards & Distinctions: "*Geoffrey Robinson is one of those unusual men who can both create concepts and then devise the means to put them into effective use. He is well known for his achievements in international circles where he is considered a leader in Social Pediatrics. This is a remarkable man, who brings great honor to Canada." -* **Dr. Robert Aldrich, MD, FAAP**

Throughout the years Geoff demonstrated a clear understanding of the changing health care needs of children and provided vision and leadership in designing the services to meet these needs. His collective work in this field earned him many distinguished honors, most important perhaps:

- **The Ross Award** – the highest award one can receive in Canada from ones' paediatric peers through the Canadian Pediatric Society.
- The **Order of BC** and subsequently, the **Order of Canada** – the highest civilian award one can receive in Canada. (Of note, there are three distinguished OC recipients in the Robinson family tree, including older brother, Basil, and also Geoff's son, Michael.)

Shortly before his death in 2006, the UBC Department of Pediatrics and BC Children's Hospital Foundation established the **Geoffrey C. Robinson Award for Health Services and Population Health Research** to honour him in perpetuity through the BC Children's Hospital and the Canadian Pediatric Society.

His academic and clinical contributions are enormous. Highlighting only a few, these include:

- Development of **Pediatric Ambulatory Care Services** in the pre-Medicare era, with early focus on support of deaf children.
- Introduction and evaluation of radical new ways of providing health services to children through **Surgical Daycare Units**.
- Establishment of the **BC Children's Diagnostic Centre**, a radical new way of bringing professional teams to the assessment of children with complex developmental problems.
- Initiation of several present day programs in BC, including the Cleft Palate and Craniofacial, Spina Bifida, the Visually and Hearing Impaired Programs, and the Child Development and Diagnostic Program, newly called "**CDBC"**, for **Complex Development and Behavior,** which now includes assessment for **FASD** and other complex conditions.
- Extensive work on the **care of children in hospital and hospital design** that was child and family friendly, including books and innovative slide-tape shows. He actually sought and got input from primary school children on their experience of hospitals and what they would like to see. The first slide show presentation was named by a child, called the "Electric Happy Hospital". The material was used by planners, locally and internationally, as they built other children's hospitals.
- Support for the development of an internationally renowned **BC Infant Development Program** through his close working relationship with Dana Brynelsen and others.
- Establishment of the innovative model of **"Care-by-Parent" units** where parents were active participants in the care of their children while they were in hospital – **"family-centered" care versus "doctor centered or professional centered" care.**
- Focus on "**Population Health**" and the creation of the first **Division of Population Health** in Canada, long before the term became popular or understood.
- And finally, his contributions to the **issues of FAS and its prevention** (which continued long after his formal "retirement"), is perhaps one of the best demonstrations of his focus on population health and his determination to do something about it.

> *"Our start in life truly has a profound and permanent effect on our final outcome. We would not be here today without Geoff Robinson's vision, genius, commitment, and mentorship. Thanks, Geoff, for our Canadian Head Start an FASD Prevention."*
>
> **– Christine Loock, MD, FRCPC, Associate Professor, UBC Paediatrics, March 7, 2007**

Plenary Interuterine Microbes: Missing or the Missing Link?

Presenter: Tamar Gur

Authors: Zameer Mohamed, Alexandra C. S. Carlisle, Alexandra C. Livesey, & Raja A. S. Mukherjee

Summary

The intrauterine environment provides a key interface between the mother and the developing fetus during pregnancy, and is a target for investigating mechanisms of fetal programming. Studies have demonstrated an association between prenatal stress and neurodevelopmental disorders. The role of the intrauterine environment in mediating this effect is still being elucidated. In this talk, I will discuss emerging preclinical and clinical evidence suggesting the existence of microbial communities in utero. I will also outline possible mechanisms of bacterial translocation to the intrauterine environment and immune responses to the presence of microbes or microbial components. I will also overview the effects of intrauterine inflammation on neurodevelopment. Finally, I will present evidence that prenatal stress leads to disruptions in the maternal microbiome that may lead to the translocation of bacteria to the intrauterine environment, eliciting an inflammatory response and resulting in deficits in neurodevelopment.

References

Elovitz, M.A. et al. (2011) Intrauterine inflammation, insufficient to induce parturition, still evokes fetal and neonatal brain injury. Int. J. Dev. Neurosci. 29, 663–671

Hsiao, E.Y. and Patterson, P.H. (2012) Placental regulation of maternal-fetal interactions and brain development. Dev. Neurobiol. 72, 1317–1326

Jašarević, E. et al. (2018) The maternal vaginal microbiome partially mediates the effects of prenatal stress on offspring gut and hypothalamus. Nat. Neurosci. 21, 1061–1071

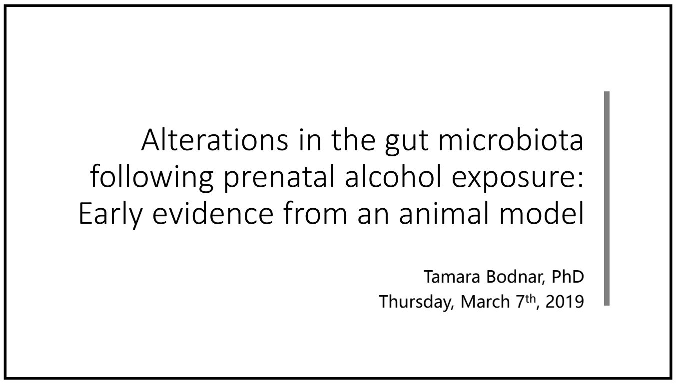
Gur, T.L. et al. (2015) Stress and the commensal microbiota: Importance in parturition and infant neurodevelopment. Front. Psychiatry 6, 1–6

Gur, T.L. et al. (2017) Prenatal stress affects placental cytokines and neurotrophins, commensal microbes, and anxiety-like behavior in adult female offspring. Brain. Behav. Immun. 64, 50–58

Plenary

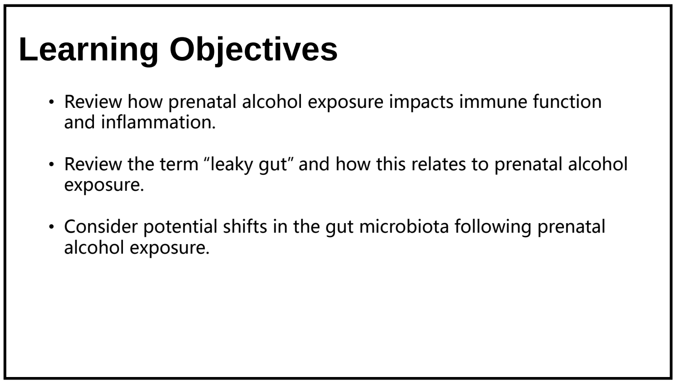
Alterations in the Gut Microbiota Following PAE: Early Evidence from an Animal Model

Presenter: Tamara Bodnar



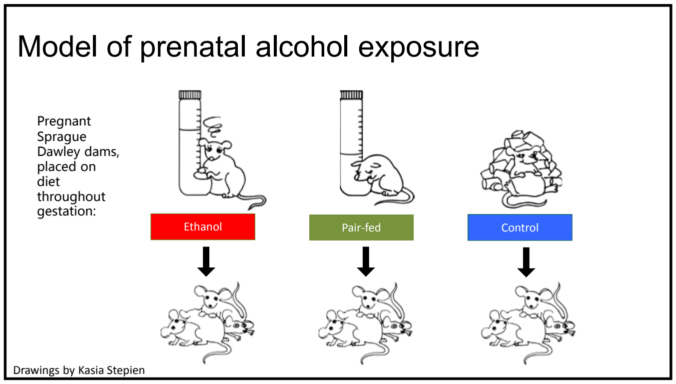
Alterations in the gut microbiota following prenatal alcohol exposure: Early evidence from an animal model

Tamara Bodnar, PhD
Thursday, March 7th, 2019



Learning Objectives

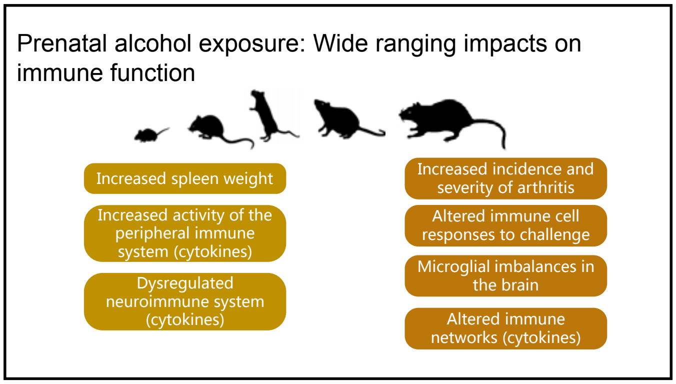
- Review how prenatal alcohol exposure impacts immune function and inflammation.
- Review the term "leaky gut" and how this relates to prenatal alcohol exposure.
- Consider potential shifts in the gut microbiota following prenatal alcohol exposure.



Model of prenatal alcohol exposure

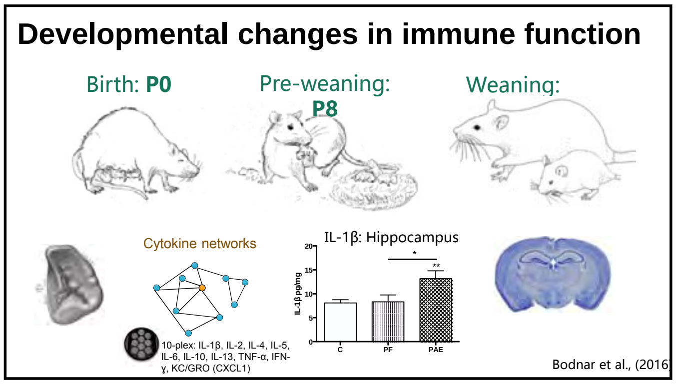
Pregnant Sprague Dawley dams, placed on diet throughout gestation:

Drawings by Kasia Stepien



Prenatal alcohol exposure: Wide ranging impacts on immune function

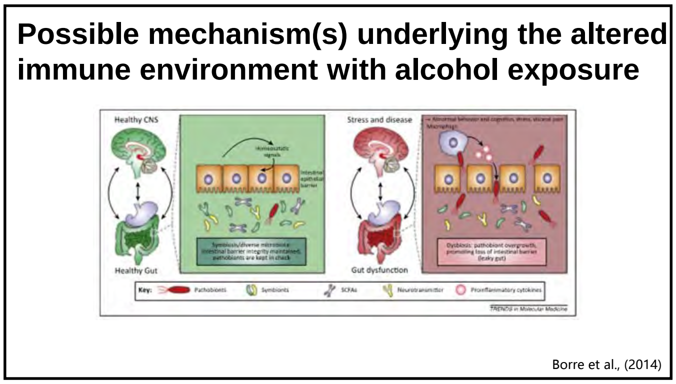
- Increased spleen weight
- Increased activity of the peripheral immune system (cytokines)
- Dysregulated neuroimmune system (cytokines)
- Increased incidence and severity of arthritis
- Altered immune cell responses to challenge
- Microglial imbalances in the brain
- Altered immune networks (cytokines)



Developmental changes in immune function

10-plex: IL-1β, IL-2, IL-4, IL-5, IL-6, IL-10, IL-13, TNF-α, IFN-γ, KC/GRO (CXCL1)

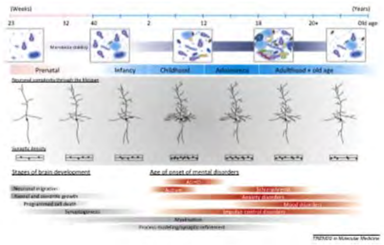
Bodnar et al., (2016)



Possible mechanism(s) underlying the altered immune environment with alcohol exposure

Borre et al., (2014)

Possible mechanism(s) underlying the altered immune environment with alcohol exposure



Borre et al., (2014)

References and Grant Support

- Bodnar TS, Hill LA, Weinberg J (2016). Evidence for an immune signature of prenatal alcohol exposure in female rats. *Brain, Behavior, and Immunity*, 58: 130-141.
- Bodnar, T.S., Raineki, C., Wertelecki, W., Yevtushok, L., Plotka, L., Zymak-Zakutnya, N., Honerkamp-Smith, G., Wells, A., Rolland, M., Woodward, T.S., Coles, C.D., Kable, J.A., Chambers, C.D., Weinberg, J., and the CIFASD (2018) Altered maternal immune networks are associated with adverse child neurodevelopment: Impact of alcohol consumption during pregnancy. *Brain Behavior, and Immunity*, 73: 205-215.
- Borre, Y.E., O'Keeffe, G.W., Clarke, G., Stanton, C., Dinan, T.G., Cryan, J.F., (2014). Microbiota and neurodevelopmental windows: implications for brain disorders. Trends Mol Med 20, 509-518.
- Engen, P.A., Green, S.J., Voigt, R.M., Forsyth, C.B., Keshavarzian, A., (2015). The Gastrointestinal Microbiome: Alcohol Effects on the Composition of Intestinal Microbiota. Alcohol Res 37, 223-236.

kids brain health network

Canadian Foundation on Fetal Alcohol Research

CIFASD

NIH National Institute on Alcohol Abuse and Alcoholism

A1a

Comparisons of the BRIEF Parental Report and Neuropsychological Clinical Tests of Executive Function in FASD: Data from the UK National Specialist Clinic

Alexandra Carlisle

Authors: Zameer Mohamed, Alexandra C. S. Carlisle, Alexandra C. Livesey, & Raja A. S. Mukherjee

Objectives

- What is Executive Function (EF) and what is the rationale for service evaluation of EF tools
- Outcomes of service evaluation including correlation between carer reports of EF difficulties and clinic based neuropsychological measures and comparison with global data
- Consider implications for single practitioners and the UK National Specialist Clinic

What is EF (Diamond, 2012)?

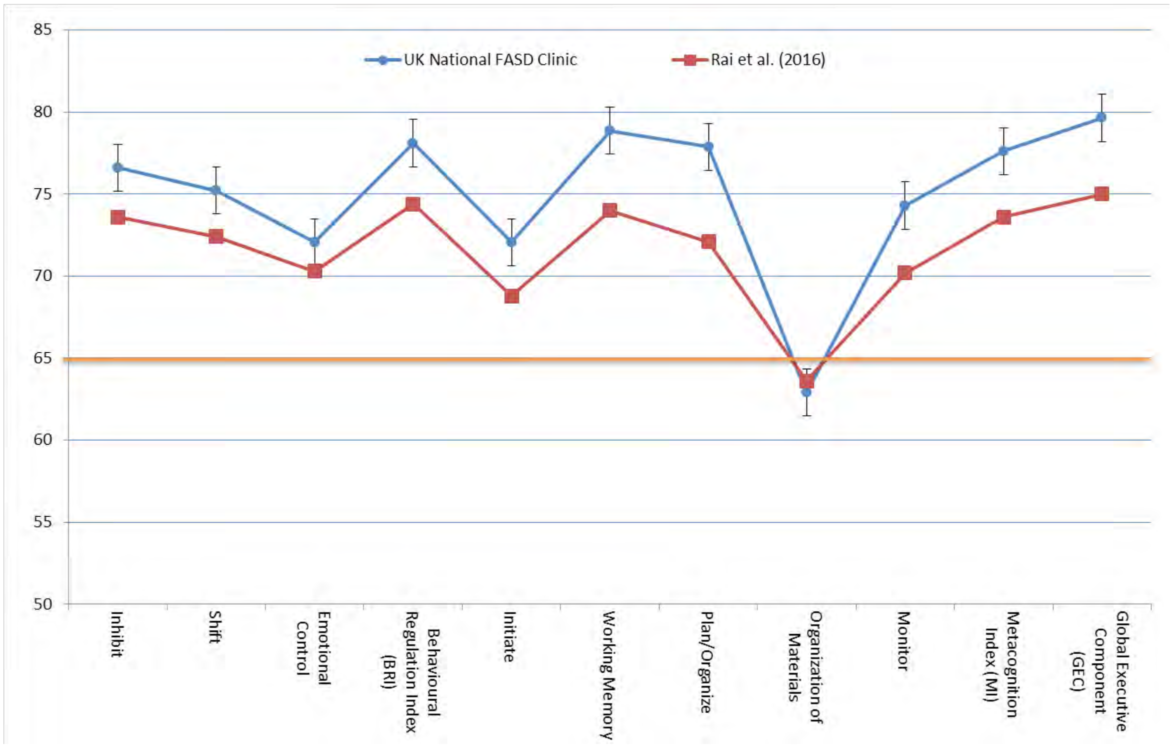
- A set of cortical processes carried out by the brain that are needed in order to complete a task
- Effortful processes where going on ‘automatic pilot’ would not be sufficient
- The basis of EF consists of Working Memory, Inhibitory Control, and Cognitive Flexibility
- From these, higher order EFs are built such as reasoning, problem solving, and planning

Rationale for conducting service evaluation

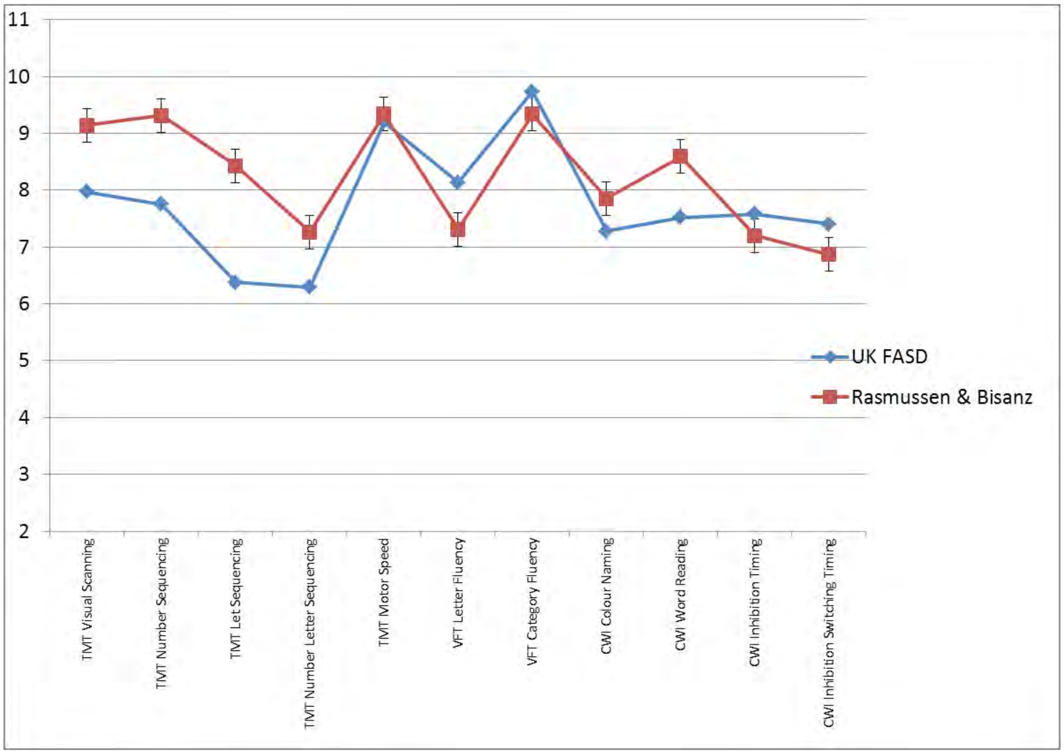
- What is the profile of EF in children with FASD in the UK?
- Is there a correlation between carer reports of EF difficulties and clinic based neuropsychological measures?
- Is the UK Profile of Executive Function similar to that seen globally?

Results

Behaviour Rating Index of Executive Functioning (BRIEF) - Mean caregiver scores for all Scales and Indices. Normative mean is 50; scaled scores that are equal to or greater than 65 (1.5 standard deviations away from the mean) represent clinically elevated executive dysfunction, as stated by the BRIEF (Gioia et al., 2000). n = 51.N.B. Error bars for all figures show standard error. Outcomes from UK National Clinic in comparison to data from Rai et al (2016).



Delis Kaplan Executive Function System Tests (D-KEFS) - Mean scores for 11 tests used in the UK National FASD Clinic in comparison to data from Rasmussen & Bisanz (2009). Normative mean is 10.



No correlation between the BRIEF and the D-KEFS in all but 2 subtests (Letter Fluency & Inhibit Scale, r = .342; Letter Fluency & the Behavioural Regulation Index, r = .327).

So What?

- This audit provides the first profile of executive functioning (EF) outcomes in a UK FASD sample
- Both executive function measures used in our clinic show a profile of executive dysfunction similar to that of Canadian cohorts indicating similarities between FASD populations in different countries
- Both measures can be used to inform the neuro-behavioural aspect of diagnosis - however single practitioners with limited access to resources can use the BRIEF as a quick tool to view EF profile
- The results will help guide the FASD clinic process – reviewing the FASD neuropsychological ‘toolkit’

References

Astley, S. J. (2004). Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code – Third Edition. Seattle: University of Washington Publication Services.

Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., and LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal,172(Suppl.), S1–S21.

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., & Rosales, T. (2016a) Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. Canadian Medical Association Journal, 188 (3):, 191–197.

Delis, D. C., Kaplan, E., and Kramer, J. H. (2001). Delis-Kaplan Executive Function System (DKEFS). San Antonio, TX: The Psychological Corporation.

Diamond, A. (2012). Executive Functions. Annual Review of Psychology (64). 10.1146/annurev-psych-113011-143750.

Gioia, G. A., Isquith, P. K., Guy, S. C., & Kenworthy, L. (2000b). Behavior Rating Inventory of Executive Function. Odessa, FL: Psychological Assessment Resources

Rai, J. K., Abecassis, M., Casey, J. E., Flaro, L., Erdodi, L. A., and Roth, R. M. (2017). Parent rating of executive function in fetal alcohol spectrum disorder: A review of the literature and new data on Aboriginal Canadian children. Child Neuropsychology, 23(6), 713–732.

Rasmussen, C., and Bisanz, J. (2009). Executive functioning in children with fetal alcohol spectrum disorders: Profiles and age-related differences. Child Neuropsychology, 15(3), 201–215.

A1b

Changes in the Corpus Callosum in Newborn Infants with PAE

Neil Aiton

Authors: Neil Aiton, MIchael Suttie

Learning Objectives

1. Demonstrate the importance identifying earlier markers of prenatal alcohol exposure
2. Visualise the corpus callosum easily using trans-fontanelle ultrasound
3. Demonstrate differences that can be seen in the shape of the corpus callosum in response to PAE

Objectives

Pilot study to compare the differences in the corpus callosum (CC) in newborn infants with and without prenatal alcohol exposure attending a substance misuse clinic.

Methods

Analysis of anonymised images obtained from routine cranial ultrasound performed through the anterior fontanelle during the first few weeks after birth. (Phillips HD11: S4-8, L5-12 probes). Seven infants with significant prenatal alcohol exposure were compared with six infants without alcohol exposure, but who had been exposed to other drugs during pregnancy: cocaine, crack cocaine, diazepam, methadone, methylphenidate, aripiprazole, over a six month period. Manually traced annotations of the corpus callosum were extracted from a mid-sagittal plane and converted to a 3D surface representation for shape analysis using dense surface modelling (DSM). DSM techniques provide a comprehensive set of tools for the objective analysis of anatomic shape differences, previously used to identify dysmorphology of the face and brain in adolescent and adult populations

Results

Anterior fontanelle ultrasound imaging of neonates provides mid-saggital representations of the corpus callosum sufficient for surface based shape analysis. Given the small sample size of this pilot we lack the statistical power to justify differences observed between exposed and unexposed groups. However, further work is continuing to undertake analysis in greater number of babies, explore the intra- and inter-rater measurement variation which will help to show the range of detectable difference, and perform comparison with normal infants (rather than infants who have also been exposed to other adverse antenatal experiences).

Conclusion

Qualitative differences have been observed in the shape and size of the corpus callosum in newborn infants with prenatal alcohol exposure seen in the clinic. Similar changes have been demonstrated in adolescents and young adults with prenatal alcohol exposure and in a very small number of infants.[1] [2] [3] However this has never been systematically studied in infants.

There are cogent reasons to develop methods of earlier diagnosis in children as this has been shown to improve outcome.

Absence of changes in facial appearance does not exclude the possibility of future neuro-developmental impairment, therefore the presence of neurobiological markers are potentially important in: 1) helping to develop methods to improve confidence in earlier diagnosis, 2) may have a function as early markers of future neuro-developmental problems and 3) perhaps have utility in population screening for those at risk of FASD.
Ultrasound is an ubiquitous, mature technology which is non-invasive, well-tolerated with no adverse consequences, and not requiring sedation in infants. Clear views of the CC can be obtained through trans-fontanelle imaging and the boundaries can be identified relatively easily.

Further work is required to develop ranges of normal values in normal infants, explore which types of measurement are most discriminatory and to develop techniques of image-processing and analysis which would allow easy application for the non-specialist operator/clinician.

References

[1]Yang et al 2011, [2] Bookstein et al 2005 & 2007, [3]Grant,T et al 2006

A1c Alterations in Brain Structural Connectome of Children and Youth with PAE

Xiangyu Long

Authors: Xiangyu Long, Graham Little, Sarah Treit, Christian Beaulieu and Catherine Lebel

Learning Objectives

1. Identify brain areas where structure is altered in individuals with FASD;
2. Describe relationships between brain structure and cognitive functions in FASD;

Summary

Drinking alcohol during pregnancy lead to prenatal alcohol exposure (PAE) and may cause various developmental disorders, which was termed as fetal alcohol spectrum disorder (FASD) (Chudley et al., 2005; Jacobson and Jacobson, 2002; Riley et al., 2011). Using diffusion magnetic resonance imaging (MRI) techniques, white matter connectivity has been shown to be reduced in widespread brain areas in children and youth with PAE (Fan et al., 2015; Fryer et al., 2009; Lebel et al., 2008; Li et al., 2009; Ma et al., 2005; Paolozza et al., 2017; Santhanam et al., 2011; Sowell et al., 2008; Wozniak et al., 2010). The widespread nature of these findings suggests that structural network connectivity is altered at a global level. Graph-theory analysis is a powerful way to investigate the complex brain network (Bassett and Bullmore, 2006; Bullmore and Sporns, 2009; Park and Friston, 2013). Two previous studies investigated the brain's functional connectome in children and youth with PAE using resting-state functional magnetic resonance imaging (MRI) (Wozniak et al., 2013, 2017). They found lower global efficiency and atypical network metrics compared to healthy controls. In the current study, we aimed to detail the changes of the structural connectome in children and youth with PAE using diffusion tensor imaging (DTI) based network analysis.

This study combines data from two research cohorts: 1) The Kids Brain Health Network (Reynolds et al., 2011) and The Canadian Institutes of Health Research FASD project (Lebel et al., 2008). The final sample included 97 children and adolescents with PAE and 103 unexposed controls, ranging from 5-18 years. T1-weighted structural images and diffusion tensor images were collected and preprocessed by ExploreDTI version 4.8.6 (Leemans et al., 2009) and FSL (Jenkinson et al., 2002; Jenkinson and Smith, 2001).

The Structural connectome analysis was performed. 1. Both nodal and whole brain averaged graph theoretical metrics were calculated for each individual connectivity matrix using the GRETNA toolbox (Wang et al., 2015): clustering coefficient (Cp), shortest path length (Lp), small-worldness (i.e., lambda, gamma and sigma value), local efficiency (Eloc), global efficiency (Eg), betweenness centrality (BC), network degree centrality (DC). The interaction (i.e., total number of edges) between and within seven networks described in (Yeo et al., 2011) were examined.

In the results, PAE group presented a trend-level higher lambda and small-worldness than control groups showed similar small-worldness. Global efficiency, degree centrality, and participation coefficient were all significantly lower in the PAE group than controls. Shortest path length and betweenness centrality were signifincatly higher in the PAE group compared to controls. Four nodes showed significant group differences in nodal metrics. Widespread decreased connectivity among networks was detected in the PAE group compared to controls.

In conclusion, we show significantly decreased global efficiency, degree centrality, and participation coefficient, as well as increased shortest path length and betweenness centrality in youth with PAE compared to unexposed controls. Furthermore, interactions between networks are significantly weaker in the PAE group. This provides the first evidence of a disrupted structural connectome in PAE, suggesting that widespread, long lasting global alterations to the brain's structural networks are caused by prenatal exposure to alcohol.

References

Bassett, D. S., and Bullmore, E. (2006). Small-world brain networks. Neurosci. 12, 512–523. doi:10.1177/1073858406293182.

Bullmore, E., and Sporns, O. (2009). Complex brain networks: Graph theoretical analysis of structural and functional systems. Nat. Rev. Neurosci. 10, 186–198. doi:10.1038/nrn2575.

Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., LeBlanc, N., et al. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. CMAJ 172, S1–S21. doi:10.1503/cmaj.1040302.

Fan, J., Meintjes, E. M., Molteno, C. D., Spottiswoode, B. S., Dodge, N. C., Alhamud, A. A., et al. (2015). White matter integrity of the cerebellar peduncles as a mediator of effects of prenatal alcohol exposure on eyeblink conditioning. Hum. Brain Mapp. 36, 2470–2482. doi:10.1002/hbm.22785.

Fryer, S. L., Schweinsburg, B. C., Bjorkquist, O. A., Frank, L. R., Mattson, S. N., Spadoni, A. D., et al. (2009). Characterization of White Matter Microstructure in Fetal Alcohol Spectrum Disorders. Alcohol. Clin. Exp. Res. 33, 514–521. doi:10.1111/j.1530-0277.2008.00864.x.

Jacobson, J. L., and Jacobson, S. W. (2002). Effects of prenatal alcohol exposure on child development. Alcohol Res. Health 26, 282–6. doi:10.1111/acer.12395.

Jenkinson, M., Bannister, P., Brady, M., and Smith, S. (2002). Improved optimization for the robust and accurate linear registration and motion correction of brain images. Neuroimage 17, 825–41.

Jenkinson, M., and Smith, S. (2001). A global optimisation method for robust affine registration of brain images. Med. Image Anal. 5, 143–56.

Lebel, C., Rasmussen, C., Wyper, K., Walker, L., Andrew, G., Yager, J., et al. (2008). Brain diffusion abnormalities in children with fetal alcohol spectrum disorder. Alcohol. Clin. Exp. Res. 32, 1732–1740. doi:10.1111/j.1530-0277.2008.00750.x.

Leemans, A., Jeurissen, B., Sijbers, J., and Jones, D. (2009). ExploreDTI: a graphical toolbox for processing, analyzing, and visualizing diffusion MR data. Proc. 17th Sci. Meet. Int. Soc. Magn. Reson. Med. 17, 3537.

Li, L., Coles, C. D., Lynch, M. E., and Hu, X. (2009). Voxelwise and Skeleton-Based Region of Interest Analysis of Fetal Alcohol Spectrum Disorders in Young Adults. Hum. Brain Mapp. 30, 3265–3274. doi:10.1016/j.asieco.2008.09.006.EAST.

Ma, X., Coles, C. D., Lynch, M. E., LaConte, S. M., Zurkiya, O., Wang, D., et al. (2005). Evaluation of corpus callosum anisotropy in young adults with fetal alcohol syndrome according to diffusion tensor imaging. Alcohol. Clin. Exp. Res. 29, 1214–1222. doi:10.1097/01.ALC.0000171934.22755.6D.

Paolozza, A., Treit, S., Beaulieu, C., and Reynolds, J. N. (2017). Diffusion tensor imaging of white matter and correlates to eye movement control and psychometric testing in children with prenatal alcohol exposure. Hum. Brain Mapp. 38, 444–456. doi:10.1002/hbm.23371.

Park, H. J., and Friston, K. (2013). Structural and functional brain networks: From connections to cognition. Science (80-.). 342. doi:10.1126/science.1238411.

Reynolds, J. N., Weinberg, J., Clarren, S., Beaulieu, C., Rasmussen, C., Kobor, M., et al. (2011). Fetal alcohol spectrum disorders: gene-environment interactions, predictive biomarkers, and the relationship between structural alterations in the brain and functional outcomes. Semin. Pediatr. Neurol. 18, 49–55. doi:10.1016/j.spen.2011.02.006.

Riley, E. P., Infante, M. A., Warren, K. R., Court, A., Diego, S., and Warren, K. R. (2011). Fetal alcohol spectrum disorders: An cverview. Neuropsychol. Rev. 21, 73–80. doi:10.1007/s11065-011-9166-x.Fetal.

Santhanam, P., Coles, C. D., Li, Z., Li, L., Lynch, M. E., and Hu, X. (2011). Default mode network dysfunction in adults with prenatal alcohol exposure. Psychiatry Res. - Neuroimaging 194, 354–362. doi:10.1016/j.pscychresns.2011.05.004.

Sowell, E. R., Johnson, A., Kan, E., Lu, L. H., Van Horn, J. D., Toga, A. W., et al. (2008). Mapping White Matter Integrity and Neurobehavioral Correlates in Children with Fetal Alcohol Spectrum Disorders. J. Neurosci. 28, 1313–1319. doi:10.1523/JNEUROSCI.5067-07.2008.

Wang, J., Wang, X., Xia, M., Liao, X., Evans, A., and He, Y. (2015). GRETNA: a graph theoretical network analysis toolbox for imaging connectomics. Front. Hum. Neurosci. 9, 386. doi:10.3389/fnhum.2015.00386.

Wozniak, J. R., Mueller, B. A., Bell, C. J., Muetzel, R. L., Hoecker, H. L., Boys, C. J., et al. (2013). Global Functional Connectivity Abnormalities in Children with Fetal Alcohol Spectrum Disorders. Alcohol. Clin. Exp. Res. 37, 748–756. doi:10.1111/acer.12024.

Wozniak, J. R., Mueller, B. a., Chang, P. N., Muetzel, R. L., Caros, L., and Lim, K. O. (2010). Diffusion Tensor Imaging in Children with Fetal Alcohol Spectrum Disorders. Alcohol Clin Exp Res. 30, 1799–1806. doi:10.1086/597422.Tumor.

Wozniak, J. R., Mueller, B. A., Mattson, S. N., Coles, C. D., Kable, J. A., Jones, K. L., et al. (2017). Functional connectivity abnormalities and associated cognitive deficits in fetal alcohol Spectrum disorders (FASD). Brain Imaging Behav. 11, 1432–1445. doi:10.1007/s11682-016-9624-4.

Yeo, B. T. T., Krienen, F. M., Sepulcre, J., Sabuncu, M. R., Hollinshead, M., Roffman, J. L., et al. (2011). The organization of the human cerebral cortex estimated by intrinsic functional connectivity. J. Neurophysiol. 106, 1125–1165. doi:10.1152/jn.00338.2011.

A1d Understanding and Assessing Affect Regulation Problems in FASD

Valerie Temple, Shirley McMillan, Josee Casati

Authors: Valerie Temple, Shirley McMillan, Ann Lindsay, Josee Casati, Bruce Edwards, Paula Green

Background

This study proposes a framework for assessing Affect Regulation (AR) in the context of diagnosing FASD. AR is the ability to control and modulate emotional responses. Individuals with FASD often have significant deficits in AR ability. The new Canadian Guidelines for Diagnosis of FASD (Cook et al., 2016) include AR deficits in criteria for diagnosis. Although it is recommended that AR be assessed, limited information was given in the new Guidelines regarding how this should be accomplished. As a result, FASD clinics have had difficult deciding and agreeing if AR deficits are present or absent in any individual assessed. Clarification regarding operational guidelines for assessing AR are needed in order to improve the reliability of FASD diagnostic criteria. This study aims to propose clear guidelines for establishing the presence or absence of AR deficits in FASD and evaluate interrater reliability on this proposed framework.

The Relationship between FASD and Affect Regulation

A great deal of research has found a relationship between FASD and AR. Experiments with animal models of FASD have found a link between prenatal alcohol exposure and increased neuroendocrine response to stress (Weinberg et al., 2008). Prenatal alcohol exposure was found in mouse models to permanently alter the neuroendocrine stress response resulting in hyper-reactivity to environmental stressors. This means individuals with prenatal alcohol exposure may be physiologically predisposed to react with greater distress to events in their lives. This hyper-reactivity to stress can lead to disorders of emotional dysregulation such as clinical levels of anxiety and depression. The relationship between prenatal alcohol exposure and emotional dysregulation is further supported by many epidemiological studies with humans which find very high rates of depression and anxiety disorders in those with prenatal alcohol exposure. (O'Connor et al., 2009).

Our Research Questions

Given that individuals with prenatal alcohol exposure often have deficits in AR, and AR is now one of the 10 domains to be assessed in FASD diagnosis, how does an FASD clinic establish if AR deficits are present in an individual assessed? As not every FASD clinic has access to a psychiatrist to evaluate mental health and AR, can a relatively simple set of criteria be used to establish if AR deficits are present? Can the criteria be reliably used by different clinicians? (i.e., can different clinicians use the criteria on a variety of individuals and agree about whether AR deficits are present or not).

Method

This study was conducted within an Adult (18 years of age and older) FASD Diagnostic clinic in Toronto, Ontario. The clinic is embedded in an agency serving individuals with developmental disabilities funded by the provincial government.

Developing the Proposed Evaluation Criteria for AR

Criteria for assessing AR deficits was developed using information provided in the new Canadian Guidelines (Cook et al., 2016). According to the Guidelines, deficits in AR are present when diagnostic criteria for a depression or anxiety disorder are currently met according to DSM-5 (APA, 2013) definitions. The Guidelines further note that the AR deficits should be long-standing patterns of emotional dysregulation, present for a significant period of time across the lifespan. They should not be short-term responses to adverse life conditions (e.g., foster home placement, bullying at school, etc). Using this description two operational criteria were developed by the FASD clinic team. The criteria were then piloted on 10 cases and revised based on feedback from clinicians. The final criteria are listed in Table 1.

The first criteria in Table 1 defines specific ways in which a current diagnosis of depression or anxiety can be established. This includes diagnoses given by a physician or psychologist at the FASD clinic, diagnoses made by another healthcare professional, or a variety of ways diagnoses can be inferred from file data (e.g., recent treatment or hospitalization for depression/anxiety). Suggested time-frames for what constitutes a current diagnosis are based on DSM-5 (APA, 2013) which states that about 80% of depressive episodes resolve over about 2 years. For this reason, a diagnosis given within the past 2 years is considered current.

The second criteria was developed to ensure that AR deficits are persistent and have been present for a significant period of time across the lifespan. This was achieved by requiring an additional diagnosis of depression or anxiety to have been given in the past. The same methods of defining a case of depression or anxiety were applied. Using the same logic as above, the past diagnosis must have been made more than 2 years ago.

For a case to be defined as having AR deficits, the individual must have met both of the two criteria listed in Table 1.

Participants and Reliability Analysis

All records from the Adult Diagnostic clinic were reviewed and 21 adults with an existing diagnosis of FASD were randomly chosen from the clinic's database. After choosing cases, two clinicians (a PhD. level Psychologist and a PhD. Level Nurse Specialist) rated each case to decide if AR deficits were present or absent. Raters used the proposed criteria listed below in Table 1 and were blind to each other's ratings. Cohen's Kappa was used to compare ratings of the two clinicians.

Table 1: Criteria for Establishing Affect Regulation (AR) Deficits in FASD Diagnosis

For diagnosis of FASD, an AR deficit is present if the individual meets criteria from both 1 and 2 below:
1. Individual has a current diagnosis of depression or anxiety established in one or more of these ways: a. Diagnosis was given at the FASD clinic or b. Diagnosis was given in the past 2 years by another healthcare professional or c. Individual received treatment for depression or anxiety in the last 2 years including anti-depression or anti-anxiety medication, counselling or hospitalization for anxiety or depression
2. Individual has a previous history of depression or anxiety (prior to 2 years ago) as demonstrated in one or more of these ways: a. Diagnosis of depression or anxiety was given by a healthcare professional in the past or b. Individual received treatment for depression or anxiety in the past including anti-depressant or anti-anxiety medication, counselling or hospitalization for anxiety or depression

Results/Discussion

For the 21 individuals reviewed, 6 (29%) were judged by both raters to have AR deficits. Using the proposed criteria, inter-rater reliability was high with a 90% agreement between raters. Cohen's Kappa for agreement was also high at .79. Using this method may simplify the process of AR assessment and enhance the validity of the category by establishing a historical pattern of dyregulation as well as current deficits.

It is hoped that other clinics will explore using this method and offer suggestions for refining and improving the method. We would appreciate feedback and suggestions from other clinics. As well, we would welcome those working with children to provide comments about the usefulness of this method and comments regarding minimum ages at which it might be implemented. Future researchers might consider creating a screening tool for AR deficits in FASD. Screening may help by identifying individuals most likely to have AR deficits and focusing full mental health assessments on these individuals.

References

American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5). American Psychiatric Pub; 2013 May 22.

Cook JL, Green CR, Lilley CM, Anderson SM, Baldwin ME, Chudley AE, Conry JL, LeBlanc N, Loock CA, Lutke J, Mallon BF, Temple VK, Rosales T. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. Canadian Medical Association Journal, 188, 3, 191-7.

O'Connor MJ, Paley B. Psychiatric conditions associated with prenatal alcohol exposure. Developmental Disabilities Research Reviews. 2009 Jan 1;15(3):225-34.

Weinberg, J. Sliwowska, J.H, Lan, N. & Hellemans, K.G.C. (2008). Prenatal Alcohol Exposure: Foetal Programming, the Hypothalamic-Pituitary-Adrenal Axis and Sex Differences in Outcome. Journal of Neuroendocrinology, 20, 4, 470-488.

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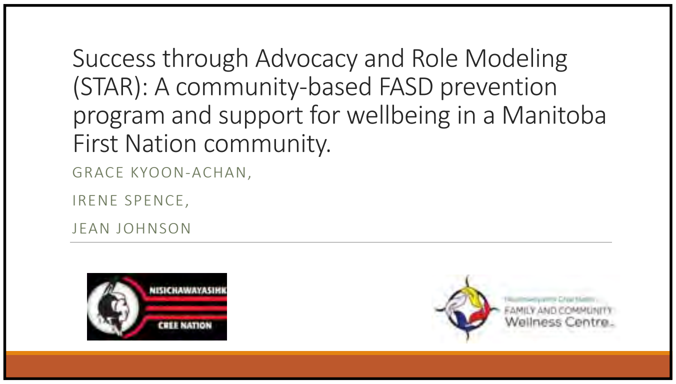
A2a

Success through Advocacy and Role Modeling (STAR): A Community-Based FASD Prevention Program and Support for Wellbeing in a Manitoba First Nation Community

Grace Kyoon-achan, Irene Spence, Jean Johnson



Success through Advocacy and Role Modeling (STAR): A community-based FASD prevention program and support for wellbeing in a Manitoba First Nation community.

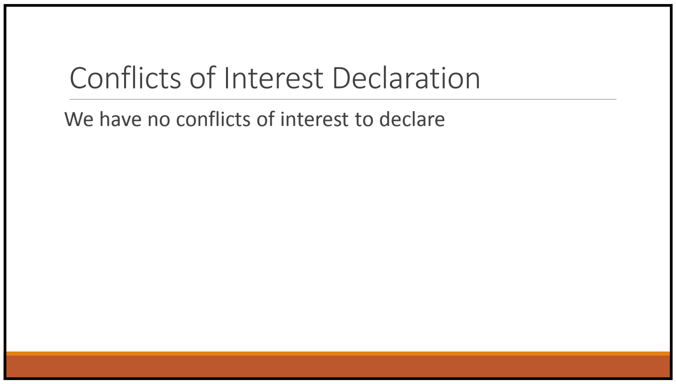
GRACE KYOON-ACHAN,

IRENE SPENCE,

JEAN JOHNSON

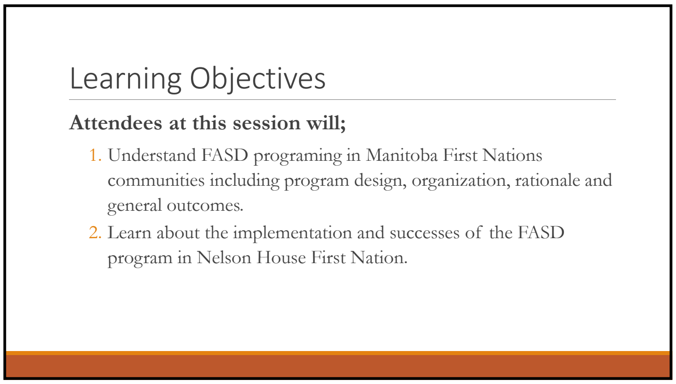
NISICHAWAYASIHK CREE NATION

FAMILY AND COMMUNITY Wellness Centre



Conflicts of Interest Declaration

We have no conflicts of interest to declare

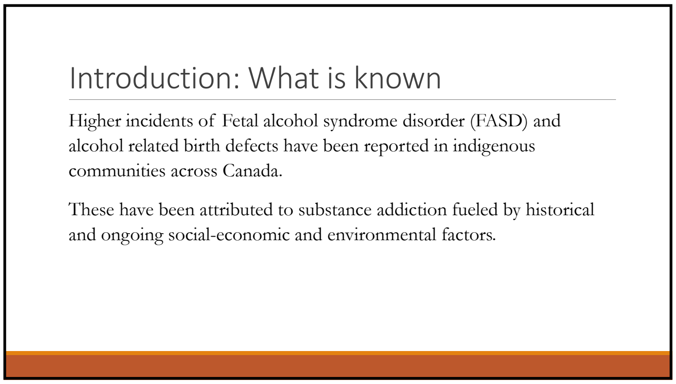


Learning Objectives

Attendees at this session will;

1. Understand FASD programing in Manitoba First Nations communities including program design, organization, rationale and general outcomes.
2. Learn about the implementation and successes of the FASD program in Nelson House First Nation.

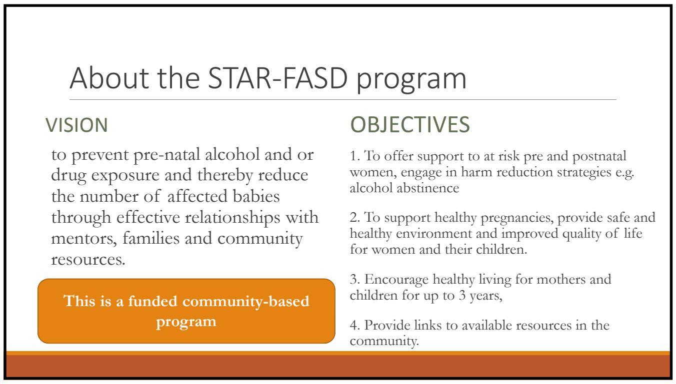
About Nelson House First Nation



Introduction: What is known

Higher incidents of Fetal alcohol syndrome disorder (FASD) and alcohol related birth defects have been reported in indigenous communities across Canada.

These have been attributed to substance addiction fueled by historical and ongoing social-economic and environmental factors.



About the STAR-FASD program

VISION

to prevent pre-natal alcohol and or drug exposure and thereby reduce the number of affected babies through effective relationships with mentors, families and community resources.

This is a funded community-based program

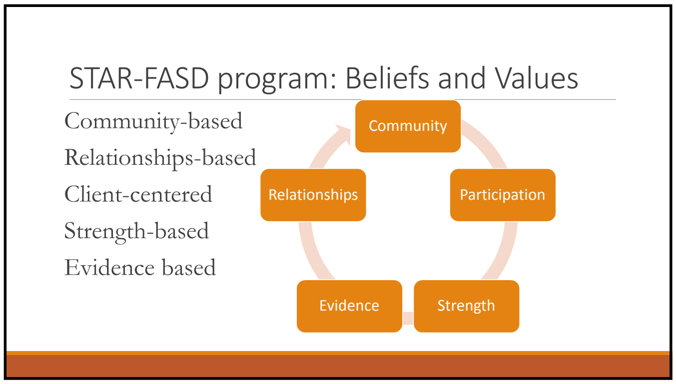
OBJECTIVES

1. To offer support to at risk pre and postnatal women, engage in harm reduction strategies e.g. alcohol abstinence

2. To support healthy pregnancies, provide safe and healthy environment and improved quality of life for women and their children.

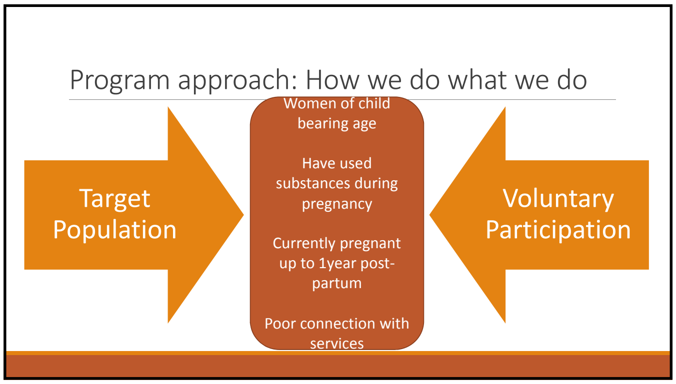
3. Encourage healthy living for mothers and children for up to 3 years,

4. Provide links to available resources in the community.



STAR-FASD program: Beliefs and Values

Community-based
Relationships-based
Client-centered
Strength-based
Evidence based



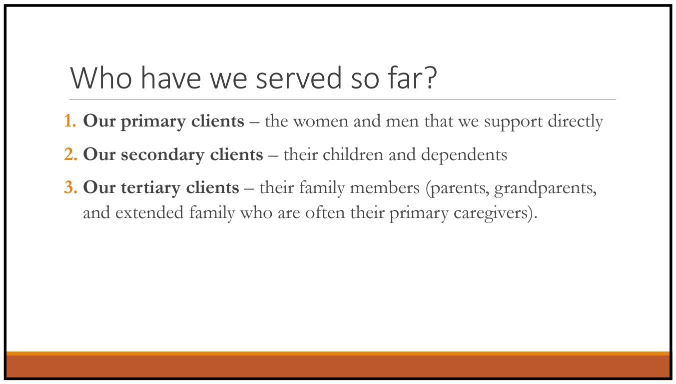
Program approach: How we do what we do

Women of child bearing age

Have used substances during pregnancy

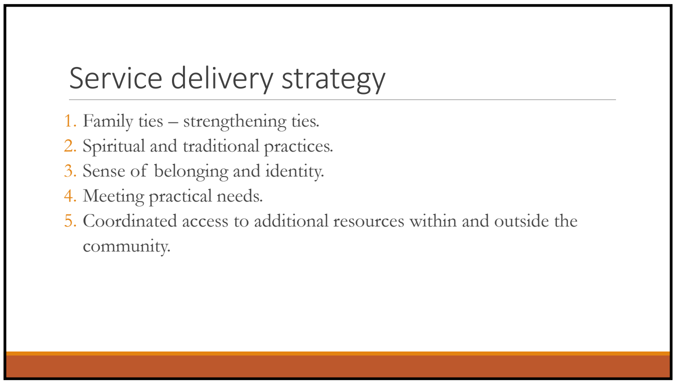
Currently pregnant up to 1year post-partum

Poor connection with services



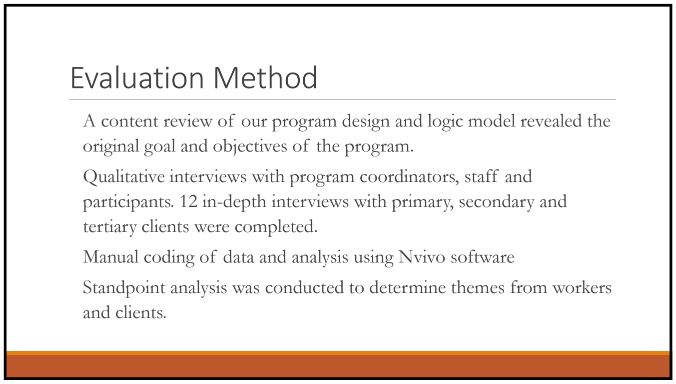
Who have we served so far?

1. **Our primary clients** – the women and men that we support directly
2. **Our secondary clients** – their children and dependents
3. **Our tertiary clients** – their family members (parents, grandparents, and extended family who are often their primary caregivers).



Service delivery strategy

1. Family ties – strengthening ties.
2. Spiritual and traditional practices.
3. Sense of belonging and identity.
4. Meeting practical needs.
5. Coordinated access to additional resources within and outside the community.



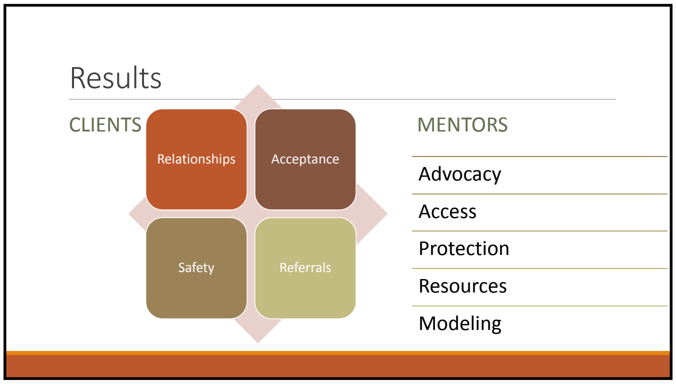
Evaluation Method

A content review of our program design and logic model revealed the original goal and objectives of the program.

Qualitative interviews with program coordinators, staff and participants. 12 in-depth interviews with primary, secondary and tertiary clients were completed.

Manual coding of data and analysis using Nvivo software

Standpoint analysis was conducted to determine themes from workers and clients.

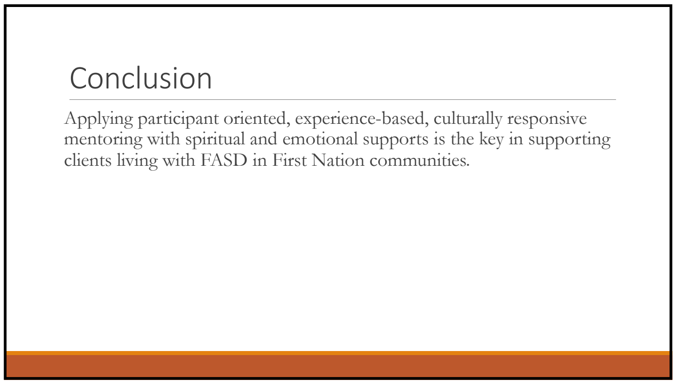


Results

CLIENTS

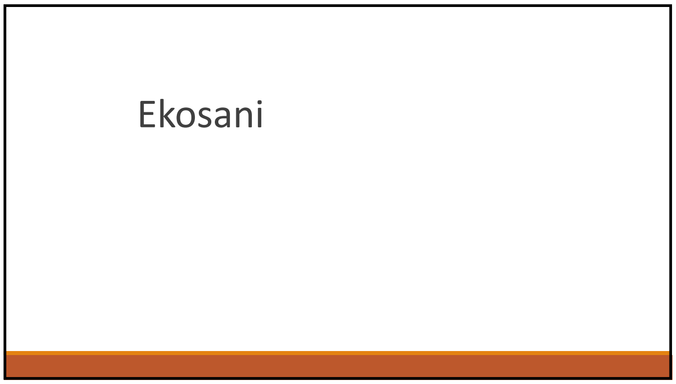
MENTORS

- Advocacy
- Access
- Protection
- Resources
- Modeling



Conclusion

Applying participant oriented, experience-based, culturally responsive mentoring with spiritual and emotional supports is the key in supporting clients living with FASD in First Nation communities.



Ekosani

A2b Systematic Review of Prevention Interventions to Reduce PAE and FASD in Indigenous Communities

Martyn Symons

Authors: Martyn Symons, Rebecca Pedruzzi, Elizabeth Milne

Learning Objectives

1. Evaluate and synthesis outcomes from studies of FASD prevention in Indigenous communities
2. Consider the difficulties in conducting research in this area
3. Assess common sources of bias when designing new research in this area

Objectives:
FASD is a preventable, lifelong neurodevelopmental disorder caused by prenatal alcohol exposure which negatively impacts Indigenous communities around the world. Many prevention interventions have been implemented but few adequately evaluated. Evidence for the effectiveness of FASD prevention interventions in Indigenous/Aboriginal populations internationally was reviewed and summarised and recommendations made for future research in this area.

Methods:
The MEDLINE, Embase, CINAHL Plus, Web of Science, PsycINFO, SocINDEX, and Informit databases were searched until 22/08/2017 for intervention papers published in peer-reviewed scientific journals, with results, targeting prenatal alcohol exposure and FASD in Indigenous populations, excluding workforce interventions.

Results:
There was significant heterogeneity in the ten included studies. Populations targeted included non-pregnant women of child-bearing age, pregnant women, school children and the general public. Study designs included one randomised controlled trial, five cohort studies with pre-post design, one cross-sectional study with different pre- and post-intervention groups, and four studies collected post-intervention data. Studies assessed changes in knowledge, and/or changes in risk for prenatal alcohol exposure including self-reported alcohol consumption, use of birth control or a combination of both. The methodological quality of all studies was rated as ‘Poor’. Studies were subject to substantial bias due to issues such as high loss to follow-up, lack of control groups and the reliance on self-report measures to assess the main outcome.

Conclusions:
There is little robust evidence that interventions aiming to reduce the risk of FASD in Indigenous populations have been effective. Future studies should continue to address the cultural and contextual factors fundamental to successful work with Indigenous populations, and be designed, implemented and evaluated using rigorous methods.

A2c Multipronged Strategy Needed: FASD Awareness, Prevention and Support in an American Indian Community

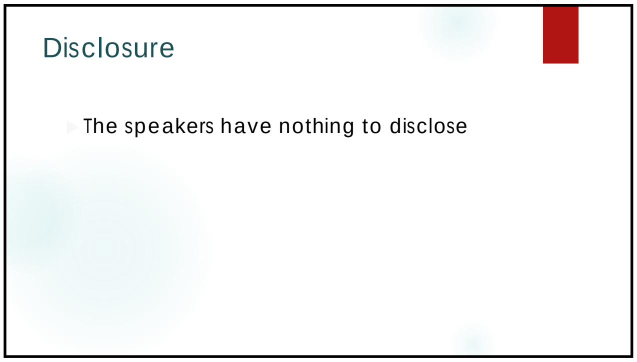
Presenters: Annika Montag, Rhonda Romero, Toni Jensen

Authors: Annika Montag, Rhonda Romero, Toni Jensen, Ami Admire, Amiyonette Goodblanket, Dan Calac, Conner Whitten, Christina Chambers

Multipronged Strategy Needed: FASD Awareness, Prevention and Support in an American Indian Community

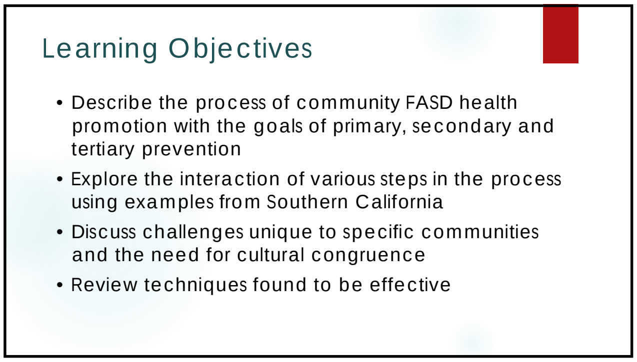
Annika Montag, Rhonda Romero, Toni Jensen, Ami Admire, Amiyonette Goodblanket, Dan Calac, Conner Whitten, Christina Chambers

The 8th International Conference on FASD Research: Research, Results and Relevance, Vancouver, BC, Canada
March 7th, 2019



Disclosure

- The speakers have nothing to disclose



Learning Objectives

- Describe the process of community FASD health promotion with the goals of primary, secondary and tertiary prevention
- Explore the interaction of various steps in the process using examples from Southern California
- Discuss challenges unique to specific communities and the need for cultural congruence
- Review techniques found to be effective

Welcome to Indian Country and Healthy Native Nation

The desert geography of this region highly influences tribal culture, traditions, and ceremonies. Tribes in this area remain active in their Bird Singing, Peon games, and other cultural and ceremonial activities.

First Steps in Addressing FASD

- Topic prioritized by Tribal Board
- Approved by SCTHC (Southern California Tribal Health Clinic) IRB
- Local Native community members hired and trained
- Local partnerships were developed to gain approval and to incorporate local expertise

Sequence of Approach

- **Study 1:** Scope – community risk for alcohol-exposed pregnancy?
  - Results: More than a third of women of childbearing age were at high risk of having an alcohol-exposed pregnancy
- **Study 2:** Support for Families – needs and priorities?
  - Issue: locating families affected by FASD
- **Study 3:** Prevalence of FASD?
  - Results: total FASD prevalence estimated at 4.1%
- **Study 4:** Child Development Resource Center
  - Prevalence and correlates of developmental disabilities among community children?
  - Caregiver population capacity, challenges, and resource needs?

Healthy Native Nation: Our Mission

> "To increase awareness, provide advocacy and support for families affected by FASD, and to improve and strengthen the lives of those living with FASD."

Barriers

- Lack of Information about the risks associated with alcohol use during pregnancy
- Lack of Trust
- Stigma
- Social Isolation
- Lack of Transportation

Utilizing art from local artists in our educational messages

Reaching out to youth

Interactive youth education projects

Involving native youth to help create prevention materials

Hands-on education presentations

Outreach & education at annual traditional gatherings

Community Pow Wows where Healthy Native Nation has had table displays each year

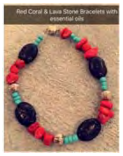
Community education at traditional annual celebrations

Talking Circle/Support Group

Parent /Caregiver Support Group

Gathering monthly with parents and caregivers to discuss issues relating to Fetal Alcohol Spectrum Disorders


SUPPORT
Makes A Difference!
2019 SUPPORT GROUP SCHEDULE
For Parents and Caregivers of Children With Special Needs
Sponsored by Healthy Native Nation Family Support Project
MEETINGS:
2nd Tuesday of Each Month
4-5 pm
January 8 ... Your Child's Self Esteem
February 12 ... Open Discussion & Personalized Photo Pot Craft
March 12 ... Children & Chores
April 9 ... Open Discussion & Flavored Warmers Craft
May 7 ... Rewarding Success
June 11 ... Open Discussion & Nail Polish Marble Art Craft
July 9 ... Parent/Child Play Interaction
August 13 ... Open Discussion & Beaded Window Chimes Craft
September 10 ... Behavior Problems
October 15 ... Open Discussion & Feather or Beach Rock Art
November 12 ... Positive Parenting
December 10 ... Open Discussion & Beaded Ornament Craft


Red Coral & Lava Stone Bracelets with essential oils

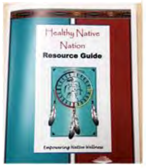
Reinforcing our message in the community

Healthy Native Nation Resource Library with books, brochures, flyers, videos & one-on-one training


HEALTHY NATIVE NATION MOVES FORWARD

Quarterly community newsletter articles keeps our communities updated on Healthy Native Nation activities


Grocery Bags with native art

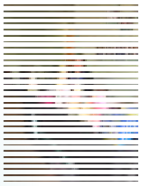

Healthy Native Nation
Resource Guide
Empowering Native Wellness

Community Resource Directory


Protecting Your Unborn Baby
Be safe: Have an alcohol-free pregnancy
Healthy Native Nation

Educational Brochures

Networking: Medical OB Clinic Education Monthly gift bags for pregnant women



Healthy Native Nation participated in eight OB clinics reaching 64 native women over the past 1 ½ years.
Various clinic departments continue to donate items for gift bags

[redacted]

Developmental Chart in all exam rooms of the clinic

Conferences & Trainings

- We partnered with NOFAS for a conference targeting women in recovery with over 60 participants
- FASD and the Law Conference drew over 65 lawyers, judges and community representatives
- Trained staff, educators, professional groups throughout the project

Annual Art Show

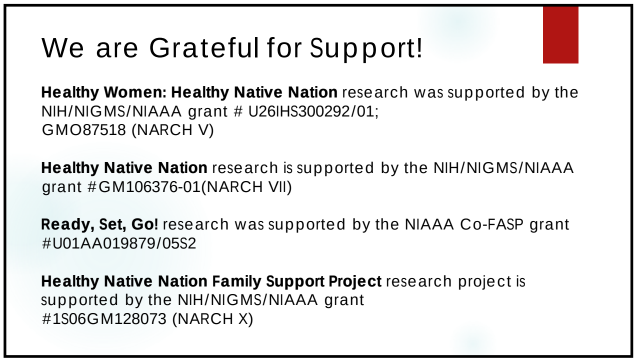
Summary – Strategies and Prioritized Support

- Cultural focus
- Local concepts and images
- Outreach to where people are
- Reinforce the message
- Networking
- Support Group
- Education and Training
- Resource Library and Guide
- Recurring Events

Lessons Learned

- **Cultural congruence**
  - Intervention
  - Motivation
  - Methods
- **Community involvement**
  - All aspects of study
  - Control of data
- **Community Strengths**
  - Resilience
  - Family
  - Altruism
  - Social structure

It's All About Respect!!



We are Grateful for Support!

Healthy Women: Healthy Native Nation research was supported by the NIH/NIGMS/NIAAA grant # U26IHS300292/01; GMO87518 (NARCH V)

Healthy Native Nation research is supported by the NIH/NIGMS/NIAAA grant #GM106376-01(NARCH VII)

Ready, Set, Go! research was supported by the NIAAA Co-FASP grant #U01AA019879/05S2

Healthy Native Nation Family Support Project research project is supported by the NIH/NIGMS/NIAAA grant #1S06GM128073 (NARCH X)

A2d Prevalence of FASD in an American Indian Reservation-Based Sample

Annika Montag

Authors: Annika Montag, Rhonda Romero, Toni Jensen, Amiyonette Goodblanket, Ami Admire, Conner Whitten, Daniel Calac, Miguel Del Campo, Kenneth Lyon Jones, Christina Chambers

Learning Objectives

1. Estimate the prevalence of FASD among Southern California American Indians
2. Compare and contrast with national estimates
3. Recognize the possibility of cultural bias in prevalence estimates of FASD

Background

Fetal Alcohol Spectrum Disorders (FASD) include physical, learning, and behavioral disabilities that represent a significant public health problem. Early intervention is crucial to avoid secondary disabilities, yet FASDs are frequently under-diagnosed or misdiagnosed.

Methods

The NIH-NIAAA Collaboration on FASD Prevalence (CoFASP) study recently estimated the minimum prevalence of FASD in four regions of the U.S. to range from 1.1-5.0% among first-grade aged children. Within CoFASP, an ancillary study was also conducted to obtain an FASD prevalence estimate in a Southern California American Indian community. In 2016, American Indian children between 5 and 7 years of age and their caregivers were recruited in collaboration with Southern California Tribal Health Clinic. Children were assessed for physical features and growth by a study dysmorphologist and neurobehavioral testing was performed by trained psychometrists. Parent or guardian interviews assessed child behavior and prenatal exposures including alcohol.

Results

Of 488 children identified as eligible to participate, 119 families consented and 113 of these completed assessments. Participating children were an average of 77.0 ± 10.8 months old and 53.8% were female. Caregivers were an average of 35.8 ± 10.1 years old and 82.6% were birth mothers. Forty percent were married and most had completed some college education or higher. Approximately one third (35.4%) of mothers reported consuming any alcohol in pregnancy and 26.5% met study criteria for risky alcohol exposure in pregnancy. The overall minimum prevalence of FASD in this sample was 4.1%. No cases of FAS were identified; 70% of the children classified as FASD met criteria for alcohol related neurodevelopmental disorder.

Conclusions

Participants were self-selected and data may not reflect the entire population. However, the study was broadly publicized within the community, and local Native staff used culturally congruent methods to raise awareness to encourage participation. Prevalence estimates found in this sample are consistent with the prevalence estimates noted in the general population samples in the overall CoFASP study.

A3a Alcohol Use During Pregnancy - A Portuguese Study

Maria Xavier

Authors: M. R. Xavier, P. Dias, C. Martins

Learning Objectives

1. Describe the patterns of alcohol consumption in a sample of pregnant Portuguese women
2. Recognize the complexity of relations between psychological dimensions of pregnancy and alcohol consumptions
3. Discuss importance of adequate screening and non-punitive/collaborative work between health care professionals

Summary

Maternal alcohol consumption during pregnancy is a significant health problem because of the risks for negative prenatal, neonatal and later neurobehavioral outcomes ranging from subtle developmental problems to fetal alcohol syndrome. In spite of the increase of consumption of Portuguese women, data about alcohol use during pregnancy is scarce.

This work aims to describe patterns of alcohol consumption and possible relations with psychological experience of pregnancy in a sample of 1000 pregnant Portuguese women. Recruitment strategies included healthcare professionals, word of mouth, collaboration with community/health services and national websites and social networking sites commonly consulted by pregnant women (in–person self-report questionnaires and online questionnaires). The questionnaires included standardized scales (AUDIT and Pregnancy and Motherhood Attitudes Scale) and questions about sociodemographics, gestation and parity, and healthcare.

Data concerning descriptive and inferential analysis about alcohol use and attitudes toward pregnancy and maternity will be present. Despite World Health Organization, European and Portuguese governmental concerns and recommendations, we found that approximate 20% (in-person and online) pregnant women continue to drink during pregnancy and that consumptions are related to differences on some dimensions of the psychological experience of pregnancy.

We defend that adequate screening and report strategies must be organized based on a non-punitive/collaborative approach between different professionals involved in health care arena. We hope that this kind of work represents an alert and a step for future research as a base to setting out effective strategies for prevention, screening and management of alcohol consumption during pregnancy in our country.

A3b Influences on Drinking Choices by Indigenous and NonIndigenous Pregnant Women in Australia

Evi Muggli

Authors: Evi Muggli, Sophie Gibson, Della Forster, Cate Nagle

Learning Objectives

1. Reflect on why some women drink alcohol in pregnancy and why an abstinence message is not always effective
2. Improve maternity clinician conversations around alcohol use in pregnancy to help women make informed choices

Background

Current research suggests that alcohol use in pregnancy continues to be prevalent despite antenatal guidelines advising against drinking. The 2009 Australian National Guidelines to Reduce Health Risks from Drinking Alcohol, recommend that it is safest for women to abstain from drinking alcohol completely throughout the duration of their pregnancy(1). However, data from two large national surveys of Australian women aged 18 to 45 years found that 34-49% of women consumed alcohol in pregnancy(2, 3) and that despite women's awareness that drinking alcohol in pregnancy can lead to lifelong disabilities in a child, nearly one third intended to drink alcohol in a future pregnancy(2). Whilst knowledge of the harms of alcohol consumption during pregnancy is important, it is apparent that an awareness alone does not discourage some women from drinking when pregnant. The prevalence of pregnancy alcohol consumption has also been reported in other high income countries. For example, an international cross-cohort comparison of the prevalence of alcohol use during pregnancy, revealed that high rates of alcohol consumption in pregnancy, between 20 and 80%, were evident, and despite knowledge of the relevant guidelines(4). Of additional concern are the levels of alcohol consumed in some sub-populations. For example, an Australian survey reported that of the 55% of Indigenous women who consumed alcohol in pregnancy, nearly half drank at least two to three times per week and almost all consumed a minimum of seven standard drinks per occasion(5). Similarly, a 2017 systematic review found that around one in five Indigenous women in the US and Canada drink at binge levels when pregnant(6).

Objective

The objective of this qualitative study was to explore influences on the drinking choices of pregnant women in a population with frequent and heavy peer drinking (i.e. in two Australian Indigenous communities) and to compare and contrast these with those of non-Indigenous pregnant women from a range of backgrounds

Methods

Participants were recruited from three public and one private health service in Victoria, Australia, and included socioeconomically disadvantaged and/or regional areas, as well as two Indigenous settings in Northern Territory (remote) and Victoria (regional). Eligibility criteria were being pregnant, ability to speak and write in English and being aged 18 years or over (to provide informed consent).

Individual and group interviews consisted of brief introductions followed by a guided discussion of women's attitudes towards alcohol use during pregnancy, their understanding of the harms of pregnancy drinking and views on collecting alcohol use information for clinical management and reporting purposes. All discussions were audiotaped with participant consent and transcribed verbatim and participant names and study suites were replaced with pseudonyms. Transcripts were analysed using inductive content analysis(7).

Ethics approval was granted by the Australian Institute of Health and Welfare, the Human Research Ethics Committees of the Royal Children's Hospital Cabrini Hospital, Mercy Health, Western Health, Goulburn Valley Health, the Research Sub-Committee of Congress Alukura, Alice Springs, and the Central Australian Human Research Ethics Committee.

Results

14 Indigenous and 14 non-Indigenous pregnant women participated in this study. Analysis identified five themes which influenced women's ability to abstain from alcohol in pregnancy:

1. Understanding - Women understood that drinking alcohol when pregnant was "bad", potentially causing harm to their developing baby. However, many were unsure about the nature of harm and often thought that it was safe to drink some alcohol after the first 12 weeks or that some types of alcohol were more harmful than others. Despite standard drink labelling on alcoholic drink beverages, the women in our study talked about their drinks in terms of the drink size they would actually consume.

2. Informing - Some women perceived the severity of harm from occasional alcohol use to be low. This was usually based on their personal observations of the behaviour of family and friends, and an awareness of the lack of convincing research evidence on harm from low consumption patterns. Consequently, beliefs about the benefits of abstaining from alcohol completely were also low and the barriers to taking such action, for example when at a social event, were seen to outweigh any risks. Together, these perceptions permitted nuanced decisions by individual women about how much alcohol consumption was to be without risk of harm, despite receiving health messages advising complete abstinence. Women who commonly saw heavy alcohol use in their community were more likely to believe that there could be serious harm from alcohol to their child and that complete abstinence was important.

3. Choosing - The individual drinking choices of non-Indigenous women were often autonomous, while Indigenous women were more likely to follow the advice of clinicians.

4. Conceptualising - Women who referred to their unborn baby as an individual entity and described the child as a real person, were much more likely to abstain from alcohol without question than women who spoke about the importance of maintaining a healthy pregnancy. In our study, women who felt responsible for the “baby inside” were predominantly of Indigenous background or from maternity services based in lower sociodemographic areas. None of our study participants were at risk for alcohol misuse and it is more likely that despite a commitment to a healthy pregnancy, those with higher health literacy formed a more abstract concept of the developing fetus, thereby making decisions with a prenatal rather than maternal focus.

5. Enabling - Despite an understanding of the potential for harm from alcohol consumption and clinician advice, a pregnant woman’s social environment may limit her ability to abstain. Previous research with Indigenous communities indicates that while Australian Aboriginal women are less likely to drink alcohol, if they do drink, it is done so at risky levels. (3, 5). This was supported by our conversations with Indigenous women who spoke about the need for a strong, supportive family in environments such as public housing town camps, where high-risk alcohol use is common. All women in our study perceived that there was an expectation on them to drink alcohol in social situations when not pregnant and explained that this influenced their decision or ability to abstain. The pressure to comply with such social norms, especially in early gestation and before the pregnancy is disclosed to others, are well documented in Australia and other Western countries with a similar alcohol use culture(8, 9).

Interpretation

The outcomes from discussions with pregnant women in our study illustrate that abstinence from alcohol has many facets, rendering a simple abstinence message ineffective in many cases.

To improve women’s knowledge of the harms from alcohol and their own susceptibility, health advice should include specific education to correct misinformation about ‘safe’ gestational timing, and increase understanding of the ‘standard alcoholic drink’ concept to address the mistaken belief that some types of drink are less harmful or even beneficial to one’s health. Further, we need to help develop a more accurate perception of FASD and provide a clear message that is evidence-based. Many women are aware of the current lack of evidence for harm associated with low or occasional alcohol use and infer from this that it is safe to drink some alcohol. It is not currently known if there is a ‘safe’ threshold of exposure, but alcohol is an established teratogen, acting either directly, or through its metabolites, and affecting the regulation of cellular functions(10). While exposure may not necessarily result in adverse clinical outcomes for the child, it does mean that fetal development is influenced at a biological level in response to alcohol. We need to reframe discussions around harm prevention or whether there is a potentially ‘safe’ threshold, to messages about the importance of alcohol abstinence in maximising health and cognitive outcomes for the unborn child.

For women with problematic alcohol use, or whose social and cultural environment makes abstinence difficult, clinicians can play an important role in supporting and encouraging reduction in intake where possible. There is good evidence that brief interventions can be effective. These usually follow the ‘3 As’ and include building rapport, verbal reinforcement, goal setting to build confidence and assisting with personal circumstances(13, 14). Building rapport and providing culturally safe and holistic antenatal care is especially important for Indigenous women who may experience a disproportionate rate of adverse circumstances(15, 16).

References

1. National Medical Health and Research Council. Australian guidelines to reduce health risks from drinking alcohol; Guideline 4: Pregnancy and Breastfeeding. Canberra: NHMRC; 2009.
2. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, et al. Attitudes and behaviour predict women's intention to drink alcohol during pregnancy: the challenge for health professionals. BMC Public Health. 2011;11:584.
3. Australian Institute of Health and Welfare. 2016 National Drug Strategy Household Survey:detailed findings. Drug Statistics series no. 31. Australian Institute of Health and Welfare, Australian Government Department of Health and Ageing.; 2017. Contract No.: Cat. no. PHE 214. Canberra: AIHW.
4. O'Keeffe LM, Kearney PM, McCarthy FP, Khashan AS, Greene RA, North RA, et al. Prevalence and predictors of alcohol use during pregnancy: findings from international multicentre cohort studies. BMJ Open. 2015;5(7):e006323.
5. Fitzpatrick JP, Latimer J, Ferreira ML, Carter M, Oscar J, Martiniuk AL, et al. Prevalence and patterns of alcohol use in pregnancy in remote Western Australian communities: The Lililwan Project. Drug Alcohol Rev. 2015;34(3):329-39.
6. Popova S, Lange S, Probst C, Parunashvili N, Rehm J. Prevalence of alcohol consumption during pregnancy and Fetal Alcohol Spectrum Disorders among the general and Aboriginal populations in Canada and the United States. Eur J Med Genet. 2017;60(1):32-48.
7. Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107-15.
8. Jones SC, Telenta J. What influences Australian women to not drink alcohol during pregnancy? Aust J Prim Health. 2012;18(1):68-73.
9. Skagerstrom J, Haggstrom-Nordin E, Alehagen S. The voice of non-pregnant women on alcohol consumption during pregnancy: a focus group study among women in Sweden. BMC Public Health. 2015;15:1193.
10. Ehrhart F, Roozen S, Verbeek J, Koek G, Kok G, van Kranen H, et al. Review and gap analysis: molecular pathways leading to fetal alcohol spectrum disorders. Molecular psychiatry. 2018.
11. Hellemans KG, Sliwowska JH, Verma P, Weinberg J. Prenatal alcohol exposure: fetal programming and later life vulnerability to stress, depression and anxiety disorders. Neurosci Biobehav Rev. 2010;34(6):791-807.
12. Muggli E, Matthews H, Penington A, Claes P, O'Leary C, Forster D, et al. Association Between Prenatal Alcohol Exposure and Craniofacial Shape of Children at 12 Months of Age. JAMA Pediatr. 2017;171(8):771-80.
13. Carson G, Cox LV, Crane J, Croteau P, Graves L, Kluka S, et al. Alcohol use and pregnancy consensus clinical guidelines. J Obstet Gynaecol Can. 2010;32(8 Suppl 3):S1-31.
14. Breen C, Awbery E, Burns L. Supporting Pregnant Women who use Alcohol or other Drugs: a review of the evidence. National Drug and Alcohol Research Centre, UNSW Australia.; 2014.
15. McBain-Rigg KE, Veitch C. Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa. Aust J Rural Health. 2011;19(2):70-4.
16. Clarke M, Boyle J. Antenatal care for Aboriginal and Torres Strait Islander women. Australian family physician. 2014;43(1):20-4.

A3c

Midwives' Assessment of Expecting Mothers' Alcohol Use (MAMA) – A UK-Wide Mixed Methods Study of the Implementation of the 2016 CMO Drinking Guidelines

Lisa Schölin, Lesley Smith

MAMA

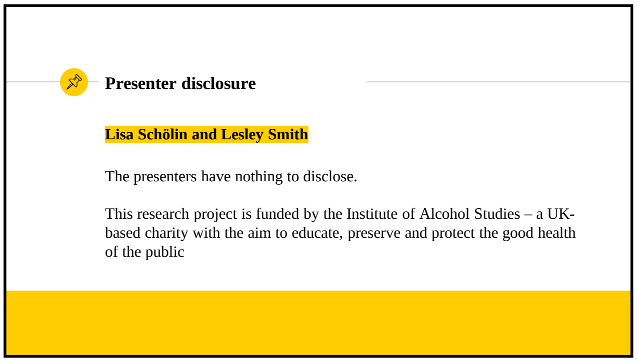
Midwives' **A**ssessment of expecting **M**others' **A**lcohol use

Dr Lisa Schölin
School of Health in Social Science
University of Edinburgh

Professor Lesley Smith
School of Faculty of Health Sciences
University of Hull

Project team

- Lisa Schölin, University of Edinburgh (PI)
- Lesley Smith, University of Hull
- Julie Watson, University of Hull
- Judith Dyson, Unviersity of Hull

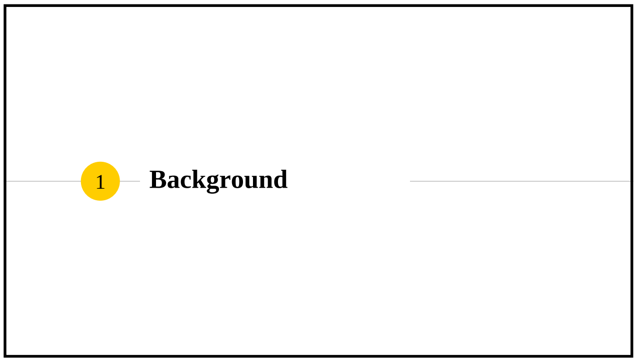


Presenter disclosure

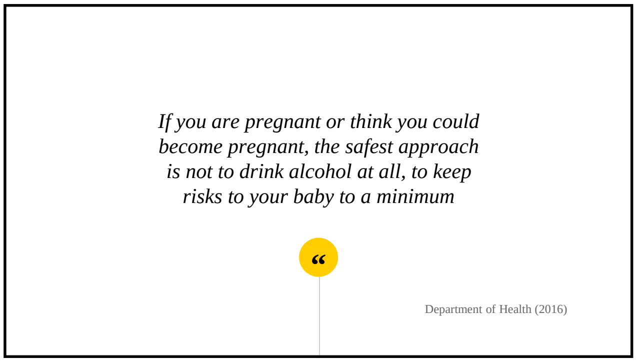
Lisa Schölin and Lesley Smith

The presenters have nothing to disclose.

This research project is funded by the Institute of Alcohol Studies – a UK-based charity with the aim to educate, preserve and protect the good health of the public

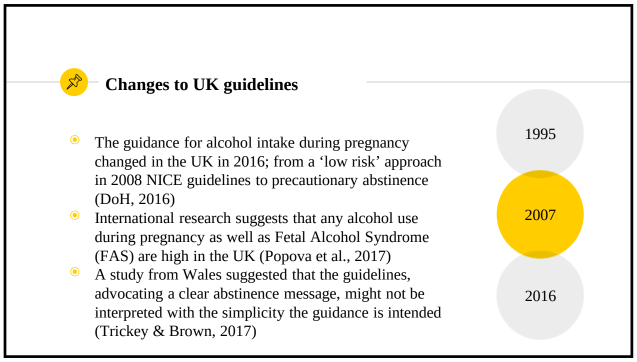


1 **Background**



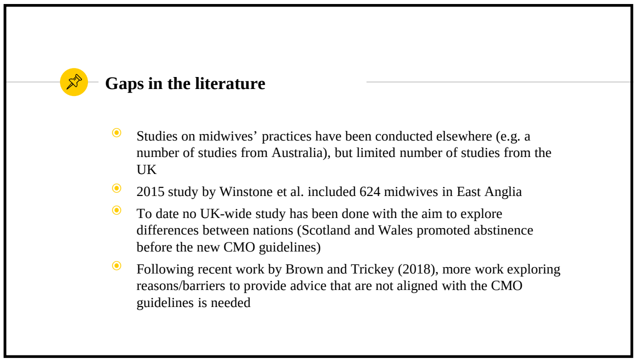
If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum

Department of Health (2016)



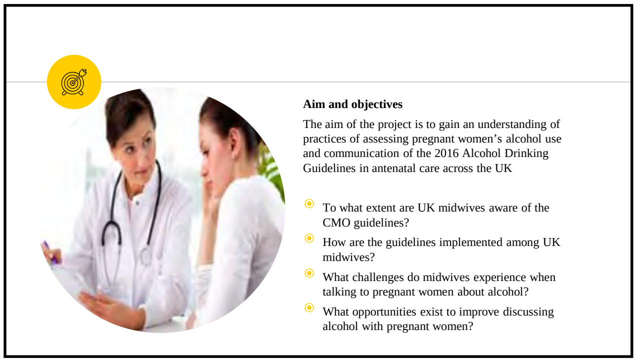
Changes to UK guidelines

- The guidance for alcohol intake during pregnancy changed in the UK in 2016; from a 'low risk' approach in 2008 NICE guidelines to precautionary abstinence (DoH, 2016)
- International research suggests that any alcohol use during pregnancy as well as Fetal Alcohol Syndrome (FAS) are high in the UK (Popova et al., 2017)
- A study from Wales suggested that the guidelines, advocating a clear abstinence message, might not be interpreted with the simplicity the guidance is intended (Trickey & Brown, 2017)



Gaps in the literature

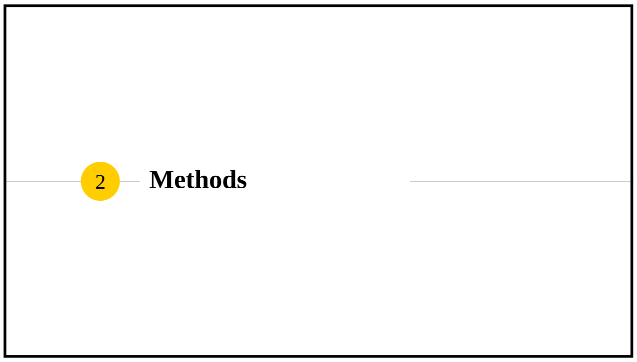
- Studies on midwives' practices have been conducted elsewhere (e.g. a number of studies from Australia), but limited number of studies from the UK
- 2015 study by Winstone et al. included 624 midwives in East Anglia
- To date no UK-wide study has been done with the aim to explore differences between nations (Scotland and Wales promoted abstinence before the new CMO guidelines)
- Following recent work by Brown and Trickey (2018), more work exploring reasons/barriers to provide advice that are not aligned with the CMO guidelines is needed



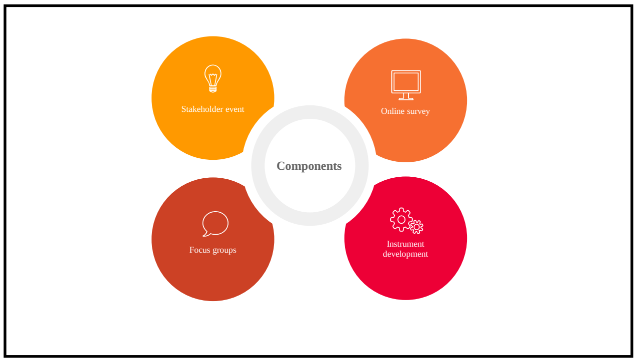
Aim and objectives

The aim of the project is to gain an understanding of practices of assessing pregnant women's alcohol use and communication of the 2016 Alcohol Drinking Guidelines in antenatal care across the UK

- To what extent are UK midwives aware of the CMO guidelines?
- How are the guidelines implemented among UK midwives?
- What challenges do midwives experience when talking to pregnant women about alcohol?
- What opportunities exist to improve discussing alcohol with pregnant women?



2 Methods



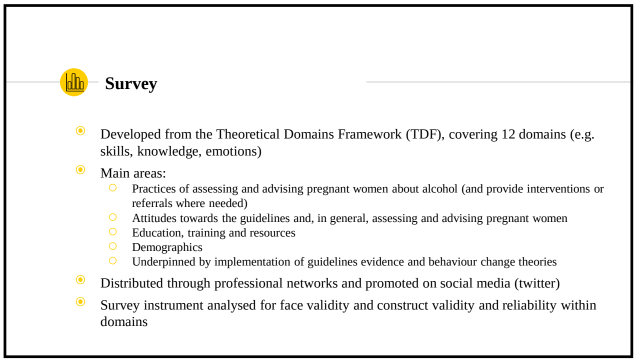
Stakeholder event

Online survey

Components

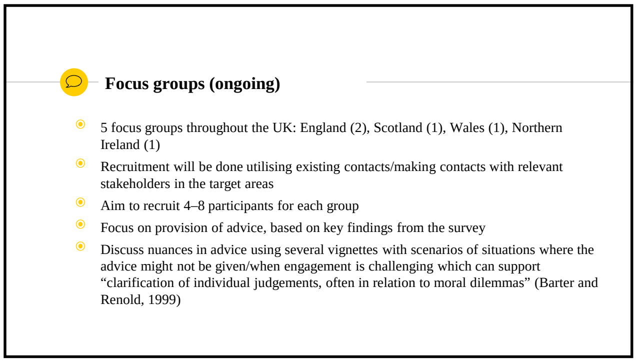
Focus groups

Instrument development



Survey

- Developed from the Theoretical Domains Framework (TDF), covering 12 domains (e.g. skills, knowledge, emotions)
- Main areas:
  - Practices of assessing and advising pregnant women about alcohol (and provide interventions or referrals where needed)
  - Attitudes towards the guidelines and, in general, assessing and advising pregnant women
  - Education, training and resources
  - Demographics
  - Underpinned by implementation of guidelines evidence and behaviour change theories
- Distributed through professional networks and promoted on social media (twitter)
- Survey instrument analysed for face validity and construct validity and reliability within domains



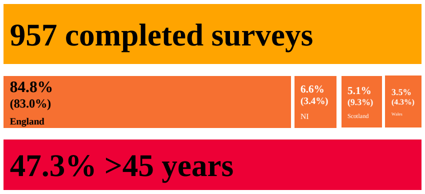
Focus groups (ongoing)

- 5 focus groups throughout the UK: England (2), Scotland (1), Wales (1), Northern Ireland (1)
- Recruitment will be done utilising existing contacts/making contacts with relevant stakeholders in the target areas
- Aim to recruit 4–8 participants for each group
- Focus on provision of advice, based on key findings from the survey
- Discuss nuances in advice using several vignettes with scenarios of situations where the advice might not be given/when engagement is challenging which can support "clarification of individual judgements, often in relation to moral dilemmas" (Barter and Renold, 1999)

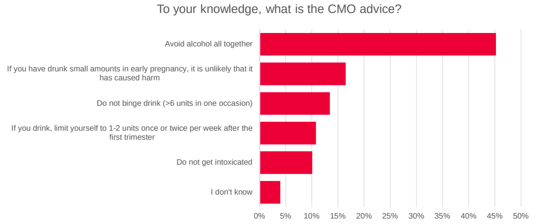
3

Results

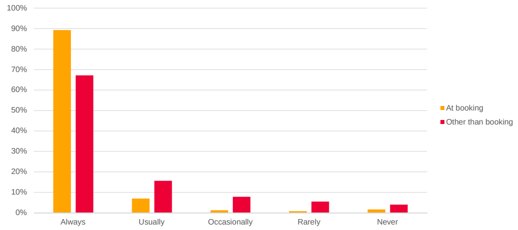
Survey response



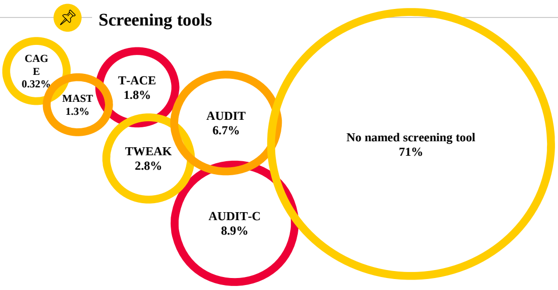
57% aware of the CMO guidelines



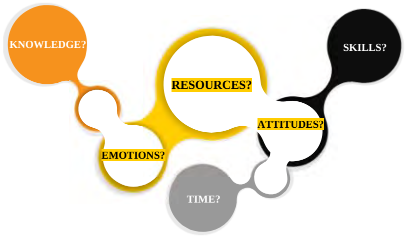
Abstinence advice at booking/other than booking

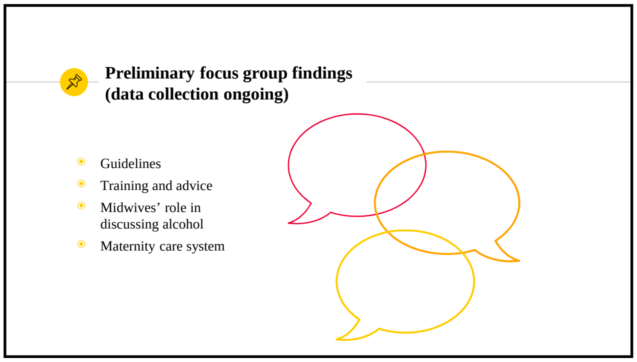


Screening tools



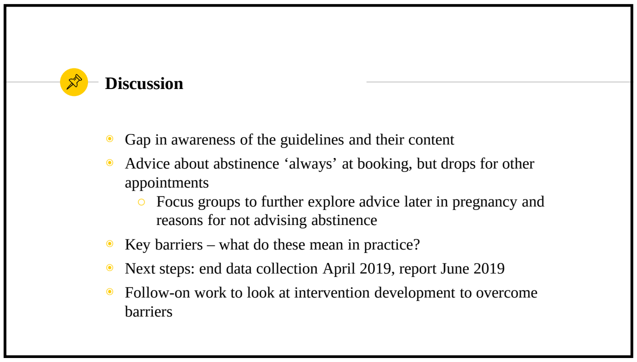
Barriers





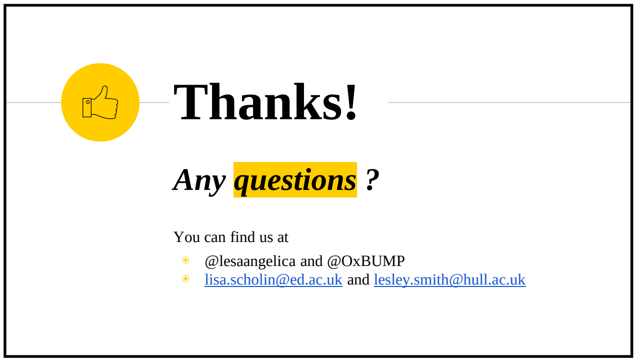
Preliminary focus group findings (data collection ongoing)

- Guidelines
- Training and advice
- Midwives' role in discussing alcohol
- Maternity care system



Discussion

- Gap in awareness of the guidelines and their content
- Advice about abstinence 'always' at booking, but drops for other appointments
  - Focus groups to further explore advice later in pregnancy and reasons for not advising abstinence
- Key barriers – what do these mean in practice?
- Next steps: end data collection April 2019, report June 2019
- Follow-on work to look at intervention development to overcome barriers



Thanks!

Any questions ?

You can find us at

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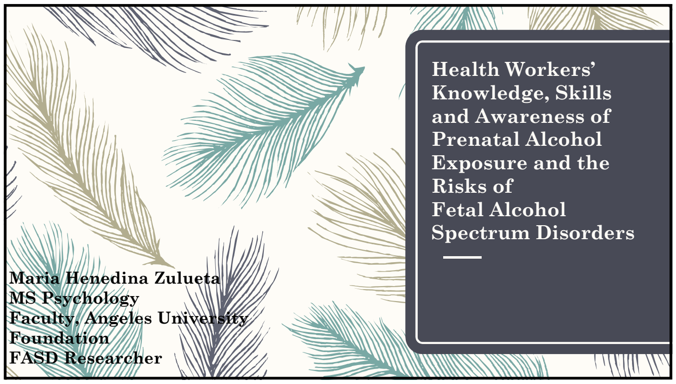
- lisa.scholin@ed.ac.uk and lesley.smith@hull.ac.uk

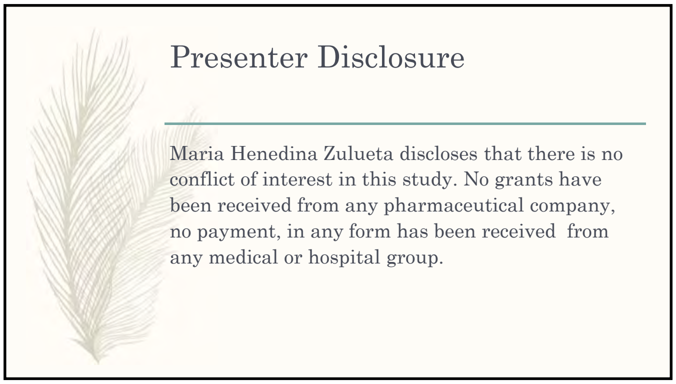
A3d Health Workers' Practices of Maternal Health Care and Awareness of FASD in the Philippiness

Maria H. Zulueta, Olga A. Tulabut



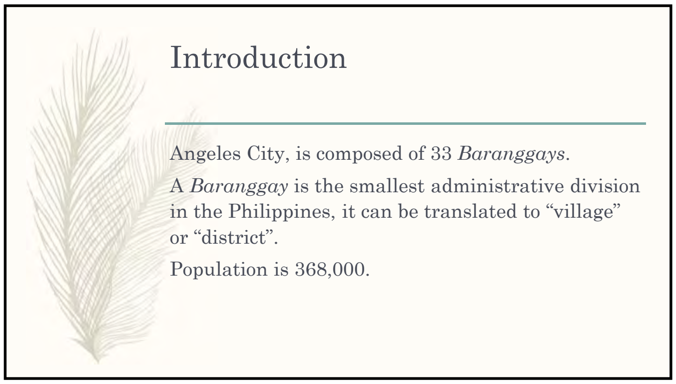
Health Workers' Knowledge, Skills and Awareness of Prenatal Alcohol Exposure and the Risks of Fetal Alcohol Spectrum Disorders

Maria Henedina Zulueta
MS Psychology
Faculty, Angeles University Foundation
FASD Researcher



Presenter Disclosure

Maria Henedina Zulueta discloses that there is no conflict of interest in this study. No grants have been received from any pharmaceutical company, no payment, in any form has been received from any medical or hospital group.

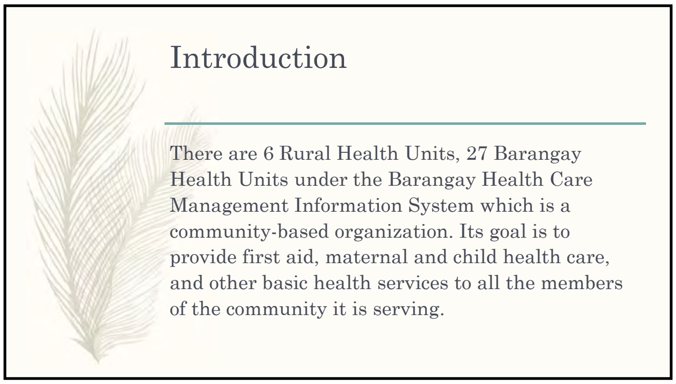


Introduction

Angeles City, is composed of 33 *Baranggays*.

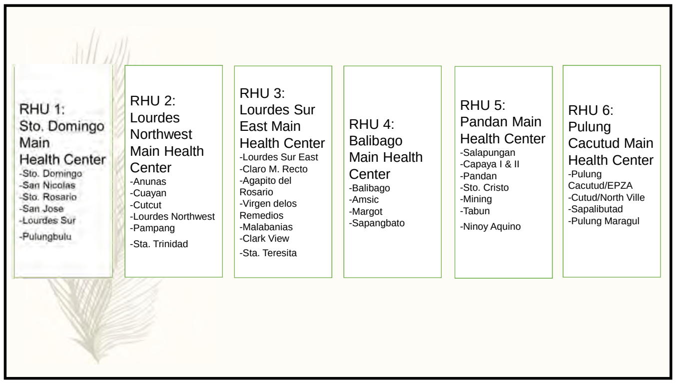
A *Baranggay* is the smallest administrative division in the Philippines, it can be translated to "village" or "district".

Population is 368,000.



Introduction

There are 6 Rural Health Units, 27 Barangay Health Units under the Barangay Health Care Management Information System which is a community-based organization. Its goal is to provide first aid, maternal and child health care, and other basic health services to all the members of the community it is serving.



RHU 1: Sto. Domingo Main Health Center
-Sto. Domingo
-San Nicolas
-Sto. Rosario
-San Jose
-Lourdes Sur
-Pulungbulu

RHU 2: Lourdes Northwest Main Health Center
-Anunas
-Cuayan
-Cutcut
-Lourdes Northwest
-Pampang
-Sta. Trinidad

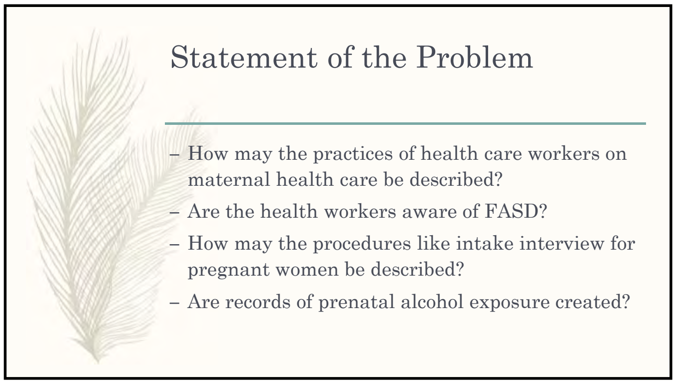
RHU 3: Lourdes Sur East Main Health Center
-Lourdes Sur East
-Claro M. Recto
-Agapito del Rosario
-Virgen delos Remedios
-Malabanias
-Clark View
-Sta. Teresita

RHU 4: Balibago Main Health Center
-Balibago
-Amsic
-Margot
-Sapangbato

RHU 5: Pandan Main Health Center
-Salapungan
-Capaya I & II
-Pandan
-Sto. Cristo
-Mining
-Tabun
-Ninoy Aquino

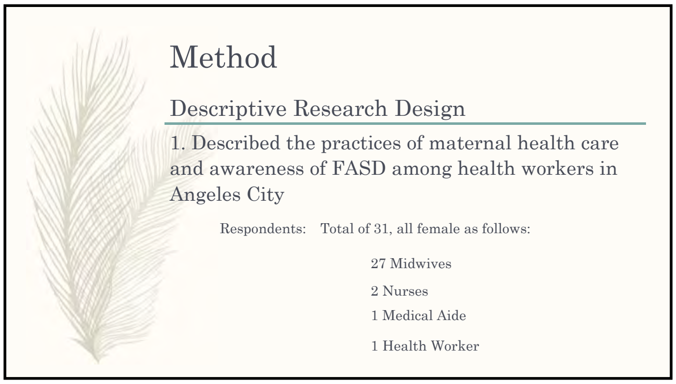
RHU 6: Pulung Cacutud Main Health Center
-Pulung Cacutud/EPZA
-Cutud/North Ville
-Sapalibutad
-Pulung Maragul

clueless



Statement of the Problem

- How may the practices of health care workers on maternal health care be described?
- Are the health workers aware of FASD?
- How may the procedures like intake interview for pregnant women be described?
- Are records of prenatal alcohol exposure created?



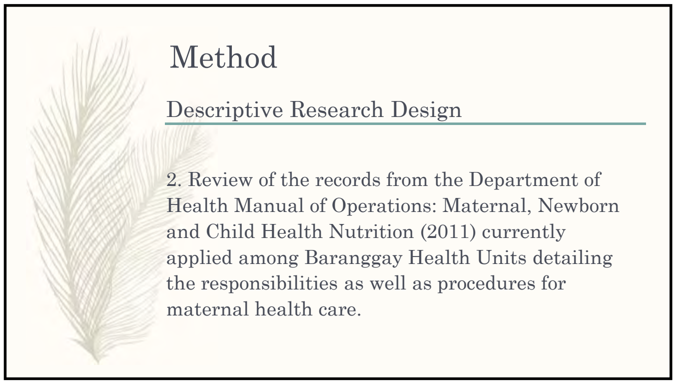
Method

Descriptive Research Design

1. Described the practices of maternal health care and awareness of FASD among health workers in Angeles City

Respondents: Total of 31, all female as follows:

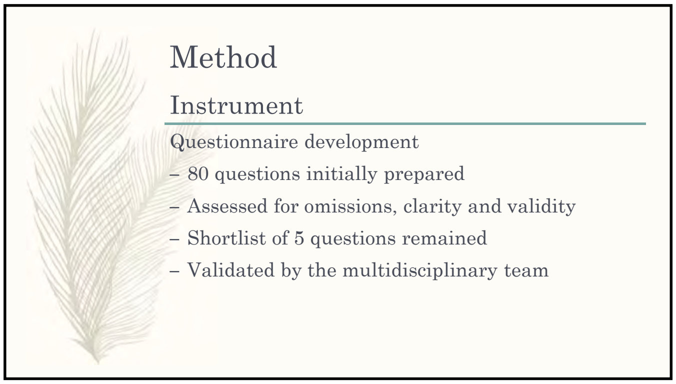
27 Midwives
2 Nurses
1 Medical Aide
1 Health Worker



Method

Descriptive Research Design

2. Review of the records from the Department of Health Manual of Operations: Maternal, Newborn and Child Health Nutrition (2011) currently applied among Baranggay Health Units detailing the responsibilities as well as procedures for maternal health care.

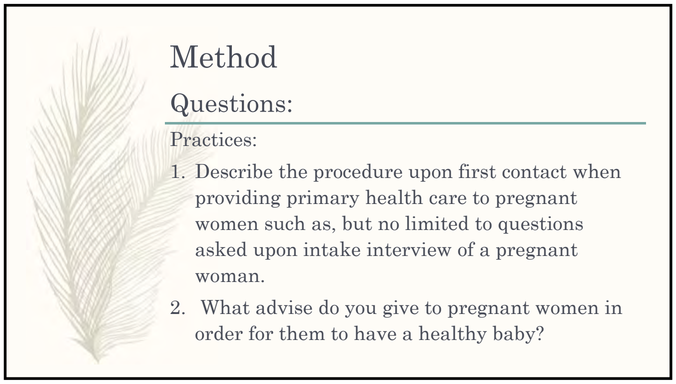


Method

Instrument

Questionnaire development

- 80 questions initially prepared
- Assessed for omissions, clarity and validity
- Shortlist of 5 questions remained
- Validated by the multidisciplinary team

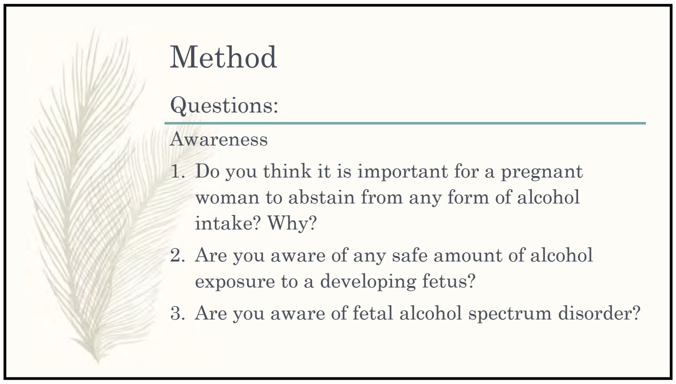


Method

Questions:

Practices:

1. Describe the procedure upon first contact when providing primary health care to pregnant women such as, but no limited to questions asked upon intake interview of a pregnant woman.
2. What advise do you give to pregnant women in order for them to have a healthy baby?

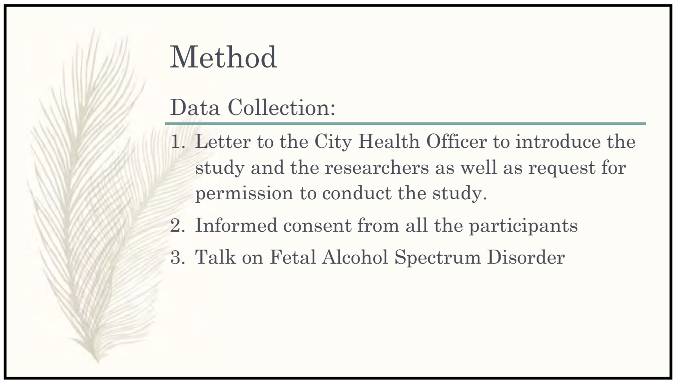


Method

Questions:

Awareness

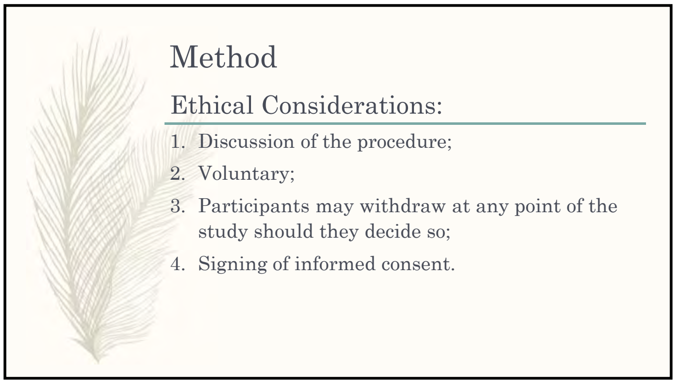
1. Do you think it is important for a pregnant woman to abstain from any form of alcohol intake? Why?
2. Are you aware of any safe amount of alcohol exposure to a developing fetus?
3. Are you aware of fetal alcohol spectrum disorder?



Method

Data Collection:

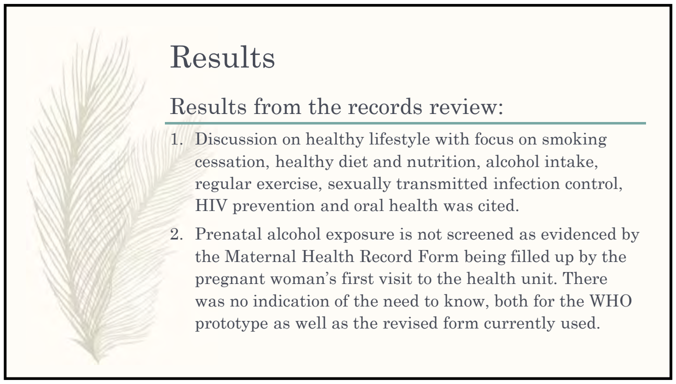
1. Letter to the City Health Officer to introduce the study and the researchers as well as request for permission to conduct the study.
2. Informed consent from all the participants
3. Talk on Fetal Alcohol Spectrum Disorder



Method

Ethical Considerations:

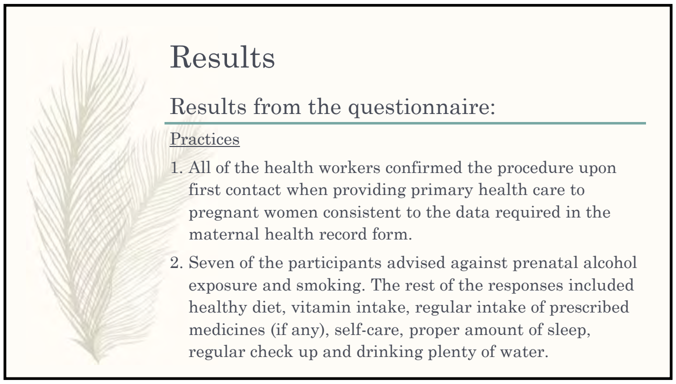
1. Discussion of the procedure;
2. Voluntary;
3. Participants may withdraw at any point of the study should they decide so;
4. Signing of informed consent.



Results

Results from the records review:

1. Discussion on healthy lifestyle with focus on smoking cessation, healthy diet and nutrition, alcohol intake, regular exercise, sexually transmitted infection control, HIV prevention and oral health was cited.
2. Prenatal alcohol exposure is not screened as evidenced by the Maternal Health Record Form being filled up by the pregnant woman's first visit to the health unit. There was no indication of the need to know, both for the WHO prototype as well as the revised form currently used.

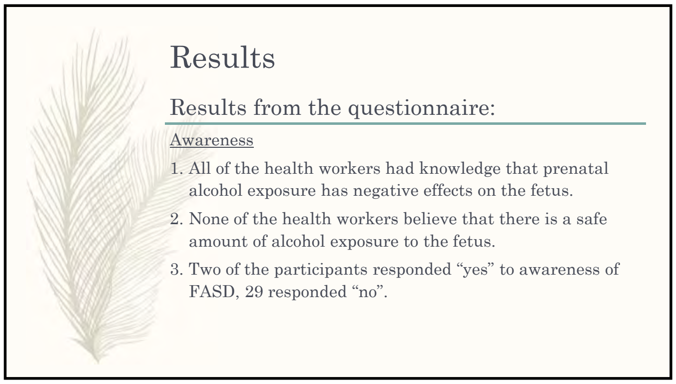


Results

Results from the questionnaire:

Practices

1. All of the health workers confirmed the procedure upon first contact when providing primary health care to pregnant women consistent to the data required in the maternal health record form.
2. Seven of the participants advised against prenatal alcohol exposure and smoking. The rest of the responses included healthy diet, vitamin intake, regular intake of prescribed medicines (if any), self-care, proper amount of sleep, regular check up and drinking plenty of water.

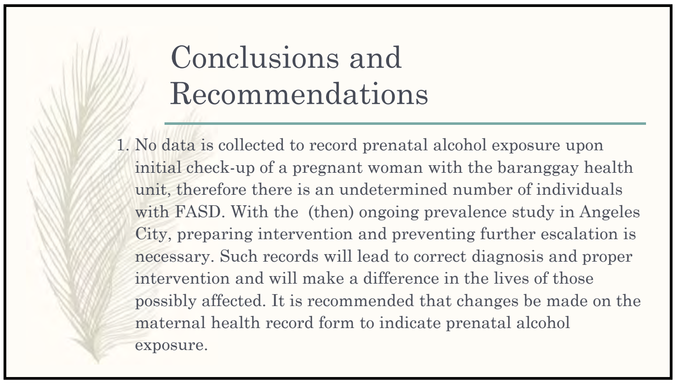


Results

Results from the questionnaire:

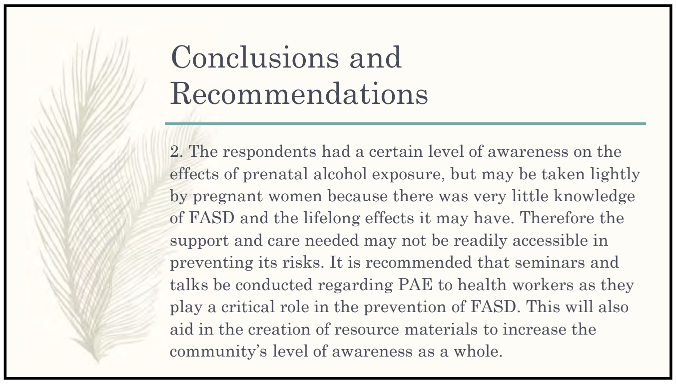
Awareness

1. All of the health workers had knowledge that prenatal alcohol exposure has negative effects on the fetus.
2. None of the health workers believe that there is a safe amount of alcohol exposure to the fetus.
3. Two of the participants responded "yes" to awareness of FASD, 29 responded "no".



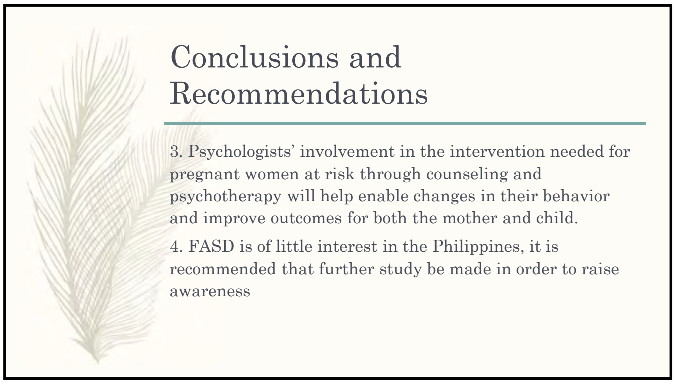
Conclusions and Recommendations

1. No data is collected to record prenatal alcohol exposure upon initial check-up of a pregnant woman with the baranggay health unit, therefore there is an undetermined number of individuals with FASD. With the (then) ongoing prevalence study in Angeles City, preparing intervention and preventing further escalation is necessary. Such records will lead to correct diagnosis and proper intervention and will make a difference in the lives of those possibly affected. It is recommended that changes be made on the maternal health record form to indicate prenatal alcohol exposure.



Conclusions and Recommendations

2. The respondents had a certain level of awareness on the effects of prenatal alcohol exposure, but may be taken lightly by pregnant women because there was very little knowledge of FASD and the lifelong effects it may have. Therefore the support and care needed may not be readily accessible in preventing its risks. It is recommended that seminars and talks be conducted regarding PAE to health workers as they play a critical role in the prevention of FASD. This will also aid in the creation of resource materials to increase the community's level of awareness as a whole.



Conclusions and Recommendations

3. Psychologists' involvement in the intervention needed for pregnant women at risk through counseling and psychotherapy will help enable changes in their behavior and improve outcomes for both the mother and child.

4. FASD is of little interest in the Philippines, it is recommended that further study be made in order to raise awareness

A4a

Primary Cilia Dysfunction as a Novel Pathogenic Mechanism of Birth Defects in FASD

Karen Boschen

Learning Objectives

1. Compare and contrast the “classic” craniofacial defects associated with Fetal Alcohol Syndrome with the subtle midline defects associated with neurulation-stage-specific alcohol exposure
2. Recognize primary cilia dysfunction as a disease state with important implications for normal development

Summary

Neurulation-stage alcohol exposure (gestational day [GD] 8-10 in mice) is associated with midline craniofacial and brain defects that likely arise due to disrupted Sonic hedgehog (Shh) pathway signaling. Shh signaling occurs within primary cilia, organelles that extend from most cells. Perturbed cilia structure or function, such as disruptions due to genetic ciliopathies, result in similar phenotypic outcomes as those seen in patients with prenatal alcohol exposure, suggesting a similarly shared molecular basis. Dysregulation of cilia function in some ciliopathies results in abnormal Shh signaling, leading to structural defects of midline tissue. In this study, we examined whether neurulation-stage alcohol exposure disrupts the Shh pathway and induces a “transient” ciliopathy in the embryo. Female C57BL/6J mice were administered two doses of alcohol (2.9 g/kg/dose) or vehicle on GD9 (equivalent to the early fourth week of human development). Twelve hours later, the rostroventral region of the neural tube (RVNT) that gives rise to midline brain regions altered by alcohol exposure was dissected and analyzed. Reductions in Shh and the transcription factor Gli1, the cell cycle gene Ccnd1, the ratio of Gli3 isoforms in the full-length activator state, and cell layer volume were observed, demonstrating significant alterations of the Shh pathway. These changes were preceded by differential expression of multiple genes related to ciliogenesis, intraflagellar protein trafficking, and cilia stability. These data suggest alcohol-induced alterations to cilia function in the neural tube as a novel pathway through which ethanol causes craniofacial and neuroanatomical dysmorphologies. Future work will investigate whether neurulation-stage alcohol alters post-translational modifications to ciliary tubulin or cell cycle kinetics in the RVNT. Supported by NIAAA grants U01AA021651 to SEP and F32AA026479 to KEB and conducted as part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD).

A4b

Alcohol Exposure Around Conception Impairs Heart Function and Alters Estrogen Regulated Genes in Female Offspring

Karen Moritz

Learning Objectives

1. Demonstrate the effects of alcohol around conception on blood pressure and heart function in male and female offspring
2. Evaluate the role of sex hormones in the development of cardiovascular dysfunction

Objectives

Alcohol exposure during pregnancy is known to impair cardiovascular function in offspring. While many women decrease alcohol consumption during pregnancy, exposure during the periconceptional period is common. This study aimed to explore cardiovascular function following periconceptional alcohol (PC:EtOH) exposure in a rat model. We hypothesised that PC:EtOH would induce cardiac dysfunction and that outcomes may be sex specific due to differences in cardiac estrogen signalling in males and females.

Methods

Sprague Dawley rats received a control or 12.5%v/v ethanol liquid diet from four days before until four days after mating (PC:EtOH). Offspring were born and cardiovascular function assessed. Langendorff pressure-volume experiments were performed at 5 months, blood pressure and activity analysis (via radio-telemetry) at 12 months and heart function (echocardiography) at 12-14 months. At 18 months, left ventricle (LV) and blood samples were collected for analysis. LV expression of the estrogen receptor (Esr1), the angiotensin receptor type 1 (Agtr1a) and Hsp90a was measured by QPCR and plasma estrogen concentrations measured by ELISA.

Results

Female but not male PC:EtOH offspring had increased left ventricular internal diameter during systole (LVIDs, $P<0.05$), reduced cardiac output ($P<0.05$) and a trend toward reduced fractional shortening ($P=0.08$). Cardiac pressure-volume relationships and blood pressure were not altered in either sex although telemetry measurements showed that female offspring exposed to PC:EtOH had higher levels of activity ($P<0.05$). PC:EtOH increased LV ESR1 ($P_{Trt}<0.05$), HSP90a and Agtr1a expression ($P_{Int}<0.05$) with post hoc analysis indicating an increase in females only ($P<0.01$). PC:EtOH increased plasma estrogen concetrations in females ($P<0.05$).

Conclusion

PC:EtOH has long lasting detrimental effects on in vivo heart function of female offspring, associated with altered cardiac expression of estrogen related genes. Given heart function in younger animals was largely unaffected by PC:EtOH, the results suggest hormonal influences and age may be underlying this dysfunction. This is of interest given the increased incidence of cardiovascular disease in post-menopausal women and suggests that PC:EtOH can influence progression of age related heart dysfunction.

A4c

PAE Reduces 5-HT Concentration in Mouse Intestinal Muscle and Mucosa

Katarzyna Kowalska

Authors: Katarzyna Dylag, Paul Gard, Bhavik Patel

Learning Objectives

1. Get acquinted with the impaired gut function among individuals with FASD
2. Acquire knowledge about an example animal model of FASD

Summary

The influence of prenatal alcohol exposure on the serotoninergic system in the brain has been well studied, however its influence on the serotoninergic system in the gastrointestinal system remains unknown. The objective of the study was to use a mouse model of prenatal alcohol exposure to investigate the effects on serotonin and its metabolites and precursors in colonic tissue. This study used treatment of mouse breeding harems with 5% ethanol with saccharin via drinking water throughout pregnancy and compared the results with a saccharin control group. Tryptophan, serotonin (5-HT) and 5- hydroxyindoleacetic acid (5-HIAA) concentrations were measured in the longitudinal muscle myenteric plexus (LMMP) and mucosa of intestinal tissue by high- performance liquid chromatography (HPLC). Decreased 5-HT concentrations in mucosa and LMMP (females only) were observed in prenatally exposed mice compared to controls. Increases in mucosal and LMMP tryptophan concentration were only observed in prenatally exposed female mice.

In conclusion, prenatal alcohol exposure causes a decrease in conversion of tryptophan to 5-HT in both muscle and mucosa although the effect is more pronounced in females. The observed sex difference may be related to changes associated with the estrous cycle.

A4d

Fetal Alcohol Exposures Promote the Development of Aggressive Tumors in the Endocrine Glands

Dipak Sarkar

Learning Objectives

1. Does fetal alcohol exposure increase the susceptible to develop cancer?
2. What are the tissues susceptible to develop cancer?
3. How does alcohol exposure program the fetal gland to increase their susceptibility to develop cancer?

Summary

There have been several studies demonstrating that alcohol abuse promotes development of aggressive tumors in breast, prostate, pancreas, and colon tissues in human patients. Whether fetal alcohol exposures promote development of aggressive tumors in the offspring during adult period are not well studied. Using rat animal model of fetal alcohol exposure, we studied the susceptibility of the growth of aggressive tumors in the mammary, prostate and the pituitary glands during the adult period.

Pregnant laboratory rats were fed between gestational days 7 and 21 with a liquid diet containing alcohol, pair-fed with isocaloric liquid diet, or fed ad libitum with rat chow. Between 50 to 90 days of age, fetal alcohol-exposed and control rats were given a dose of N-Nitroso-N-methylurea (NMU) to induce mammary cancer growth in female offspring, NMU and testosterone to induce prostate tumor in male offspring, or ovariectomized and implanted with an estrogen capsule to induce pituitary tumors in female offspring. Mammary glands, prostate glands or pituitary tissues were processed for determination of biochemical changes and histopathologies for tumor characterization.

In the case of mammary tumor development, overall tumor multiplicity was greater in the offspring from the alcohol-fed group compared to the control groups, indicating a decrease in tumor latency. Alcohol-exposed animals developed more malignant tumors and more estrogen receptor-α-negative tumors relative to the control groups. In the case of prostate tumorigenesis, prenatal alcohol-exposed rats showed histological evidence for high-grade prostatic intraepithelial neoplasia (PIN) primarily in the ventral prostate, whereas control animals showed only low-grade PIN. Prenatally ethanol-exposed rats treated with carcinogen and testosterone also showed increased number of proliferative cells and androgen receptor with concomitant decreased levels of tumor suppressor proteins in the ventral prostate. Our results also show that pituitaries of fetal alcohol-exposed rats upon estrogen challenge developed prolactin-secreting tumors (prolactinomas) that were hemorrhagic and often penetrated into the surrounding tissue. Pituitary tumors of fetal alcohol-exposed rats produced higher levels of hemorrhage-associated genes and proteins and multipotency genes and proteins. Cells of pituitary tumor of fetal alcohol exposed rat grew into tumor spheres in ultra-low attachment plate, expressed multipotency genes, formed an increased number of colonies, showed enhanced cell migration, and induced solid tumors following inoculation in immunodeficient mice.

These data suggest that fetal alcohol exposure programs some of the endocrine tissue to develop aggressive tumors. Although the exact mechanism for the tumor promotion effect of fetal alcohol is not clearly established, but our preliminary studies suggest the possibility that fetal alcohol programs some of these endocrine cells acquire stemness that enhances neoplastic properties for developing aggressive tumors.

A5a

Developmental Traits and Characteristics of Children with FASD: An Interactive Workshop over the Meaning of Population-Based Data from the Recent Collaborative USA Prevalence Studies and Two Decades of Experience in South Africa

Philip A. May

Learning Objectives

1. Examine results from two, large, general-population studies of children with FASD and typically-developing children in the USA and South Africa
2. Recognize variability among individual children within both studies and trends over time in South Africa
3. Reflect on the meaning of the data and trends in these studies for further appreciation of individual variation among children and across cultures

Summary

This is an interactive discussion with members of the audience to address a very important question. What are the common characteristics and individual variations in development among 5 to 7 year olds in two countries found in population-based studies of FASD and what evidence do we have across the lifespan? How do these traits inform us and how can they/should they be interpreted at the individual, familial, and societal level within any specific culture, city, or country? The discussion will begin with a presentation of the details of multivariate descriptive data from recent population-based studies of individuals with FASD and controls from general populations in the USA and South Africa and the USA and then move to more targeted explorations which have been completed in these populations. These data have broad applicability to many human populations.

A5b PAE as Risk Factor for ADHD: Results of a Brazilian Longitudinal Cohort

Erikson F. Furtado

Authors: Erikson F. Furtado, Daniel Pagnin, Maria Luiza Zamboni-Grecco

Learning Objectives:

1. Recognize PAE as an important risk factor for ADHD
2. Identify and criticize common flaws in FASD outcome studies

Background

Women's alcohol use has increased as a function of economic development and changing gender roles. This extended to childbearing age, including pregnancy. One in 10 pregnant women consume alcohol in USA. In Brazil, one in five pregnant women reported drinking at a risky level for fetal damage, according to screening methods (T-ACE) for problematic alcohol use. Detrimental consequences of alcohol include a range of developmental problems, presently identified as fetal alcohol spectrum disorders (FASD).Prenatal alcohol exposure (PAE) is a risk factor for mental disorders in childhood. We investigated the association between PAE and child psychiatric disorders, with a focus on Attention Deficit Hyperactivity Disorder (ADHD), controlling for confounding factors.

Methods

Longitudinal prospective study of a Brazilian cohort of 449 healthy pregnant women and their offspring. Pregnancy data included, frequency/quantity of alcohol use per gestational trimester, binge drinking episodes, mental health status, general and gestational health and sociodemographic variables. At 12-year follow-up, 81 mother-child pairs were interviewed. K-SADS-PL interview (Kiddie Schedule for Affective Disorders and Schizophrenia–Present and Lifetime Version) was used to assess current children's mental disorders. Diagnoses were arranged in externalizing/internalizing disorders. Once an association with externalizing disorders has been confirmed, a logistic regression was used to test the influence of alcohol consumption in all trimesters and binge drinking on the occurrence of attention deficit hyperactivity disorder (ADHD), controlling for child's sex and mother's mental disorder.

Results

The most prevalent diagnose was ADHD (21/81; 25.9%). Maternal current mental disorder, binge drinking in pregnancy, or alcohol consumption in all trimesters, explained 7.3%, 5.3%, 11.6%, and 9% of ADHD variance. ADHD was five times more likely associated with binge drinking during pregnancy or alcohol consumption in all trimesters of pregnancy. Those alcohol use patterns increased the variance of ADHD by 19%.

Conclusions

Episodic binge drinking (alcohol use of three or more drinks per occasion) during pregnancy significantly increased children's risk for ADHD. Binge drinking at any time during pregnancy or alcohol consumption in all trimesters enhanced the risk for ADHD in children at age 12 years by five times. Our study also suggests that low-moderate doses of alcohol have a risk effect when consumed in a regular manner; that is, in all trimesters of pregnancy. This implies that the risk effect of low-moderate doses of alcohol during pregnancy should be assessed in combination with the length of alcohol use during pregnancy.

A6a

Two by Two: Describing Twins with PAE in Manitoba

Sandra Marles, Shelley Proven, Kellsey Scheepers, Sheryle Marshall, Ana Hanlon-Dearman

Learning Objectives:

1. Summarize the twin study literature and determine what it tells us about PAE in twins
2. Analyze our twin pairs, their assessment and diagnostic outcomes, including similarities and differences
3. Reflect on the literature and our data with our audience and learn about other clinics' and families' experience with twins with PAE

Summary

Twin studies give us a glimpse into the contribution of our genes and our environment to the way we develop. However, twins with prenatal alcohol exposure/FASD are infrequently described. Twin studies help us understand the contributions of both genetic and environmental influences on various traits. At the Manitoba FASD Centre, we have a cohort of 33 twin pairs, both identical and fraternal, that received a multidisciplinary assessment in our clinic from 2000-2018. These twin pairs offer a valuable opportunity to better understand the relative impacts of familial and environmental influences, as well as the impact of prenatal alcohol exposure on individual outcomes.

There are two types of twins: identical (monozygous or MZT) and fraternal (dizygous or DZT). Identical twins are formed from the early division of a single fertilized egg. They are the most closely related of all family relationships but there are still genetic differences. Segal (2011) lists some of the genetic variations that will be described in the presentation. The incidence is fairly uniform amongst all populations: about 4/1000. Fraternal twins (dizygous or DZT) result from the fertilization of 2 released eggs by 2 sperm. There is a variable incidence of DZT in different populations.

This presentation will describe our cohort of twins as well as the results of the assessment of our multidisciplinary team including relevant findings from physical examination, significant impairments of brain domains and medical history.

A6b

FASD Diagnostic Discordance among Twins and Siblings

Susan Astley Hemingway, Julian Davies, Tracy Jirikowic, Erin Olson, John C. Thorne

Authors: Susan Astley Hemingway, Julia M Bledsoe MD, Julian K Davies, Tracy Jirikowic, Erin M Olson, John C. Thorne

Learning Objectives:

1. Describe how often fetuses with virtually identical prenatal alcohol exposures present with discordant FASD diagnostic outcomes
2. Recognize that risk of FASD is not just dependent on the level of prenatal alcohol exposure—fetal genetics plays an important role
3. Be able to explain that we currently do not know which fetuses are especially vulnerable to the adverse effects of prenatal alcohol exposure. Thus, to protect all fetuses, especially the most genetically vulnerable, the only safe amount to drink is none at all

Open Access Online Publication:
Hemingway SJA, Bledsoe JM, Davies JK, Brooks A, Jirikowic T, Olson EM, and Thorne JC. Twin study confirms virtually identical prenatal alcohol exposures can lead to markedly different fetal alcohol spectrum disorder outcomes-fetal genetics influences fetal vulnerability. Advances in Pediatric Research 5:23. doi:10.24105/apr.2019.5.23

https://www.longdom.org/articles/twin-study-confirms-virtually-identical-prenatal-alcohol-exposures-can-lead-to-markedly-different-fetal-alcohol-spectrum.pdf

Background

Risk of fetal alcohol spectrum disorder (FASD) is not based solely on the timing and level of prenatal alcohol exposure (PAE). The effects of teratogens can be modified by genetic differences in fetal susceptibility and resistance. This is best illustrated in twins.

Objective

To compare the prevalence and magnitude of pairwise discordance in FASD diagnoses across monozygotic twins, dizygotic twins, full-siblings, and half-siblings sharing a common birth mother.

Methods

Data from the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network clinical database was used. Sibling pairs were matched on age and PAE, raised together, and diagnosed by the same University of Washington interdisciplinary team using the FASD 4-Digit Code. This design sought to assess and isolate the role of genetics on fetal vulnerability/resistance to the teratogenic effects of PAE by eliminating or minimizing pairwise discordance in PAE and other prenatal/postnatal risk factors.

Results

As genetic relatedness between siblings decreased from 100% to 50% to 50% to 25% across the four groups (9 monozygotic twin pairs, 39 dizygotic twin pairs, 27 full-sibling pairs, and 9 half-sibling pairs sharing the same birth mother), the prevalence of pairwise discordance in FASD diagnoses increased from 0% to 44% to 59% to 78%. Despite virtually identical PAE, 4 pairs of dizygotic twins had FASD diagnoses at opposite ends of the fetal alcohol spectrum—Partial Fetal Alcohol Syndrome versus Neurobehavioral Disorder/Alcohol-Exposed.

Conclusion

Despite virtually identical PAE, fetuses can experience vastly different FASD outcomes. Thus, to protect all fetuses, especially the most genetically vulnerable, the only safe amount to drink is none at all.

References

Astley SJ. Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code. J Popul Ther Clin Pharmacol Vol 20(3):e416-467;November 15, 2013.

Astley SJ. Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, 3rd edition. 2004, University of Washington Publication Services, Seattle WA.

A7

The Tipping Point: Translation of Research Outcomes from the First Prevalence Study of FASD Among Sentenced Youth in Australia Is Driving Policy Initiatives for Health, Child Protection and Justice

Raewyn Mutch, Rochelle Watkins

Authors: Raewym Mutch, Hayley Passmore, Natalie Kippin, Sharynne Hamilton, Rochelle Watkins

Learning Objectives

1. Describe, discuss and demonstrate how mixed-methods research delineates the nature of Tipping Points
2. Reflect and discuss the hierarchy and practical application when translating Tipping Points to change practice and policy
3. Demonstrate new research-informed training resources for custodial officers; recognising and responding to neurodevelopmental difficulties

Objectives

Neurodevelopmental impairments including FASD can predispose young people to engagement with the law. This presentation will discuss how translation of research outcomes from the first prevalence study to estimate FASD among sentenced young people in Australia has been a tipping point for change; change across health, child protection and justice policy and practices. Key drivers for change, their hierarchy, utility and capacity for generalisation to other jurisdictions will be described. Training resources developed for the custodial workforce to recognise and care for individuals with neurodevelopmental difficulties will be demonstrated. The training resources and prevalence study activities were powerful mechanisms for engagement, and assisted with tipping system change. Qualitative yarning considered the impact of the study on participants and their long term hopes.

Methods

Screening and multidisciplinary neurodevelopmental clinical assessments were completed on young people, aged 10 years to 17 years and 11 months, and sentenced to detention in the only youth detention centre in Western Australia. The clinical assessments occurred from May 2015 to December 2016. FASD was diagnosed according to the Australian Guide to the Diagnosis of FASD. Development of training resources for custodial officers to better understand and care for young people with neurocognitive impairment occurred in parallel to the prevalence study. Training resource trial and evaluation is almost complete. Yarning was undertaken to qualitatively assess the impact of the study on the young people and their circles of care.

The 2-3 clinical cases demonstrate the possible beneficial effects of speech-language therapy for children with FASD.

Results

99 young people completed a full assessment (88% of those consented; 60% of the 166 approached to participate); 93% were male and 74% were Aboriginal. These young people were a representative sample of all young people in detention in Western Australia. 88 young people (89%) had at least one domain of severe neurodevelopmental impairment, and 36 were diagnosed with FASD, a prevalence of 36% (95% CI 27% to 46%). The majority of young people with FASD had severe impairment in academic, attention, executive functioning and/or language domains.

Conclusions

This study documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of which had not been previously identified. These findings highlight the vulnerability of young people within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation. Translation of the research outcomes became a tipping point for change to policy and practice. There is now evidence to support the recommendation for comprehensive neurodevelopmental and health assessments of all young people engaged with the justice system. There are now resources to train custodial officers to recognise and better care for individuals with impairment. There is culturally secure mechanisms for safe yarning and story-telling to transform the care of young people in detention. Translation of the study outcomes and greater recognition of FASD is now driving change for policy and practice for police, child protection, education, health and law.

A8

Assessing the Neurocognitive Function in People with FASD: Subtleties of Presentation and Lessons from Three European FASD Specialist Clinics for Diagnosis and Management

Raja Mukherjee, Alexandra Carlisle, Alexandra Livesey, Jennifer Shields, Gro Løhaugen

Learning Objectives

1. Identify the strengths and weaknesses of neurocognitive testing in FASD
2. Explore the toolkit of testing and facilitate discussion about bespoke testing toolkits for FASD

Summary

The broad neurocognitive deficits associated with Fetal alcohol spectrum disorders are generally well known and established. Research over the last 30 years have identified deficits in intellectual function, memory, executive function, adaptive ability as just a few of the areas that are impaired in this group. These functional deficits are corroborated by structural and functional brain scanning data highlighting that interconnectivity remains an issue. Despite this, there remains very few highly specialist neuro psychological centres that are regularly assessing the broad neurological and neurodevelopmental profile associated with FASD in Europe. This means that the subtleties of presentation across a range of tools remains uncertain to many. These lead to diagnostic and therapeutic quandaries.

This workshop will be led by specialist psychologists and practitioners from three established clinics in Europe based in Norway, Scotland and England. All offer comprehensive assessment of individuals. The workshop will highlight and present practice-based knowledge and emerging data from these clinics as to which neuropsychological tests are most sensitive and most useful in identifying the range of deficits seen. The facilitators will share clinical experience of which test offer the most utility form a diagnostic perspective but also therapeutically. Ceiling effects and discussion of clinical utility will take place. These will be combined with case discussions and facilitated presentations to answer some of the more difficult and subtle issues found with FASD diagnosis and management. Based on the extensive experience of these centres is hoped that those attending the workshop will gain a better understanding of how to assess this complex condition at local, regional and national level requirements.

A9

Still Fighting for a Future: Where We Were and Where We Are Now. Exploring 15 Years of Progress on FASD in Canada

Kelly Harding, Dorothy Reid, Shana Mohr, Jan Lutke, Marsha Wilson

Learning Objectives

1. Identify and analyze recommended Actions for Change cited in the 2004 Fighting for a Future symposia proceedings
2. Critically analyze and discuss developments in the 6 key areas identified and share best practices and promising approaches to supporting individuals with FASD across the lifespan
3. Equip individuals with FASD and parents with information on what works to assist in advocating for services and supports
4. Identify current gaps in the field and the need for ongoing, applied research that addresses areas that have made minimal progress in the past 15 years
5. Highlight the importance of including caregivers in research

Abstract

In 2004, a geographically diverse group of birth, foster, and adoptive parents/grandparents of adolescents and adults diagnosed with FASD from British Columbia came together to discuss the complexity of FASD and the needs for supports and services to improve outcome for individuals with FASD. Six broad areas of need were identified with specific calls for action to change identified within each area. The six areas were: homelessness; finances; physical and mental health; education, programming and employment; legal and addictions; and family support. In this presentation, we will highlight the changes that have occurred in these areas in the past 15 years, summarizing and triangulating findings collected from multiple data sources including: an environmental scan of programs and services across Canada; a literature review; and a historical document review of pertinent CanFASD Research Network reports (e.g., annual reports). These components will be synthesized to discuss the progress made, as well as the progress that is still needed, to support individuals with FASD and their families across the lifespan. Areas which continue to need research will be identified. Best practices and promising approaches will be highlighted, and implications for promoting hope for the future in families raising individuals with FASD will be discussed.

For more information please see Appendix I - Fighting for a Future: FASD and 'the system': adolescents, adults and their families and the state of affairs. Proceedings from a two-day Forum: June 19 & 20, 2004; Surrey, British Columbia

A10

Addressing FASD in Remote and Urban Indigenous Communities: Rewards and Challenges

Elizabeth Elliott, Christine Loock

Learning Objectives

1. Discuss varying patterns of reported alcohol use in pregnancy in urban vs rural/ remote, non-Indigenous/Indigenous populations, and risk /protective factors effecting occurrence/ recurrence of FASD
2. Review processes of engagement, forming partnerships, community consultation and seeking consent for research
3. Identify the challenges and rewards of research with Indigenous communities

Summary

FASD is common in Indigenous communities where people have experienced historic trauma and continuing disadvantage. FASD is increasing recognised as a cause of developmental, learning and behavioural problems which in turn impact social cohesion and continuation of language and culture through generations. We will present Studies prioritised by and conducted in partnership with Aboriginal people will be presented. The interactive, case-based presentation involving Indigenous presenters will use film, music, art and case examples from remote and urban settings on FASD prevalence, consent-seeking, management of behavioural problems and education to illustrate the challenges and rewards of research with Indigenous people and its benefits for identification, management and prevention of FASD.

B1a

YOUNG INVESTIGATOR

The Influence of Moderate Prenatal Ethanol Exposure on the Central Amygdala: An Investigation of CRF1 ReceptorRegulated GABAergic Transmission in Adolescents

Siara Rouzer

THE INFLUENCE OF MODERATE PRENATAL ETHANOL EXPOSURE ON THE CENTRAL AMYGDALA: AN INVESTIGATION OF CRF1 RECEPTOR-REGULATED GABAERGIC TRANSMISSION IN ADOLESCENTS.

Siara Rouzer, M.S

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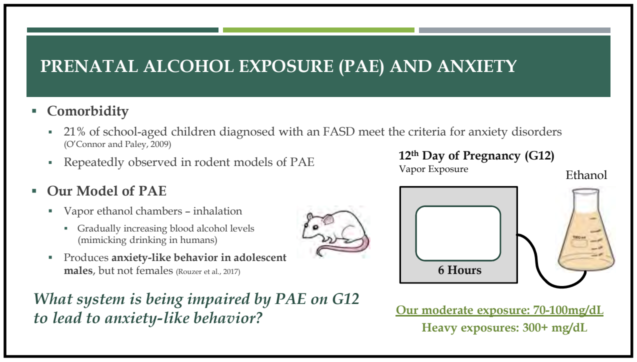
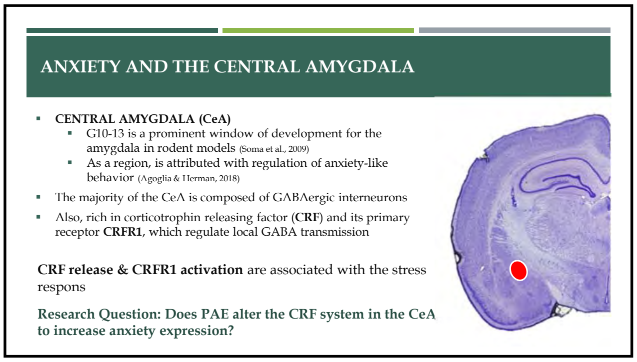


PRENATAL ALCOHOL EXPOSURE (PAE) AND ANXIETY

- **Comorbidity**
  - 21% of school-aged children diagnosed with an FASD meet the criteria for anxiety disorders (O'Connor and Paley, 2009)
  - Repeatedly observed in rodent models of PAE
- **Our Model of PAE**
  - Vapor ethanol chambers – inhalation
    - Gradually increasing blood alcohol levels (mimicking drinking in humans)
  - Produces **anxiety-like behavior in adolescent males**, but not females (Rouzer et al., 2017)

What system is being impaired by PAE on G12 to lead to anxiety-like behavior?

Our moderate exposure: 70-100mg/dL
Heavy exposures: 300+ mg/dL

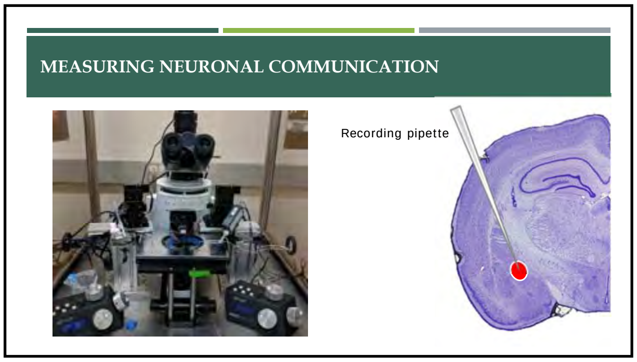


ANXIETY AND THE CENTRAL AMYGDALA

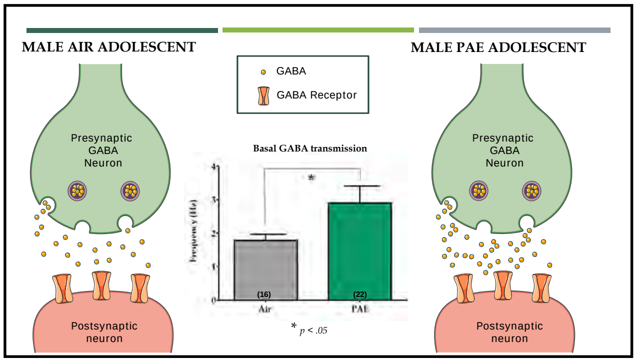
- CENTRAL AMYGDALA (CeA)
  - G10-13 is a prominent window of development for the amygdala in rodent models (Soma et al., 2009)
  - As a region, is attributed with regulation of anxiety-like behavior (Agoglia & Herman, 2018)
- The majority of the CeA is composed of GABAergic interneurons
- Also, rich in corticotrophin releasing factor (**CRF**) and its primary receptor **CRFR1**, which regulate local GABA transmission

CRF release & CRFR1 activation are associated with the stress respons

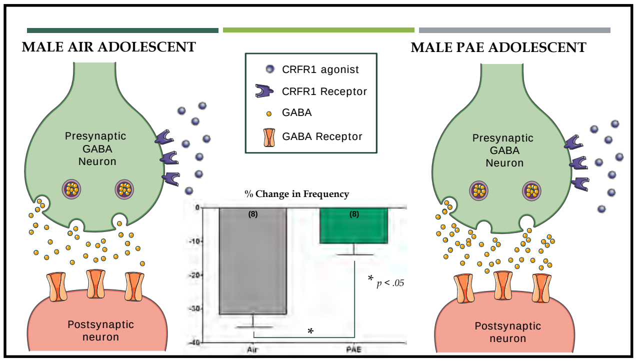
Research Question: Does PAE alter the CRF system in the CeA to increase anxiety expression?



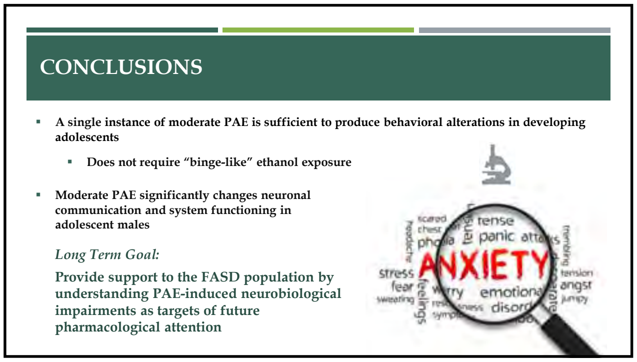
MEASURING NEURONAL COMMUNICATION



* $p < .05$



* $p < .05$

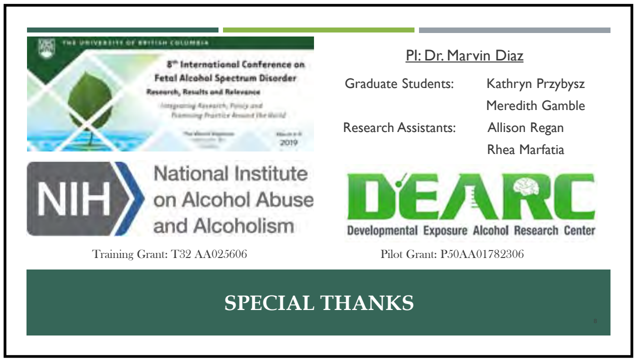


CONCLUSIONS

- A single instance of moderate PAE is sufficient to produce behavioral alterations in developing adolescents
    - Does not require "binge-like" ethanol exposure
- Moderate PAE significantly changes neuronal communication and system functioning in adolescent males

Long Term Goal:

Provide support to the FASD population by understanding PAE-induced neurobiological impairments as targets of future pharmacological attention



PI: Dr. Marvin Diaz

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Meredith Gamble

Research Assistants: Allison Regan
Rhea Marfatia

Training Grant: T32 AA025606

Pilot Grant: P50AA01782306

SPECIAL THANKS

THE INFLUENCE OF MODERATE PRENATAL ETHANOL EXPOSURE ON THE CENTRAL AMYGDALA: AN INVESTIGATION OF CRF1 RECEPTOR-REGULATED GABAERGIC TRANSMISSION IN ADOLESCENTS.

Siara Rouzer, M.S

Alcohol & Development Lab
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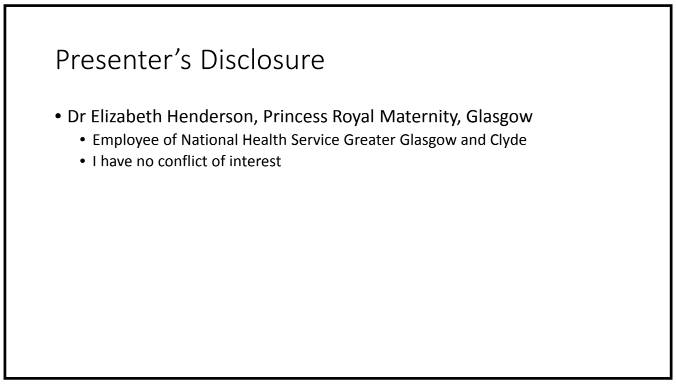
B1b

Identifying the Pattern and Prevalence of Alcohol Consumption in Pregnancy Using Infant Biomarkers and Confidential Postnatal Maternal Interview

Elizabeth Henderson

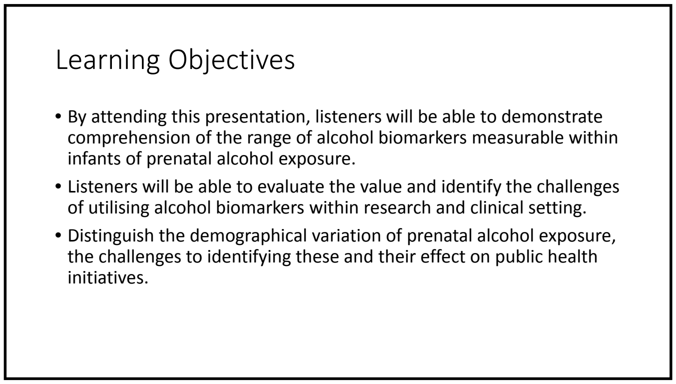
Identifying the pattern and prevalence of alcohol consumption in pregnancy

Dr Elizabeth Henderson, Princess Royal Maternity, Glasgow
Dr Helen Mactier, Princess Royal Maternity, Glasgow
Donata Favretto, University Hospital of Padova
David Young, University of Strathclyde



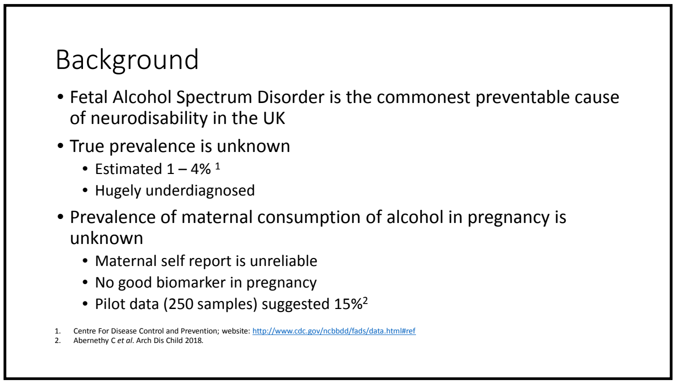
Presenter’s Disclosure

- Dr Elizabeth Henderson, Princess Royal Maternity, Glasgow
  - Employee of National Health Service Greater Glasgow and Clyde
  - I have no conflict of interest



Learning Objectives

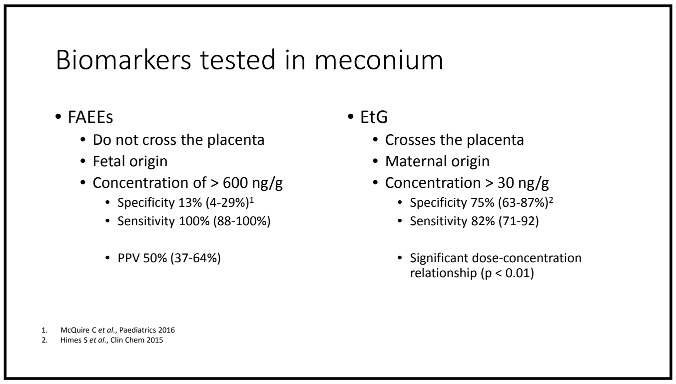
- By attending this presentation, listeners will be able to demonstrate comprehension of the range of alcohol biomarkers measurable within infants of prenatal alcohol exposure.
- Listeners will be able to evaluate the value and identify the challenges of utilising alcohol biomarkers within research and clinical setting.
- Distinguish the demographical variation of prenatal alcohol exposure, the challenges to identifying these and their effect on public health initiatives.



Background

- Fetal Alcohol Spectrum Disorder is the commonest preventable cause of neurodisability in the UK
- True prevalence is unknown
  - Estimated 1 – 4% [1]
  - Hugely underdiagnosed
- Prevalence of maternal consumption of alcohol in pregnancy is unknown
  - Maternal self report is unreliable
  - No good biomarker in pregnancy
  - Pilot data (250 samples) suggested 15%[2]

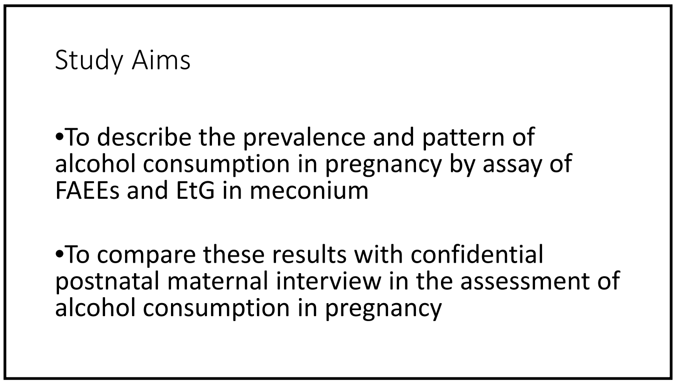
1. Centre For Disease Control and Prevention; website: http://www.cdc.gov/ncbbdd/fads/data.html#ref
2. Abernethy C *et al*. Arch Dis Child 2018.



Biomarkers tested in meconium

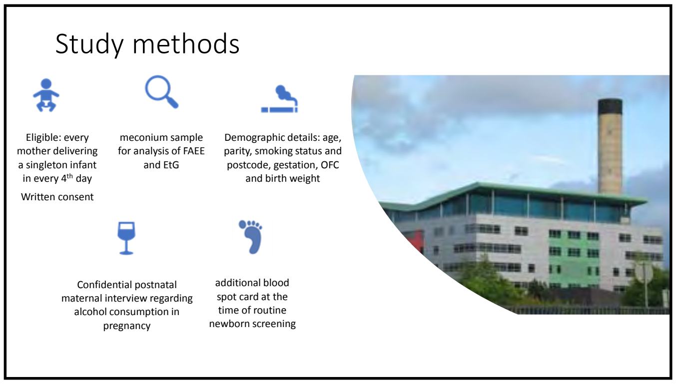
- FAEEs
  - Do not cross the placenta
  - Fetal origin
  - Concentration of > 600 ng/g
    - Specificity 13% (4-29%)[1]
    - Sensitivity 100% (88-100%)
    - PPV 50% (37-64%)
- EtG
  - Crosses the placenta
  - Maternal origin
  - Concentration > 30 ng/g
    - Specificity 75% (63-87%)[2]
    - Sensitivity 82% (71-92)
    - Significant dose-concentration relationship ($p < 0.01$)

1. McQuire C *et al.*, Paediatrics 2016
2. Himes S *et al.*, Clin Chem 2015



Study Aims

- To describe the prevalence and pattern of alcohol consumption in pregnancy by assay of FAEEs and EtG in meconium
- To compare these results with confidential postnatal maternal interview in the assessment of alcohol consumption in pregnancy



Study methods

Eligible: every mother delivering a singleton infant in every 4th day

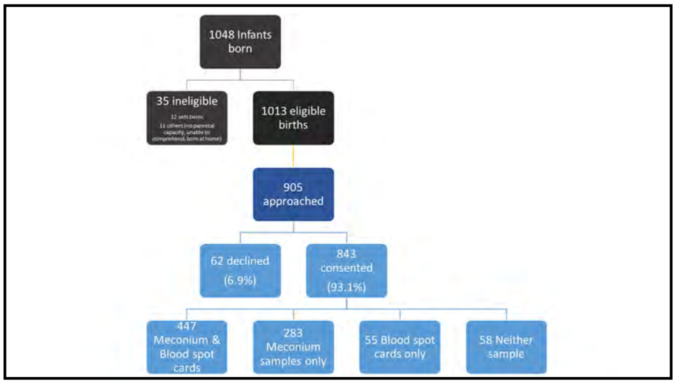
Written consent

meconium sample for analysis of FAEE and EtG

Demographic details: age, parity, smoking status and postcode, gestation, OFC and birth weight

Confidential postnatal maternal interview regarding alcohol consumption in pregnancy

additional blood spot card at the time of routine newborn screening



1048 Infants born

35 ineligible
12 sets twins
11 others (no parental capacity, unable to comprehend, born at home)

1013 eligible births

905 approached

62 declined (6.9%)

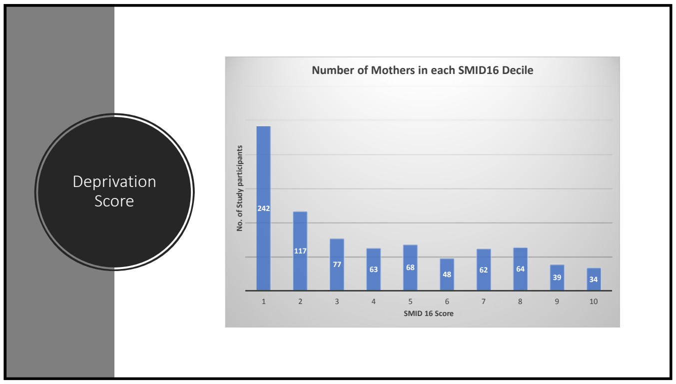
843 consented (93.1%)

447 Meconium & Blood spot cards

283 Meconium samples only

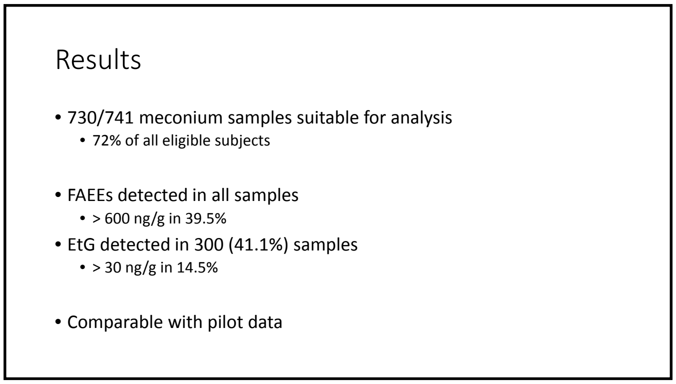
55 Blood spot cards only

58 Neither sample



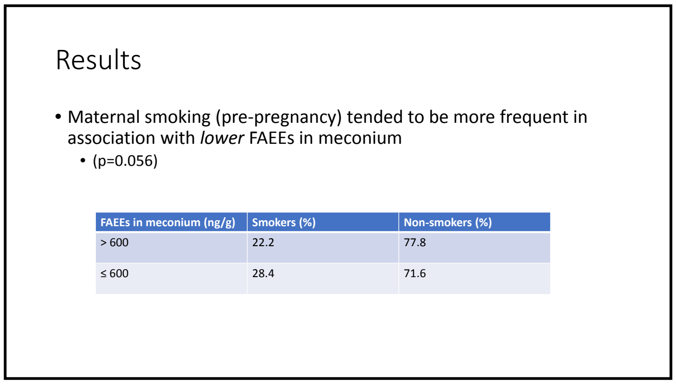
Deprivation Score

Number of Mothers in each SMID16 Decile



Results

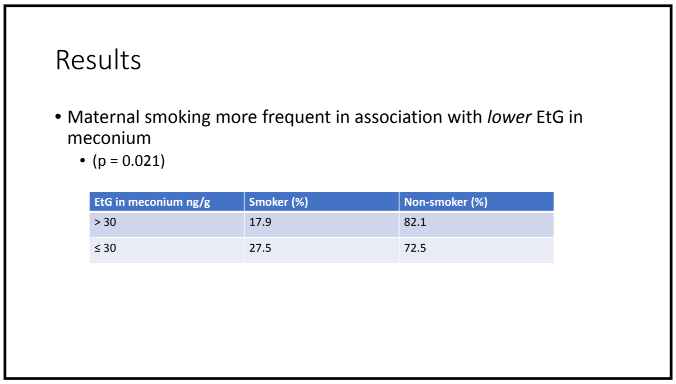
- 730/741 meconium samples suitable for analysis
  - 72% of all eligible subjects
- FAEEs detected in all samples
  - > 600 ng/g in 39.5%
- EtG detected in 300 (41.1%) samples
  - > 30 ng/g in 14.5%
- Comparable with pilot data



Results

- Maternal smoking (pre-pregnancy) tended to be more frequent in association with *lower* FAEEs in meconium
  - (p=0.056)

FAEEs in meconium (ng/g)	Smokers (%)	Non-smokers (%)
> 600	22.2	77.8
≤ 600	28.4	71.6



Results

- Maternal smoking more frequent in association with *lower* EtG in meconium
  - (p = 0.021)

EtG in meconium ng/g	Smoker (%)	Non-smoker (%)
> 30	17.9	82.1
≤ 30	27.5	72.5

Results

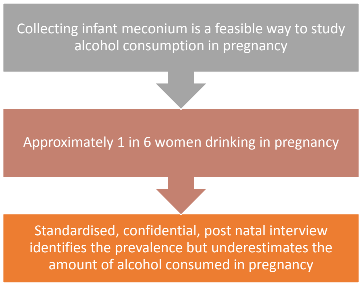
- Pre-pregnancy non-smoking mothers were more likely to provide a meconium sample from their baby
  - 84.2% smokers gave samples *vs* 88.0% non-smokers
- There was *no* difference in maternal age or SMID 16 between mothers who consented and those that declined.

Results

- 114 (13.5%) mothers declared alcohol consumption at any point after 20 weeks' gestation
  - 8 mothers admitted to > 3 units on any one occasion

- No association with any other demographic factor, including
  - Maternal age, parity, BMI
  - Gestation, birth weight
- Poverty (as measured by postcode) does not predict alcohol consumption in pregnancy

Conclusion



Collecting infant meconium is a feasible way to study alcohol consumption in pregnancy

Approximately 1 in 6 women drinking in pregnancy

Standardised, confidential, post natal interview identifies the prevalence but underestimates the amount of alcohol consumed in pregnancy

Thank you

Questions?

Glasgow Children's Hospital Charity

References

1. Centre For Disease Control and Prevention; website: http://www.cdc.gov/ncbbdd/fads/data.html#ref
2. Abernethy C *et al*. Arch Dis Child 2018.
3. JAMC, 25 NOV 2003, 169 (11), 1184
4. McQuire C *et al.*, Paediatrics 2016
5. Himes S *et al.*, Clin Chem 2015
6. Scottish Government SIMD http://simd.scot/2016/#/simd2016/BTTTFTT/10/-4.2627/55.8853/ Accessed Jan 2019

B1c The Role of the Proteasome in the Development of FASD

Olivia Weeks

Learning Objectives

1. Recognize the need to identify the molecular pathways implicated in FASD
2. Describe the function of the proteasome in normal and stressed cells
3. Evaluate evidence that EAE causes protein misfolding and prevents the elimination of faulty proteins
4. Discuss the impacts of proteasome dysfunction on the developmental features of FASD, including organ defects

Introduction

The molecular mechanisms responsible for the teratogenicity of ethanol are largely uncharacterized, and many signaling pathways implicated in FASD remain unidentified. Identifying how ethanol disrupts normal cell function during development is critical for understanding FASD and potential therapeutic interventions. In this presentation, we describe the novel impacts of embryonic alcohol exposure (EAE) on the function of the proteasome, a complex that is responsible for eliminating damaged or unnecessary proteins in the cell. Using a zebrafish model of FASD, we demonstrate that EAE causes an accumulation of ubiquitinated proteins in developing organs and induces a compensatory up-regulation of proteasome components to deal with the resulting protein stress. Through proteasome activity assays, we demonstrate that ethanol and acetaldehyde, the primary metabolic product of ethanol metabolism, specifically inhibit the chymotrypsin-like activity of the proteasome, preventing it from degrading proteins. If proteasome inhibition plays a key role in ethanol's teratogenicity, we would expect proteasome inhibition to exacerbate FASD phenotypes. Pharmacological inhibition of the proteasome with Bortezomib and MG132 treatment sensitized fish to EAE, suggesting that the proteasome is a critical regulator of FASD phenotypes. Fetal proteasome inhibition resulted in organ malformations and short stature phenotypes characteristic of FASD; however, several FASD phenotypes were not significantly impacted by proteasome dysregulation. This suggests that proteasome inhibition following EAE may be responsible for some, but not all, of the teratogenic effects of ethanol. Taken together, these data point to the importance of protein homeostasis in normal development and pinpoint the proteasome as an important target of EAE.

Objective 1

Zebrafish as a tool to Identify Molecular Pathways Contributing to FASD

Danio rerio, the zebrafish, is a tropical freshwater fish from the Ganges river that is commonly used in scientific and medical research. Zebrafish are a preferred animal model because they are easily raised in an aquarium setting, lay hundreds of eggs per week, and have an external fertilization process that enables scientists to directly observe development[1]. Additionally, there is a high degree of conservation between human and zebrafish on a genomic and physiological level[2]. Zebrafish have nearly all of the major organs that humans have, except for lungs, mammary glands, and the prostate gland, and present with approximately 84% of the genes known to cause human disease[3, 4].

Zebrafish larvae have been developed as a vertebrate model organism for FASD because they are easily exposed to ethanol during development and recapitulate key features of the human syndrome[5, 6], including:

- developmental delay[6]
- craniofacial anomalies[7]
- organ malformations[9, 10]
- short stature[6, 7]
- cardiac defect[8]
- behavioral alterations[8]

In our laboratory, larvae are exposed to 0 – 1% ethanol during critical developmental periods, such as 12 hours post fertilization (hpf) through five days post fertilization (dpf)[11]. Studies conclude that the tissue concentration of ethanol in the embryos ranges from ~24-37% of external ethanol concentrations[11]. Our model employs a 0.5% - 1.0% ethanol exposure, which is in the range that is physiologically relevant for humans.

Because zebrafish recapitulate FASD phenotypes, they can be used to interrogate the molecular mechanisms of disease initiation. One of our primary goals is to use zebrafish to identify EAE target genes. In order to do this, we have conducted RNA sequencing efforts on affected larvae and adults and have identified genes that are over and under-expressed in affected individuals

RNA Sequencing

In order for a cell to make protein, DNA must first be transcribed into RNA. The amount of RNA in a cell at any given time provides an idea of which genes are being expressed in the cell and at what quantity. To identify the amount of RNA that is made from each gene, RNA sequencing is often deployed[12, 13]. Relevant cells are isolated, tissues are homogenized, and RNA is extracted and sequenced.

In order to identify genes that are impacted by EAE, we performed RNA sequencing on control and EAE zebrafish (1% Ethanol from 12 hpf – 5 dpf) at 7 dpf, two days after the ethanol exposure ceased (Figure 1). We identified thousands of genes that are dysregulated by EAE and performed gene set enrichment analysis (GSEA) to identify the pathways in which these genes fall (Figure 2). We identified the ubiquitin-dependent proteasome pathway to be overrepresented; in particular, genes encoding the proteins of the 26S proteasome complex were significantly overexpressed. Similarly, many genes mediating endoplasmic reticulum degradation (ERAD) and the unfolded protein stress response (UPR) were upregulated. This suggested to us that the proteasome plays a significant role in FASD and we sought to understand what the consequence proteasome dysfunction is to the developing embryo.

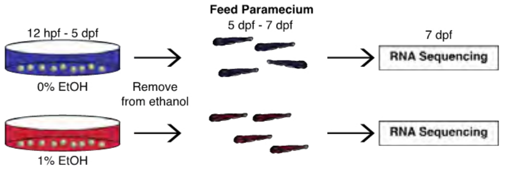


Figure 1: **RNA sequencing of FASD Zebrafish Larvae**. Embryos were exposed to 0% or 1% EtOH from 12 hpf – 5 dpf, transferred to clean water, and fed a paramecium diet. At 7 dpf after 2 days off of ethanol treatment, whole larvae were homogenized and subject to RNA sequencing to identify significant gene expression changes.

Objective 2

The 26S Proteasome

The 26S proteasome regulates the degradation of proteins involved in critical cellular processes[14]. Degrading proteins is necessary for many reasons, several of which are presented here. First, proteins can fold improperly and need to be eliminated from the cell to prevent their accumulation or rogue activity[14]. Second, the presence or absence of proteins is tightly controlled to facilitate certain processes such as cell division or growth[14]. A cell may need to actively eliminate specific proteins in order to proceed with an ongoing cellular event. Third, old proteins need to be recycled as building blocks for the creation of new proteins[14]. Fourth, proteins need to be broken down into smaller pieces, known as peptides, for recognition by the immune system[14]. There are specialized proteasomes called "immunoproteasomes" whose primary role is to produce peptide antigens to be recognized by antigen-presenting cells of the adaptive immune system[15].
The proteasome is a complex that consists of two subunits, a 20S core and a 19S regulatory particle (Figure 3)[16]. The 19S regulatory cap sits on either end of the barrel-shaped 20S core and identifies substrates targeted for degradation (Figure 3)[16]. Following substrate identification, it removes the ubiquitin tag, unfolds, and pushes proteins into the 20S core particle for degradation (Figure 3) [16]. The barrel-shaped core is responsible for cleaving proteins into smaller pieces. This is achieved by β-subunits within the core that have unique protease activity[16]. Each proteasome subunit has the ability to cleave proteins in specialized ways. It is therefore said that the proteasome has caspase-like, trypsin-like, and chymotrypsin-like activity[16]. Blocking normal proteasome activity can produce a host of consequences, including the accumulation of proteins that have been targeted for elimination. Protein accumulation can clog the workings of the cell, disrupt normal cell signaling, and contribute to numerous pathologies.

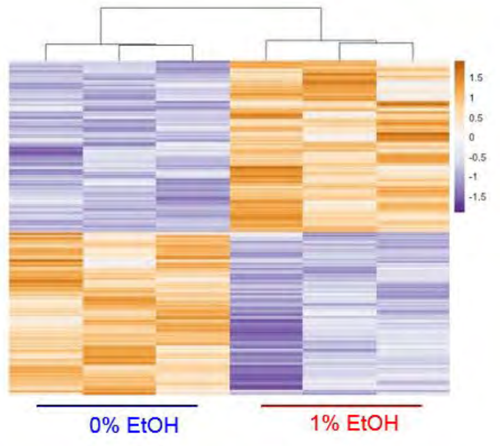


Figure 2: Heatmap of Significantly Altered Gene Expression in FASD zebrafish. Zebrafish with 1% embryonic ethanol exposure had thousands of dysregulated genes. Each row on the heatmap represents one gene, and each column represents one pooled biological replicate. Orange genes are upregulated and purple genes are downregulated.

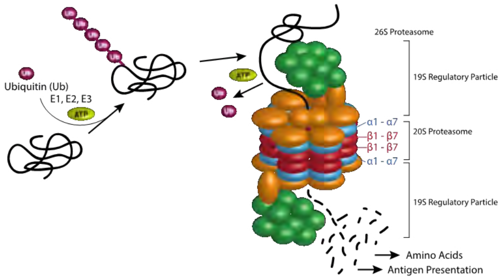


Figure 3: Structure and Function of the 26S Proteasome*. Proteins are targeted for degradation via ubiquitination. Polyubiquitinated proteins are recognized by the 19S regulatory particle and ubiquitin is removed. Proteins are then threaded into and degraded by the 20S proteasome core. Resulting peptides are recycled into amino acids or used for antigen presentation. *Based on figures from Goldberg, 2012; Tanaka, 2009

Objective 3

FASD and the Ubiquitin-Dependent Proteasome

EAE has previously be shown to alter the expression of proteins within the ubiquitin-proteasome pathway, especially β type-7 proteins from the 20S core complex, in ex vivo mouse cultures [17, 18]. There are some limitations to previous studies that could be addressed with additional models. Ex vivo cultured cells or embryos are not exposed to the same levels of the metabolic byproducts of ethanol, including acetaldehyde, as they would be in vivo. It is unknown whether acetaldehyde exposure from the mother's ethanol metabolism would impact the expression or activity of the proteasome in a different way than has been described in cell culture. Additionally, most of the animals studied have been pre-embryonic day 14, and it remains to be determined whether the effect of ethanol on the proteasome shift with age. Our study begins to address these limitations and identifies limitations of the zebrafish model that should also be considered.

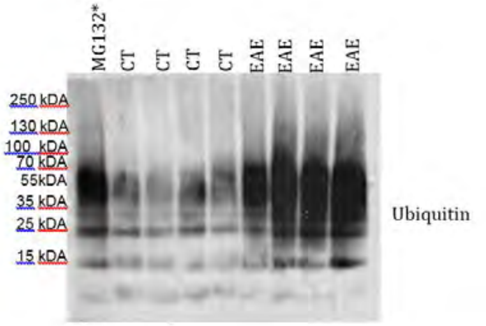


Figure 4: FAE Increases the Accumulation of Ubiquitinated Proteins. Western blot against ubiquitin reveals that proteasome inhibitor MG132 and EAE (1% EtOH, 12 hpf – 5 dpf) induce the accumulation of ubiquitinated proteins at 5 dpf.

In order to test whether EAE impacts the degradation of ubiquitinated proteins, we performed western blotting (WB) for ubiquitin after 0% or 1% EtOH exposure from12 hpf – 5 dpf (Figure 4). The resulting WB showed excess ubiquitinated protein, suggesting that a) ethanol induces excess misfolded proteins that are targeted for degradation, b) ethanol impairs the ability of the proteasome to degrade ubiquitinated proteins, or c) both (Figure 4). Furthermore, we performed WB for components of the 20S proteasome and found that there was significantly more 20S proteasome in the 1% EtOH treated protein extracts than controls, demonstrating that there is a compensatory up-regulation of the proteasome in an attempt to deal with the protein load. Excess proteasome in the presence of accumulated ubiquitinated protein suggests that the embryo can sense the excess protein but cannot properly eliminate it.

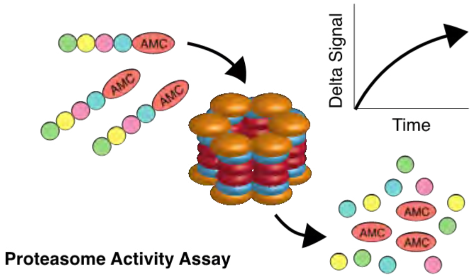


Figure 5: Proteasome Activity Assay. Fluorogenic proteasome substrates are cleaved by the proteasome. Over time, fluorescence increases, and the change in signal is calculated over time in order to determine total proteasome activity.

Ethanol and Acetaldehyde Impair Proteasome Function

We next sought to test whether ethanol specifically impairs proteasome function. Proteasome activity can be assayed ex vivo in protein isolates with the help of proteasome substrates that produce fluorescent signal when cleaved
(Figure 5). Substrates that can be cleaved by the caspase-like, trypsin-like, and chymotrypsin-like activities of the proteasome were added to protein extracts from 0% and 1% EtOH exposed larvae and the amount of fluorescent signal produced was recorded (Figure 5). Importantly, 1% EtOH exposure inhibited the chymotrypsin-like activity of the proteasome but not the caspase-like or trypsin-like activities (Figure 6). This demonstrates that EAE specifically inhibits chymotrypsin-like proteasome function.

