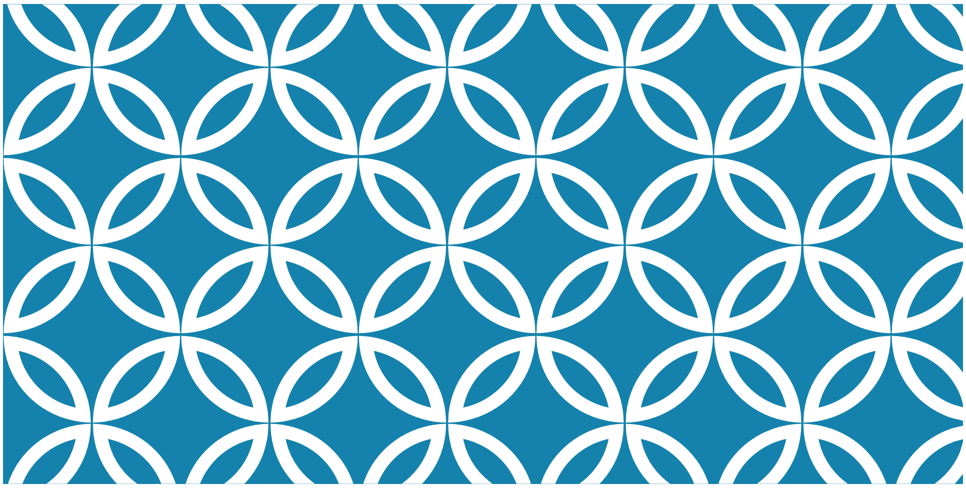

BEFORE, DURING AND AFTER: GETTING THE MOST OUT OF ASSESSMENT

Allison Pooley
Executive Director
The Asante Centre

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Referral streams

Mentorship and consultation

Speech-language and occupational therapy

Education and training

Resource development

Research

Primary care

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WHY DIAGNOSE?

ADDRESSING YOUR PRECONCEPTIONS

Who says FASD needs to have a stigma?

Who believes a diagnosis is a label?

Who says service eligibility is the primary reason to get an assessment?

Who believes service connection will make everything better?

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REFERRAL

Where is the best fit for referral?

- Stream/agency?
- Assessment type? (e.g. FASD/CCY/ASD/Psych)

What is the family's readiness?

- Encourage proactivity
- "Hardest, and best thing I've done for my kid."

How old is the child/youth, and what has already been done in the community?

Remember: Assessment is not a diagnosis!

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PREPARING THE CHILD/YOUTH

What do they already know?

What pre-conceptions do they have?

Who is their safest person/people?

Are you using consistent language to explain?

Are you listening to their needs? Allowing space for concerns?

How will they hear the results and from who?

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FIRST APPOINTMENT

Reduce anxiety through familiarity and normalizing (e.g. Environment, clinicians, reason for being there)

Use common language across caregivers/guardians, child/youth, clinicians

- E.g. What does the child/youth call the caregiver? What can they expect to happen (e.g. testing vs. activities vs. games)? What will they learn?

Best: sleep, breakfast, medications, supports

Ask questions

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WHAT DO THE APPOINTMENTS LOOK LIKE?

Psychology

Medical

Speech-language

Occupational therapy

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ADAPTIVE FUNCTIONING

Critical for service eligibility

Prepare the caregiver

Given a form? Do together! Give examples.

What is the understanding of the psychologist, and the informant?

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FAMILY CONFERENCE

Prepare for grief, processing, and fallout

Come prepared with questions

Take notes for family to refer back to

Offer recommendations for care planning

Think about who should receive a report

Can clinicians fill out service eligibility forms (e.g. CLBC, PWD, DTC)

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SELF-CARE

You did not cause the concerns, and you cannot fix them. Period.

Be as passionate about "small" wins for yourself as you are for your clients.

Families will always need more of you than you can give. Boundaries are your source of sanity.

Encourage community connections. Be a safety pin, not a crutch.

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FOLLOW-UP

Prioritize recommendations e.g. health care needs, urgent vs. important

Start applications for service eligibility to build your team

Create a quick reference sheet with the family to hand out to supports?

Visualize strengths and areas for growth

Call a case manager when questions arise

Learn and teach about percentiles and brain domains; help individualize them

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TO SHARE OR NOT TO SHARE?

