

# Parenting with Fetal Alcohol Spectrum Disorder: Needs, Challenges, and Opportunities for Support and Research

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Kelly Harding, PhD<sup>a,b</sup>; Katherine Flannigan, PhD, R. Psych<sup>a</sup>; Audrey McFarlane, MBA<sup>a</sup>; Dorothy Reid, MA<sup>c</sup>; Marsha Wilson, MA<sup>c</sup>

<sup>a</sup>Canada FASD Research Network

<sup>b</sup>Laurentian University, Sudbury, ON

<sup>c</sup>Family Advisory Committee, Canada FASD Research Network

## Issue:

In Article 23 of the United Nations [Convention on the Rights of Persons with Disabilities](#), it is stated that all persons with disabilities have the right to decide freely whether or not to become parents, and to have access to information and resources that support this right. However, it is often difficult for persons with developmental disabilities to exercise their right to parent, even when compared to other disability groups [1-3]. There is some evidence about the challenges and needs of parents with developmental disabilities in general, but very few studies have been focused specifically on the concerns of parents with Fetal Alcohol Spectrum Disorder (FASD). Recognizing this significant gap, researchers have been calling for more investigation into this area for the last two decades [4-7].

**The purpose of this paper is to summarize the limited available literature about parents with FASD and to provide recommendations for future research, practice, and policy directions.**

## Background:

It is generally assumed that, like most adults, many individuals with FASD will have children of their own [5, 8]. In Streissguth et al.'s seminal work in the 1990s exploring the adverse outcomes experienced by a large group of individuals with FASD in the United States (US), 28% of females and 10% of males over 12 years of age had one or more child [7]. Of these children, less than 50% were still in the care of their parent, which is not uncommon for children of parents with disabilities [9-11]. Compared to non-parents with FASD in this study, parents with FASD were more likely to have experienced challenges with unstable housing and homelessness, domestic violence, disrupted school experiences, trouble with the law, and substance use [7].

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Insight into the potential experiences of parents with FASD can be gained from the perspectives of their caregivers who have prominent voices around this issue. These perspectives are critical, given the intergenerational impacts of FASD and the fact that many caregivers may be raising their grandchildren [12, 13]. Specifically, caregivers tend to have concerns for their children's ability to attain independence, which are compounded when they imagine the added demands that parenting would place on their children [14]. Moreover, because some caregivers worry that their children may be more vulnerable to early, or multiple, pregnancies, there are further concerns that they, as grandparents, may have to assume the parenting role in an effort to support their grandchildren and their children [14]. Caregivers fear for the sustained duration of support and have asked for guidance and help in understanding the best ways to support their children and to foster success in parenting experiences.

There is a considerable amount of literature on the needs of parents who have mental health challenges or disabilities other than FASD [4, 15]. Although the functional abilities and potential challenges of these parents may be similar to those of parents with FASD, it is unknown whether the complexities of FASD may lead to additional or unique challenges. Specific research with this population is scarce, and what does exist is small-scale and out-of-date. As a result, very little is currently known about how to best support individuals with FASD who are parents. The limited research in this area is described below.

### **1. Identified Needs and Experiences of Parents with FASD**

In a small 2005 Canadian study conducted to explore the perspectives of parents with FASD, researchers identified the most pressing needs of this group as: support with the practical and domestic skills required to care for their children, training on parenting skills and child development, assistance with obtaining public and social services, and formal and informal relational support [4]. Participants noted that comprehensive, wrap-around systems of care, tailored to parents with FASD, would be necessary to better meet the needs of these parents. Specifically, participants called for in-home service provision, advocacy, community support, outreach, counselling, pregnancy programs, and education for parents with FASD. Additionally, participants noted that supports should be individualized to account for each parent's unique strengths and challenges.

In a similar study, Canadian researchers examined the experiences of adults with FASD in relation to parenting through in-depth interviews with a small group of parents, support people, and service providers [6]. The researchers identified five key areas of relevance for parents with FASD. First, participants shared their hopes and goals as parents, expressing a desire for their children to become "good people" and to "break the cycle" of addiction, abuse, and involvement with child welfare. Parents also identified many successes, such as maintaining custody of their children, receiving affection and positive attachment from their children, and effectively implementing daily living strategies to facilitate successful parenting.