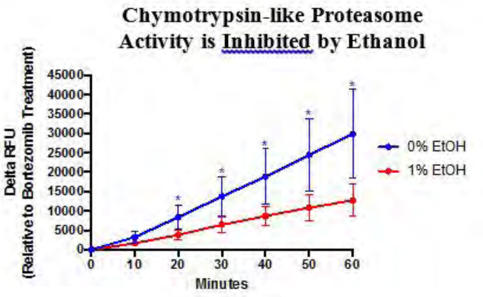


Figure 6: Chymotrypsin-like Proteasome Activity Assay. Embryonic exposure to 1% EtOH significantly impaired the chymotrypsin-like activity of the proteasome at 5 dpf. Cleavage of the Suc-LLVY-AMC fluoreogenic substrate was assayed.

We next sought to determine whether ethanol or its metabolic byproducts are responsible for impairing proteasome function. Since acetaldehyde has been proposed to inhibit proteasome function in alcoholic liver disease (ALD), we evaluated whether embryonic acetaldehyde exposure was sufficient to block proteasome activity[19]. Embryos were 100x more sensitive to acetaldehyde exposure, and treatment with 0.01% acetaldehyde was tolerable overnight. Larvae were exposed to 0.01% acetaldehyde from 4.5 – 5 dpf and protein extracts were harvested. 0.01% acetaldehyde exposure significantly impaired chymotrypsin-like proteasome activity, confirming that the metabolic byproducts of ethanol rather than ethanol itself are likely responsible for the proteasome impairment.

Since the metabolic byproducts of ethanol impair proteasome function, it is important to consider limitations of the current FASD models that we utilize. For instance, cell culture assays looking to understand more than just the impacts of ethanol exposure may need to employ treatments of ethanol and acetaldehyde since alcohol metabolism will be limited in that setting. Furthermore, it is important to recognize that zebrafish also lack the ability to rapidly metabolize alcohol before ~ 72 hpf when hepatocytes form. This means that acetaldehyde exposure in the zebrafish model is likely limited before day 3, and that additional exposures to acetaldehyde may be necessary to mimic all the stressors that a mammal might experience given that the pregnant mother can produce acetaldehyde at all phases of development.

Objective 4

Developmental Impacts of Proteasome Inhibition

If proteasome inhibition is a key mechanism of ethanol's toxicity to the developing embryo, we hypothesized that proteasome inhibition would sensitize fish to EAE. In order to test this hypothesis, developing embryos were exposed to 0% or 1% ethanol in the presence or absence of proteasome inhibitors MG132 and Bortezomib[20]. Embryonic exposure to Bortezomib significantly increased the lethality of EAE, confirming that a functional proteasome is required to protect the embryo for ethanol exposure.

We next sought to evaluate which FASD phenotypes might be attributable to proteasome inhibition. In order to do this, embryos were exposed to proteasome inhibitors during embryogenesis. Embryonic exposure to proteasome inhibitors induced fetal growth restriction and impaired the maturation of the gastrointestinal tract among other organs. However, in initial trials, kidney development, a known target of EAE, was largely unaffected. These findings demonstrate that proteasome inhibition may be critical for the development of some FASD phenotypes but not others.

Reference

Grunwald, D.J., Eisen, J.S. , Headwaters of the zebrafish — emergence of a new model vertebrate. Nature Reviews Genetics, 2002. 3: p. 717-724.

Lieschke, G.J.a.C.-P.D., Animal models of human disease: zebrafish swim into view. Nature Reviews Genetics, 2007.

Howe, K., et al., The zebrafish reference genome sequence and its relationship to the human genome. Nature 2013. 496: p. 498 - 503.

Kalueff, A., Stewart, M.A., Gerlai, R., Zebrafish as an emerging model for studying complex brain disorders. Trends in Pharmacological Sciences, 2014. 35(2): p. 63 - 75.

Lovely, C.B., Y. Fernandes, and J.K. Eberhart, Fishing for Fetal Alcohol Spectrum Disorders: Zebrafish as a Model for Ethanol Teratogenesis. Zebrafish, 2016.

Loucks, E., Ahlgren - S., Assessing teratogenic changes in a zebrafish model of fetal alcohol exposure. Journal of visualized experiments: JoVE, 2012.

Marrs, J.A., et al., Zebrafish fetal alcohol syndrome model: effects of ethanol are rescued by retinoic acid supplement. Alcohol 2010. 44(7-8): p. 707-715.

Li, X., et al., Alcohol exposure leads to unrecoverable cardiovascular defects along with edema and motor function changes in developing zebrafish larvae. Biology Open, 2016. 5(8): p. 1128-1133.

Bilotta, J., et al., Ethanol exposure alters zebrafish development: a novel model of fetal alcohol syndrome. Neurotoxicology and teratology, 2004. 26(6): p. 737-743.

McCarthy, N., et al., Pdgfra protects against ethanol-induced craniofacial defects in a zebrafish model of FASD. Development, 2013.

Lovely, C.B. and J.K. Eberhart, Commentary: catching a conserved mechanism of ethanol teratogenicity. Alcoholism, clinical and experimental research, 2014. 38(8): p. 2160-2163.

Wickramasinghe, S., Canovas, A., Rincon, Gonzalo, Medrano, J.F., RNA-Sequencing: A tool to explore new frontiers in animal genetics. Livestock Science, 2014. 166: p. 206-216.

Wang, Z., Gerstein, M., Snyder, M., RNA-Seq: a revolutionary tool for transcriptomics. Nature Reviews Genetics, 2009. 10.

Lecker, S.H., Goldberg, A.L., Mitch, E.W., Protein Degradation by the Ubiquitin-Proteasome Pathway in Normal and Disease States. JASN, 2006. 17: p. 1807-1819.

Kimura, H., Caturegli, P., Takahashi, M., Suzuki, K., Journal of Immunology Research, 2015.

Tanaka, K., The proteasome: Overview of structure and functions. Proceedings of the Japan Academy. Series B, Physical and Biological Sciences, 2009.

Gutala, R., Wang, J., Kadapakkam, S., Hwang, Y., Ticku, M. , Microarray Analysis of Ethanol-Treated Cortical Neurons Reveals Disruption of Genes Related to the Ubiquitin-Proteasome Pathway and Protein Synthesis. Alcoholism: Clinical and Experimental Research, 2004. 28(12): p. 1779-1788.

Mason, S., Anthony, B., Lai, X, Ringham, H.N., Wang, M. , Ethanol exposure alters protein expression in a mouse model of fetal alcohol spectrum disorders. International Journal of Proteomics, 2012.

Rouach, H., Andraud, E., Aufrere, G., Beauge, F. , The effects of acetaldehyde in vitro on proteasome activities and its potential involvement after alcoholization of rats by inhalation of ethanol vapours. Alcohol and Alcoholism 2005. 40(5): p. 359-66.

Goldberg, A.L., Development of proteasome inhibitors as research tools and cancer drugs. The Journal of Cell Biology, 2012. 199(4): p. 583-588.

B1d Altered Embryo and Placental Development Following Exposure to Alcohol Around Conception

Karen Moritz

Authors: Karen Moritz, Jacinta Kalisch-Smith

Learning Objectives

1. Analyse the effects of alcohol exposure conception of embryo development
2. Determine the impact of alcohol around conception on placental development and fetal growth

Objectives

Alcohol exposure is common around conception and prior to pregnancy recognition, but often ceases soon after. Maternal periconceptional alcohol exposure (PC-EtOH) in rat dams has been previously shown to cause fetal growth restriction and changes in the late gestation placenta. It also resulted in the development of adult onset disease, including insulin insensitivity, often in a sexually dimorphic manner. However, the mechanisms by which PC-EtOH can cause this programming are relatively unexplored. In this study we characterised the effects of alcohol on pre-implantation development and alterations to the early uterine environment. We then explored the interactions and communication between the embryo and uterus and the resultant effects on placental development across gestation**.**

Methods

To study the effects of PC-EtOH in vivo, Sprague-Dawley rat dams were given a liquid diet containing either control (0% v/v EtOH) or EtOH (12.5% v/v EtOH) from embryonic (E) day -4 to E4. At E5 we determined cell number of the pre-implantation embryo and its capacity to differentiate into cells required for invasion. Maternal plasma and uterine samples were collected over the peri-implantation period (E5-E7) to assess the maternal hormonal environment, and uterine responses for implantation and maintenance of pregnancy in response to the invading PC-EtOH exposed embryo. Placental development was examined after PC-EtOH in the immature (E13), definitive (E15) and late gestation (E20) placenta.

Results

Pre-implantation studies showed PC-EtOH altered inner cell mass count, trophoblast differentiation (to trophoblast giant cells- TGC's) and trophoblast behaviour. PC-EtOH also caused reduced expression of Prl4a1, a gene exclusively expressed by TGCs for communication with decidual natural killer cells (dNK). The embryos exposed to alcohol had evidence of altered DNA methylation. Whilst no changes to oestrogen or progesterone levels were observed, alterations to their receptors (Esr1 and Pgr), and downstream response genes (including those involved in vasculogenesis) were found, particularly at E7. Genes involved in dNK maturation and function were markedly decreased by PC-EtOH at E7, suggesting that when the embryo is invading that the uterine responses are altered. Investigation of invasion of spiral artery trophoblast giant cells at E13 demonstrated a decrease in PC-EtOH females only. At E15, PC-EtOH, caused increased resorptions, decreased labyrinth wet weight and reduced maternal blood space volume in both sexes. This suggests impaired or slowed development of the definitive placenta in mid gestation following PC-EtOH, but by E20, compensatory growth of the placenta had occurred. This 'catch-up' in placental growth, however, was not significant enough to prevent the fetal growth deficit.

Conclusions

Alcohol around conception can have impacts of the embryo prior to implantation through altering gene expression possible via altered DNA methylation. This results in altered placental development including impairments in invasion, placental remodelling and placental function. This impacts fetal viability as well as fetal growth and development in a sex specific manner. This work suggests that emphasis should be placed on health advice for women to cease alcohol consumption when planning a pregnancy.

B1e

A Comparison of Two Alcohol Use Biomarkers with Selfreported Quantity, Frequency, and Timing of Alcohol Consumption in Antenatal Clinics in South Africa

Julie Hasken

Authors: J. Hasken, A-S Marais, M.M. De Vries, W.O. Kalberg, D. Buckley, C.D.H. Parry, S. Seedat, P.A. May

Learning Objectives

1. Describe two effective biomarkers to detect moderate to heavy alcohol use, ethyl glucuronide (EtG) and phosphatidylethanol (PEth).
2. Describe how to use these markers in research and clinical applications to detect alcohol consumption in the past 7 days or over a period of 3 months
3. Explain that women in these study communities in South Africa report their alcohol use accurately

Background

In many communities of the Western Cape Province of South Africa, binge drinking is common for 40% of women of childbearing age. This contributes greatly to a high prevalence of fetal alcohol spectrum disorders (FASD).

Methods

Prenatal alcohol use data obtained from maternal, self-reported drinking history are compared to two biomarkers of alcohol use: phosphatidylethanol (PEth) from bloodspots and ethyl glucuronide (EtG) in fingernails. Women from antenatal clinics in a high FASD prevalence area (n=161) participated in this study. Because most drinking occurs on weekends, bloodspots were collected on Monday or Tuesday. Since fingernail samples analyzed for EtG record longer-term alcohol use, they were collected at either: first contact (the same time as the blood) or in a return visit. A value of ≤8 ug was considered indication of alcohol consumption for both PEth and EtG.

Results

There is substantial agreement between self-reported alcohol use and combined results from these two biomarkers. As measured by self-reported quantity frequency, 69.2% reported drinking. Positive alcohol use values were obtained with one or both biomarkers for 63.4% of participants. The biomarkers combined identified 5.8% less drinking than self-report; however this was not statistically significant (p=0.275). Among women who were identified as drinkers by both biomarkers, the mean value for PEth was 218.0 (SD=184.8, range: 11.0-914) and the mean EtG value was 99.0 (SD=102.6, range: 9.7-522). These women reported 5.6 (SD=3.5) drinks per drinking day (DDD) in the 3 months prior to pregnancy and 2.3 (SD=2.9) DDD in the previous 7 days. Women who were identified as a drinker by PEth, but not EtG, had a mean PEth level of 44.6 (SD=46.1) and reported 0.7 (SD=1.8) DDD in previous 7 days. Women identified by EtG, but not PEth, had a mean EtG level of 40.8 (SD=61.9) and reported 6.1 (SD=4.9) DDD in the 3 months prior to pregnancy. PEth and EtG are positively correlated with DDD and number of drinking days.

Conclusions

South African women in this community report alcohol use honestly and accurately. Self-reported alcohol use actually exceeds that detected by either PEth or EtG used individually.

B2a

YOUNG INVESTIGATOR

Mitigating the Stress Response in Children Affected by PAE from a Bio-Psycho-Social Framework

Paul Jerry (on Behalf of Bethany Zelent)

Abstract

Prenatal alcohol exposure (PAE) has long-lasting effects on the bio-psycho-social functioning of children. Since PAE is in itself a trauma, the symptoms of PAE can be exacerbated by post-natal traumas, increasing stress sensitivity. Additionally, the stress response is inhibited in PAE from its neurocognitive deficits, which will be addressed using the framework of resiliency and attachment. Evidence-based interventions should target adaptive stress responses for both the child affected by PAE and their caregiver(s). This paper outlines bio-psycho-social interventions from a strengths-based approach including lifestyle changes and positive parenting strategies.

TAMING THE TORNADO

The impacts of stress are heightened by the presence of PAE, including low socioeconomic status populations being at a higher risk for the prevalence of PAE, 17% of children in care have a PAE diagnosis, a sensitivity to maltreatment and caregiver separation.

9/1000

9/1000 live births in North America are affected by prenatal alcohol exposure (PAE), the leading preventable cause of birth defects.

$5.3B

PAE costs Canadians $5.3 billion annually, an estimated $14 342 per individual for support, even more, if the child enters the welfare system.

PROTECTIVE FACTORS

Early diagnosis, before age 6
Attunement with the caregiver
Raised by the biological family
Positive parenting techniques, including believing the child is capable of success
Stable and supportive home
Less caregiver stress

RISK FACTORS

Early life stress (ELS) and PAE are associated with low birth weight, learning deficiencies, hyperactivity
Risk factors include maternal nutrition, socioeconomic status, ethnic origin, drug use, caregiver stress
Punishment based parenting

EFFECTS OF PAE

PAE has been found to create deficits in learning, memory, executive function, decision making, planning, intelligence, language and behaviour. These challenges also increase caregiver stress, which has been found to lead to poorer cognitive functioning in children. Punishment in parenting was shown to be associated with more behaviour problems.

INTERVENTIONS

Exercise is a protective factor against impacts of stress

Nutrition & supplements can relieve PAE deficiencies

Medication allows for regulatory functioning by lowering stress

Sleep mitigates the stress response and maximizes potential

Community support can reduce caregiver stress and increase parenting skills

Parenting skills should predict and prevent misbehaviour

B2b Mutual Support - Moral Support: A Mini-Break for Families Raising Youngsters with FASD

Alison Frieling, Gisela Michalowski

Over the years, our organisation has come to realise the importance of support, respite and networking for families of children and adolescents with FASD. In Germany, during the late 90's, parents of children with FASD “met” for the first time (via the internet), having finally found out why their children were so different. They longed for the opportunity to meet face to face. FASD was not at all well-known then and families were often completely isolated and had no support for their children, even if they had been diagnosed with FASD.

Initially, the idea of organising a weekend break was purely to get away and meet like-minded people. Many parents had no alternative but to bring along their children with FASD, so it had to be a family occasion.

In 2003, when the first family weekend break was organised, neither the benefits nor the potential of an event like this had been identified. No-one realised just how important it could and indeed would be. For many of the children it would be the first time in their life that they actually had fun, could relax and felt accepted. For the parents it was a relief to experience a feeling of being understood, to come out of isolation and to learn more about FASD from the others.

This first family weekend in 2003 was a testing ground - 60 people attended and things went so well, that it was decided to plan ahead for the next year. A draft concept was developed and included things like funding, a choice of location, activities and supervision for the children, topics for adult training sessions etc.

Quite by chance, three elements had been successfully linked in an equation:

Education + Fun + Family Time = Well-Being / empowered “Happy Families”

The combination of these three elements became the basic concept and organisation was streamlined as the number of families wanting to participate continued to rise from year to year. Each of these three elements now required more attention making a more detailed approach necessary in the planning phase.

As the importance of being knowledgeable about FASD was recognised - bearing in mind that FASD was still very much an unknown condition even in professional circles - the need for education became even more apparent. Knowledge is one factor that leads to empowerment and empowerment is what parents need in order to be able to advocate for their children. This realisation meant that the element "education" needed to be further developed. As well as seminars and workshops run by members of our organisation, external professional speakers are also invited to join us and have spoken on a variety of topics, covering a wide range of subjects. These include trauma and bonding issues; mental health concerns; special educational or pedagogic approaches; forms of therapy; legal issues etc.

The element "fun" i.e. supervised activities for the children also requires careful preparation and is costly because of the carer/child ratio necessary. (The word "child” is misleading – in this context “children” as opposed to parents includes adolescents and even young adults.)

We work with basic ratio of 1 teamer/carer to 3 children but always calculate with enough reserves so as to be able to deal with any kind of difficult situation or emergency.

Activities are planned for all age groups but also according to the children's likes/dislikes and capabilities. As well as group activities, there are special projects in which all children can participate. The aim of these activities is to improve the children's self-esteem and self-confidence. In recent years we have engaged groups from the performing arts and nature projects to work with the children. A group of bikers on quad bikes and trikes “surprised” us and took the children for a ride. This was arranged by a biker-father who didn’t know how many fellow bikers would follow up on his request.

"Family time" is the third element and the most flexible of the three. Some activities require advanced planning - a crazy paper chase or a sports-day type competition where families or groups of families compete against one another. But "family time" can mean just being together and enjoying one another's company, something many families don't manage to find time for in everyday life.

Concepts have been revised and modified to improve the quality and value of this event. We self-monitor and take time to reflect on the event during the last morning session.

60 people came to the first weekend break in 2003 and this event has become more popular from year to year.
On average, now 140 - 160 people register for the family mini-break. A conscious decision has been taken to limit numbers; first to coincide with the choice of youth hostel (number of rooms) and second to preserve an informal, familiar atmosphere. What began in 2003 as just one weekend has turned into an annual 5-day event.

The whole family benefits from this concept. Those who come along for the first time are frequently overwhelmed by the sense of belonging and fellowship. This alone can make a huge difference - possibly the difference between being on the point of despair or being able to trust that things will be okay and that there is hope.

Anyone who has looked into learning theories will be familiar with the idea that stress affects memory and learning. Creating a relaxed atmosphere is one contribution towards an environment conducive to learning and this has a positive effect on both parents and children.

B2c The Impact of Micronutrient Supplementation in Alcohol Exposed Pregnancies on Reaction Time Responses in Ukrainian Preschoolers

Julie Kable

Authors: Kable J, Coles C, Yevtushok L, Zymak-Zakutnya N, Wertelecki W, Jones K, Chambers C

Learning Objectives

1. Explain how preschool reaction time, a measure of sustained attention, is impacted by PAE and micronutrient supplementation.
2. Explain the differential impact of prenatal alcohol exposure and multivitamin supplementation by gender on preschool reaction time responses.

Objectives

Deficits in attentional regulation skills are common in children with a history of prenatal alcohol exposure (PAE). The potential of micronutrients to ameliorate the impact of prenatal alcohol exposure on reaction time performance and the associated physiological reaction was explored in a clinical trial conducted in Ukraine.

Methods

Women who differed in prenatal alcohol use were recruited during pregnancy and assigned to one of three groups (No study-provided supplements, Multivitamin/Mineral Supplement (MVM), or MVM plus Choline Supplement). A preschool reaction time task was used to assess outcomes in the offspring when they were between 3.5 to 4.5 years of age. The reaction time task involved the participant making a response to a series of chromatic pictures presented on a computer screen. Children were instructed to press a response button as quickly as possible. An initial fixation slide, which consisted of a cross centrally located on the screen, was shown for 1000 msec and was followed by the target stimulus for a total 2500 msec. After the target stimulus, the child was presented with a feedback slide for 1500 msec that was either a large yellow smiling or frowning face. A total of 39 stimuli were presented. The first three were regarded as training trials and were discarded. Thirty stimuli from the same category (animals) were then presented, followed by 6 stimuli from a novel category (vehicles). The results were then analyzed relative to the two conditions. Outcomes analyzed relative to task performance were number correct, mean latency of the response, and variability in the latency of the response. Data was analyzed separately for males and females due to gender differences.

Results

Sustained Component: Among females, PAE was associated with fewer correct responses ($F(1,110) = 9.609, p < .002$) and more variability in their response time ($F(1, 110) = 5.343, p < .023$). For males, those who received MVM had more correct responses ($F(1,119) = 4.084, p < .046$) and reduced response latency ($F(1, 119) = 7.859, p < .006$).

Novelty Component: A significant PAE * choline interaction was found in males ($F(1, 118) = 4.276, p < .041$) where choline supplementation improved the latency of the response but only in those who did not have a history of PAE.

Conclusions

PAE and MVM usage during pregnancy differentially impacted performance during a preschool reaction time task for males and females. In females, PAE adversely impacted performance but males' performance was more sensitive to the MVM exposure. Choline supplementation also improved performance in males but only for those who did not have a history of PAE.

References

ADHD, Vigilance tasks, and FASD:

Boyd TA, Ernhart CB, Greene TH, Sokol RJ, Martier S. Prenatal alcohol exposure and sustained attention in the preschool years. Neurotoxicol Teratol. 1991;13(1):49-55. PubMed PMID: 2046626.

Coles CD, Platzman KA, Raskind-Hood CL, Brown RT, Falek A, Smith IE. A comparison of children affected by prenatal alcohol exposure and attention deficit, hyperactivity disorder. Alcohol Clin Exp Res. 1997;21(1):150-61. Epub 1997/02/01. doi: 00000374-199702000-00022 [pii]. PubMed PMID: 9046388.

Herman CS, Kirchner GL, Streissguth AP, Little RE. Vigilance paradigm for preschool children used to relate vigilance behavior to IQ and prenatal exposure to alcohol. Percept Mot Skills. 1980;50(3 Pt 1):863-7. Epub 1980/06/01. PubMed PMID: 7402868.

Kooistra L, Crawford S, Gibbard B, Ramage B, Kaplan BJ. Differentiating attention deficits in children with fetal alcohol spectrum disorder or attention-deficit-hyperactivity disorder. Dev Med Child Neurol. 2010;52(2):205-11. Epub 2009/06/25. doi: 10.1111/j.1469-8749.2009.03352.x. PubMed PMID: 19549201.

Mattson SN, Crocker N, Nguyen TT. Fetal alcohol spectrum disorders: neuropsychological and behavioral features. Neuropsychology review. 2011;21(2):81-101. doi: 10.1007/s11065-011-9167-9. PubMed PMID: 21503685; PMCID: PMC3410672.

Streissguth AP, Barr HM, Sampson PD, Parrish-Johnson JC, Kirchner GL, Martin DC. Attention, distraction and reaction time at age 7 years and prenatal alcohol exposure. Neurobehav Toxicol Teratol. 1986;8(6):717-25. Epub 1986/11/01. PubMed PMID: 3808187.

Ukrainian Cohort and Study Design:

Coles CD, Kable JA, Keen CL, Jones KL, Wertelecki W, Granovska IV, Pashtepa AO, Chambers CD, Cifasd. Dose and Timing of Prenatal Alcohol Exposure and Maternal Nutritional Supplements: Developmental Effects on 6-Month-Old Infants. Maternal and child health journal. 2015;19(12):2605-14. doi: 10.1007/s10995-015-1779-x. PubMed PMID: 26164422; PMCID: PMC4644455.

Kable JA, Coles CD, Keen CL, Uriu-Adams JY, Jones KL, Yevtushok L, Kulikovsky Y, Wertelecki W, Pedersen TL, Chambers CD, Cifasd. The impact of micronutrient supplementation in alcohol-exposed pregnancies on information processing skills in Ukrainian infants. Alcohol. 2015;49(7):647-56. doi: 10.1016/j.alcohol.2015.08.005. PubMed PMID: 26493109; PMCID: PMC4636447.

B2d Understanding the Needs of Families Raising Individuals with FASD

Malgosia Tomanik

Authors: Malgosia Tomanik, Sylvia Roozen, Gerjo Kok, Leopold M.G. Curfs

Learning Objectives

1. Describe the families' needs related to accessing support services.
2. Describe the procedure for an adequate needs assessment related to FASD
3. Describe potential gaps in the existing support system

Objectives

The impact of FASD affects families worldwide. Research indicates that adequate support services can improve outcomes for families and individuals with FASD. In addition, parental involvement in the intervention process can lead to better outcomes as well. Unfortunately, little is known about the needs of families raising individuals with FASD, and their experiences in accessing support services. The aim of the present study is to identify these needs, and any potential gaps in currently available support services.

Methods

25 families of individuals with FASD (aged 5 -19 yrs.) were recruited through the Fraser Valley Child Development Centre Key Worker Programs in four geographic areas of British Columbia: Abbotsford, Chilliwack, Mission, and Fraser Cascades. A mixed method approach was used consisting of two phases. First, the Family Quality of Life Survey – 2006 (FQOLS-2006) was conducted to measure concepts of Importance, Opportunities, Initiative, Stability, Attainment, and Satisfaction in domains such as Support from Disability Related Services, Health, and others.

Second, qualitative measurements were used in the form of semi-structured interviews to generate more in-depth responses in respect to perceived support services.

Results

Overall, data resulting from the questionnaires provided insights into the availability and accessibility of services, as well as satisfaction with the services. The most important outcome was related to the need for specific services such as: systematic respite, support with significant life transitions, access to knowledgeable community professionals, and flexible and coordinated services. Qualitative measures (in-depth interviews) showed potential gaps between existing services and the needs of the families (e.g. long waitlists, not having all needs met, little practical support).

Conclusion

FASD support services are needed in order to provide interventions that will meet the unique needs and circumstances of each family. This tailor made aspect of the general programs is of most importance. The stability and support of the home environment are crucial factors, and should be supported whenever possible. Service providers can improve their service delivery, and build collaborative partnerships with families, by understanding and addressing the needs of the families. Research looking at the family experiences of raising individuals with FASD, and accessing services, is necessary in order to enhance good support

B3a

Working Towards a Shared Assessment Framework – A Review of Australian Neurodevelopmental Disorder Guidelines

Narelle Mullan

Authors: Narelle Mullan Kiah Evans, Amy Finlay-Jones, Jenny Downs, Bahareh Afsharnejad, Elissa Strumpher

Learning Objectives:

1. Explain the overlap in Australian neurodevelopmental disorder diagnosis guidelines
2. Recall the challenges and advantages of a transdiagnostic approach to screening and assessment

Objective

The short-term aim of this project is to understand how the current Australian clinical guidance documents for neurodevelopmental disorder (NDD) diagnosis work together, and to learn from clinicians and families how to better coordinate the process of diagnosis through a shared framework.

The assessment of children and young people for NDD is complex, time-consuming and involves several different health professionals including paediatricians, psychiatrists, speech pathologists, psychologists and occupational therapists.

Recently, Australian clinical guidelines have been developed separately to help child health professionals diagnose different NDDs. It is now becoming clear that children may have more than one NDD, for example the co-occurrence of ASD and FASD is starting to be accepted by researchers and clinicians. Consultation with health professionals and community members during the development of the ASD and FASD Diagnosis Guidelines has highlighted the importance of raising awareness of other NDDs among clinicians diagnosing a specific NDD.

Methods

This project involved two parts and each part was guided by a Steering Group of clinical experts and community members with lived experience:

1. Part one was a review of existing Australian and international clinical guidance documents for NDD diagnosis to explore similarities and differences between guidelines.
2. Part two involved online and workshop consultations with clinical experts and community members. The purpose of this consultation was to identify current gaps in knowledge about NDD diagnosis, as well as potential benefits and challenges which may come from having a shared framework to guide the process of diagnosing one or more NDDs in children.

Results

Initial review of the guidelines and early consultation highlighted identification and subsequent treatment typically depends on assessment of developmental problems that only emerge from around 2-3 years of age. The final round of consultation and review conclusions will be delivered in October 2018, however work to date has highlighted the need for early identification and intervention approaches for neurodevelopmental disorders, and a broader program of research to increase knowledge of transdiagnostic approaches to assessment.

B3b The Process of Elaborating Polish Guidelines for Diagnosis of FASD

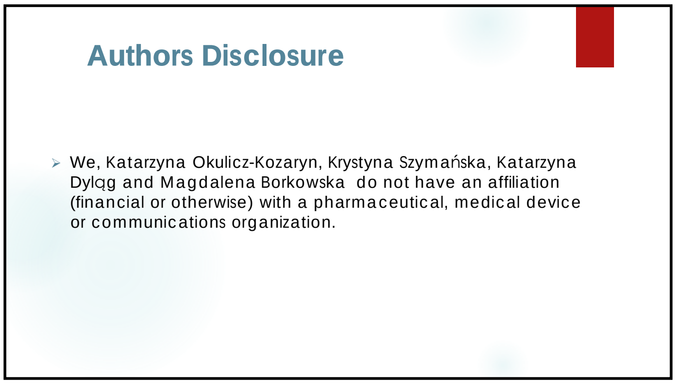
Katarzyna Okulicz-Kozaryn

The process of elaborating Polish guidelines for diagnosis of fetal alcohol spectrum disorder AGREE.PL project

KATARZYNA OKULICZ-KOZARYN, KRYSTYNA SZYMAŃSKA
KATARZYNA DYLĄG, MAGDALENA BORKOWSKA

PARPA THE STATE AGENCY FOR PREVENTION OF ALCOHOL-RELATED PROBLEMS

SZPITAL DZIECIĘCY

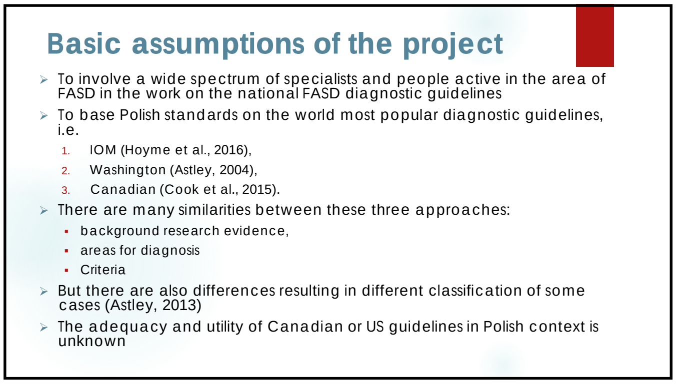


Authors Disclosure

- We, Katarzyna Okulicz-Kozaryn, Krystyna Szymańska, Katarzyna Dyląg and Magdalena Borkowska do not have an affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization.

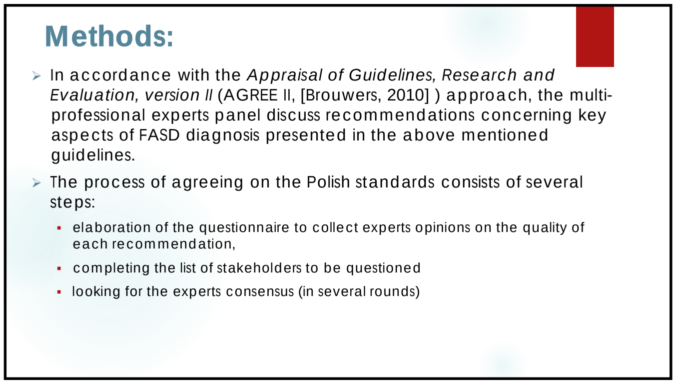
Background
current situation in Poland

- According to different estimates alcohol consumption during pregnancy in Poland ranges from 15% to 40%
- The prevalence of FASD is not lower than 2% among schoolchildren.
- FASD is often not recognized or recognized late
- FASD diagnosis from one center/organization are sometimes questioned by another center/organization
- The quality of diagnosis is generally unknown and not reflecting the growing research evidence in the area of FASD
- Broad, professional **discussion on the national standards of FASD diagnosis has been missing**.



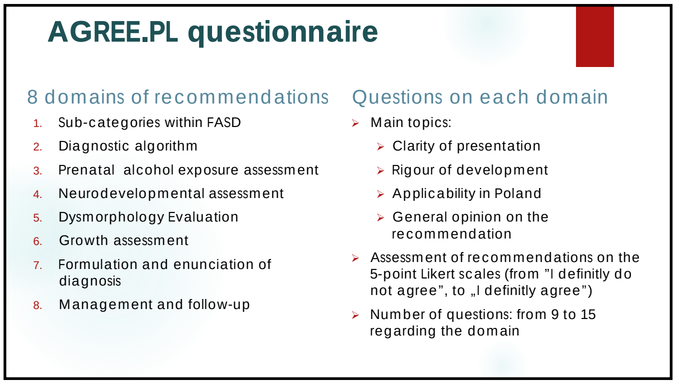
Basic assumptions of the project

- To involve a wide spectrum of specialists and people active in the area of FASD in the work on the national FASD diagnostic guidelines
- To base Polish standards on the world most popular diagnostic guidelines, i.e.
  1. IOM (Hoyme et al., 2016),
  2. Washington (Astley, 2004),
  3. Canadian (Cook et al., 2015).
- There are many similarities between these three approaches:
  - background research evidence,
  - areas for diagnosis
  - Criteria
- But there are also differences resulting in different classification of some cases (Astley, 2013)
- The adequacy and utility of Canadian or US guidelines in Polish context is unknown



Methods:

- In accordance with the *Appraisal of Guidelines, Research and Evaluation, version II* (AGREE II, [Brouwers, 2010]) approach, the multi-professional experts panel discuss recommendations concerning key aspects of FASD diagnosis presented in the above mentioned guidelines.
- The process of agreeing on the Polish standards consists of several steps:
  - elaboration of the questionnaire to collect experts opinions on the quality of each recommendation,
  - completing the list of stakeholders to be questioned
  - looking for the experts consensus (in several rounds)



AGREE.PL questionnaire

8 domains of recommendations

1. Sub-categories within FASD
2. Diagnostic algorithm
3. Prenatal alcohol exposure assessment
4. Neurodevelopmental assessment
5. Dysmorphology Evaluation
6. Growth assessment
7. Formulation and enunciation of diagnosis
8. Management and follow-up

Questions on each domain

- Main topics:
  - Clarity of presentation
  - Rigour of development
  - Applicability in Poland
  - General opinion on the recommendation
- Assessment of recommendations on the 5-point Likert scales (from "I definitly do not agree", to „I definitly agree")
- Number of questions: from 9 to 15 regarding the domain

Sample question:

1. The recomendation is precise – clearly indicates how to differentiate between various sub-cathegories of FASD

	1 I definitely do not agree	2 I rather do not agree	3 It is hard to say	4 I rather agree	5 I definitely agree
IOM guidelines [Hoyme et al., 2016]					
Canadian guidelines [Cook et al., 2015]					
4-digit code [Astley, 2004]					
Substantiation/comments					

Experts panel

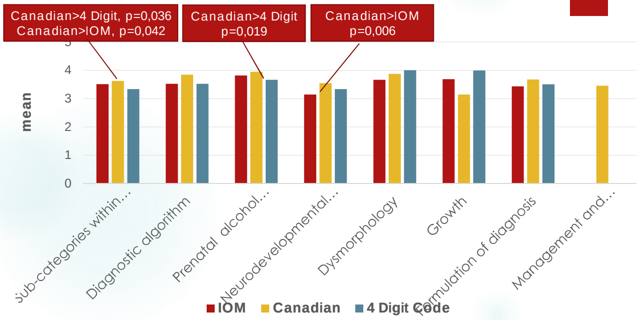
Invitation to participate
- Sent to 45 individuals
- Sent to 13 FASD centers

Answers received
- Refusal - 6
- Indication of another person – 5
- No answer – 23
- Acceptance - 29

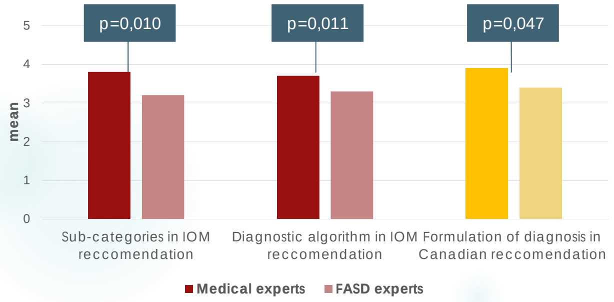
Collected expertise (n=31)
- Medical experts (n=10)
- Experts in a FASD center (n=14)
- Medical and FASD experts (n=7)

Experts' opinions

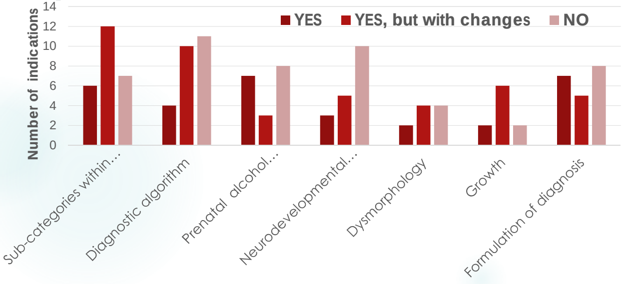
8 domains of recommendations

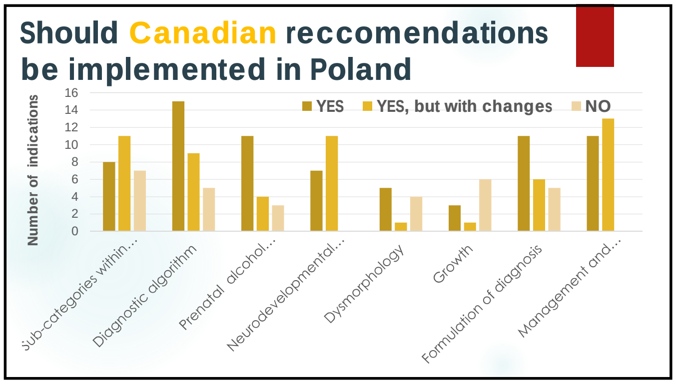


Medical vs FASD experts

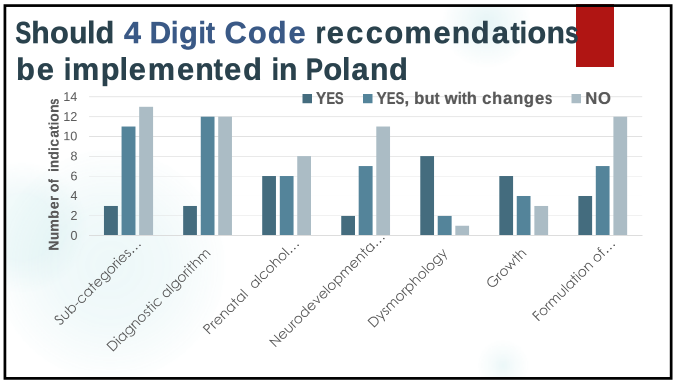


Should IOM reccomendations be implemented in Poland





Should Canadian reccomendations be implemented in Poland



Should 4 Digit Code reccomendations be implemented in Poland

Summary of discussion at the 1st experts' meeting (24-25 January 2019)

Medical aspects

- **Quite easy** – dysmorphology and growth assessment are not very controversial. Key task is to select growth charts to be used in Poland (it should be harmonized with recommendations of the pediatric and neonatologists associations.
- **Useful** – to start systematic assessment of the prenatal alcohol exposure (pilot project of the Institute of Mother and Child and Clinical Children Hospital in Warsaw + (probably) some other hospitals - Objective – to recognize early a group of children at risk of FASD
- **Necessary** – to develop standards of neurodevelopmental assessment (in depth understanding of biological mechanisms and factors determining structural and functional development of CNS is needed)
- **Proposed** – to develop 3-stage diagnostic algorithm:
  1. Screening I (gynecology-obstetric ward, neonatology ward)
  2. Screening II (pediatrician, family doctor, PHCU).
  3. Diagnosis – specialized FASD facility in close cooperation with highly specialized medical center (genetic, neuroimaging, neurometabolic, ... assessment)

Psychological aspects

General consensus

- Scope of assessment – broad, covering all cognitive, emotional and social functions
- Acknowledgement of environmental factors (family, school)

Disputable

- Selection of psychological and neuropsychological tools (first list of validated tests will be elaborated by the work group, soon)
- Selection of the cut-off point (1,5 or 2 SD) is an open question
- What should by the meaning of the general IQ assessment?
- How to deal with comorbidity: should other neurodevelopmental disorders be recognized in a patient with FASD or should an individual cognitive profile be prepared ?
- Very problematic is inter-sectoral cooperation (between education and health care systems) and educational judicature
- How psychologists working out-of health-care system should refer children for FASD diagnosis?

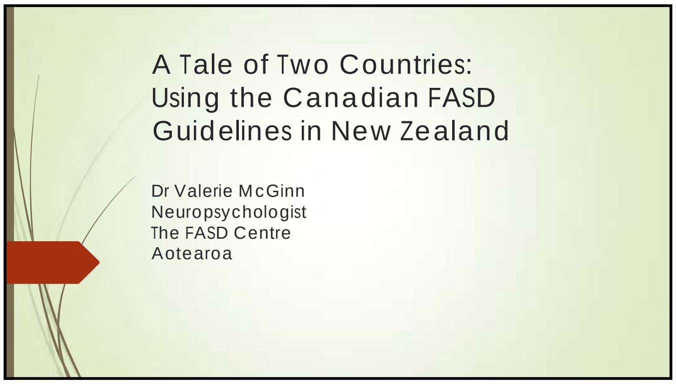
Next steps

1. Work in four sub-groups to elaborate proposals of"
   1. Group 1 – dysmorphology and growth assessment
   2. Group 2 – prenatal alcohol exposure assessment
   3. Group 3 – neurodevelopmental assessment
   4. Group 4 - diagnostic algorithm + management and follow –up
2. To develop understanding of biological mechanisms of neurodevelopmental disorders (lecture(s) for all members of the panel)
3. To meet again

B3c

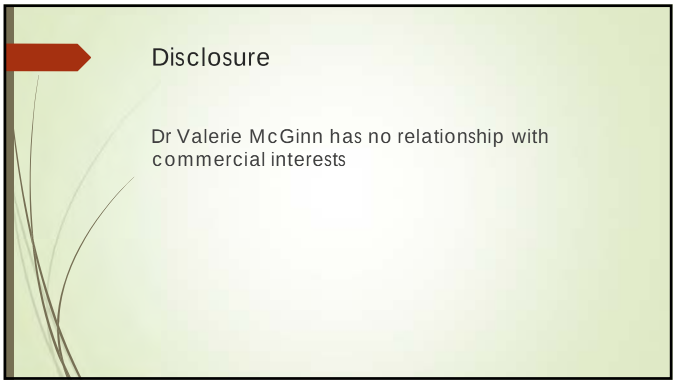
A Tale of Two Countries: Applying the Canadian Guidelines to FASD Diagnosis in New Zealand

Valerie McGinn



A Tale of Two Countries: Using the Canadian FASD Guidelines in New Zealand

Dr Valerie McGinn
Neuropsychologist
The FASD Centre
Aotearoa



Disclosure

Dr Valerie McGinn has no relationship with commercial interests

New Zealand Aotearoa

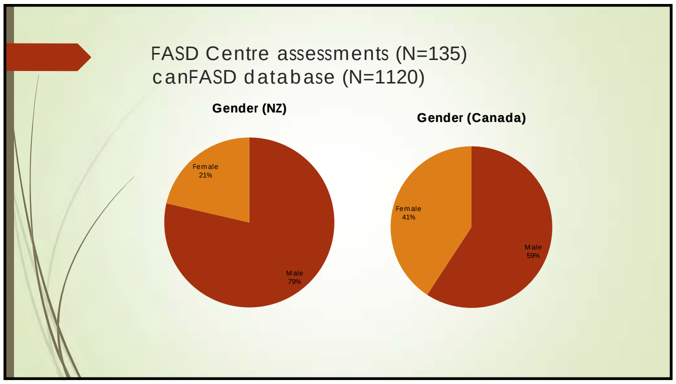
- A British colonised Pacific country
- Population 4.7 million
- 750,000 Maori (15%)
- Median age Maori 25, total 38 Years
- Urbanised 86%
- UNICEF 27% kids in poverty (33% Maori)
- 12% pregnancies heavily alcohol exposed

FASD Diagnosis Develops In New Zealand

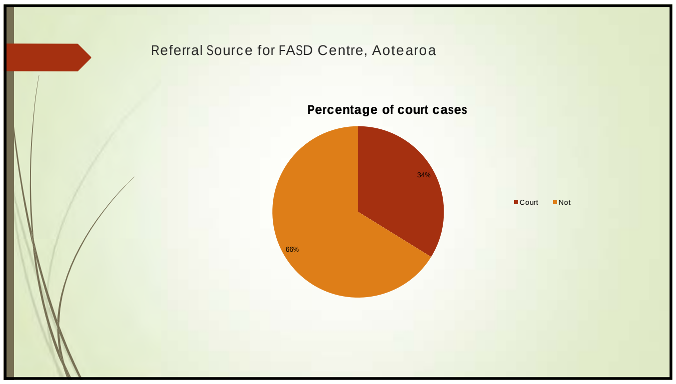
- Driven by Christine Rogan, Alcohol Healthwatch
- 2008 investigation into how to do it
- Adopted 2005 Canadian Guidelines
- Some capacity developed in DHBs
- FASD Centre team developed
- Referrals from Oranga Tamariki, Justice, PCSS
- FASD not a funded disability still in NZ

FASD: A guideline for diagnosis across the lifespan (Cook et al, 2015)

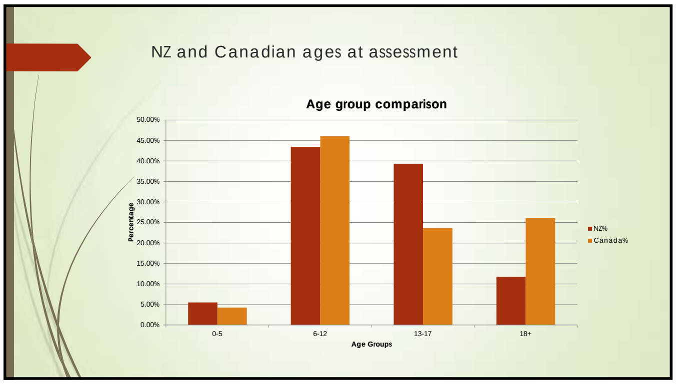
- Training in guidelines November 2015
- 47 FASD clinicians attended
- Consensus reached to adopt revision
- 01/01/16 all changed
- Update of clinicians after one year



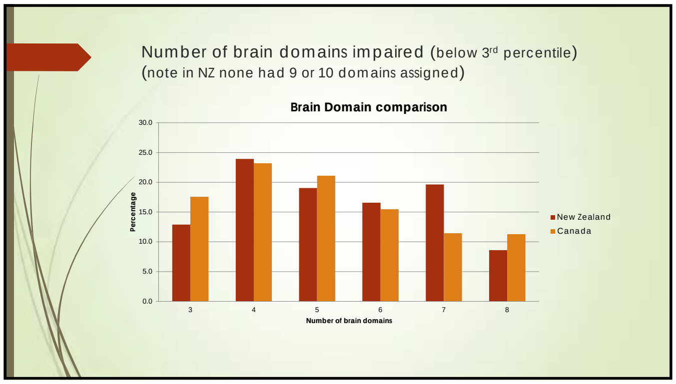
FASD Centre assessments (N=135) canFASD database (N=1120)



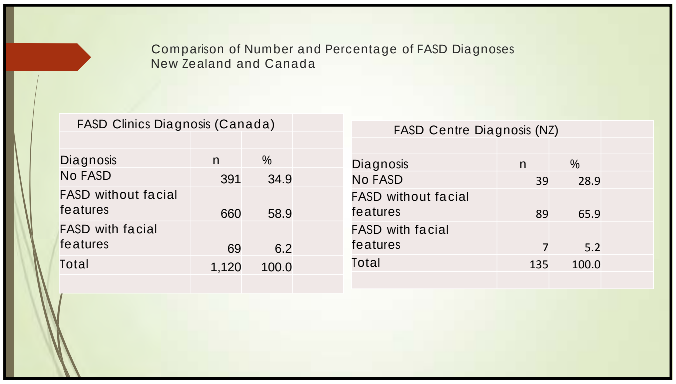
Referral Source for FASD Centre, Aotearoa



NZ and Canadian ages at assessment



Number of brain domains impaired (below 3rd percentile)
(note in NZ none had 9 or 10 domains assigned)



Comparison of Number and Percentage of FASD Diagnoses
New Zealand and Canada

FASD Clinics Diagnosis (Canada)

Diagnosis	n	%
No FASD	391	34.9
FASD without facial features	660	58.9
FASD with facial features	69	6.2
Total	1,120	100.0

FASD Centre Diagnosis (NZ)

Diagnosis	n	%
No FASD	39	28.9
FASD without facial features	89	65.9
FASD with facial features	7	5.2
Total	135	100.0

B4a

FASD Prevention - What to Change in the First Place?

Sylvia Roozen

Authors: Sylvia Roozen, Gjalt-Jorn Peters, Gerjo Kok, David Townend, Jan Nijhuis, Ger Koek, Leopold Curfs

Learning Objectives

1. Describe the families' needs related to accessing support services.
2. Describe the procedure for an adequate needs assessment related to FASD
3. Describe potential gaps in the existing support system

Objectives

Fetal Alcohol Spectrum Disorders remains an important health problem worldwide and might even be the leading preventable form of neurodevelopmental disorders. Current prevention efforts have not yet been successful in decreasing the FASD prevalence estimates. Prevention is warranted. Planning evidence-based health promoting programs requires an adequate understanding of what needs to change in the first place. Therefore the aim of the present study is to identify these and provide a first step on the road to theory- and evidence-based intervention development.

Methods

Two systematic literature reviews were conducted in multiple databases using two extensive queries. Keywords and relevant synonyms were related to FASD, pregnancy, behavior (e.g., alcohol use, binge drinking, BAC), and determinants (e.g., risk perception, norms, attitude, self-efficacy). Studies were included when e.g., written in English, included human participants, reported maternal alcohol use and or determinants in relation to FASD diagnosis. Experts in the field of alcohol were consulted for data aggregation.

Results

Twenty-one studies reported maternal alcohol drinking behaviors and twenty-five psycho-social determinants. A substantial heterogeneity in the applied measures for alcohol consumption and determinants was observed. Measures were operationalized differently (e.g., dichotomous, nominal, continuous measures), and comparisons between pregnant women who drink and those who didn't drink were often not reported. This heterogeneity precluded aggregations or meta-analyses of the data. Instead, data were qualitatively inspected.

Conclusion

The current knowledge on maternal alcohol drinking behaviors and its determinants in relation to FASD is limited. Evidence-based preventive measures necessitate identifying which prenatal alcohol drinking behavior(s) are most in need of intervention. The state of the literature has little guidance to offer in terms of what behaviors and determinants (i.e. why individuals engage in the relevant undesirable and desirable behaviors) health promotion programs should target on. Because designing effective interventions first and foremost requires a thorough understanding of the target behavior(s) and their determinants, it is therefore important that future research considers the limitations identified from these reviews so that in the future, a clearer picture may emerge.

References

Roozen S, Kok G, Curfs L. Fetal Alcohol Spectrum Disorders: Knowledge Synthesis. Maastricht: Maastricht University Press; 2017. https://cris.maastrichtuniversity.nl/portal/files/16028548/eBook_Fetal_Alcohol_Spectrum_Disorders_Knowledge_Synthesis.pdf

Roozen, Sylvia, Diane Black, GJ Y. Peters, Gerjo Kok, David Townend, J. G. Nijhuis, G. H. Koek, and L. M. G. Curfs. "Fetal alcohol spectrum disorders (FASD): an approach to effective prevention." Current developmental disorders reports 3, no. 4 (2016): 229-234.

Kok, Gerjo, Nell H. Gottlieb, Gjalt-Jorn Y. Peters, Patricia Dolan Mullen, Guy S. Parcel, Robert AC Ruiter, María E. Fernández, Christine Markham, and L. Kay Bartholomew. "A taxonomy of behaviour change methods: an Intervention Mapping approach." Health psychology review 10, no. 3 (2016): 297-312.

France, Kathryn E., Robert J. Donovan, Carol Bower, Elizabeth J. Elliott, Janet M. Payne, Heather D'Antoine, and Anne E. Bartu. "Messages that increase women's intentions to abstain from alcohol during pregnancy: results from quantitative testing of advertising concepts." BMC Public Health 14, no. 1 (2014): 30.

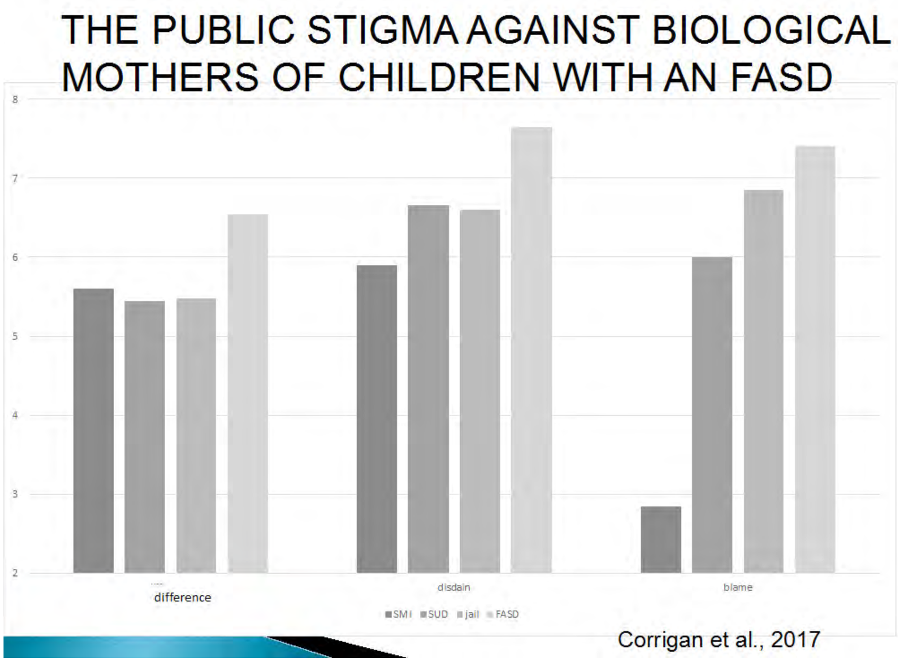
B4b

Reducing Stigma Towards Birth Mothers in Healthcare Providers: Warrior Moms Stand Up, Speak Up: Curriculum for Birth Mothers

Kathleen T. Mitchell

Changing the Things We Can ~
The Stories of Warrior Moms

The CEMR was developed to train and empower women that have given birth to a child with a fetal alcohol spectrum disorder (FASD), or who have used alcohol or other substances during their pregnancies, to share about their experience with healthcare providers in order to reduce stigma. It is not uncommon for healthcare providers to have biased notions and stigmatizing attitudes towards birth mothers (Corrigan et al., 2018) as many are not uneducated about addiction and the possibility of recovery. Research has shown that when healthcare providers hear directly from a person with real life experience that interaction reduces the stigma and stereotypes and harmful beliefs (Corrigan et al., 2014; Corrigan et al, 2018).


THE PUBLIC STIGMA AGAINST BIOLOGICAL MOTHERS OF CHILDREN WITH AN FASD

Corrigan et al., 2017

Table: A 2017 study showed that the general public viewed mothers of children with FASD with greater disdain, more different and more responsible than women than women with mental illness, substance use disorders or women that had been in jail (Corrigan et al., 2018).

A later study conducted by Corrigan et al., 2018 used a community based participatory program (CBPP) approach to identify the existing stigma of biological mothers of children with an FASD and stigma of individuals with an FASD. The CBPP developed focus groups that would reveal a better understanding of the existing stigma. The five focus groups included: adults with FASD, biological mothers of children with FASD, other relatives of children with FASD including adoptive parents or siblings, pediatric health providers, and obstetrical health providers. The questions asked of the focus groups started with a general question of how you would explain Fetal Alcohol Spectrum Disorders to other people, and then asked more specific questions that revealed people's attitudes and beliefs about individuals with FASD and their biological mothers. The research project found that physicians and providers have hidden stigma and negative attitudes towards mothers that have children with an FASD. The collective focus groups reported the following stereotype beliefs about birth mothers of children with FASD:

- They are very unstable
- They are ignorant
- They are selfish people
- They are uneducated
- They are child abusers.
- They are addicts/alcoholics.
- They are unable to change.
- They have poor social relationships

Individuals with FASD are stigmatized, just as their biological mothers are. Corrigan et al. (2018) reported that focus groups held with healthcare providers and families living with FASD generally believed that individuals all fit into a particular stereotype of individuals. Below are some of the adjectives or comments used to describe individuals with an FASD:

- Dfferent
- Brain disordered
- Damaged goods
- Retarded
- Immature, incapable of ever acting their age
- Cursed - they have a bad prognosis or permanent damage
- Lazy
- Violent
- Unable to pay attention
- Unable to learn
- Unable to form relationships

Goal and Objectives

The goal of the CEMR is to reduce the stigma and bias that healthcare providers may have towards birth mothers of children with FASDs and to empower women with their own story told in their own voice. Witnessing a heartfelt testimonial from a woman that has used substances during pregnancy or has a child with FASD is a powerful tool to combat the stigma, preconceived stereo-typing, and bias's that healthcare providers may have. The belief is that when stigma is reduced amongst providers it will ultimately:

1) Decrease future alcohol and other substance exposure pregnancies.

2) Increase the likelihood of intervention, treatment and support for the birth mother.

3) Improve identification, accurate diagnosis and care of children with an FASD

The CEMR includes two separate modules:

Module One: Stigma and Birth Mothers of Children with an FASD

Learning Objectives

After completing Module One, the learner should be able to:

- Describe how stigma has impacted your life, other birth mothers, and families living with FASD.

- Provide at least two examples of person first language.
- Articulate three FASD public health messages that do not perpetuate stigma towards women.

Module Two: From Victim to Warrior Moms: Empowering Birth Mothers

Learning Objectives

After completing Module Two, the learner should be able to:

- Name the 3 essential aspects of telling your story that healthcare providers need to hear.
- Define empowerment and how that relates to the experience of telling your story to healthcare providers.
- Discuss what you want healthcare providers to do to help prevent future cases of FASD.
- Develop a list of three things that providers can do to help mothers that are using alcohol and other substances.

In addition to the two learning modules, the CEMR includes background narrative, group lesson plans, activities and handouts, a sample one-day and two-day training agenda, a training evaluation, a PowerPoint template to provide to program participants and national resources.

Who would use the CEMR?

Professionals who treat women with alcohol use disorders (AUD) or substance use disorders (SUD) or provide support to biological mothers of children that have been exposed to alcohol or other substances who are interested in sharing their experiences to increase knowledge about FASDs and addiction and reduce stigma.

Who would be trained using the CEMR?

The curriculum seeks to prepare birth mothers of children with FASDs to be effective speakers. The criteria for inclusion includes:

- Women that are stable in their recovery from addiction and have two years clean and sober from alcohol or other substances.
- Women that have received support and have processed their own grief and are emotionally stable in their process of grief and acceptance in having a child diagnosed with an FASD.
- Women that have support from their children and family members to participate as a speaker.

The main target group of the CEMR is mothers to children with an FASD. However, the CEMR can be modified to train women to tell their stories that have used other substances during pregnancy such as opioids or marijuana. Poly-drug use is very common for women with alcohol use disorders (AUD) and having substance use disorders (SUD) is a risk factor for having a child with an FASD. The CEMR can also be modified to train individuals with an FASD and other family members to speak. Women, individuals with an FASD and family members that are courageous enough to speak out and share their stories about alcohol or other substance exposure in a public forum should be empowered with knowledge and basic facts about both FASD and addiction, be trained and prepared to speak effectively and be respected and valued at the actual training event.

The benefit to women that participate in the CEMR training incudes increased education and awareness about stigma, FASD and addiction. Participants in the training process their unique life experiences with other women with similar backgrounds. Participants will learn techniques on how to tell their story in a concise, organized, interesting and compelling way to reduce the stigma that healthcare providers may have towards birth mothers. The women benefit by bonding with other birth mothers and together work to educate physicians and healthcare providers to support women and prevent substance exposed pregnancies and FASDs.

References

Corrigan, P.W., & Kosyluk, K.A. (2014). Mental illness stigma: Types, constructs, and vehicles for change.

Corrigan, PW., Shah, BB, Lara, JL, Mitchell, KT., Combs, P., Simmes, D, Jones, Kenneth L. Stakeholder Perspectives on the Stigma of Fetal Alcohol Spectrum Disorder. Addiction Research and Theory. 2018. https://doi.org/10.1080/16066359.2018.1478413

Corrigan, PW., Shah, BB, Lara, JL, Mitchell ,KT., Simmes D, Jones, Kenneth L. Addressing the public health concerns of Fetal Alcohol Spectrum Disorder: Impact of stigma and health literacy. Drug and Alcohol Dependence 2017 https://doi.org/10.1016/j.drugalcdep.2017.12.027

Corrigan PW, Lara JL, Shah BB, Mitchell KT, Simmes D, Jones KL. The public stigma of birth mothers of children with fetal alcohol spectrum disorders. Alcohol Clin Exp Res. 2017 Jun;41(6):1166-1173.

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To order the CEMR contact:

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B4c A Brief Intervention with a Lasting Impact

Leana Olivier

Authors: Leana Olivier, Jaco G Louw, Lian-Marie Drotsky, Denis Viljoen

Learning Objectives

1. Provide an overview of a brief motivational interviewing and support programme which can be used to support pregnant women to abstain or reduce their alcohol consumption during pregnancy as to prevent or lower the risk of FASD
2. Describe the various stages of the programme
3. Discuss the impact of the intervention on the lives of the women and their children

Introduction

With FASD prevalence rates as high as 26 to 282/1000, there is a dire need for non-judgemental, compassionate and cost effective prevention programmes in South Africa. The Foundation for Alcohol Related Research (FARR) developed a brief motivational interviewing and support programme for pregnant women. The Healthy Mother Healthy Baby (HMHB) Programme was piloted and implemented in 10 different rural and urban communities. This presentation will provide an overview of the programme, results and partnership with the local Departments of Health (DoH).

Methods

In the project areas all the pregnant women (< 20 weeks gestation) were invited, through the DoH's antenatal clinics, to enroll in the HMHB Programme. To promote healthier pregnancies and healthier babies and alleviate stigma, pregnant women (PW) were enrolled irrespective of their alcohol/substance abuse history.

After completing an AUDIT screen and interview, PW were allocated to four risk groups and a designated Community Worker (CW). The PW received a booklet, "My Special Booklet", and based on the regime for each risk group, attended brief motivational interviewing (BMI) groups, individual sessions, participated in video-based discussion and activity groups. Heavy drinkers received supportive home visits and those who were addicted were offered rehabilitation. Post-delivery, the women were visited by the CW's and at 9 months their babies received paediatric and FASD assessments. Infants could then optionally enroll in FARR's Early Childhood Development programme. Information obtained were recorded in patient files, data were captured on REDCAP.

Results

To date 3,013 PW in 10 project sites in 4 provinces enrolled in the programme. The retention rate of the various project sites vary between 78% to 97%. The majority of PW were allocated to Risk Groups 1 and 2 (83,8%). 16,2% of the PW were allocated to Risk Groups 3 and 4, which placed them at high risk of having babies with FASD. To date a total of 2,1281 babies were born, 1,597 of these babies have already been assessed at 9 months of age. The impact of the programme and the outcomes of the babies with FASD are currently being analysed and will be ready at the time of the presentation.

Conclusions

This simple, compassionate and cost effective BMI programme, supplemented the basic antenatal services of the Department of Health and provided sufficient support to the majority of pregnant women to either stop drinking during pregnancy or to cut down on their drinking (harm reduction). Within a short period of time the programme positively impacted on the lives of the participating women and their children.

B4d

Knowledge and Practices of Health Professionals Concerning Fetal Alcohol Syndrome in Reunion Island (France)

Bérénice Doray

Authors: Bérénice Doray, Nelly Maroudin Viramale, Barbara Delmotte, Karine Josse, Stéphanie Sotaca, Stéphanie Robin, Justine Lanneaux, Marilyn Tallot,Augustin Rousselle, Marie-Line Jacquemont, Alize Payet, Sonia Henkous, Lucie Rebourg, Michel Spodenkiewicz

Objectives

Fetal Alcohol Spectrum Disorder represents a major public health problem. Concerning about 1 in 100 births, it is the most common cause of neurocognitive disorders and difficulty of social insertion. Fetal Alcohol Syndrome (FAS) is the most severe form and concerns one in 1,000 births. The purpose of this study was to identify current knowledge and practices concerning FAS among pediatricians (P), gynecologists (G), general practitioner (GP) and midwives (M).

Methods: Three questionnaires were developed by the Resource Center of Reunion Island. They were distributed in 2016, by e-mail by the regional perinatal network or before training sessions organized by the Resource Center.

Results

134 responses were obtained from 74 M, 24 G, 20 GP and 16 P.

If 97.8% of participants declared to know the term “FAS” for Fetal Alcohol Syndrome, the correct prevalence (1/1,000) was given only by 46% of the professionals, (P: 56%, G: 54%, M: 47%).

The best-known clinical signs were: microcephaly (84%), psychomotor impairment (95%), behavioral disorders (91%) and social maladjustment (78%). On the other hand, only 9.7% of professionals were able to describe the facial dysmorphy (G: 21%, P:16%, M:7%, GP:5%).

Concerning prevention, only 51% of G and M and 36% of P and GP declared to systematically inform teenage girls and women of childbearing age about the risks of prenatal alcohol exposure. During pregnancy, the necessity of abstinence was well-known by 98.5% of professionals; 85% of G, M and GP declared to ask systematically for alcohol consumption.

Nevertheless, in daily practice, alcohol consumption was systematically questioned by only 13.5% (M), 37.5% (G) and 42% (GP) if fetal growth restriction. The explanations were lack of knowledge in 35% of cases, fear of stigmatizing in 32%, lack of time in 20%, and lack of interest in 7%.

The end of the questionnaire concerned training of health professionals: 24% feel prepared to talk to a pregnant woman about her consumption, 36% a little prepared, 31% unprepared, 8% unprepared.

Only 10% of G, M and GP felt prepared to follow and take care of a pregnant woman with an addiction to alcohol

and 21% of P and GP believed they were well prepared to diagnose a child with FAS.

Similarly, 9% of P and GP felt well prepared to follow and care for a child with FAS, 15% somewhat prepared, 46% not well prepared and 24% not prepared.

Conclusion

This study demonstrates correct theoretical knowledge of the effects of prenatal exposure to alcohol among health professionals in Reunion Island.

Nevertheless, it shows real difficulties in daily practice, concerning both diagnosis and prevention. The majority of professionals are not well prepared to diagnose and manage a pregnant woman with alcohol problem or a child with FAS. Moreover, the messages of prevention are insufficiently relayed to young women of childbearing age.

Training programs about FAS need to be organized within continuing education programs. This is one of the objectives of the Resource Center of Reunion Island.

B5a

YOUNG INVESTIGATOR

Challenges and Resiliency in Aboriginal Adults with FASD

Melanie Samaroden, Paul Jerry

Resiliency in Aboriginal Adults with Fetal Alcohol Spectrum Disorder

Thesis Supervisor: Dr. Paul Jerry, PhD
Melanie Samaroden, BA BA BEd
3rd year Master's in Counselling Psychology Student

Resiliency and Dysfunctional Resiliency

- The ability to endure adversity and have a better chance of successfully overcoming adversity.
- More research is needed to understand how more Aboriginal adults with FASD can learn or improve their resiliency.
- Resiliency has both internal and external components; external components are the supports that a person receives to help them persevere, while the internal component is the self.
- Dysfunctional resiliency occurs when a person adopts a coping mechanism that gives the support they are lacking, but is not a positive change and can lead to more negative behaviours.

Participatory Action Research

"If you have come to help me you are wasting your time, but if you have come because your liberation is bound up with mine, then let us work together" (Lila Watson, as cited in Conrad, 2015)

Qualitative Research – Participatory Action Research (PAR)

- PAR balances the power differential between researcher and participants – especially important when try to reduce colonialist effects.
- PAR involves the participants and their community in the research process.
- I am not Aboriginal; therefore, PAR allows the community's values and culture to be understood from the perspective of the participants, rather than myself, the researcher.
- PAR follows the principles of OCAP: Ownership, Control, Access, and Possession

Thank you!

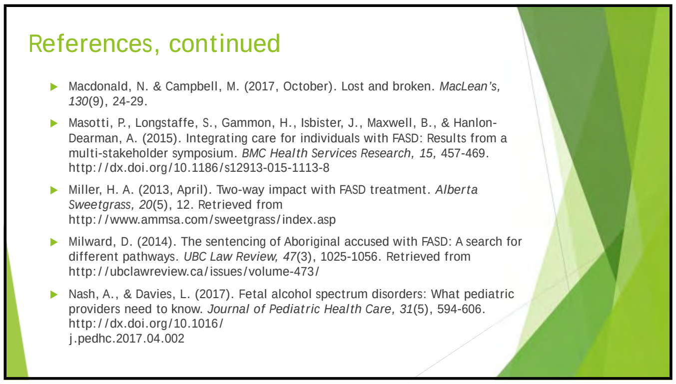
Questions?

References

- Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., Reynolds, J. N., & Racine, E. (2016). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics, 9*(1), 65-77. http://dx.doi.org/10.1093/phe/phv012
- Blue, A., Darou, W., Ruano, C. (2010). Engaging the elder within: Bridging and honouring the cultural spaces in counselling with First Nations. In N. Arthur & S. Collins (Eds.), *Culture-Infused Counselling 2nd Edition* (p. 259-284). Calgary, AB: Counselling Concepts.
- Bracken, D. C. (2008). Canada's Aboriginal people, fetal alcohol syndrome and the criminal justice system. *British Journal of Community Justice, 6*(3), 21-33. Retrieved from http://www.cjp.org.uk
- Brown, J., Mitchell, M., Wartnik, A., & Russell, A. (2015, November). FASD and the courts: A reference for legal professionals. *Bench & Bar of Minnesota*, 24-28. Retrieved from www.mnbar.org
- Burnside, L. & Fuchs, D. (2013). Bound by the clock: The experiences of youth with FASD transitioning to adulthood from child welfare care. *First Peoples Child & Family Review: An Interdisciplinary Journal, 8*(1), 41-62. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/200

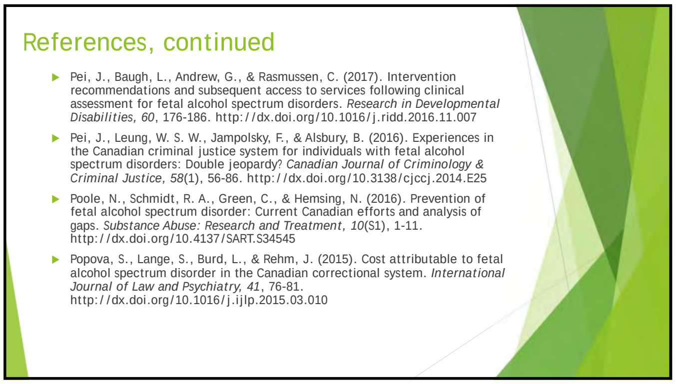
Refences, continued

- Canadian Broadcasting Corporation. (2009). *Unique project helps keep FASD teens out of jail.* Retrieved from www.cbc.ca/news/canada/edmonton/unique-project-helps-keep-fasd-teens-out-of-jail-1.827083
- Canadian Institutes of Health Research., Natural Sciences and Engineering Research Council Canada., Social Sciences and Humanities Research Council of Canada. (2014). *Tri-council policy statement: Ethical conduct for research involving humans.* Ottawa: Secretariat on Responsible Conduct of Research.
- Duquette, C. & Orders, S. (2013). Postsecondary educational experiences of adults with fetal alcohol spectrum disorder. *International Journal of Special Education, 28*(3), 68-81. Retrieved from http://www.eric.ed.gov/contentdelivery/servlet/ERICServlet?accno=EJ1024417
- Eni, R. & Senecal, S. (2009). Pathways to fetal alcohol spectrum disorder in Aboriginal communities. *Canadian Diversity, 7*(3), 85-92. Retrieved from http://www.acs-aec.ca/
- Knorr, L. & McIntyre, L. J. (2016). Resilience in the face of adversity: Stories from adults with fetal alcohol spectrum disorders. *Exceptionality Education International, 26*(1), 53-75. Retrieved from http://ir.lib.uwo.ca/eei/vol26/iss1/4



References, continued

- Macdonald, N. & Campbell, M. (2017, October). Lost and broken. *MacLean's, 130*(9), 24-29.
- Masotti, P., Longstaffe, S., Gammon, H., Isbister, J., Maxwell, B., & Hanlon-Dearman, A. (2015). Integrating care for individuals with FASD: Results from a multi-stakeholder symposium. *BMC Health Services Research, 15*, 457-469. http://dx.doi.org/10.1186/s12913-015-1113-8
- Miller, H. A. (2013, April). Two-way impact with FASD treatment. *Alberta Sweetgrass, 20*(5), 12. Retrieved from http://www.ammsa.com/sweetgrass/index.asp
- Milward, D. (2014). The sentencing of Aboriginal accused with FASD: A search for different pathways. *UBC Law Review, 47*(3), 1025-1056. Retrieved from http://ubclawreview.ca/issues/volume-473/
- Nash, A., & Davies, L. (2017). Fetal alcohol spectrum disorders: What pediatric providers need to know. *Journal of Pediatric Health Care, 31*(5), 594-606. http://dx.doi.org/10.1016/j.pedhc.2017.04.002

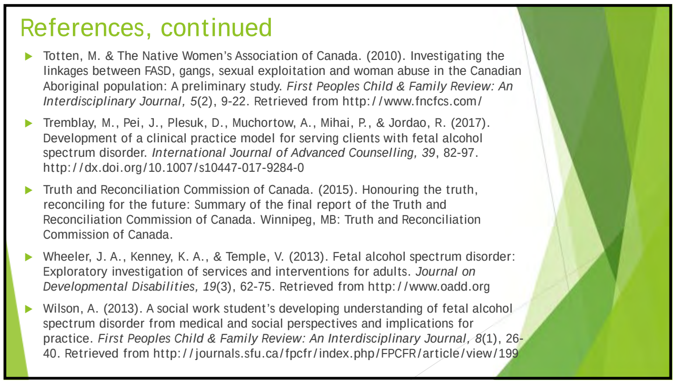


References, continued

- Pei, J., Baugh, L., Andrew, G., & Rasmussen, C. (2017). Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders. *Research in Developmental Disabilities, 60*, 176-186. http://dx.doi.org/10.1016/j.ridd.2016.11.007
- Pei, J., Leung, W. S. W., Jampolsky, F., & Alsbury, B. (2016). Experiences in the Canadian criminal justice system for individuals with fetal alcohol spectrum disorders: Double jeopardy? *Canadian Journal of Criminology & Criminal Justice, 58*(1), 56-86. http://dx.doi.org/10.3138/cjccj.2014.E25
- Poole, N., Schmidt, R. A., Green, C., & Hemsing, N. (2016). Prevention of fetal alcohol spectrum disorder: Current Canadian efforts and analysis of gaps. *Substance Abuse: Research and Treatment, 10*(S1), 1-11. http://dx.doi.org/10.4137/SART.S34545
- Popova, S., Lange, S., Burd, L., & Rehm, J. (2015). Cost attributable to fetal alcohol spectrum disorder in the Canadian correctional system. *International Journal of Law and Psychiatry, 41*, 76-81. http://dx.doi.org/10.1016/j.ijlp.2015.03.010

References, continued

- Popova, S., Lange, S., Probst, C., Parunashvili, N., & Rehm, J. (2017). Prevalence of alcohol consumption during pregnancy and fetal alcohol spectrum disorders among the general and Aboriginal populations in Canada and the United States. *European Journal of Medical Genetics, 60*, 32-48. http://dx.doi.org/10.1016/j.ejmg.2016.09.010
- Rutman, D., Hubberstey, C., Poole, N., Hume, S., & Van Bibber, M. (2016). Developing and using a common framework to evaluate FASD programs: Results of a three-year Canadian project. *International Journal of Mental Health Addiction, 14*, 472-482. http://dx.doi.org/10.1007/s11469-015-9597-3
- Samaroden, M. (2018). Challenges and resiliency in Aboriginal adults with fetal alcohol spectrum disorder. *First Peoples Child & Family Review, 13*(1), 8-19. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/index
- Shankar, I. (2015). The making of a medical disorder: Tracing the emergence of fetal alcohol spectrum disorder in Alberta. *Social Work in Public Health, 30*, p. 38-50. http://dx.doi.org/10.1080/19371918.2014.938930
- Tait, C. (2009). Disruptions in nature, disruptions in society: Aboriginal Peoples of Canada and the "making" of fetal alcohol syndrome. In L. J. Kirmayer & G. G. Valaskakis (Eds.), *Healing traditions: The mental health of Aboriginal People in Canada* (pp. 196-220). Vancouver, Canada: UBC Press.

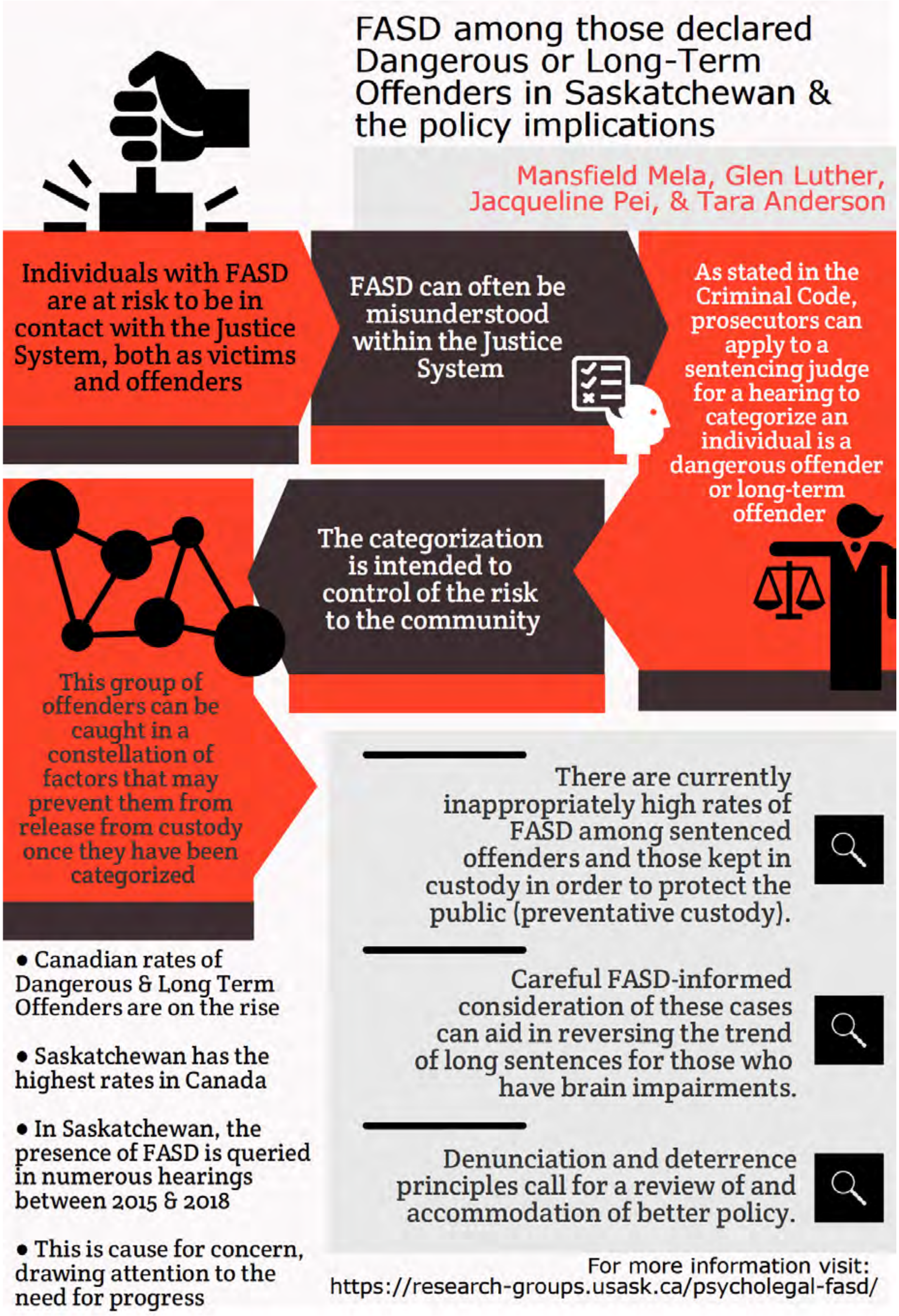


References, continued

- Totten, M. & The Native Women's Association of Canada. (2010). Investigating the linkages between FASD, gangs, sexual exploitation and woman abuse in the Canadian Aboriginal population: A preliminary study. *First Peoples Child & Family Review: An Interdisciplinary Journal*, *5*(2), 9-22. Retrieved from http://www.fncfcs.com/
- Tremblay, M., Pei, J., Plesuk, D., Muchortow, A., Mihai, P., & Jordao, R. (2017). Development of a clinical practice model for serving clients with fetal alcohol spectrum disorder. *International Journal of Advanced Counselling, 39*, 82-97. http://dx.doi.org/10.1007/s10447-017-9284-0
- Truth and Reconciliation Commission of Canada. (2015). Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada. Winnipeg, MB: Truth and Reconciliation Commission of Canada.
- Wheeler, J. A., Kenney, K. A., & Temple, V. (2013). Fetal alcohol spectrum disorder: Exploratory investigation of services and interventions for adults. *Journal on Developmental Disabilities, 19*(3), 62-75. Retrieved from http://www.oadd.org
- Wilson, A. (2013). A social work student's developing understanding of fetal alcohol spectrum disorder from medical and social perspectives and implications for practice. *First Peoples Child & Family Review: An Interdisciplinary Journal, 8*(1), 26-40. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/199

B5b Rates of FASD Among Offenders Declared Dangerous in Saskatchewan (Canada) and the Policy Implications

Mansfield Mela, Glen Luther, Jacqueline Pei



FASD among those declared Dangerous or Long-Term Offenders in Saskatchewan & the policy implications

Mansfield Mela, Glen Luther, Jacqueline Pei, & Tara Anderson

Individuals with FASD are at risk to be in contact with the Justice System, both as victims and offenders

FASD can often be misunderstood within the Justice System

As stated in the Criminal Code, prosecutors can apply to a sentencing judge for a hearing to categorize an individual is a dangerous offender or long-term offender

The categorization is intended to control of the risk to the community

This group of offenders can be caught in a constellation of factors that may prevent them from release from custody once they have been categorized

- Canadian rates of Dangerous & Long Term Offenders are on the rise
- Saskatchewan has the highest rates in Canada
- In Saskatchewan, the presence of FASD is queried in numerous hearings between 2015 & 2018
- This is cause for concern, drawing attention to the need for progress

There are currently inappropriately high rates of FASD among sentenced offenders and those kept in custody in order to protect the public (preventative custody).

Careful FASD-informed consideration of these cases can aid in reversing the trend of long sentences for those who have brain impairments.

Denunciation and deterrence principles call for a review of and accommodation of better policy.

For more information visit:
https://research-groups.usask.ca/psycholegal-fasd/

B5c Finding the Balance - Integrating Indigenous Worldview with Western Clinical FASD Assessment

Courtney Fraser, Melanie Nelson

Description

This presentation involves an in-depth look at the growth opportunities created when an Indigenous organization and a Western clinic-based organization partner to support the Indigenous community, and the community at large. Emphasis will be placed on changes in FASD assessment support services, steps taken to integrate a two-lens approach, and beginning approaches to considering trauma within the practice of assessment. This presentation will support professionals (clinicians, researchers, non-profits and government organizations) in creating Indigenous partnerships, addressing Calls to Action of the Truth and Reconciliation Commission (TRC), and will support attendees in addressing and working from a decolonized framework.

Organization

This presentation will be conducted from in Indigenous worldview and will consist of on open dialogue between presenters and attendees to support professionals in understanding how their work may impact Indigenous peoples/ communities, and how to create change from a culturally responsive perspective. This presentation is appropriate for community members/professionals who are starting their journey with Truth and Reconciliation and for individuals who are looking for the next steps and adapting the Western clinical model for FASD assessments.

Learning Objectives

1. Recognize the importance of Indigenous value systems and how predominant western medical models can alienate or unintentionally reinforce intergenerational trauma
2. Identify ways to engage with Indigenous community stakeholders to partner and address the Calls to Actions made by the Truth and Reconciliation Commission of Canada
3. Examine practical applications of how to integrate an Indigenous worldview while walking together and occupying the same space with a western medical program
4. Review lessons learned and next steps in developing the integration of Indigenous worldview in standardized assessment practices

Key Topics

Indigenous Worldview
Indigenous Support Implementation
Two-Lens Model Structure
Truth and Reconciliation
Cultural Bias and Testing
Testing Reform

What Will You Walk Away With

This presentation will challenge the participants to think outside of their current worldview and to reflect on best practices when working with Indigenous peoples. Professionals will leave this presentation having a better understanding of unintentional harm that may be caused when working with Indigenous peoples, and they will have a starting point to begin integrating and increasing cultural sensitivity through clinical assessment practices. Having a better understanding of Indigenous worldview and the impacts an agency/profession can have on Indigenous communities will foster the professionals' abilities to address the TRC's calls to action.

References:

Truth and Reconciliation Commission of Canada. (2015). Report of the Truth and Reconciliation Commission of Canada: Calls to Actions. Winnipeg: Truth and Reconciliation Commission of Canada.
May PA, Chambers CD, Kalberg WO, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA. 2018;319(5):474–482. doi:10.1001/jama.2017.21896

B6a

To See or Not to See - Considerations when Intaking Complex FASD Referrals

Sheryle Marshall, Sharon Wazney, Ana Hanlon-Dearman, Kellsey Scheepers

Authors: Sheryle Marshall, Sharon Wazney, Ana Hanlon-Dearman, Kellsey Scheepers, Sally Longstaffe, Sandra Marles

Learning Objectives

1. Describe the development of the multidisciplinary intake team: who is involved, what are the critical roles of specific team members in contributing to intake decisions
2. Discuss the decision pathways and outcomes for complex referrals
3. Stimulate discussion on approaches to managing the complexity of referrals for FASD assessment
4. Describe the impact that the intake team has on the allocation of clinical resources and waitlist management.

Abstract

The Manitoba FASD Centre has been providing assessment for children and youth prenatally exposed to alcohol for two decades. The Centre was established in 1999 as the Clinic for Alcohol & Drug Exposed Children (CADEC). The Manitoba FASD Centre receives over 420 referrals per year with support of Diagnostic Coordinators throughout the province. With the increase and complexity of the referrals a formal intake team was established in 2010. Approximately 35% of referrals we receive are discussed by our intake team. The development of a multi- disciplinary intake team was a critical component in the review of complex referrals received by the Centre. Not all children/youth referred to the Centre meet Canadian Guidelines criteria to proceed for diagnostic assessment but all referrals benefit from comprehensive intake review and recommendations.

Factors that require consideration include: the extent of the prenatal alcohol exposure, the severity of behavioral and learning challenges, and medical, environmental, or genetic factors. Social factors that can influence the best timing for an assessment to help ensure a positive outcome for both the child/youth and their family also require consideration.

Data gathered from clinical discussions at the intake team meetings has been descriptively analyzed for relevant themes and processes. Multidisciplinary team members will present rationale for intake pathways and processes for management. We will encourage audience questions and active sharing of their experiences and intake pathways in the spirit of a community of intake practice. This presentation would be of particular interest to clinical coordinators, physicians, and clinicians/professionals who make and receive FASD referrals.

B6b Affect Regulation (AR) in PAE and FASD

Valerie Temple, Hasu Rajani, Mansfield Mela

Authors: Valerie Temple, Hasu Rajani, Mansfield Mela, Jocelynn Cook

Learning Objectives

1. Acquire skills to identify AR deficits in FASD
2. Link AR deficits with a variety of mental health outcomes and consider new ways of viewing these challenges
3. Enhance diagnostic skills for the AR domain of FASD

Background

Affect Regulation (AR) refers to the ability to modulate and control emotional arousal. Individuals with FASD frequently have deficits in AR along with high rates of mental health disorders. The revised Canadian Guidelines for diagnosis of FASD (Cook et al., 2016) now include AR as 1 of 10 neurodevelopmental domains to be evaluated in the process of FASD assessment.

Support for including the AR domain in FASD diagnosis comes from a variety of human studies as well as animal research models. In humans, epidemiological research has found very high levels of comorbid psychiatric problems in FASD including mood and anxiety disorders (Weyrauch et al., 2017). In addition to human studies, experiments with animals have shown a direct link between PAE and increased neuroendocrine response to stress. PAE impacts the brain mechanisms involved in the stress response and this can lead to hyper-reactivity to stress, and in turn, a predisposition to psychiatric disorders associated with emotional dysregulation such as anxiety or depression (Hellemans et al., 2010; Weinberg et al., 2008).

The objectives of this research project were as follows: Study 1) examine AR deficits in FASD and how they may be related to various mental health outcomes; Study 2) investigate if the addition of the AR domain to FASD Diagnostic Guidelines in 2016 has resulted in a significant increase in the number of diagnoses of FASD in Canada.

Method/ Results

Data source:

Our research analyzed information from the Canadian National Database for FASD (Clarren et al., 2015). The National Database includes information about FASD diagnoses made at 26 different clinics across 9 provinces in Canada. After completing an FASD assessment locally, participating clinics input information for individual patients into a REDcap (Research Electronic Data Capture) database. REDcap is secure web application for building and managing online surveys and databases created expressly for clinical research.

Data entered by clinics into REDcap includes the following: patient prenatal exposures and demographics; sources of referral and place of residence; comorbid medical and psychiatric diagnoses (e.g., Conduct Disorder, ADHD etc.); current medications; results of the neurodevelopmental assessments (e.g., medical, psychological, OT, communication assessments); final FASD diagnosis; and recommendations made following the assessment.

Study 1:

A total of 404 individuals diagnosed with FASD or PAE-At Risk for FASD (Cook et al., 2016) between January 2016 and March 2018 using the new Guidelines were identified from the National Database for this study.

Thirty-seven percent had AR deficits reported. Individuals with AR deficits were older (mean age 18.7) than those without AR deficits (mean age 13.5 years) [F (1, 388) = 30.38, p<.001]. No significant differences were found between those with and without AR deficits for gender [X2 (1, N=401) = .02, p=.89] or level of intellectual ability [X2 (2, N=379) = 2.64, p=.27].

Individuals with and without AR deficits were compared across a variety of outcomes using odds ratios (ORs). In this analysis, the ORs indicate the likelihood that an attribute (e.g., a comorbid diagnosis, suicide attempt, etc.) is present in the AR deficit group. If the OR is less than 1, there is lower risk or less likelihood that that attribute is present in the AR deficit group. Higher numbers indicate greater likelihood that the attribute is present in the AR deficit group.

Results found individuals with AR deficits were at significantly higher risk for having a diagnosis of Attachment Disorder (OR 4.9), Conduct Disorder (OR 4.8), and Post-traumatic Stress Disorder (OR 7.4) than those without AR deficits. Individuals with AR deficits were also significantly more likely to have attempted suicide (OR 9.1).

Study 2:
A total of 769 cases assessed between January 2016 and October 2018 using the new Guidelines were identified from the National Database for Study 2. This included individuals receiving an FASD diagnosis, a PAE-At Risk designation, or no FASD diagnosis.

Cases were then divided into three groups: 1) those with two or fewer domains of impairment; 2) those with three domains of impairment only; and 3) those with four or more domains of impairment.

ORs were calculated for two models using logistic regression. The first model investigated the odds of having an AR deficit, two domains of impairment, and no FASD diagnosis versus having an AR deficit, three domains of impairment, and receiving an FASD diagnosis. Results of this analysis found that although the odds of having an AR deficit were greater in the three domain group than the two domain group (OR 1.9; 95% C.I. of .97 - 3.8) they were not significantly greater (p=.058). This means that AR deficits were almost twice as likely to be found in the three domain group than the two domain group, but the result did not achieve statistical significance.

The second model compared the odds of having an AR deficit, two domains of impairment, and no FASD diagnosis versus having an AR deficit, four or more domains of impairment, and an FASD diagnosis. Results found that individuals in the four or more domain group were much more likely to have AR deficits (OR, 6.1; 95% C.I. of 3.8 - 9.7) and this difference was statistically significant (p<.0001). This indicates that individuals with a greater degree of impairment (four or more domains of deficit) were 6 times more likely to have AR deficits than those with less impairment (two or fewer domains of deficit).

Discussion

Several mental health issues were found to be more common in individuals with FASD and AR deficits including Attachment Disorder, Conduct Disorder, and PTSD. Past suicide attempts were also found to be more frequent in those with AR deficits.

The association between AR deficits and suicide attempts presents a possible avenue for targeted intervention. If, as research suggests (Alvik et al., 2011) AR deficits and intense emotionality can be recognized early in children, effective coping strategies and environmental supports might be aimed at this particularly vulnerable group to decrease their risk during times of increased stress or challenge. The elevated rate of PTSD in the AR deficits group suggests having emotional dysregulation increases the likelihood of a more adverse reaction to any traumatic event experienced. This suggests another area of targeted intervention for those with AR deficits.

Individuals with FASD and AR deficits were older at diagnosis. Previous research has found that older age at diagnosis is a risk factor for a variety of adverse outcomes (Streissguth et al., 2004).

With regards to the effect of the new AR category on FASD diagnoses, our review found that AR deficits were most likely to be identified in cases with 4 or more domains of impairment. This suggests that the addition of the new AR domain may, in some cases, be the deciding factor in making an FASD diagnosis, but is more often an additional area of impairment identified among many.

References

Alvik A, Torgerson AM, Aalen OO, et al. Binge alcohol exposure once a week in early pregnancy predicts temperament and sleeping problems in the infant. Early Human Develop. 2011;87(12):827-833.

Clarren S, Halliwell CI, Werk CM, et al. Consistent collection and reporting of FASD data from across Canada: a feasibility study. J Pop Ther Clin Pharmacol. 2015;22(3):e211-228.

Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. CMAJ. 2016;188(3):191-7.

Hellemans KG, Sliwowska JH, Verma P et al. Prenatal alcohol exposure: fetal programming and later life vulnerability to stress, depression, and anxiety disorders. Neurosci Biobehav Rev. 2010;34:791-807.

Streissguth AP, Bookstein FL, Barr HM et al. Risk factors for adverse outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004;25(4):228-238.

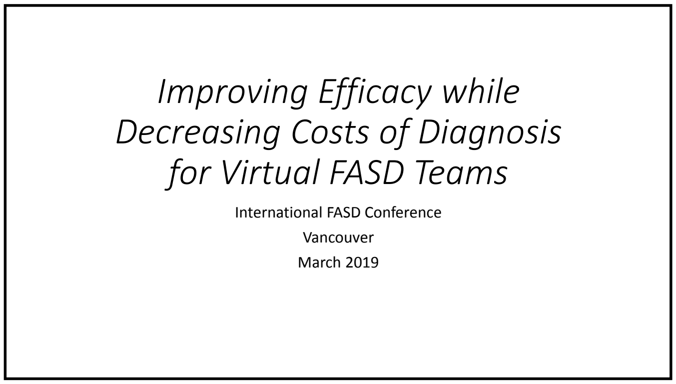
Weinberg J, Sliwowska JH, Lan N et al. Prenatal alcohol exposure: foetal programming, the hypothalamic-pituitary-adrenal axis and sex differences in outcome. J Neuroendocrinol. 2008;20(4):470-488.

Weyrauch D, Schwartz M, Hart B et al. Comorbid mental disorders in fetal alcohol spectrum disorder: a systematic review. J Dev Behav Pediatr. 2017;38(40):283-291.

B7

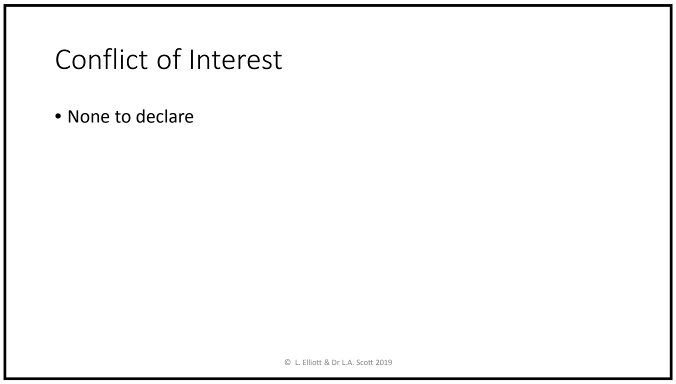
Improving Efficacy while Decreasing Costs of Diagnosis for Virtual FASD Teams

Louise Scott, Liv Elliot



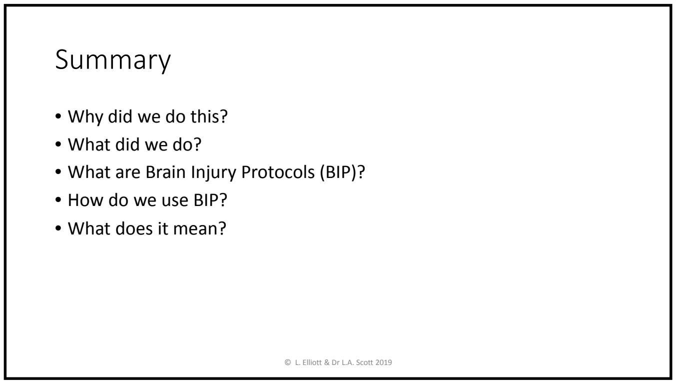
Improving Efficacy while Decreasing Costs of Diagnosis for Virtual FASD Teams

International FASD Conference
Vancouver
March 2019



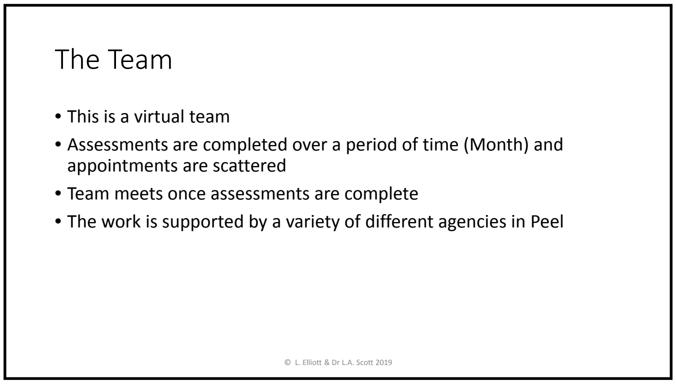
Conflict of Interest

- None to declare



Summary

- Why did we do this?
- What did we do?
- What are Brain Injury Protocols (BIP)?
- How do we use BIP?
- What does it mean?

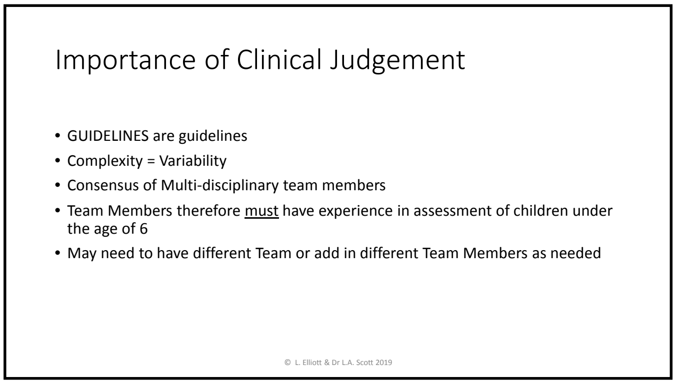


The Team

- This is a virtual team
- Assessments are completed over a period of time (Month) and appointments are scattered
- Team meets once assessments are complete
- The work is supported by a variety of different agencies in Peel

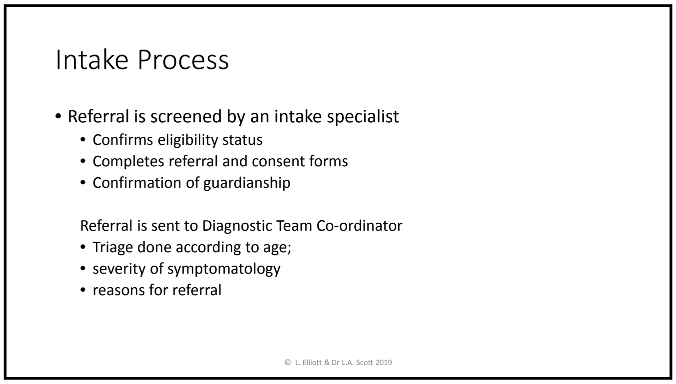
Members of the Team

- Social Worker
- Developmental Paediatrician
- Neuropsychologist
- Psychometrist
- Occupational Therapist
- Speech and Language Pathologist



Importance of Clinical Judgement

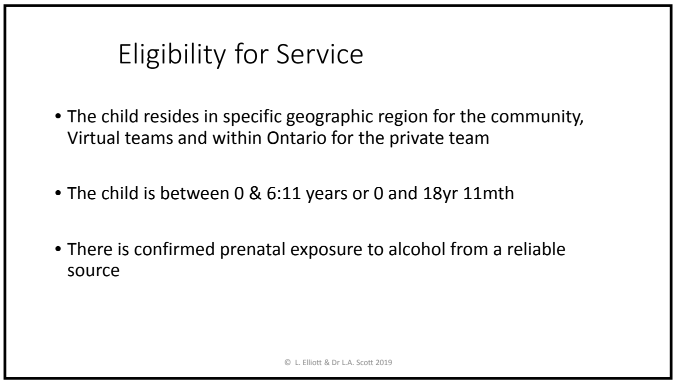
- GUIDELINES are guidelines
- Complexity = Variability
- Consensus of Multi-disciplinary team members
- Team Members therefore <u>must</u> have experience in assessment of children under the age of 6
- May need to have different Team or add in different Team Members as needed



Intake Process

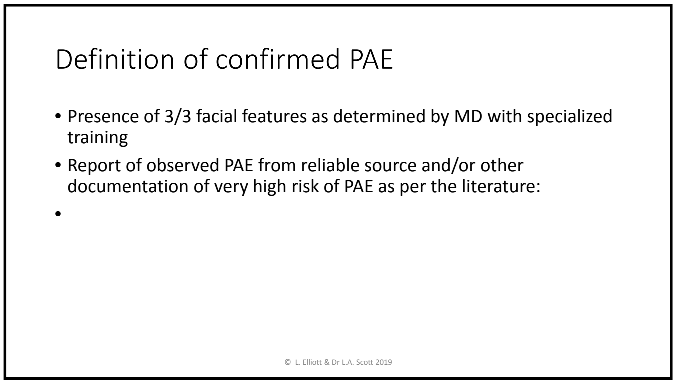
- Referral is screened by an intake specialist
  - Confirms eligibility status
  - Completes referral and consent forms
  - Confirmation of guardianship

  Referral is sent to Diagnostic Team Co-ordinator
  - Triage done according to age;
  - severity of symptomatology
  - reasons for referral



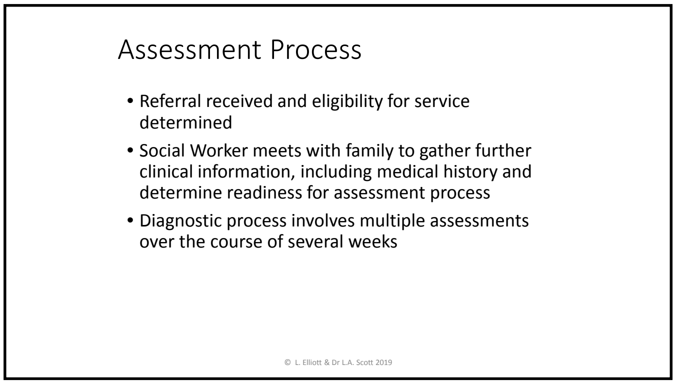
Eligibility for Service

- The child resides in specific geographic region for the community, Virtual teams and within Ontario for the private team
- The child is between 0 & 6:11 years or 0 and 18yr 11mth
- There is confirmed prenatal exposure to alcohol from a reliable source



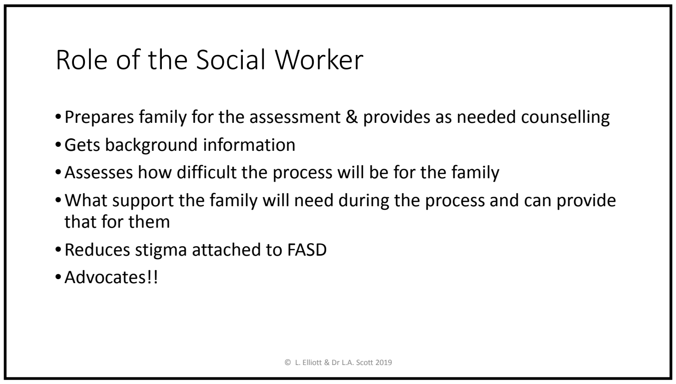
Definition of confirmed PAE

- Presence of 3/3 facial features as determined by MD with specialized training
- Report of observed PAE from reliable source and/or other documentation of very high risk of PAE as per the literature:
-



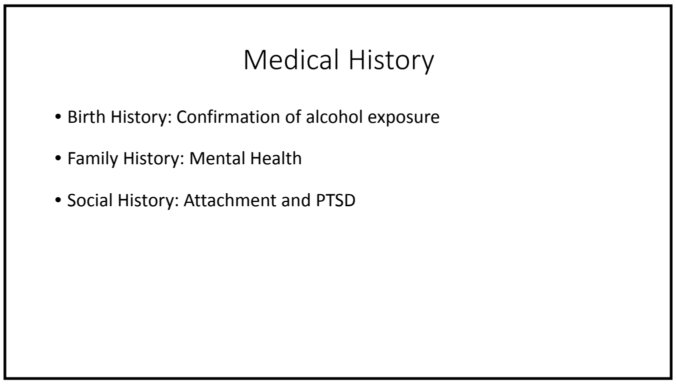
Assessment Process

- Referral received and eligibility for service determined
- Social Worker meets with family to gather further clinical information, including medical history and determine readiness for assessment process
- Diagnostic process involves multiple assessments over the course of several weeks



Role of the Social Worker

- Prepares family for the assessment & provides as needed counselling
- Gets background information
- Assesses how difficult the process will be for the family
- What support the family will need during the process and can provide that for them
- Reduces stigma attached to FASD
- Advocates!!



Medical History

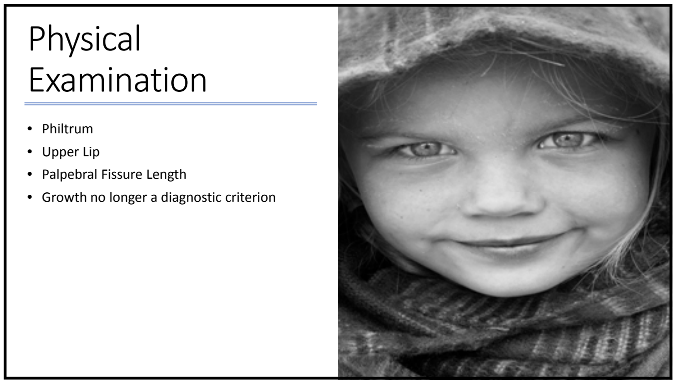
- Birth History: Confirmation of alcohol exposure
- Family History: Mental Health
- Social History: Attachment and PTSD

FASD Diagnosis

- Collaborative Effort
- Medical (Paediatrician, Developmental Paediatrician)
- Social Worker
- Speech and Language Pathologist
- Occupational Therapist
- Neuro-psychologist (Neurocognitive)

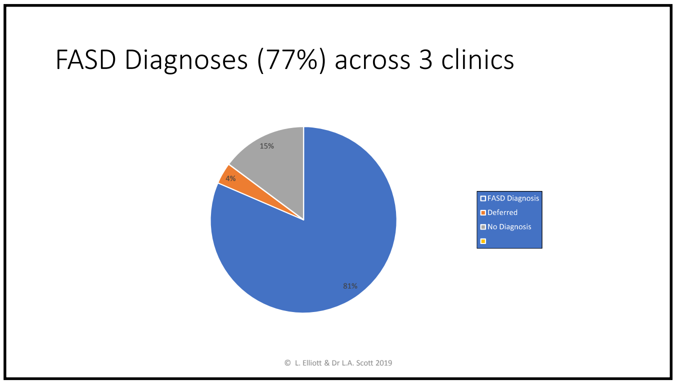
Medical Assessment

- Identify co-morbidities: Neurodevelopmental Disorders
- Oppositional Defiant Disorder
- Attention Deficit Disorder
- Learning Disabilities
- Depression and Anxiety



Physical Examination

- Philtrum
- Upper Lip
- Palpebral Fissure Length
- Growth no longer a diagnostic criterion



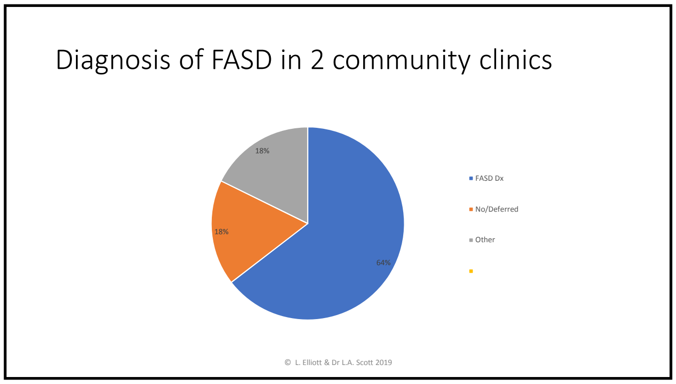
FASD Diagnoses (77%) across 3 clinics

3 Ontario FASD Clinics

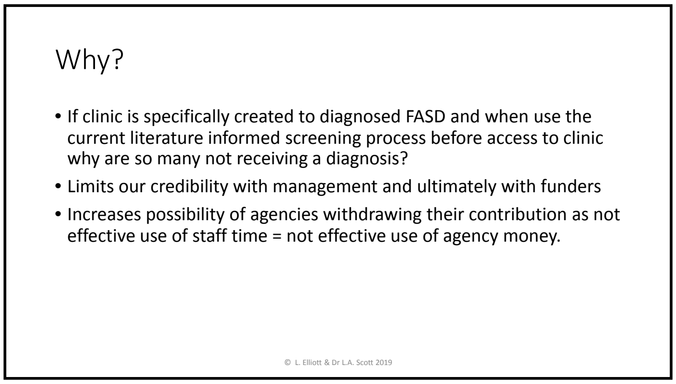
- 2 are publicly funded clinics with virtual teams
- 1 private clinic (specializing in all forms of paediatric Brain Injury)
- All have full multi-disciplinary teams as described above
- Some staff overlap amongst clinics
- All used same confirmation of PAE at time of sampling
- When compared FASD diagnostic rates there were striking differences (i.e.: 100% to 61%)

Other Diagnoses given instead of FASD

- ADHD
- GDD
- Deferred until older
- Learning Disability
- None or No diagnosis

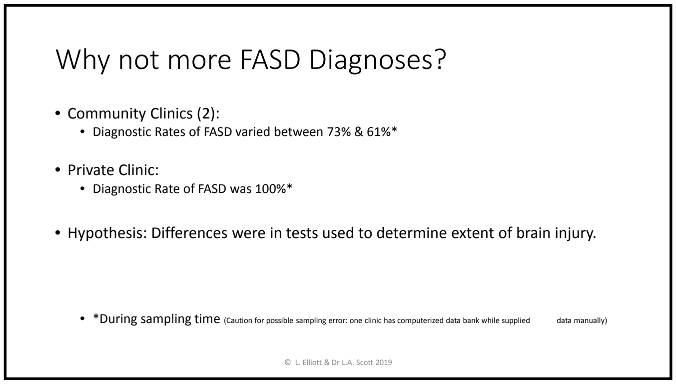


Diagnosis of FASD in 2 community clinics



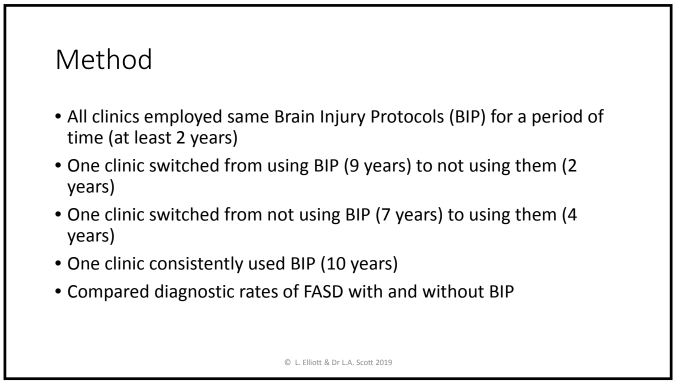
Why?

- If clinic is specifically created to diagnosed FASD and when use the current literature informed screening process before access to clinic why are so many not receiving a diagnosis?
- Limits our credibility with management and ultimately with funders
- Increases possibility of agencies withdrawing their contribution as not effective use of staff time = not effective use of agency money.



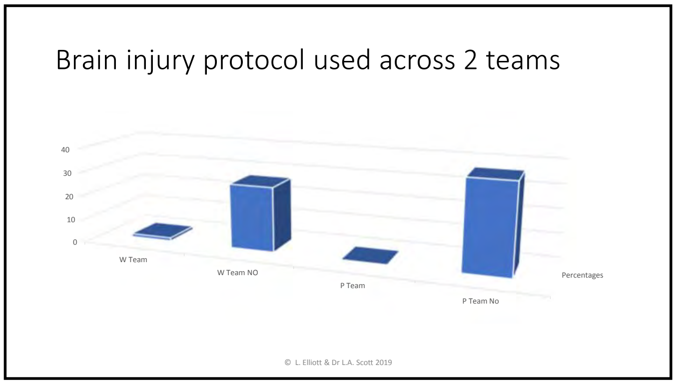
Why not more FASD Diagnoses?

- Community Clinics (2):
  - Diagnostic Rates of FASD varied between 73% & 61%*
- Private Clinic:
  - Diagnostic Rate of FASD was 100%*
- Hypothesis: Differences were in tests used to determine extent of brain injury.
  - *During sampling time (Caution for possible sampling error: one clinic has computerized data bank while supplied data manually)



Method

- All clinics employed same Brain Injury Protocols (BIP) for a period of time (at least 2 years)
- One clinic switched from using BIP (9 years) to not using them (2 years)
- One clinic switched from not using BIP (7 years) to using them (4 years)
- One clinic consistently used BIP (10 years)
- Compared diagnostic rates of FASD with and without BIP



Brain injury protocol used across 2 teams

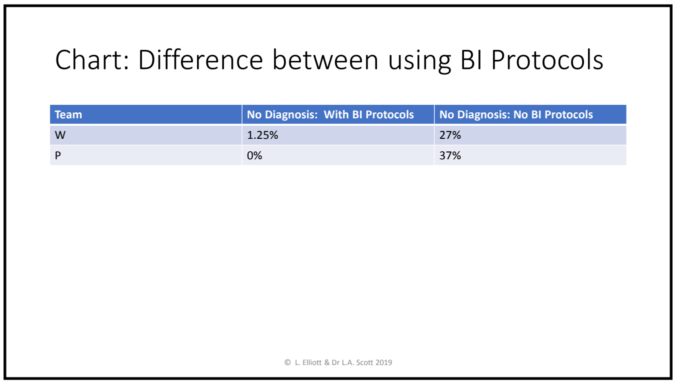
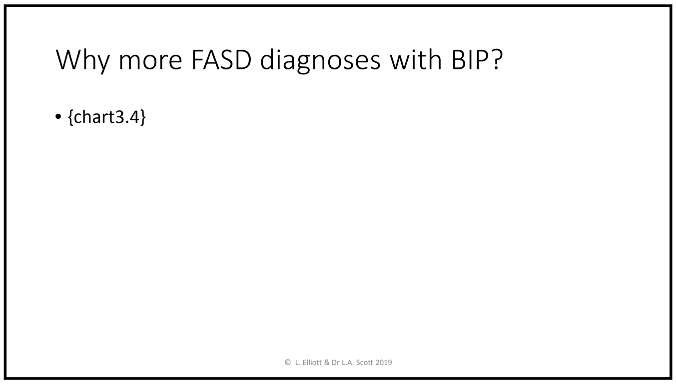


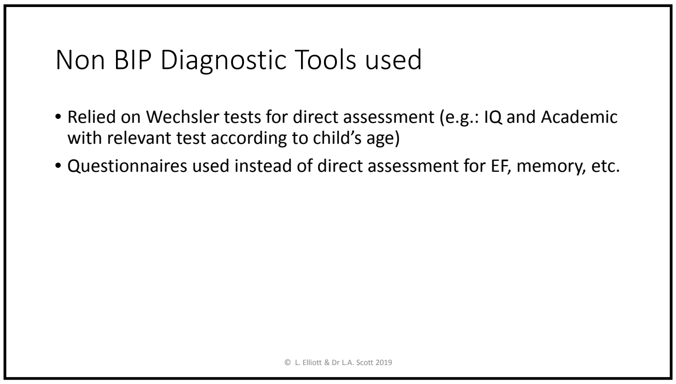
Chart: Difference between using BI Protocols

Team	No Diagnosis: With BI Protocols	No Diagnosis: No BI Protocols
W	1.25%	27%
P	0%	37%



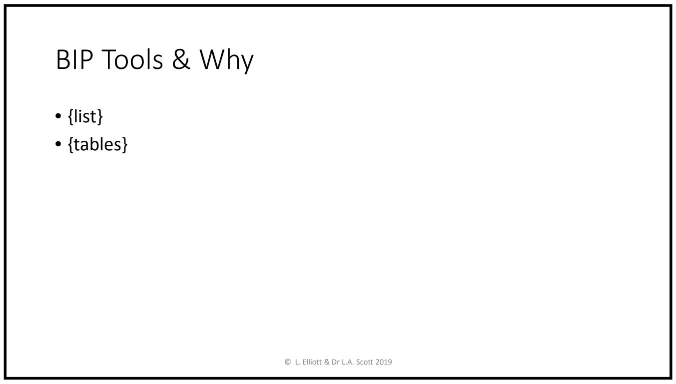
Why more FASD diagnoses with BIP?

- {chart3.4}



Non BIP Diagnostic Tools used

- Relied on Wechsler tests for direct assessment (e.g.: IQ and Academic with relevant test according to child's age)
- Questionnaires used instead of direct assessment for EF, memory, etc.



BIP Tools & Why

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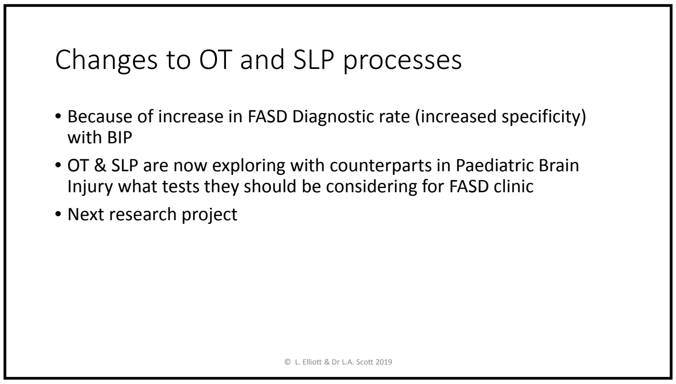
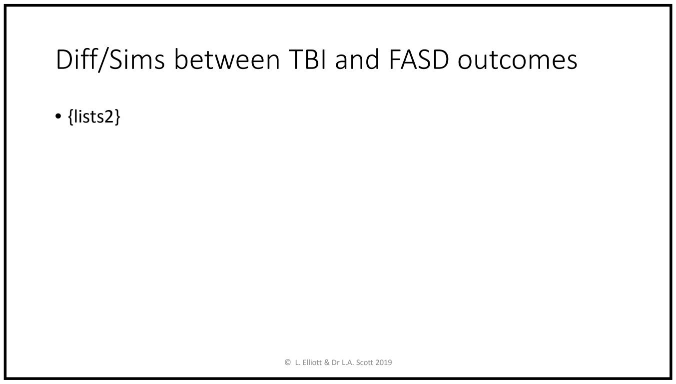
- {tables}



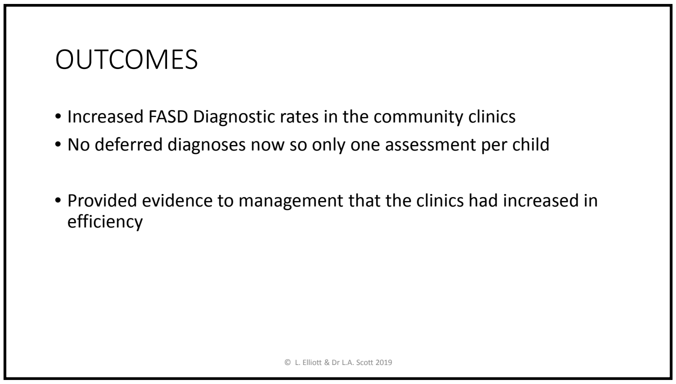
Changes to OT and SLP processes

- Because of increase in FASD Diagnostic rate (increased specificity) with BIP
- OT & SLP are now exploring with counterparts in Paediatric Brain Injury what tests they should be considering for FASD clinic
- Next research project



Diff/Sims between TBI and FASD outcomes

- {lists2}



OUTCOMES

- Increased FASD Diagnostic rates in the community clinics
- No deferred diagnoses now so only one assessment per child

- Provided evidence to management that the clinics had increased in efficiency

Summary

Summary

Thanks for listening!

- For more information or to ask questions or if you would like a copy of this presentation please contact:
- Liv Elliott: Peel Infant and Child Development Services: liv.elliott@thp.ca
- Dr. Louise Scott: Dr. L. A. Scott & Associates: drscottassociates@execulink.com

B8

Mental Health and Brain Abnormalities in Children with PAE and Co-occurring Risks

Catherine Lebel, Carly McMorris, Ben Gibbard, Chris Tortorelli

Learning Objectives

1. Identify underlying neurological correlates of mental health in children and youth with PAE
2. Identify how neuropsychology processes of children and youth with PAE relate to mental health issues
3. Describe how mental health in FASD impacts diagnosis and service delivery

Summary

Over 90% of individuals with FASD have co-occurring mental health issues. In this symposium, we will explore mental health symptoms and disorders in children and youth with FASD from four different perspectives: neuroscience, neuropsychology, assessment and diagnosis, and child welfare policy.

Introduction

Along with primary deficits in learning, development, and behaviour, over 90% of individuals with FASD have co-occurring mental health problems. Among the most common are hyperactivity and depression, which typically emerge in childhood and adolescence. Mental health problems can impact all aspects of a child's life, and are critical to consider in assessment, diagnosis, and treatment of individuals with FASD. We are conducting an ongoing study of mental health, brain alterations, and co-occurring postnatal risks in children and youth with prenatal alcohol exposure (PAE). Preliminary data shows that 63% have clinically significant mental health symptoms and 73% have co-occurring postnatal risks. In this symposium, we will explore mental health symptoms in children and youth with FASD from four different angles: neuroscience, neuropsychology, assessment and diagnosis, and child welfare policy. A multi-disciplinary approach to understanding mental health problems in children and youth with FASD is critical for providing appropriate supports and maximizing adaptive outcomes.

Neuroscience

In youth without FASD, internalizing and externalizing symptoms are associated with alterations to the hippocampus, amygdala, and frontal brain areas. These same regions are altered in children with FASD, suggesting that brain abnormalities may underlie the vulnerability to anxiety and depression. We find that weaker structural brain connectivity in frontal-temporal white matter in children with FASD is associated with increased anxiety. Furthermore, this weaker white matter connectivity mediates the relationship between FASD and increased anxiety symptoms. Postnatal risks are an important moderator of this relationship.

Neuropsychology

It is well-established that youth with FASD have neuropsychological deficits in various areas, including cognitive functioning, memory, language, executive functioning, and attention. These neuropsychological deficits have been implicated as underlying mechanisms for the development of mental health issues in youth without FASD. Similarly, in our sample, parent-reported mental health symptoms are positively correlated with both behavioural and parent-report measures of executive functioning. Postnatal risks and IQ will be examined as potential moderators of this relationship.

Assessment and Diagnosis

The implications of these findings with respect to the diagnosis of mental health disorders in children and youth with FASD will be reviewed. Particular attention will be made to integrating these findings with existing FASD diagnostic guidelines, and the evolving understanding of how mental health disorders may be a core feature of FASD or compounded by the interaction of cumulative risk.

Child Welfare

For many children and youth who require intervention and support from child welfare agencies, FASD is a significant diagnosis or diagnostic query that is reflected in assessment, case planning, policies, and procedures. To receive services through child welfare implies that there is a substantive risk present that affects the child's safety. FASD alone is not enough and so it is important to note that the presence of postnatal risks (physical, sexual, emotional abuse, neglect) is a required component. In this symposium we will demonstrate importance for considering additional risks makes for case planning, implementation and decision making, and ultimately, understanding the life journey of the family members involved.

Broader Impact:
A better understanding of the neurological correlates and neuropsychological profiles of individuals with mental health issues and FASD is critical for properly serving children and youth and their families. Diagnosis and service delivery can benefit from a better understanding of the underlying causes of mental health issues in children and youth exposed to prenatal alcohol.

References

EP Riley, MA Infante, KR Warren. Fetal alcohol spectrum disorders: an overview. Neuropsychology Review 21: 73. 2011.

PW Kodituwakku. Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: a review. Neurosci Biobehav Rev 31: 192. 2007.

PA May, A Baete, J Russo, AJ Elliott, J Blankenship, WO Kalberg, D Buckley, M Brooks, J Hasken, O Abdul-Rahman, MP Adam, LK Robinson, M Manning, HE Hoyme. Prevalence and characteristics of fetal alcohol spectrum disorders. Pediatrics 134: 855. 2014.

J Pei, K Denys, J Hughes, C Rasmussen. Mental health issues in fetal alcohol spectrum disorder. J Ment Health 20: 438. 2011.

C Famy, AP Streissguth, AS Unis. Mental illness in adults with fetal alcohol syndrome or fetal alcohol effects. Am J Psychiatry 155: 552. 1998.

A Fagerlund, I Autti-Ramo, HE Hoyme, SN Mattson, M Korkman. Risk factors for behavioural problems in foetal alcohol spectrum disorders. Acta Paediatr 100: 1481. 2011.

K Denys, C Rasmussen, D Henneveld. The effectiveness of a community-based intervention for parents with FASD. Community Ment Health J 47: 209. 2011.

C Lebel, C McMorris, P Kar, C Ritter, Q Andre, C Tortorelli, WB Gibbard. Characterizing adverse prenatal and postnatal experiences in children. Birth Defects Research in press: 2018.

WC Drevets, JL Price, ML Furey. Brain structural and functional abnormalities in mood disorders: implications for neurocircuitry models of depression. Brain Struct Funct 213: 93. 2008

JL Price, WC Drevets. Neurocircuitry of mood disorders. Neuropsychopharmacology 35: 192. 2010.

R Kerestes, CG Davey, K Stephanou, S Whittle, BJ Harrison. Functional brain imaging studies of youth depression: a systematic review. NeuroImage. Clinical 4: 209. 2014.

C Lebel, C Rasmussen, K Wyper, L Walker, G Andrew, J Yager, C Beaulieu. Brain diffusion abnormalities in children with fetal alcohol spectrum disorder. Alcoholism Clinical and Experimental Research 32: 1732. 2008.

X Long, G Little, C Beaulieu, C Lebel. Sensorimotor network alterations in children and youth with prenatal alcohol exposure. Human Brain Mapping in press: 2018.

A Nardelli, C Lebel, C Rasmussen, G Andrew, C Beaulieu. Extensive deep gray matter volume reductions in children and adolescents with fetal alcohol spectrum disorders. Alcoholism Clinical and Experimental Research 35: 1404. 2011.

D Zhou, C Lebel, C Lepage, C Rasmussen, A Evans, K Wyper, J Pei, G Andrew, A Massey, D Massey, C Beaulieu. Developmental cortical thinning in fetal alcohol spectrum disorders. Neuroimage 58: 16. 2011.

JR Wozniak, BA Mueller, CJ Bell, RL Muetzel, HL Hoecker, CJ Boys, KO Lim. Global Functional Connectivity Abnormalities in Children with Fetal Alcohol Spectrum Disorders. Alcoholism, clinical and experimental research 2012.

EM Moore, R Migliorini, MA Infante, EP Riley. Fetal Alcohol Spectrum Disorders: Recent Neuroimaging Findings. Current developmental disorders reports 1: 161. 2014.

JR Wozniak, BA Mueller, PN Chang, RL Muetzel, L Caros, KO Lim. Diffusion tensor imaging in children with fetal alcohol spectrum disorders. Alcohol Clinical and experimental research 30: 1799. 2006.

SN Mattson, N Crocker, TT Nguyen. Fetal alcohol spectrum disorders: neuropsychological and behavioral features. Neuropsychology Review 21: 81. 2011.

SJ Astley, HC Olson, K Kerns, A Brooks, EH Aylward, TE Coggins, J Davies, S Dorn, B Gendler, T Jirikowic, P Kraegel, K Maravilla, T Richards. Neuropyschological and behavioral outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. Can J Clin Pharmacol 16: e178. 2009.

CR Green, AM Mihic, SM Nikkel, BC Stade, C Rasmussen, DP Munoz, JN Reynolds. Executive function deficits in children with fetal alcohol spectrum disorders (FASD) measured using the Cambridge Neuropsychological Tests Automated Battery (CANTAB). J Child Psychol Psychiatry 50: 688. 2009.

J Pei, J Job, K Kully-Martens, C Rasmussen. Executive function and memory in children with Fetal Alcohol Spectrum Disorder. Child neuropsychology : a journal on normal and abnormal development in childhood and adolescence 17: 290. 2011.

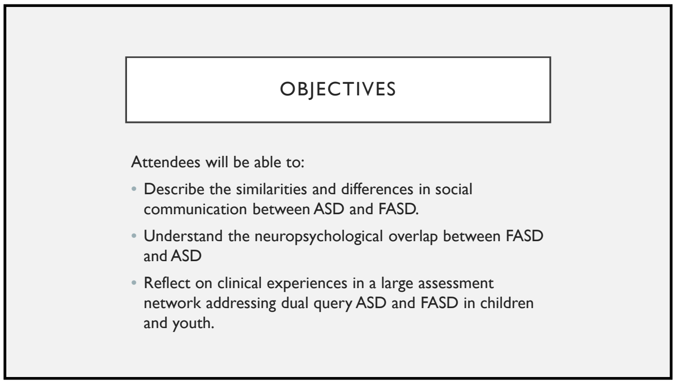
B9a

Contrasts in FASD and ASD: A Clinical Perspective from BC's Provincial Diagnostic Networks

Armansa Glodjo, Jamie Hack, Kelly Price

CONTRASTS IN FASD AND ASD:
A CLINICAL PERSPECTIVE FROM BC'S PROVINCIAL DIAGNOSTIC NETWORKS

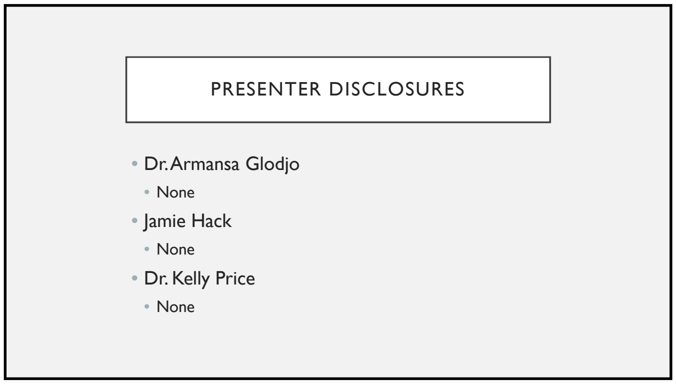
Armansa Glodjo, MD, MSc, FRCPC
Jamie Hack, MSc, SLP
Kelly Price, Ph.D., R. Psych
March 8, 2019



OBJECTIVES

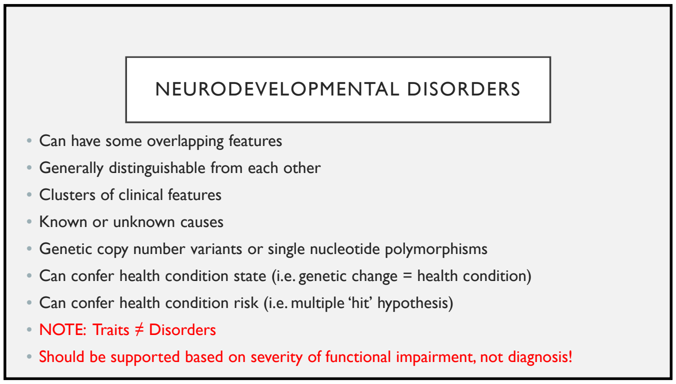
Attendees will be able to:

- Describe the similarities and differences in social communication between ASD and FASD.
- Understand the neuropsychological overlap between FASD and ASD
- Reflect on clinical experiences in a large assessment network addressing dual query ASD and FASD in children and youth.



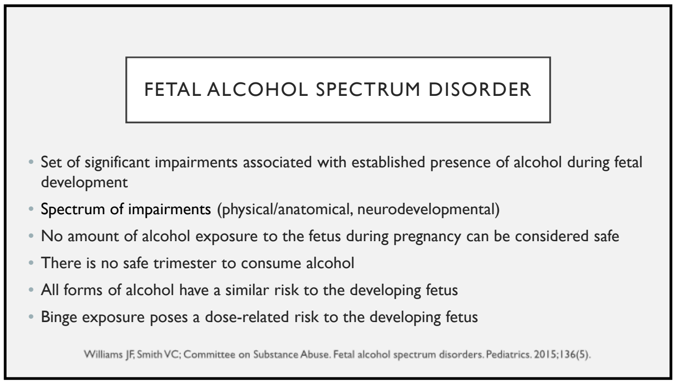
PRESENTER DISCLOSURES

- Dr. Armansa Glodjo
  - None
- Jamie Hack
  - None
- Dr. Kelly Price
  - None



NEURODEVELOPMENTAL DISORDERS

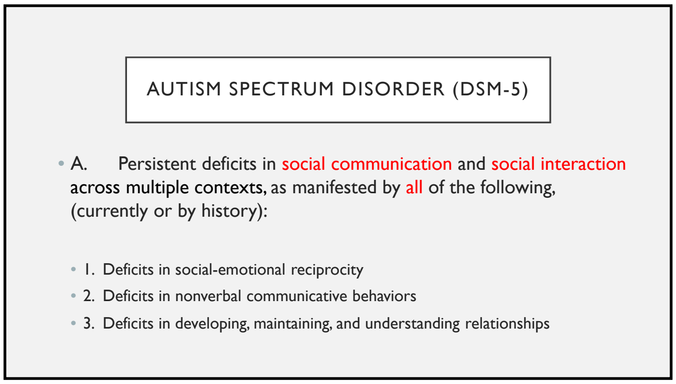
- Can have some overlapping features
- Generally distinguishable from each other
- Clusters of clinical features
- Known or unknown causes
- Genetic copy number variants or single nucleotide polymorphisms
- Can confer health condition state (i.e. genetic change = health condition)
- Can confer health condition risk (i.e. multiple 'hit' hypothesis)
- NOTE: Traits ≠ Disorders
- Should be supported based on severity of functional impairment, not diagnosis!



FETAL ALCOHOL SPECTRUM DISORDER

- Set of significant impairments associated with established presence of alcohol during fetal development
- Spectrum of impairments (physical/anatomical, neurodevelopmental)
- No amount of alcohol exposure to the fetus during pregnancy can be considered safe
- There is no safe trimester to consume alcohol
- All forms of alcohol have a similar risk to the developing fetus
- Binge exposure poses a dose-related risk to the developing fetus

Williams JF, Smith VC; Committee on Substance Abuse. Fetal alcohol spectrum disorders. Pediatrics. 2015;136(5).



AUTISM SPECTRUM DISORDER (DSM-5)

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, (currently or by history):
  - 1. Deficits in social-emotional reciprocity
  - 2. Deficits in nonverbal communicative behaviors
  - 3. Deficits in developing, maintaining, and understanding relationships

AUTISM SPECTRUM DISORDER (DSM-5)

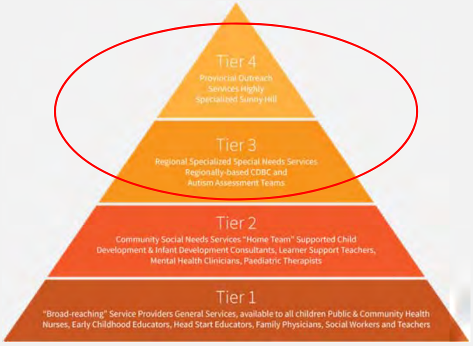
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following (currently or by history):
  - 1. Stereotyped/ repetitive motor movements, use of objects, or speech
  - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
  - 3. Highly restricted, fixated interests that are abnormal in intensity or focus
  - 4. Hyper/ Hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

AUTISM SPECTRUM DISORDER (DSM-5)

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

NEURODEVELOPMENTAL DISORDERS

- Require assessments by experienced individual clinicians and/or by experienced multidisciplinary clinical teams
- Diagnostic assessments include causative and functional investigations
- BC: require Tier 3 services (regionally located specialized services) and/or Tier 4 services (unique specialized services located in centre(s) of excellence)



BRITISH COLUMBIA'S PROVINCIAL DIAGNOSTIC ASSESSMENT NETWORKS

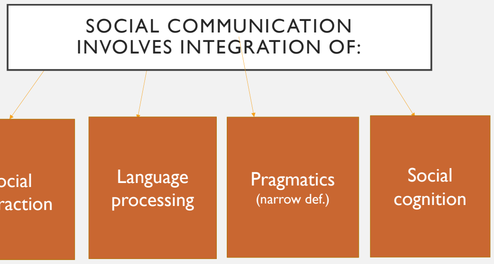
- Diagnostic teams in all BC health authorities
- BC Autism Assessment Network (BCAAN)
  - Established in 2003; initial year funded for 150 assessments
  - 2017/18: ~ 3800 new referrals/yr; ~ 2100 assessments/yr
  - All assessments informed by gold standard instruments (ADOS-2 and ADI-R)
- BC Complex Developmental Behavioural Conditions Network (CDBC)
  - Established in 2006
  - 2017/18: ~ 2000 new referrals/yr; ~1100 assessments/yr
  - Single clinician or multiple clinician assessments

BC DATA

- TBA

SOCIAL COMMUNICATIVE COMPETENCE REQUIRES:

The ability to *interpret both nonverbal and verbal messages*, depending on the *specific context of the interaction*, using implicit knowledge about the *socio-cultural interaction rules*, while *planning your own contribution*, and (hopefully) *managing one's behavior* during the interaction



SOCIAL COMMUNICATION INVOLVES INTEGRATION OF:

from work of Adams 2005, Brinton & Fujiki 2014

CONVERSATION

- Reduced responsiveness to communication partner's utterance
- Interrupting/overlapping comments
- Verbosity, with unrelated comments
- Inappropriate feedback to partner
- Organizational difficulties
- Socially inappropriate questions, responses, statements, topics, jokes
- "Chatty" but "shallow"
- Limited ability to exchange information effectively within a conversation; difficulty providing adequate and relevant info to partner

NARRATIVES

- Shorter, incomplete; Organization difficulties
- Fewer cohesive devices (pronouns, conjunctions); logical links often missing between events
- Ambiguous referencing; difficulty distinguishing between shared/new info (e.g. inappropriate use of articles to refer and maintain reference)
- Increased proportion of vague statements and reduced proportion of informative ones
- Difficulty explaining what they have seen or heard in a logical manner
- Difficulty determining and conveying relevant info
- Failure to derive necessary inferences and conclusions from a passage

SOCIAL COGNITION

- Reduced perspective-taking on Theory of Mind tasks (inferring mental states of other and using this info to predict intentions, beliefs, emotions, desires); difficulty with false belief tasks even when simplified format
- Difficulty perceiving and interpreting social cues, especially subtle ones
- Difficulty interpreting affective information (judging emotions, e.g. based on facial expressions)
- Indiscriminately friendly ("overly social")
- Reduced ability to anticipate consequences of their actions behavior
- Difficulty recognizing social (or physical) risk, poor judgment, engaging in risky behaviors
- Difficulty effectively grasping underlying reasons for and meaning of appropriate behaviors
- Increasing challenges in sophisticated social contexts
- Reduced empathy, guilt

SOCIAL REASONING

- In social problem-solving tasks (group-entry and provocation situations): chose higher proportion of aggressive or inept solutions; evaluated competent responses as less effective; were less likely to attribute benign intent to another child; encoded less information about vignette (missed cues)
- Difficulty explaining problems, providing details
- Difficulty generalizing newly-acquired skills to a variety of contexts
- May repeat same misguided action regardless of consequences
- Avoidant, careless or impulsive approach to solving everyday problems

PEER INTERACTION

- Peer victimization and rejection; teasing/bullying
- Fewer opportunities for acquiring new skills and experiencing consequences of positive interaction due to *reputational bias* (how they are viewed by peers)
- Difficulty cooperating, sharing
- Viewed as immature compared to age peers
- Miss or misinterpret peers' intents – may ignore or respond negatively to peers' attempts to interact
- Difficulty following rules in games
- Blurting out silly, irritating or inappropriate comments that upset others
- Fewer sustained close relationships
- May become withdrawn, socially isolated, avoidant

IN GROUP SETTINGS

- In classroom-based studies: less time socially engaged, and exhibited more time in passive/disengaged and irrelevant performance (proportion and average length in each, but # instances of prosocial was higher for FASD). IQ not a factor.
- Significant changeability as measured in rate of changing between dimensions, i.e. varying their manner of social performance frequently between behavior states; and significantly more variable in day-to-day performance (re proportion of time spent in prosocial/engaged versus irrelevant) across days. Resulting in perception by others of unpredictable, irregular, unstable performance in social communication.
- Socially inappropriate questions, responses, topics, jokes in classroom or workplace
- May discuss personal info not appropriate for situation
- Socially indiscriminate behaviors from peer pressure, gang membership, promiscuity
- Anti-social behaviors such as cheating, stealing, bullying

WHAT IS ASD?

What causes it?

What are the symptoms?

WHAT IS FASD?

What causes it?

What are the symptoms?

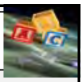
NONE OF THESE ARE PART OF THE DIAGNOSIS:

- Acting out
- Inability to manage money
- Can't learn from consequences
- Inappropriately friendly to strangers
- Mental health problems
- Trouble with the law
- Inappropriate sexual behaviour
- Alcohol and drug problems
- Passive
- Stubborn
- Fearless
- Irritable
- Mood swings
- Difficulty sleeping
- Difficulty adapting to change
- Easily over stimulated
- Truancy
- Teasing or bullying

FETAL ALCOHOL SPECTRUM DISORDER

		#	#	#		#		
Definite	4						4	High Risk
Probable	3						3	Some Risk
Possible	2						2	Unknown
Unlikely	1	X	X	X		X	1	No Risk
Brain Effects		Growth	Face	Brain		Prenatal Alcohol		Prenatal Alcohol

AN ALPHABET OF CAUSES



- **A**buse
- **B**irth weight
- **C**igarettes
- **D**eprivation
- **E**nvironment
- **F**amine
- **G**enetics
- **H**ead…
- **I**njury
- pre**J**udice
- **K**nowledge
- **L**ead
- **M**aternal depression
- **N**utrition
- **O**xygen deprivation
- **P**overty
- **Q**uality of maternal bonding
- **R**egulation of emotion
- **S**tress
- **T**emperament
- **U**ndersocialization
- **V**ision
- **W**itnessing of violence
- **X**-rays?
- **Y**-chromosome
- **Z**inc deficiencies

ASD SYMPTOMS IN FASD

- Difficulties with social cues, particularly faces and gaze
- Comprehension of mental states and emotions of others
- Resistance to change
- Understanding prosody
- Abnormal sensory responses
- Difficulty relating to people and initiating social interactions
- Deficiencies in social language processing
- Passive or active-but-odd characteristics during interactions.

Stevens, Nash, Koren,& Rovet (2013)

SOCIAL DIFFICULTIES IN FASD

Strengths	Weaknesses
initiating conversations	perseveration
inviting others to join activities	withdrawing
showing concern for others	not taking appropriate turns
	interacting poorly

Stevens, Nash, Koren,& Rovet (2013)

ARE THERE FASD *SYMPTOMS* IN ASD?

How do we answer that question…?

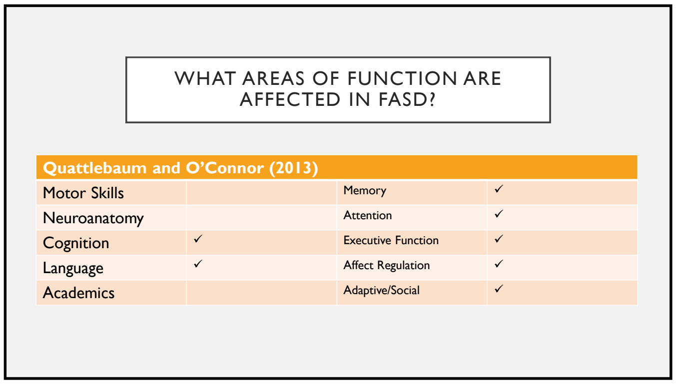
What are the symptoms of FASD?

WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

Motor Skills		Memory	
Neuroanatomy		Attention	
Cognition		Executive Function	
Language		Affect Regulation	
Academics		Adaptive/Social	

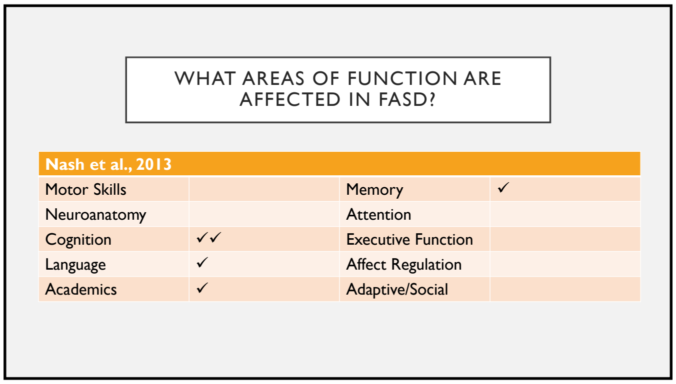
WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

Rasmussen et al (2006)			
Motor Skills		Memory	✓
Neuroanatomy		Attention	✓
Cognition	✓✓	Executive Function	
Language		Affect Regulation	
Academics		Adaptive/Social	



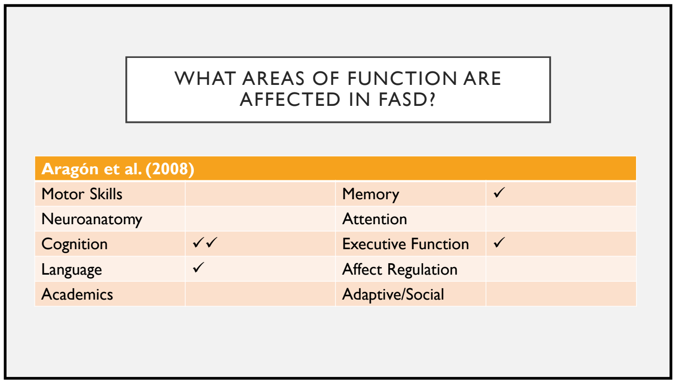
WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

Quattlebaum and O'Connor (2013)			
Motor Skills		Memory	✓
Neuroanatomy		Attention	✓
Cognition	✓	Executive Function	✓
Language	✓	Affect Regulation	✓
Academics		Adaptive/Social	✓



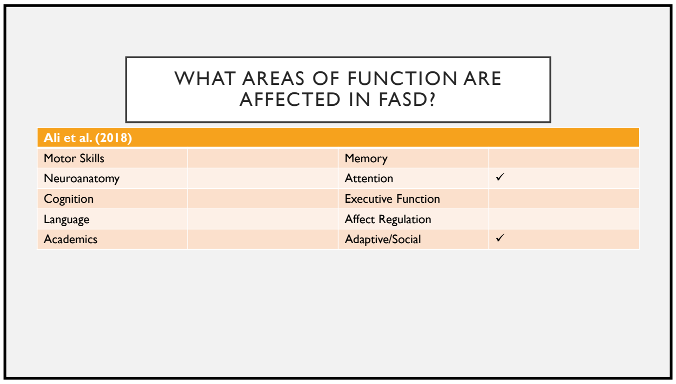
WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

Nash et al., 2013			
Motor Skills		Memory	✓
Neuroanatomy		Attention	
Cognition	✓✓	Executive Function	
Language	✓	Affect Regulation	
Academics	✓	Adaptive/Social	



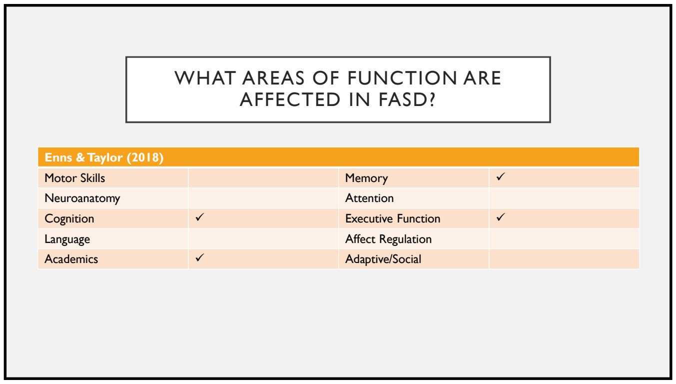
WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

Aragón et al. (2008)			
Motor Skills		Memory	✓
Neuroanatomy		Attention	
Cognition	✓✓	Executive Function	✓
Language	✓	Affect Regulation	
Academics		Adaptive/Social	



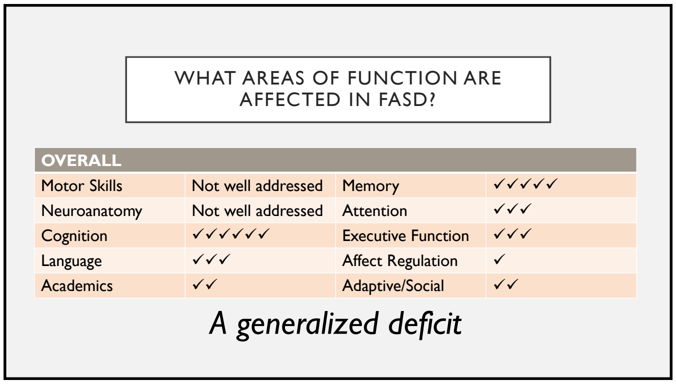
WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

Ali et al. (2018)			
Motor Skills		Memory	
Neuroanatomy		Attention	✓
Cognition		Executive Function	
Language		Affect Regulation	
Academics		Adaptive/Social	✓



WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

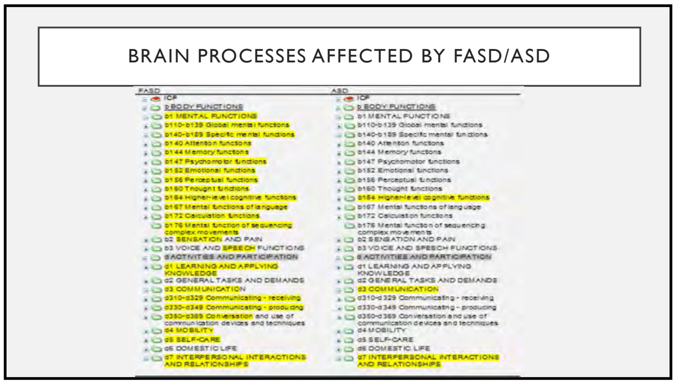
Enns & Taylor (2018)			
Motor Skills		Memory	✓
Neuroanatomy		Attention	
Cognition	✓	Executive Function	✓
Language		Affect Regulation	
Academics	✓	Adaptive/Social	



WHAT AREAS OF FUNCTION ARE AFFECTED IN FASD?

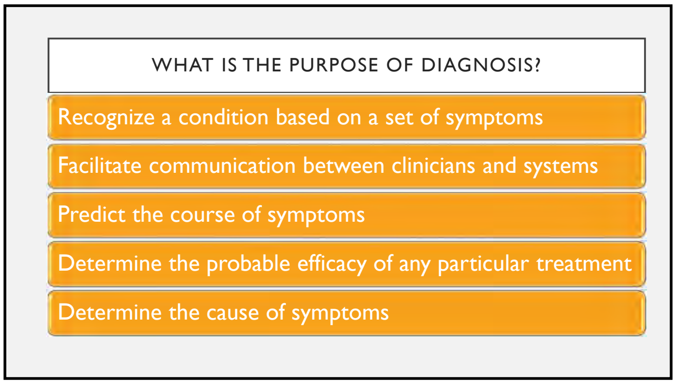
OVERALL			
Motor Skills	Not well addressed	Memory	✓✓✓✓✓
Neuroanatomy	Not well addressed	Attention	✓✓✓
Cognition	✓✓✓✓✓✓	Executive Function	✓✓✓
Language	✓✓✓	Affect Regulation	✓
Academics	✓✓	Adaptive/Social	✓✓

A generalized deficit



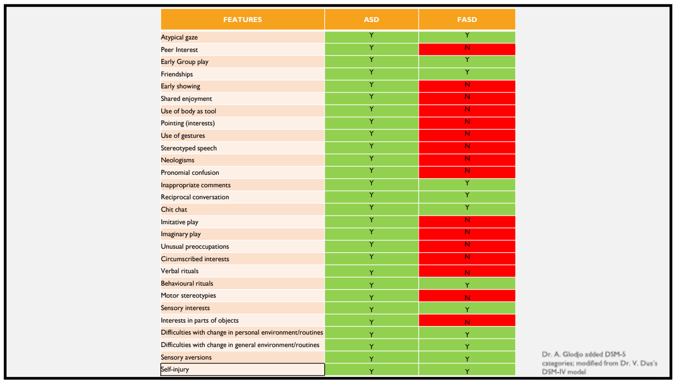
BRAIN PROCESSES AFFECTED BY FASD/ASD

FASD	ASD
ICF	ICF
b BODY FUNCTIONS	b BODY FUNCTIONS
b1 MENTAL FUNCTIONS	b1 MENTAL FUNCTIONS
b110-b139 Global mental functions	b110-b139 Global mental functions
b140-b189 Specific mental functions	b140-b189 Specific mental functions
b140 Attention functions	b140 Attention functions
b144 Memory functions	b144 Memory functions
b147 Psychomotor functions	b147 Psychomotor functions
b152 Emotional functions	b152 Emotional functions
b156 Perceptual functions	b156 Perceptual functions
b160 Thought functions	b160 Thought functions
b164 Higher-level cognitive functions	b164 Higher-level cognitive functions
b167 Mental functions of language	b167 Mental functions of language
b172 Calculation functions	b172 Calculation functions
b176 Mental function of sequencing complex movements	b176 Mental function of sequencing complex movements
b2 SENSATION AND PAIN	b2 SENSATION AND PAIN
b3 VOICE AND SPEECH FUNCTIONS	b3 VOICE AND SPEECH FUNCTIONS
d ACTIVITIES AND PARTICIPATION	d ACTIVITIES AND PARTICIPATION
d1 LEARNING AND APPLYING KNOWLEDGE	d1 LEARNING AND APPLYING KNOWLEDGE
d2 GENERAL TASKS AND DEMANDS	d2 GENERAL TASKS AND DEMANDS
d3 COMMUNICATION	d3 COMMUNICATION
d310-d329 Communicating - receiving	d310-d329 Communicating - receiving
d330-d349 Communicating - producing	d330-d349 Communicating - producing
d350-d369 Conversation and use of communication devices and techniques	d350-d369 Conversation and use of communication devices and techniques
d4 MOBILITY	d4 MOBILITY
d5 SELF-CARE	d5 SELF-CARE
d6 DOMESTIC LIFE	d6 DOMESTIC LIFE
d7 INTERPERSONAL INTERACTIONS AND RELATIONSHIPS	d7 INTERPERSONAL INTERACTIONS AND RELATIONSHIPS



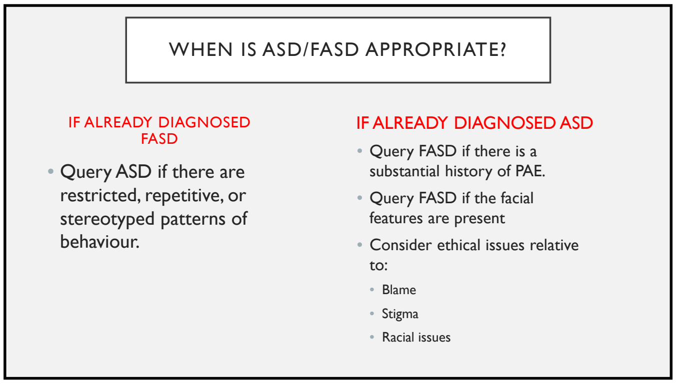
WHAT IS THE PURPOSE OF DIAGNOSIS?

- Recognize a condition based on a set of symptoms
- Facilitate communication between clinicians and systems
- Predict the course of symptoms
- Determine the probable efficacy of any particular treatment
- Determine the cause of symptoms



FEATURES	ASD	FASD
Atypical gaze	Y	Y
Peer Interest	Y	N
Early Group play	Y	Y
Friendships	Y	Y
Early showing	Y	N
Shared enjoyment	Y	N
Use of body as tool	Y	N
Pointing (interests)	Y	N
Use of gestures	Y	N
Stereotyped speech	Y	N
Neologisms	Y	N
Pronomial confusion	Y	N
Inappropriate comments	Y	Y
Reciprocal conversation	Y	Y
Chit chat	Y	Y
Imitative play	Y	N
Imaginary play	Y	N
Unusual preoccupations	Y	N
Circumscribed interests	Y	N
Verbal rituals	Y	N
Behavioural rituals	Y	Y
Motor stereotypies	Y	N
Sensory interests	Y	Y
Interests in parts of objects	Y	N
Difficulties with change in personal environment/routines	Y	Y
Difficulties with change in general environment/routines	Y	Y
Sensory aversions	Y	Y
Self-injury	Y	Y

Dr. A. Glodjo added DSM-5 categories; modified from Dr. V. Dua's DSM-IV model



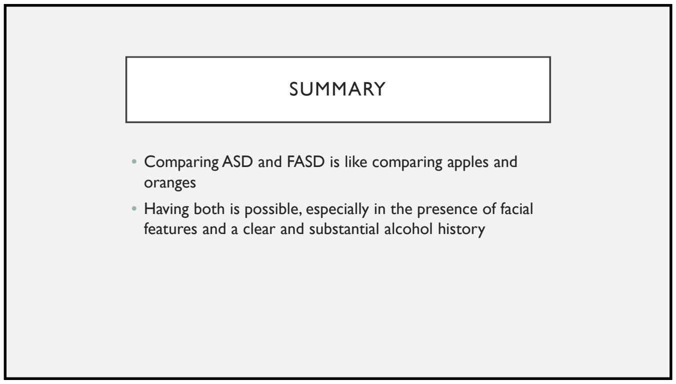
WHEN IS ASD/FASD APPROPRIATE?

IF ALREADY DIAGNOSED FASD

- Query ASD if there are restricted, repetitive, or stereotyped patterns of behaviour.

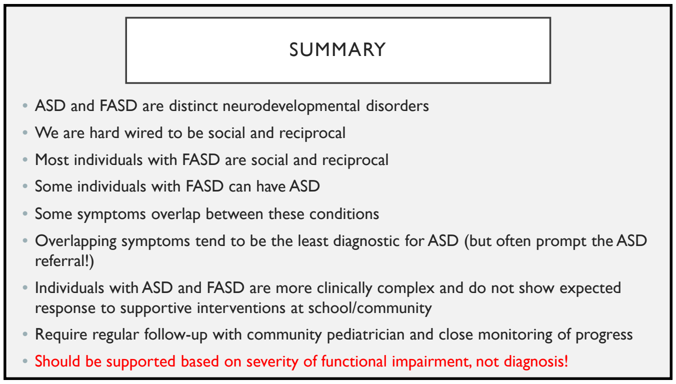
IF ALREADY DIAGNOSED ASD

- Query FASD if there is a substantial history of PAE.
- Query FASD if the facial features are present
- Consider ethical issues relative to:
  - Blame
  - Stigma
  - Racial issues



SUMMARY

- Comparing ASD and FASD is like comparing apples and oranges
- Having both is possible, especially in the presence of facial features and a clear and substantial alcohol history



SUMMARY

- ASD and FASD are distinct neurodevelopmental disorders
- We are hard wired to be social and reciprocal
- Most individuals with FASD are social and reciprocal
- Some individuals with FASD can have ASD
- Some symptoms overlap between these conditions
- Overlapping symptoms tend to be the least diagnostic for ASD (but often prompt the ASD referral!)
- Individuals with ASD and FASD are more clinically complex and do not show expected response to supportive interventions at school/community
- Require regular follow-up with community pediatrician and close monitoring of progress
- Should be supported based on severity of functional impairment, not diagnosis!

B9b International Perspectives on FASD and ASD: Clinical Expert Panel Discussion

Session Co-Chairs: Armansa Glodjo, Christine Loock
Presenters: Barbara Fitzgerald, Claire D. Coles, Raja Mukherjee

B10

Emerging Approaches to FASD Prevention in Canada

Nancy Poole, Rose Schmidt, Michelle Fortin, Kelly Harding, Nicole Pasquino, Toni Winterhoff

Learning Objectives:

1. Identify opportunities for collaborative and cross-sectoral partnerships to develop new approaches to FASD prevention
2. Describe emerging issues and trends in substance use, women's health, public policy, sex and gender based analysis and Indigenous wellness relevant to FASD prevention

Background

In Canada, the context for preventing alcohol use in pregnancy is shifting with the recent legalization of cannabis, the release of the recommendations of the Truth and Reconciliation Commission, and recent initiatives to improve the capacity of health care and social service providers to deliver alcohol brief interventions in a range of settings. This presentation will profile ongoing work by the Centre of Excellence for Women's Health, the Canada FASD Research Network, First Nations Health Authority and Options for Sexual Health to develop innovative and integrated approaches to FASD prevention.

Methods

As part of a two-year project (2016-2018), the Centre of Excellence for Women's Health and the Canada FASD Research Network conducted a series of regional meetings across the country with multidisciplinary experts from professional health and social care organizations to determine existing supports and strategies for addressing alcohol, cannabis, and other substance use with women in the perinatal period. These meetings include physicians, midwives, and nurses, as well as representatives from sexual health clinics, violence prevention, pregnancy outreach, substance use, and Indigenous health services. In collaboration with the Thunderbird Partnership Foundation, a meeting was held in 2017 to highlight ongoing action on Indigenous approaches to wellness, FASD, and reconciliation. These meetings resulted in new partnerships and initiatives to respond to emerging issues and challenges in FASD prevention.

Results

This presentation will profile three emerging approaches to FASD prevention in the Canadian context: an integrated public policy approach to alcohol and cannabis use during pregnancy; the development and expansion of a program to support Indigenous mothers in the Fraser Salish region of British Columbia; and new approaches to brief intervention on substance use and contraception in sexual health settings. Each presenter will discuss "lessons learned" within their context, strategies for intersectoral collaboration, and how the changing socio-political landscape is creating new opportunities for addressing alcohol use before and during pregnancy with a range of populations.

Conclusion

Collaborative and cross-sectoral partnerships can support the development of new approaches to FASD prevention that better respond to the needs of diverse women across Canada.

Plenary

Cannabinoids Exacerbate Alcohol-induced Birth Defects in Rodents and Zebrafish

Scott Parnell

Learning Objectives:

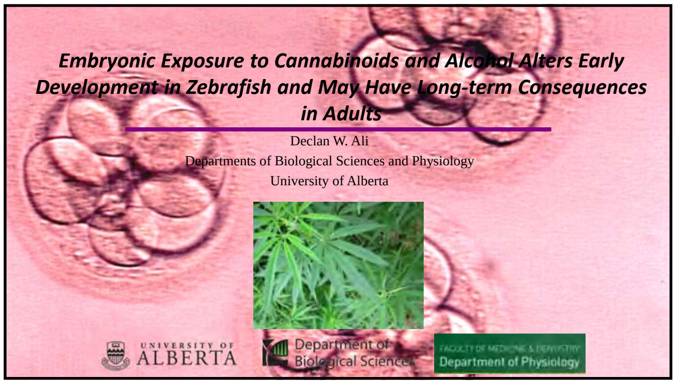
1. Recognize that cannabinoids, including marijuana, can be teratogenic during early pregnancy in a manner similar to alcohol.
2. Appreciate that alcohol and cannabinoids together can exacerbate the effects of each other.
3. Discover the mechanism by which alcohol and cannabinoids interact.

We tested whether cannabinoids (CBs) potentiate alcohol-induced birth defects in mice and zebrafish, and explored the underlying pathogenic mechanisms on Sonic Hedgehog (Shh) signaling. The CBs, Δ9-THC, cannabidiol, HU-210, and CP-55,940 caused alcohol-like effects on craniofacial and brain development and synergistically potentiated alcohol teratogenesis, phenocopying Shh mutations. CBs reduced Shh signaling by inhibiting Smoothened (Smo), while Shh mRNA or a CB1 receptor antagonist attenuated CB-induced birth defects. Co-immunoprecipitation experiments identified novel CB1-Smo heteromers coupled to both Gαi and Gαs proteins, suggesting allosteric CB1-Smo interactions. We demonstrate that both alcohol and CB exposure impair vital Shh signaling early in development through the combined inhibition of Gαi and the CB1-mediated stimulation of Gαs. In addition to the immense public health importance of this work, this study establishes a novel link between two distinct signaling pathways and has widespread implications for development, as well as diseases such as addiction and cancer.

Plenary

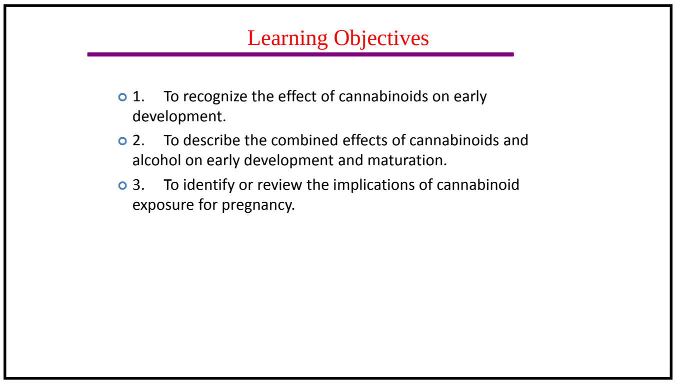
Embryonic Exposure to Cannabinoids and Alcohol Alters Early Development in Zebrafish and May Have Long-term Consequences in Adults

Declan Ali



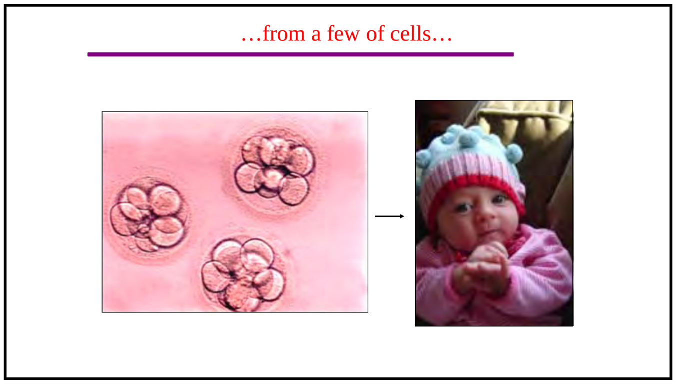
Embryonic Exposure to Cannabinoids and Alcohol Alters Early Development in Zebrafish and May Have Long-term Consequences in Adults

Declan W. Ali
Departments of Biological Sciences and Physiology
University of Alberta

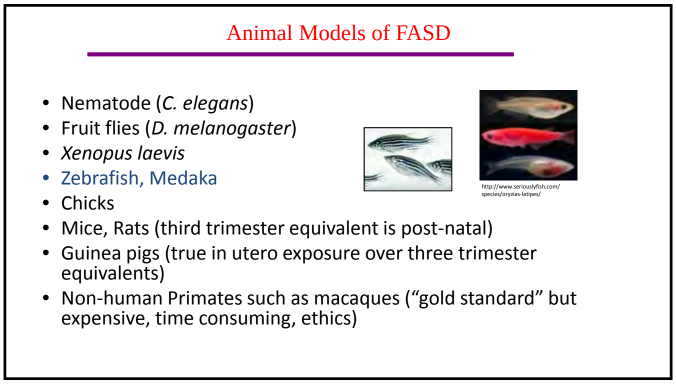


Learning Objectives

- 1. To recognize the effect of cannabinoids on early development.
- 2. To describe the combined effects of cannabinoids and alcohol on early development and maturation.
- 3. To identify or review the implications of cannabinoid exposure for pregnancy.



…from a few of cells…



Animal Models of FASD

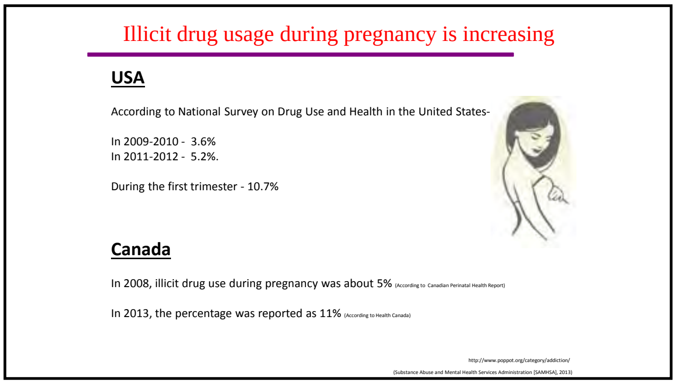
- Nematode (*C. elegans*)
- Fruit flies (*D. melanogaster*)
- *Xenopus laevis*
- Zebrafish, Medaka
- Chicks
- Mice, Rats (third trimester equivalent is post-natal)
- Guinea pigs (true in utero exposure over three trimester equivalents)
- Non-human Primates such as macaques (“gold standard” but expensive, time consuming, ethics)

http://www.seriouslyfish.com/species/oryzias-latipes/

Your Body: Can Hypnosis Get You Moti...

HEALTH

CDC: 1 in 10 pregnant women report alcohol use



Illicit drug usage during pregnancy is increasing

USA

According to National Survey on Drug Use and Health in the United States-

In 2009-2010 - 3.6%
In 2011-2012 - 5.2%.

During the first trimester - 10.7%

Canada

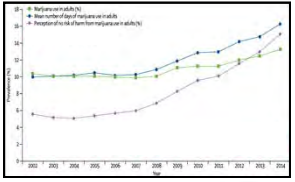
In 2008, illicit drug use during pregnancy was about 5% (According to Canadian Perinatal Health Report)

In 2013, the percentage was reported as 11% (According to Health Canada)

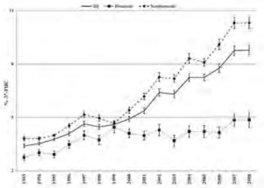
http://www.poppot.org/category/addiction/
(Substance Abuse and Mental Health Services Administration [SAMHSA], 2013)

More pregnant women are smoking marijuana to tame morning sickness: study

- In 2002, about 2.4 % of women admitted to smoking pot while pregnant.
- By 2014, about 4% said they got high during their pregnancy.



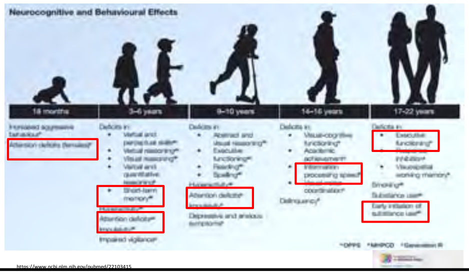
Increasing marijuana use in adults



Potency trends of marijuana

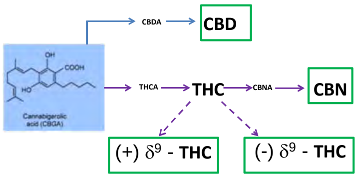
Prenatal exposure of marijuana

- ☐ Cognitive
- ☐ Behavioral and
- ☐ Neuropsychiatric defects



https://www.ncbi.nlm.nih.gov/pubmed/22103415

Cannabinoids

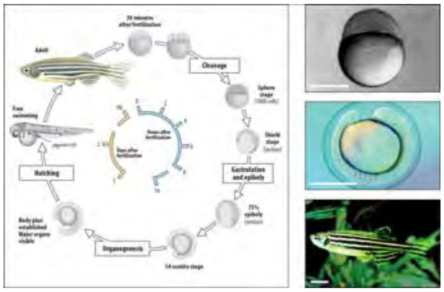


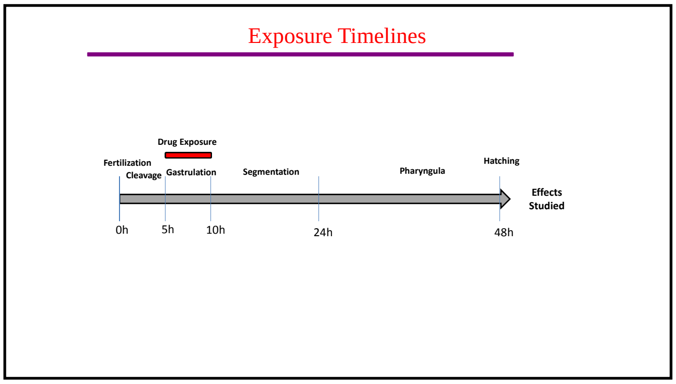
Gaoni and Mechoulam, 1964

Our study:

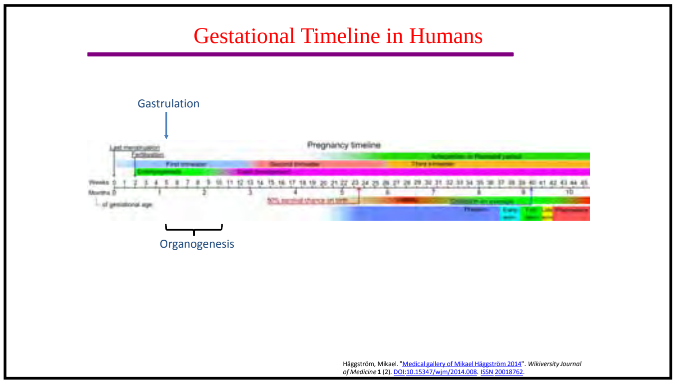
- Effect of THC, cannabinol, cannabidiol and alcohol (ethanol) on neurodevelopment and neuromuscular activity in embryos
- Effects on zebrafish locomotion
- What role do endocannabinoids play in communication between cells
- Expose zebrafish embryos to THC, cannabinol and cannabidiol during the gastrulation stage of development and then determine the effect on neuronal function.

Zebrafish Development



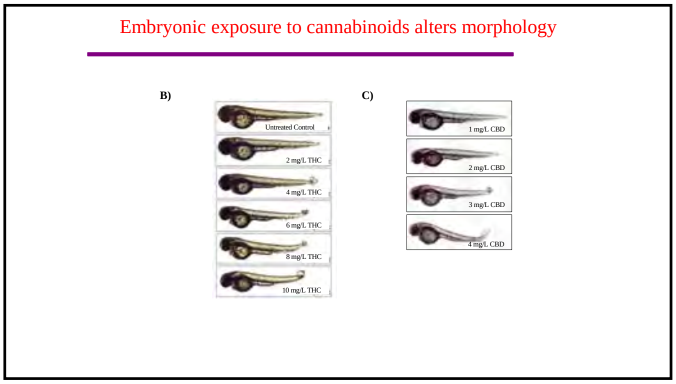


Exposure Timelines

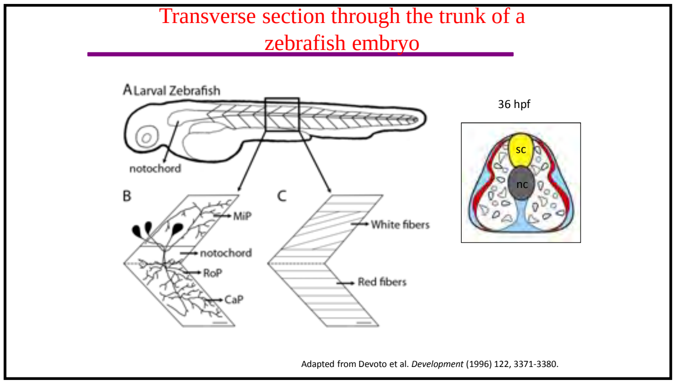


Gestational Timeline in Humans

Häggström, Mikael. "Medical gallery of Mikael Häggström 2014". *Wikiversity Journal of Medicine* **1** (2). DOI:10.15347/wjm/2014.008. ISSN 20018762.

