



**“Well Where’s He Supposed to Live?”:
Experiences of Adoptive Parents of Adult
Children with FASD in Ontario**

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Conflict of Interest

- We have no conflicts of interest to declare



Learning Objectives

1. Apply an emerging adulthood theoretical framework to the experiences of parents and caregivers as they contend with the difficulties associated with their child's transition to adulthood
2. Identify and discuss the reported challenges faced by families living in Ontario, Canada regarding transitional aged youth with FASD
3. Demonstrate opportunities for improved communication between families of individuals with FASD and service providers to support the successful transition of children with FASD to adulthood



Families Raising Children with FASD

- Experience of raising a child with FASD may be different from that of other developmental disabilities (*Coons et al., 2016; Watson et al., 2013*)
- Family characteristics
 - Family resources, family structure, and socioeconomic status
 - Child characteristics (e.g., externalizing and internalizing behaviours)
- Parents and caregivers face enormous challenges emotionally, physically, socially, and financially, as well as challenges in dealing with professionals and the community, and accessing services
- Importance of the lived experience



Children's Transition through Developmental Stages

- Increased uncertainties and challenges
- Parents' goals for their children change
 - Change in family roles or core functions
- Shift in services
- Increased perceived stress



Available Supports for Children with Disabilities in Ontario

- The use of supports regarded as facilitative for family adaptation
- Two support categories:
 - Formal
 - Informal
- Social support and respite care associated with decreased levels of perceived parental stress
- Early service use and interventions lead to better long term outcomes



Emerging Adulthood

- Living within the home of a caregiver as an adult (18-25 years old; *Arnett, 2000*)
- Exhibit a pattern of moving in and out of their parents' home and do not view that movement pattern as a negative reflection upon their adult status
- Diverse experiences
- Prolonger period of exploration and often postpone traditional adult transitions

Adults with FASD

- Primary impairments and secondary adverse outcomes can make employment difficult to maintain
- Parents often become heavily involved
 - 80% of adults with FASD reside with their parents

Emergent Adulthood

Accept
Responsibility

Independent
Decisions

Financial
Independence



Research Questions

1. What is the lived experience of parents raising children with FASD in Ontario?
 - How are parents adapting to the demands associated with their children's transition into the next developmental stage?
2. What supports do parents require to facilitate adaptation?



Methods

Qualitative Method

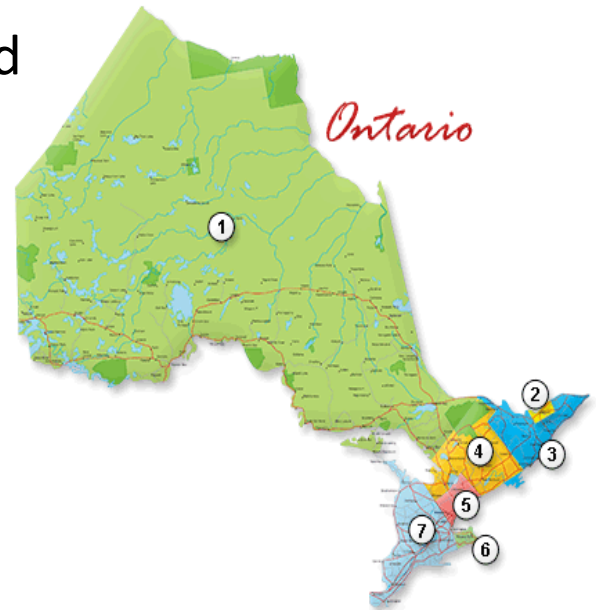
- Interpretative phenomenological analysis
- Goal: To understand what it is like to “walk in another’s shoes”

Quantitative Method

- Questionnaire on Resources and Stress – Friedrich’s Version
- Measures aspects of stress as experienced by families of a child with a disability

Participants: Larger Study

- Participants are from across Ontario, Canada and have at least one child diagnosed with or suspected of having FASD
- Mothers $N = 55$
 - 34 adoptive, 6 biological, 5 foster, 8 grand/great-grandmothers, 1 step mother, 1 aunt
- Fathers $N = 20$
 - 12 adoptive, 2 biological, 3 foster, 2 grand/great-grandfathers, 1 step father



