

Best Practice Research – Canada FASD Research Network

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Linking research and practice: stronger together

- Canada FASD research network
- Family Advisory Committee
- What have we learned about caregivers?
- What have we learned about intervention?
- Why do we need to work together?

Canada Northwest FASD Partnership

- An alliance of four western provinces and three northern territories
- Focus on inter-jurisdictional approaches to:
 - diagnosis, prevention, intervention and care and support of individuals who are affected by FASD

CanFASD Research Network

- Canada's first comprehensive national FASD research network
- Network focuses on generating research evidence helpful in improving outcomes
- Recognized the need for including the voice of individuals with FASD and their caregivers

CanFASD Family Advisory Committee

The Mission of the Family Advisory Committee is to:

- Advise on research priorities for families impacted by FASD; and
- assist in translating results of research to ensure they are accessible to families.

(2014)



Why is Family Involvement in Research Important?

To support the FASD community we need to close the gap between researchers,

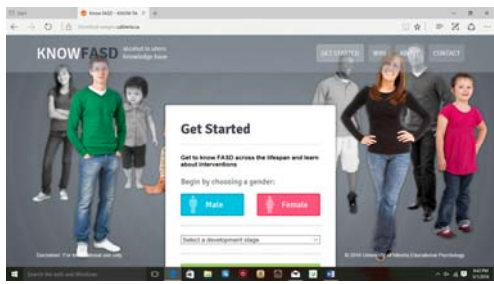
service providers, individuals and families living with FASD.



Finding FASD Research



Reliable Sources of FASD research Information



WWW.CanFASD.CA

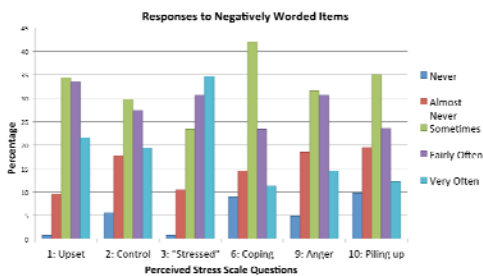


CanFASD Issue Papers

- Breastfeeding and FASD
- Caregiver Needs and Stress in Caring for Individuals with Fetal Alcohol Spectrum Disorder: Lay Summary
- Computer Game Interventions for Individuals with FASD
- Dose-response effect of alcohol consumption during pregnancy and prenatal alcohol exposure: A brief review
- Employment and FASD: Strategies for Success
- FASD & Employment Report, April 2016
- FASD and the Criminal Justice System
- FASD, Stress and Mental Health
- Meconium Screening for FASD in Pregnancy
- Nutritional Supplementation and FASD
- Prevention of FASD: A multi-level model
- Social and Economic Cost of FASD
- Stigma, Discrimination and FASD
- Warning Labels
- Why is FASD diagnosis important?

CAREGIVERS NEEDS

A lifespan approach: considering caregiver needs



Bobbitt, S., Baugh, L., Andrew, G., Cook, J., Green, C., Pei, J., Rasmussen, C. (2016)

Considering Caregiver Needs

- Caregivers reported:
 - many **needs and concerns** in caring for an individual with FASD
 - Highest needs among caregivers with **adolescents and adults**
 - more positive ratings on their 'experience of caregiving'
 - high levels of **stress**, which was highly correlated with many areas of need and concern
- These results have important **policy implications** for informing areas of need to be targeted with supports and services
- Efforts should be made to reduce caregiver stress and needs/concerns, which may improve well-being

FROM UNDERSTANDING TO INTERVENING....

The value of caregivers (Zarnegar, Hambrick, Perry, Azem, Peterson, 2016)

- Intervention with children with prenatal alcohol exposure and maltreatment experiences
- Using:
 - **Child-Parent Psychotherapy** is relationship-focused, reflective, and developmentally oriented
 - **Mindful Parenting Education** aims to
 - **improve caregivers' understanding** of the regulatory challenges of their adopted children with FASD
 - **while reducing stress** through promoting caregiver attainment of self-regulation, parenting skills, and their sense of parental self-efficacy.