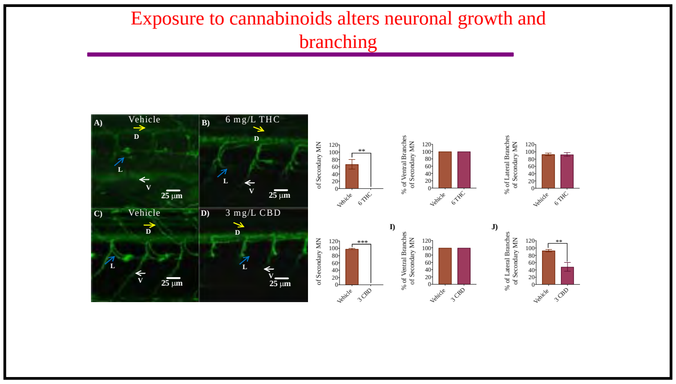


Embryonic exposure to cannabinoids alters morphology

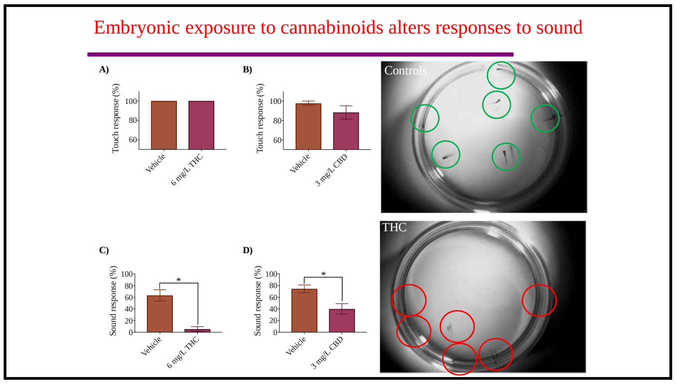


Transverse section through the trunk of a zebrafish embryo

Adapted from Devoto et al. *Development* (1996) 122, 3371-3380.



Exposure to cannabinoids alters neuronal growth and branching

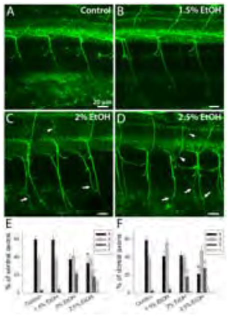


Embryonic exposure to cannabinoids alters responses to sound

Summary

- Zebrafish embryos exposed to THC or CBD experience morphological defects.
- Zebrafish embryos exposed to THC or CBD exhibit reduced hatching, survival and heart rates.
- Zebrafish embryos exposed to THC or CBD exhibit reduced branching patterns of motoneurons and fewer neuromuscular junctions.
- Zebrafish embryos show reduced sensation to sound

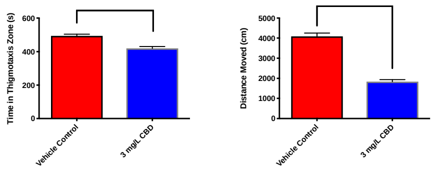
Embryonic exposure to alcohol alters motor neurons



Embryonic exposure to CBD alters adult behavior/locomotion

Time spent in Thigmotaxis

Distance moved



Acknowledgements

- Md Ruhul Amin (PhD student)
- Kazi T, Ahmed(PhD student)
- Janatul Ferdous (MSc student)
- Parv Shah (undergraduate student)

References

- Ahmed, K.T. et al. *Scientific Reports* (2018) 8:10518.
- Devoto, S.H. et al. *Development* (1996) 122: 3371-3380.
- Mechoulam, R. and Gaoni Y., *J Am Chem Soc* (1965) 87:3273-3275.
- Häggström, M. "Medical gallery of Mikael Häggström 2014". *Wikiversity Journal of Medicine* **1** (2). DOI:10.15347/wjm/2014.008. ISSN 20018762.
- Shan, S. et al. *Neurotoxicology and Teratology* (2015) 48: 18-27.
- Substance Abuse and Mental Health Services Administration [SAMHSA], 2013)

Presenter Disclosure

- Declan W. Ali

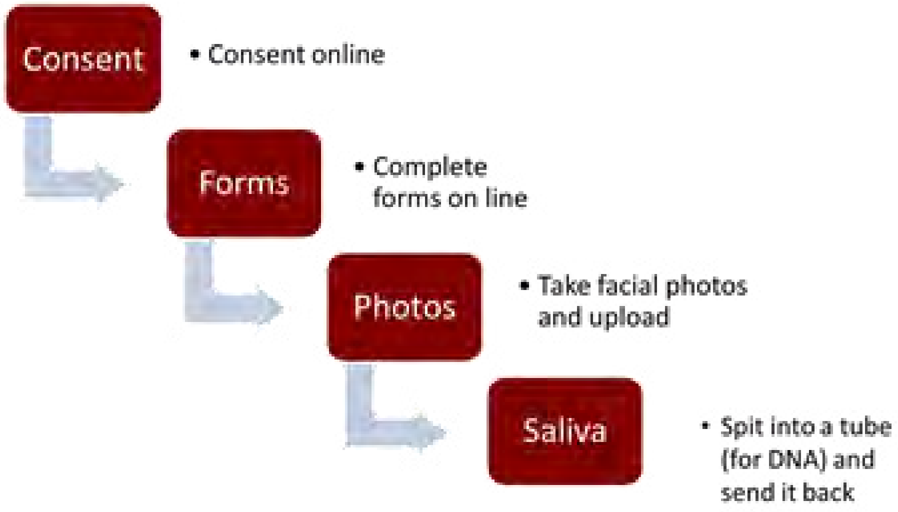
- Relationship with commercial interests:
  None

Plenary

Registry Updates: Advancing Research through Participation

Tatiana Foroud, Claire D. Coles

Understanding the genetic effects of prenatal alcohol exposure requires large numbers of people willing to participate. Online recruitment of individuals with prenatal alcohol exposure is an innovative tool to enrich the sample for these individuals. Individuals are able to complete the consent online, upload a facial photo through a secure web portal, and provide a saliva sample through the mail, reducing cost and burden. The web portal can be expanded to include cognitive testing. This is a highly efficient method of enrolling individuals into research studies.



Help improve the lives of people with FASD.

Exposure to alcohol before birth may cause Fetal Alcohol Spectrum Disorders (FASD).

About 50 out of 1,000 people in the US will experience some type of FASD.

FASD has a range of effects on people.

This can make it hard to diagnose and treat people with FASD.

TAKE ACTION! Join our research study.

We are trying to understand the FASD spectrum. By joining our study, you can help us learn about FASD and help improve the lives of people with FASD.

https://digfasd.org/

Plenary 1

The Collaborative Initiative on FASD: New Findings on Screening

Edward Riley

The Collaborative Initiative on FASD: New Findings on Screening

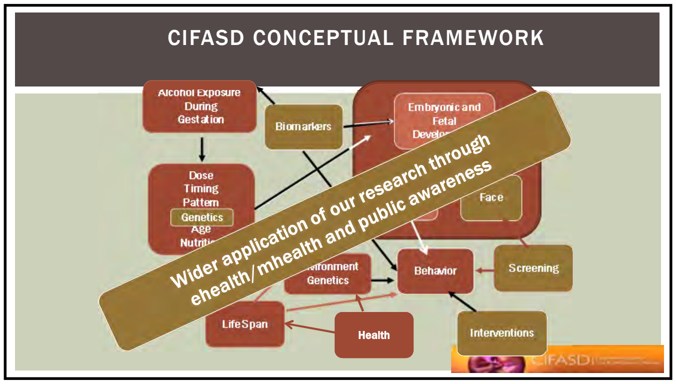
Ed Riley, PhD

Distinguished Research Professor
Center for Behavioral Teratology
San Diego State University
San Diego, CA, USA

I have no conflict of interest to report and no financial relationship with any commercial interest

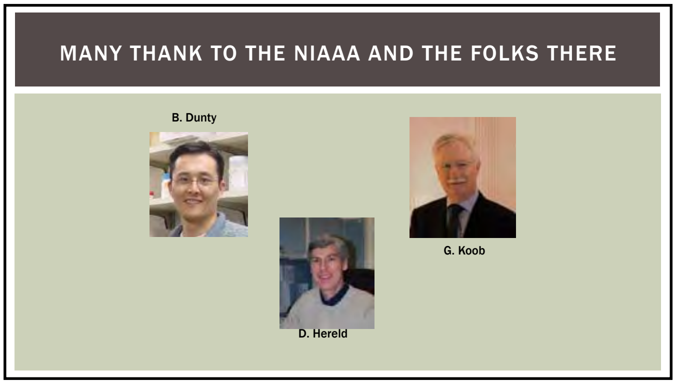
COLLABORATIVE INITIATIVE ON FASD

- An international, multidisciplinary collaboration of both basic and clinical research projects
- Established in 2003 with funding from NIAAA to enhance the definitive diagnoses of FASD at different stages of the lifespan based on biological, physical, and/or behavioral assessment and to improve outcomes in individuals with FASD.



CIFASD CONCEPTUAL FRAMEWORK

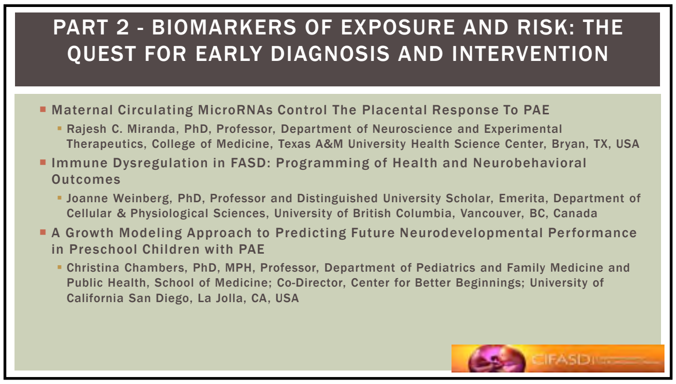
Wider application of our research through ehealth/mhealth and public awareness



MANY THANK TO THE NIAAA AND THE FOLKS THERE

PART 1 - THE GENETICS OF FASD: CIFASD STUDIES IN FISH, MICE, AND HUMANS

- Genetic and Bioinformatic Approaches to Understanding Alcohol Teratogenesis
  - Johann Eberhart, PhD, Associate Professor, Molecular Biosciences, University of Texas at Austin, Austin, TX, USA
- Diving into Social Deficits with a Zebrafish Model
  - Yohaan Fernandes, PhD, Molecular Biosciences, University of Texas at Austin, Austin, TX, USA
- Genetic Modifiers of Susceptibility to PAE in Mice
  - Scott Parnell, PhD, Assistant Professor, Bowles Centre for Alcohol Studies, Department of Cell Biology and Physiology, University of North Carolina, Chapel Hill, NC, USA
- The Genetics of FASD: Accelerating Research Advances
  - Tatiana Foroud, PhD, Professor, Department of Medical and Molecular Genetics, School of Medicine, Indiana University, Indianapolis, IN, USA



PART 2 - BIOMARKERS OF EXPOSURE AND RISK: THE QUEST FOR EARLY DIAGNOSIS AND INTERVENTION

- Maternal Circulating MicroRNAs Control The Placental Response To PAE
  - Rajesh C. Miranda, PhD, Professor, Department of Neuroscience and Experimental Therapeutics, College of Medicine, Texas A&M University Health Science Center, Bryan, TX, USA
- Immune Dysregulation in FASD: Programming of Health and Neurobehavioral Outcomes
  - Joanne Weinberg, PhD, Professor and Distinguished University Scholar, Emerita, Department of Cellular & Physiological Sciences, University of British Columbia, Vancouver, BC, Canada
- A Growth Modeling Approach to Predicting Future Neurodevelopmental Performance in Preschool Children with PAE
  - Christina Chambers, PhD, MPH, Professor, Department of Pediatrics and Family Medicine and Public Health, School of Medicine; Co-Director, Center for Better Beginnings; University of California San Diego, La Jolla, CA, USA

PART -3 -AUTOMATING THE DIAGNOSIS AND TREATMENT OF FAS

- Development and Implementation of a Mobile Screening Tool for Identification of Children Affected by Prenatal Alcohol
  - Sarah Mattson, PhD, Professor, Department of Psychology, San Diego State University, San Diego, CA, USA
- 3D Facial Analysis for the Objective Identification of FASD Associated Facial Dysmorphology
  - Michael Suttie, PhD, Researcher, Medical Image Analysis, Nuffield Department of Women's Reproductive Health, University of Oxford, Oxford, UK
- Families Moving Forward – Connect: Developing a Mobile Health Intervention for Families Raising Children with FASD
  - Christie Petrenko, PhD, Clinical Psychologist and Researcher, Mt. Hope Family Center, University of Rochester, Rochester, NY, USA
  - Cristiano Tapparello, PhD, Research Associate, Department of Electrical and Computer Engineering, University of Rochester, Rochester, NY

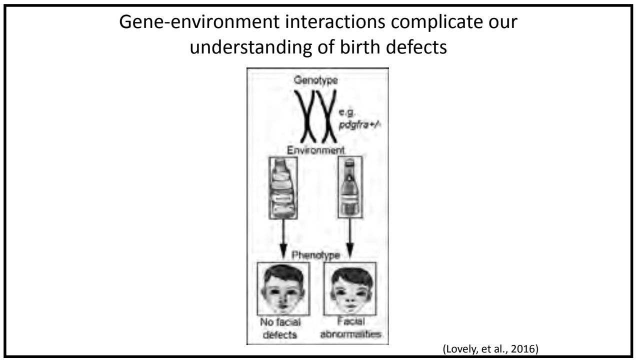
THANK YOU

Ed Riley
eriley@sdsu.edu

Plenary 1

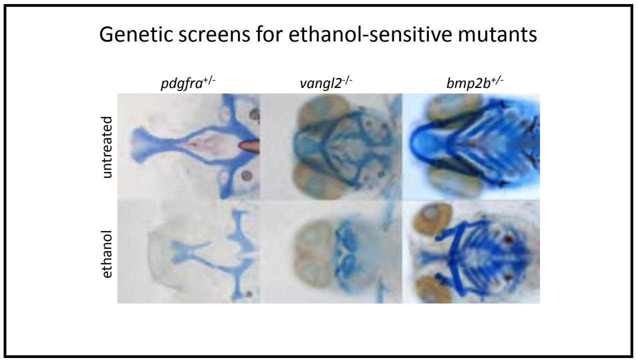
Genetic and Bioinformatic Approaches to Understanding Alcohol Teratogenesis

Johann Eberhart

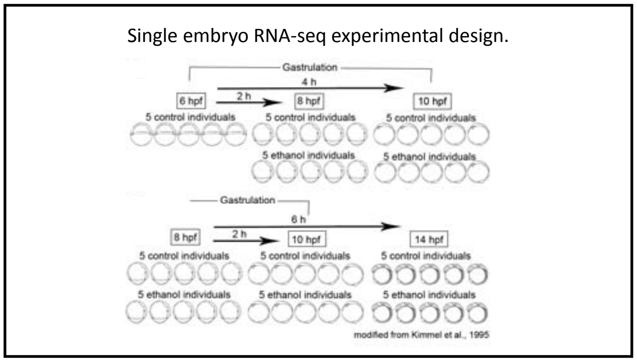


Gene-environment interactions complicate our understanding of birth defects

(Lovely, et al., 2016)

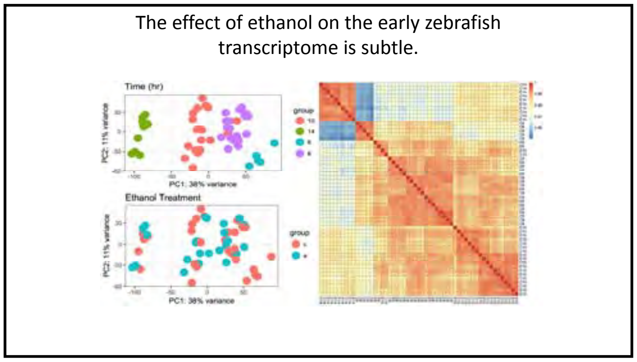


Genetic screens for ethanol-sensitive mutants

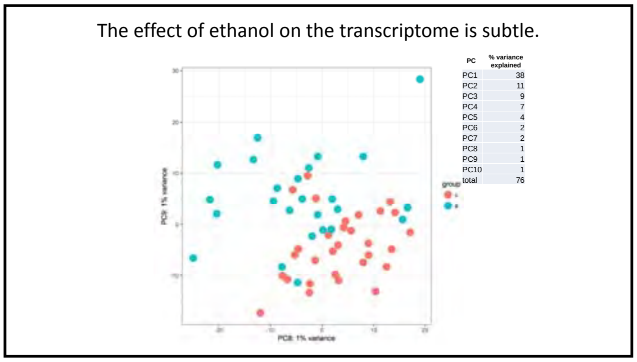


Single embryo RNA-seq experimental design.

modified from Kimmel et al., 1995

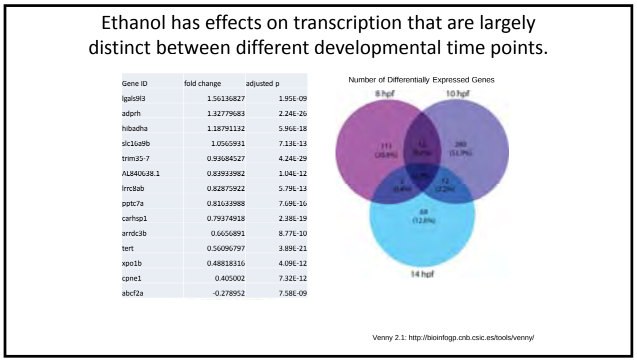


The effect of ethanol on the early zebrafish transcriptome is subtle.



The effect of ethanol on the transcriptome is subtle.

PC	% variance explained
PC1	38
PC2	11
PC3	9
PC4	7
PC5	4
PC6	2
PC7	2
PC8	1
PC9	1
PC10	1
total	76

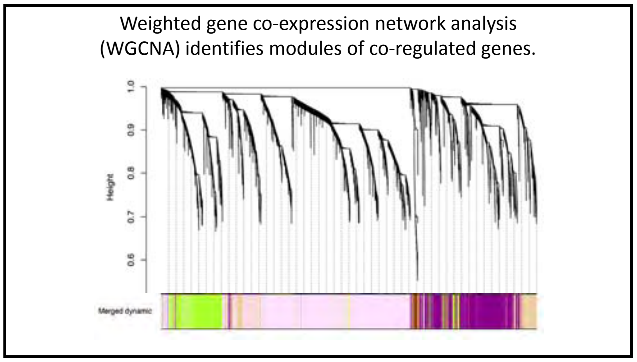


Ethanol has effects on transcription that are largely distinct between different developmental time points.

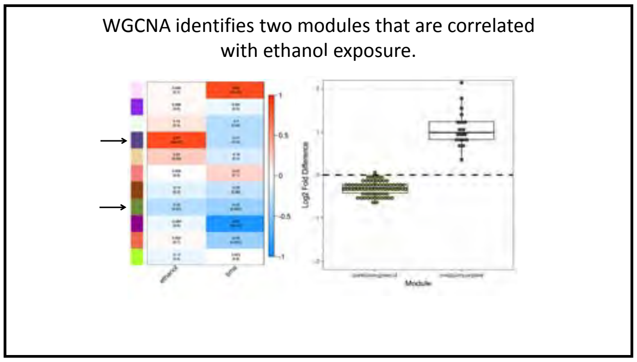
Gene ID	fold change	adjusted p
lgals9l3	1.56136827	1.95E-09
adprh	1.32779683	2.24E-26
hibadha	1.18791132	5.96E-18
slc16a9b	1.0565931	7.13E-13
trim35-7	0.93684527	4.24E-29
AL840638.1	0.83933982	1.04E-12
lrrc8ab	0.82875922	5.79E-13
pptc7a	0.81633988	7.69E-16
carhsp1	0.79374918	2.38E-19
arrdc3b	0.6656891	8.77E-10
tert	0.56096797	3.89E-21
xpo1b	0.48818316	4.09E-12
cpne1	0.405002	7.32E-12
abcf2a	-0.278952	7.58E-09

Number of Differentially Expressed Genes

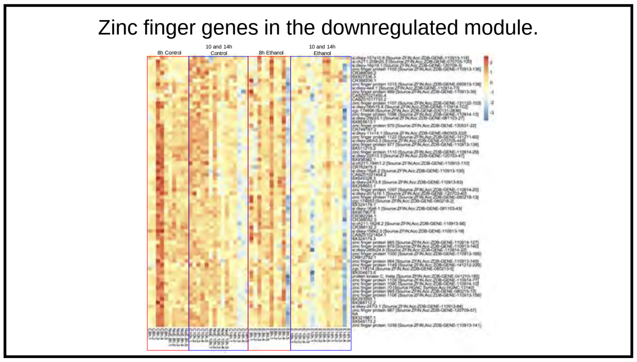
Venny 2.1: http://bioinfogp.cnb.csic.es/tools/venny/



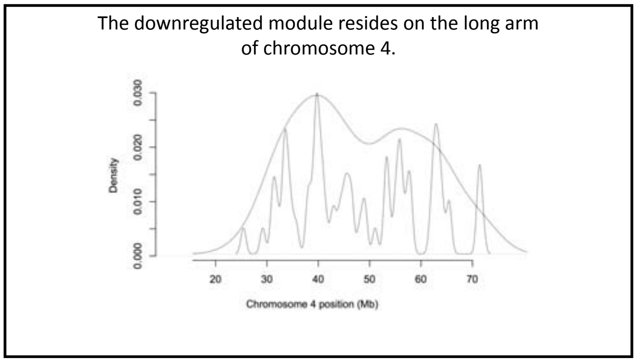
Weighted gene co-expression network analysis (WGCNA) identifies modules of co-regulated genes.



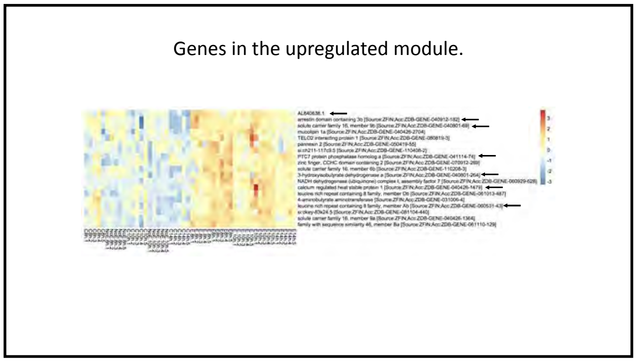
WGCNA identifies two modules that are correlated with ethanol exposure.



Zinc finger genes in the downregulated module.

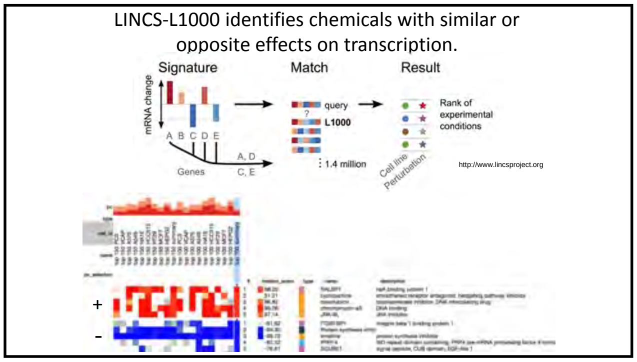


The downregulated module resides on the long arm of chromosome 4.



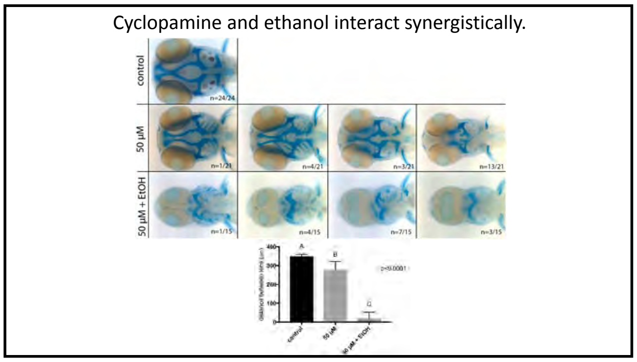
Genes in the upregulated module.

AL840638.1 ←
arrestin domain containing 3b [Source:ZFIN;Acc:ZDB-GENE-040912-182] ←
solute carrier family 16, member 9b [Source:ZFIN;Acc:ZDB-GENE-040801-69] ←
mucolipin 1a [Source:ZFIN;Acc:ZDB-GENE-040426-2704]
TELO2 interacting protein 1 [Source:ZFIN;Acc:ZDB-GENE-080819-3]
pannexin 2 [Source:ZFIN;Acc:ZDB-GENE-050419-55]
si:ch211-117c9.5 [Source:ZFIN;Acc:ZDB-GENE-110408-2]
PTC7 protein phosphatase homolog a [Source:ZFIN;Acc:ZDB-GENE-041114-74] ←
zinc finger, CCHC domain containing 2 [Source:ZFIN;Acc:ZDB-GENE-070912-289]
solute carrier family 16, member 6b [Source:ZFIN;Acc:ZDB-GENE-110208-3]
3-hydroxyisobutyrate dehydrogenase a [Source:ZFIN;Acc:ZDB-GENE-040801-264] ←
NADH dehydrogenase (ubiquinone) complex I, assembly factor 7 [Source:ZFIN;Acc:ZDB-GENE-060929-628]
calcium regulated heat stable protein 1 [Source:ZFIN;Acc:ZDB-GENE-040426-1479] ←
leucine rich repeat containing 8 family, member Db [Source:ZFIN;Acc:ZDB-GENE-061013-487]
4-aminobutyrate aminotransferase [Source:ZFIN;Acc:ZDB-GENE-031006-4]
leucine rich repeat containing 8 family, member Ab [Source:ZFIN;Acc:ZDB-GENE-060531-43] ←
si:dkey-83k24.5 [Source:ZFIN;Acc:ZDB-GENE-081104-440]
solute carrier family 16, member 9a [Source:ZFIN;Acc:ZDB-GENE-040426-1364]
family with sequence similarity 46, member Ba [Source:ZFIN;Acc:ZDB-GENE-061110-129]

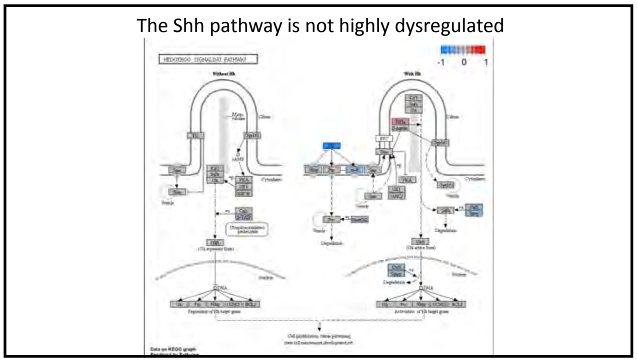


LINCS-L1000 identifies chemicals with similar or opposite effects on transcription.

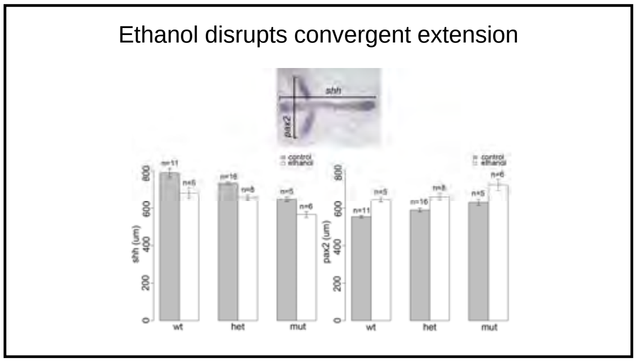
http://www.lincsproject.org



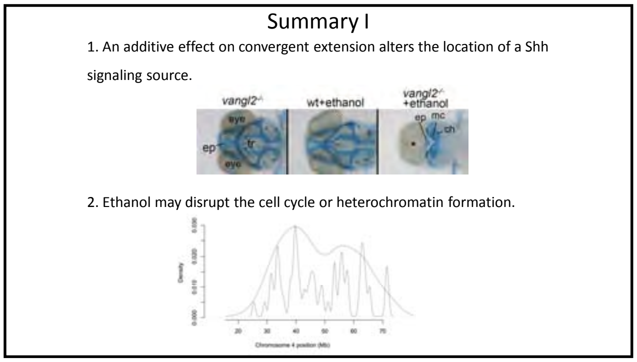
Cyclopamine and ethanol interact synergistically.



The Shh pathway is not highly dysregulated



Ethanol disrupts convergent extension



Summary I

1. An additive effect on convergent extension alters the location of a Shh signaling source.

2. Ethanol may disrupt the cell cycle or heterochromatin formation.

Learning Objectives

1. Explain how gene-ethanol interactions modify outcomes of ethanol exposure
2. Outline how bioinformatics can predict modifiers of ethanol exposures

Abstract

While prenatal ethanol exposure causes FASD, numerous other variables modulate the effects of ethanol exposures. Genetic modifiers are important among these variables. However, we have very limited understanding of the identity and function of these genes. We have used the genetic tractability of zebrafish to characterize the genetic susceptibility to FASD. Our genetic screens have identified numerous mutants that develop facial defects when exposed to normally subteratogenic concentrations of ethanol. Of these, ethanol-exposed vangl2 mutants develop severe midfacial defects. To understand how ethanol disrupts facial development, we performed transcriptomic analyses on control and embryos exposed to subteratogenic doses of ethanol. We found that ethanol exposure has very subtle, albeit detectable, effects on global gene expression. We sought to use these global changes in gene expression to identify molecules that mimic or antagonize the effects of ethanol via the LINCS L1000 dataset. This dataset predicted the Sonic Hedgehog (Shh) pathway inhibitor, cyclopamine, would mimic the effects of ethanol. Indeed, we find that ethanol and cyclopamine strongly interact to disrupt midfacial development. Interestingly, pathway-based analyses did not identify alterations in the overall activity of the Shh pathway. Collectively, these results suggest that the midfacial defects in ethanol-exposed vangl2 mutants is due to an indirect interaction between ethanol and the Shh pathway. Vangl2 functions as part of a signaling pathway that regulates coordinated cell movements during midfacial development. Consistent with an indirect model, we find that a critical source of Shh signaling that separates the developing eye field into bilateral eyes becomes mispositioned in ethanol-exposed vangl2 mutants.

Plenary 1

Diving into Social Deficits with a Zebrafish Model

Yohann Fernandez

Learning Objectives

1. Describe how the zebrafish can be used to model one of the alcohol-induced social deficits, which is one of the most frequent and devastating symptom of FASD
2. Describe how the zebrafish can be used to provide mechanistic insight into alcohol induced social deficits

Why use zebrafish to model FASD?
Altered social behavior is a symptom of FASD (Kodituwakku, 2007; Rasmussen et al., 2011). Understanding social cues (Streissguth et al., 1991), beginning and maintaining reciprocal friendships (Roebuck, Mattson, & Riley, 1999) as well as initiating suitable intimate relationships are issues that individuals with FASD face (Kelly, Day, & Streissguth, 2000). Additionally, individuals with FASD also have higher rates of legal problems, depression and suicide (Kelly et al., 2000). Hence, it is of utmost importance that we, better understand the mechanism(s) responsible for alcohol-induced social alterations.

Knowing precisely when an ethanol exposure occurred is a major challenge in understanding FASD. Zebrafish fertilization occurs externally, thus the deleterious effects of ethanol on the organ systems of an embryo can be precisely measured. Zebrafish share a basic brain layout and neurochemistry with mammals (Chatterjee & Gerlai, 2009; Tropepe & Sive, 2003). In addition to structural similarities, zebrafish display a wide repertoire of complex behaviors, such as social behavior, which are relevant to FASD. Unlike many other animal model systems, zebrafish from social groups (called shoals) (Norton & Bally-Cuif, 2010), thus they are an excellent model system with which to understand how prenatal ethanol exposures can alter social behavior.

How do you measure zebrafish social behavior?
When a single zebrafish sees a group of zebrafish, whether the group is a live shoal or a computer animation, the single zebrafish will reduce the distance to the group and will remain in close proximity to the group (Fernandes & Gerlai, 2009; Fernandes et al., 2018). This measurement of proximity provides a robust measure of the social response.

Does embryonic alcohol exposure alter social behavior in zebrafish?
Yes. I (Fernandes & Gerlai, 2009; Fernandes, Rampersad, & Gerlai, 2015b; 2015a; Fernandes et al., 2014) and others (Baggio et al., 2017; Buske & Gerlai, 2011; Mahabir, Chatterjee, & Gerlai, 2014; Parker et al., 2014; 2016) have shown that embryonic ethanol exposure disrupts social behavior in zebrafish. Together our work supports the use of zebrafish for modeling alcohol-induced alterations to social behavior.

How can zebrafish provide an insight into the mechanisms responsible for alcohol-induced alterations to social behavior?
Over 70% of human genes are present in zebrafish (K. Howe et al., 2013). Furthermore, there are numerous genetic tools available in zebrafish (Driever et al., 1994; Rasooly et al., 2003) that can be used to characterize FASD risk and resilience. For these reasons, zebrafish can provide mechanistic understanding of the neurobehavioral alterations in FASD due to the ability to combine behavioral, imaging and genetic analyses.

How am I using zebrafish to investigate the potential mechanisms behind alcohol-induced social alterations?
My research uses zebrafish to examine how genetic and environmental signaling through the mammalian target of rapamycin (mTOR), modulates the deleterious effects of alcohol on the brain and behavior.

What is mTOR?
The mammalian target of rapamycin is a serine-threonine kinase that is highly conserved from yeast to humans. The mTOR pathway is known to sense the environmental and cellular nutrition as well as energy status and is made up of two complexes: mTORC1 and mTORC2 (Weichhart, 2012). The mTORC1 pathway regulates diverse functions including social behavior (Schneider et al., 2016). My research examines the roles that two components of mTORC1 pathway: Tuberous sclerosis complex (Tsc) and Raptor play in social behavior. Tsc1 is a negative regulator of mTORC1, which means that in the absence of tsc1, mTORC1 will be over active. Raptor, on the other hand, is essential to the function of mTORC1. When Raptor is absent, mTOR signaling is reduced or absent. Thus, if ethanol-induced

alterations to social behavior are mediate via mTORC1, then analysis of mutations in these two genes will provide deep understanding in the risk and resilience to ethanol.

My preliminary data suggest that a loss of a single copy of raptor further disrupts alcohol-induced social behavior. Conversely, a loss of a single copy of tsc1a appears to suppress alcohol-induced social alterations. Taken together my earlier data suggests that mTOR plays a role in the effect that alcohol exposure has on social behavior.

Other thoughts? Dopamine?

Across vertebrates, social behavior is mediated by the neurotransmitter dopamine. (Garcia et al., 2010; Scerbina, Chatterjee, & Gerlai, 2012; Shin et al., 2018; Yamaguchi et al., 2017). In humans and other animal species, prenatal alcohol exposure has been shown to reduce the activity of the dopaminergic system (Schneider et al., 2011). I have shown that fish with embryonic alcohol exposure have a reduced dopamine response to social stimulus compared to control fish (Fernandes, Rampersad, & Gerlai, 2015a). To build on previous work, I examined social behavior of fezf2 zebrafish mutants. In the forebrain of these fish, selective subgroups of dopamine neurons are reduced (Rink & Guo, 2004) My preliminary data suggests that a loss of a single copy of fezf2 appears to alter social behavior in a fashion similar to ethanol. Collectively, my data suggest that ethanol-induced alterations to forebrain dopaminergic neurons may underlie the social alterations in FASD.

Conclusions

The goal of my presentation was to provide a blueprint of how zebrafish can be used to investigate the potential mechanisms responsible for social alterations in individuals with FASD. My preliminary data suggests that alcohol may alter social behavior via mTORC1. Additionally, my data suggest that a depletion of dopamine neurons in the forebrain may be associated this social behavior. This research is evidence that the zebrafish is an excellent model system with which to characterize the effects of ethanol on social behavior.

References:

Baggio, S., Ben Hur Mussulini, de Oliveira, D. L., Gerlai, R., & Rico, E. P. (2017). Embryonic alcohol exposure leading to social avoidance and altered anxiety responses in adult zebrafish. Behavioural Brain Research, 1–0. http://doi.org/10.1016/j.bbr.2017.08.039

Buske, C., & Gerlai, R. (2011). Early embryonic ethanol exposure impairs shoaling and the dopaminergic and serotoninergic systems in adult zebrafish. Neurotoxicology and Teratology, 33(6), 698–707. http://doi.org/10.1016/j.ntt.2011.05.009

Chatterjee, D., & Gerlai, R. (2009). High precision liquid chromatography analysis of dopaminergic and serotoninergic responses to acute alcohol exposure in zebrafish. Behavioural Brain Research, 200(1), 208–213. http://doi.org/10.1016/j.bbr.2009.01.016

Driever, W., Stemple, D., Schier, A., & Solnica-Krezel, L. (1994). Zebrafish: genetic tools for studying vertebrate development. Trends in Genetics, 10(5), 152–159. http://doi.org/10.1016/0168-9525(94)90091-4

Fernandes, Y., & Gerlai, R. (2009). Long-Term Behavioral Changes in Response to Early Developmental Exposure to Ethanol in Zebrafish. Alcoholism, Clinical and Experimental Research, 33(4), 601–609. http://doi.org/10.1111/j.1530-0277.2008.00874.x

Fernandes, Y., Rampersad, M., & Gerlai, R. (2015a). Embryonic alcohol exposure impairs the dopaminergic system and social behavioral responses in adult zebrafish. The International Journal of Neuropsychopharmacology, 18(6). http://doi.org/10.1093/ijnp/pyu089

Fernandes, Y., Rampersad, M., & Gerlai, R. (2015b). Impairment of social behaviour persists two years after embryonic alcohol exposure in zebrafish: A model of fetal alcohol spectrum disorders. Behavioural Brain Research, 292, 102–108. http://doi.org/10.1016/j.bbr.2015.05.060

Fernandes, Y., Rampersad, M., Jones, E. M., & Eberhart, J. K. (2018). Social deficits following embryonic ethanol exposure arise in post-larval zebrafish. Addiction Biology, 4, 29–10. http://doi.org/10.1111/adb.12649

Fernandes, Y., Tran, S., Abraham, E., & Gerlai, R. (2014). Embryonic alcohol exposure impairs associative learning performance in adult zebrafish. Behavioural Brain Research, 265, 181–187. http://doi.org/10.1016/j.bbr.2014.02.035

Garcia, J. R., MacKillop, J., Aller, E. L., Merriwether, A. M., Wilson, D. S., & Lum, J. K. (2010). Associations between Dopamine D4 Receptor Gene Variation with Both Infidelity and Sexual Promiscuity. PLoS ONE, 5(11), e14162–6. http://doi.org/10.1371/journal.pone.0014162

Howe, K., Clark, M. D., Torroja, C. F., Torrance, J., Berthelot, C., Muffato, M., et al. (2013). The zebrafish reference genome sequence and its relationship to the human genome. Nature, 496(7446), 498–503. http://doi.org/10.1038/nature12111

Jones, L. J., & Norton, W. H. J. (2015). Using zebrafish to uncover the genetic and neural basis of aggression, a frequent comorbid symptom of psychiatric disorders. Behavioural Brain Research, 276, 171–180. http://doi.org/10.1016/j.bbr.2014.05.055

Kelly, S. J., Day, N., & Streissguth, A. P. (2000). Effects of prenatal alcohol exposure on social behavior in humans and other species. Neurotoxicology and Teratology, 22(2), 143–149.

Kodituwakku, P. W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. Neuroscience & Biobehavioral Reviews, 31(2), 192–201. http://doi.org/10.1016/j.neubiorev.2006.06.020

Mahabir, S., Chatterjee, D., & Gerlai, R. (2014). Strain dependent neurochemical changes induced by embryonic alcohol exposure in zebrafish. Neurotoxicology and Teratology, 41(C), 1–7. http://doi.org/10.1016/j.ntt.2013.11.001

Norton, W., & Bally-Cuif, L. (2010). Adult zebrafish as a model organism for behavioural genetics. BMC Neuroscience, 11, 90. http://doi.org/10.1186/1471-2202-11-90

Parker, M. O., Annan, L. V., Kanellopoulos, A. H., Brock, A. J., Combe, F. J., Baiamonte, M., et al. (2014). The utility of zebrafish to study the mechanisms by which ethanol affects social behavior and anxiety during early brain development. Progress in Neuro-Psychopharmacology and Biological Psychiatry, 55, 94–100. http://doi.org/10.1016/j.pnpbp.2014.03.011

Parker, M. O., Evans, A. M.-D., Brock, A. J., Combe, F. J., Teh, M.-T., & Brennan, C. H. (2016). Moderate alcohol exposure during early brain development increases stimulus-response habits in adulthood. Addiction Biology, 21(1), 49–60. http://doi.org/10.1111/adb.12176

Rasmussen, C., Becker, M., McLennan, J., Urichuk, L., & Andrew, G. (2011). An evaluation of social skills in children with and without prenatal alcohol exposure. Child: Care, Health and Development, 37(5), 711–718. http://doi.org/10.1111/j.1365-2214.2010.01152.x

Rasooly, R. S., Henken, D., Freeman, N., Tompkins, L., Badman, D., Briggs, J., et al. (2003). Genetic and genomic tools for zebrafish research: The NIH zebrafish initiative. Developmental Dynamics : an Official Publication of the American Association of Anatomists, 228(3), 490–496. http://doi.org/10.1002/dvdy.10366

Rink, E., & Guo, S. (2004). The too few mutant selectively affects subgroups of monoaminergic neurons in the zebrafish forebrain. Neuroscience, 127(1), 147–154. http://doi.org/10.1016/j.neuroscience.2004.05.004

Roebuck, T. M., Mattson, S. N., & Riley, E. P. (1999). Behavioral and psychosocial profiles of alcohol-exposed children. Alcoholism, Clinical and Experimental Research, 23(6), 1070–1076. http://doi.org/10.1111/j.1530-0277.1999.tb04227.x

Scerbina, T., Chatterjee, D., & Gerlai, R. (2012). Dopamine receptor antagonism disrupts social preference in zebrafish: a strain comparison study. Amino Acids, 43(5), 2059–2072. http://doi.org/10.1007/s00726-012-1284-0

Schneider, M. L., Moore, C. F., & Adkins, M. M. (2011). The Effects of Prenatal Alcohol Exposure on Behavior: Rodent and Primate Studies. Neuropsychology Review, 21(2), 186–203. http://doi.org/10.1007/s11065-011-9168-8

Schneider, M., Vries, P. J., Schönig, K., Rößner, V., & Waltereit, R. (2016). mTOR inhibitor reverses autistic-like social deficit behaviours in adult rats with both Tsc2 haploinsufficiency and developmental status epilepticus. European Archives of Psychiatry and Clinical Neuroscience, 267(5), 455–463. http://doi.org/10.1007/s00406-016-0703-8

Shin, S., Pribiag, H., Lilascharoen, V., Knowland, D., Wang, X.-Y., & Lim, B. K. (2018). Drd3 Signaling in the Lateral Septum Mediates Early Life Stress-Induced Social Dysfunction. Neuron, 97(1), 195–208.e6. http://doi.org/10.1016/j.neuron.2017.11.040

Streissguth, A. P., Aase, J. M., Clarren, S. K., Randels, S. P., LaDue, R. A., & Smith, D. F. (1991). Fetal alcohol syndrome in adolescents and adults. JAMA: the Journal of the American Medical Association, 265(15), 1961–1967. http://doi.org/10.1001/jama.1991.03460150065025

Tropepe, V., & Sive, H. L. (2003). Can zebrafish be used as a model to study the neurodevelopmental causes of autism? Genes, Brain and Behavior, 2(5), 268–281. http://doi.org/10.1046/j.1601-183X.2003.00038.x

Weichhart, T. (2012). mTor: methods and protocols. New York: Humana Press: Springer. http://doi.org/DOI 10.1007/978-1-61779-430-8

Yamaguchi, Y., Lee, Y.-A., Kato, A., Jas, E., & Goto, Y. (2017). The Roles of Dopamine D2 Receptor in the Social Hierarchy of Rodents and Primates. Scientific Reports, 1–10. http://doi.org/10.1038/srep43348

Plenary 1

Genetic Modifiers of Susceptibility to PAE in Mice

Scott Parnell

Learning Objectives:

1. Recognize that genetics can modify susceptibility to prenatal alcohol exposure
2. Learn new genes that modify susceptibility to alcohol and what this tells us about cellular mechanisms

Not all children who are prenatally exposed to alcohol present with the characteristic craniofacial features of Fetal Alcohol Syndrome (FAS). While there are numerous factors that contribute to this variation, there is a strong genetic component to an individual's susceptibility to prenatal alcohol exposure (PAE). This genetic component is also present in mice, in which some strains of mice are more susceptible to PAE compared to other strains. Likewise, knocking out even one copy of certain genes can modify susceptibility to alcohol. We recently identified two closely related sub-strains of mice that differ in their response to alcohol. C57BL/6J mice phenocopy the craniofacial and brain abnormalities observed in human FAS populations. However, the C57BL/6N strain derived from similar stock 200 generations ago, does not exhibit these same effects. RNA-Seq was used to compare the transcriptomic differences between these strains when the embryo is at the critical developmental window for the severest craniofacial and brain defects. We identified 80 differentially expressed genes between the embryos of these strains. Subsequent work in mice has shown that important factors involved in primary cilia, growth factor transduction, and cellular redox balance can either increase or decrease susceptibility to PAE. This work will be important in identifying genes that can be further tested in humans, and provide a better understanding of alcohol's mechanisms.

Plenary 1

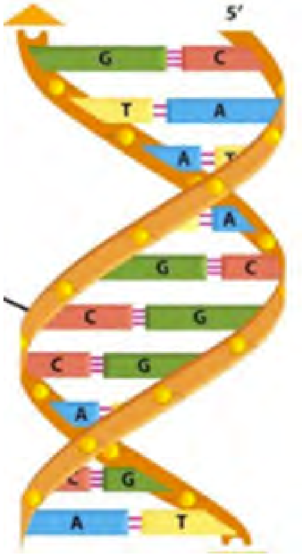
The Genetics of FASD: Accelerating Research Advances

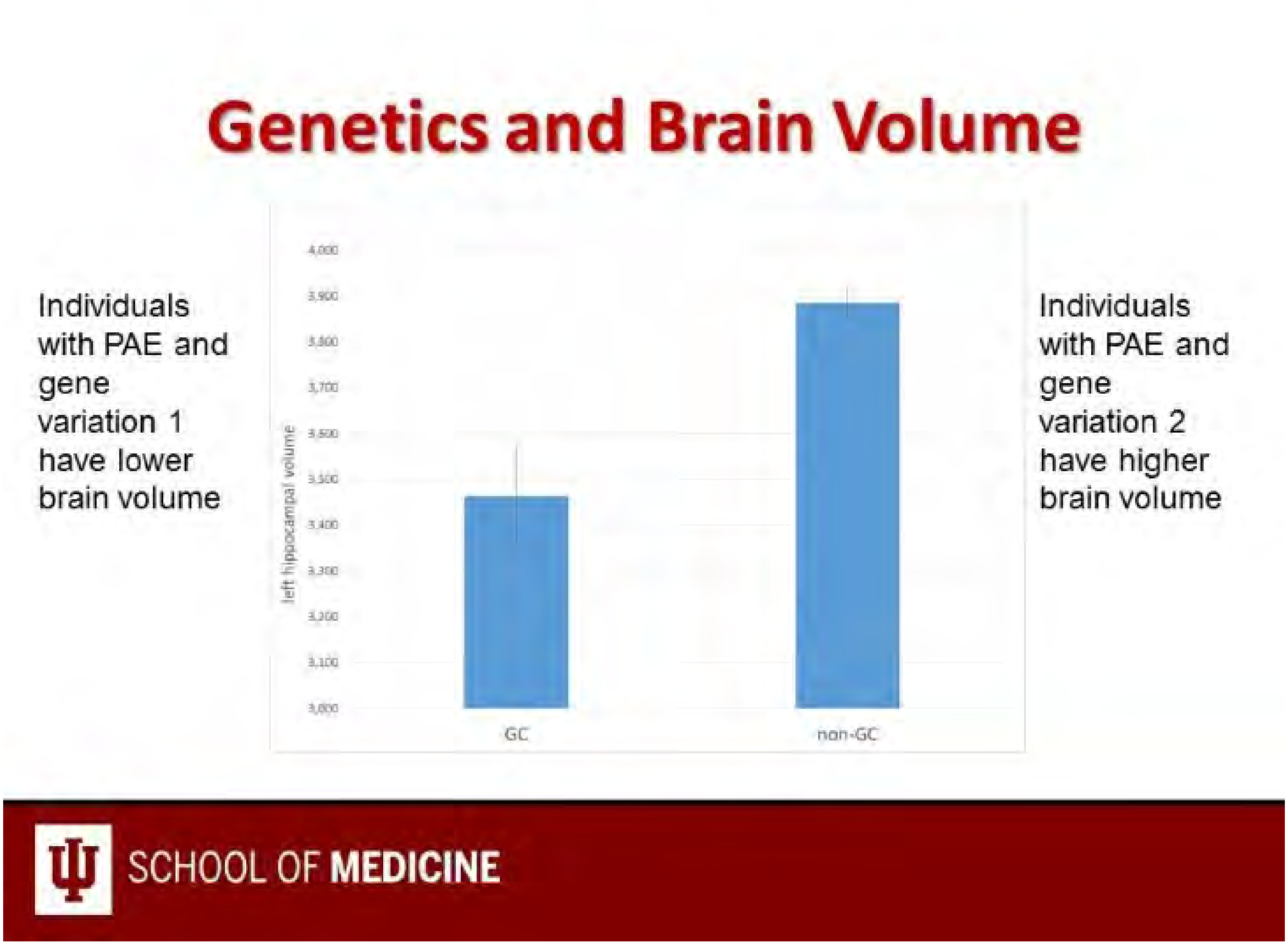
Tatiana Foroud

Learning Objectives:

1. Describe how genetics may play a role in the risk for FASD
2. Integrate online research opportunities for families with FASD

- **Everyone's DNA is slightly different**
- **There may be some DNA changes that make some individuals more susceptible to the effects of alcohol exposure in utero**





Genetics and Brain Volume

Individuals with PAE and gene variation 1 have lower brain volume

Individuals with PAE and gene variation 2 have higher brain volume

SCHOOL OF MEDICINE

Help improve the lives of people with FASD.

Exposure to alcohol before birth may cause Fetal Alcohol Spectrum Disorders (FASD).

About 50 out of 1,000 people in the US will experience some type of FASD.

FASD has a range of effects on people.

This can make it hard to diagnose and treat people with FASD.

TAKE ACTION! Join our research study.

We are trying to understand the FASD spectrum. By joining our study, you can help us learn about FASD and help improve the lives of people with FASD.

https://digfasd.org/

Plenary 1

Maternal Circulating MicroRNAs Control The Placental Response To PAE

Rajesh C. Miranda

Authors: Alexander M. Tseng, Amanda H. Mahnke, Alan Wells, Nihal A. Salem, Andrea M. Allan, Victoria H.J. Roberts, Natali Newman, Christopher D. Kroenke, Kathleen A. Grant, Lisa K. Akison, Karen M. Moritz, Christina D. Chambers, Rajesh C. Miranda & CIFASD

Learning Objectives:

1. Evaluate the importance of Epithelial Mesenchymal Transition in placental development and fetal growth.
2. Identify key functions of microRNAs
3. Describe how microRNAs are not only biomarkers that aid in diagnosis, but contribute to the pathophysiology of FASD

Introduction/ Rationale

Prenatal alcohol exposure (PAE) is common. The global prevalence of alcohol use during pregnancy is estimated at 9.8% 1, and a 2013 study found that, within the United States, 18% of women reported alcohol consumption during pregnancy, and 6.6% engaged in binge-drinking episodes2. In the state of Texas, we recently reported an average state-wide third-trimester rate of alcohol exposure of 8.4%, with rates as high as 17.7% in some localities3.

FASD is difficult to diagnose. A recent case ascertainment study in four school systems in the United States reported that between 1.1 and 5% of school-aged children are likely to have a FASD (weighted prevalence estimate of between 3.1 and 9.8%). However, only a tiny fraction (less than 1%) of the children who were ultimately diagnosed, had ever previously received a diagnosis4. We lack the resources and expertise to diagnose all of the infants and children who are at risk for developing FASD. Furthermore, children with an undiagnosed FASD are at risk for developing secondary disabilities.

Rationale. The discrepancy between the high prevalence of PAE and the low prevalence of diagnosed FASD forms the rationale for identifying biomarkers that predict infant and child outcomes due to prenatal alcohol exposure.

MicroRNAs (miRNAs) as biomarkers for predicting effects of prenatal alcohol exposure

The biology of microRNAs (miRNAs). MiRNAs are small (~20-25 nucleotides in length) ribonucleic acid sequences that are encoded in the genomes of all plants and animals. miRNAs are not translated into proteins and are therefore classified as non-protein-coding RNA molecules. Their major function is to serve as adaptors to a class of proteins called the Argonauts (Ago1, 2, 3 and 4), to facilitate their binding to messenger RNAs (mRNAs). miRNA-mediated binding to Ago proteins to target mRNAs results in the inhibition of protein translation.

MiRNAs play an important role in development because they provide a mechanism for cells to progress from one differentiation stage to the next, by repressing the translation of proteins that are no longer needed for the next stage of maturation. A number of studies in animal models have shown that alcohol alters the expression of miRNAs in developing tissues and that these alterations explain some of the diminished brain growth due to prenatal alcohol exposure (e.g.,5). Moreover, miRNAs are secreted into body-fluids and therefore, are potential endocrine factors that can be assessed, as biomarkers for the health of the secreting tissues, and consequently help diagnose disease. An analogy would be assessing plasma thyroid hormone levels as a biomarker for thyroid function to diagnose hypothyroidism.

Objectives

We previously identified 11 miRNAs which were significantly elevated in the plasma of mothers whose infants were affected by maternal alcohol consumption (Heavily Exposed Affected: HEa) compared to infants who were apparently unaffected by alcohol exposure (Heavily Exposed Unaffected: HEua) or unexposed (UE) controls6. The objective of this study was to assess our prediction that these HEamiRNAs influence epithelial-mesenchymal transition (EMT), a cell biological pathway which equips placental trophoblasts with the molecular tools needed to invade the maternal uterine endometrium. EMT activation is essential for placental growth and for the ability of the placenta to transmit nutrition from the mother to fetus. Consequently successful placental EMT for fetal growth and maturation.

Methods
The effect of prenatal alcohol exposure (PAE) and the moderating effects of HEamiRNAs on placental EMT were assessed in rodent and non-human primate voluntary alcohol consumption paradigms. To directly investigate the interaction between HEamiRNAs and ethanol on placenta, we assessed their effects on the cytotrophoblastic BeWO and extravillous/invasive HTR8 human trophoblast cell lines.

Results
We report that PAE inhibited expression of placental EMT pathway members in rodent and non-human primate voluntary alcohol consumption models. Furthermore, in non-human primates, HEamiRNAs mediated effects of PAE on EMT pathway inhibition. When administered together, but not separately, HEamiRNAs significantly retarded cell cycle progression and reduced invasiveness of trophoblasts, pointing to their collective role in modulating the placental growth and invasion deficits seen in PAE. HEamiRNAs impaired expression of core EMT pathway members in both cytotrophoblastic and extravillous trophoblasts, and additionally, interfered with maturation-dependent calcium dynamics, while promoting syncytialization-dependent increases in placental hormone expression. This collective effect of HEamiRNAs mirrored the increased human chorionic gonadotrophin (hCG) levels we observed in HEa group mothers. Finally, HEamiRNAs administered together, decreased fetal growth parameters in a mouse model.

Conclusions
Taken together, our data suggests that HEamiRNAs act as maternal endocrine molecules that interfere with placental development. Disruption of placental EMT is accompanied by decreased fetal growth. Thus, maternal HEamiRNAs are biomarkers for PAE effects and also contribute to the pathology of FASD.

This research was supported by grants from the NIH, P50 AA022534 (AMA), U01 AA014835 and the Office of Dietary Supplements (CDC), R24 AA019431 (KAG), R01 AA021981 (CDK), R01 AA024659 (RCM), F31 AA026505 (AMT) and support from National Health and Medical Research Council of Australia (KMM).

References

Popova, S., Lange, S., Probst, C., Gmel, G. & Rehm, J. Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. The Lancet Global Health 5, e290-e299, doi:10.1016/S2214-109X(17)30021-9 (2017).

SAMHSA. The NSDUH Report: 18 percent of pregnant women drink alcohol during early pregnancy. NSDUH Report (2013).

Bakhireva, L. N. et al. Prevalence of Prenatal Alcohol Exposure in the State of Texas as Assessed by Phosphatidylethanol in Newborn Dried Blood Spot Specimens. Alcohol Clin Exp Res 41, 1004-1011, doi:10.1111/acer.13375 (2017).

May, P. A. et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA 319, 474-482, doi:10.1001/jama.2017.21896 (2018).

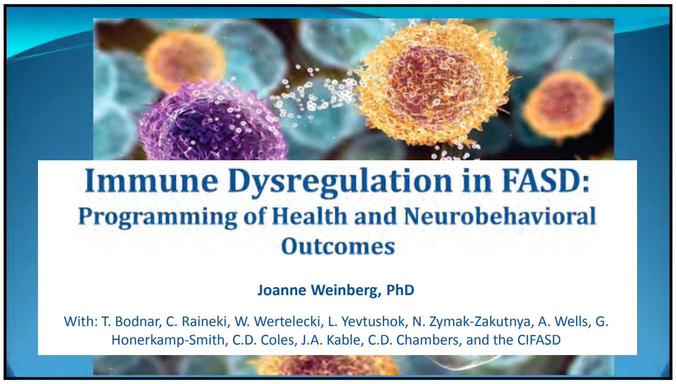
Pappalardo-Carter, D. L. et al. Suppression and epigenetic regulation of MiR-9 contributes to ethanol teratology: evidence from zebrafish and murine fetal neural stem cell models. Alcohol Clin Exp Res 37, 1657-1667, doi:10.1111/acer.12139 (2013).

Balaraman, S. et al. Plasma miRNA Profiles in Pregnant Women Predict Infant Outcomes following Prenatal Alcohol Exposure. PLoS One 11, e0165081, doi:10.1371/journal.pone.0165081 (2016).

Plenary 1

Immune Dysregulation in FASD: Programming of Health and Neurobehavioral Outcomes

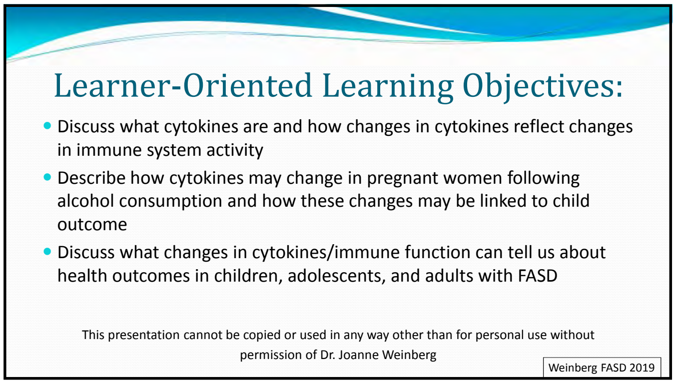
Joanne Weinberg



Immune Dysregulation in FASD:
Programming of Health and Neurobehavioral Outcomes

Joanne Weinberg, PhD

With: T. Bodnar, C. Raineki, W. Wertelecki, L. Yevtushok, N. Zymak-Zakutnya, A. Wells, G. Honerkamp-Smith, C.D. Coles, J.A. Kable, C.D. Chambers, and the CIFASD



Learner-Oriented Learning Objectives:

- Discuss what cytokines are and how changes in cytokines reflect changes in immune system activity
- Describe how cytokines may change in pregnant women following alcohol consumption and how these changes may be linked to child outcome
- Discuss what changes in cytokines/immune function can tell us about health outcomes in children, adolescents, and adults with FASD

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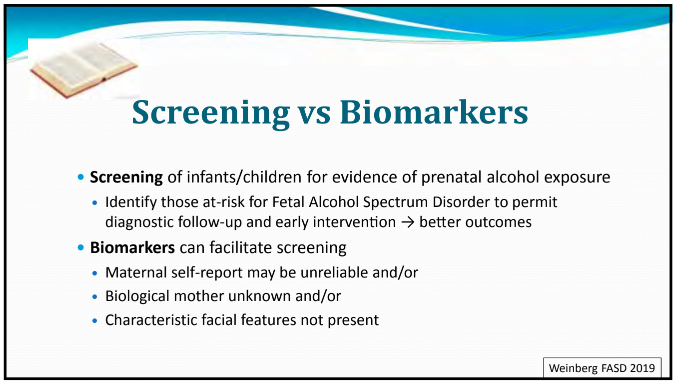

Screening vs Biomarkers

- **Screening** of infants/children for evidence of prenatal alcohol exposure
  - Identify those at-risk for Fetal Alcohol Spectrum Disorder to permit diagnostic follow-up and early intervention → better outcomes
- **Biomarkers** can facilitate screening
  - Maternal self-report may be unreliable and/or
  - Biological mother unknown and/or
  - Characteristic facial features not present

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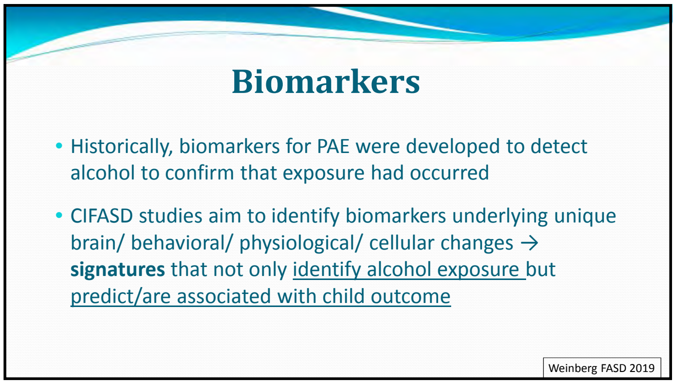

Biomarkers

- Historically, biomarkers for PAE were developed to detect alcohol to confirm that exposure had occurred
- CIFASD studies aim to identify biomarkers underlying unique brain/ behavioral/ physiological/ cellular changes → **signatures** that not only identify alcohol exposure but predict/are associated with child outcome

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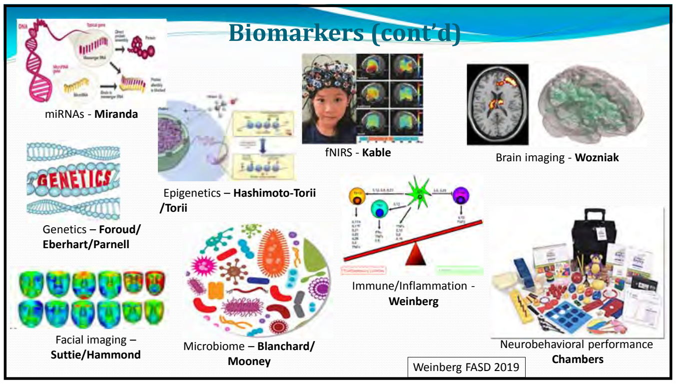

Biomarkers (cont'd)

miRNAs - **Miranda**

Epigenetics – **Hashimoto-Torii /Torii**

fNIRS - **Kable**

Brain imaging - **Wozniak**

Genetics – **Foroud/ Eberhart/Parnell**

Immune/Inflammation - **Weinberg**

Facial imaging – **Suttie/Hammond**

Microbiome – **Blanchard/ Mooney**

Neurobehavioral performance **Chambers**

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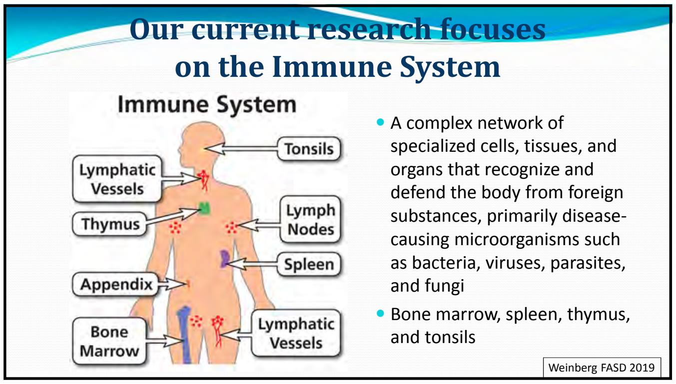

Our current research focuses on the Immune System

- A complex network of specialized cells, tissues, and organs that recognize and defend the body from foreign substances, primarily disease-causing microorganisms such as bacteria, viruses, parasites, and fungi
- Bone marrow, spleen, thymus, and tonsils

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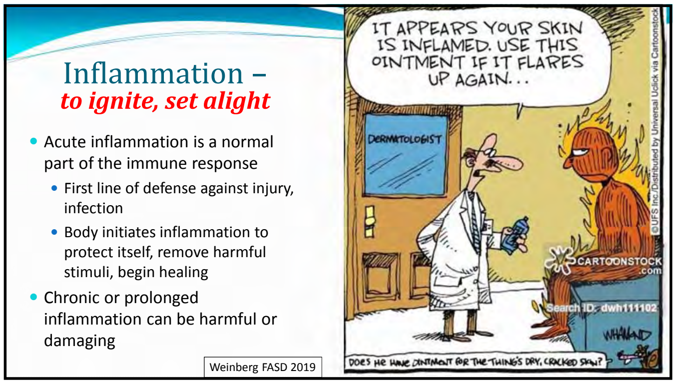

Inflammation –
to ignite, set alight

- Acute inflammation is a normal part of the immune response
  - First line of defense against injury, infection
  - Body initiates inflammation to protect itself, remove harmful stimuli, begin healing
- Chronic or prolonged inflammation can be harmful or damaging

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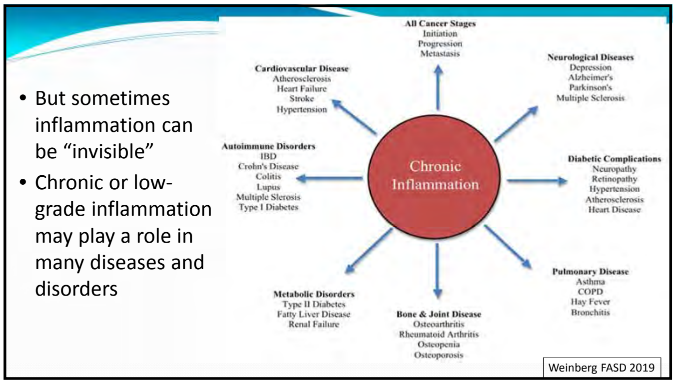

- But sometimes inflammation can be "invisible"
- Chronic or low-grade inflammation may play a role in many diseases and disorders

Chronic Inflammation

All Cancer Stages
Initiation
Progression
Metastasis

Neurological Diseases
Depression
Alzheimer's
Parkinson's
Multiple Sclerosis

Diabetic Complications
Neuropathy
Retinopathy
Hypertension
Atherosclerosis
Heart Disease

Pulmonary Disease
Asthma
COPD
Hay Fever
Bronchitis

Bone & Joint Disease
Osteoarthritis
Rheumatoid Arthritis
Osteopenia
Osteoporosis

Metabolic Disorders
Type II Diabetes
Fatty Liver Disease
Renal Failure

Autoimmune Disorders
IBD
Crohn's Disease
Colitis
Lupus
Multiple Slerosis
Type I Diabetes

Cardiovascular Disease
Atherosclerosis
Heart Failure
Stroke
Hypertension

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Our study

- Alcohol, in addition to being a teratogen that alters brain and biological development, is an early life insult \that programs developing systems and increases risk for diseases/disorders over the life course
- Data from our animal model of prenatal alcohol exposure found:
  - More severe and prolonged inflammation (arthritis) in animals exposed to alcohol than in controls following immune challenge
  - Immune dysregulation appears to be present from birth onward
- The immune system is important not only for health but also plays a key role in brain development in the fetus
  - Alcohol-induced changes in immune/inflammatory mechanisms may therefore play a role in the neurobehavioral deficits – cognitive function, self-regulation, adaptive functiont - hat are well documented in children with FASD

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Immune dysregulation in FASD: Programming of health and neurobehavioral outcomes

- Dr. Joanne Weinberg, PI
- Co-Is: Drs. Tammy Bodnar, Charlis Raineki, Tim Oberlander
- With: Dr. Chris Loock, Jan Lutke
- Consultants: Brenda Knight, Julie Conry
- Lab Team: Linda Ellis, Wayne Yu, Amanda Chao
- With: Claire Coles, Therese Grant, Christina Chambers

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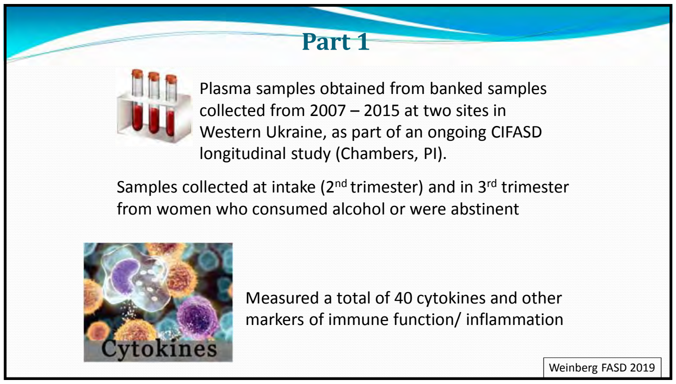

Part 1

Plasma samples obtained from banked samples collected from 2007 – 2015 at two sites in Western Ukraine, as part of an ongoing CIFASD longitudinal study (Chambers, PI).

Samples collected at intake (2nd trimester) and in 3rd trimester from women who consumed alcohol or were abstinent

Measured a total of 40 cytokines and other markers of immune function/ inflammation

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What are cytokines?

- "Immunomodulating agents" - agents that modulate or alter the immune system response
  - Released in response to immune challenge – infection, injury, etc
- "cyto" = cell and "kinos" = movement
- Cytokine are important for
  - Cell to cell communication of immune and other cells
  - Attracting cells/directing cells towards sites of inflammation, infection and trauma
  - Regulating growth and repair of blood vessels
  - Increasing blood flow to areas of injury/challenge

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Methods (cont'd)

- Further subdivision of results based on child outcome

Group	Maternal Ethanol Consumption	Child Outcome (Neuro Score)
(1)	Ethanol	Affected (FASD)
(2)	Ethanol	Unaffected (no FASD)
(3)	Control	Unaffected (normal neurobehavioral score)
(4)	Control	Affected (low neurobehavioral score)

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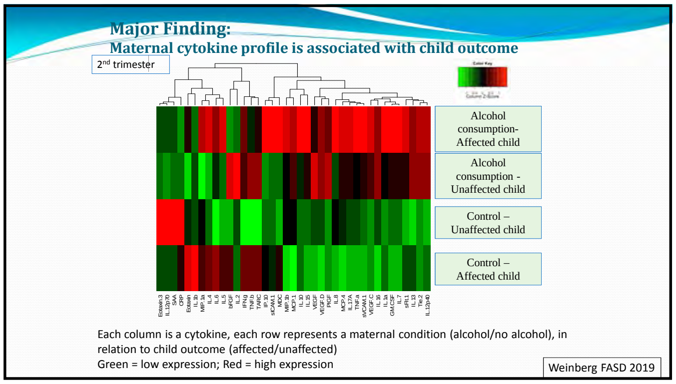

Major Finding:
Maternal cytokine profile is associated with child outcome

Each column is a cytokine, each row represents a maternal condition (alcohol/no alcohol), in relation to child outcome (affected/unaffected)
Green = low expression; Red = high expression

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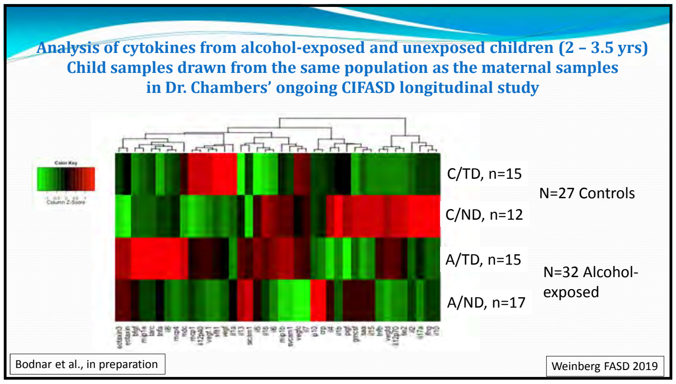

Analysis of cytokines from alcohol-exposed and unexposed children (2 – 3.5 yrs)
Child samples drawn from the same population as the maternal samples in Dr. Chambers' ongoing CIFASD longitudinal study

Bodnar et al., in preparation

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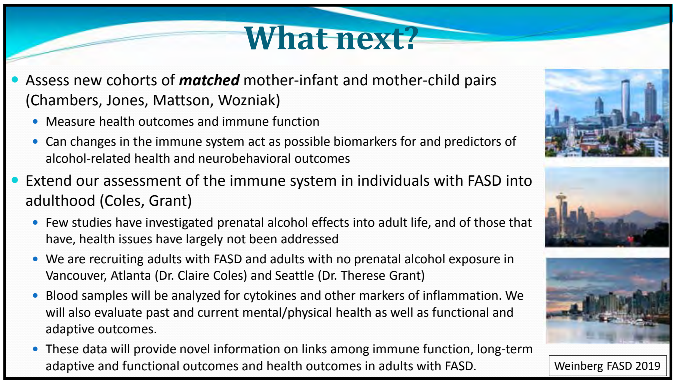

What next?

- Assess new cohorts of ***matched*** mother-infant and mother-child pairs (Chambers, Jones, Mattson, Wozniak)
  - Measure health outcomes and immune function
  - Can changes in the immune system act as possible biomarkers for and predictors of alcohol-related health and neurobehavioral outcomes
- Extend our assessment of the immune system in individuals with FASD into adulthood (Coles, Grant)
  - Few studies have investigated prenatal alcohol effects into adult life, and of those that have, health issues have largely not been addressed
  - We are recruiting adults with FASD and adults with no prenatal alcohol exposure in Vancouver, Atlanta (Dr. Claire Coles) and Seattle (Dr. Therese Grant)
  - Blood samples will be analyzed for cytokines and other markers of inflammation. We will also evaluate past and current mental/physical health as well as functional and adaptive outcomes.
  - These data will provide novel information on links among immune function, long-term adaptive and functional outcomes and health outcomes in adults with FASD.

Weinberg FASD 2019

Conclusions

- This is the first clinical study in the FASD field to identify the immune profile/phenotype of women drinking alcohol during pregnancy and linking their profiles to child outcome
- The maternal cytokine profile can provide information on:
  - Which children will be affected and which will be resilient
  - If neurobehavioral problems in children are related to alcohol exposure or to other factors
- This could potentially provide a biomarker – in this case, an **immune signature** - that might help us predict which children may be at risk for neurobehavioral problems, and what maternal factors may be protective
- Implications beyond health outcomes to functioning of the children in multiple domains (eg., attention, cognitive function, adaptive function)

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Acknowledgments

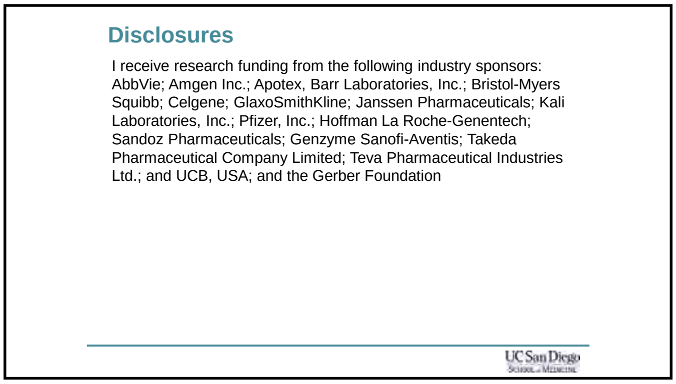
Plenary 1

The Role of Trajectories in Clinical Prediction of Future FASD Outcomes

Christina Chambers

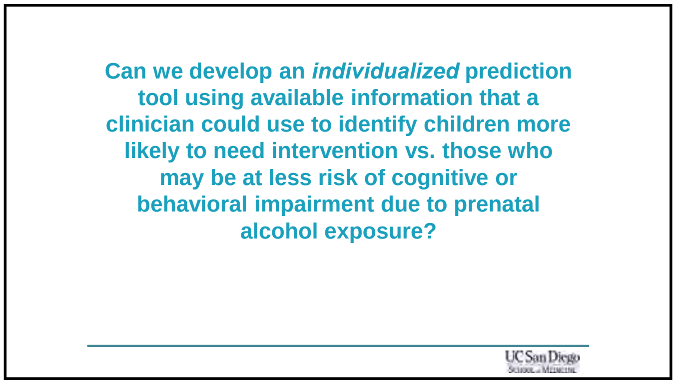
The Role of Trajectories in Clinical Prediction of Future FASD Outcomes

Christina Chambers, PhD, MPH
Alan Wells, MS
University of California San Diego and the CIFASD

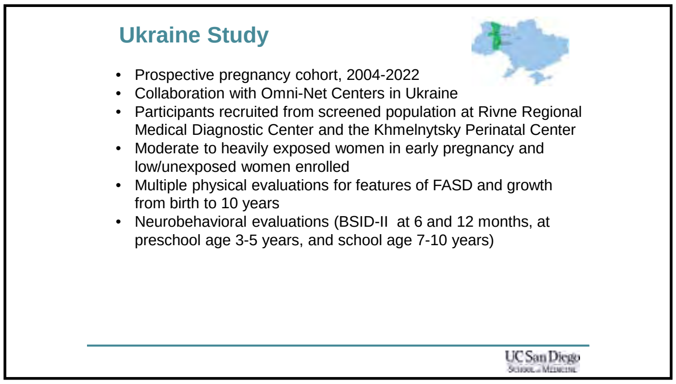


Disclosures

I receive research funding from the following industry sponsors: AbbVie; Amgen Inc.; Apotex, Barr Laboratories, Inc.; Bristol-Myers Squibb; Celgene; GlaxoSmithKline; Janssen Pharmaceuticals; Kali Laboratories, Inc.; Pfizer, Inc.; Hoffman La Roche-Genentech; Sandoz Pharmaceuticals; Genzyme Sanofi-Aventis; Takeda Pharmaceutical Company Limited; Teva Pharmaceutical Industries Ltd.; and UCB, USA; and the Gerber Foundation



Can we develop an *individualized* prediction tool using available information that a clinician could use to identify children more likely to need intervention vs. those who may be at less risk of cognitive or behavioral impairment due to prenatal alcohol exposure?



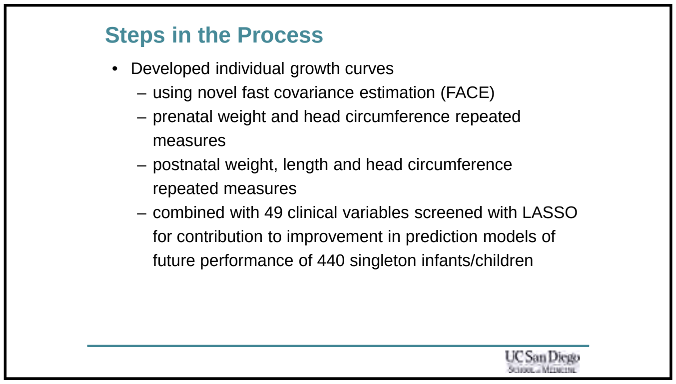
Ukraine Study

- Prospective pregnancy cohort, 2004-2022
- Collaboration with Omni-Net Centers in Ukraine
- Participants recruited from screened population at Rivne Regional Medical Diagnostic Center and the Khmelnytsky Perinatal Center
- Moderate to heavily exposed women in early pregnancy and low/unexposed women enrolled
- Multiple physical evaluations for features of FASD and growth from birth to 10 years
- Neurobehavioral evaluations (BSID-II at 6 and 12 months, at preschool age 3-5 years, and school age 7-10 years)

Included Vitamin/Mineral Supplement Intervention

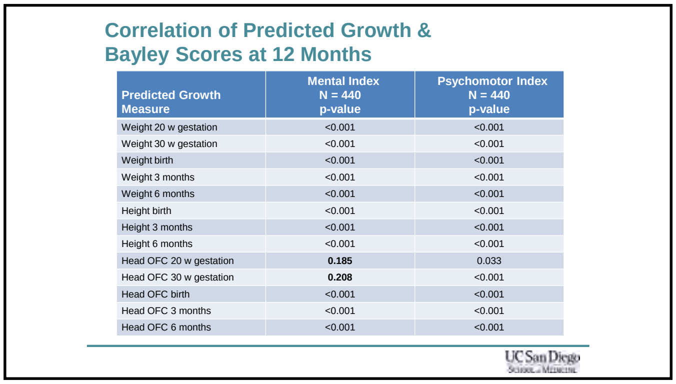
Additional 750 mg choline supplement for 25%

Multivitamin /mineral supplement provided for 50%



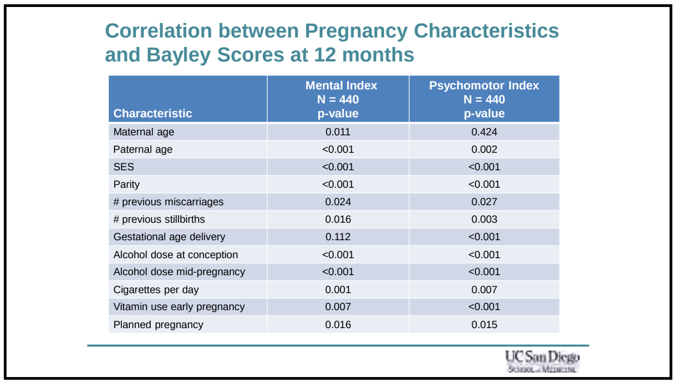
Steps in the Process

- Developed individual growth curves
  - using novel fast covariance estimation (FACE)
  - prenatal weight and head circumference repeated measures
  - postnatal weight, length and head circumference repeated measures
  - combined with 49 clinical variables screened with LASSO for contribution to improvement in prediction models of future performance of 440 singleton infants/children



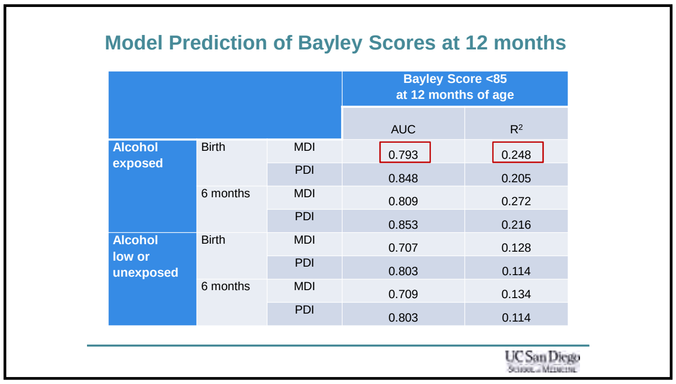
Correlation of Predicted Growth & Bayley Scores at 12 Months

Predicted Growth Measure	Mental Index N = 440 p-value	Psychomotor Index N = 440 p-value
Weight 20 w gestation	<0.001	<0.001
Weight 30 w gestation	<0.001	<0.001
Weight birth	<0.001	<0.001
Weight 3 months	<0.001	<0.001
Weight 6 months	<0.001	<0.001
Height birth	<0.001	<0.001
Height 3 months	<0.001	<0.001
Height 6 months	<0.001	<0.001
Head OFC 20 w gestation	**0.185**	0.033
Head OFC 30 w gestation	**0.208**	<0.001
Head OFC birth	<0.001	<0.001
Head OFC 3 months	<0.001	<0.001
Head OFC 6 months	<0.001	<0.001



Correlation between Pregnancy Characteristics and Bayley Scores at 12 months

Characteristic	Mental Index N = 440 p-value	Psychomotor Index N = 440 p-value
Maternal age	0.011	0.424
Paternal age	<0.001	0.002
SES	<0.001	<0.001
Parity	<0.001	<0.001
# previous miscarriages	0.024	0.027
# previous stillbirths	0.016	0.003
Gestational age delivery	0.112	<0.001
Alcohol dose at conception	<0.001	<0.001
Alcohol dose mid-pregnancy	<0.001	<0.001
Cigarettes per day	0.001	0.007
Vitamin use early pregnancy	0.007	<0.001
Planned pregnancy	0.016	0.015



Model Prediction of Bayley Scores at 12 months

			Bayley Score <85 at 12 months of age	
			AUC	R^2
Alcohol exposed	Birth	MDI	0.793	0.248
		PDI	0.848	0.205
	6 months	MDI	0.809	0.272
		PDI	0.853	0.216
Alcohol low or unexposed	Birth	MDI	0.707	0.128
		PDI	0.803	0.114
	6 months	MDI	0.709	0.134
		PDI	0.803	0.114

Next Steps in the Process

- Expanded the individualized trajectories to include growth, clinical data (with or without previous Bayley results) available up to five years of age for 305 children
- Examined how well the trajectories predicted
  - preschool age neurobehavioral testing results on DAS II and CBCL
  - classification of the child as FASD using Hoyme et al updated clinical classification criteria (2016)

Preschool Outcomes

- 60 of 305 (20%) of children in the preschool sample met criteria for FASD
  - 16.1% met criteria for any cognitive deficit
  - 44.6% met criteria for any behavioral deficit

Prediction of FASD Classification in Alcohol Exposed Children

	AUC N = 92	R^2
Model with growth trajectory only	0.561	0.079
Model with clinical covariates and growth trajectory	0.813	0.300
Model with clinical covariates, growth trajectory and previous Bayley scores	0.824	0.295

Prediction of Deficits in Preschool Outcomes in Full Sample Using Trajectories with Clinical Covariates, Growth Trajectory, and Previous Bayley

	AUC N = 304	R^2
DAS II Non Verbal Reasoning	0.720	0.107
DAS II Spatial Reasoning	0.910	0.144
CBCL Anxiety/Depression	0.713	0.113
CBCL ADHD	0.751	0.126
Any Cognitive Deficit	0.698	0.085
Any Behavioral Deficit	0.727	0.142

Does it Matter if the Child Exhibits Catch-up Growth?

Fetal Alcohol Growth Restriction and Cognitive Impairment

R. Colin Carter, MD, MMSc,[a] Joseph L. Jacobson, PhD,[b,c,d] Christopher D. Molteno, MD,[b] Neil C. Dodge, PhD,[d] Ernesta M. Meintjes, PhD,[c] Sandra W. Jacobson, PhD[b,c,d]

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Fetal alcohol-related growth restriction from birth through young adulthood and moderating effects of maternal prepregnancy weight

R. Colin Carter, MD, MMSc[1], Joseph L. Jacobson, PhD[2,3], Robert J. Sokol, MD[4], Malcolm J. Avison, PhD[6], and Sandra W. Jacobson, PhD[2,3]

Small at Birth and Catch-up Growth vs. No Catch-up at 1 year

	Exposed N = 168	Low or Unexposed N = 217
At Birth % predicted <10th Centile		
Weight	8.9%	3.2%
Length	0.5%	0.4%
OFC	10.9%	4.4%
% Small at Birth with Catch-up at 1 Year	N = 37	
Weight	52.0%	
Length	0%	
OFC	31.2%	

Catch-up Growth and Performance on Bayley at 1 Year

	Catchup Mean Bayley Score	No Catchup Mean Bayley Score	p-value T-test
Head Circumference	N = 13	N = 12	
MDI	87.39	73.75	0.018
PDI	93.00	74.08	0.002
Weight	N = 22	N = 10	
MDI	87.32	74.30	0.091
PDI	91.86	74.80	0.008

Risk and Resilience Profiles for FASD

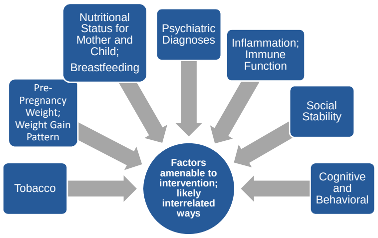
Findings suggest individual prediction models may be feasible to use in clinical practice to assign risk scores for children prenatally exposed to alcohol who are at high risk of delay vs. less likely to be impaired as they grow

Risk and Resilience Profiles for FASD

- Adding biomarkers to the algorithm as they become available in this ongoing study
  - o Cardiac orienting response; fNIRs
  - o Prenatal and early infancy miRNA profile
  - o Prenatal and early infancy markers of inflammation

- Long term goals:
  - o Identify and implement as early as possible intervention strategies for children at most risk of future delay
  - o Determine factors that seem to protect against future delays to inform future interventions

Intervention Targets



Nutritional Status for Mother and Child; Breastfeeding

Psychiatric Diagnoses

Inflammation; Immune Function

Pre-Pregnancy Weight; Weight Gain Pattern

Social Stability

Tobacco

Factors amenable to intervention; likely interrelated ways

Cognitive and Behavioral

Plenary 1

Development and Implementation of a Mobile Screening Tool for Identification of Children Affected by PAE

Sarah Mattson

Authors: Mattson, S.N., Doyle, L.R., Chockalingam, G. and Jones, K.L.

Learning Objectives:

1. Describe a newly-developed mobile application for improved identification of youth with FASD which being tested in clinical settings
2. Examine the data collected using this tool and identify strengths and weaknesses of the tool.

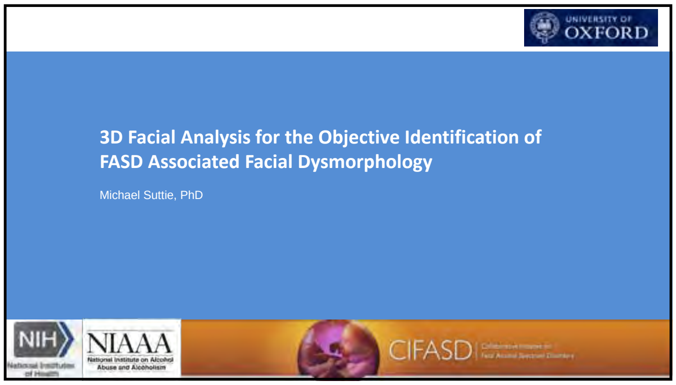
Abstract

The prevalence of fetal alcohol spectrum disorders (FASD) in the US has been recently estimated to be 31.1 to 98.5 per 1,000 (May et al., 2018) supporting and emphasizing the significant social and community impact of this disorder. However, although epidemiological studies support this rate, the same study and other recent studies (e.g., Chasnoff et al., 2015) suggest that nearly all affected children are not accurately identified. In the May et al., study, only 2 of the 222 affected children had been previously identified and in the Chasnoff et al. study only 20% of foster and adopted youth with an FASD had been previously identified. Given these high rates of missed diagnosis, there is a need for improved tools that can be used for identification of FASD. We developed a decision tree tool that can be used in both research and clinical settings to identify children affected by prenatal alcohol exposure (Goh et al., 2016). Recently, we have developed a mobile application that allows the decision tree to be deployed in real time in clinical settings. This eTree is currently being tested in a FASD specialty clinic and over 100 children have been evaluated. Of the youth with confirmed or suspected prenatal alcohol exposure, 65% are identified as affected based on the decision tree while only 11% of youth without histories of prenatal alcohol exposure are mis-classified as affected. Data collection will continue and additional analyses are planned. For example, we will compare results based on referral source (hospital-based clinic vs. university research project. We are also in the process of developing algorithms using machine learning and neural networks. Current results support the use of the eTree in accurately identifying youth who are affected by prenatal alcohol exposure. Research supported by NIAAA Grant U01 AA014834.

Plenary 1

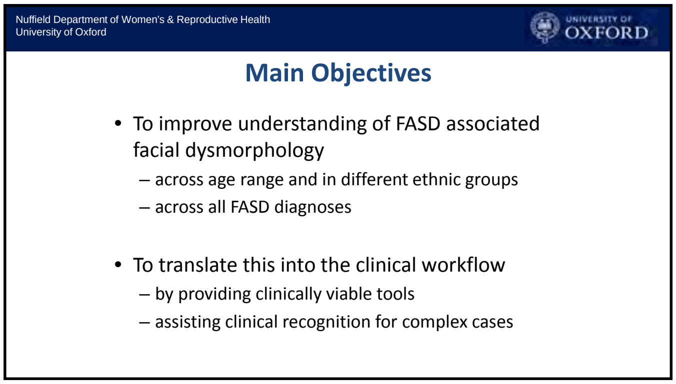
3D Facial Analysis for the Objective Identification of FASD Associated Facial Dysmorphology

Michael Suttie



3D Facial Analysis for the Objective Identification of FASD Associated Facial Dysmorphology

Michael Suttie, PhD



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Main Objectives

- To improve understanding of FASD associated facial dysmorphology
  - across age range and in different ethnic groups
  - across all FASD diagnoses
- To translate this into the clinical workflow
  - by providing clinically viable tools
  - assisting clinical recognition for complex cases

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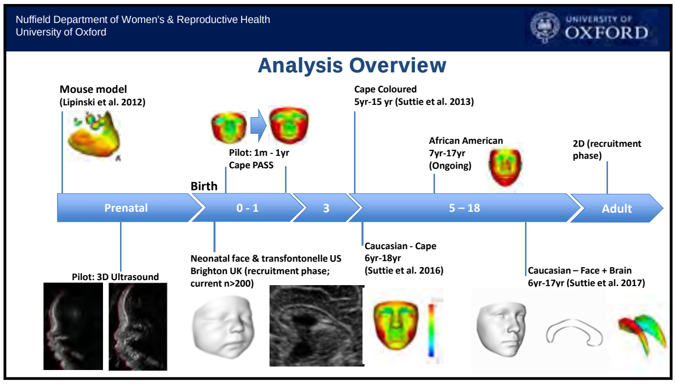
Static 3D Facial Photogrammetry



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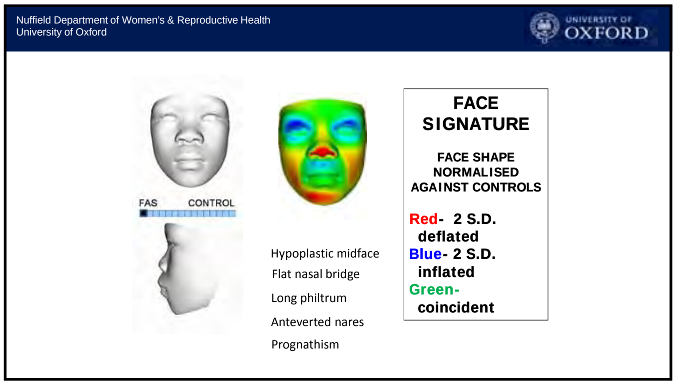
Analysis Overview



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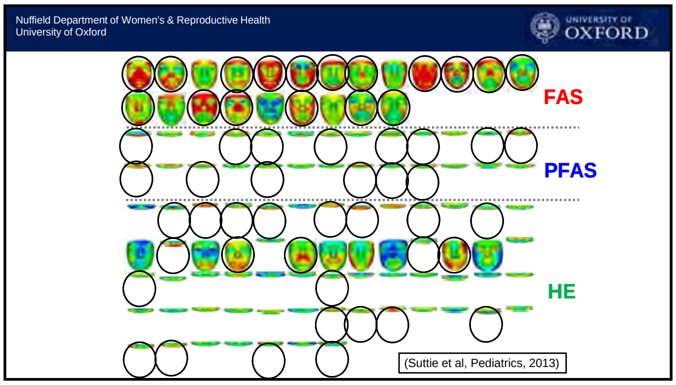
Hypoplastic midface
Flat nasal bridge
Long philtrum
Anteverted nares
Prognathism

FACE SIGNATURE

FACE SHAPE NORMALISED AGAINST CONTROLS

Red- 2 S.D. deflated
Blue- 2 S.D. inflated
Green- coincident



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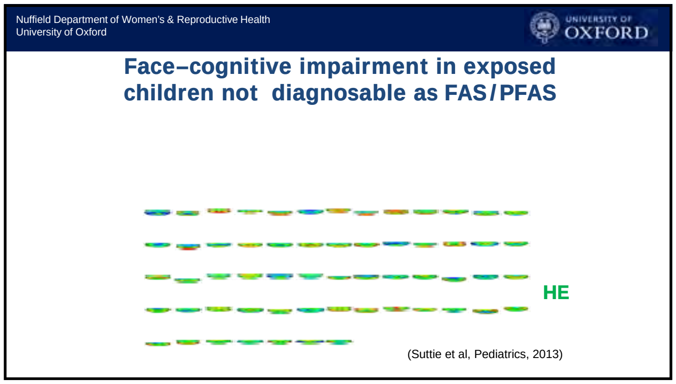
(Suttie et al, Pediatrics, 2013)



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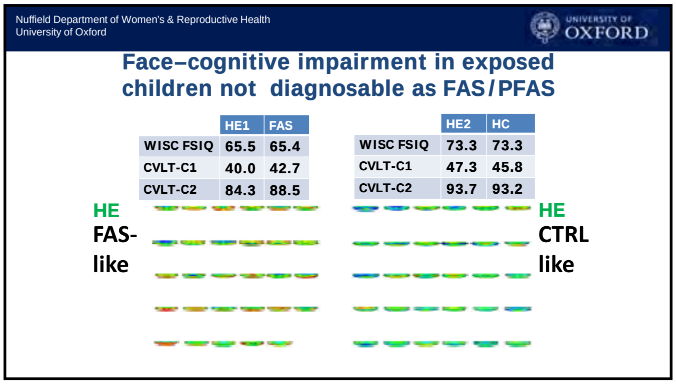
Face–cognitive impairment in exposed children not diagnosable as FAS/PFAS

(Suttie et al, Pediatrics, 2013)



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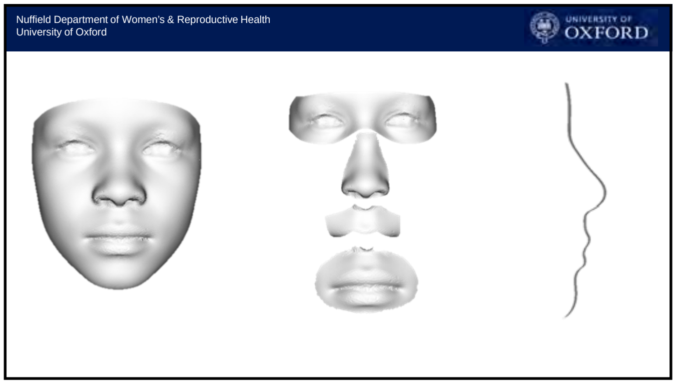
Face–cognitive impairment in exposed children not diagnosable as FAS/PFAS

	HE1	FAS
WISC FSIQ	65.5	65.4
CVLT-C1	40.0	42.7
CVLT-C2	84.3	88.5

	HE2	HC
WISC FSIQ	73.3	73.3
CVLT-C1	47.3	45.8
CVLT-C2	93.7	93.2



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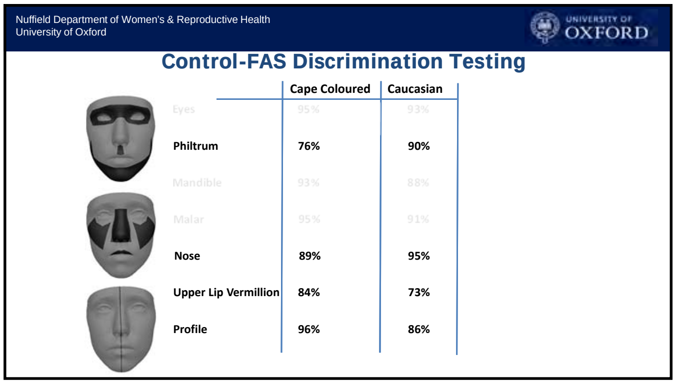

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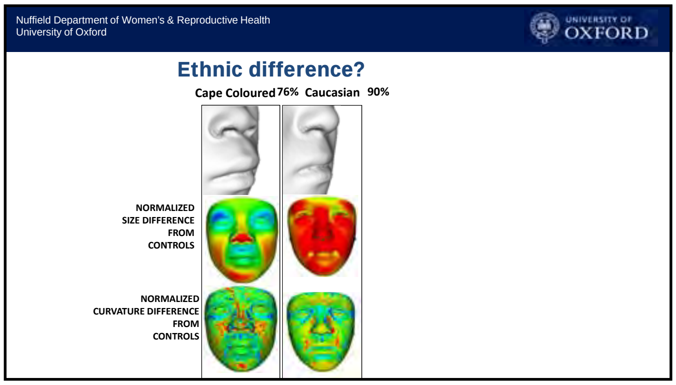
Control-FAS Discrimination Testing

	Cape Coloured	Caucasian
Eyes	95%	93%
Philtrum	76%	90%
Mandible	93%	88%
Malar	95%	91%
Nose	89%	95%
Upper Lip Vermillion	84%	73%
Profile	96%	86%



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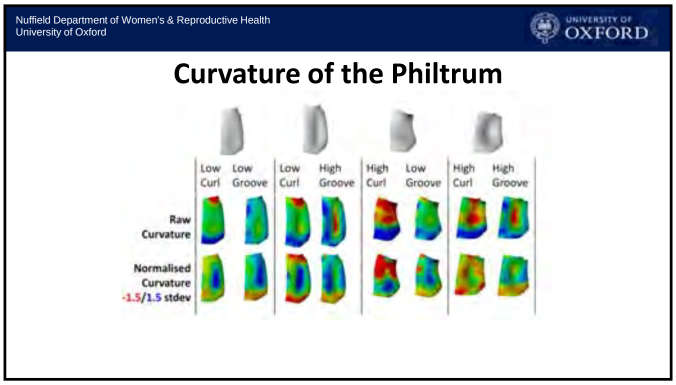
Ethnic difference?



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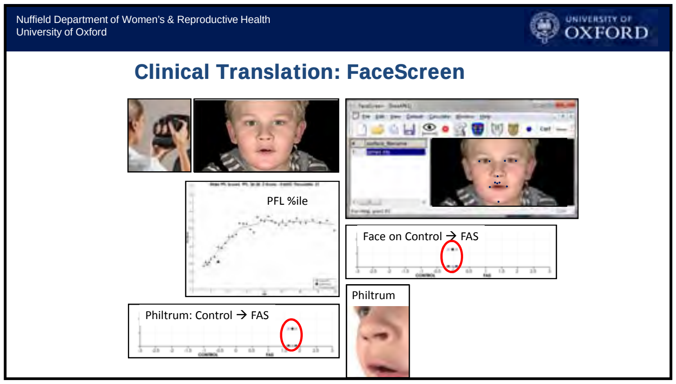
Curvature of the Philtrum



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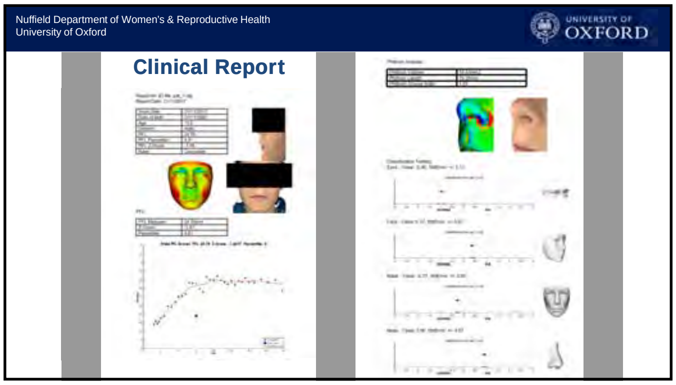
Clinical Translation: FaceScreen



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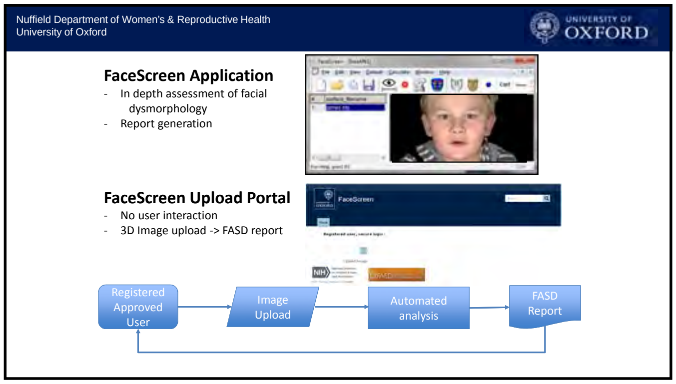
Clinical Report



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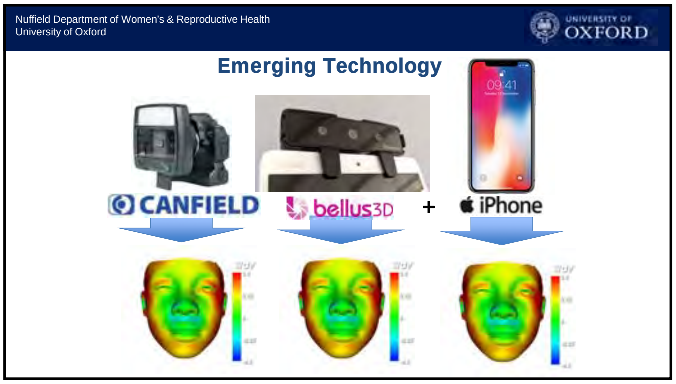
FaceScreen Application

- In depth assessment of facial dysmorphology
- Report generation

FaceScreen Upload Portal

- No user interaction
- 3D Image upload -> FASD report



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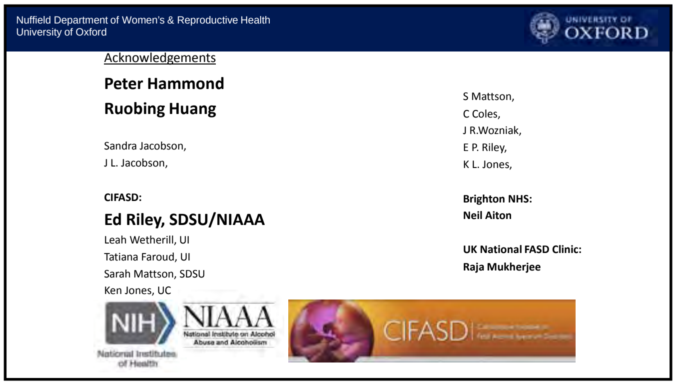
Emerging Technology



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K L. Jones,

Brighton NHS:
Neil Aiton

UK National FASD Clinic:
Raja Mukherjee

Plenary 1

Families Moving Forward – Connect: Developing a Mobile Health Intervention for Families Raising Children with FASD

Christie Petrenko, Cristiano Tapparello

Learning Objectives:

1. State how a mobile health intervention could reduce barriers and increase access to FASD-informed care.
2. Describe key features of the FMF Connect app.
3. Evaluate the presentation of the FMF Connect prototype and consider their opinions of the development process and app features.

Background/ Rationale

Fetal alcohol spectrum disorders (FASD) affect approximately 2-5% of the US population [1]. Unfortunately, the vast majority of families cannot access FASD-informed interventions. Barriers to care occur because a knowledgeable and skilled workforce is lacking [2,3], and there are family-level barriers such as limited financial resources, inability to access childcare, and stigma [4]. Access to appropriate FASD-informed care is even more limited in less densely populated areas. Many families try peer-to-peer and self-help strategies, but it can be difficult to evaluate the credibility and effectiveness of information provided through these modalities. Innovative intervention delivery is needed to broaden the reach of FASD-informed care and improve the quality of life for children with FASD and their families.

The primary objective of this project is to develop and evaluate the efficacy of a mobile health (mHealth) application (“app”) to directly provide caregivers with evidence-based content and peer-moderated support they can easily access and use to improve outcomes for their children and families. The app, called FMF Connect, is derived from the scientifically-validated Families Moving Forward (FMF) Program, developed at Seattle Children’s Research Institute/ University of Washington. The FMF Program has shown promising results for child and caregiver outcomes in prior trials with families raising children with FASD. [5]-[7].

Methods

This project follows a systematic approach to the development and evaluation of the FMF Connect mHealth intervention. First, FMF content, principles, and methods were adapted for the mHealth format, with the addition of unique content and features. Literature review and expert consultation in the fields of instructional design, ethics and technology, and behavior change principles informed this process. The app utilizes a cloud-based infrastructure to transparently but securely distribute information and was built on our existing open source framework for the development of medical apps [8], and those of others [9]. During the initial development process, focus group methods were used to solicit perspectives from diverse families on aspects such as interface design, ease of use, relevance of components and content, and barriers and facilitators of use. A total of 25 caregivers participated in 7 focus groups across 5 U.S. cities from December 2017 – June 2018. Data were analyzed thematically. Next steps will involve initial beta-testing of the prototype demonstrated during the presentation with a small group of users, followed by larger feasibility and randomized-controlled trials.

The content, principles, and methods of the therapist-led FMF Program were more readily translated into the FMF Connect app than predicted. Although much of the content is preserved, the flow of content delivery differs somewhat in FMF Connect to be more amenable to self-direction by caregivers. FMF Connect has been implemented leveraging the functionalities offered by modern smartphones and considering the different ways in which users interact with them. As an example, using FMF Connect caregivers will be able to access content through easily digestible learning modules that can be viewed in various formats (text, audio, video), and will be able to customize the app according to their preference and needs. In addition, the app integrates open source frameworks and state of the art methodologies for mobile app development to ensure data privacy and security.

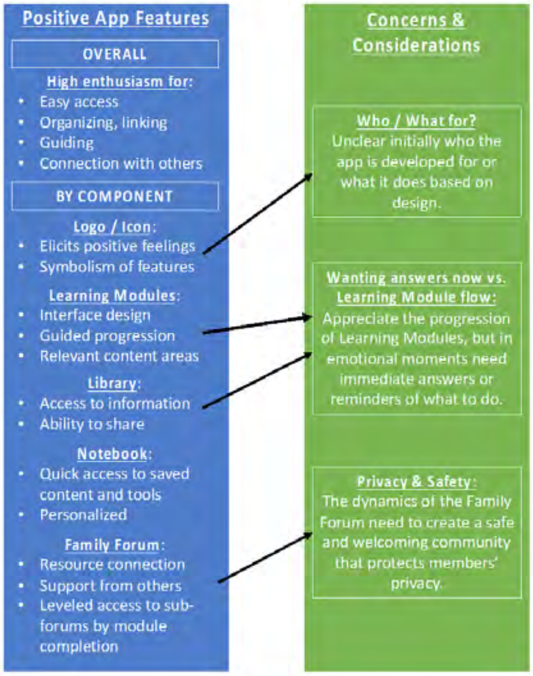
FMF-Connect Design and Components

Figure 1 illustrates the components of FMF Connect and the interface design of the Learning Modules home screen.

Evaluation of App Interface Design and Components

Figures 2 and 3 summarize the findings that garnered the most enthusiasm and discussion during focus groups. These are the themes that were most important to participants. The left-hand column in Figure 2 (blue) illustrates the features of the FMF Connect app that were viewed most favorably. Participants emphasized the interconnections between app components and the ease of access to important content and support from other parents. The right-hand column of Figure 2 (green) summarizes three main concerns or considerations raised by participants. Participants grappled with these topics in group discussion. Opinions were mixed or evolved over the course of the discussion. A number of suggestions were offered about how to respond to these considerations.

Figure 2



Positive App Features

OVERALL

High enthusiasm for:
- Easy access
- Organizing, linking
- Guiding
- Connection with others

BY COMPONENT

Logo / Icon:
- Elicits positive feelings
- Symbolism of features

Learning Modules:
- Interface design
- Guided progression
- Relevant content areas

Library:
- Access to information
- Ability to share

Notebook:
- Quick access to saved content and tools
- Personalized

Family Forum:
- Resource connection
- Support from others
- Leveled access to sub-forums by module completion

Concerns & Considerations

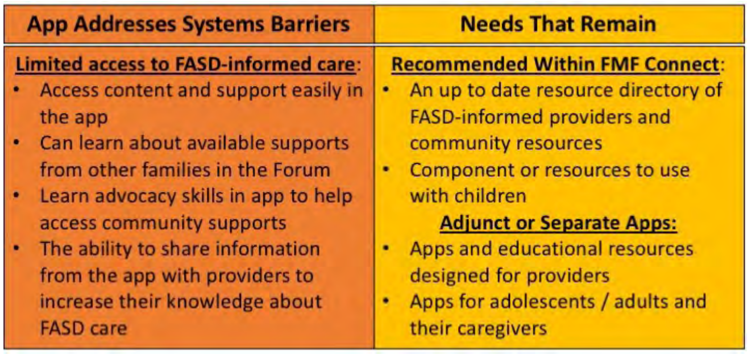
Who / What for?
Unclear initially who the app is developed for or what it does based on design.

Wanting answers now vs. Learning Module flow:
Appreciate the progression of Learning Modules, but in emotional moments need immediate answers or reminders of what to do.

Privacy & Safety:
The dynamics of the Family Forum need to create a safe and welcoming community that protects members' privacy.

Consistent with our prior work [2], participants spoke with strong emotion about the systems barriers they face in obtaining supports and services for their children. The left side of Figure 3 summarizes how participants perceived ways the FMF Connect app could help families address some of these systems barriers. The right side includes areas where participants want additional focus, either within or adjunct to the app. The desire to share information with providers, family members, and the individual with FASD was frequently raised. The goal was often stated as helping them understand the experience of the person with FASD in order to better support them.

Figure 3



App Addresses Systems Barriers	Needs That Remain
Limited access to FASD-informed care: • Access content and support easily in the app • Can learn about available supports from other families in the Forum • Learn advocacy skills in app to help access community supports • The ability to share information from the app with providers to increase their knowledge about FASD care	**Recommended Within FMF Connect:** • An up to date resource directory of FASD-informed providers and community resources • Component or resources to use with children **Adjunct or Separate Apps:** • Apps and educational resources designed for providers • Apps for adolescents / adults and their caregivers

Conclusion

FMF Connect is a promising, novel intervention with potential to reach many families in need and reduce significant barriers to care, resulting in broader public health impact. After initial beta-testing, a small-scale feasibility trial and larger randomized controlled trial are planned to investigate how families utilize the app and its efficacy in improving child and family outcomes.

References

P. A. May, J. P. Gossage, W. O. Kalberg, L. K. Robinson, D. Buckley, M. Manning and H. E. Hoyme, "Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies," Developmental Disabilities Research Reviews, vol. 15, pp. 176-192, 2009.

C. L. M. Petrenko, N. Tahir, E. C. Mahoney and N. P. Chin, "Prevention of secondary conditions in fetal alcohol spectrum disorders: Identification of systems-level barriers," Maternal and Child Health Journal, vol. 18, pp. 1496-505, 2014.

D. M. Ryan, D. M. Bonnett and C. B. Gass, "Sobering thoughts: town hall meetings on fetal alcohol spectrum disorders," American Journal of Public Health, vol. 96, pp. 2098-2101, 2006.

C. L. M. Petrenko, M. E. Alto, A. R. French and S. M. Freeze, "'I'm doing my part, I just need help from the community': Intervention implications of foster and adoptive parents' experiences raising children and young adults with FASD," Journal of Family Nursing, in press.

J. Bertrand, "Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects," Research in developmental disabilities, vol. 30, no. 5, pp. 986-1006, 2009.

H. C. Olson and J. Sparrow, "Using Positive Behavior Support Techniques with Families: Fetal Alcohol Spectrum Disorders Intervention," in The Expanding World of PBS: Science, Values & Vision. 13th International Conference on PBS, San Francisco, CA.

C. L. M. Petrenko, M. E. Pandolfino and R. L. K, "Findings from the Families on Track preventive intervention pilot trial with children with FASD and their families," Alcoholism: Clinical and Experimental Research, vol. 41, pp. 1340-1351, 2017.

C. Tapparello, W. Heinzelman, K. Conn and C. A. Mullen, "ManageMyCondition: A Standard Framework for the Development of Cloud-based Medical Condition Management Applications," in IEEE International Workshop on Cloud Connected Health (CCH), Washington D.C., 2016

Apple, "ResearchKit," 03 2015. [Online]. Available: http://researchkit.org.

Plenary 2 Global Action on FASD Prevention Research, Policy and Practice

Description
Since the EUFASD conference in London (2016) Sylvia Roozen (Netherlands), James Fitzpatrick (Australia), Nancy Poole (Canada) and Leana Olivier (South Africa) have been working together to coordinate an International FASD Prevention Interest Group designed to: promote knowledge exchange on FASD prevention at international conferences and through joint publications; plan for a multi-country FASD prevention study; and link global action on FASD prevention overall. This plenary will highlight research, practice and policy developments in FASD prevention from around the world, and offer the opportunity for participants to discuss and provide information on how their interests and activities fit within a global context.

Learning Objectives:

1. Provide an overview of global developments in FASD prevention activities and research
2. Share evidence from selected FASD prevention research projects, representing activities at all levels of FASD prevention
3. Describe plans and current developments for an International FASD Prevention Interest Group
4. Gather information on FASD prevention activities being undertaken by plenary participants, through table discussions and handouts
5. Facilitate discussion of opportunities for involvement in international activities on FASD prevention

FASD PREVENTION INTERNATIONALLY | Overview of advances and plans

- S. Roozen, PhD, Maastricht University, the Netherlands

A wide variety of international FASD prevention and management activities have been carried out such as large-scale national campaigns, research networks, mobilizing advocacy, and strengthening maternal and child health through brief interventions, motivational interviewing, screening and improvement of management and care. The complexity of intervention development is sometimes overlooked in health promotion. This is for sure the case concerning FASD. Evidence-based health promotion intervention aimed at the field of FASD is a complex process. The complexity lies within an in-depth description of interventions and their development. To main objective of this presentation is to provide an overview on how far we have come on FASD prevention. Examples from various international programs and methods will be presented.

LEVEL 1 – Overview of approaches to increasing awareness, health promotion, & implementation of supportive alcohol policy

- N. Poole, PhD, Centre of Excellence for Women's Health, Canada

Level 1 prevention efforts often focus on broad awareness building. In the prevention intervention literature, studies evaluate a variety of print, TV, web and social media campaigns and materials that promote alcohol and pregnancy awareness and reduce stigma towards substance using women, including those reaching sub groups such as adolescents, college students, higher income women and men as partners. Alcohol policy initiatives have also been studied, such as the use of alcohol warning labels and community and state alcohol policies and strategies. This presentation will provide a brief overview of the Level 1 prevention approaches being utilized around the world, and what has been learned to date that can guide the work going forward.

LEVEL 1 – Changes in awareness and alcohol use in pregnancy from Make FASD History project, Australia

- M. Symons, PhD, Kids Telethon Kids Institute, Australia

Community-led FASD prevention activities have been underway in the predominantly Aboriginal Kimberley region of remote North-Western Australia since 2010 as part of the Marulu FASD strategy. This presentation will provide a brief overview of these activities and the outcome measures now available. Self-reported alcohol consumption was collected from pregnant women by midwives from 2008 until 2015 with the addition of the AUDIT-C in 2016. A total of 400 surveys of knowledge, attitudes and practices around alcohol consumption and FASD were conducted in the general population before and after a prevention mass media campaign in 2014. There has been a reduction in self-reported drinking during pregnancy over the prevention period, general knowledge about the dangers of alcohol consumption is now high and appropriate practices encouraging. This has led to a wider roll-out of these approaches.

LEVEL 2 – Preconception prevention approaches – Project Choices model USA

- K. Ingersoll, PhD, University of Virginia, USA

This presentation will offer evidence from selected US-based AEP prevention research projects based on the seminal CHOICES study. The Choices study found brief intervention to be efficacious with women in the preconception period, through supporting change on both alcohol and use of contraception. Adaptations including those with College women, Native American women, Briefer, Telephone, and Internet modes have now been studied. What works in these dual focused preconception interventions designed to prevent FASD, as to what number of sessions are most helpful, for whom, in what settings will be addressed.

LEVEL 2 – Approach to Increasing capacity by midwives for brief alcohol interventions – Scotland

- L. Scholin, PhD, School of Health in Social Science, University of Edinburgh

Screening and brief interventions (SBIs) are promoted in international guidelines from WHO as key to identifying pregnant women who drink alcohol and who may require different levels of support to reduce risk. However, few countries have universally implemented SBIs at a national level and there is limited evidence for how to best address alcohol in the antenatal setting. Scotland established a national SBI programme in 2008 in primary care, accident and emergency care and antenatal care. This presentation will provide an overview of the programme and draw upon findings from a qualitative study of implementation leaders' reflections on approaches taken locally about how and when to screen pregnant women, when to provide an intervention, and challenges to implementing the national programme in the antenatal setting.

Level 3 and 4 – Healthy Mothers Healthy Babies model in South Africa

- L. Olivier PhD, Foundation for Alcohol Research, South Africa

Results and findings from FASD prevalence and other studies in South Africa has led to the development of this brief motivational interviewing and support program which is offered to all pregnant women (whether they are using substances of abuse or not) in high-risk areas. At present the program is being implemented on 11 project sites. The program is offered by trained workers living in the communities and in partnership with the Department of Health. Babies born to participating clients receive pediatric, FASD and neurodevelopmental assessment at 9 months of age. Infants and their mothers can then join Early Childhood Development (ECD) support groups.

All Level - Prevention linked to diagnosis, support and research in Australian communities – building on the Marulu strategy

- J. Fitzpatrick FRACP PhD Kids Telethon Institute, Australia

Communities with documented high rates of FASD in Australia have themselves led multi-faceted approaches to FASD Prevention, Diagnosis and Therapy. Implementing these strategies with fidelity, within a research framework, and establishing models of community ownership and funding sustainability, is challenging. Promising examples of such strategies will be presented based on ten years of translational research and service delivery in remote Australian communities. Importantly, the key role of partnership models and sustainable funding strategies will be discussed.

Systematic FASD prevention programs – and introducing the table discussion

- S. Roozen, PhD, Maastricht University, the Netherlands

There is a need to use systematic approaches for adapting evidence based behavioural interventions for FASD prevention. Lessons can be learned from a framework that has been applied in various other health promoting fields. Evidence-based insights and tools for systematic development of effective interventions related to alcohol consumption during pregnancy and FASD prevention will be provided. Thereafter we invite the audience for a broader engagement to discuss various aspects of prevention in four different groups.

The presentations will be followed by Table discussions and large group discussion

There will also be the opportunity to provide information on country specific FASD prevention initiatives through an online survey.

C1a

Prevalence of Urinary System Defects Among Patients with FASD

Katarzyna Kowalska

Author: Katarzyna Dylag

Learning Objectives

1. Realize the prevalence of genitourinary system defects among FASD individuals
2. Reflect ultrasound screening among FASD individuals.

Background

The teratogenic effet of alcohol on the developing fetus is well studied, however the stystem that is mostly affected is central nervous system. The effect ot alcohol on other systems including genitourinary system remains controversial. Data from the animal studies suggest an increased rate of genitourinary system defects among individuals with prenatal alcohol exposure. On the other hand, Taylor et al. in a human cross sectional study did not demonstrate an increased prevalence.

Methods

The study was conducted as a cross-sectional study. 100 patients of St. louis Children Hospital age 1 month-18 years-old, diagnosed with FASD were included in the study. All patients had an abdominal ultrasound done, serum creatinine level measured and blood pressure (twice) taken . The results were compared with control group.

Results

Results will be available in 2 months. Preliminary results on the group of 50 patients are presented below:
Congenital kidney defects were observed in 31% of the patients. Duplication of pelvicalyceal system , dilatation of the pyelocalyceal system , renal pyramids overgrowth, partially external renal pelvis. Two paients (2%) were diagnosed with congenital hydronephrosis, one (0.5%) had renal medullar cysts and one had a horseshoe kidney. Abnormal bladder (atonic bladder, decreased bladder volume, elongated-in-shape bladder, abnormal bladder perystalsis was observed) in 7% of the patients. Urethera defect (hypospadiasis) was observed in 1 patient.

Conclusion

Congenital genitourinary system defects are more prevalent among FASD patients, however the majority of the defects are not clinically significant.

C1b

Physical Health Impacts of FASD: Preliminary Results from a Caregiver Survey

Natasha Reid

Learning Objectives

1. Recognise the potential physical health impacts of FASD
2. Identify health conditions that children and young people with FASD may be at higher risk of experiencing

Objectives

To date there has been extensive clinical research documenting the impacts that prenatal alcohol exposure (PAE) can have on the developing brain. However, comparatively limited clinical research has investigated the influence that PAE can have on other health outcomes. Preclinical research has demonstrated that PAE can result in high blood pressure, renal dysfunction and early signs of diabetes and obesity. At the 7th International FASD conference it was suggested that rather than describing FASD as a brain-based disorder, it should be described as a “whole-body” disorder.” Outcomes from an informal survey conducted in a cohort of young adults with FASD suggested they experience a myriad of diseases including early onset arthritis, and hypertension. Consequently, the aim of the current research was to investigate potential health impacts for children and young people with FASD.

Methods

We conducted an online survey (https://child-health-research.centre.uq.edu.au/participate-fetal-alcohol-spectrum-disorder-research) of caregivers who have children or young people with a formal diagnosis of FASD. Caregivers were asked to report whether their child experienced and/or had been with diagnosed a range of health conditions.

Results

In the first 6-months we have had 68 surveys completed. Children/young people ranged from 5 – 21-years and 62% were male. Responses were obtained from Australia (45.6%); United States (22.1%); Canada (13.2%); United Kingdom (4.4%); New Zealand (8.8%) and South Africa (2.9%). Caregivers reported high rates of sleep problems (66.2%), bowel/digestive problems (35.3%), allergies (32.4%) and joint pain (32.4%). In addition, children/adolescents with FASD had been diagnosed with heart problems (32.4%); high blood pressure (8.8%); skin problems (29.2%; e.g. eczema, dermatitis); asthma (32.4%); recurrent infections (20.6%); and hypothyroidism (4.4%).

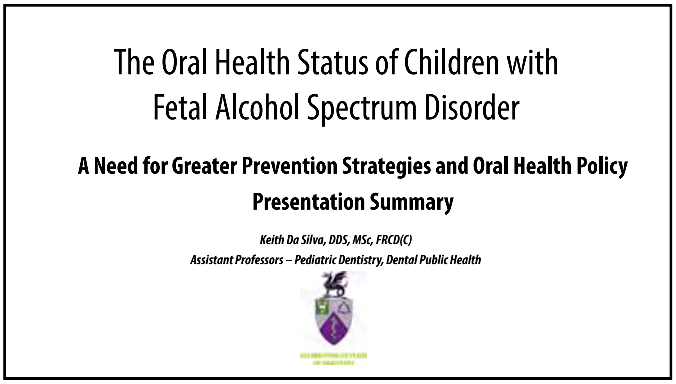
Conclusions

The preliminary results from the caregiver survey suggest that children and young people with FASD may be at higher risk of experiencing a range of health difficulties. Further research is needed, specifically direct assessments of health outcomes for children and young people with FASD compared to age and sex matched typically developing children and young people

C1c

The Oral Health Status of Children with FASD

Keith Da Silva

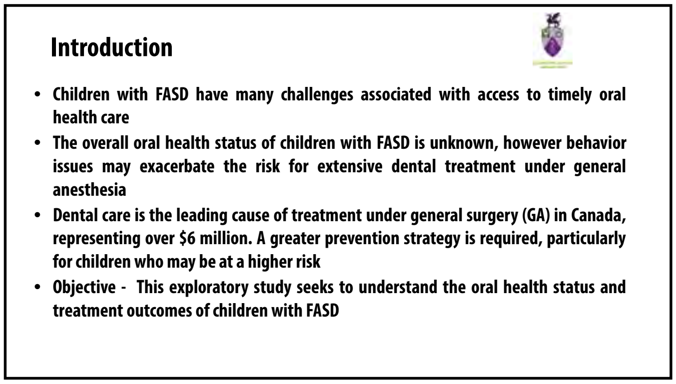


The Oral Health Status of Children with Fetal Alcohol Spectrum Disorder

A Need for Greater Prevention Strategies and Oral Health Policy

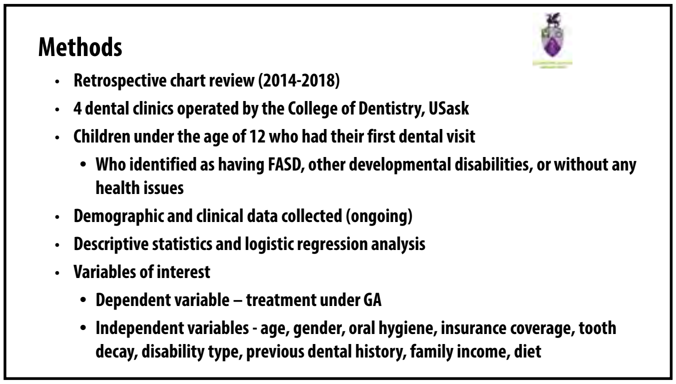
Presentation Summary

Keith Da Silva, DDS, MSc, FRCD(C)
Assistant Professors – Pediatric Dentistry, Dental Public Health



Introduction

- Children with FASD have many challenges associated with access to timely oral health care
- The overall oral health status of children with FASD is unknown, however behavior issues may exacerbate the risk for extensive dental treatment under general anesthesia
- Dental care is the leading cause of treatment under general surgery (GA) in Canada, representing over $6 million. A greater prevention strategy is required, particularly for children who may be at a higher risk
- Objective - This exploratory study seeks to understand the oral health status and treatment outcomes of children with FASD



Methods

- Retrospective chart review (2014-2018)
- 4 dental clinics operated by the College of Dentistry, USask
- Children under the age of 12 who had their first dental visit
  - Who identified as having FASD, other developmental disabilities, or without any health issues
- Demographic and clinical data collected (ongoing)
- Descriptive statistics and logistic regression analysis
- Variables of interest
  - Dependent variable – treatment under GA
  - Independent variables - age, gender, oral hygiene, insurance coverage, tooth decay, disability type, previous dental history, family income, diet

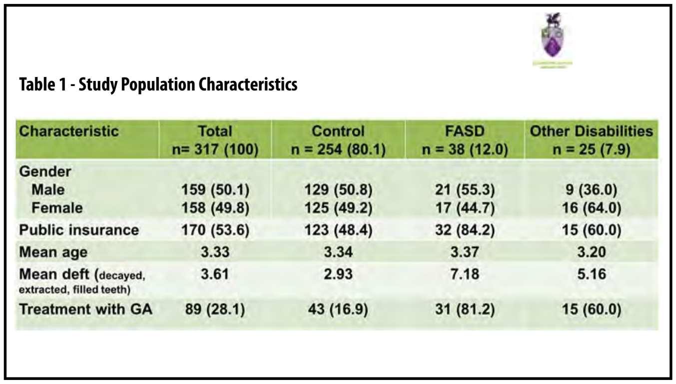


Table 1 - Study Population Characteristics

Characteristic	Total n= 317 (100)	Control n = 254 (80.1)	FASD n = 38 (12.0)	Other Disabilities n = 25 (7.9)
Gender				
Male	159 (50.1)	129 (50.8)	21 (55.3)	9 (36.0)
Female	158 (49.8)	125 (49.2)	17 (44.7)	16 (64.0)
Public insurance	170 (53.6)	123 (48.4)	32 (84.2)	15 (60.0)
Mean age	3.33	3.34	3.37	3.20
Mean deft (decayed, extracted, filled teeth)	3.61	2.93	7.18	5.16
Treatment with GA	89 (28.1)	43 (16.9)	31 (81.2)	15 (60.0)

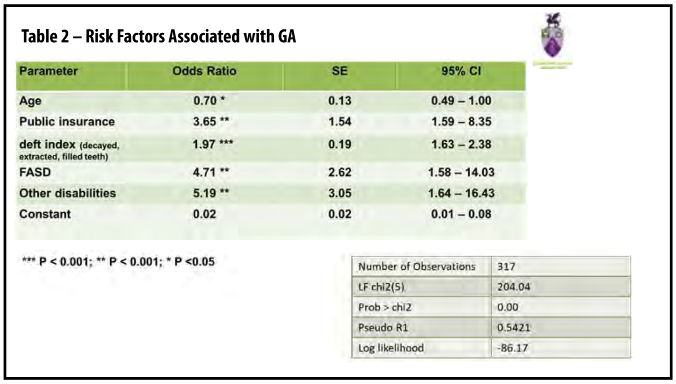
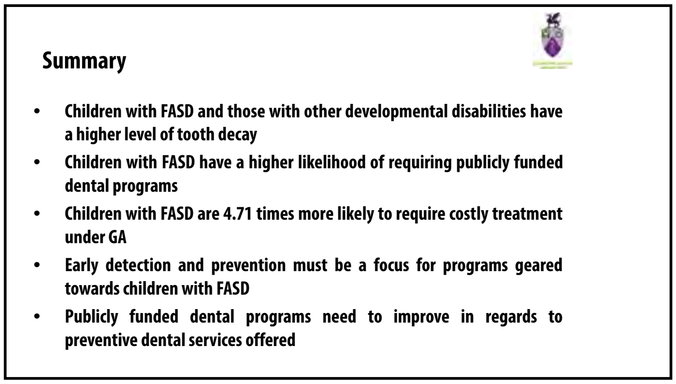


Table 2 – Risk Factors Associated with GA

Parameter	Odds Ratio	SE	95% CI
Age	0.70 *	0.13	0.49 – 1.00
Public insurance	3.65 **	1.54	1.59 – 8.35
deft index (decayed, extracted, filled teeth)	1.97 ***	0.19	1.63 – 2.38
FASD	4.71 **	2.62	1.58 – 14.03
Other disabilities	5.19 **	3.05	1.64 – 16.43
Constant	0.02	0.02	0.01 – 0.08

*** P < 0.001; ** P < 0.001; * P <0.05

Number of Observations	317
LF chi2(5)	204.04
Prob > chi2	0.00
Pseudo R1	0.5421
Log likelihood	-86.17



Summary

- Children with FASD and those with other developmental disabilities have a higher level of tooth decay
- Children with FASD have a higher likelihood of requiring publicly funded dental programs
- Children with FASD are 4.71 times more likely to require costly treatment under GA
- Early detection and prevention must be a focus for programs geared towards children with FASD
- Publicly funded dental programs need to improve in regards to preventive dental services offered

C1d Characteristics and Outcomes of Patients with FASD Presenting to the Emergency Department – A Retrospective Chart Review

Brittni Webster

Authors: Brittni Webster, Segun Oyedokun, Mansfield Mela, Kevin Durr, Tara Anderson

Learning Objectives

1. Appreciate that FASD is a challenging diagnosis to make and is largely under-recognized in our society. It is particularly challenging to recognize in the emergency department
2. Recognize that while FASD carries large psychological and social burdens, it also carries a large economic burden with one of the largest contributors being the cost associated with acute care medical services
3. Identify patterns of emergency department use by this unique patient population may allow for earlier recognition and diagnosis of the disorder, as well as for the provision of truly tailored patient centred care

Introduction

Given the challenges associated with making the diagnosis, fetal alcohol spectrum disorder (FASD) is largely known to be an under-recognized and under-diagnosed medical condition. As such, the true prevalence of the disorder is unknown, but the most current conservative estimate is that as many as 2-3% of all live births within Canada may be complicated by the disorder--and rates are likely to continue to rise. Previous research regarding FASD has demonstrated a large psychological, social, and economic burden associated with the disease. When examined closely, one of the largest contributors to the overall economic burden of the disease is the cost associated with high utilization rates of acute care medical services by this unique patient population, with an estimated cost upwards of $200 million per year. Curious to better understand the usage patterns of acute care medical services by patients living with FASD in Saskatchewan, a retrospective chart review was performed to help delineate the true nature of the problem, while simultaneously providing insight as to how Saskatchewan emergency departments can recognize possible cases of FASD and ultimately help those patients gain access to the care, services, and programs they need.

Methods

Participants with a diagnosis of FASD were identified via a database maintained by the Department of Psychiatry. A further search of all paper and electronic medical records within Saskatoon's three major hospitals identified additional participants with a documented ICD-10 code consistent with the diagnosis. Emergency department visits by all identified participants, over a 6 year span, were examined. The resultant data set was then analyzed descriptively.

Results

Forty-five participants, contributing to 740 unique ED visits, were identified and examined.. Twenty participants were female. Twenty-five were male. Age at time of presentation ranged from 3 to 56 years old. Chief complaints, as well as discharge diagnoses varied widely, but mental health and social problems were among those most frequently cited. Repeat ED visits within a 48 hour time frame were not uncommon. Two outliers presented with an increased frequency, having 180 and 117 ED visits respectively.

Conclusions

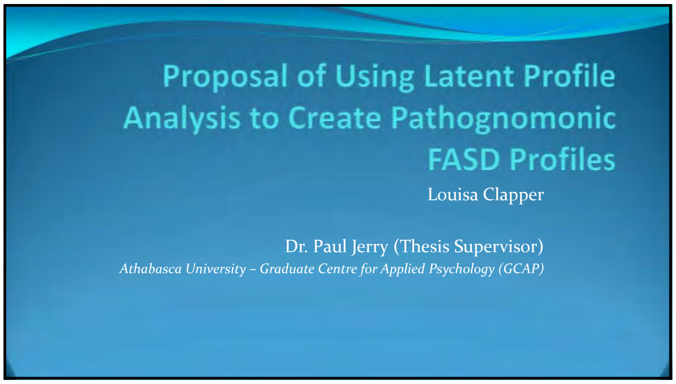
As expected only a small number of participants were identified for the purposes of this study, in keeping with the notion that FASD is grossly under-recognized and under-diagnosed in our communities. Unsurprisingly, however, several participants proved to make high utilization of our emergency departments, some visiting almost daily. The reason for the visits were often found to be have a large psychosocial component, and rarely were ancillary services such as social work or mental health outreach workers ever utilized by the emergency department team. Recurrent visits for psychosocial problems may be an indicator for emergency department clinicians to at least consider the diagnosis of FASD and to consider implicating care plans that include other non-medical services.

C2a

YOUNG INVESTIGATOR

Proposal of Using Latent Profile Analysis to Create Pathognomonic FASD Profiles

Louisa Clapper, Paul Jerry

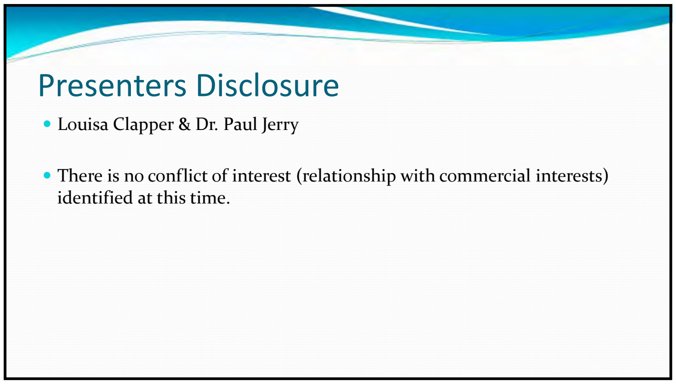


Proposal of Using Latent Profile Analysis to Create Pathognomonic FASD Profiles

Louisa Clapper

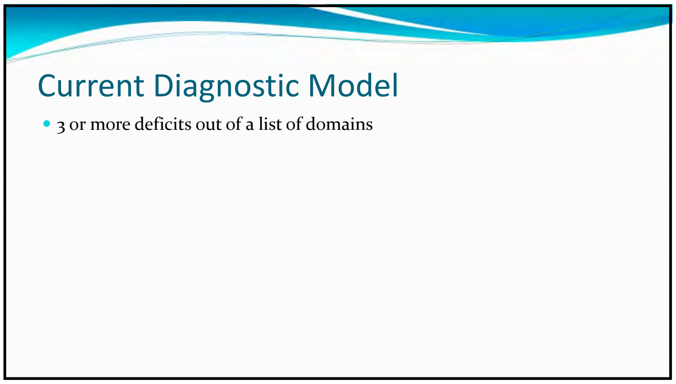
Dr. Paul Jerry (Thesis Supervisor)

Athabasca University – Graduate Centre for Applied Psychology (GCAP)



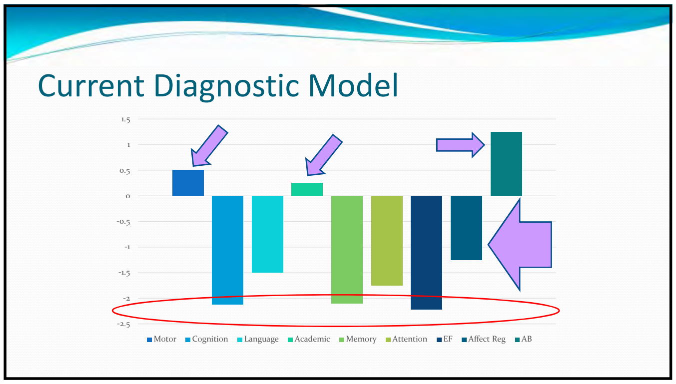
Presenters Disclosure

- Louisa Clapper & Dr. Paul Jerry
- There is no conflict of interest (relationship with commercial interests) identified at this time.

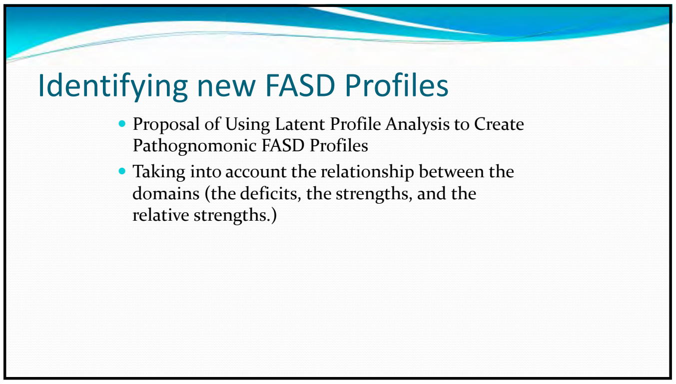


Current Diagnostic Model

- 3 or more deficits out of a list of domains

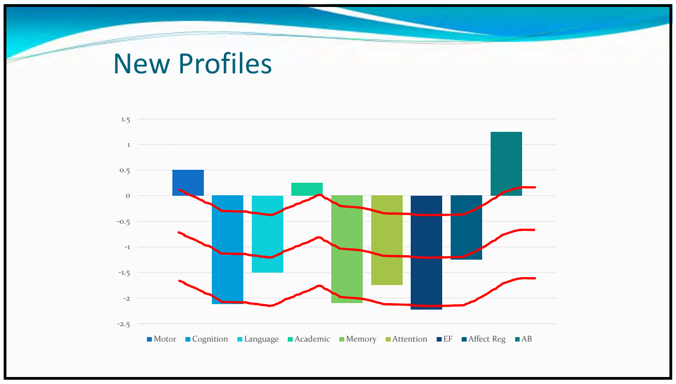


Current Diagnostic Model



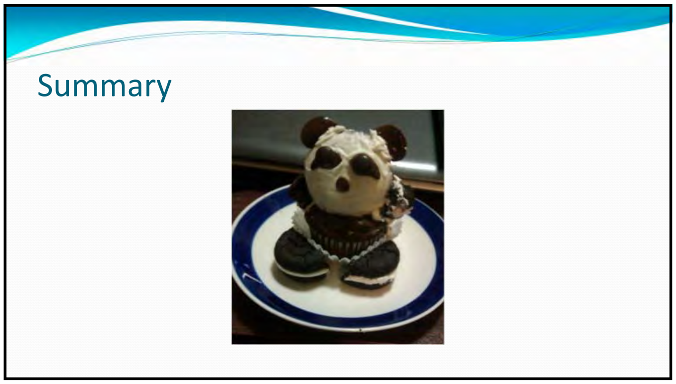
Identifying new FASD Profiles

- Proposal of Using Latent Profile Analysis to Create Pathognomonic FASD Profiles
- Taking into account the relationship between the domains (the deficits, the strengths, and the relative strengths.)



New Profiles

Summary



Summary

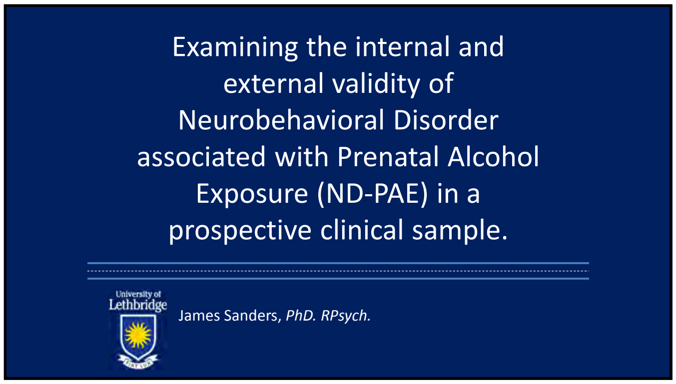
Special Thanks

- GCAP and Dr. Jerry
- Individuals with FASD and their support team

C2b

Examining the Internal and External Validity of Neurobehavioral Disorder Associated with PAE (ND-PAE) in a Prospective Clinical Sample

James Sanders



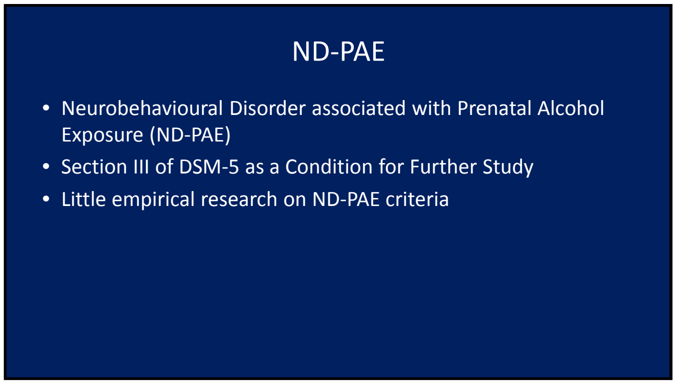
Examining the internal and external validity of Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE) in a prospective clinical sample.

University of Lethbridge

James Sanders, *PhD. RPsych.*

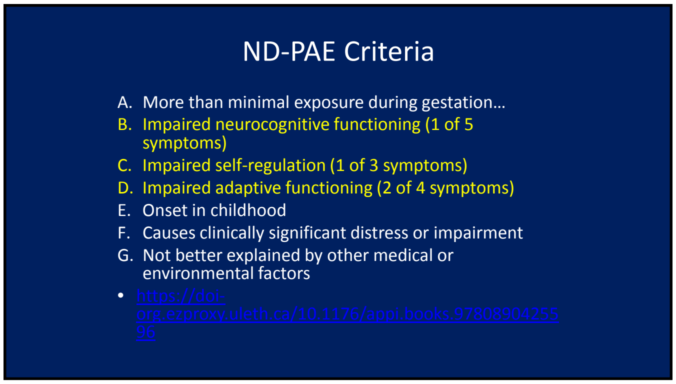
Diagnosis of FASD

- Diagnosis of FASD needed to access services
- Multidisciplinary clinical assessment costly



ND-PAE

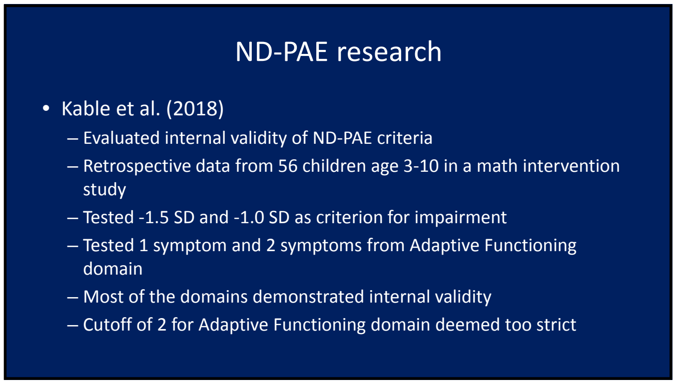
- Neurobehavioural Disorder associated with Prenatal Alcohol Exposure (ND-PAE)
- Section III of DSM-5 as a Condition for Further Study
- Little empirical research on ND-PAE criteria



ND-PAE Criteria

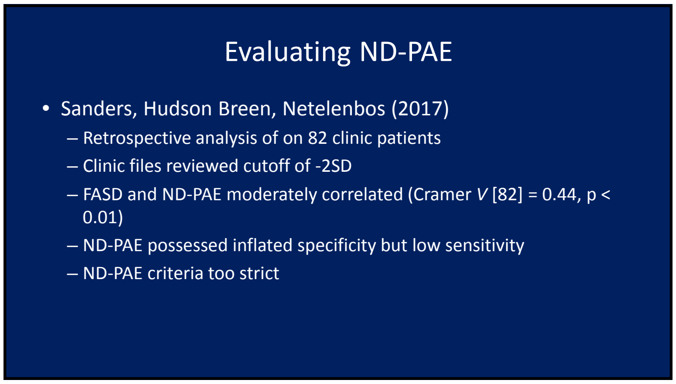
A. More than minimal exposure during gestation…
B. Impaired neurocognitive functioning (1 of 5 symptoms)
C. Impaired self-regulation (1 of 3 symptoms)
D. Impaired adaptive functioning (2 of 4 symptoms)
E. Onset in childhood
F. Causes clinically significant distress or impairment
G. Not better explained by other medical or environmental factors

- https://doi-org.ezproxy.uleth.ca/10.1176/appi.books.9780890425596



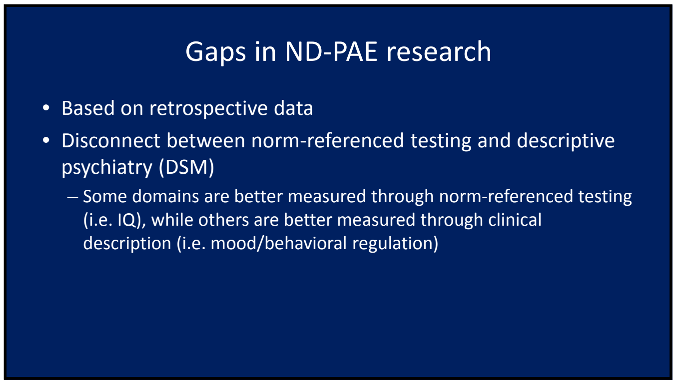
ND-PAE research

- Kable et al. (2018)
  - Evaluated internal validity of ND-PAE criteria
  - Retrospective data from 56 children age 3-10 in a math intervention study
  - Tested -1.5 SD and -1.0 SD as criterion for impairment
  - Tested 1 symptom and 2 symptoms from Adaptive Functioning domain
  - Most of the domains demonstrated internal validity
  - Cutoff of 2 for Adaptive Functioning domain deemed too strict



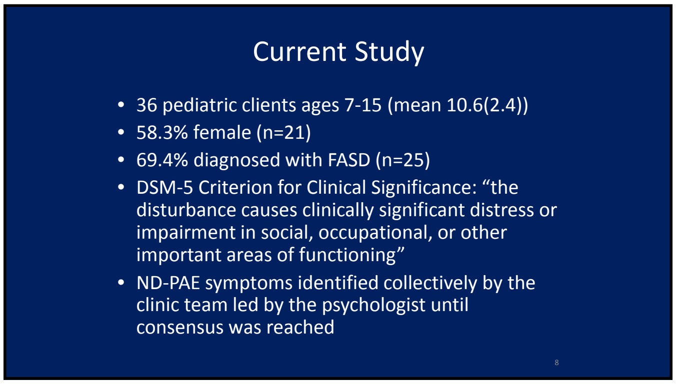
Evaluating ND-PAE

- Sanders, Hudson Breen, Netelenbos (2017)
  - Retrospective analysis of on 82 clinic patients
  - Clinic files reviewed cutoff of -2SD
  - FASD and ND-PAE moderately correlated (Cramer *V* [82] = 0.44, $p < 0.01$)
  - ND-PAE possessed inflated specificity but low sensitivity
  - ND-PAE criteria too strict



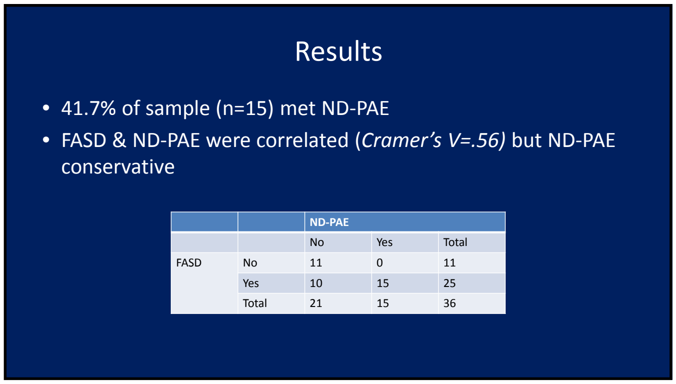
Gaps in ND-PAE research

- Based on retrospective data
- Disconnect between norm-referenced testing and descriptive psychiatry (DSM)
  - Some domains are better measured through norm-referenced testing (i.e. IQ), while others are better measured through clinical description (i.e. mood/behavioral regulation)



Current Study

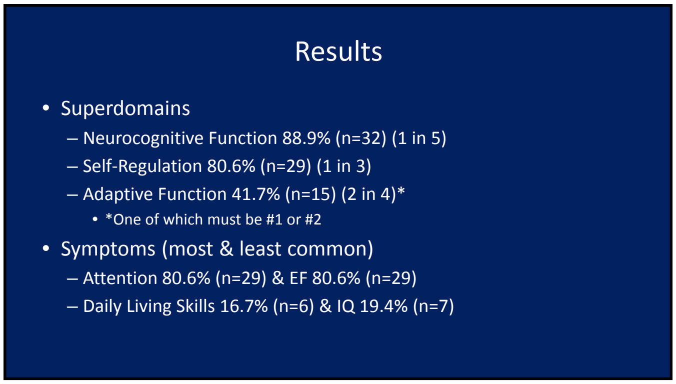
- 36 pediatric clients ages 7-15 (mean 10.6(2.4))
- 58.3% female (n=21)
- 69.4% diagnosed with FASD (n=25)
- DSM-5 Criterion for Clinical Significance: "the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning"
- ND-PAE symptoms identified collectively by the clinic team led by the psychologist until consensus was reached



Results

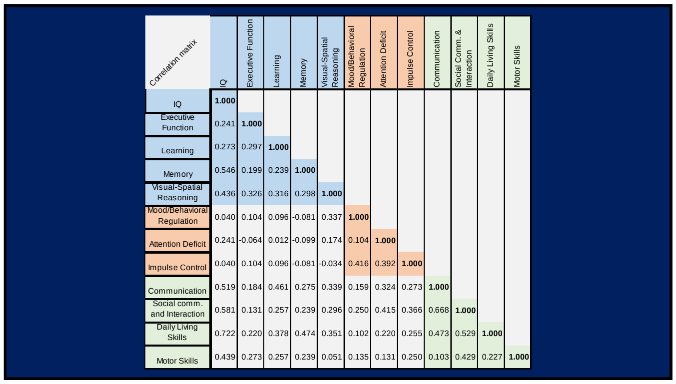
- 41.7% of sample (n=15) met ND-PAE
- FASD & ND-PAE were correlated (*Cramer's V=.56)* but ND-PAE conservative

		ND-PAE		
		No	Yes	Total
FASD	No	11	0	11
	Yes	10	15	25
	Total	21	15	36

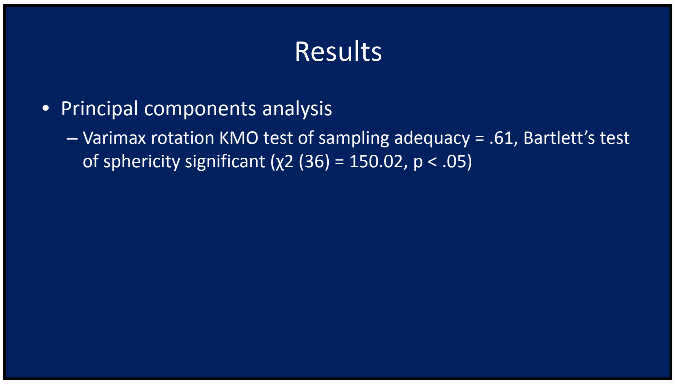


Results

- Superdomains
  - Neurocognitive Function 88.9% (n=32) (1 in 5)
  - Self-Regulation 80.6% (n=29) (1 in 3)
  - Adaptive Function 41.7% (n=15) (2 in 4)*
    - *One of which must be #1 or #2
- Symptoms (most & least common)
  - Attention 80.6% (n=29) & EF 80.6% (n=29)
  - Daily Living Skills 16.7% (n=6) & IQ 19.4% (n=7)

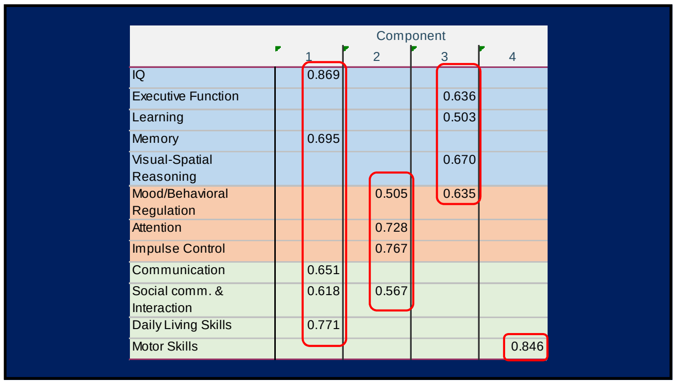


Correlation matrix	IQ	Executive Function	Learning	Memory	Visual-Spatial Reasoning	Mood/Behavioral Regulation	Attention Deficit	Impulse Control	Communication	Social Comm. & Interaction	Daily Living Skills	Motor Skills
IQ	**1.000**											
Executive Function	0.241	**1.000**										
Learning	0.273	0.297	**1.000**									
Memory	0.546	0.199	0.239	**1.000**								
Visual-Spatial Reasoning	0.436	0.326	0.316	0.298	**1.000**							
Mood/Behavioral Regulation	0.040	0.104	0.096	-0.081	0.337	**1.000**						
Attention Deficit	0.241	-0.064	0.012	-0.099	0.174	0.104	**1.000**					
Impulse Control	0.040	0.104	0.096	-0.081	-0.034	0.416	0.392	**1.000**				
Communication	0.519	0.184	0.461	0.275	0.339	0.159	0.324	0.273	**1.000**			
Social comm. and Interaction	0.581	0.131	0.257	0.239	0.296	0.250	0.415	0.366	0.668	**1.000**		
Daily Living Skills	0.722	0.220	0.378	0.474	0.351	0.102	0.220	0.255	0.473	0.529	**1.000**	
Motor Skills	0.439	0.273	0.257	0.239	0.051	0.135	0.131	0.250	0.103	0.429	0.227	**1.000**



Results

- Principal components analysis
  - Varimax rotation KMO test of sampling adequacy = .61, Bartlett's test of sphericity significant (χ2 (36) = 150.02, p < .05)



	Component			
	1	2	3	4
IQ	0.869			
Executive Function			0.636	
Learning			0.503	
Memory	0.695			
Visual-Spatial Reasoning			0.670	
Mood/Behavioral Regulation		0.505	0.635	
Attention		0.728		
Impulse Control		0.767		
Communication	0.651			
Social comm. & Interaction	0.618	0.567		
Daily Living Skills	0.771			
Motor Skills				0.846

Components

1. Adaptive Behavior & Independent Living Skills
    - IQ, Memory, Communication, Social Communication & Interaction, Daily Living Skills
2. ADHD
    - Attention, Impulse Control, (Mood/Behavioral & Social)

Components

3. Executive Functioning and Learning
    - EF, Learning, Visual-Spatial Reasoning, Mood/Behavioral Regulation
4. Motor Skills
    - Motor

Discussion

- This ND-PAE study appears to be the first:
    - prospective study
    - to use a descriptive psychiatry approach
- ND-PAE criteria strict
- General consistency in correlations between symptom domains

Discussion

- Re-conceptualization of ND-PAE
    1. Adaptive Behavior & Independent Living Skills
    2. ADHD
    3. Executive Functioning and Learning
    4. Motor Skills
- This re-conceptualization and other empirical-based approaches invite more research

References

Kable, J. A., & Coles, C. D. (2018). Evidence Supporting the Internal Validity of the Proposed ND-PAE Disorder. *Child Psychiatry & Human Development*, *49*(2), 163-175.

Sanders, J. L., Breen, R. E. H., & Netelenbos, N. (2017). Comparing diagnostic classification of neurobehavioral disorder associated with prenatal alcohol exposure with the Canadian fetal alcohol spectrum disorder guidelines: a cohort study. CMAJ open, 5(1), E178.

C2c Language Development in Children with FASD: What Do We Know About Learning Processes in Light of Cognitive Profiles?

Sara Kover, John C. Thorne


Language Development in Children with FASD:

What Do We Know About Learning Processes in Light of Cognitive Profiles?

March 8, 2019
International Conference on FASD

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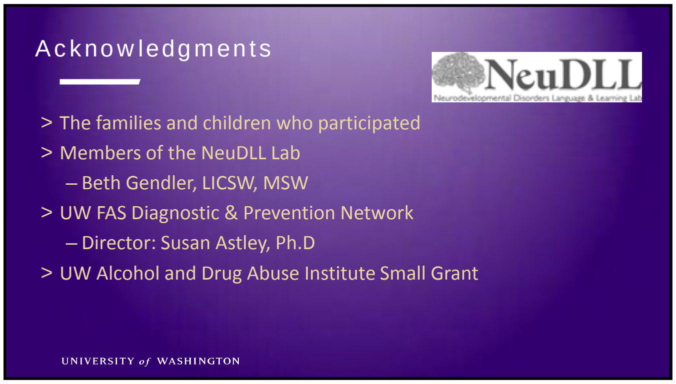
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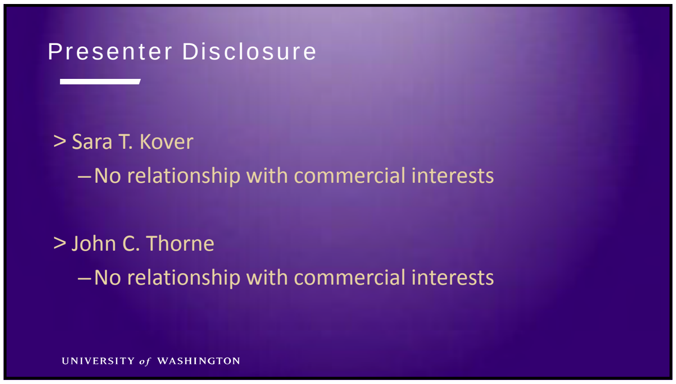
Presenter Disclosure

- Sara T. Kover
  - No relationship with commercial interests
- John C. Thorne
  - No relationship with commercial interests

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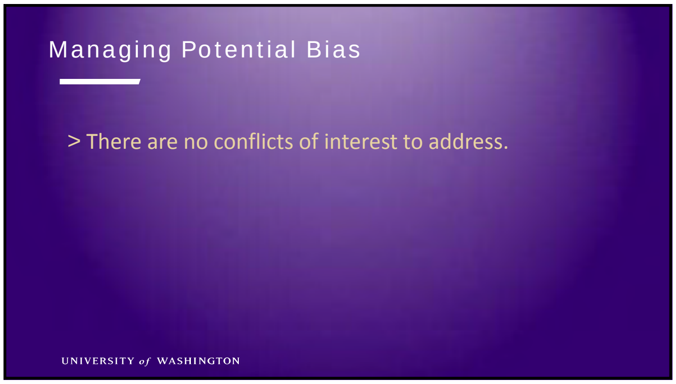
Managing Potential Bias

- There are no conflicts of interest to address.

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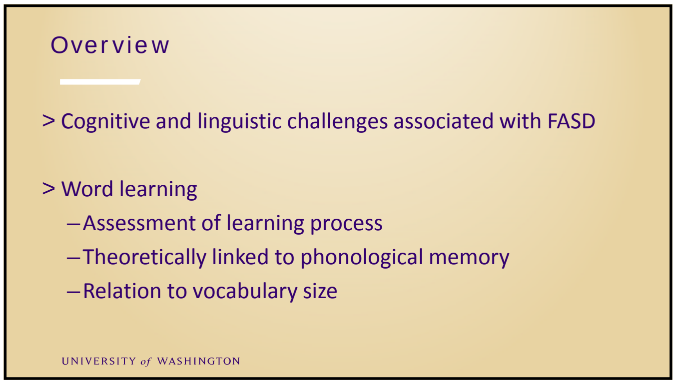
Overview

- Cognitive and linguistic challenges associated with FASD
- Word learning
  - Assessment of learning process
  - Theoretically linked to phonological memory
  - Relation to vocabulary size

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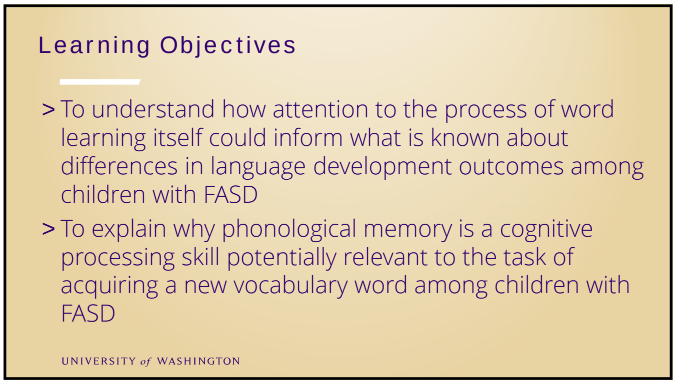
Learning Objectives

- To understand how attention to the process of word learning itself could inform what is known about differences in language development outcomes among children with FASD
- To explain why phonological memory is a cognitive processing skill potentially relevant to the task of acquiring a new vocabulary word among children with FASD

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Word Learning

Link between a label and its meaning (referent)

Language Development in FASD

- Language and communication deficits frequently reported (Kodituwakku, 2007)
- Below age-expectations on norm-referenced assessments (Coggins et al., 2007; Wyper & Rasmussen, 2011)
- Some delays undetected
- What are the contributors to language outcomes?
  - –Vocabulary size

Neurocognitive Impairments

- Attention (Lee et al., 2004; Mattson et al., 2006)
- Memory (Crocker et al., 2011; O'Hare et al., 2009)
- Auditory learning and memory (Willford et al., 2004; Lewis et al., 2015)

Word Learning

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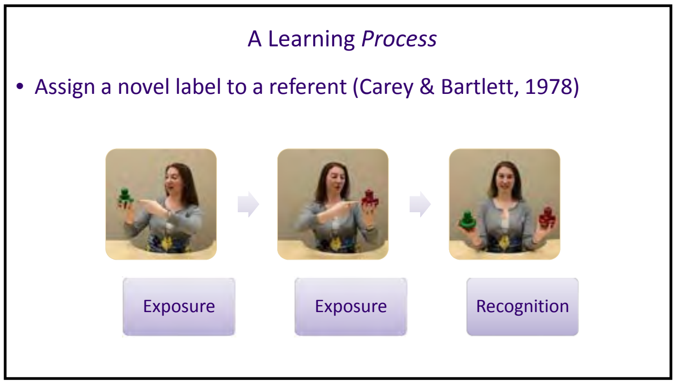
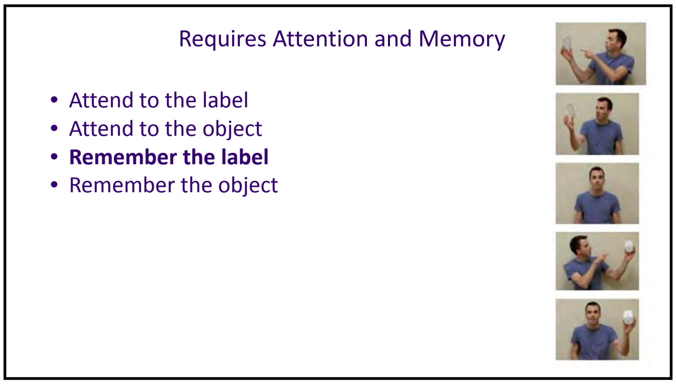


A Learning *Process*

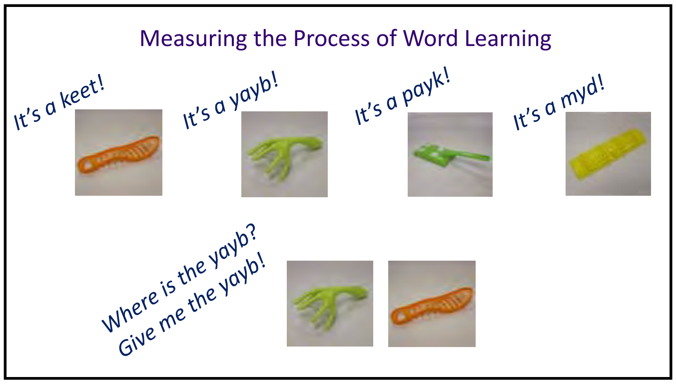
- Assign a novel label to a referent (Carey & Bartlett, 1978)

Exposure → Exposure → Recognition



Requires Attention and Memory

- Attend to the label
- Attend to the object
- **Remember the label**
- Remember the object



Measuring the Process of Word Learning

It's a keet!

It's a yayb!

It's a payk!

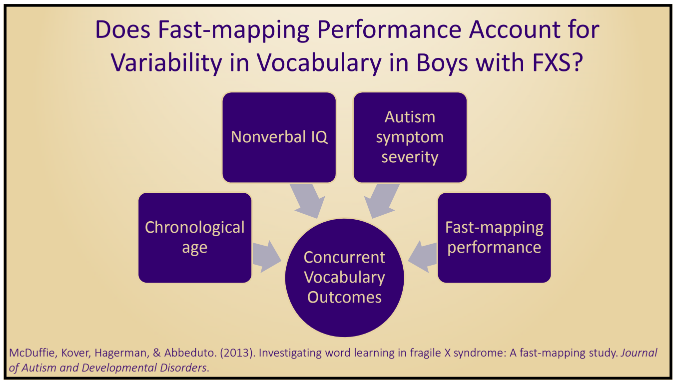
It's a myd!

Where is the yayb?

Give me the yayb!

Utility of Word Learning Assessment

- Autism spectrum disorder
  (Venker et al., 2016; Venker et al., 2018)
- Fragile X syndrome
  (Benjamin et al., 2015; McDuffie et al., 2013; Thurman et al., 2015)



Does Fast-mapping Performance Account for Variability in Vocabulary in Boys with FXS?

Nonverbal IQ

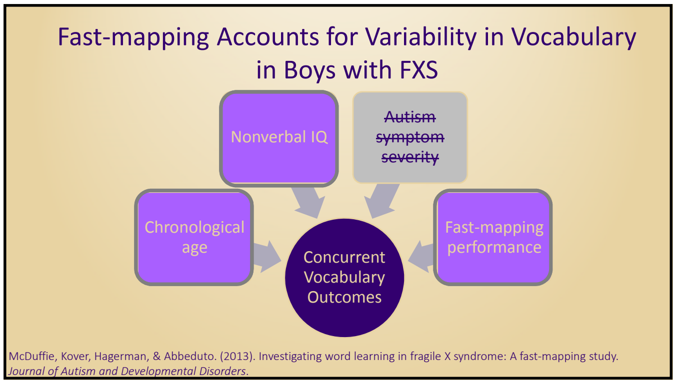
Autism symptom severity

Chronological age

Fast-mapping performance

Concurrent Vocabulary Outcomes

McDuffie, Kover, Hagerman, & Abbeduto. (2013). Investigating word learning in fragile X syndrome: A fast-mapping study. *Journal of Autism and Developmental Disorders.*



Fast-mapping Accounts for Variability in Vocabulary in Boys with FXS

Nonverbal IQ

~~Autism symptom severity~~

Chronological age

Fast-mapping performance

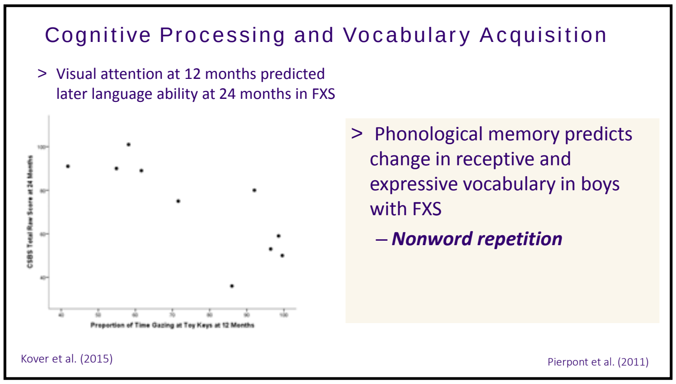
Concurrent Vocabulary Outcomes

McDuffie, Kover, Hagerman, & Abbeduto. (2013). Investigating word learning in fragile X syndrome: A fast-mapping study. *Journal of Autism and Developmental Disorders.*

Word Learning and Cognitive Processing

- Attention and Memory
- Typical development and neurodevelopmental disorders

(Gathercole, 2006; Kannass & Oakes, 2008; Kover & Ellis Weismer, 2014; Kover et al., 2015)



Cognitive Processing and Vocabulary Acquisition

> Visual attention at 12 months predicted later language ability at 24 months in FXS

> Phonological memory predicts change in receptive and expressive vocabulary in boys with FXS
  – ***Nonword repetition***

Kover et al. (2015)

Pierpont et al. (2011)

Research Questions

> Do individual differences in **word learning** and **phonological memory** relate to variability in receptive and expressive vocabulary among children with FASD?
  – Are receptive vocabulary, expressive vocabulary, word learning, and phonological memory correlated?
  – Are word learning and phonological memory unique predictors of vocabulary size, accounting for age and nonverbal cognition?