Questions and Considerations around Sharing the Assessment Results/Diagnosis with the Client

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SHOULD IT BE SHARED?

Why share the results/diagnosis with the client?

- Advantages/disadvantages

Why might the client be hesitant to hear the results/diagnosis?

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AT WHAT AGE?

Which clients is it appropriate to share the results/diagnosis with (chronological vs. developmental age)?

What are the differences between children, youth and adults?

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WHAT SHOULD BE SHARED?

Specific diagnoses?

Recommendations?

Strengths/weaknesses?

Family/social information?

In what detail, and at what age?

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WHO SHOULD SHARE?

Parents/caregivers?

Diagnostic team?

Group/individual?

Should the client be part of the Family Conference, and if so, in what instances?

Who should hear the information first?

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HOW SHOULD IT BE SHARED?

Verbally/visually?

Timing?

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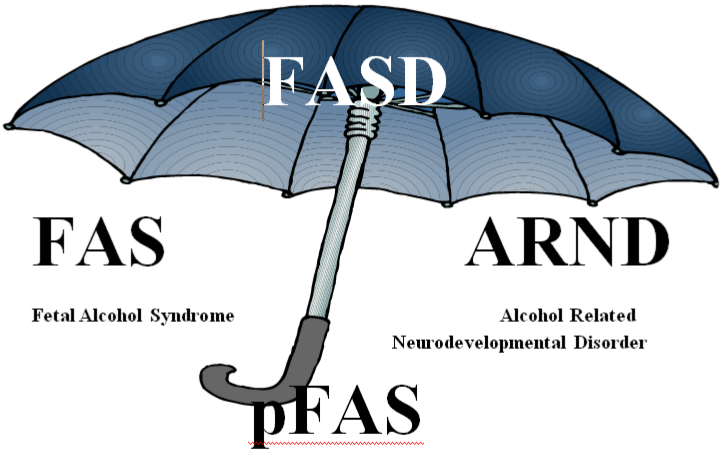

FASD

FAS

Fetal Alcohol Syndrome

ARND

Alcohol Related
Neurodevelopmental Disorder

pFAS

Partial Fetal Alcohol Syndrome

Dr. Julianne Conry

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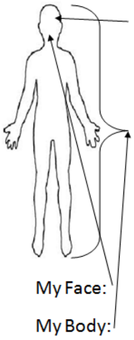
My Assessment:



My Brain

What I am good at:

What is hard for me:

What helps:

My Face:

My Body:

My Diagnosis:

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My Brain:

What I am good at:

What is hard for me:

What can help:

My Diagnosis:

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THIS IS ME: MY LIFE BOOK

Record of personal views, likes and dislikes told in their own words and illustrated with drawings and clip art. Youth are encouraged to describe what makes them angry and what helps to calm them down. Typical chapters titles are: what I want people to know about me; my learning style; my goals and plans; my circle of support; and what helps me have a good sleep.

“Creating the book helps someone living with FASD understand themselves, make sense of the world around them, and communicate effectively with other people,” says Deidre Bissonnette.

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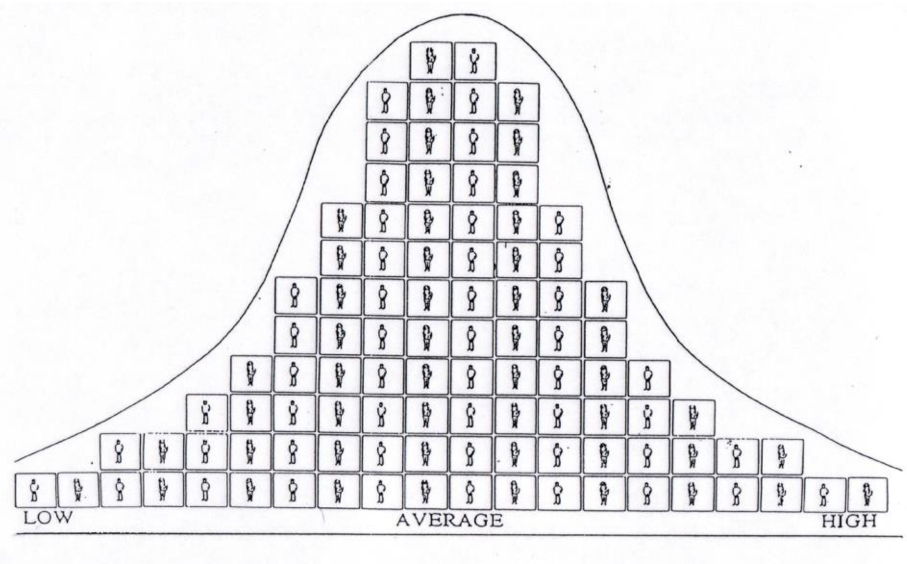