The value of caregivers (Zarnegar, Hambrick, Perry, Azen, Peterson, 2016)

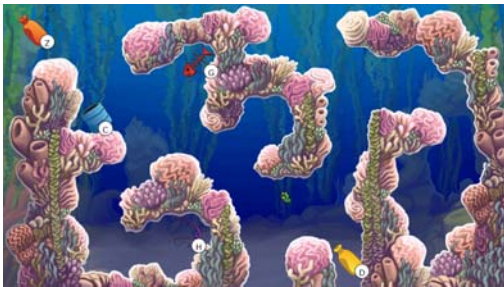
- Children's **functioning significantly improved** in several developmental domains.
- Parents' **general distress and their distress regarding the parent-child interaction decreased**.



Core intervention research themes:

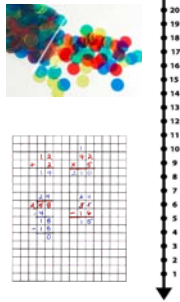
- Change can occur: evidence for both individualized approaches and support systems
 - Individualized approaches
 - Support Systems – the power of relationship
- Adopting a growth mindset

Practice plus strategies



The MILE Program: Strategy evolution

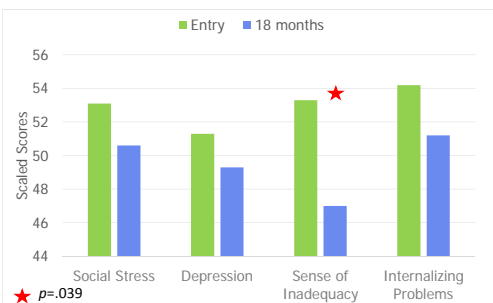
- Remediate underlying cognitive factors
 - General learning ability**
 - Slower pace of instruction
 - Active learning
 - Touch, talk, experiment
 - Working memory**
 - Small pieces of info
 - Rhymes/songs
 - Cues
 - Repetition/practice
 - Time for recall
 - Visual-spatial skills**
 - Tactile objects/manipulatives
 - Guide visual attention
 - Add structure to paper
 - Vertical number line



The value of relationship

- Nesting direct interventions with system level supports can both equip and support individuals with FASD

Mentoring approaches have impact!



The importance of Mindsets



- **Mindsets:** people's beliefs about human abilities and characteristics.
- Just change the way you think!

The Benefits of Growth Mindsets

- Overcoming Obstacles
- Increased Effort
- Higher Expectations (of others)
- Confronting Challenges
- Persistence
- Motivation

Imagine the benefits of growth mindsets for
AND towards individuals with FASD

Perspective matters (Petrenko, Pandolfino, Roddenbery, 2016)

- Caregivers who viewed their children's misbehavior as relating to their disabilities used strategies to prevent misbehavior and were generally **more successful in managing behavior**.
- Caregivers that reported a primary reliance on punishments tended to be **less successful** in managing behavior, and described feeling **more frustrated**.
- Targeting **caregiver attributions of behavior and related parenting practices** may:
 - reduce child behavior problems,
 - increase parenting sense of competence,
 - and improve family functioning



WORKING TOGETHER

we need to work together

Caregivers, researchers, individuals with FASD, service providers and policy makers need to work together to improve outcomes for individuals with FASD.



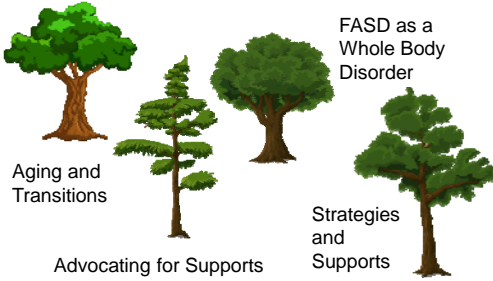
FASD Research: Learning Together is an example of such collaborative model.

FASD Research: Learning Together Workshop — Regina, August 2016



60 participants attended two day workshop

FASD Research: Learning Together Workshop -- Regina, August 2016



Working together

- The reciprocity between researchers and families: we need to work together!
- Why?
 - Making meaning
 - Optimizing approaches
 - Avoiding harm
 - Getting information to the people who need it
 - Enhancing social policy

In short: helping make the lives of those living with FASD better

The whole is greater than the sum of the parts

- When we work together we are strongest
- Ideal when we share:
 - Understandings
 - Mindsets
 - Goals
 - Priorities
 - Knowledge - both empirical and experiential
 - Respect

So what can you do?

- Become aware of sources of empirically based FASD Research like www.canfasd.ca
- Provide resource material to those you support
- Encourage individuals with FASD and their caregivers to participate in FASD research
- Be curious and share your curiosity
- Don't hesitate to share your questions



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