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Participants

> 25 children with FASD
> Ages 4 to 9 years old (*M* = 6.91; *SD* = 1.57)
> Leiter-3 nonverbal IQ (*M* = 100.4; *SD* = 11.79)
> Recruited in UW FAS-Diagnostic and Prevention Network
> Completed two sessions on the same or different days

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Measures

> Vocabulary Size
  – Peabody Picture Vocabulary Test (PPVT-4)
  – Expressive Vocabulary Test (EVT-2)

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Vocabulary Size

	M	*SD*	Range
PPVT-4 (Receptive Vocabulary)			
Growth Score	149.32	16.43	125 - 185
Standard Score	100.72	13.33	74 - 132
EVT-2 (Expressive Vocabulary)			
Growth Score	149.25	12.62	130 - 178
Standard Score	97.00	13.82	74 - 126

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Potential Correlates of Vocabulary Size

> Word Learning
  – Exposure: 8 novel label-object pairings
  – Test: 16 total test trials

> Phonological Memory
  – Repetition of nonwords of increasing length
  – Accuracy score

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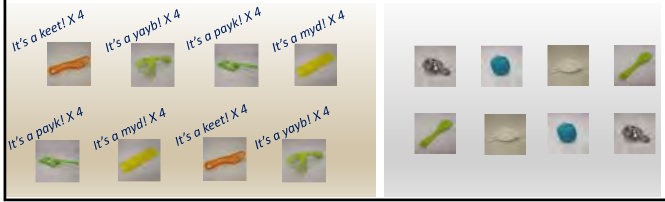
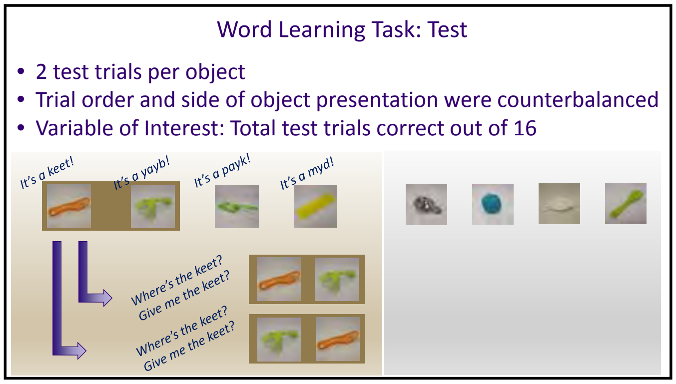
Word Learning Task: Exposure

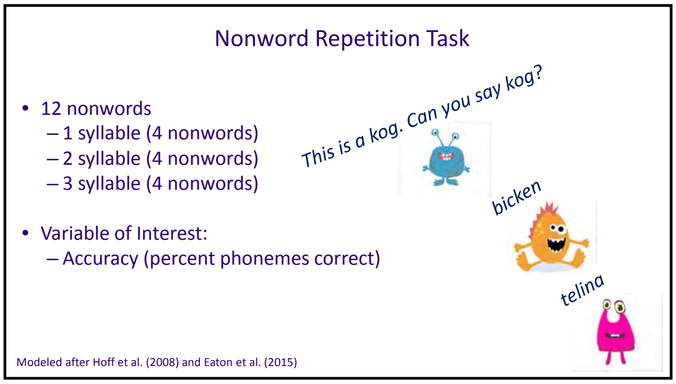
- 8 novel label-object pairs (4 label-object pairs per session)
- 8 exposures to each
  – 4 labels in two presentations
- Labels and objects were counterbalanced





Word Learning Task: Test

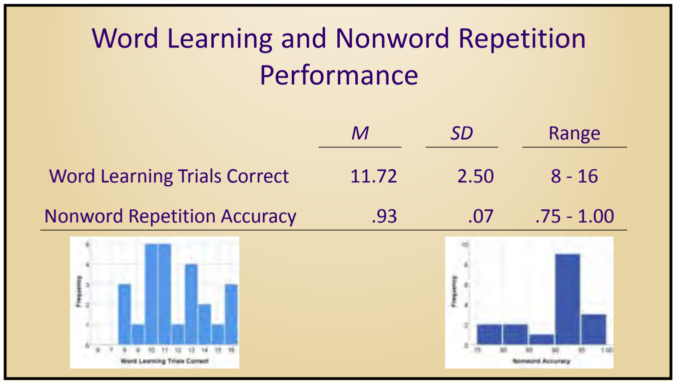
- 2 test trials per object
- Trial order and side of object presentation were counterbalanced
- Variable of Interest: Total test trials correct out of 16



Nonword Repetition Task

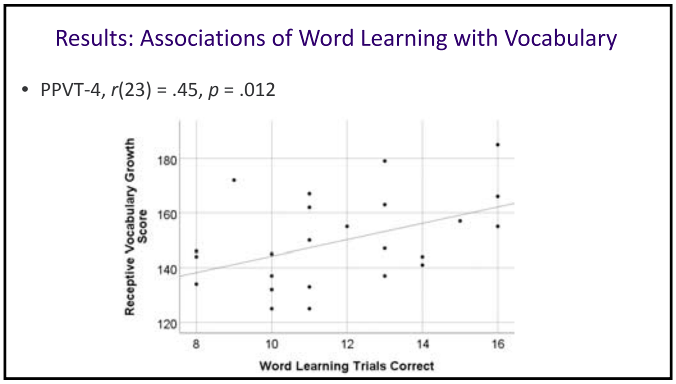
- 12 nonwords
  - 1 syllable (4 nonwords)
  - 2 syllable (4 nonwords)
  - 3 syllable (4 nonwords)
- Variable of Interest:
  - Accuracy (percent phonemes correct)

Modeled after Hoff et al. (2008) and Eaton et al. (2015)



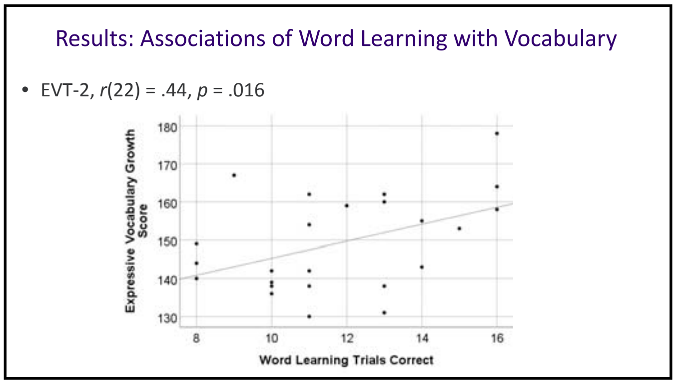
Word Learning and Nonword Repetition Performance

	M	*SD*	Range
Word Learning Trials Correct	11.72	2.50	8 - 16
Nonword Repetition Accuracy	.93	.07	.75 - 1.00



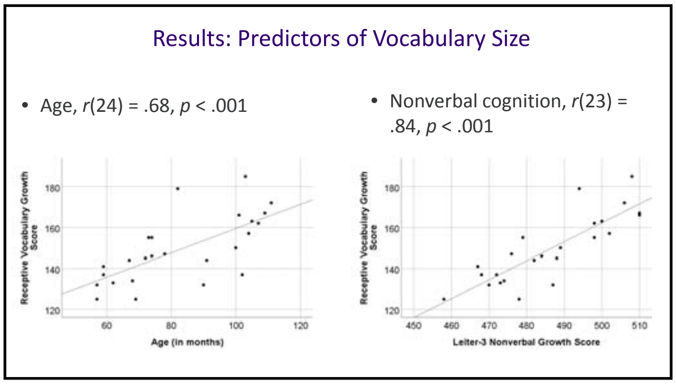
Results: Associations of Word Learning with Vocabulary

- PPVT-4, *r*(23) = .45, *p* = .012



Results: Associations of Word Learning with Vocabulary

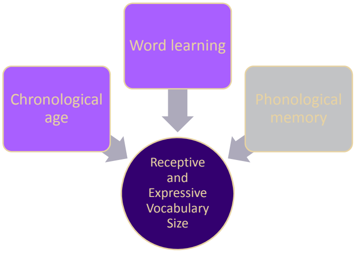
- EVT-2, *r*(22) = .44, *p* = .016



Results: Predictors of Vocabulary Size

- Age, *r*(24) = .68, *p* < .001
- Nonverbal cognition, *r*(23) = .84, *p* < .001

Results: Multiple Regression Predicting Vocabulary Size



Word learning

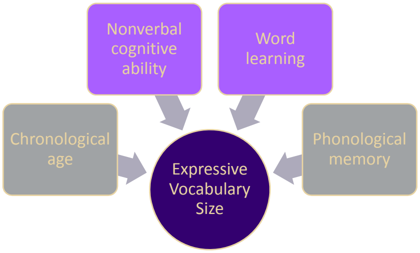
Chronological age

Phonological memory

Receptive and Expressive Vocabulary Size

- For example, the relation between word learning and receptive vocabulary was significant when controlling for age, *t*(22) = 2.05, *p* = .028.

Results: Multiple Regression Predicting Vocabulary Size



Nonverbal cognitive ability

Word learning

Chronological age

Phonological memory

Expressive Vocabulary Size

- The relation with expressive vocabulary was significant when controlling for age and nonverbal cognition, *t*(20) = 1.92, *p* = .037.

Summary of Findings

- Word learning was correlated with receptive and expressive vocabulary
- Phonological memory was not correlated with vocabulary

- Word learning predicted receptive vocabulary controlling age
- Word learning predicted expressive vocabulary controlling both age and nonverbal cognition

Conclusions

- Vocabulary acquisition processes, such as foundational word learning ability, are associated with individual differences in receptive and expressive vocabulary size

- Further investigation needed for the role of cognitive processing (e.g., phonological memory)

- Relevance to educators, SLPs, and others who support children with FASD

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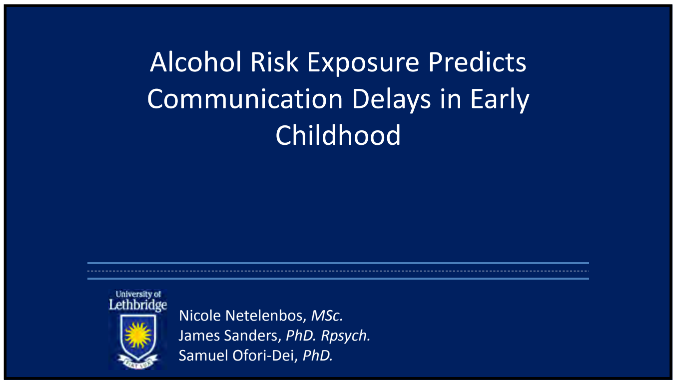
References

- Benjamin, D., McDuffie, A., Thurman, A., Kover, S. T., Mastergeorge, A., Hagerman, R., & Abbeduto, L. (2015). Effect of speaker gaze on word learning in fragile X syndrome and autism. *Journal of Speech, Language, and Hearing Research*, *58*, 383-395.
- Carey, S., & Bartlett, E. (1978). Acquiring a single new word. *Papers and Reports on CHild Language Development*, *15*, 17–29.
- Coggins, T. E., Timler, G. R., & Olswang, L. B. (2007). A state of double jeopardy: impact of prenatal alcohol exposure and adverse environments on the social communicative abilities of school-age children with fetal alcohol spectrum disorder. *Language, Speech, and Hearing Services in Schools*, *38*(2), 117–27. http://doi.org/10.1044/0161-1461(2007/012)
- Crocker, N., Vaurio, L., Riley, E. P., & Mattson, S. N. (2011). Comparison of verbal learning and memory in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcoholism, Clinical and Experimental Research*, *35*(6), 1114–21. http://doi.org/10.1111/j.1530-0277.2011.01444.x
- Dunn, L. M., & Dunn, D. M. (2007). *Peabody Picture Vocdabulary Test, Fourth Edition*. Minneapolis, MN: Pearson Assessments.
- Eaton, C., Newman, R., Ratner, N., & Rowe, M. (2015). Non-word repetition in 2-year-olds: Replication of an adapted paradigm and a useful methodological extension. Clinical Linguistics & Phonetics, 29(7), 523-535. Retrieved August 1, 2015.
- Gathercole, S. E. (2006). Nonword repetition and word learning: The nature of the relationship. *Applied Psycholinguistics*, *27*, 513–543.
- Hoff, E., Core, C., & Bridges, K. (2008). Non-word repetition assesses phonological memory and is related to vocabulary development in 20- to 24-month-olds. Journal of Child Language, 35, 903–916. Retrieved August 1, 2015.
- Kannass, K. N., & Oakes, L. M. (2008). The Development of Attention and Its Relations to Language in Infancy and Toddlerhood. *Journal of Cognition and Development*, *9*(2), 222–246. http://doi.org/10.1080/15248370802022696
- Kodituwakku, P. W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: a review. *Neuroscience and Biobehavioral Reviews*, *31*(2), 192–201. http://doi.org/10.1016/j.neubiorev.2006.06.020
- Kover, S., McCary, L. M., Ingram, A. M., Hatton, D. D., & Roberts, J. E. (2015). Language Development in Infants and Toddlers With Fragile X Syndrome: Change Over Time and the Role of Attention. *American Journal on Intellectual and Developmental Disabilities*, *120*(2), 125–144. http://doi.org/10.1352/1944-7558-120.2.125
- Kover, S. T., & Ellis Weismer, S. (2014). Lexical characteristics of expressive vocabulary in toddlers with autism spectrum disorder. *Journal of Speech, Language, and Hearing Research*, *57*(4), 1428–1441. http://doi.org/10.1044/2014_JSLHR-L-13-0006
- Lee, K. T., Mattson, S. N., & Riley, E. P. (2004). Classifying children with heavy prenatal alcohol exposure using measures of attention. *Journal of the International Neuropsychological Society : JINS*, *10*(2), 271–7. http://doi.org/10.1017/S1355617704102142
- Lewis, C., Thomas, K., Dodge, N., Moltena, C., Meintjes, E., Jacobson, J., & Jacobson, S. (2015). Verbal learning and memory impairment in children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research, 39*(4), 2015.
- Mattson, S. N., Calarco, K. E., & Lang, A. R. (2006). Focused and shifting attention in children with heavy prenatal alcohol exposure. *Neuropsychology*, *20*(3), 361–9. http://doi.org/10.1037/0894-4105.20.3.361
- McDuffie, A., Kover, S. T., Hagerman, R., & Abbeduto, L. (2013). Investigating word learning in fragile x syndrome: A fast-mapping study. *Journal of Autism and Develompental Disorders, 43*(7), 1676–1691. http://doi.org/10.1007/s10803-012-1717-3
- O'Hare, E. D., Lu, L. H., Houston, S. M., Bookheimer, S. Y., Mattson, S. N., O'Connor, M. J., & Sowell, E. R. (2009). Altered frontal-parietal functioning during verbal working memory in children and adolescents with heavy prenatal alcohol exposure. *Human Brain Mapping*, *30*(10), 3200–3208. http://doi.org/10.1002/hbm.20741
- Roid, G. H., & Miller, L. J. (2013). Leiter International Performance Scale, Third Edition (Leiter-3). WPS.
- Thurman, A., McDuffie, A., Kover, S. T., Hagerman, R. J., Channell, M. M., Mastergeorge, A., & Abbeduto, L. (2015). Use of emotional cues for lexical learning: A comparison of autism spectrum disorder and fragile X syndrome. *Journal of Autism and Develompental Disorders*, *45*, 1042-1061
- Willford, J. a., Richardson, G. a., Leech, S. L., & Day, N. L. (2004). Verbal and Visuospatial Learning and Memory Function in Children With Moderate Prenatal Alcohol Exposure. *Alcoholism: Clinical & Experimental Research*, *28*(3), 497–507. http://doi.org/10.1097/01.ALC.0000117868.97486.2D
- Wyper, K. R., & Rasmussen, C. R. (2011). Language impairments in children with fetal alcohol spectrum disorders. *Journal of Population Therapeutics and Clinical Pharmacology = Journal de La Thérapeutique Des Populations et de La Pharamcologie Clinique*, *18*(2), e364–76.

C2d Alcohol Risk Exposure Predicts Communication Delays in Early Childhood

Nicole Netelenbos



Alcohol Risk Exposure Predicts Communication Delays in Early Childhood

University of Lethbridge

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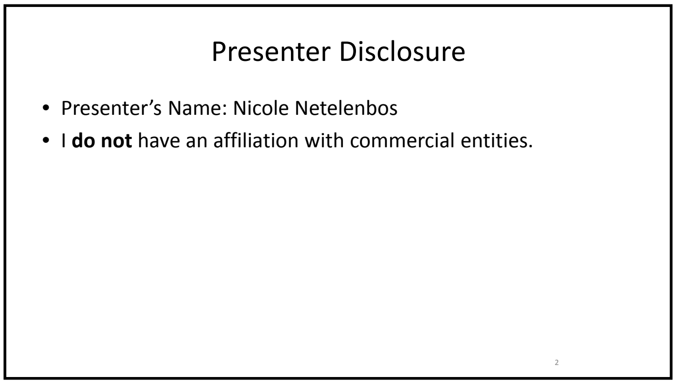
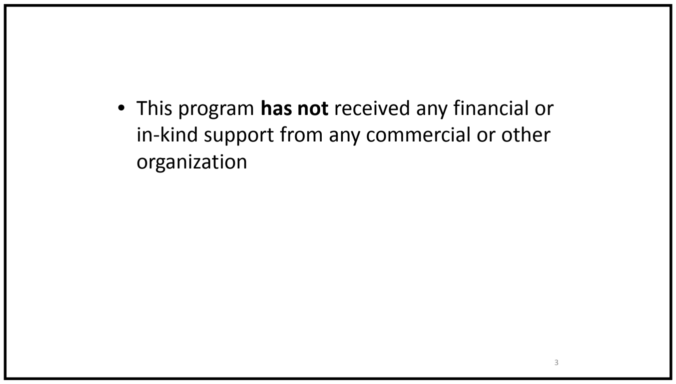
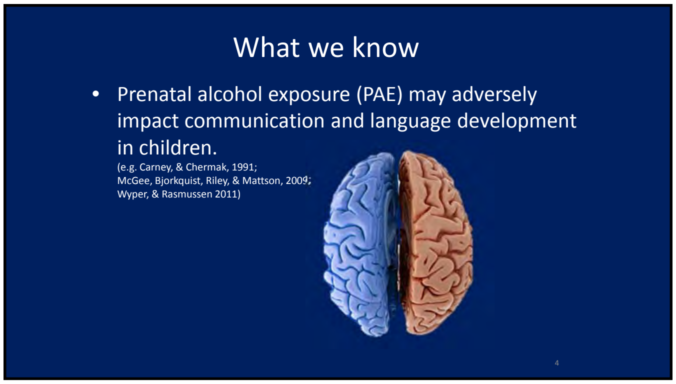


Presenter Disclosure

- Presenter's Name: Nicole Netelenbos
- I **do not** have an affiliation with commercial entities.

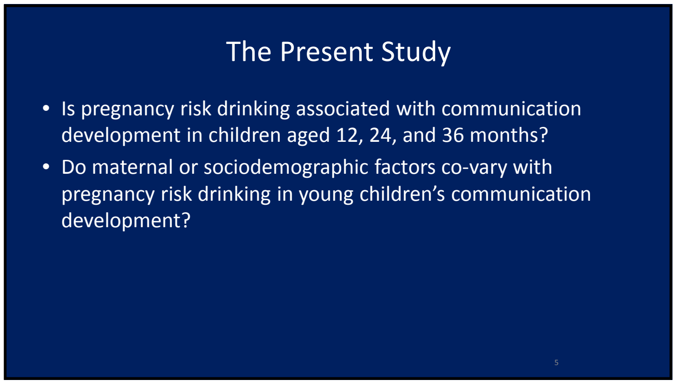


- This program **has not** received any financial or in-kind support from any commercial or other organization



What we know

- Prenatal alcohol exposure (PAE) may adversely impact communication and language development in children.
(e.g. Carney, & Chermak, 1991;
McGee, Bjorkquist, Riley, & Mattson, 2009;
Wyper, & Rasmussen 2011)



The Present Study

- Is pregnancy risk drinking associated with communication development in children aged 12, 24, and 36 months?
- Do maternal or sociodemographic factors co-vary with pregnancy risk drinking in young children's communication development?

What makes our study different

- *Indirect measure* of pregnancy risk drinking.
- Exploring the communication development in *very young* children from 12-36 months of age.
- *Prospective longitudinal* dataset.

How might we assess for pregnancy risk drinking?

Direct Measures: Women are specifically asked about their alcohol consumption behaviors specific to pregnancy via interviews or questionnaires.

Indirect Measures: Standardized screening measures can be used as an index in identifying alcohol misuse without directly probing into specifics of alcohol use during pregnancy.

How might we assess for language development?

- Parent and teacher rating scales are a practical and effective method (e.g. Ages and Stages Questionnaire).

Methods

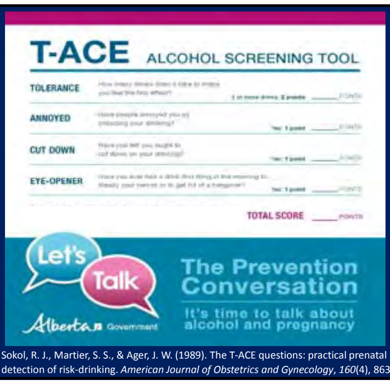
- Secondary data analysis of All Our Families (AOF) database.
- AOF has followed over 3,000 pregnant women and their children in Calgary, Alberta.
- Data was collected via mailed questionnaires.

The present study included:
N = 1066 at 12 months
N = 1282 at 24 months
N = 1529 at 36 months

Measures

The Dependent Variable:
- The T-ACE (Tolerance, Annoyed, Cut Down, Eye-opener)

The Independent Variable:
- The Ages and Stages Questionnaire (ASQ-3rd edition)



T-ACE ALCOHOL SCREENING TOOL

TOLERANCE

ANNOYED

CUT DOWN

EYE-OPENER

TOTAL SCORE

Let's Talk

The Prevention Conversation

It's time to talk about alcohol and pregnancy

Alberta Government

Sokol, R. J., Martier, S. S., & Ager, J. W. (1989). The T-ACE questions: practical prenatal detection of risk-drinking. *American Journal of Obstetrics and Gynecology*, *160*(4), 863-870.

The Ages and Stages Questionnaire (ASQ-3rd edition)

- A valid measure in identifying children who are at risk for developmental delays.
- Includes five domains of development, including language/communication.
- Can assess children between the ages of 1 month to 66 months.

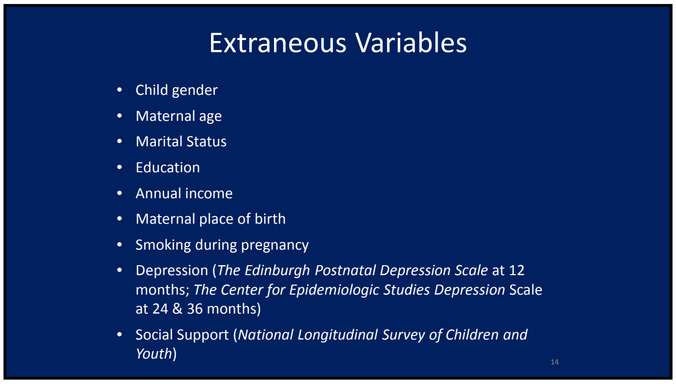
Squires, J., & Bricker, D. (2009). Ages & Stages Questionnaires, Third Edition (ASQ-3). Baltimore, MD: Brookes Publishing

The T-ACE

- Completed at <25 weeks gestation.
- Cut-off level of 3 or more points to identify high-risk drinkers.

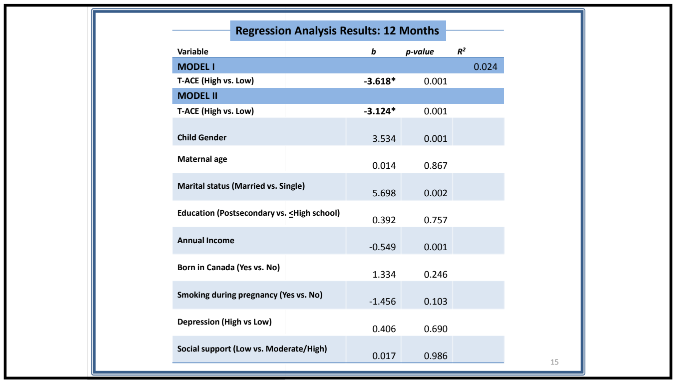
The ASQ

- Completed at 12, 24, and 36 months post-partum.
- Scores range from 0 to 60.



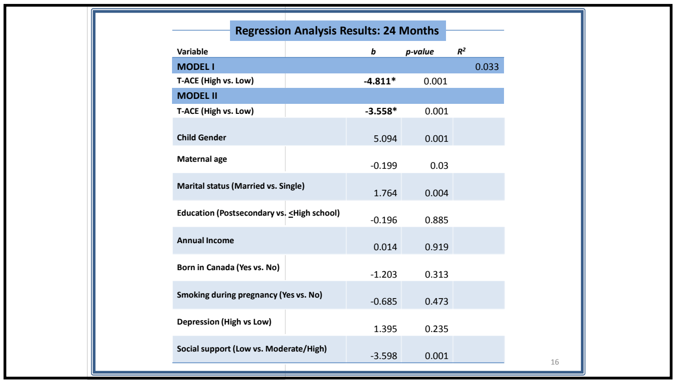
Extraneous Variables

- Child gender
- Maternal age
- Marital Status
- Education
- Annual income
- Maternal place of birth
- Smoking during pregnancy
- Depression (*The Edinburgh Postnatal Depression Scale* at 12 months; *The Center for Epidemiologic Studies Depression* Scale at 24 & 36 months)
- Social Support (*National Longitudinal Survey of Children and Youth*)



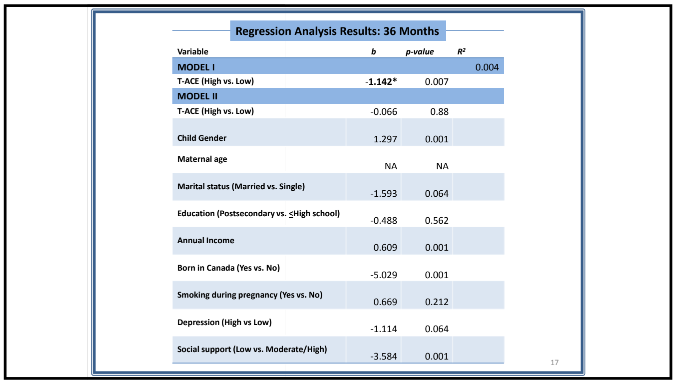
Regression Analysis Results: 12 Months

Variable	*b*	*p-value*	R^2
MODEL I			0.024
T-ACE (High vs. Low)	**-3.618***	0.001	
MODEL II			
T-ACE (High vs. Low)	**-3.124***	0.001	
Child Gender	3.534	0.001	
Maternal age	0.014	0.867	
Marital status (Married vs. Single)	5.698	0.002	
Education (Postsecondary vs. ≤High school)	0.392	0.757	
Annual Income	-0.549	0.001	
Born in Canada (Yes vs. No)	1.334	0.246	
Smoking during pregnancy (Yes vs. No)	-1.456	0.103	
Depression (High vs Low)	0.406	0.690	
Social support (Low vs. Moderate/High)	0.017	0.986	



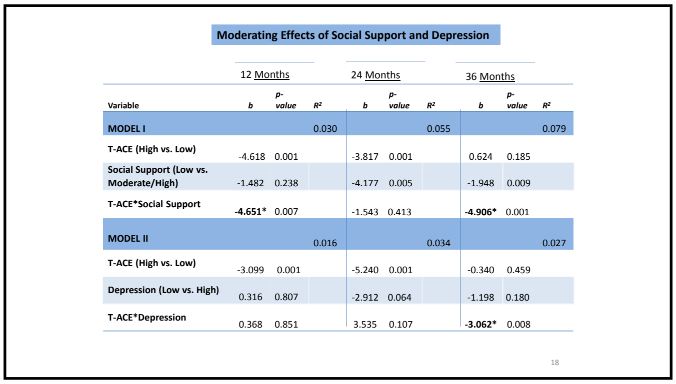
Regression Analysis Results: 24 Months

Variable	*b*	*p-value*	R^2
MODEL I			0.033
T-ACE (High vs. Low)	**-4.811***	0.001	
MODEL II			
T-ACE (High vs. Low)	**-3.558***	0.001	
Child Gender	5.094	0.001	
Maternal age	-0.199	0.03	
Marital status (Married vs. Single)	1.764	0.004	
Education (Postsecondary vs. ≤High school)	-0.196	0.885	
Annual Income	0.014	0.919	
Born in Canada (Yes vs. No)	-1.203	0.313	
Smoking during pregnancy (Yes vs. No)	-0.685	0.473	
Depression (High vs Low)	1.395	0.235	
Social support (Low vs. Moderate/High)	-3.598	0.001	



Regression Analysis Results: 36 Months

Variable	*b*	*p-value*	R^2
MODEL I			0.004
T-ACE (High vs. Low)	**-1.142***	0.007	
MODEL II			
T-ACE (High vs. Low)	-0.066	0.88	
Child Gender	1.297	0.001	
Maternal age	NA	NA	
Marital status (Married vs. Single)	-1.593	0.064	
Education (Postsecondary vs. ≤High school)	-0.488	0.562	
Annual Income	0.609	0.001	
Born in Canada (Yes vs. No)	-5.029	0.001	
Smoking during pregnancy (Yes vs. No)	0.669	0.212	
Depression (High vs Low)	-1.114	0.064	
Social support (Low vs. Moderate/High)	-3.584	0.001	

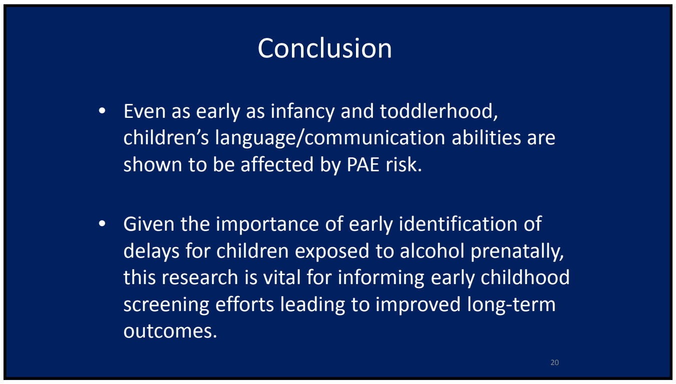


Moderating Effects of Social Support and Depression

	12 Months			24 Months			36 Months		
Variable	*b*	*p-value*	R^2	*b*	*p-value*	R^2	*b*	*p-value*	R^2
MODEL I			0.030			0.055			0.079
T-ACE (High vs. Low)	-4.618	0.001		-3.817	0.001		0.624	0.185	
Social Support (Low vs. Moderate/High)	-1.482	0.238		-4.177	0.005		-1.948	0.009	
T-ACE*Social Support	**-4.651***	0.007		-1.543	0.413		**-4.906***	0.001	
MODEL II			0.016			0.034			0.027
T-ACE (High vs. Low)	-3.099	0.001		-5.240	0.001		-0.340	0.459	
Depression (Low vs. High)	0.316	0.807		-2.912	0.064		-1.198	0.180	
T-ACE*Depression	0.368	0.851		3.535	0.107		**-3.062***	0.008	

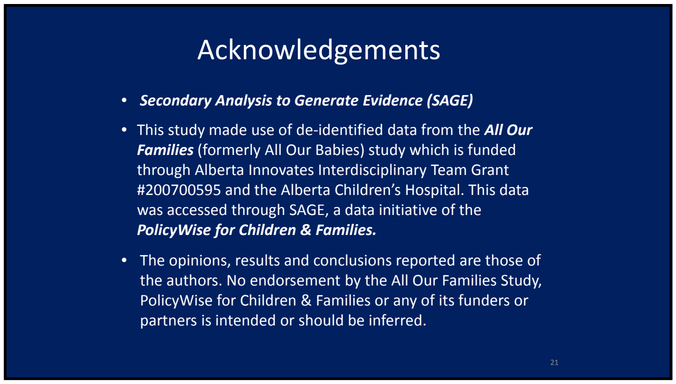
Discussion

- High-risk maternal drinking results in child communication delays by approximately 3-fold ($p < 0.05$) at 12, 24, and 36 months of age, even after controlling for child and mothers' demographic characteristics.
- Social support moderates these effects at 12 and 36 months of age.
- Depression moderates these effects at 36 months of age.



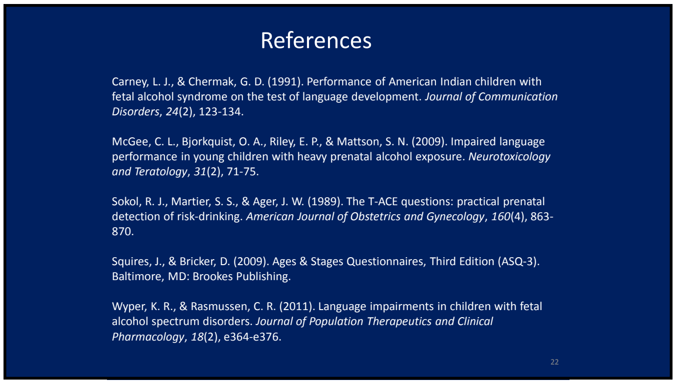
Conclusion

- Even as early as infancy and toddlerhood, children's language/communication abilities are shown to be affected by PAE risk.
- Given the importance of early identification of delays for children exposed to alcohol prenatally, this research is vital for informing early childhood screening efforts leading to improved long-term outcomes.



Acknowledgements

- ***Secondary Analysis to Generate Evidence (SAGE)***
- This study made use of de-identified data from the ***All Our Families*** (formerly All Our Babies) study which is funded through Alberta Innovates Interdisciplinary Team Grant #200700595 and the Alberta Children's Hospital. This data was accessed through SAGE, a data initiative of the ***PolicyWise for Children & Families.***
- The opinions, results and conclusions reported are those of the authors. No endorsement by the All Our Families Study, PolicyWise for Children & Families or any of its funders or partners is intended or should be inferred.



References

Carney, L. J., & Chermak, G. D. (1991). Performance of American Indian children with fetal alcohol syndrome on the test of language development. *Journal of Communication Disorders*, *24*(2), 123-134.

McGee, C. L., Bjorkquist, O. A., Riley, E. P., & Mattson, S. N. (2009). Impaired language performance in young children with heavy prenatal alcohol exposure. *Neurotoxicology and Teratology*, *31*(2), 71-75.

Sokol, R. J., Martier, S. S., & Ager, J. W. (1989). The T-ACE questions: practical prenatal detection of risk-drinking. *American Journal of Obstetrics and Gynecology*, *160*(4), 863-870.

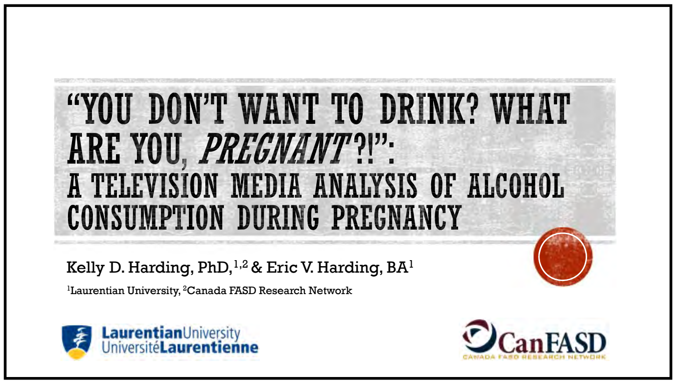
Squires, J., & Bricker, D. (2009). Ages & Stages Questionnaires, Third Edition (ASQ-3). Baltimore, MD: Brookes Publishing.

Wyper, K. R., & Rasmussen, C. R. (2011). Language impairments in children with fetal alcohol spectrum disorders. *Journal of Population Therapeutics and Clinical Pharmacology*, *18*(2), e364-e376.

C3a

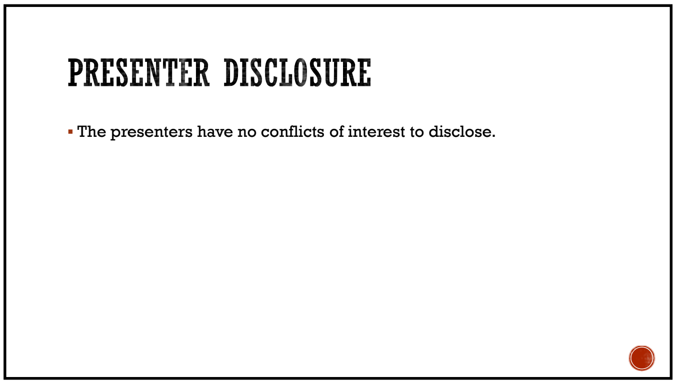
"You Don't Want to Drink? What Are You, Pregnant!?": A Television Media Analysis of Alcohol Consumption During Pregnancy

Kelly Harding, Eric Harding



"YOU DON'T WANT TO DRINK? WHAT ARE YOU, *PREGNANT*?!": A TELEVISION MEDIA ANALYSIS OF ALCOHOL CONSUMPTION DURING PREGNANCY

Kelly D. Harding, PhD,[1,2] & Eric V. Harding, BA[1]
[1]Laurentian University, [2]Canada FASD Research Network



PRESENTER DISCLOSURE

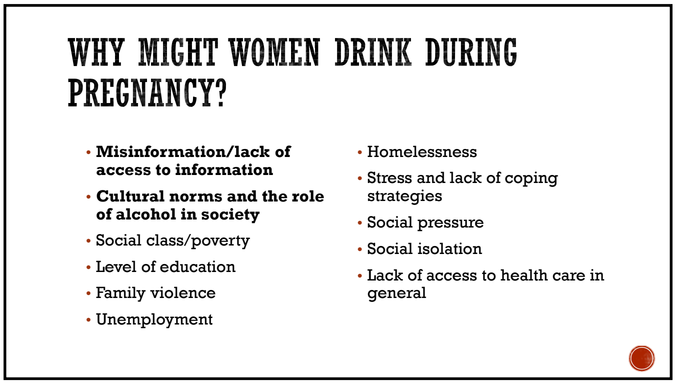
- The presenters have no conflicts of interest to disclose.

Is it wrong to drink alcohol while pregnant? Even the experts disagree

Though it is generally agreed binge-drinking poses significant risks to a foetus, authorities are split on the effect of moderate alcohol intake after 12 weeks

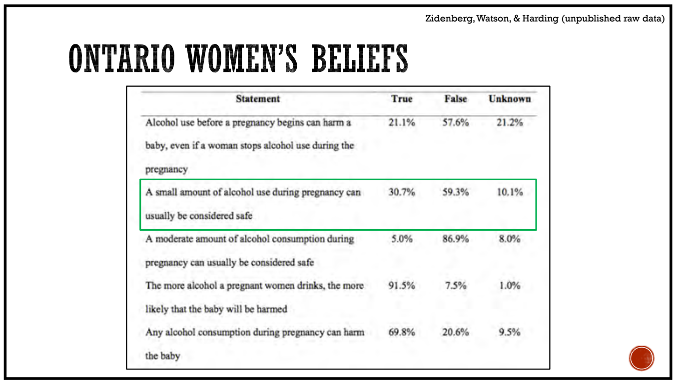
Stop Mommy-Shaming Pregnant Women Who Have A Glass Of Wine

Why I Drank While I Was Pregnant



WHY MIGHT WOMEN DRINK DURING PREGNANCY?

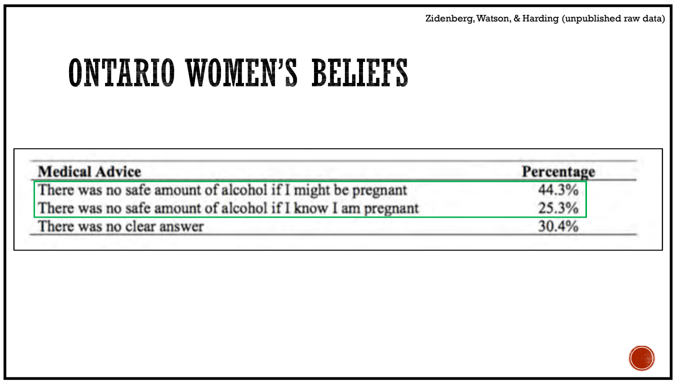
- **Misinformation/lack of access to information**
- **Cultural norms and the role of alcohol in society**
- Social class/poverty
- Level of education
- Family violence
- Unemployment
- Homelessness
- Stress and lack of coping strategies
- Social pressure
- Social isolation
- Lack of access to health care in general



Zidenberg, Watson, & Harding (unpublished raw data)

ONTARIO WOMEN'S BELIEFS

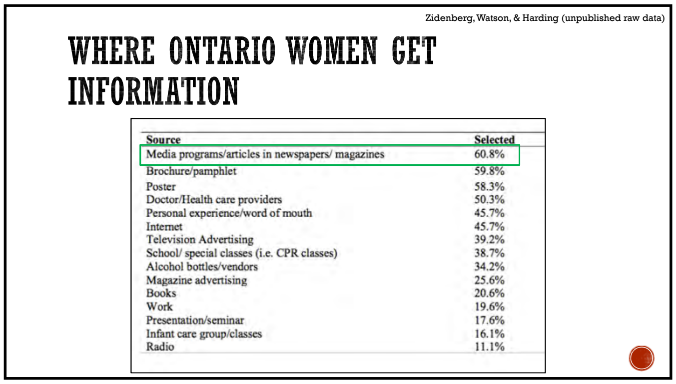
Statement	True	False	Unknown
Alcohol use before a pregnancy begins can harm a baby, even if a woman stops alcohol use during the pregnancy	21.1%	57.6%	21.2%
A small amount of alcohol use during pregnancy can usually be considered safe	30.7%	59.3%	10.1%
A moderate amount of alcohol consumption during pregnancy can usually be considered safe	5.0%	86.9%	8.0%
The more alcohol a pregnant women drinks, the more likely that the baby will be harmed	91.5%	7.5%	1.0%
Any alcohol consumption during pregnancy can harm the baby	69.8%	20.6%	9.5%



Zidenberg, Watson, & Harding (unpublished raw data)

ONTARIO WOMEN'S BELIEFS

Medical Advice	Percentage
There was no safe amount of alcohol if I might be pregnant	44.3%
There was no safe amount of alcohol if I know I am pregnant	25.3%
There was no clear answer	30.4%



Zidenberg, Watson, & Harding (unpublished raw data)

WHERE ONTARIO WOMEN GET INFORMATION

Source	Selected
Media programs/articles in newspapers/ magazines	60.8%
Brochure/pamphlet	59.8%
Poster	58.3%
Doctor/Health care providers	50.3%
Personal experience/word of mouth	45.7%
Internet	45.7%
Television Advertising	39.2%
School/ special classes (i.e. CPR classes)	38.7%
Alcohol bottles/vendors	34.2%
Magazine advertising	25.6%
Books	20.6%
Work	19.6%
Presentation/seminar	17.6%
Infant care group/classes	16.1%
Radio	11.1%

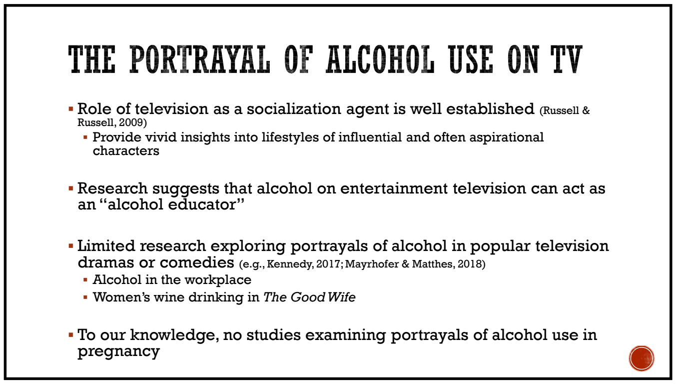
culture war reporters

Shame Day: *How I Met Your Mother* and FASD

Kat (2013)

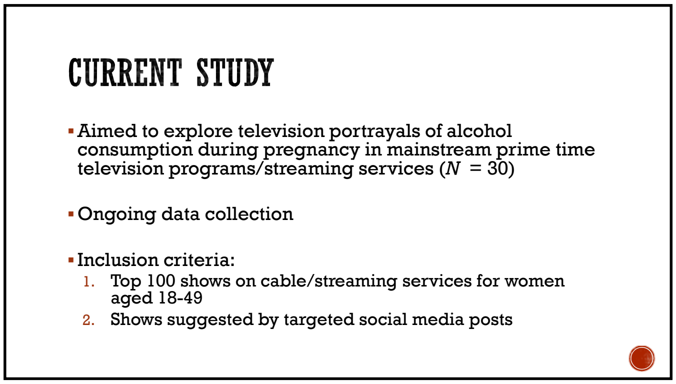
"SHAME DAY"

- Some television shows, such as *How I Met Your Mother* and *The Mindy Project*, have received viewer backlash for their portrayals of alcohol use during pregnancy



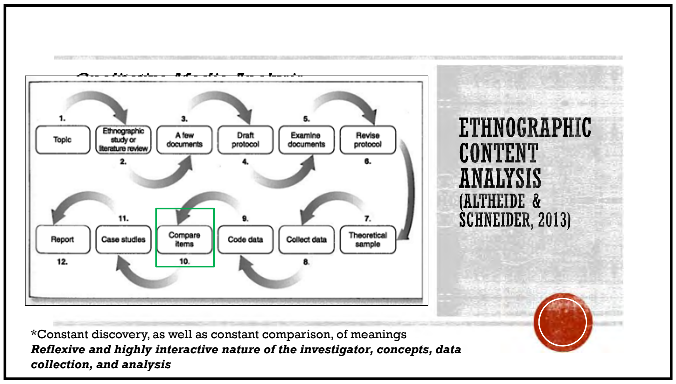
THE PORTRAYAL OF ALCOHOL USE ON TV

- Role of television as a socialization agent is well established (Russell & Russell, 2009)
  - Provide vivid insights into lifestyles of influential and often aspirational characters
- Research suggests that alcohol on entertainment television can act as an "alcohol educator"
- Limited research exploring portrayals of alcohol in popular television dramas or comedies (e.g., Kennedy, 2017; Mayrhofer & Matthes, 2018)
  - Alcohol in the workplace
  - Women's wine drinking in *The Good Wife*
- To our knowledge, no studies examining portrayals of alcohol use in pregnancy



CURRENT STUDY

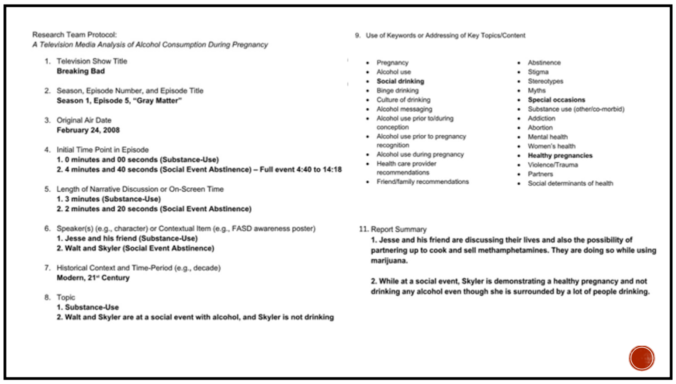
- Aimed to explore television portrayals of alcohol consumption during pregnancy in mainstream prime time television programs/streaming services ($N = 30$)
- Ongoing data collection
- Inclusion criteria:
  1. Top 100 shows on cable/streaming services for women aged 18-49
  2. Shows suggested by targeted social media posts



ETHNOGRAPHIC CONTENT ANALYSIS (ALTHEIDE & SCHNEIDER, 2013)

*Constant discovery, as well as constant comparison, of meanings

Reflexive and highly interactive nature of the investigator, concepts, data collection, and analysis



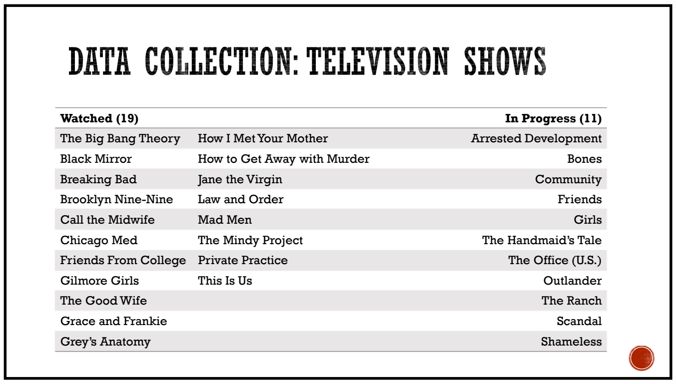
Research Team Protocol:

A Television Media Analysis of Alcohol Consumption During Pregnancy

1. Television Show Title
   Breaking Bad
2. Season, Episode Number, and Episode Title
   Season 1, Episode 5, "Gray Matter"
3. Original Air Date
   February 24, 2008
4. Initial Time Point in Episode
   1. 0 minutes and 00 seconds (Substance-Use)
   2. 4 minutes and 40 seconds (Social Event Abstinence) – Full event 4:40 to 14:18
5. Length of Narrative Discussion or On-Screen Time
   1. 3 minutes (Substance-Use)
   2. 2 minutes and 20 seconds (Social Event Abstinence)
6. Speaker(s) (e.g., character) or Contextual Item (e.g., FASD awareness poster)
   1. Jesse and his friend (Substance-Use)
   2. Walt and Skyler (Social Event Abstinence)
7. Historical Context and Time-Period (e.g., decade)
   Modern, 21st Century
8. Topic
   1. Substance-Use
   2. Walt and Skyler are at a social event with alcohol, and Skyler is not drinking
9. Use of Keywords or Addressing of Key Topics/Content
   - Pregnancy
   - Alcohol use
   - **Social drinking**
   - Binge drinking
   - Culture of drinking
   - Alcohol messaging
   - Alcohol use prior to/during conception
   - Alcohol use prior to pregnancy recognition
   - Alcohol use during pregnancy
   - Health care provider recommendations
   - Friend/family recommendations
   - Abstinence
   - Stigma
   - Stereotypes
   - Myths
   - **Special occasions**
   - Substance use (other/co-morbid)
   - Addiction
   - Abortion
   - Mental health
   - Women's health
   - **Healthy pregnancies**
   - Violence/Trauma
   - Partners
   - Social determinants of health

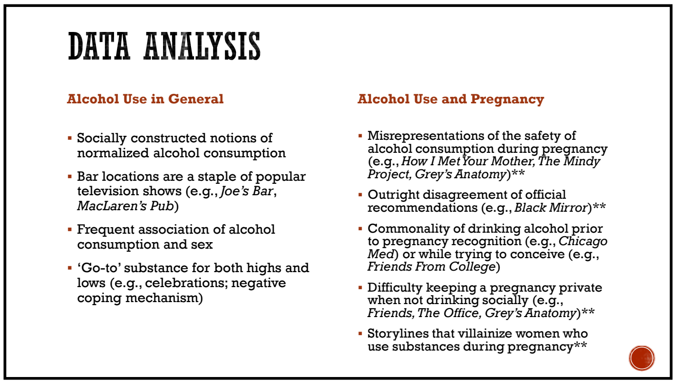
11. Report Summary
    1. Jesse and his friend are discussing their lives and also the possibility of partnering up to cook and sell methamphetamines. They are doing so while using marijuana.

    2. While at a social event, Skyler is demonstrating a healthy pregnancy and not drinking any alcohol even though she is surrounded by a lot of people drinking.



DATA COLLECTION: TELEVISION SHOWS

Watched (19)		In Progress (11)
The Big Bang Theory	How I Met Your Mother	Arrested Development
Black Mirror	How to Get Away with Murder	Bones
Breaking Bad	Jane the Virgin	Community
Brooklyn Nine-Nine	Law and Order	Friends
Call the Midwife	Mad Men	Girls
Chicago Med	The Mindy Project	The Handmaid's Tale
Friends From College	Private Practice	The Office (U.S.)
Gilmore Girls	This Is Us	Outlander
The Good Wife		The Ranch
Grace and Frankie		Scandal
Grey's Anatomy		Shameless



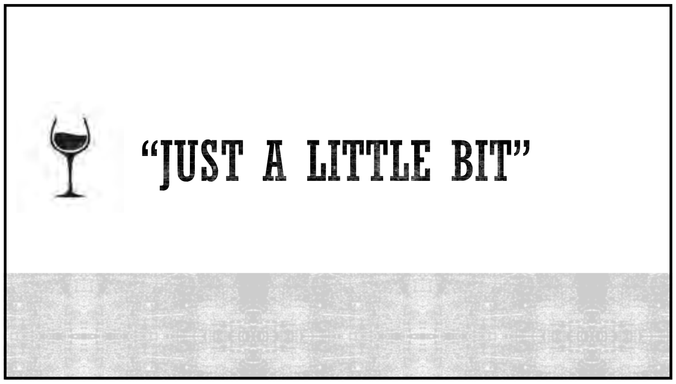
DATA ANALYSIS

Alcohol Use in General

- Socially constructed notions of normalized alcohol consumption
- Bar locations are a staple of popular television shows (e.g., *Joe's Bar*, *MacLaren's Pub*)
- Frequent association of alcohol consumption and sex
- 'Go-to' substance for both highs and lows (e.g., celebrations; negative coping mechanism)

Alcohol Use and Pregnancy

- Misrepresentations of the safety of alcohol consumption during pregnancy (e.g., *How I Met Your Mother, The Mindy Project, Grey's Anatomy*)**
- Outright disagreement of official recommendations (e.g., *Black Mirror*)**
- Commonality of drinking alcohol prior to pregnancy recognition (e.g., *Chicago Med*) or while trying to conceive (e.g., *Friends From College*)
- Difficulty keeping a pregnancy private when not drinking socially (e.g., *Friends, The Office, Grey's Anatomy*)**
- Storylines that villainize women who use substances during pregnancy**



"JUST A LITTLE BIT"

"Hey, hey, hey, hey! Pregnant women can't drink alcohol!"

"No. My doctor says it's O.K. to have a sip of wine every now and then…. Dr. Sonya's great! Whenever you ask her if you can have something she's like…"

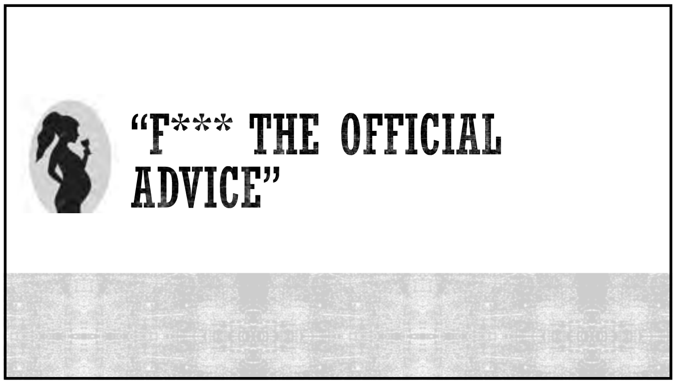
"Just a little bit…"

"Alcohol?"

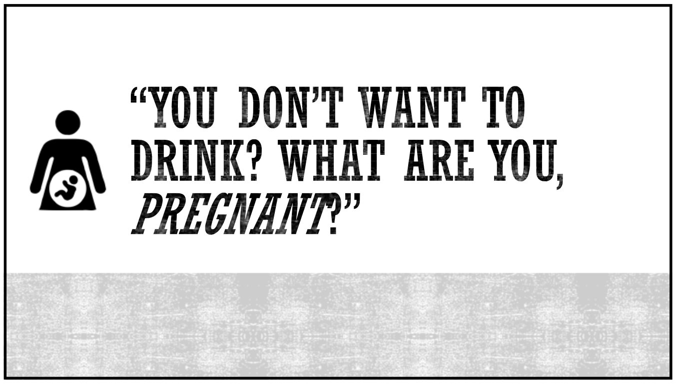
"Yeah."

"I tried to have a sip of your beer last month, you called me Casey Anthony."

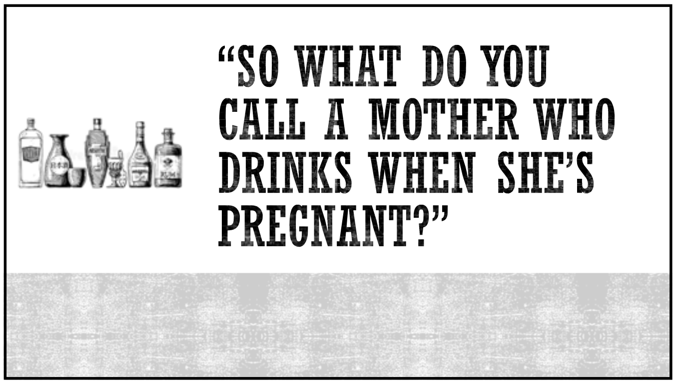
"Not tonight."



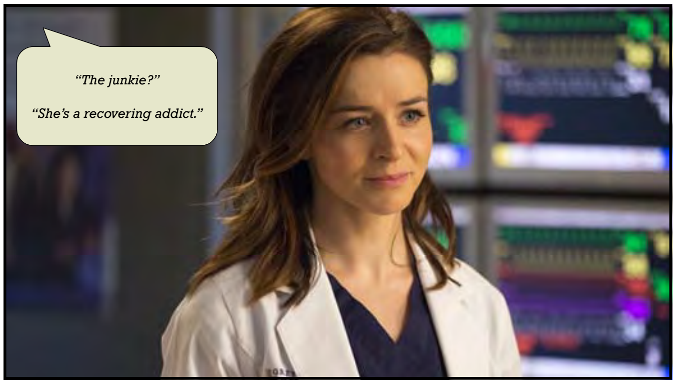
“F*** THE OFFICIAL ADVICE”

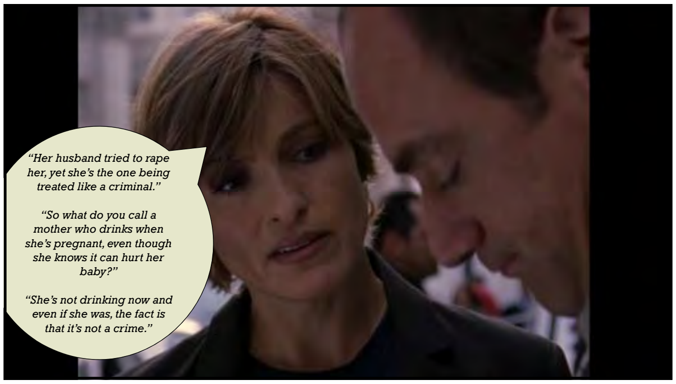


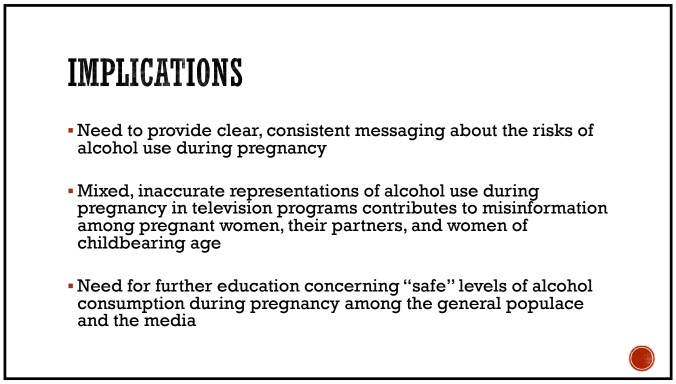
“YOU DON’T WANT TO DRINK? WHAT ARE YOU, *PREGNANT*?”



"SO WHAT DO YOU CALL A MOTHER WHO DRINKS WHEN SHE'S PREGNANT?"

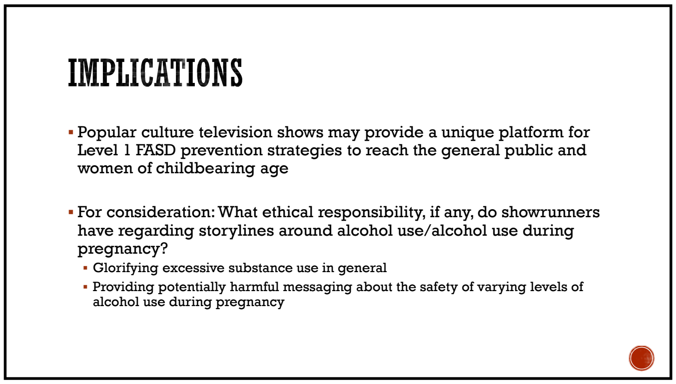






IMPLICATIONS

- Need to provide clear, consistent messaging about the risks of alcohol use during pregnancy
- Mixed, inaccurate representations of alcohol use during pregnancy in television programs contributes to misinformation among pregnant women, their partners, and women of childbearing age
- Need for further education concerning "safe" levels of alcohol consumption during pregnancy among the general populace and the media



IMPLICATIONS

- Popular culture television shows may provide a unique platform for Level 1 FASD prevention strategies to reach the general public and women of childbearing age
- For consideration: What ethical responsibility, if any, do showrunners have regarding storylines around alcohol use/alcohol use during pregnancy?
  - Glorifying excessive substance use in general
  - Providing potentially harmful messaging about the safety of varying levels of alcohol use during pregnancy

THANK YOU!

- For further information:
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  - Eric Harding ex_harding@laurentian.ca

C3b

Social Media Contribution to Public Education – Campaign “Pregnancy Without Alcohol” in Poland

Jolanta Terlikowska

Learning Objectives

1. Identify how we may use social media to create effective health promotion.

Objectives
Identify possibilities of an online educational campaign to increase awareness for the harmful effects of alcohol during pregnancy in Poland. There is a need to look for new ways to build effective methods to reduce the number of women who drink alcohol during pregnancy and to disseminate knowledge about the harmful effects of such behavior. Social media can be one of such tools. The Polish language version of Facebook appeared 10 years ago and has gathered over 16 million active users, 80% of them logs in every day. Users in Poland spend average one hour and 45 minutes on the platform every day, which gives them 22nd place in the world. This is a huge potential that can be used to disseminate the educational message.

Methods
The project includes the use of social media most popular in Poland: Facebook, Instagram and Tweeter. We will assess to what extent they can be effective in reaching recipients with educational content. We pay special attention to the possibility of using preventive strategies in this environment, whose effectiveness has been scientifically proven, such as building normative beliefs or personal decisions. The study includes a comparison of which type of messages is best perceived by the recipients.

Results
Possibilities of personalization of the message and precise targeting allows to reach a very wide group of appropriate recipients with a message tailored to the needs of users, i.e. pregnant women. As the part of the “Pregnancy Without Alcohol” campaign, there were achieved over 780,000 post engagements and more than 2,630,000 post views within 7 months. A computing culture of over 20,000 people was built, people who have been following the posted content on a regular basis. Involvement of significant people, running webinars, running a blog www.ciazabezalkoholu.info additionally allowed not only to increase the reach of campaign recipients, but also to activate recipients to interact and present their own attitudes and behaviors in the area of not drinking alcohol during pregnancy.

Conclusion
There is a huge potential in social media. An amazing force in social media is that, if they work well, they are not only able to capture what people are interested in, what topics they talk about, what information they share, but also consciously shape these areas. These data have been used for a long time to create advertisements and offers tailored to the needs of users. The same pathways can and should be used to raise awareness effectively, not only in the area of FASD prevention, but in a wide range of activities in the field of public health.

C3c

The Impact of Stigma on Parents and Children with FASD in the Child Welfare System

Peter W. Choate, Dorothy Badry

MOUNT ROYAL UNIVERSITY 1910

UNIVERSITY OF CALGARY

THE IMPACT OF STIGMA ON PARENTS AND CHILDREN WITH FASD IN THE CHILD WELFARE SYSTEM

DOROTHY BADRY, PHD – UNIVERSITY OF CALGARY

PETER CHOATE, PHD – MOUNT ROYAL UNIVERSITY

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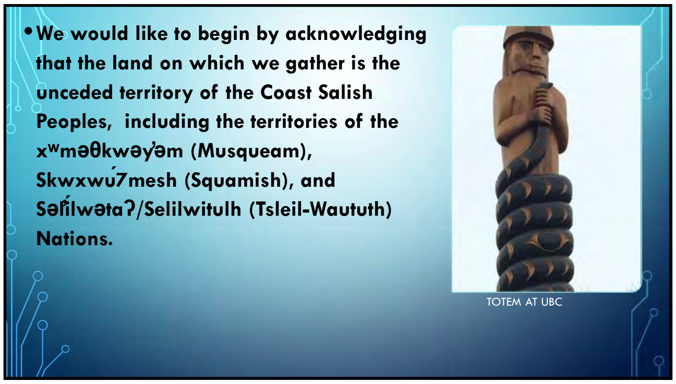
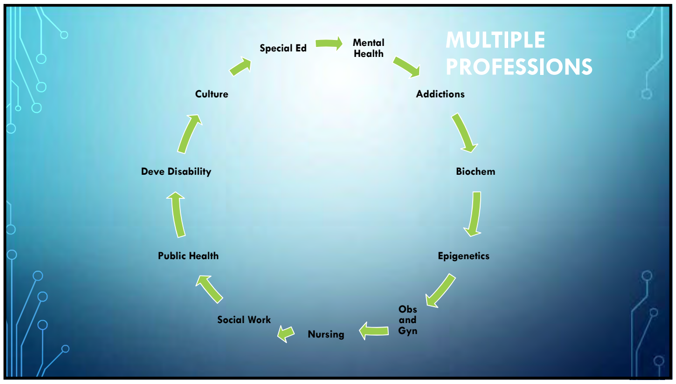


- We would like to begin by acknowledging that the land on which we gather is the unceded territory of the Coast Salish Peoples, including the territories of the xʷməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

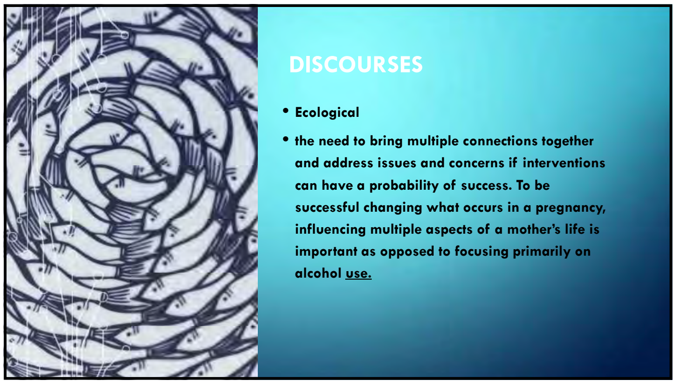
TOTEM AT UBC

THE PROJECT

- A scoping review to begin to understand how stigma and shame inform the professional dialogue around FASD

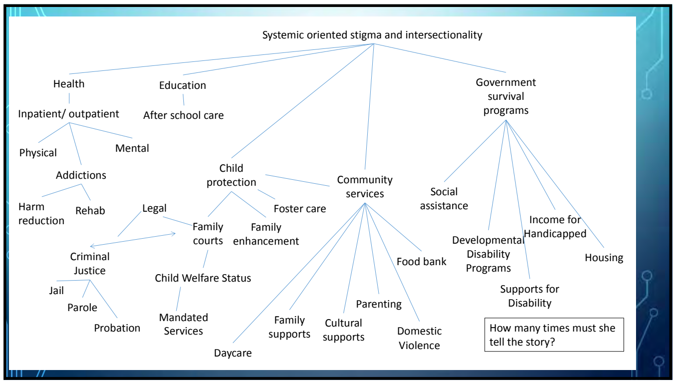


MULTIPLE PROFESSIONS

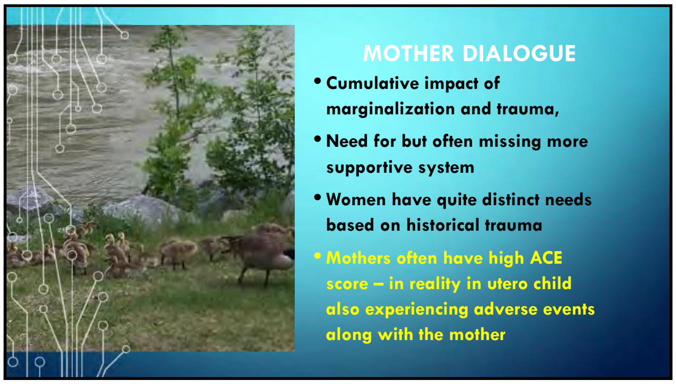


DISCOURSES

- Ecological
- the need to bring multiple connections together and address issues and concerns if interventions can have a probability of success. To be successful changing what occurs in a pregnancy, influencing multiple aspects of a mother's life is important as opposed to focusing primarily on alcohol use.

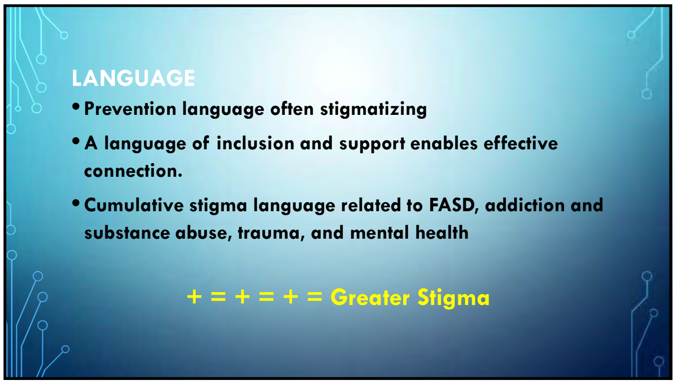


How many times must she tell the story?



MOTHER DIALOGUE

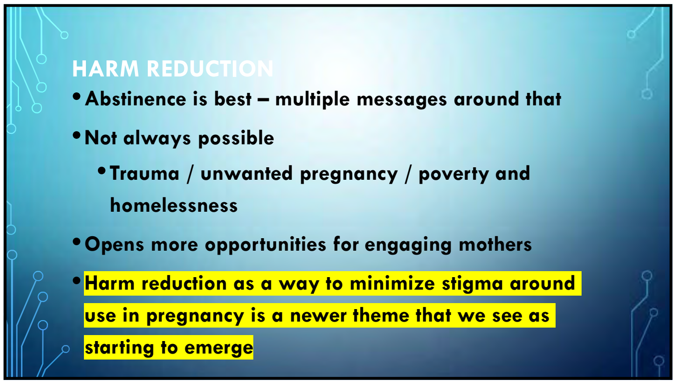
- Cumulative impact of marginalization and trauma,
- Need for but often missing more supportive system
- Women have quite distinct needs based on historical trauma
- Mothers often have high ACE score – in reality in utero child also experiencing adverse events along with the mother



LANGUAGE

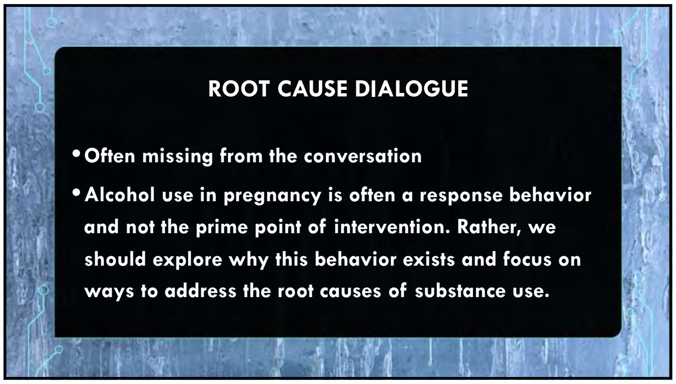
- Prevention language often stigmatizing
- A language of inclusion and support enables effective connection.
- Cumulative stigma language related to FASD, addiction and substance abuse, trauma, and mental health

+ = + = + = Greater Stigma



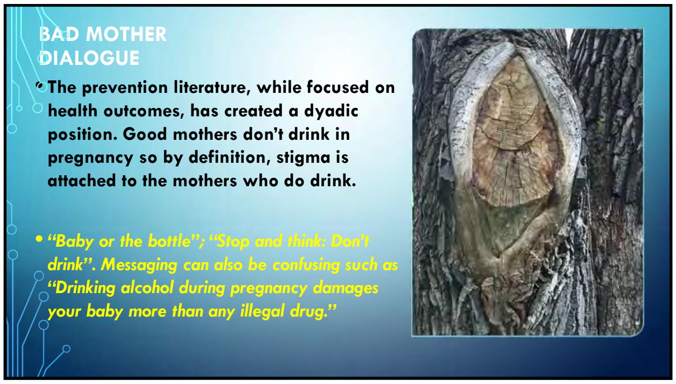
HARM REDUCTION

- Abstinence is best – multiple messages around that
- Not always possible
  - Trauma / unwanted pregnancy / poverty and homelessness
- Opens more opportunities for engaging mothers
- Harm reduction as a way to minimize stigma around use in pregnancy is a newer theme that we see as starting to emerge



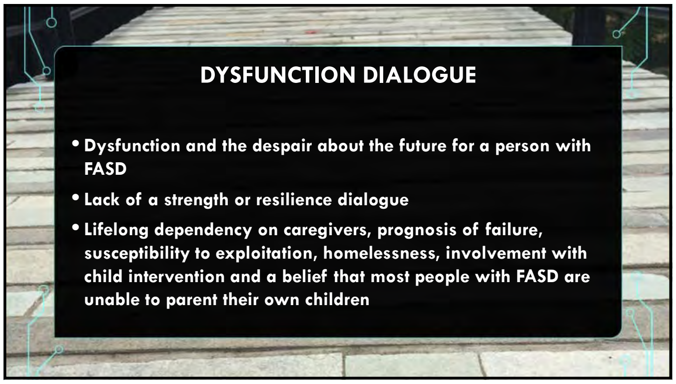
ROOT CAUSE DIALOGUE

- Often missing from the conversation
- Alcohol use in pregnancy is often a response behavior and not the prime point of intervention. Rather, we should explore why this behavior exists and focus on ways to address the root causes of substance use.



BAD MOTHER DIALOGUE

- The prevention literature, while focused on health outcomes, has created a dyadic position. Good mothers don't drink in pregnancy so by definition, stigma is attached to the mothers who do drink.
- *"Baby or the bottle"; "Stop and think: Don't drink". Messaging can also be confusing such as "Drinking alcohol during pregnancy damages your baby more than any illegal drug."*

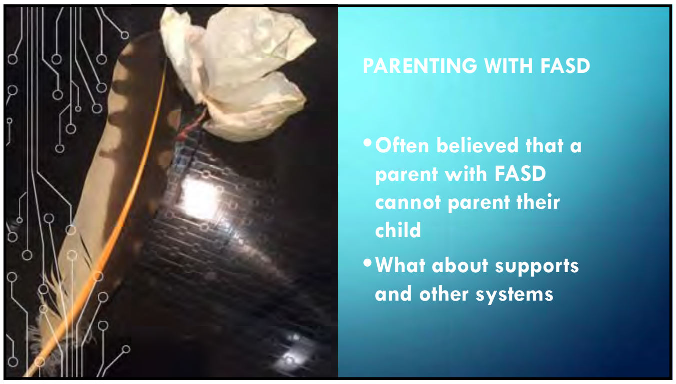


DYSFUNCTION DIALOGUE

- Dysfunction and the despair about the future for a person with FASD
- Lack of a strength or resilience dialogue
- Lifelong dependency on caregivers, prognosis of failure, susceptibility to exploitation, homelessness, involvement with child intervention and a belief that most people with FASD are unable to parent their own children

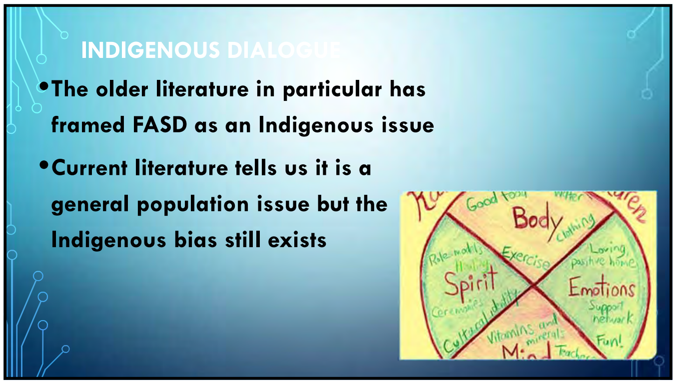
FASD AS A WHOLE-BODY DISORDER

- These can include a wide range of physiological problems ranging from Irritable Bowel Syndrome, Sleep Apnea, Rheumatoid Arthritis, Adult Chronic Ear Infections, Crohn's Disease, Celiac, Ulcerative Colitis and early Dementia



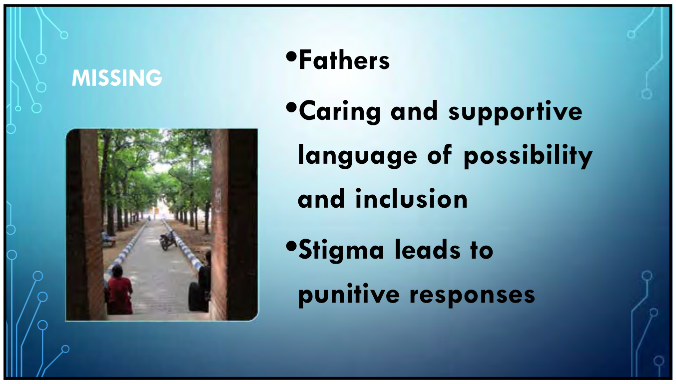
PARENTING WITH FASD

- Often believed that a parent with FASD cannot parent their child
- What about supports and other systems



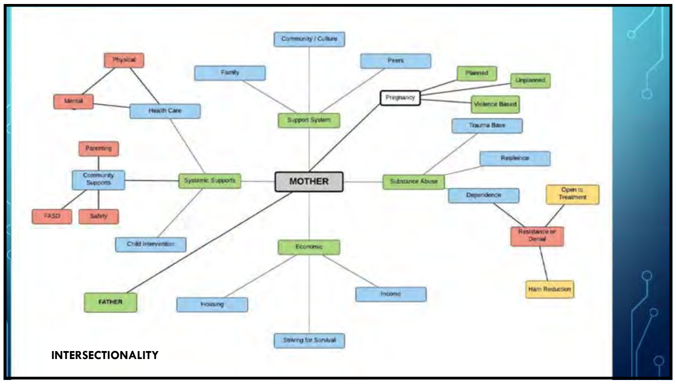
INDIGENOUS DIALOGUE

- The older literature in particular has framed FASD as an Indigenous issue
- Current literature tells us it is a general population issue but the Indigenous bias still exists



MISSING

- Fathers
- Caring and supportive language of possibility and inclusion
- Stigma leads to punitive responses



INTERSECTIONALITY

REVERSING THE DIALOGUE

- Professional education focused on inclusion
- Prevention efforts that support and are open to harm reduction
- Outreach to populations that are more marginalized
- Increasing recognition of the whole body disorder
- Language that FASD is a societal issue not a mother issue
- Bring fathers into the conversation

C3d

The International SAFTHON Update: Challenging Public Opinion and Influencing FASD Prevention Policies

Denis Lamblin, Joëlle Balanche

Learning Objectives

1. Describe a new tool to increase awareness about FASD
2. Show how this event convinced partners to join this initiative from SAF France
3. Share the first results in terms of communication as well as the impacts on national policies
4. Facilitate the creation of an International Committee to propose this tool, the Safthon, to as many countries as possible so it turns into a global event and the issue is better dealt with, in all countries, as some are still struggling

Summary

Though fetal alcohol consumption is the main cause of avoidable disorders, the observation is of very little consideration for FASD in prevention policies, in France and elsewhere.

For 2 years now, SAF FRANCE and its partners continue to challenge the public opinion by developing a new tool: the SAFTHON.

Following the second edition of the SAFTHON, this communication will present

*The objectives of the SAFTHON

*The favorable ground (information requests);

* The means used : communication campaign/ financing ;

* The first results: media coverage, reactions of the State ;

* The national and international perspectives with the creation of an International Steering Committee

Key words:
International SAFTHON (FASTHON), Policy, Prevention

C4a PGIF - A Placental Biomarker for Early Diagnosis of FASD Brain Defects

Bruno Gonzalez

Authors: B Gonzalez, M Lecuyer, A Laquerrière, S Jégou, C Sautreuil, S Bekri, P Marcorelles, S Marret

Learning Objectives

1. Demonstrate that alcohol impairs a functional placenta-brain axis involved in angiogenesis
2. Characterize placental factors predictive of alcohol-induced brain defects

Context & Positioning

I.1. Fetal alcohol exposure: State of the art and clinical issue

The last report from the World Health Organization on Alcohol and Health indicates that fetal alcohol exposure is a leading cause of acquired neonatal handicap in the world.[1] It is also important to mention that troubles resulting from in utero alcohol exposure affect infants from both developing and industrialized countries.[2] As an example, 2 to 5 ‰ children in USA are affected by severe alcohol-induced deficits and societal costs have been evaluated at 4 billion dollars per year.[3] In France, prevalence of the fetal alcohol syndrome (FAS), which is the most severe form of fetal alcohol spectrum disorders (FASD), is 1 to 1.5 ‰ birth.[4]

These clinical and economic data are both substantial and underappreciated. Substantial, because FASD affect the youngest part of the population with long term consequences regarding educational and social integration. For example, a large proportion of infants exposed in utero to alcohol will become early school leavers.[5] Underappreciated, because if it is easy for a clinician to establish the diagnosis of FAS based on specific characteristics such as cranio-facial dysmorphisms, most of FASD children do not exhibit dysmorphisms but have neurobehavioral impairments, frequently misdiagnosed until school-age.[6,7]

“Challenge for clinicians is to perform the early diagnosis of FASD to save precious years of care”[8]

I.2. Early diagnosis of FASD: guarantees of better recovery

Brain is a plastic organ with a strong potential of recovery after a lesion. For example, this plasticity is noticeable in adults after stroke with possible motor and/or cognitive recovery. However, this plasticity decreases with age. In neonates and young children, brain is developing and the potential of recovery is high. For example, it has been demonstrated for autism that earlier the neurobehavioral stimulation was engaged better were the improvements.[9]

Earlier the FASD diagnosis would be established, better would be the clinical care, and optimal the functional recovery

I.3. Limitations of EXPOSURE biomarkers

To date, a great effort has been done to characterize biomarkers of in utero alcohol exposure.10,11 Several biochemical tests have been developed from the meconium or the hairs.10 However, they are “EXPOSURE” biomarkers which answer at the following question: Was the infant exposed or not to alcohol during fetal life?

This type of biomarkers, even if required, is unable to ensure adequate clinical care for several reasons:

- No threshold of alcohol toxicity has been characterized and an established exposure during pregnancy will be not necessarily lead to neurodevelopmental troubles. Consequently, it is not socially and economically realistic to follow all infants exposed to alcohol.
- Alcohol consumption habits are changing and progressively chronic consumption decreases in favor of acute exposure such as drunkenness during week-ends.12 Because most of « EXPOSURE » biomarkers are targeted on alcohol metabolites and alcohol toxicity there is a real risk of false negative.
- For a given dose, the effects on the developing brain would be different depending of the age of the fetus supporting the notion of windows of vulnerability.

EXPOSURE biomarkers do not prejudge of fetal brain defects
BRAIN DEFECTS biomarkers of in utero alcohol exposure are required

I.4. Fetal brain angiogenesis and neurodevelopment

During brain development, angiogenesis is concomitant with neurogenesis and vessels provide to nervous cell nutrients, oxygen and soluble trophic factors.13 However, several recent studies revealed a more specific interaction between neonatal endothelial cells and guidance of migrating nervous cells i.e. GABA interneurons14 and oligodendrocytes.15

Correct brain angiogenesis is required for a correct positioning of GABA interneurons and oligodendrocyte precursors

II. Working hypothesis

Placenta is an ephemeral organ which regulates materno-fetal exchanges by providing nutrients, oxygen but also trophic factors to the fetus. Using pre-clinical and clinical approaches, researchers from Inserm U1245, in collaboration with clinicians from the Department of Neonatal Pediatrics and Intensive Care, Rouen hospital, demonstrated in both mouse and human that in utero alcohol exposure impairs brain vasculature.16 In addition, it has been shown by Dan Savage's group that alcohol alters the expression of placental genes including PlGF.17 Because placenta is a major source of pro-angiogenic factors including PlGF,18 we hypothesized that:

- **In utero alcohol exposure would disrupt a functional « Placenta/Brain » axis involved in brain angiogenesis**
- **Alcohol-induced vascular defects in the fetal brain would contribute to neurodevelopmental impairments**

III. Main results

In mice, prenatal alcohol exposure resulted in marked impairments of the cortical vasculature consisting in a reduced density and a loss of the radial orientation of microvessels.16 These morphometric defects were associated with a modification of VEGF receptors expression and, in particular, Western blot experiments revealed a strong decrease of cortical VEGFR1. In human, we evidenced a stage-dependent alteration of the vascular network in the cortex of alcohol-exposed foetuses (AEF): while no modification was observed from GW20 to GW22 between control and AEF groups, the radial organization of cortical microvessels was clearly altered in AEF patients from GW30 to GW38.

The placenta is an important source of pro-angiogenic factors and some of them such as PlGF are mainly expressed by this organ while its unique receptor VEGFR1 (shared with VEGFA and VEGFB) is expressed in the fetal brain.18 Using human recombinant PlGF, we showed in mice that placental PlGF can be released in the fetal blood and reach the fetal brain.19 In addition, in utero electroporation experiments performed in the placenta revealed that a targeted repression (ShRNA) or over-expression (CRISPR/dCas9) of PlGF in the placenta mimicked the effects of alcohol on VEGFR1 expression and rescued the alcohol-induced vessel disorganization, respectively. In human, we performed a molecular and morphological analysis of placental vasculature from women consuming alcohol.19 Results showed that prenatal alcohol exposure impairs placental angiogenesis and reduces PlGF levels. Interestingly, angiogenesis defects observed in the human fetal brain markedly correlated with placental vascular impairments.19 Altogether, these data support that placental PlGF disruption impairs the fetal brain angiogenesis.

IV. Possible impact and benefits

While alcohol exposure during pregnancy represents a major cause of neonatal handicap with major educational, societal and financial consequences for both industrialized and developing countries, the diagnosis of fetal alcohol spectrum disorder (FASD) remains to be improved. In fact, only the most severe form, the fetal alcohol syndrome, is diagnosed perinatally whereas most of FASD children are misdiagnosed until they are school-age. Consequently, precious years of clinical care are lost. These statements result, at least in part, from the absence of biomarkers of "alcohol-induced brain defects". Indeed, presently biomarkers of fetal alcohol exposure do not prejudge of neurodevelopmental defects. Studies from researchers of Inserm Unit 1245 support that placental PlGF is involved in the control of the fetal brain angiogenesis suggesting a functional "Placenta-Brain" axis. PlGF assay could help identify infants with brain damage associated with in utero alcohol exposure, thus contributing to an early diagnosis of FASD and prompt intervention. This work was patented (FR1555727/ PCT/EP2016/064480) and (FR1661813).

V. References

1. Global status report on Alcohol and Health. World Health Organization, Geneva, Switzerland, 2014, pp. 1-392.
2. Popova S, Lange S, Probst C, Gmel G, Rehm J. Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. Lancet Glob Health 2017, 5:e290-e299.
3. Bakoyiannis I et al. Fetal alcohol spectrum disorders and cognitive functions of young children. Rev Neurosci. 2014, 25:631-9.
4. Toutain S and Germanaud D. Exposition prénatale à l’alcool et troubles causés par l’alcoolisation fœtale Prenatal alcohol exposure and troubles caused by fetal exposure. [French] Expertise collective Inserm “Déficiences intellectuelles”. 2016, http://www.ipubli.inserm.fr/bitstream/handle/10608/6816/Communication_I-1.html.
5. Streissguth AP et al. Fetal alcohol syndrome in adolescents and adults. In Journal of the American Medical Association, 1991, 265:1961-7.
6. Chasnoff IJ et al. Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. Pediatrics 2015, 135:264-70.
7. Breiner P et al. Identifying the neurobehavioral phenotype of fetal alcohol spectrum disorder in young children. J Popul Ther Clin Pharmacol. 2013, 20:e334-9.
8. Hoyme HE et al. Updated Clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders. Pediatrics. 2016, 138:e20154256.
9. Lerna A et al. Long-term effects of PECS on social-communicative skills of children with autism spectrum disorders: a follow-up study. Int J Lang Commun Disord. 2014, 49:478-85.
10. Joya X et al. Determination of maternal-fetal biomarkers of prenatal exposure to ethanol: a review. J Pharm Biomed Anal. 2012, 69:209-22.
11. Bakhireva LN and Savage DD. Focus on: biomarkers of fetal alcohol exposure and fetal alcohol effects. Alcohol Res Health 2011, 34:56-63.
12. Miller JW et al. Binge drinking and associated health risk behaviors among high school students. Pediatrics 2007, 119:76-85.
13. Carmeliet P and Tessier-Lavigne M. Common mechanisms of nerve and blood vessel wiring. Nature 2005, 436:193-200.
14. Won C et al. Autonomous vascular networks synchronize GABA neuron migration in the embryonic forebrain. Nat Commun. 2013;4:2149.
15. Tsai HH et al. Oligodendrocyte precursors migrate along vasculature in the developing nervous system. Science 2016, 351:379-84.
16. Jégou S et al. Prenatal alcohol exposure affects vasculature development in the neonatal brain. Ann Neurol. 2012, 72:952-60.
17. Rosenberg MJ et al. Effects of moderate drinking during pregnancy on placental gene expression. Alcohol 2010, 44:673-90.
18. Cao Y et al. Placenta growth factor: identification and characterization of a novel isoform generated by RNA alternative splicing. Biochem Biophys Res Commun. 1997, 235:493-8.
19. Lecuyer M et al. PLGF, a placental marker of fetal brain defects after in utero alcohol exposure. Acta Neuropathol Commun. 2017, 5:44.

C4b Estimating PAE in West Virginia Using Residual Newborn Screening Specimens

Stefan Maxwell

Estimating Prenatal Alcohol Exposure in West Virginia using Residual Newborn Screening specimens

Stefan R Maxwell MD FAAP

Clinical Assoc. Prof. Pediatrics, WVU School of Medicine

PEDIATRIX MEDICAL GROUP

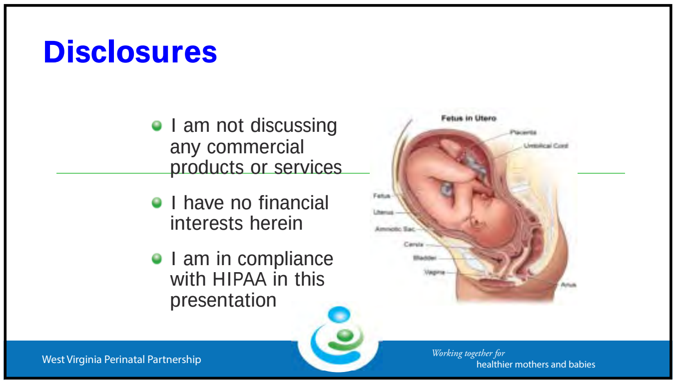
Director NICU Women & Children's Hospital, Charleston, W.V.

8th International Conference on Fetal Alcohol Spectrum Disorder: Research, Results and Relevance

The Westin Bayshore. Vancouver B.C.

West Virginia Perinatal Partnership

Working together for healthier mothers and babies



Disclosures

- I am not discussing any commercial products or services
- I have no financial interests herein
- I am in compliance with HIPAA in this presentation

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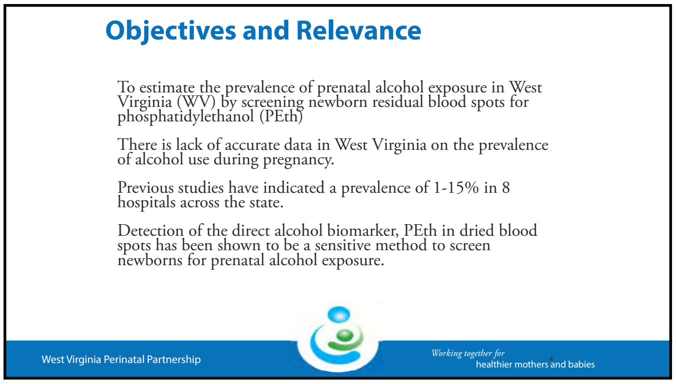

Objectives and Relevance

To estimate the prevalence of prenatal alcohol exposure in West Virginia (WV) by screening newborn residual blood spots for phosphatidylethanol (PEth)

There is lack of accurate data in West Virginia on the prevalence of alcohol use during pregnancy.

Previous studies have indicated a prevalence of 1-15% in 8 hospitals across the state.

Detection of the direct alcohol biomarker, PEth in dried blood spots has been shown to be a sensitive method to screen newborns for prenatal alcohol exposure.

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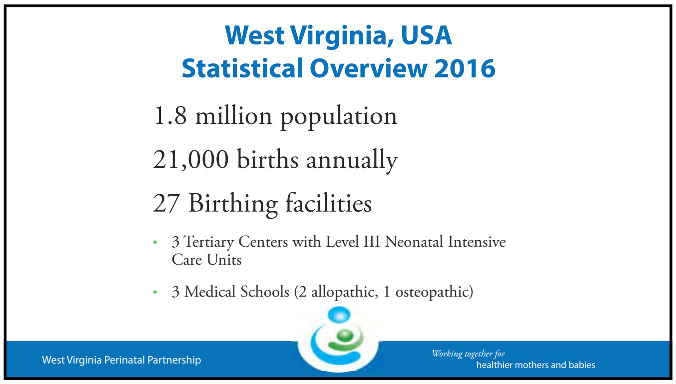

West Virginia, USA
Statistical Overview 2016

1.8 million population

21,000 births annually

27 Birthing facilities

- 3 Tertiary Centers with Level III Neonatal Intensive Care Units
- 3 Medical Schools (2 allopathic, 1 osteopathic)

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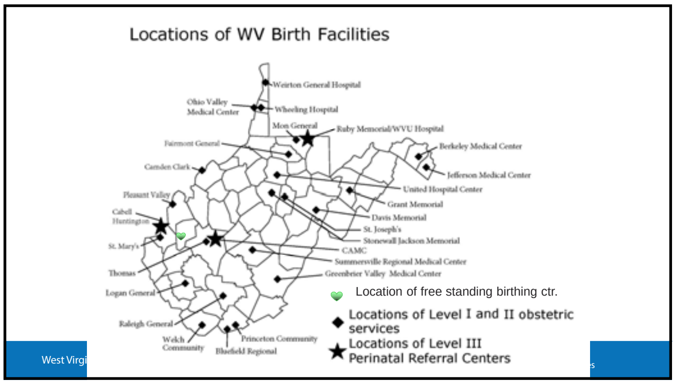


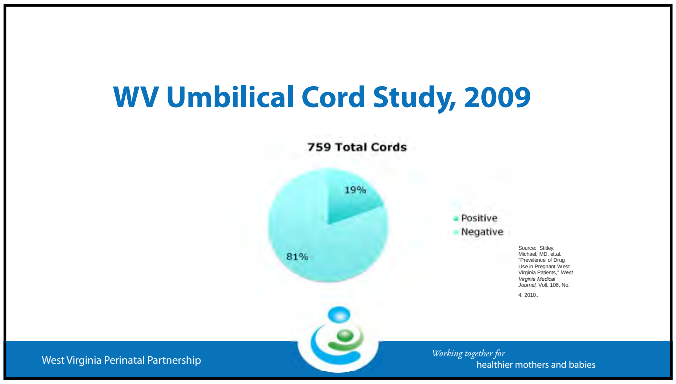
Locations of WV Birth Facilities

💚 Location of free standing birthing ctr.

◆ Locations of Level I and II obstetric services

★ Locations of Level III Perinatal Referral Centers

West Virgi



WV Umbilical Cord Study, 2009

Source: Stitley, Michael, MD, et.al. "Prevalence of Drug Use in Pregnant West Virginia Patients," *West Virginia Medical Journal*, Voll. 106, No. 4, 2010.

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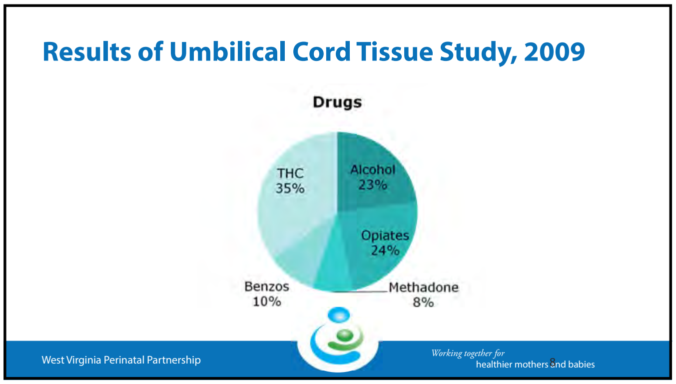

Results of Umbilical Cord Tissue Study, 2009

West Virginia Perinatal Partnership

Working together for healthier mothers and babies

Detection of alcohol rates in pregnancy

- Stitely ML. et al WV Med J 2010,106:48-52

  --Cord study (anonymous) 39/759 = 5.1%

  --Birth cert/WV Birth score: 13/1079=1.2%
- Detection rates at W&C Hosp, and WMC

  --Cord study (anonymous) : 11/133 = 8.3%

  --Birth cert/WV Birth score :2/283 =0.7%

  Urine screens (3/1/12-1/31/13): 6/545 =1.1%

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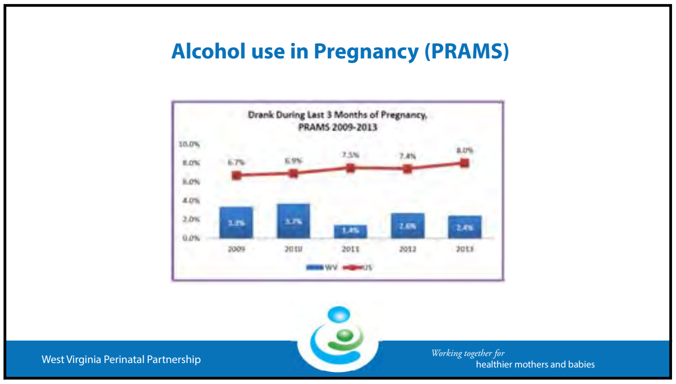

Alcohol use in Pregnancy (PRAMS)

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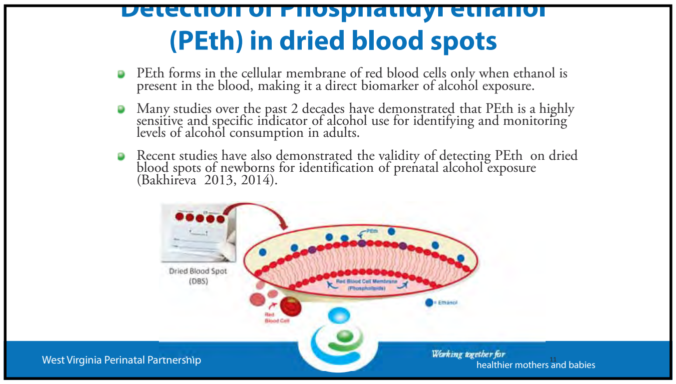

Detection of Phosphatidyl ethanol (PEth) in dried blood spots

- PEth forms in the cellular membrane of red blood cells only when ethanol is present in the blood, making it a direct biomarker of alcohol exposure.
- Many studies over the past 2 decades have demonstrated that PEth is a highly sensitive and specific indicator of alcohol use for identifying and monitoring levels of alcohol consumption in adults.
- Recent studies have also demonstrated the validity of detecting PEth on dried blood spots of newborns for identification of prenatal alcohol exposure (Bakhireva 2013, 2014).

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Improving screening for alcohol consumption during pregnancy with phosphatidylethanol (Bracero et al) Reproductive Toxicology 74(2017) 104-107

- Compared rates of alcohol use between urine ethanol testing and self-reporting (Method 1) and PEth dried blood spot testing and self-reporting (Method 2)
- Method 2 identified more alcohol users than Method 1.
- Combining both methods resulted in a detection rate of 10.2% in the first trimester or at first antenatal visit

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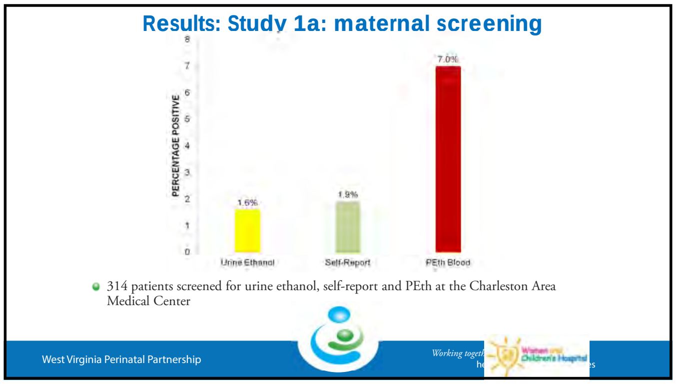
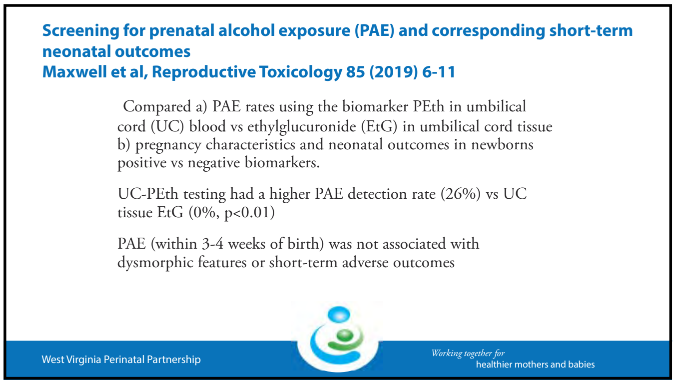


Results: Study 1a: maternal screening

- 314 patients screened for urine ethanol, self-report and PEth at the Charleston Area Medical Center

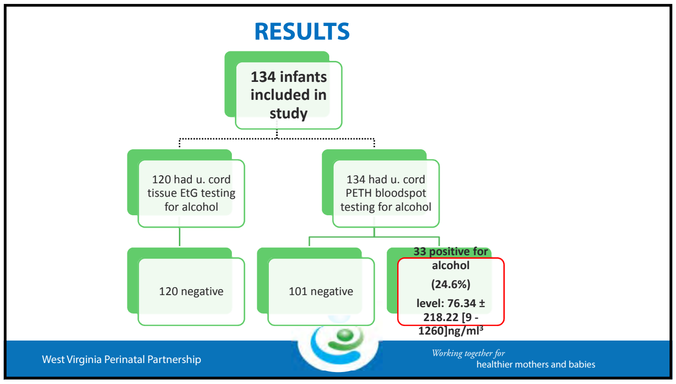


Screening for prenatal alcohol exposure (PAE) and corresponding short-term neonatal outcomes
Maxwell et al, Reproductive Toxicology 85 (2019) 6-11

Compared a) PAE rates using the biomarker PEth in umbilical cord (UC) blood vs ethylglucuronide (EtG) in umbilical cord tissue b) pregnancy characteristics and neonatal outcomes in newborns positive vs negative biomarkers.

UC-PEth testing had a higher PAE detection rate (26%) vs UC tissue EtG (0%, p<0.01)

PAE (within 3-4 weeks of birth) was not associated with dysmorphic features or short-term adverse outcomes



RESULTS

134 infants included in study

120 had u. cord tissue EtG testing for alcohol

134 had u. cord PETH bloodspot testing for alcohol

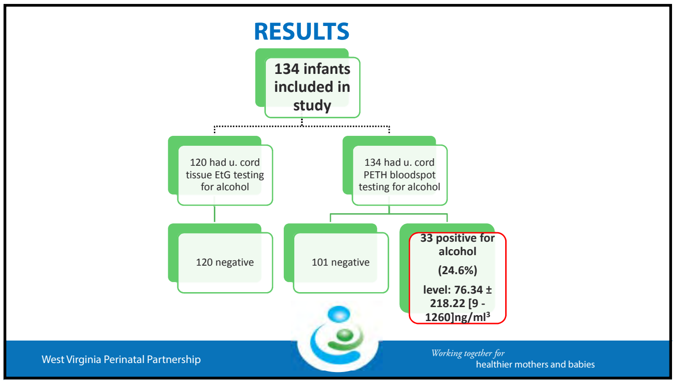
120 negative

101 negative

33 positive for alcohol

(24.6%)

level: 76.34 ± 218.22 [9 - 1260]ng/ml^3



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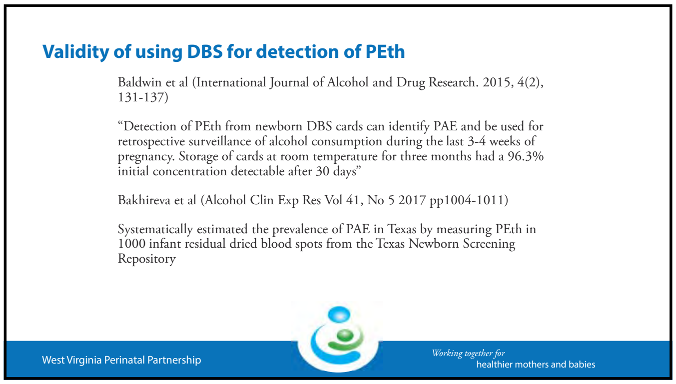


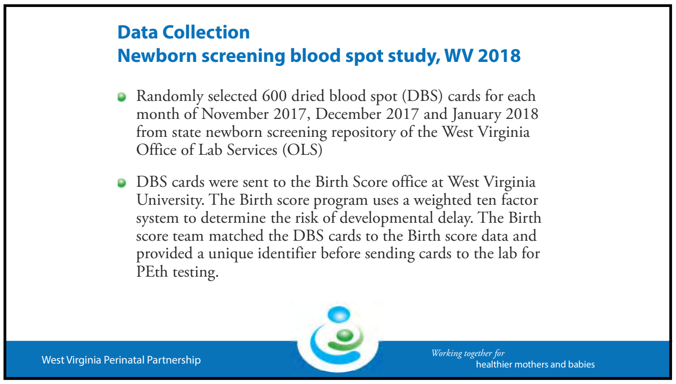
Validity of using DBS for detection of PEth

Baldwin et al (International Journal of Alcohol and Drug Research. 2015, 4(2), 131-137)

"Detection of PEth from newborn DBS cards can identify PAE and be used for retrospective surveillance of alcohol consumption during the last 3-4 weeks of pregnancy. Storage of cards at room temperature for three months had a 96.3% initial concentration detectable after 30 days"

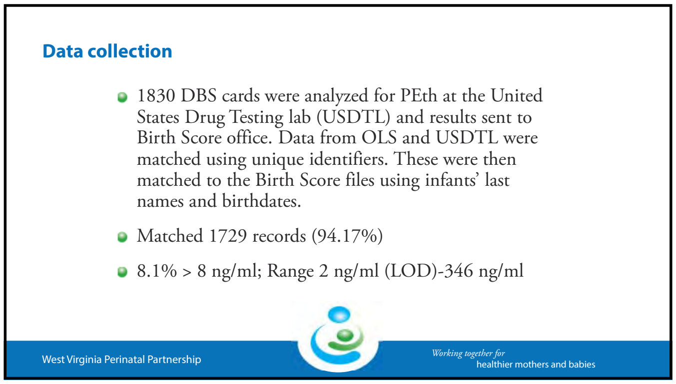
Bakhireva et al (Alcohol Clin Exp Res Vol 41, No 5 2017 pp1004-1011)

Systematically estimated the prevalence of PAE in Texas by measuring PEth in 1000 infant residual dried blood spots from the Texas Newborn Screening Repository



Data Collection
Newborn screening blood spot study, WV 2018

- Randomly selected 600 dried blood spot (DBS) cards for each month of November 2017, December 2017 and January 2018 from state newborn screening repository of the West Virginia Office of Lab Services (OLS)
- DBS cards were sent to the Birth Score office at West Virginia University. The Birth score program uses a weighted ten factor system to determine the risk of developmental delay. The Birth score team matched the DBS cards to the Birth score data and provided a unique identifier before sending cards to the lab for PEth testing.



Data collection

- 1830 DBS cards were analyzed for PEth at the United States Drug Testing lab (USDTL) and results sent to Birth Score office. Data from OLS and USDTL were matched using unique identifiers. These were then matched to the Birth Score files using infants' last names and birthdates.
- Matched 1729 records (94.17%)
- 8.1% > 8 ng/ml; Range 2 ng/ml (LOD)-346 ng/ml

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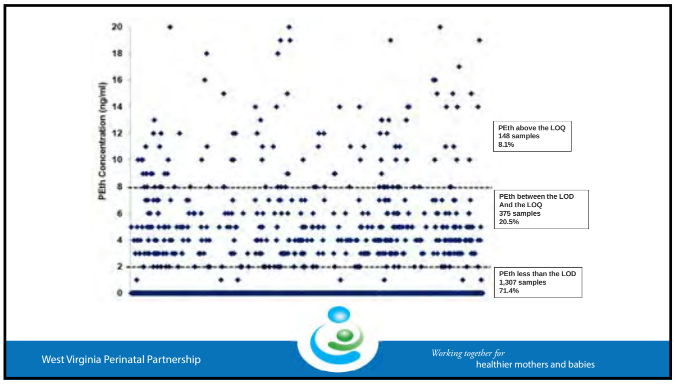

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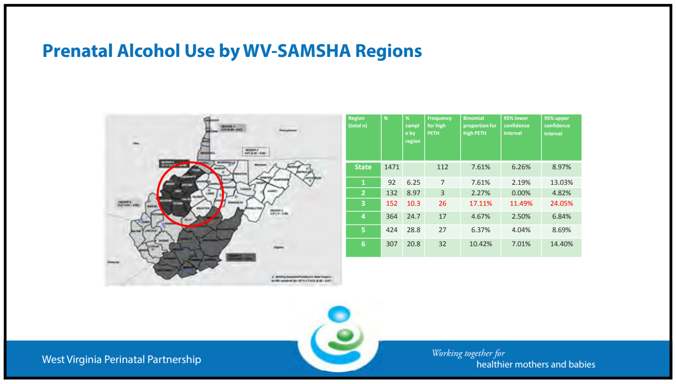

Prenatal Alcohol Use by WV-SAMSHA Regions

Region (total n)	N	% sample by region	Frequency for high PETH	Binomial proportion for high PETH	95% lower confidence interval	95% upper confidence interval
State	1471		112	7.61%	6.26%	8.97%
1	92	6.25	7	7.61%	2.19%	13.03%
2	132	8.97	3	2.27%	0.00%	4.82%
3	152	10.3	26	17.11%	11.49%	24.05%
4	364	24.7	17	4.67%	2.50%	6.84%
5	424	28.8	27	6.37%	4.04%	8.69%
6	307	20.8	32	10.42%	7.01%	14.40%

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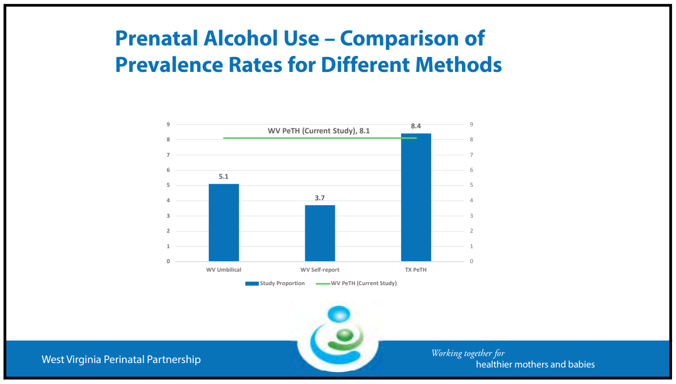

Prenatal Alcohol Use – Comparison of Prevalence Rates for Different Methods

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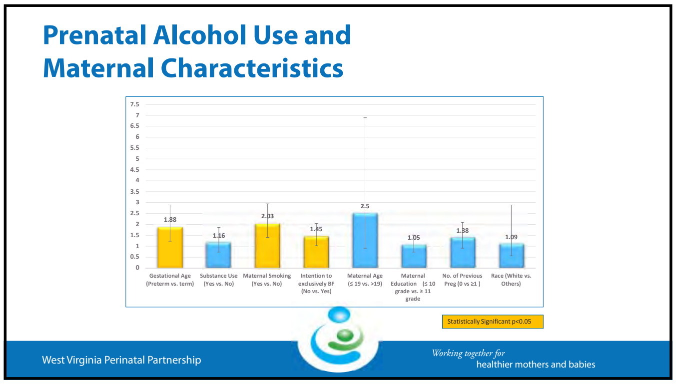

Prenatal Alcohol Use and Maternal Characteristics

Statistically Significant p<0.05

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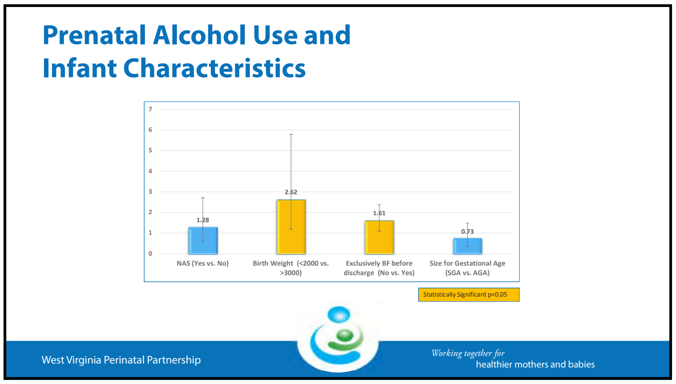

Prenatal Alcohol Use and Infant Characteristics

Statistically Significant p<0.05

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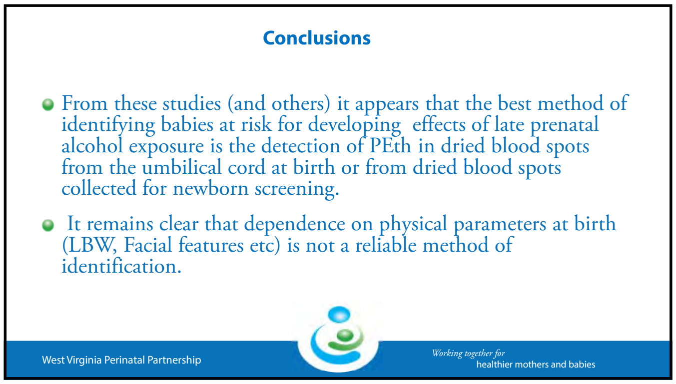

Conclusions

- From these studies (and others) it appears that the best method of identifying babies at risk for developing effects of late prenatal alcohol exposure is the detection of PEth in dried blood spots from the umbilical cord at birth or from dried blood spots collected for newborn screening.
- It remains clear that dependence on physical parameters at birth (LBW, Facial features etc) is not a reliable method of identification.

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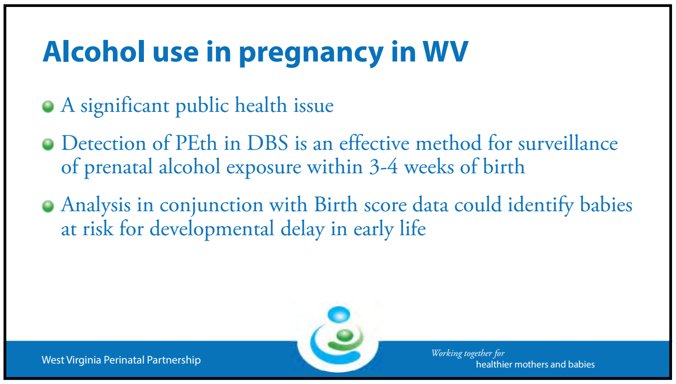

Alcohol use in pregnancy in WV

- A significant public health issue
- Detection of PEth in DBS is an effective method for surveillance of prenatal alcohol exposure within 3-4 weeks of birth
- Analysis in conjunction with Birth score data could identify babies at risk for developmental delay in early life

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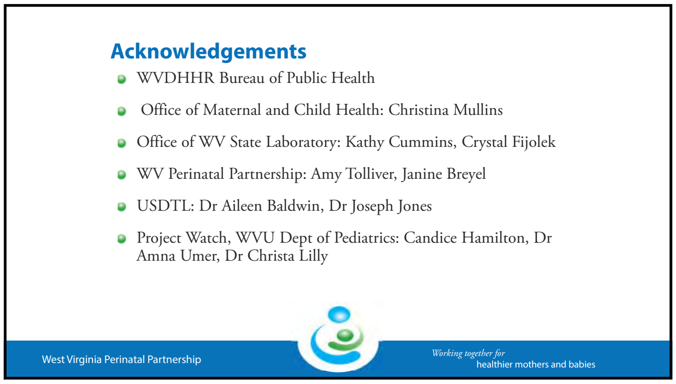

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- Project Watch, WVU Dept of Pediatrics: Candice Hamilton, Dr Amna Umer, Dr Christa Lilly

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Questions?

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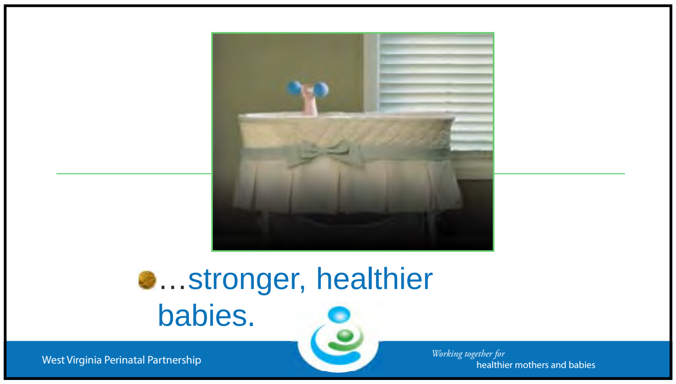

- …stronger, healthier babies.

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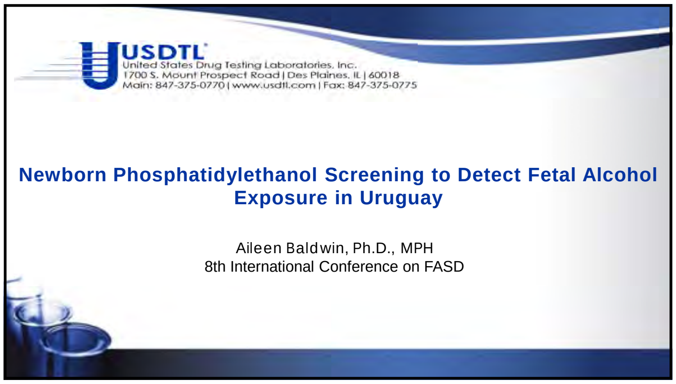
C4c

Newborn Phosphatidyethanol Screening to Detect Fetal Alcohol Exposure in Uruguay

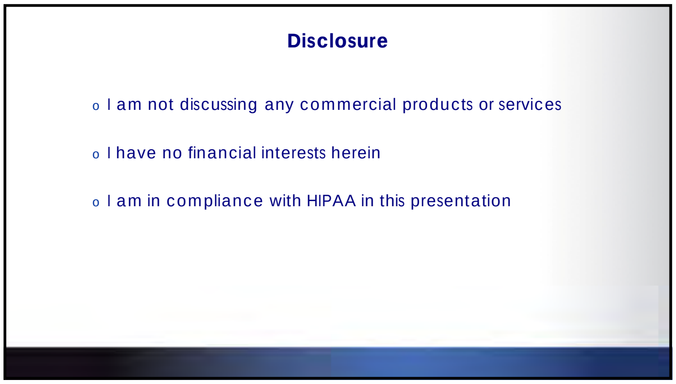
Aileen Baldwin



USDTL
United States Drug Testing Laboratories, Inc.
1700 S. Mount Prospect Road | Des Plaines, IL | 60018
Main: 847-375-0770 | www.usdtl.com | Fax: 847-375-0775

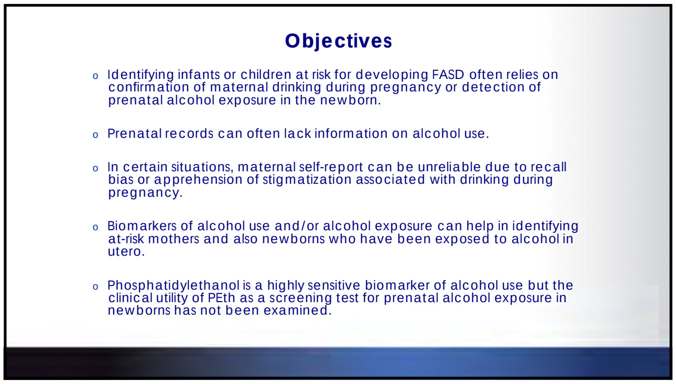
Newborn Phosphatidylethanol Screening to Detect Fetal Alcohol Exposure in Uruguay

Aileen Baldwin, Ph.D., MPH
8th International Conference on FASD



Disclosure

- I am not discussing any commercial products or services
- I have no financial interests herein
- I am in compliance with HIPAA in this presentation

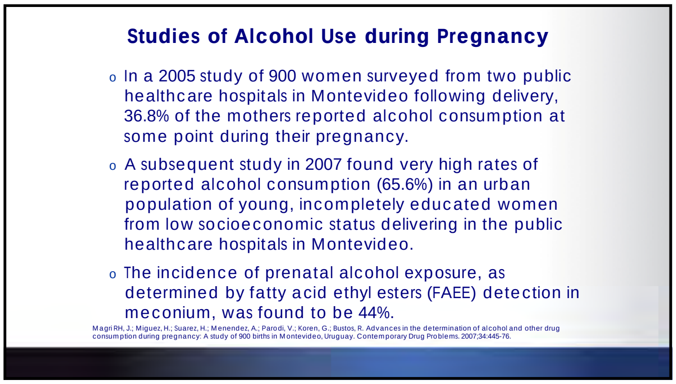


Objectives

- Identifying infants or children at risk for developing FASD often relies on confirmation of maternal drinking during pregnancy or detection of prenatal alcohol exposure in the newborn.
- Prenatal records can often lack information on alcohol use.
- In certain situations, maternal self-report can be unreliable due to recall bias or apprehension of stigmatization associated with drinking during pregnancy.
- Biomarkers of alcohol use and/or alcohol exposure can help in identifying at-risk mothers and also newborns who have been exposed to alcohol in utero.
- Phosphatidylethanol is a highly sensitive biomarker of alcohol use but the clinical utility of PEth as a screening test for prenatal alcohol exposure in newborns has not been examined.

Uruguay

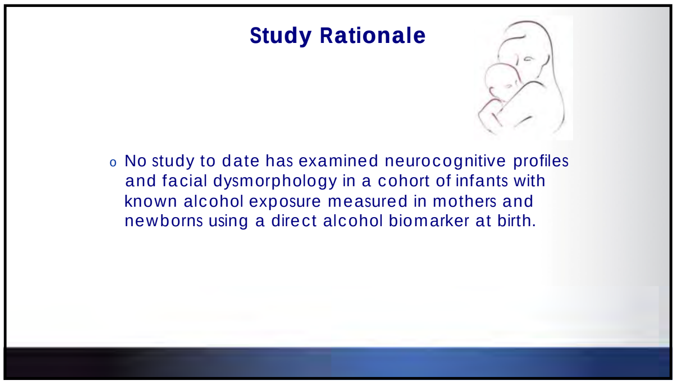
- Cultural patterns of drinking alcohol in Uruguay have changed in the last 30 years, from moderate consumption with meals to more risky patterns of heavy alcohol consumption.
- Drinking during pregnancy is common in Uruguay, in part due to a lack of information given to pregnant women about possible alcohol-related risks from drinking during pregnancy.
- National surveys do not assess alcohol consumption during pregnancy in Uruguay, although recent epidemiological studies have demonstrated that it is a significant problem.



Studies of Alcohol Use during Pregnancy

- In a 2005 study of 900 women surveyed from two public healthcare hospitals in Montevideo following delivery, 36.8% of the mothers reported alcohol consumption at some point during their pregnancy.
- A subsequent study in 2007 found very high rates of reported alcohol consumption (65.6%) in an urban population of young, incompletely educated women from low socioeconomic status delivering in the public healthcare hospitals in Montevideo.
- The incidence of prenatal alcohol exposure, as determined by fatty acid ethyl esters (FAEE) detection in meconium, was found to be 44%.

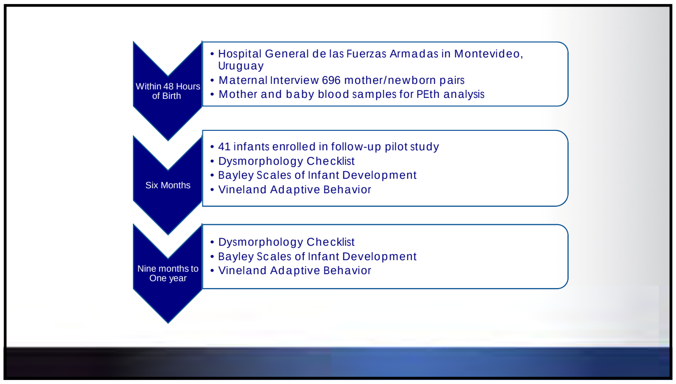
Magri RH, J.; Miguez, H.; Suarez, H.; Menendez, A.; Parodi, V.; Koren, G.; Bustos, R. Advances in the determination of alcohol and other drug consumption during pregnancy: A study of 900 births in Montevideo, Uruguay. Contemporary Drug Problems. 2007;34:445-76.



Study Rationale

- No study to date has examined neurocognitive profiles and facial dysmorphology in a cohort of infants with known alcohol exposure measured in mothers and newborns using a direct alcohol biomarker at birth.

Design

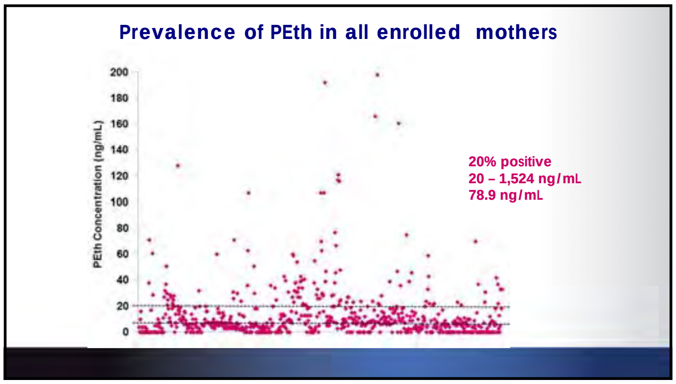


Within 48 Hours of Birth
- Hospital General de las Fuerzas Armadas in Montevideo, Uruguay
- Maternal Interview 696 mother/newborn pairs
- Mother and baby blood samples for PEth analysis

Six Months
- 41 infants enrolled in follow-up pilot study
- Dysmorphology Checklist
- Bayley Scales of Infant Development
- Vineland Adaptive Behavior

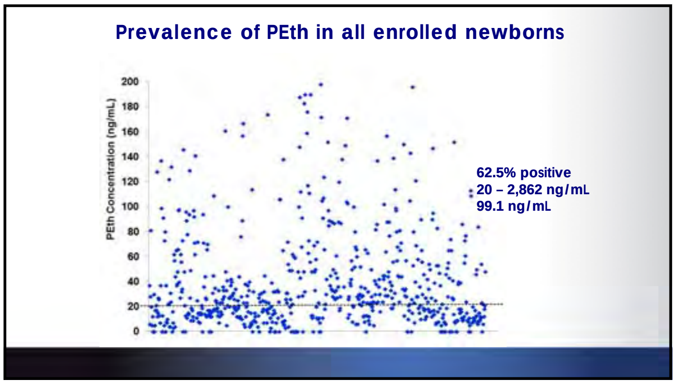
Nine months to One year
- Dysmorphology Checklist
- Bayley Scales of Infant Development
- Vineland Adaptive Behavior

Biomarker Results



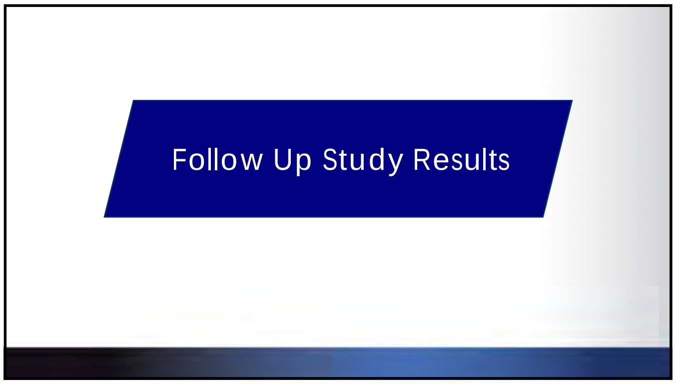
Prevalence of PEth in all enrolled mothers

20% positive
20 – 1,524 ng/mL
78.9 ng/mL

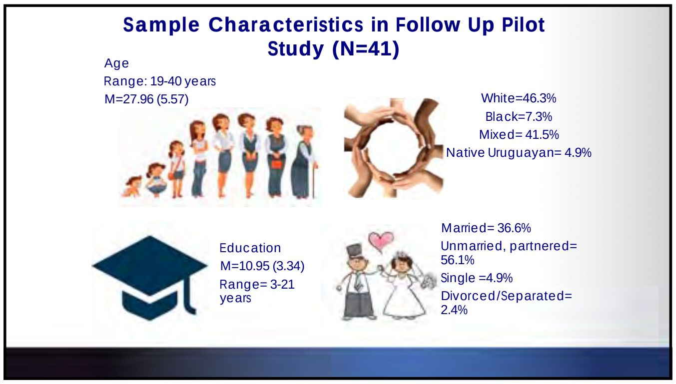


Prevalence of PEth in all enrolled newborns

62.5% positive
20 – 2,862 ng/mL
99.1 ng/mL



Follow Up Study Results



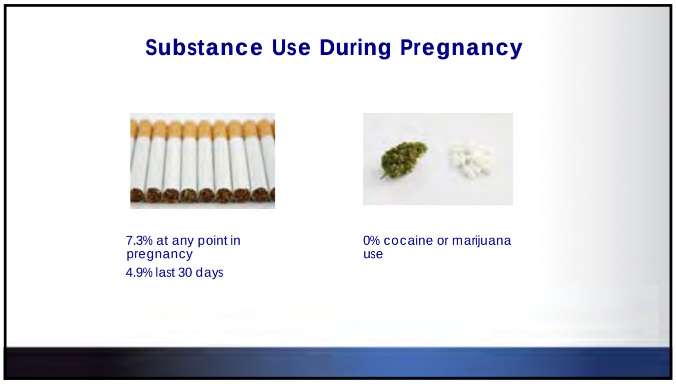
Sample Characteristics in Follow Up Pilot Study (N=41)

Age
Range: 19-40 years
M=27.96 (5.57)

White=46.3%
Black=7.3%
Mixed= 41.5%
Native Uruguayan= 4.9%

Education
M=10.95 (3.34)
Range= 3-21 years

Married= 36.6%
Unmarried, partnered= 56.1%
Single =4.9%
Divorced/Separated= 2.4%



Substance Use During Pregnancy

7.3% at any point in pregnancy
4.9% last 30 days

0% cocaine or marijuana use

Alcohol Use During Pregnancy

Self-Report

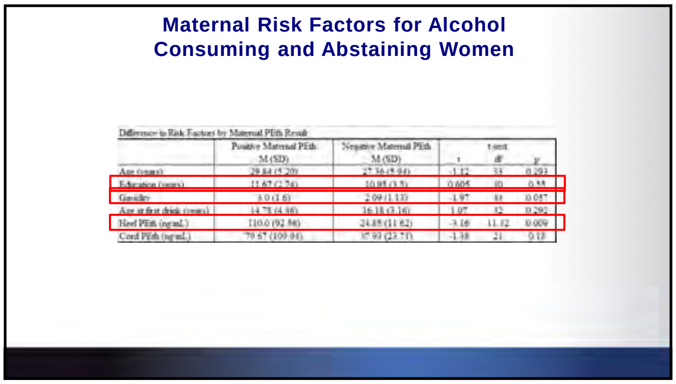
First Trimester= 25%
Second Trimester= 4.9%
Last Trimester= 9.8%
Any point in pregnancy = 26.8%

Maternal PEth

Positive =29.3%
Negative= 56.1%
Missing= 14.6%

Average PEth= 34.58ng/mL

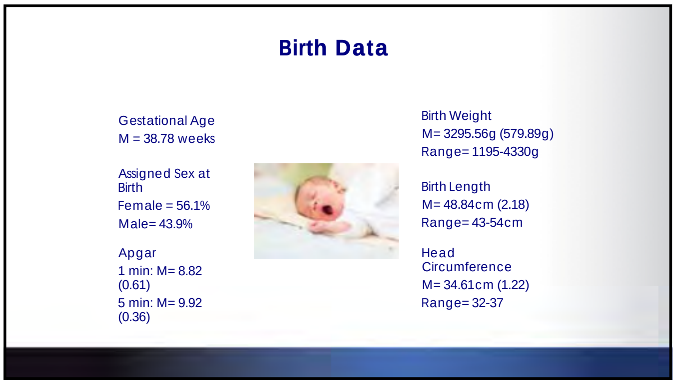
Range= 8 -128 ng/mL



Maternal Risk Factors for Alcohol Consuming and Abstaining Women

Difference in Risk Factors by Maternal PEth Result

	Positive Maternal PEth	Negative Maternal PEth	t-test		
	M (SD)	M (SD)	t	df	p
Age (years)	29.84 (5.20)	27.36 (5.94)	-1.12	33	0.293
Education (years)	11.67 (2.74)	10.95 (3.5)	0.605	10	0.55
Gravidity	3.0 (1.6)	2.09 (1.13)	-1.97	33	0.057
Age at first drink (years)	14.78 (4.86)	16.18 (3.16)	1.07	32	0.292
Heel PEth (ng/mL)	110.0 (92.86)	24.85 (11.62)	-3.16	11.12	0.009
Cord PEth (ng/mL)	79.67 (109.04)	37.93 (23.71)	-1.38	21	0.18



Birth Data

Gestational Age
M = 38.78 weeks

Assigned Sex at Birth
Female = 56.1%
Male= 43.9%

Apgar
1 min: M= 8.82 (0.61)
5 min: M= 9.92 (0.36)

Birth Weight
M= 3295.56g (579.89g)
Range= 1195-4330g

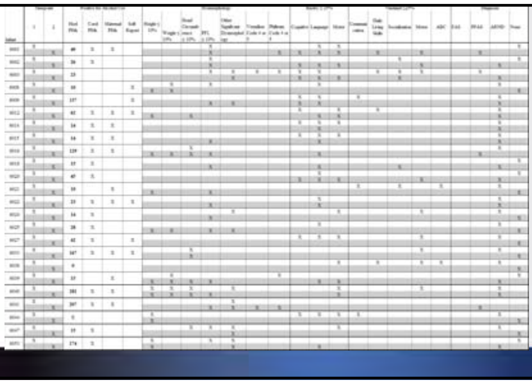
Birth Length
M= 48.84cm (2.18)
Range= 43-54cm

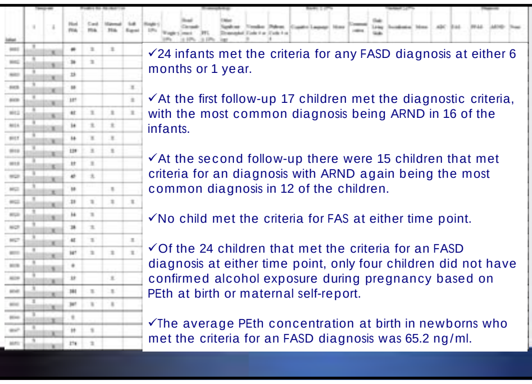
Head Circumference
M= 34.61cm (1.22)
Range= 32-37

Infant Biomarker Results

Umbilical Cord Blood PEth	Heel Stick Blood PEth
Positive= 63.4% Negative= 9.8% Missing= 26.8%	Positive= 65.9% Negative= 14.6% Missing= 19.5%
Mean Positive PEth= 54.9ng/mL	Mean Positive PEth= 61.8 ng/mL
Range= 13 - 367ng/mL	Range= 8 - 281ng/mL

Infants Meeting FASD Criteria





✓24 infants met the criteria for any FASD diagnosis at either 6 months or 1 year.

✓At the first follow-up 17 children met the diagnostic criteria, with the most common diagnosis being ARND in 16 of the infants.

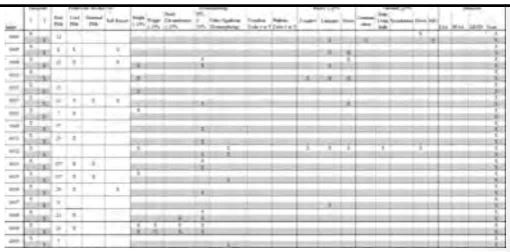
✓At the second follow-up there were 15 children that met criteria for an diagnosis with ARND again being the most common diagnosis in 12 of the children.

✓No child met the criteria for FAS at either time point.

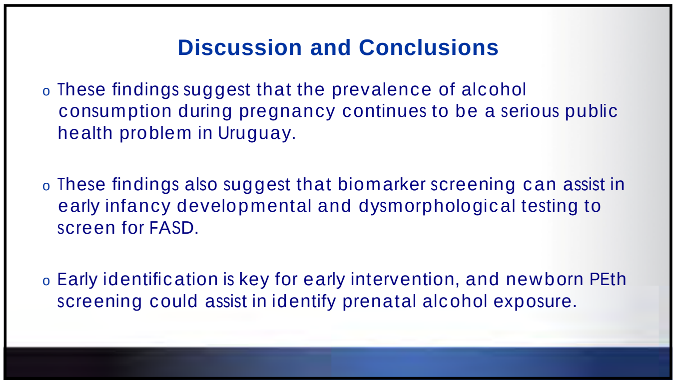
✓Of the 24 children that met the criteria for an FASD diagnosis at either time point, only four children did not have confirmed alcohol exposure during pregnancy based on PEth at birth or maternal self-report.

✓The average PEth concentration at birth in newborns who met the criteria for an FASD diagnosis was 65.2 ng/ml.

Infants Not Meeting FASD Criteria



✓17 children did not meet the criteria for an FASD diagnosis at 6 months or 1 year time points.
✓17.6% of the mothers had a positive PEth at the time of birth, compared to 45% of the mothers who had a child that did meet the criteria for an FASD.
✓The average PEth concentration at birth in newborns who did not meet the criteria for an FASD diagnosis was 37.5 ng/ml.



Discussion and Conclusions

- These findings suggest that the prevalence of alcohol consumption during pregnancy continues to be a serious public health problem in Uruguay.
- These findings also suggest that biomarker screening can assist in early infancy developmental and dysmorphological testing to screen for FASD.
- Early identification is key for early intervention, and newborn PEth screening could assist in identify prenatal alcohol exposure.

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C4d Gestational Binge Drinking and Fetal Growth: Systematic Review of Prospective Cohort Studies

Lesley Smith

UNIVERSITY OF HULL

Gestational binge drinking and fetal growth: systematic review of prospective cohort studies

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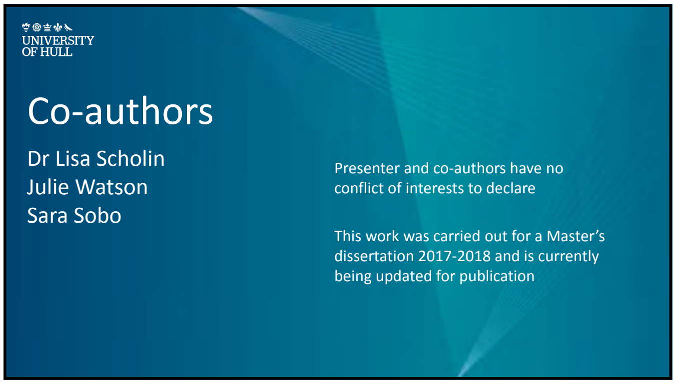

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Presenter and co-authors have no conflict of interests to declare

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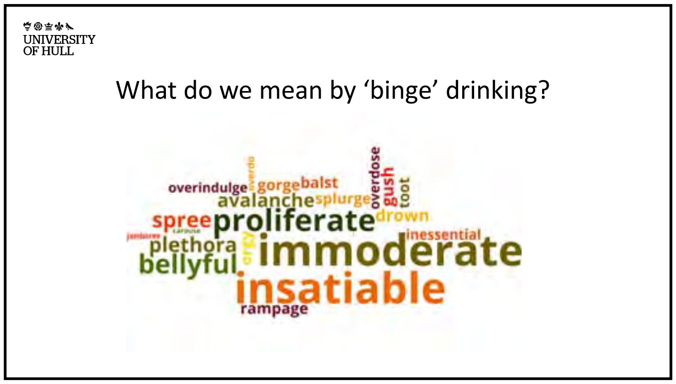

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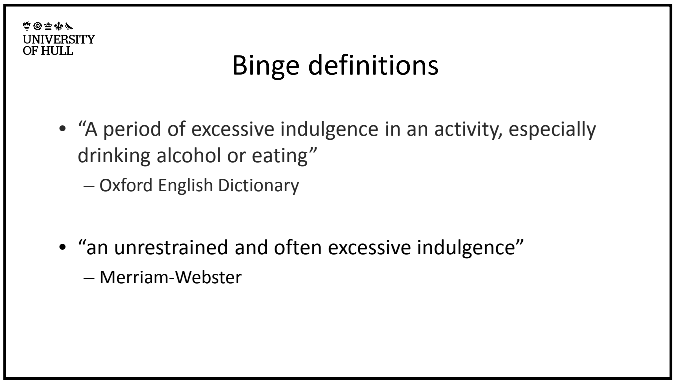
What do we mean by 'binge' drinking?



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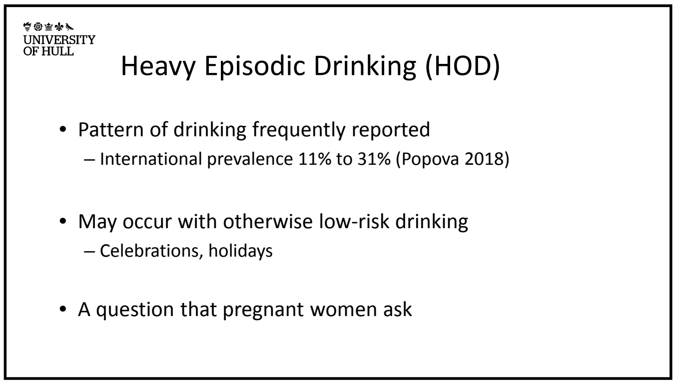
Binge definitions

- "A period of excessive indulgence in an activity, especially drinking alcohol or eating"
  - Oxford English Dictionary
- "an unrestrained and often excessive indulgence"
  - Merriam-Webster



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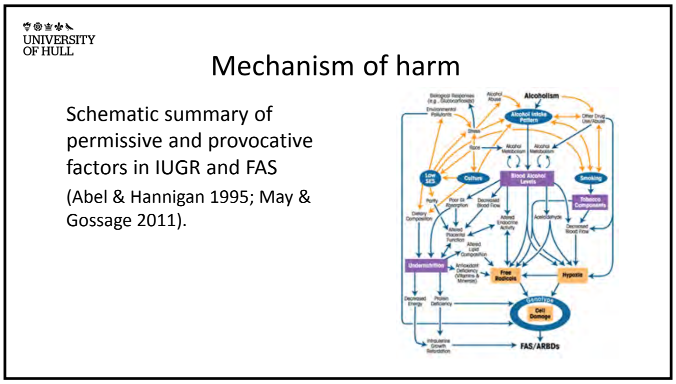
Heavy Episodic Drinking (HOD)

- Pattern of drinking frequently reported
  - International prevalence 11% to 31% (Popova 2018)
- May occur with otherwise low-risk drinking
  - Celebrations, holidays
- A question that pregnant women ask



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Mechanism of harm

Schematic summary of permissive and provocative factors in IUGR and FAS

(Abel & Hannigan 1995; May & Gossage 2011).

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RESEARCH REPORT

Systematic review of the fetal effects of prenatal binge-drinking

Jane Henderson, Ulrik Kesmodel, Ron Gray

NIH Public Access
Author Manuscript

NIH-PA Author Manuscript

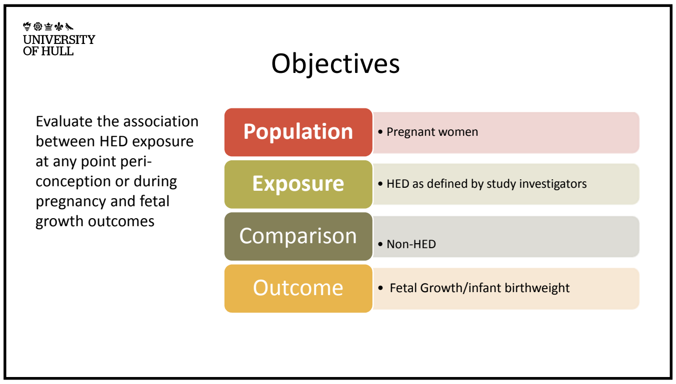
Dose-response relationship between alcohol consumption before and during pregnancy and the risks of low birth weight, preterm birth and small-size-for-gestational age (SGA) – A systematic review and meta-analyses

Jayadeep Patra, Rachel Bakker, Hyacinth Irving, Vincent W.V. Jaddoe, Shobha Malini, and Jürgen Rehm

Abstract

The Association of Mild, Moderate, and Binge Prenatal Alcohol Exposure and Child Neuropsychological Outcomes: A Meta-Analysis

Audrey L. Flak, Su Su, Jacquelyn Bertrand, Clark H. Denny, Ulrik S. Kesmodel, and Mary E. Cogswell



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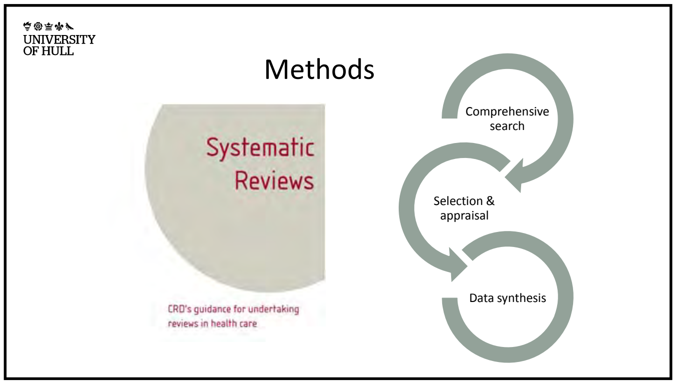
Objectives

Evaluate the association between HED exposure at any point peri-conception or during pregnancy and fetal growth outcomes

Population	• Pregnant women
Exposure	• HED as defined by study investigators
Comparison	• Non-HED
Outcome	• Fetal Growth/infant birthweight



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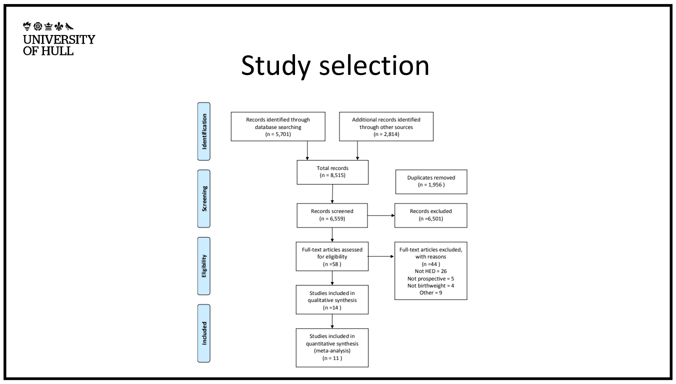
Methods



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Study selection

Records identified through database searching (n = 5,701)

Additional records identified through other sources (n = 2,814)

Total records (n = 8,515)

Duplicates removed (n = 1,956)

Records screened (n = 6,559)

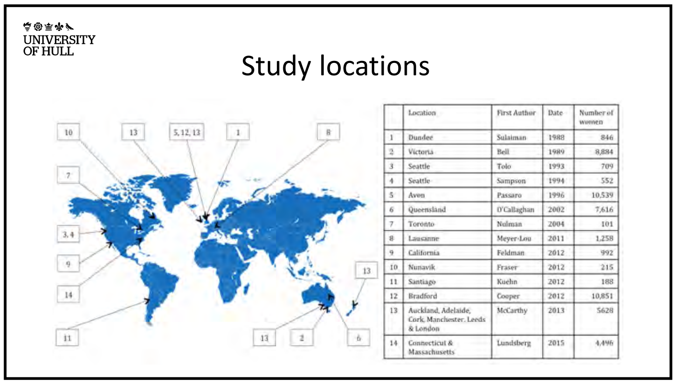
Records excluded (n =6,501)

Full-text articles assessed for eligibility (n =58)

Full-text articles excluded, with reasons (n =44)
Not HED = 26
Not prospective = 5
Not birthweight = 4
Other = 9

Studies included in qualitative synthesis (n =14)

Studies included in quantitative synthesis (meta-analysis) (n = 11)



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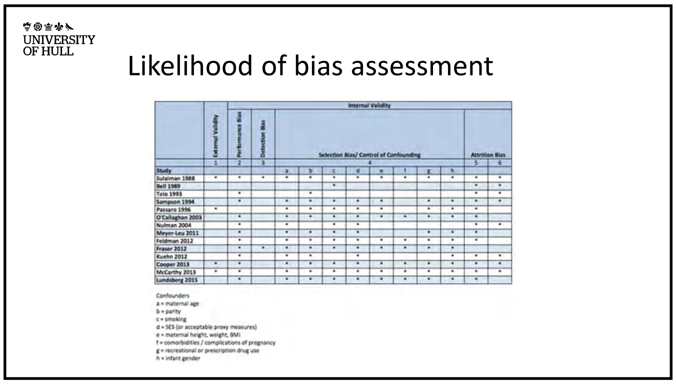
Study locations

	Location	First Author	Date	Number of women
1	Dundee	Sulaiman	1988	846
2	Victoria	Bell	1989	8,884
3	Seattle	Tolo	1993	709
4	Seattle	Sampson	1994	552
5	Avon	Passaro	1996	10,539
6	Queensland	O'Callaghan	2002	7,616
7	Toronto	Nulman	2004	101
8	Lausanne	Meyer-Lou	2011	1,258
9	California	Feldman	2012	992
10	Nunavik	Fraser	2012	215
11	Santiago	Kuehn	2012	188
12	Bradford	Cooper	2012	10,851
13	Auckland, Adelaide, Cork, Manchester, Leeds & London	McCarthy	2013	5628
14	Connecticut & Massachusetts	Lundsberg	2015	4,496



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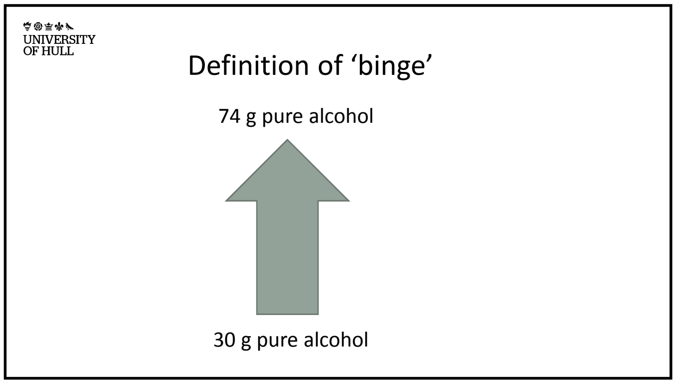
Likelihood of bias assessment

	External Validity	Internal Validity											
		Performance Bias	Detection Bias	Selection Bias/ Control of Confounding								Attrition Bias	
	1	2	3	4								5	6
Study				a	b	c	d	e	f	g	h		
Sulaiman 1988	•	•	•	•	•	•	•	•	•	•	•	•	•
Bell 1989						•						•	•
Tolo 1993		•			•							•	•
Sampson 1994		•		•	•	•	•	•		•	•	•	•
Passaro 1996	•			•	•	•	•	•		•	•	•	
O'Callaghan 2003		•		•	•	•	•	•	•	•	•	•	
Nulman 2004		•		•		•	•					•	•
Meyer-Leu 2011		•		•	•	•	•			•	•	•	
Feldman 2012		•		•	•	•	•	•	•	•	•	•	
Fraser 2012		•	•	•	•	•	•	•	•	•	•		
Kuehn 2012		•		•	•		•				•	•	•
Cooper 2013	•	•		•	•	•	•	•	•	•	•	•	•
McCarthy 2013	•	•		•	•	•	•	•	•	•	•	•	•
Lundsberg 2015		•		•	•	•	•	•	•	•	•	•	

Confounders
a = maternal age
b = parity
c = smoking
d = SES (or acceptable proxy measures)
e = maternal height, weight, BMI
f = comorbidities / complications of pregnancy
g = recreational or prescription drug use
h = infant gender



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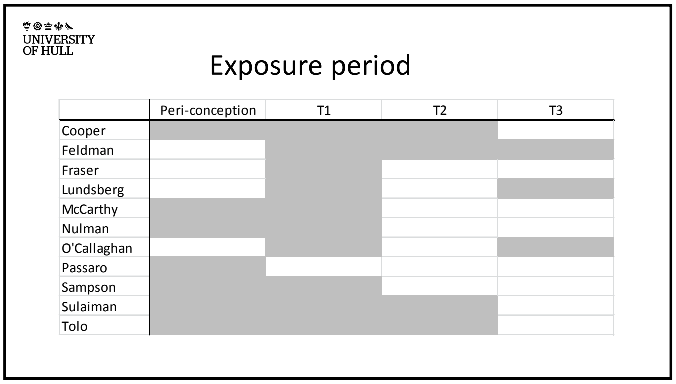
Definition of 'binge'

74 g pure alcohol

30 g pure alcohol



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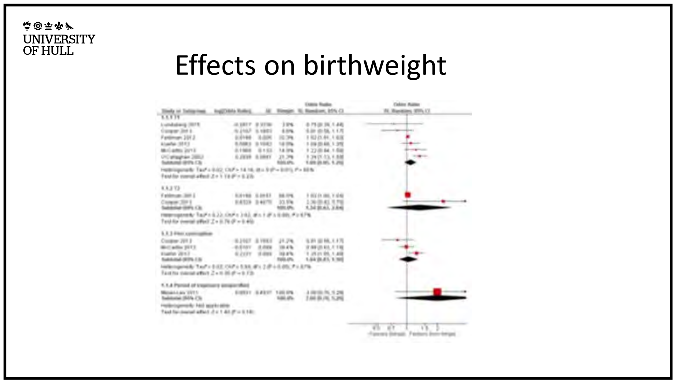
Exposure period

	Peri-conception	T1	T2	T3
Cooper	▨	▨	▨	
Feldman		▨	▨	▨
Fraser		▨		
Lundsberg		▨		▨
McCarthy	▨	▨		
Nulman	▨	▨		
O'Callaghan		▨		▨
Passaro	▨			
Sampson	▨	▨		
Sulaiman	▨	▨	▨	
Tolo	▨	▨	▨	



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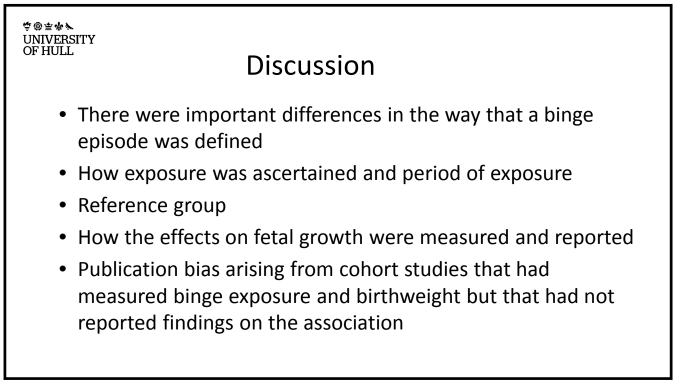
Effects on birthweight



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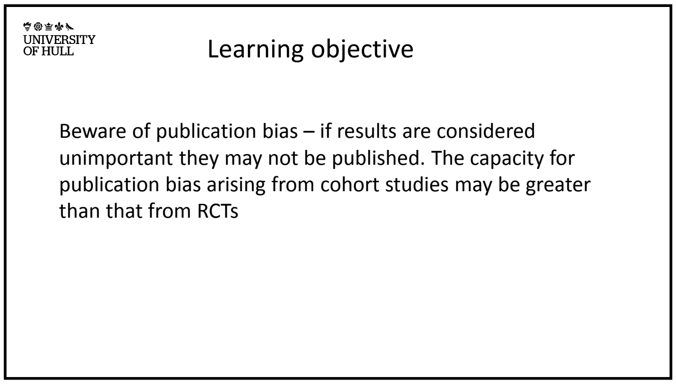
Discussion

- There were important differences in the way that a binge episode was defined
- How exposure was ascertained and period of exposure
- Reference group
- How the effects on fetal growth were measured and reported
- Publication bias arising from cohort studies that had measured binge exposure and birthweight but that had not reported findings on the association



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Learning objective

Beware of publication bias – if results are considered unimportant they may not be published. The capacity for publication bias arising from cohort studies may be greater than that from RCTs

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Thank you
Any Questions?

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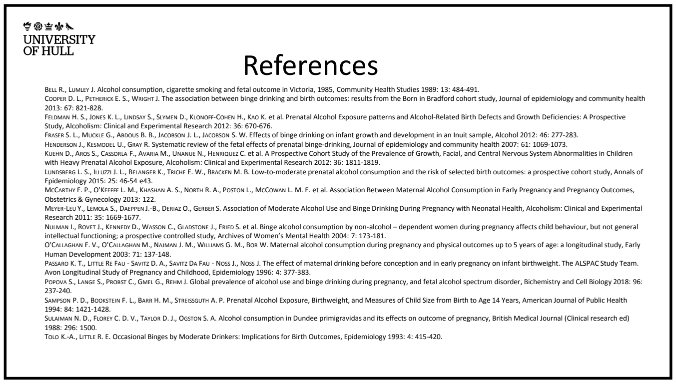

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References

Bell R., Lumley J. Alcohol consumption, cigarette smoking and fetal outcome in Victoria, 1985, Community Health Studies 1989: 13: 484-491.
Cooper D. L., Petherick E. S., Wright J. The association between binge drinking and birth outcomes: results from the Born in Bradford cohort study, Journal of epidemiology and community health 2013: 67: 821-828.
Feldman H. S., Jones K. L., Lindsay S., Slymen D., Klonoff-Cohen H., Kao K. et al. Prenatal Alcohol Exposure patterns and Alcohol-Related Birth Defects and Growth Deficiencies: A Prospective Study, Alcoholism: Clinical and Experimental Research 2012: 36: 670-676.
Fraser S. L., Muckle G., Abdous B. B., Jacobson J. L., Jacobson S. W. Effects of binge drinking on infant growth and development in an Inuit sample, Alcohol 2012: 46: 277-283.
Henderson J., Kesmodel U., Gray R. Systematic review of the fetal effects of prenatal binge-drinking, Journal of epidemiology and community health 2007: 61: 1069-1073.
Kuehn D., Aros S., Cassorla F., Avaria M., Unanue N., Henriquez C. et al. A Prospective Cohort Study of the Prevalence of Growth, Facial, and Central Nervous System Abnormalities in Children with Heavy Prenatal Alcohol Exposure, Alcoholism: Clinical and Experimental Research 2012: 36: 1811-1819.
Lundsberg L. S., Illuzzi J. L., Belanger K., Triche E. W., Bracken M. B. Low-to-moderate prenatal alcohol consumption and the risk of selected birth outcomes: a prospective cohort study, Annals of Epidemiology 2015: 25: 46-54 e43.
McCarthy F. P., O'Keeffe L. M., Khashan A. S., North R. A., Poston L., McCowan L. M. E. et al. Association Between Maternal Alcohol Consumption in Early Pregnancy and Pregnancy Outcomes, Obstetrics & Gynecology 2013: 122.
Meyer-Leu Y., Lemola S., Daeppen J.-B., Deriaz O., Gerber S. Association of Moderate Alcohol Use and Binge Drinking During Pregnancy with Neonatal Health, Alcoholism: Clinical and Experimental Research 2011: 35: 1669-1677.
Nulman I., Rovet J., Kennedy D., Wasson C., Gladstone J., Fried S. et al. Binge alcohol consumption by non-alcohol – dependent women during pregnancy affects child behaviour, but not general intellectual functioning; a prospective controlled study, Archives of Women's Mental Health 2004: 7: 173-181.
O'Callaghan F. V., O'Callaghan M., Najman J. M., Williams G. M., Bor W. Maternal alcohol consumption during pregnancy and physical outcomes up to 5 years of age: a longitudinal study, Early Human Development 2003: 71: 137-148.
Passaro K. T., Little Re Fau - Savitz D. A., Savitz Da Fau - Noss J., Noss J. The effect of maternal drinking before conception and in early pregnancy on infant birthweight. The ALSPAC Study Team. Avon Longitudinal Study of Pregnancy and Childhood, Epidemiology 1996: 4: 377-383.
Popova S., Lange S., Probst C., Gmel G., Rehm J. Global prevalence of alcohol use and binge drinking during pregnancy, and fetal alcohol spectrum disorder, Bichemistry and Cell Biology 2018: 96: 237-240.
Sampson P. D., Bookstein F. L., Barr H. M., Streissguth A. P. Prenatal Alcohol Exposure, Birthweight, and Measures of Child Size from Birth to Age 14 Years, American Journal of Public Health 1994: 84: 1421-1428.
Sulaiman N. D., Florey C. D. V., Taylor D. J., Ogston S. A. Alcohol consumption in Dundee primigravidas and its effects on outcome of pregnancy, British Medical Journal (Clinical research ed) 1988: 296: 1500.
Tolo K.-A., Little R. E. Occasional Binges by Moderate Drinkers: Implications for Birth Outcomes, Epidemiology 1993: 4: 415-420.

C5a

Creating a Contextual Setting for Health Professionals to Discuss Alcohol and Pregnancy - A Strategy Based on Knowledge Translation

Louise Gray

Learning Objectives

1. Demonstrate a practical application of prevention and awareness approaches based on research knowledge.
2. Enable participants to articulate and replicate the project model.

Background

At the Vancouver International FASD conference in 2017 speakers outlined the critical role that women’s health care providers have in engaging with women and promoting alcohol free pregnancies. Projects highlighted the high-level of confidence women have in health professionals when it comes to pregnancy advice, the need for positive messages and indicators that brief engagements by health professionals can be very effective. However, research also shows that professionals are often reluctant to raise alcohol consumption and that health professional’s benefit from guidance and support to better address this topic with patients. The project combined this knowledge and identified a media partner to use a multi-pronged strategy in a group of Doctors surgeries across the greater Sydney metropolitan are in New South Wales, Australia. This project is set within the context of examining alternate ways to transmit public health messages. In an increasingly digital world where consumers are bombarded by information and advertising; health messages must be competitive and strategic to influence behaviour.

The strategy used

1. Outreach via Email Directing Marketing (EDM) with cover information and a short video targeted at clinicians by a recognised expert in FASD and one of the leading paediatricians in Australia;
2. A digital TV message in the waiting room targeted towards the demographics of the location;
3. Print material about alcohol and pregnancy with website address to support digital information available in waiting room.

Results

In a 2-month project period across 539 clinic sites in greater Sydney, New South Wales, Australia, the campaign, which included an advertisement every 30 minutes on a loop, had the following
results:

- 1 in 5 of the survey respondents saw the advertisement;
- 4 in 5 of those who saw the digital display said they would speak to a friend or family member about alcohol/FASD if they were pregnant;
- More than half of the respondents indicated that they had learned something about the impact of alcohol on pregnancy that they did not know;
- Over 1/3 of the respondents took action after seeing the digital display;
- One third of health professionals who received the EDM opened it, which exceeded industry standards by 50%; the CTR (Click Through Rate) was 4 times higher than industry standards.

Conclusion

The campaign was a pilot project and demonstrated value as a strategy to increase awareness of FASD, prevent alcohol exposed pregnancy and increase engagement and awareness of FASD in a health care setting.

C5b

Patterns of Alcohol Intake of Pregnant and Lactating Women in Rural Western Australia

Martyn Symons

Authors: Elizabeth Tearne, Kylee Cox, Dr. Martyn Symons, Dr Roslyn Giglia

Learning Objectives

1. Identify the patterns of alcohol consumption and breastfeeding in a rural area of Australia
2. Assess the timing of infant feeding in regard to alcohol consumption
3. Consider the implications for designing public health campaigns

Objectives

Previous surveys and research have identified a gap in alcohol consumption data for women during the period of lactation, particularly in rural areas of developed countries. Understanding the drinking profile of antenatal and postnatal women in this population will aid in the effective targeting and dissemination of public health interventions. This is the first alcohol consumption data collected from pregnant and breastfeeding women living in rural Western Australia (WA).

Methods

A prospective cohort of 489 mothers and their infants were recruited between April 2010 and November 2011. All women were followed up at 4, 10, 16, 26, 32, 40 and 52 weeks postpartum. Data were analysed to determine the prevalence and patterns of alcohol consumption during pregnancy and lactation. Survival analysis was used to examine the associations between risky alcohol consumption and duration of breastfeeding.

Results

Approximately 20% of women consumed alcohol during pregnancy, with a predominance of women from older age groups and smokers. At four, six and 12 months postpartum; 45.9%, 47.0% and 51.9% of breastfeeding mothers were consuming alcohol respectively. Breastfeeding women most often reported consuming alcohol just after feeding the baby with 44%, 30.8% and 28.2% reporting this at one, four and six months postpartum respectively. Risky drinking (more than 2 standard drinks per occasion) while breastfeeding was significantly associated with shorter duration of any breastfeeding but not with exclusive breastfeeding. Drinking practice before pregnancy was significantly associated with duration of breastfeeding.

Conclusions for Practice

There remains a considerable proportion of women who continue to drink during pregnancy. Although proven successful, public health campaigns now need to target women who are older and who smoke. Women are continuing to consume alcohol during the period of lactation, with the majority doing so at low levels.

C5c

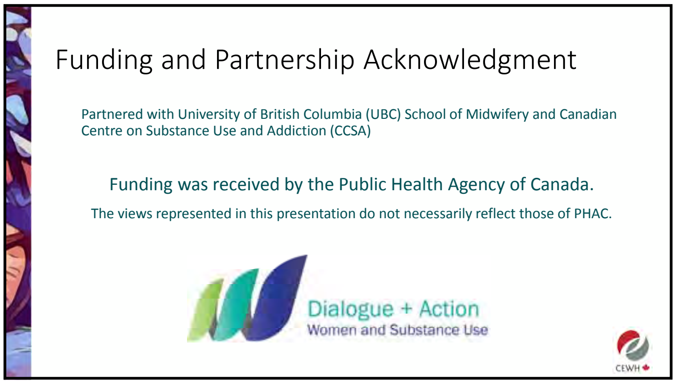
Discussing Multiple Substances by Multiple Providers, as a Key FASD Prevention Strategy

Rose Schmidt

Discussing Multiple Substances by Multiple Providers as a Key FASD Prevention Strategy

Rose Schmidt, Research Manager
Centre of Excellence for Women's Health

8th International Conference on FASD
March 2019

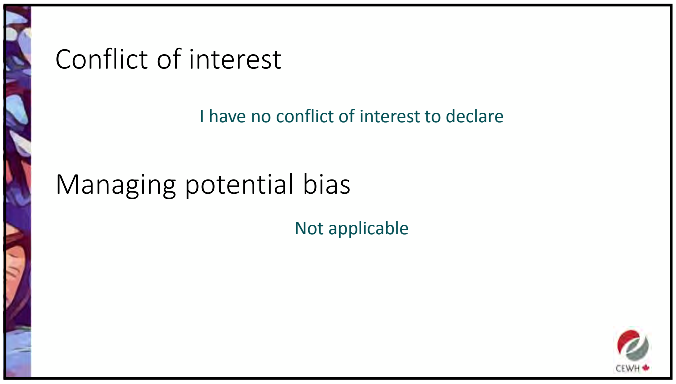


Funding and Partnership Acknowledgment

Partnered with University of British Columbia (UBC) School of Midwifery and Canadian Centre on Substance Use and Addiction (CCSA)

Funding was received by the Public Health Agency of Canada.

The views represented in this presentation do not necessarily reflect those of PHAC.

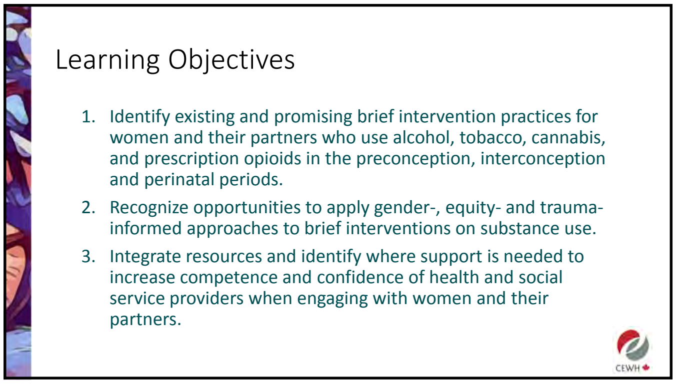


Conflict of interest

I have no conflict of interest to declare

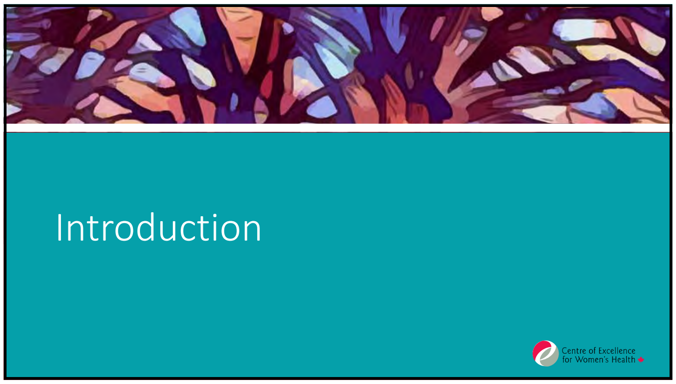
Managing potential bias

Not applicable

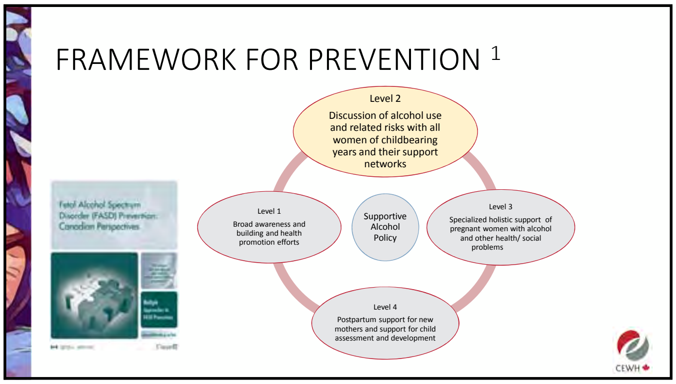


Learning Objectives

1. Identify existing and promising brief intervention practices for women and their partners who use alcohol, tobacco, cannabis, and prescription opioids in the preconception, interconception and perinatal periods.
2. Recognize opportunities to apply gender-, equity- and trauma-informed approaches to brief interventions on substance use.
3. Integrate resources and identify where support is needed to increase competence and confidence of health and social service providers when engaging with women and their partners.



Introduction



FRAMEWORK FOR PREVENTION [1]

Level 2
Discussion of alcohol use and related risks with all women of childbearing years and their support networks

Level 1
Broad awareness and building and health promotion efforts

Supportive Alcohol Policy

Level 3
Specialized holistic support of pregnant women with alcohol and other health/ social problems

Level 4
Postpartum support for new mothers and support for child assessment and development

Brief Intervention and Support

- Collaborative conversations between an individual and a health care or social service provider about a health issue.
- Many models and terms to describe brief interventions and support, e.g.
  - Screening, brief intervention, and referral (SBIR) to treatment (SBIRT)
- Clinical guidelines recommend screening all women and that brief interventions should be conducted with women who "screen positive" [2]

CEWH

Methods

Centre of Excellence for Women's Health

Goal

- To inspire and facilitate health and social service providers to incorporate discussions on alcohol, tobacco, cannabis, and prescription opioid use with women and their partners.

Dialogue + Action
Women and Substance Use

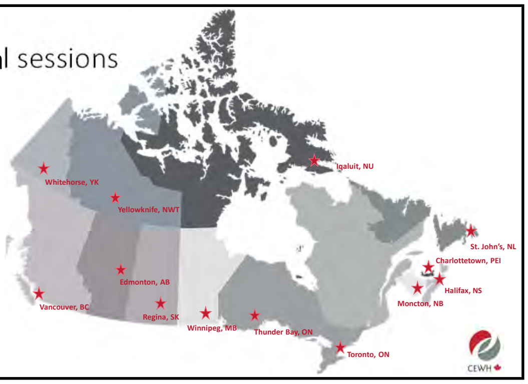
CEWH

Methods

1. Reviewed and summarized existing evidence
2. Environmental scan of current practices
   - Meetings with leaders in 12 provinces and territories to support discussions about alcohol with women of childbearing age by:
     - Midwives
     - Nurses
     - Physicians
     - Pregnancy outreach workers
     - Sexual health workers
     - Substance use service providers
     - Violence against women service providers
     - Indigenous service providers
3. Promoting promising practices

CEWH

Regional sessions



CEWH

Results

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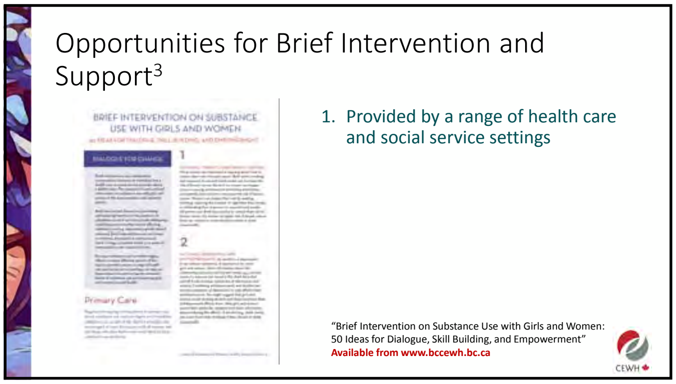
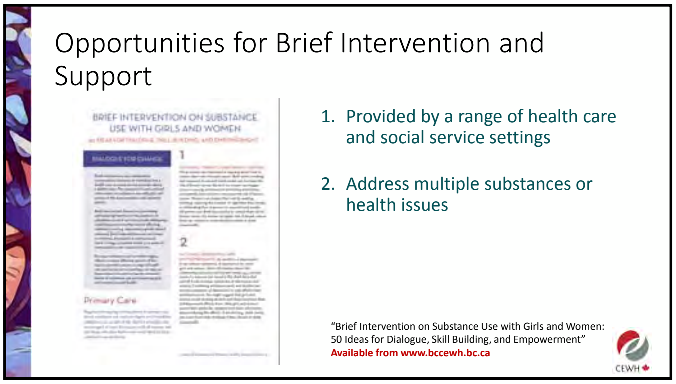


Opportunities for Brief Intervention and Support[3]

1. Provided by a range of health care and social service settings

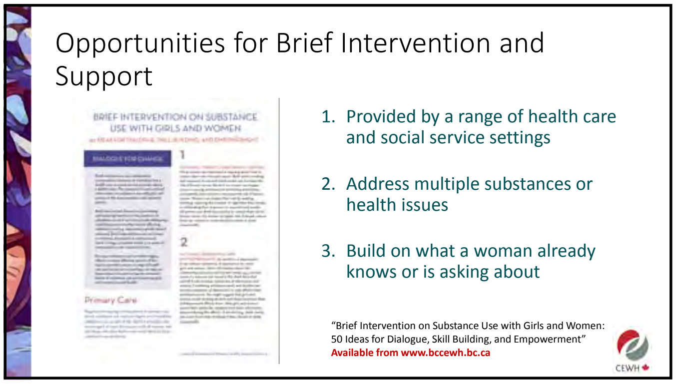
"Brief Intervention on Substance Use with Girls and Women: 50 Ideas for Dialogue, Skill Building, and Empowerment"
Available from www.bccewh.bc.ca



Opportunities for Brief Intervention and Support

1. Provided by a range of health care and social service settings
2. Address multiple substances or health issues

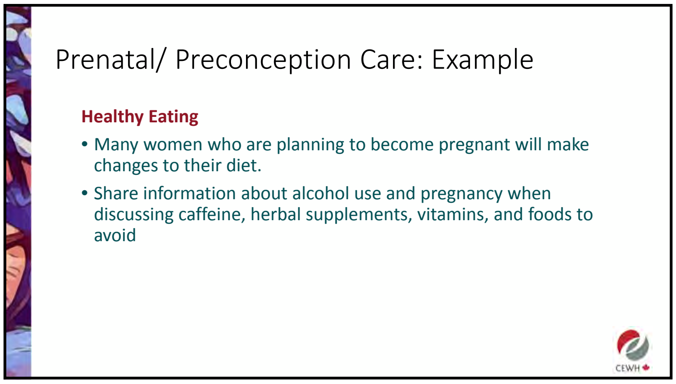
"Brief Intervention on Substance Use with Girls and Women: 50 Ideas for Dialogue, Skill Building, and Empowerment"
Available from www.bccewh.bc.ca



Opportunities for Brief Intervention and Support

1. Provided by a range of health care and social service settings
2. Address multiple substances or health issues
3. Build on what a woman already knows or is asking about

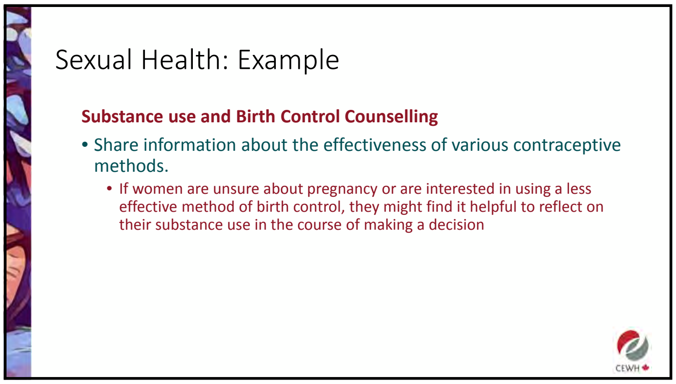
"Brief Intervention on Substance Use with Girls and Women: 50 Ideas for Dialogue, Skill Building, and Empowerment"
Available from www.bccewh.bc.ca



Prenatal/ Preconception Care: Example

Healthy Eating

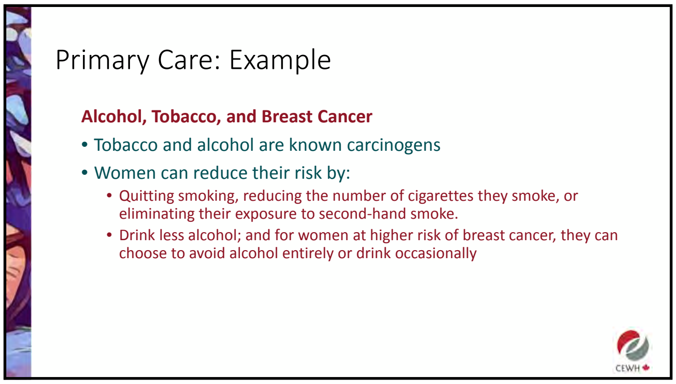
- Many women who are planning to become pregnant will make changes to their diet.
- Share information about alcohol use and pregnancy when discussing caffeine, herbal supplements, vitamins, and foods to avoid



Sexual Health: Example

Substance use and Birth Control Counselling

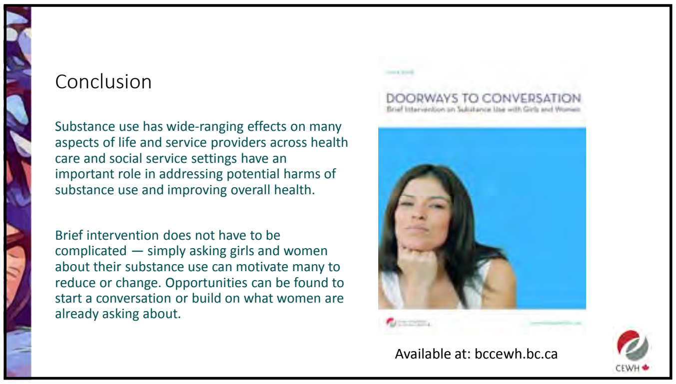
- Share information about the effectiveness of various contraceptive methods.
  - If women are unsure about pregnancy or are interested in using a less effective method of birth control, they might find it helpful to reflect on their substance use in the course of making a decision



Primary Care: Example

Alcohol, Tobacco, and Breast Cancer

- Tobacco and alcohol are known carcinogens
- Women can reduce their risk by:
  - Quitting smoking, reducing the number of cigarettes they smoke, or eliminating their exposure to second-hand smoke.
  - Drink less alcohol; and for women at higher risk of breast cancer, they can choose to avoid alcohol entirely or drink occasionally



Conclusion

Substance use has wide-ranging effects on many aspects of life and service providers across health care and social service settings have an important role in addressing potential harms of substance use and improving overall health.