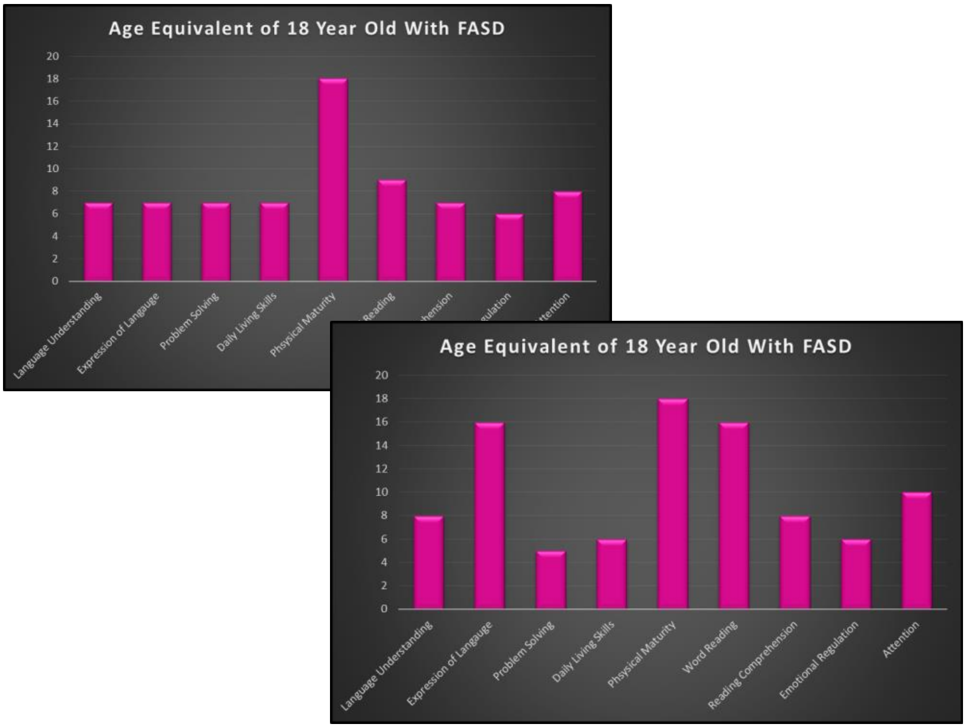

SOME POINTS TO REMEMBER

Confirm with the caregivers regarding how best to provide the results and who would be the best person to do this

Be honest and concise – more concrete, less abstract

Strengths based is crucial

Consider providing visual and written feedback to help the individuals process

Consider the client's communication abilities, personal maturity, emotional stability/regulation, family dynamics and support system

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NAVIGATING DIAGNOSIS AND SYSTEMS:
UNDERSTANDING THE LIVED EXPERIENCE OF PEOPLE WITH FASD

Presentation:

- Allison Pooley, Asante Centre
- Dr. Michelle Stewart, University of Regina
- Paul Gordon, PLEA
- with Alexandra Johnson, University of Regina

ON DIAGNOSIS AND GRIEF

“Understand that they may not be able to accomplish exactly what they dreamed of accomplishing….they’re going to be in grief, and I think that they have the right to be in grief.”

DRAX – GUARDIANS OF THE GALAXY

SUPPORTS BEFORE & AFTER DIAGNOSIS:

“I wish you guys had like the stuff on the continued counseling for a minimum of a year based on your … assessment, because things will come up, things will happen, and they may seek out the wrong path instead of having the right choices in front of them.”

+

“Counseling sessions to start before you even do the assessment … like there needs to be counseling after and before.”

FOSTERING COMMUNITY/BREAKING BARRIERS

“If I can help somebody by telling my story by admitting that I have FASD, maybe that will help somebody break through their barriers.”