Participants

- $N = 20$
- Accessed through FASD support organizations and social media (e.g., Facebook)
- Respondent-driven sampling
- Child age range 19 – 37 ($M = 27$)

Parent Characteristic	<i>n</i>	%
Gender		
Male	5	35
Female	15	75
Current Marital Status		
Married	16	80
Divorced	2	10
Single	2	10
Family Type		
Adoptive Mother	15	75
Adoptive Father	4	20
Step Father	1	5
Number of Children with FASD		
1	17	85
2	3	15



Results

Housing and Transition into Adult Housing

- “Cause he’s gonna stay here, he’s not leaving”: Difficulty managing change
- “He’s too good for this, but not bad enough for that...He shouldn’t be living there”: Lack of appropriate adult housing

Managing Money/ Finances

- “There was always a reason why she wasn’t eligible”: Difficulty accessing adult services
- “If you gave the kid \$100 it would be gone”: Adult child difficulty procuring and managing finances

Individual Characteristics

- “The level of risks they take are huge”: Risky behaviours
- “She seems to be able to find jobs. She has trouble holding onto them”: Difficulty maintaining employment

HOUSING



**“Cause he’s gonna stay here, he’s not leaving”:
Difficulty managing change**

“It’s like he’s always a child but he doesn’t want to be a child.
It’s like we’re stuck.”

-Sharon, mother to two adult children with FASD

“The stress was unbelievable. No, he didn’t wanna come home. As far as he was concerned he was doing fine. And then he was back. And then he went out. And then he was back.”

- Trevor, father to one son with FASD

“I often worry about what will happen to _____”

**“He’s too good for this, but not bad enough for that... He shouldn’t be living there”:
Lack of appropriate adult housing**

“[He needs] a built in community housing project...that totally understands the problem, lets the kid be independent as an adult, gives them some rules and responsibilities, but yet [someone] is there saying ‘shower day is today’ or ‘you’re not going out the door till you’ve brushed your teeth.’”

-Ivan, father of two adult children with FASD

MANAGING MONEY/FINANCES



“There was always a reason why she wasn’t eligible”: Difficulty accessing adult services

- Stefanie recalls being turned down for a funding opportunity because her son “was one [IQ] point above” the cut off for the qualifying level of IQ
- Ivan encountered the same issue when applying for services and described why his son is “not dumb enough” because “his IQ’s too high so you can’t [access services]”

“Family members had to go without things
because of _____”

**“If you gave the kid \$100 it would be gone”:
Adult child difficulty procuring and managing finances**

“If he does get a part time job, that’s partially deducted from his ODSP, which is reasonable, but what’s the incentive of him getting up and going out to do anything. On the other hand, if he wasn’t getting ODSP we have to be financially responsible for him.”

-Stacey, mother of one son with FASD

INDIVIDUAL CHARACTERISTICS



**“The level of risks they take are huge”:
Risky behaviours**

“He will go and put himself in extreme[ly] dependent situations, very exploitive situations.

When he’s living on the street with...people who exploit him for selling drugs.”

-Peter, father to two sons with FASD



“_____ can't pay attention for very long”

**“She seems to be able to find jobs. She has trouble holding onto them”:
Difficulty managing employment**

“They're so anxious to please and so anxious they have this new job, they're going to do so well. But with every passing day the expectations are more, and more, and then they realize they can't do it.”

-Gabrielle, mother of one daughter with FASD



Discussion

- Struggling to move out of the emergent adulthood life stage into adulthood
 - 50% of children older than 25
- Parents report moderate to high levels of perceived parental stress (job instability, struggling with financial independence)

Conclusion: Providing parents with required services will help balance their demands and capabilities, facilitating adaptation to their children's transition into adulthood.



Conclusions

- Despite moderate to high levels of reported parenting stress, families identify ways to successfully adapt to their individual situations
 - Need to bolster resources for families, including semi-independent housing and access to adult services for their adult children
 - “safe, supported housing” environments
 - Need to address qualifications for services (e.g., ODSP) and education of service providers (e.g., characteristics of adults with FASD)



Value of Listening to Families

- Importance of mixed methods
 - Families were very excited to tell their story
 - Therapeutic effect
- Understanding what families do in order to transform from a family in crisis to a functioning family is important when implementing family support programs

Questions or Comments?

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