Brief intervention does not have to be complicated — simply asking girls and women about their substance use can motivate many to reduce or change. Opportunities can be found to start a conversation or build on what women are already asking about.

Available at: bccewh.bc.ca

References

1. Poole, N., *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*. 2008, Ottawa, ON: PHAC.
2. Carson, G., et al., *Alcohol Use and Pregnancy Consensus Clinical Guidelines.* Journal of Obstetrics and Gynaecology Canada (JOGC), 2010. 32(8): p. S1-S2.
3. Nathoo, T., et al., *Doorways to Conversation: Brief Intervention on Substance Use with Girls and Women*. 201, Vancouver, BC: Centre of Excellence for Women's Health.

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C5d The Prevention Conversation: Let's Talk About Alcohol and Pregnancy: a New CanFASD Online Training Resource

Hélène Wirzba

The Prevention Conversation
Let's Talk About Alcohol and Pregnancy
A New CanFASD Online Training Resource

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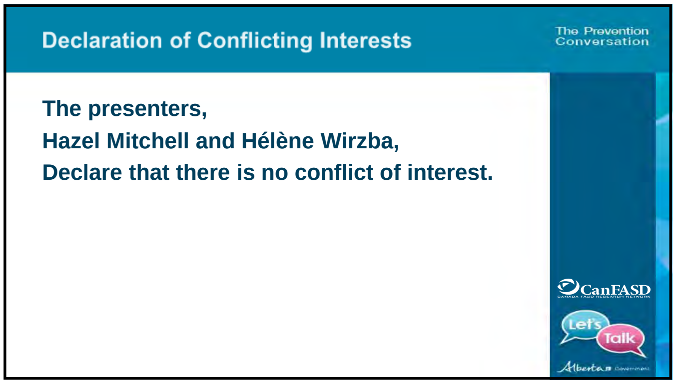
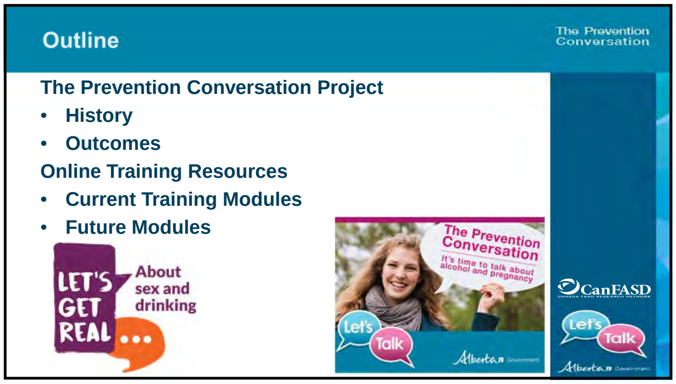
Dr. Hélène Wirzba, MD, CE
Evaluation Consultant

8th International Conference on Fetal Alcohol Spectrum Disorder
C5d - March 8, 2019, 1:45 – 3:15 PM



Declaration of Conflicting Interests

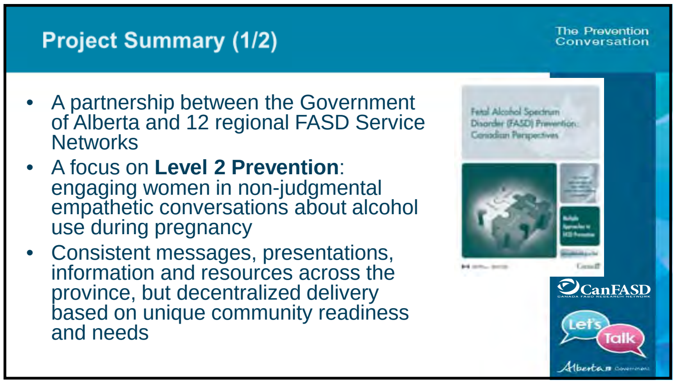
The presenters,
Hazel Mitchell and Hélène Wirzba,
Declare that there is no conflict of interest.



Outline

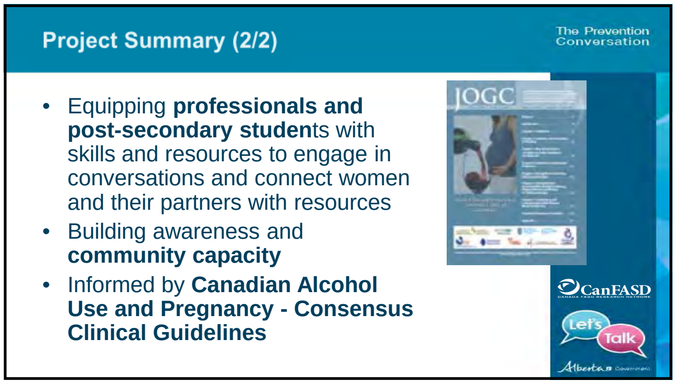
The Prevention Conversation Project
- **History**
- **Outcomes**

Online Training Resources
- **Current Training Modules**
- **Future Modules**



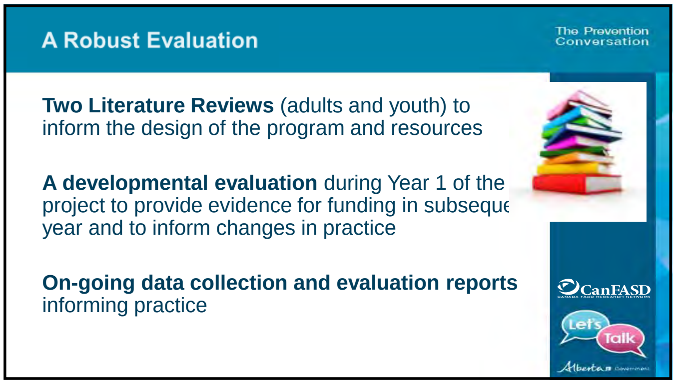
Project Summary (1/2)

- A partnership between the Government of Alberta and 12 regional FASD Service Networks
- A focus on **Level 2 Prevention**: engaging women in non-judgmental empathetic conversations about alcohol use during pregnancy
- Consistent messages, presentations, information and resources across the province, but decentralized delivery based on unique community readiness and needs



Project Summary (2/2)

- Equipping **professionals and post-secondary student**s with skills and resources to engage in conversations and connect women and their partners with resources
- Building awareness and **community capacity**
- Informed by **Canadian Alcohol Use and Pregnancy - Consensus Clinical Guidelines**

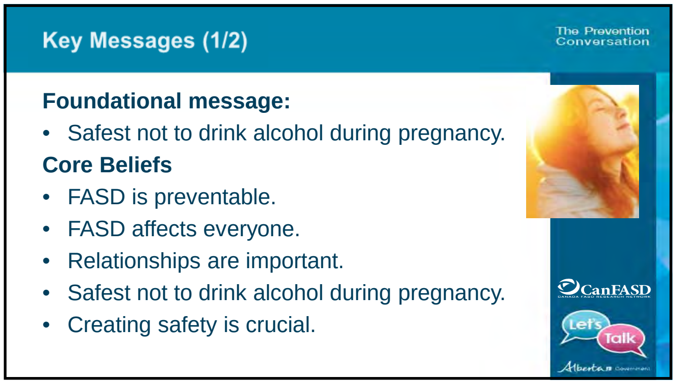


A Robust Evaluation

Two Literature Reviews (adults and youth) to inform the design of the program and resources

A developmental evaluation during Year 1 of the project to provide evidence for funding in subseque year and to inform changes in practice

On-going data collection and evaluation reports informing practice



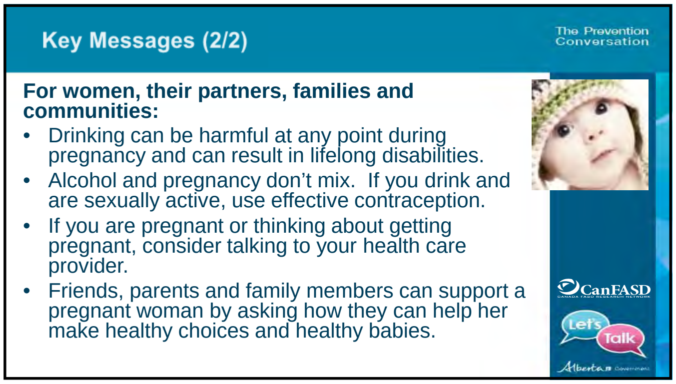
Key Messages (1/2)

Foundational message:

- Safest not to drink alcohol during pregnancy.

Core Beliefs

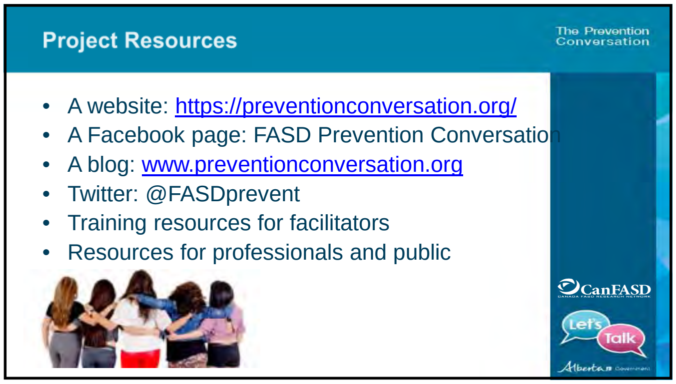
- FASD is preventable.
- FASD affects everyone.
- Relationships are important.
- Safest not to drink alcohol during pregnancy.
- Creating safety is crucial.



Key Messages (2/2)

For women, their partners, families and communities:

- Drinking can be harmful at any point during pregnancy and can result in lifelong disabilities.
- Alcohol and pregnancy don't mix. If you drink and are sexually active, use effective contraception.
- If you are pregnant or thinking about getting pregnant, consider talking to your health care provider.
- Friends, parents and family members can support a pregnant woman by asking how they can help her make healthy choices and healthy babies.

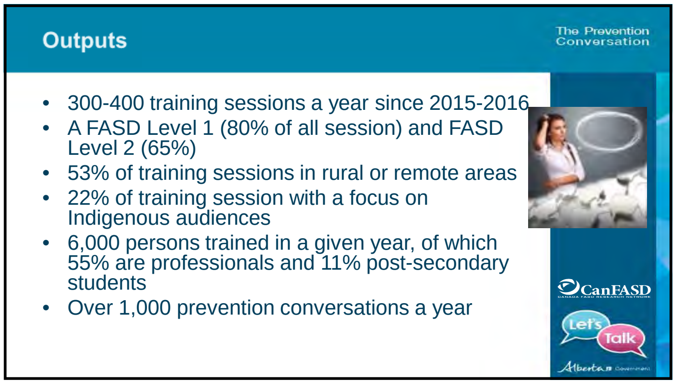


Project Resources

- A website: https://preventionconversation.org/
- A Facebook page: FASD Prevention Conversation
- A blog: www.preventionconversation.org
- Twitter: @FASDprevent
- Training resources for facilitators
- Resources for professionals and public

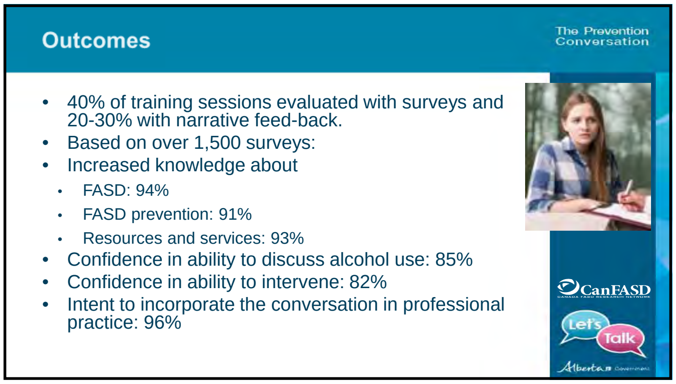
An Evolving Project

- New resources developed yearly
- **Let's Get Real:** an approach to support the adolescent population (ages 12-18)
- Common to all resources:
  - Resources for professionals and other individuals supporting youth
  - Communication focus: healthy, positive life style, accurate, effective, and sensitive information
  - Emphasis on attitudes and beliefs, alcohol and drugs, sex and pregnancy



Outputs

- 300-400 training sessions a year since 2015-2016
- A FASD Level 1 (80% of all session) and FASD Level 2 (65%)
- 53% of training sessions in rural or remote areas
- 22% of training session with a focus on Indigenous audiences
- 6,000 persons trained in a given year, of which 55% are professionals and 11% post-secondary students
- Over 1,000 prevention conversations a year

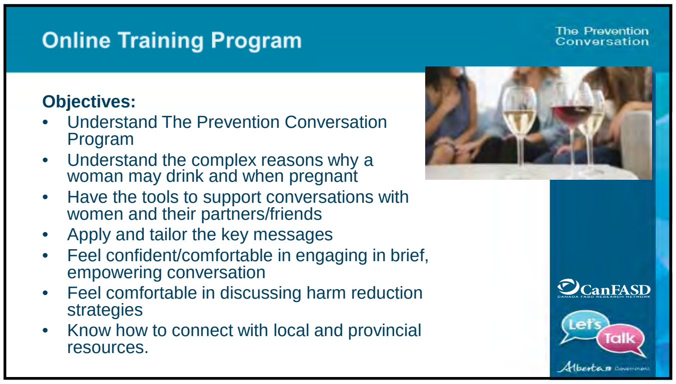


Outcomes

- 40% of training sessions evaluated with surveys and 20-30% with narrative feed-back.
- Based on over 1,500 surveys:
- Increased knowledge about
  - FASD: 94%
  - FASD prevention: 91%
  - Resources and services: 93%
- Confidence in ability to discuss alcohol use: 85%
- Confidence in ability to intervene: 82%
- Intent to incorporate the conversation in professional practice: 96%

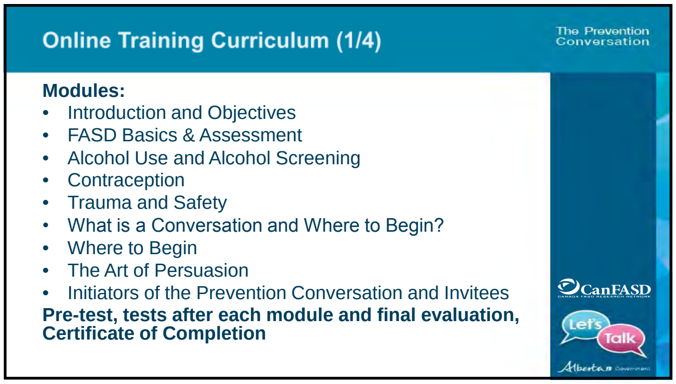
Lessons Learned

- Community development & professional networking are first steps to engage professionals and post-secondary students.
- An understanding of resources available in the community.
- Integration and collaboration with other FASD services.
- Professionals need a basic understanding of FASD in order to engage in conversations.
- Requests to expand the program to new target groups.
- urces beyond Alberta



Online Training Program

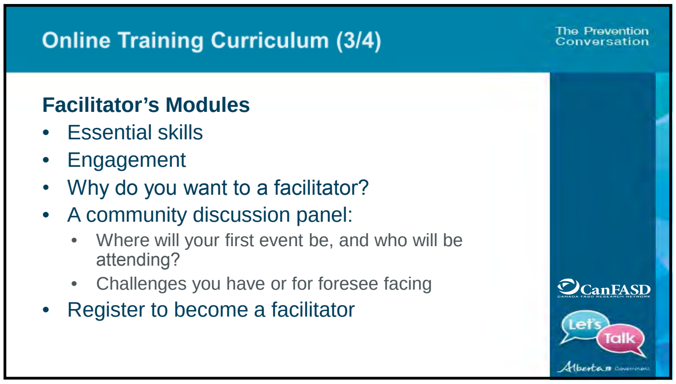
Objectives:
- Understand The Prevention Conversation Program
- Understand the complex reasons why a woman may drink and when pregnant
- Have the tools to support conversations with women and their partners/friends
- Apply and tailor the key messages
- Feel confident/comfortable in engaging in brief, empowering conversation
- Feel comfortable in discussing harm reduction strategies
- Know how to connect with local and provincial resources.



Online Training Curriculum (1/4)

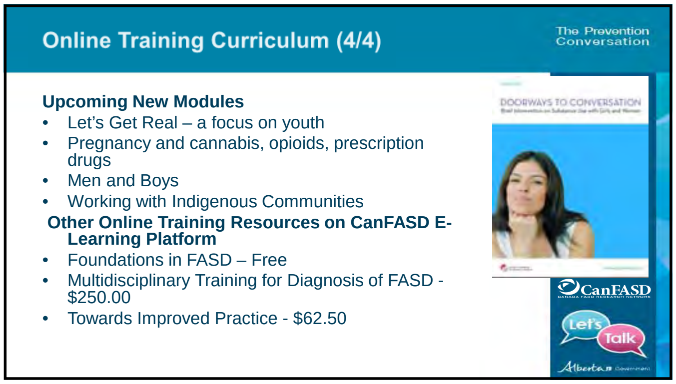
Modules:
- Introduction and Objectives
- FASD Basics & Assessment
- Alcohol Use and Alcohol Screening
- Contraception
- Trauma and Safety
- What is a Conversation and Where to Begin?
- Where to Begin
- The Art of Persuasion
- Initiators of the Prevention Conversation and Invitees

Pre-test, tests after each module and final evaluation, Certificate of Completion



Online Training Curriculum (3/4)

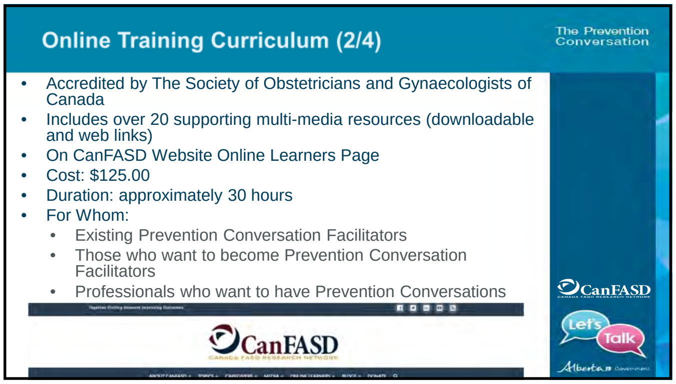
Facilitator's Modules
- Essential skills
- Engagement
- Why do you want to a facilitator?
- A community discussion panel:
  - Where will your first event be, and who will be attending?
  - Challenges you have or for foresee facing
- Register to become a facilitator



Online Training Curriculum (4/4)

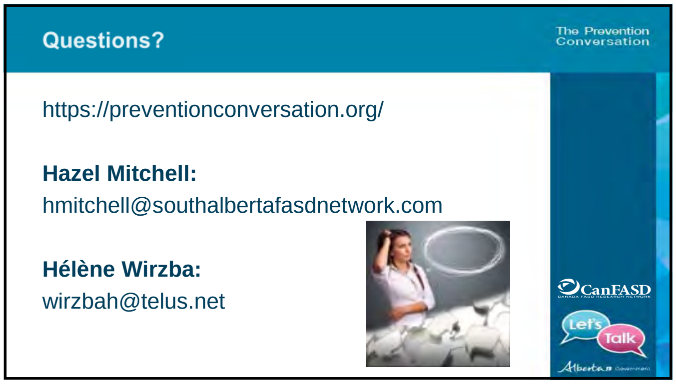
Upcoming New Modules
- Let's Get Real – a focus on youth
- Pregnancy and cannabis, opioids, prescription drugs
- Men and Boys
- Working with Indigenous Communities

Other Online Training Resources on CanFASD E-Learning Platform
- Foundations in FASD – Free
- Multidisciplinary Training for Diagnosis of FASD - $250.00
- Towards Improved Practice - $62.50



Online Training Curriculum (2/4)

- Accredited by The Society of Obstetricians and Gynaecologists of Canada
- Includes over 20 supporting multi-media resources (downloadable and web links)
- On CanFASD Website Online Learners Page
- Cost: $125.00
- Duration: approximately 30 hours
- For Whom:
  - Existing Prevention Conversation Facilitators
  - Those who want to become Prevention Conversation Facilitators
  - Professionals who want to have Prevention Conversations



Questions?

The Prevention Conversation

https://preventionconversation.org/

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C6a Accuracy of Motor Assessment in the Diagnosis of FASD

Erin Branton, Danielle Johnston

Learning Objectives

1. Compare and contrast the accuracies of motor assessments used in the diagnosis of FASD
2. Explore implications for motor assessment relevant to diagnostic teams
3. Identify gaps in the research in motor assessment and explore future research needed

Background

The research team members work on the Pediatric Specialty Clinic in Camrose, located in central Alberta. The Pediatric Specialty Clinic is a diagnostic clinic that sees children to explore a diagnosis of FASD. It is a multi-disciplinary clinic consisting of a Pediatrician, Speech Language Pathologist, Occupational Therapist, Physical Therapist, Psychologist and Social Worker.

The Camrose Pediatric Specialty Clinic uses the Canadian FASD Diagnostic Guideline, “Fetal Alcohol Spectrum Disorder (FASD): a guideline for diagnosis across the lifespan” 1. To qualify for an FASD diagnosis there needs to be confirmation of prenatal alcohol exposure (PAE), as well as evidence of pervasive brain dysfunction that cannot be explained by any other diagnosis1. Evidence of pervasive brain dysfunction is defined as scoring 2 standard deviations (-2SD) below the mean (2nd percentile or below), in 3 or more neurodevelopmental domains1.

The primary role of the Occupational Therapist (OT) and Physical Therapist (PT) in the assessment of FASD is in determining if there is a severe motor impairment. The OTs and PTs on the Camrose Pediatric Specialty Clinic assess fine motor, gross motor and visual motor skills. As well, a physical and neurological exam is completed including reflexes, tone, strength, coordination and balance to add information to the evaluation of motor skills and neurological integrity. The physical exam also adds additional information to rule in or out other conditions such as Developmental Coordination Disorder or Cerebral Palsy. One of the other main roles for OT and PT is looking at the impact on function and to provide recommendations for the family, front line therapists and service partners (including teachers and case workers).

The current version of the Canadian guideline recommends the use of either total motor scores or multiple subtest scores for motor assessment1. Our team had some clinical questions with regards to the motor domain:

- Why were some children not scoring with a severe motor impairment despite obvious functional deficits?
- Is it more accurate to use fine motor and gross motor scores separately or use combined scores?
- Is it more accurate to use multiple subtests or total motor scores?
- How many is multiple subtests?

We refined our questions and initiated a research project with the following three objectives:

1. Determine the diagnostic accuracy of motor assessments and subtests listed in the Canadian guideline
2. Determine if a severe motor impairment can be more accurately identified by using multiple subtest scores or total motor scores
3. Investigate which standard deviation cut off is most accurate in identifying a motor domain impairment

Methods

A cross-sectional diagnostic study of 63 children aged 6 – 17 years seen through the Pediatric Specialty Clinic from 2010-2017 was completed. Ethics approval was received for this study through the University of Alberta Research Ethics Board. Diagnostic accuracy and alternate cut-offs were calculated for the Movement Assessment Battery for Children 2nd edition (MABC-2)2, Bruininks-Oseretsky Test of Motor Proficiency 2nd edition, Short Form (BOT-2SF)3 and Beery-Buktenica Developmental Test of Visual Motor Integration 6th edition (BeeryVMI-6)4.

Results: Children who received an FASD diagnosis were found to have higher rates of motor difficulties compared to children who did not receive a diagnosis. Fine motor difficulties were more prevalent than gross motor difficulties. As well, substantially more children exhibited functional motor concerns than scored with a severe motor impairment.

In regards to motor assessment accuracies, the MABC-2 total motor score at -2SD was more sensitive (0.30; 95% CI 0.17-0.46; p <0.01) than the BOT-2SF (0.02; 95% CI 0.00-0.12) which was very low. The MABC-2 total motor score was more accurate than any combination of subtest scores.

Due to the low accuracies of the listed motor assessments at -2SD, or 2nd percentile or below, we explored various cut off percentiles to see if accuracies could be improved. The MABC-2 was found to be the most accurate at 2nd percentile, supporting current practice for that assessment (0.3/.95). Our analysis showed the highest accuracy on motor assessments was found at the 5th percentile (-1.5SD). For multiple subtests the highest accuracy was found using the MABC-2 MD and Beery MC (0.40/1.00). For a single subtest the highest accuracies were found using the Beery MC (0.68/0.90) or administering both the MABC-2 MD & Beery MC and using either score (0.75/0.84). This means that if the 5th percentile was used as a cut off to indicate severe dysfunction, more children would be correctly identified as having a motor impairment without a substantial increase in false identification, resulting in overall greater accuracy compared to current guideline recommendations.

Implications

1. Use of the BOT-2 SF when diagnosing FASD should be re-considered
    - The BOT-2 SF identified only 2% of children with FASD as having a severe motor impairment, compared to 30% of children identified by the MABC-2 total motor score
    - This increased percentage of children with FASD identified using the MABC-2 fits more closely with motor deficits observed clinically and reported by families and teachers
    - The Camrose Pediatric Specialty Clinic has discontinued its use
2. Total motor score of the MABC-2 should be considered by diagnostic FASD clinics
    - The MABC-2 is significantly more sensitive than BOT-2-SF
    - Both require similar administration requirements (time, space and materials, and both can be administered by an OT or PT, however we recommend having both disciplines)
    - The MABC-2 is useful when looking at a variety of diagnoses, for instance it is the gold standard when assessing for Developmental Coordination Disorder
    - It is listed in the Canadian FASD Guideline
3. Motor skills should routinely be assessed during FASD diagnosis, to document motor difficulties and ensure appropriate interventions and supports are put in place
    - In children with FASD, 30% were found to have a severe motor impairment, 54% had difficulties with dressing, 60% had lower than expected printing speed, and 76% had difficulties with tying shoelaces
    - We know from the literature that motor skills also impact attention, learning, physical and mental health, however motor skills are often overlooked during FASD assessment
4. The impact of motor deficits on daily function should be investigated
    - In children that did not meet criteria of a severe motor impairment, significant functional difficulties were common, indicating that the standardized tests may not be picking up all of the children with a clinically significant motor impairment
    - Enables therapists to provide meaningful recommendations to family and school

Current Research

- Through a literature search we were unable to find any studies looking specifically at the sensitivity and specificity of motor assessments used in FASD diagnosis.
- Lucas et al, 20135 evaluated the inter-rater and test-retest reliability of the BOT2-SF in Australian aboriginal children prenatally exposed to alcohol. This was the first known study evaluating the reliability of the BOT-2 Short Form in the assessment of FASD. This study found excellent inter-rater reliability and fair to good test-retest reliability, however did not evaluate accuracy.
- Lucas et al, 20146 completed a systematic review of gross motor deficits in children prenatally exposed to alcohol. Their meta-analysis showed a significant association between a diagnosis of FASD or moderate to heavy PAE, and gross motor impairment, including balance, coordination, and ball skills.
- Doney et al, 20147 completed a systematic review to explore fine motor skills in children prenatally exposed to alcohol. Complex fine motor skills, (e.g. visual-motor integration), were more frequently impaired than basic fine motor skills (e.g. grip strength) and measures that specifically assessed fine motor skills identified impairments more consistently than more general assessments. Fine motor impairments were associated with moderate to high PAE levels.
- Lucas et al, 20168 examined the rates of motor impairment in children with FASD, children with PAE and children without PAE, using the BOT-2 complete form. The prevalence of motor impairment (-2SD) was 9.5% in children with FASD, 3.3% in children with PAE and 0.0% in children without PAE.

Future Research

1. This study provides preliminary evidence of the accuracies of motor assessments in FASD diagnosis however more research is needed
    - The Canadian FASD guideline includes an appendix which lists examples of motor assessments for various age groups. However, this list of assessments is based on commonly used tools across Canadian FASD diagnostic clinics and not recommended assessments based on research evidence, due to very little research evidence available in this area.
2. Based on the results from our study, the use of single subtest score as evidence of severe motor impairment in FASD diagnosis should be further evaluated
    - The Australian Guide to the diagnosis of FASD (released in 2016)9, was modified based on the Canadian guide released in 2015, and the diagnostic criteria are very similar. One main difference between the 2 guides, is the Australian one accepts a severely impaired score on one or more major subtest score (gross motor, fine motor, graphomotor and visuo-motor integration) as evidence of a severe impairment, whereas the Canadian guideline uses multiple subtest scores.
3. More research is needed to explore optimal clinical cut off score to indicate a severe motor impairment in FASD diagnosis
    - The 2016 Clinical Guidelines for Diagnosing FASD in the Journal of American Academy of Pediatrics10, uses a clinical cut off score of ≥1.5 SD to indicate a developmental delay, as they argue that their "goal is improved sensitivity and greater inclusion of children in the complete continuum of FASD".
    - Our study indicated that using the 5th percentile (-1.5 SD) to indicate a severe motor impairment may improve accuracy, in that it identifies many more children as having a significant motor impairment, while minimally raising the false identification.
4. An Activity of Daily Living (ADL) measure or questionnaire that is tailored for children with potential FASD would standardize the evaluation of functional impairments.
    - Our study results highlight the high frequency of significant functional motor deficits in children with FASD. As clinicians we consistently hear from families and schools that motor deficits impact their function during activities such as printing, dressing, and eating.
    - Our clinic was unable to find an ADL measure that captures all of the functional aspects we like to evaluate in our clinic, therefore our team uses one that we created. While this serves the purposes of our clinic, it is not standardized or norm referenced.

References

Cook, J., Green, C., Lilley, C., Anderson, S., Baldwin, M.J., Chudley, A., Conry, J., LeBlanc, N., Loock, C., Lutke, J., Mallon, B., McFarlane, A., Temple, V., & Rosales, T., (2016) Fetal Alcohol spectrum disorder: a guideline for diagnosis across the lifespan. Canadian Medical Association Journal.

Henderson, S., Sugden, D., & Barnett, A. (2007). Movement Assessment Battery for Children- Second Edition, Examiner's Manual. Pearson Assessment, London, UK

Bruininks RH., Bruininks BD. (2005). The Bruininks-Oseretsky Test of Motor Proficiency Manual, (2nd ed, pp. 1-72). Circle Pines, MN: AGS Publishing.

Beery, K.E., & Beery, N.A. (2010). The Beery-Buktenica Developmental Test of Visual-Motor Integration (6th ed.). Minneapolis, MN: Pearson Assessments.

Lucas BR, Latimer J, Doney R, Ferreira ML, Adams R, Hawkes G, et al. The Bruininks-Oseretsky Test of Motor Proficiency-Short Form is reliable in children living in remote Australian Aboriginal communities. BMC pediatrics 2013;13(1):135

Lucas, B., Latimer, J., Pinto, R., Perreira, M., Koney, R., Lau, M., Jones, T., Dries, D., & Elliott, E. (2014) Gross motor Deficits in Children Prenatally Exposed to Alcohol: A Meta-analysis. Pediatrics 134(1) 192-209.

Doney R, Lucas BR, Jones T, Howat P, Sauer K, Elliott EJ. Fine motor skills in children with prenatal alcohol exposure or fetal alcohol spectrum disorder. J Dev Behav Pediatr 2014;35(9):598-609.

Lucas, B., Doney, R., Latimer, J., Watkins, R., Tsang, T., & Hawkes, G. et al. (2016). Impairment of motor skills in children with fetal alcohol spectrum disorders in remote Australia: The Lililwan Project. Drug and Alcohol Review.

Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)".

Hoyme HE, Kalberg WO, Elliott AJ, Blankenship J, Buckley D, Marais A, et al. Updated Clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders. Pediatrics 2016 Aug;138(2):e20154256.

C6b

A Novel Integrated Approach in Addressing the Primary & Secondary Symptoms of FASD: The Relative Efficacy of QEEG Guided Neurofeedback & HRV Therapy with Physical Therapy to address Developmental Coordination Disorder (DCD) and Parent Consultation

Ajeet Charate, Smita Charate

Learning Objectives

1. Identify and understand the importance of a QEEG assessment in understanding the primary issues of FASD
2. Describe the different kinds and Neurofeedback treatments and HRV trainings
3. Recognize the value and critical importance of addressing DCD symptoms
4. Reflect on how the integrated approach model may apply to current practices and research

Abstract

Presenters will discuss their clinical experience in using a novel approach in treating primary symptoms of FASD. This presentation will discuss the use of QEEG assessments in assessing and identifying primary issues in FASD. How neurofeedback with Heart Rate Variability trainings can improve symptoms in individuals with FASD. Case examples with findings of pre and post treatment QEEG assessments will be discussed. The integrated treatment approach is critical in addressing areas that are commonly missed with traditional treatments. The presentation will discuss about Developmental Coordination Disorder (DCD) and its treatment philosophy utilizing Movement Based Learning. While these treatments are important in addressing some of the primary issues of FASD, how parent consultation is crucial in addressing the secondary / learnt behaviors.

There are not many non-invasive treatments that can assess and treat some of the primary behavioral issues in individuals with FASD. Our clinical experience shows that QEEG - guided neurofeedback treatments with heart rate variability trainings improves attention, focus, anxiety, executive functioning, information processing and transitional issues in individuals with FASD. We find that following treatments these individuals are more receptive to suggestions and less reactive to stressors. Many individuals with FASD have sensory processing, balance, coordination and joint issues that are never addressed. This integrated approach includes a trained physical therapist evaluating and treating DCD symptoms. Movement based learning strategies have shown a huge improvement in individuals with FASD. The presentation will discuss some case examples.

Coordination disorder, sometimes referred to as motor clumsiness, is a significant movement condition that is thought to affect up to 10 percent of children. DCD is commonly associated with other diagnoses such ADHD, learning disabilities (LD), and emotional and behavioral disorders.That said our observation is that often times clients with FASD have associated symptoms of DCD.

Common Symptoms of DCD are:

- Delayed motor milestones
- Clumsiness (dropping or bumping into objects, walls, furniture)
- Slowness and difficulty with motor skills such as difficulty with catching a ball, or riding a bike, difficulty tying shoes, swimming.
- Difficulty playing team sports due to coordination deficits
- Gait abnormalities

Treatment protocols:

We have developed an integrated approach to holistically treat the person with FASD. We believe Physical therapy and perceptual motor training (combining movement with tasks that require thinking, like math or reading) are the best ways to treat coordination disorders. Using movement based learning strategies has been very rewarding to these children. QEEG assessments assist in identifying and discussing the primary behavioral issues that may be interfering with their academic and overall performances. It can further identify coherence / connectivity issues in the brain. Neurofeedback treatments with HRV trainings can help resolve many of the identified abnormalities.

C7 A Two-Tiered Model for Diagnosis of FASD: Neurodevelopmental Assessment

Claire Coles

A TWO TIERED MODEL FOR DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDERS: NEURODEVELOPMENTAL ASSESSMENT

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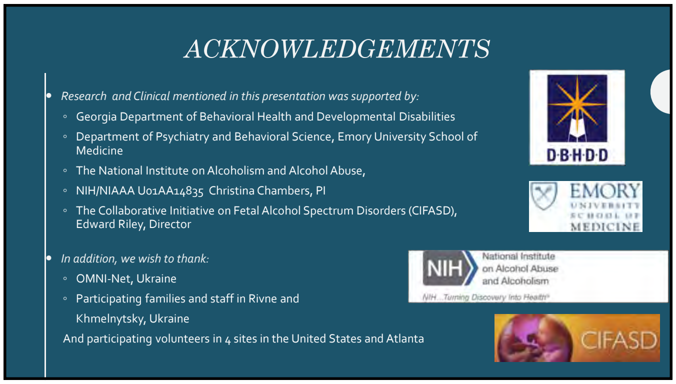
Emory Neurodevelopment and Exposure Clinic (ENEC)
Emory University School of Medicine, Atlanta, GA

8th International Conference on Fetal Alcohol Spectrum Disorder: Research, Results and Relevance *- Integrating Research, Policy and Promising Practice Around the World.*
Vancouver, BC, March 7. 2019



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  - Department of Psychiatry and Behavioral Science, Emory University School of Medicine
  - The National Institute on Alcoholism and Alcohol Abuse,
  - NIH/NIAAA U01AA14835 Christina Chambers, PI
  - The Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), Edward Riley, Director
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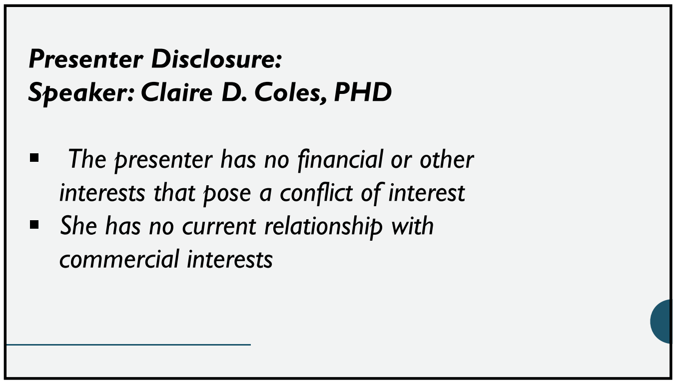
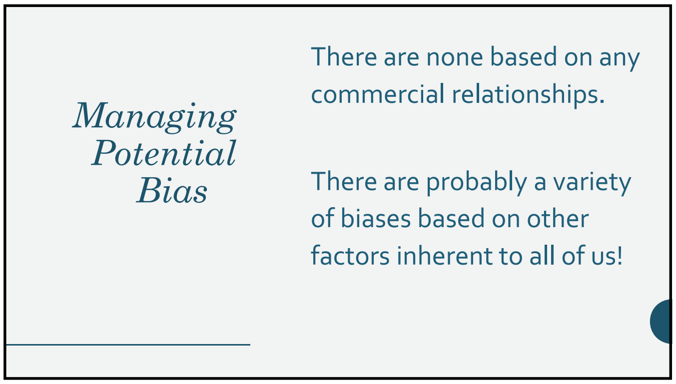
  - OMNI-Net, Ukraine
  - Participating families and staff in Rivne and Khmelnytsky, Ukraine

And participating volunteers in 4 sites in the United States and Atlanta



Presenter Disclosure:
Speaker: Claire D. Coles, PHD

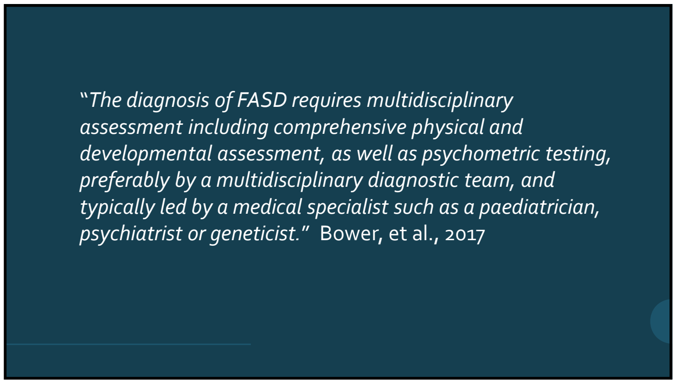
- *The presenter has no financial or other interests that pose a conflict of interest*
- *She has no current relationship with commercial interests*



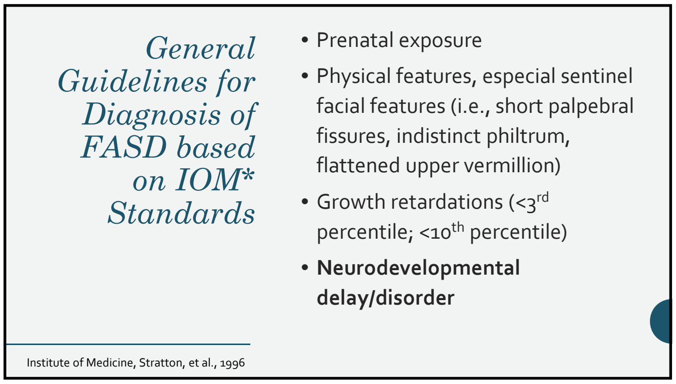
Managing Potential Bias

There are none based on any commercial relationships.

There are probably a variety of biases based on other factors inherent to all of us!



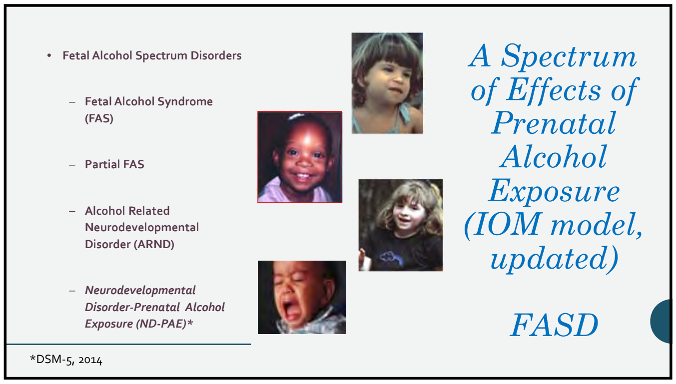
> *"The diagnosis of FASD requires multidisciplinary assessment including comprehensive physical and developmental assessment, as well as psychometric testing, preferably by a multidisciplinary diagnostic team, and typically led by a medical specialist such as a paediatrician, psychiatrist or geneticist."* Bower, et al., 2017



General Guidelines for Diagnosis of FASD based on IOM* Standards

- Prenatal exposure
- Physical features, especial sentinel facial features (i.e., short palpebral fissures, indistinct philtrum, flattened upper vermillion)
- Growth retardations (<3rd percentile; <10th percentile)
- **Neurodevelopmental delay/disorder**

Institute of Medicine, Stratton, et al., 1996

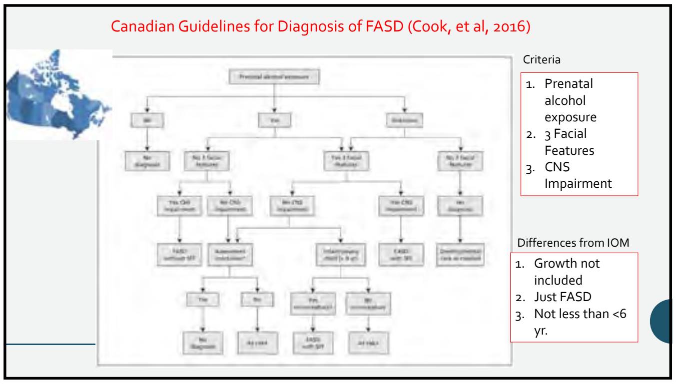


- Fetal Alcohol Spectrum Disorders
  - Fetal Alcohol Syndrome (FAS)
  - Partial FAS
  - Alcohol Related Neurodevelopmental Disorder (ARND)
  - *Neurodevelopmental Disorder-Prenatal Alcohol Exposure (ND-PAE)**

A Spectrum of Effects of Prenatal Alcohol Exposure (IOM model, updated)

FASD

*DSM-5, 2014



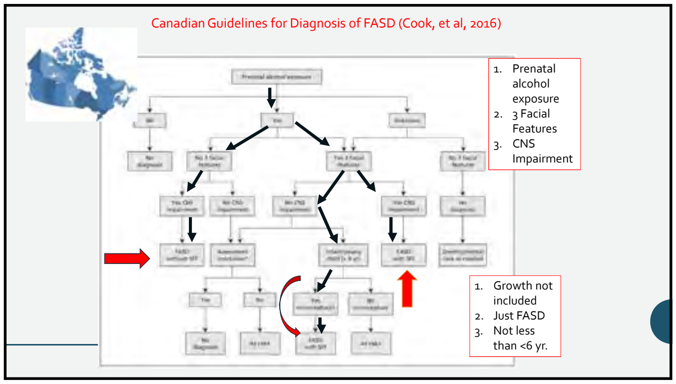
Canadian Guidelines for Diagnosis of FASD (Cook, et al, 2016)

Criteria

1. Prenatal alcohol exposure
2. 3 Facial Features
3. CNS Impairment

Differences from IOM

1. Growth not included
2. Just FASD
3. Not less than <6 yr.



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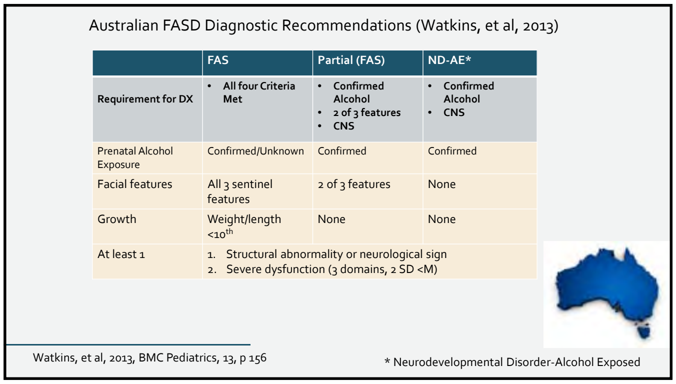
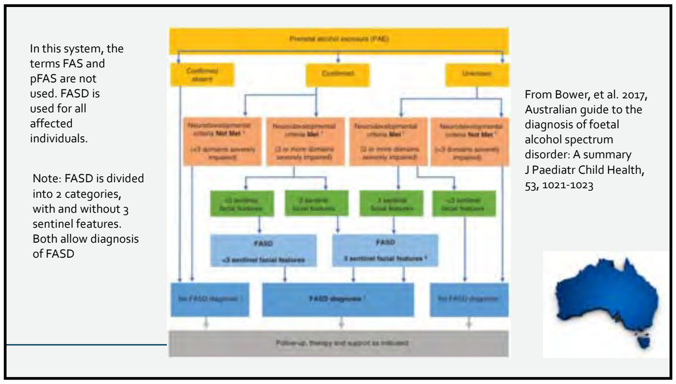


Australian FASD Diagnostic Recommendations (Watkins, et al, 2013)

	FAS	Partial (FAS)	ND-AE*
Requirement for DX	• **All four Criteria Met**	• **Confirmed Alcohol** • **2 of 3 features** • **CNS**	• **Confirmed Alcohol** • **CNS**
Prenatal Alcohol Exposure	Confirmed/Unknown	Confirmed	Confirmed
Facial features	All 3 sentinel features	2 of 3 features	None
Growth	Weight/length <10th	None	None
At least 1	1. Structural abnormality or neurological sign 2. Severe dysfunction (3 domains, 2 SD <M)		

Watkins, et al, 2013, BMC Pediatrics, 13, p 156

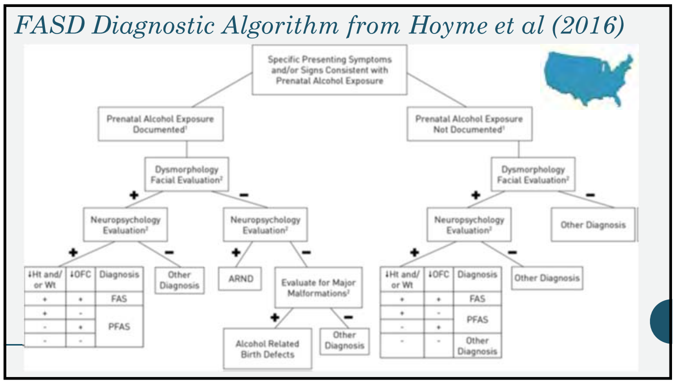
* Neurodevelopmental Disorder-Alcohol Exposed



In this system, the terms FAS and pFAS are not used. FASD is used for all affected individuals.

Note: FASD is divided into 2 categories, with and without 3 sentinel features. Both allow diagnosis of FASD

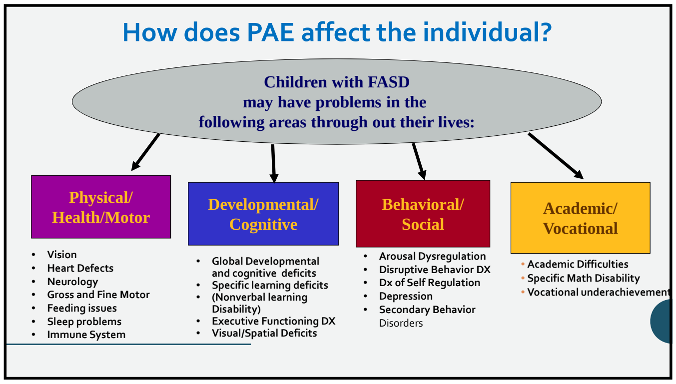
From Bower, et al. 2017, Australian guide to the diagnosis of foetal alcohol spectrum disorder: A summary J Paediatr Child Health, 53, 1021-1023



FASD Diagnostic Algorithm from Hoyme et al (2016)

↓Ht and/ or Wt	↓OFC	Diagnosis
+	+	FAS
+	-	PFAS
-	+	
-	-	

↓Ht and/ or Wt	↓OFC	Diagnosis
+	+	FAS
+	-	PFAS
-	+	
-	-	Other Diagnosis



How does PAE affect the individual?

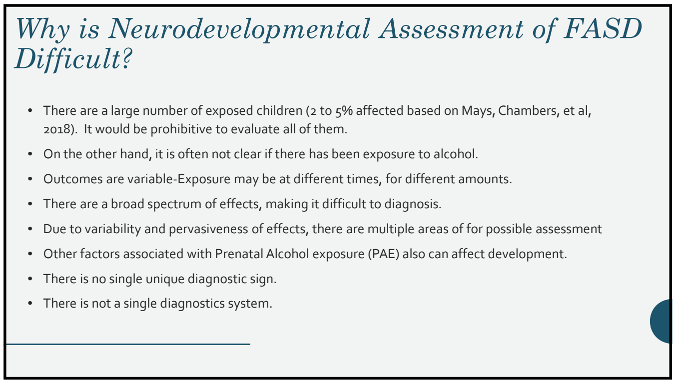
Children with FASD may have problems in the following areas through out their lives:

Physical/ Health/Motor
- Vision
- Heart Defects
- Neurology
- Gross and Fine Motor
- Feeding issues
- Sleep problems
- Immune System

Developmental/ Cognitive
- Global Developmental and cognitive deficits
- Specific learning deficits
- (Nonverbal learning Disability)
- Executive Functioning DX
- Visual/Spatial Deficits

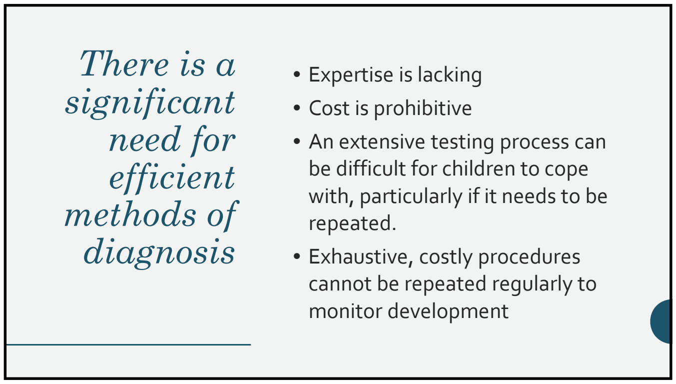
Behavioral/ Social
- Arousal Dysregulation
- Disruptive Behavior DX
- Dx of Self Regulation
- Depression
- Secondary Behavior Disorders

Academic/ Vocational
- Academic Difficulties
- Specific Math Disability
- Vocational underachievement



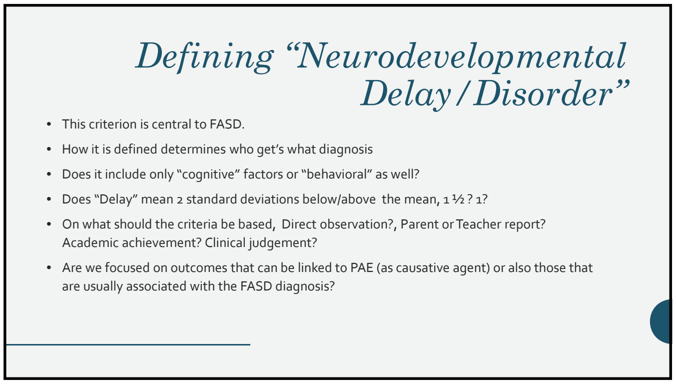
Why is Neurodevelopmental Assessment of FASD Difficult?

- There are a large number of exposed children (2 to 5% affected based on Mays, Chambers, et al, 2018). It would be prohibitive to evaluate all of them.
- On the other hand, it is often not clear if there has been exposure to alcohol.
- Outcomes are variable-Exposure may be at different times, for different amounts.
- There are a broad spectrum of effects, making it difficult to diagnosis.
- Due to variability and pervasiveness of effects, there are multiple areas of for possible assessment
- Other factors associated with Prenatal Alcohol exposure (PAE) also can affect development.
- There is no single unique diagnostic sign.
- There is not a single diagnostics system.



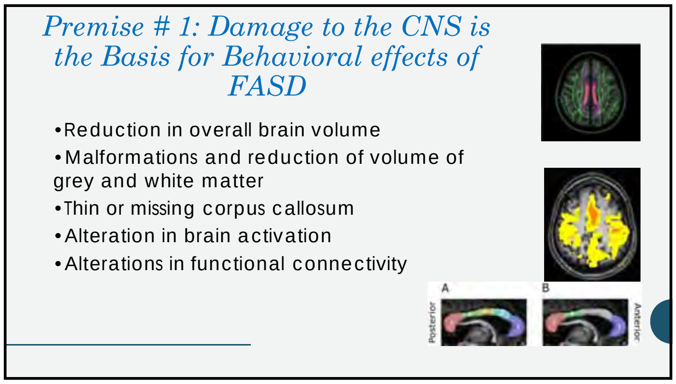
There is a significant need for efficient methods of diagnosis

- Expertise is lacking
- Cost is prohibitive
- An extensive testing process can be difficult for children to cope with, particularly if it needs to be repeated.
- Exhaustive, costly procedures cannot be repeated regularly to monitor development



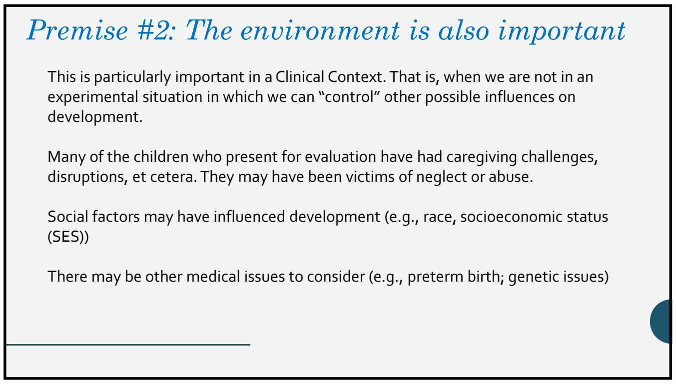
Defining “Neurodevelopmental Delay / Disorder”

- This criterion is central to FASD.
- How it is defined determines who get’s what diagnosis
- Does it include only “cognitive” factors or “behavioral” as well?
- Does “Delay” mean 2 standard deviations below/above the mean, 1 ½ ? 1?
- On what should the criteria be based, Direct observation?, Parent or Teacher report? Academic achievement? Clinical judgement?
- Are we focused on outcomes that can be linked to PAE (as causative agent) or also those that are usually associated with the FASD diagnosis?



Premise # 1: Damage to the CNS is the Basis for Behavioral effects of FASD

- Reduction in overall brain volume
- Malformations and reduction of volume of grey and white matter
- Thin or missing corpus callosum
- Alteration in brain activation
- Alterations in functional connectivity



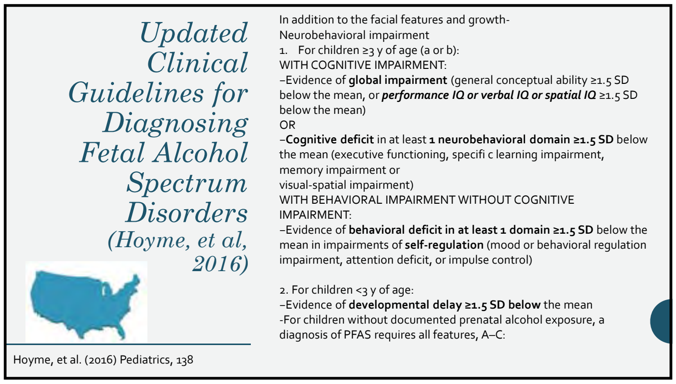
Premise #2: The environment is also important

This is particularly important in a Clinical Context. That is, when we are not in an experimental situation in which we can “control” other possible influences on development.

Many of the children who present for evaluation have had caregiving challenges, disruptions, et cetera. They may have been victims of neglect or abuse.

Social factors may have influenced development (e.g., race, socioeconomic status (SES))

There may be other medical issues to consider (e.g., preterm birth; genetic issues)

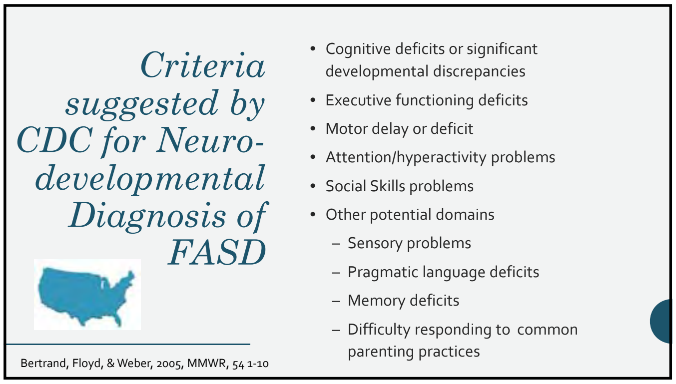


Updated Clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders (Hoyme, et al, 2016)

In addition to the facial features and growth-
Neurobehavioral impairment
1. For children ≥3 y of age (a or b):
WITH COGNITIVE IMPAIRMENT:
–Evidence of **global impairment** (general conceptual ability ≥1.5 SD below the mean, or ***performance IQ or verbal IQ or spatial IQ*** ≥1.5 SD below the mean)
OR
–**Cognitive deficit** in at least **1 neurobehavioral domain ≥1.5 SD** below the mean (executive functioning, specific learning impairment, memory impairment or
visual-spatial impairment)
WITH BEHAVIORAL IMPAIRMENT WITHOUT COGNITIVE IMPAIRMENT:
–Evidence of **behavioral deficit in at least 1 domain ≥1.5 SD** below the mean in impairments of **self-regulation** (mood or behavioral regulation impairment, attention deficit, or impulse control)

2. For children <3 y of age:
–Evidence of **developmental delay ≥1.5 SD below** the mean
-For children without documented prenatal alcohol exposure, a diagnosis of PFAS requires all features, A–C:

Hoyme, et al. (2016) Pediatrics, 138



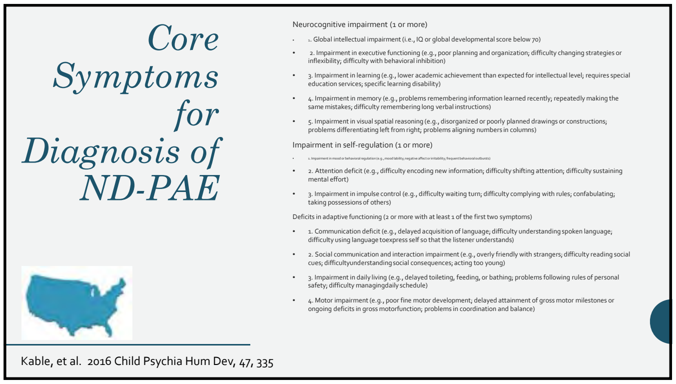
Criteria suggested by CDC for Neuro-developmental Diagnosis of FASD

- Cognitive deficits or significant developmental discrepancies
- Executive functioning deficits
- Motor delay or deficit
- Attention/hyperactivity problems
- Social Skills problems
- Other potential domains
  - Sensory problems
  - Pragmatic language deficits
  - Memory deficits
  - Difficulty responding to common parenting practices

Bertrand, Floyd, & Weber, 2005, MMWR, 54 1-10

Neurodevelopmental Domains for Diagnosis of FASD (Austrian System: Bower et al (2017)

- Brain Structure/Neurology
- Motor Skills
- Cognition
- Language
- Academic Achievement
- Memory
- Attention
- Executive Functioning, including impulse control and hyperactivity
- Affect regulation
- Adaptive Behaviour, social skills or social communication



Core Symptoms for Diagnosis of ND-PAE

Neurocognitive impairment (1 or more)

- 1. Global intellectual impairment (i.e., IQ or global developmental score below 70)
- 2. Impairment in executive functioning (e.g., poor planning and organization; difficulty changing strategies or inflexibility; difficulty with behavioral inhibition)
- 3. Impairment in learning (e.g., lower academic achievement than expected for intellectual level; requires special education services; specific learning disability)
- 4. Impairment in memory (e.g., problems remembering information learned recently; repeatedly making the same mistakes; difficulty remembering long verbal instructions)
- 5. Impairment in visual spatial reasoning (e.g., disorganized or poorly planned drawings or constructions; problems differentiating left from right; problems aligning numbers in columns)

Impairment in self-regulation (1 or more)

- 1. Impairment in mood or behavioral regulation (e.g., mood lability; negative affect or irritability; frequent behavioral outbursts)
- 2. Attention deficit (e.g., difficulty encoding new information; difficulty shifting attention; difficulty sustaining mental effort)
- 3. Impairment in impulse control (e.g., difficulty waiting turn; difficulty complying with rules; confabulating; taking possessions of others)

Deficits in adaptive functioning (2 or more with at least 1 of the first two symptoms)

- 1. Communication deficit (e.g., delayed acquisition of language; difficulty understanding spoken language; difficulty using language toexpress self so that the listener understands)
- 2. Social communication and interaction impairment (e.g., overly friendly with strangers; difficulty reading social cues; difficultyunderstanding social consequences; acting too young)
- 3. Impairment in daily living (e.g., delayed toileting, feeding, or bathing; problems following rules of personal safety; difficulty managingdaily schedule)
- 4. Motor impairment (e.g., poor fine motor development; delayed attainment of gross motor milestones or ongoing deficits in gross motorfunction; problems in coordination and balance)

Kable, et al. 2016 Child Psychia Hum Dev, 47, 335

Clinical Assessment of FASD in the United Kingdom (Mukherjee, et al.)

The Surrey Clinic carries out detailed assessments looking at communication and brain function, cognition, risk assessment, attention problems, hyperactivity and aggression.

The assessment takes two days. The first devoted to observation of behavior, non-verbal interactions, cognitive, sensory and communicative Profile. The second day includes questionnaires, review of records, and scoring of materials. *

* From information on the website: https://www.fasdclinic.com/about-us/what-we-do

Measures included in assessment of neuro-development in FASD

- Cambridge Neuropsychological Test Automated Battery (CANTAB)
- Delis-Kaplan Executive Function System (D-KEFS)
- Morris Virtual Water Maze (MVWM)
- Neurobehavioral Evaluation System 3 (NES3)
- Grooved Pegboard
- Progressive Planning Task
- Visual Discrimination Reversal Learning Test
- Visual Motor Integration Test Total

Mattson, et al, 2010, Alcohol Clin Exp Res, 34, p 1640

Tests identifying neuro-developmental effects of PAE

- CMS (Children's Memory Scale)-Stories
- D-KEFS Tower
- WISC-IV Memory Index
- WISC-IV Verbal Comprehension Index
- WRAT 4-Math Calculations
- WRAT4-Spelling

Enns & Taylor, 2016, Child Neuropsychol

CoFASP Surveillance Study*

*Collaboration on FASD Prevalence

NIAAAU01 AA019894 (May) and U01 AA019879 (Chambers) from the National Institute on Alcohol Abuse and Alcoholism (NIAAA).

- For the recent surveillance study of 4 communities in the United States, the following battery was used to identify the neurodevelopmental effects associated with the prevalence of FASD.
  - Differential Abilities Scale, 2nd Edition: DAS
  - The Berry-Buktenica Developmental Test of Visual-Motor Integration (6th edition): VMI
  - NEPSY Subtests, Executive Functioning and Attention; Visual/Motor
  - Bracken Basic Concepts Scale, 3rd Edition
  - Child Behavior Checklist-Parent and Teacher Forms, CBCL/TRF
  - Vineland Adaptive Behavior Scales, 2nd Edition (VABS)

Mays, et al (2018), JAMA, 319, 474-482

Using this battery, 222 children were identified as FASD

- This was equivalent to a rate of 2 to 5% of 6054 children screened. Of these 27 meet criteria for fetal alcohol syndrome (FAS), 104 met criteria for partial FAS (pFAS), and 91 met criteria for Alcohol Related Neurodevelopmental Disorder (ARND).
- To be diagnosed with FAS or pFAS, physical features and/or growth were required.
- Those with ARND were identified based on:
  - Confirmed prenatal exposure to alcohol
  - Scores on Tests of Development and Behavior (mentioned above).

The Emory Neurobehavioral and Developmental Clinic (ENEC)

- Located in Atlanta Georgia, within the Child and Adolescent Program, Department of Psychiatry and Behavioral Science, Emory University School of Medicine.
- Funded by a grant from the Georgia State Legislature and Medicaid.
- Goal is the diagnosis and treatment of affected children who cannot receive appropriate care in other context.

A 2-Tiered approach allows ***diagnosis*** *of disorder and* ***identification*** *of areas of need.*

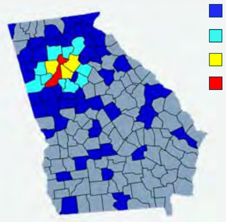
Tier 1: Diagnosis. This can be done in a morning allowing more efficient care of high risk group.

1. Screens out those who need care from those who do not
2. Redirects individuals without alcohol effects to more appropriate resources.
3. Allows the immediate treatment of alcohol-affected individuals
4. Identifies areas of need for Tier 2 assessment and intervention.

Tier 2: Comprehensive assessment and care directed at specific needs of the individual

Who comes to the Clinic

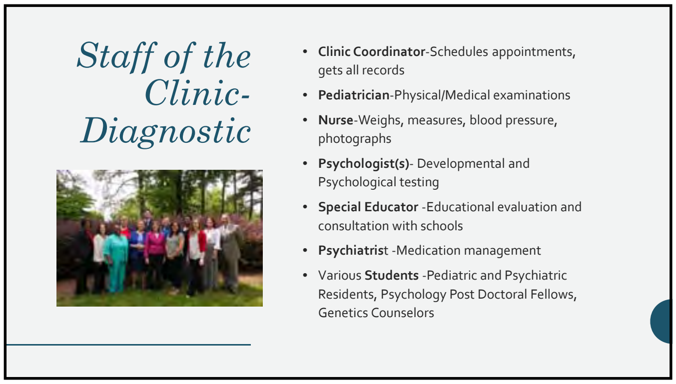
- Children, 0 to 21, average 4.9 yrs
- With prenatal exposure to alcohol and drugs
- From Atlanta and State
- Referred from:
  - Newborn nurseries
  - Pediatrician's offices
  - Other physicians' practices
  - Department of family and children's services
  - Social service agencies
  - Schools
  - Adoption agencies
  - Genetics Service
  - Family Support Groups
  - Internet
  - Etc….



Number of referrals by County

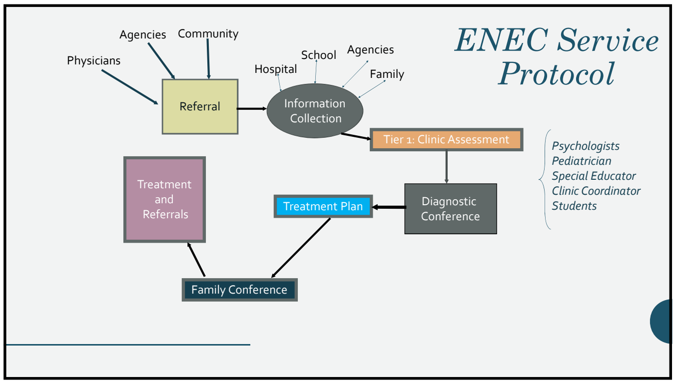
🟦	1 to 9
🟦	10-39
🟨	40-79
🟥	80 or more

State of Georgia, with 159 counties



Staff of the Clinic-Diagnostic

- **Clinic Coordinator**-Schedules appointments, gets all records
- **Pediatrician**-Physical/Medical examinations
- **Nurse**-Weighs, measures, blood pressure, photographs
- **Psychologist(s)**- Developmental and Psychological testing
- **Special Educator** -Educational evaluation and consultation with schools
- **Psychiatris**t -Medication management
- Various **Students** -Pediatric and Psychiatric Residents, Psychology Post Doctoral Fellows, Genetics Counselors

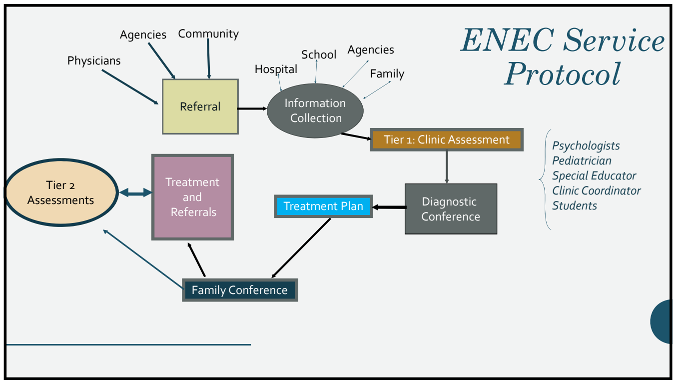


ENEC Service Protocol

Physicians
Agencies
Community
Referral
Hospital
School
Agencies
Family
Information Collection
Tier 1: Clinic Assessment

Psychologists
Pediatrician
Special Educator
Clinic Coordinator
Students

Diagnostic Conference
Treatment Plan
Treatment and Referrals
Family Conference



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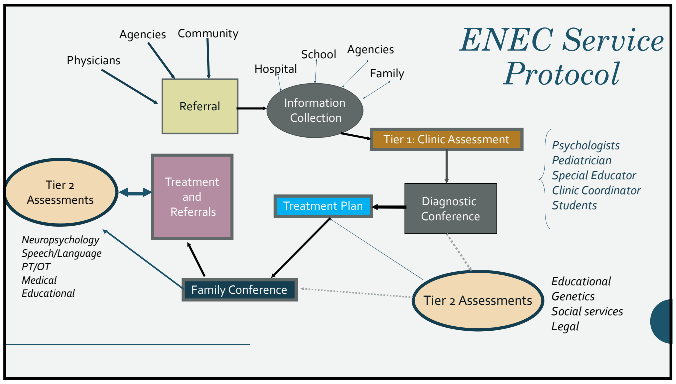
Students

Diagnostic Conference
Treatment Plan
Treatment and Referrals
Tier 2 Assessments
Family Conference



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Family
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Tier 1: Clinic Assessment

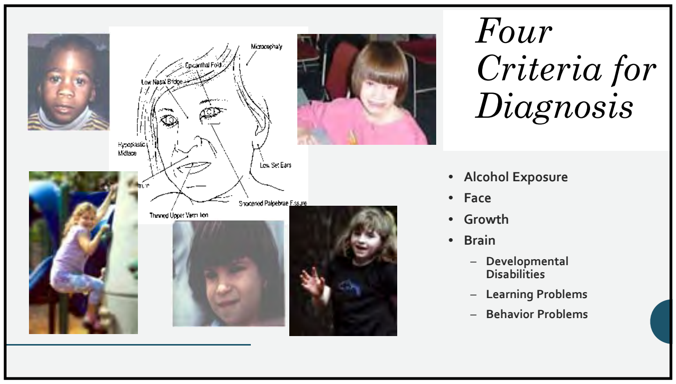
Psychologists
Pediatrician
Special Educator
Clinic Coordinator
Students

Diagnostic Conference
Treatment Plan
Treatment and Referrals
Tier 2 Assessments

Neuropsychology
Speech/Language
PT/OT
Medical
Educational

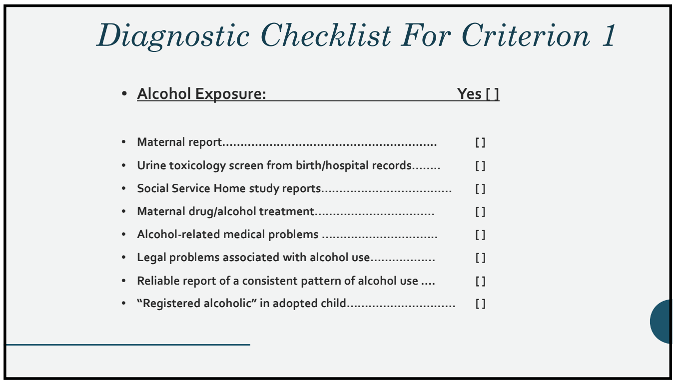
Family Conference
Tier 2 Assessments

Educational
Genetics
Social services
Legal



Four Criteria for Diagnosis

- Alcohol Exposure
- Face
- Growth
- Brain
  - Developmental Disabilities
  - Learning Problems
  - Behavior Problems



Diagnostic Checklist For Criterion 1

- Alcohol Exposure: Yes [ ]

- Maternal report…………………………………………………… [ ]
- Urine toxicology screen from birth/hospital records…….. [ ]
- Social Service Home study reports……………………………… [ ]
- Maternal drug/alcohol treatment…………………………… [ ]
- Alcohol-related medical problems …………………………… [ ]
- Legal problems associated with alcohol use……………… [ ]
- Reliable report of a consistent pattern of alcohol use …. [ ]
- "Registered alcoholic" in adopted child………………………… [ ]

Comments on Maternal Alcohol Use:

This is hard

- Note: The list does not include "*suspected*" alcohol use because:
  - The woman used drugs including marijuana.
  - Someone thinks that she drank but never observed it themselves.
  - There is a legal battle going on over custody.
  - There is a general suspicion about the woman's character and behavior.
  - The child has behavioral characteristics that some people associated with alcohol exposure.
  - The child was adopted internationally.

Exposure History Determined at Clinic

- No Exposure
- Exposure Cannot be Determined
- Alcohol Exposed
- Other Exposure (e.g., cocaine, prescription drugs, opiates, marijuana)

Criterion 2: Growth Deficiency (<10th %)

Either at birth or currently

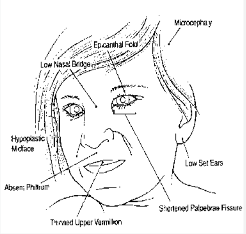
- <u>Growth Deficiency:</u>

- **Birth weight percentile...........................[ ]**
- **Birth length percentile........................... [ ]**
- **Current weight percentile..................... [ ]**
- **Current height percentile..................... [ ]**

Obtaining Information for Growth Criteria

- Birth Records:
  - weight, length, head circumference
  - Percentiles
  - Gestational Age
- Current Growth:
  - weight, length, head circumference
  - Percentiles
- Identifying any other factors that may account for growth failure rather than alcohol exposure.
  - Neglect
  - Feeding disorders
  - Medical conditions

Identification of Physical Features



- ***Facial Features***
- **Other physical features**

Dysmorphia Checklist

LEGEND:
0 = ABSENT
- = NOT DETERMINABLE
+ = PRESENT

PED SCORE:

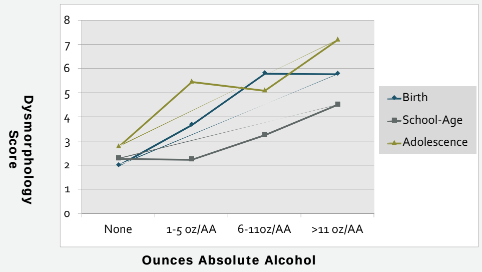
SCORER'S INITIALS

PLEASE COMPLETE SIDE B

Pediatric/Genetics Checklist
Scores >=10

Must be completed by a physician.

Dose/Response Relationship between Dysmorphology Scores and oz AA/wk



Lynch, et al., 2004

Criterion 3: Dysmorphology

- **Checklist Score: Yes [ ]**

- Dysmorphology Score...............................[ ]

(Scores greater than 10 suggest alcohol effects.)

- Narrative disqualifier:

(This is used if we think that the score is not measuring alcohol pathology but is the result of other factors.)

Criterion 4: Neurodevelopmental

CNS Damage: [ ]

- CATEGORY 1:
  - Birth Head circumference percentile (< 2 yrs)...... .... [ ]
  - Head circumference Percentile.................................. ...[ ]
  - CT/MRI Abnormality Past...[]
  - CT/MRI Present...[ ]
  - Cognitive/Intellectual Ability.....................................[ ]
  - Visual-spatial Ability...[ ]
-
- CATEGORY 2:
  - Graphomotor Skills.. [ ]
  - Math Skills.. [ ]
  - Executive Function Skills...................................... [ ]
  - Working Memory.. [ ]
  - Processing Speed... [ ]
  - Memory Organizational Skills.......................... [ ]
  - Learning/Encoding Deficit.................................... [ ]
  - Other (list:_______________________________) [ ]

Narrative disqualifier:

(This is used if we think that the score is not measuring alcohol pathology but is the result of other factors.)

Neurodevelopmental Test Batteries

Infants (1 to 2 hours)

- Bayley Scales of Infant and Toddler Development, 3rd Edition
- Vineland Adaptive Behavior Scales, 3rd Edition, Comprehensive Interview
- *>18 months, Child Behavior Checklist*

Preschool/School Age (1 ½ to 3 hours)

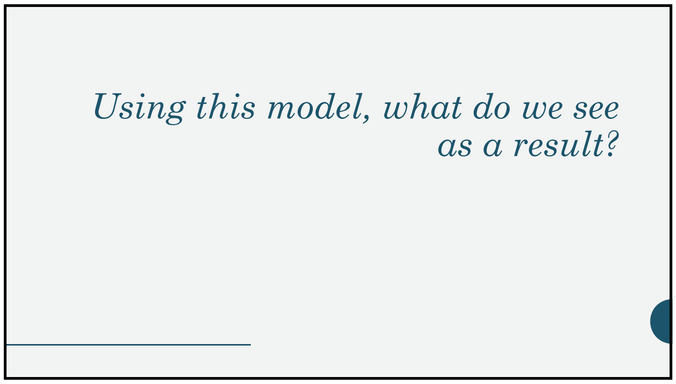
- Differential Ability Scales (DAS)
  - Preschool Version
  - School Age Version
- Achievement Tests
- Peabody Picture Vocabulary Test (PPVT-III)
- Developmental Test of Visual-Motor Integration (VMI)
- Vineland Adaptive Behavior Scales (VABS)
- *Child Behavior Checklists, Teacher Report Form –Questionnaires*

Criterion 4: Evidence of Neurodevelopmental Deficit

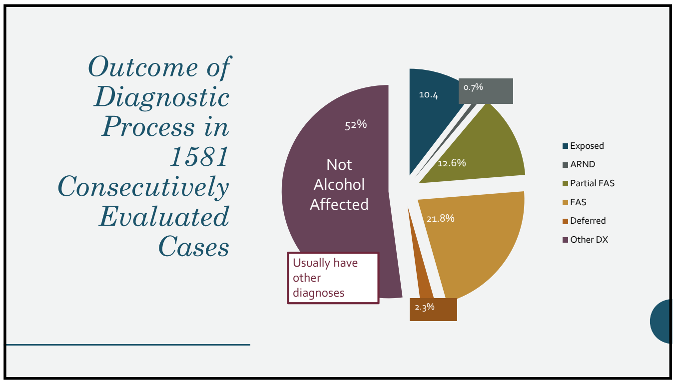
- The following are accepted as evidence of neurodevelopmental deficits:
  - Bayley score ≤ 85 (Bayley Scales of Infant and Toddler Development, 3rd Ed)
  - IQ score ≤ 70, That is 2 Standard Deviations from Mean of 100
  - Verbal/Performance Split of 15 or more points, either V>P or P>V
  - Academic Standard Score 1 SD (15 points) less than IQ
  - Math Standard Score 1 SD less than IQ
  - Math Standard Score 1 SD less than other Academic scores
  - Multiple Standard scores on tests between 70 and 84
  - Neurological diagnosis (e.g., seizures, cerebral palsy)

Clinical Conference

- Same day as Evaluation appointment
- All Clinic professionals and students
- Each professional presents findings
- FAS Criteria examined for FAS Dx
- Other Medical, Social, Psychological and Educational findings discussed
- **Further tests and investigations proposed (Tier 2)**
- Treatment plan developed in relation to presenting questions
- Recommendations recorded

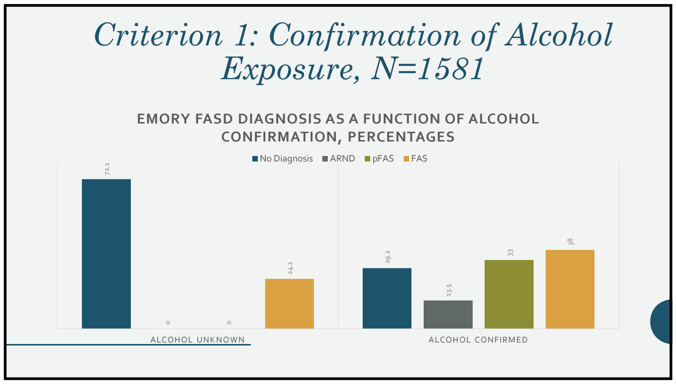


Using this model, what do we see as a result?



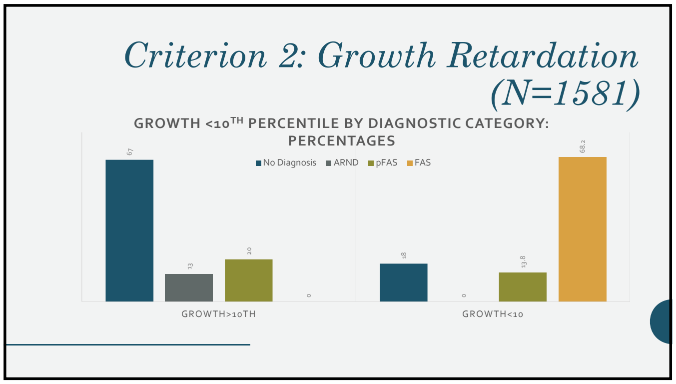
Outcome of Diagnostic Process in 1581 Consecutively Evaluated Cases

Usually have other diagnoses



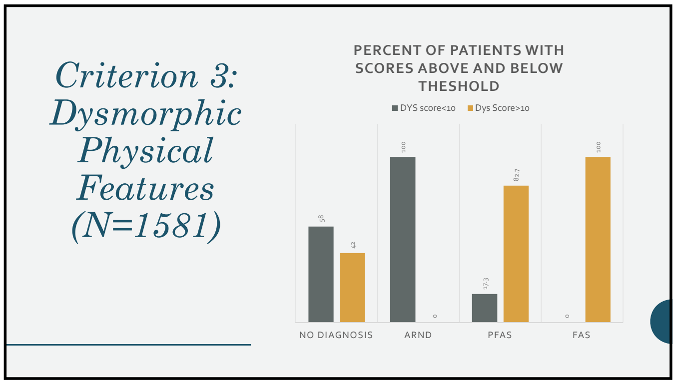
Criterion 1: Confirmation of Alcohol Exposure, N=1581

EMORY FASD DIAGNOSIS AS A FUNCTION OF ALCOHOL CONFIRMATION, PERCENTAGES



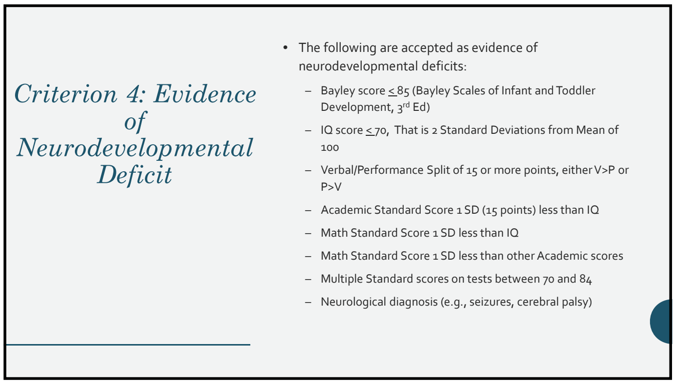
Criterion 2: Growth Retardation (N=1581)

GROWTH <10TH PERCENTILE BY DIAGNOSTIC CATEGORY: PERCENTAGES



Criterion 3: Dysmorphic Physical Features (N=1581)

PERCENT OF PATIENTS WITH SCORES ABOVE AND BELOW THESHOLD



Criterion 4: Evidence of Neurodevelopmental Deficit

- The following are accepted as evidence of neurodevelopmental deficits:
  - Bayley score ≤ 85 (Bayley Scales of Infant and Toddler Development, 3rd Ed)
  - IQ score ≤ 70, That is 2 Standard Deviations from Mean of 100
  - Verbal/Performance Split of 15 or more points, either V>P or P>V
  - Academic Standard Score 1 SD (15 points) less than IQ
  - Math Standard Score 1 SD less than IQ
  - Math Standard Score 1 SD less than other Academic scores
  - Multiple Standard scores on tests between 70 and 84
  - Neurological diagnosis (e.g., seizures, cerebral palsy)

Criterion 4: Percent of Each Diagnostic Group with Neurodevelopmental Deficits (Total N=1581)

Measure of Neurodevelopment	No Diagnosis (n=704)	ARND (n=111)	pFASD (n=271)	FAS (n=495)
Neurological DX*	23 (3.27 %)	4 (3.60%)	22 (8.12%)*	47 (9.49%)*
Bayley DQ <85(N=383)#	*56 (7.95%)*	*20 (18.01%)*	*35 (18.45%)*	*138 (27.87%)**
IQ<70 (N=1198)	89 (12.64%)	21 (18.92%)	53 (19.56%)	128 (25.86%)
Verbal>Performance	40 (5.68%)	14 (12.61%)	20 (7.38%)	37 (7.47%)
Performance>Verbal	59 (8.38%)	13 (11.71%)	27 (9.96%)	50 (10.10%)
Academic<IQ	96 (13.63%)	25 (22.52%)	50 (18.45%)	95 (19.19%)
Math<IQ	49 (6.96%)	11 (9.90%)	25 (9.23%)	43 (8.69%)
Math <Academics	42 (5.97%)	7 (6.3%)	33 (12.18%)	56 (11.31%)
Multiple Standard Scores, 70-84	374 (53.13%)	84 (75.67%)	186 (68.63%)	365 (73.73%)

*Statistical difference

For Bayley, total N=383

Criterion 4: Neurodevelopmental Deficits Observed (N=1581)

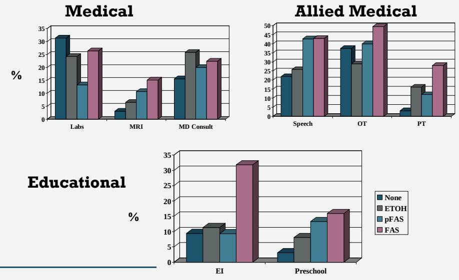
Measure of Neurodevelopment	No Diagnosis (n=704)	ARND (n=111)	pFASD (n=271)	FAS (n=495)
Neurological DX*	23 (1.45 %)	4 (0.25%)	22 (1.39%)*	47 (2.97%)*
Bayley DQ <85(N=383)#	*56 (14.62%)*	*20 (5.22%)*	*35 (9.14%)*	*138 (36%)**
IQ<70 (N=1198)	89 (7.42%)	21(1.75%)	53 (4.42%)	128 (10.68%)
Verbal>Performance	40 (3.38%)	14 (1.83%)	20 (1.69%)	37 (3.13%)
Performance>Verbal	59 (4.99%)	13 (1.1%)	27 (2.28%)	50 (4.23%)
Academic<IQ	96 (8.11%)	25 (2.11%)	50 (4.23%)	95 (8.03%)
Math<IQ	49 (4.14%)	11 (0.93%)	25 (2.11%)	43 (3.63%)
Math <Academics	42 (3.55%)	7 (0.59%)	33 (2.79%)	56 (4.73%)
Multiple Standard Scores, 70-84	374 (30.76%)	84 (7.10%)	186 (15.72%)	365 (30.85%)
*Statistical difference				

For Bayley, total N=383 and Percentages are number <85/383 in each category; for other categories, N=1198 and percentages are calculated with that number as denominator.

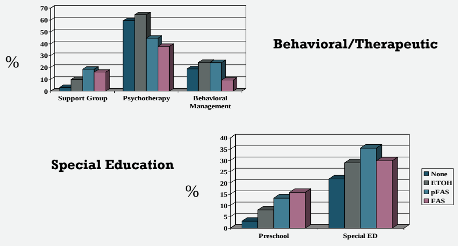
Questions about diagnosis of FASD

- Clinical applicability of the diagnosis
- What is necessary?
- How will the diagnosis be used? That is, what is the purpose of a FASD Dx?
- Does diagnosis equal assessment of clinical needs.

Services Recommended after Dx (%): Infants



Additional Services Recommended after Dx (%): School Age



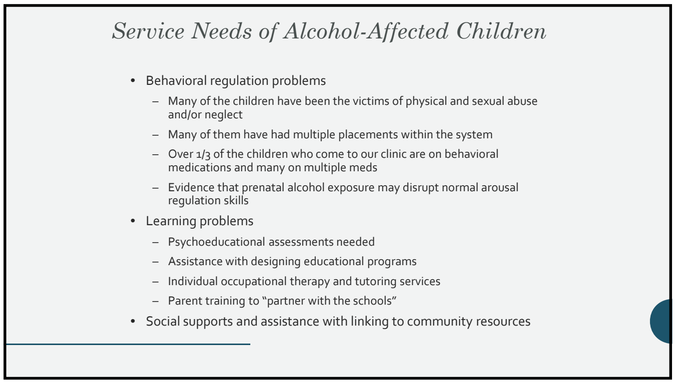
What is the Tier 2 Assessment?

(and how is it determined?)

- Based on results of Tier 1 Assessment.
- Based of Previous assessments and diagnoses.
- Based on Diagnoses made.
- Based on Gaps in knowledge.
- Based on Assessment of resources, personal and social.

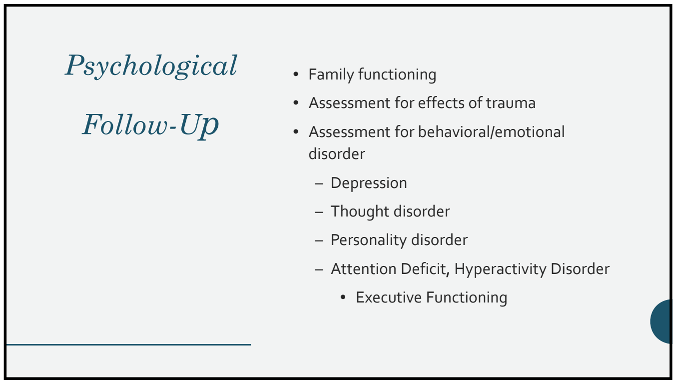
Medical Referrals for Tier 2

- Hearing and vision assessments
- Physical therapy assessments
- Speech/language Therapy
- Occupational Therapy
- Various medical specialists
  - Neurology
  - Endocrinology
  - ENT
  - Gynecology
  - Genetics
    - Microarray
    - Autism panel



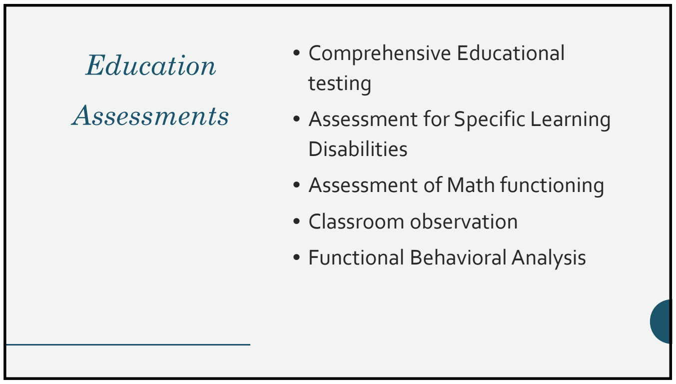
Service Needs of Alcohol-Affected Children

- Behavioral regulation problems
  - Many of the children have been the victims of physical and sexual abuse and/or neglect
  - Many of them have had multiple placements within the system
  - Over 1/3 of the children who come to our clinic are on behavioral medications and many on multiple meds
  - Evidence that prenatal alcohol exposure may disrupt normal arousal regulation skills
- Learning problems
  - Psychoeducational assessments needed
  - Assistance with designing educational programs
  - Individual occupational therapy and tutoring services
  - Parent training to "partner with the schools"
- Social supports and assistance with linking to community resources



Psychological Follow-Up

- Family functioning
- Assessment for effects of trauma
- Assessment for behavioral/emotional disorder
  - Depression
  - Thought disorder
  - Personality disorder
  - Attention Deficit, Hyperactivity Disorder
    - Executive Functioning



Education Assessments

- Comprehensive Educational testing
- Assessment for Specific Learning Disabilities
- Assessment of Math functioning
- Classroom observation
- Functional Behavioral Analysis

NEURODEVELOPMENTAL OUTCOMES OF PRENATAL ALCOHOL EXPOSURE:

EXPERIENCE OF THE UKRAINIAN COHORT

Bayley Scales of Infant Development (2nd Edition)

Mental Development Index (MDI) (M=100, SD=15)
Includes: Problem solving, Prelinguistic Development

Psychomotor Development Index (PDI) (M=100, SD=15)
Includes: Fine and Gross Motor Development

BSID-II OUTCOMES AT 6 MONTHS M(SD)(N=190). MULTIVARIATE ANALYSIS

Alcohol Exposure	None		Alcohol Exposed	
Micronutrients	**None (n=24)**	**Supplement (n=19)**	**None (n=20)**	**Supplement (n=24)**
Mental (MDI)	91.43 (10.81)	93.91 (5.55)	88.27 (14.04)	92.96 (6.28)
Motor (PDI)	93.13 (9.68)	92.07 (10.78)	89.78 (18.31)	92.51 (10.40)

Alcohol, MDI ($F_{1,}$)=2.3,p<.13; NS; PDI ($F_{1,}$)=6.99p<.009

Supplement, MDI ($F_{1,}$)<6.99,p<.009; ; PDI ($F_{1,83}$)<1, NS

No significant interactions.

IMPACT OF 1ST TRIMESTER ALCOHOL DOSE (OZ/AA) AND MICRONUTRIENTS: MENTAL DEVELOPMENT (MDI)*

Variable	β	Chi Sq	df	Significance
MVM[1]	-3.904	9.257	1	.002
Baby Gender[2]	-2.72	4.419	1	.036
EtOH 1st Trimester[3]	-13.678	8.224	1	.004
SES[4]	.145	5.833	1	.016[4]

* Generalized Linear modeling controlling for potential confounders, including child sex and socioeconomic status (SES).

[1] Vitamin supplements associated with higher scores
[2] Female gender associated with higher scores
[3] More alcohol associated with lower scores
[4] Higher SES associated with higher scores

IMPACT OF 1ST TRIMESTER ALCOHOL DOSE (OZ/AA) AND MICRONUTRIENTS ON MOTOR DEVELOPMENT (PDI)*

Variable	β	Chi Sq	df	Significance
MVM	-.933	.264	1	.607
EtOH 1st Trimester[1]	-20.71	9.035	1	.003
SES[2]	.209	5.867	1	.015
Smoking[3]	.933	5.322	1	.021

* Generalized Linear modeling controlling for potential confounders, including socioeconomic status (SES) and cigarette smoking.

[1] More alcohol associated with lower scores
[2] Higher SES associated with higher scores
[3] Smoking associated with lower scores

NONVERBAL PRESCHOOL TEST BATTERY FOR EFFECTS OF PAE

CHILD-Direct Testing

- ☐ Leiter- Attention Sustained*
- ☐ Differential Ability Scales (DAS)*
  - Picture Similarities
  - Pattern Construction
  - Matrices
  - Copying
- ☐ Self-Ordered Pointing Task (SOPT)
- ☐ "Corsi" Blocks
- ☐ Motor Inhibition (Draw a Line Slowly)
- ☐ AB Task
- ☐ Delayed Attention
- ☐ Hand Game for Preschoolers
- ☐ NEPSY II*
  - Speeded Naming
  - Statues
- ☐ NEPSY I Visual Attention*

These are Standardized tests. Others are experimental.

PARENT Questionnaires

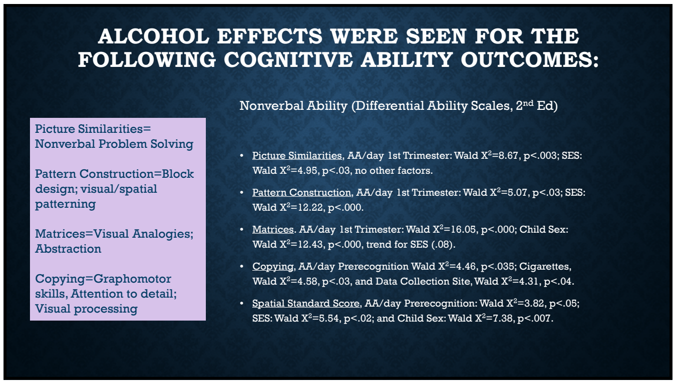
- ☐ Child Behavior Checklist (CBCL)*
- ☐ Preschool BRIEF*
- ☐ Preschool Children's Behavior Questionnaire*
- ☐ Vineland Adaptive Behavior Scales, 2nd Ed (VABS-2)*

Characteristics of Preschool Sample (N=243)

	No Alcohol			Alcohol			
	No MVM (n=61)	MVM (n=42)	+Chol (n=40)	No MVM (n=45)	MVM (n=21)	+Chol (n=34)	
Child Age M (SD)	3.89 (0.28)	3.95 (0.33)	3.94 (0.28)	4.05 (0.38)	3.90 (0.35)	3.98 (0.34)	NS
Child Sex (% male)	45.9%	57.14%	65%	48.9%	57.14%	47.1%	NS
Child Ability M (SD) DAS-II, Nonverbal SS	94.36 (14.42)	97.24 (15.91)	91.68 (15.05)	92.04 (17.39)	91.86 (15.92)	92.47 (14.45)	NS
SES M(SD) Hollingshead	41.24 (11.22)	38.76 (12.90)	43.40 (9.96)	37.68 (10.32)	34.76 (10.02)	31.97 (11.46)	Etoh: $F_{(2,234)}$=17.6, p<.000
Ounces AA/day Preconceptual M (SD)	0	0	0	0.57 (0.49)	0.52 (0.27)	0.64 (0.59)	Etoh: $F_{(2,237)}$=175.68, p<.000
Cigarettes/wk M (SD)	1.54 (7.04)	0	0	9.71 (14.44)	8.44 (13.89)	10.52 (15.51)	Etoh: $F_{(2,234)}$=44.28, p<.000

DATA ANALYSIS

- Generalized Linear Regression (GLR) was used to create models of factors affecting children's test outcomes.
- The following factors were considered in models:
-
  - Alcohol per day during first Trimester (oz/AA/day 1st Trimester)
  - Alcohol per day before pregnancy recognition (oz/AA/day preconceptual)
  - Multivitamin/mineral supplementation in pregnancy (MVM)
  - Number of Cigarettes Smoked during pregnancy
  - Data Collection Site
  - Child Sex
  - Socioeconomic Status (SES)
  - Gestational Age (GA)
  - Mother's Education



ALCOHOL EFFECTS WERE SEEN FOR THE FOLLOWING COGNITIVE ABILITY OUTCOMES:

Picture Similarities= Nonverbal Problem Solving

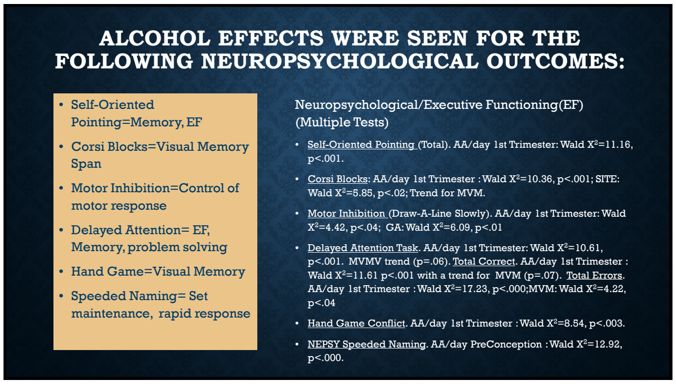
Pattern Construction=Block design; visual/spatial patterning

Matrices=Visual Analogies; Abstraction

Copying=Graphomotor skills, Attention to detail; Visual processing

Nonverbal Ability (Differential Ability Scales, 2nd Ed)

- Picture Similarities, AA/day 1st Trimester: Wald X^2=8.67, p<.003; SES: Wald X^2=4.95, p<.03, no other factors.
- Pattern Construction, AA/day 1st Trimester: Wald X^2=5.07, p<.03; SES: Wald X^2=12.22, p<.000.
- Matrices. AA/day 1st Trimester: Wald X^2=16.05, p<.000; Child Sex: Wald X^2=12.43, p<.000, trend for SES (.08).
- Copying, AA/day Prerecognition Wald X^2=4.46, p<.035; Cigarettes, Wald X^2=4.58, p<.03, and Data Collection Site, Wald X^2=4.31, p<.04.
- Spatial Standard Score, AA/day Prerecognition: Wald X^2=3.82, p<.05; SES: Wald X^2=5.54, p<.02; and Child Sex: Wald X^2=7.38, p<.007.

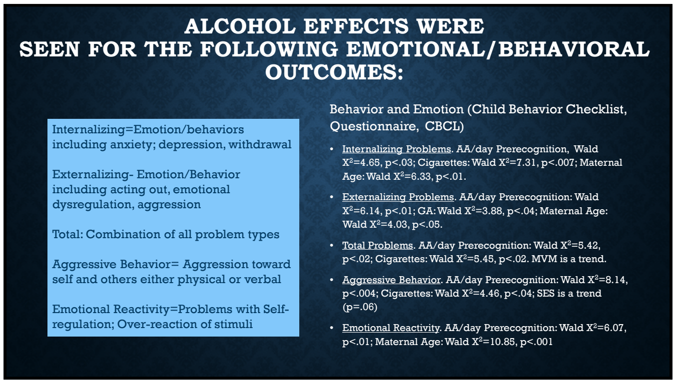


ALCOHOL EFFECTS WERE SEEN FOR THE FOLLOWING NEUROPSYCHOLOGICAL OUTCOMES:

- Self-Oriented Pointing=Memory, EF
- Corsi Blocks=Visual Memory Span
- Motor Inhibition=Control of motor response
- Delayed Attention= EF, Memory, problem solving
- Hand Game=Visual Memory
- Speeded Naming= Set maintenance, rapid response

Neuropsychological/Executive Functioning(EF) (Multiple Tests)

- Self-Oriented Pointing (Total). AA/day 1st Trimester: Wald X^2=11.16, p<.001.
- Corsi Blocks: AA/day 1st Trimester : Wald X^2=10.36, p<.001; SITE: Wald X^2=5.85, p<.02; Trend for MVM.
- Motor Inhibition (Draw-A-Line Slowly). AA/day 1st Trimester: Wald X^2=4.42, p<.04; GA: Wald X^2=6.09, p<.01
- Delayed Attention Task. AA/day 1st Trimester: Wald X^2=10.61, p<.001. MVMV trend (p=.06). Total Correct. AA/day 1st Trimester : Wald X^2=11.61 p<.001 with a trend for MVM (p=.07). Total Errors. AA/day 1st Trimester : Wald X^2=17.23, p<.000;MVM: Wald X^2=4.22, p<.04
- Hand Game Conflict. AA/day 1st Trimester : Wald X^2=8.54, p<.003.
- NEPSY Speeded Naming. AA/day PreConception : Wald X^2=12.92, p<.000.



ALCOHOL EFFECTS WERE SEEN FOR THE FOLLOWING EMOTIONAL/BEHAVIORAL OUTCOMES:

Internalizing=Emotion/behaviors including anxiety; depression, withdrawal

Externalizing- Emotion/Behavior including acting out, emotional dysregulation, aggression

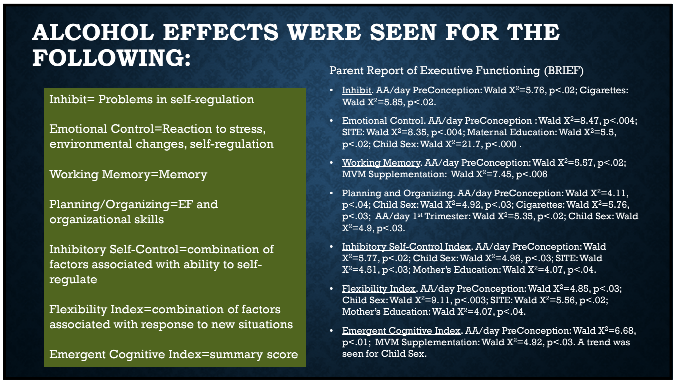
Total: Combination of all problem types

Aggressive Behavior= Aggression toward self and others either physical or verbal

Emotional Reactivity=Problems with Self-regulation; Over-reaction of stimuli

Behavior and Emotion (Child Behavior Checklist, Questionnaire, CBCL)

- Internalizing Problems. AA/day Prerecognition, Wald X^2=4.65, p<.03; Cigarettes: Wald X^2=7.31, p<.007; Maternal Age: Wald X^2=6.33, p<.01.
- Externalizing Problems. AA/day Prerecognition: Wald X^2=6.14, p<.01; GA: Wald X^2=3.88, p<.04; Maternal Age: Wald X^2=4.03, p<.05.
- Total Problems. AA/day Prerecognition: Wald X^2=5.42, p<.02; Cigarettes: Wald X^2=5.45, p<.02. MVM is a trend.
- Aggressive Behavior. AA/day Prerecognition: Wald X^2=8.14, p<.004; Cigarettes: Wald X^2=4.46, p<.04; SES is a trend (p=.06)
- Emotional Reactivity. AA/day Prerecognition: Wald X^2=6.07, p<.01; Maternal Age: Wald X^2=10.85, p<.001



ALCOHOL EFFECTS WERE SEEN FOR THE FOLLOWING:

Inhibit= Problems in self-regulation

Emotional Control=Reaction to stress, environmental changes, self-regulation

Working Memory=Memory

Planning/Organizing=EF and organizational skills

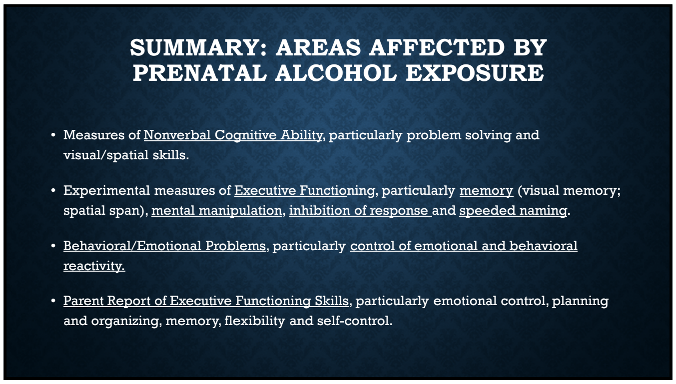
Inhibitory Self-Control=combination of factors associated with ability to self-regulate

Flexibility Index=combination of factors associated with response to new situations

Emergent Cognitive Index=summary score

Parent Report of Executive Functioning (BRIEF)

- Inhibit. AA/day PreConception: Wald X^2=5.76, p<.02; Cigarettes: Wald X^2=5.85, p<.02.
- Emotional Control. AA/day PreConception : Wald X^2=8.47, p<.004; SITE: Wald X^2=8.35, p<.004; Maternal Education: Wald X^2=5.5, p<.02; Child Sex: Wald X^2=21.7, p<.000 .
- Working Memory. AA/day PreConception: Wald X^2=5.57, p<.02; MVM Supplementation: Wald X^2=7.45, p<.006
- Planning and Organizing. AA/day PreConception: Wald X^2=4.11, p<.04; Child Sex: Wald X^2=4.92, p<.03; Cigarettes: Wald X^2=5.76, p<.03; AA/day 1st Trimester: Wald X^2=5.35, p<.02; Child Sex: Wald X^2=4.9, p<.03.
- Inhibitory Self-Control Index. AA/day PreConception: Wald X^2=5.77, p<.02; Child Sex: Wald X^2=4.98, p<.03; SITE: Wald X^2=4.51, p<.03; Mother's Education: Wald X^2=4.07, p<.04.
- Flexibility Index. AA/day PreConception: Wald X^2=4.85, p<.03; Child Sex: Wald X^2=9.11, p<.003; SITE: Wald X^2=5.56, p<.02; Mother's Education: Wald X^2=4.07, p<.04.
- Emergent Cognitive Index. AA/day PreConception: Wald X^2=6.68, p<.01; MVM Supplementation: Wald X^2=4.92, p<.03. A trend was seen for Child Sex.



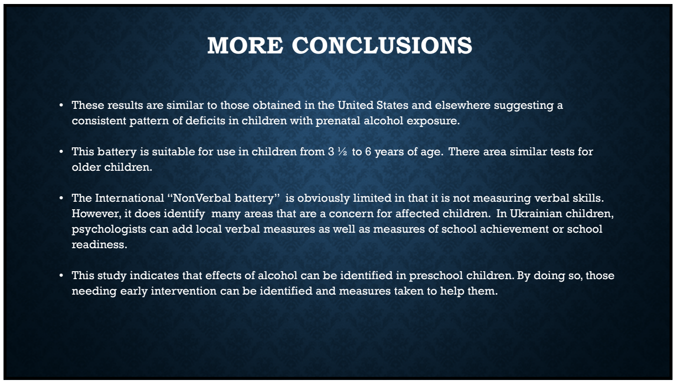
SUMMARY: AREAS AFFECTED BY PRENATAL ALCOHOL EXPOSURE

- Measures of Nonverbal Cognitive Ability, particularly problem solving and visual/spatial skills.
- Experimental measures of Executive Functioning, particularly memory (visual memory; spatial span), mental manipulation, inhibition of response and speeded naming.
- Behavioral/Emotional Problems, particularly control of emotional and behavioral reactivity.
- Parent Report of Executive Functioning Skills, particularly emotional control, planning and organizing, memory, flexibility and self-control.

MEASURES NOT SENSITIVE TO ALCOHOL EFFECTS

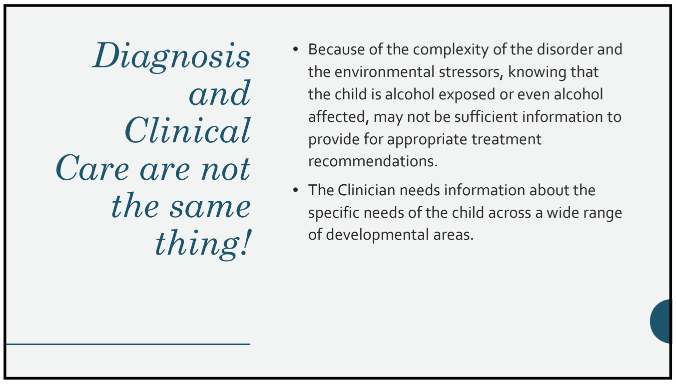
- Measures of Sustained Attention, Leiter-Attention Sustained and NEPSY Visual Attention were not sensitive to alcohol effects.
- One measure of Executive Functioning, the AB Task was not sensitive.
- NEPSY Statues task reflected effects of cigarette exposure but not alcohol.

So, NOT Sustained Attention or Motor Inhibition



MORE CONCLUSIONS

- These results are similar to those obtained in the United States and elsewhere suggesting a consistent pattern of deficits in children with prenatal alcohol exposure.
- This battery is suitable for use in children from 3 ½ to 6 years of age. There area similar tests for older children.
- The International "NonVerbal battery" is obviously limited in that it is not measuring verbal skills. However, it does identify many areas that are a concern for affected children. In Ukrainian children, psychologists can add local verbal measures as well as measures of school achievement or school readiness.
- This study indicates that effects of alcohol can be identified in preschool children. By doing so, those needing early intervention can be identified and measures taken to help them.



Diagnosis and Clinical Care are not the same thing!

- Because of the complexity of the disorder and the environmental stressors, knowing that the child is alcohol exposed or even alcohol affected, may not be sufficient information to provide for appropriate treatment recommendations.
- The Clinician needs information about the specific needs of the child across a wide range of developmental areas.

C8/D8 Is Iron Deficiency Impeding Personalized and/or Precision Medicine in Individuals with FASD? Ways out of the Iron Conundrum

James Connor, Alison Frieling, Osman Ipsiroglu, Mansfield Mela, Beth Potter, Alexandra Rauscher
Moderated by: Dorothy Reid, Christine Loock, Lori Vitale Cox

Learning Objectives

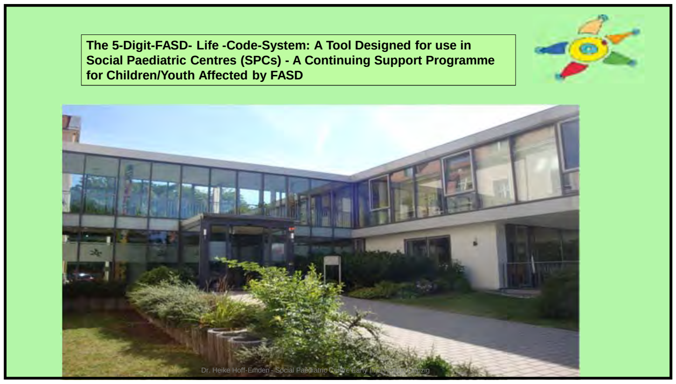
1. Review associations of ID/metabolism with the pathophysiology of FASD genesis
2. Present ID-scoping review results and H-Behaviour presentations
3. Review communication challenges in clinical practice from the perspectives of families and clinicians
4. Introduce the methodology of the proposed Iron Supplementation Study, which will focus on effects of iron supplementation and brain-iron-levels in context with patient-centered and health system outcomes

Background

Iron deficiency (ID) is the most common nutritional deficiency worldwide. Low socioeconomic status is a major risk factor for having ID. Animal and clinical research over the last 20 years has indicated a complex and relatively unexplored interaction between hyperactive-like behaviours, intractable chronic insomnia, iron deficiency and Prenatal Alcohol Exposure (PAE). This research is of particular relevance because the challenging/disruptive behaviours of children and youth with PAE have typically been attributed to daytime-focused clinical explanatory models. ID as a cause of hyperactive-like behaviours or of underlying sleep disorders, such as intractable chronic insomnia due to restless legs syndrome since early infancy, have not been investigated as possible causes. ID affects brain development, aggravates disruptive behaviours and interacts with the effects of psychotropic drugs. The members of the International Iron Conundrum Research Consortium are investigating characteristic voluntary movement patterns using video recordings and exploring urge-to-move- and movement soothes-behaviours using pictograms (icons) and play cards. Analysis of these ‘H-behaviours’ (hyperactivity / hyper-/hypoarousability in the wake state, hyper¬motor-restlessness in the sleep state) can potentially be used as a biomarker to indicate response to iron supplementation and psychotropic drugs and personalize medicine. A new brain-iron-magnet-resonance-imaging measurement protocol allows the connection of H-behaviours with brain development.

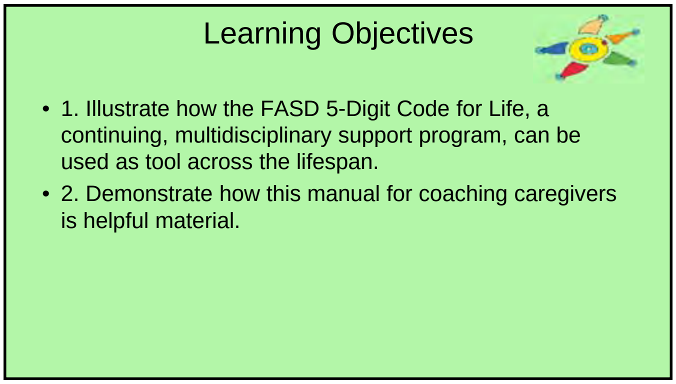
C9 The 5-Digit-FASD-Life-Code-System - A tool Designed for use in Social Paediatric Centres (SPCs) - A Continuing Support Programme for Children/ Youth Affected by FASD

Heike Hoff-Emden



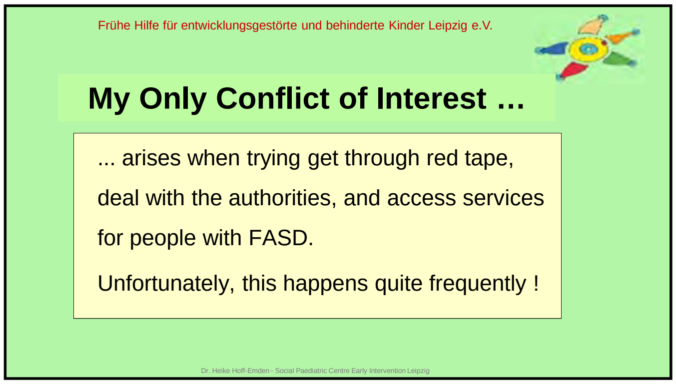
The 5-Digit-FASD- Life -Code-System: A Tool Designed for use in Social Paediatric Centres (SPCs) - A Continuing Support Programme for Children/Youth Affected by FASD

Dr. Heike Hoff-Emden - Social Paediatric Centre Early Intervention Leipzig



Learning Objectives

- 1. Illustrate how the FASD 5-Digit Code for Life, a continuing, multidisciplinary support program, can be used as tool across the lifespan.
- 2. Demonstrate how this manual for coaching caregivers is helpful material.



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My Only Conflict of Interest …

... arises when trying get through red tape, deal with the authorities, and access services for people with FASD.

Unfortunately, this happens quite frequently !

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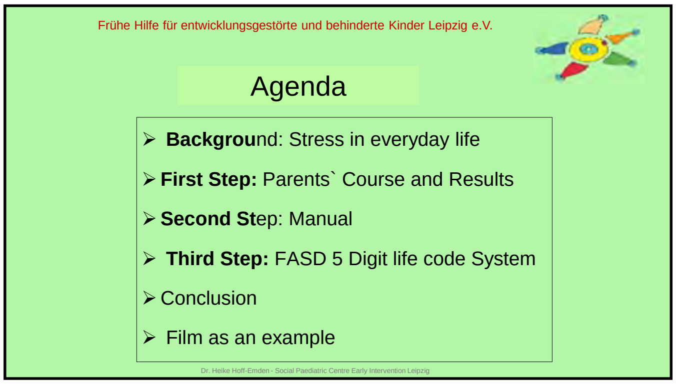

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Agenda

- ➢ **Background**: Stress in everyday life
- ➢ **First Step:** Parents` Course and Results
- ➢ **Second Step**: Manual
- ➢ **Third Step:** FASD 5 Digit life code System
- ➢ Conclusion
- ➢ Film as an example

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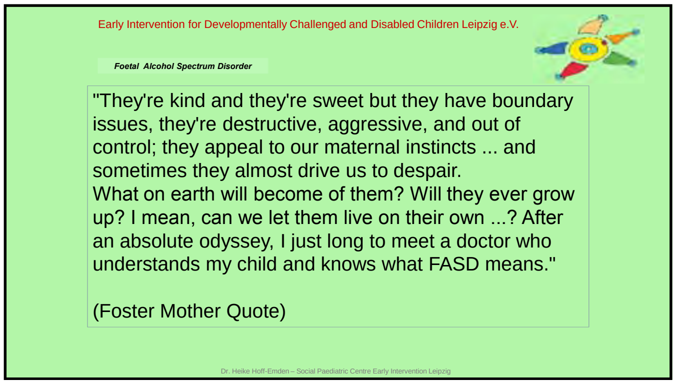

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Foetal Alcohol Spectrum Disorder

"They're kind and they're sweet but they have boundary issues, they're destructive, aggressive, and out of control; they appeal to our maternal instincts ... and sometimes they almost drive us to despair.
What on earth will become of them? Will they ever grow up? I mean, can we let them live on their own ...? After an absolute odyssey, I just long to meet a doctor who understands my child and knows what FASD means."

(Foster Mother Quote)

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"Inner and outer war"- stimulus words: "how are you ? " daily form dependent

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Parental coaching

5 appointments (1 / per month) 12 carers (foster and adoptive parents)

Key topics were:

- Basic knowledge about FASD
- Strategies for everyday life, emergency plans
- Personalized advancement, avoiding overstrain
- Questions pertaining to social law, suitable schooling and
- job outlook
- How to reduce stress for everyone, using role-play to help
- Handle difficult situations

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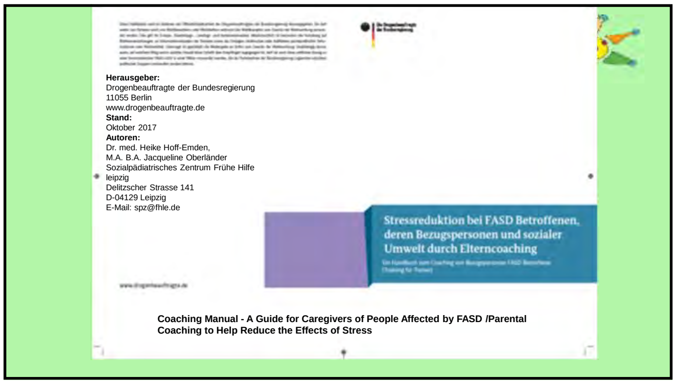

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Oktober 2017
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Stressreduktion bei FASD Betroffenen, deren Bezugspersonen und sozialer Umwelt durch Elterncoaching

Coaching Manual - A Guide for Caregivers of People Affected by FASD /Parental Coaching to Help Reduce the Effects of Stress

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Content of the Manual

– Train trainers who work with those affected and their caregivers.
Basic knowledge combined with emotionally moving examples
Psychoeducation, modular construction
FASD as a "total plan," 5 digit life code
Helpful materials
Results of parent training
Resources

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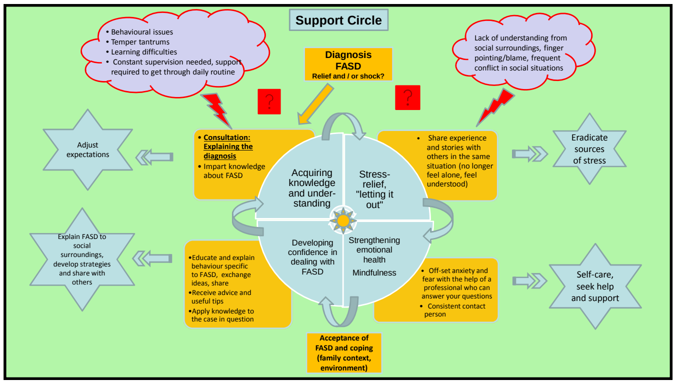

Support Circle

- Behavioural issues
- Temper tantrums
- Learning difficulties
- Constant supervision needed, support required to get through daily routine

Diagnosis FASD
Relief and / or shock?

Lack of understanding from social surroundings, finger pointing/blame, frequent conflict in social situations

?

?

Adjust expectations

- **Consultation: Explaining the diagnosis**
- Impart knowledge about FASD

Acquiring knowledge and understanding

Stress-relief, "letting it out"

- Share experience and stories with others in the same situation (no longer feel alone, feel understood)

Eradicate sources of stress

Explain FASD to social surroundings, develop strategies and share with others

- Educate and explain behaviour specific to FASD, exchange ideas, share
- Receive advice and useful tips
- Apply knowledge to the case in question

Developing confidence in dealing with FASD

Strengthening emotional health

Mindfulness

- Off-set anxiety and fear with the help of a professional who can answer your questions
- Consistent contact person

Self-care, seek help and support

Acceptance of FASD and coping (family context, environment)

Main-Procedure in SPC

1. Caregivers fill out FASD-specific Questionnaire and send to SPC
2. FASD Diagnostic Day(s): Anamnestic, Physical, Neuropsychological examinations, other Therapists
3. Coordinate results (interdisciplinary treatment plan)
4. Talk about results and explain report to caregivers and patients (5 digit Life code starts)
5. Follow-ups, half year, opportunities for telephone consults, crisis intervention

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FASD –
A Total Work of Art
5-Digit Code for Life

5 Digit Life Code

1) Check for physical abnormalities and co-morbid conditions
2) Neuro psychology/check trauma-related issues /social behaviour
3) Coordinate treatment (medication, physical and psychological therapies)
4) Determine the level of social participation (or isolation) - work to improve it
5) Create a network for life.

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- Examine, send to specialists
- Explain results
- Report:
  - Social-medical and neuropsychological results
  - Interdisciplinary treatment plan and advice
- Follow–up/guidance

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Frequent Comorbidities = Explain and Send to Specialists

In FASD, the following comorbidities are common and specialists should be consulted:

- Ophthalmologist - Routine Screening
- ENT - Routine examination: hearing test, submucosal cleft palate
- Pediatric Gastroenterologist – Supplementary diet, fructose-lactose intolerance, Celiac Disease
- Pediatric cardiologist - Rule out a heart defect
- Urologist - Sonography necessary to detect malformations
- Orthopedist - Skeletal deformities, foot deformities, hypermobility of the joints
- EEG - Further neuropaediatric diagnostic
- Anesthesiologists - Before surgery: paradoxical reactions to narcotic possible, intubation problems

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Observed Comoribities with FASD

- Celiac Disease
- Prosopagnosia
- Limitation of the visual field
- Genetic abnormalities
- Autism
- Immunodeficiencies

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- Neuropsychological Diagnostic
- Describe Behaviour
- Check PTBS
- Translate Results into Advice for Daily Life

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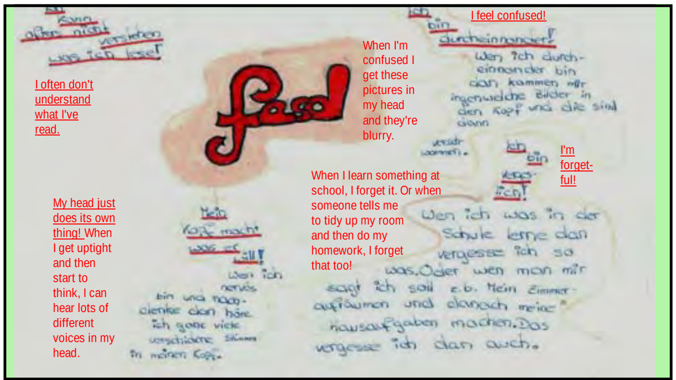
Spatial-constructive skills
Spatial-constructive skills
fine motor skills

Neuropsychological Diagnostic

- Cognitive Abilities
- Attention/Awareness (z.B. KITAP, TAP, CPT)
- Ability to Learn/Memory Functions (z.B. VLMT, DCS)
- Executive Functions (BRIEF-Questionnaire, Tower of London)
- Dyslexia/Dyscalculia
- Socio-emotional Development /Behavioural problems
- Spatial-constructive Skills
- Fine Motor Skills



Ich kann often nicht verstehen was ich lese!

I often don't understand what I've read.

Ich bin durcheinnander!

I feel confused!

Wen ich durcheinnander bin dan kammen mir irgenwelche Bilder in den Kopf und die sind dann verschwommen.

When I'm confused I get these pictures in my head and they're blurry.

Ich bin vergess-lich!

I'm forget-ful!

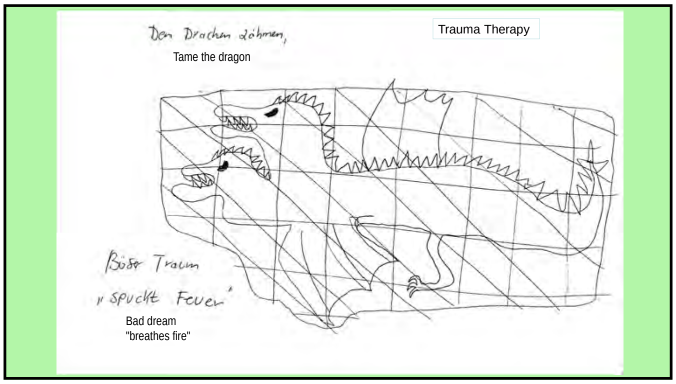
Mein Kopf macht was er will! Wen ich nervös bin und nach-denke dan höre ich ganz viele verschiedene Stimmen in meinen Kopf.

My head just does its own thing! When I get uptight and then start to think, I can hear lots of different voices in my head.

Wen ich was in der Schule lerne dan vergesse ich so was. Oder wen man mir sagt ich soll z.b. Mein Zimmer aufräumen und danach meine hausaufgaben machen. Das vergesse ich dan auch.

When I learn something at school, I forget it. Or when someone tells me to tidy up my room and then do my homework, I forget that too!

"Dealing with Anger"



Trauma Therapy

Den Drachen zähmen,

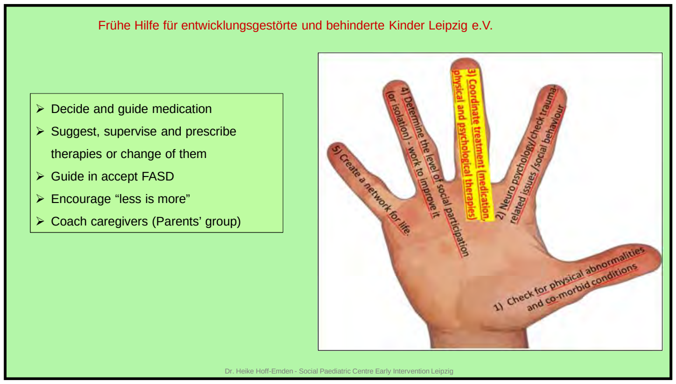
Tame the dragon

Böser Traum

„spuckt Feuer"

Bad dream

"breathes fire"



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- Decide and guide medication
- Suggest, supervise and prescribe therapies or change of them
- Guide in accept FASD
- Encourage "less is more"
- Coach caregivers (Parents' group)

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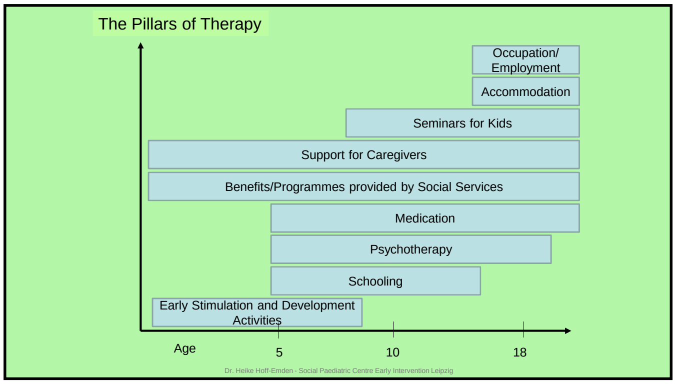

The Pillars of Therapy

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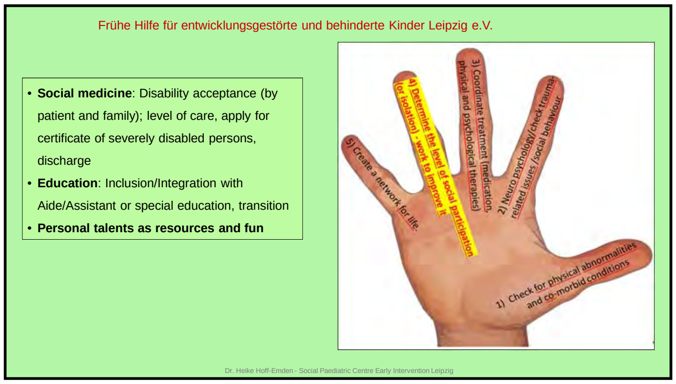

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- **Social medicine**: Disability acceptance (by patient and family); level of care, apply for certificate of severely disabled persons, discharge
- **Education**: Inclusion/Integration with Aide/Assistant or special education, transition
- **Personal talents as resources and fun**

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FASD and the most important social-legal questions

Die Drogenbeauftragte der Bundesregierung

Die Fetale Alkoholspektrumstörung

Die wichtigsten Fragen der sozialrechtlichen Praxis

3. Auflage von 0ktober 2017

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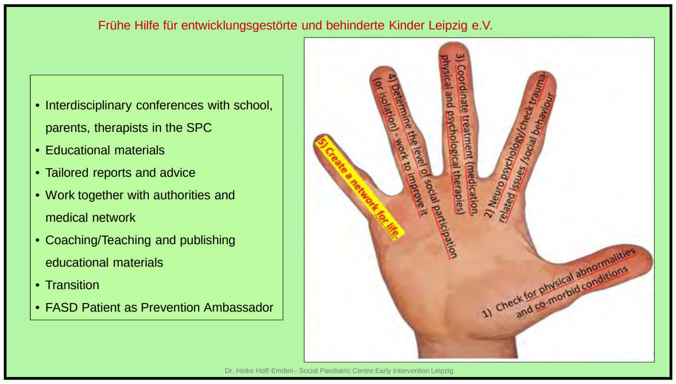

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- Interdisciplinary conferences with school, parents, therapists in the SPC
- Educational materials
- Tailored reports and advice
- Work together with authorities and medical network
- Coaching/Teaching and publishing educational materials
- Transition
- FASD Patient as Prevention Ambassador

1) Check for physical abnormalities and co-morbid conditions

2) Neuro psychology/check trauma-related issues /social behaviour

3) Coordinate treatment (medication, physical and psychological therapies)

4) Determine the level of social participation (or isolation) - work to improve it

5) Create a network for life.

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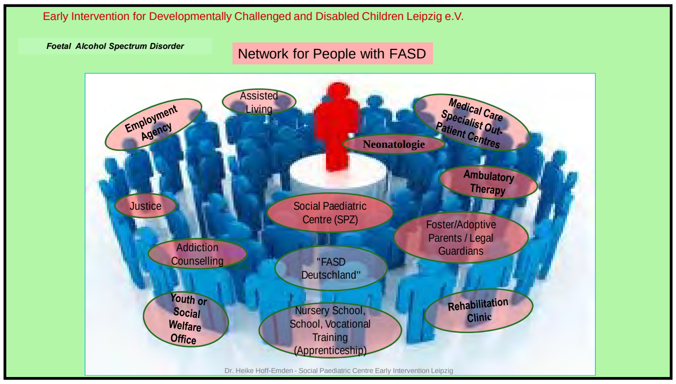

Early Intervention for Developmentally Challenged and Disabled Children Leipzig e.V.

Foetal Alcohol Spectrum Disorder

Network for People with FASD

Employment Agency

Assisted Living

Medical Care Specialist Out-Patient Centres

Neonatologie

Ambulatory Therapy

Justice

Social Paediatric Centre (SPZ)

Foster/Adoptive Parents / Legal Guardians

Addiction Counselling

"FASD Deutschland"

Youth or Social Welfare Office

Nursery School, School, Vocational Training (Apprenticeship)

Rehabilitation Clinic

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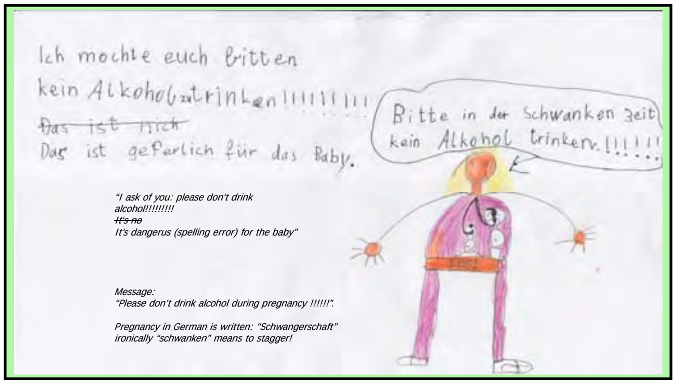


Ich mochte euch bitten
kein Alkohol zu trinken!!!!!!!!!
~~Das ist nich~~
Das ist gefarlich für das Baby.

Bitte in der Schwanken zeit
kein Alkohol trinken.!!!!!!

"I ask of you: please don't drink alcohol!!!!!!!!!
~~It's no~~
It's dangerus (spelling error) for the baby"

Message:
"Please don't drink alcohol during pregnancy !!!!!!".

Pregnancy in German is written: "Schwangerschaft"
ironically "schwanken" means to stagger!

Conclusion

- FASD Patients need continuing, multidimensional support provided by a multidisciplinary team and their own personal support network (SPC is ideal to manage it)
- Materials for parental coaching or the community like manuals are necessary
- Individually tailored reports are essential
- The 5-Digit FASD Life Code system is pathway for FASD Patients and their social support community after Diagnosis

References

- Becker G., Hennicke K., Klein M. (Hrsg.) (2015). Unter Mitarbeit von Landgraf M., Suchtgefährdete Erwachsene mit Fetalen Alkohol-Spektrum-Störungen: Diagnostik, Screening-Ansätze und Interventionsmöglichkeiten. Berlin/Boston: Walter de Gruyter.
- Die Drogenbeauftragte der Bundesregierung Bundesministerium für Gesundheit (Hrsg.). (2014,2017). Die Fetale Alkoholspektrum-Störung: Die wichtigsten Fragen der sozialrechtlichen Praxis. Berlin: Schleuse01 Werbeagentur GmbH. (Autoren Schindler.G., Hoff-Emden, H.)
- Die Drogenbeauftragte der Bundesregierung Bundesministerium für Gesundheit (Hrsg.). (2017). Stressreduktion bei FASD Betroffenen, deren Bezugspersonen und sozialer Umwelt durch Elterncoaching. (Hoff-Emden, H., Oberländer, J.)
- Domsch H., Lohaus A. (2010). ESF: Elternstressfragebogen: Manual. Göttingen: Hogrefe Verlag.
- Himmelreich, M., Luttke CJ, Travis E. (2017). The Lay of the Land: Final Results of a Health Survey of 500+ Adults with Diagnosed FASD, 7th International Conference on Fetal alcohol spectrum disorders 2017.
- Landgraf M, Heinen F. (2016). S3-Leitlinie: Diagnose der Fetalen Alkoholspektrumstörungen FASD: Kurzfassung. AWMF-Registriernummer: 022-025.
- World Health Organization International Study on the Prevalence of Fetal Alcohol Spectrum Disorder (FASD) Canadian Component (4/18) ,A report prepared by the Institute for Mental Health Policy Research, Centre for Addiction and Mental Health (Popopva, S. et al.)

C10

Families Moving Forward – Connect: Developing a Mobile Health Intervention for Families Raising Children with FASD

Christie Petrenko, Christiano Tapparello, Jennifer Parr

Learning Objectives:

1. Identify at least one barrier that contributes to families not receiving FASD-informed care.
2. State how a mobile health intervention could reduce barriers and increase access to FASD-informed care.
3. Review existing focus group data on the FMF Connect app.
4. Evaluate presentation of the FMF Connect prototype and express their opinions of the development process and app features.

Background/ Rationale

Fetal alcohol spectrum disorders (FASD) affect approximately 2-5% of the US population [1]. Unfortunately, the vast majority of families cannot access FASD-informed interventions. Barriers to care occur because a knowledgeable and skilled workforce is lacking [2,3], and there are family-level barriers such as limited financial resources, inability to access childcare, and stigma [4]. Access to appropriate FASD-informed care is even more limited in less densely populated areas. Many families try peer-to-peer and self-help strategies, but it can be difficult to evaluate the credibility and effectiveness of information provided through these modalities. Innovative intervention delivery is needed to broaden the reach of FASD-informed care and improve the quality of life for children with FASD and their families.

The primary objective of this project is to develop and evaluate the efficacy of a mobile health (mHealth) application (“app”) to directly provide caregivers with evidence-based content and peer-moderated support they can easily access and use to improve outcomes for their children and families. The app, called FMF Connect, is derived from the scientifically-validated Families Moving Forward (FMF) Program, developed at Seattle Children’s Research Institute/ University of Washington. The FMF Program has shown promising results for child and caregiver outcomes in prior trials with families raising children with FASD. [5]-[7].

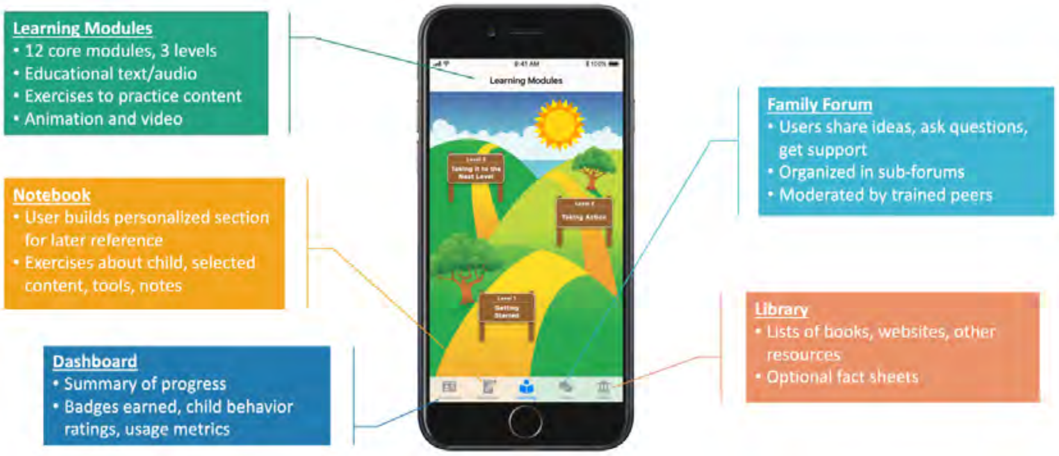
Methods

This project follows a systematic approach to the development and evaluation of the FMF Connect mHealth intervention. First, FMF content, principles, and methods were adapted for the mHealth format, with the addition of unique content and features. Literature review and expert consultation in the fields of instructional design, ethics and technology, and behavior change principles informed this process. The app utilizes a cloud-based infrastructure to transparently but securely distribute information and was built on our existing open source framework for the development of medical apps [8], and those of others [9]. During the initial development process, focus group methods were used to solicit perspectives from diverse families on aspects such as interface design, ease of use, relevance of components and content, and barriers and facilitators of use. A total of 25 caregivers participated in 7 focus groups across 5 U.S. cities from December 2017 – June 2018. Data were analyzed thematically. Next steps will involve initial beta-testing of the prototype demonstrated during the presentation with a small group of users, followed by larger feasibility and randomized-controlled trials.

The content, principles, and methods of the therapist-led FMF Program were more readily translated into the FMF Connect app than predicted. Although much of the content is preserved, the flow of content delivery differs somewhat in FMF Connect to be more amenable to self-direction by caregivers. FMF Connect has been implemented leveraging the functionalities offered by modern smartphones and considering the different ways in which users interact with them. As an example, using FMF Connect caregivers will be able to access content through easily digestible learning modules that can be viewed in various formats (text, audio, video), and will be able to customize the app according to their preference and needs. In addition, the app integrates open source frameworks and state of the art methodologies for mobile app development to ensure data privacy and security.

FMF-Connect Design and Components

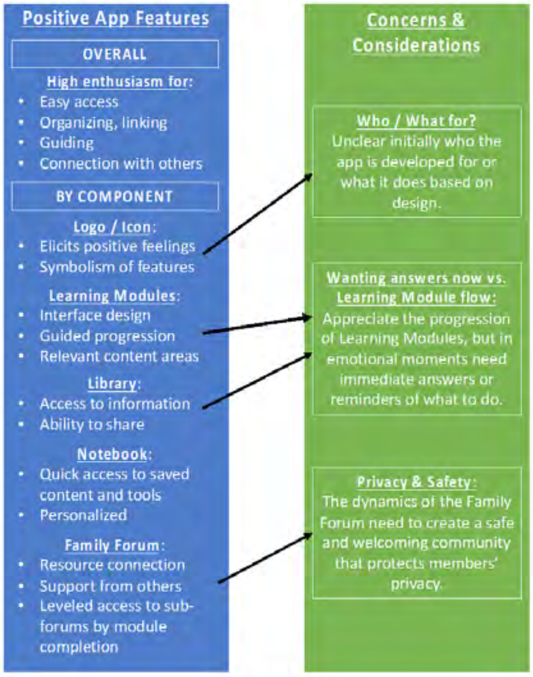
Figure 1 illustrates the components of FMF Connect and the interface design of the Learning Modules home screen.



Evaluation of App Interface Design and Components

Figures 2 and 3 summarize the findings that garnered the most enthusiasm and discussion during focus groups. These are the themes that were most important to participants. The left-hand column in Figure 2 (blue) illustrates the features of the FMF Connect app that were viewed most favorably. Participants emphasized the interconnections between app components and the ease of access to important content and support from other parents. The right-hand column of Figure 2 (green) summarizes three main concerns or considerations raised by participants. Participants grappled with these topics in group discussion. Opinions were mixed or evolved over the course of the discussion. A number of suggestions were offered about how to respond to these considerations.

Figure 2



Positive App Features

OVERALL

High enthusiasm for:
- Easy access
- Organizing, linking
- Guiding
- Connection with others

BY COMPONENT

Logo / Icon:
- Elicits positive feelings
- Symbolism of features

Learning Modules:
- Interface design
- Guided progression
- Relevant content areas

Library:
- Access to information
- Ability to share

Notebook:
- Quick access to saved content and tools
- Personalized

Family Forum:
- Resource connection
- Support from others
- Leveled access to sub-forums by module completion

Concerns & Considerations

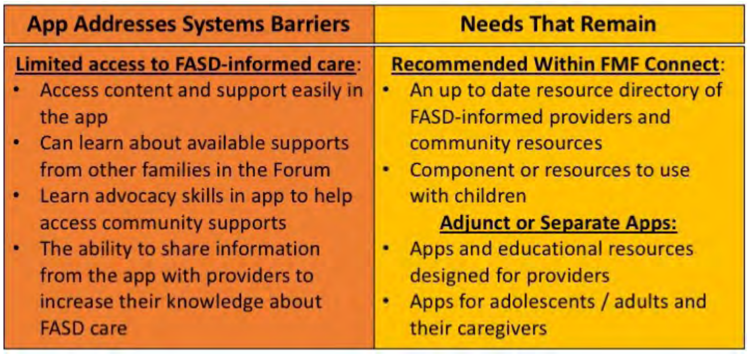
Who / What for?
Unclear initially who the app is developed for or what it does based on design.

Wanting answers now vs. Learning Module flow:
Appreciate the progression of Learning Modules, but in emotional moments need immediate answers or reminders of what to do.

Privacy & Safety:
The dynamics of the Family Forum need to create a safe and welcoming community that protects members' privacy.

Consistent with our prior work [2], participants spoke with strong emotion about the systems barriers they face in obtaining supports and services for their children. The left side of Figure 3 summarizes how participants perceived ways the FMF Connect app could help families address some of these systems barriers. The right side includes areas where participants want additional focus, either within or adjunct to the app. The desire to share information with providers, family members, and the individual with FASD was frequently raised. The goal was often stated as helping them understand the experience of the person with FASD in order to better support them.

Figure 3



App Addresses Systems Barriers	Needs That Remain
Limited access to FASD-informed care: • Access content and support easily in the app • Can learn about available supports from other families in the Forum • Learn advocacy skills in app to help access community supports • The ability to share information from the app with providers to increase their knowledge about FASD care	**Recommended Within FMF Connect:** • An up to date resource directory of FASD-informed providers and community resources • Component or resources to use with children **Adjunct or Separate Apps:** • Apps and educational resources designed for providers • Apps for adolescents / adults and their caregivers

Conclusion

FMF Connect is a promising, novel intervention with potential to reach many families in need and reduce significant barriers to care, resulting in broader public health impact. After initial beta-testing, a small-scale feasibility trial and larger randomized controlled trial are planned to investigate how families utilize the app and its efficacy in improving child and family outcomes.

References

P. A. May, J. P. Gossage, W. O. Kalberg, L. K. Robinson, D. Buckley, M. Manning and H. E. Hoyme, "Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies," Developmental Disabilities Research Reviews, vol. 15, pp. 176-192, 2009.

C. L. M. Petrenko, N. Tahir, E. C. Mahoney and N. P. Chin, "Prevention of secondary conditions in fetal alcohol spectrum disorders: Identification of systems-level barriers," Maternal and Child Health Journal, vol. 18, pp. 1496-505, 2014.

D. M. Ryan, D. M. Bonnett and C. B. Gass, "Sobering thoughts: town hall meetings on fetal alcohol spectrum disorders," American Journal of Public Health, vol. 96, pp. 2098-2101, 2006.

C. L. M. Petrenko, M. E. Alto, A. R. French and S. M. Freeze, "'I'm doing my part, I just need help from the community': Intervention implications of foster and adoptive parents' experiences raising children and young adults with FASD," Journal of Family Nursing, in press.

J. Bertrand, "Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects," Research in developmental disabilities, vol. 30, no. 5, pp. 986-1006, 2009.

H. C. Olson and J. Sparrow, "Using Positive Behavior Support Techniques with Families: Fetal Alcohol Spectrum Disorders Intervention," in The Expanding World of PBS: Science, Values & Vision. 13th International Conference on PBS, San Francisco, CA.

C. L. M. Petrenko, M. E. Pandolfino and R. L. K, "Findings from the Families on Track preventive intervention pilot trial with children with FASD and their families," Alcoholism: Clinical and Experimental Research, vol. 41, pp. 1340-1351, 2017.

C. Tapparello, W. Heinzelman, K. Conn and C. A. Mullen, "ManageMyCondition: A Standard Framework for the Development of Cloud-based Medical Condition Management Applications," in IEEE International Workshop on Cloud Connected Health (CCH), Washington D.C., 2016

Apple, "ResearchKit," 03 2015. [Online]. Available: http://researchkit.org.

D1a

The Importance of Emotion Recognition and School Functioning in Children with FASD

Andi Crawford

Learning Objectives

1. Describe important influences on educational adaptive functioning
2. Demonstrate the importance of social and emotional skills and relationships in the school setting

Summary

This current study investigated the school adaptive functioning of children with FASD and was supported by a strong partnership with Te Wāhanga Hauora Māori (Māori Health Service). Findings are discussed with regard to both the psychological literature and a Te Ao Māori worldview.

Children with FASD often have extremely low adaptive behaviour due to the severity of brain impairment, sometimes lower than expected given their level of intellectual functioning. Impairments in executive functioning (e.g. planning, cognitive flexibility and self-regulation) are thought to underlie many difficulties in adaptive functioning. Recent findings suggest children with FAS may also have difficulties with social cognition (e.g. emotion recognition, theory of mind social problem-solving). This research project aimed to investigate which factors (IQ, executive functioning, social cognition and Adverse Childhood Events, ACEs) predict school adaptive functioning in children (8-12 years) with FASD. A comparison group was included which was matched on age, gender, ethnicity, maternal education and deprivation index. Findings were also considered within the context of psychosocial complexity that exists for children with FASD in this study, including implications for required support services.

Children in the FASD group performed significantly below the comparison group, on all cognitive tasks and all measures of school adaptive functioning, and demonstrated severe neurological impairment. Although IQ, executive functioning, social cognition and ACEs were significantly correlated with teacher-rated adaptive functioning for the FASD group, when multiple linear regression analyses were performed, social cognition, especially recognising emotions on adults' faces, was the only significant independent predictor of teacher-rated adaptive function, even after including for IQ, executive functioning and ACEs in the model. This is important from a Te Ao Māori perspective as Māori society is built upon whakapapa and whanaungatanga which requires highly developed social and emotional skills.

D1b

Perspectives of Supporting Adopted Children with PAE: An Interpretative Phenomenological Analysis

Jennifer Shields

Learning Objectives

1. Reflect upon the needs of social workers supporting looked after children with prenatal alcohol exposure
2. Consider the impact of an FASD diagnosis on the perspectives of the child in the eyes of the social worker and potential adopters
3. Consider this data when raising awareness of FASD with partner agencies, with a view to ensuring strengths and optimal outcomes of children are incorporated

Objectives

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella-term describing life-long disabilities that can result from alcohol exposure in-utero. FASD is estimated to effect between 3 - 6 % of children in Scotland. Children with FASD are over-represented within fostering and adoption services, but few studies explore social workers' views of FASD and the impact upon children and families within social services. As Scotland moves forward with developing service pathways for FASD, it is imperative that we concurrently measure and explore both the intended and unintended consequences that this may have on our partner agencies and services. This is the first study in Scotland to explore the impact of developing awareness and diagnosis of FASD from the perspective of social work services.

Methods

We explored social workers' experiences of supporting children with prenatal alcohol exposure within Adoption Services in Scotland. Five social workers were recruited for semi-structured interviews undertaken by a trainee clinical psychologist. Understanding of FASD, perceptions of confidence discussing a diagnosis with potential adoptive parents, and the personal, professional and emotional impact of working with affected children were explored. Interviews were transcribed verbatim. Themes were elicited using Interpretative Phenomenological Analysis.

Results

There were four super-ordinate themes identified: 1) lack of knowledge and awareness 2) dealing with uncertainty 3) impact of the diagnosis and 4) vulnerability. Experiences of the adoption process were classified: 1) social worker's experience 2) perceived experience of adoptive parents and 3) of the child with FASD. Distinct subordinate themes identified within each of these three groups offered valuable insights. All interviews detailed the complex interaction effects which occur between worker, prospective families and affected children during the adoption process. Perceived inadequacy of knowledge and uncertainty around the negative impact of FASD played important roles in the child's journey through adoption services.

Conclusions

This study facilitated insights into the perspectives of social workers, in particular, the degree to which they felt an FASD diagnosis would negatively affect prospective adoptive families. Social workers described their knowledge of FASD as limited, whilst conversely detailing to families that the potential trajectory of the child would be largely negative. Experiences, attitudes and decisions of the social worker are pivotal to adoptive parents' and ultimately the child's journey. Given the Scottish Government's initiatives to increase identification and diagnosis of FASD, the impact of this on other services should be carefully considered. It is therefore vital that initiatives to raise awareness of FASD encompasses a balanced view of difficulties whilst communicating the strengths and potential of the child (when appropriate supports and early interventions are in place). Social workers should be consulted in regards to service development for children and families affected by FASD.

D1c Improved Parenting Skills of Adoptive Parents with Young Children with FASD

Zohreh Zarnegar

Learning Objectives

1. Identify four brain functioning domains of a normally developing young child
2. Integrate mindful parenting education in child-parent dyadic intervention.
3. Demonstrate the importance of early intervention with young children with FASD
4. List psychosocial constructs impacting parenting capacities

Abstract

This presentation will highlight the potential benefits of using an individualized four-brain functioning system assessment and intervention protocol to identify and treat the neurodevelopmental derailments of young children diagnosed with Fetal Alcohol Spectrum Disorder (FASD); and report on their adoptive parents' improved parenting skills and knowledge, as well as their reduced stress level that had negatively impacting their relationship with their adoptive young children.

This presentation will also address contributing factors predicting significant parenting skills improvement amongst adoptive parents of young children with FASD after one-year follow-up to a 6-months of intensive intervention, the results of which were published in 2016 (see the reference list.)

Methods

Methods applied in the study included drawing on a sample of young children with FASD and their adopting parents who were referred for assessment and treatment intervention, ten families met all the criteria for inclusion in the study. A pre-post 6-months' time interval battery of neurodevelopmentally appropriate evaluation protocol assessing four brain functioning system of alcohol-exposed young children, and parental skills caring for them were applied.

Treatment intervention included a six-months of intensive infant-early childhood mental health treatment of Child-Parent Psychotherapy (CPP), requiring participation of each child/parent(s) unit, and Mindful Parent Education (MPE) weekly sessions for the parents of children in the study.
Related-samples Wilcoxon signed-rank tests, and reliable change analyses were applied to validate reliability of the possible pre-post score changes.

The most parsimonious structural equation model was applied to evaluate the psychosocial mediators of the relationship between parental capacities with continuation of children's improvement in a one-year follow-up study.

Results of the original study

Using intensive mental health intervention modalities for both children (Child-Parent Psychotherapy) and their parents (Mindful Parenting Education), this study showed statistically significant improvement on children's neurodevelopmental functioning in six month time period as well as measured parental skills (the quality of parent-child interactions, parent(s) ability to be mindful of, and work through their own emotions, ability to understand child's special needs, and seek help when needed).

At the end of the first six months intervention, adoptive parents of children in the study collectively requested continuation of intervention, especially their need and desire for further Mindful Parent Education. A follow - up study was conducted one-year later to evaluate the outcome of additional one-year intensive intervention with these families.

Results of the one-year follow up:

Reported here are the adoptive parents' self-report on the impacts of the one year added training on their measured parenting skills, and reduced stress level. They also identified continuing growth and improvement of their adoptive children's psychosocial and relational domains.

Conclusion

From 38 young children with diagnosis of FASD, ten (10) entered this research study with multiple neurodevelopmental disabilities. After 6-months intensive neurodevelopmentally focused, individually tailored mental health intervention, these young children presented significant improving functioning in the real world, which represents potential for effectiveness of early intervention.

Improvement on the measured parenting skills were reported by the adoptive parents, emphasizing importance of parenting education on stress reduction, child-parent relationship, parenting emotional self-awareness and mindful functioning, and support system. The one-year follow-up revealed reliability of the earlier findings with additional benefits.

References

Abidin, R. R. (1992). The determinants of parenting behavior. Journal of Clinical Child Psychology, 21, 407–412.

Abidin, R. R. (1995). Parenting stress index professional manual (3rd ed.). Odessa, FL: Psychological Assessment Resources, Inc.

American Academy of Pediatrics. (2000). Fetal alcohol syndrome and alcohol related Neurodevelopmental disorders. Pediatrics, 106(2), 358-361.

Astley, S., Stachowiak, J., Clarren, S., & Clausen, C. (2002). Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. Journal of Pediatrics, 141(5), 712-717.

Azar, S. T. (1986). A framework for understanding child maltreatment: An integration of cognitive behavior and developmental perspectives. Canadian Journal of Behavioural Science, 18, 340–355.

Bertrand, J. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. Research in Developmental Disabilities, 30, 986-1006.

Lieberman, A. F., Chu, A., Van Horn, P., & Harris, W. W. (2011). Trauma in early childhood: Empirical evidence and clinical implications. Development and Psychopathology, 23, 397–410.

Lieberman, A. F., & Van Horn, P. (2008). Psychotherapy with infants and young children: Repairing the effects of stress and trauma on early attachment. New York, NY: The Guilford Press.

Lieberman, A. F., Van Horn, P., & Ghosh Ippen, C. (2005). Toward evidence-based treatment: Child-Parent Psychotherapy with the preschoolers exposed to marital violence. Journal of the American Academy of Child & Adolescent Psychiatry, 44, 1241–1248. doi:10.1097/01.chi.0000181047.59702.58

Lieberman, A. F., Van Horn, P., & Ghosh Ippen, C. (2006). Child-Parent Psychotherapy: 6-month follow-up of a randomized controlled trial. Journal of the American Academy of Child & Adolescent Psychiatry, 45, 913–918. doi:10.1097/01.chi.0000222784.03735.92

Perry, B. D. (2006). The Neurosequential Model of Therapeutics: Applying principles of neuroscience to clinical work with traumatized and maltreated children. In N. B. Webb (Ed.), Working with traumatized youth in child welfare (pp. 27–52). New York, NY: The Guilford Press.

Perry, B. D. (2008). Child maltreatment: A neurodevelopmental perspective on the role of trauma and neglect on psychopathology. In T. P. Beauchaine & S. P. Hinshaw (Eds.), Child and adolescent psychopathology (pp. 93–129). Hoboken, NJ: John Wiley.

Perry, B. D. (2014). The Neurosequential Model of Therapeutics in young children. In K. Brandt, B. D. Perry, S. Seligman, & E. Tronick (Eds.), Infant and early childhood mental health: Core concepts and clinical practice (pp. 21–54). Washington, DC: American Psychiatric Press.

Roebuck-Spencer, T. M., Mattson, S. N., & Riley, E. P. (1999). Behavioral and psychosocial profiles of alcohol exposed children. Alcohol: Clinical Experience Research, 23, 1070–1076.

Sanders, M. R. (2003). Triple-P—Positive Parenting Program: A population approach to promoting competent parenting. Australian e-Journal for the Advancement of Mental Health, 2, 127–143. doi:10.5172/jamh.2.3.127

Shonkoff, J. P., & Garner, A. S. (2012). The lifelong effects of early childhood adversity and toxic stress. American Academy of Pediatrics, 129, e232. doi:10.1542/peds.2011-2663

Siegel, D. J. (2003). An interpersonal neurobiology of psychotherapy: The developing mind and the resolution of trauma. In M. Solomon & D. J. Siegel (Eds.), Healing trauma (pp. 1–56). New York, NY: W.W. Norton.

Siegel, D. J. (2007). The mindful brain: Reflection and attunement in the cultivation of well-being. New York, NY: W.W. Norton.

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK.(2004). Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. Dev. Behav. Pediatr. 25, 228–329.

Williford, A. P., Calkins, S. D., & Keane, S. P. (2007). Predicting change in parenting stress across childhood: Child and maternal factors. Journal of Abnormal Child Psychology, 35, 251–263.

Wolfe, D. A. (1999). Child abuse: Implications for child development and psychopathology. Thousand Oaks, CA: Sage Publications, Inc.

Zarnegar, Z., Hambrick, E.P., Perry, B.D., Azen, S.P., and Peterson, C. (2016). Clinical improvements in adopted children with fetal alcohol spectrum disorders through neurodevelopmentally informed clinical intervention: A pilot study. Clinical Child Psychology and Psychiatry, 21(4) 551–567.

D1d

Service Providers' Perspectives on Available Policies and Interventions for FASD

Babatope Adebiyi

Learning Objectives

1. Identify the available clauses of FASD policy and interventions that exist for the prevention and management of FASD in South Africa
2. Describe the policy requirements for FASD in South Africa

Background

Fetal alcohol spectrum disorders (FASD) are among the leading causes of developmental and intellectual disabilities in individuals. Although efforts are being made toward the prevention and management of FASD in South Africa, the prevalence remains high. The sustained high prevalence could be attributed to several reasons, including the lack of policy for a coordinated effort to prevent, diagnose and manage FASD nationally.

Objectives

In this study, our aim was to explore the perspectives of service providers (health and allied professionals, teachers, social workers) on the prevention and management of FASD towards developing a guideline to inform policy.

Method

Guided by the exploratory qualitative research design, we purposively sampled relevant service providers in the field of FASD prevention and management for focus group discussions. Nine of these discussions were conducted with an average of six to eight participants per discussion session. The discussants were asked various questions on the current and required interventions and practices for the prevention and management of FASD. Following the Framework Method, data were transcribed verbatim and analysed using the thematic content analysis approach.

Results

Our findings show that aspects of the prevention and management of alcohol-related conditions are present in various policies. However, there is no clear focus on coordinated, multi-sectoral efforts for a more comprehensive approach to the prevention and management of FASD. The participants recognized the need for specific requirements on broad-based preventive awareness programs, training and support for parents and caregivers, inclusive education in mainstream schools and training of relevant professionals.

Conclusion

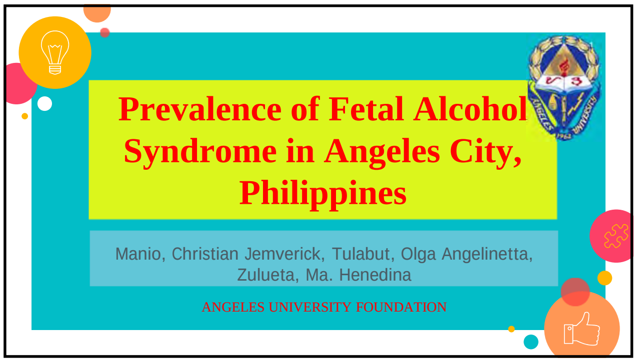
Comprehensive and coordinated prevention and management programs guided by a specific policy could improve the prevention and management of FASD. Policy formulation demonstrates commitment from the government, highlights the importance of the disease, and elaborates on context-specific prevention and management protocols.

D2a

YOUNG INVESTIGATOR

Fetal Alcohol Syndrome Among Children in Public Elementary Schools in Angeles City, Phillippines

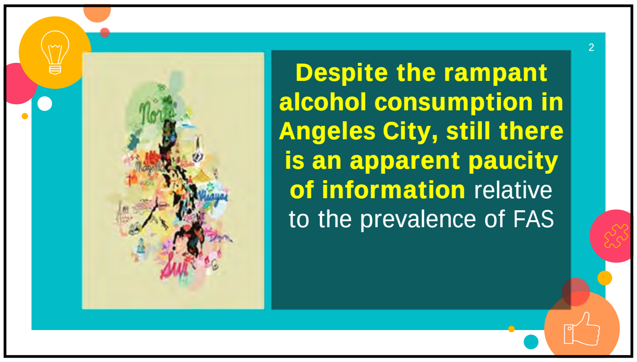
Olga A. Tulabut, Christian J. Manio



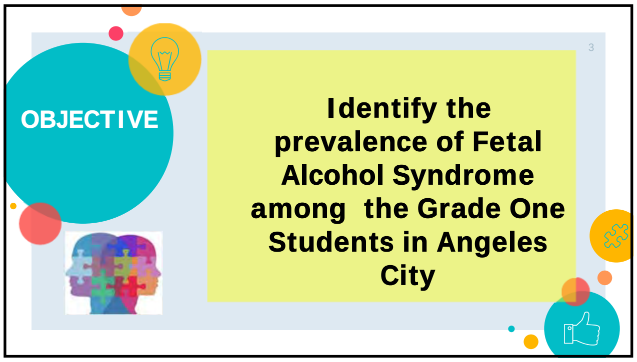
Prevalence of Fetal Alcohol Syndrome in Angeles City, Philippines

Manio, Christian Jemverick, Tulabut, Olga Angelinetta, Zulueta, Ma. Henedina

ANGELES UNIVERSITY FOUNDATION

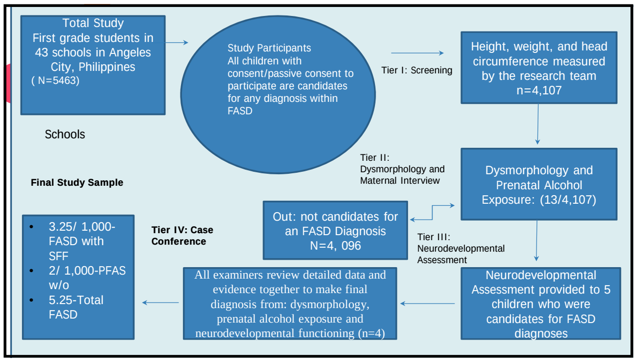


Despite the rampant alcohol consumption in Angeles City, still there is an apparent paucity of information relative to the prevalence of FAS



OBJECTIVE

Identify the prevalence of Fetal Alcohol Syndrome among the Grade One Students in Angeles City



Total Study
First grade students in 43 schools in Angeles City, Philippines
(N=5463)

Schools

Study Participants
All children with consent/passive consent to participate are candidates for any diagnosis within FASD

Tier I: Screening

Height, weight, and head circumference measured by the research team
n=4,107

Tier II:
Dysmorphology and Maternal Interview

Dysmorphology and Prenatal Alcohol Exposure: (13/4,107)

Out: not candidates for an FASD Diagnosis
N=4, 096

Tier III:
Neurodevelopmental Assessment

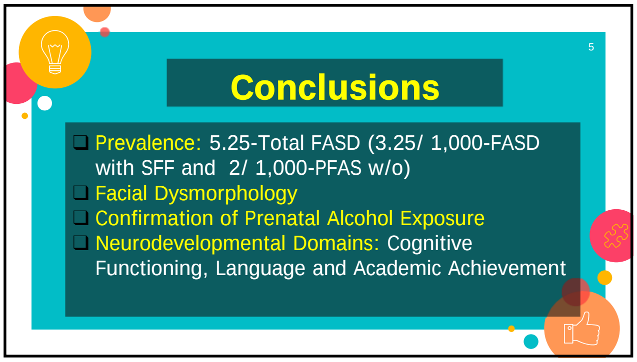
Neurodevelopmental Assessment provided to 5 children who were candidates for FASD diagnoses

All examiners review detailed data and evidence together to make final diagnosis from: dysmorphology, prenatal alcohol exposure and neurodevelopmental functioning (n=4)

Tier IV: Case Conference

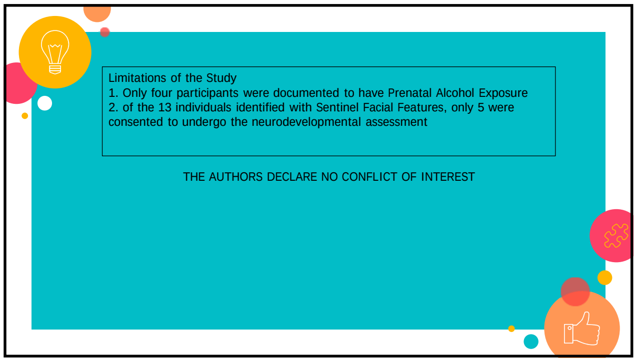
Final Study Sample

- 3.25/ 1,000-FASD with SFF
- 2/ 1,000-PFAS w/o
- 5.25-Total FASD



Conclusions

- ☐ Prevalence: 5.25-Total FASD (3.25/ 1,000-FASD with SFF and 2/ 1,000-PFAS w/o)
- ☐ Facial Dysmorphology
- ☐ Confirmation of Prenatal Alcohol Exposure
- ☐ Neurodevelopmental Domains: Cognitive Functioning, Language and Academic Achievement



Limitations of the Study
1. Only four participants were documented to have Prenatal Alcohol Exposure
2. of the 13 individuals identified with Sentinel Facial Features, only 5 were consented to undergo the neurodevelopmental assessment

THE AUTHORS DECLARE NO CONFLICT OF INTEREST

D2b Identifying Facial Features Associated with PAE in Newborn Infants Using 2D and 3D Imaging

Neil Aiton

Authors: Neil Aiton, MIchael Suttie

Learning Objectives

1. Observe the typical photographic techniques for taking clinical photographs for identification of features of PNAE
2. Identify with confidence the subtle features associated with PNAE in infants
3. Summarize the research taking place in this area to assist in future diagnosis

Objectives

To compare 2D and 3D photography using computerised analysis for earlier detection of craniofacial changes in newborn infants with and without prenatal alcohol exposure.

Method

3D photography (Vectra H1, Canfield Scientific, NJ) and standard 2D facial photography performed on newborn infants recruited on the maternity ward and in a specialist substance misuse clinic in a UK teaching hospital. The images are stored and analysed anonymously. The mothers are given a questionnaire to complete regarding their alcohol consumption during pregnancy which is also collected and stored anonymously. Imaging and questionnaire data are linked with a unique research number.

Analysis of 3D imaging data is undertaken by previously described methodology[1] using dense surface modelling (DSM) from which facial profiling can be extracted. Linear profiles were extracted directly from lateral facial 2D images. Further computerised analysis using established methodology[2] is undertaken on the 2D photographs.

Prospective analysis intention: 4 groups: No PNAE (control group - to provide reference values for the model), Low levels of PNAE (<4 units per week), Moderate levels of PNAE (>4 units per week), high levels of PNAE (>11 units per week)
Ethical approval obtained.

Results

(initial pilot group, n=40)
Problems related to photographing newborn infants successfully overcome to produce technically acceptable 3D image reconstructions from which DSM surface-modelling can be obtained. Facial profiling successfully extracted using techniques described. Limited numbers at the present time mean that statistical comparisons between groups are not valid to produce meaningful results.

Conclusions:

Pilot analysis shows that technically successful results can be achieved in this difficult to photograph group of patients.

Continued active recruitment is ongoing over the next 6 months which should allow analysis of several hundred infants and allow the successful modelling of normal values (and will contribute to accessible data repositories (CIFASD) for future research). This will allow statistical comparisons to be made with the groups who have been exposed to alcohol in pregnancy. Midline facial profiling in particular has been shown in pilot studies to be highly discriminative with an ROC curve value of 0.95.
A strength of this study is the effort made with regard to anonymisation of data collection regarding alcohol consumption in pregnancy which is likely to help with validity and reliability of this data which historically is notoriously difficult to collect.

Early diagnosis of FASD has been shown to improve outcome, and techniques such as this may prove to have an important role in 1) early diagnosis of infants on the fasd spectrum, 2) utility in population screening or 3) determining infants at increased risk of future neurodevelopmental problems (because of the relationship between facial features and neurodevelopmental outcome.[3])

References

Suttie et al, 2013 Alcohol Clin Exp Res, & Pediatrics 131(3) e779-88 2)Astley et al: www.fasdpn.org 3) Yang Y et al, Alcohol Clin Exp Res 2012; 36:798–806

D2c Improving Assessments for FASD in Canada; An Approach to Co-Morbid Psychiatric Diagnoses and Treatment for Children in Care

Mitesh Patel, Sabrina Agnihotri

Authors: Mitesh Patel, Sabrina Agnihotri, Connor Hawkins, Leo Levin, Deborah Goodman, Alexander Simpson

Learning Objectives

1. Identify the roles of child protection workers and primary care providers in triaging FASD in children and youth accessing formal care systems
2. Appreciate the prevalence of co-morbid psychiatric conditions in children and youth with FASD and the role of psychiatric assessment in developing full treatment recommendations

Background

Several challenges exist when making a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) and identifying co-morbid psychiatric illness, particularly for children and youth accessing child welfare services. These include a lack of understanding and comfort expressed by health care providers in their knowledge of FASD and limited resources to facilitate timely assessments in community settings.

Objectives

To describe an integrated three-phase approach to the identification of FASD and psychiatric comorbidity for children and youth in care. This approach consisted of: 1) completion of a standardized neurobehavioral screen by a Child Protection Worker; 2) assessment by a pediatrician, including facial measurements and; 3) integration of findings in a psychiatric assessment. We will also summarize demographic information and treatment recommendations for those who have accessed the service to date.

Methods

A retrospective chart review was conducted of 18 clients who were referred by their pediatrician for psychiatric assessment to determine if they met criteria for FASD.

Results

The majority of participants (14/18, 78%) who were suspected of a diagnosis of FASD by a pediatrician were determined to have met criteria following psychiatric assessment and integration of findings. Psychiatric comorbidity was present in all youth referred for consideration of an FASD diagnosis and resulted in further psychiatric treatment recommendations.

Conclusions

This study supports the utility of an integrated three-phase approach to diagnosing FASD in children and youth in care, while also identifying co-morbid psychiatric illness and providing treatment recommendations. Based on our preliminary findings, we recommend that youth who access formal care systems be screened for FASD and provided with appropriate pediatric and psychiatric assessments. This model of care facilitated early diagnosis of FASD and treatment of comorbid psychiatric disorders by employing existing physician services in a community setting.

D2d The Benefits of Innovation: A Triage System for FASD Assessment Intake

Marcel Zimmet

Authors: Zimmet M, Williams C, Phillips N, Bunby R, Sze D, Barnett D, Fernando N, Hort J, Simon A, Elliott E

Learning Objectives

1. Highlight the benefits of quality improvement and innovation in clinical FASD practice
2. Promote the use of triage systems in the outpatient setting
3. Identify novel approaches to address unique challenges of FASD assessment

Background

In 2016, a multidisciplinary FASD assessment service was established within a paediatric tertiary teaching hospital in New South Wales, Australia's most populous state comprising 1.5 million children under 15 years of age. As the only specialised FASD service for the state, demand for assessment increased steadily over the first year, with wait time from referral to first appointment extending to between 6 to 12 months. A quality improvement project was undertaken to improve patient access and engagement, using the existing clinical team.

Aims

The primary aim was to implement triage screening of all new patients within 1 month of receiving their referral.
The secondary aim was to reduce the average wait time from referral to first consultation, as well as wait time to multidisciplinary assessment. A further aim was enhanced parent consumer engagement.

Methods

We implemented a novel three-level triage system addressing unique aspects of FASD assessment, prioritising psychosocial risk and prevention opportunities (e.g. children living with their birth mother), age (<2yo or 16-18yo), clarity of prenatal alcohol exposure in referral information, and other psychosocial risk factors (e.g. acute mental health issues). This triage system was used at intake meetings, which occurred on a fortnightly basis. Past patients were retrospectively triaged to allow comparison.

Triage was complimented by a novel paediatric Intake Consultation facilitating face-to-face patient engagement and explanation of our diagnostic process, information gathering about prenatal alcohol exposure, screening for physical FASD features (including facial photo analysis), and planning of multidisciplinary assessment. Telehealth or phone consultations were used for rural families. Dec 2017 was a pilot period with implementation Jan-May 2018.

We aimed to see Triage I patients for Intake Consultation within 1 month of triage, and multidisciplinary assessment within 3 months (if required), with corresponding targets for Triage II and III patients 3/6 months, and 6/12 months respectively.

A parent was involved in the planning and feedback stages.

Results

All new patients were triaged within 1 month of referral. Average wait time to first (Intake) consultation was reduced compared to pre-existing wait times: Triage I - 3.9 months earlier, Triage II - 2.7 months earlier, and Triage III - 1.6 months earlier. Within the study period, 67% of Triage I patients required or qualified for multidisciplinary assessment, while this was the case for only 42% of Triage II and 40% of Triage III patients. 54% of new patients (Triage I and II) had a reduced wait time until multidisciplinary assessment: 1.9 and 0.5 months respectively. There was a 60% increase in new patients seen for assessment, with the same rate of monthly new referrals and the same clinical resources.

The parent consumer provided positive qualitative feedback regarding the new triage and intake system.

Conclusions

Use of a triage system has helped to stratify our waitlist and improve access to FASD assessment. Waiting times until first appointment and full multidisciplinary assessment have decreased, in conjunction with the implementation of a novel paediatric Intake Consultation. Opportunities and challenges remain to sustain and improve these assessment pathways in the longer term.