+

“It’s a support that I would say is something that only people with FASD can kind of understand. For me, walking into a room with twenty other individuals who have FASD [...] it’s just kind of like, I can completely let my guard down because everybody in this room knows exactly what I’m going through and so to, you know, for someone to have that, I think would also be really good, you know.”

AREAS FOR NEW RESEARCH & ADVOCACY

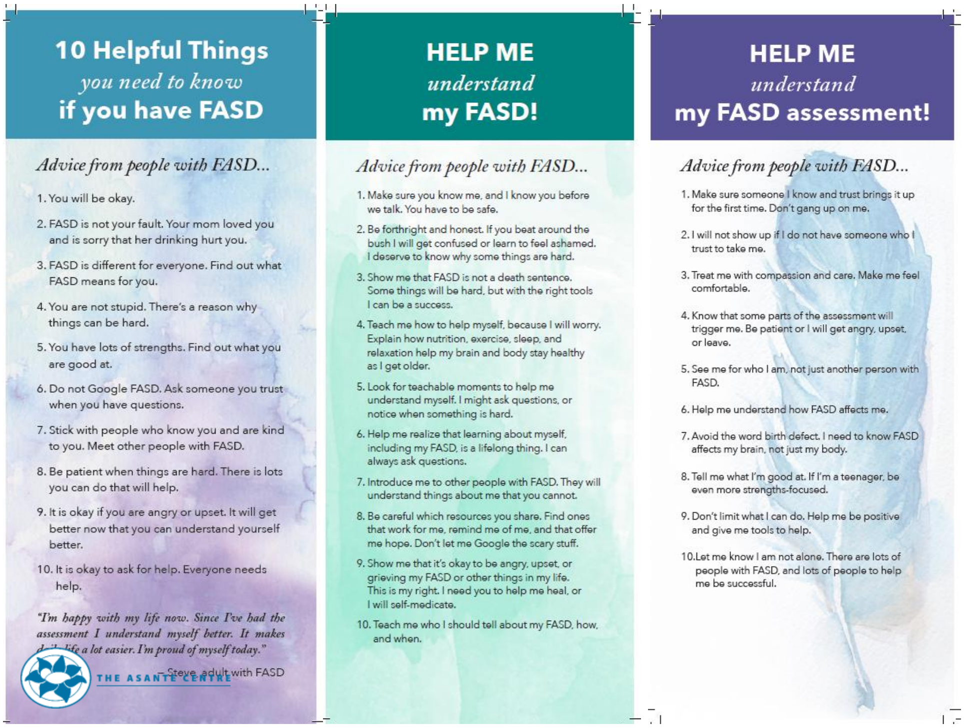
“I’m kind of wondering what the future holds in terms of how is this going to effect me when I am older…Who’s going to be there in terms of helping me and what is that going to look like.”

+

“What happens when I retire?”

+

“…those are the two big ones, I think, right? Is credit cards but [also] phones, right?”



10 Helpful Things *you need to know* if you have FASD

Advice from people with FASD...

1. You will be okay.
2. FASD is not your fault. Your mom loved you and is sorry that her drinking hurt you.
3. FASD is different for everyone. Find out what FASD means for you.
4. You are not stupid. There's a reason why things can be hard.
5. You have lots of strengths. Find out what you are good at.
6. Do not Google FASD. Ask someone you trust when you have questions.
7. Stick with people who know you and are kind to you. Meet other people with FASD.
8. Be patient when things are hard. There is lots you can do that will help.
9. It is okay if you are angry or upset. It will get better now that you can understand yourself better.
10. It is okay to ask for help. Everyone needs help.

"I'm happy with my life now. Since I've had the assessment I understand myself better. It makes daily life a lot easier. I'm proud of myself today."

– Steve, adult with FASD

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HELP ME *understand* my FASD!

Advice from people with FASD...