Despite having some success, parents with FASD in these studies also noted many challenges and barriers including system-level restrictions; lack of time, funding, personnel, resources and education; service providers' skills, attitudes, and expectations; and limited service access and coordination [4]. At the individual level, parents with FASD reported facing cognitive and sensory impairments, social vulnerability, lack of social supports and positive parenting role

models, exposure to intimate partner violence, substance use, and poverty and homelessness, all of which may compromise their ability to maintain health and safety for themselves and their family [6]. At the societal level, participants spoke of two broad, seemingly opposing, challenges. On the one hand, they identified concerns related to stigmatization, intense scrutiny, and pre-judgement of their parenting abilities because of their disability. Paradoxically, participants also reported that service providers overestimated their abilities or trivialized their disability. In both cases they experienced a lack of meaningful understanding of their unique challenges that make parenting difficult, for which support may be most beneficial. Finally, at the policy-level, parents also feared that asking for help could trigger an unwanted child welfare investigation [6].

## **2. Supporting Parents with FASD**

The evidence on interventions for parents with FASD is limited, however, promising findings have been drawn from research on the Parent-Child Assistance Program (PCAP). PCAP is a community-based intervention model involving long-term one-to-one mentorship and advocacy for women at risk of having an alcohol-exposed pregnancy. Broadly, the program helps clients to understand and address their needs and make appropriate connections with community resources [8, 16, 17]. PCAP was not originally designed for parents with FASD, but researchers have modified the model to accommodate clients with FASD, and its effectiveness has been assessed in two preliminary studies [5, 16].

In 2004, Grant and colleagues conducted a small pilot study in the US to implement a 12-month modified PCAP program with 19 women with FASD [16]. Many of the clients had complex needs and marked vulnerability, including low levels of education, experiences of childhood abuse, multiple children, serious medical conditions, comorbid psychiatric diagnoses, history of incarceration, and substance use. Important components of the program included case management to help clients obtain a formal diagnosis of FASD for themselves and their children, identify their parenting needs, and connect to substance use treatment as necessary [8, 16]. Additionally, clients were supported to address their basic needs (e.g., housing, food, hygiene, and safety), and make appropriate connections with community resources that would remain after they were no longer enrolled in the program [16]. Mentors also worked to educate community service providers about how to adapt supports for clients with FASD. The program led to substantial improvements for positive health outcomes for participants, including decreased substance use, increased use of contraception, improved access to health care services, and stabilized housing [16].

Another adaptation of the PCAP model was implemented in Canada in the early to mid-2000s through the Step by Step program. This program involved mentorship for up to three years, focusing on supporting families to bolster connections to their community, as well as accessing necessary resources and supports (e.g., employment support, housing, addictions support, respite, etc.). The researchers examined the effectiveness of this program in reducing the needs and increasing the goal achievement of 29 parents with FASD [5]. The most commonly reported need among participants in this study was family parenting, and although there was some positive change noted in this area, more substantial improvements were found in other categories, such as reduced experiences of abuse; social problems, housing, and transportation;

and access to community resources. Similarly, parents' goals most commonly related to parenting, and again, although some achievements were noted in this area, more gains were found in achieving self-care and health-related goals as positive outcomes of the program [5].

### 3. Implications and Next Steps

A number of important implications can be drawn from this small body of research, regarding both the priorities of parents with FASD, as well as how programs might be tailored to meet the needs of this population. First, Denys et al. noted that, although improving parenting skills and family functioning may be important goals for parents with FASD, these priorities may be considered secondary to more urgent needs like crisis reduction, safety, stable housing, food security, financial stability, and treatment for acute mental health and substance use challenges [5]. Meeting the basic needs of parents with FASD seems to be a necessary first step to set them up to benefit from specific parenting training or skill-building [5]. Second, the complex needs of parents with FASD in this research underscores how a multifaceted and dynamic approach is required for this group, including recognizing the importance of long-term, individualized, and comprehensive supports.

Third, with respect to program implementation, Grant and colleagues noted that client engagement may pose a unique challenge when working with parents with FASD [16]. For these clients, cognitive impairments may require service providers to adjust programming goals. That is, whereas the primary goal for a parent *without* FASD may be to develop the individual's abilities or independence, a more appropriate goal for a parent with FASD may be to increase service use from the outside in, by building FASD-specific capacity among service providers and creating a wide network of professionals capable of delivering services to this population [16]. Additionally, it may be helpful to work towards *interdependence* rather than independence for parents with FASD [18]. Programming that supports families, including both the parent and child and those that implement adapted mentorship models, such as PCAP, may be helpful ways of supporting parents with FASD to achieve this interdependence.