D2e FASD in Motion: Case Surveillance and Diagnosis in Australia in the 21st Century

Marcel Zimmet

Authors: Zimmet M, Williams C, Phillips N, Phu A, Fitzpatrick J, Shelton D, Wilkins A, Edwards K, Webster H, Zurynski Y, Watkins R, Bower C, Elliott E

Learning Objectives

1. Map changes in FASD diagnosis over time, in relation to national initiatives and changes in diagnostic criteria
2. Inform discussion about national approaches to FASD diagnosis and data collection
3. Generate debate regarding opportunities and limitations of specialised FASD diagnostic clinics
4. Identify clinician-related barriers to FASD diagnosis

Study Objectives

The first Australian national data set for the entire FASD spectrum aimed to capture emerging diagnostic and demographic patterns, in order to inform clinical practice, surveillance, education, service delivery and public health initiatives.

Methods

Prospective national surveillance was undertaken from Jan 2015 - Dec 2017. Paediatricians, using national FASD diagnostic guidelines, reported children (<15 years) diagnosed to the Australian Paediatric Surveillance Unit (APSU). Cases were defined as those fulfilling prenatal alcohol exposure and neurodevelopmental criteria, with 3 or <3 sentinel facial features (SFF).

Results

There were 280 verified FASD cases: 22% had 3 SFF, while 78% had <3 SFF (no features 40%, 1 feature 30 %, 2 features 30%). More than half the children diagnosed were in foster/adoptive care (54%) or Indigenous (59%).
Cases were reported by 38 paediatricians who comprise ~2% of the 1851 paediatricians in Australia (~1500 report to the APSU). 84% of cases were diagnosed by 7 paediatricians who work in FASD specific multidisciplinary assessment clinics. Compared to other paediatricians, clinicians with FASD expertise more commonly diagnosed FASD with <3 SFF, than with 3 SFF (82% vs 57% $p < 0.001$).

There was a four-fold increase (93 vs 23 cases per year) in reporting of FASD cases compared to the last surveillance period in 2001-4, when reporting was restricted to FAS/PFAS according to 1996 IOM criteria. Incidence rates have more than tripled (2.04 vs 0.58 per 100,000 children < 15y). More specifically, the number of reported cases of children with all 3 SFF has increased threefold (20 vs 9 per year). The ratio of FASD cases with 3 SFF to <3 SFF was 1:3.6 in 2014-17, compared to 1:2.4 in 2001-04.

The median age of diagnosis has increased to 8.5 years from 3 years (FASD 3 SFF - 7.6y and <3 SFF - 9.2y). The female to male ratio has remained consistent 1.3:1 vs 1:1. Reported concurrent prenatal methamphetamine has increased fourfold. Overall, 30% of cases had chromosomal microarray testing and 8% had karyotype testing, the vast majority normal.

Conclusions

There has been an increase in the diagnosis of FASD in Australia over the last decade coinciding with development of specialist FASD clinics, national diagnostic guidelines and broadening of the FASD spectrum to include children with no sentinel facial features. The increased diagnostic reporting has been primarily driven by 7 FASD expert paediatricians, suggesting significant limitations in diagnosis and/or reporting of FASD by Australian paediatricians in general. This may reflect ongoing concerns and misconceptions about FASD diagnosis. A priority remains improving awareness of diagnostic rationale, methodology and surveillance (using the new national FASD registry), in conjunction with ongoing public health prevention measures.

D3a Infant Circulating MicroRNAs as Biomarkers of Effect in FASD

Amanda H. Mahnke

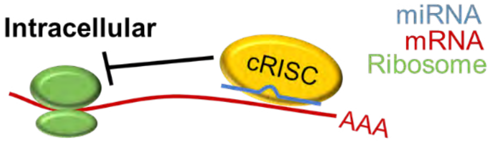
Authors: Amanda H. Mahnke, Georgios D. Sideridis, Nihal A. Salem, Alexander M. Tseng, R. Colin Carter, Neil C. Dodge, Aniruddha B. Rathod, Christopher D. Molteno, Ernesta M. Meintjes, Sandra W. Jacobson, Rajesh C. Miranda, Joseph L. Jacobson

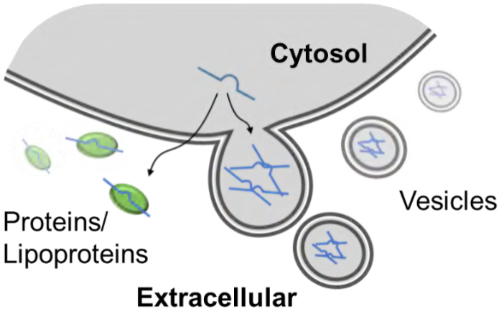
Learning Objectives

1. Explain how infant circulating miRNAs can be biomarkers of prenatal alcohol exposure
2. Recognize that infant sex may contribute to circulating miRNA profiles
3. Discuss evidence that circulating miRNAs predict infant growth and behavioral outcomes

Background

- miRNAs as endocrine factors
    - Within the cell, miRNAs act to prevent protein formation
    - miRNAs can be released from the cell and packaged in vesicles or bound to proteins and lipoproteins
    - miRNAs in released in circulation (cirmiRNAs) are thought to signal between organs, thereby acting as endocrine factors or hormones





- miRNAs as biomarkers of prenatal alcohol exposure
    - cirmiRNA content in plasma is altered in pregnant women following alcohol exposure (Gardiner et al., 2016; Balaraman et al., 2016)
    - Altered maternal cirmiRNAs can predict infant outcome, i.e. whether the infant will develop physical characteristics of prenatal alcohol exposure
    - Can infant cirmiRNAs also indicate alcohol exposure?
    - Can infant cirmiRNAs predict developmental outcomes?

Sampling Cohort and Methods

- 68 infants from the larger prospective South African Cape Colored cohort (Carter et al., 2016; Jacobson et al., 2017)
- Control and heavily alcohol exposed pregnancies
- Infant plasma samples collected at 2 weeks and 6.5 months of age
- Using qPCR, 752 cirmiRNAs were assessed
- 148 cirmiRNAs were found in >80% samples and further analyzed

Results

- cirmiRNA expression profile is altered in prenatal alcohol exposed infants
- Some cirmiRNAs may be altered in a sex-specific manner
- Confirmatory factor analysis:
  - Grouped cirmiRNAs in factor pools based on variance
  - cirmiRNAs within factor pools are associated with developmental pathways
- Preliminary mediation analysis suggests:
  - The variance in expression of cirmiRNAs in the 2 weeks of age factor pools explains the effects of alcohol on growth
  - The variance in expression of cirmiRNAs in a 6.5 months of age factor pool explains the effects of alcohol on cognitive function

Conclusions

- cirmiRNAs are altered in prenatal alcohol exposed infants
- Factor pools of cirmiRNAs are associated with developmental pathways
- cirmiRNAs altered at 2 weeks of age may explain and predict the effects of PAE on growth outcomes
- cirmiRNAs altered at 6.5 months of age may explain and predict the effects of PAE on cognitive outcomes

This work was funded by R21 AA024055.

D3b

Fetal Sex Is a Determinant of Maternal Plasma MicroRNA Responses to PAE: Evidence from an Analysis of a Ukraine Cohort

Nihal A. Salem

Authors: Nihal A. Salem, Amanda H. Mahnke, Christina Chambers, Rajesh C. Miranda, CIFASD

Learning Objectives

1. Recognize a statistical technique based on iterative resampling to estimate statistical parameters in human populations based on studies with small sample sizes
2. Recognize that maternal circulating miRNAs which serve as biomarkers for infant birth outcomes due to prenatal alcohol exposure, also exhibit patterns of co-regulated expression that are dependent on the sex of the infant
3. Recognize that fetal variables like sex modify maternal endocrine responses to prenatal alcohol exposure

Introduction

We previously reported that maternal and neonatal plasma microRNA (miRNA) can be used as biomarkers for fetal alcohol exposure in an Ovine model (Balaraman et al., 2014) ,in a cohort of pregnant women recruited from Ukraine, we reported (Balaraman et al., 2016) that miRNA secreted into plasma of alcohol-exposed pregnant mothers could predict growth and other deficits in the new-born infant. In this study pregnant women were classified as unexposed to alcohol (UE), heavily exposed, with affected infants (HEa) or heavily exposed with apparently unaffected infants (HEua), and plasma samples were obtained at mid-pregnancy and at the end of the third trimester. In this study infant sex was a significant contributor in the random forest analysis classification accuracy of the samples into one of the three groups (HEa, HEua, UE).

Research Questions

I performed secondary analyses on the published secreted miRNA data to ask the following questions:

1. Is there evidence for coordinated secretion of miRNAs?
2. Is there an effect of alcohol exposure on coordinated secretion?
3. Does fetal sex determine maternal miRNA profiles in response to alcohol exposure?

Analyses Methods

To study the coordinated expression of secreted miRNAs, I performed correlation analyses between the expression levels of the secreted miRNAs, followed by computing the number of significant correlations in each exposure group. I then segregated the data by infant sex and computed number of significant cross-correlations in each group.

Segregating the data by infant sex results in the decrease of sample size in each group, to test the stability of the number of significant correlations in each group. I performed bootstrap resampling analyses in which each group is iteratively resampled with replacement to simulate the population from which each group was drawn. In each iteration, the number of significant correlations was computed and the resulting numbers from all iterations where used to construct histogram of the distribution of the number of correlations in the simulated population.

Finally, to determine if the alcohol-sensitivity of maternal miRNAs was influenced by the sex of the fetus, I performed Bootstrap resampling Analysis of Variance on each of the miRNAs, with both sexes combined or separated, and identified the proportion of iterations for which the null hypothesis was rejected in each of the three comparisons (males and females combined , male infants only or female infants only). Those miRNAs which exhibited an increased proportion of significant iterations in sex segregated comparison over the combined comparison were identified as infant sex-specific, alcohol-sensitive maternal miRNAs.

Results:

Our analysis shows that:

1. Alcohol exposure increased significant cross-wise miRNA correlations in maternal plasma samples collected at the second and the third trimester. The number of significant correlations was higher in the HEa group compared to HEua group, and both groups exhibited a higher number of significant cross-correlations compared to UE mothers.
2. In Re-analyzing maternal miRNAs by infant sex, we found that HEa and HEua group mothers who gave birth to female infants exhibited increased cross-correlations in plasma miRNA expression in both second and third trimesters, compared to mothers who subsequently gave birth to male infants.
3. Iterative bootstrap analyses confirmed the stability of increased cross-correlations in miRNA expression patterns specifically in HEa and HEua mothers of female infants.

Conclusions

MicroRNAs exhibit coordinated expression plasma of pregnant alcohol-exposed women who give birth to affected infants compared to exposed mothers that give birth to apparently un-affected infants, or control mothers. Fetal sex is an important determinant of miRNA responses to alcohol exposure in pregnant mothers. Alcohol exposure may result in coordinated secretory activity of tissues that contribute to circulating miRNAs in a pregnant mother who later gives birth to an affected infant.

References

Balaraman, S., Lunde, E.R., Sawant, O., Cudd, T.A., Washburn, S.E., and Miranda, R.C. (2014). Maternal and Neonatal Plasma Micro RNA Biomarkers for Fetal Alcohol Exposure in an Ovine Model. Alcoholism: Clinical and Experimental Research 38, 1390-1400.

Balaraman, S., Schafer, J.J., Tseng, A.M., Wertelecki, W., Yevtushok, L., Zymak-Zakutnya, N., Chambers, C.D., and Miranda, R.C. (2016). Plasma miRNA Profiles in Pregnant Women Predict Infant Outcomes following Prenatal Alcohol Exposure. PLoS One 11, e0165081.

D3c A Unique Mouse Model to Identify Genetic Polymorphisms that Modify Outcomes in PAE

Susan Smith

Authors: Susan Smith, Eneda Pjetri, Nipun Saini, Walter Friday, Joshua Baulch, Brandon Presswood, Wenliang Zhang, George Flentke

Learning Objectives

1. Explain how genetic polymorphisms in the mother and fetus can help explain the variable impact of PAE upon an affected individual
2. Develop a better comprehension of how factors including nutrition, rates of alcohol metabolism, and stress response can interact with genes to affect the fetus's vulnerability to FASD

Objectives

Although individuals diagnosed with FASD share common cognitive, behavioral, and physical characteristics, the severity of these outcomes varies substantially. Genetic background is known to significantly modify PAE outcomes; however, these influential polymorphisms are inadequately described. To identify novel candidate loci, we screened alcohol vulnerability in a unique genetic resource, the Collaborative Cross (CC) mouse initiative.

Methods

The CC mouse strains were bred from eight inbred and wild-derived strains to create fixed lineages recapitulating human genetic heterozygosity. We initiated screens of their alcohol vulnerability including blood alcohol concentrations (BAC), drinking preference, stress-induced hyperthermy (SIH), and fetal vulnerability to PAE. Controls receive no-treatment or maltodextrin, and C57Bl/6J serves as reference strain. All consume the same fixed-nutrient, semi-purified diet to reveal gene × nutrient × alcohol interactions.

Results

As proof of principle, we randomly selected twelve CC strains for analysis. Five have exceptional alcohol responses. Alcohol clearance varies widely: at 30-min following a single oral gavage (3 g/kg), mean BACs were <100 mg/dl for two strains and >350 mg/dl for a third; for C57Bl/6J it was 220 mg/dl. Two additional strains are exceptionally vulnerable to alcohol and die within 5min and 60min, respectively, following administration of a single oral dose of 3g/kg alcohol. To date, three CC strains have been tested for their vulnerability to PAE (3g/kg daily GD8.5-19.5). Of these, one strain has a 37% fetal malformation rate; a second developed a PAE-dependent preeclampsia fatal to dams by gestational day 10.5; mean BACs were only 175 mg/dl. Detailed analysis of gestational growth, placental efficiency, and fetal dysmorphology is underway. Genetics also affects basal stress responses, and mean change in body temperature (assessed using SIH) of these strains ranges from -0.2°C to +1°C. Despite consuming identical, nutritionally-adequate diets, these strains exhibit gene x nutrient interactions that significantly modify fertility, appetite, body composition, and metabolic efficiency; metabolome analysis is underway.

Conclusions

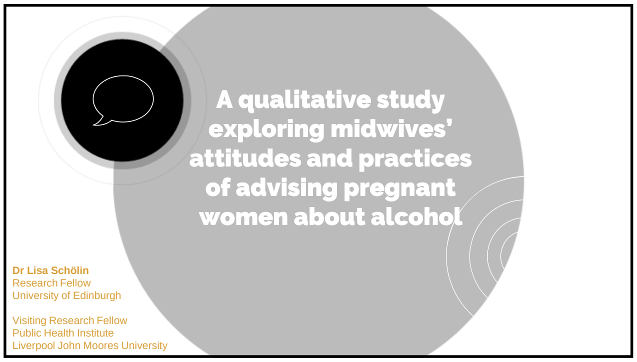
Our data show that gene polymorphisms strongly affect adult and fetal alcohol responses. The exceptional diversity of these CC strains accelerates our ability to capture novel polymorphisms affecting PAE outcomes, and is a powerful complement to existing alcohol studies that use recombinant inbred strains such as BxD. The CC strains have been deeply sequenced and have extensive SNP maps, and are thus a powerful discovery tool to identify candidate genetic and epigenetic influences upon risk and outcome in human cohorts of FASD.

[Supported by the Precision Nutrition Initiative at UNC-NRI.]

D4a

A Qualitative Study Exploring Midwives' Attitudes and Practices of Advising Pregnant Women About Alcohol in England and Sweden

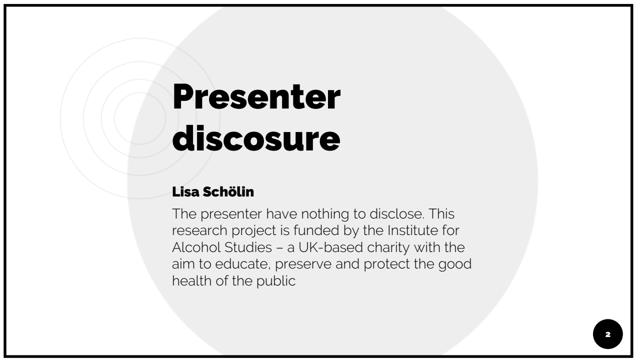
Lisa Schölin



A qualitative study exploring midwives' attitudes and practices of advising pregnant women about alcohol

Dr Lisa Schölin
Research Fellow
University of Edinburgh

Visiting Research Fellow
Public Health Institute
Liverpool John Moores University



Presenter discosure

Lisa Schölin

The presenter have nothing to disclose. This research project is funded by the Institute for Alcohol Studies – a UK-based charity with the aim to educate, preserve and protect the good health of the public

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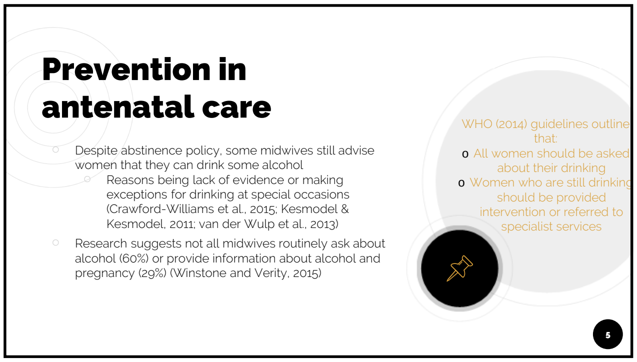
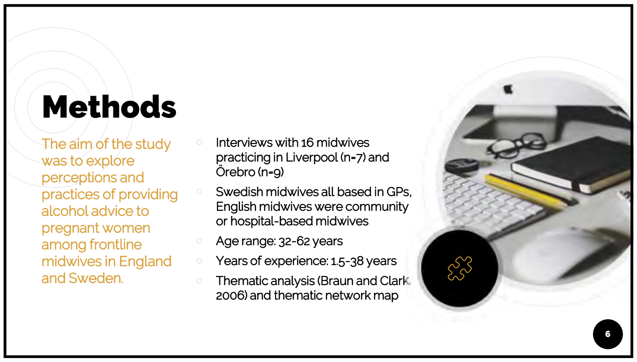
Popova et al. (2017)



Prevention in antenatal care

- Despite abstinence policy, some midwives still advise women that they can drink some alcohol
  - Reasons being lack of evidence or making exceptions for drinking at special occasions (Crawford-Williams et al., 2015; Kesmodel & Kesmodel, 2011; van der Wulp et al., 2013)
- Research suggests not all midwives routinely ask about alcohol (60%) or provide information about alcohol and pregnancy (29%) (Winstone and Verity, 2015)

WHO (2014) guidelines outline that:
- All women should be asked about their drinking
- Women who are still drinking should be provided intervention or referred to specialist services



Methods

The aim of the study was to explore perceptions and practices of providing alcohol advice to pregnant women among frontline midwives in England and Sweden.

- Interviews with 16 midwives practicing in Liverpool (n=7) and Örebro (n=9)
- Swedish midwives all based in GPs, English midwives were community or hospital-based midwives
- Age range: 32-62 years
- Years of experience: 1.5-38 years
- Thematic analysis (Braun and Clark, 2006) and thematic network map

Pregnant women's lifestyles/promoting a healthy lifestyle

- Most women stop drinking; some English midwives questioned clients' honesty
- Partners rarely change their drinking habits – can be hard to engage
- Women's drinking in general was seen as a public health concern

I actually think that people drink incredible amounts. And it is shocking sometimes when you hear how young women drink. They are wasted (Swedish midwife 8)

In general I think alcohol is just a massive issue for this country and this region in general [...] massive public health issue isn't it (English midwife 1)

- Abstinence preferred as the advice to give to women
- Difference in interpretation of risk at drinking small levels
- Routine questions used in both countries – difference in how formalised they were

Well we know that the risks are but we don't know what level would be at risk, so I would give the information, I think that we should all be singing from the same hymn sheet (English midwife 7)

Antenatal practices

Midwifery role

- Discussing alcohol is part of the role – MI useful skill
- Relationship and trust important components
- Identified problem to advise women who drank before knowing about the pregnancy – guidance requested

I would really like to know what advice could be given to somebody say who've done it for about eight weeks. And maybe heavily. So I don't know what the implications of that are. So I should be able to give her that advice, you know, what we do (English midwife 1)

I never say that it's not dangerous. I don't think I have ever said that, but you are very tempted. Because you want to do good (Swedish midwife 7)

Discussion

- Cultural differences in risk perception seem to be part of both general public's attitudes and practicing midwives' (Schölin et al., 2017)
- Midwives support abstinence as a message – practical guidance for supporting inadvertent exposure needed
- Women want and do seek reassurance – equipping midwives to give good advice is important
- Media framing may both support and hamper abstinence guidelines (McCallum & Holland, 2017) – communicating the complexity of the evidence is difficult, clear communication in antenatal care is key

Small alcoholic drink a day during pregnancy 'has no effect on baby'

Pregnant women can have a small alcoholic drink a day without it harming the development of their children, a study has found.

g birth and boozing? The risks of
king during pregnancy

Pregnant? It's okay to drink two glasses of wine a week says study

BABY BOOZE How many alcohol units can you drink while pregnant, how many are safe and what's foetal alcohol syndrome?

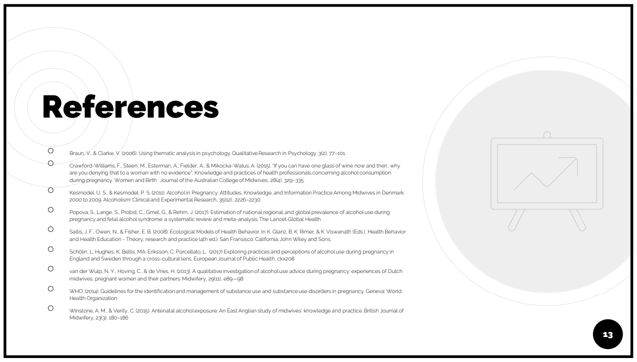
There has long been a debate on whether expectant mums can enjoy their favourite tipple

Mirror

Lover's secret boozing during pregnancy le
damaged

Matthew Kaye can't talk properly, has difficulty walking due to curvature of the spine, coul
suffers from learning difficulties

Lisa Schölin, Karen Hughes, Mark A. Bellis, Charli Eriksson & Lorna Porcellato (2018) "I think we should all be singing from the same hymn sheet" – English and Swedish midwives' views of advising pregnant women about alcohol, Drugs: Education, Prevention and Policy, DOI: 10.1080/09687637.2018.1478949



References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.
- Crawford-Williams, F., Steen, M., Esterman, A., Fielder, A., & Mikocka-Walus, A. (2015). "If you can have one glass of wine now and then, why are you denying that to a woman with no evidence": Knowledge and practices of health professionals concerning alcohol consumption during pregnancy. Women and Birth : Journal of the Australian College of Midwives, 28(4), 329–335.
- Kesmodel, U. S., & Kesmodel, P. S. (2011). Alcohol in Pregnancy: Attitudes, Knowledge, and Information Practice Among Midwives in Denmark 2000 to 2009. Alcoholism: Clinical and Experimental Research, 35(12), 2226–2230.
- Popova, S., Lange, S., Probst, C., Gmel, G., & Rehm, J. (2017). Estimation of national,regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. The Lancet Global Health.
- Sallis, J. F., Owen, N., & Fisher, E. B. (2008). Ecological Models of Health Behavior. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), Health Behavior and Health Education - Theory, research and practice (4th ed.). San Fransisco: California: John Wiley and Sons.
- Schölin, L; Hughes, K; Bellis, MA; Eriksson, C; Porcellato, L. (2017) Exploring practices and perceptions of alcohol use during pregnancy in England and Sweden through a cross-cultural lens, European Journal of Public Health, ckx208
- van der Wulp, N. Y., Hoving, C., & de Vries, H. (2013). A qualitative investigation of alcohol use advice during pregnancy: experiences of Dutch midwives, pregnant women and their partners. Midwifery, 29(11), e89—98
- WHO. (2014). Guidelines for the identification and management of substance use and substance use disorders in pregnancy. Geneva: World Health Organization
- Winstone, A. M., & Verity, C. (2015). Antenatal alcohol exposure: An East Anglian study of midwives' knowledge and practice. British Journal of Midwifery, 23(3), 180–186

Thanks!

Any questions?

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D4b Nurturing Families: Piloting a Modified Parent Child Assistance Program (PCAP) in Perth

Martyn Symons, James P. Fitzpatrick

Authors: Symons M, Meehan J, Raymond N, Finlay-Jones A

Background

Exposure to alcohol and other drugs (AOD) during pregnancy can lead to serious adverse child outcomes, including FASD. The Parent-Child Assistance Program (PCAP) supports disengaged women with problematic AOD use, who are pregnant or have young children. In the US and Canada PCAP has helped reduce alcohol exposed pregnancies, promote abstinence, increase employment and family planning and improve child outcomes. Economic modelling showed a CAD$22M saving to the Canadian Government from reducing FASD prevalence.

Methods

A slightly modified version of the PCAP was piloted in Australia. Home visitation case management was provided to ten women by an experienced psychotherapist who assisted them to engage with services effectively to meet their own goals via a combination of relational theory, motivational interviewing and harm reduction concepts. Case management was provided in a non-judgmental way and guaranteed for three years. Client satisfaction was measured using the validated Treatment Perceptions Questionnaire. Staff were interviewed to determine changes needed to adapt the PCAP program for Australia and program delivery was compared with standard PCAP using available audit forms.

Results

Outcomes for women after 6-12 months were compared to baseline using a previously developed composite measure scored in the following domains: Utilisation of alcohol/drug treatment; abstinence from alcohol and drugs; family planning (use of birth control and subsequent pregnancies); health and well-being of the target child; and appropriate connection with community services. Over 80% had improved connection to services and were using birth control. The majority were moving towards their goals and were abstinent. Nurturing families differed to the traditional PCAP model with a wider range of child ages, more in depth AOD counselling by the case-manager, less direct supervision and altered data collection.

Conclusions

Pilot results will inform the methodology for a larger prospective cohort control study comparing PCAP with treatment as usual over three years. If successful, PCAP could help prevent FASD across Australia.

D4c

Perceptions About Alcohol Use During Pregnancy in France, Portugal and Spain – A Cross-Cultural Qualitative Study

Maria Xavier

Authors: Xavier, M.R, Franco, R, Charro, B, Hoffmeister, K, Fruscione, M, López-Pinto, I

Learning Objectives

1. Identify differences and similarities between the 3 groups of participants
2. Consider importance of cultural dimensions related to alcohol use during pregnancy
3. Discuss importance of qualitative approach to understand alcohol use during pregnancy

Abstract

Considering children prenatally exposed to alcohol present substantial challenge to societies and considering minimum safe dose of alcohol during pregnancy is unknown, WHO suggest zero consumption. Despite, research shows that there is a substantial number of women who continue to drink.

Taking into consideration that information is needed to make an informed decision about alcohol use during pregnancy (AUDP), understanding the accessibility and quality of information available to pregnant women is an issue for research. This qualitative study explores attitudes of Portuguese, Spanish and French pregnant women regarding AUDP, knowledge about the impact of AUDP, accessibility and quality of information available.

Semi-structured interviews were conducted with 20 French (Toulouse), 21 Portuguese (north region) and 23 Spanish (Madrid) pregnant women. Interviews were audio recorded and transcribed verbatim. Data were qualitative analyzed using a semi-inductive approach. Theoretical saturation was achieved in Portuguese and French groups.

In the three groups pregnant women reveals alcohol consumption at some point during pregnancy (festive events). Pregnant women (French, Portuguese and Spanish) described mixed messages and confusions about consequences of AUDP. In Portugal and Spain, participants reported limitations concerning accessibility of information available and social pressure to drink. French participants argued that it is easy to find information related to AUDP.

Practices and perspectives towards AUDP have common points and differences between, as described by the three groups of participants. In spite of the differences, it seems that Portuguese and Spanish groups point that type and quality of information don't allow a clearly informed decision about AUDP.

Keywords

Alcohol consumption; pregnancy; women; information

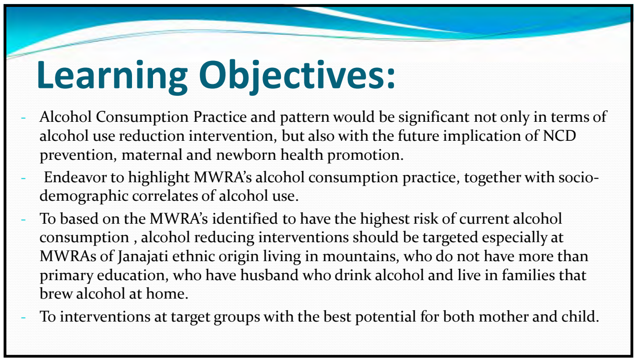
D4d

Alcohol Consumption Practices among Married Women of Reproductive Age in Nepal: A Population Based Household Survey

Kul Bahadur Chand

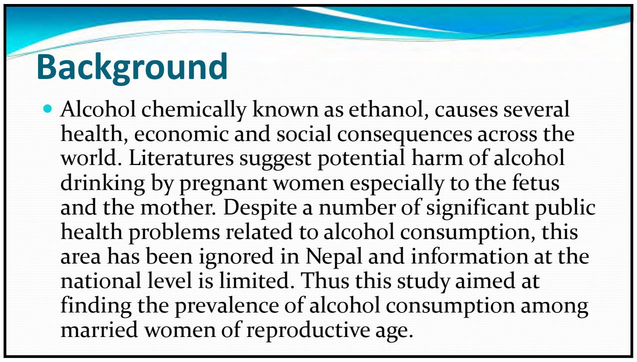
Alcohol Consumption Practices among Married Women of Reproductive Age in Nepal: A Population Based Household Survey

-Kul Bahadur Chand- Nepal Disabled and Helpless Rehabilitation



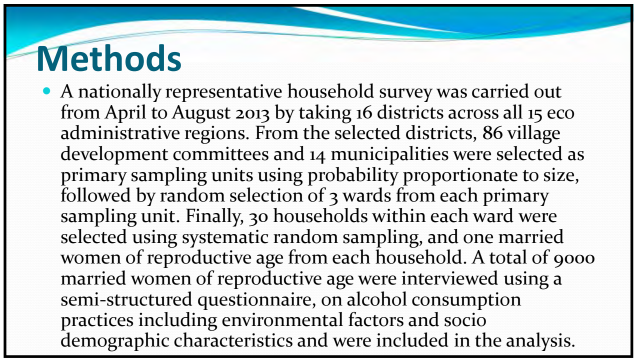
Learning Objectives:

- Alcohol Consumption Practice and pattern would be significant not only in terms of alcohol use reduction intervention, but also with the future implication of NCD prevention, maternal and newborn health promotion.
- Endeavor to highlight MWRA's alcohol consumption practice, together with socio-demographic correlates of alcohol use.
- To based on the MWRA's identified to have the highest risk of current alcohol consumption , alcohol reducing interventions should be targeted especially at MWRAs of Janajati ethnic origin living in mountains, who do not have more than primary education, who have husband who drink alcohol and live in families that brew alcohol at home.
- To interventions at target groups with the best potential for both mother and child.



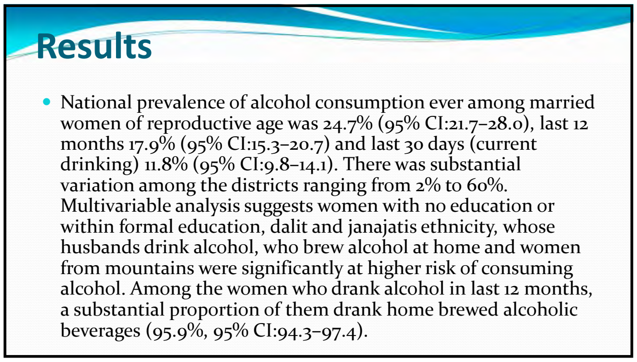
Background

- Alcohol chemically known as ethanol, causes several health, economic and social consequences across the world. Literatures suggest potential harm of alcohol drinking by pregnant women especially to the fetus and the mother. Despite a number of significant public health problems related to alcohol consumption, this area has been ignored in Nepal and information at the national level is limited. Thus this study aimed at finding the prevalence of alcohol consumption among married women of reproductive age.



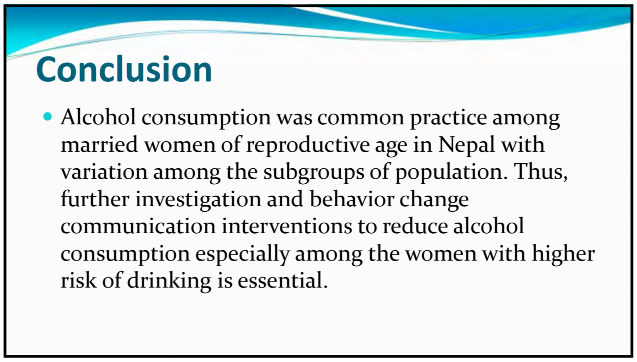
Methods

- A nationally representative household survey was carried out from April to August 2013 by taking 16 districts across all 15 eco administrative regions. From the selected districts, 86 village development committees and 14 municipalities were selected as primary sampling units using probability proportionate to size, followed by random selection of 3 wards from each primary sampling unit. Finally, 30 households within each ward were selected using systematic random sampling, and one married women of reproductive age from each household. A total of 9000 married women of reproductive age were interviewed using a semi-structured questionnaire, on alcohol consumption practices including environmental factors and socio demographic characteristics and were included in the analysis.



Results

- National prevalence of alcohol consumption ever among married women of reproductive age was 24.7% (95% CI:21.7–28.0), last 12 months 17.9% (95% CI:15.3–20.7) and last 30 days (current drinking) 11.8% (95% CI:9.8–14.1). There was substantial variation among the districts ranging from 2% to 60%. Multivariable analysis suggests women with no education or within formal education, dalit and janajatis ethnicity, whose husbands drink alcohol, who brew alcohol at home and women from mountains were significantly at higher risk of consuming alcohol. Among the women who drank alcohol in last 12 months, a substantial proportion of them drank home brewed alcoholic beverages (95.9%, 95% CI:94.3–97.4).



Conclusion

- Alcohol consumption was common practice among married women of reproductive age in Nepal with variation among the subgroups of population. Thus, further investigation and behavior change communication interventions to reduce alcohol consumption especially among the women with higher risk of drinking is essential.

D5a

A New Molecular Etiology of FASD: Retinoic Acid Deficiency Induces FASD-Like Craniofacial and Neurodevelopmental Malformations

Berardino Petrelli

Authors: Berardino Petrelli, Arzu Ozturk, Molly Pind, Hossaena Ayele, Abraham Fainsod, Geoffrey G. Hicks

Learning Objectives

1. Understand the molecular basis of how Prenatal Alcohol Exposure reduces retinoic acid levels during critical developmental stages in early gestation
2. Learn how retinoic acid deficiency (Vitamin A Deficiency) at early gestation results in later craniofacial malformations that are reminiscent of those found in PAE (FASD) mice
3. Recognize how Vitamin A supplementation during pregnancy may prevent or reduced FASD neurodevelopmental outcomes

Objectives

Prenatal alcohol exposure (PAE) resulting in Fetal Alcohol Spectrum Disorder (FASD) is the most common cause of neurodevelopmental impairments in the western world, with a prevalence of 1% in Canada. It is well established in Xenopus models that a single exposure to alcohol during gastrulation is sufficient to induce the developmental defects associated with FASD. Acute ethanol exposure overwhelms the aldehyde metabolic enzymes that would normally convert retinol (Vitamin A) to retinoic acid (RA). We hypothesize that PAE reduces RA levels during critical developmental stages in early gastrulation and this aberration drives the later craniofacial malformations associated with FASD.

Methods

To biochemically mimic the alcohol-induced RA deficiency in vivo, we genetically engineered a mouse expressing Cyp26A1 from the endogenous Goosecoid (Gsc) promoter. The Gsc promoter dictates spatial-temporal expression to the Spemann Mangold Organizer at gastrulation. Cyp26A1 degrades endogenous RA in these cells, mimicking the reduced RA levels induced by acute alcohol exposure and dysregulating neural crest cells induction.

Results

Gsc:Cyp26A1 mice were derived by germline transmission; F1 mice are born with a Mendelian ratio of 0.66:1 (het:wt , n=351). This loss of mutant embryo viability may reflect the prevalent miscarriages observed in human pregnancies with PAE. Gsc:Cyp26A1xRARE-LacZ E8.5 embryos show reduction in RA activity in the frontonasal prominence region (LacZ expression in early face and forebrain). Mutant embryos also demonstrate body-axis developmental variation, indicating early developmental perturbation of retinoic acid pathways in FASD relevant tissues (n=48). E18.5 embryos were next examined using scanning electron microscopy to demonstrate mutant embryos have sentinel FASD craniofacial malformations: larger philtrum-to-philtrum-lip length ratio, smaller bigonial line width, and smaller whisker pad area compared to WT littermates (n=66). Gsc:Cyp26A1 mice also develop craniofacial malocclusions at significantly higher rates than WT littermates (12.5% vs 0.04%; n=208 and 3711, respectively).

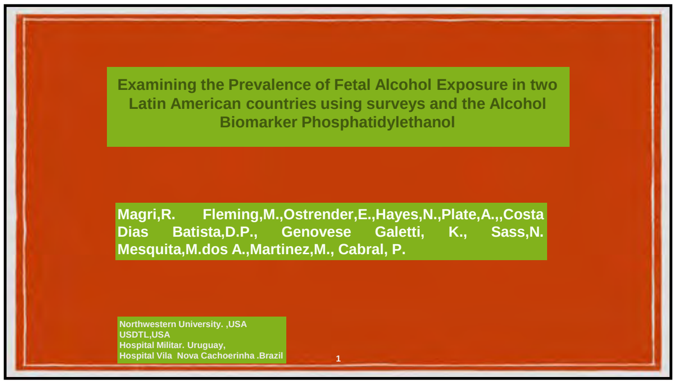
Conclusion

Taken together, our data provide in vivo evidence that strongly supports retinoic acid deficiency as a major molecular etiology of craniofacial malformations associated with FASD. The finding suggests Vitamin A supplementation may significantly reduce or prevent FASD outcomes in children with PAE.

D5b

Examining the Prevalence of Fetal Alcohol Exposure in Two Latin American Countries Using Surveys and Alcohol Biomarker Phosphatidylethanol

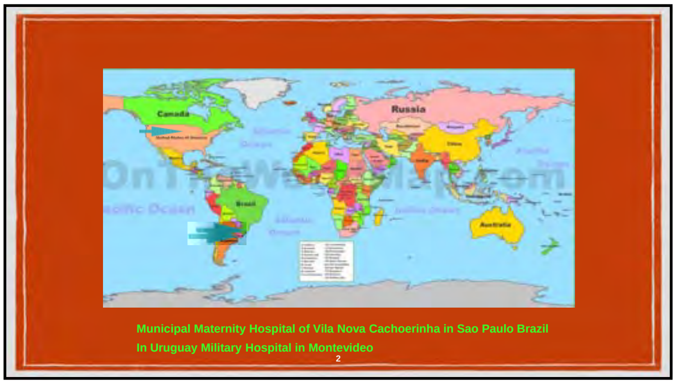
Raquel Magri



Examining the Prevalence of Fetal Alcohol Exposure in two Latin American countries using surveys and the Alcohol Biomarker Phosphatidylethanol

Magri,R. Fleming,M.,Ostrender,E.,Hayes,N.,Plate,A.,,Costa Dias Batista,D.P., Genovese Galetti, K., Sass,N. Mesquita,M.dos A.,Martinez,M., Cabral, P.

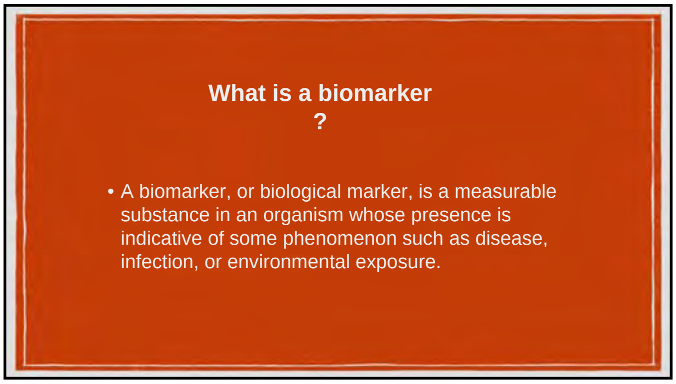
Northwestern University. ,USA
USDTL,USA
Hospital Militar. Uruguay,
Hospital Vila Nova Cachoerinha .Brazil



Municipal Maternity Hospital of Vila Nova Cachoerinha in Sao Paulo Brazil
In Uruguay Military Hospital in Montevideo

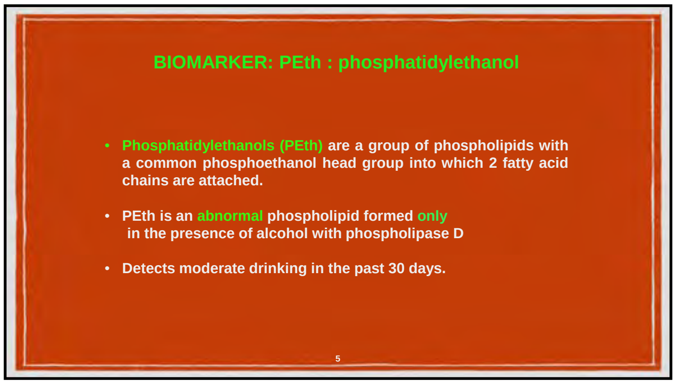
What is our research methodology?

- We conduct self report alcohol assessments investigating, validating and adjusting with another tool, a biological biomarker.
- We use biomarkers in both mothers and newborns.



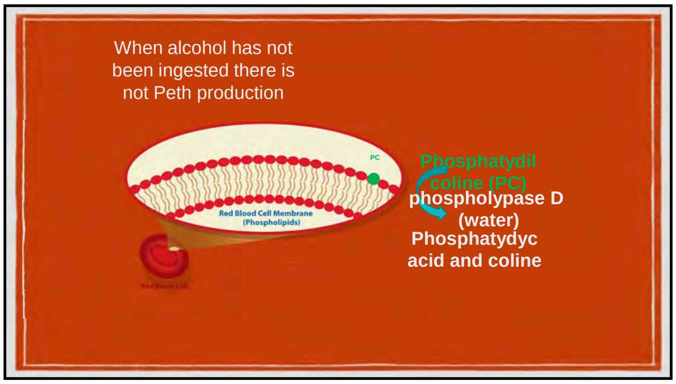
What is a biomarker ?

- A biomarker, or biological marker, is a measurable substance in an organism whose presence is indicative of some phenomenon such as disease, infection, or environmental exposure.



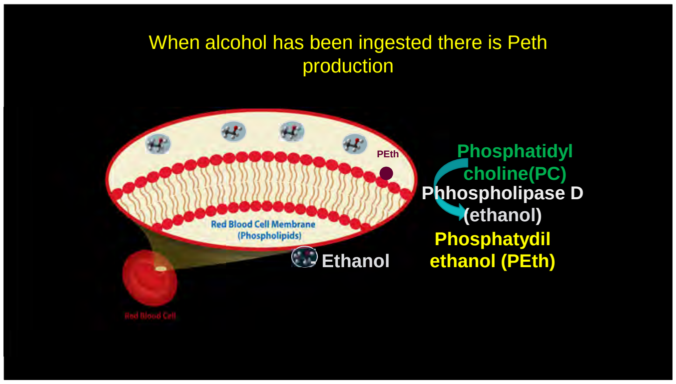
BIOMARKER: PEth : phosphatidylethanol

- Phosphatidylethanols (PEth) are a group of phospholipids with a common phosphoethanol head group into which 2 fatty acid chains are attached.
- PEth is an abnormal phospholipid formed only in the presence of alcohol with phospholipase D
- Detects moderate drinking in the past 30 days.



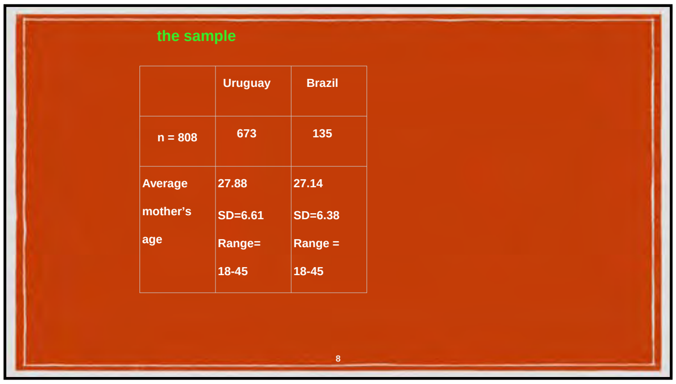
When alcohol has not been ingested there is not Peth production

Phosphatydil coline (PC)
phospholypase D
(water)
Phosphatydyc acid and coline



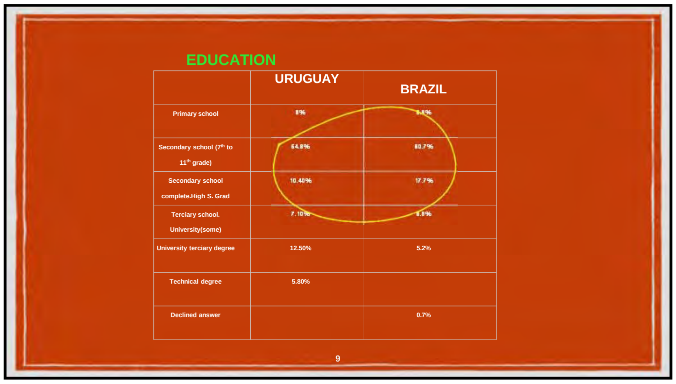
When alcohol has been ingested there is Peth production

Phosphatidyl choline(PC)
Phhospholipase D
(ethanol)
Phosphatydil ethanol (PEth)



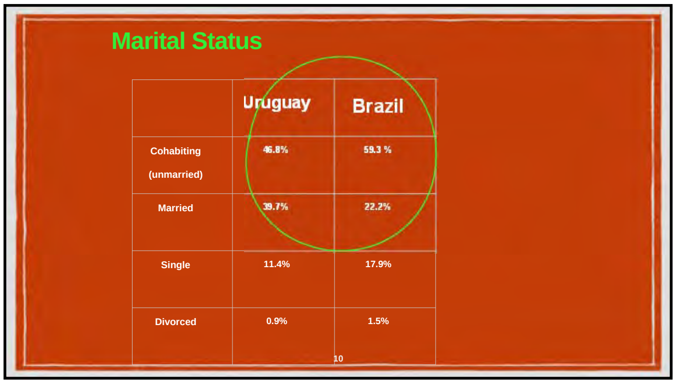
the sample

	Uruguay	Brazil
n = 808	673	135
Average mother's age	27.88 SD=6.61 Range= 18-45	27.14 SD=6.38 Range = 18-45



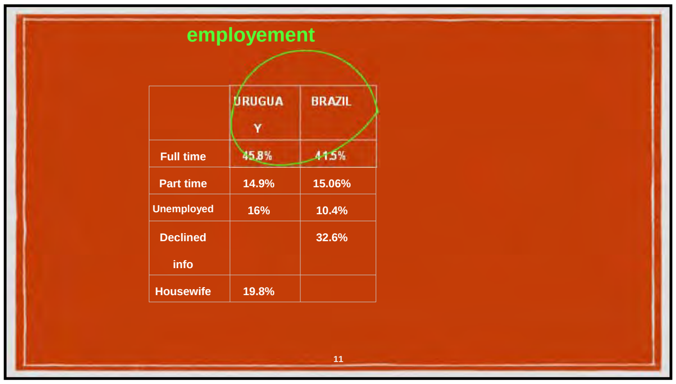
EDUCATION

	URUGUAY	BRAZIL
Primary school	8%	6.8%
Secondary school (7th to 11th grade)	64.8%	60.7%
Secondary school complete.High S. Grad	10.40%	17.7%
Terciary school. University(some)	7.10%	8.8%
University terciary degree	12.50%	5.2%
Technical degree	5.80%	
Declined answer		0.7%



Marital Status

	Uruguay	Brazil
Cohabiting (unmarried)	46.8%	59.3 %
Married	39.7%	22.2%
Single	11.4%	17.9%
Divorced	0.9%	1.5%

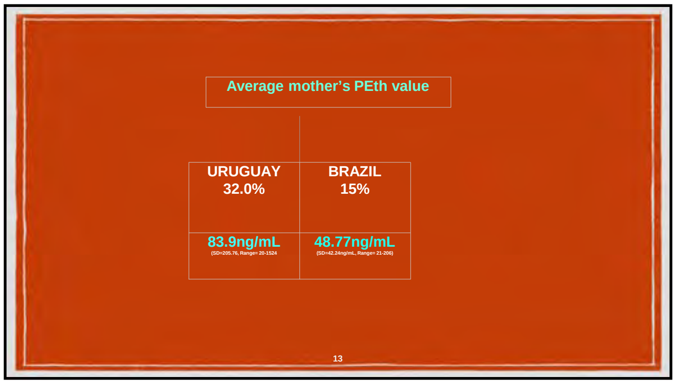


employement

	URUGUAY	BRAZIL
Full time	45.8%	41.5%
Part time	14.9%	15.06%
Unemployed	16%	10.4%
Declined info		32.6%
Housewife	19.8%	

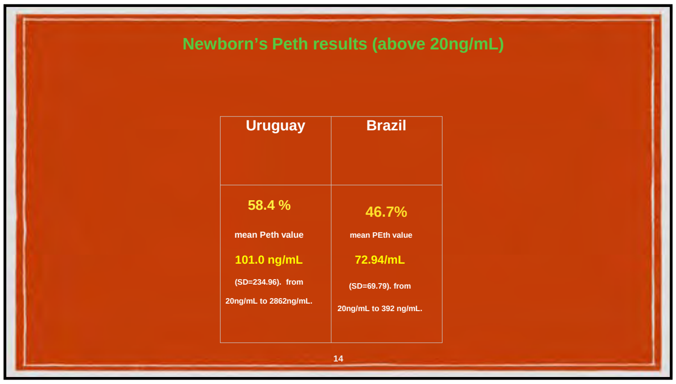
Alcohol self report use

	Uruguay	Brazil
Any trimester	56.5%	65.7%
First trimester	49.77%	44.8%
Second trimester	26.9%	17.2%
Third trimester	8.17%	23.2%



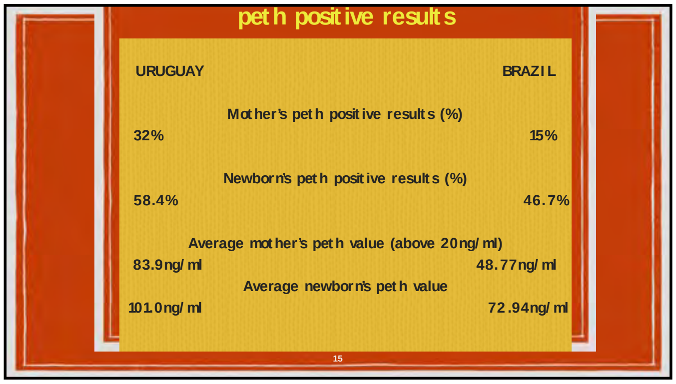
Average mother's PEth value

URUGUAY 32.0%	BRAZIL 15%
83.9ng/mL (SD=205.76, Range= 20-1524	48.77ng/mL (SD=42.24ng/mL, Range= 21-206)



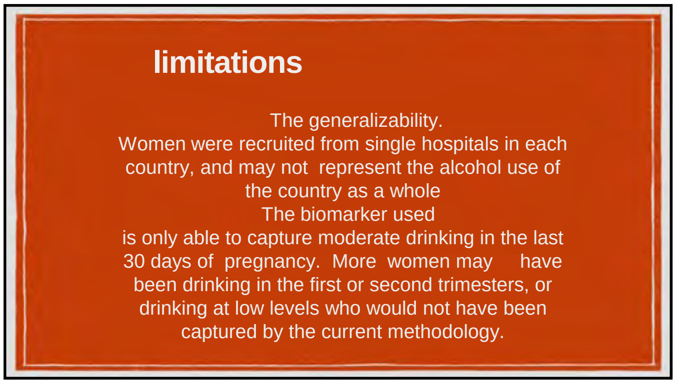
Newborn's Peth results (above 20ng/mL)

Uruguay	Brazil
58.4 % mean Peth value 101.0 ng/mL (SD=234.96). from 20ng/mL to 2862ng/mL.	46.7% mean PEth value 72.94/mL (SD=69.79). from 20ng/mL to 392 ng/mL.



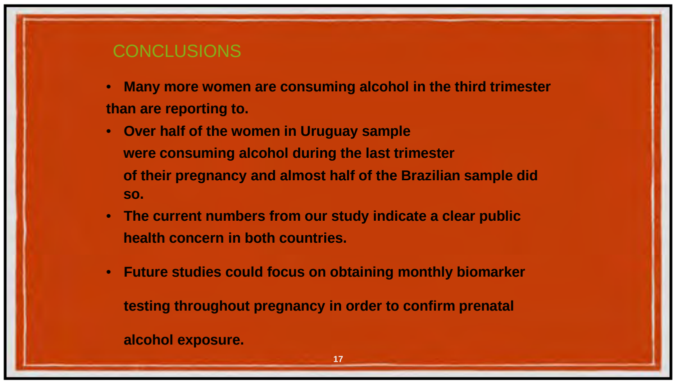
peth positive results

	URUGUAY	BRAZIL
Mother's peth positive results (%)	32%	15%
Newborn's peth positive results (%)	58.4%	46.7%
Average mother's peth value (above 20ng/ml)	83.9ng/ml	48.77ng/ml
Average newborn's peth value	101.0ng/ml	72.94ng/ml



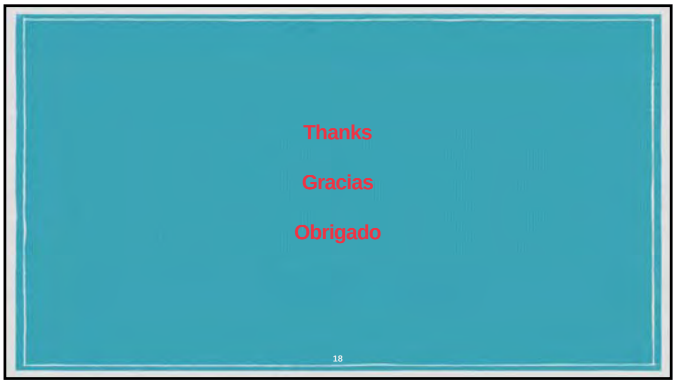
limitations

The generalizability.
Women were recruited from single hospitals in each country, and may not represent the alcohol use of the country as a whole
The biomarker used
is only able to capture moderate drinking in the last 30 days of pregnancy. More women may have been drinking in the first or second trimesters, or drinking at low levels who would not have been captured by the current methodology.



CONCLUSIONS

- **Many more women are consuming alcohol in the third trimester than are reporting to.**
- **Over half of the women in Uruguay sample were consuming alcohol during the last trimester of their pregnancy and almost half of the Brazilian sample did so.**
- **The current numbers from our study indicate a clear public health concern in both countries.**
- **Future studies could focus on obtaining monthly biomarker testing throughout pregnancy in order to confirm prenatal alcohol exposure.**



Thanks

Gracias

Obrigado

D5c

Alcohol Effects on the Proteome of Fetal Neural Stem Cell Derived Extracellular Vesicles: A Novel Mechanism for Alcohol Teratogenesis

Dae Chung

Authors: Dae Chung, Alexander Tseng, Marisa Pinson, Lawrence Dangott, Susan Weintraub, Rajesh Miranda

Learning Objectives

1. Understanding the effects of prenatal alcohol exposure on fetal neural stem cells
2. Learning about miRNAs and extracellular vesicles
3. Measuring altered extracellular vesicle miRNAs
4. Assessing the influence altered miRNAs have on fetal neural stem cells
5. Further looking into the proteome of extracellular vesicles

Introduction

Prenatal alcohol exposure can result in a cluster of craniofacial, neuro-cognitive and growth deficits that are collectively termed Fetal Alcohol Spectrum Disorders (FASD). Neural stem cells (NSCs) are particularly vulnerable to alcohol (ethanol) exposure during the late first through the second trimester, when they give birth to most of the neurons of the adult brain. Extracellular vesicles (EVs) may serve as a means of communication to synchronize the NSC niche. We hypothesized that ethanol influences the cargo of NSC EVs, which in return can alter the NSC proliferation and differentiation. To test this, we investigated the effect of ethanol on EV miRNAs and proteins, and the functional effect of altered EV miRNAs on naive NSCs.

Methods

Micro-dissected gestational day 12.5-derived mouse cortical neuroepithelial cells were propagated as non-adherent neurospheres and subjected to a dose-range of ethanol. RNA from neurospheres was isolated and cDNA was synthesized. EVs were isolated by a modified ultracentrifugation method. Western blot and transmission electron microscope were used on isolated EVs. For miRNA analysis, PCR amplification was performed, while EV proteome was assessed by LC-MS/MS, then analyzed using Mascot and Scaffold.

Results

We identified a subset of EV miRNAs whose expression levels were significantly induced by ethanol treatment. Using a gain of function analysis, we show overexpression of one of these differentially expressed miRNAs, miR-140-3p, increased NSC growth. We further showed that miR-140-3p influences expression of key differentiation-associated mRNA transcripts. In our proteomic analysis, we identified over 1600 proteins in EVs that were expressed at approximately equal levels in EVs derived from four biological replicates.

Summary/Conclusion

Ethanol exposure significantly altered the miRNA content of EVs released by NSCs, and increased miR-140-3p in differentiating NSCs suggests the emergence of an aberrant astroglial maturation stage. The proteomic data have shown that EVs are enriched for regulatory proteins, including transcription factors and those that control mRNA translation. Such proteins and altered miRNAs influence stem cell behavior in the fetal brain, offering the possibility of EVs to effect fetal brain growth.

Conflict of Interest Statement:

The authors declare no conflict of interest.

References:

ADACHI, J., MIZOI, Y., FUKUNAGA, T., OGAWA, Y., UENO, Y. & IMAMICHI, H. 1991. Degrees of alcohol intoxication in 117 hospitalized cases. J Stud Alcohol, 52, 448-53.

BAGLIO, S. R., ROOIJERS, K., KOPPERS-LALIC, D., VERWEIJ, F. J., PÉREZ LANZÓN, M., ZINI, N., NAAIJKENS, B., PERUT, F., NIESSEN, H. M., BALDINI, N. & PEGTEL, D. M. 2015. Human bone marrow- and adipose-mesenchymal stem cells secrete exosomes enriched in distinctive miRNA and tRNA species. Stem Cell Research & Therapy, 6, 127.

BALARAMAN, S., LUNDE, E. R., SAWANT, O., CUDD, T. A., WASHBURN, S. E. & MIRANDA, R. C. 2014. Maternal And Neonatal Plasma MicroRNA Biomarkers For Fetal Alcohol Exposure In An Ovine Model. Alcoholism, clinical and experimental research, 38, 1390-1400.

BALARAMAN, S., SCHAFER, J. J., TSENG, A. M., WERTELECKI, W., YEVTUSHOK, L., ZYMAK-ZAKUTNYA, N., CHAMBERS, C. D. & MIRANDA, R. C. 2016. Plasma miRNA Profiles in Pregnant Women Predict Infant Outcomes following Prenatal Alcohol Exposure. PLOS ONE, 11, e0165081.

BALARAMAN, S., TINGLING, J. D., TSAI, P.-C. & MIRANDA, R. C. 2013. Dysregulation of microRNA Expression and Function Contributes to the Etiology of Fetal Alcohol Spectrum Disorders. Alcohol Research : Current Reviews, 35, 18-24.

BALARAMAN, S., WINZER-SERHAN, U. H. & MIRANDA, R. C. 2012. Opposing actions of ethanol and nicotine on microRNAs are mediated by nicotinic acetylcholine receptors in fetal cerebral cortical-derived neural progenitor cells. Alcoholism, clinical and experimental research, 36, 1669-1677.

BYSTRON, I., BLAKEMORE, C. & RAKIC, P. 2008. Development of the human cerebral cortex: Boulder Committee revisited. Nature Reviews Neuroscience, 9, 110.

CAMARILLO, C., KUMAR, L. S., BAKE, S., SOHRABJI, F. & MIRANDA, R. C. 2007. Ethanol regulates angiogenic cytokines during neural development: Evidence from an in vitro model of mitogen-withdrawal induced cerebral cortical neuroepithelial differentiation. Alcoholism, clinical and experimental research, 31, 324-335.

CAMARILLO, C. & MIRANDA, R. C. 2008. Ethanol exposure during neurogenesis induces persistent effects on neural maturation: evidence from an ex vivo model of fetal cerebral cortical neuroepithelial progenitor maturation. Gene expression, 14, 159-171.

CHEEMA, Z. F., WEST, J. R. & MIRANDA, R. C. 2000. Ethanol induces Fas/Apo [apoptosis]-1 mRNA and cell suicide in the developing cerebral cortex. Alcohol Clin Exp Res, 24, 535-543.

EL ANDALOUSSI, S., MÄGER, I., BREAKEFIELD, X. O. & WOOD, M. J. A. 2013. Extracellular vesicles: biology and emerging therapeutic opportunities. Nature Reviews Drug Discovery, 12, 347.

H RASHED, M., BAYRAKTAR, E., G, K. H., ABD-ELLAH, M. F., AMERO, P., CHAVEZ-REYES, A. & RODRIGUEZ-AGUAYO, C. 2017. Exosomes: From Garbage Bins to Promising Therapeutic Targets. Int J Mol Sci, 18.

IRACI, N., LEONARDI, T., GESSLER, F., VEGA, B. & PLUCHINO, S. 2016. Focus on Extracellular Vesicles: Physiological Role and Signalling Properties of Extracellular Membrane Vesicles. International Journal of Molecular Sciences, 17, 171.

JANAS, A. M., SAPOŃ, K., JANAS, T., STOWELL, M. H. B. & JANAS, T. 2016. Exosomes and other extracellular vesicles in neural cells and neurodegenerative diseases. Biochimica et Biophysica Acta (BBA) - Biomembranes, 1858, 1139-1151.

KARLSEN, T. A., JAKOBSEN, R. B., MIKKELSEN, T. S. & BRINCHMANN, J. E. 2014. microRNA-140 targets RALA and regulates chondrogenic differentiation of human mesenchymal stem cells by translational enhancement of SOX9 and ACAN. Stem Cells Dev, 23, 290-304.

LI, T., LI, H., LI, T., FAN, J., ZHAO, R. C. & WENG, X. 2014. MicroRNA expression profile of dexamethasone-induced human bone marrow-derived mesenchymal stem cells during osteogenic differentiation. J Cell Biochem, 115, 1683-91.

MAIER, S. E., MILLER, J. A. & WEST, J. R. 1999. Prenatal binge-like alcohol exposure in the rat results in region-specific deficits in brain growth. Neurotoxicol Teratol, 21, 285-91.

MATHIVANAN, S., JI, H. & SIMPSON, R. J. 2010. Exosomes: Extracellular organelles important in intercellular communication. Journal of Proteomics, 73, 1907-1920.

MAY, P. A., CHAMBERS, C. D., KALBERG, W. O., ZELLNER, J., FELDMAN, H., BUCKLEY, D., KOPALD, D., HASKEN, J. M., XU, R., HONERKAMP-SMITH, G., TARAS, H., MANNING, M. A., ROBINSON, L. K., ADAM, M. P., ABDUL-RAHMAN, O., VAUX, K., JEWETT, T., ELLIOTT, A. J., KABLE, J. A., AKSHOOMOFF, N., FALK, D., ARROYO, J. A., HERELD, D., RILEY, E. P., CHARNESS, M. E., COLES, C. D., WARREN, K. R., JONES, K. L. & HOYME, H. E. 2018. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA, 319, 474-482. MILLER, M. 1989. Effects of prenatal exposure to ethanol on neocortical development: II. Cell proliferation in the ventricular and subventricular zones of the rat. The Journal of Comparative Neurology, 287 326-338.

MILLER, M. W. & NOWAKOWSKI, R. S. 1991. Effect of prenatal exposure to ethanol on the cell cycle kinetics and growth fraction in the proliferative zones of fetal rat cerebral cortex. Alcohol Clin Exp Res, 15, 229-32.

MIRANDA, R. C. 2014. MicroRNAs and ethanol toxicity. Int Rev Neurobiol, 115, 245-84.

MIRANDA, R. C., SANTILLANO, D. R., CAMARILLO, C. & DOHRMAN, D. 2008. Modeling the impact of alcohol on cortical development in a dish: strategies from mapping neural stem cell fate. Methods Mol Biol, 447, 151-68.

PAPPALARDO-CARTER, D. L., BALARAMAN, S., SATHYAN, P., CARTER, E. S., CHEN, W. J. & MIRANDA, R. C. 2013. Suppression and epigenetic regulation of MiR-9 contributes to ethanol teratology: evidence from zebrafish and murine fetal neural stem cell models. Alcohol Clin Exp Res, 37, 1657-67.

PEREGO, C., VANONI, C., BOSSI, M., MASSARI, S., BASUDEV, H., LONGHI, R. & PIETRINI, G. 2000. The GLT-1 and GLAST glutamate transporters are expressed on morphologically distinct astrocytes and regulated by neuronal activity in primary hippocampal cocultures. J Neurochem, 75, 1076-84.

PROCK, T. L. & MIRANDA, R. C. 2007. Embryonic Cerebral Cortical Progenitors Are Resistant to Apoptosis, but Increase Expression of Suicide Receptor DISC-complex Genes and Suppress Autophagy Following Ethanol Exposure. Alcoholism, clinical and experimental research, 31, 694-703.

RATAJCZAK, J., WYSOCZYNSKI, M., HAYEK, F., JANOWSKA-WIECZOREK, A. & RATAJCZAK, M. Z. 2006. Membrane-derived microvesicles: important and underappreciated mediators of cell-to-cell communication. Leukemia, 20, 1487-95.

ROOZEN, S., PETERS, G. J., KOK, G., TOWNEND, D., NIJHUIS, J. & CURFS, L. 2016. Worldwide Prevalence of Fetal Alcohol Spectrum Disorders: A Systematic Literature Review Including Meta-Analysis. Alcohol Clin Exp Res, 40, 18-32.

SALONE, V., HENRIONNET, C., BRANLANT, C., GILLET, P. & PINZANO, A. 2014. Both miRNA-29b downregulation and miRNA-140 overexpression drive respectively MSC proliferation and chondrogenic differentiation in collagen scaffold. Osteoarthritis and Cartilage, 22, S319-S320.

SANTILLANO, D. R., KUMAR, L. S., PROCK, T. L., CAMARILLO, C., TINGLING, J. D. & MIRANDA, R. C. 2005. Ethanol induces cell-cycle activity and reduces stem cell diversity to alter both regenerative capacity and differentiation potential of cerebral cortical neuroepithelial precursors. BMC Neuroscience, 6, 59-59.

SATHYAN, P., GOLDEN, H. B. & MIRANDA, R. C. 2007. Competing Interactions between Micro-RNAs Determine Neural Progenitor Survival and Proliferation after Ethanol Exposure: Evidence from an Ex Vivo Model of the Fetal Cerebral Cortical Neuroepithelium. The Journal of Neuroscience, 27, 8546.

SELVAMANI, A., WILLIAMS, M. H., MIRANDA, R. C. & SOHRABJI, F. 2014. Circulating miRNA profiles provide a biomarker for severity of stroke outcomes associated with age and sex in a rat model. Clin Sci (Lond), 127, 77-89.

TETTA, C., GHIGO, E., SILENGO, L., DEREGIBUS, M. C. & CAMUSSI, G. 2013. Extracellular vesicles as an emerging mechanism of cell-to-cell communication. Endocrine, 44, 11-9.

THERY, C., OSTROWSKI, M. & SEGURA, E. 2009. Membrane vesicles as conveyors of immune responses. Nat Rev Immunol, 9, 581-593.

THÉRY, C., ZITVOGEL, L. & AMIGORENA, S. 2002. Exosomes: composition, biogenesis and function. Nature Reviews Immunology, 2, 569.

TINGLING, J. D., BAKE, S., HOLGATE, R., RAWLINGS, J., NAGSUK, P. P., CHANDRASEKHARAN, J., SCHNEIDER, S. L. & MIRANDA, R. C. 2013. CD24 expression identifies teratogen-sensitive fetal neural stem cell subpopulations: evidence from developmental ethanol exposure and orthotopic cell transfer models. PLoS One, 8, e69560.

TSAI, P.-C., BAKE, S., BALARAMAN, S., RAWLINGS, J., HOLGATE, R. R., DUBOIS, D. & MIRANDA, R. C. 2014. MiR-153 targets the nuclear factor-1 family and protects against teratogenic effects of ethanol exposure in fetal neural stem cells. Biology Open, 3, 741-758.
YOSHIMURA, A., ADACHI, N., MATSUNO, H., KAWAMATA, M., YOSHIOKA, Y., KIKUCHI, H., ODAKA, H., NUMAKAWA, T., KUNUGI, H., OCHIYA, T. & TAMAI, Y. 2018. The Sox2 promoter-driven CD63-GFP transgenic rat model allows tracking of neural stem cell-derived extracellular vesicles. Disease Models & Mechanisms, 11, dmm028779.
ZHAN, C., MA, C. B., YUAN, H. M., CAO, B. Y. & ZHU, J. J. 2015. Macrophage-derived microvesicles promote proliferation and migration of Schwann cell on peripheral nerve repair. Biochem Biophys Res Commun, 468, 343-8.
ZHANG, J., LI, S., LI, L., LI, M., GUO, C., YAO, J. & MI, S. 2015. Exosome and Exosomal MicroRNA: Trafficking, Sorting, and Function. Genomics, Proteomics & Bioinformatics, 13, 17-24.

D5d Functional Connectivity in a Rat Model of FASD: A Pilot Study Using Resting State Functional MRI

Sandra Mooney

Learning Objectives

1. Review what functional magnetic resonance imaging is and what it tells us about brain functional connectivity
2. Recognize the effects of prenatal alcohol exposure has on cognitive behavior in a rodent model
3. Consider the effect of prenatal alcohol exposure has on brain functional connectivity in a rodent model

Cognition is defined as thinking, knowing, and/or perceiving. Cognitive ability is affected by many things including age, nutrition, and environmental factors. It can also be altered by fetal alcohol exposure; this is seen in humans with a Fetal Alcohol Spectrum Disorder (FASD) and is also modeled in animal studies. We found that prenatal exposure to a low dose of alcohol disrupts working (“short-term”) memory in adolescent animals and cognitive flexibility (the ability to change mental gears) in young adult rats. Two regions of the brain that are important for cognition are prefrontal cortex and striatum. We sought to examine whether prenatal alcohol exposure altered the connectivity between these parts of the brain.

Spontaneous brain activity occurs even when a person or animals is resting resulting in changes in the level of oxygen in the blood. Functional magnetic resonance imaging (fMRI) is a technique that uses an MRI scanner to measure the changes in blood oxygenation. When the signal fluctuations for two brain regions consistently occur at the same time, it is inferred that these regions are functionally connected. And the more closely the signals between the two regions map together, the stronger the connectivity is thought to be. Thus, resting state functional connectivity is a way to examine the functional organization of the brain. Task-driven fMRI is the functional connectivity that is measured while a person is performing a task; this can be looking at different images, hearing different sounds, or doing a test. In people with a FASD, task-driven fMRI shows that the frontal cortex is hyper-connected with the putamen (part of the striatum important for organization of movement) and is hypo-connected to the dorsal caudate (part of the striatum important for executive function).

In our study, we exposed rats to a low dose of alcohol during the prenatal period (3% ethanol in liquid diet, resulting in blood alcohol concentrations around 30 mg/dl), trained them on a working memory test during adolescence, tested them on a test of cognitive flexibility in young adulthood, then scanned them and collected resting state fMRI images. For functional connectivity analysis, a seed was placed in prefrontal cortex (which included both prelimbic cortex and anterior cingulate cortex).

Both male and female alcohol-exposed rats showed deficits in the working memory training and in the test of cognitive flexibility, however the effect was stronger in the males. Male, but not female, alcohol-exposed rats showed less functional connectivity between prefrontal cortex and dorsal striatum than control animals. In a follow-up study where the seed was placed in dorsal striatum there was less connectivity between it and the prefrontal cortex, orbitofrontal cortex, or cerebellum in males. But in females, connectivity between striatum and somatosensory cortex was lower. Prenatal alcohol exposure alters functional connectivity across brain regions. These alterations persist into adulthood and display both regional and sex-dependent differences. These findings may help explain the sex differences in behavior outcomes seen in animal models of FASD.

D6

Evidence Informed Guidelines for the Multidisciplinary Assessment of Preschoolers Prenatally Exposed to Alcohol

Ana Hanlon-Dearman, Kellsey Scheepers, Shelley Proven, Sandra Marles

Learning Objectives

1. Describe clinical outcomes of preschoolers with PAE seen at the MB FASD Centre
2. Recommend diagnostic assessments for preschoolers referred with PAE
3. Enhance the Canadian Guideline recommendations for domains predictive of FASD diagnosis in preschoolers

The recent Canadian FASD Diagnostic Guidelines (Cook et al 2015) describes the assessments recommended for individuals with prenatal alcohol exposure in various age groups. While a diagnostic team is recommended for infants and preschoolers, there are recognized challenges in the diagnostic assessment in the current guidelines. The interpretation of brain domains constituting global impairment in prescoolers is not well described in the literature and there has been broad clinical reluctance to consider the interpretation of clinical assessments as definitively diagnostic in this age group.

The Manitoba FASD Centre has been providing informed multidisciplinary assessments for infants and preschoolers with prenatal alcohol exposure since the late 1990s, and has been making diagnoses informed by research and experienced clinical judgment. A comprehensive language assessment and profile of preschoolers is evidence-based and informs diagnostic assessment using the Canadian Guidelines. It also facilitates early referral to speech and language pathology as well as strategies for early intervention. The development of an occupational profile is also critical in preschoolers for the purpose of an FASD assessment, diagnosis and early occupational therapy intervention.

Our research results show that standardized assessments of both motor and sensory domains are imperative to develop targeted interventions for preschoolers and contribute to a comprehensive understanding of motor based tasks, problem behaviours and social skills. A standardized assessment of motor and sensory processing skills, together with a comprehensive assessment of language are significant predictors of FASD diagnosis for preschoolers prenatally exposed to alcohol. Together with and global assessments of cognitive and behavioural measures, and applied with appropriate medical differential diagnosis, they specifically inform the diagnostic assessment of FASD in preschoolers.

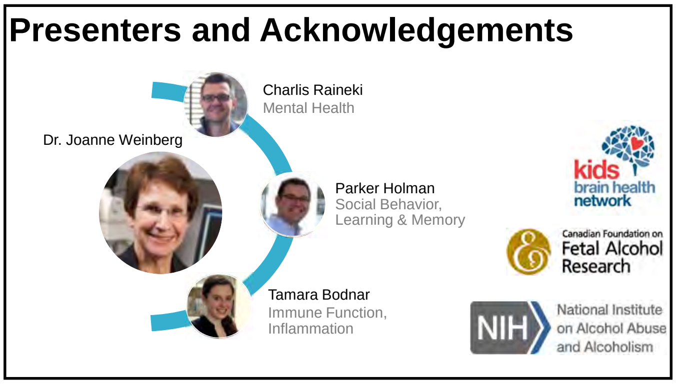
Over 15 years of multidisciplinary data of infant and preschool data has been analyzed to described observed patterns and make recommendations for preschool diagnostic guidelines. Multidisciplinary diagnostic team members will present these recommendations along with their clinical supporting evidence. Domains of clinical diagnostic significance will be presented with clinical scenarios for their application and discussion, for both children with and without dysmorphology.

D7 Modulatory Role of Postnatal Environment on the Effects of PAE: Risk vs. Resilience

Charlis Raineki, Parker J. Holman, Tamara Bodnar

D7 - Modulatory Role of Postnatal Environment on the Effects of PAE: Risk vs. Resilience

Charlis Raineki, PhD
Parker J. Holman, MS, MSEd
Tamara Bodnar, PhD



Presenters and Acknowledgements

Dr. Joanne Weinberg

Charlis Raineki
Mental Health

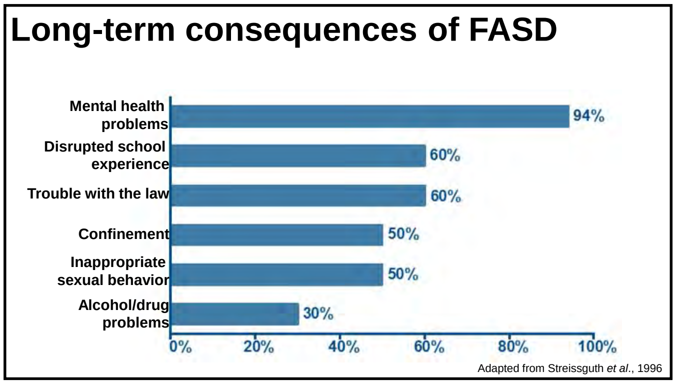
Parker Holman
Social Behavior, Learning & Memory

Tamara Bodnar
Immune Function, Inflammation

Learning Objectives

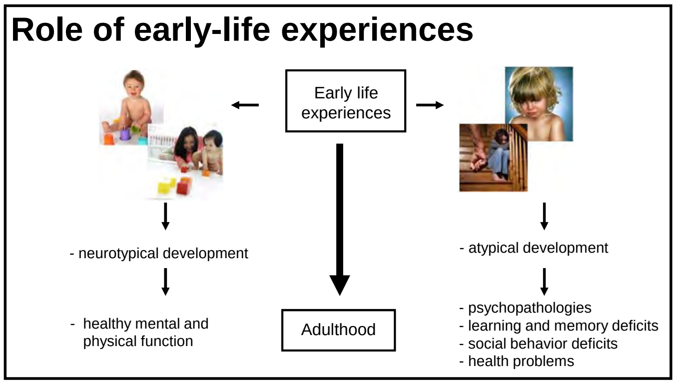
- *Gain an understanding of how early-life adversity impacts neurobehavioral development and in the context of PAE*
- *Discuss the impact of alterations in early life immune system development in shaping the response to immune challenge in adulthood, and the possible consequences for health across the life course*
- *Increasing the awareness of how critical the early postnatal environment is for shaping individual neurodevelopmental trajectories*
- *Discuss implications for cross-cutting intervention strategies and potential resiliency factors that may confer a protective advantage*

Long-term consequences of FASD



Adapted from Streissguth *et al.*, 1996

Role of early-life experiences



Early life experiences

- neurotypical development

- healthy mental and physical function

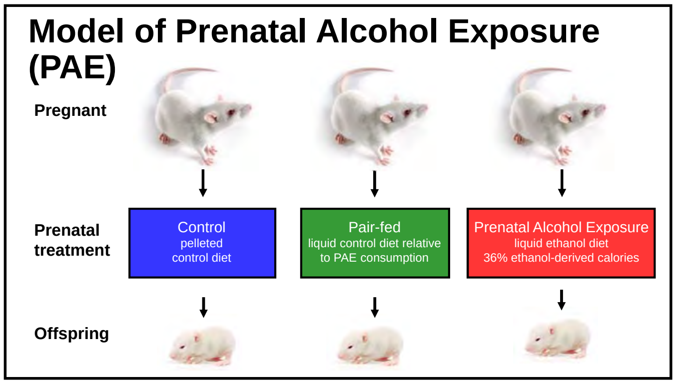
Adulthood

- atypical development

- psychopathologies
- learning and memory deficits
- social behavior deficits
- health problems

FASD and adversity exposure

- Individuals with FASD are at a higher risk of encountering more stressful environments throughout the lifespan
  - Placement in foster care
  - Unstable family environment



Model of Prenatal Alcohol Exposure (PAE)

Pregnant

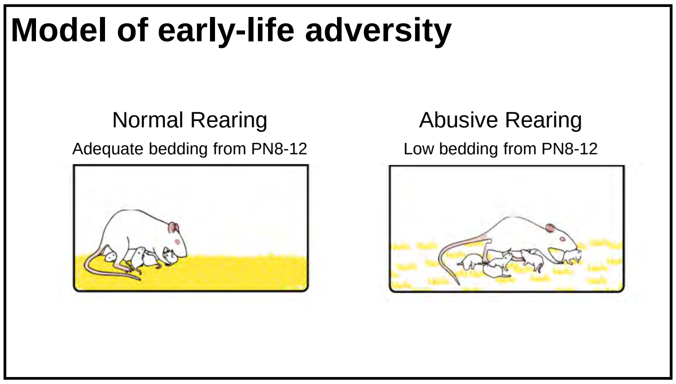
Prenatal treatment

Control
pelleted
control diet

Pair-fed
liquid control diet relative
to PAE consumption

Prenatal Alcohol Exposure
liquid ethanol diet
36% ethanol-derived calories

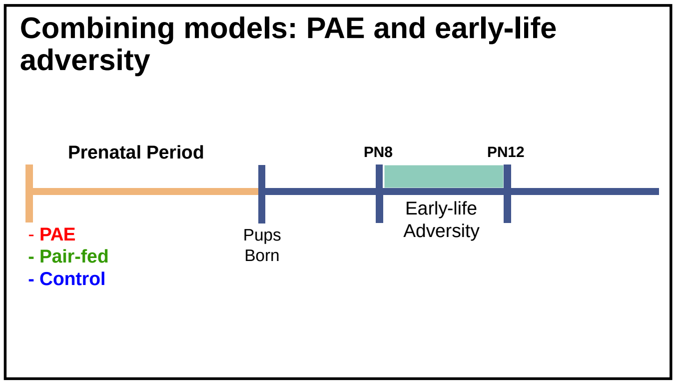
Offspring



Model of early-life adversity

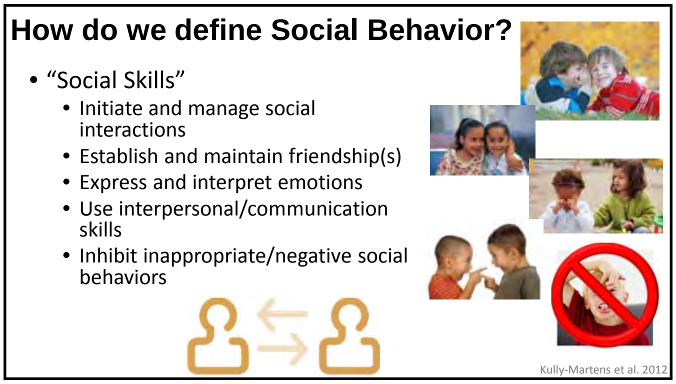
Normal Rearing
Adequate bedding from PN8-12

Abusive Rearing
Low bedding from PN8-12



Combining models: PAE and early-life adversity

- **PAE**
- **Pair-fed**
- **Control**



How do we define Social Behavior?

- "Social Skills"
  - Initiate and manage social interactions
  - Establish and maintain friendship(s)
  - Express and interpret emotions
  - Use interpersonal/communication skills
  - Inhibit inappropriate/negative social behaviors

Kully-Martens et al. 2012

Children with FASD show changes in social behaviors across development

Infancy	Periadolescence	Adolescence / Adulthood
• **Disruption in Mother-Infant Dyad** (O'Connor et al. 1992; 2006) • **Disrupted sleeping/feeding rhythms; Increased irritability** (Coles & Platzman 1993) • **Less "social monitoring" behaviors** (Jirikowic et al. 2016)	• **Low scores on social behavior assessments** (Thomas 1998; O'Connor et al. 2006; Regehr 2015; Stevens et al. 2015) • **Impulsivity** (McGee et al. 2008) • **High scores on "problem behavior" assessments** (Stevens et al. 2015)	• **Low scores on social behavior assessments** (Moore & Riley 2015) • **Increased risk for interactions with criminal justice system** (Streissguth et al. 1996; MacPherson & Chudly 2007)

For review, see Kelly, Day, & Streissguth 2000; Mattson, Crocker, & Nguyen 2011; Kully-Martens et al. 2012

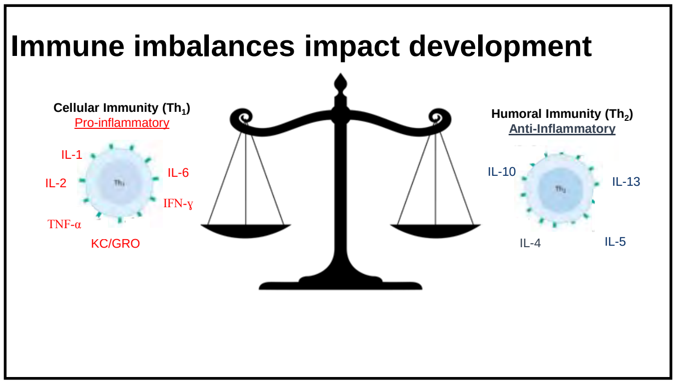
Immune function is altered following prenatal alcohol exposure

Human

- Increased susceptibility to infections
- Increased risk (15 fold) of early-life sepsis in very low-birth weight infants
- Increased rates of asthma, nasal airway inflammation, persistent skin rashes
- Decreased numbers of immune cells, impaired response to stimulation
- Increased incidence of cancers

Animal Models

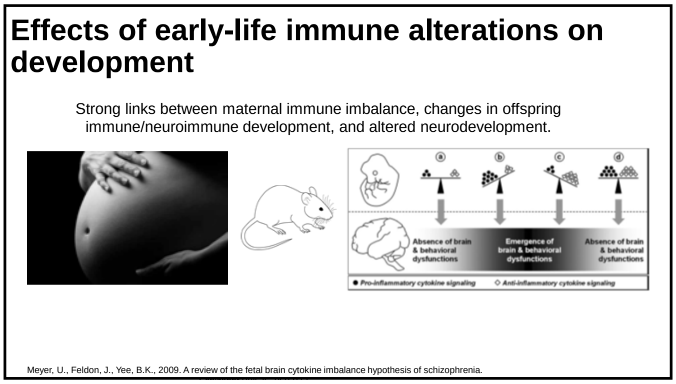
- Increased susceptibility to infections
- Deficits in adaptive immunity
- Impaired immune organ development (thymus)
- Deficits in development of immunological memory
- Increased susceptibility to cancers
- Deficits in lactational transfer of immunity (mother → offspring)



Immune imbalances impact development

Cellular Immunity (Th_1)
Pro-inflammatory

Humoral Immunity (Th_2)
Anti-Inflammatory



Effects of early-life immune alterations on development

Strong links between maternal immune imbalance, changes in offspring immune/neuroimmune development, and altered neurodevelopment.

Meyer, U., Feldon, J., Yee, B.K., 2009. A review of the fetal brain cytokine imbalance hypothesis of schizophrenia.

References

- Bodnar TS, Hill LA, Weinberg J (2016). Evidence for an immune signature of prenatal alcohol exposure in female rats. *Brain, Behavior, and Immunity*, 58: 130-141.
- Holman PJ, Ellis L, Morgan E, Weinberg J (2018). Prenatal alcohol exposure disrupts male adolescent social behavior and oxytocin receptor binding in rodents. *Hormones and Behavior*, 105: 115-127.
- Raineki C, Bodnar TS, Holman PJ, Baglot SL, Lan N, Weinberg J (2017). Effects of early-life adversity on immune function are mediated by prenatal environment: Role of prenatal alcohol exposure. *Brain, Behavior, and Immunity*, 66: 210-220.
- Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics* 25: 228-238.

D8/C8

Is Iron Deficiency Impeding Personalized and/or Precision Medicine in Individuals with FASD? Ways out of the Iron Conundrum (Continued)

James Connor, Alison Frieling, Osman Ipsiroglu, Mansfield Mela, Beth Potter, Alexandra Rauscher

Moderated by: Dorothy Reid, Christine Loock, Lori Vitale Cox

Please see page 222 for more information on this session.

D9 Increasing Healthcare Providers' Knowledge in the Prevention of Alcohol-Exposed Pregnancies and Identification and Care of Individuals with FASD: Development and Promotion of a Website and Online Training Courses

Catherine Hutsell, Kathleen T. Mitchell, Tonya McFadden, Alexandra Edwards

Learning Objectives

1. Describe a collaboration among healthcare provider organizations and partners to develop a website and online courses to increase providers' knowledge and practices around the prevention of AEPs and identification and care of individuals with FASDs
2. Discuss facilitators and barriers to promotion and uptake of the website and online courses
3. Describe how to navigate the Collaborative for Alcohol-Free Pregnancy FASD training website and online courses

Background

Healthcare professionals play a crucial role in the prevention of AEPs and identification and care of individuals with FASDs. Prior to 2014, CDC funded awardees to develop and implement training courses on various aspects of FASDs for US medical and allied-health students and practitioners. These were in-person courses with limited reach. A key suggestion from an independent expert panel review of CDC's FASD program conducted in 2013 was to develop a website and online training courses that are available nationwide and thus have greater national reach with target audiences to promote practice change.

Methods

To support this broader reach, in 2014, CDC funded U.S. healthcare provider organizations, partners across six disciplines (family medicine, medical assisting, nursing, obstetrics-gynecology, pediatrics, and social work) and the National Organization on Fetal Alcohol Syndrome to collaborate in the development of a training website and online courses with consistent, science-based messages about the prevention of AEPs and identification and care of individuals with FASDs. An Online Training and Website Development Workgroup of awardee representatives was formed to facilitate this collaboration. The group identified five training courses needed across their disciplines. A subgroup of representatives provided design input and resources for inclusion on the website and additional subgroups for each of the online courses identified individual course goal(s), learning objectives, and content. Awardees also identified healthcare providers from their respective disciplines to pilot test the courses in partial fulfillment of requirements for continuing education, and implemented multiple strategies to promote the website and courses.

Results

Input from awardees representing the six targeted healthcare disciplines ensured the resources, content, and science-based messages were relevant and provided in an easily accessible format. Promotional efforts by awardees included development and support of champion networks to promote the website and courses, and required completion of online courses before attendance at in-person trainings. Preliminary feedback from awardees and course participants indicates satisfaction with the courses, and intention to change practice behavior when relevant. Challenges experienced in getting providers to complete courses include competing priorities in time and interest, and not understanding their role in the prevention of AEPs and identification and care of individuals with FASDs.

Conclusions

Collaboration with awardees representing the targeted healthcare disciplines and their partners facilitated development of consistent, science-based content across multiple disciplines. Collaboration also allowed awardees to focus more time and resources on other activities to support practice change in the prevention of AEPs and identification and care of individuals with FASDs.

Plenary

Prenatal Alcohol Exposure and Sleep

Sarah M. Inkelis

Learning Objectives

1. Explore the evidence base for sleep disturbance in clinical and preclinical models of prenatal alcohol exposure
2. Identify research methods for studying sleep in humans
3. Consider the neurobehavioral correlates of sleep disruption, and how this may relate to the neurobehavioral profile of individuals with prenatal alcohol exposure

Introduction

Children with prenatal alcohol exposure (PAE) suffer from a multitude of problems, including cognitive and behavioral impairments that impact quality of life into adulthood1. These impairments are associated with adaptive dysfunction, academic difficulties and psychopathology: factors that negatively impact quality of life as well as caregiver and family function. Some of these behavioral and cognitive alterations may be exacerbated by additional factors, such as trouble sleeping. Caregivers of children with fetal alcohol spectrum disorders (FASD) often report that their child has problems with sleep, and poor sleep quality is associated with PAE2. The limited literature indicates that PAE is associated with fragmented sleep, increased levels of arousals from sleep, mild sleep disordered breathing, and melatonin secretion abnormalities3,4. In typically developing populations, sleep difficulties are related to neurobehavioral deficits that are consistent with dysfunction of the prefrontal cortex, as well as hyperactive behaviors and mood disturbances5,6. Moreover, lack of sleep is also associated with obesity, cardiovascular disease, stress, and inflammation7. Thus, sleep disturbance is a clinically relevant issue that deserves further exploration in the FASD population.

Measurement of Sleep

Prevalence rates for pediatric sleep disorders in the general population are estimated to be between 28 and 36%8, though the rate of this problem in children with PAE is unknown. Sleep is important to early neurodevelopment, and on average, children spend more time asleep during the first five years of life than in all other waking activities combined9. Similar to adults, children exhibit two types of sleep that cycle multiple times throughout the night: rapid eye movement (REM) sleep, and non-REM (NREM) sleep. NREM sleep is further divided into three different stages (i.e., N1, N2, N3). These stages are defined by measures of brain activity, eye movements, and muscle tone, and typically follow a 90-minute cycle that repeats several times per night10. Polysomnography is considered the gold-standard of sleep measurement, and uses electroencephalography (EEG) to monitor the electrophysiological activity of the brain during sleep. Electrodes placed on the scalp and body obtain measures of brain activation, eye movements, muscle activity, and heart rate. The combination of these measures is used to classify the polysomnographic recording into the various stages of sleep10. Actigraphy is another validated method for studying sleep, and uses a small accelerometer to detect movement. Movement data are sampled over several days or weeks, providing a measure of activity and rest, and thus, a proxy for sleep and wake parameters (e.g., sleep onset latency, total sleep time, percent of time spent asleep, total wake time, percent of time spent awake, number of awakenings)11. Because actigraphy is used in a person's natural environment over an extended period of time (versus one night of polysomnography), it is considered a more ecologically valid measure of sleep, and can be useful for studying sleep in populations for whom polysomnography would be impractical12.

Prenatal Alcohol Exposure and Sleep

Maternal alcohol intake disrupts fetal sleep-wake cycles and breathing movements as early as week 37 of gestation13, and is also associated with sleep fragmentation (i.e., brief awakenings that occur during sleep) in infants14. Most published studies have described sleep and circadian disturbances in infants with FASD, demonstrating that those exposed to alcohol prenatally exhibit more sleep problems, disrupted sleep state cycle length, and abnormal EEG patterns15,16. Although data are limited, caregivers of children with FASD continue to report sleep problems beyond infancy2, including problems with falling asleep, sleep duration, night wakings, bedtime resistance, sleep anxiety, and parasomnias (i.e., bedwetting, sleep talking, and night terrors), at a higher rate than controls2,3. Objective data obtained from limited (n = 5, n = 36)3,4 polysomnography studies indicate children with FASD have decreased sleep efficiency, increased sleep fragmentation, mild sleep disordered breathing, and abnormal melatonin secretion3,4. Prenatal alcohol exposure is also associated with significantly longer sleep onset latency and shorter sleep duration, as measured by actigraphy2,17. Furthermore, animal models show that alcohol exposure in utero disrupts sleep-wake behavior and negatively affects circadian rhythm2,18,19,20, suggesting that altered circadian rhythmicity and sleep disruption are a primary consequence of developmental alcohol exposure.

Sleep and Neurobehavioral Function

Sleep disturbance is related to poorer performance in domains that reflect functioning of the prefrontal cortex, and is also associated with hyperactive behaviors and mood disturbances. These cognitive and behavioral problems mirror many of the neurobehavioral characteristics associated with PAE, such as poor executive functioning, inattention, and behavioral and mood dysregulation. Sleep fragmentation in particular, which reduces time spent in the deeper, restorative stages of sleep21, is associated with increased daytime sleepiness and a pattern of cognitive deficits consistent with dysfunction of the prefrontal cortex5,6,22. It has also been suggested that sleep disturbances diminish an individual's ability to regulate emotion and behavior9,23. In children, sleep-related impairment is often acted out rather than expressed verbally, and poor sleepers have a greater prevalence of behavior problems21, including hyperactivity, impulsivity, and aggression24. Furthermore, insomnia is a core symptom of depression, and sleep fragmentation is also associated with changes in mood, particularly increased negative mood and feeling more depressed25. Additionally, sleep problems in early childhood are predictive of early onset alcohol, marijuana, and other drug use26**.**

Clinical Implications for FASD

It is possible that sleep problems may also contribute to or exacerbate the effects of PAE on cognition, behavior, and health. Sleep disturbance has been reported to be as high as 86% in children with other neurodevelopmental disorders, such as autism spectrum disorder (ASD), Down syndrome, and ADHD27, and others have reported that the effects of sleep disturbance are more severe in these populations28. Many of the symptoms of sleep deprivation manifest in behavioral patterns seen in those of FASD, particularly inattention and mood disturbance29,30. Unfortunately, sleep disorders often go undiagnosed and untreated in children with FASD31. This has resulted in an over-reliance on pharmaceutical interventions, particularly for treatment of ADHD, without formal assessment of sleep disorder as a potential alternative etiology31. Furthermore, the effectiveness of other interventions delivered to individuals with FASD may be markedly reduced when sleep disturbance is present32. The prevalence of sleep disturbance in the FASD population is still unknown, but its effects have the potential to be wide-ranging. Therefore, elucidating the characteristics of sleep problems in these individuals is critically important to further understanding factors that influence executive dysfunction, inattention, and other behavioral problems in FASD.

References

Spohr, H. L., Willms, J., & Steinhausen, H. C. (2007). Fetal alcohol spectrum disorders in young adulthood. J Pediatr, 150(2), 175-179, 179 e171. doi:10.1016/j.jpeds.2006.11.044

Wengel, T., Hanlon-Dearman, A. C., & Fjeldsted, B. (2011). Sleep and sensory characteristics in young children with fetal alcohol spectrum disorder. J Dev Behav Pediatr, 32(5), 384-392. doi:10.1097/DBP.0b013e3182199694

Chen, M. L., Olson, H. C., Picciano, J. F., Starr, J. R., & Owens, J. (2012). Sleep problems in children with fetal alcohol spectrum disorders. J Clin Sleep Med, 8(4), 421-429. doi:10.5664/jcsm.2038

Goril, S., Zalai, D., Scott, L., & Shapiro, C. M. (2016). Sleep and melatonin secretion abnormalities in children and adolescents with fetal alcohol spectrum disorders. Sleep Medicine, 23, 59-64. doi:10.1016/j.sleep.2016.06.002

Kheirandish, L., & Gozal, D. (2006). Neurocognitive dysfunction in children with sleep disorders. Dev Sci, 9(4), 388-399. doi:10.1111/j.1467-7687.2006.00504.x

Gozal, D., O'Brien, L., & Row, B. W. (2004). Consequences of snoring and sleep disordered breathing in children. Pediatr Pulmonol Suppl, 26, 166-168.

Mullington, J. M., Haack, M., Toth, M., Serrador, J. M., & Meier-Ewert, H. K. (2009). Cardiovascular, inflammatory, and metabolic consequences of sleep deprivation. Prog Cardiovasc Dis, 51(4), 294-302. doi:10.1016/j.pcad.2008.10.003

Meltzer, L. J., Plaufcan, M. R., Thomas, J. H., & Mindell, J. A. (2014). Sleep problems and sleep disorders in pediatric primary care: treatment recommendations, persistence, and health care utilization. J Clin Sleep Med, 10(4), 421-426. doi:10.5664/jcsm.3620

Dahl, R. E. (1996). The impact of inadequate sleep on children's daytime cognitive function. Semin Pediatr Neurol, 3(1), 44-50.

Iber, C., Ancoli-Israel, S., Chessonn, A., & Quan, S. (2007). The AASM manual for the scoring of sleep and associated events: rules, terminology and technical specifications (1st ed.). Westchester Illinois: American Academy of Sleep Medicine.

Ancoli-Israel, S., Cole, R., Alessi, C., Chambers, M., Moorcroft, W., & Pollak, C. P. (2003). The role of actigraphy in the study of sleep and circadian rhythms. Sleep, 26(3), 342-392.

Morgenthaler, T., Alessi, C., Friedman, L., Owens, J., Kapur, V., Boehlecke, B., . . . American Academy of Sleep, M. (2007). Practice parameters for the use of actigraphy in the assessment of sleep and sleep disorders: an update for 2007. Sleep, 30(4), 519-529.

Mulder, E. J., Morssink, L. P., van der Schee, T., & Visser, G. H. (1998). Acute maternal alcohol consumption disrupts behavioral state organization in the near-term fetus. Pediatr Res, 44(5), 774-779. doi:10.1203/00006450-199811000-00022

Troese, M., Fukumizu, M., Sallinen, B. J., Gilles, A. A., Wellman, J. D., Paul, J. A., . . . Hayes, M. J. (2008). Sleep fragmentation and evidence for sleep debt in alcohol-exposed infants. Early Hum Dev, 84(9), 577-585. doi:10.1016/j.earlhumdev.2008.02.001

Scher, M. S., Richardson, G. A., & Day, N. L. (2000). Effects of prenatal cocaine/crack and other drug exposure on electroencephalographic sleep studies at birth and one year. Pediatrics, 105(1 Pt 1), 39-48.

Inkelis, S. M., & Thomas, J. D. (2018). Sleep in Infants and Children with Prenatal Alcohol Exposure. Alcohol Clin Exp Res. doi:10.1111/acer.13803

Pesonen, A. K., Raikkonen, K., Matthews, K., Heinonen, K., Paavonen, J. E., Lahti, J., . . . Strandberg, T. (2009). Prenatal origins of poor sleep in children. Sleep, 32(8), 1086-1092.

Earnest, D. J., Chen, W. J., & West, J. R. (2001). Developmental alcohol and circadian clock function. Alcohol Res Health, 25(2), 136-140.

Sakata-Haga, H., Dominguez, H. D., Sei, H., Fukui, Y., Riley, E. P., & Thomas, J. D. (2006). Alterations in circadian rhythm phase shifting ability in rats following ethanol exposure during the third trimester brain growth spurt. Alcohol Clin Exp Res, 30(5), 899-907. doi:10.1111/j.1530-0277.2006.00105.x

Hilakivi, L. (1986). Effects of prenatal alcohol exposure on neonatal sleep-wake behaviour and adult alcohol consumption in rats. Acta Pharmacol Toxicol (Copenh), 59(1), 36-42.

Sadeh, A., Gruber, R., & Raviv, A. (2002). Sleep, neurobehavioral functioning, and behavior problems in school-age children. Child Dev, 73(2), 405-417.

Beebe, D. W. (2006). Neurobehavioral morbidity associated with disordered breathing during sleep in children: a comprehensive review. Sleep, 29(9), 1115-1134.

Wolfson, A. R., & Carskadon, M. A. (1998). Sleep schedules and daytime functioning in adolescents. Child Dev, 69(4), 875-887.

Owens, J. A. (2009). Neurocognitive and behavioral impact of sleep disordered breathing in children. Pediatr Pulmonol, 44(5), 417-422. doi:10.1002/ppul.20981

Stepanski, E. J. (2002). The effect of sleep fragmentation on daytime function. Sleep, 25(3), 268-276.

Wong, M. M., Brower, K. J., Fitzgerald, H. E., & Zucker, R. A. (2004). Sleep problems in early childhood and early onset of alcohol and other drug use in adolescence. Alcohol Clin Exp Res, 28(4), 578-587.

Robinson-Shelton, A., & Malow, B. A. (2016). Sleep Disturbances in Neurodevelopmental Disorders. Curr Psychiatry Rep, 18(1), 6. doi:10.1007/s11920-015-0638-1

Ingrassia, A., & Turk, J. (2005). The use of clonidine for severe and intractable sleep problems in children with neurodevelopmental disorders--a case series. Eur Child Adolesc Psychiatry, 14(1), 34-40. doi:10.1007/s00787-005-0424-4

Chervin, R. D., Hedger, K., Dillon, J. E., & Pituch, K. J. (2000). Pediatric sleep questionnaire (PSQ): validity and reliability of scales for sleep-disordered breathing, snoring, sleepiness, and behavioral problems. Sleep Med, 1(1), 21-32.

Mattson, S. N., Crocker, N., & Nguyen, T. T. (2011). Fetal alcohol spectrum disorders: neuropsychological and behavioral features. Neuropsychol Rev, 21(2), 81-101. doi:10.1007/s11065-011-9167-9

Ipsiroglu, O. S., McKellin, W. H., Carey, N., & Loock, C. (2013). “They silently live in terror...” why sleep problems and night-time related quality-of-life are missed in children with a fetal alcohol spectrum disorder. Soc Sci Med, 79, 76-83. doi:10.1016/j.socscimed.2012.10.027

Jan, J. E., Asante, K. O., Conry, J. L., Fast, D. K., Bax, M. C., Ipsiroglu, O. S., . . . Wasdell, M. B. (2010). Sleep Health Issues for Children with FASD: Clinical Considerations. Int J Pediatr, 2010. doi:10.1155/2010/639048

Plenary

The Golden Tie - Understanding and Supporting Healthy Sleep in FASD

Ana Hanlon Dearman

Learning Objectives

1. Characterize the range of sleep difficulties in individuals with FASD by linking research and clinical information to the biology of sleep and FASD
2. Discuss the impact of disordered sleep on individual and family functioning
3. Describe an evidence informed and rational approach to the sleep related concerns with specific recommendations for families and care providers

E1a

YOUNG INVESTIGATOR

Mental Health and Service use Among Adolescents and Young Adults with FASD

Allison McNeil

Learning Objectives

1. Describe the development of mental health from early adolescence into young adulthood among individuals with FASD
2. Describe service use patterns among individuals with FASD and their family members during early adolescence and into young adulthood
3. Explore the relationships between mental health development and service use among individuals with FASD
4. Consider appropriate intervention components for adolescents and young adults with FASD

Background

The transition from early adolescence into adulthood is a challenging time, often accompanied by a desire for independence. For individuals with FASD, this transition is frequently complicated by mental health problems. As such, service use (e.g., medical/educational supports) among this population is high. Although researchers agree that mental health challenges are common among this population, surprisingly little is known about the development of mental health during this crucial transition. Additionally, despite high rates of services accessed, the impact of these services on later mental health has not yet been explored. Understanding mental health development and how service use impacts later mental health is an important step to better supporting individuals with FASD. The following research questions were explored: What is the developmental trajectory of mental health from early adolescence into young adulthood among individuals with FASD? Does service use (i.e., educational, medical, social, mental health) intensity among individuals with FASD and their family members change from early adolescence into young adulthood?

Methods:

Individuals previously diagnosed with FASD (n = 16) were assessed at time one (M age = 13 years) and again at time two (M age = 18.1). During both assessments, caregivers and individuals with FASD completed the Beahviour Assessment System for Children (BASC-2). Caregivers additionally participated in a semi-structured interview exploring services used by the participants and their families.

Results:

Results suggest that mental health development remains stable from early adolescence into young adulthood. However, differences in the severity of symptoms were reported; caregivers reported clinically elevated concerns while individuals with FASD reported average concerns (compared to the norm). Service use across both time points remained high and stable (MT1 = 10.5; MT2 = 11.4)

Conclusion:

Mental health development during the transition from adolescence into young adulthood among individuals with FASD appears to remain stable. Additionally, during this transition, these individuals and their family members report accessing a high number of services such as counselling support and medication. Although stable, significant mental health concerns continue to be reported by caregivers despite access to a number of interventions and supports. Notably, these same concerns are not reported by the individuals with FASD themselves. Results shed light on the need to develop increasingly tailored mental health interventions for this population, particularly during the transition into adulthood. Finally, the inclusion of psycho-education around mental health and healthy functioning for adolescents with FASD may help foster self-awareness and reduce the stigma surrounding FASD and mental health concerns.

E1b The Life Situation of Young People with Prenatal Substance Exposure. ADEF Helsinki – Research Project (Alcohol and/or Drug Exposure During Fetal Life)

Niina-Maria Nissinen

Learning Objectives

1. Identify the basics of register-data research
2. Indicate how register data can be used in research investigating the long-term effects of prenatal substance exposure
3. Summarize the effects of out-of-home placement on the developmental outcomes among young people with and without substance exposure

Overview of the presentation

In the presentation titled as “The life situation of adolescents and young adults with prenatal substance exposure”, I will present the results of ADEF Helsinki (alcohol and/or drug expo-sure during fetal life) research project, which will be published later in two articles. The first study focuses on the life situation, and the second on mental and behavioural disorders in adolescents and young adults with prenatal substance exposure. The results are compared to unexposed matched controls**.**

ADEF Helsinki research project

Aim:

ADEF Helsinki (Alcohol and/or Drug Exposure during Fetal life) research project is a longitudinal register-based case-control cohort study. The overall aim of ADEF Helsinki is to investigate the overall developmental outcomes (life situation, malformations, somatic health, mental and behavioural disorders, parity and pregnancies, use of medication, rehabilitation) of adolescents and young adults with prenatal substance exposure. Additionally, the aim is to investigate the effects of dual exposure to substances and traumatic experiences (caused by out-of-home-care, and mother’s stressful life situation, morbidity) on the developmental outcomes.

Data:

Pregnant women with substance misuse were first identified at the maternity clinics of healthcare centres of the Helsinki metropolitan area by the community midwives. The identified pregnant women (n=524) were referred to the three special antenatal clinics (i.e. HAL clinics) at The Hospital District of Helsinki and Uusimaa (HUS) for pregnancy follow-up. These HAL clinics (abbreviation for illegal drugs, alcohol and drugs) are designed to meet the needs of substance misusing mothers and pregnant women. Pregnancies were followed up in multidisciplinary service settings, and follow-up visits were every 2-4 weeks. During the pregnancy follow-up information was collected on the background of the mother, pregnancy, substance use and delivery. Intensified support and easy access to addiction treatment and/or psychiatric care were offered.

The exposed group (i.e. cases) consists of children (n=615) born to these women in 1992-2001. Following the inclusion criteria, the control group consists of unexposed children (n=1787) born to women (n=1792) with no evidence of alcohol and/or substance misuse in any of the national registers at the beginning of the study. The mother-child control pairs were identified from the national registers and matched for maternal age, parity, the number of fe-tuses, the month of birth and the delivery hospital of the index child. Three controls were ob-tained for each case to ensure that enough controls are included in the analyses.

The clinical follow-up data collected of the case mothers were linked with register data from several mandatory national health and social welfare registers, including hospital discharge register, population census data, register of criminal records, and child welfare register, for instance. Similar register data was collected for the matched mother-child control pairs. Data linkages were done by using the unique identification number (coded in a concealed form af-ter the data linkages) assigned to each Finnish citizen at birth or migration. The follow-up is from birth until the end of 2016 or death.

The place of the research and the research team:

ADEF Helsinki research is carried out at the Folkhälsan Research Center in Helsinki, Finland. The principal investigator is Anne Kopo-nen (PhD, Adjunct Professor of Social Psychology). The research team also include Niina-Maria Nissinen (PhD student in health sciences and project coordinator of ADEF Helsinki project), professor Mika Gissler (PhD), Hanna Kahila (PhD, MD), Taisto Sarkola (Adjunct Professor, MD), and professor Ilona Autti-Rämö (MD).

Summary of the presentation

Aim:

The present study investigates the life situation of adolescents and young adults with prenatal substance exposure in terms of completed secondary education, troubles with the law, out-of-home placements, and the use of basic social benefits. Besides, the results of mental and behavioural disorders are presented.

Results:

The final study population consisted of cases (n=615) whose mothers were using substances (alcohol/illegal drugs) during pregnancy and controls (n=1787) whose mothers' did not have any evidence of substance use during pregnancy in any of the registers at the begin-ning of the follow-up. Of the cases, 50.7% were females compared to 48.3% of the controls. The mean follow-up time for cases was 18.8 years and 18.6 years for controls.

According to the mothers' self-estimates and the results from voluntary urine toxicology screening tests, nearly 55% of the cases were exposed prenatally to alcohol, approximately 40% to illegal drugs, and 14% to both alcohol and illegal drugs. However, these are only in-dicative estimates. Substance exposure (e.g. alcohol, illegal drugs, drugs, multiple substances) could be detected in each case.

The information of FASD diagnoses was obtained from the register of malformations, and 7.5% of the cases were diagnosed with FASD. Approximately 8.1% of the cases were diag-nosed with neonatal abstinence syndrome (NAS). Regarding other malformations, 3.6% of the cases were diagnosed with microcephaly, ~2% with thin upper lip, and ~2% with dysmorphic facial features.

The information regarding completed secondary education and the socioeconomic status was obtained from the population census data collected every year by Statistic Finland. Of those aged 16 or more (i.e. completed basic education), 25.2% of the cases and 33.2% of the con-trols had completed secondary education (p=0.002). Cases were more likely to have complet-ed a vocational training compared to controls (18.1% vs. 14.7%, respectively). Controls were more likely to have completed high school education compared to cases (17.8% vs. 6.9%, re-spectively) (p=0.000). Controls who have been placed in out-of-home care (OHC) at least once were less likely to have finished secondary education (p=0.000). No differences were found among cases who have OHC history. Regarding the socioeconomic status, long-term unemployment (i.e. unemployed more than 6 months) was slightly more common among cases than controls. Controls were more often categorized as students and self-employed/upper-level employees compared to cases (p=0.001).

Regarding out-of-home care (OHC), nearly 64% of the cases have been placed in OHC at least once compared to approximately 8% of the controls (p=0.000). Cases were younger at the first placements compared to controls (4.7 years vs. 9.6 years, respectively) (p=0.000), and the mean length of the custody was longer among cases than controls (8.9 years vs. 3.3 years, respectively) (p=0.000).

The information on the troubles with the law was obtained from the register of criminal rec-ords. Statistically significant differences were found between cases and controls, and between males and females. Nearly 10% of the case males had at least one mark in criminal record compared to ~1% of the control males (p=0.000). Less than 1% of the case and control fe-males had a mark in the criminal record (p=0.194). Small differences were observed in the mean number of crimes per person, and in the mean length of the sentence but the differences were not statistically significant. A majority of both cases and controls with a mark in the criminal record have been placed on OHC.

Statistically significant differences were also found in the use of basic social assistance, and cases and/or their family members were more likely to have received basic social assistance compared to controls (p=0.000). On average, cases have received basic social assistance for 2.8 years compared to 2.37 years among controls (p=0.004). A majority of both cases and con-trols who have receives basic social assistance, have been placed at least once in OHC.

The information on the diagnosed mental and behavioural disorders was obtained from the hospital discharge register including inpatient and outpatient visits. According to the results, 54.6% of the cases and 26.4% of the controls have received mental and/or behavioural disor-der related diagnosis (i.e. ICD10 categories F00-F99) from inpatient or outpatient clinic (p=0.000). Statistically significant differences in outpatient and inpatient visits due to the mental and behavioural disorders were found in nearly all subcategories of ICD10 F00-F99.

According to hospital admissions, cases had more inpatient and outpatient visits with atten-tion deficit hyperactive disorder (ADHD) diagnosis (ICD10 category F90) (p=0.000). Cases were also more likely to have prescribed ADHD medicines compared to controls (p=0.000).

The diagnosed mental and behavioural disorders were compared among cases and controls who were placed in OHC at least once. The OHC seems to increase the health care use due to diagnosed mental and behavioural disorders both among cases and controls and decreased the differences between them.

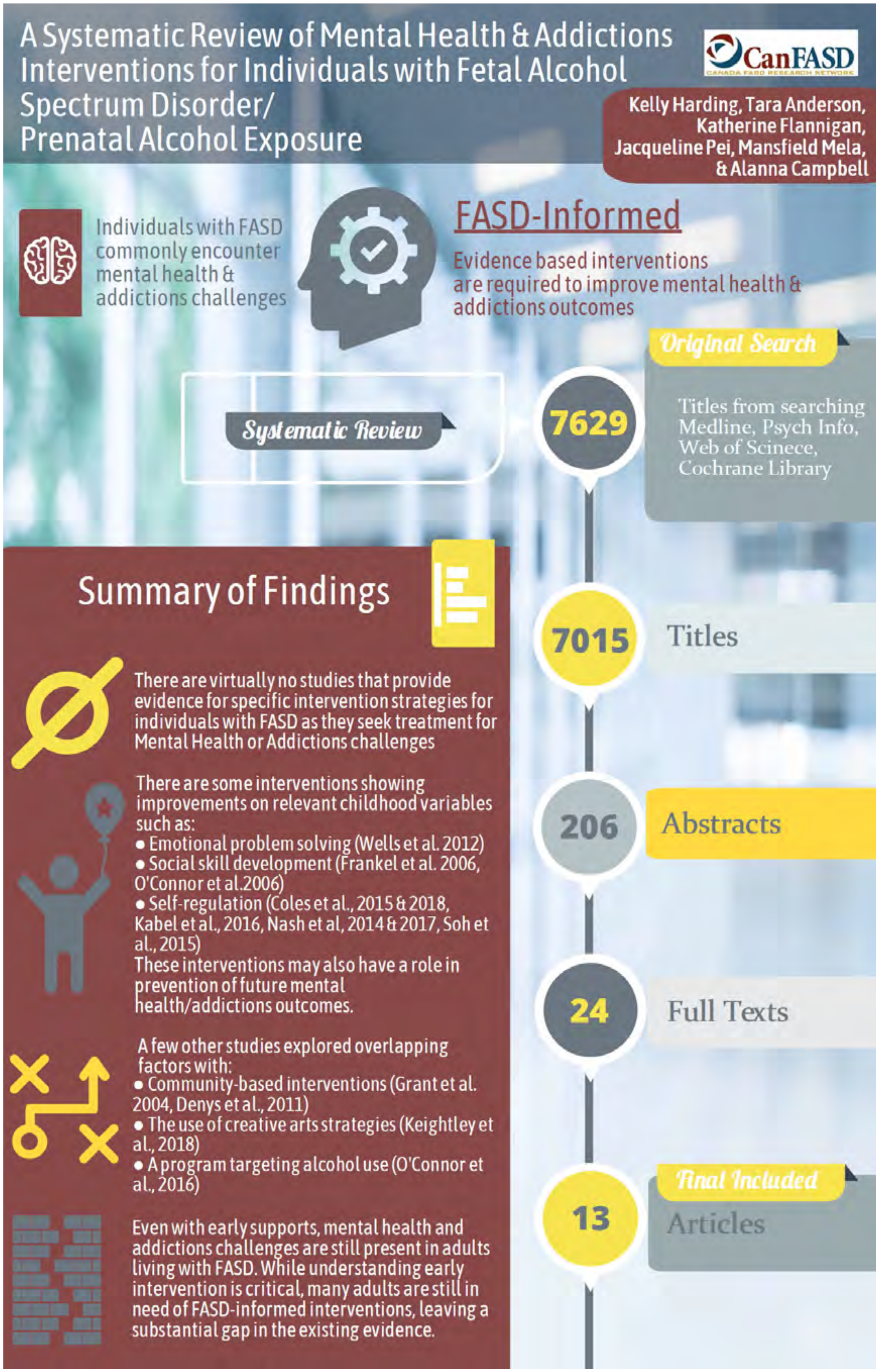
Conclusion:
In line with the previous studies, this study showed that the beginning of inde-pendent life was more difficult for adolescents and young adults with prenatal substance ex-posure compared to their unexposed matched dyads. Differences were seen in the completed secondary education and in the socioeconomic status but contrary to earlier studies, troubles with the law were not very common among exposed. Along with previous studies, the diag-nosed mental and behavioural disorders were more common among cases than controls. It is important to notice that among both cases and controls those with out-of-home placement history had the poorest outcomes.

ADEF Helsinki research project will continue investigating the use of healthcare services ac-cording to somatic diseases, the use of prescribed medicines, the substance abuse problems, abortions and births among cases and controls, and the use of rehabilitation services, for in-stance. The first study results have shown the importance of investigating the association with the caregiving environment, which will be further investigated at ADEF Helsinki research project.

E1c

A Systematic Review of Mental Health and Addictions Interventions for Individuals with FASD/PAE

Kelly Harding, Tara Anderson, Mansfield Mela, Jacqueline Pei



A Systematic Review of Mental Health & Addictions Interventions for Individuals with Fetal Alcohol Spectrum Disorder/ Prenatal Alcohol Exposure

CanFASD
CANADA FASD RESEARCH NETWORK

Kelly Harding, Tara Anderson, Katherine Flannigan, Jacqueline Pei, Mansfield Mela, & Alanna Campbell

Individuals with FASD commonly encounter mental health & addictions challenges

FASD-Informed

Evidence based interventions are required to improve mental health & addictions outcomes

Systematic Review

Original Search

7629 Titles from searching Medline, Psych Info, Web of Scinece, Cochrane Library

7015 Titles

206 Abstracts

24 Full Texts

Final Included

13 Articles

Summary of Findings

There are virtually no studies that provide evidence for specific intervention strategies for individuals with FASD as they seek treatment for Mental Health or Addictions challenges

There are some interventions showing improvements on relevant childhood variables such as:
- Emotional problem solving (Wells et al. 2012)
- Social skill development (Frankel et al. 2006, O'Connor et al.2006)
- Self-regulation (Coles et al., 2015 & 2018, Kabel et al., 2016, Nash et al, 2014 & 2017, Soh et al., 2015)

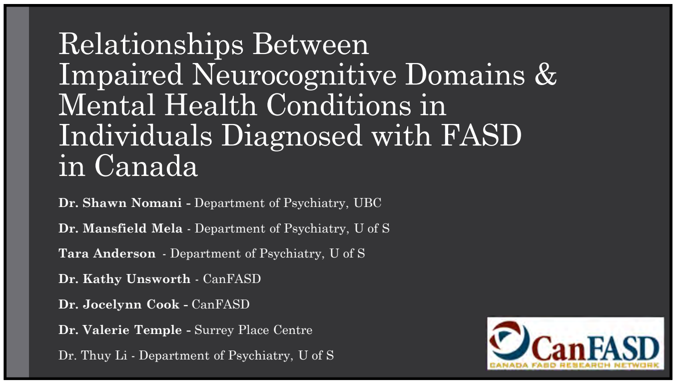
These interventions may also have a role in prevention of future mental health/addictions outcomes.

A few other studies explored overlapping factors with:
- Community-based interventions (Grant et al. 2004, Denys et al., 2011)
- The use of creative arts strategies (Keightley et al., 2018)
- A program targeting alcohol use (O'Connor et al., 2016)

Even with early supports, mental health and addictions challenges are still present in adults living with FASD. While understanding early intervention is critical, many adults are still in need of FASD-informed interventions, leaving a substantial gap in the existing evidence.

E1d Description of the Relationship Between Impaired Neurodevelopmental Brain Domains and Comorbid Mental Disorders in Individuals Diagnosed with FASD in Canada

Mansfield Mela, Shawn Nomani, Tara Anderson



Relationships Between Impaired Neurocognitive Domains & Mental Health Conditions in Individuals Diagnosed with FASD in Canada

Dr. Shawn Nomani - Department of Psychiatry, UBC

Dr. Mansfield Mela - Department of Psychiatry, U of S

Tara Anderson - Department of Psychiatry, U of S

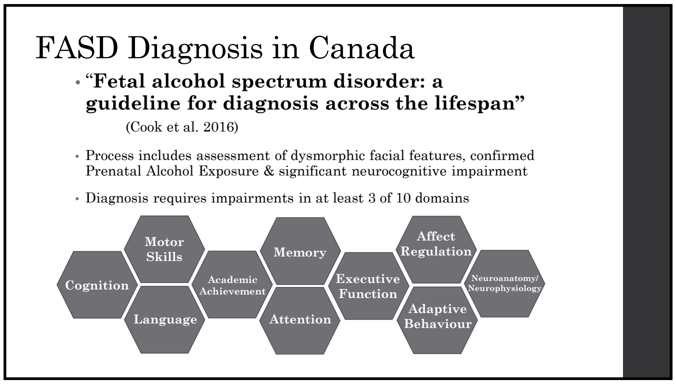
Dr. Kathy Unsworth - CanFASD

Dr. Jocelynn Cook - CanFASD

Dr. Valerie Temple - Surrey Place Centre

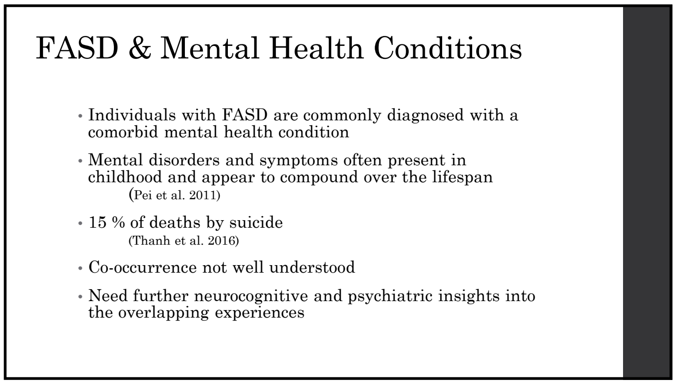
Dr. Thuy Li - Department of Psychiatry, U of S

CanFASD
CANADA FASD RESEARCH NETWORK



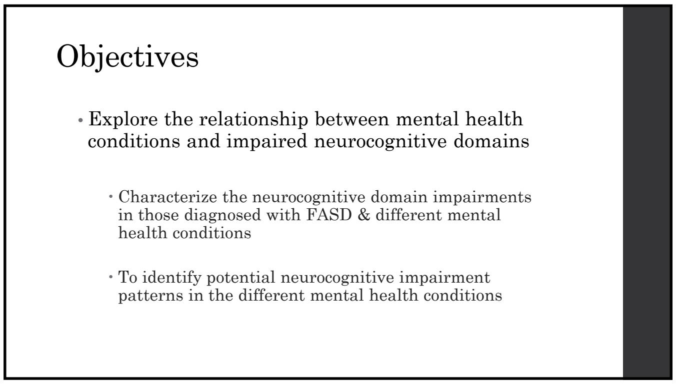
FASD Diagnosis in Canada

- **"Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan"**
  (Cook et al. 2016)
- Process includes assessment of dysmorphic facial features, confirmed Prenatal Alcohol Exposure & significant neurocognitive impairment
- Diagnosis requires impairments in at least 3 of 10 domains



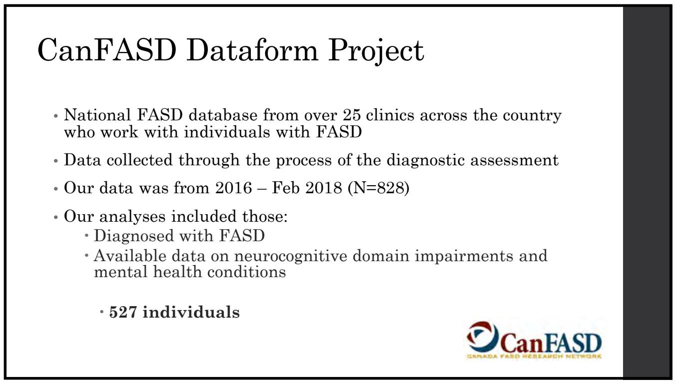
FASD & Mental Health Conditions

- Individuals with FASD are commonly diagnosed with a comorbid mental health condition
- Mental disorders and symptoms often present in childhood and appear to compound over the lifespan
  (Pei et al. 2011)
- 15 % of deaths by suicide
  (Thanh et al. 2016)
- Co-occurrence not well understood
- Need further neurocognitive and psychiatric insights into the overlapping experiences



Objectives

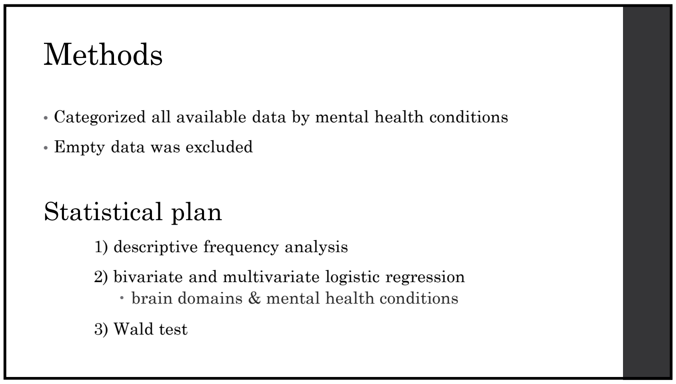
- Explore the relationship between mental health conditions and impaired neurocognitive domains
  - Characterize the neurocognitive domain impairments in those diagnosed with FASD & different mental health conditions
  - To identify potential neurocognitive impairment patterns in the different mental health conditions



CanFASD Dataform Project

- National FASD database from over 25 clinics across the country who work with individuals with FASD
- Data collected through the process of the diagnostic assessment
- Our data was from 2016 – Feb 2018 (N=828)
- Our analyses included those:
  - Diagnosed with FASD
  - Available data on neurocognitive domain impairments and mental health conditions
    - **527 individuals**

CanFASD
CANADA FASD RESEARCH NETWORK



Methods

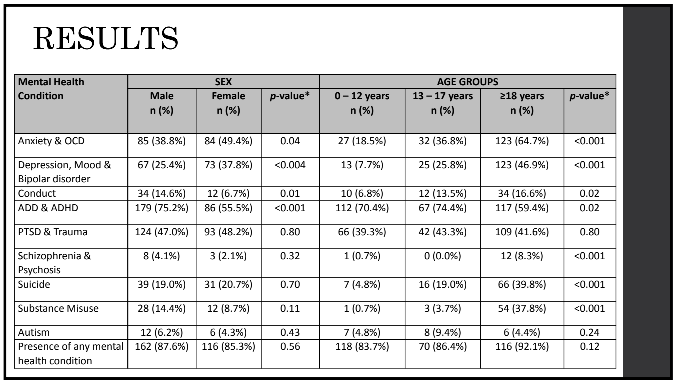
- Categorized all available data by mental health conditions
- Empty data was excluded

Statistical plan

1) descriptive frequency analysis

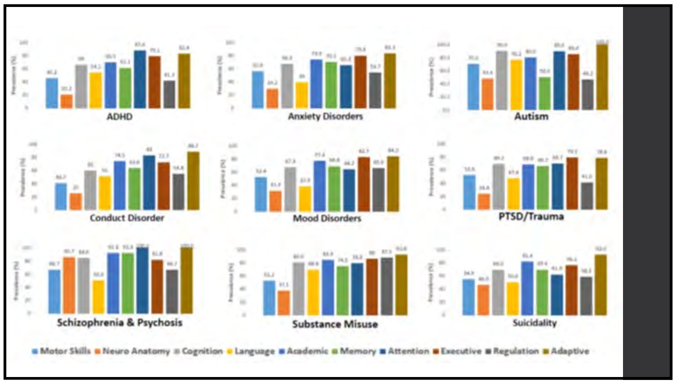
2) bivariate and multivariate logistic regression
  - brain domains & mental health conditions

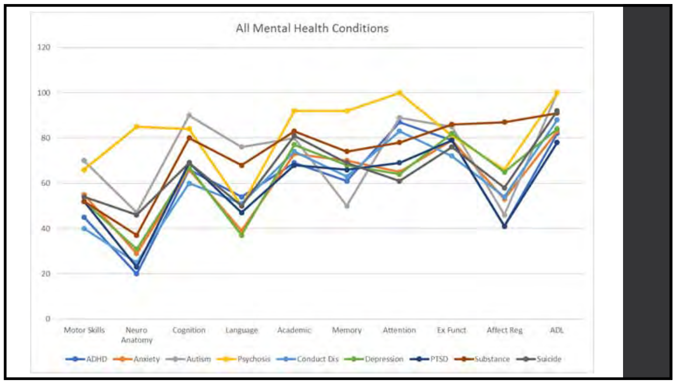
3) Wald test

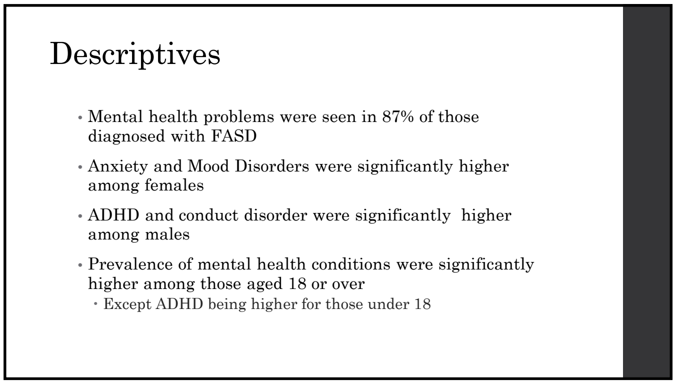


RESULTS

Mental Health Condition	SEX			AGE GROUPS			
	Male n (%)	Female n (%)	*p*-value*	0 – 12 years n (%)	13 – 17 years n (%)	≥18 years n (%)	*p*-value*
Anxiety & OCD	85 (38.8%)	84 (49.4%)	0.04	27 (18.5%)	32 (36.8%)	123 (64.7%)	<0.001
Depression, Mood & Bipolar disorder	67 (25.4%)	73 (37.8%)	<0.004	13 (7.7%)	25 (25.8%)	123 (46.9%)	<0.001
Conduct	34 (14.6%)	12 (6.7%)	0.01	10 (6.8%)	12 (13.5%)	34 (16.6%)	0.02
ADD & ADHD	179 (75.2%)	86 (55.5%)	<0.001	112 (70.4%)	67 (74.4%)	117 (59.4%)	0.02
PTSD & Trauma	124 (47.0%)	93 (48.2%)	0.80	66 (39.3%)	42 (43.3%)	109 (41.6%)	0.80
Schizophrenia & Psychosis	8 (4.1%)	3 (2.1%)	0.32	1 (0.7%)	0 (0.0%)	12 (8.3%)	<0.001
Suicide	39 (19.0%)	31 (20.7%)	0.70	7 (4.8%)	16 (19.0%)	66 (39.8%)	<0.001
Substance Misuse	28 (14.4%)	12 (8.7%)	0.11	1 (0.7%)	3 (3.7%)	54 (37.8%)	<0.001
Autism	12 (6.2%)	6 (4.3%)	0.43	7 (4.8%)	8 (9.4%)	6 (4.4%)	0.24
Presence of any mental health condition	162 (87.6%)	116 (85.3%)	0.56	118 (83.7%)	70 (86.4%)	116 (92.1%)	0.12

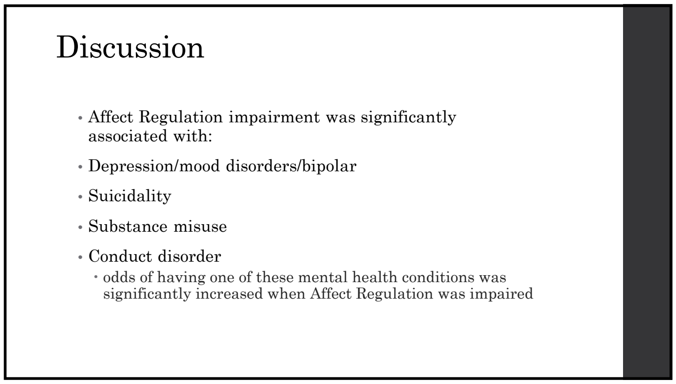






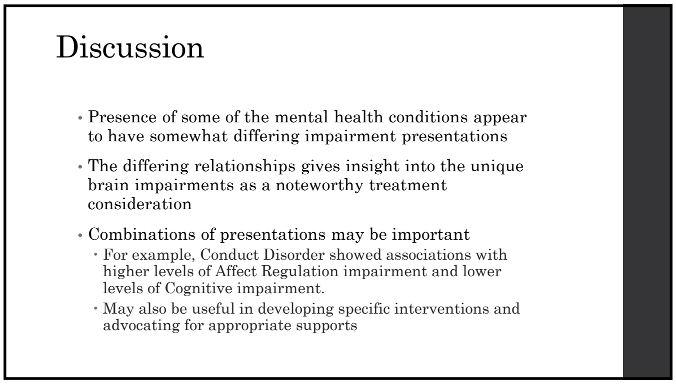
Descriptives

- Mental health problems were seen in 87% of those diagnosed with FASD
- Anxiety and Mood Disorders were significantly higher among females
- ADHD and conduct disorder were significantly higher among males
- Prevalence of mental health conditions were significantly higher among those aged 18 or over
  - Except ADHD being higher for those under 18



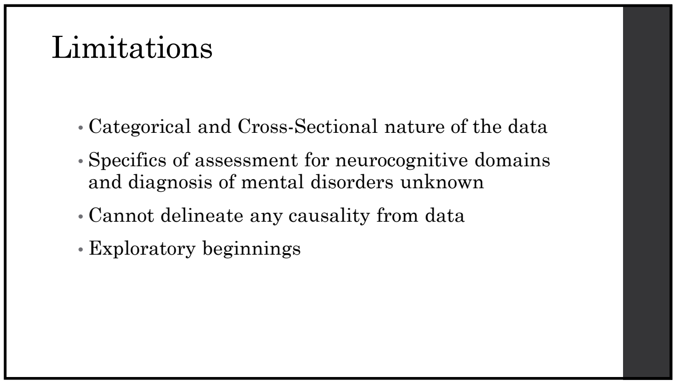
Discussion

- Affect Regulation impairment was significantly associated with:
- Depression/mood disorders/bipolar
- Suicidality
- Substance misuse
- Conduct disorder
  - odds of having one of these mental health conditions was significantly increased when Affect Regulation was impaired



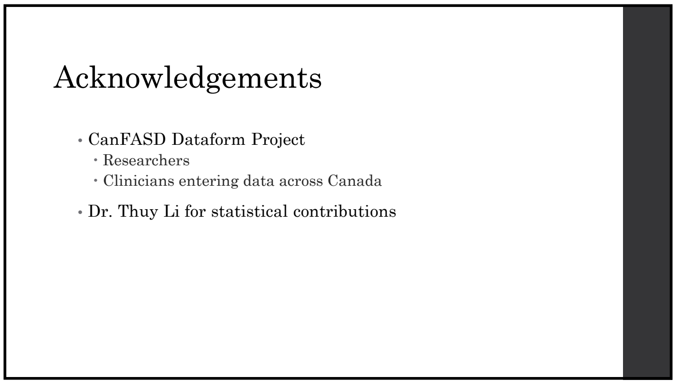
Discussion

- Presence of some of the mental health conditions appear to have somewhat differing impairment presentations
- The differing relationships gives insight into the unique brain impairments as a noteworthy treatment consideration
- Combinations of presentations may be important
  - For example, Conduct Disorder showed associations with higher levels of Affect Regulation impairment and lower levels of Cognitive impairment.
  - May also be useful in developing specific interventions and advocating for appropriate supports



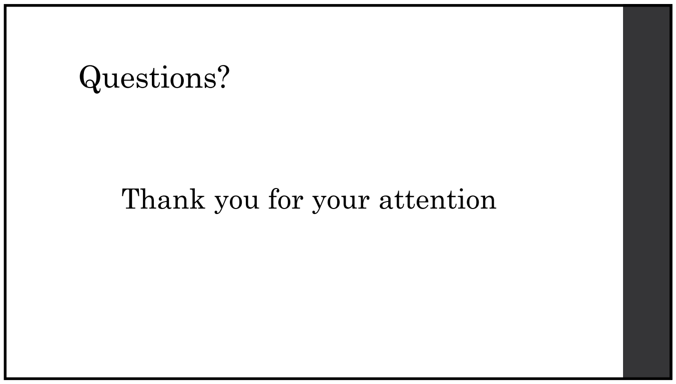
Limitations

- Categorical and Cross-Sectional nature of the data
- Specifics of assessment for neurocognitive domains and diagnosis of mental disorders unknown
- Cannot delineate any causality from data
- Exploratory beginnings



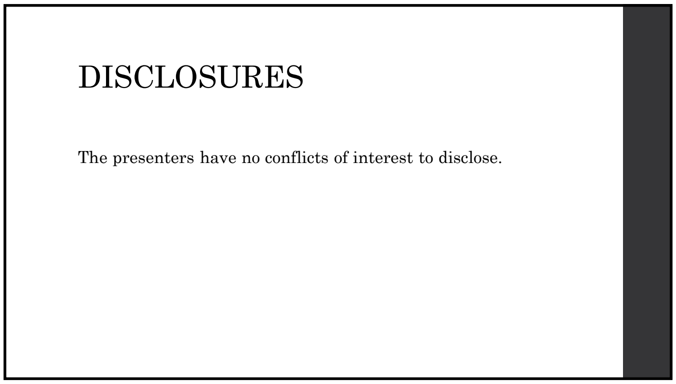
Acknowledgements

- CanFASD Dataform Project
  - Researchers
  - Clinicians entering data across Canada
- Dr. Thuy Li for statistical contributions



Questions?

Thank you for your attention



DISCLOSURES

The presenters have no conflicts of interest to disclose.

E1e

Building an FASD System of Care within Michigan's Community Mental Health System

Katherine Fitzpatrick

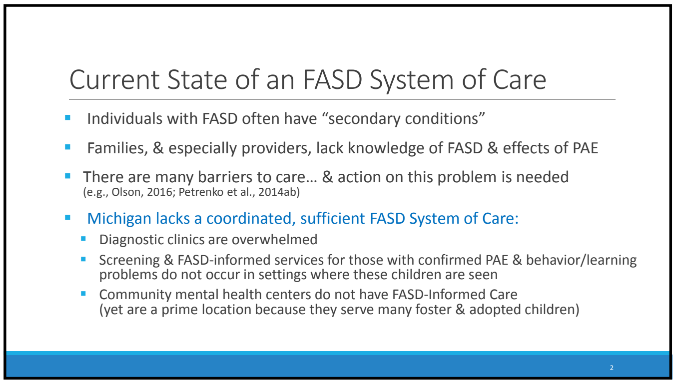
Building an FASD System of Care within Michigan's Community Mental Health System

Michigan Department of Health and Human Services
Mental Health Services for Children and Families

Presenter: Katherine Fitzpatrick, MA

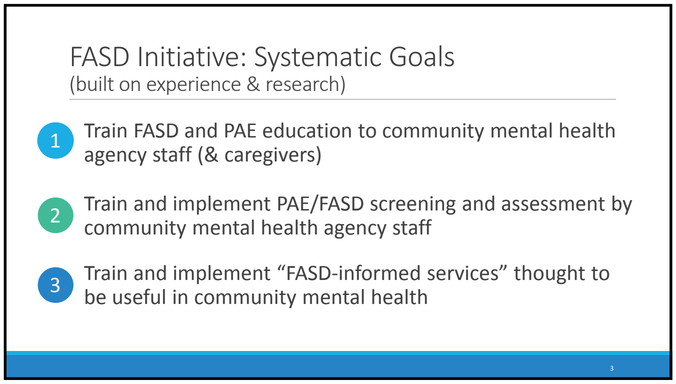
MARCH 2019

8TH INTERNATIONAL CONFERENCE ON FETAL ALCOHOL SPECTRUM DISORDER



Current State of an FASD System of Care

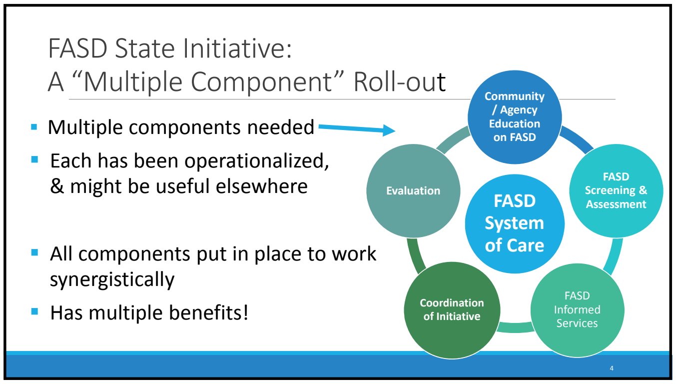
- Individuals with FASD often have "secondary conditions"
- Families, & especially providers, lack knowledge of FASD & effects of PAE
- There are many barriers to care… & action on this problem is needed (e.g., Olson, 2016; Petrenko et al., 2014ab)
- Michigan lacks a coordinated, sufficient FASD System of Care:
  - Diagnostic clinics are overwhelmed
  - Screening & FASD-informed services for those with confirmed PAE & behavior/learning problems do not occur in settings where these children are seen
  - Community mental health centers do not have FASD-Informed Care (yet are a prime location because they serve many foster & adopted children)



FASD Initiative: Systematic Goals

(built on experience & research)

1. Train FASD and PAE education to community mental health agency staff (& caregivers)
2. Train and implement PAE/FASD screening and assessment by community mental health agency staff
3. Train and implement "FASD-informed services" thought to be useful in community mental health



FASD State Initiative: A "Multiple Component" Roll-out

- Multiple components needed
- Each has been operationalized, & might be useful elsewhere
- All components put in place to work synergistically
- Has multiple benefits!

FASD System of Care

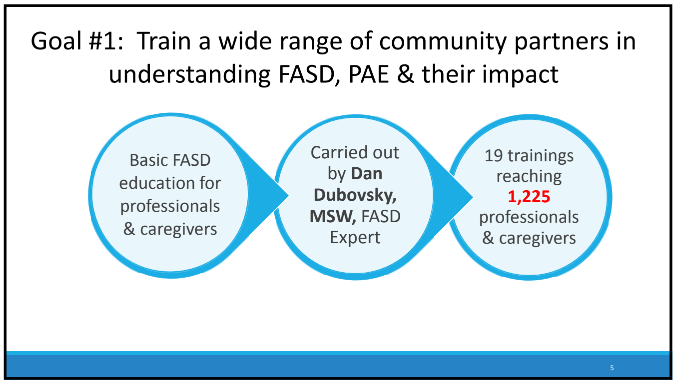
Community / Agency Education on FASD

FASD Screening & Assessment

FASD Informed Services

Coordination of Initiative

Evaluation

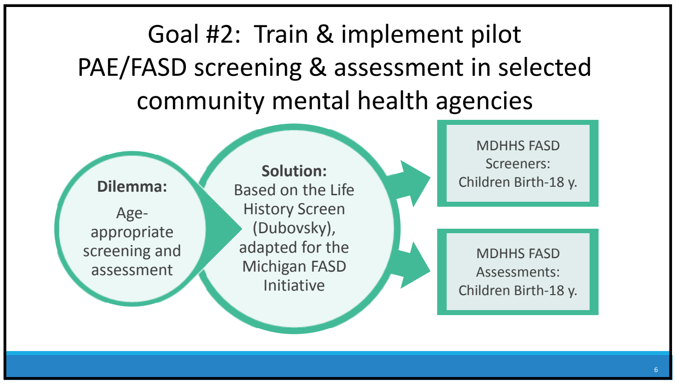


Goal #1: Train a wide range of community partners in understanding FASD, PAE & their impact

Basic FASD education for professionals & caregivers

Carried out by **Dan Dubovsky, MSW,** FASD Expert

19 trainings reaching **1,225** professionals & caregivers



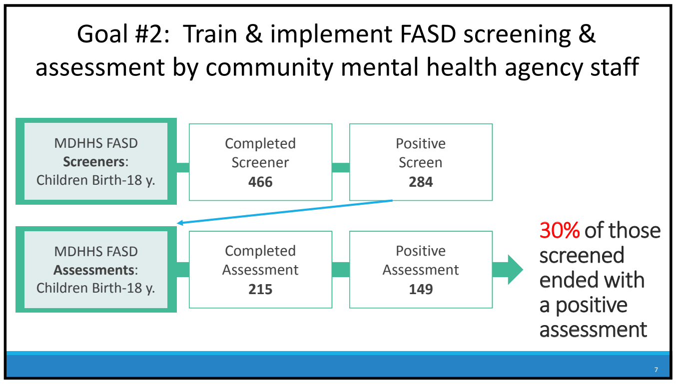
Goal #2: Train & implement pilot PAE/FASD screening & assessment in selected community mental health agencies

Dilemma: Age-appropriate screening and assessment

Solution: Based on the Life History Screen (Dubovsky), adapted for the Michigan FASD Initiative

MDHHS FASD Screeners: Children Birth-18 y.

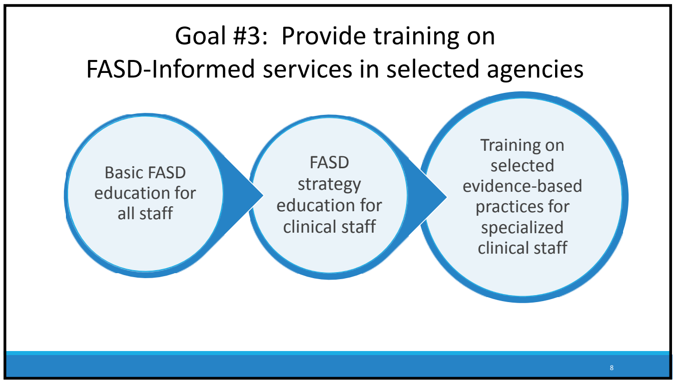
MDHHS FASD Assessments: Children Birth-18 y.



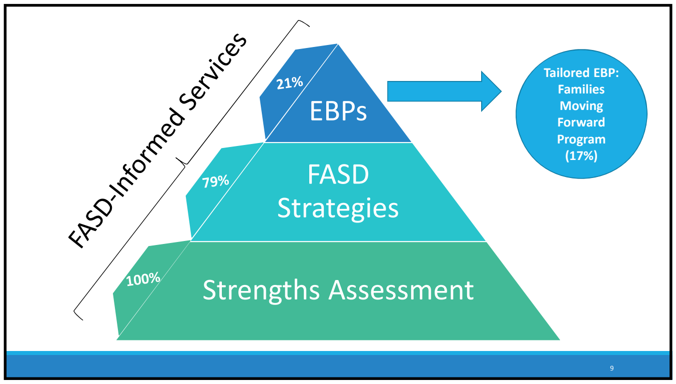
Goal #2: Train & implement FASD screening & assessment by community mental health agency staff

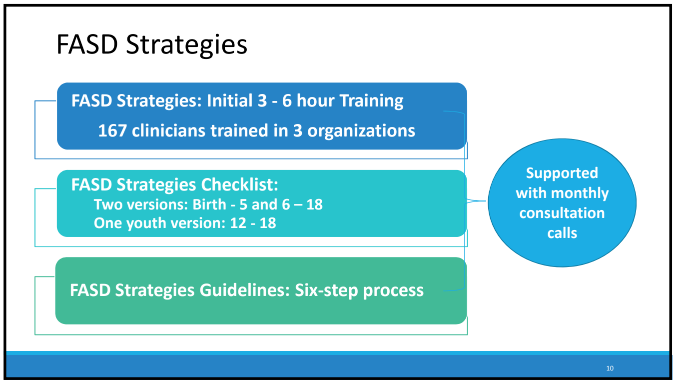
MDHHS FASD **Screeners**: Children Birth-18 y.	Completed Screener **466**	Positive Screen **284**
MDHHS FASD **Assessments**: Children Birth-18 y.	Completed Assessment **215**	Positive Assessment **149**

30% of those screened ended with a positive assessment



Goal #3: Provide training on FASD-Informed services in selected agencies





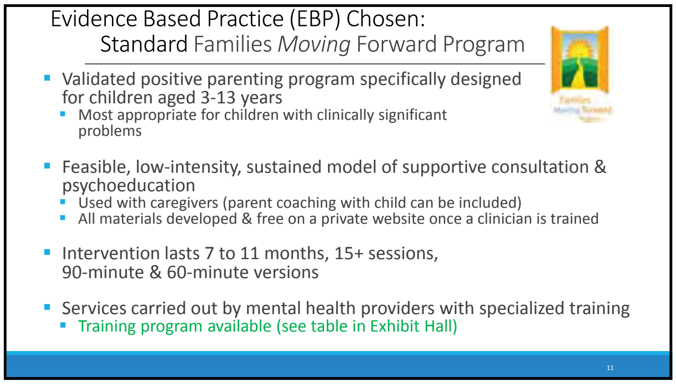
FASD Strategies

FASD Strategies: Initial 3 - 6 hour Training
167 clinicians trained in 3 organizations

FASD Strategies Checklist:
Two versions: Birth - 5 and 6 – 18
One youth version: 12 - 18

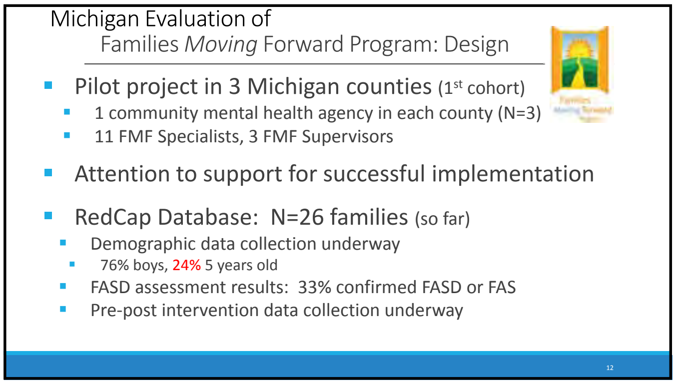
FASD Strategies Guidelines: Six-step process

Supported with monthly consultation calls



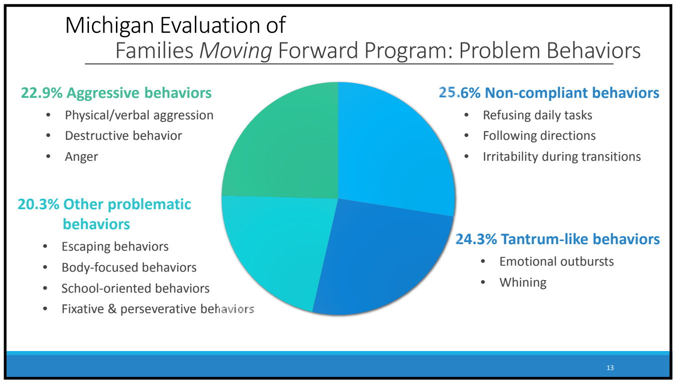
Evidence Based Practice (EBP) Chosen: Standard Families *Moving* Forward Program

- Validated positive parenting program specifically designed for children aged 3-13 years
  - Most appropriate for children with clinically significant problems
- Feasible, low-intensity, sustained model of supportive consultation & psychoeducation
  - Used with caregivers (parent coaching with child can be included)
  - All materials developed & free on a private website once a clinician is trained
- Intervention lasts 7 to 11 months, 15+ sessions, 90-minute & 60-minute versions
- Services carried out by mental health providers with specialized training
  - Training program available (see table in Exhibit Hall)



Michigan Evaluation of Families *Moving* Forward Program: Design

- Pilot project in 3 Michigan counties (1st cohort)
  - 1 community mental health agency in each county (N=3)
  - 11 FMF Specialists, 3 FMF Supervisors
- Attention to support for successful implementation
- RedCap Database: N=26 families (so far)
  - Demographic data collection underway
    - 76% boys, 24% 5 years old
  - FASD assessment results: 33% confirmed FASD or FAS
  - Pre-post intervention data collection underway



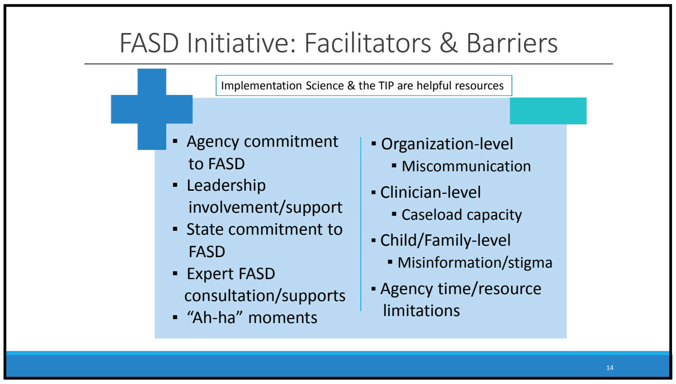
Michigan Evaluation of Families *Moving* Forward Program: Problem Behaviors

22.9% Aggressive behaviors
- Physical/verbal aggression
- Destructive behavior
- Anger

25.6% Non-compliant behaviors
- Refusing daily tasks
- Following directions
- Irritability during transitions

20.3% Other problematic behaviors
- Escaping behaviors
- Body-focused behaviors
- School-oriented behaviors
- Fixative & perseverative behaviors

24.3% Tantrum-like behaviors
- Emotional outbursts
- Whining

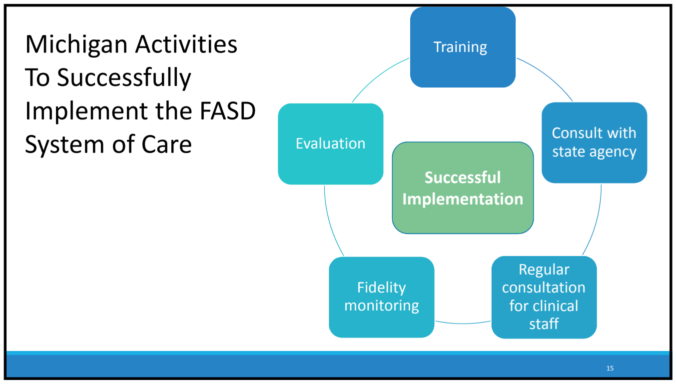


FASD Initiative: Facilitators & Barriers

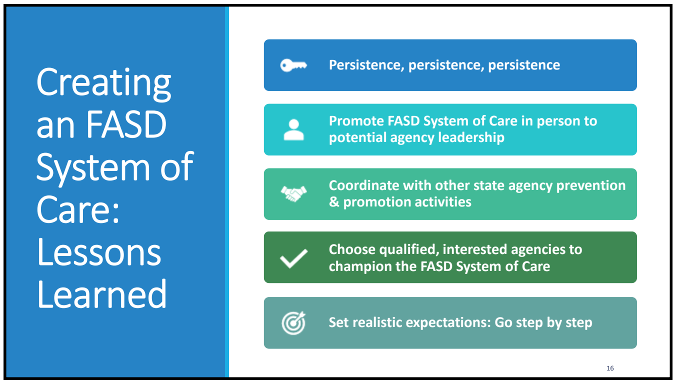
Implementation Science & the TIP are helpful resources

- Agency commitment to FASD
- Leadership involvement/support
- State commitment to FASD
- Expert FASD consultation/supports
- "Ah-ha" moments

- Organization-level
  - Miscommunication
- Clinician-level
  - Caseload capacity
- Child/Family-level
  - Misinformation/stigma
- Agency time/resource limitations

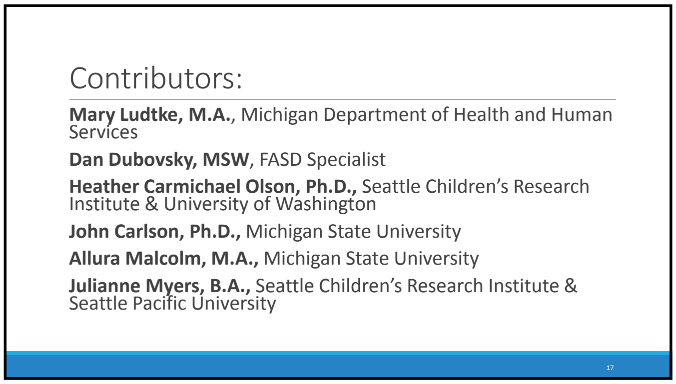


Michigan Activities To Successfully Implement the FASD System of Care



Creating an FASD System of Care: Lessons Learned

- **Persistence, persistence, persistence**
- **Promote FASD System of Care in person to potential agency leadership**
- **Coordinate with other state agency prevention & promotion activities**
- **Choose qualified, interested agencies to champion the FASD System of Care**
- **Set realistic expectations: Go step by step**



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E2a Identifying Neuropsychological Tools for FASD Assessment in Poland

Magdalena Borkowska

Authors: Magdalena Borokowska, Sylvia Roozen, Katarzyna Okulicz-Kozaryn, Leopold Curfs

Learning Objectives

1. Discuss the current situation in Poland and needs in the area of the neuropsychological assessment being a part of FASD diagnosis
2. Outline the steps towards Polish neuropsychological assessment guidelines in FASD diagnostic process

Summary

Complexity of neuropsychological deficits in FASD, requires application of proper tools in an assessment process. Therefore, it is important to select appropriate tests which are psychometrically sound and to interpret their results in accordance with the guidelines for diagnosis of FASD.

The aim of this study is to investigate available neuropsychological tools and identify what tools are in use, and can be recommended for use in Poland.

Scoping literature review of global neuropsychological assessment for FASD, was conducted to identify literature describing neuropsychological tools in relations to FASD. Moreover a questionnaire was sent out to 10 FASD clinics in Poland to investigate which neuropsychological tools are being used as a part of a FASD diagnosis.

In Poland there are no standards of Fetal Alcohol Spectrum Disorders diagnosis and the neuropsychological assessment process is generally unclear and determined by individual preferences of the professional(s) engaged. The most common are measures of the "cognitive profile", IQ level, and/or speech competences and the most popular tool are DSR (Child Developmental Scale), IDS-P (Intelligence and Developmental Scale for pre-school children), IDS (Intelligence and Developmental Scale for school children), Leiter (Non-verbal Intelligence Scale), SB5 (Stanford – Binet IQ Scale 5th edition). The assessment of other neuro-cognitive functions (for ex. attentional control, selective attention, and inhibition, cognitive flexibility, divided attention, and working memory, goal setting, planning, and reasoning) is usually based on experimental clinical trials and/or observation.

As specialists emphasize using the experimental clinical trials requires competences in proper chose and then adequate interpretation of results/observation according to the deficits that the individual with FASD can have. That is why the clinical trials can be seen as the solution for the lack of neuropsychological tools but on the other side used by not qualified and experienced specialists can be very risky.

Lack of national diagnostic guidelines and few neuropsychological tests, which are psychometrically sound, available in Poland make FASD diagnosis incomparable across different places/centers. Moreover, reliability and accuracy of FASD diagnosis as a whole process, remains questionable.

References

Astley, S.J. (2004). Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code. Third Edition

Jocelynn L. Cook, Courtney R. Green, Christine M. Lilley, Sally M. Anderson et al. (2015). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. www.cmaj.ca

H. Eugene Hoyme, MD, Wendy O. Kalberg, MA, LED, c Amy J. Elliott,et al. (2016). A Practical Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine Criteria. Pediatrics. 2016; 138(2):e20154256

Jadczak-Szumiło, T. (2015). Problemy diagnostyczne dzieci z FASD – implikacje diagnozy Podsumowanie 15 lat badań własnych nad problemem dzieci z FASD w Polsce . Materiał konferencyjny

Jadczak - Szumiło, T. (2009). Neuropsychologiczny profil dziecka z FASD. Studium przypadku. Wydawnictwo PARPAMEDIA

Klecka, M., Janas-Kozik, M., Krupka-Matuszczyk, I.(2010). Rozwój diagnostyki poalkoholowego spektrum zaburzeń rozwojowych – przegląd narzędzi diagnostycznych. Psychiatr. Psychol. Klin., 10(4), 298-302

Krasowicz-Kupis, G., Wiejak, K., Gruszczyńska, K. (2015). Katalog metod diagnozy rozwoju poznawczego dziecka na etapie edukacji przedszkolnej i wczesnoszkolnej. Tom I – narzędzia dostępne w poradniach PP i szkołach. IBE

Landgraf, M.N., Nothacker, M., Heinen, F. (2013). Diagnosis of fetal alcohol syndrome (FAS): German guidline version 2013. The European Paediatric Neurology Society. 17, 437-446

Palicka, I., Śmigiel, R., Pesz, K., Janas-Kozik, M., Klecka, M. (2016). Diagnostyka FASD według 4-cyfrowego Kwestionariusza Diagnostycznego S. Astley – znaczenie badania neuropsychologicznego. Standardy Medyczne. Pediatria. T.13, 112-116

Palicka, I., Śmigiel, R. (2017). Walidacja narzędzia diagnostycznego „Skale Inteligencji Rozwoju dla Dzieci w Wieku Przedszkolnym (IDS-P) z udziałem grupy dzieci z rozpoznanym zespołem alkoholowym według kryteriów waszyngtońskich. Pediatria Polska

Roozen, S., Kok, G., Curfs, L.M.G. (2017). Knowledge Synthesis. Fetal Alcohol Spectrum Disorders. Governor Kremers Center - Maastricht University Medical Center and the Department of Applied Psychology, Maastricht University, Faculty of Psychology and Neuroscience

Szczupał, B. (2013). Dziecko z FASD – problemy diagnostyczne oraz wybrane strategie i metody pracy. Rozprawy Społeczne, 1(VII), 79-87

E2b Similarities and Differences in Motor Coordination and Sensory Processing Integration among Children with FASD and Children with Developmental Coordination Disorder

Liat Hen-Herbst

Learning Objectives

1. Describe motor performance, sensory processing and integration behaviors in children with FASD as compared to children with DCD.
2. Describe the relationships between sensory and motor outcomes in children with FASD and children with DCD.

Aims

Children with FASD and children with DCD can present with overlap in symptomology in both motor skills and sensory processing and integration. One way to distinguish between FASD and DCD is to examine the differences in their sensory-motor profiles. This study compared children with FASD and children with DCD in (a) motor performance, as measured using the MABC-2 subscales and total motor score and (b) sensory processing behaviors, as measured using the Sensory Processing Measure (SPM)-Home form subscales and total sensory scores; and (c) explored relationships between motor coordination and parent reported sensory processing and integration behaviors.

Background

Motor coordination and sensory processing and integration challenges often co-occur in children with FASD and with DCD. Individuals with diagnoses on the fetal alcohol spectrum can have significant neurological damage that affects fine and gross motor skills and visual-motor integration. Specific motor challenges include poor balance, coordination and ball skills (Lucas et al., 2014), as well as decreased fine motor coordination (Doney et al., 2014). Motor impairments among children with DCD include marked delays in achieving motor milestones, poor motor coordination and difficulty learning motor skills (Zwicker, Suto, Harris, Vlasakova & Missiuna, 2018).

Motor coordination is intrinsically linked to sensory feedback. Skills that tap into the physical aspects between person and objects—for example, bending, stabilizing, hand grasping, holding, coordinating, and manipulating, as well as modulating movement and force—are supported by efficient sensory processing and the integration of basic sensory systems such as the visual, vestibular, and tactile systems (White, Mulligan, Merrill & Wright, 2007).

Children affected by prenatal alcohol exposure also have poorer sensory processing than non-exposed children (Carr, Agnihotri, & Keightley, 2010; Franklin, Deitz, Jirikowic, & Astley, 2008; Jirikowic, Olson & Kartin, 2008). Likewise, sensory processing and integration diffculties in association with DCD have been described including tactile sensitivity and diminished organization of visually perceived information, proprioception, and vestibular function (Goyen et al., 2011; Zoia, Pelamatti, Cuttini, Casotto & Scabar, 2002; Allen & Casey, 2017). Understanding profiles between clinical groups and the relationships between sensory and motor behaviors can guide more targeted interventions.

Method

This was a secondary analysis of baseline data from a sensorimotor assessment battery gathered for a larger study. The Movement Assessment Battery for Children–2 (MABC-2) (Henderson, Sugden, & Barnett, 2007) was administered by a licensed pediatric physical therapist in a university laboratory. The Sensory Processing Measure–Home (SPM-Home) form (Parham, Ecker, Miller Kuhaneck, Henry & Glennon, 2007) was completed by children's parents. Data from 21 children with FASD and 21 with DCD, ages 5 to 13 years, were compared. Children with FASD were diagnosed using the four-digit diagnostic code (Astley, 2004). Children with DCD either had a medical diagnosis of DCD or met all DSM-V diagnostic criteria of DCD. They did not have prenatal alcohol exposure based on screening questions at the time of enrollment. Performance on the MABC-2 and SPM-Home were compared using MANOVA and adjusted for age. Correlations were analyzed using Spearman's rho correlation.

Results

Both groups had mild to moderate motor problems on the MABC-2 Total Motor score, FASD [M=6.86 (2.80)] and DCD [M=4.86 (2.69)]. No significant group differences were found on the total score or MABC-2 subtest scores (Manual Dexterity, Aiming and Catching, and Balance) suggesting comparable patterns of motor performance. Significant group differences were found on the SPM-Home total score. Children with FASD had higher total T scores [M = 66.8 (7.18)], indicating more atypical sensory processing behaviors, than children with DCD [M=62.24 (4.97)]. Significant group differences were found on Vision, Touch, Body Awareness, and Planning and Ideas subtests. All subtest scores except the Balance subtest were higher in the group of children with FASD. There were no significant relationships between motor skills and sensory processing and integration behaviors for the group with FASD. For the DCD group, significant moderate correlations were found between scores on SPM Planning and Ideas (motor planning) and MABC-2 Balance (r=-.47), Fine Motor (r=-.54), and Total Motor scores (r=-.46); and between the SPM Vision and MABC-2 Aiming and Catching (r=-.46), Fine motor (r=-.48) and Total Motor score (r=-.49).

Conclusion

Children with FASD and children with DCD had similar motor profiles, but sensory processing and integration profiles were significantly different. Children with FASD had more atypical sensory processing and integration behaviors across multiple sensory domains than children with DCD, though both groups showed more atypical behaviors as compared to the normative sample. The significant negative correlations between motor planning and visual processing behaviors and motor performance on the MABC-2 for the children with DCD, might suggest that underlying sensory processing concerns may be affecting motor performance among this group verses those with FASD. Results are preliminary and should be interpreted with caution due to the small sample size and use of secondary data. However, findings suggest more research is warranted to corroborate these comparisons and relationships to further inform clinical assessment and intervention.

References

Allen, S., & Casey, J. (2017). Developmental coordination disorders and sensory processing and integration: Incidence, associations and co-morbidities. British Journal of Occupational Therapy, 80(9), 549-557.

Astley, S. J. (2004) Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, 3rd ed. Seattle, WA: University of Washington Publication Services.

Carr, J. L., Agnihotri, S., & Keightley, M. (2010). Sensory processing and adaptive behavior deficits of children across the fetal alcohol spectrum disorder continuum. Alcoholism: Clinical and Experimental Research, 34(6), 1022-1032.

Doney, R., Lucas, B. R., Jones, T., Howat, P., Sauer, K., & Elliott, E. J. (2014). Fine motor skills in children with prenatal alcohol exposure or fetal alcohol spectrum disorder. Journal of Developmental & Behavioral Pediatrics, 35(9), 598-609. doi: 10.1097/DBP.0000000000000107

Franklin, L., Deitz, J., Jirikowic, T., & Astley, S. (2008). Children with fetal alcohol spectrum disorders: problem behaviors and sensory processing. The American journal of Occupational Therapy, 62(3), 265.

Goyen, T. A., Lui, K., & Hummell, J. (2011). Sensorimotor skills associated with motor dysfunction in children born extremely preterm. Early human development, 87(7), 489-493.

Henderson, S. E., Sugden, D. A., & Barnett, A. L. (2007). Movement Assessment Battery for Children-2. Harcourt Assessment

Jirikowic, T., Olson, H. C., & Kartin, D. (2008). Sensory processing, school performance, and adaptive behavior of young school-age children with fetal alcohol spectrum disorders. Phyical and Occupational Therapy in Pediatrics, 28(2), 117-136.

Lucas, B. R., Latimer, J., Pinto, R. Z, Ferreira, M. L., Doney, R., Lau, M., Jones, T., Dries, D., Elliott, E. J. (2014). Gross motor deficits in children prenatally exposed to alcohol: A meta-analysis. Pediatrics. 2014 Jul;134(1): e192-209. doi: 10.1542/peds.2013-3733.

Parham, L. D., Ecker, C., Miller Kuhaneck, H., Henry, D. A., & Glennon, T. J. (2007). Sensory processing measure (SPM): manual. Los Angeles, CA: Western Psychological Services.

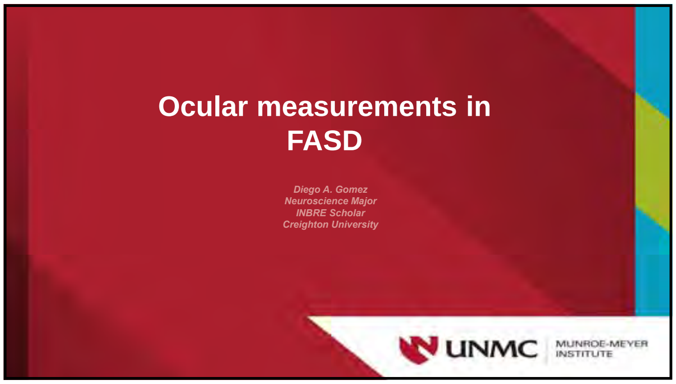
White, B. P., Mulligan, S., Merrill, K., & Wright, J. (2007). An examination of the relationships between motor and process skills and scores on the sensory profile. American Journal of Occupational Therapy, 61(2), 154-160.

Zoia, S., Pelamatti, G., Cuttini, M., Casotto, V., & Scabar, A. (2002). Performance of gesture in children with and without DCD: effects of sensory input modalities. Developmental Medicine and Child Neurology, 44(10), 699-705.

Zwicker, J. G., Suto, M., Harris, S. R., Vlasakova, N., & Missiuna, C. (2018). Developmental coordination disorder is more than a motor problem: children describe the impact of daily struggles on their quality of life. British Journal of Occupational Therapy, 81(2), 65-73.

E2c FASD and Assessment of Ocular Measurements and Features

Diego Gomez



Ocular measurements in FASD

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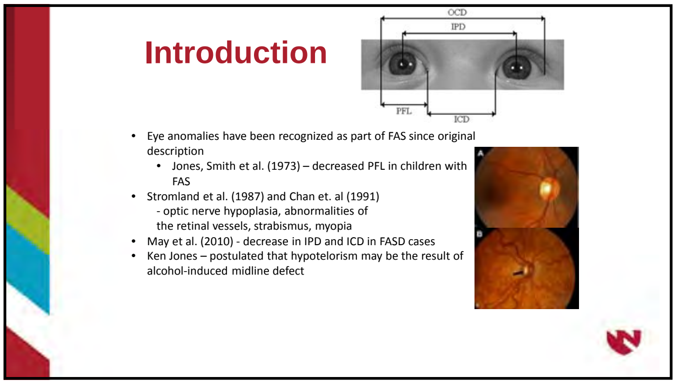
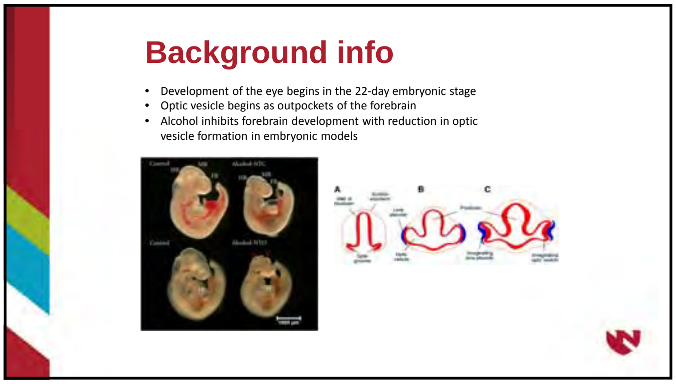


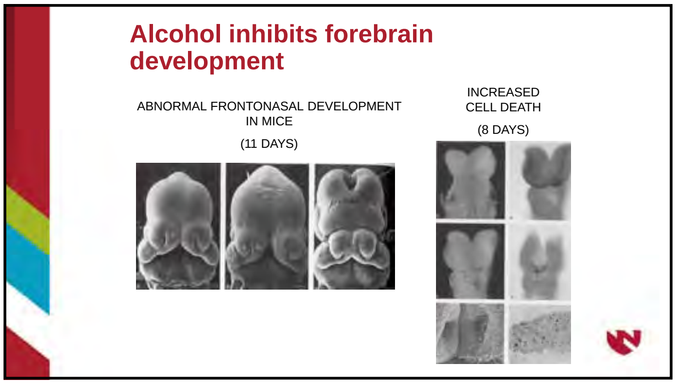
Introduction

- Eye anomalies have been recognized as part of FAS since original description
  - Jones, Smith et al. (1973) – decreased PFL in children with FAS
- Stromland et al. (1987) and Chan et. al (1991)
  - optic nerve hypoplasia, abnormalities of the retinal vessels, strabismus, myopia
- May et al. (2010) - decrease in IPD and ICD in FASD cases
- Ken Jones – postulated that hypotelorism may be the result of alcohol-induced midline defect



Background info

- Development of the eye begins in the 22-day embryonic stage
- Optic vesicle begins as outpockets of the forebrain
- Alcohol inhibits forebrain development with reduction in optic vesicle formation in embryonic models



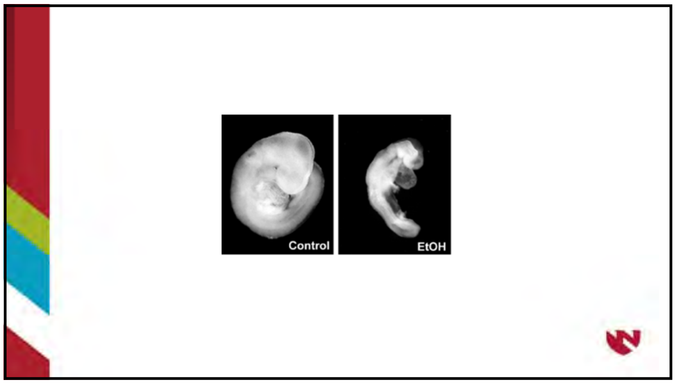
Alcohol inhibits forebrain development

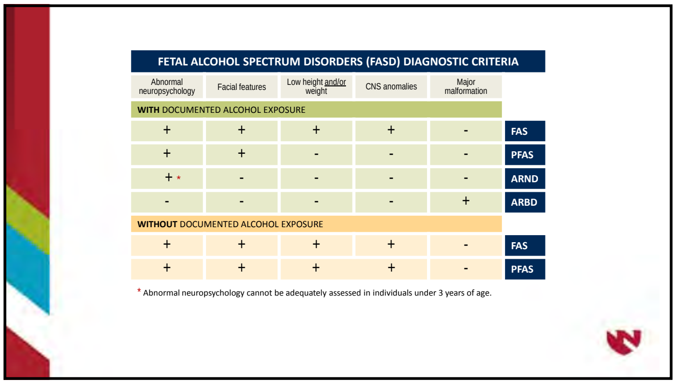
ABNORMAL FRONTONASAL DEVELOPMENT IN MICE

(11 DAYS)

INCREASED CELL DEATH

(8 DAYS)





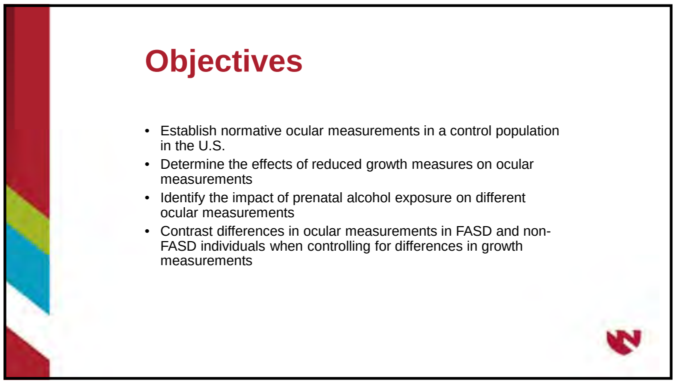
FETAL ALCOHOL SPECTRUM DISORDERS (FASD) DIAGNOSTIC CRITERIA

Abnormal neuropsychology	Facial features	Low height and/or weight	CNS anomalies	Major malformation	
WITH DOCUMENTED ALCOHOL EXPOSURE					
+	+	+	+	-	FAS
+	+	-	-	-	PFAS
+ *	-	-	-	-	ARND
-	-	-	-	+	ARBD
WITHOUT DOCUMENTED ALCOHOL EXPOSURE					
+	+	+	+	-	FAS
+	+	+	+	-	PFAS

* Abnormal neuropsychology cannot be adequately assessed in individuals under 3 years of age.