1. Make sure you know me, and I know you before we talk. You have to be safe.
2. Be forthright and honest. If you beat around the bush I will get confused or learn to feel ashamed. I deserve to know why some things are hard.
3. Show me that FASD is not a death sentence. Some things will be hard, but with the right tools I can be a success.
4. Teach me how to help myself, because I will worry. Explain how nutrition, exercise, sleep, and relaxation help my brain and body stay healthy as I get older.
5. Look for teachable moments to help me understand myself. I might ask questions, or notice when something is hard.
6. Help me realize that learning about myself, including my FASD, is a lifelong thing. I can always ask questions.
7. Introduce me to other people with FASD. They will understand things about me that you cannot.
8. Be careful which resources you share. Find ones that work for me, remind me of me, and that offer me hope. Don't let me Google the scary stuff.
9. Show me that it's okay to be angry, upset, or grieving my FASD or other things in my life. This is my right. I need you to help me heal, or I will self-medicate.
10. Teach me who I should tell about my FASD, how, and when.

HELP ME *understand* my FASD assessment!

Advice from people with FASD...

1. Make sure someone I know and trust brings it up for the first time. Don't gang up on me.
2. I will not show up if I do not have someone who I trust to take me.
3. Treat me with compassion and care. Make me feel comfortable.
4. Know that some parts of the assessment will trigger me. Be patient or I will get angry, upset, or leave.
5. See me for who I am, not just another person with FASD.
6. Help me understand how FASD affects me.
7. Avoid the word birth defect. I need to know FASD affects my brain, not just my body.
8. Tell me what I'm good at. If I'm a teenager, be even more strengths-focused.
9. Don't limit what I can do. Help me be positive and give me tools to help.
10. Let me know I am not alone. There are lots of people with FASD, and lots of people to help me be successful.

EXTRA SLIDES FOR REFERENCE

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2015 CANADIAN GUIDELINES

Terminology

New designation

Change to brain domains

New brain domain

Relation to DSM

2015 CANADIAN GUIDELINES

The FASD: A Guideline for Diagnosis Across the Lifespan were published in Dec 2015 (www.cmaj.ca, prev. Version 2005)

Rationale:

- Target diagnostic guidelines for young children and adults
- Simplify terminology of diagnoses
- Redistribute findings of brain domains' testing to prevent double-counting same areas of challenge

NEW TERMINOLOGY

Fetal alcohol spectrum disorder (FASD) with sentinel facial findings

- Person exhibits classic manifestation of FAS facial characteristics (i.e. smooth philtrum, short paplebral fissures, and thin upper lip)
- Growth delay is removed as a criterion (i.e. Previously sentinel “physical” findings, now simply “facial”
- Alcohol exposure is confirmed or unconfirmed (due to evidence of exposure from facial characteristics)

Fetal alcohol spectrum disorder (FASD) with no sentinel facial findings

- Person has absent or mild facial characteristics of FAS
- Alcohol exposure is confirmed

Both diagnoses indicate the same level of brain dysfunction

- At least three areas of impairment in neurodevelopmental domains; scoring criteria remain unchanged from 2005
- OR microcephaly in infants/young children

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NEW TERMINOLOGY CONTINUED

*At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure

- A **designation** (not a diagnosis)
- Designed for young children who have confirmed prenatal alcohol exposure, but do not yet have sufficient evidence of brain dysfunction to warrant a diagnosis
- Designated infants/children should have a re-assessment as they get older to confirm or rule out an FASD diagnosis

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THE EVOLUTION OF TERMINOLOGY

The Face	***The Brain***	*The Body*
Fetal alcohol syndrome (FAS)	Fetal Alcohol Spectrum Disorder (FASD)	Fetal alcohol spectrum disorder with sentinel facial findings
Fetal alcohol effects (FAE)	Fetal alcohol syndrome (FAS)	Fetal alcohol spectrum disorder with no sentinel facial findings
	Partial fetal alcohol syndrome (pFAS)	*At risk of FASD
	Alcohol related neurodevelopmental disorder (ARND)	

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CHANGES TO BRAIN DOMAINS

Old	New
Hard and soft neurological signs	Motor skills (sensory integration removed)
Brain structure	Neuroanatomy/ neurophysiology
Communication	Language
Attention deficit/ hyperactivity	Attention
N/A	Affect regulation (includes depression, anxiety, mood dysregulation) – new domain

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CONSISTENT BRAIN DOMAINS

Memory

Executive function (includes impulse control and hyperactivity)

- While the term is consistent, executive function has been redefined to better differentiate it from attention

Academic achievement

Adaptive behaviour, social skills, or social communication

Cognition

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