

“THE KNOWLEDGE JUST HAS TO GET OUT THERE”: PARENTS’ REFLECTIONS ON AWARENESS OF FASD IN ONTARIO

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FAMILIES RAISING CHILDREN WITH FASD

- Caregiver stress of raising a child with FASD may be different from that of other developmental disabilities
- More rewarding and more difficult
- Importance of the lived experience
- Lack of knowledge of the disability
 - Insufficient knowledge by health professionals and service providers
 - Awareness and understanding of FASD remain low

KNOWLEDGE AND AWARENESS OF FASD

- Mixed results regarding level of knowledge of FASD amongst health care providers
- Despite the Public Health Agency of Canada's framework for action, awareness of FASD still remains low in the general population
- Barriers in getting help from support networks, medical and mental health professionals, schools, government agencies, and community organizations

THEORY AND METHODOLOGY

METHODS

■ Mixed Methods Design

■ Qualitative Interviews

- Basic Interpretive Inquiry (Merriam, 2002, 2009)

■ Questionnaires

- Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995)
- Family Crisis Oriented Personal Scales (F-COPES; McCubbin, Olson, & Larsen, 1991)
- Family Resource Scale (FRS; Dunst & Leet, 1986)
- Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988)
- Questionnaire on Resources and Stress – Friedrich's Short Form (QRS-F; Friedrich, Greenberg, & Crnic, 1983)
- The Hope Scale (Snyder et al., 1991)
- The Child Behavior Checklist (CBCL; Achenbach, 1991, 2000)

RESEARCH QUESTIONS

- Primary research questions informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1998)
 1. What is the lived experience of raising a child with FASD in Ontario, Canada?
 2. What are the factors that facilitate and *hinder* successful family adaptation?

PARTICIPANTS

- Participants are from across Ontario, Canada and have at least one child diagnosed with or suspected of having FASD
- Mothers $N=58$
 - (12 biological, 2 step-parent, 39 adoptive, 5 foster)
- Fathers $N=26$
 - (4 biological, 3 step-parent, 16 adoptive, 3 foster)



RESULTS

“THE KNOWLEDGE JUST HAS TO GET OUT THERE”: KNOWLEDGE AND AWARENESS OF FASD IN ONTARIO

- **“Doctors and Nurses and Teachers All Need to Be Educated”**
 - More Training For Professionals
- **“When People Understand, Their Attitudes Change”**
 - More Knowledge and Awareness of FASD
- **“They’re Better Out West...Ontario’s About the Slowest Province”**
 - Lack of Perceived Support in Ontario

“DOCTORS AND NURSES AND TEACHERS ALL NEED TO BE EDUCATED”: MORE TRAINING FOR PROFESSIONALS

Both my girls have fetal alcohol. I listened to what the doctor said, I never drank, the doctor said have a drink each night, it'll help the baby sleep and you'll get a better sleep. So I produced two fetal alcohol children. Those two have produced eleven fetal alcohol children.

**- Adrianna,
*biological grandmother to four children with FASD***

“DOCTORS AND NURSES AND TEACHERS ALL NEED TO BE EDUCATED”: MORE TRAINING FOR PROFESSIONALS

Teachers really didn't have any understanding of FAS and issues around that. He was...smoking dope, he was defiant, to say he was...threatening me with sharp objects...I mean, I talked to the principal, I talked to the teacher...I put together...an “Alexander operating manual” with information about FAS. I mean the teacher just thought he was being lazy and a goofball. They truly, truly didn't get it.

**- Robyn,
step-grandmother to one son with FASD**

RECOMMENDATIONS FROM PARENTS

Doctors and nurses and teachers all need to be educated. And even if they think they don't need to be educated, they need to be re-educated. And that's such a big deficit. *Such a big deficit.*

- Stacey,
adoptive mother to one son with FASD

“WHEN PEOPLE UNDERSTAND, THEIR ATTITUDES CHANGE”: MORE KNOWLEDGE AND AWARENESS OF FASD

- **Lack of knowledge and understanding of FASD from those in the general public**
- **Families discussed feeling isolated and unsupported**
- **Expressed feeling judged by those in their communities**
- **Subthemes:**
 - **“Education is what it boils down to”: The need for education about FASD**
 - **“FASD is the white elephant”: A call for awareness**

“EDUCATION IS WHAT IT BOILS DOWN TO”: THE NEED FOR EDUCATION ABOUT FASD

I want changes and these kids deserve that...You know, the awareness and prevention and all that. Like my friends, they didn't know. They all have kids, they were pregnant...Nobody knows about FAS. “What's FASD?” And these are all mothers!

**- Kristen,
adoptive mother to two children with FASD**

“EDUCATION IS WHAT IT BOILS DOWN TO”: THE NEED FOR EDUCATION ABOUT FASD

She looks normal. You expect her to be normal.

**- Mandy & Joseph,
adoptive parents to one daughter with FASD**

RECOMMENDATIONS FROM PARENTS

A lot of my issues with FAS come from society in general. People need to stop judging those who made a mistake and drank when pregnant, as people that are horrible. They need to realize that drinking's an addiction; nobody sets out to harm their child. It's just the way it is and instead of judging them, offer them help...I see a lot of people talk about "Throw those in jail who drank when they were pregnant." That's not going to help women...That's going to make women hide their drinking and be even less likely to tell their doctors. There needs to be more, not telling a woman it's okay to drink when you're pregnant, but more acceptance so that the woman will feel safe to tell the doctor.

- Kendra,
biological mother to one daughter with FASD

“FASD IS THE WHITE ELEPHANT”: A CALL FOR AWARENESS

She would have a meltdown in public basically....There's been a lot of times I've had to just leave my shopping cart and say "I'm really sorry"....But in public, in some other places where there's parents that are very judgmental or their kid has been frightened from her and they turn around and make comments and I have a flyer that I did up and I say "Really? My kid has a problem. What's yours?" And then I just hand them the flyer and walk away.

**- Caitlin,
adoptive mother to one daughter with FASD**

“THEY’RE BETTER OUT WEST...ONTARIO’S ABOUT THE SLOWEST PROVINCE”: LACK OF PERCEIVED SUPPORT IN ONTARIO

I mean, the biggest thing for me is that...FASD is still not recognized in Ontario as a disability.

Often times I almost wish that they were diagnosed with something else. So that they could be provided with more services.

**- Leslie,
*adoptive mother of two sons with FASD***

“THEY’RE BETTER OUT WEST...ONTARIO’S ABOUT THE SLOWEST PROVINCE”: LACK OF PERCEIVED SUPPORT IN ONTARIO

I’m scared. I’m scared ‘cause there’s not a lot of things in Ontario for Mackenzie and not a lot of places. The neuropsychologist said that when Mackenzie turns 16, if something has not happened in Ontario yet, move out West. And when a neuropsychologist is telling you that, it’s sad. It’s scary.

**- Jennifer,
adoptive mother of one son with FASD**

CONCLUSIONS

- Imperative that professionals increase their knowledge and understanding of FASD, including the physical, neurological, and behavioural features of FASD, in addition to the collective family experience
- The need for first hand and contextualized education of professionals in numerous disciplines

CONCLUSIONS

- Early education about FASD and the addition of FASD to university and medical school curriculums
- Stressors that do not originate internally within the family, but rather are often the result of limited support in the greater community

VALUE OF LISTENING TO FAMILIES

- Importance of including qualitative methodologies
 - Families were very excited to tell their stories
 - Therapeutic effect
- Families are the most qualified and knowledgeable individuals about the realities of raising a child with FASD
 - Professionals can be educated by listening to their stories

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Questions or Comments?