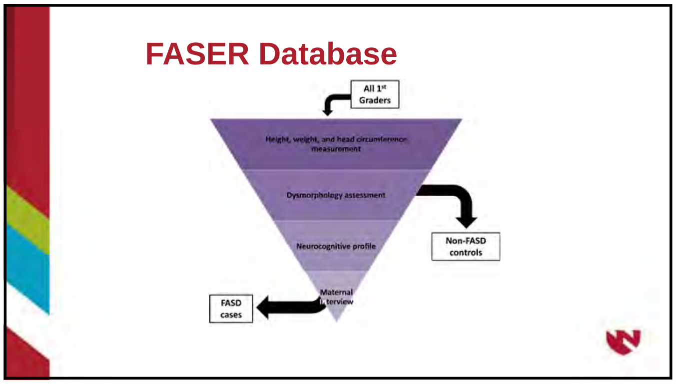
What effect does growth reduction have on ocular measurements?

If alcohol has a reproducible effect on ocular measurements, is it independent of its effect on growth?

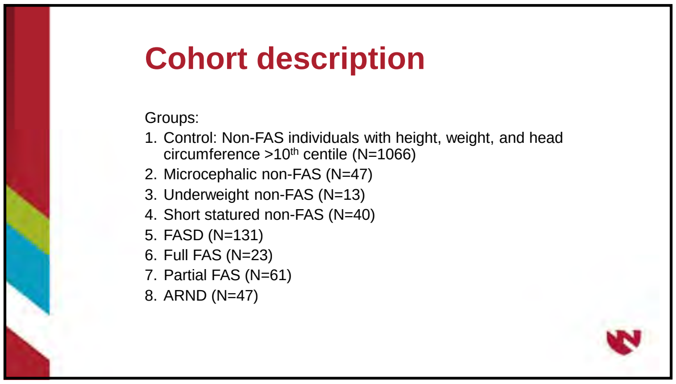


Objectives

- Establish normative ocular measurements in a control population in the U.S.
- Determine the effects of reduced growth measures on ocular measurements
- Identify the impact of prenatal alcohol exposure on different ocular measurements
- Contrast differences in ocular measurements in FASD and non-FASD individuals when controlling for differences in growth measurements



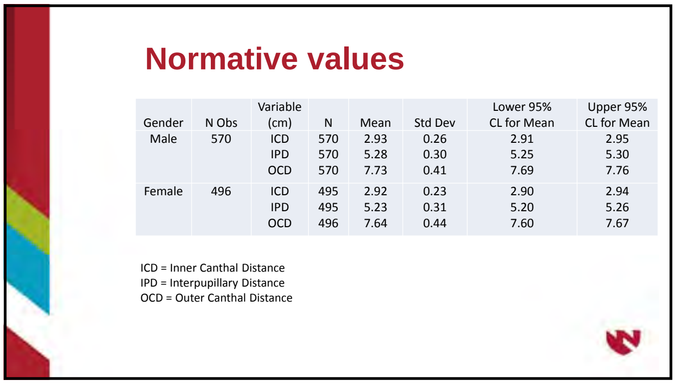
FASER Database



Cohort description

Groups:

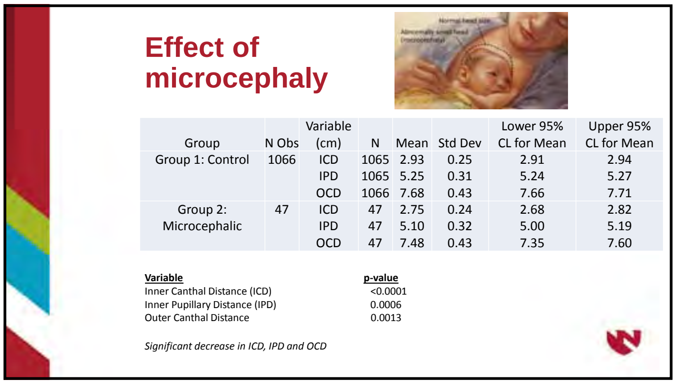
1. Control: Non-FAS individuals with height, weight, and head circumference >10th centile (N=1066)
2. Microcephalic non-FAS (N=47)
3. Underweight non-FAS (N=13)
4. Short statured non-FAS (N=40)
5. FASD (N=131)
6. Full FAS (N=23)
7. Partial FAS (N=61)
8. ARND (N=47)



Normative values

Gender	N Obs	Variable (cm)	N	Mean	Std Dev	Lower 95% CL for Mean	Upper 95% CL for Mean
Male	570	ICD	570	2.93	0.26	2.91	2.95
		IPD	570	5.28	0.30	5.25	5.30
		OCD	570	7.73	0.41	7.69	7.76
Female	496	ICD	495	2.92	0.23	2.90	2.94
		IPD	495	5.23	0.31	5.20	5.26
		OCD	496	7.64	0.44	7.60	7.67

ICD = Inner Canthal Distance
IPD = Interpupillary Distance
OCD = Outer Canthal Distance

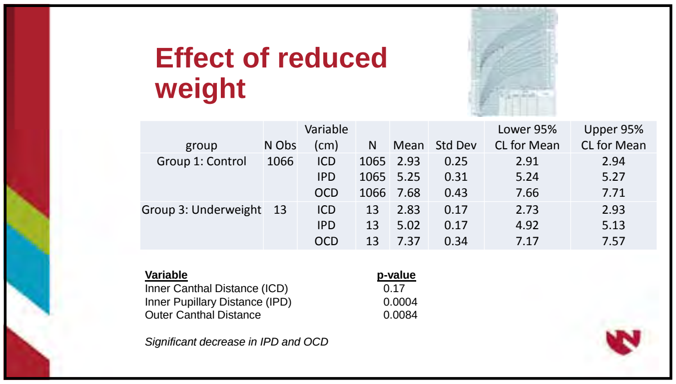


Effect of microcephaly

Group	N Obs	Variable (cm)	N	Mean	Std Dev	Lower 95% CL for Mean	Upper 95% CL for Mean
Group 1: Control	1066	ICD	1065	2.93	0.25	2.91	2.94
		IPD	1065	5.25	0.31	5.24	5.27
		OCD	1066	7.68	0.43	7.66	7.71
Group 2: Microcephalic	47	ICD	47	2.75	0.24	2.68	2.82
		IPD	47	5.10	0.32	5.00	5.19
		OCD	47	7.48	0.43	7.35	7.60

Variable	p-value
Inner Canthal Distance (ICD)	<0.0001
Inner Pupillary Distance (IPD)	0.0006
Outer Canthal Distance	0.0013

Significant decrease in ICD, IPD and OCD

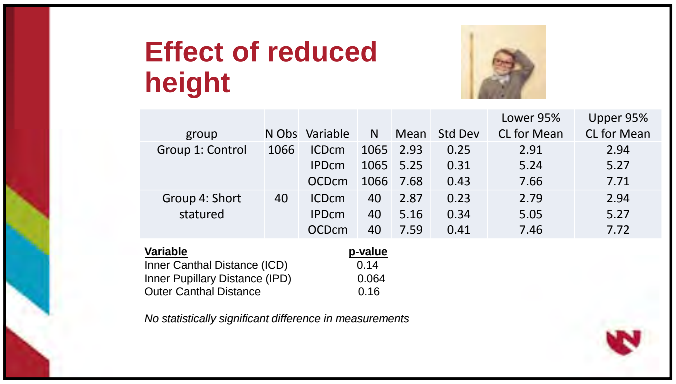


Effect of reduced weight

group	N Obs	Variable (cm)	N	Mean	Std Dev	Lower 95% CL for Mean	Upper 95% CL for Mean
Group 1: Control	1066	ICD	1065	2.93	0.25	2.91	2.94
		IPD	1065	5.25	0.31	5.24	5.27
		OCD	1066	7.68	0.43	7.66	7.71
Group 3: Underweight	13	ICD	13	2.83	0.17	2.73	2.93
		IPD	13	5.02	0.17	4.92	5.13
		OCD	13	7.37	0.34	7.17	7.57

Variable	**p-value**
Inner Canthal Distance (ICD)	0.17
Inner Pupillary Distance (IPD)	0.0004
Outer Canthal Distance	0.0084

Significant decrease in IPD and OCD

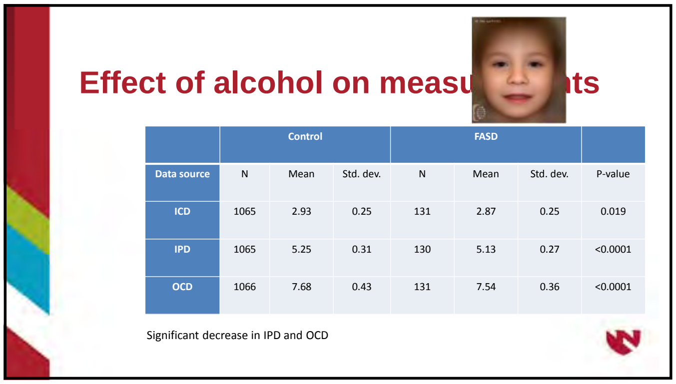


Effect of reduced height

group	N Obs	Variable	N	Mean	Std Dev	Lower 95% CL for Mean	Upper 95% CL for Mean
Group 1: Control	1066	ICDcm	1065	2.93	0.25	2.91	2.94
		IPDcm	1065	5.25	0.31	5.24	5.27
		OCDcm	1066	7.68	0.43	7.66	7.71
Group 4: Short statured	40	ICDcm	40	2.87	0.23	2.79	2.94
		IPDcm	40	5.16	0.34	5.05	5.27
		OCDcm	40	7.59	0.41	7.46	7.72

Variable	**p-value**
Inner Canthal Distance (ICD)	0.14
Inner Pupillary Distance (IPD)	0.064
Outer Canthal Distance	0.16

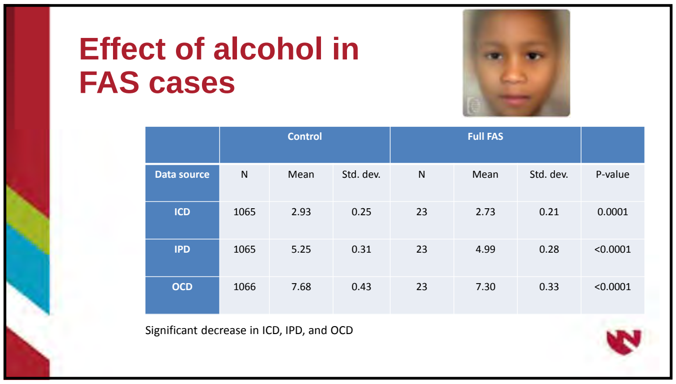
No statistically significant difference in measurements



Effect of alcohol on measu ts

	Control			FASD			
Data source	N	Mean	Std. dev.	N	Mean	Std. dev.	P-value
ICD	1065	2.93	0.25	131	2.87	0.25	0.019
IPD	1065	5.25	0.31	130	5.13	0.27	<0.0001
OCD	1066	7.68	0.43	131	7.54	0.36	<0.0001

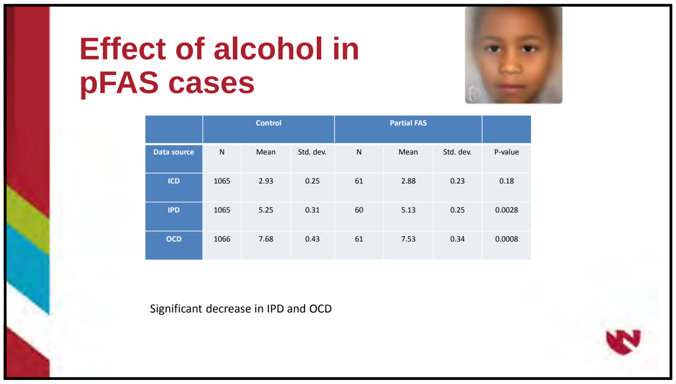
Significant decrease in IPD and OCD



Effect of alcohol in FAS cases

	Control			Full FAS			
Data source	N	Mean	Std. dev.	N	Mean	Std. dev.	P-value
ICD	1065	2.93	0.25	23	2.73	0.21	0.0001
IPD	1065	5.25	0.31	23	4.99	0.28	<0.0001
OCD	1066	7.68	0.43	23	7.30	0.33	<0.0001

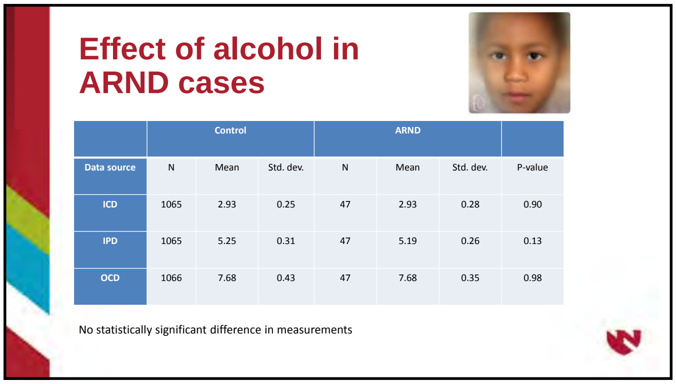
Significant decrease in ICD, IPD, and OCD



Effect of alcohol in pFAS cases

	Control			Partial FAS			
Data source	N	Mean	Std. dev.	N	Mean	Std. dev.	P-value
ICD	1065	2.93	0.25	61	2.88	0.23	0.18
IPD	1065	5.25	0.31	60	5.13	0.25	0.0028
OCD	1066	7.68	0.43	61	7.53	0.34	0.0008

Significant decrease in IPD and OCD



Effect of alcohol in ARND cases

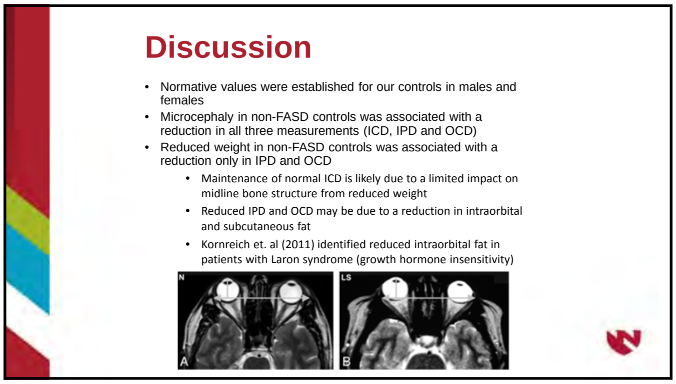
	Control			ARND			
Data source	N	Mean	Std. dev.	N	Mean	Std. dev.	P-value
ICD	1065	2.93	0.25	47	2.93	0.28	0.90
IPD	1065	5.25	0.31	47	5.19	0.26	0.13
OCD	1066	7.68	0.43	47	7.68	0.35	0.98

No statistically significant difference in measurements

Microcephaly versus FAS

	Microcephaly (non-FASD)			FAS			
Data source	N	Mean	Std. dev.	N	Mean	Std. dev.	P-value
ICD	47	2.75	0.24	23	2.73	0.21	0.73
IPD	47	5.10	0.32	23	4.99	0.28	0.16
OCD	47	7.48	0.43	23	7.30	0.33	0.092

No statistically significant difference in measurements

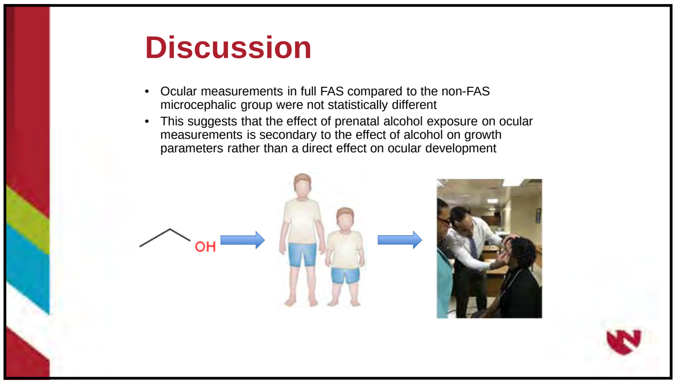


Discussion

- Normative values were established for our controls in males and females
- Microcephaly in non-FASD controls was associated with a reduction in all three measurements (ICD, IPD and OCD)
- Reduced weight in non-FASD controls was associated with a reduction only in IPD and OCD
    - Maintenance of normal ICD is likely due to a limited impact on midline bone structure from reduced weight
    - Reduced IPD and OCD may be due to a reduction in intraorbital and subcutaneous fat
    - Kornreich et. al (2011) identified reduced intraorbital fat in patients with Laron syndrome (growth hormone insensitivity)

Discussion

- Reduced height in non-FASD controls was not associated with a reduction in any ocular measurements
- FASD was associated with a reduction in IPD and OCD when compared to controls
- Full FAS was associated with a reduction in all three measurements (ICD, IPD and OCD)
    - All of these individuals were microcephalic
- Partial FAS was associated with a reduction in IPD and OCD
    - The criteria for pFAS diagnosis includes growth deficiency (height and/or weight)
- ARND was not associated with a reduction in any measures
    - The criteria for ARND does not include any reductions in OFC, height or weight



Discussion

- Ocular measurements in full FAS compared to the non-FAS microcephalic group were not statistically different
- This suggests that the effect of prenatal alcohol exposure on ocular measurements is secondary to the effect of alcohol on growth parameters rather than a direct effect on ocular development

Acknowledgements

FASER Team
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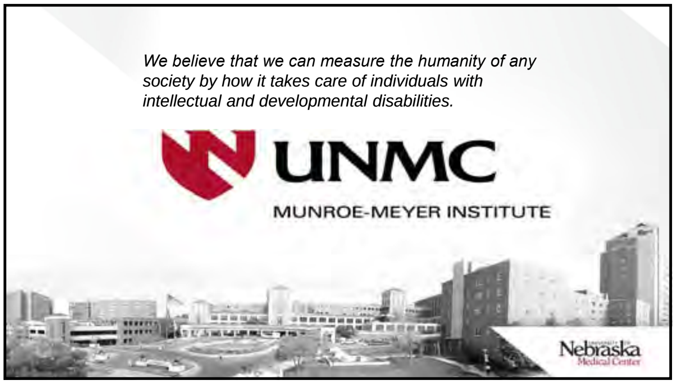

We believe that we can measure the humanity of any society by how it takes care of individuals with intellectual and developmental disabilities.

E2d

Prevalence and Patterns of Sensory Processing Behaviors in a Large Clinical Sample of Children with PAE

Tracy Jirikowic, John C. Thorne

Authors: Tracy Jirikowic, John Thorne PhD, Susan McLaughlin, Tiffany Waddington, KC Lee, Susan J Astley Hemingway
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Learning Objectives

1. Describe the prevalence of sensory processing symptoms in a large clinical population of children with diagnoses on the fetal alcohol spectrum
2. Describe sensory processing patterns and behaviors associated with prenatal alcohol exposure

Background

Atypical responses to sensation are reported to occur at strikingly high rates among children affected by prenatal alcohol exposure (Abele-Webster, et al., 2012; Astley, 2010; Carr et al., 2010; Franklin et al., 2008; Jirikowic et al., 2008). However, systematic examination of the prevalence and patterns of sensory processing and integration dysfunction across the fetal alcohol spectrum is lacking. Recognizing sensory processing and integration differences in this group of vulnerable and often underserved children has implications for diagnosis and intervention. Poorly modulated responses to sensation may be an indicator of CNS dysfunction; and understanding sensory processing patterns can provide insights into maladaptive or dysregulated behaviors and inform targeted interventions.

Purpose

The purposes of this study were to describe the prevalence of sensory processing symptoms in a large clinical population of children systematically diagnosed with FASD, to examine risk factors associated with atypical responses to sensation, and to explore sensory processing patterns across this population.

Methods

A retrospective analysis of clinical data from the Fetal Alcohol Syndrome Diagnostic and Prevention Network (FASDPN) at the University of Washington from 2000 and 2016 was completed. Participants were a) ages 3 through 11 years old at time of diagnosis, b) received a diagnosis on the fetal alcohol spectrum [Fetal Alcohol Syndrome (FAS); Partial FAS (PFAS); Static Encephalopathy/Alcohol-Exposed (SE/AE); and Neurobehavioral Disorder/Alcohol-Exposed (ND/AE)] using an interdisciplinary approach guided by empirically validated criteria (Astley 2004, 2013), and c) had a completed Short Sensory Profile (SSP; McIntosh et. al., 1999). The SSP is a 38-item caregiver questionnaire that measures children's behavioral responses to sensation in daily life. Caregivers rank the frequency of behavior responses on a 5-point Likert scale (1 = almost always; 2 = frequently; 3 = occasionally; 4 = seldom; 5 = almost never). Raw scores are categorized as typical performance (scores at or above -1.0 SD from the mean), probable differences (scores between -1.0 and -2.0 SD from the mean) and 3) definite difference (at or below -2.0 SD from the mean).

Descriptive statistics (means, SDs, proportions) were used to profile the study population. Subjects with missing data on more than one-third of the items in any SSP domain were excluded. Relationships between the SSP total score and SSP domain score categories (typical performance, probable difference, and definite difference) and selected child demographics (age, gender, ADHD; co-occurring prenatal and postnatal risk factors) and FASD diagnosis and features were examined using chi-squared (χ^2) and Fisher's exact tests. All results were considered significant at $p < .05$. Post-hoc analyses of sensory processing patterns were exploratory and were not corrected for multiple comparisons, thus should be interpreted with caution.

Results

The sample (n = 325) consisted of 201 males and 124 females age 3.03 to 10.97 years. Children had a range of diagnoses on the fetal alcohol spectrum, with the largest proportion diagnosed with ND/AE (60.6%), followed by SE/AE (29.5%) and 9.8% with FAS or PFAS. The sample is representative of the larger FAS DPN population (Astley, 2010). Preliminary analyses showed a high proportion of children (73.2%) had definite differences (-2.0 SD from the mean) on the SSP total score. The highest proportion of definite differences were in the domains of Auditory Filtering (81.8%) and Underresponsive/Sensation Seeking (80.0%) followed by Tactile Sensitivity (50.2%). Definite differences in other domains were noted, but to a lesser extent, for Visual-Auditory Sensitivity (38.2)% ; Low Energy/Weakness (33.5%) Taste/Smell Sensitivity (27.1%), and Movement Sensitivity (21.2%).

Atypical sensory processing (Definite Difference on SSP total score) was significantly more prevalent among patients with confirmed PAE at reportedly high levels (Alcohol Rank 4) than among patients with confirmed PAE at unknown or reportedly lower levels (Alcohol Rank 3) (χ^2 = 8.2, p = .004). The prevalence of atypical sensory processing (SSP total scores in the definite difference range) was comparably high (70% to 77%) across all FASD diagnoses. The same pattern of distribution was observed across the four Growth Ranks, Face Ranks and CNS Ranks, with the prevalence of atypical sensory processing (SSP total scores in the definite difference range) comparably high (67% to 81.7%).

The prevalence of atypical sensory processing behaviors (SSP total scores in the definite difference range) did not vary significantly by age or clinical ranking of prenatal risk factors or postnatal risk factors. Significant differences by gender were found. Males were significantly more likely to have Definite Differences in the total score (78.1%) than females (65.3%) (χ^2 = 6.4, p = .011). Although a higher proportion of children with ADHD (73.1%) had definite differences in the SSP total score than those without ADHD (68.9%), differences in the total score were not statistically significant (χ^2 = 3.2, p = .07).

Conclusions

Behavioral symptoms of atypical sensory processing and integration were highly prevalent across this systematically diagnosed clinical sample of children on the fetal alcohol spectrum. Higher levels of prenatal alcohol exposure in association with increased symptom prevalence, over and above other risk and demographic characteristics, lends support for altered sensory processing as another domain of CNS function affected by the teratogenic impact of PAE.

References

Astley, S. J. (2004) Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, 3rd ed. Seattle, WA: University of Washington Publication Services.

Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network. Canadian Journal of Clinical Pharmacology, 17, e132-164.

Astley, S. J. (2013). Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code. Journal of Population Therapeutics and Clinical Pharmacology, 20(3):e416-467; November 15, 2013.

Carr, J. L., Agnihotri, S., & Keightley, M. (2010). Sensory processing and adaptive behavior deficits of children across the fetal alcohol spectrum disorder continuum. Alcoholism: Clinical and Experimental Research, 34(6), 1022-1032. doi:10.1111/j.1530-0277.2010.01177.x

Jirikowic, T., Olson, H. C., & Kartin, D. (2008). Sensory processing, school performance, and adaptive behavior of young school-age children with fetal alcohol spectrum disorders. Physical and Occuupational Therapy in Pediatrics, 28(2), 117-136.

McIntosh, D. N., Miller, L. J., Shyu, V., & Dunn, W. (1999). Overview of the Short Sensory Profile. In W. Dunn (Ed.), The Sensory Profile: User's manual. San Antonio, TX: The Psychological Corporation.

Wengel, T., Hanlon-Dearman, A. C., Fjeldsted, B. (2011). Sleep and sensory characteristics in young children with fetal alcohol spectrum disorder. Journal of Developmental and Behavioral Pediatrics, 32, 384-392.

E3a

Polysubstance Use and Its Impact on FASD Diagnosis and Outcomes: Data from the UK National Specialist FASD Clinic

Raja Mukherjee

Authors: Raja Mukherjee, Zameer Mohamed, Alexandra Carlisle, Alexandra Livesey

Learning Objectives

1. Delineate the effects of prenatal alcohol form other substances
2. Identify where possible a unique profile of FASD supporting its presentation where polysubstance use is described

Background:

Previous literature has suggested a link between alcohol use and of various substances. However, research is scarce in considering the complexities and differences in aetiologies between children exposed to prenatal alcohol abuse alone, and those exposed to effects of prenatal polysubstance abuse. The goal of this study was to delineate as far as possible the effects of polysubstance abuse, in a UK cohort of children with Fetal Alcohol Spectrum Disorders (FASD).

Methods:

Data was analysed for 91 cases of FASD seen in the UK national specialist clinic (52.7% Male, 47.3% Female, mean age = 11 years). Children with FASD were differentiated into two groups by either having prenatal alcohol exposure only (PAO), or additional prenatal polysubstance abuse (PPA). ANOVA was conducted explore any group differences on scores on the Weschler Intelligence Scale for Children (WISC), Short Sensory Profile (SSP), and the Developmental Behaviour Checklist (DBC).

Results:

Initial exploratory analysis revealed that the PAO group had significantly lower (thus more impaired) mean scores on the Verbal Comprehension Index and specific subtests on the Working Memory Index of the WISC. However, The PPA group show more sensory difficulty. Additional analysis will be completed to consider any further neurodevelopmental differences between groups.

Conclusion:

Preliminary results indicate some aetiological differences between PAO children and PPA children, although limited. Children within the PAO group may have specific areas of cognitive weakness compared to the PPA group, namely in Verbal Comprehension and in aspects of Working Memory. The PPA group may have more difficulty with aspects of sensory processing. More analysis will be conducted to try to further delineate and the effect of different prenatal drugs in addition to alcohol on children. Clinical outcomes and explanations are considered in relation to behaviour, mental health, educational and social development of children with FASD.

E3b Patterns of Prenatal Alcohol Use That Predict Infant Growth and Development

Gretchen Bandoli

Patterns of Prenatal Alcohol Use That Predict Infant Growth and Development

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UC San Diego School of Medicine

March 9, 2019

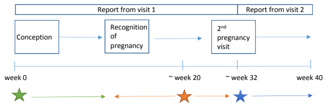
Disclosures

Funding for this research came from the National Institutes of Health/National Institute of Alcohol Abuse and Alcoholism grant number U01 AA019879, the Collaboration on Fetal Alcohol Spectrum Disorders Prevalence (CoFASP)

UC San Diego School of Medicine

Study design

- Prospective cohort study of pregnant women in western Ukraine conducted as part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD)
- 471 participants with two pregnancy interviews and singleton, live births.



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Trajectory results

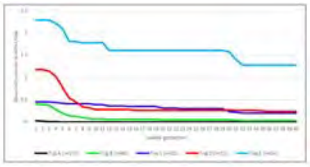

Table 1. Trajectory characteristics (mean, min, max) by trajectory group

	Trajectory A n=277	Trajectory B n=96	Trajectory C n=23	Trajectory D n=51	Trajectory E n=24
Mean ozAA/day across gestation (mean (sd))	0.00 (0.01)	0.05 (0.06)	0.31 (0.16)	0.26 (0.32)	1.58 (0.65)
Mean ozAA/day by trimester					
Mean ozAA/day TM1 (mean (sd))	0.01 (0.02)	0.18 (0.08)	0.42 (0.12)	0.62 (0.41)	2.14 (1.22)
Mean ozAA/day TM2 (mean (sd))	0.00 (0.01)	0.06 (0.06)	0.33 (0.14)	0.27 (0.32)	1.61 (0.65)
Mean ozAA/day TM3 (mean (sd))	0.00 (0.02)	0.04 (0.06)	0.23 (0.16)	0.24 (0.33)	1.36 (0.68)

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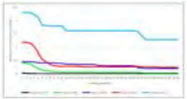
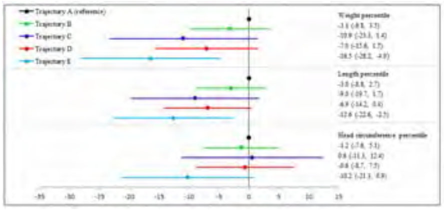
Birth outcomes





Models were adjusted for vitamin use in pregnancy, Hollingshead SES, maternal age at enrollment, maternal smoking status and gestational age at enrollment

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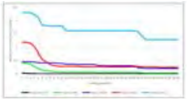
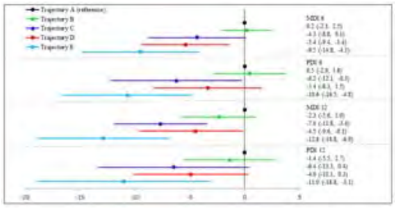
Neurodevelopmental outcomes





N=351; vitamin use in pregnancy, Hollingshead SES, maternal age at enrollment, maternal smoking status and gestational age at enrollment. Stabilized inverse probability censoring weights were applied to account for loss to follow up.

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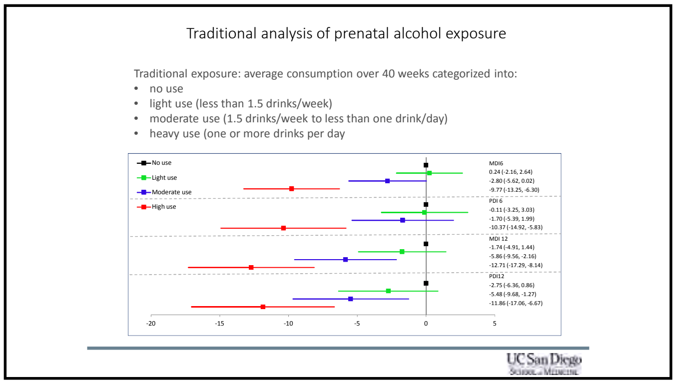
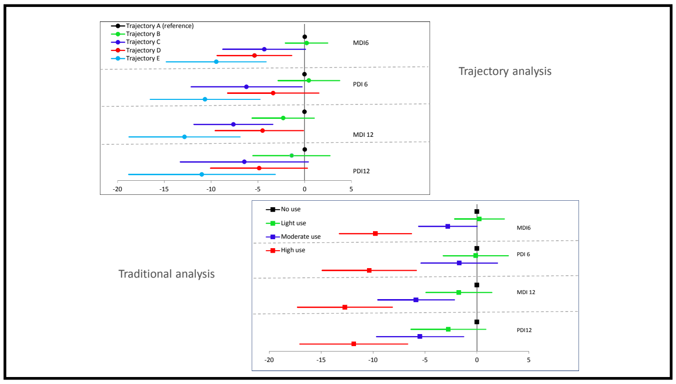


Traditional analysis of prenatal alcohol exposure

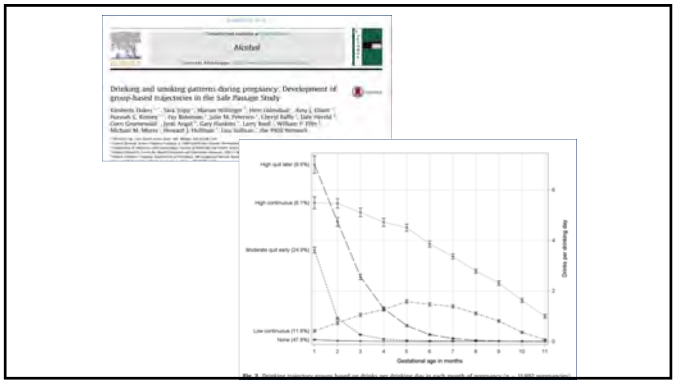
Traditional exposure: average consumption over 40 weeks categorized into:

- no use
- light use (less than 1.5 drinks/week)
- moderate use (1.5 drinks/week to less than one drink/day)
- heavy use (one or more drinks per day



Trajectory analysis

Traditional analysis



Alcohol

Drinking and smoking patterns during pregnancy: Development of group-based trajectories in the Safe Passage Study

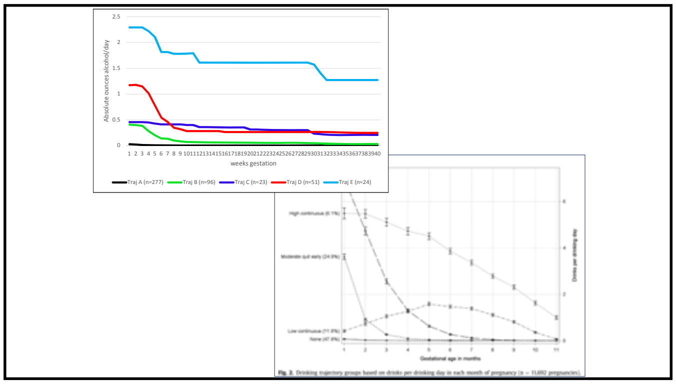
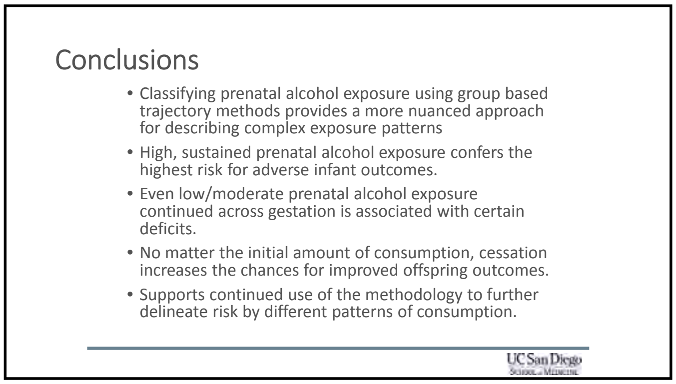


Fig. 2. Drinking trajectory groups based on drinks per drinking day in each month of pregnancy (n = 11,692 pregnancies).



Conclusions

- Classifying prenatal alcohol exposure using group based trajectory methods provides a more nuanced approach for describing complex exposure patterns
- High, sustained prenatal alcohol exposure confers the highest risk for adverse infant outcomes.
- Even low/moderate prenatal alcohol exposure continued across gestation is associated with certain deficits.
- No matter the initial amount of consumption, cessation increases the chances for improved offspring outcomes.
- Supports continued use of the methodology to further delineate risk by different patterns of consumption.

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- CoFASP
- We wish to acknowledge the contribution of: OMNI-Net, Ukraine, and participating families and staff in Rivne and Khmelnytsky, Ukraine.
- Full paper: Bandoli G, Coles CD, Kable JA, et al. Patterns of Prenatal Alcohol Use That Predict Infant Growth and Development. Pediatrics. January 2019:e20182399. doi:10.1542/peds.2018-2399.

E3c

The Impact of Maltreatment on Cognitive and Behavioural Functioning in Children with FASD

Alan Price

Learning Objectives

1. Describe current knowledge on the impact of trauma in children with FASD
2. Discuss the experiences of adoptive parents of children with FASD and trauma in the UK
3. Explain social policy problems relevant to children with FASD and trauma in the UK

Children with Foetal Alcohol Spectrum Disorders (FASD) and children with a history of traumatic experiences such as neglect or abuse (trauma) in early childhood, can develop a similar pattern of cognitive and behavioural difficulties. In children with both FASD and a history of trauma, there might be a compounding effect, where cognitive and/or behavioural functioning is more severely impacted compared to children with either single exposure, but this question has not been sufficiently addressed. Meanwhile, it has been suggested that the kinds of adverse environments that children with FASD often experience, could impact the presentation of FASD, or better explain some of its symptoms.

We designed a series of studies to address the question: What is the impact of trauma on cognitive and behavioural functioning in children with FASD? First, a systematic literature review was conducted of published research into the dual exposure of prenatal alcohol and postnatal trauma. Following this, an online survey with measures of trauma, empathy and behavioural difficulties was completed by 245 carers of children aged 4-16 with FASD. Next, a cognitive study was conducted where intelligence, working memory and inhibitory control were assessed in three groups of children aged 8-14 – one group with FASD and trauma, another group with FASD without trauma, and a group of typically developing control children. Functional near infra-red spectroscopy (fNIRS) was used to detect any differences in activity in the prefrontal cortex between the three groups during the working memory task. Finally, a series of semi-structured interviews was conducted with 12 adoptive parents (or pairs of parents) of children aged 8-14 with FASD, around half of whom also had a history of trauma.

The systematic review revealed that only three studies had investigated the impact of trauma in children with FASD. Two further studies had also investigated the impact of FASD in children with trauma. The review found that FASD was associated with more severe cognitive and behavioural deficits in children with trauma, but the impact of trauma in children with FASD appeared to be more subtle. The online survey found children with FASD had severe behavioural difficulties and poor empathy, but found no relationship between trauma and empathy, and a weak positive correlation between trauma and behavioural difficulties in children with FASD. The cognitive study found children with FASD had average intelligence, and their inhibitory control and working memory scores were similar to those of typically developing children. It also found no impact of trauma on intelligence, working memory or inhibitory control in children with FASD. The fNIRS data showed no difference in prefrontal cortex activity between the three groups. The parents of children with FASD children reported behavioural problems in their children, and that these were difficult and stressful. Parents of children with FASD and a history of trauma also reported that their children received some services related to attachment and trauma, but no children received services designed for children with FASD. The parents' biggest concern was the lack of recognition and support for children with FASD. Schools, adoption agencies and Social Services seemed to be set up to deal with trauma or attachment issues in children, but many did not have appropriate training to deal with children with FASD.

The conclusion of these studies is that behavioural functioning and empathy in children with FASD can be problematic regardless of a history of trauma, and that the impact of trauma on cognitive and behavioural functioning may be relatively subtle in children with FASD. Healthcare, social and educational professionals should be aware that in children with both exposures, any cognitive or behavioural dysfunction may be more likely to be due to FASD than trauma. As such, children with these histories should be considered prenatally, rather than environmentally affected, and should be treated accordingly. Further studies are needed to extend these findings, especially that separate the effects of abuse from the effects of neglect, and that also include a group of children with trauma but not FASD.

E3d

Nutrition Implications for FASD

Sunil Bishwokarma

Learning Objectives

1. Determine the optimal amount of a nutrient needed to reduce a specific detrimental outcome of FASD and on the long-term effects of such supplementation
2. Determine the nutritional status of the pregnant women at risk of alcohol consumption to establish the need for nutritional intervention

Abstract

Prenatal alcohol exposure produces a multitude of detrimental alcohol-induced defects in children collectively known as fetal alcohol spectrum disorder (FASD). Children with FASD often exhibit delayed or abnormal mental, neural, and physical growth. Socioeconomic status, race, genetics, parity, gravidity, age, smoking, and alcohol consumption patterns are all factors that may influence FASD. Optimal maternal nutritional status is of utmost importance for proper fetal development, yet is often altered with alcohol consumption. It is critical to determine a means to resolve and reduce the physical and neurological malformations that develop in the fetus as a result of prenatal alcohol exposure. Because there is a lack of information on the role of nutrients and prenatal nutrition interventions for FASD, the focus of this review is to provide an overview of nutrients (vitamin A, docosahexaenoic acid, folic acid, zinc, choline, vitamin E, and selenium) that may prevent or alleviate the development of FASD. Results from various nutrient supplementation studies in animal models and FASD-related research conducted in humans provide insight into the plausibility of prenatal nutrition interventions for FASD. Further research is necessary to confirm positive results, to determine optimal amounts of nutrients needed in supplementation, and to investigate the collective effects of multiple-nutrient supplementation.

FASD is a complex, multifactorial, and intriguing disorder. The consequences that can ensue from alcohol consumption vary on the spectrum from producing little to no effect to fetal mortality. Because numerous metabolic derangements can develop as a result of alcohol consumption during pregnancy, it is critical to find ways to minimize and reduce the physical and neurological malformations that develop in the fetus. Although robust information on the role of nutrients and intervention are scarce in FASD, potential nutrients have been reviewed, such as vitamin A, DHA, folic acid, zinc, choline, vitamin E, and selenium. The information garnered yielded mixed results regarding the impact of supplementation. Consequently, nutrient supplementation is only a part of a total strategy to ameliorate the impact of FASD.

Regardless of alcohol consumption, prenatal supplementation must be carefully planned to avoid the risk of human pregnancy complications. High concentrations of plasma vitamin A can cause teratogenic effects, and there is evidence of increased cancer risks with folic acid supplementation . Single nutrients should be more carefully monitored. Because FASD is the result of multiple metabolic impairments, supplementation with 1 nutrient may not be effective to fully reverse the damage induced by alcohol consumption. As stated in the Introduction, there are questions regarding how much and which nutrients should be provided during pregnancy to alleviate the severity of the outcome of FASD. It would be ideal if we could follow the nutritional status of alcohol-consuming pregnant mothers throughout pregnancy. However, this is difficult to accomplish because of significant underreporting by affected individuals.

E4a Using Technology in Novel Approaches to Prevent Alcohol Exposed Pregnancies

Jessica Hanson, Mary Velasquez, Karen Ingersoll

Learning Objectives Session E4a

- **Learning Objectives:**
- Identify the key components of evidence-based face to face interventions for AEP
- Describe three examples of how face to face interventions can be transformed for technological delivery or data collection.
- Provide demonstrations of online or technologically-based AEP prevention programs
- Detail lessons learned and pilot outcomes from studies using technology to prevent alcohol-exposed pregnancies

Pilot Efficacy of an eHealth Intervention to Reduce AEP Risk: *CARRII*

8th International Conference on FASD
March 9, 2019 Session E4a

Karen Ingersoll, PhD, University of Virginia
kareningersoll@virginia.edu

Alcohol-Exposed Pregnancy

- Occurs when alcohol is ingested during pregnancy
- 50% of U.S. pregnancies are unintended
- Challenging to find childbearing age (18-44) women, drinking at risky levels, not intending pregnancy, but not preventing it with effective, consistent contraception habits, and screen/intervene
- Goals: reduce risky drinking AND increase effective and consistent contraception

eHealth Interventions

- Usually transform evidence-based F2F health behavior interventions for web delivery
- Not a static website
- Intervention uses functions enabled by web delivery
  - Automated, prompted assessment
  - Information provided via multimedia
  - Personalization to user based on prior answers
  - Interactivity to engage user, encourage exploration of alternatives, and encourage user choices and decisions
  - May use weekly metering and self-monitoring HW to mimic F2F counseling

Basis of CARRII: CHOICES

- 4 sessions of MI+ Feedback for women who drink at risky levels and use ineffective contraception (AEP risk), with all intervention content (information and evoking own choices) personalized and tailored to each woman by the counselor
- Primary outcomes from an efficacy trial with 830 women showed that CHOICES reduced the proportion of women at risk for AEP from 100% to 34% on average.
- Secondary analyses showed that both the CHOICES Activities and the Motivational Interviewing style contributed to changes in drinking and contraception.
- CHOICES is an NREPP program disseminated by

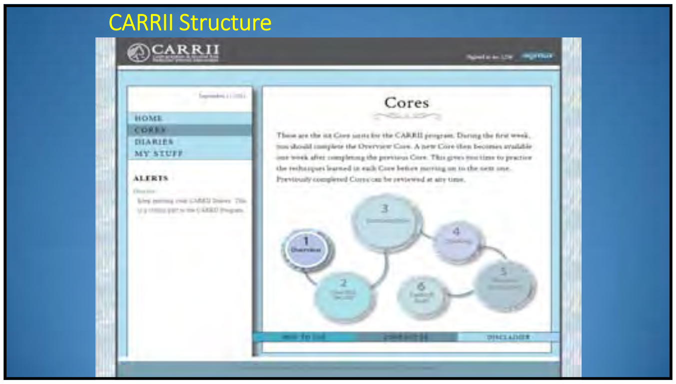
CARRII – Contraception and Alcohol Risk Reduction Internet Intervention

CARRII Home

Great job completing the How To Use tutorial.

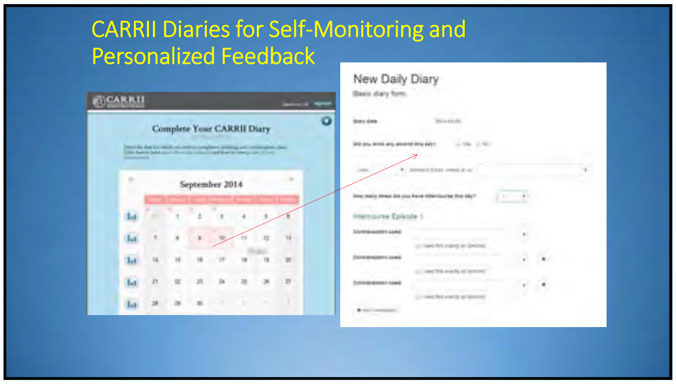
It is now time to complete the Overview Core.

Click the CORES button to the left and select the Overview Core. The icon for the Overview Core is displayed in color and clickable. All other Cores will be grayed out because they are not yet available to review.

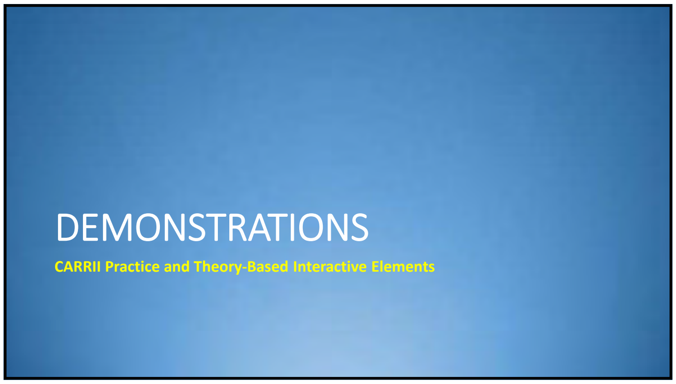


CARRII Structure

These are the six Core units for the CARRII program. During the first week, you should complete the Overview Core. A new Core then becomes available one week after completing the previous Core. This gives you time to practice the techniques learned in each Core before moving on to the next one. Previously completed Cores can be reviewed at any time.

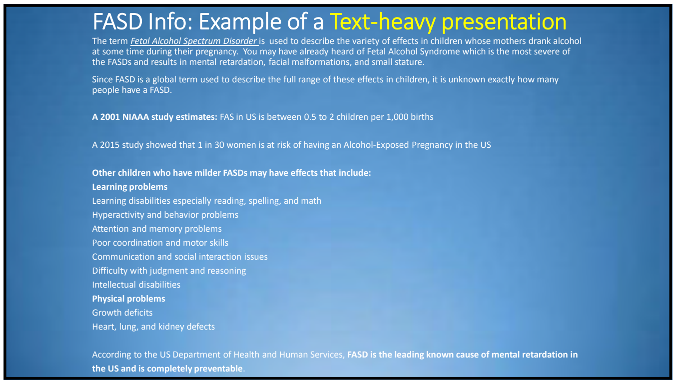


CARRII Diaries for Self-Monitoring and Personalized Feedback



DEMONSTRATIONS

CARRII Practice and Theory-Based Interactive Elements



FASD Info: Example of a Text-heavy presentation

The term *Fetal Alcohol Spectrum Disorder* is used to describe the variety of effects in children whose mothers drank alcohol at some time during their pregnancy. You may have already heard of Fetal Alcohol Syndrome which is the most severe of the FASDs and results in mental retardation, facial malformations, and small stature.

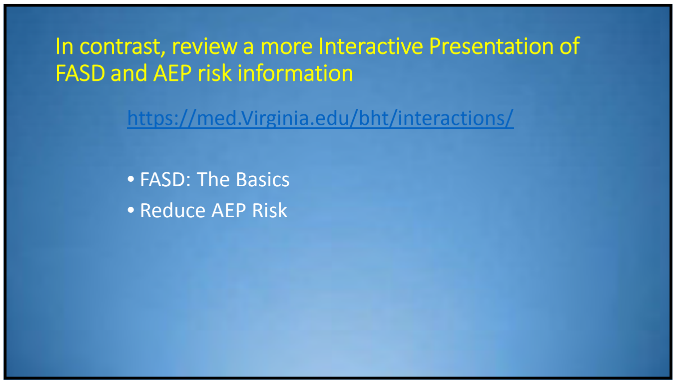
Since FASD is a global term used to describe the full range of these effects in children, it is unknown exactly how many people have a FASD.

A 2001 NIAAA study estimates: FAS in US is between 0.5 to 2 children per 1,000 births

A 2015 study showed that 1 in 30 women is at risk of having an Alcohol-Exposed Pregnancy in the US

Other children who have milder FASDs may have effects that include:
Learning problems
Learning disabilities especially reading, spelling, and math
Hyperactivity and behavior problems
Attention and memory problems
Poor coordination and motor skills
Communication and social interaction issues
Difficulty with judgment and reasoning
Intellectual disabilities
Physical problems
Growth deficits
Heart, lung, and kidney defects

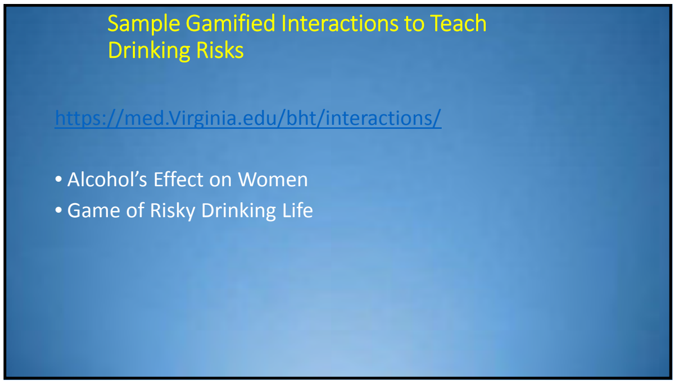
According to the US Department of Health and Human Services, **FASD is the leading known cause of mental retardation in the US and is completely preventable**.



In contrast, review a more Interactive Presentation of FASD and AEP risk information

https://med.Virginia.edu/bht/interactions/

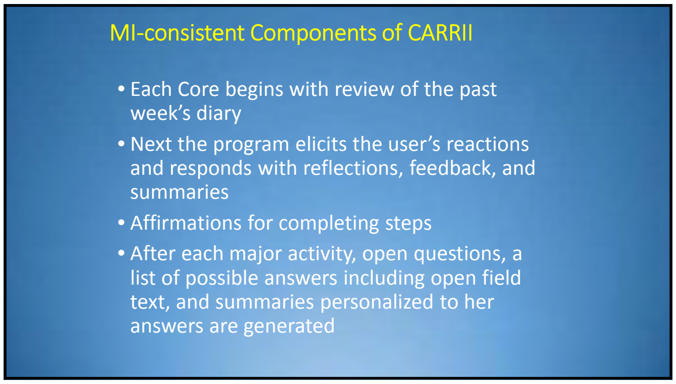
- FASD: The Basics
- Reduce AEP Risk



Sample Gamified Interactions to Teach Drinking Risks

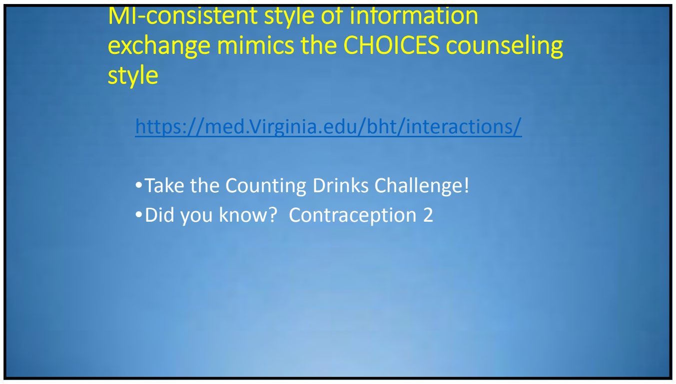
https://med.Virginia.edu/bht/interactions/

- Alcohol's Effect on Women
- Game of Risky Drinking Life



MI-consistent Components of CARRII

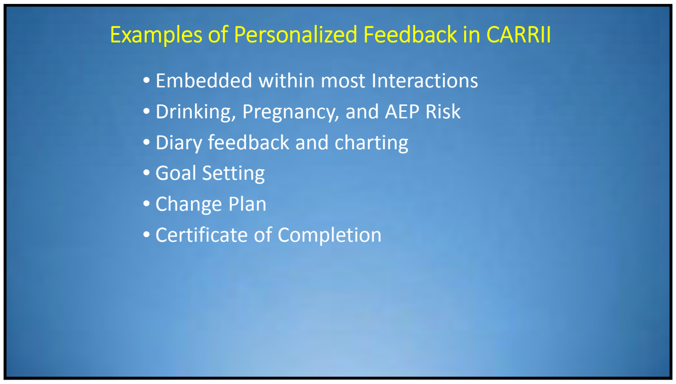
- Each Core begins with review of the past week's diary
- Next the program elicits the user's reactions and responds with reflections, feedback, and summaries
- Affirmations for completing steps
- After each major activity, open questions, a list of possible answers including open field text, and summaries personalized to her answers are generated



MI-consistent style of information exchange mimics the CHOICES counseling style

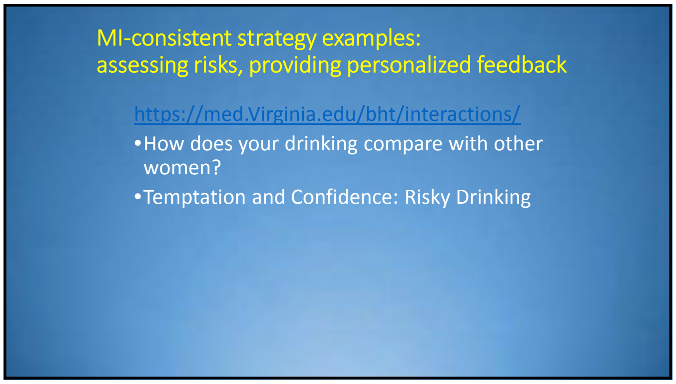
https://med.Virginia.edu/bht/interactions/

- Take the Counting Drinks Challenge!
- Did you know? Contraception 2



Examples of Personalized Feedback in CARRII

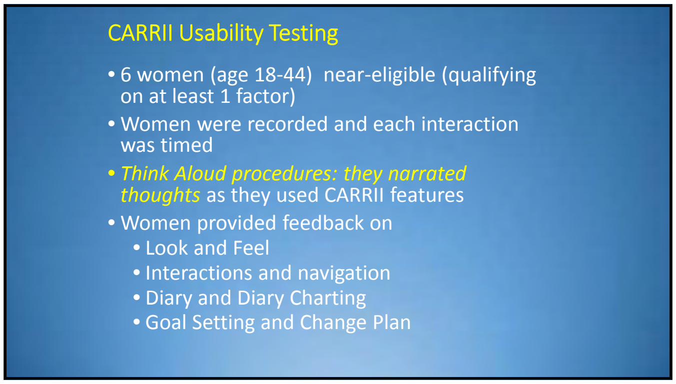
- Embedded within most Interactions
- Drinking, Pregnancy, and AEP Risk
- Diary feedback and charting
- Goal Setting
- Change Plan
- Certificate of Completion



MI-consistent strategy examples: assessing risks, providing personalized feedback

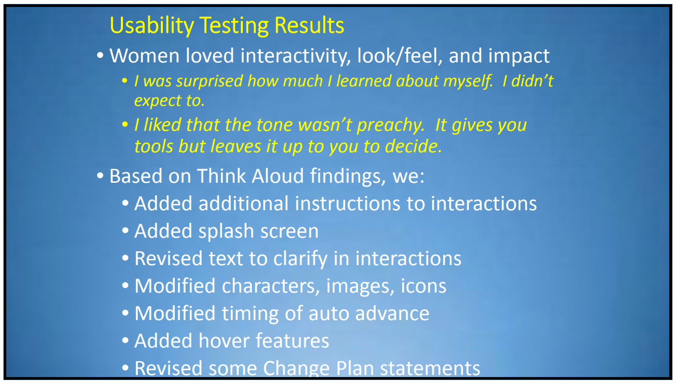
https://med.Virginia.edu/bht/interactions/

- How does your drinking compare with other women?
- Temptation and Confidence: Risky Drinking



CARRII Usability Testing

- 6 women (age 18-44) near-eligible (qualifying on at least 1 factor)
- Women were recorded and each interaction was timed
- *Think Aloud procedures: they narrated thoughts* as they used CARRII features
- Women provided feedback on
  - Look and Feel
  - Interactions and navigation
  - Diary and Diary Charting
  - Goal Setting and Change Plan



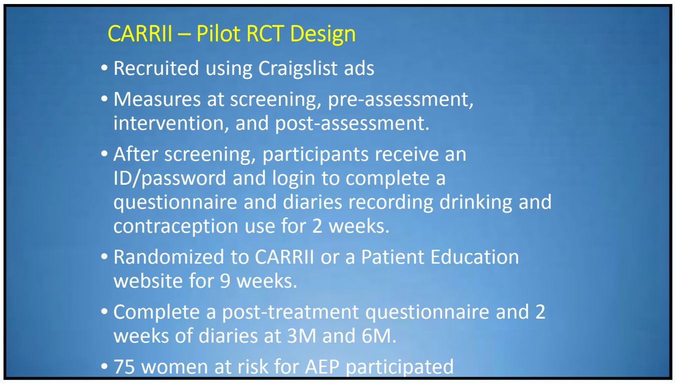
Usability Testing Results

- Women loved interactivity, look/feel, and impact
  - *I was surprised how much I learned about myself. I didn't expect to.*
  - *I liked that the tone wasn't preachy. It gives you tools but leaves it up to you to decide.*
- Based on Think Aloud findings, we:
  - Added additional instructions to interactions
  - Added splash screen
  - Revised text to clarify in interactions
  - Modified characters, images, icons
  - Modified timing of auto advance
  - Added hover features
  - Revised some Change Plan statements

CARRII Pilot RCT

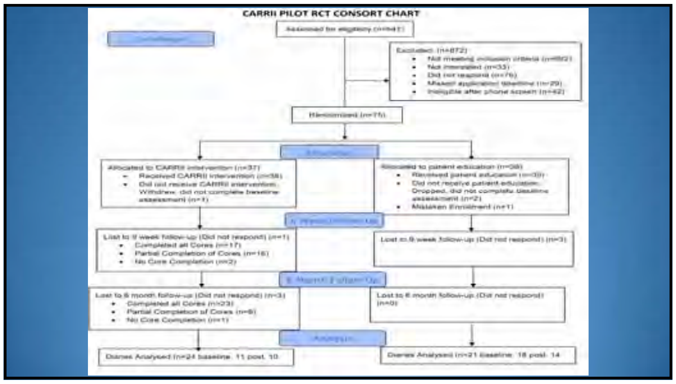
NIH R34 AA020853

Ingersoll K, Frederick C, MacDonnell K, et al. A Pilot RCT of an Internet Intervention to Reduce the Risk of Alcohol-Exposed Pregnancy. *Alcohol Clin Exp Res*. 2018;42(6):1132-1144. doi:10.1111/acer.13635



CARRII – Pilot RCT Design

- Recruited using Craigslist ads
- Measures at screening, pre-assessment, intervention, and post-assessment.
- After screening, participants receive an ID/password and login to complete a questionnaire and diaries recording drinking and contraception use for 2 weeks.
- Randomized to CARRII or a Patient Education website for 9 weeks.
- Complete a post-treatment questionnaire and 2 weeks of diaries at 3M and 6M.
- 75 women at risk for AEP participated



CARRII PILOT RCT CONSORT CHART

Enrollment

Assessed for eligibility (n=947)

Excluded (n=872)
- Not meeting inclusion criteria (n=692)
- Not interested (n=33)
- Did not respond (n=76)
- Missed application timeline (n=29)
- Ineligible after phone screen (n=42)

Randomized (n=75)

Allocation

Allocated to CARRII intervention (n=37)
- Received CARRII intervention (n=36)
- Did not receive CARRII intervention: Withdrew, did not complete baseline assessment (n=1)

Allocated to patient education (n=38)
- Received patient education (n=35)
- Did not receive patient education: Dropped, did not complete baseline assessment (n=2)
- Mistaken Enrollment (n=1)

9 Week Follow-Up

Lost to 9 week follow-up (Did not respond) (n=1)
- Completed all Cores (n=17)
- Partial Completion of Cores (n=16)
- No Core Completion (n=2)

Lost to 9 week follow-up (Did not respond) (n=3)

6 Month Follow-Up

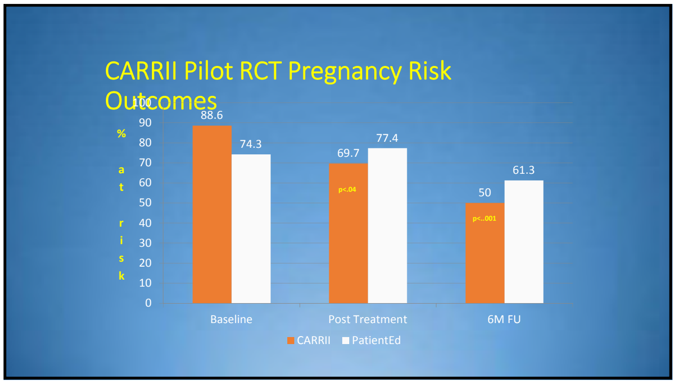
Lost to 6 month follow-up (Did not respond) (n=3)
- Completed all Cores (n=23)
- Partial Completion of Cores (n=6)
- No Core Completion (n=1)

Lost to 6 month follow-up (Did not respond) (n=0)

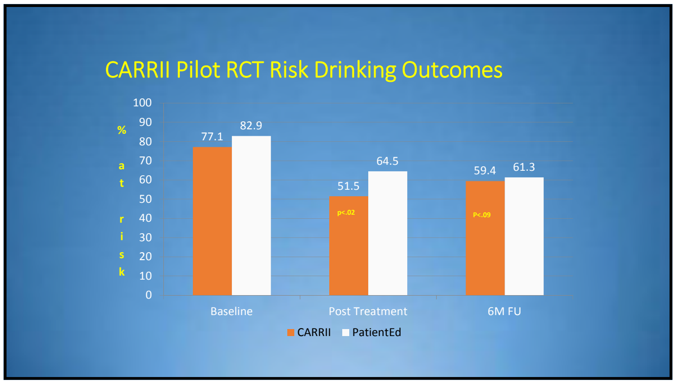
Analysis

Diaries Analysed (n=24 baseline, 11 post, 10

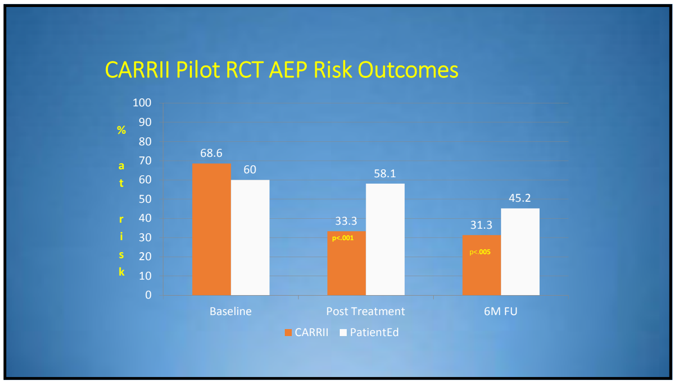
Diaries Analysed (n=21 baseline, 18 post, 14



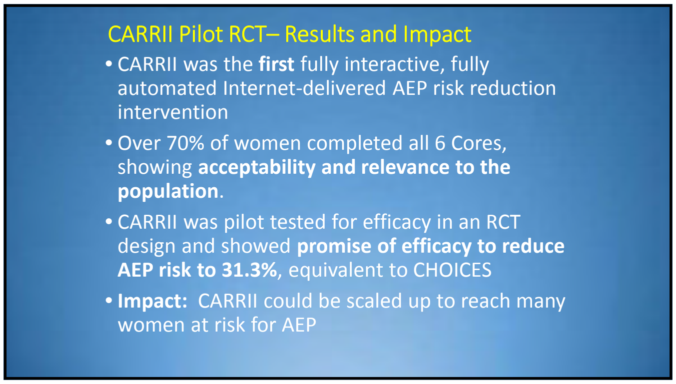
CARRII Pilot RCT Pregnancy Risk Outcomes



CARRII Pilot RCT Risk Drinking Outcomes

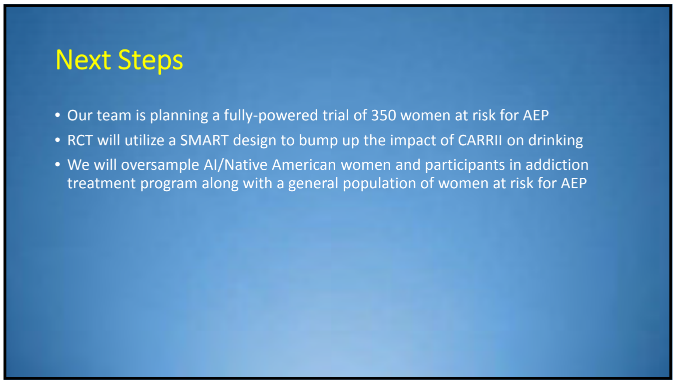


CARRII Pilot RCT AEP Risk Outcomes



CARRII Pilot RCT– Results and Impact

- CARRII was the **first** fully interactive, fully automated Internet-delivered AEP risk reduction intervention
- Over 70% of women completed all 6 Cores, showing **acceptability and relevance to the population**.
- CARRII was pilot tested for efficacy in an RCT design and showed **promise of efficacy to reduce AEP risk to 31.3%**, equivalent to CHOICES
- **Impact:** CARRII could be scaled up to reach many women at risk for AEP



Next Steps

- Our team is planning a fully-powered trial of 350 women at risk for AEP
- RCT will utilize a SMART design to bump up the impact of CARRII on drinking
- We will oversample AI/Native American women and participants in addiction treatment program along with a general population of women at risk for AEP

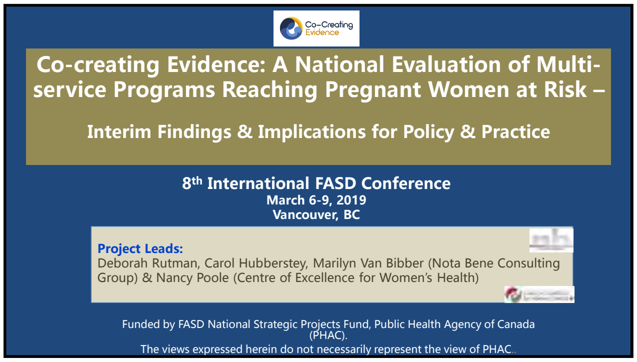
Thanks to the CARRII Team

- Karen Ingersoll Ph.D. , Principal Investigator
- Lee Ritterband Ph.D., Co-investigator
- Christina Frederick, Project Coordinator
- Michelle Hilgart, Ph.D., Instructional Designer
- Steve Johnson and Gabe Heath, Developers
- Mary Velasquez, Ph.D. Expert Reviewer
- Kirsten MacDonnell, Study Coordinator, and numerous undergraduate Research Assistants
- Holly Lord, Ph.D., Data Analyst
- Thanks to NIAAA for funding the R34 project!

E4b

Co-Creating Evidence: A National Evaluation of Multi-service Programs Reaching Pregnant Women at Risk - Interim Findings and Implications for Policy and Practice

Deborah Rutman, Carol Hubberstey, Marilyn Van Bibber, Nancy Poole



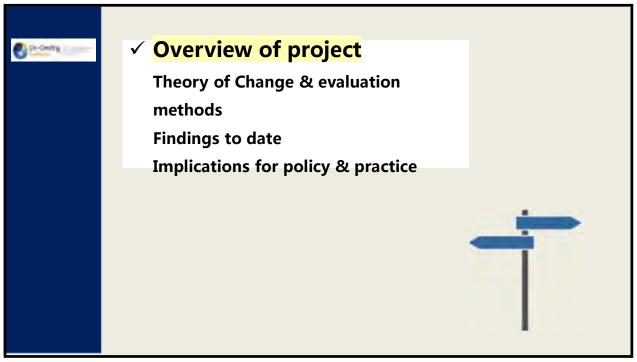
Co-creating Evidence: A National Evaluation of Multi-service Programs Reaching Pregnant Women at Risk –

Interim Findings & Implications for Policy & Practice

8th International FASD Conference
March 6-9, 2019
Vancouver, BC

Project Leads:
Deborah Rutman, Carol Hubberstey, Marilyn Van Bibber (Nota Bene Consulting Group) & Nancy Poole (Centre of Excellence for Women's Health)

Funded by FASD National Strategic Projects Fund, Public Health Agency of Canada (PHAC).
The views expressed herein do not necessarily represent the view of PHAC.

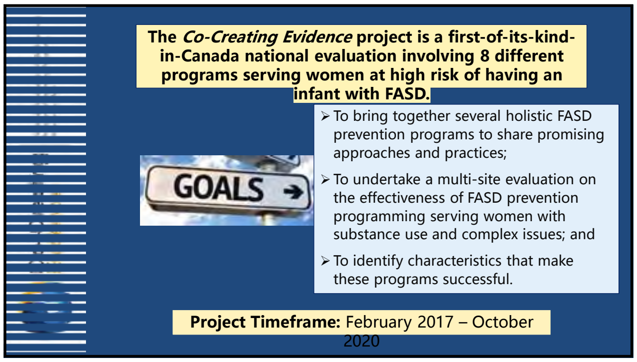


✓ **Overview of project**

Theory of Change & evaluation methods

Findings to date

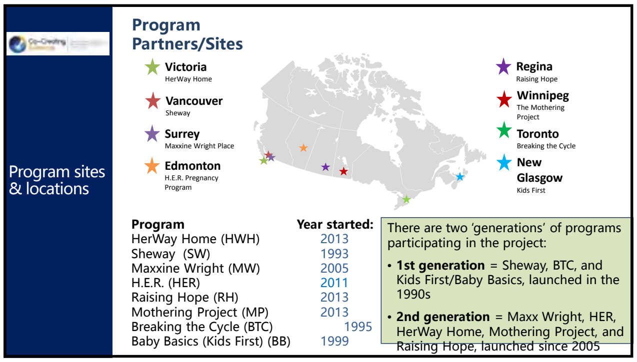
Implications for policy & practice



The *Co-Creating Evidence* project is a first-of-its-kind-in-Canada national evaluation involving 8 different programs serving women at high risk of having an infant with FASD.

- To bring together several holistic FASD prevention programs to share promising approaches and practices;
- To undertake a multi-site evaluation on the effectiveness of FASD prevention programming serving women with substance use and complex issues; and
- To identify characteristics that make these programs successful.

Project Timeframe: February 2017 – October 2020



Program sites & locations

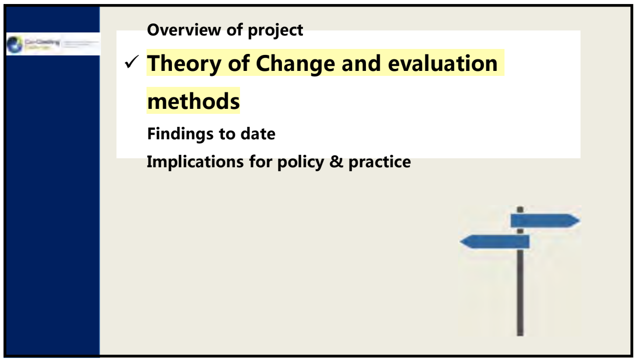
Program Partners/Sites

Victoria HerWay Home
Vancouver Sheway
Surrey Maxxine Wright Place
Edmonton H.E.R. Pregnancy Program
Regina Raising Hope
Winnipeg The Mothering Project
Toronto Breaking the Cycle
New Glasgow Kids First

Program	**Year started:**
HerWay Home (HWH)	2013
Sheway (SW)	1993
Maxxine Wright (MW)	2005
H.E.R. (HER)	2011
Raising Hope (RH)	2013
Mothering Project (MP)	2013
Breaking the Cycle (BTC)	1995
Baby Basics (Kids First) (BB)	1999

There are two 'generations' of programs participating in the project:

- **1st generation** = Sheway, BTC, and Kids First/Baby Basics, launched in the 1990s
- **2nd generation** = Maxx Wright, HER, HerWay Home, Mothering Project, and Raising Hope, launched since 2005

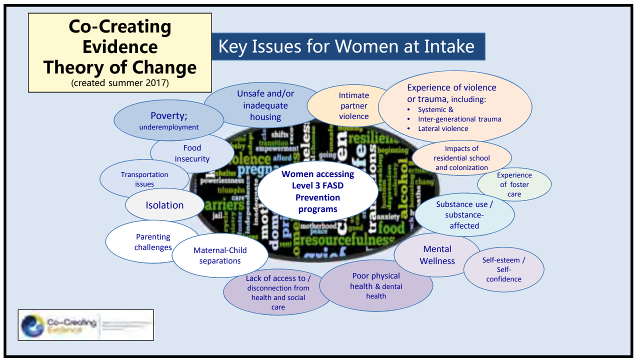


Overview of project

✓ **Theory of Change and evaluation methods**

Findings to date

Implications for policy & practice



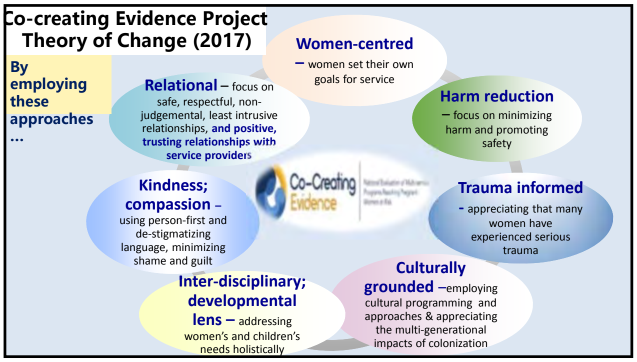
Co-Creating Evidence Theory of Change
(created summer 2017)

Key Issues for Women at Intake

Women accessing Level 3 FASD Prevention programs

Unsafe and/or inadequate housing
Intimate partner violence
Experience of violence or trauma, including:
- Systemic &
- Inter-generational trauma
- Lateral violence

Impacts of residential school and colonization
Experience of foster care
Substance use / substance-affected
Self-esteem / Self-confidence
Mental Wellness
Poor physical health & dental health
Lack of access to / disconnection from health and social care
Maternal-Child separations
Parenting challenges
Isolation
Transportation issues
Food insecurity
Poverty; underemployment



Co-creating Evidence Project Theory of Change (2017)

By employing these approaches …

Relational – focus on safe, respectful, non-judgemental, least intrusive relationships, **and positive, trusting relationships with service providers**

Women-centred – women set their own goals for service

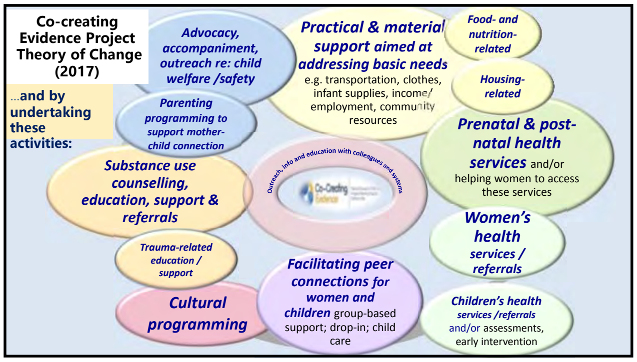
Harm reduction – focus on minimizing harm and promoting safety

Kindness; compassion – using person-first and de-stigmatizing language, minimizing shame and guilt

Trauma informed - appreciating that many women have experienced serious trauma

Inter-disciplinary; developmental lens – addressing women's and children's needs holistically

Culturally grounded –employing cultural programming and approaches & appreciating the multi-generational impacts of colonization



Co-creating Evidence Project Theory of Change (2017)

…and by undertaking these activities:

Advocacy, accompaniment, outreach re: child welfare /safety

Parenting programming to support mother-child connection

Practical & material support aimed at addressing basic needs e.g. transportation, clothes, infant supplies, income/ employment, community resources

Food- and nutrition-related

Housing-related

Substance use counselling, education, support & referrals

Outreach, info and education with colleagues and systems

Prenatal & post-natal health services and/or helping women to access these services

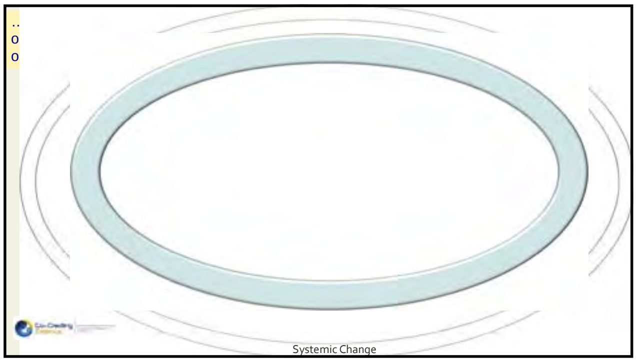
Trauma-related education / support

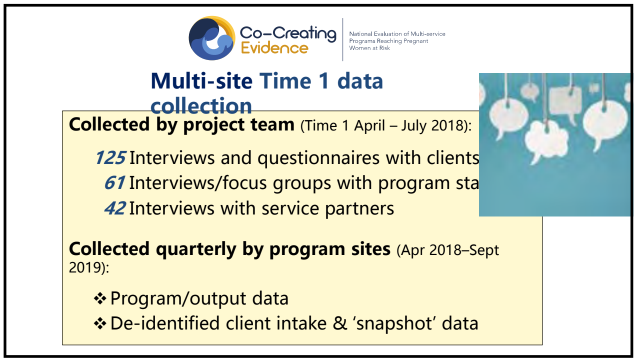
Women's health services / referrals

Cultural programming

Facilitating peer connections for women and children group-based support; drop-in; child care

Children's health services /referrals and/or assessments, early intervention





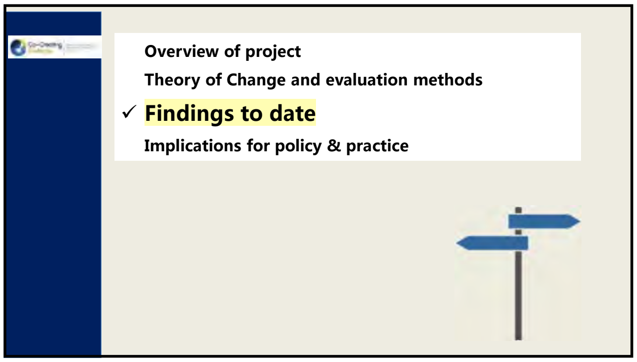
Multi-site Time 1 data collection

Collected by project team (Time 1 April – July 2018):

125 Interviews and questionnaires with clients
61 Interviews/focus groups with program sta
42 Interviews with service partners

Collected quarterly by program sites (Apr 2018–Sept 2019):

❖ Program/output data
❖ De-identified client intake & 'snapshot' data



Overview of project

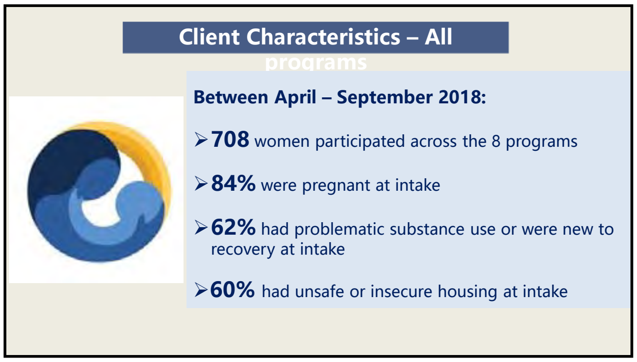
Theory of Change and evaluation methods

✓ **Findings to date**

Implications for policy & practice

At a glance:
What services/activities do the programs provide?

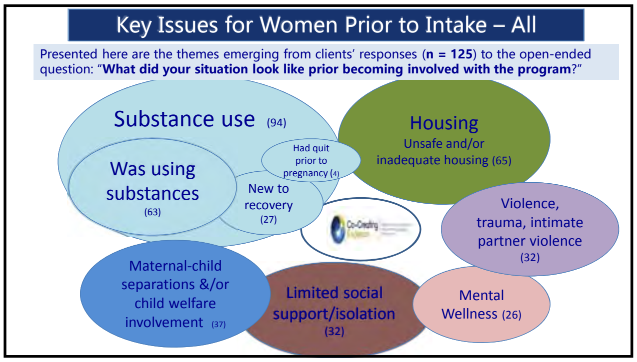
Child care on site
Housing
Pre-natal / post-natal
Substance use counselling
Child welfare support
Basic needs support
Mental health/ trauma
Food / nutrition
Outreach
Cultural programming



Client Characteristics – All programs

Between April – September 2018:

- **708** women participated across the 8 programs
- **84%** were pregnant at intake
- **62%** had problematic substance use or were new to recovery at intake
- **60%** had unsafe or insecure housing at intake



Key Issues for Women Prior to Intake – All

Presented here are the themes emerging from clients' responses (**n = 125**) to the open-ended question: "**What did your situation look like prior becoming involved with the program**?"

Substance use (94)

Was using substances (63)

New to recovery (27)

Had quit prior to pregnancy (4)

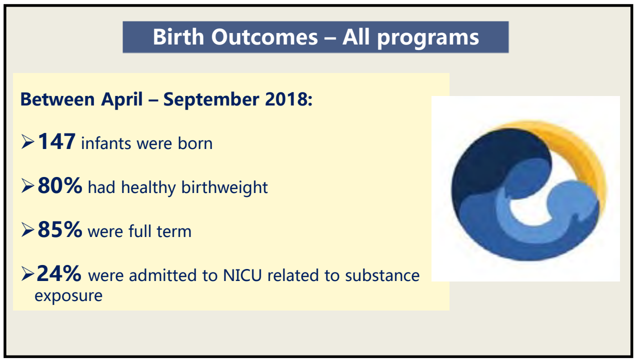
Housing
Unsafe and/or inadequate housing (65)

Violence, trauma, intimate partner violence (32)

Maternal-child separations &/or child welfare involvement (37)

Limited social support/isolation (32)

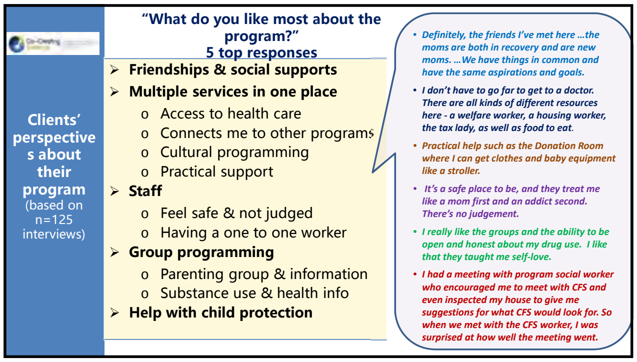
Mental Wellness (26)



Birth Outcomes – All programs

Between April – September 2018:

- **147** infants were born
- **80%** had healthy birthweight
- **85%** were full term
- **24%** were admitted to NICU related to substance exposure



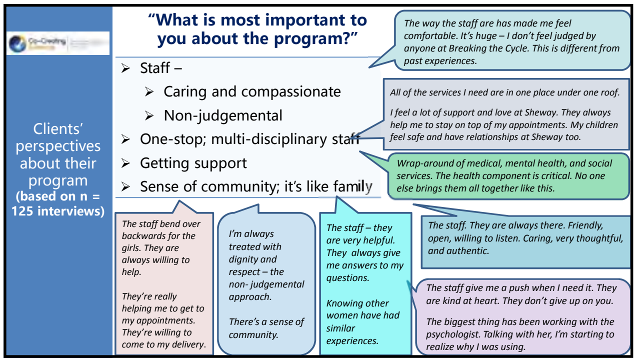
Clients' perspectives about their program (based on n=125 interviews)

"What do you like most about the program?"

5 top responses

- **Friendships & social supports**
- **Multiple services in one place**
  - Access to health care
  - Connects me to other programs
  - Cultural programming
  - Practical support
- **Staff**
  - Feel safe & not judged
  - Having a one to one worker
- **Group programming**
  - Parenting group & information
  - Substance use & health info
- **Help with child protection**

- *Definitely, the friends I've met here …the moms are both in recovery and are new moms. …We have things in common and have the same aspirations and goals.*
- *I don't have to go far to get to a doctor. There are all kinds of different resources here - a welfare worker, a housing worker, the tax lady, as well as food to eat.*
- *Practical help such as the Donation Room where I can get clothes and baby equipment like a stroller.*
- *It's a safe place to be, and they treat me like a mom first and an addict second. There's no judgement.*
- *I really like the groups and the ability to be open and honest about my drug use. I like that they taught me self-love.*
- *I had a meeting with program social worker who encouraged me to meet with CFS and even inspected my house to give me suggestions for what CFS would look for. So when we met with the CFS worker, I was surprised at how well the meeting went.*



Clients' perspectives about their program (**based on n = 125 interviews**)

"What is most important to you about the program?"

- Staff –
  - Caring and compassionate
  - Non-judgemental
- One-stop; multi-disciplinary staff
- Getting support
- Sense of community; it's like family

The way the staff are has made me feel comfortable. It's huge – I don't feel judged by anyone at Breaking the Cycle. This is different from past experiences.

All of the services I need are in one place under one roof.

I feel a lot of support and love at Sheway. They always help me to stay on top of my appointments. My children feel safe and have relationships at Sheway too.

Wrap-around of medical, mental health, and social services. The health component is critical. No one else brings them all together like this.

The staff bend over backwards for the girls. They are always willing to help.

They're really helping me to get to my appointments. They're willing to come to my delivery.

I'm always treated with dignity and respect – the non- judgemental approach.

There's a sense of community.

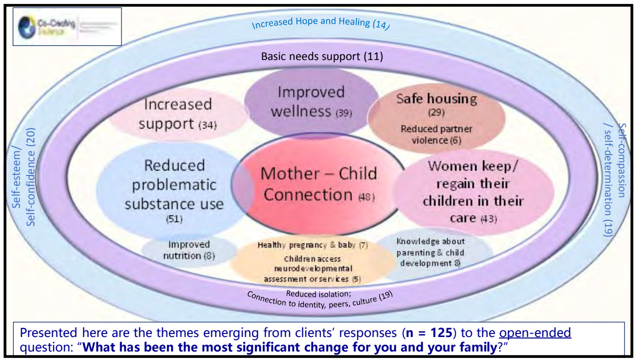
The staff – they are very helpful. They always give me answers to my questions.

Knowing other women have had similar experiences.

The staff. They are always there. Friendly, open, willing to listen. Caring, very thoughtful, and authentic.

The staff give me a push when I need it. They are kind at heart. They don't give up on you.

The biggest thing has been working with the psychologist. Talking with her, I'm starting to realize why I was using.



Increased Hope and Healing (14)

Basic needs support (11)

Self-esteem/ Self-confidence (20)

Self-compassion / self-determination (19)

Increased support (34)

Improved wellness (39)

Safe housing (29)

Reduced partner violence (6)

Reduced problematic substance use (51)

Mother – Child Connection (48)

Women keep/ regain their children in their care (43)

Improved nutrition (8)

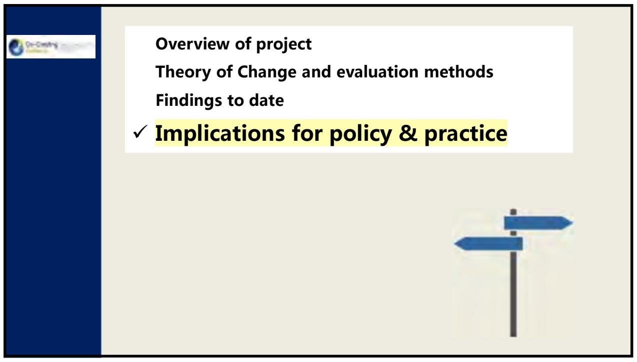
Healthy pregnancy & baby (7)

Children access neurodevelopmental assessment or services (5)

Knowledge about parenting & child development 8)

Reduced isolation; Connection to identity, peers, culture (19)

Presented here are the themes emerging from clients' responses (**n = 125**) to the open-ended question: "**What has been the most significant change for you and your family**?"

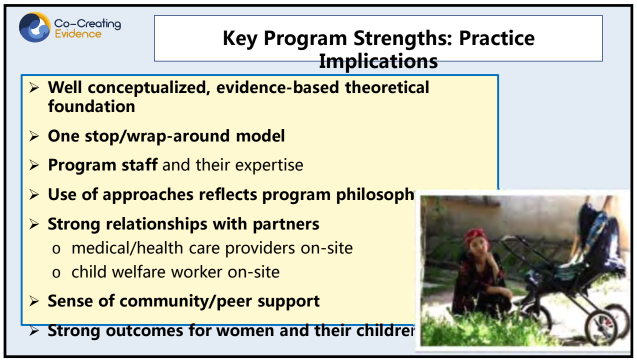


Overview of project

Theory of Change and evaluation methods

Findings to date

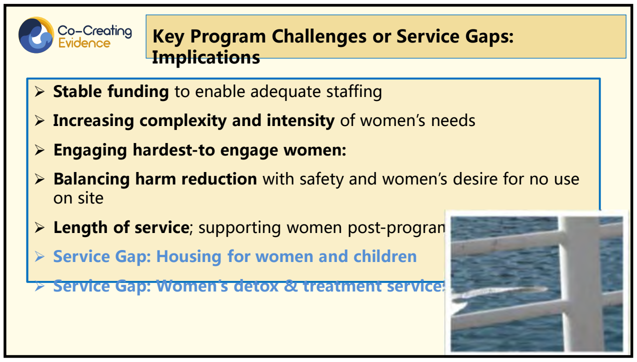
✓ Implications for policy & practice



Co-Creating Evidence

Key Program Strengths: Practice Implications

- **Well conceptualized, evidence-based theoretical foundation**
- **One stop/wrap-around model**
- **Program staff** and their expertise
- **Use of approaches reflects program philosoph**
- **Strong relationships with partners**
    - medical/health care providers on-site
    - child welfare worker on-site
- **Sense of community/peer support**
- **Strong outcomes for women and their childre**



Co-Creating Evidence

Key Program Challenges or Service Gaps: Implications

- **Stable funding** to enable adequate staffing
- **Increasing complexity and intensity** of women's needs
- **Engaging hardest-to engage women:**
- **Balancing harm reduction** with safety and women's desire for no use on site
- **Length of service**; supporting women post-progran
- Service Gap: Housing for women and children
- Service Gap: Women's detox & treatment service

Co-Creating Evidence

Lessons learned – Importance of:

- Taking time with the project's developmental phase; creating project 'identity'
- Bringing program partners together, early on and face-to-face, to build community and shared purpose
- Having frequent and regular communication and opportunities to provide input
- Providing adequate compensation to programs in recognition of staff's time
- Creating site-specific and synthesized/multi-site report/KT in formats that can be used flexible and can be used by programs

For more information:

Deborah Rutman or Carol Hubberstey

Nota Bene Consulting Group
drutman@uvic.ca or carolmarie@shaw.ca

E5

Service Evaluation of the Fetal Alcohol Assessment and Support Team in NHS Ayrshire and Arran, Scotland

Jennifer Shields, Fiona McGruer

Learning Objectives

1. Assess FASD service pathway provision in NHS Scotland and the UK
2. Acquire knowledge of the processes, outcomes and stakeholder perspectives of a service innovation novel to the Scottish context
3. Evaluate the appropriateness of broad neurodevelopmental versus specific FASD assessment pathways
4. Reflect on lived experience of FASD service pathways and carers' perceptions about difficulties accessing services

Objectives

Given an estimated UK prevalence of 2-6% (Popova et al, 2017; Lange et al, 2017), there is a critical need to develop FASD assessment and support services in Scotland. From 2015 - 2018, the FAAS Team piloted the first Scottish assessment, diagnosis and support pathway for children affected by prenatal alcohol exposure in NHS Ayrshire and Arran (based upon the Canadian diagnostic model, Cook et al, 2016). 36 pilot children received assessment, support and intervention from a multidisciplinary team comprising Occupational Therapy, Speech and Language Therapy, Clinical Psychology, Paediatrics and an FASD Coordinator. This work aimed to evaluate this pilot service and report learning regarding FASD assessment and diagnosis in the Scottish context, and the needs of affected children and families.

Methods

We utilised the trident method to evaluate the FAAS Team (Ellis & Hogard, 2006). This method involves the study of service process, outcomes from the service, and stakeholder perspectives on a service. The first element, (1) Process analysed inputs and the timeline provided by the FAAS Team versus treatment as usual (TAU) services (e.g. CAMHS and Community Paediatric teams). In respect of (2) Outcomes, we administered a pre/post questionnaire battery measuring: quality of life, mental health and behaviours in primary care givers and their children and recorded subsequent supports provided to children and families. (3) Perspectives comprised qualitative interviews with carers and educational professionals and satisfaction questionnaires administered to carers and multiagency professionals. In addition, we recorded the amount of training delivered by the FAAS Team and used pre/post questionnaires to measure training impacts.

Results

Process: The pilot FASD project provided input to over 200 children across NHS Ayrshire & Arran. This is the first Scottish health board to implement FASD assessment within treatment as usual services via multidisciplinary assessment and multiagency intervention.

Outcomes: Quality of life, mood and behaviour were negatively affected in children, particularly their resilience, perception of achievements, and risk taking behaviours. Care givers reported strong coping skills and belief in their parenting. All families were enabled to access education and community inputs.

Perspectives: themes from qualitative interviews indicated parents had to “fight to be heard” and subsequently “felt heard by the FAAS Team”. They reported experiencing stigma and felt their parenting was doubted. Professionals reported feeling “informed but not yet empowered” to work with affected individuals. Strategies were highlighted as an area where education professionals wished to collaborate more with clinicians. Questionnaires demonstrated satisfaction with FAAS Team work. Training was delivered to over 4000 individuals across Scotland.

Conclusions:

The FAAS Team pilot process led to implementation of FASD assessment in treatment as usual settings. The trident approach yielded information on necessary components of the assessment process, expected outcomes, and inputs required to support children and families affected by FASD in Scotland. Recommendations of this evaluation were submitted to the Scottish Government. The FAAS Team now has a national consultancy, training, research, and pathway development remit, to encourage the development of multiagency assessment and support services for those affected across Scotland.

E6

Playing to Our Strengths: Peer Mentoring for Teens and Adults with FASD

Michelle Stewart, Myles Himmelreich, Katrina Griffin, Krystal Glowatski

Learning Objectives

1. Describe the Playing to Our Strengths Toolkit
2. Conduct improv games from the Toolkit
3. Apply the logic of the mentors' creativity to the games in the Toolkit
4. Analyze the effectiveness of the Toolkit, based on long term evaluations

Abstract

The Asante Centre began a peer-to-peer mentoring group in fall 2017, where adults and youth living with FASD spend time together, learning about their disability, making friends, building community, and focusing on their strengths. In May 2018, the Playing to Our Strengths Toolkit (from Dr. Michelle Stewart's research) was incorporated into the mentoring group, along with lesson plans that focus on multimodal learning techniques – blending visual, verbal, and experiential approaches. The Toolkit was developed based on demand from people living with FASD for more focus on strengths, and less attention paid to deficits. The incorporation of the improv toolkit has added an extra element in the youth's understanding of various aspects of FASD, while also making learning fun, interactive, and hands-on – making the lessons more impactful. The youth have responded positively to the mentoring program, demonstrating extensive learning of their strengths, and perhaps even more importantly, have created a community of their own in which they can be themselves. Such a community has contributed to positive self-identity for the youth, which has also been noticed by their families, meaning the impacts of the group extend beyond the weekly mentoring sessions. As this is a new implementation of the Toolkit, ongoing evaluations have been conducted from the outset, reflecting success of the Toolkit, from the perspective of the mentors, as well as the need for flexibility in the toolkit, so the mentors can adapt activities in the moment. During this presentation, Dr. Stewart will discuss the development of the toolkit, and how the partnership with her research and the Asante Centre came to fruition. Myles and Katrina will lead experiential activities, demonstrating the adaptations made to the toolkit over time and discuss the lessons they have learned along this journey. Krystal will discuss the lesson plans, evaluation techniques, and results.

Methods

This is an evaluation project, focusing on the perspectives of the mentors regarding the Playing to Our Strengths Toolkit. Evaluation sessions were conducted weekly for a 14-week period, with a research assistant leading focused discussions with the adult mentors.

Results

Results indicate the toolkit has embedded strengths and weaknesses, such that the games in the toolkit can sometimes be too abstract for the developmental levels of the youth (as opposed to their chronological ages). Simultaneously, the mentors find the toolkit useful when thinking creatively in order to adapt games for a particular audience.

Conclusion

Many iterations of the games have been developed over time, effectively expanding the toolkit into positive, and useful directions.

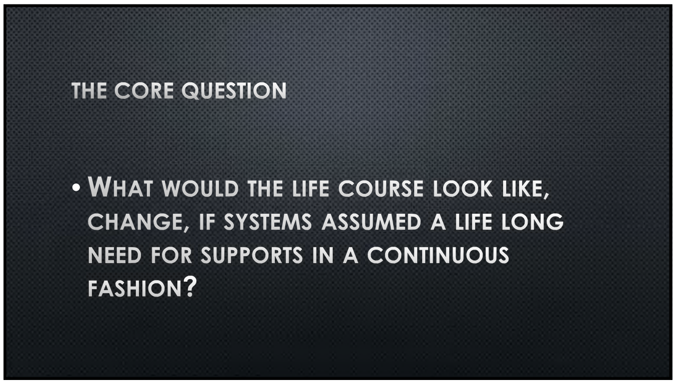
E7 FASD and Child Welfare Issues Across the Lifespan: Research, Policy and Practice

Peter W. Choate, Dorothy Badry

FASD AND CHILD WELFARE ISSUES ACROSS THE LIFESPAN: RESEARCH, POLICY AND PRACTICE

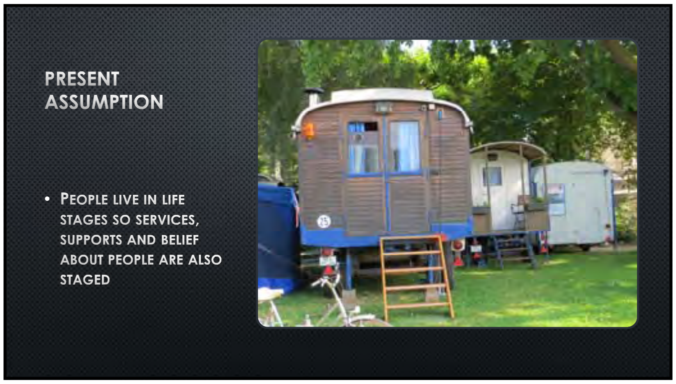
PETER CHOATE, PHD, MOUNT ROYAL UNIVERSITY

DOROTHY BADRY, PHD, UNIVERSITY OF CALGARY



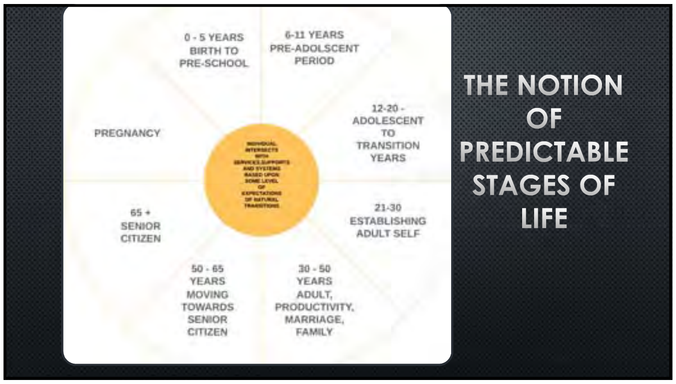
THE CORE QUESTION

- WHAT WOULD THE LIFE COURSE LOOK LIKE, CHANGE, IF SYSTEMS ASSUMED A LIFE LONG NEED FOR SUPPORTS IN A CONTINUOUS FASHION?



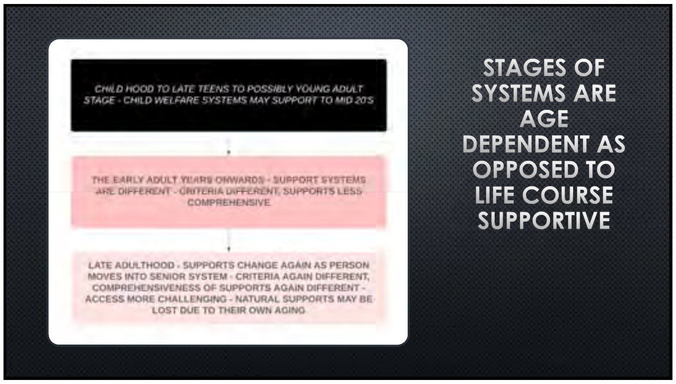
PRESENT ASSUMPTION

- PEOPLE LIVE IN LIFE STAGES SO SERVICES, SUPPORTS AND BELIEF ABOUT PEOPLE ARE ALSO STAGED



THE NOTION OF PREDICTABLE STAGES OF LIFE

THE DISABILITY DOES NOT GO AWAY, GET BETTER OR DIMINISH SO WHY MIGHT SUPPORTS?

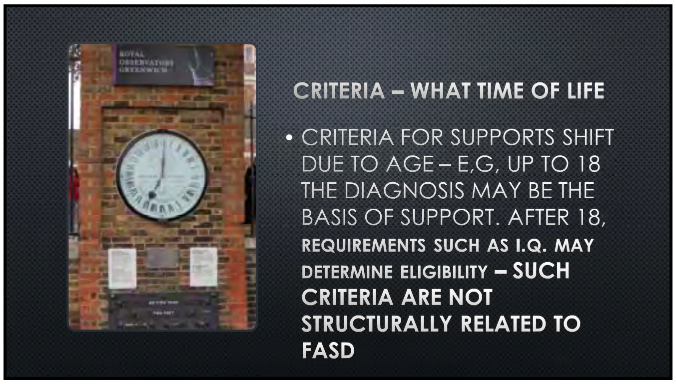


STAGES OF SYSTEMS ARE AGE DEPENDENT AS OPPOSED TO LIFE COURSE SUPPORTIVE

CHILD HOOD TO LATE TEENS TO POSSIBLY YOUNG ADULT STAGE - CHILD WELFARE SYSTEMS MAY SUPPORT TO MID 20'S

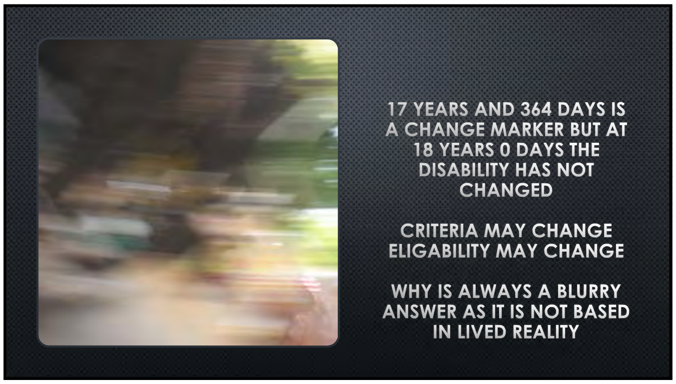
THE EARLY ADULT YEARS ONWARDS - SUPPORT SYSTEMS ARE DIFFERENT - CRITERIA DIFFERENT, SUPPORTS LESS COMPREHENSIVE

LATE ADULTHOOD - SUPPORTS CHANGE AGAIN AS PERSON MOVES INTO SENIOR SYSTEM - CRITERIA AGAIN DIFFERENT, COMPREHENSIVENESS OF SUPPORTS AGAIN DIFFERENT - ACCESS MORE CHALLENGING - NATURAL SUPPORTS MAY BE LOST DUE TO THEIR OWN AGING



CRITERIA – WHAT TIME OF LIFE

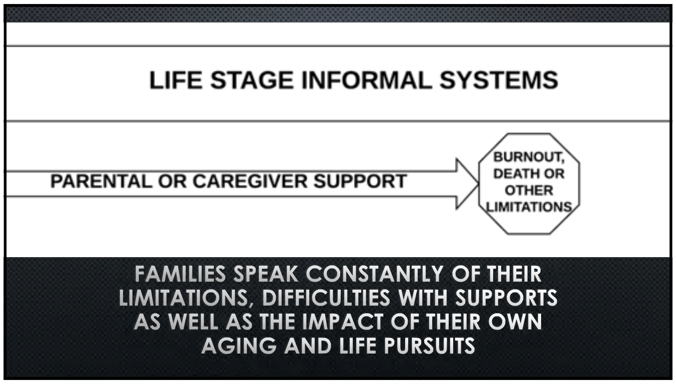
- CRITERIA FOR SUPPORTS SHIFT DUE TO AGE – E,G, UP TO 18 THE DIAGNOSIS MAY BE THE BASIS OF SUPPORT. AFTER 18, REQUIREMENTS SUCH AS I.Q. MAY DETERMINE ELIGIBILITY – SUCH CRITERIA ARE NOT STRUCTURALLY RELATED TO FASD



17 YEARS AND 364 DAYS IS A CHANGE MARKER BUT AT 18 YEARS 0 DAYS THE DISABILITY HAS NOT CHANGED

CRITERIA MAY CHANGE ELIGABILITY MAY CHANGE

WHY IS ALWAYS A BLURRY ANSWER AS IT IS NOT BASED IN LIVED REALITY

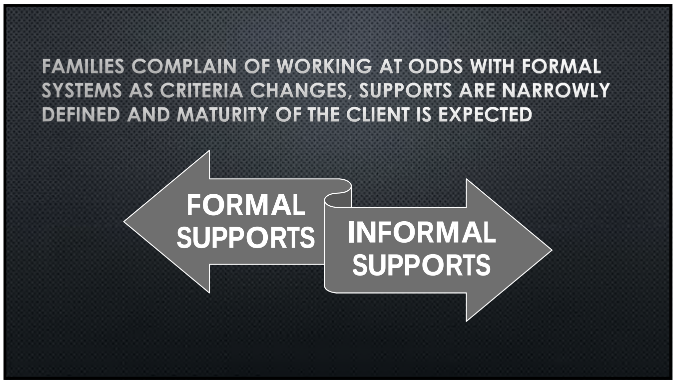


LIFE STAGE INFORMAL SYSTEMS

PARENTAL OR CAREGIVER SUPPORT

BURNOUT, DEATH OR OTHER LIMITATIONS

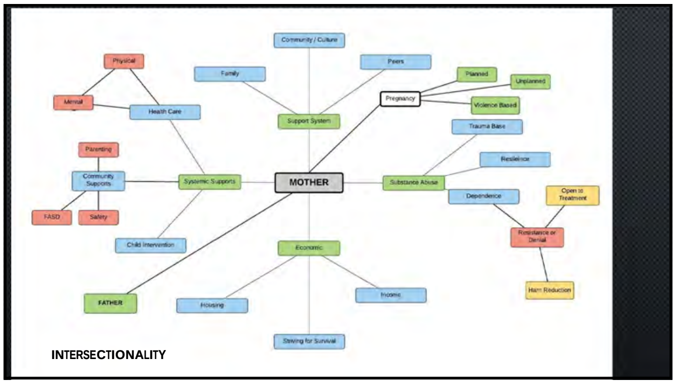
FAMILIES SPEAK CONSTANTLY OF THEIR LIMITATIONS, DIFFICULTIES WITH SUPPORTS AS WELL AS THE IMPACT OF THEIR OWN AGING AND LIFE PURSUITS



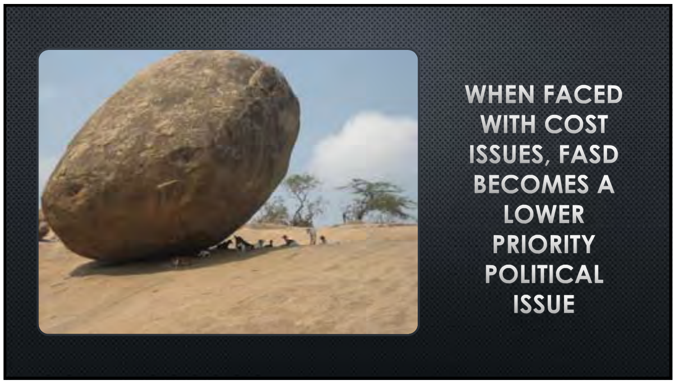
FAMILIES COMPLAIN OF WORKING AT ODDS WITH FORMAL SYSTEMS AS CRITERIA CHANGES, SUPPORTS ARE NARROWLY DEFINED AND MATURITY OF THE CLIENT IS EXPECTED

FORMAL SUPPORTS

INFORMAL SUPPORTS



INTERSECTIONALITY



WHEN FACED WITH COST ISSUES, FASD BECOMES A LOWER PRIORITY POLITICAL ISSUE

01

HEALTH CARE DOLLARS ARE BEING CHALLENGED WHILE WE NEED TO RECOGNIZE THE NEED FOR LIFE LONG SUPPORTS FOR THOSE MODERATELY TO SEVERELY AFFECTED

02

MILDLY AFFECTED ARE NOT WITHOUT SUPPORT NEEDS

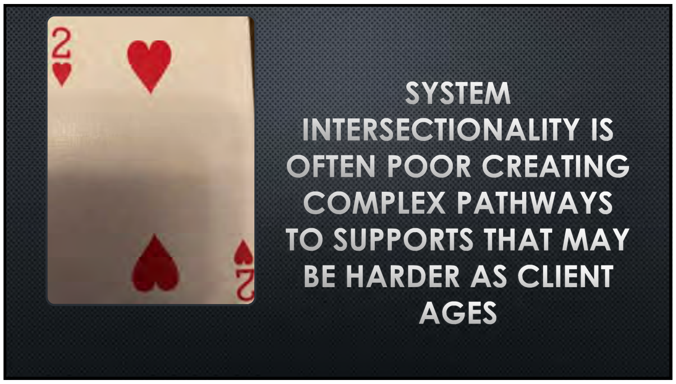
THERE IS A LARGE QUESTION OF PUBLIC POLICY SUPPORTS OVER LIFETIME COMEPTING WITH BUDGETARY PRIORITIES AND PRESSURE ON PUBLIC SPENDING

OUR 7 HURDLES

DO YOU HAVE OTHERS?

THE INABILITY OF FAMILY TO SUSTAIN – THEY TOO ARE TRAVELLING THE LIFE SPAN OF FASD

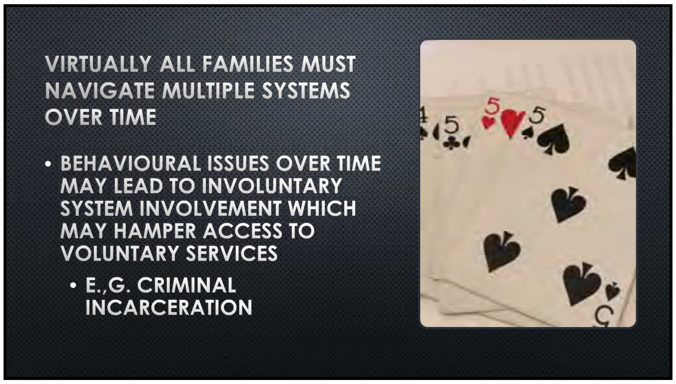
- THE CHALLENGES NEVER STOP
- THE GRIEF STAYS
- THE PHYISCAL AND EMOTIONAL TOLL
- THE PRICE IS STEEP



SYSTEM INTERSECTIONALITY IS OFTEN POOR CREATING COMPLEX PATHWAYS TO SUPPORTS THAT MAY BE HARDER AS CLIENT AGES

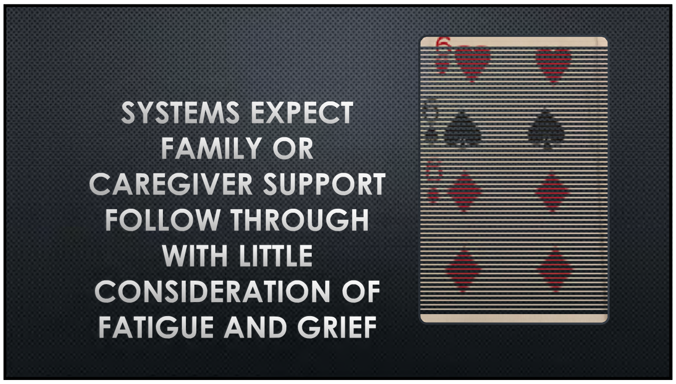
POVERTY IS EMBEDDED IN THE SUPPORT SYSTEMS

RESOURCES AND ECONOMIC INTERSECTIONS ARE BASED IN PUBLIC POLICY AND THE PERCEIVED WORTH OF THE POPULATION



VIRTUALLY ALL FAMILIES MUST NAVIGATE MULTIPLE SYSTEMS OVER TIME

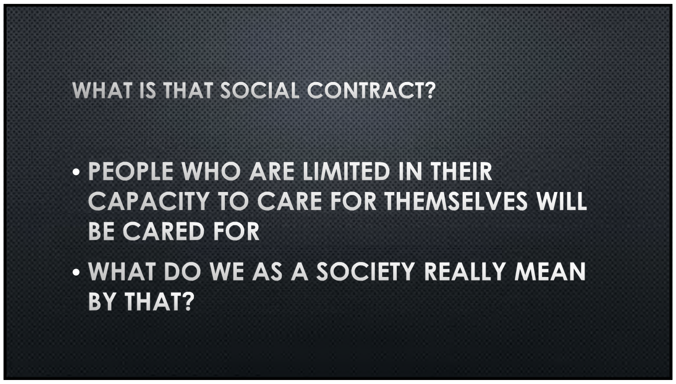
- BEHAVIOURAL ISSUES OVER TIME MAY LEAD TO INVOLUNTARY SYSTEM INVOLVEMENT WHICH MAY HAMPER ACCESS TO VOLUNTARY SERVICES
  - E.,G. CRIMINAL INCARCERATION



SYSTEMS EXPECT FAMILY OR CAREGIVER SUPPORT FOLLOW THROUGH WITH LITTLE CONSIDERATION OF FATIGUE AND GRIEF

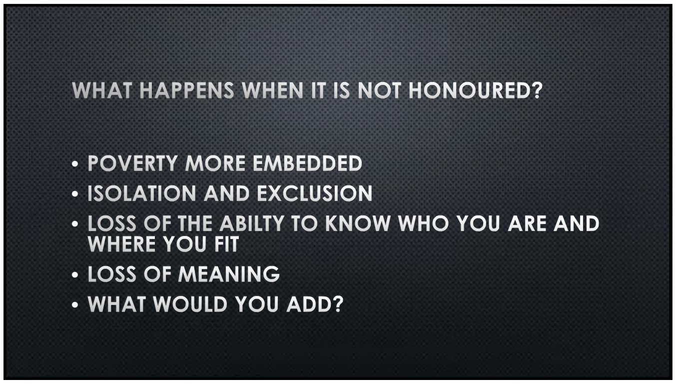
MISINFORMATION AND RIGIDITY OF UNDERTSANDING FASD IS A CONSTANT BARRIER

THERE IS A COMPLICATED SOCIAL CONTRACT WITH SOCIETY AND PEOPLE WITH DISABILITIES



WHAT IS THAT SOCIAL CONTRACT?

- PEOPLE WHO ARE LIMITED IN THEIR CAPACITY TO CARE FOR THEMSELVES WILL BE CARED FOR
- WHAT DO WE AS A SOCIETY REALLY MEAN BY THAT?



WHAT HAPPENS WHEN IT IS NOT HONOURED?

- POVERTY MORE EMBEDDED
- ISOLATION AND EXCLUSION
- LOSS OF THE ABILTY TO KNOW WHO YOU ARE AND WHERE YOU FIT
- LOSS OF MEANING
- WHAT WOULD YOU ADD?

E8

Bringing Together Australian Families' Experiences of FASD

Marcel Zimmet, Cheryl Dedman, Natasha Reid, Natalie Phillips, Heidi Webster, Tanzi Collinge

Learning Objectives

1. Understand what parents want and need for their family members with FASD
2. Identify ways to better incorporate patient experience in clinical FASD practice
3. Inform planning of FASD related diagnostic and support services
4. Empower individuals, parents and families to continue engaging in research about living with FASD

Overview

This session presents Australian families' experiences of FASD assessment, diagnosis and support by combining caregiver and support organisation perspectives with research from three of Australia's specialist FASD diagnostic clinics. We aim to illuminate pathways to better, FASD-informed service provision and caregiver support.

Themes that will be discussed relate to:

- FASD having a significant impact on child quality of life and family functioning
- The importance of timing and quality of the diagnostic process and feedback to caregiver experience, including provision of information regarding a range of supports and health issues
- Limitations in and difficulties accessing health care services for children with FASD

Session Details

1. *Introduction - Marcel Zimmet*

2. *Parent Perspectives on FASD Diagnosis - Cheryl Dedman*

A FASD diagnosis journey from baby to adolescence…our Son:

- Pre-diagnosis: What's wrong, what's happening, how do we get help, can anybody help….survival
- Post-diagnosis: What the assessments mean, how to use them, constant research, constantly advocating, the journey continues….survival, but some management days.
- FASD…Find Your Strength: Benefits and positive outcomes of using strengths for education, daily living skills and regulation. As parents, using our strengths to teach and develop our son. Finding strength for ourselves, mentally and physically to continue the journey.
- The Journey Forward: What we'd imagined and what actually is; what we need to do to plan and develop for our son's future; continue the passion to fight for justice for those affected by FASD; educating and empowering ourselves and others.

3. *Family Experiences and Impact of FASD Diagnosis and Support – Quantitative and Qualitative Studies from Three Specialist FASD Clinics:*

<u>CICADA FASD Service - Sydney/New South Wales - Natalie Phillips</u>

42 caregivers completed a self-administered survey about caring for a child with FASD. Key findings included:

- On average, it took 4 years between first signs/symptoms and receiving a FASD diagnosis.
- Nearly 75% of caregivers consulted 3 or more doctors before receiving a correct diagnosis.
- 93% were very satisfied or satisfied with how they were told about their child's diagnosis.
- Using standardised measures, the psychosocial impact of caring for a child with FASD was reported as 'moderate' (on average), but greater for families caring for a child with poorer health-related quality of life.
- Few families (28%) believed they had adequate access to health services.
- The main barriers to accessing health services (i.e., specialist doctors and allied health professionals) were long wait periods (58%), distance of travel (48%) and care for other siblings (42%).

Gold Coast Child Development Service - Natasha Reid

12 caregivers participated in interviews to provide information on their lived experiences of caring for a child with FASD. Themes that emerged were:

- A desire for future support for their child, although uncertainty about how this support could be accessed
- An understanding of FASD prior to assessment, but a concern that this condition was not recognised as a disability
- That assessment provided validation for caregiver concerns
- That caregivers felt respected and understood by the clinical team and the process of diagnosis was empowering.

Sushine Coast Child Development Service – Heidi Webster

15 caregivers participated in interviews to provide information on their lived experiences of caring for a child with FASD. Themes that emerged included:

- Appreciation of the ability to access assessment locally with the clinic, as previously this may have required significant travel and wait time at other centres
- A sense of support from the assessment and diagnostic process, which facilitated a deeper understanding of their child's strengths and weaknesses as well as an ability to advocate for their child for educational and community support services
- Variability in accessing supports in the community even after diagnosis, furthering fears for their child's future.

4. Providing FASD support in a digital world – Tanzi Collinge

The National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD) Australia is the oldest established FASD dedicated organisation in Australia and has been supporting parents, carers, individuals and frontline service providers for more than 20 years. The challenge of reaching across a large country with a widespread population has resulted in NOFASD developing expertise in digital reach, digital technology and simple, sustainable and inexpensive support strategies. These strategies, and others, can be adapted for populations around the world and include: a national helpline, a comprehensive website, educational outreach workshops, webinars and printed resources.

5. Reflections/discussion - Audience/presenters

Themes to be explored:

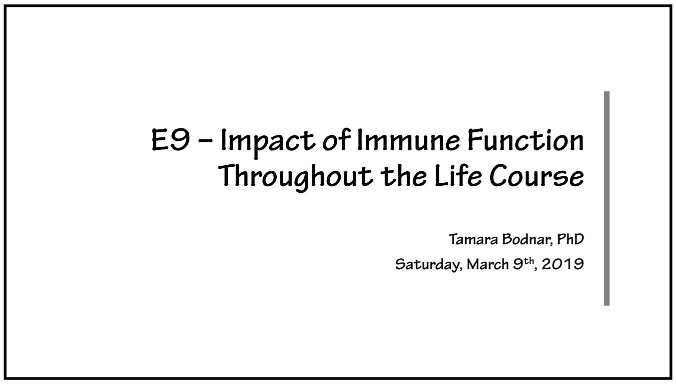
- Parents of children living with FASD report significant psychosocial and quality of life impacts, as well as diagnostic delays and lack of access to health care services.
- Access to support groups/organisations, psychological support and a range of information should be available to all parents receiving a life-changing diagnosis of FASD for their child or adolescent.
- The need for ongoing development of diagnostic and support services, including FASD-informed clinician education to prevent avoidable diagnostic delays, promote early diagnosis and intervention, and provide ongoing support.

E9

Sterling Clarren Award Presentation

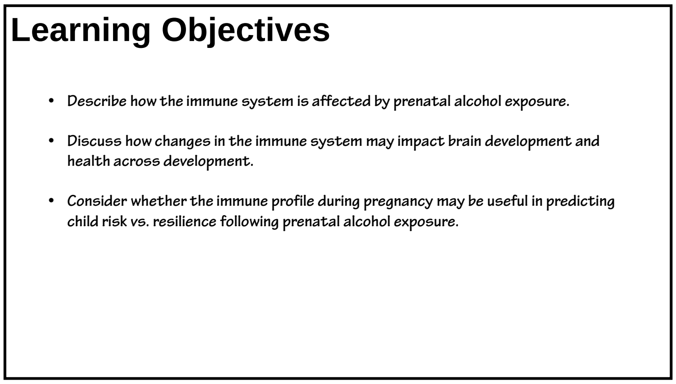
Impact of PAE on Immune Function Throughout the Life Course

Tamara Bodnar



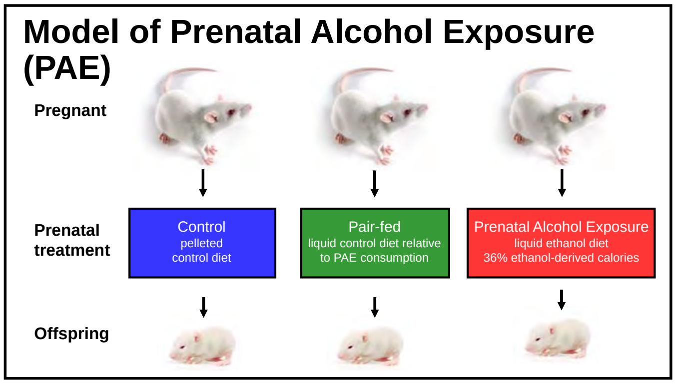
E9 – Impact of Immune Function Throughout the Life Course

Tamara Bodnar, PhD
Saturday, March 9th, 2019



Learning Objectives

- Describe how the immune system is affected by prenatal alcohol exposure.
- Discuss how changes in the immune system may impact brain development and health across development.
- Consider whether the immune profile during pregnancy may be useful in predicting child risk vs. resilience following prenatal alcohol exposure.



Model of Prenatal Alcohol Exposure (PAE)

Pregnant

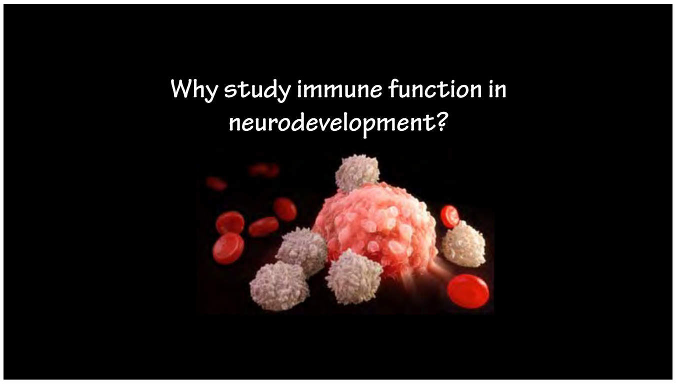
Prenatal treatment

Control
pelleted control diet

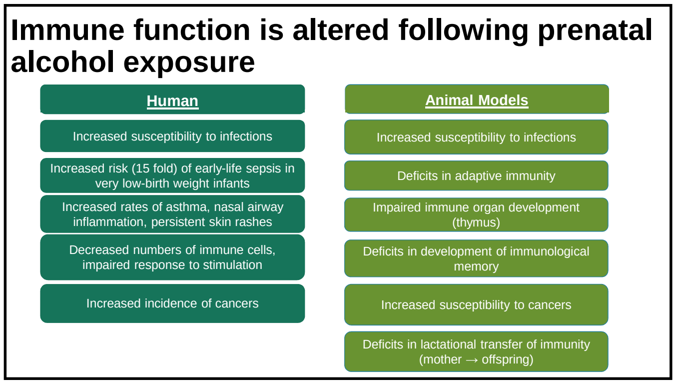
Pair-fed
liquid control diet relative to PAE consumption

Prenatal Alcohol Exposure
liquid ethanol diet
36% ethanol-derived calories

Offspring



Why study immune function in neurodevelopment?



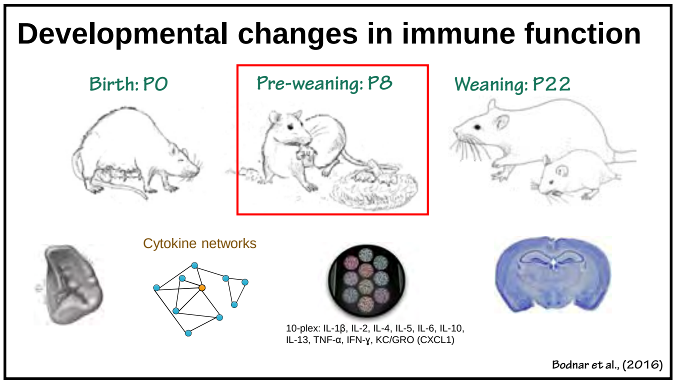
Immune function is altered following prenatal alcohol exposure

Human

- Increased susceptibility to infections
- Increased risk (15 fold) of early-life sepsis in very low-birth weight infants
- Increased rates of asthma, nasal airway inflammation, persistent skin rashes
- Decreased numbers of immune cells, impaired response to stimulation
- Increased incidence of cancers

Animal Models

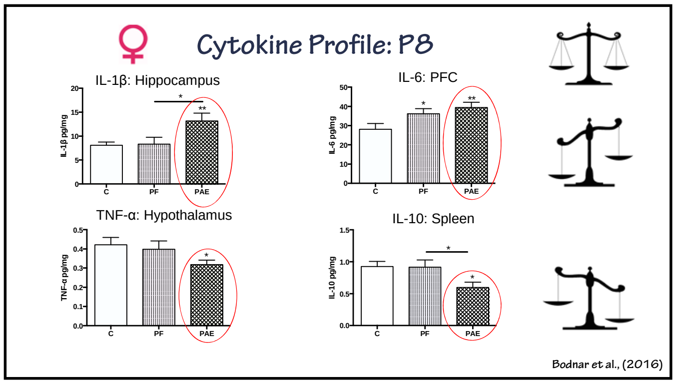
- Increased susceptibility to infections
- Deficits in adaptive immunity
- Impaired immune organ development (thymus)
- Deficits in development of immunological memory
- Increased susceptibility to cancers
- Deficits in lactational transfer of immunity (mother → offspring)



Developmental changes in immune function

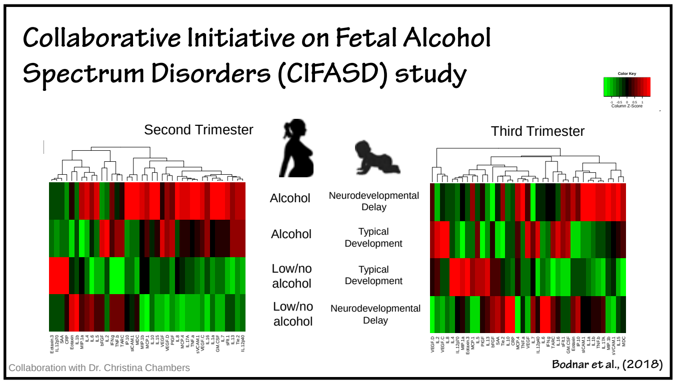
10-plex: IL-1β, IL-2, IL-4, IL-5, IL-6, IL-10, IL-13, TNF-α, IFN-γ, KC/GRO (CXCL1)

Bodnar et al., (2016)



Cytokine Profile: P8

Bodnar et al., (2016)



Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) study

Collaboration with Dr. Christina Chambers

Bodnar et al., (2018)

References and Grant Support

- Bodnar TS, Hill LA, Weinberg J (2016). Evidence for an immune signature of prenatal alcohol exposure in female rats. *Brain, Behavior, and Immunity*, 58: 130-141.
- Bodnar, T.S., Raineki, C., Wertelecki, W., Yevtushok, L., Plotka, L., Zymak-Zakutnya, N., Honerkamp-Smith, G., Wells, A., Rolland, M., Woodward, T.S., Coles, C.D., Kable, J.A., Chambers, C.D., Weinberg, J., and the CIFASD (2018) Altered maternal immune networks are associated with adverse child neurodevelopment: Impact of alcohol consumption during pregnancy. *Brain Behavior, and Immunity*, 73: 205-215.
- Raineki C, Bodnar TS, Holman PJ, Baglot SL, Lan N, Weinberg J (2017). Effects of early-life adversity on immune function are mediated by prenatal environment: Role of prenatal alcohol exposure. *Brain, Behavior, and Immunity*, 66: 210-220.

Plenary

Criminal Culpability through the Lens of FASD

Karen Steele

Learning Objectives:
1. Identify generally-held societal assumptions that contribute to findings of criminal culpability
2. Consider why real-life implications of a FASD clash with traditional findings of criminal culpability such that what is generally assumed to be intentional may not be
3. Identify considerations and develop strategies for more accurately forming criminal culpability inquiries

Criminal culpability (criminal responsibility) measures the degree to which a person can be held morally or legally responsible for action (or inaction). It is a graduated dividing line—a spectrum—assigning, first, whether blame, guilt, or fault exists and, if so, to what degree. It starts with the premise that wrongdoing must be "conscious" before it's "criminal," and then uses a basic formula: a "bad" act plus some degree of "bad" intent leads to societal support for a certain degree of punishment. The basic question is: Does society as a whole "say" that, given what this person did and given what their intent was, do they deserve some form of punishment and, if so, how much?

The first part of our basic question looks at whether the "bad" act qualifies as a punishable act, and whether there is (and to what degree) "bad" intent associated with that act.

It's been said that people think intention is immediately and intuitively recognizable, requiring no complex or sophisticated interpretive act on the part of the beholder. The problem with this is that it relies on unquestioned underlying assumptions: we're all alike, we all think alike, and, prejudicially, people who don't think like us don't matter. We know these assumptions aren't true. Our brains and bodies are all somewhat different, their development being influenced by a number of intrinsic and extrinsic forces, alone, and in combination, leading to or influencing different functioning, including thinking, deciding, acting. Rather than being immediately recognizable, intent is inferred from the relationships between words, actions, environments and contexts, through the lens of generally-held assumptions and presumed expectations about what it all means.

The second part of our basic question is, assuming you're able to say that a person committed a "bad" act with "bad" intent, do they deserve punishment and, if so, how much?

Sentencing is society's imposition of punishment in response to a violation of criminal laws. The goal is to denounce unlawful conduct and address the harm that flows to victims and to society at large. Labels vary, but, sentencing principles in Canada and the United States rely on an overall principle of proportionality, meaning, a sentence must be proportionate to or reflect the gravity of the offense and the degree of responsibility of the offender, each of which bring to mind aggravating and mitigating circumstances as to both offense and offender. Beyond that overarching principle, sentencing seeks retribution, deterrence, separation, rehabilitation, reparation, and, increasingly, restorative justice.

Added to the both parts of our basic question is our evolving understanding—what we now know that we did not know decades ago or even a few years ago when laws were written and case precedents established. This is a continual, ever on-going process. Its application is broad in that it must be allowed to and does impact society's current standards, expectations and understanding, including society's understanding of intent and levels of punishment.

Persons without a visible condition/disability are assumed to be normal. They are assumed to perform according to their own autonomy (or choice or free will). They are expected to perform according to societal standards. For a person with a FASD—a brain-based condition seen not with the eye but instead through observation of function (and, increasingly, through structural and/or biological indicators), as that function interacts with various contexts—generally-held assumptions and expectations don't square with reality. This calls into question inferences of intent and application of society's sentencing calculus as a result of faulty societal assumptions and expectations.

Our job is to help others see the world as it truly is, including for the person with a FASD, and do so based on our current, evolved, understanding (including hope for the future through use of forward-thinking mitigation). By translating current scientific understanding into a storytelling (or narrative) form specific to the person with a FASD, we can convey lifelikeness, sameness or verisimilitude, reducing prejudicial us-them reactions; we can ably explore the relationships between words, actions, environments and contexts, from which inferences about intent may more accurately be formed; and we can more completely and accurately apply the overall principle of proportionality in meting out criminal responsibility.

P01

Changes in Alcohol Consumption in Response to Pregnancy Recorded Using Anonymous Questionnaire Methodology

Neil Aiton

Authors: Neil Aiton, Anna Ferguson

Objective
Using anonymous questionnaire methodology, to determine the alcohol consumption in women immediately prior to pregnancy and how this changes in response to pregnancy.

Method
Pregnant women were recruited on the postnatal ward and in a substance misuse clinic of a University teaching hospital in the UK as part of a larger study to attempt to identify the facial features associated with prenatal alcohol exposure in newborn infants.

Women were given a confidential questionnaire to complete asking for details of their alcohol consumption immediately prior to pregnancy, and - if they changed their alcohol consumption in response to pregnancy - at what point they did so, and what factor was important to them in influencing that change. They were also asked about their consumption during the last month of pregnancy.

Strenuous attempts were made to ensure that the questionnaire was kept anonymous and could not be linked back to women, and this was made clear to all women.

Ethical approval was obtained for the study.

Results

- (pilot results n=37)
- All women except one completed the questionnaire successfully.
- 15 women (40%) did not drink at all in the month prior to becoming pregnant. 10 women (27%) described themselves as getting ‘drunk’ during the month before, 3 on multiple occasions (two >10 times).
- 16 changed their consumption in response to pregnancy, with nearly all reducing quickly or stopping completely.
- 5 women did not confirm pregnancy until 8-15 weeks gestation or greater. 4 of these responded by stopping completely or reducing ‘quickly’ (one did drink alcohol at all.
- No woman described themselves as getting drunk in the last month of pregnancy, and 5 women recorded a consumption of 2 units or less per week. 2 women (5%) admitted to cannabis smoking.
- 8 (21%) ceased drinking because of planning a pregnancy.

Conclusion
This study is still actively recruiting over the next 6 months. Rigorous statistical analysis has not been undertaken in this initial pilot sample due to small sample size.

Collecting anonymous questionnaire data in this way has proven to possible and appears to be acceptable to the women recruited.

Just a small initial sample demonstrates that alcohol consumption in women of childbearing age is potentially problematic, with over a quarter regularly getting drunk each month, (particularly If 40-50% of pregnancies are unplanned).

13% did not become aware of their pregnancy until between 8-15 weeks, and although all these women ceased their alcohol consumption in response to becoming pregnant, this is not necessarily early enough to be confident of avoiding an impact on the fetus from prenatal alcohol exposure.

An encouraging number, one fifth stopped because they were planning a pregnancy.

More work is required to understand womens’ drinking habits and to help provide appropriate and relevant advice

P02

The Relationship Between Brain Structure and Mental Health Problems in Children nd Adolescents with PAE

Quinn Andre

Authors: Quinn Andre, Carly McMorris, Preeti Kar, Chantel Ritter, Ben Gibbard, Christina Tortorelli, Catherine Lebel

Introduction

Prenatal alcohol exposure (PAE) is a risk factor for future mental health disorders. Adolescence is often when symptoms first emerge for both people with and without PAE. Studies in adolescents without PAE show relationships between symptoms of mental health disorders and brain structure in the limbic system and prefrontal cortex, but the relationship between PAE, brain structure, and mental health symptoms is unclear. This paucity of literature presents an opportunity for neuroimaging studies to connect brain structure to mental health issues in children and adolescents with PAE. We examined structures in the limbic system and prefrontal cortex (PFC) to determine the neurological correlates of mental health issues in individuals with PAE.

Methods

22 children with PAE aged 6-16 years and 22 age- and sex-matched controls received an MRI scan at the Alberta Children's Hospital, and their parents completed the Behavioural Assessment System for Children (BASC-2). We measured volume of the amygdala, hippocampus, anterior cingulate gyrus, superior frontal gyrus, and medial frontal gyrus, as well as total brain volume. Diffusion tensor imaging (DTI) was used to measure white matter microstructure in three frontal/limbic tracts: the uncinate fasciculus, fornix, and cingulum. The PAE and control groups were compared on brain and behavioural measures; correlations were examined between brain measures and mental health symptoms.

Results

Children and youth with PAE showed significantly more hyperactivity ($t=5.57$, $p<0.001$), aggressive behaviour ($t=3.44$, $p=0.001$), and conduct problems ($t=3.56$, $p=0.001$) than controls. Children and youth with PAE also had smaller volumes in the right anterior cingulate ($t=-3.49$, $p=0.001$) and right superior frontal gyrus ($t=-3.13$, $p=0.003$). Weaker structural connectivity (lower fractional anisotropy) was found in the left and right cingulum ($t=-2.14$, $p=0.041$), and the left uncinate fasciculus ($t=-2.118$, $p=0.042$) in children and youth with PAE. Children and youth with PAE had significant associations between the right fornix and internalizing symptoms (e.g., depression and anxiety) ($r=0.55$, $p=0.01$), such that weaker connectivity (higher mean diffusivity) was associated with worse internalizing symptoms. Controls had an opposite relationship (i.e., stronger connectivity with worse internalizing symptoms). The left anterior cingulate gyrus ($r=-0.49$, $p=0.047$), right amygdala ($r=-0.59$, $p=0.005$), and total cortical volume ($r=-0.46$, $p=0.038$) all held negative relationships with hyperactivity in the PAE cohort, but no relationship was found in the controls.

Conclusion

These findings provide evidence that PAE is associated with different relationships between brain structure and mental health symptoms than controls. This supports further research and clinical consideration for the specific needs of children with PAE and their mental health, as they may differ from individuals without PAE.

P03

Transition to Adulthood in FASD: Journey with a Road Map or GPS

Gail Andrew

Abstract

Transition is a planned movement of youth from child centered to adult orientated supports. This includes not only health care needs but also psychosocial, educational and vocational supports and personal goals and choices. For youth with disabilities that impact their ability to plan and organize, use judgment, communicate effectively and follow instructions, they need to rely on a caregiver or mentor to facilitate the transition process. The transition process and adult care system are also very complicated: gaps and fragmented services, difficulties in navigating , lack of communication across supports, barriers related to funding based on IQ scores and not function, assumptions that the youth and/or their caregiver are able to advocate and navigate on their own. This has been clearly vocalized by the disability community, their caregivers and professionals. In 2012, the Canadian Association of Pediatric Health Centers (CAPHC) took this on as a priority and developed a community of practice approach to involve all key stakeholders in developing the Canadian Guidelines on Transition published in 2016 on CAPHC.org. This included a review of the literature on transition using the Agree system to identify evidence based practices and venting with experts using a modified Delphi process. The current work of CAPHC involves implementing these guidelines and evaluating outcomes. Dr. Gail Andrew from the Glenrose FASD Clinical Services was one of the contributing authors to the CAPHC Guidelines and is currently active in the implementation process in all of Alberta, funded by Alberta initiatives and CIHR.

Fetal Alcohol Spectrum Disorder is a population that brings additional challenges to successful transition. A major concern is insuring that the youth/young adult with FASD have a team that advocates with and for them. There is also the need to provide education in adult services and supports to understand the disability of FASD and develop FASD informed practices, such as in employability options. There is a critical need to reduce stigma about FASD in the general population as well as in specific support sectors. The Glenrose FASD Clinical Services has been providing diagnosis and assessment for over 15 years and uses a collaborative community partnership model to access supports and services for individuals diagnosed with FASD. This has included transition work. Navigation has emerged as a key process of transition but a real person as a “navigator” is often needed to make this successful. The Glenrose team is currently involved in a critical appraisal of the navigation process with Kids Brain Health Network. This presentation will review the Canadian guidelines on transition with an FASD lens and what is in place and working but also gaps and next steps. Case examples of success and challenges will be used to illustrate the need for advocacy in this ongoing work. Collaborative engagement with the community has been critical. Influencing policy is the next step to ensure continued supports.

P04 Disruption of Retinal Vascular Development, a Witness of PAE?

Carole Brasse-Lagnel

Authors: Marion Dumanoir, Camille Sautreuil, Maryline Lecointre, Cécile Léger Léger, Michelle Hauchecorne, Bruno, J Gonzalez, Stéphane Marret, Carole Brasse-Lagnel

Objectives

Beside developmental lesions which are a devastating consequence of prenatal alcohol exposure (PAE) [1], ocular abnormalities, as microphtalmia and retina vessels tortuosity, have been described in fetal alcohol syndrome [2]. We previously showed that PAE affects cortical vasculature acting especially on angiogenesis [3]. As angiogenesis and neurogenesis are concomitant, we hypothesized that vascular disorders could contribute in PAE neuronal and vision disorders. However, the underlying PAE molecular mechanisms on brain cortical and retina vascular effects remain poorly understood.

Methods

In this work, we used a mouse model to investigate effects of prenatal alcohol exposure on the retinal vascular network in vivo. The influence of ethanol on angiogenesis was also characterized in a culture of neonate brain microvascular endothelial cells (BMVECs).

Results

A developmental time course study shows that PAE altered retinal neuronal and vascular development. Indeed, results showed a decrease of retinal vessel density and sprout numbers were fewer in PAE mice at 2 and 5 days after birth, suggesting less angiogenesis. Numbers of filopodia were similar between PAE and control mice. Arteriovenous crossovers were also significantly more frequent in retina from PAE mice, indicating impaired vessel organization. Some anatomic alterations persisted 10 and 15 days after birth. Furthermore, in these mice, the expression of some angiogenic factors was modulated, with an increase of VEGFR1/VEGFR2 mRNA ratio. In MBVECs, we observed a direct effect of ethanol 50 mM on tubulogenesis with an inhibition of the Dll4/Notch pathway known to be a regulator of angiogenesis, leading to changes in gene expression of its targets, VEGFR-1 and VEGFR-2.

Conclusion

Altogether, these results suggest that cerebral vascular disorders previously observed in FAS children are also found in the retina of mice. Moreover, the modulation of a signaling pathway such as Dll4/Notch could contribute to the defects in retinal angiogenesis observed after PAE. The retina is a readily accessible part of the central nervous system, the question could be raised whether retinal vascular disorders could reflect ethanol-induced cerebral vascular disorders.

This work is supported by "Fondation de France", "Fondation pour la recherche en alcoologie", by "Fondation motrice" and ANR 2018. *[1] Burd L. et al., Neurotoxicol Teratol., [2003]; [2] Strömland K. et al., Acta Ophtalmol Suppl., [1985]; [3] Jégou S. et al., Ann Neurol., [2012]; [4] Carmeliet P. et al., Nature., [2005]***.**

P05

The Standardization of Diagnostic Criteria for FASD: Implications for Research, Clinical Practice and Population Health

Jasmine Brown

Authors: Jasmine Brown, Roger Bland, Egon Jonsson, Andrew J. Greenshaw

Objective
Fetal Alcohol Spectrum Disorder (FASD) is a preventable disorder, marked by a range of physical and mental disabilities, which is caused by maternal alcohol consumption. Although recognized by the scientific and medical community as a clinical disorder, no internationally standardized diagnostic tool yet exists for FASD.

Methods and Results
This review seeks to analyze the discrepancies of existing diagnostic tools for FASD, and the repercussions these differences have on research, public health, and government policy.

Conclusions
Disagreement on the adoption of a standardize tool is reflective of existing gaps in research on the conditions and factors that influence fetal vulnerability to damage from exposure. This discordance has led to variability in research findings, inconsistencies in government messaging, and misdiagnoses or missed diagnoses. The objective measurement of the timing and level of prenatal alcohol exposure is key to bridging these gaps, however, there is conflicting or limited evidence to support the use of existing measures.

P06

Genetic Testing in FASD Assessments in Scotland – What Lessons Did We Learn?

Sarah Brown

Authors: Sarah Brown, Sheelagh Joss, Daniela Pilz

Objectives

The prevalence of FASD in the UK is poorly defined, but estimated at 1-4% (Popova, 2017). When considering a diagnosis of FASD, review by a clinical geneticist has been advocated. In Scotland our resource is 1 clinical geneticist per 330,000. We propose that genetic testing must be used judiciously and review of every FASD case is impractical.

Methods

36 children were assessed and genetic testing considered. Genetic testing/array CGH (aCGH) was requested if any of the following were present - dysmorphic features outwith FASD spectrum, microcephaly, structural malformation, family history of learning disability or recurrent miscarriages (recommended by Clayton-Smith, 2012).

Results

36 children attended for assessment. 26 (72%) received a diagnosis of FASD. Alcohol history unknown in 8. Marked facial features present in 12 (facial features score of 4, Astley, 2004; further 9 children had a score of 3). 4 known to be microcephalic at birth (unknown in 14 children). 14 microcephalic at time of assessment. 28 underwent genetic testing - 25 had a normal aCGH and 3 had an abnormality detected. The abnormalities detected were (1) loss at 2q13, (2) loss at 6p25.1, (3) gain at 15q11.1-11.2. These were discussed with a geneticist, but not thought to be wholly responsible for the presenting phenotype.

Conclusions

We propose that all children assessed for FASD undergo genetic testing. This reflects recommendations that an aCGH is a first line test in individuals with developmental difficulties (Miller 2010), has cost-saving implications (Sagoo, 2014), and is now readily available. An aCGH is particularly important for those in whom marked facial features (all 3 facial features) are used as a proxy for prenatal alcohol exposure (Cook et al, 2016). If the aCGH is negative, discussion with a geneticist is still recommended. Where there is a paucity of information regarding the family history an aCGH is warranted. An abnormal aCGH should always be discussed with a clinical geneticist.

P07

Risk Assessment in FASD – Why Paediatricians Need Training in Mental Health and Risk

Sarah Brown, Jennifer Shields

Objectives

Children affected by prenatal alcohol exposure (PAE) present to a variety of health services. UK FASD assessment is coordinated by Paediatrics or Child & Adolescent Mental Health Services. Over 90% of PAE-affected individuals experience co-morbid mental health disorders, with high rates of both externalising and internalising symptoms. Mood disorders, including increased suicide risk, may be less apparent to Paediatricians. This data arguably provides a rationale for mental health and risk training to be required for all paediatric staff working with children and young people affected by prenatal alcohol exposure.

Methods

Risk was assessed in 36 children with PAE. The Children's Depression Inventory (CDI) was used in 22/36 children and data was converted to z-scores. We recorded i) responses to items asking about suicidal ideation, ii) if children required formal risk assessment, and iii) if children were referred on to CAMHS in relation to risk. 32/36 carers were administered the Strength and Difficulties Questionnaire (SDQ) to record externalizing and internalizing behaviours. SDQ data was converted to z-scores.

Results

(1) Children affected by PAE do not score significantly highly on the CDI but do score significantly highly on the SDQ. Although known mental health risk was an exclusion criteria for FAAST involvement, (2) 11 children (30.6%) required a full formal risk assessment. (3) 5 children were referred to CAMHS (13.9%), 3 in regards to mental health risk (8.3%), and 2 in regards to risk due to impulsive behaviour (5.6%). (4) Of those who completed the CDI, 31.8% of children stated that they had thought about suicide and 4.5% wanted to complete suicide.

Conclusions

Paediatricians must be aware that children affected by PAE are at high risk of mental health difficulties. Risk requires in-depth assessment and is not typically apparent in screening. Screening should be utilized as a 'conversation starter'. Paediatricians may require Mental Health First Aid and CAMHS risk assessment training. If children known to CAMHS are referred to Paediatrics for FASD consideration, we would recommend that shared care is maintained.

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P08

Parent, Carer and Professionals' Perspectives on FASD Services in Scotland

Jennifer Shields

Authors: Jennifer Shields, Fiona McGruer

Objectives

Parent and carer involvement is a crucial element of the design and delivery of FASD services. Previous qualitative work, which elucidated experiences of parenting a child affected by prenatal alcohol exposure (e.g. Watson et al., 2013; Michaud & Temple, 2013) touched upon barriers to accessing assessment. In the current context of emerging care pathways for FASD in Scotland, and as part of the Fetal Alcohol Assessment and Support (FAAS) Team service evaluation, we aimed to gather multiple perspectives in respect to FASD assessment services.

Methods

We recruited parents, carers and educational professionals of children who accessed assessment by the FAAS Team and offered the opportunity to participate in semi-structured interviews. Participants were asked broad questions regarding the process of accessing assessment, assessment process, feedback and resulting outcomes of this. Questioning focused on the individuals' lived experiences and reflections on the FAAS Team processes. Interview recordings were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA).

Results

This qualitative method ascertained parent, carers and professionals' experiences of the pilot service, perceptions of FASD diagnosis, and of accessing FASD support services in Scotland. Thus far, this dataset represents views of biological parents (of both sexes), adoptive parents, kinship carers, foster carers and professionals. Emergent carer themes include: (1)The 'fight' to be heard and access services in Scotland and (2) the experience of being heard by the pilot service, (3) working to understand the child, (4) the experience of the process, (5) the parent as an expert, (6) stigmatisation of the parent/carer by the diagnosis, (7) protection of the parent/carer and the child by the diagnosis, (8) being supported or unsupported, and (9) the ongoing fight for the future. Emergent professional themes include: (1) being informed but not yet empowered, (2) wanting to collaborate with clinicians, (3) willingness to use flexible strategies, (4) lived experience of FASD, and (5) barriers to implementing strategies. Each theme encapsulates a number of subthemes to fully elucidate the experience of interviewees.

Conclusions

The design and delivery of future services should be strongly informed by the experiences of all stakeholders, particularly carers and multiagency professionals working to support the family and child. We must be mindful of the challenges in accessing FASD services and the impact of this in Scotland. Further research is required in regards to positive and negative impacts of the diagnosis itself.

P09

Neuropsychological Profiles of Scottish Children Affected by PAE

Jennifer Shields

Authors: Jennifer Shields, Fiona McGruer

Objectives

Children with prenatal alcohol exposure (PAE) may exhibit impaired neurodevelopment in multiple brain domains. Difficulties include borderline range cognitive ability, poor memory, impaired motor and language skills, and marked executive dysfunction (Kodituwakku, 2009). We aimed to analyse neuropsychological assessment outcomes of children assessed by the Fetal Alcohol Assessment and Support (FAAS) Team in NHS Ayrshire and Arran. Further elucidation of neuropsychological and functional profiles of affected individuals brings us closer to establishing a potential neuropsychological phenotype of FASD in Scotland. This phenotype may inform efficient identification and assessment of affected individuals.

Methods

We extracted data for 42 children who accessed input from the FAAS Team in relation to PAE. This comprised standardised assessment of nine brain domains: structure, cognition, motor/sensory function, language, memory, attention, executive function, adaptive function/social perception and affect regulation. Standardised assessment scores were converted to z-scores. Analysis was undertaken to i) determine relationships between domains ii) explore potential phenotypes characterising PAE and iii) consider how, in future, this may inform assessment protocols.

Results

Preliminary analyses indicate: 1) More marked impairments in older children. 2) Female children are typically more impaired across domains. 3) Children largely scored -1.5 standard deviations (SD) below population norms in cognition, with 31% scoring -2SD for full scale IQ (Intellectual Disability), however using discrepancy analysis, 4) variability in cognitive scores did not readily indicate a global intellectual disability (therefore only 8% diagnosed with ID). 5) Executive functioning was on average -1.5 SD below the mean and 6) was a predictor of adaptive functioning ($t = 2.3$, $p = 0.04$; 31.2% predictive model), whilst cognitive scores are not. 7) A parent completed screening tool for executive function (BRIEF) correlated with formal assessment using C-BADS, ($r = 0.53$, $p = 0.02$). 8) Formal tests of attention suggest selective and everyday attention impairments are related to executive dysfunction ($r=0.67$, $p=0.0003$) whilst 9) sustained attention was related to sensory-motor abilities ($r= 0.64$, $p = 0.008$).

Conclusions

A relationship between executive function and adaptive function appears in the context of borderline/low-average cognition, and may be an indication of a potential neuropsychological profile associated with PAE. Assessment of attention suggests that selective and everyday attention is correlated with executive function, whilst sustained attention (mediated by the parietal lobe) is strongly correlated to motor difficulties, and is relatively less impaired. Overall data suggests affected children move away from the population mean as they age. Female children may be more impaired when a need for assessment is recognised. As screening of executive function is strongly correlated to formal testing, the BRIEF may offer an effective means of quickly screening for difficulties in children with PAE. Our data evidences the value of comprehensive neuropsychological assessment and the need for greater sample sets to allow for robust conclusions to be made. This data could also contribute to international samples towards elucidating a potential neurodevelopmental phenotype of FASD, thus informing identification and assessment protocols.

P10

Communicating Brain Domains - A Positive, Visual (and Quick) Method for Multidisciplinary Team Feedback

Jennifer Shields

Authors: Fiona Burslem, James Anderson, Jennifer Shields

Objectives
FASD diagnosis is assessed through a multidisciplinary approach, using standardised testing where appropriate (Cook et al. 2016; Astley, 2004). A comprehensive multidisciplinary team (MDT) formulation report is complex and can be a lengthy process. To reduce the time families wait for feedback and to maximize understanding, our team developed a one page visual report to summarise the child's profile of strengths and difficulties. This can be used with the child/young person, family, educational and support staff.

Methods
Two versions of the report were developed: one for the child/young person and one for adults with whom assessment findings were shared. Both versions feature a basic graphic representing the brain, with 'domains' and functional areas labeled. The terminology used is easily understood and represents the areas assessed by the MDT. During the feedback discussion, the young person is taken on a 'journey' around their brain. To ensure the feedback was positively framed, a 'medal' sticker was awarded to each brain area (gold, silver, bronze). In the adult version of the report, green, orange and red stickers were used. The sticker used represented assessment findings, where gold (green) represented within -1 standard deviation (SD) from the mean, silver (orange) represented -1 to -2 SD from the mean, and bronze (red) represented -2 SD or more.

Results
Feedback ascertained indicated children, carers and clinicians found it useful to have information presented visually and valued the brevity of the information. Understanding strengths and difficulties enabled those around the child to implement strategies without delay. A more comprehensive, formulation-based report was then produced to offer a detailed account of the child's individual profile.

Conclusion
We found that the visual report feedback method was well-received due to its simplicity, ease of understanding, speed of delivery, and appeal to children. This method can easily be adapted for different sites and services, and for different assessment protocols.

P11

Professionals' Changing Knowledge, Confidence and Attitudes on FASD within Health and Social Care Partnerships in Ayrshire, Scotland

Jennifer Shields

Authors: Fiona McGruer, James Anderson, Jennifer Shields

Objectives

Assessment and diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in multidisciplinary teams is a relatively recent endeavour in Scotland. Assessment is dependent upon professionals' awareness of FASD and confidence in how to formally identify, assess, and support affected individuals. Early identification is associated with reduction in adverse outcomes. This research aimed to i) establish a benchmark of Ayrshire-based professionals' knowledge, confidence, and attitudes in relation to FASD and ii) determine whether this changed following the three-year pilot Fetal Alcohol Assessment and Support Team (FAAST), who delivered pan-Ayrshire training to approximately 4,000 multiagency professionals.

Methods

In February 2016, we emailed a cross-sectional online questionnaire to Ayrshire professionals from health and social care partnership services working alongside individuals with FASD. This elicited self-reported knowledge, confidence, attitudes data, in addition to respondents' demographic data. We issued shorter versions of this survey to attendees before and after each 2017 FAAST training session. The cross-sectional online questionnaire was repeated in February 2018 following the conclusion of the FAAST pilot's work, to measure change across the partnerships.

Results

Prior to the FAAST pilot training, professionals rated their knowledge and confidence regarding FASD as low. It was a concern that a large proportion of those professionals stated they were actively working with individuals suspected to be affected by FASD. Data from training questionnaires revealed strong increases in knowledge and confidence after each training session, however the follow up pan-Ayrshire questionnaire revealed only a small positive change in how professionals viewed their knowledge. Professionals also reported low confidence in their competencies across assessment, diagnosis, and care management of affected individuals. Attitudes towards FASD diagnoses across both time points were positive, with increases in numbers of professionals who viewed the diagnosis as helpful.

Conclusion

A targeted awareness and diagnostic training programme can improve professionals' knowledge, confidence, and attitudes around FASD, however, at an Ayrshire wide level, multiagency professionals' knowledge remained relatively low; with professionals reporting a lack of confidence implementing their knowledge of FASD. This finding indicates a crucial need for a comprehensive training and supervision framework which specifies the skills and practical competencies required for each professional's roles. This is particularly pertinent in health services workers involved in assessment and diagnosis. The principles of implementation science could be used to effect lasting change in practice around FASD in Scotland.

P12

A Multi-disciplinary FASD Awareness Training Programme for Professionals and Caregivers in Ayrshire and Arran

Rachel Burn

Objectives

NHS Ayrshire and Arran has embraced the Scottish Government 'No Alcohol, No Risk' message for some time and promotes this message with women of child bearing age at every appropriate contact. Awareness of FASD is increasing in this region, therefore Professionals ability to provide support to children and families affected by FASD is dependent upon their own knowledge and confidence. As a result a tiered multi-disciplinary training calendar was designed with the aim to:

- Increase knowledge, understanding and attitudes of professionals and caregivers around alcohol use during pregnancy and FASD; and
- Provide professionals and caregivers with strategies to support individuals affected by FASD.

Methods

Our training calendar was distributed across NHS Ayrshire and Arran and the Health and Social Care Partnerships via email. Level 1 full-day training covered attitudes around alcohol and pregnancy, alcohol units, the importance of the delivery of ante-natal Alcohol Brief Interventions (ABI), fetal development, how alcohol affects fetal neurodevelopment, FASD definition and characteristics, FASD prevalence, information on assessment and diagnostic pathways, and a presentation on lived experience by an affected young person. Level 2 half-day training comprised of information on strategies and approaches to support affected individuals and details of the local support group. Paper evaluation questionnaires were administered following training.

Results

The training calendar was fully booked within weeks. Over and above the calendar sessions, demand for training continued to be high throughout the year. Evaluation data highlighted that it was difficult for staff to be available to attend a full day plus a half-day session. This resulted in bespoke training sessions also being delivered to a diverse range of staff groups including health and social care, education and the third sector. Evaluations also revealed increased knowledge and understanding. Qualitative evaluation data highlighted the importance of making FASD training mandatory for staff working across the Health and Social Care Partnerships, including Education.

Conclusion

Our targeted multi-disciplinary training programme, conducted with the aim of improving awareness and knowledge around FASD, was effective and resulted in professionals being more confident therefore being able to provide advice, guidance and support to children and families affected by FASD

P13

Listening to Families: Perceptions of the Complex Developmental Behaviour Conditions Assessment and Transition to Community Services

Nicky Cairncross

Authors: Nicky Cairncross, Nancy Lanphear, Lesley Howie, Maya Gislason, Kimberly Miller

Background

The Complex Developmental Behavioural Conditions (CDBC) team at Sunny Hill Health Centre for Children (SHHC) serves children with Tier 6 sub-speciality, interdisciplinary assessment, diagnosis, consultation, and referrals.
The team creates a Complex Developmental Assessment Summary (CDAS) report and provides this to the legal guardians (family) in a final family conference. The CDAS is intended to provide families with a developmental profile, recommendations and available resources. The objectives of this project were to: 1. understand the experiences of families of children who had been assessed and diagnosed with Fetal Alcohol Spectrum Disorder (FASD) at SHHC; and, 2. ascertain the success with which families were able to implement and connect with the recommended resources. This project forms part of a larger Western Canada initiative aimed at improving coordination of care for families affected by neurodevelopmental conditions.

Methods

Semi-structured 1:1 telephone interviews were conducted with 15 legal guardians (families) of children who were assessed by the CDBC team who received confirmation of the diagnosis of FASD. Inductive analysis was undertaken during data collection to refine interview questions iteratively. In this mixed methods study, each interview was transcribed verbatim, coded, and analyzed using thematic analysis in collaboration with stakeholders. The qualitative analysis focused on participants' experiences of the assessment and feelings of connection to community resources while quantitative analysis examined the proportion of recommendations families were able to implement.

Results

87% of families described significantly positive experiences with the assessment process. Key challenges identified were associated with processing the volume of information presented in the family conference and implementing the recommendations in the CDAS through connecting with community-based services. For example:

- 33% felt they needed further clarification and support in understanding / implementing the recommendations given in the CDAS; but felt they were unable to re-contact the assessment centre (SHHC)
- Six families (40%) had more then 10% of their interviews coded as “Connected but…” They were connected to services but did not describe an active/strong connection
- The families who appeared most “connected” identified one person who had an in-depth understanding of their child's needs.

Conclusions

While families reported generally positive experiences, the volume of information left many feeling that an opportunity for follow-up following their FC would be beneficial. All families had implemented from 25%- 83% of recommendations, but the quality of these connections were not always strong. Identification of a single go–to person could help facilitate the transition from assessment in a sub-specialty centre to community. These finding support the potential benefit of identifying ‘navigators’ mandated to strengthening connection and clarity during the transition to community services.

P14

Through the OT Lens: Finding the Missing Perspective on a Multi-Disciplinary School Based Team

Janet Carioni

Abstract

The Catholic District School Board of Eastern Ontario Special Education Department established a multi-disciplinary team to expand and better serve students with complex special education needs. The vision included hiring the school board's first Occupational Therapist to build capacity, provide comprehensive assessment of sensory processing and self-regulation needs, and collaborate with the multi-disciplinary team to establish practical school-based programs to support students with a history of trauma, mental health needs and neurodevelopmental challenges. This presentation will provide an overview of the process of how the school-based multi-disciplinary team was created and summarize the evaluation of effectiveness.

P15

CAMP – A FASD Community. An Annual Weeklong Summer Camp Program for Children Ages 9 - 18

Ajeet Charate, Jessica Rutherford

Abstract

CAMP FASD was born from an idea, a hope and intention, to create a space in which children and young people with FASD could feel part of a community, build friendships, learn and develop new skills. Individuals with FASD live and grow in a world that is constantly judging their actions and behaviors. They live in a state of constant anxiety and fear of not succeeding in an environment that values effective communication and age appropriate behaviors. Camp has been carefully designed by a team of experts to provide a supervised and specialized environment that the outside world simply cannot offer.

This presentation will discuss the goal of camp, which is to provide a safe environment in which each individual camper can enjoy, learn and participate in a wide range of activities in a safe environment, and how this is goal is measured and met each year. There are a vast number of benefits to attending camp, which are supported by parent and caregiver testimonials, including:

1. Building Friendships: CAMP provides an opportunity for campers to form and build lasting relationships
2. Improving Social Communication: CAMP engages campers in social activities designed to develop communication among peer groups
3. Developing Life Skills: CAMP focuses on building life skills to assist each individual for everyday life
4. Non-judgmental & Safe Environment: CAMP offers a non judgmental, trusting, non threatening and a safe environment
5. Providing Respite Care: Allows caregivers to recharge their battery, while campers are having fun at CAMP

This presentation will discuss each of the benefits of CAMP listed above in the context of the impact it has had on the lives of the campers. It will discuss in detail the challenges faced in planning, organisation and facilitation of a residential camp specifically for children and young people with FASD and the methods applied to each process. The presenters will also provide an overview of the staff recruitment and training process and how this has evolved each year of camp to ensure the staff team are best equipped to work in this environment.

P16

Creativity is Key: Repurposing Art Practices to Develop a Learning Programme for Children and Young People with FASD

Jessica Rutherford

Abstract

This poster will provide an overview of an ongoing PhD study and will discuss the study in the context of the research objectives, whilst using the opportunity to raise awareness of interdisciplinary practices arising from the arts, as well as the opportunities surrounding arts practices benefiting from other fields of study.

The objectives of this research surround the development of a specifically designed Learning Programme which uses the animation film making process as an educational tool when working with Children and Young People with FASD.

There are a number of Learning Outcomes for audiences of this presentation which include:

- Recognize ways in which arts practices can be adapted to act as a creative and engaging educational tools
- Discuss and consider ways in which cross disciplinary studies can become interconnected with the arts in ways that can benefit participants with measurable outcomes.
- Identify the optimum learning environment for this population when working within the arts.
- Consider alternative approaches to education for a ‘pedagogically bereft’ (Carpenter, 2011) population

The film making process is a tangible, multisensory and tactile approach in which a significant amount of learning can be embedded. This particular programme is intended to supplement and support the child or young person’s current education and further their understanding of specific concepts rather than teach them, with a process that builds on knowledge as it progresses to completion. The Learning Programme will be further developed to produce a transferable and verifiable model of education which can be used in classroom settings with a particular supply of readily available resources.

The Learning Programme has been designed with an action research focus, for which participants will produce all elements required to create an animated film in a creative and exploratory way. This allows them to explore their own current understanding of a topic through completion of a series of tasks, under the guidance of an Animator and a Teaching Assistant. All participants will undergo pre and post testing when participating in this programme of learning, determining the current level of understanding of the topic against the learning outcomes outlined in the National Curriculum. The same test will be repeated upon completion of the programme and a gain in knowledge calculated.

The environment in which the Learning Programme takes place is a large consideration of this study. Upon completion of a detailed Literature Review, an optimum learning environment has been designed that allows an animation studio to become an engaging and versatile classroom designed specifically to enrich the learning experience for those with FASD.

P17

The NB FASD Dream Catcher Service Delivery Model

Annette Cormier

Authors: Annette Cormier, Cynthia Sewell

Background

The NB FASD Centre of Excellence works with many community partners and government agencies and provides services to more than 450 families in NB.The Centre is a leader for its interdisciplinary approach. Its model is supported by First Nations and western science. Through engagement with the elders, a dialogue on FASD in each community began. The elders wanted to make sure the services delivered would follow the cultural norm of the communities in addressing the links of FASD to historical trauma, residential school, stigmatization, poverty, isolation and false hope. The Centre has tailored its services to meet the needs of these communities by creating a unique service delivery model. This model was designed to support the safety and the well-being of Frist Nation's children and families. The Model was also created to respects the mandate and the recommendations of the TRC's: 94 Call to actions.

Objectives

The purpose of this presentation is to share a First Nation's culturally appropriate FASD delivery model, which looks at Dr. Leroy Little Bear's works on western science and First Nations scientific approaches. To share a Mi'kmaq Theory, and the concepts of the Lnoeigoti Model: Apigsigtoagen for Deep-rooted Community Based Conflict Resolution; in regards to working with individuals living with FASD, their families, and their communities.

Methods

We will give an overview of theoretical background from First Nations research regarding conflict resolution and First Nation scientific methods. Then, we will present an outline of the NB FASD Centre of Excellence and our "FASD Dream Catcher Service Delivery Model" for First Nation culturally appropriate service delivery. This Model will show how it places the clients living with FASD, their families, community and culture at the core of the process. This model weaves culturally appropriate links using the Apigsigtoagen theory and allows the silos to be addressed with the professionals involved. Because of the complexity of an FASD diagnosis, this allows for collaborative and respectful work that results in better delivery of services to the client living with FASD and their families.

Anticipated Outcomes

This model ensures the First Nations' cultural safety and appropriateness of services across sectors, addresses FN historical trauma in the province of NB, and supports best practice. The model addresses front-line health care by addressing the Indigenous determinants of health; identifying "gaps" to prevent secondary and tertiary effects that occur as a result of missing community services, or that do not meet the real needs that individuals living with FASD live. We hope to measure a decline in admission to tertiary care, keep young people in schools and reduce the effects with the justice system. And most importantly, keep individuals living with FASD in their communities.

Conclusion

Apigsigtoagen is a Mi'kmaq First Nations peacemaking approach to begin the healing and reconciliation process necessary for forgiveness, collaboration, rethinking, and thanksgiving (gratitude) within the First Nation communities of Eastern Canada. This model is a living document, which means that this document can and must change according to the changing needs of the family.

P18 Epidemiology of Fetal Alcohol Syndrome in Reunion Island - Registry of Congenital Malformations of Reunion Island 2003-2015

Bérénice Doray

Objectives

Fetal Alcohol Spectrum Disorder represents a major public health problem. Concerning about 1 in 100 births, it is the most common cause of neurocognitive disorders and difficulty of social insertion. Fetal Alcohol Syndrome (FAS) is the most complete and visible form including growth retardation, dysmorphic syndrome, malformations, neurocognitive and behavioral disorders and concerns one in 1,000 births.

The aim of this study was to determine recent epidemiologic data concerning FAS throughout the territory.

Methods

A population-based retrospective study was performed from data of the Registry of Congenital Malformations of Reunion Island. All cases with FAS were recorded among live births, stillbirths and terminations of pregnancy whom mothers lived and gave birth in Reunion Island between 2003 and 2015.

Results

122 cases were registered. The total prevalence was 6 per 10,000 births with a number of births between 4 and 14 per year. This population was composed of 115 livebirths, 2 stillbirths and 5 terminations of pregnancy. The diagnosis was performed prenatally in 31% of the cases, at birth in 61% and during the first year of life in 8%. The majority of cases (72%) were born in the south of the Island, 3% of cases were born at home. Maternal vulnerability factors were identified, including pregnancy not declared or declared late (14 cases), pregnancy not well monitored (17 cases), anonymous birth (1 case), but also mothers out of care, previous foster children. Concerning malformations, brain malformations were the most frequent (70%) including 12 cases of microcephaly and 6 cases of agenesis of the corpus callosum. The other frequent anomalies were cardiac malformations (30%), cleft lip or cleft lip palate (15%), renal malformations (9%). Fetal growth restriction was identified in 61% of the cases, severe in 50% of the cases.

Conclusion

These results confirmed:

1. The high prevalence of FAS in Reunion Island of 6 per 10,000 total births. This result was lower than the prevalence classically reported of 10 per 10,000. One hypothesis is that the restrictive criteria for inclusion in the registry led to register only the most severe cases with a well-known maternal alcohol use. Does this result reflect a truly higher prevalence on Reunion Island or rather a better ability from professionals trained for a long time to diagnose this condition? Similarly, is FAS really more frequent in the South of the Island or is it only the effect of a overrepresentation of experienced professionals? If this last hypothesis is true, the improvement of knowledge, using training programs offered by the FASD Resource Center of Reunion Island should lead to remove this difference in the future.

2. The frequency of maternal factors of vulnerability (especially pregnancy not or belatedly declared or not well-monitored) that can help to alert the professionals of perinatality.
3. That fetal hypotrophy, brain abnormalities (especially microcephaly and agenesis of the corpus callosum) andcardiac malformations constitute major FAS symptoms that should systematically make suspect a prenatal alcohol exposure.

P19

"My Doctor Says It's O.K. to Have a Sip of Wine Every Now and Then": Alcohol Use During Pregnancy on *How I Met Your Mother* (TV Show)

Eric Harding

Authors: Eric Harding, Kelly Harding, Shelley L. Watson

Objectives

The mass media is a common source for obtaining information on alcohol use during pregnancy among pregnant women and women of childbearing age. Mainstream media, particularly television, often delivers inaccurate information and inconsistent messages regarding 'safe levels' of drinking. The portrayal of pregnancy and pregnant characters in sitcoms is problematic, providing potentially hazardous scenarios that may influence the attitudes of impressionable viewers. The sitcom, How I Met Your Mother, which aired from 2005 to 2014, is a well-known example of misinformation regarding drinking during pregnancy. The purpose of this study is to address the proposed research question: How is drinking and substance use during pregnancy portrayed on How I Met Your Mother and what influence may these portrayals have on the attitudes of pregnant women?

Method

The television sitcom How I Met Your Mother was analysed utilising ethnographic content analysis (Altheide & Schneider, 2013). The content and role of the show's media narratives in the social construction of alcohol meanings were examined regarding the safety of prenatal alcohol exposure. The entire series was analysed (N = 208), where each episode was screened for portrayals of alcohol use, alcohol use during pregnancy, and attitudes regarding alcohol use during pregnancy. This study is part of a larger project examining television narratives among popular prime time television programs.

Results

Results indicate several problematic portrayals of, and attitudes regarding, alcohol use during pregnancy on How I Met Your Mother. One of the most prominent examples that has received considerable attention in social media is the advice provided by Lily Aldrin's OBGYN, Dr. Sonya, in season 7 episode 4. Dr. Sonya recommends that Lily could drink 'just a little bit!' of wine, providing poor medical advice from a perceived medical authority. The already muddled message regarding safe levels of alcohol consumption during pregnancy in the mass media is further complicated by Dr. Sonya's recommendation which does not indicate exactly what amount or frequency is implied by 'just a little bit.' Beyond this notable example, How I Met Your Mother contains countless other examples of substantially problematic alcohol use and the varying attitudes of alcohol use during pregnancy from the cast of characters. These depictions and attitudes regarding alcohol use during pregnancy reflect the larger issue surrounding the representation of socially acceptable drinking in the mass media. How I Met Your Mother and other popular television programs often depict inaccurate information concerning safe levels of alcohol consumption during pregnancy.

Conclusions

The results of this study demonstrate the importance of providing a clear and accurate message regarding the risks of alcohol use during pregnancy. The mixed, inaccurate representations of alcohol use during pregnancy in television programs may contribute to misinformation among pregnant women, their partners, and women of childbearing age. The potential implications of these results include the possibility of providing media sources with clear and consistent messaging for future programming, raising awareness of misleading depictions of alcohol use and pregnancy, and furthering education concerning safe levels of alcohol consumption during pregnancy among the general populace.

P20

Assessing Brain Function in FASD: Measures Used by Clinicians in Alberta, Canada

Kelly Harding, Colleen Burns, Brent Symes

Authors: Kelly Harding, Katherine Flannigan, Colleen Buns, Hasu Rajani, Bren Symes

Objectives
Early diagnosis of FASD is a significant protective factor that can mitigate some of the challenges experienced by people with FASD. FASD assessment and diagnosis is critical for connecting individuals and their families with appropriate services, resources, and supports. The suggested “gold standard” for FASD assessment involves a multidisciplinary diagnostic team and comprehensive battery of tests to evaluate neurodevelopmental functioning across ten brain domains. The current Canadian Guideline for diagnosis of FASD outlines a list of testing measures suggested to assess for FASD; however, very little research exists to explore the tools that are being used in clinical practice. The purpose of the current study was to gain a better understanding of the testing measures used by FASD clinicians in Alberta, Canada.