Finally, it is important to note that in all the research reviewed, many of the participants had suspected FASD, but were not diagnosed. This lack of diagnosis is important, as Denys and colleagues reported that having a formal diagnosis was associated with significantly greater reductions in parent needs [5]. It may be that a formal diagnosis allows for access to financial assistance and other services [5, 19]. Therefore, it is important that programs serving clients who may have FASD consider the possibility of referral for assessment and help to facilitate this process once other acute client needs have been addressed.

### Recommendations for Research, Practice, and Policy:

Some preliminary evidence exists on the experiences and needs of parents with FASD; however, this research is small-scale and increasingly out-of-date. There is an urgent need to draw more research, practice, and policy attention to the complexity of issues faced by this group.

- **Future research.** More qualitative research and cohort studies are needed to better understand the experiences and needs of individuals with FASD who become parents. Important research questions may include:

- What proportion of individuals with FASD are parents? At what age are individuals with FASD becoming parents?
- What are the critical support needs of parents with FASD and the most effective ways of meeting these needs?
- What are the strengths and successes of parents with FASD?
- How do the experiences of parents with FASD differ from the experiences of parents with other disabilities or with no disability?
- What roles do spouses, partners, parents, and other family members play in supporting parents with FASD?
- What role does the child welfare system play in supporting youth with FASD who become parents?
- How might parenting supports change across the lifespan?
- What are the long-term outcomes of parents with FASD and their children?
- **Service delivery.** Several important findings from the literature may guide service delivery for parents with FASD.
  - **Support related to sexual health, contraception, and understanding the risks of drinking when pregnant.** Women with FASD who wish to have children should be provided with sexual health and contraception information to support healthy pregnancies. These supports should be tailored to account for the needs and abilities of women with FASD, so that they can meaningfully plan pregnancies and involve their support networks. Given the higher rate of substance use among individuals with FASD, education about the risks of alcohol and other substance use during pregnancy will be an important component of this education.
  - **Basic needs.** Although parent training may be a priority for some parents with FASD, for others, these skills may take a back seat to more pressing concerns, such as acquiring safe and stable housing, adequate nutrition, a livable income, and physical and mental health treatment. Meeting these basic needs should be of highest priority for all parents with FASD so that they are equipped to develop the skills needed to best care for themselves and their children.
  - **Supportive mentorship.** In addition to addressing basic needs, there is some promising, albeit limited, data on the effectiveness of supportive mentorship for parents with FASD. From this evidence-base, it appears that service efforts involving advocacy, outreach, and connection with community resources that are tailored to the individual needs of parents with FASD may contribute to positive outcomes.
  - **Comprehensive care.** Parents with FASD report a wide array of complex needs, and thus interventions for this group should be individualized, flexible, comprehensive, and multisectoral. Service providers should consider the impacts of compromised social determinants of health, such as limited income and social status, access to health care, education and employment opportunities, and social support systems, as well as adverse life experiences that are common for

people with FASD. Ongoing support for parents with FASD should be provided to sustain success across the lifespan.

- **Strengths-based support.** Consideration of strengths and resiliency factors including characteristics and qualities of the parent, child, and external factors that may be harnessed to provide meaningful services and optimize positive outcomes. In addition, services should be provided in a non-judgmental, non-stigmatizing way to best support families.
- **FASD-informed.** FASD education, training, and support should be offered to professionals who provide services for all parents, and especially parents with disabilities and compromised social determinants of health. Training should include strategies for identifying individuals who may have FASD, referring for assessment, and accommodating for those who have been diagnosed. Training for child welfare workers on options for wrapping support around pregnant women and new mothers with FASD and their children will also be key.
- **Policy.** FASD-informed policy, funding, and resources are urgently needed to support the research directions and service recommendations included here.

### Conclusion:

Individuals with FASD and their family members have many concerns and needs related to parenting. In order to facilitate the right to parent among individuals with FASD, urgent action is needed to better understand the needs, challenges, strengths, and experiences among this population. This evidence would help to inform evidence-based approaches to encourage healthy, safe, and nurturing home environments for parents with FASD and their children.

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