Methods
A survey was sent to clinic coordinators of 23 Alberta FASD clinics between October 2016 and January 2017, requesting them to distribute the survey to their team members, including physicians, psychologists, speech language pathologists (SLPs), and occupational therapists (OTs). Participants had the option to either type or hand-write their responses and return the survey via e-mail or by post.

Results
Surveys were returned from 19 clinics (83% response rate) including child, adult, and combined child/adult clinics. Individual respondents (N = 36) included 16 psychologists, 10 SLPs, 9 OTs, and 1 clinic coordinator. A wide range of measures (both direct and indirect) (n = 173), were reported by clinics to assess various brain domains, with the highest number in the language domain and the lowest in the cognition domain. Many tests were used to assess functioning across multiple brain domains. Some clinics reported using outdated or abbreviated versions of tests. There was significant overlap of measures used across clinics, particularly in cognition, adaptive behaviour, and executive functioning. Most of the commonly used measures aligned with those suggested in the Canadian Guideline; however, there were also many additional commonly reported measures outside of those suggestions in the Guideline, especially in the Adaptive Behaviour and Affect Regulation domains.

Conclusions
This study reveals important information about the use of testing measures in FASD assessment and sheds light on the commonalities in practice across clinics in Alberta. Results also demonstrate strong convergence of direct and indirect measures to assess brain function. This research has the potential to promote conversation and collaboration between clinics to identify useful, current, and reliable measures that may not have been identified in previous guidelines. Ultimately, identifying a comprehensive, reliable, and usable test battery of measures for FASD assessment will improve the clarity and accuracy of the diagnostic process and facilitate advancements in the field.

P21

Pathways to Inclusion: Examining Regional Policy Supporting Individuals with FASD

Alexandra Johnson

Abstract

Individuals with Fetal Alcohol Spectrum Disorder (FASD) are often excluded from regional policies supporting individuals with cognitive disabilities. This exclusion is an unintended outcome of the implementation of policy that may be too limited in its eligibility criteria, coupled with ongoing stigma and misunderstanding of FASD as a neuro-cognitive condition. Individuals with FASD disproportionately experience adverse life outcomes and are overrepresented in the criminal justice system. Research suggests that community supports mitigate risk for justice involvement and adverse life experiences for those with FASD. The Truth and Reconciliation Commission (TRC) of Canada has levied a call to all levels of government to ensure "appropriate community supports are in place for those with FASD". As such, the research question guiding this project is: how do regional policies affect transition planning processes for youth with FASD as they age out of youth supports?

There are discrepancies in the level and nature of supports provided to individuals with FASD in comparison with other neuro-cognitive conditions. While the discrepancies in funding and access to services are experienced throughout the life-course of individuals with FASD, these discrepancies are particularly evident during the process of "aging out". Aging out is the process by which individuals who were previously supported under regional child and family services reach adulthood and must seek out adult supports. There are challenges associated with the aging out process even in the absence of a complex neuro-cognitive condition, but these challenges are intensified for individuals with FASD . As both the child and family services acts and policies supporting individuals with cognitive disabilities are enacted by provincial/territorial governments, regional analysis will focus on the Cognitive Disability Strategy (CDS) of Saskatchewan. This research addresses a gap in the literature by focusing on a highly racialized disability in the context of Saskatchewan, a prairie province with a high proportion of Indigenous peoples.

This SSHRC-funded research project will focus on obtaining the perspectives of individuals who apply for CDS supports on behalf of individuals with FASD. These individuals have familiarity with the circumstances of FASD clients prior to application and knowledge of the challenges facing these clients if they fail to qualify for adult supports. Twenty-five participants in Saskatchewan (12 caseworkers and 13 child protection workers) will be interviewed in semi-structured face-to-face interviews approximately 45 minutes in length. The qualitative data analysis process will employ open coding of audio recordings through Nvivo and thematic analysis to highlight salient experiences among participants, and identify recurrent barriers and concerns among the participants.

This research will examine if and to what extent individuals with FASD may be marginalized by the implementation of regional policy. This study will highlight the relevance of regional policy in influencing the pathways to justice involvement for individuals with FASD, and focus on the outcomes associated with successful application and failure to qualify for CDS. Responding to the TRC Calls to Action, this timely research will explore of the role for policy in securing necessary supports for individuals with FASD.

P22 White Matter Microstructure in Young Children with PAE

Preeti Kar

Authors: Preeti Kar, Carly McMorris, Jess Reynolds, Melody Grohs, Chantel Ritter, Christina Tortorelli, Ben Gibbard, Catherine Lebel

Background

Fetal alcohol spectrum disorder (FASD) refers to a broad spectrum of disabilities resulting from prenatal alcohol exposure (PAE). Children with FASD have widespread neurological dysfunction resulting in cognitive, behavioral and social-emotional challenges.

Previous neuroimaging research has focused on understanding brain development in 7- to 20-year-olds with FASD, and has shown decreased white matter connectivity. However, little is known about brain structure in younger (2- to 6-year-old) children with PAE. With extensive brain development taking place during this timeframe, understanding the neurological profile of these children could be critical for early identification and early intervention of FASD.

Objective

This study aimed to identify white matter abnormalities in young children with PAE.

Methods

We studied 45 children (24 males; 5.24±1.07 years) with confirmed PAE, compared to 45 age- and sex-matched controls without PAE. Children underwent magnetic resonance imaging (MRI) including diffusion tensor imaging (DTI), a technique that provides information about white matter microstructure. Image processing was completed using ExploreDTI, and semi-automated deterministic tractography was used to delineate 10 major white matter tracts: the pyramidal tract, corpus callosum (genu, body, splenium), cingulum, fornix, inferior fronto-occipital fasciculus, inferior longitudinal fasciculus, superior longitudinal fasciculus including arcuate, and uncinate fasciculus. Mean fractional anisotropy (FA) and mean diffusivity (MD) were obtained for each tract, measures that reflect microstructural properties such as myelination, axonal packing and/or coherence.

Results

A multivariate analysis of covariance, controlling for age and sex, revealed significant group differences overall in FA ($p=0.002$) and MD ($p=0.009$). Compared to controls, children with PAE had significantly lower FA in the fornix ($p=0.013$) and the right superior longitudinal fasciculus ($p=0.037$). Lower MD was also observed in children with PAE in the left ($p=0.047$) and right uncinate fasciculi ($p=0.003$) as well as the right fronto-occipital fasciculus ($p=0.027$).

Discussion

Preliminary findings demonstrate that white matter microstructural abnormalities are present in young children with PAE. The lower FA in the fornix and the right superior longitudinal fasciculus, tracts associated with language, memory and cognition, suggests reduced myelination, axonal packing, and/or coherence in children with PAE. On the contrary, young children with PAE had lower MD, which suggests more myelination, axonal packing, and/or coherence, in the uncinate fasciculus, a tract associated with social-emotional processing. While this has not been observed in previous neuroimaging research in the FASD population, it has been noted in youth and adults with adverse childhood experiences (e.g. abuse, neglect, caregiver separation, maternal mental health), and thus may be driven by the postnatal trauma experienced by this sample of children. High levels of childhood stress may encourage early, rapid development of regions and circuitry related to social-emotional functioning. In support of this hypothesis, although not significant, children in our sample with both PAE and postnatal adversities had lower MD in the right uncinate fasciculus than both children with PAE and no postnatal adversities and controls. Future analysis will try to further disentangle the role of other prenatal exposures and specific postnatal exposures in white matter microstructure.

P23

Self-Care in Caregivers of Children with FASD: How Do Caregivers Engage in Self-Care and What Are the Benefits and Obstacles for Doing So?

Carson Kautz

Authors: Carson Kautz, Jennifer Parr, Christie Petrenko

Objectives

Approximately 2-5% of children are impacted by Fetal Alcohol Spectrum Disorders (FASD) and have a variety of neurological and physical symptoms. Research highlights the difficulties of caring for a child with a disability; however, little has been published related to caregivers' care for themselves. Self-care is a critical resource for not only caregivers' own physical and mental health, but also for the benefit of their children. This poster aims to examine confidence and frequency of engaging in self-care in caregivers of children with FASD.

Methods

Forty-six caregivers (ages 31-65) of children with FASD completed a brief survey of self-care practices. Caregivers were asked to identify self-care strategies and obstacles, rate their abilities and confidence in taking care of their physical and mental health, and rate how often they engaged in self-care. Additionally, they reported on perceived parenting efficacy, stress, family needs met, child behavior, and family demographics. Analyses were descriptive. Self-care strategies and obstacles were grouped together to yield categories. Correlation analyses examined associations between self-care confidence and frequency and measures of child and family functioning.

Results

Self-care strategies fell into seven overarching categories including: being present, seeking social support, maintaining physical health, engaging in hobbies, consuming media, treating oneself to small luxuries, and seeking information. Common obstacles fell into eight categories, which were time restraints, lack of resources, family needs and challenges, exhaustion, health issues, mood, logistics, and pride. Caregivers with greater confidence in self-care abilities were significantly more likely to report higher satisfaction in parenting ($p=.016$), lower parental distress ($p-.027$), and more family needs being met ($p=.001$). Caregiver ratings of abilities and confidence were significantly correlated with caregiver report of how often they engaged in self-care ($p=.013$); however, caregiver report of how often they engaged in self-care was not significantly correlated with any other measure. Caregiver ratings of abilities and confidence were not significantly correlated with caregiver ratings of child behavior ($p>.05$), caregiver ratings of child impairment ($p>.05$), or perceived parenting efficacy ($p>.05$). Neither caregiver ratings of abilities and confidence nor caregiver ratings of frequency engaged in self-care were significantly correlated with child age ($p>.05$) or gross family household income ($p>.05$).

Conclusions

Strategies for and obstacles to self-care reported by caregivers were varied. Significant correlations imply feelings of competence and confidence in caring for oneself are related to parenting satisfaction, lower parental distress, and family needs being adequately met, but not to caregiver impressions of child impairment and behavior. How often caregivers engaged in self-care was not significantly associated with any other measure, which may imply that caregivers' confidence in caring for their well-being may be more important than frequency of self-care activities. Notably, self-care habits were not related with child age or family income. Given the relations with other indices of family functioning, attending to caregivers' self-care is critical. Interventions and future research should focus on methods to enhance caregivers' feelings of confidence in their self-care abilities. Helping caregivers prioritize self-care and reducing obstacles will be important.

P24

Development of a FASD Screening Tool

Catherine Lipman

Authors: Catherine Lipman, Denise Bothe, Rachel Tangen, Hudson Taylor, Nori Minich, Kiran Prasad, Nancy Roizen

Objectives
Fetal alcohol spectrum disorders (FASD) are a common cause of developmental disabilities. Some children are at particularly high risk for FASD (e.g. children in foster care). Early diagnosis and intervention decrease adverse outcomes. It is therefore important to screen for FASD in high-risk populations. The objective of this study was to develop a FASD screening tool that identifies children in high-risk populations who are at risk for all types of FASD.

Methods
We developed a FASD screening tool based on both recently updated FASD diagnostic guidelines and the FASD 4-Digit Diagnostic Code. Patients screened positive if any of the following 3 criteria were met: documented prenatal alcohol exposure; 3 out of 3 fetal alcohol syndrome facial features (FASFF); or 2 out of 3 FASFF plus a history of growth deficiency, central nervous system abnormality, or birth defect. The screening tool was used to evaluate children 3-12 years old who had previously presented to a FASD clinic between 2010 to 2017. The results of facial photograph analysis, growth measurements, and a review of medical information that would have been available prior to the clinic visit were used to retrospectively screen patients. Screening results were compared to the results of a FASD diagnostic evaluation using the FASD 4-Digit Diagnostic Code. FASD were defined as fetal alcohol syndrome (FAS), partial FAS, static encephalopathy/alcohol exposed and neurobehavioral disorder/alcohol exposed.

Results
Of the 107 patients who presented to the clinic, 73 met inclusion criteria. 97% of those children were not in biological mother’s care and many had prior diagnoses of psychiatric (63%), developmental (44%), learning (38%), or cognitive (16%) problems. The sensitivity, specificity, and positive and negative predictive values of the screening tool were 0.96, 0.75, 0.91, and 0.88, respectively. The screener identified children at risk for all types of FASD.

Conclusions
These findings suggest that the screening tool, tested retrospectively in a high-risk population, was sensitive, relatively specific, and identified children at risk for the full range of FASD. Given that many children evaluated in the FASD clinic were not in their biological mother’s care and had psychiatric, developmental, learning, or cognitive problems diagnosed prior to FASD evaluation, it may be useful to use this screening tool in settings catering to similar populations, such as foster care, adoption, developmental-behavioral, and psychiatric clinics.

P25

Promising Practice in Post-Assessment Support Services

Jill Lundgren, Sylvie Horan, Candace Windisch

Abstract

For the past 15 years, Enviros has strived to provide high quality post-assessment support to individuals living with FASD and their families. Through our two FASD programs, we work alongside individuals and their supports to achieve their potential and increase their overall wellbeing. The services we provide are based on the core belief that the quality of life for those living with FASD is improved through environmental adaptation, increased capacity of support systems, and an individualized approach that takes strengths and interests into consideration and utilizes the FASD Assessment Report to understand the client's unique strengths and needs.

In 2017 we embarked on an evaluative research project with Policy Wise which examined the effectiveness of our program model, in addition to a literature review pertaining to FASD and caregiver support. The research process used a mixed-methods approach, including an evaluating of the literature, one-to-one interviews, outcome data analysis, focus groups, and a review of the program documents. The results of the evaluation project demonstrated that:

- Caregivers experienced statistically significant improvements in knowledge and education, skill development, community resources, self-care, and educational support after completing our programs.

- Children living with FASD experienced statistically significant decrease in risk factors after their caregivers completed the programs.

- Through FASD education and a better understanding of a child's assessment and diagnosis, caregivers demonstrated increased ability to make environmental changes and to advocate on their child's behalf.

This presentation will review the research project process, findings, and implications for broader practice in FASD programs. Bringing together our humble journey of hurdles and milestones, and what we've learned through the research project, this presentation will increase knowledge in the following areas:

- Leading Practice: Through a thorough review of the literature, attendees will leave with a clear description of what is available in the literature pertaining to leading practices in serving individuals and families impacted by FASD.

- Caregiver Experience: Attendees will gain a deeper understanding of the caregiver experience and support needs through research findings, as well as the shared stories of hundreds of caregivers we have had the privilege of working with.

- Program Evaluation and Data Collection: Through sharing our experience with the research project, and feedback we've received from Policy Wise, we hope to provide insight into effective data collection and program evaluation.

P26 Case Management in Pregnancy to Prevent FASD in High Risk Pregnancies: A Trial in South Africa

Philip A. May, Julie Hasken, Dixie Marie Hedrick

Authors: A-S Marais, M.M. De Vries, W.O. Kalberg, D. Buckley, J. Hasken, S. Seedat, C.D.H. Parry, P.A. May

Purpose

Women at high risk of prenatal alcohol use from two communities in the Western Cape Province of South Africa (ZA) participated in case management (CM) to prevent and/or minimize the severity of fetal alcohol spectrum disorders (FASD) using Motivational Interviewing (MI) and Community Reinforcement approach (CRA). Developmental outcomes of the children born to the women in CM were compared with offspring of mothers who were not in CM.

Methods

Women were recruited from community health clinics as early as possible in pregnancy and followed 60 months postpartum. The CM intervention targeted women at highest risk for bearing a child with a FASD. Risk was determined by scores on the Self-Administered Questionnaire (SAQ) and the Alcohol Use Disorders Identification Test (AUDIT). Case management was initiated quickly after screening to reduce or eliminate drinking early in pregnancy. Children born to CM mothers (N=42) and those whose mothers were not in CM (N=175) were followed in infancy and early childhood to track physical traits and developmental and behavioral outcomes.

Results

At 5 years of age a final diagnosis was provided for all of the children. More of the children of the CM mothers were diagnosed within the continuum of FASD (75%) compared with 52% of the children whose mothers did not receive CM. This was expected, as the highest risk mothers were in CM. All children were assessed using the Bayley in the early months and at 60 months using the Kaufman Assessment Battery for Children (KABC-II). Diagnostic categories within the FASD continuum were: 1) fetal alcohol syndrome (FAS); 2) partial fetal alcohol syndrome (PFAS); 3) alcohol related neurobehavioral deficits (ARND); 4) alcohol related birth defects (ARBD). At 6 weeks of age, children with FASD who were born to mothers in CM were on average: longer, weighed more, had larger occipital frontal (head) circumference (OFC), longer palpebral fissure length (PFL- eye opening), and lower total dysmorphology scores compared to children with FASD whose mothers drank prenatally but were not in CM. On the Bayley scores, the children who were exposed showed extreme variability at each testing time period. This pattern of better physical outcomes is sustained at 5 years of age, although all of the alcohol-exposed children scored significantly worse on the KABC than unexposed children. The scores of the children from CM were on average higher than those not in CM, and there was no significant difference in the sequential short term memory. Overall, the likelihood of having a child with FASD appears to have reduced by 55%.

Conclusion

CM during pregnancy was associated with better physical outcomes for children at risk of FASD, but not necessarily better neurobehavioral outcomes by 5 years of age.

P27

Development and Initial Validation of a New Screening Tool for Young Children with FASD

Stewart McDougall

Authors: Stewart McDougall, Fiona Arney, Andrea Gordon, Amy Finlay-Jones3

Objectives

There is an urgent need to improve screening and early identification of children with Fetal Alcohol Spectrum Disorder (FASD), particularly amongst children who do not display the facial features. Caregiver- completed behavioral observation measures have shown promise in identifying children who are in need of referral and assessment from a multi-disciplinary diagnostic team. While these tools show promise, there are currently no validated screening tools developed for young children living with FASD. The objective of this presentation is to report on the development of a new screening tool for children living with FASD, and to report initial results from pilot testing of the tool. The screening tool is intended to indicate children who would most benefit from referral to specialist diagnostic services.

Methods

This project followed measure development guidelines, and included four major stages: 1) literature review, 2) interviews with caregivers and clinicians, 3) item pool development and content validation and, 4) pilot testing. The methodology of stages one, two, and three are briefly summarized below:

1. A scoping review was undertaken, examining the breadth of the literature examining the differences between children (up to the age of 13) with FASD, and typically developing peers.

2. Interviews with caregivers (n=15), and clinicians (n=5) who care for children with FASD, to explore the difficulties experienced by their children, the early warning signs and what triggered the assessment and referral process.

3. Through the literature and qualitative data collection process 95 candidate items were generated and subsequently reviewed by experts (n=8 caregivers and clinicians). Following a process of revising and refining the items, a final screening tool containing 61 items was pilot tested.

To pilot test the tool, online recruitment of families raising children with FASD, and typically developing peers was conducted. Participants were invited to complete an online survey comprising the screening tool, demographic factors including lifestyle during pregnancy, and measures for convergent/divergent validation against the, the Childhood Inventory of Executive Function, the Strengths and Difficulties questionnaire, and the Neurobehavioural Screening Tool. Participants were invited to take part in a re-administration of the study to determine the test re-test reliability of the tool.

Data will be analysed using Item Response Theory to examine the psychometric properties of the tool. Additionally, classical test theory indices of reliability (e.g., internal consistency, test-retest reliability) will also be examined. The validity of the tool will be tested through three sets of analyses; examining the differences in scores between children with FASD and peers, calculating the sensitivity and specificity of the tool, and examining the correlations with other measures administered.

Results

The measure development process (stages 1, 2, and 3) and preliminary results of the pilot testing will be presented.

Conclusion

The screening tool has been developed following an extensive literature review and with substantial input from caregivers of children living with FASD, and clinicians. Future research directions, and studies to further test the validity of the tool are discussed.

P28

Changing the Conversation, Promoting Dignity: Reflections from the FrameWorks Institute's work on reframing FASD in Manitoba and the 2019 Canada Northwest FASD Partnership National Symposium

Holly Gammon

Abstract

Objective 1: Recognize existing gaps between expert and public understanding of FASD, and identify initial strategic recommendations by the FrameWorks Institute to bridge these gaps by using communications strategies to reframe FASD.

Objective 2: Review the work of the Canada Northwest FASD Partnership National Symposium (Feb 6-7, 2019 in Winnipeg, MB).

The ways in which we communicate about FASD have the power to impact societal values. By analyzing communication patterns and developing strategies to reframe the conversation, we can transform public discourse about FASD to promote dignity and generate program and policy support for people with FASD, their families and communities, and women who use alcohol in pregnancy.

This presentation will provide an overview of the 2017 report "Seeing the Spectrum: Mapping the Gaps between Expert and Public Understandings of FASD in Manitoba" by the FrameWorks Institute. This report outlines the gaps between expert and societal understanding of FASD: how alcohol impacts fetal development, the effects of FASD, why women use alcohol during pregnancy, and ideas about FASD prevention and awareness. FrameWorks then provides initial strategic recommendations to bridge gaps in understanding about FASD, and how to reframe the issue of FASD in ways that evoke more effective public understanding, support, and promotion of dignity for those impacted by FASD. A synopsis of the report, along with key quotes from a presentation on the report by Nat Kendall-Taylor, CEO of FrameWorks, will be presented.

The 2019 National Symposium in Winnipeg, MB will continue the work begun by the "Seeing the Spectrum" report by engaging a diverse and dynamic group of FASD stakeholders from across Canada. Following an Innovative Engineering methodology, Symposium attendees will begin the process of developing and testing frames used to communicate about FASD that promote dignity for people with FASD and women who drink alcohol during pregnancy. This presentation will provide an overview of the Symposium, including information from the evaluation report, an overview of preliminary Symposium findings, and photographs and written reflections from the Symposium.

Reframing FASD in Canada is a process that must engage the public in meaningful ways, recognizing that we all have a role to play in FASD prevention and support. People with lived experience are our experts, including people with FASD, their families and communities, and women who drink alcohol during pregnancy. The reframing process also needs to engage with those with professional experience, such as FASD service providers, researchers, policy makers, and key stakeholders. Finally, it is important that we engage people with fresh perspectives- philanthropists, media members, people with expertise in communications and marketing, Indigenous leaders, and up-and-coming community leaders. This poster will provide information for people to consider how they can engage in the process of developing and testing FASD communication frames, and how they can stay involved and informed about the ongoing work of this project.

P29 Carer Stress in FASD: Data from the UK National Specialist FASD Clinic

Raja Mukherjee

Authors: Zameer Mohamed, Alexandra Carlisle, Alexandra Livesey, Raja Mukherjee

Background

Previous research in FASD has started to look at the unique stress that is placed upon carers of children with Fetal Alcohol Spectrum Disorders (FASD). The goal of this research was to analyse outcomes from carer stress questionnaires (i.e. from carers of children with an FASD diagnosis in the UK) to better understand the nature of this stress.

Method

88 carers of children with FASD, aged 6-12, completed the Parental Stress Index. Descriptive statistics, regression analysis, ANOVA, and question by question analysis were all carried out in order to investigate the exact nature of stress in carers of children with FASD.

Results

Five out of the six child domains were in the clinically significant range for stress, with the exception of the Reinforces Parent subscale. In comparison, none of the Parent Domain subscales were in the clinically significant range for stress. Regression analysis showed that three of the child domains and one of the parent domains contributed significantly to the overall stress reported by parents. Only the parent-child attachment subscale in both Domains showed a significant difference in stress between age groups of carers.

Conclusion

Overall there is significant stress in carers of children with FASD. Aspects in both sides of the child and parent relationship dyad contribute to overall stress of carers, in all carer age groups. This suggests the needs of caregivers with FASD are wide ranging, and should be a noteworthy target for intervention.

P30

Community Priorities for FASD Research in Australia

Narelle Mullan

Authors: Narelle Mullan, Kiah Evans, Amy Finlay-Jones, Jenny Downs, Bahareh Afsharnejad, Elissa Strumpher

Objective
The short-term aim of this project is to understand how the current Australian clinical guidance documents for neurodevelopmental disorder (NDD) diagnosis work together, and to learn from clinicians and families how to better coordinate the process of diagnosis through a shared framework.

The assessment of children and young people for NDD is complex, time-consuming and involves several different health professionals including paediatricians, psychiatrists, speech pathologists, psychologists and occupational therapists.

Recently, Australian clinical guidelines have been developed separately to help child health professionals diagnose different NDDs. It is now becoming clear that children may have more than one NDD, for example the co-occurrence of ASD and FASD is starting to be accepted by researchers and clinicians. Consultation with health professionals and community members during the development of the ASD and FASD Diagnosis Guidelines has highlighted the importance of raising awareness of other NDDs among clinicians diagnosing a specific NDD.

Methods
This project involved two parts and each part was guided by a Steering Group of clinical experts and community members with lived experience:

1. Part one was a review of existing Australian and international clinical guidance documents for NDD diagnosis to explore similarities and differences between guidelines.
2. Part two involved online and workshop consultations with clinical experts and community members. The purpose of this consultation was to identify current gaps in knowledge about NDD diagnosis, as well as potential benefits and challenges which may come from having a shared framework to guide the process of diagnosing one or more NDDs in children.

Results:
Initial review of the guidelines and early consultation highlighted identification and subsequent treatment typically depends on assessment of developmental problems that only emerge from around 2-3 years of age. The final round of consultation and review conclusions will be delivered in October 2018, however work to date has highlighted the need for early identification and intervention approaches for neurodevelopmental disorders, and a broader program of research to increase knowledge of transdiagnostic approaches to assessment.

P31

Empowering Approaches to Reducing the Harms of Alcohol Use in Girls

Nancy Poole

Authors: Nancy Poole, Tasnim Nathoo, Marbella Carlos

Background

Alcohol is the leading substance used by Canadian youth. The average age at which girls first drink alcohol in Canada is 13 years old and young women have the highest rates of heavy and binge drinking of all age groups of women. Interventions to reduce the harms of alcohol use in girls and young women requires attention to issues such as mental wellness, sexuality, eating disorders, weight concerns, and sexual assault. This presentation describes an approach to girl-specific health promotion that uses an empowerment framework emphasizing popular education/critical thinking, the assets and capacities of girls' own realities and experiences, the development of self-advocacy and life skills, and social action and change.

Methods

In 2012, the Centre of Excellence Women's Health and the Girls Action Foundation began a multi-year project to research, develop, test and disseminate information and resources on best practices in health promotion for girls. In 2015, in collaboration with partners in six communities in Nova Scotia, British Columbia, Ontario, and Quebec, and a national advisory committee of diverse stakeholders and knowledge experts, the Girls Action Foundation began to develop and pilot a toolkit for girls' programmers that focuses on healthy living for girls, including a focus on alcohol and other substance use. The "Take Care" toolkit was released in fall of 2018 and includes a workshop guide for working with girls and young women.

Results

An empowerment approach to girls' alcohol use can create safe spaces for discussing personal values and the pros and cons of substance use, sharing information and getting support for changes girls might want to make, and addressing the interconnected factors influencing girls' alcohol use. Findings from this project suggest that girls are the best source of information about their own health and in determining which interventions and support will be the most helpful for them and that a focus on harm reduction and girls' lived experiences are important in creating inclusive spaces for all girls.

Conclusions

Service providers working with girls and young women can use principles and practices related to girl-specific health promotion to provide girls with the knowledge, resources, and support they need to make healthy choices related to alcohol use and their health.

P32

Indigenous Approaches to FASD Prevention: Enacting the Truth and Reconciliation Commission's Call to Action 33

Nancy Poole, Lindsay Wolfson

Authors: Lindsay Wolfson, Nancy Poole, Carol Hopkins, Rose Schmidt, Kathy Unsworth

Objectives
To bring attention to the opportunities for collaborative action on Canada's Truth and Reconciliation Commission's Call to Action #33, which highlights the need to develop culturally appropriate FASD preventive programs. This poster will describe the eight tenets for FASD Prevention developed in a meeting of experts in FASD prevention and Indigenous health held in May 2017 in Vancouver co-sponsored by the Centre of Excellence for Women's Health, the CanFASD Research Network and the Thunderbird Partnership Foundation and highlight ongoing action on Indigenous wellness and reconciliation in FASD prevention approaches.

Methods
The Consensus Statement and its eight tenets for enacting Call to Action #33 were collaboratively developed during and following the initial national meeting. The tenets align with Indigenous knowledge and wellness models, including the First Nations Mental Wellness Continuum Framework. Following the meeting 5 booklets on Indigenous Approaches to FASD Prevention were created to support community-based work, including one entitled Reconciliation and Healing.

Results
This poster will visually capture the eight Consensus Statement tenets and a timeline of Indigenous Approaches to FASD prevention in Canada starting in the late 1970s; highlight what decolonizing FASD prevention might look like; and offer reflective questions about FASD prevention and reconciliation.

Conclusions
The Consensus Statement and subsequently created community booklets invite long overdue critical thinking and action on culturally-informed FASD prevention, and dedication to reconciliation as outlined by the Truth and Reconciliation Commission.

P33

FASD in Aboriginal Youth: A Descriptive Study of Presentations to Child & Adolescent Psychiatric Emergency

Sinead Nugent

Objectives

This study sought to examine presentations of Aboriginal youth with Fetal Alcohol Spectrum Disorder (FASD) admitted to the Child & Adolescent Psychiatric Emergency (CAPE) at BC Children's Hospital over a 6-year period.

Methods

A retrospective chart review of admissions to CAPE between 2009 and 2014 identified all patients with a diagnosis of FASD. Information was collected using the Discharge Abstract Database.

Results

84 admissions were recorded (64 patients, 20 repeat admissions). 56% were identified as Aboriginal and 44% as non-Aboriginal. The Aboriginal group made up 62% of all admissions. Behavior problems (54% Aboriginal, 77% non-Aboriginal), suicidality (46% Aboriginal and 42% non-Aboriginal), and psychotic symptoms (27% Aboriginal, 23% non-Aboriginal) were the most common admission reasons. 71% of non-Aboriginal patients had a diagnosis of ADHD and 43% had a diagnosis of ODD compared to 33% and 25% of Aboriginal patients. Depressive (19%) and stress-related disorders (28%) were higher in the Aboriginal group than the non-Aboriginal group (7% and 14%). 7% of non-Aboriginal patients changed placement on discharge compared to 23% of Aboriginal patients. 45% of non-Aboriginal admissions were discharged to their family homes compared to 23% of Aboriginal admissions. 35% of non-Aboriginal admissions were discharged to foster care compared to 52% of Aboriginal admissions.

Conclusions

8% of the BC child population identifies as Aboriginal, yet a disproportionate number have diagnoses of FASD and require emergency psychiatric admission for co-occurring mental health crises. This highlights a critical need for further research into the mental health of this group to inform the development of culturally informed therapeutic interventions.

P34

Psychotropic Medication Use in 200 Children with FASD: A Retrospective Chart Review of the Medication Prescribing from the Only FASD Diagnostic Clinic in the Southern Half of Saskatchewan

Susan Petryk

Background
FASD is a complex brain condition associated with prenatal alcohol exposure (PAE) affecting cognitive, neurological, social and interpersonal functions leading to lifelong disability. Many children with FASD require psychopharmacological treatments for comorbid emotional and behaviour problems. Some clinicians have theorized that there could be an algorithm for medication use in FASD. Some feel that doses may tend to be higher in this population. However, there is very little data on medication use specifically in FASD. A review of a comprehensive and multi-year psychotropic medication database of patients seen in the only FASD diagnostic clinic in southern Saskatchewan was explored to see if it could provide any insights into the usual medications and doses typically prescribed in this population and if there was a correlation between the level of FASD and medication use.

Methods
A retrospective chart review was made of the last medication followup of 200 consecutive clients seen between January 2008 - June 2018. Data collected includes demographic description of the clients assessed, primary and secondary diagnoses, all current medications, the extent of polypharmacy, and doses (mg/kg) of certain medications.

Results
A total of 34.2% individuals with FASD were not using any medication, 35.8% were on single medication and 30% used 2 or more, which is much higher than occurs in same age peers in the general population. For those with any reported level of PAE medication use was 71.2%. The most frequently used medications are stimulants, which is usually prescribed for the most commonly diagnosed comorbidity of Attention Deficit Hyperactivity Disorder (67.8%). The severity of brain impairment and reported PAE had some correlation to the use of medication. For those who had possible brain damage/dysfunction (DPN brain 2; total number=63), medication use was 82.5%, but those with probable or definite brain damage/dysfunction (DPN brain 3 and 4; total number=140) medication use was 65.7%. No correlation was found between medication type, dose or polypharmacy and the level of severity for growth deficit, or sentinel facial findings, or brain impairment or PAE level.

Conclusion
The results of this study may be interest to those currently trying to build medication algorithms for children with FASD but who have previously been limited by lack of clinical data. While more children with FASD seem to require medication there is no indication from this data that children with FASD require higher doses of medication and caution against over dosing children with FASD is warranted. This data does not support an FASD specific algorithm for medication prescribing but the study was limited by a small number of patients, retrospective design, single (most recent) time point and single prescribing clinician. Correlations should be explored through a prospective, longitudinal, multicentre study. This study does demonstrate that collection of medication use data is relatively simple and could be done easily and efficiently through a clinician data form.

P35

Gag-Like Proteins as RNA Chaperones for Intercellular Communication: Novel Mediators of Prenatal Alcohol Effects

Marisa Pinson

Authors: Marisa Pinson, Dae Chung, Sunwoo Koo, Larry Dangott, Rajesh Miranda

Abstract:

Extracellular vesicles (EVs) are nano-sized membrane-bound vesicles released by cells that may serve as a means of intercellular communication by transporting biological information between cells. Recently the Gag-Like Protein (GLP) Arc has been identified in neuron derived EVs, and found to transport its own mRNA between neurons. There are numerous GLPs present in the human genome and a number of these GLPs, such as Arc, are highly expressed in the brain. These GLPs may function like Arc, and the ancestral retrovirus Gag protein, in their ability to interact with mRNA and self-target for membrane bound export in EVs. This raises the exciting possibility that GLPs may chaperone RNA in intercellular transport and therefore, serve as a means for programming the multipotency and differentiation of neural stem cell ensembles. GLPs may also serve as a potential point of intervention in mitigating consequences of prenatal alcohol exposure. In line with this reasoning, we evaluated the role of GLPs in neural development under basal and ethanol exposure conditions by measuring expression levels of RNA transcripts using qRT-PCR and of proteins using immunoblot. In addition, we determined the presence of GLP RNA transcripts and proteins in EVs in a similar manner. Finally, we assessed the interaction between GLPs and the different types of RNA using an Agilent Bioanalyzer. Results show that expression of certain GLPs are decreased during differentiation, suggesting a role in preservation of stem cell renewal and prevention of differentiation. However, expression of other GLPs is increased, implying a role in promoting maturation. Furthermore, ethanol exposure resulted in a dose related increase in expression of most GLPs. These data indicate that GLPs may play an important role in neural development and support a hypothesis that GLPs may mediate a compensatory mechanism for cell survival after ethanol exposure. Further understanding how GLPs mediate and coordinate neural development may lead to interventions that moderate the harmful effects of prenatal alcohol exposure.

P36

The Best Possible Start: Perspectives from Parents of Children with or at High Risk for FASD

Misty Pruner

Authors: Misty Pruner, Tracy Jirikowic, Heather Carmichael Olsen

Background
The developmental outcomes and life course trajectories of children with or at-risk for fetal alcohol spectrum disorders (FASD) are optimized when individual and family needs are identified early on and met by early intervention (EI) providers with FASD-specific training. However, little is known about access to and quality of EI services with this population.

Purpose
By exploring the lived experiences of parents raising children with or at high risk for FASD in their child’s first three years of life this study aimed to a) identify characteristics of EI practice that are both supportive and challenging for parents; b) identify gaps within the current EI system of care; and c) inform the training and competency needs for EI providers working with this population.

Method
Twenty-five biological and adoptive parents of children with or at high risk for FASD participated in this qualitative study. Three focus groups were conducted using a semi-structured interview guide. Participants described their experience with EI, as well as other supports and challenges faced in their child’s first three years of life. Informed by conventional content analysis, the interviews were transcribed, coded and organized into meaningful groups. Themes consistent across participant groups were identified, as well as differences among participant experiences.

Results
Themes were identified and organized into three categories: (1) needs of the child, (2) needs and priorities of the parents and (3) EI capacity. When parents talked about their child’s developmental needs, they all discussed how EI was meeting those needs. In contrast, when parents expressed concern for their child’s social-emotional development, a description of how EI was supporting these needs was missing from the conversation. Parents appreciated when EI providers were truthful, provided anticipatory guidance, and connected them with supports for their own social-emotional well-being. Yet, there were unmet needs for respite care, and support for basic needs related to child or family survival was not consistently recognized as being a top priority for families. Young children with FASD and their parents also encountered a multitude of transitions in their child’s early years and later. Parents wanted more support navigating these transitions as they entered or moved through different systems of care.

Conclusions
Common EI supports and needs between biological and adoptive parent groups were identified. In addition, perspectives and needs unique to each parent group were revealed. Parents appreciated and endorsed the importance of EI and the provision of individualized, family-centered supports and resources. Examination of the gaps and unmet needs that are common and distinct underscore the importance of an FASD-informed approach to EI. The results of this study highlight potential areas to develop EI enhancements that would tailor supports for the complex needs of this diverse population of children and parents.

P37

Understanding the Health Needs of People with FASD and Other Neurodevelopmental Disorders

Myles Himmelreich, Allison Pooley

Authors: Myles Himmelreich, Allison Pooley, Kyle Sue

Objectives

Individuals with FASD and other neurodevelopmental disorders have complex health issues, many differing from those of the general population both in complexity and prevalence. Good primary care identifies the person's health concerns to improve quality of life, to improve access to health care, and to prevent suffering, morbidity, and premature death. For example, the average lifespan of a person with fetal alcohol spectrum disorder (FASD) is only 34 years old (Thanh & Jonsson, 2016); many of these premature deaths could be prevented through specialized mental health and chronic pain intervention.

The field of FASD has a significant impetus right now for research on the medical needs of affected individuals as they age, especially following a survey of over 500 adolescents and adults with FASD illuminated concerns (Himmelreich, Lutke, & Travis, 2016). The field of complex trauma has proven associated lifelong medical challenges, but no one has yet looked at the overlapping brain impacts of both toxic developmental stressors. This project helps generate knowledge on these far too common yet unaddressed concerns and share those learnings in both practical and educational ways.

Methods

Asante Centre primary care practitioners are committed to expanding knowledge of complex care for people with FASD, a community that is severely under-served and misunderstood. Research is just beginning to question direct impacts of these developmental influences on healthcare, which this work supports through learning and knowledge exchange. FASD and complex trauma are recognized as "full-body" diagnoses that have severe impacts on the brain but also cellular development, the immune system, brain chemistry for mental health and addiction, metabolic systems, skeletal formulation, organ development and health, and more. To address these issues from a specialized perspective with appropriate health care allows earlier intervention and decrease reliance on emergency systems.

Results

Family physicians with training in developmental disabilities serve individuals with FASD and other neurodevelopmental diversities, informed by FASD Consultants with personal and professional experience in the field of FASD. The needs of individuals with FASD within healthcare settings are unique both in terms of direct health impacts and the brain-based considerations of adherence to healthcare recommendations. Specialized care has a significant positive impact on physical and mental wellbeing.

Conclusions

The general, physical, behavioural, and mental health concerns of people with FASD demand adapted procedures due to the interacting biologic, psycho-affective, and social factors related to the disability. This includes greater involvement of caregivers and community collaboration to help offset the intellectual, communication, memory, and reasoning deficits characteristic of neurodevelopmental diversities. Ethical issues such as informed consent must be considered in depth. Consultation services by the Asante Centre's specialized general practitioner supports community practitioners in adjusting their practices to better serve patients with FASD and other neurodevelopmental disorders according to Canadian best practice guidelines.

P38

What it Takes to Care for Individuals with FASD: A CanFASD Family Advisory Committee Photovoice Project

Dorothy Reid, Marsha Wilson

Abstract

Photovoice is a qualitative method used for community-based participatory action research in which marginalized community members are empowered to share their wisdom through pictures and words to reach a wider audience of decision makers, researchers and service providers. The overarching goal of this approach is to provide an opportunity for the participants to become, "catalysts for social action and change in their own communities". (www.flinders.edu.au/sabs/fippm-c4c-files/All%20about%20Photovoice.pdf)

The Family Advisory Committee (FAC) of the CanFASD Research Network is a group of dedicated and committed caregivers of individuals with FASD from across Canada who seek to make a difference for individuals with FASD and their families by helping to shape the course of community dialogue and research. Collectively we have often felt that our voices are not being heard by those who can make a positive difference in the lives of our loved ones. With the goal of affecting positive change for families, the FAC embarked on a photovoice project in 2018. The primary aim of the project was to describe and depict the challenges faced by those who support individuals with FASD and to reflect on how the attribute of resiliency can help ameliorate some of those challenges. In this session, the participants will view an 11-minute photovoice video and have the opportunity to discuss the resiliency of, and challenges faced by caregivers of individuals with FASD.

P39 The Impact of Placements on Mental Health Outcomes in Children Exposed to Alcohol Prenatally

Chantel Ritter

Authors: Chantel Ritter, Catherine Lebel, Quinn Andre, Preeti Kar, Ben Gibbard, Christina Tortorelli, Carly McMorris

Introduction

Prenatal alcohol exposure can cause significant impairments in neurobehavioral and cognitive abilities that fall on a continuum known as fetal alcohol spectrum disorder (FASD). FASD is one of the leading causes of developmental disability in the western world, with an estimated prevalence of 4% of Canadians, and rate of 2.5 times more common that autism spectrum disorder. Approximately 90% of individuals with FASD experience co-occurring mental health disorders, substantially higher than the general population at 20%. Individuals with FASD represent approximately 9-22% of Canadians with a mental health disorder. Prenatal alcohol exposure (PAE) alone is enough to result in negative outcomes, however, PAE rarely occurs in isolation. Individuals with FASD are often victims of multiple dysfunctions including alcohol prenatally, abuse, multiple foster homes, neglect, school disruptions, and trouble with the law, which leads to a host of negative outcomes.

Methods

Participants were recruited from the Cumulative Risk Diagnostic Clinic at the Alberta Children's Hospital, FASD parent support groups, and Calgary and Region Child and Family Services. Children aged 7-15 were assessed using the WASI-II, and the BASC2-PRS. Information regarding each child's postnatal environment was collected from kin members, adoptive parents, along with documentation.

Results

The current analysis included 27 children aged 7-15 (FSIQ M = 87.50, SD = 11.57). To determine the effect on postnatal risks in combination with prenatal risks, an ANOVA was conducted. Children and youth with prenatal and postnatal risks experienced more externalizing issues on the BASC-2 (M = 74.00, SD = 15.204), than those with prenatal risks alone (M = 61.47, SD = 9.023, t(1, 26) = -2.696, $p < .05$). Similarly, children and youth with both prenatal and postnatal risks experienced more internalizing issues on the BASC-2, (M = 62.69, SD = 18.508), than prenatal alone (M = 54.60, SD = 17.233, t(1, 26) = -1.198, $p < .05$). Also, prenatal and postnatal risks increased hyperactivity scores on the BASC-2 (M = 74.69, SD = 9.241), than prenatal risks alone (M = 62.33, SD = 9.069, t(1, 26) = -3.565, $p < .05$). When investigating the effects of placement on outcomes (M = 2.00, SD = 1.88, Range = 1-10), two or more placements were associated with greater externalizing symptoms, t(1,26) = -1.947, $p < .05$, and greater hyperactivity, t(1,26) = -2.046, $p < .05$, than one placement.

Conclusion

Adverse postnatal experience and PAE resulted in greater externalizing, internalizing, and hyperactivity symptoms. When investigating type of postnatal risk, two or more placements were associated with greater externalizing and hyperactivity symptoms. This information is critical as many children exposed to alcohol prenatally are subsequently placed into care and may experience more than one placement. This study provides initial evidence for new approaches including multiple risk factors that could help clinicians/professionals identify and assess children who may have been exposed to alcohol prenatally.

P40

Peripheral RNA Biomarkers for the Prediction of Neurocognitive Deficits in the Mouse Models of FASD and Gestational Diabetes

Junko Sasaki, Toru Sasaki

Authors: Junko Sasaki, Toru Sasaki, Payal Banerjee, Akihisa Igawa, Christopher Lazarski, Vanessa Niba, Heather Carryl, Shahid Mohammad, Yuka Imamura Kawasawa, Hirotaka Nishi, Masaaki Torii, Kazue Hashimoto-Torii

Abstract

Adverse prenatal environment, such as alcohol exposure and gestational diabetes, is tightly linked to the neurocognitive problems after birth. Importantly, the magnitudes of cognitive problems can vary even among patients who received similar levels and patterns of exposure to adverse environment. In other words, the exposure levels themselves are not accurate predictors for the neurobehavior problems. Therefore, identifying other, more definitive biomarkers is highly desired to accurately predict behavior problems in order to achieve early interventions.

We have found that the mouse models of Fetal Alcohol Spectrum Disorders (FASD) and Gestational Diabetes exhibit similar deficiencies in the motor skill development/learning, with variable severities that might be, in part, due to our use of outbred strains with genetic variability as humans do.

From these animals, we collected white blood cells and separated them into immune cell subtypes (T cell, B cell and monocytes). RNA sequencing of these cell subtypes identified putative RNA biomarkers whose expression patterns across cell types are highly correlated with the indices of motor skill learning of individual animals. In the gene list, the genes that encode risk factors for intellectual disabilities and immune response genes were enriched. These biomarkers identified for the shared endophenotype of different diseases, FASD and gestational diabetes, may serve as universal biomarkers across broader types of diseases for the prediction of the magnitude of neurobehavioral deficits.

P41

The Emergence of Patient-Oriented Research: An Opportunity for Research on FASD

Uta Sboto-Frankenstein

Authors: Uta Sboto-Frankenstein, Rebecca Barnes, Jennifer Cartwright, Taylor Hainstock, Tara McMillan

Introduction

The BC SUPPORT (SUpport for People and Patient-Oriented Research and Trials) Unit Vancouver Island Centre is one of five regional centres across BC that is designated to promote the Strategy for Patient-Oriented Research (SPOR), a federal initiative under the Canadian Institutes of Health Research (CIHR). CIHR identifies four key stakeholder groups including patients, researchers, health care providers, and healthcare decision-makers, to collaboratively ensure that POR is done in partnership with patients, answers questions that matter to patients, and aims to improve healthcare. The POR approach is becoming more common in BC with important and widespread applications in Canadian health research including research on Fetal Alcohol Spectrum Disorder (FASD).

Method

Through collaboration with the University of Victoria and Island Health, the BC SUPPORT Unit Vancouver Island Centre provides in-kind assistance to research teams who wish to carry out POR across Island Health geographies. This support is realized through the provision and collaboration of patient liaison support, research navigation and knowledge brokering services, data access and use, as well as the delivery of CIHR POR training modules. The patient liaison promotes patient engagement through meaningful recruitment of and active collaboration with patient partners throughout the research process. The research navigator facilitates the formation of multidisciplinary POR teams, provides POR education and grant support, and ensures continued integration of the patient voice in research. Success in any research, including investigations into FASD, depends on what we do with the research findings; the knowledge broker works with multidisciplinary research teams to define and communicate with target audiences and integrates research findings into evidence-informed practice.

Results

POR can empower people with lived experience of FASD and their loved ones to become proactive partners who help shape health research and health care. SPOR funds research in areas of importance to patients and creates hubs of expertise in the provinces and territories that unite patients, caregivers, families, researchers, policy-makers, and health care providers. SPOR builds capacity in POR and promotes patient engagement. For FASD patients and their loved ones this means that they have a say in which health topics are researched. For FASD researchers this means benefiting from the perspectives and experiences of people with lived experience of FASD, and for the health care system it means having access to research evidence that health care providers and decision-makers need to improve FASD supports.

Conclusions

The POR approach is about connecting people living with FASD and their families with researchers and conducting research in partnership with health care providers, policy and decision makers. This multidisciplinary POR partnership ensures that research findings are meaningfully implemented into evidence-based practice.

P42

Caregiver Experiences of the Diagnostic Assessment Process for FASD

Heidi Webster

Authors: Heidi Webster, Mary Katsikitis, Andrew Wood, Jessica Doak

Background/Introduction
In response to growing concerns about potential lifelong disabilities related to prenatal alcohol exposure, a number of specialist diagnostic services have been established. In 2016, one of those services was established in Queensland Health's Child Development Service (CDS) on the Sunshine Coast, Australia, to provide appropriate diagnosis, assist parents/caregivers to develop a post-diagnosis management plan, and link families with relevant support services.

Objectives
The aim of this study was to follow up the parents/caregivers of children diagnosed with FASD through the Sunshine Coast CDS FASD clinic to assess engagement in post-diagnosis management plans, and evaluate child and parent/caregiver post-diagnosis outcomes.

Methods/ Activity
To evaluate engagement with post-diagnosis management plans and outcomes, a qualitative phenomenological approach and a semi-structured interview was used. Parents/caregivers were asked to describe their experience of the assessment process, benefits of the post-diagnosis management plan, barriers to following the post-diagnosis management plan, and future directions for the family following the assessment.

Results/Relevance
The results of this study highlight the importance of understanding the experience of parents/caregivers who have gone through the FASD diagnostic process, and the barriers to engagement in post-diagnostic management plans. The findings from this study will help to shape future service delivery and improve outcomes for children diagnosed with FASD and their parents/carers.

Conclusions
Parents and caregivers appreciate the ability to access local assessment and diagnosis of children in their care, following establishment of the Sunshine Coast CDS FASD clinic in 2016, which has led to a reduced need to travel considerable distances and wait for assessment on lengthy waiting lists in other available Australian FASD-diagnostic services.

Caregiver responses highlight a range of emotional impacts, including hopes and fears for their child's future. Where local community support services suitable for families of children diagnosed with FASD are still under-developed and under-resourced, providing barriers to accessing post-diagnosis support, innovative and ad-hoc existing supports need to be explored. Some families were able to access a pilot parenting support program, Parenting Under Pressure (PuP) delivered by clinical masters psychology students via individualised parent/ carer identified needs-based home-visiting parenting support. This was highly valued and recommended by the parents and carers who were able to avail of this service.

Engagement of school staff in a post-diagnosis education and support planning process individualised for each child, with FASD-team clinicians, parents/ caregivers and educational staff, was reported to be highly effective in reducing school non-attendance, increasing educational engagement and providing social-emotional support for parents and carers. Due to the formation of effective school and caregiver alliances, positive individualised educational and behavioural support plans were developed for children diagnosed with FASD, which benefited both the children receiving a FASD diagnosis and their families.

Further engagement of Government and non-Government funded agencies to provide tailored parenting and family support programs for families who are caring for children with FASD is greatly needed in Australia, where assessment and diagnostic services are still difficult to access and support services tailored for FASD are not yet widely available.

P43

Pregnant Women's Attitudes Regarding Alcohol Use During Pregnancy and Accessibility and Quality of Information Available – A Qualitative Study

Maria Xavier

Authors: Maria Xavier, Kerstin Hofmeister

Abstract

Considering children prenatally exposed to alcohol present substantial challenges to parents, schools, and societies and considering minimum safe dose of alcohol during pregnancy is unknown, WHO, EU and different countries suggest zero consumption. Despite of that, research shows that there is a substantial number of women who continue to drink.

Taking into consideration that information is the base to make an informed decision about alcohol use during pregnancy, understanding the availability and quality of information available to pregnant women is also an issue for research.

As far as we know, in Portugal no studies have looked at the pregnant women's attitudes regarding alcohol use during pregnancy and accessibility and quality of information available. This work presents a qualitative approach exploring these dimensions.

Participants were 21 pregnant women recruited (until theoretical saturation was achieved) through snowball sampling strategies and at one public health center. After informed consent, in-depth interviews were conducted, transcribed and then thematically analyzed.

Two participants described alcohol use during pregnancy (social use). Pregnant women reported mixed messages and confusion about consequences of prenatal exposure to alcohol and about safe level of consumption, with implications on decision to drink during pregnancy. Mass media and relatives were mentioned as the most important sources of information about alcohol in general. Lack of consistent screening and information from healthcare professionals is other result. None of the participants knew existing international or national guidelines.

Evidence-based information is the base to make an informed decision about alcohol use during pregnancy. As this study showed, there are limitations with accessibility and quality of information available, including for pregnant women. To ensure that all (pregnant) women are aware of alcohol recommendations for pregnancy, we underline the importance of the different professionals involved in healthcare arena, particularly within pregnancy care setting.

P44

Policy Makers' Perspectives on Available Policies and Interventions for FASD

Babatope Adebiyi

Introduction

Fetal Alcohol Spectrum Disorder (FASD) have a high prevalence in South Africa, especially among the poor socioeconomic communities. While various activities, programmes, and services have been designed and implemented to prevent prenatal alcohol exposure and manage some of the functional limitations associated with FASD, prenatal alcohol consumption remains a complex problem.

Objectives

In this study, we explored the perspectives of policy makers on existing guidelines/policies for FASD, current practices and interventions, and what practices and intervention could be included towards developing a guideline for FASD.

Method

Guided by the exploratory qualitative research design, we purposively sampled relevant policy makers in the field of FASD prevention and management. Ten in-depth interviews were conducted. The interviewees were asked various questions on the current and required interventions and practices for the prevention and management of FASD. Following the Framework Method, data were transcribed verbatim and analysed using the thematic content analysis approach.

Result

Applying a working analytical framework to the data, we found that there is no specific policy for the prevention and management of FASD in South Africa, however, clauses of FASD policy exist in other policy documents. In addition, school-based support teams, preventive services to women, screening, identification, assessment, and support for children and general developmental screening are some of the current practices. Nevertheless, multi-sectoral collaboration for the prevention and management of FASD, a structured programme for the prevention and management of FASD, disease-focused training for service providers and parents and individual-based management and social welfare plan are aspects that should be included in the policy.

Conclusion

While there are generic clauses in existing policies that could be attributed to the prevention and management of FASD, these clauses and guidelines have not been effective in preventing and managing FASD. One of the reasons for the ineffectiveness could be the lack of a specific policy for a holistic and coordinated approach to the prevention and management of FASD.

P45

A Scoping Review on Global Distribution of the Prevention and Management Interventions for FASD Across the Life Span (2007-2017)

Babatope Adebiyi

Background

The global prevalence of Fetal Alcohol Spectrum Disorder (FASD) remains high despite the various preventive, diagnostic and management interventions that have been designed and implemented to tackle the issue in various settings. Although various prevention, diagnosis and management interventions and programmes exist across different regions of the world, their distribution is not concomitant with the prevalence of FASD in the various regions. The aim of the scoping review is to identify and classify prevention and management interventions of FASD reported globally across the life span to map the concentration of these interventions across the globe.

Methods

We conducted a scoping review searching databases such as Ebsco Host (Academic Search Complete, ERIC, SoINDEX, Health Source: Nursing/Academic Edition, CINAHL, Medline and Psych-ARTICLES), SAGE Journals, Sabinet and PubMed. Two reviewers independently screened studies for eligibility and used the Effective Public Health Project assessment tool to assess the methodological rigour of the included studies. A framework approach to data analysis was done and a narrative approach was used to synthesise and report on the findings.

Results

Fifty-three articles met the inclusion criteria for this study. All the twenty-two prevention intervention studies reported promising outcomes by empowering women to stop alcohol consumption during pregnancy. All the thirty-one management interventions were found effective in improving mathematical and social skills, the family adaptation, self-regulation and motor and cognitive performance except one pharmacological intervention that was not effective. Although Europe and Africa have relatively high prevalence of FASD, only a small number of interventions to address FASD were identified. Most (42) of the preventive and management interventions for FASD were reported in America, particularly in the United States of America and the least amount of these studies were found in Europe (3) and Australia (3). Five (5) of these interventions were found in Africa.

Conclusion

The uneven distribution of interventions designed for the prevention and management of FASD vis-à-vis the burden of FASD in the different regions calls for a concerted effort for knowledge and intervention sharing to enhance the design of contextually sensitive preventive and management policy in the different regions.

Fighting for a Future

FASD and 'the system': adolescents, adults and their families and the state of affairs

Proceedings from a two-day Forum: June 19 & 20, 2004; Surrey, British Columbia

Prepared by Jan Lutke, Senior FASD Consultant, and
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"The future is not the result of choices among alternative paths offered by the present but a place that is created. Created first in the mind and will, created next in activity. The future is not some place we are going to but one we are creating. The paths are not to be found, but made, and the activity of making them changes both the maker and the destination."

John Schaar

Dedication

To all the adolescents and adults with FASD who struggle every day to make sense of a world that doesn't make sense; who face more obstacles in one day that we will face in a lifetime and who continue to try long after any other person would have quit.

To our last breaths, we will fight for you.

A heartfelt thank you is made to *Brewers of Canada* who provided funding to bring all participants together to participate in this two-day forum. Without their help, this forum and the resulting "Fighting for a Future" report would not have been possible.

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Executive Summary

“Nothing changes until it does.”

“There is an urgent need for action to proactively support adolescents and adults with FASD rather than reactively apply ineffective costly measures. The current tragedy in the lives of adults with FASD and their families is a compelling case for action in itself; but the negative social impact on others and social costs related thereto present an overwhelming case for action. Adults with FASD would greatly benefit from coordinated energized action by community, government, business and not-for-profit organizations.” *Larry Guthrie; Director, Risk Management and Financial Services, School District #36, Province of B.C.; parent of an adult with FASD*

To begin the process of addressing this issue, a large, geographically diverse group of birth, foster and adoptive parents, all who are professionally employed in different areas of society, and who have adult children with formally diagnosed FASD, came together in a forum organized by *Connections: Serving Adolescents and Adults with FASD* and funded by *Brewers of Canada.*

During this process, the assembled parents identified what they believed to be the most relevant needs and issues facing adolescents and adults with FASD in today’s society. As well, they explored ideas around service delivery models and services they believe, based on personal and professional experience with this population, would enhance support for individuals with FASD and their families. These two areas are detailed in this report. Lastly, the working group commenced an initial strategic planning process determining what would be needed to effect systemic change to increase not only awareness about these issues and needs, but also to increase, develop and specifically allot service provision and funding to support the needs of persons with FASD and their families. A mechanism was put in place to continue this work and a second two day meeting is planned for September 25 and 26, 2004.

This report has tried to be as representative as possible of the issues and information that were discussed. Many of the same points came up over and over again within different small working sessions. The interconnections cut across all jurisdictions and all areas, much like knocking over a set of dominos. In the interest of brevity, we have tried to ensure that wherever possible, different information is presented in different places. All of it is critically important.

Broad recommendations derived from the proceedings are as follows. For a complete list of recommendations and steps under each area, please refer to the table of contents and the body of this document.

Broad Recommendations

1. ***Safe, stable, secure, supported, structured, supervised, subsidized housing (7S model) should be considered the primary key to broad risk management for adults with FASD. The absence of housing is the absence of everything.***

2. ***The deployment of financial resources specifically targeted at FASD service delivery should be undertaken and considered a primary broad risk management tool for working with adolescents and adults with FASD.***

3. ***The development and funding of targeted health care delivery and mental health treatment should be considered as a primary broad risk management tool for working with adolescents and adults with FASD. The provision of funded long-term mental health care to parents and other family members should be available, funded and encouraged as a risk reducing tool in the maintenance of essential supports to individuals with FASD.***

4. ***The development and funding of targeted educational, vocational, employment and other programming that is specific to adolescents and adults with FASD should be considered as a primary broad risk management tool. It should also be considered as a risk reduction tool in its ability to help maintain both residential and family placements and to provide 'respite' to parents.***

5. ***Involvement with the legal and addictions systems occurs when other risk reduction strategies have been ineffective for a variety of reasons. However, because it is in the position of having to provide services to individuals with FASD regardless, it could also provide a pivotal***

intervention point. The development and funding of targeted legal and addiction services that are specific to adolescents and adults with FASD should be considered as a primary risk management tool.

6. ***The development and funding of consultative processes that have the authority to direct, monitor and evaluate changes specific to the support needs of adolescents and adults with FASD and the particular needs of their families should be considered as a primary broad risk management tool.***

End Note

Adolescents and adults have unacceptably high level of difficulties that severely impact on the quality of their lives and the lives of those who love and care about them. Their brain damage is significant but rarely understood by those without extensive experience with them. Stability of family placement may mask the extent of their problems during childhood but cannot usually continue to do so upon adolescence. Adulthood presents a crisis point, even for those families who have managed up to that time. Those with FASD do not conform to current standards or guidelines for service eligibility in systems because most are not mentally handicapped, other systems insist the adult (who is adaptively a child) agree to services and still others have expectations for performance within programs the individual with FASD cannot possibly meet. Because they are not eligible for or are not receiving any support services, their disability remains ‘hidden’ when they come into contact with the legal and addiction systems. These systems treat them as entirely competent adults with the capacity to understand, plan and take responsibility for their actions in the same manner as any other developmentally normal person. They are deemed competent to make decisions with consequences they have no understanding of. The very low level of societal protection and support afforded them by our systems compromises their lives far beyond that caused by their disability. Their adult lives spiral out of control and the cost to them, their families and society at large is incalculable.

It is unacceptable.

The time for change is now.

FASD and 'the system': adolescents, adults and their families and the state of affairs

Preamble

"My child's biggest handicap is society's insistence on autonomy."

How does one describe the multifaceted complexities of FASD in a paragraph? How do you explain, succinctly, the extent of the havoc it can cause in the absence of effective supports? How do you make it clear that mental handicap, the commonly understood definition for developmental disability used in society, is the very *least* of the problems associated with FASD?

Perhaps the best and most accurate description comes out of a book called *Attention, Memory and Executive Function,* edited by G. Reid Lyon, Ph.D. and Norman A. Krasnegor, Ph.D., from the Human Learning and Behavior Branch of the National Institute of Child Health and Human Development in the United States:

> "Human learning and behaviour are dependent upon the ability to pay attention to critical features in the environment; retain and retrieve information; and select, deploy, monitor and control cognitive strategies to learn, remember and think. Without these abilities, we could not plan, solve problems or use language. Likewise, being absent of the capacity to attend, remember, organize and structure data within our world, we would be incapable of modifying our behaviour when confronted with new situations. More directly, it would be impossible to generalize what we already know to novel situations and to acquire new concepts and strategies in coping with current, anticipated and forthcoming events if we were not vigilant and attentive, if we could not remember the relevant cues in the environment that led to previous reinforcement, and if we were not strategic in our efforts. Thus attention, memory and executive function (mental control processes) play a central role in thinking, problem solving and other complex symbolic activities involved in oral language, reading, writing, mathematics and social behaviour."
>
> G. Reid Lyon, in "Attention, Memory and Executive Function"

There is, currently, and in our opinion, no better explanation of why adults with FASD are so disabled.

Introduction

In case you didn't know. . .

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term now used to describe the group of individuals who have been damaged by prenatal alcohol exposure. Under this umbrella, are found the three main medical diagnoses that describe this birth defect: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (PFAS), and Alcohol Related Neurodevelopmental Disorder (ARND). While there are physical differences between diagnoses, ***all*** involve damage to the brain. There is no 'better' diagnosis to have; all can be equally disabling. All are permanent.

FASD is an equal opportunity birth defect, It is found in individuals of ***all*** races, ***all*** ethnic and cultural backgrounds and occurs across ***all*** socio-economic strata. In the largest study of its kind, fully 60% of those diagnosed were Caucasian, 25% were Native American, 7% were African American, 6% were Hispanic, 1% were Asian and 1% were listed as 'other'. (Streissguth et al., 1996).

The vast majority of persons with FASD do not have outward or obvious physical findings that would lead one to think "birth defect"; the primary locus of their birth defects is in the brain. As the child with FASD grows into adulthood, these "primary disabilities" ***do not*** disappear, or even diminish, with age. Their disabilities become ever more obvious, difficult to manage and appear to be exacerbated with the expectations for autonomous, acceptable function within mainstream society that partner with increasing age. Available research also clearly indicates that the "higher functioning" (by IQ measures) individual with FASD is even *more* likely to experience difficulty. (Streissguth et al., 1996).

In the absence of the ***appropriate*** resources, direct services and intensive and time consuming interventions usually required for individuals with FASD, by adulthood many have developed what were first described by Dr. Streissguth, and are now widely acknowledged, as "secondary disabilities". Secondary disabilities are best described as those that were not present at birth (in other words, not caused by the syndrome itself), but result from our failure to recognize and understand the primary disabilities, to intervene early, and to support permanently. These secondary acquired disabilities included such things as early school dropout, lack of employment, substance abuse, mental health disorders, unstable living situations often leading to homelessness, and trouble with the law. The result has been an enormous influx of adults into the populations of those most marginalized and disenfranchised in our society: the homeless, the incarcerated, the mentally ill, those with addictions. They now overwhelm service systems ill equipped to deal with their complex needs. (*Health Canada FAS/FAE Initiative National Synthesis Report;* Health Canada, 2001)

Why is this important?

"Give me a reason to care."

Fetal Alcohol Spectrum Disorder (FASD) is a truly unique 'special need' requiring very different approaches to support and intervention not compatible with those used with more conventionally understood disabilities. Individuals with FASD have been described, aptly, as the 'orphan children' of disability in Canada, poorly understood, poorly served, quickly discarded, and often disposable. They are often the last of the least; the truly disenfranchised. In the 30 years since FASD was first described, research has not kept pace with the burgeoning numbers of affected persons. The lack of professional understanding of the extent to which this disability is different than other handicaps and requires different approaches, has meant we are now in the urgent position of attempting to play 'catch-up' in a major way.

The accepted rate of FAS, which is by far the *least* common of the birth defects caused by drinking in pregnancy, is 1.9/1000 for *full* FAS in North America (combination of full FAS, PFAS and ARND) the accepted rate is *a minimum of* 1/100 in North America, or 1% of population. (May and Gossage, 2001 and Sampson et al., 1997).

Conservatively, the minimum number of individuals with FASD in Canada is 1% of population, or about 317,146 (Cdn population October 2003 of 31,714,637) *Stats Canada Data;* persons, in B.C., would be 41,586 (BC population October 2003 of 4,158,649). For the population ages 15 and older, there are over 25,848,000 persons in Canada, of whom about 258,480 can be expected to have FASD. There are just over 2,879,600 people between 15 and 64 in B.C, of who 28,796 can be expected to have FASD. This is conservatively the ***lowest*** number of individuals with FASD that can be expected to exist in Canada and B.C. This is not a high-risk statistic; merely the reality of the numbers for the population in general. While there is no definitive research on actual numbers of adults with FASD found in specific sub-populations, they appear to become concentrated in certain areas of society where rates can be expected to be much higher than 1% (i.e.: homeless, incarcerated).

In some communities which are considered to be high risk due to alcohol abuse, and in which all children between 0 and 19 have been examined and assessed, rates are 1/5. (Robinson, Conry, and Conry, 1988; and Williams, Obaido and McGee, *1999)*.

There is no research on children in foster care but of the 800 to 1,000 available for adoption in B.C., at least 80% have a history of prenatal alcohol exposure. (Ministry of Children and Families Development, Adoption Education Programs Information to Prospective Adoptive Parents, Province of B.C.). Rates can be expected to be very high in adopted persons (and is likely a factor in the number of adoptions that break down in adolescence). International adoptions from Russia and the Eastern Bloc countries show approximately 15% of children with full FAS (the PFAS and ARND cannot be diagnosed because of an absence of documented history of maternal alcohol use in pregnancy; only full FAS can be diagnosed in the absence of this history). (Aronson, Jane M.D. (1997); *Prevalence of FAS and FAE in Pre-Adoptive Evaluations of Children in Russian Orphanages).* Current research and partner studies between Russia and San Diego State University in the USA show rates even higher. Dr. Ron Federrici, an adoption physician estimates that of the children he has seen in some Russian orphanages, fully 38% are FAS (*Peggy Oba, personal communication)*. Highest rates in the world are in South Africa where the rate for *full* FAS is 40.5 to 46.4 per 1,000 - PFAS and ARND are not even considered in this statistic. (*Fetal Alcohol Syndrome – the South African Nightmare (2003);* Journal of FAS International*).*

While there is currently no way to tell which women are most likely to give birth to an alcohol affected child, it is known that once a woman has given birth to such a child, the likelihood that each succeeding pregnancy will be affected increases dramatically. Rates of FASD in sibling groups range from a low of 170 per 1,000 (17%) for older sibs and a high of 771 per 1,000 (77%) for younger siblings once a child has been diagnosed in a sibling group. The implications for families should be obvious. Many will be raising more than one affected individual.

The average IQ in FASD is between 75 and 85, with the full range in FASD being between 20 and 140+ (*intellectual* mental handicap is IQ <70) but ***almost all*** individuals with FASD have an adaptive quotient (AQ) <70. AQ measure one's ability to function day to day *without* supports in the areas of communication, socialization, daily living skills (personal and community), time management, employment, critical thinking, judgment, etc.). Adaptive functioning can be measured and scored, using test instruments in the same way as IQ. AQ <70 is considered *adaptive* mental handicap.

In almost all other individuals, whether handicapped by some other mechanism or not, IQ and AQ are within a couple of points of each other, compliment each other and work together to create a whole, allowing for independent functioning. One of only a couple of exceptions to this is FASD. The gap between IQ and AQ is huge in

FASD, anywhere from 10 to 60 points. The average AQ in one study is about 53, clearly in the moderately mentally handicapped range, defined as scores below 55. (Russell, 2003). Additionally, Streissguth et al. (1996) report the average IQ in 178 clients with FAS was 79 with an average AQ of 61; while 295 clients with FAE (now PFAS/ARND) had an average IQ of 90 and an average AQ of 67. Adults with FASD are handicapped to such a degree that they are unable to manage the mechanics of daily life or access services or supports on their own; the process is too difficult for them.

Appropriate and effective schooling that meets the educational and vocational needs of adolescents and adults with FASD does not currently exist unless they meet eligibility requirements for mental handicap, severe behaviour disorder or occasionally, severe learning disability. ***As a general rule, there is no funding category into which they fit***. Even when eligibility for services has been allowed, existing programs and services seem to be a poor fit and unable to meet what are quite different needs. As a result, most find themselves in inadequate settings which only serve to exacerbate their difficulties with learning, peers and teachers to the point where their schooling ends well short of completion. Research shows that overall, 60% of individuals with FASD over the age of 12 have been suspended, expelled or dropped out. According to Streissguth et al. (1996*)*, the following rate of disrupted schooling is noted in those with FASD over the age of 12:

Sample	Disrupted Schooling (Percentage)
• Females with PFAS/ARND (ages 21 – 51)	76%
• Males with PFAS/ARND (ages 12 – 20)	76%
• Males with PFAS/ARND (ages 21 – 51)	70%
• Males with FAS (ages 12 – 20)	70%
• Females with FAS (ages 21 – 51)	52%
• Females with PFAS/ARND (ages 12 – 20)	50%
• Males with FAS (ages 21 – 51)	43%
• Females with FAS (ages 12 – 20)	30%

Of this group of adolescents and adults, over 70% had repeated problems with attention, 60% had repeatedly incomplete homework, almost 50% had failed a grade, and almost 40% had *repeatedly* failed classes.

Behaviour problems were cited at very high rates as follows:

■ Difficulty getting along with peers:	60% (ages 12 – 20) 54% (ages 21-51)
• Disruptive in class:	57% (ages 12 – 20) 44% (ages 21-51)
• Disobeying school rules:	49% (ages 12-20) 34% (ages 21-51)
• Talking back to teachers:	45% (ages 12-20) 33% (ages 21-51)
• Fighting:	38% (ages 12-20) 31% (ages 21-51)
• Truancy:	37% (ages 12-20) 38% (ages 21-51)

Forty percent of these individuals had been in special education classes of some sort – a service that has been clearly ineffective for them, given the very high rates of difficulty and disrupted schooling.

Sole qualification in B.C. for eligibility for even minimal adult support services from Community Living Services (CLS) of the Ministry of Children and Families (MCFD) is *IQ alone* below 70. Adaptive function is not factored in *unless* the individual has an IQ <70, at which time it is clearly recognized that the individual will need help with all areas of daily living. (CLS of MCFD is the only branch of social services where even the most minimal of supports can be obtained, and is not able to adequately serve the numbers of its current clients). At no time are the serious executive functioning deficits found in those with FASD who are considered to be 'high functioning' factored in. (Kerns et al.,1997).

While there is a dearth of hard research on adults with FASD over time, there is a magnitude of anecdotal information from multiple sources, all reporting the same thing. This lack of eligibility and lack of support service provision is directly tied to poor outcomes in FASD, and undoubtedly related to homelessness in this group of adults. Individuals with FASD are seriously disabled by their prenatal alcohol exposure and resultant brain damage and unable to maintain stable housing, live independently, maintain employment and healthy lifestyles unsupported.

Attention Deficit Hyperactive Disorder (ADHD) is also a commonly seen co-morbid disorder with FASD – different studies estimate between 60-85% of affected individuals. The ADHD is ***different*** from typical ADHD and is likely a particular clinical subtype of ADHD that is caused by prenatal alcohol exposure, and can be seen with FASD or without FASD. As such, it frequently does not respond as well to medication and occasionally, medication may actually make it worse. Individuals with FASD related attention deficit have difficulty with "encode" (integration of information and generalization) and "shift" (perseveration; changing approaches or tasks) components of attention, whereas those with typical ADHD have trouble focusing and sustaining attention. ***The distinction is critical for effective intervention***. (O'Malley and Nanson, 2001; and Coles, 2001). From an intervention standpoint it may also be critical to consider how many adults with a childhood diagnosis of ADHD are, in fact, persons with undiagnosed FASD, and not ADHD at all. Misdiagnosis is common for a variety of reasons, including bias and the unwillingness of physicians to 'label' a child as alcohol affected. Given the connection between early alcohol use, alcoholism (leading eventually to homelessness) and a 'diagnosis' of ADHD, this must be considered (Smith, Molina and Pelham, 2002).

Research also indicates that the mental health disorders so prevalent with FASD do not begin in adulthood, but rather start in childhood (O'Connor et al., 2002; O'Connor and Kasari, 2000*;* Steinhausen, Willms and Spohr, 1993*;* and Steinhausen, Nestler and Spohr, 1982).

Mental health problems are overwhelmingly prevalent co-morbid diagnoses in adults with FASD, and due to the nature of their brain damage, standard mental health treatment has not been effective. Overall, 94% of affected individuals with a diagnosis of FASD have at least one mental health diagnosis in adulthood. According to Streissguth et al. (1996), the following is noted in adults:

Mental Health Diagnosis	Percentage of Sample
• Depression	52%
• Continuing ADHD problems	Over 40%
• Suicide threats	43%
• Panic attacks	33%
• Psychosis (hearing voices / seeing visions)	29%
• Suicide attempts	23%

- 100% of alcohol affected men (PFAS/ARND) have at least one mental health diagnosis
- 88% of men with full FAS have at least one of the above100% of women with FASD have at least one of the above
- IQ over 85 is ***not*** a protective factor, and rates are highest in this group (although only slightly)

Research on adults with FASD has increasingly demonstrated over the years that substantial mental illness accompanies this syndrome (Famey, et al.,1998; Lohr and Bracha, 1989; Lohr and Bracha, 1978; Cadoret and Riggins-Caspers, 2000; and Carmichael-Olson, Morse and Huffine, 1998).

Research also shows that adults with FASD have high rates of substance use disorders. Streissguth et al. (1996) found that 30% of adult males over 21 with FAS had substance use disorders and 54% of adult males over 21 with PFAS or ARND had substance use disorders. The rates were even higher in women with FASD. Among clients with alcohol and drug abuse problems, alcohol abuse preceded drug abuse by an average of two years. Similar rates were also found in B.C. (Clark, 2003). Parents and professionals working with adults often report an 'all or nothing' problem with substance use, and that *any* use leads quickly to serious addiction. To date, and most likely due to the nature of their brain damage, conventional treatment programs have not been effective with this population. Substance use leads very quickly to the loss of whatever community supports, housing placements and employment options that may have been provided and leads individuals into criminal activity.

Overall, according to the Secondary Disability Study, 35% of those aged 12 and over with FASD have problems with drugs and alcohol:

Sample	**Drug & Alcohol Problems (Percentage)**
Females with PFAS/ARND (aged 21 – 51)	70%
Males with PFAS/ARND (aged 21 – 51)	54%
Females with PFAS/ARND (aged 12 – 20)	38%
Females with FAS (aged 21 – 51)	37%
Males with FAS (aged 12 – 20)	32%
Males with FAS (aged 21 – 51)	30%
Males with PFAS/ARND (aged 12 – 20)	30%
Females with FAS (aged 12 – 20)	4%

- 23% have been in treatment – and 70% of these had their first alcohol treatment before the age of 21
- alcohol abuse precedes drug problems by 2 years
- 65% of those over 12 who abused alcohol went on to abuse street drugs

Trouble with the law figures range from about 24% to 60%+, depending on the studies, which are limited in number. For those 21 and over, Streissguth et al. (1996), found that:

- rate of crime for adult males with FAS – 57%; adult females with FAS – 45%;

- adult males with PFAS/ARND – 77%; adult females with PFAS/ARND – 65%
- crimes committed by adults with FASD:

Crime	Percentage of Sample (age 21+)
Against persons (everything from shoplifting to murder)	42%
Possession / selling drugs	23%
Vehicular	20%
Property offences	17%
Sexual assault	14%
Status offence	9%
Other	7%

For those age 12 – 20, Streissguth et al. (1996) found the following:

- rate of crime for males (age 12-20) with FAS was 59%; females with FAS was 40%
- rate of crime for males (age 12-20) with PFAS/ARND was 71%; females with PFAS/ARND was 57%
- crimes committed by males and females (age 12-20) were:

Crime	Percentage of Sample (age 12 – 20)
Against persons (everything from shoplifting to murder)	47%
Possession / selling drugs	18%
Vehicular	5%
Property offences	28%
Sexual assault	14%
Status offence	11%
Other	6%

- For youth and adults with FAS - 31% committed shoplifting/theft as their first offense, and for those with PFAS/ARND 39% committed shoplifting/theft as their first offense.
- Only 5-6% of individuals with FASD committed assault as their first offense; and only about 2-5% committed child molestation as their first offense.
- Only 5% of people with FAS experience their first trouble with the law after the age of 20.

Streissguth et al. (1996) also found that 80% of those in trouble with the law also had disrupted schooling; and 69% of those who commit crimes against persons also have problems with alcohol and/or drugs. ***Lack of alcohol and/or drug problems cuts the rate of trouble with the law by almost half.***

To date, legal decisions have assumed, erroneously, that low IQ or facial features must be present for disability, which results in judicial decisions with serious consequences for the individual *(Fetal Alcohol Syndrome/Fetal Alcohol Effects Legal Resource Center, Fetal Alcohol and Drug Unit, University of Washington School of Medicine and University of Washington School of Law, July 2003)*. These adults are among those most likely to become homeless upon release from prison, the least likely to be able to apply for social assistance and very likely to have lost family support.

No mechanism exists to track rates of FASD in Canadian jails. The minimum number, based on the 1/100 or 1% accepted statistical rate would be 1,539 inmates with FASD in the combined provincial and federal systems (148,797 provincial and 20,372 federal inmates = 1,354 provincial FASD and 185 federal FASD) (Burd, Selfridge, Klug, Juelson 2003; Burd, Martsolf and Juelson, 2004). These numbers assume that only 1 in 100 of those in jail has FASD, when limited studies indicate up to 60% (or 60 out of 100 people with FASD) are in trouble with the law – which would mean that the numbers incarcerated with FASD should be much higher than 1 in 100 in the general inmate population. People with FASD are ***concentrated*** in jails – use of general population data may not be reflective. *The corrections system is the only system that cannot deny 'eligibility' – in the absence of supports (housing, employment programs, counseling, support workers, etc.) it is the default social safety net for adults with FASD.*

For those adults with FASD over the age of 21, fully 80% are unable to live independently (FAS – men 80%; women 85%; PFAS/ARND - men 100%; women 70%). *This finding is independent of IQ scores* (Streissguth et al., 1996). Streissguth et al. (1996) found that adults with FASD were unable to:

Activities of Daily Living	**Percentage of Sample Having Difficulty**
▪ Manage money	83%
▪ Poor judgment	82%
▪ Make decisions	78%
▪ Poor organization skills	77%
▪ Obtain social services	70%
▪ Get medical care	67%
▪ Handle interpersonal relationships	57%
▪ Grocery shop	52%
▪ Cook meals	49%
▪ Structure leisure activities	48%
▪ Stay out of trouble	48%
▪ Handle hygiene	37%
▪ Use public transportation	24%

The urgent need for safe, stable housing that can provide support for financial management, chores, nutrition, shopping, hygiene, health care, addiction treatment and all the other areas that make up daily living has been identified consistently by researchers (Clark, 2003; and Rutman, LaBerge and Wheway, 2002) and is referenced throughout these documents. Adults with FASD have consistently proven to be unable to live independently. They have complex, multi-faceted needs that cannot be addressed in isolation or through existing resources, programs and intervention models.

Similarly, for an adult over 21, research has documented that fully 80% are unable to obtain or retain a job, *regardless of IQ*: FAS – men 72%; women 96%; PFAS/ARND – men 76%, women 65%. Streissguth et al. (1996), report that problems experienced in employment include the following:

Employment Related Problem Areas:	**Percentage of Sample Had Difficulty**
▪ Easily frustrated	65%
▪ Poor task comprehension	57%
▪ Poor judgment	55%
▪ Social problems	54%
▪ Fired	50%
▪ Unreliable	42%
▪ Anger management	42%
▪ Problems with supervisor	40%
▪ Lying	33%
▪ Lose jobs without understanding why	30%

Employment is not a current reality for most adults with FASD because of the lack of services and supports necessary to make it happen. For those who might potentially be able to manage some work, residential supports must be in place *first* or the possibility is nothing more than an idea that will never be tested.

As with the general population, individuals with FASD also become parents. Their disabilities, however, can make adequate parenting very difficult in the absence of sustained, long-term supports. Such supports are almost always available only through family, and family become tired and burned out. In the absence of such support, or on the loss of it, many adults with FASD lose custody of their children to child protection services. In order to prevent the permanent loss of grandchildren, families may then have to step in and commit to raising one or more grandchildren, a task most are no longer able to afford – physically, financially and emotionally - the reasons why support to the adult child ended in the first place.

Research on adults with FASD as parents is very limited; what does exist, states

- only 30% were diagnosed before they became parents
- 11% diagnosed around the time they became parents
- 59% diagnosed after they became parents
- Child apprehension rate from mothers was 36%
- Child abandonment rate by fathers was 45%
- 40% of the mothers drank in their pregnancies
- 17% of those children diagnosed FAS/PFAS
- Additional 13% suspected of being FASD

Anecdotal reporting states that these may well be conservative figures in terms of child apprehension and technical abandonment

What Does It All Mean?

"***You can pay now or you can pay NOW. There is no such thing as 'pay later'."***

The economic costs of FASD are enormous. Estimates for cost range from a low of 1.5 million dollars to a high of five million dollars US (2.9 million ++ Cdn) per individual over the course of a lifetime. These figures do not include the costs of incarceration, lost productivity, burden on families and poor quality of life (*FASD Fact Sheet, FASD Center for Excellence, Substance Abuse and Mental Health Services Administration, US Department of Health, 2003)*. Only minimal costs for residential care are included and only for those with mental handicaps up to the age of 21.

A 2004 updated cost estimate for FAS *alone* puts the dollar figure at two million per individual. While adding in some costs for residential care to age 65 for mentally handicapped individuals, most associated costs are still not included, and none of the costs associated with PFAS and ARND. In a study published in 2001, the un-reimbursed cost to families in North Dakota for FASD was more than $17,000 US per child per year *(*Burd, Klug, Hoesel, Moum, 2001). Current adjusted cost of FAS *alone* in the United States is estimated to be $3.6 *billion* dollars a year. (*Cost of Fetal Alcohol Spectrum Disorders;* American Journal of Medical Genetics Part C (Seminars in Medial Genetics); Volume 127C; 2004)

> "There is an urgent need for action to proactively support adults with FASD rather than reactively apply ineffective costly measures. The current tragedy in the lives of adults with FASD and their families is a compelling case for action in itself; but the negative social impact on others and social costs related thereto present an overwhelming case for action. Adults with FASD would greatly benefit from coordinated energized action by community, government, business and not-for-profit organizations." *Larry Guthrie, parent, Director, Risk Management and Financial Services, School District #36, Province of B.C.*

The lack of resources and services to address the specific needs of older adolescents and adults with Fetal Alcohol Spectrum Disorder (FASD) is a looming social tragedy of epidemic proportions, unprecedented in recent Canadian history. With the lifetime costs for one individual with FASD (exclusive of the legal system) now estimated at over two million dollars US, the financial costs of continuing to ignore this population should be of equal concern to all systems. There is an *urgent*, indeed *critical*, need to increase the visibility and understanding of this permanent, lifelong disability, and its consequences for the individual, family and society.

What Now? Who? Why?

"At the end of the day, everyone else gets to go home."

To begin the process of addressing this issue, a large, geographically diverse group of birth and adoptive parents, all who are professionally employed in different areas of their community and who have adult children with formally diagnosed FASD, came together in a forum organized by *Connections: Serving Adolescents and Adults with FASD* and funded by *Brewers of Canada.*

This group of parents was invited to participate in this process based on a combination of considerations: post secondary education or training, professional background, personal experience, experience working with adults with FASD, family makeup and adequate mental health. Collectively, this group was aware of almost every resource and service currently available in B.C. for those with 'special needs' and had experience with all of them. They were highly cognizant of the differences between all other disabilities and FASD, and the pitfalls therein. Their children, with two exceptions, ranged from very late adolescence to mid thirties in age, and covered the spectrum of disability. IQs represented the full range as reported in the research – from a low of 47 to a high of 120. Some had been diagnosed in early childhood, some in adolescence and some not until adulthood. Some were functioning within acceptable limits and some were on the streets or in jail. About 30% of their adult children were also parents. Many struggled with substance use disorders. All their children have had many difficulties in life to overcome and ***all*** require supports in adulthood for function. ***None*** are completely independent.

This hand-picked group consisted of adoptive and birth parents who are also professionals in the community. Some began with significant personal and financial resources at their disposal. Some began with only a little, and some began with nothing at all. Over the years, irrespective of differences, each has had experiences all too similar while raising a child with FASD. Regardless of where the journey began, each family in the room arrived at the same fork of recognition in the road. Once the resources have been exhausted, and they always will be because they are finite, there is no safety net for either the family or the affected adult. Thus the experiences of all families (professional, white-collar, blue-collar, impoverished or recovering from substance use) raising someone with FASD are similar in this respect. The issue is not whether or not they will run out of resources, but only ***when*** they will run out of resources. Social standing, personal resources, personal health, and money do not protect in the long term. They only delay the inevitable. The family, however constructed, is the ‘mini-institution’: when it can no longer meet the needs of the adult with FASD, everything fails.

FASD is the ‘great leveler’. In this simple but overwhelming fact lie the commonality of experience, and the ability to work together for a purpose greater than one’s differences.

Process:

"***Is anyone listening – we are out of time."***

This two day forum was held June 19 and 20, 2004*,* in the Lower Mainland area of B.C. Participants were charged with determining which specific issues were in most urgent need of address and determining the most effective and organized way to begin the long-term process of effecting positive change.

One parent's vision:

> "A Canada where adults with FASD can contribute positively within
> their communities and be supported to lead fulfilling, productive lives
> *within the limits of their disability".*

During this process, the assembled parents determined what they believed to be the most relevant needs and issues facing adolescents and adults with FASD in today's society. As well, they explored ideas around service delivery models and services they believe, based on personal and professional experience with this population, would enhance support for individuals with FASD and their families. Lastly, the working group commenced an initial strategic planning process determining what would be needed to effect systemic change to increase not only awareness about these issues and needs, but also to increase, develop and specifically allot service provision and funding to support the needs of persons with FASD and their families. A mechanism was put in place to continue this work and a second two day meeting is planned for September 2004.

The following is a summary of the key issues presented on the first day of this forum.

Strategic Needs Analysis:

"How do you eat an elephant? One bite at a time."

GOAL: to determine, define and refine multiple issues in order to group collectively under five or six topic headings, without relevance to priority, in order to provide a framework for the 'next steps' development of a strategic plan of action

DISCUSSION: a concentrated, facilitated discussion was held in the group as a whole across a very wide range of concerns. Consensus was reached that issues could best be synthesized under the following headings:

- Housing and Homelessness
- Finances
- Health and Mental Health
- Education, Programming and Employment
- Legal and Addictions
- Family Support

The large group then separated into smaller working groups represented by the six themes above.   Each group was tasked with elaborating on and defining these six key areas of issues. Without limiting the discussions, they were asked to broadly consider (1) what needs are specific to the issue; (2) what gaps exist in service to address this issue and (3) recommendations for action. The following are the results from these facilitated small working groups discussions.

Housing / Homelessness

"The absence of a home is the absence of everything."

This group began by posing two questions "what does housing mean?", and "what is independence related to?" It determined that housing meant more than four walls and a roof; a place to live. Rather, a successful housing situation should be a safe home; a place to belong and a place to be; a place in which all other activities of life occur in, out of, or around. It is intimately related to the concepts of being 'independent' and 'responsible', and largely inseparable from the ability to manage activities of daily living (ie: household chores, paying bills, appropriate social behavior and interactions with others, obtaining and maintaining financial stability). For the non-alcohol impacted adult it is an expected function and rite of passage to which very little thought is given. The ability to just '*do*' is automatic.

For the adult with FASD, housing is the foundation upon which everything else rests. *The absence of housing is the absence of everything*. Housing – especially housing that is a *home* - means being part of a community, socializing, buying groceries, accessing transportation and community services, forming relationships and friendships, developing history, and having a safe place to go and be. These are crucial components of being able to take part in society in a meaningful way, and will be essential for those growing up with FASD today who will become tomorrow's adults. This housing – these *homes* - must be available, affordable and accessible regardless of IQ. A comprehensive range of supported housing services and options will be required and should be designed to meet the individual needs of persons with FAS. *Systems must not assume that all persons with FASD are the same or require the same sorts of approaches and levels of support.* One size does not fit all.

There was wide ranging discussion about what 'independence' meant, and a lengthy list of necessary individual functions was drawn up. Consensus was that independence could best be described as the 'ability to come and go as you please, as needed, safely, within the law, without help and without problems'. How do systems and people determine an individual's ability to do this? In the absence of a mental handicap, there is no set way, they just do it, and usually it is based on 'snapshot' appearances and language use which can be particularly deceptive with FASD. Discussion centered on the complexities of such inaccurate functional expectations and whether or not these were ever realistic for late adolescents and adults with FASD, irrespective measured IQ. Given research, the extent of the adaptive handicaps seen in this population and the collective practical, professional and personal experience, it is the position of this group that adolescents and adults with FASD will likely always need varying degrees of help with daily living, regardless of living situation. They will need someone or a system in place over time to ensure that the activities of daily living are both manageable and managed. It was noted that "people gravitate to whatever works for them, good or bad – that's the normal thing to do. With FASD, every little piece has to be put together for them." Without this, the expectations for 'independence' are too high and the result is almost always practical or actual homelessness once the family is no longer able to provide the extensive financial and practical supports that are needed to allow for adult function. At some point, all people have to leave home, and systems must come to terms with the new and emerging demographic of FASD.

The importance of individual living programs was emphasized within an environment best able to provide a very high degree of safety to residents, as well as 24 hour per day, 7 day per week supervision availability. Great emphasis was placed on the need for, and provision of 'external structures' to increase the ability of persons with FASD to function acceptably in the housing environment, however constructed. It was strongly recommended that a zero-tolerance policy in housing be viewed as not only unrealistic, but highly detrimental to the success of maintaining housing placements for older adolescents and adults with FASD experiencing the highest level of secondary disabilities and most difficulty with behaviours.

Housing that provides various kinds of on-site staff support, peer mentoring, outreach workers, volunteers, 'relationship referees' and leisure buddies was seen as critical for efficacy. Built in programs attached to different kinds of housing may provide for skill development and should be geared to the unique needs of each resident. Given the very wide range in cognitive functioning seen with FASD, an equally wide range of programming will be required to address this. Programs should include assistance with all activities of daily living as housing is the base in and from which such activities occur. Leisure and recreation programs are also vital program components to decrease social isolation, boredom and the effects of negative peer pressure among adolescents and adults with FASD. They should be viewed as integral components, and not as add-ons to be discarded when funding is tight.

At the present time, there are no long-term supported or transitional housing services available anywhere in B.C. specifically designed to meet the complex needs of adults with FASD who either cannot, or do not live at home. Their need is acute. Currently, if they are served at all, they are provided for within existing emergency shelters on a very temporary basis. The most dysfunctional are often among the most difficult clients, combining not only brain damage, but addictions and mental health issues.

Very occasionally, they may find housing within low-cost housing units prepared to accept them, but the absence of continuous on-site support and supervision makes this a most unworkable situation leading to eviction even from resources designed for those with special needs. These adults have the deceptive *appearance* of capability, but no actual, underlying ability.

The adaptive handicap that is the hallmark of FASD means the impacted adult has no ability to function or handle the 'nuts and bolts' that make up daily life, problem solve, handle changes, think critically, use judgment or modify behaviour without skilled help. More importantly, the impact of this disability is such that most of those with it have little or no insight into their disability or awareness of the extent to which they require support. They are simply bewildered, frustrated and hostile when things go wrong as they are want to do – consistently, persistently and with ever increasingly more serious consequences for both the individual himself and society. They have significantly impaired ability to learn from consequences and such poor memory that learning is not well retained, if retained at all. At risk and practical homelessness is the *norm* for adults with FASD, even for those who still have some degree of community or family support, and absolute homelessness is often the reality in the absence of such supports. Increasingly, over time, those adults who were "at risk" become the absolute homeless and likely make up a sizeable portion of those adults on the streets who are completely without even the possibility of stable housing at the present time. It is this absolute "*knowing* what will happen" that places families in such untenable positions.

There is limited research on adults with FASD and the ability to live independently. What does exist and an abundance of anecdotal evidence is consistently clear that over 80% are unable to function in the absence of supports well enough to live on their own or maintain employment. This group of adult clients rarely qualifies for social service supports via the Community Living Service system even though they have a medical diagnosis of a syndrome known to severely limit function. It is unarguably true that a significant percentage of them will end up homeless and/or incarcerated due to the extent of their adaptive deficits, especially once they no longer live in the family home. Research has also found that the rates of difficulty with independent living are greatest in the group of so-called 'high functioning' adults with FASD – those with the highest IQ scores (average of 90). This group is also over-represented in those with mental health issues and substance abuse disorders. The result is a very hard-to-house group of individuals in the best of circumstances.

However, the consensus of opinion over many years of those living and working directly with affected adults who are not able to maintain housing is that a goodly portion of them *could* be housed successfully, *if* behaviour can be stabilized and *if* long term supports are made available as and when they are needed, and *if* a crisis response system is in place.

Many adults with FASD are difficult to house, no question about it. They do not follow rules because they do not understand them or that they are unaware that those rules are meant for them, too. They cannot remember them, they cannot apply them and they cannot be expected to learn from them and change behaviour as a result of them. This is the consequence of brain damage, *not* deliberate, thought-out or planned behaviour. Any proposed resource would have to work around these deficits, and have a different set of expectations – that: such behaviour is 'normal' for FASD; such things are bound to happen and are not a reason for exclusion from the residence; a very high level of on-going support is required for appropriate and positive function; such support will need to be in place for life; and must acknowledge and accept that change is a very slow process.

For the most part adults with FASD who are not able or are unwilling to live in a family home 'couch-surf' - sleeping wherever they can find a bed for the night until they run out of places to go. Some of them sleep outdoors. Regardless of where they stay, their needs are poorly understood and they require a much greater intensity, consistency and persistency of support and supervision than is possible to provide without the development of a specific housing service for those with FASD.

It is anticipated, based on what is currently known about those adults with FASD who are functioning and the precise nature and types of supports they receive from families and support persons, that such a model could: reduce the high rates of criminal involvement to get basic needs met; facilitate the development of skills on an FASD developmental timeline; reduce the high rates of untreated mental illness in this population; improve physical health and nutrition; reduce addiction; provide positive social support networks; develop pre-employment readiness skills and encourage re-connection with supportive family members.

Adolescents and adults with *diagnosed* FASD and *suspected* FASD are overwhelmingly over-represented in the population of persons with addiction and mental health issues, those who are homeless, and in particular, those who are perpetually at risk of becoming homeless. They are among the most difficult to maintain in stable housing.

Any proposed solution must seek to begin the process of addressing residential housing and supports from a systematic, planned, multi-pronged approach which will provide long-term (*not* short-term) supportive housing, stabilization of FASD behaviours leading or related to homelessness, transitional and outreach services for those who do not require intensive supports, and crisis services to prevent homelessness. It must use recommended FASD intervention protocols based on what is currently known about this group of high risk, high need adults, and attempt to develop ‘best practice’ approaches based on experience gained. Due to the large numbers of people in society who have FASD, the need is significant for this type of housing service.

Action for Change:

There is a critical need to develop, co-ordinate and fund a system of housing care for adolescents and adults with FASD, with eligibility based on either diagnosis ***or*** adaptive deficits, which will:

- ☐ Investigate, design, develop, create, locate and manage a full range of permanent, flexible housing support alternatives to incorporate a 'good fit' for individuals with FASD.
- ☐ Find and fund a broad range of appropriate and flexible supported housing services on a case-by-case basis for those impacted with FASD to meet a wide spectrum of need, and provide a continuum of education & support for landlords and caregivers.
- ☐ Subsidize rents for those who are able to manage on their own with less help but who are not able to live successfully with a roommate in order to provide adequate standard of living
- ☐ Design and implement Individualized Living Programs (ILPs)
- ☐ Case manage *very* specifically and *very* flexibly to each individual
- ☐ Discard the 'zero tolerance' concept
- ☐ Understand, support and fund the concept of 'on-going temporary crisis management'
- ☐ In all cases, recognize that the inability to manage money combined with a poverty income will require financial trusteeship to prevent eviction
- ☐ In all cases, place the emphasis on safety of the individual
- ☐ Provide ongoing evaluation to develop 'best practices' models for sustainable housing supports for adolescents and adults with FASD

Safe, stable, secure, supported, structured, supervised subsidized housing (7S Model) should be considered the primary key to broad risk management for adults with FASD. The absence of housing is the absence of everything.

Finances

"Money, money, everywhere, but not a cent to spare."

This session began by asking the questions "what do we know about the costs to society?" and "what do we know about costs to the family system?"

There are only a handful of studies with respect to the costs of FASD, and none are inclusive of all costs. None look at quality of life and none factor in indirect costs to the family. Service costs are based on those provided to individuals with mental handicaps and do not include anything for the majority who are not. Much of the research estimates costs for FAS alone, and does not include the much larger costs for PFAS and ARND. All studies are American. The most current of these studies now estimates costs over the lifetime (to age 65) for one person with FASD to be $2,000,000 US or, translated into August 2004 Canadian dollars, about $2,640,000.

None of these studies includes the costs of the criminal legal system, possibly because costs are much lower due to the differences in their system. In Canada, those costs are very high, as we use a rehabilitative system of justice rather than a strictly punitive one. A provincial jail cell in B.C. costs in the order of $150-250 per day (between $4,500 and $7,500 per month or $54,750 and $91,250 per year). A federal jail cell costs in the order of $100,000 per year and up, depending on classification. Juvenile facilities are even more costly, running at the rate of about $300 per day or $9,000 per month and $108,000 per year. These costs are not factored into costs of FASD to society. Costs for crime itself, insurance, policing, court time and staff costs, cost of legal aid or lawyers, judges, probation and parole services, victim compensation, etc. are also not factored in. An individual with FASD who has become embroiled within the legal system and is incarcerated may spend much of his adult life in jail since we have, at the present time, no alternatives to support him elsewhere. With increasing length of sentence for each crime, it is logical to estimate that such an individual would very quickly cost society over $1,000,000 in jail cell alone, and could potentially reach $2,000,000 for jail time by his 45th birthday. The omission of this data would seem to be a significant oversight.

The costs of foster care can be considerable. B.C. uses a leveled system of care, in which caregivers are 'paid' according to a set of demonstrated knowledge skills and abilities, without regard to the child who may be placed there. Rates of compensation, designed to cover all costs of the child and, in some cases, a small ‘fee’ for the caregiver, range from a low of about $750 per month for ‘regular care’ to a high of about $2,700 per month for ‘Level 3 care’ . In some instances costs are much more than this for very difficult adolescents who may be maintained in highly specialized and staffed resources. These costs can range upwards of $10,000 per month per child. Many children with FASD will be found in the leveled system homes, and most of those residing in regular rate homes are there only because budget constraints do not allow for placement elsewhere. Their behaviour usually escalates in the absence of skilled parenting and they ‘cascade up’ the levels of care, becoming ever more expensive to maintain in increasingly costly resources.

Regardless, foster care costs, exclusive of anything not paid directly to the caregiver, amount to between $9,000 and $32,400 per year per child. Should a child remain in the foster system for 10 years (which many do) this cost alone can reach $324,000. This cost does not include social work time, court time, treatment costs, supervision for visits, or the multitude of other costs associated with foster care. If the child is returned to the biological family, parents may well be on social assistance. Supports such as daycare services, respite care and family counseling may well be provided. Should the child be placed for adoption, it is likely that limited financial assistance will now be provided to the family and/or that specific services will be paid for. These are all cost items. Basic financial maintenance, respite care, treatment with a competent therapist, orthodontia, extra supervision costs, etc., can add up to very substantial amounts of money. One parent will most likely be required to leave employment to provide full-time care and supervision to the child at costs in the neighbourhood of $30,000 or more per year in lost income to the new family. This is not a temporary employment absence as with the birth of a child, but one which will become increasingly necessary as the child grows up, and often becomes acute in adolescence and adulthood.

What about the cost to society of an adult with FASD who is now a parent? Typically, systems remove children from these parents after many costly failed attempts to provide short-sighted, temporary stop-gap service measures to “fix” the problem. All existing supports fail to accommodate brain damage and have expectations for function that cannot be met without ongoing in-home or on-sight services. If family does not want to lose grandchildren, or see the adult child lose a child, they must step in and assume legal custody with all of the unsupported attendant costs – financial, legal, social, emotional, psychological, moral, physical and mental – and the multitude of long-term problems that can be expected to occur. Disabled adults who become disabled parents are still the disabled *children* of the family. Both the adult and his/her family continue to experience the problems of living with a disability in which the affected adult has very little insight into the nature of that disability This simply compounds the problems and costs facing the family trying to keep both their adult child and grandchild safe. At some point, this too, often becomes unworkable.

Studies looking at lifetime costs of FASD to society look at residential costs only for those with FASD who are mentally handicapped. Some studies only look at that cost to the age of 21, while two studies included this to age 65 for those with moderate and severe cases of mental handicap. In this latter case, 80% of the lifetime costs were related to this one cost alone. This is of interest, because it would seem logical that lifetime costs would be much higher for those individuals who are mentally handicapped, especially those whose IQs fall below 55 (the cutoff point for moderate mental handicap). However, in the absence of actual dollar figures for those services adults with FASD who are not mentally handicapped use in the absence of supported housing, we might think that only these adults are costing society a great deal of money. It is the position of this group that this would be a grievously erroneous assumption. Many adolescents and adults with FASD who are not mentally handicapped are getting their housing needs met through incarceration. Many are among the homeless with all of the attendant healthcare costs, substance use issues, petty crime, abuse, policing costs, cost to tourism and sustainability of our cities. Many lose their children to the foster care system. Many, if not most, are on social assistance of some form, living far below the poverty line. Many are involved in a revolving door type of rental-eviction-rental-eviction lifestyle in which damage deposits and belongings are lost repeatedly. Many are subsidized by family at great cost and to the eventual detriment of the family, resulting in loss of a support system for the adult. All of these are residential care costs.

Adults with FASD without any dependent children who receive the Persons with a Disability (PWD) funding in B.C. of $786/month can expect to be paid $433,872 between the ages of 19 and 65 (46 years) at current rates. Add the cost of medical premiums ($29,808 over 46 years), minimal dental care ($23,000 over 46 years), basic prescription coverage for psychiatric medications (averaged at minimum of $150/month or $82,800 over 46 years); and yearly bus pass ($2,070 over 46 years). Minimum cost (46 years) to society is $571,550.00 ($12,425 per year) for social assistance support. The costs can only go up from here and will be borne by someone or some other system.

Lack of supported employment programs, job coaches, and vocational training mean that adults with FASD have no *legal* options beyond PWD funding and whatever monies family can contribute to their support. Research in this area has found that 80% of all individuals with FASD, regardless of IQ, are unable to *maintain* employment. Adolescents and adults with FASD, like all others, need a “reason to get up in the morning”, a job where they feel productive if only for a couple of hours a day, a week or a few days a month. Many are likely capable of working at least part-time, or some of the time, or even all of the time, ***if*** the right supports and circumstances are in place. To accomplish this, one would need a funded campaign to increase awareness and understanding of adolescents and adults with FASD amongst employers. Support for employers as well as for both regular employees and the employee with FASD would be needed (i.e. job coaches available, employer incentives, financial subsidies etc.) The need to remove barriers to obtaining employment (such as homelessness, addiction, transportation etc.) are seen an interconnected to the issue of the employability of persons with FASD. In addition the need for built in mechanisms to assist with money management are also seen as essential to ensure that the necessities of daily living are paid for and to avoid the common occurrences of eviction, inadequate nutrition, health issues etc. which can directly affect the ability to hold a job.

Health care costs that society pays on behalf of adolescents and adults with FASD can be substantial. Lack of adequate diet due to inability to manage the tasks of budgeting, shopping and food preparation combined with a common lack of hunger leads to malnutrition. The inability to follow medical regimes or remember to take medications is an everyday occurrence. Safe sex is an oxymoron. Substance abuse is common. Rates of HIV and Hepatitis C are likely higher than the population norms. Mental health issues are overwhelmingly present and poorly managed. Schizophrenia *may* be more prevalent in FASD; bi-polar certainly is. Psychiatric hospital beds in B.C. cost between $200 and $600 per day. Any stress exacerbates anxiety and depression which often leads to more substance use which leads to more unsafe behaviour. High pain tolerance is normal. Untreated injuries and illnesses occur regularly leading to higher medical treatment costs. Circumstances that could have been managed in a doctor's office or clinic become admissions to hospital. Acute care admissions, depending on severity, can be enormously costly. Effective use of birth control is problematic, leading to unwanted and unplanned pregnancies, abortions, substance use in pregnancy, poor prenatal care and poor birth outcomes, all at high cost.

Addictions and alcoholism as disease processes run rampant in those with FASD who begin to use and do not appear to be amenable to any existing treatment protocols as presently designed. Yet those with FASD are referred to and admitted into costly treatment programs time and time again from which virtually none benefit, at least in part because these programs are based on the premise of intact neurological function. Detox beds cost between $80 and $185 per day and may refuse treatment based on the high number of times an individual has used it. Outpatient treatment services are waitlisted and others may go wanting while those with FASD fail to show up for appointments because they do not have the ability to remember and get there on their own, but are expected to do so as a measure of commitment to change. All currently existing alcohol and drug counseling and treatment services depend on a deep intrinsic motivation to change, self reflection, insight and impulse control. As such, they are not appropriate for those with FASD, no matter the degree of addiction. Money spent on such programming could be better spent elsewhere. FASD specific alcohol and drug treatment needs to be developed, funded, piloted and evaluated.

Funded access to both assessment and diagnostic services for adolescents and adults was seen as a priority need. Many affected adults remain undiagnosed as a result of lack of financial resources. Participants talked about this as a violation of both the Canadian Charter of Rights and Freedoms and the Canada Health Act. They were unaware of any other medical diagnostic process an adult would be unable to access in the absence of money. Those who have had the luxury of a childhood diagnosis still require assessment services in adulthood, but few meet the eligibility requirements to obtain them and virtually none can afford them.

Adolescents with FASD may incur far less in the way of educational costs simply because many of them are no longer in school. However, for those who are still in an educational placement in B.C., most will have at least a ‘learning disability’ designation that has likely been with them since early elementary school. Many high school students with FASD who have managed to stay in school have designations allowing for higher levels of personal support, specialized programming or classroom placement, all at considerable cost. Depending on the designation, additional funding of amounts between \$6,000 and \$15,000 per student per year are available to a school (\$30,000 to \$75,000 over five years of high school; between \$72,000 and \$180,000 for 12 years of school) for a student *being maintained within a regular classroom setting.* Students who are in highly specialized or intensively supervised settings for students with mental handicaps or severe behavioural problems cost much more than that. However, the reality is that the vast majority of students with FASD receive little, if any, support to learn or keep them in school. The result is school failure, suspension, expulsion or drop-out. And with that, comes early involvement with drugs and alcohol, negative peer groups and criminal activity.

Students with FASD who do receive such supports are expected to require them for only short amounts of time, share the service with another child (or more than one); use the service only part time or on specific days, and to reach a state of function where support is no longer needed. Unlike other permanent disabilities, where support is funded on a long-term basis, individuals with FASD (and their families) are punished for not “getting better”.

What is the cost to an education setting of not having the resources to provide an effective learning situation for a child with FASD? How much high priced time is spent dealing with behaviours, suspensions, families, outside agencies, writing reports, etc.? What is the cost to other students of a teacher's time spent not in teaching, but in trying to control a child who is overwhelmed, over-stimulated and under-served? What is the cost to society of a lack of education in an individual? What is the cost to society of not providing the same high cost supports to all students with FASD that are available to some? It is those supports that enable an adolescent with FASD to stay in school successfully – and staying in school on a daily basis provides a necessary structure to prevent involvement in antisocial activities of all types.

Adolescents and adults with FASD are usually financially dependent upon their families for a goodly part of their support, if not all of it. Few are able to maintain employment to a degree that would allow them to be self sufficient. While many do qualify for Persons with Disability (PWD) funding in B.C., they are completely dependent upon the actions of others to even begin the complicated access process for this assistance. While a token payment ($105) for the assessment is provided to the assessor by the government, it is left up to the individual or family to make up the difference in cost of this assessment. The hourly rate that most people allowed to do these assessments charge is in the neighbourhood of $150 an hour, and an average assessment can take anywhere from four to 10 hours and involves considerable detail that would only be known to someone intimately familiar with the individual. Many professionals are not comfortable doing an assessment on a client they do not know well.

The maximum amount payable monthly under PWD assistance is $786. Others are not able to access even this small income as they are unable to undertake what is a complicated and onerous process without help and access to an "assessor". The shelter portion of PWD money is $325 per month, with no subsidies available. This is an amount totally out-of-keeping with the cost of living in B.C., which has the highest housing costs in Canada and where rent for a tiny basement suite starts at $500 per month if you are lucky. A yearly bus pass is available for $45, but no provision is made for lost passes which must be replaced at $10 per occasion (plus cost of bus fare for the six weeks it takes for a replacement). Medical coverage is provided, along with some basic prescription drug coverage. However, *many* prescribed medications are not covered, and whole classes of drugs are not obtainable for those on disability who cannot afford to pay for them. No over-the-counter medications of any sort are covered. Eye exams are not fully covered ($75 fee; only $45 paid and only once in two years), nor are replacement costs for eye glasses. Dental coverage is limited to $500 per calendar year, an amount barely adequate for a check-up and cleaning. Costs of all other medically necessary services (ie: physiotherapy, splints, orthotics, etc.) are not covered in almost all cases. Crisis grants are non-existent. A best-case scenario, after rent of $500, leaves an adult with FASD, even if he had excellent budgetary management skills, with only $286 per month for *all* other expenses: food, laundry, personal care, transportation, clothing, utilities such as a phone, medications, etc. This assumes the adult has no other bills of any sort, has absolutely no recreation, entertainment or personal life, does not smoke, drink or use drugs and never buys so much as a chocolate bar. In the absence of budgeting skills never in evidence with FASD, actual physical survival is dependent on the financial resources of others, either family or through the proceeds of crime. Even when the adult is living at home, this funding will not cover his costs.

Consistently, the inability to manage money, budget and avoid debt creates chaos in the lives of those with FASD, leaving family members to deal with consequences. Refusal to do so leaves the disabled adult at the mercy of others, hungry, homeless, taken advantage of and uncared for. Yet systems refuse to allow trusteeship of these very limited PWD funds in the absence of either agreement by the adult or a legal finding of incompetency. Even when such things as Power of Attorney or letters waiving confidentiality have been signed, they are not always honoured by different offices, agencies, companies and individuals. When a family does seek a finding of incompetency, and manages to acquire it, they become legally responsible for the actions of their adult child and all the costs that can entail. Finance companies, 1-900 numbers, internet scams, credit card companies, cell phone contracts, buy now – pay later offers, car leases, car rentals, – all take advantage of the gullible adult with FASD. Over and over again, potentially simple solutions to large problems are overlooked in the rush to practice a view of equality that fails to recognize that treating all people equally does not mean treating all people the same.

As well, the direct costs that able families absorb until they can no longer do so also include such high cost things as essential counseling and therapy, education and vocational programs, the costs of assessment and diagnosis, alcohol and drug programs, legal costs for adequate counsel and supervision costs for grandchildren. These are the types of services that may keep the adolescent or adult out of trouble and/or out of jail, but they are almost never paid for except by family. These costs are directly related to disability. They often come at a time in the lives of parents when they are least likely to be able to afford them – savings, lines of credit, loan possibilities and re-mortgaging have all been exhausted. Monthly income is stagnant, early retirement due to health concerns is a real possibility, and costs related to other children go unmet. What happens to the majority of families who never had the financial resources to start with?

For a break down of costs the family of an adult with FASD can expect to need to pay over time on a yearly basis, please see Appendix A.

The lack of financial resources to provide services and support to adolescents and adults with FASD and their families is seen as an area with dire and potentially fatal consequences. Lack of financial resources to support persons with FASD usually leads to social isolation, homelessness, victimization, criminal justice involvement, addiction, child protection concerns, mental and physical health problems, lack of vocational opportunities and family breakdown. The lack of recognition of FASD as a disability and the absence of the financial services and resources that go along with that recognition has been described as "systems abuse" by families. The true economic cost to society of not providing adequate financial resources to persons with FASD is far greater than the cost of proactive service provision.

There are also indirect costs to parents and families of persons impacted with FASD (i.e. serious stress and related health concerns for parents, loss of income due to costs associated with FASD, loss of property, lost opportunities, inadequate funds for other children, loss of parent time, loss of other children, social stigma and isolation, loss of extended family relationships and friendships, lack of personal safety, care of grandchildren, family and/or marriage breakdown, never ending grief, fear of what will happen to their adult child when they die, etc.). It is impossible to put a dollar amount to these things that largely constitute quality of life.

Health costs are enormous for both the parents and thus to the individual with FASD. The incidence of chronic physical and stress related mental health problems in parents is high leading to further loss of income. Participants described a "snowball effect" in which increased financial costs lead to increased health concerns, which then lead to increased financial insecurity and further health concerns. Family monies which should fund retirement and normal costs of 'healthy' children (ie: sports, lessons, education) are exhausted early on.

> *"What happens to our kids when we are not here?"*

An issue of critical concern for parents and families is these long-term costs they are responsible for when no other funded services are available to them – *and which will continue to be incurred after their deaths.* Many parents support their adult children with FASD financially, physically, socially, and emotionally well into their retirement years, indeed until they are no longer physically able to do so, and the societal perception of the "golden years" of retirement and rest are no longer a reality for them. Parents have long since realized that the issues facing individuals with FASD are an unrealistic and unfair burden to impose on other family members and the cost of burnout filters through to everyone involved. Participants reported that often family and friends are not necessarily allies, and because of a lack of understanding, abandon families in need. There is a definite need for a "life plan" for individuals with

FASD that includes supporting families through the provision of a variety of respite and life-long support services as is done with all other developmental disabilities. In this respect, many feel we are light years behind those who are dealing with other disabilities (IQ below 70) and the cost to society is huge.

There is a need for a paradigm shift among all systems to see the value and cost benefit savings that could be obtained through the provision of realistic, funded supports within systems (i.e. social work, education, employment programming, justice, etc.). It is cheaper for society and communities to pay now in terms of providing adequate support services to individuals with FASD and their families. You cannot put off paying until some amorphous time in the future – today is already yesterday's future. The costs will not disappear as time goes on. Rather, in the absence of pro-action, the future cost of not providing services in the present becomes excessive (ie. hospital beds, prisons, etc.). Creative messages must be explored to reach all levels of service provision. Targeted, key issue training for all service providers and professionals must be mandatory. Key professionals must be identified to facilitate a greater and widespread understanding within their systems of the urgency of the issues facing adults with FASD and the *avoidable* high costs that are associated with continuing the status quo.

Action for Change:

There is a critical need to develop a system of care for adolescents and adults with FASD that can adequately develop, fund, and implement a system of care that can adequately provide the following:

- ☐ Canadian studies that:
    - o look at and include ***all*** direct and indirect costs associated with FASD to both society at large and the family;
    - o determine actual and estimated cost to each system of care (education, social work, justice, labour, health, etc)
    - o follow a large number of families and adults long-term with a view to costs;
    - o contrast costs related to effective supports vs the absence of supports;
    - o track the long-term health costs to parents of adult children with FASD
    - o provide the “proof” that proactive long-term support is cheaper than reactive intervention
- ☐ Services and a service delivery system designed specifically for those with FASD across ***all*** domains – removing funding from other ineffective services may partially fund this, as would moving money from the legal system
- ☐ Access to all services based on diagnosis rather than IQ
- ☐ Adolescent and adult diagnostic services and updated assessments – mandatory coverage for costs as with any other birth defect
- ☐ Mandatory trusteeship of PWD funds by a third party
- ☐ Access to additional monies for support needs currently paid by families
- ☐ Innovative system of in-home support and respite for families
- ☐ continuing to provide for adult children, including 24 hour access to consultation and crisis help
- ☐ Crisis response teams that meet the needs of families rather than systems
- ☐ Provision of a broad range of counseling and mental health services to other family members

The deployment of financial resources specifically targeted at FASD service delivery should be undertaken and considered a primary broad risk management tool for working with adolescents and adults with FASD.

Health / Mental Health

"Her ankle was broken in three places but they let her walk to X-ray. They didn't believe it was broken because it didn't hurt."

"The therapist said to him: You can use any language you want in my office. He replied: I only know English."

This group began with a discussion about the "denial of disability" that permeates all systems but is particularly problematic in the health care field. This denial, cloaked in the ethics of confidentiality, effectively denies individuals with FASD their basic human right to have access to appropriate and informed health care.

It has long been recognized that young children with FASD may have many health problems related to their disability, including aberrant immune responses, abnormally high pain tolerance, chronic infections, seizures, and additional physical alcohol related birth defects. ADHD is very common. What we have been slow to realize is that these conditions, which were manageable with good care, regular medical attention, nutrition, medication and on-going parental support and vigilance, are equally there in adolescence and adulthood. In fact, in the absence of such supports, health conditions deteriorate significantly in adulthood. Additionally, mental health issues such as anxiety and depression, persevarative disorders, eating disorders and problems with anger become common with the onset of puberty. As well, many adolescents and adults with FASD deal with dual diagnosis (either addictions or mental illness or both) grief and loss issues, attachment disorders, and post traumatic stress disorder due to abuse experiences.

In adulthood, many adults with FASD begin to undergo the developmental issues of young teens, at a time in life when the supports needed to support the process are no longer readily available to the individual. However, the assumption of society and its systems is that adults should be able to, and are therefore expected to manage the issues around health and mental care unsupported. The inclusion of parent advocates is essential for bridging the gap between individuals affected with FASD and health professionals who do not understand them, yet family is almost always excluded from health care and health care decisions. This is a potential prescription for disaster on several levels.

Physicians, health practitioners, nurses, psychiatrists, mental health therapists and counselors need to understand adolescents and adults with FASD in order to provide appropriate and necessary health and mental health services. At present, there is no consistent access to or dissemination of information on FASD within the medical community beyond basic diagnostic information. Even that is sketchy at best. The result is a population of 'difficult' patients who are viewed as non-compliant with care rather than as disabled. As such, they are denied the quality and quantity of care available to other disabled adults because their 'non-compliance' is assumed to be 'choice'.

It is the position of this group that access to funded FASD diagnostic services for adults is a basic Canada Health Act and Canadian Charter of Rights and Freedoms right that should be accorded to any individual suspected of having this disability. Denial of such access is a violation. Diagnosis should not only be made available but should be free of charge in accordance with all other medical diagnostic services in Canada. Diagnostic and assessment services should be comprehensive in nature as an in-depth assessment of the individual is crucial to providing information necessary to service provision. As well, updated assessments are required periodically, and should be funded. *It was noted that had an adult seeking diagnosis been assessed and diagnosed as a child, all of these services would have been covered up to his 19th birthday as part of a developmental disability. FASD, REGARDLESS OF THE AGE AT DIAGNOSIS, BEGINS AT BIRTH. It is not the fault of the individual that the diagnosis was missed in childhood. He should not be penalized for the failures of others.*

The lack of adequate health services provided to individuals with FASD is also a cause for concern. Individuals with FASD have many identified health needs which include dental issues, problematic nutrition and related needs, substandard immunity, mental health needs, vision, speech and language needs, motor control disorders, sensory integration problems, etc. High pain tolerance complicates most issues. Many individuals with FASD are also accident-prone and/or have resulting health difficulties due to their poor judgment and vulnerability. Many have, or develop, chronic health conditions. Many are unaware that they are sick and are slow to access medical care for their health needs in a timely manner, if at all. Medication monitoring services are seen as essential as many do not understand the need for or effect of the medications and are unlikely to consistently and appropriately administer them. Impaired memory makes this very much a 'hit or miss' affair at the best of times in the absence of support. Of particular note is the connection between sensory integration problems and poor dental hygiene and the subsequent need for extensive dental work. Poor state of dentition is also linked to further problems with eating. Regardless of the medical issue, they are always assumed to be competent to understand, make decisions and anticipate and accept the consequences of those 'decisions'. In the absence of a finding of incompetency, parents are not informed or included in health care decisions or the provision of care, or the lack thereof. Yet they are the ones who will become responsible for dealing with the outcomes of those actions or inactions.

Health care needs cannot be well managed in the absence of a supported living situation. Since this is not currently a reality for many adults with FASD, creative ways will need to be developed to seek out these individuals and provide crucial health care where they are. For those adults who do have at least some measure of family or community support and stable living circumstances, physical health care services will need to include funded access to such things as Meals on Wheels, liquid dietary supplements, replacement of eyeglasses, medication reminder systems (people, not pill boxes), transportation to and from medical/dental appointments, and a medical interpreter/advocate/mediator. Adequately funded dental care will be essential to prevent further health deterioration.

The need for services in the area of sexuality/birth control was also identified as a significant health care need. Free birth control should be provided to all individuals with FASD. As instruction on how to use birth control properly is not particularly likely to be effective due to the disability, consideration must be given to options that do not depend upon the individual for compliance and for some, more permanent options. Many individuals with FASD do not understand the concept of safety with respect to STD's and often are in high-risk situations (i.e. prostitution, addiction etc.) due to their vulnerability and the ease with which they can be manipulated by others. There should be provision in place to provide support to individuals with FASD to safeguard them as far as humanly possible against STD's, HIV, Hepatitis C, etc. While not directly a health care issue, other victimization in the area of sexuality (i.e. internet/chat-lines, pornography, forced 'consensual' sex etc.) was discussed. Group consensus is that such acts frequently lead to involvement in the sex trade and the attendant health care issues.

In addition, assistance for children of adults with FASD is needed. Support is required to allow adults with FASD to meet the basic and emergency health care needs of their children. Failure to do this is considered neglect, and can lead to child apprehension. Access to daycare services that work with the parents affected by FASD and provide on-site health care to their children should be encouraged. This is particularly important when limited support is otherwise available. Services to protect the adult's right to parent with supports were also seen as a gap in service delivery.

Provision of such services would be a positive mental health support and likely help to prevent further pregnancies.

The consensus in this group was that the need for effective mental health services for adolescents and adults with FASD has reached a crisis point. Over 90% of all adolescents and adults with FASD will develop a mental health disorder. They are so prevalent in this population that FASD is now considered by many to be a precursor for mental illness. Generic counseling services are not effective, and may actually makes things worse for individuals with FASD. Specialized treatment and counseling services able to address the individual needs of persons with FASD are essential and must be developed. They need to be available quickly, even immediately, as one "must strike while the iron is hot" when working with adults with FASD. At present, there are only a handful of therapists who specialize in adults with FASD, all of whom are in private practice and cost in the range of $130 to $150 per hour. Their experience and expertise must be shared and could form the basis of new 'best practices' for FASD and mental health. Adequate understanding and training of mental health clinicians can only lead to appropriate and more effective mental health treatment across the lifespan. Access to funded, appropriate, effective lifelong mental health treatment should be available. Typically, adults with FASD will need this support on a fairly regular basis, especially at times of stress and transition. Many individuals with FASD experience ongoing difficulties (loss of a family member, understanding limitations of the disability, loss of dreams/hopes, trauma, etc.). An interpreter for life issues is seen as vitally important in maintaining function. As well and wherever possible, a family member or support person should be involved in mental health treatment. The ability of this person to act as a 'reality check' for the therapist was seen as a pivotal role for providing good mental health care and services.

Increased understanding of medications and their affect on brain chemistry in FASD is crucial to providing primary mental health care. Yet science knows very little of the long term effects of these powerful medications on prenatal brain injury. Research in this field is an urgent need. Prescriptions for medication must be provided by a medical doctor, usually a psychiatrist, yet therapy is almost exclusively done by clinical psychologists. Often they have little knowledge about what the other is providing.

Mentors for individuals with FASD facing initial awareness of their disability may be helpful to their understanding. The availability of volunteer groups, buddy systems, and a hotline for individuals with FASD are also considered beneficial support services that are needed and should be provided.

Outreach services were also seen as necessary for mental health services. Individuals with FASD often have very limited self-awareness of symptoms and deterioration. The willingness of professionals to provide mental health services to the adult with FASD where he is instead of waiting for the individual with FASD to come to him or access services on his or her own could improve the overall access to health services for these individuals. It might also improve mental health outcomes. The availability of a highly skilled "SWAT team", or crisis intervention team to provide immediate mental health services to clients and parents is seen as THE key essential, as well an FAS hotline where families could obtain immediate referrals for appropriate mental health care, (along with other health, legal, leisure/recreation etc. services referrals) and support for themselves. Additionally, a directory of professionals in various systems (i.e. health, mental health, legal, addictions, support etc) who understand and have both knowledge and experience working with individuals with FASD would be most valuable to parents/caregivers and other professionals working with individuals with FASD.

Parents of individuals with FASD also experience mental health issues for which they themselves require specialized support and intervention. Living with individuals with FASD is highly stressful at the best of times. At its worst, Post Traumatic Stress Disorder can develop as a result of chronically "living on edge waiting for the other shoe to drop", persistent 'parent-bashing', and the lack of understanding from professionals, extended families, other children, friends, partners and individual parents themselves. The issue of "*systems abuse"* and its affect on the mental health of individuals with FASD and their parents is one that needs to be recognized and addressed. The results of bureaucratic denial and the subsequent, systemic punishment of parents/caregivers leads to parental exhaustion, the view of self as a failure in one's role as parent and the development of severe stress related mental health disorders. This denial of access to necessary services has led to a widespread perception that individuals with FASD and their parents/families are "disposable" members of society.

Action for Change:

1. There is an urgent need to develop a comprehensive system of physical health care delivery designed to meet the needs of adolescents and adults with FASD through:
   - ☐ Development and funding of comprehensive adult diagnostic and assessment services as a medical care ***right***
   - ☐ Development of trained medical and dental teams to which individuals with FASD can be triaged for care
   - ☐ Development of a delivery system for care that is not dependent upon the adult for implementation
   - ☐ Provision of extensive outreach services that include medication administration of all types for all needs
   - ☐ Development of a system that will allow medical personnel in the field, hospital and other medical settings to know an individual has FASD
   - ☐ Development of clinical guidelines for medical assessment and treatment whenever an individual has FASD that mandate the involvement, wherever possible, of a third party interpreter and/or family member
   - ☐ Development of PWD, medical and other assistance protocols to fund medically necessary dental care, dietary supplements, vision care, and other medical treatment that is a result of birth defect disability at no cost to individual or family
   - ☐ Provision of regular in-home public health nursing services to parents with FASD to maintain and monitor the health and wellness of their children
2. There is a critical need to develop a comprehensive system of mental health care that is designed specifically to meet the needs of adolescents and adults with FASD through:
   - ☐ Provision of immediate access without a referral
   - ☐ Funding of actual costs for effective mental health treatment
   - ☐ Development and funding of highly skilled and FASD specialized mental health care teams to which individuals with FASD can be triaged (therapists, psychiatrists, social workers, trained volunteer supports, advocate, coordinator)
   - ☐ Development and provision of mental health outreach services and mobile clinics
   - ☐ Development and provision of "where and when" treatment models

☐ Development and provision of a SWAT model approach for crisis intervention services

☐ Provision and funding of long-term mental health care needs arising *as the result* of a birth defect

☐ Development of clinical practice guidelines for the mental health treatment of individuals with FASD that mandate, wherever possible, the inclusion of a third party support or family member as interpreter

☐ Development of a process to determine 'best practice' treatment for FASD

☐ Connections with drug manufacturers to encourage research into the specific effects and interactions of medications on those with FASD, and to strongly encourage the development of new medications designed for this population

3. There is an urgent need to provide mental health care services to parents and other family members through:

☐ Access to and provision of funded mental health counseling on an on-going basis as it is needed – and the recognition that the cause is FASD and not inadequate parenting

☐ Provision of facilitated support groups

☐ Provision of a 24 hour phone line that can provide information and support, and that has the ability to access immediate help for crisis situations

☐ Provision of funded 'respite' services

☐ Provision of a funded family advocate

☐ Inclusion of parents in mental health care for the adolescent or adult

The development and funding of targeted health care delivery and mental health treatment should be considered as a primary broad risk management tool for working with adolescents and adults with FASD. The provision of funded long-term mental health care to parents and other family members should be available, funded and encouraged as a risk reducing tool in the maintenance of essential supports to individuals with FASD.

Education / Programming / Employment

> ***"What are the two things an adult with FASD can do to be like everyone else? Have a baby or get a job. Where would you rather put your money?"***
>
> ***Dr. Ann Streissguth***

The lack of understanding and awareness of the specific needs *and abilities* of individuals with FASD among educational and vocational professionals is seen as a serious issue. Specialized education, pre-vocational and vocational training and supported employment practices are the pathways to successful employment and adult life for adolescents and adults with FASD. Yet cutbacks to funding have led to serious reductions in the availability of all special needs services that lead to successful outcomes for individuals with this disability, leaving them with no "reason to get up in the morning". Adulthood is defined by the ability to "get a job", and in its absence, an adult with FASD is left with far too much time on his hands and nothing constructive to do. Few qualify for CLS programs – those that do are the lucky ones. For the rest – the large majority – the desperate need to feel part of something – anything – invariably leads to victimization, trouble, pregnancy, substance use and criminal activity. The high costs to the individual, the family and society at large could be avoided at least in part through the provision of services to include those with FASD in the mainstream of life.

It seems obvious that keeping those with FASD in school during their adolescence is critical to future success. Yet, at the present time, 60% or more are out of school after the age of 12 because there does not currently exist the kinds of programming that identify them, understand the disability and meet their needs. Many adolescents with FASD remain undiagnosed in high school and there exists a significant need to develop a process to screen for the disability at this level. General FASD screening that could be administered when students are viewed as struggling academically ***or*** presenting with significant behaviour problems would be helpful for early identification of those who should be considered for further evaluation. In a climate of education cutbacks, referral for and access to diagnosis may be a necessary step in gaining entrance through one of the necessary "gates" to more appropriate school services. Even when it does not lead to services, it is still a tool to change the view of behaviour from one of deliberate choice to one caused by brain damage. Regardless, the diagnosis begins the process of directing the future.

While it may apparent to anyone with a considerable degree of hands-on experience with FASD that these individuals are quite different from other learning disabled groups, it is not obvious to those absent this experience. There is a critical need to provide comprehensive information, education and hands-on support to teachers who have students with FASD in their classrooms. They need to understand the specific learning needs and learning styles and how to translate them into activities connected to the student's future. They have a critical need to understand behaviour in its proper context as the result of a severely impaired ability to function adaptively. A benefit of good awareness and education programs for teachers should also be a better understanding of family. Condemnation of parents as "over-protective" "over-controlling" "brooding" "enabling" or "enmeshed" with their children and the destructive interactions this sets off could be avoided.

Secondary school years are particularly difficult years that bring many challenges beyond academia to the individual with FASD (i.e.: vulnerability/victimization, peer pressure). There is a need to provide safety plans for such students as well as build in mechanisms to assist with transitions into secondary school routines. Structured programming that avoids free time and high risk settings should be encouraged. An allowance for repetition of grades is seen as beneficial or even essential in some instances when further reinforcement may be needed. The teaching of 'social skills' should be considered as a critical component of curricula and not an add-on for individuals with FASD. At present, there is no generally recognized programming for this that is not directed at mentally handicapped students. There exists a significant need to develop, pilot and implement such teaching directed specifically at those with FASD.

In addition, specialized programming is seen as vital (i.e. Industrial arts, practical components, applied career experience (ACE) programs, pre-vocational programs with job placements, life skills). An allowance for alternatives to conventional academia is both necessary and preferred. As well, all programming should be flexible, individualized, low stress and fully integrated into the community with built in transition supports. Serious consideration should be given to developing a model of education that re-thinks the purpose of schooling for this population to better address their long term needs.

A harsh reality for many individuals with FASD is that even existing services disappear after age 19 years. At this recognized 'adult' age, individuals are expected to be able to live independently, continue their education or find gainful employment, and start focusing on career goals and aspirations. The lack of realistic opportunities for individuals with FASD in the area of adult education and employment services is a huge gap in service provision leading to a bleak future. Individuals with FASD need targeted employment opportunities that allow for a range of development possibilities. Careful and thorough evaluation of actual (versus perceived) strengths and abilities is essential. Full time paid work may not be an option for many, but part-time employment is. Those on PWD funding are permitted to earn up to $400 per month without reducing their benefits. Access to this money could improve their living circumstances. Others may make effective volunteers in settings that respect their disabilities. Many will flourish in any setting that makes use of their talents and skills while modifying tasks and making allowances for their disabilities.

The availability of job coaches or "job buddies" is seen as a way to increase an individual's ability to maintain a job. Employment settings that can provide a high degree of structure, routine and repetitive tasks work well for many. Job placements that are carefully matched between the needs of the employer and the adaptive abilities of the adult with FASD can allow success for both parties. Regardless, employers require training in working with all persons with FASD (ie. how to breakdown and sequence job skills in order to teach them to someone with FASD, how to communicate for comprehension, etc). They will further require training that is quite specific to the individual being placed or hired. Job coaches and job buddies will need patience, training, consistency and commitment.

Employers will need not only awareness of what supports are needed for the employee, but also the benefits of hiring someone with FASD. Socially conscious and responsible employers should be actively sought out, recruited and well supported. Incentives, such as wage subsidies should be available to employers who hire someone with FASD. Such subsidies should remain in place until it is absolutely certain that the job has been well learned and is being performed acceptably. The employee should continue to be attached to an employment program that can provide any additional support and skill-building required to be successful on the job. As well, cost free consultation services to the employer for problem solving over time could be useful in maintaining employment.

There will always be individuals with FASD, no matter how high the IQ, who are unable to meet the conventional requirements of typical employment. Expectations of employment need to be altered to allow for part time work, shared jobs, full time work for a while with a full time break without loss of employment, seven day a week work, and the like. For others, volunteer work, and social and recreational programming are essential. As with any other adult, those with FASD need regular productive activities they can be part of. Funding for such programming will be required as few adults with FASD qualify for existing CLS programming of this type. As well, it will pay to remember that those with FASD are distinctly different from others with handicaps, and programming that has been effective for them will not necessarily work with this group. These 'high functioning' individuals require programming that does more than 'fill in time'.

Programs that address indirect employment-related needs of persons with FASD are also needed. These include money management services, life-skills coaching and mentoring, at work relationships, problem solving, advocacy and interpreter services etc. These are essential services to assist the individual with FASD not only in obtaining a job, but are crucial in maintaining one. Many individuals with FASD are fired from jobs not because of their ability to do the job itself, but because of the lack of life and social skills support required to keep the job (ie: appropriate dress, unspoken rules of the workplace, lateness, fleeing when things get difficult, not asking for help, bad debts, eviction, addiction, etc.).

No matter whether or not adolescents and adults can be maintained in school or employment, society must remember they are disabled citizens. As such, they should be eligible for, and able to access dedicated programs such as those available to all other developmentally disabled Canadians.

Action for Change:

There is an acute need to develop and fund a comprehensive range of educational, vocational, employment and other programs for adolescents and adults with FASD through:

- ☐ Creation of a education system funding category for those with a diagnosis of FASD
- ☐ Development of and implementation of an in-school screening protocol and referral system for diagnosis
- ☐ Triaging diagnosed students into specialized teaching teams in designated ‘expert’ schools
- ☐ Design, development and implementation of a new vision of vocational education for high school students with FASD that works closely with community, employers and adult education systems, incorporates life and social skills as mainstream curricula and mandates transition services
- ☐ Continuing to provide and fund education placements for adults with FASD past Grade 12
- ☐ Development and funding of FASD specific vocational skills college programs that can provide tutorial and academic supports and job placement services for those able to undertake this
- ☐ Development and funding of “FASD employment service” programs with the resources to:
    - recruit, train, retain and support a wide range of employers and employment activities
    - thoroughly assess actual (versus perceived) abilities
    - carefully match employees needs to employers needs
    - provide on-the-job training and coaching for as long as, or as often as necessary
    - provide on-site and on-going consultation to employers
    - provide classroom and other program support to those with FASD to address indirect job skill issues
    - create and manage entrepreneur type job settings for those with FASD who may have special talents
    - provide and support a range of options in terms of hours of work, how work is done, days of work, job length, etc

☐ Development of a range of other volunteer, social, recreational and life skills programming to meet the daily needs of those adults with FASD who are unable to be employed

The development and funding of targeted educational, vocational, employment and other programming that is specific to adolescents and adults with FASD should be considered as a primary broad risk management tool. It should also be considered as a risk reduction tool in its ability to help maintain both residential and family placements and to provide 'respite' to parents.

Legal & Addictions

"***There is no <u>Justice</u> System; there is a <u>Legal</u> System***"

(B.C. Provincial Court Judge)

This session began by considering the connection between substance use and criminal activity. As noted by the larger working group, the two are almost always linked together. If substance use happens first, criminal activity will almost certainly follow. If criminal activity happens first, it brings the individual with FASD into contact with those who are committing crime to support a habit. In either case, one leads inexorably to the other. Experience has taught those working with FASD that once involved with either, adolescents and adults with FASD will very likely spend their adult lives enmeshed in the criminal justice system. This is not a resilient population. The best possible solution for those with FASD is to prevent substance use and criminal activity to begin with. This requires services, supports and programs not currently available. To that end, the group posed four questions: "what is the legal definition of an adult?" "what is the legal definition of disabled?" "what defines independence and autonomy?" and "how do these things impact on the legal and addiction systems?"

If one is to look up the definition of the word 'adult' in any good dictionary, it will be defined as "fully developed and mature".[1] This clearly does not fit for adults with FASD. But neither are they considered by society and its systems to be children because they are, in fact, over the age of legal majority, as that is defined in the jurisdiction in which one lives. However, if one also looks up the definition of the word 'child', an interesting definition is provided (beyond the obvious) as "one strongly influenced by another or by a place or state of affairs"[2]. This is much more in keeping with the functioning abilities of adults with FASD, who adaptively, usually function in the moderately mentally handicapped range. However, society has no 'test' that is automatically given to every adult on his birthday to determine whether or not he should be an 'adult'. Perhaps it should.

Traditionally, an adult is considered to be anyone over the legal age of majority, which in B.C., is 19 years of age. In the legal system, 18 is used as the age at which adult penalties are imposed. In the health care systems, the age at which a child is deemed competent to refuse treatment (including for substance use) or medication can be as young as 12. The age for sexual consent is 14. Independent living

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[1] Merriam Webster's Deluxe Dictionary, 10th Collegiate Edition; 1998

[2] Ibid

situations for youth in foster care begin at 16 and are strongly encouraged as a cost savings measure. Police are reluctant to look for anyone over the age of 12 who is a runaway. Why these ages? Because, there is no legal definition of an "adult", Society and its systems have decided that individuals have the ability to understand the consequences of their actions at these ages and are competent to make those choices. And it is always assumed that a 'choice' is being made, even though those with years of experience with adolescents and adults with FASD know that 'choice' is rarely ever involved: "things just happen". Age does not match behavior.

It is clear that adolescents and adults with FASD are disabled. But what, exactly is meant by that? And if this is generally accepted, then why does this status not lead to services? Currently, the only standard by which disability is measured in FASD is IQ below 70, or mental handicap. However, the dictionary defines disabled as "made incapable or ineffective and *especially*: deprived of physical, moral or intellectual strength".[3] This would appear to be a particularly apt description of the range of deficits seen in FASD. Yet it appears that society believes this is a 'deficit of character' rather than a result of brain damage. And as long as society can cling to the position that this is character based, it can justify refusing supports and services to a group it does not see as deserving. Thus a disability is not a disability.

It is equally clear, and supported by research, that at least 80% of those with FASD will be unable to live independently, regardless of IQ. So we must ask "what does the ability to be 'independent' entail?" Again, we turn to the dictionary for a definition of the word and find the following: "not subject to control by others; self governing; not requiring or relying on something else; not looking to others for one's opinions or for guidance in conduct; not requiring or relying on others (as for care or livelihood)".[4] Autonomy and autonomous function is the goal to which society insists all learning and activity be directed. It is defined as "undertaken or carried out without outside control; self contained; existing independently of the whole; the quality or state of being self governing; self directing freedom".[5] How ironic that the commonly repeated statement "It takes a village to raise a child" should be so ignored for our adult children.

Once an individual with FASD turns 19, they are always considered to be functioning adults able to live and work independently without supports, no matter their IQ, their adaptive functioning limits, their diagnoses – and no matter what level of support they may have had during childhood and adolescence. On a 19th birthday, everything stops. The only allowance for even limited services is for those individuals with an IQ

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[3] Ibid
[4] Ibid
[5] Ibid

below 70. For the majority of adults with FASD, this criterion does not apply, yet they also do not meet the definition of independent, autonomous adult by any standard.

If an individual with FASD does not fit the conventional definition of 'adult (ie fully developed, mature, able to live independently etc.) and they do not meet the socially accepted definition of developmentally disabled (IQ below 70), where do they fit? And who provides services to a population caught in limbo?

Into this huge gap steps the criminal justice system. It is the only system that has a very simple eligibility requirement: commit a crime and you are automatically eligible for service provision. Forget your IQ. Forget your diagnosis or lack of a diagnosis. Forget your age. Forget the need for an assessment. Forget the fact the 'program' is full. Forget your family income. No need for a referral. No waiting list. "Come on in and we will provide you services because we don't have a choice in the matter". How ironic and short-sighted that the most expensive option for support is the only one always available.

The criminal justice system has become, by default, the social safety net for adolescents and adults with FASD. As such, there is a need not only for increased awareness and education about FASD among justice professionals and systems (lawyers, judges, corrections, police etc.) but for highly skilled staff who will be working directly with these individuals. This training should be mandatory for front line professionals in both legal and addictions systems. It should focus on recognition of the indicators and manifestations of disability and the likelihood of involvement in criminal acts as a result of disability rather than deliberate behaviour. A strong focus on understanding FASD as brain damage non-competence rather than conduct disorder and/or non-compliance should be emphasized. Staff working directly with those with FASD should be hand-picked for a specific skill set, patience and high tolerance for frustration. They must be provided with extensive training in how to work more effectively with this population and access to consultation services.

There is a need for FASD specific interpreters within the justice process who are available to both the individual and the system. Many individuals with FASD do not understand the legal process, especially as it relates to their basic rights. Violations of these rights occur regularly, not because the system does not care, but because the system does not understand the disability. This is particularly a problem when presented with an adult who talks well, looks good and cops an attitude. The reality that the individual understands little of what is said to him is easily missed. Many adolescents and adults with FASD may incriminate themselves, or provide false statements because of their lack of understanding. They have little concept of time, poor memory and are easily confused. Interpreters should also be available for the court process so that the individual with FASD understands their plea and disposition and is able to answer questions posed to them by the court. These questions may need to 'translated' by the interpreter. The mental health courts might be a potential model that could be more 'user friendly' for individuals with FASD. However, a challenge to this is the absence of FASD in the *Diagnostic and Statistical Manual* on *Mental Disorders (DSM-IV).*

As there are Native Court Workers available in the courts, so too should there be FASD Court Workers readily available on-site to provide assistance and support to individuals and families affected by FASD. In addition, the issue of confidentiality in the legal system poses a challenge to parent-advocacy in the court process and must be dealt with. Modifications should be made to allow for a parent/caregiver to support and advocate for the individuals with FASD. Access to specialized and affordable legal services to assist with defense should be provided. Currently, parents/caregivers who want to advocate for an adult with FASD do not have the right to access information or, in most cases, to provide information to service providers. This is exacerbated when the individual with FASD is also resistant to parent involvement because of their understanding or misunderstanding of the rights of an adult, but at the same time, has no idea how to help themselves and relies on the parent for complex issues.

Access to funded diagnostic and assessment services is also a need within the legal system. As the legal system is a catchment basin for undiagnosed individuals with FASD, it is a pivotal place for identification. A referral for diagnosis should be mandatory before sentencing in cases where crown, defense or judge suspects FASD, or the family presents evidence of the likelihood. It is likely a *Charter* violation to ignore this.

A mechanism to 'flag' individuals with FASD within the legal system might serve to increase awareness and understanding of their specific needs. In addition this would facilitate communication among justice professionals. One way to do this would be to use the Canadian Police Information System (CPIC), a system that justice professionals have access to that identifies whether someone has a criminal record, outstanding warrants, etc. This flag would then inform justice professionals that specialized intervention and protocols are required with the individual from the point of arrest onward. This flag would identify an advocate, family member or service provider who must be called, regardless of the age of the individual. Ideally, a specialized police unit could be called in to provide specific services to the individual with FASD. There is a caution in using such a mechanism in the possible occurrence of discrimination or hurt caused to the individual with FASD as a result of this information. However, it is also the undeniable reality that individuals with FASD are already discriminated against and flagged for negative attributes that are likely the result of a lack of knowledge about the disability.

Alternatives to incarceration are critically needed for individuals with FASD who enter the legal system. Prison merely puts them in with bad people and exposes them to even worse abuse. It never makes them a 'better' criminal; they always get caught; and they do not learn from the experience. A disability version of restorative justice initiatives may be a more effective alternative. It would have to be significantly adapted as this model which focuses heavily on 'accountability', may be problematic given the limits of this disability. However, it is also focused on a less punitive approach. Since individuals with FASD have great difficulty learning from their experiences and applying that information, traditional sentencing which increases penalties each time and individual is convicted should be contraindicated. It is ineffective at best and abusive at worst. *Community Circles of Support* is also a program that could potentially be adapted for those with FASD who have been in jail.

In addition, specialized programs and facilities for individuals with FASD are also needed. For those who are incarcerated, specialized units and teams that are trained in working with individuals with FASD should be utilized. Advocates should be made available at all stages of the justice process. Realistic transition planning and aftercare services must be available in the community. Specialized probation and parole services that understand FASD must be developed. FASD protocols and risk management tools must be developed to provide realistic expectations and supports. Flexibility is required to avoid persistent breaches and additional time in custody for what are disability related behaviors.

Substance use treatment services that have proven to be effective for those with FASD do not exist - anywhere. Very little emphasis has been placed on modifying, developing or providing treatment services for people with any developmental disabilities in any case, let alone FASD. FASD particularly poses and will continue to pose a very significant challenge to the addiction treatment system. Adolescents and adults with FASD are highly deceptive in their appearance of function. Their 'savant like' ability to talk well, works against them. We live in a society that believes when a person talks well, they think well. Individuals with FASD *appear* to be able to think, understand, plan, organize, develop insight, remember and follow through, but appearances are very deceiving. Traditional, language-based insight counseling methods (equally ineffective in mental health) are not appropriate for those with FASD. Thus treatment approaches and programs based on such cognitive abilities are bound to fail. It is not the individual with FASD who is failing at the program; it is the program that is not working for the individual. It is not a matter of modifying, 'chunking', repeating or restructuring existing programs. New approaches must be developed from the ground up. Considerable thought and expertise in the area of FASD and substance use needs to be involved in deciding what the actual reason for and goal of treatment is, for those with FASD, and how that might best be accomplished. Clarity of purpose is needed. Reality must be faced. And until these things come together, little is likely to change. Scarce resources will continue to be used with little benefit.

Once an individual with FASD enters existing addictions services, there are specific structural systemic problems that arise. The length of a residential treatment program is inadequate and must be longer than the usual 30 or 60 days. Location of residential programs is often a problem. There is a critical shortage of detox beds; an access system that is almost impossible for those with FASD to undertake; waiting times; a lack of ability to transfer directly from detox to residential treatment; no transitional care into the community; no follow-up services or supports. In addition, multiple barriers, such as discrimination, victimization and outright refusal of service due to "over-use" and perceived "lack of commitment to change" need to be addressed. Some recovery houses operate on the fringes of legality. 'Zero-tolerance' policies and point systems in effect in almost all facilities set up individuals with FASD for failure. They are ineffective and not based on a realistic model of addiction, especially for persons with disabilities.

There is a critical need to design and develop non-punitive, supportive residential treatment, counseling and support services for pregnant women who have FASD and are dealing with substance use issues. Women who are pregnant must be prioritized to get into treatment centres. Second generation FASD is fast becoming a serious problem. It is a definite challenge for any woman who is pregnant to access addictions services that provide support without threat of child apprehension. For the woman with FASD, the threat becomes a reality. There is a *very* high probability that she will lose her children if she tries to access help. If she fails at either outpatient or residential counseling (and that likelihood is almost 100%), she *will* lose her children and the baby at birth. Already overtaxed family will have to step in or risk permanent loss of grandchildren. Such insistence on the part of systems that she 'succeed' at a program guaranteed to cause her failure is short-sighted, punitive and cost prohibitive in the long term.

It seems so obvious that it is almost not worth saying, but there is a need for prevention and intervention services *before* addictions arise. This includes access to leisure/recreation services and programs, mentorship and positive peer support programs, vocational/volunteer opportunities, opportunities to get involved in community activities that are healthy, pro-social and completely avoid alcohol and drugs. For those few individuals with FASD who may pose concern to other individuals, there should be access to 1:1 supervision and support programs that meet their unique needs. Substance use in FASD is so poorly understood and even more ineffectively treated that money spent aggressively preventing it in the first place would be well spent.

Action for Change:

1. There is a critical need to develop a true *system of justice* for adolescents and adults with FASD that crosses jurisdictions, systems, and authorities. Such a system would provide for:
    - ☐ Development and implementation of new definitions of developmental disability that are not IQ dependent, which more accurately reflect, legally acknowledge, and effectively support adolescents and adults with FASD
    - ☐ Legal recognition that all birth defects involving congenital developmental disability, regardless of age at diagnosis begin at birth. As such, supports that would be automatically accessible by any other person with any other developmental disability birth defect should be available to those with FASD
    - ☐ Design, development, and implementation of a national campaign to shift public perception, remove stigma, and support adolescents and adults with FASD to contribute positively in the mainstream of Canadian society, as we do for those with other recognized disabilities
2. There is a critical need to develop, fund, and implement legal services for adolescents and adults with FASD which will:
    - ☐ Provide a range of information for people employed within the legal system, not only awareness and education, but also mandatory comprehensive training for those working directly with individuals with FASD on a daily basis
    - ☐ Develop and employ stringent selection criteria for the recruitment and deployment of staff, contractors, and others working directly with affected adolescents and adults
    - ☐ Develop, fund, and implement a FASD court worker program and provide access to qualified FASD interpreters at all stages of the legal process
    - ☐ Develop and implement appropriate FASD protocols for all systems of the legal process that mandates how the individual must be dealt with because of the disability
    - ☐ Develop and implement a mechanism that identifies individuals with FASD within the Canadian Police Information Centre (CPIC) in order to affect the appropriate FASD protocols
    - ☐ Provide and fund access to diagnosis as required as a *Charter* right at any step of the legal process where suspicion arises
    - ☐ Develop and fund alternatives to incarceration for the majority of those with FASD who are not violent offenders. These alternatives must not be dependent on house arrest which uses families as jailers

- ☐ Develop and implement specialized units and programs within institutions for incarcerated individuals with FASD, when other options are not available or have not been effective, which include proper transitioning to community services

- ☐ Develop and implement specialized parole and probation services for released individuals with FASD who return to the community

3. There is a critical need to develop, fund, and implement addictions services for adolescents and adults with FASD, that will:

   - ☐ Provide for and fund research to determine what is different, if anything, about substance use and addictions in this population

   - ☐ Further design, develop, fund, implement, and evaluate models of substance use treatment for those with FASD that may be more effective

   - ☐ Provide long-term follow-up to determine which models are most effective for relapse prevention

   - ☐ Provide priority access, non-punitive, supportive residential treatment, counseling and support services for pregnant women who have FASD and are dealing with substance use issues

Involvement with the legal and addictions systems occurs when other risk reduction strategies have been ineffective for a variety of reasons. However, because it is in the position of having to provide services to individuals with FASD regardless, it could also provide a pivotal intervention point. The development and funding of targeted legal and addiction services that are specific to adolescents and adults with FASD should be considered as a primary risk management tool.

Family Support

"My child was born with a disability. It is society that handicaps him.

It is society that handicaps us."

(Handicap: "a disadvantage that makes achievement unusually difficult")[6]

Regardless of how it is constructed, children are supposed to grow up in a family. In the normal course of events, and in the normal course of development, those same young people leave home some time between the ages of 19 and 25, depending on circumstances. This is the age when these adults are in post secondary education or gainfully employed, self-sufficient, responsible, respectful, socially engaged, self-directed, self-controlled, self-monitored – in other words, functional adults. They do not require the daily support of their parents. They do not need supervision. They can be trusted. These adults stay in the home as long as they do, not because they need to but because they want to. They are financially able to take care of themselves and manage their own affairs. While parents may not always agree with their decisions, those decisions are not dangerous to them. When they make a mistake, they are able to rectify the situation and learn from the experience. The decision to continue to live at home is mutually agreeable and generally works well on both sides of the equation. Parents often have the added benefit of observing first hand how well a child has turned out. The stresses are only those involved in the normal everyday course of events that happen when older people live with younger people. No matter the negative circumstances of the moment, the parent *knows* it is only a temporary blip. And parents *know* that eventually, the adult will move on with his life, and leave home, allowing them to get one with theirs. And most importantly, if for any one of a number of reasons they must ask that adult to leave the home, they *know* that adult child will be able to survive without them and do so in almost all cases, in a lawful and socially acceptable manner.

Intact families living with normally functioning adult children are not in need of support services. They do not need 'respite' or a 'break' from their children. They have not experienced many years of on-going extremely high stress levels. They have continuing access to disposable income that has not been gobbled up by a disability. They have not been forced over and over again to make choices that pit the needs of one child against the wants or needs of another. They have not been held hostage

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[6] Merriam Webster's Deluxe Dictionary, 10th Collegiate Edition; 1998

to experiences for which they could never have been prepared. They have the privilege of a life which is separate to that of their children.

The story is very different when the adult son or daughter has FASD. The adaptive functioning and developmental levels of these adults are those of much younger children, but society insists they be accorded the freedoms of an adult. They are not self directed and self controlled; they are most certainly not self sufficient and require daily support in all the areas of life; they *must* be supervised or things can go terribly wrong. The safety of everyone is frequently an issue, even though violence is not. They *cannot* manage money and have little concept of value. They are chronically manipulated by those who take financial advantage of them. Many have serious problems with mental health issues; a goodly portion develops substance use problems. Even more are out of school after Grade 8 and very, very few are employed even occasionally.

The financial burden of care for this disabled adult falls on the family *far* beyond what should be expected or is reasonable, and in ways that families with other disabled adults never experience. Financial care costs go up, not down, and can be such a drain on parental resources that continued care is not viable. PWD funding is not automatic, the process is arduous and costly, and no financial management services accompany it, making it of almost no value to a family even when approved. Support and service systems that may have been accessible or of some use in childhood disappear. The few effective resources available are costly and out of reach to most to begin with, and to all, sooner or later. Attempts by family to continue to keep these adults 'safe' are often viewed as enabling behaviour that is actively discouraged by systems that believe these adults *must* learn from experience. Personal family support falls by the wayside as extended family; friends and community systems turn away due to the chronic nature of the difficulties encountered and the 'lack of change'. Slowly and insidiously, the stress of always 'living on the edge' becomes unbearable and unmanageable with all the attendant physical and mental health sequelae for parents. Keeping them safe means 24/7 support which is time consuming and takes enormous energy. There is no end in sight, not ever. And whether or not they can be maintained in the family home or must live elsewhere, they will continue to have *high* needs for support – financial, social, moral, mental, emotional, psychological, programs, etc.

Children with FASD become young adults with FASD become middle aged adults with FASD become old adults with FASD – and they *always* have FASD. While their needs may change over time, there will *always* be needs. Disability is not a temporary condition and, makes no mistake; this is a disability quite unlike all others.

Intact families of adolescents and adults with FASD are a testament to the level of strength, resiliency and commitment these parents have to one another and to their children. A sad reality is that other families are intact, in many ways, only in that they continue to live together, because they feel they have no choice. Still others simply do not survive the experience. Regardless, all know and understand pain on a level most people would find intolerable. Denial, abandonment, anger, disbelief, hostility, victimization, grief; self blame; all are no stranger to the parent. And in the end, *each one* comes to the end of the road. There is no safety net.

And it is all so unnecessary. There may be, at the present time and in the lack of targeted and funded direct services to FASD, no way to prevent the level of difficulty many adolescents and adults experience. However, there is no excuse for the lack of support available to the family. Family support services of all kinds are readily available to those with other disabilities. They exist, and are funded, because they *are the right thing to do* and because they save society money. Support is the primary reason families are able to continue to (1) provide for the emotional needs of each other; (2) advocate for their child; (3) provide for financial needs of their child; and (4) continue to be involved on a positive, on-going basis in the lives of their children no matter where that child might be. Parents have also long since understood and accepted that the issues facing individuals with FASD are an unrealistic and unfair burden to impose on siblings now and after parental death. Where does that leave them; especially when one considers the health problems in many parents and that an early death is not unlikely? These are not minor concerns.

Support is a cost effective way to help families help their children, and the needs for these supports are known from infancy onward. Much of the information in this document is ‘old news’. Families, systems, and governments have known for at least the last 15 years that this is the case. This was well documented in the 1992 Health Canada report “*Report on the Symposium on Fetal Alcohol Syndrome and Fetal Alcohol Effects*” held in Vancouver, B.C., and very, very little has changed since that time. And while things remained ‘as is’ another generation of children with FASD became adolescents and adults. The Health Canada FAS/FAE Initiative “*National Synthesis Report*” of June 2000 reiterates this same information in even greater detail.

The results of legislative and policy inequities, the lack of system resources, bureaucratic denial and the subsequent, systemic punishment of parents/caregivers comes at a high cost to society. This denial of eligibility for and access to *essential* services has led to a widespread perception that individuals with FASD and their parents/families are somehow not deserving, not disabled and not worthy of our efforts. This is unconscionable.

Action for change:

There is an urgent need to continue to develop and fund family support services that can help to maintain or repair family systems that may be in addition to and separate from those already listed in previous sections of this document, by:

- ☐ Consulting widely with families to determine needs and most effective ways to meet them; this consultation process must seek out and be inclusive of all families in all areas of the province, urban, rural, remote and on-reserve; with specialized emphasis on the different needs of different types of families
- ☐ Development of a Standing FASD Consultation and Steering Group on Adolescent and Adult Issues to government which includes both highly skilled professionals in this area and parents as primary members, along with representatives from every ministry of government, with the authority to commit resources. This committee would be mandated to direct the development of services for those with FASD, and be accountable for them
- ☐ Formation of an Office of FASD similar to the Office of Service Equality for those with mental handicaps
- ☐ Formation of a new ministry specifically to deal with FASD, in which could be combined and nurtured the requisite knowledge, skills and abilities to make a difference; and where ‘all doors are the right door’
- ☐ Striking of a task force commission with the power to make binding recommendations for systemic change to accommodate those with FASD
- ☐ Development of a mechanism to maintain a very high profile on the issues of adolescents and adults with FASD and their families; and to focus this as an issue of *disability*, *basic human rights, equality, equity, dignity and respect*.

The development and funding of consultative processes that have the authority to direct monitor and evaluate changes specific to the support needs of adolescents and adults with FASD and in particular, their families should be considered as a primary broad risk management tool.

Summary

"You see a snapshot of my child – I live the movie."

FASD is a sustainability issue for society. No matter whom you are, where you live, what you do, what you think; FASD will touch your life. It is not a question of 'if'; only 'when'. It is common and very costly, both financially and in terms of human suffering. And while it is also preventable, we have miles to go before that is anything more than a glimmer on the horizon. It is so much easier to see alcohol abuse and alcoholism as character flaws rather than a disease process. It is so much easier to see FASD as bad behaviour by choice, the result of poor parenting. As long as society – and *we* are society – clings fast to these beliefs it will continue to encourage and participate in that "looming social tragedy of epidemic proportions unprecedented in Canadian history." Until society learns to resolve its love-hate relationship with alcohol, those who become addicted to it and those who become its victims, it will continue to ignore rather than treat, punish rather than support, and cast out rather than gather in.

This is the challenge to all of us: what is it going to take to get each and every one of us, the multiple systems and levels of government that we, in fact *employ*, and all parts of *our* society, mobilized, organized, able and willing to deal with this issue? To remove the *handicaps* that so negatively impact on the lives of those with FASD and their families. Not just talking about it, but actually doing what needs to be done in a comprehensive, targeted and meaningful way.

What will it take to allow the adults with FASD of today – and all the children who will become adults tomorrow - to live, partake, contribute, belong and enjoy life in the mainstream - in other words to have what the rest of the world takes for granted? To do anything less is unethical and unconscionable in any society that truly believes in equality.

> *If the misery of our poor be caused not by the laws of nature, but by our institutions, great is our sin.*
>
> *Charles Darwin*

Appendix A

Costs the family can expect to experience over time for an adult with FASD

Sources of income to meet costs:

An adult with FASD in B.C. has three legal sources of cash income he can access (with help) in the absence of employment or complete support from family. They are as follows

1. income assistance (welfare) of $500 per month
    a. must have lived away from, home for two years before one can apply
    b. can only be collected for two years out of every five
    c. there is a list of exceptions to the two year rule, none of which would readily apply to an individual with FASD
    d. has a lifetime limit
    e. any fraudulent conviction leads to lifetime disqualification
    f. no benefits of any sort with it
2. Persons with Persistent Multiple Barriers to Employment funding (PPMB) of $600 per month
    a. Primarily for those with alcohol and drug problems sufficient to prevent them working in the absence of effective treatment; those without *any* education; etc.
3. Persons with Disability funding (PWD) of $786 per month
    a. See previous discussions; for those considered to be unemployable; is subject to review every few years

b. Note: if living at home and paying room and board versus room rent; only the room and board amount is paid plus a small "comforts allowance"

Basic monthly costs of living for a single adult with FASD trying to live alone in a ***best case scenario*** are as follows:

Basic Item	**Receiving PWD**	**No PWD**
Rent – basement suite (cheapest accommodation)	$500.00	$500.00
Food, hygiene and household supplies (does not include laundromat cost); assumes can budget, shop; access to large grocery store; prepare and cook food	$200.00	$200.00
Utilities such as heat, light, cable (does not include internet or phone costs)	$100.00	$100.00
Medical premiums		Premium assistance available to those with limited income
Dental care (minimum amount possible to pay for check-up and cleaning yearly; no allowance for any other dental services)		$60.00 (averaged amount available to one on PWD)
Transportation (2 zone bus pass); does not include costs of 3 zone pass	$ 50.00 (averaged cost of replacement for lost passes and bus use in absence)	$120.00
Cell phone (cannot meet requirements for a landline)	$100.00	$100.00
Prescription medications (antidepressants, anti-anxiety, psychiatric)		$150.00 ***minimum***
Clothing and shoes (replacement of worn out, lost, destroyed, stolen items)	$100.00	$100.00
Haircut (male)	$ 15.00	$ 15.00
TOTAL COST PER MONTH	**$1,065.00 = MONTHLY DEFICIT OF $279**	**$1,345.00 = MONTHLY DEFICIT OF ???**

This assumes no other costs. In actuality, over the course of time, parents can expect to cover the costs of the following items, depending on the individual, the circumstances and situation of the moment:

ITEM	**COST ESTIMATE *PER INDIVIDUAL* TO FAMILY**
The overage from the above	$279.00 per month or $3,350 per year
Eye check-ups	$75.00 per year
Prescription medications not covered (all brand name, non generic; any anti-inflammatory, any sleeping medication; ***many*** antibiotics; most allergy sprays and medications	$800.00 per year
Non-prescription medications, melatonin, first aid supplies; antibiotic creams, cost of crutches, etc.	$600.00 per month
Physiotherapy, chiropractic, occupational therapy (limited to only 12 combined visits each year for ***all*** services outside doctor for PWD	$50.00 per visit after 12 PWD visits; could amount to $500.00 per month for any one service
Splints, orthotics, braces, eye glasses, (replacement costs; some initial costs due to limited coverage for PWD; all costs for others	$1,000 per year
Dental care for cavities, etc. over $700.00 PWD funding	$2,000.00 per year on average
Dental appliances and replacements (initial cost for appliance *may* be covered; approval process can take 6 months or longer)	$1,000 per year
Oral surgery (wisdom teeth)	$1,500.00 and up
All anesthetic costs for any outpatient surgery	$300.00 per occasion
Birth control	$ Variable, some covered – some not.
Mental health therapy utilizing a skilled therapist knowledgeable about FASD	$140.00 per hour; some may be coved under Residential Historical Abuse Program funding or Criminal Injuries Program (about 50%); best estimate per month is between $$280 and $560.00 per month, with crisis intervention costs ranging much higher. ***Note:*** most individuals with FASD receive no funding under RHAP or CICP
Food supplements that may be essential to health; PWD may provide $40/month with prescription; time limited	Between $480 and $1,000 per year for most; occasionally ranges as high as $1800
Cost of diagnosis (if required)	$4,000.000 one time cost
Cost of medical forms	$25.00 per form per occasion plus cost of the office visit

ITEM	COST ESTIMATE *PER INDIVIDUAL* TO FAMILY
Assessments (non PWD)	$1,000.00 per occasion and up
Cost of PWD assessments and paperwork	$250.00 to $1,000.00 each re-assessment
Damage deposits (rarely, if ever, recovered; will only be provided once by MCFD; after that, they are deduct from monthly cheque)	$250.00 per occasion on average
Utility hookups	$ 150.00 per occasion
Cleaning costs	Highly variable; depending on state, and who does the cleaning; likely about $150.00 per occasion; can be much higher
Repairs (minor)	$ 50.00 - $75.00 not including labour provided by family, per occasion
Repairs (major) – electricians, plumbers, etc.	$ 250.00 per occasion
Laundry costs (laundromat)	$ 240.00 per year
Costs of moving, including eviction costs	$ 300.00 - $400.00 per occasion
Replacement of damaged, lost, stolen goods/equipment, for individual and others	$ 750.00 per year
Insurance rider costs	$ 100.00 per year
Capital costs of furniture (used, from family, etc.)	$1,000.00 to set up
Capital costs of household goods	$2,500.00 to set up
Long distance phone calls to/from parents/adult; to other agencies, companies, etc. to deal with events	$ 600.00 per year
Replacement costs for ID, bus passes, etc.	$ 200.00 per year
Legal fees (as defendant; as victim); legal aid defense will almost certainly end in jail time	$3,500.00 per occasion for lawyer, supposes limited court time and offense; serious crime would be much higher and likely out of reach of all families at all times
Fines, tickets (may also have used the name of another leading to fines in their names)	$ 500.00 per year
Prison visit and support costs (mileage, cost of babysitter in the home, meals, money for prison canteen account, etc.)	$1,000.00 per year – highly dependent on location of prison, number of visits, etc. Could be much higher
Court costs; transcripts, etc	$ 250.00 per year
Transportation costs associated with legal situations	$ 250.00 per year
In-home supervision (bail, probation, house arrest conditions) – allows for 10 hours a week paid time at $10/hour to allow parent to leave the home	$ 400.00 per month on average – depending on length of conditions, could be about $5,000.00 per year cost to keep an adult out of jail (parents do shift work to avoid)
ICBC imposed sanctions	$ 750 - $5,000.00 depending on circumstances

ITEM	**COST ESTIMATE *PER INDIVIDUAL* TO FAMILY**
Cost of notarized documents	$ 25.00 per occasion
Handi-dart (door-to-door transportation for disabled adults unable to use bus service for a number of reasons; many with FASD would qualify)	$ 1,200.00 per year for one return trip daily Monday to Friday
Portion of vehicle costs required to continue to be accessible 24/7; insurance, maintenance, repairs	$1,200.00 per year – assumes vehicle is paid for
Cost of driving adult to and from to provide supervision/avoid problems – mileage	$1,200.00 per year
Parking (miscellaneous – meters, lots, etc., for therapy, AA meetings, appts., etc.)	$ 750.00 per year
Financial "bailouts" (credit cards, finance company loans, lines of credit, bills, fraud, possible drug debts)	Highly variable; highly expensive; usually not done; sometimes has to be
Costs of airfares, bus tickets, hotels, meals, taxis, etc. to reclaim adult kids	$1,000.00 per year on average
Cost of meals for adult on street	$ 600.00 per year
Cost of returning belongings from one location to another	$ 150.00 per year
Costs associated with illness/injury in child requiring parent to attend another city, etc.	$3,000.00 and up per occasion, depending on location (high cost airfares; short notice; plus hotels and meals)
Cigarettes	$ 600.00 per year
Recreation passes	$ 100.00 per year
Entertainment	$ 500.00 per year
Cost of accessing treatment (finding it, getting a person there, etc.)	$ 500.00 and up per occasion, depending on lost time from work, travel, location, etc.
Adult vocational services	$1,000.00 per year adult basic education
Vocational rehabilitation services	$1,000.00 and up per occasion
Vocational training courses	$3,000.00 per year and up
Employment supports (special shoes, clothing, tools, etc.)	$ 500.00 and up depending on job needs; per job placement
Cost of time spent educating employers, providing supports to them, etc.	Dependent on amount of time parent must take to do this
Clothing and shoes (additional); includes cost of having to re-outfit	$1,000.00 per year
Food	$1,000.00 per year
Personal care	$ 250.00 per year

ITEM	**COST ESTIMATE *PER INDIVIDUAL* TO FAMILY**
Gifts	$ 200.00 per year
Support to grandchildren's costs	Usually substantial costs depending on where the child is being raised; likely minimum amount is about $5,000.00 per year
Replacement of cell phones	$ 100.00 per occasion
Paid one-to-one worker	$4,800.00 per year – 5 hours per week at $20/hour
Respite care	Rarely ever due to lack of funds; would cost in neighbourhood of $150.00 per day and up

References

Aronson, Jane M.D. (1997); *Prevalence of FAS and FAE in Pre-Adoptive Evaluations of Children in Russian Orphanages;* *Adoption & Prenatal Alcohol and Drug Exposure; Research, Policy and Practice 2000*

Burd, Selfridge, Klug, Juelson *Fetal Alcohol Syndrome in the Canadian Corrections System; Journal of FAS International, September, 2003;);*

Burd, Martsolf and Juelson *Fetal Alcohol Spectrum Disorder in the Corrections System: Potential Screening Strategies; Journal of FAS International, February 2004*

(Burd, Klug, Hoesel, Moum (2001). *Development of a Comprehensive Cost Capture for Children with Severe Emotional Disorders; 13th Annual Research Conference Proceedings: A System of Care for Children's Mental Health: Expanding the Research base;* University of South Florida

Cadoret and Riggins-Caspers (2000), *Fetal Alcohol Exposure and Adult Psychopathology: Evidence from an Adoption Study;* Adoption & Prenatal Alcohol and Drug Exposure, Chapter 4

Carmichael-Olson, Morse and Huffine (1998), *Development and Psychopathology: Fetal Alcohol Syndrome and Related Conditions; Seminars in Clinical Neuropsychiatry, v 3: 4*

Clark, E. (2003), *Community Integration and Independence among Adults with Fetal Alcohol Spectrum Disorder in British Columbia, Dept. of Community Health and Epidemiology, Queen's University*

Coles (2001), *Fetal Alcohol Exposure and Attention: Moving Beyond ADHD,* Alcohol Research & Health, The Journal of the National Institute on Alcohol Abuse and Alcoholism, v 2: 3

Cost of Fetal Alcohol Spectrum Disorders; American Journal of Medical Genetics Part C (Seminars in Medial Genetics); Volume 127C; 2004

Famey, et al (1998), *Mental Illness in Adults with Fetal Alcohol Syndrome or Fetal Alcohol Effects;* American Journal of Psychiatry, v. 144: 4

FASD Fact Sheet, FASD Center for Excellence, Substance Abuse and Mental Health Services Administration, US Department of Health, 2003

Fetal Alcohol Syndrome/Fetal Alcohol Effects Legal Resource Center, Fetal Alcohol and Drug Unit, University of Washington School of Medicine and University of Washington School of Law, July 2003. http://depts.washington.edu/fadu/

G. Reid Lyon, Ph.D. and Norman A. Krasnegor, Ph.D. (eds). *Attention, Memory and Executive Function,* Human Learning and Behavior. Branch of the National Institute of Child Health and Human Development in the United States

Fayez, I., (2003) Fetal Alcohol Syndrome – the South African Nightmare; Journal of FAS International

Health Canada FAS/FAE Initiative National Synthesis Report; Health Canada, 2001

Kerns et al. (1997); *Cognitive Deficits in Non-retarded Adults with Fetal Alcohol Syndrome;* Journal of Learning Disabilities, v 30:6

Lohr and Bracha (1989) *Can Schizophrenia be Related to Prenatal Exposure to Alcohol? Some Speculations;* Schizophrenia Bulletin; v 15: 4

Lohr and Bracha (1978) *Fetal Alcohol Damage and Schizophrenia; Journal of clinical Psychiatry; v 39: 10)*

May and Gossage (2001), *Estimating the Prevalence of Fetal Alcohol Syndrome,* Alcohol Research & Health, The Journal of the National Institute on Alcohol Abuse and Alcoholism, v. 25:3;

Ministry of Children and Families Development, Adoption Education Programs Information to Prospective Adoptive Parents, Province of B.C.

O'Connor et al (2002), *Psychiatric Illness in a Clinical Sample of Children with Prenatal Alcohol Exposure;* American Journal of Drug and Alcohol Abuse, v 28: 4

O'Connor and Kasari (2000), *Prenatal Alcohol Exposure and Depressive Features in Children;* Alcoholism: Clinical & Experimental Research, v. 24: 7

O'Malley and Nanson (2001), *Clinical Implications of a Link Between Fetal Alcohol Spectrum Disorder and Attention Deficit Hyperactivity Disorder,* Canadian Journal of Psychiatry, v. 47:4)

Population data for Canada, Stats Canada CANSIM II Table 051-0001. **http://www.statcan.ca/english/Pgdb/demo10a.htm**

Population data for B.C., Stats Canada CANSIM II Table 051-0001. **http://www.statcan.ca/english/Pgdb/demo31a.htm**

Robinson, Conry, and Conry (1988) *Clinical Profile and Prevalence of Fetal Alcohol Syndrome in an isolated community in British Columbia,* Canadian Medial Association Journal.

Russell (2003) *IQ – It Just Doesn't Matter: the Role of Adaptive Functioning in Individuals with FAS/FAE/ARND,* presented at the National FASD Conference Syllabus, "Doing What Works", Vancouver 2003).

Rutman, LaBerge and Wheway (2002), *Adults Living with FAS/E: Experiences and Support Issues in British Columbia; FAS/E Support Network of B.C.*

Sampson, et al. (1997)*; Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol Related Neurodevelopmental Disorder,* Teratology

Smith, Molina and Pelham (2002), *The Clinically Meaningful Link Between Alcohol Use and Attention Deficit Hyperactive Disorder;* Alcohol Research & Health, The Journal of the National Institute on Alcohol Abuse and Alcoholism, v 26:2

Steinhausen, Willms and Spohr (1993); *Long-Term Psychopathological and Cognitive Outcomes of Children with Fetal Alcohol Syndrome;* Journal of American Academy of Child and Adolescent Psychiatry, v 32: 5

Steinhausen, Nestler and Spohr (1982); *Development of Psychopathology of Children with the Fetal Alcohol Syndrome;* Developmental and Behavioural Pediatrics; v 3: 2

Streissguth, Barr, Kogan and Bookstein (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE);* Centers for Disease Control and Prevention Grant No. RO4/CCR00851.

Williams, Obaido and McGee (1999) , *Incidence of Fetal Alcohol Syndrome in Northeastern Manitoba* Journal of Public Health.