

# FETAL ALCOHOL SPECTRUM DISORDERS AND CHALLENGES FACED BY CAREGIVERS: CLINICIANS' PERSPECTIVES

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## ABSTRACT

### Background

There is a notable absence of evidence based early interventions for young children with FASD.

### Objective

This study examines clinicians' perspectives regarding the needs of caregivers of children with FASD and how such perspectives informed the development of a family-centered early intervention for young children with prenatal alcohol exposure.

### Method

19 professionals who work with children with prenatal alcohol exposure and / or in out-of-home care were recruited to participate in focus groups. The facilitator used a semi-structured topic guide to elicit feedback from participants. These data were transcribed, coded, and categorized to reflect themes in a manner informed by a grounded theory approach. A second investigator repeated the process. Codes were chosen and assigned to data by consensus.

### Results

The coded data yielded five distinct perceived challenges faced by caregivers: (1) seeking and possibly receiving a diagnosis; (2) processing emotions and coming to terms with the child's difficulties; (3) seeking support and belonging within a knowledgeable community; (4) developing a new understanding of the child's behavior; and (5) becoming an educator, advocate, and expert on the child and FASD.

### Conclusion

Professionals believe specific capacities are essential insofar as the human service systems that caregivers engage are perceived to be under-equipped to respond to the distinct set of challenges faced by children with FASD and their families. Findings are discussed in terms of how the proposed intervention was designed to address such challenges and to cultivate those key capacities in order for families to meet their children's needs.

**Key Words:** *Professional perspectives, fetal alcohol spectrum disorders, intervention development*

Fetal Alcohol Spectrum Disorders (FASD) result from prenatal alcohol exposure (PAE), and include Fetal Alcohol Syndrome (FAS), partial FAS, Alcohol Related Neurodevelopmental Disorder (ARND), and Fetal Alcohol Effects (FAE). These disabilities can

cause birth defects that impair cognitive, behavioral, emotional, social, and physical development. Children affected by FASD may also be at risk for secondary disabilities<sup>1,2</sup> including academic difficulties and other school-related problems (e.g., expulsion, early

withdrawal), mental health issues, substance abuse problems, and confinement or incarceration.

These negative outcomes can be mitigated to some extent by early diagnosis and intervention and upbringings in positive, stable environments.<sup>2</sup> Prevalence estimates are difficult to calculate because of the complexities of diagnosis; however, in the United States, best estimates are that FAS occurs in between 2 and 7 people in 1,000, while FASD are estimated to occur in between 2% and 5% of the population.<sup>3</sup> In Canada, FAS is estimated to occur in 1 in 1,000 people.<sup>4</sup> FASD cost \$4 billion per year in the United States<sup>5</sup> and upwards of \$5 billion per year in Canada.<sup>6,7</sup>

The costs associated with FASD arise to a great extent from the complex and extensive demands that the disability places upon people it affects and their families. These demands stem in part from the broad range of the disability's effects across several domains of functioning, including cognitive, social, and adaptive. Millar et al.<sup>8</sup> suggests that "the effects of FASD vary in range and severity for each individual, likely depending on individual biology, genetic and epigenetic factors, and environmental influences".<sup>8</sup> Each person affected by FASD may have a different profile and constellation of effects depending on which aspects of their functioning have been most impacted by PAE, making standardized assessment and intervention especially challenging. Indeed, the range of possible presentations of people with FASD makes it especially challenging for children impacted by the disability to receive suitable supports in school and other clinical settings.<sup>9</sup>

The interaction between these brain-based effects of FASD and the caregiving environments of affected individuals can give rise to further challenges. For example, O'Connor, Kogan, and Findlay<sup>10</sup> found support for a model demonstrating that PAE was associated with a chain of negative outcomes for affected children. Specifically, PAE predicted children's early negative affect, which was associated with less supportive presence of mothers, which in turn predicted poorer coping skills in children, which finally was associated with decreased attachment security. Although this path analysis does not provide definitive evidence of causation, it does

raise the possibility that PAE may set in motion a cascade of adverse processes for affected children and their caregivers. Insofar as a nurturing, stable environment is one of the strongest predictors of more positive outcomes later in the lives of people with FASD<sup>2</sup>, insecure attachment poses risks to children affected by the disability. Concerns such as these are all the more salient given the disproportionate representation of children with FASD in foster and adoptive care<sup>11</sup>, the disproportionate exposure of children with FASD to negative or problematic caregiving environments<sup>12,13</sup>, and the heightened challenges associated with providing nurturing care to infants and young children in foster care.<sup>14</sup>

Psychosocial effects associated with FASD extend to and impact family members, as well. Olson, Oti, Gelo, and Beck<sup>15</sup> found that families raising a child with FASD are affected and challenged in a number of ways. For example, children with FASD require extensive or frequent support, and as the degree of necessary support increases, so, too, does the burden on caregivers.<sup>15</sup> Paley, O'Connor, Kogan, and Findlay<sup>16</sup> found that increased externalizing behavior associated with greater PAE is associated with higher levels of maternal stress, and that maternal stress rises as the availability of resources drops. In a subsequent study, Paley, O'Connor, Frankel, and Marquardt<sup>17</sup> found that impaired executive functioning, poorer adaptive functioning, externalizing and internalizing behavior problems, and adoptive parent status all made significant and independent contributions to the prediction of higher levels of child domain stress, as reported by parents on the Parenting Stress Index. Biological parent status and fewer family resources, on the other hand, were associated with higher levels of parent domain stress. In the United Kingdom, Mukherjee, Wray, Commers, Hollins, and Curfs<sup>18</sup> found that isolation and perceived lack of support exacerbate the challenges that adoptive caregivers experience when caring for a child with FASD. These findings echo those of Brown et al.<sup>11</sup> in their investigation of perceived needs of Canadian foster parents.

The psychosocial impacts of FASD are also evident as people affected by the disability and their families come into contact with human service systems, including schools, child welfare

agencies, and medical and mental health providers, who not only provide direct services to children, but may also provide resources and services to parents (e.g., psychoeducation, support groups, respite care, advocacy). To the extent that the needs of children with FASD and their caregivers are significantly higher than the general population across many domains<sup>19</sup> these interactions are likely to be ongoing and extensive. At the same time, however, there may be gaps between the needs of people affected by FASD and the resources (e.g., knowledge, time, etc.) these institutions are able to provide. In a survey conducted of pediatrician knowledge of and experience with FAS, Gahagan et al.<sup>20</sup> found that respondents were “knowledgeable about basic science, clinical signs, symptoms, and epidemiology of FAS [but were] less prepared to use diagnostic guidelines, refer for specialty consultation, or coordinate treatment for children with FAS”.<sup>20</sup> Similarly, a survey of psychologists demonstrated that they possess general knowledge of FAS but lack expertise when it comes to prevention, diagnosis, and treatment matters.<sup>21</sup> 71% of psychologists in that study identified lack of training as a barrier to diagnosis, leading its authors to conclude that further education of psychologists about FASD is needed. Though efforts to address these knowledge gaps have been recently undertaken<sup>22</sup> the literature suggests that clients seeking services for FASD-related issues may encounter professionals who are unprepared to assess and manage them.

The interactions among children with FASD and their families, professionals responsible for diagnosing and managing the disability, and educational systems, for example, may give rise to challenges for professionals and families alike. Lack of expertise about FASD may lead medical and mental health professionals to diagnose disorders that reflect behavioral symptomatology without considering PAE as a possible etiology of the behaviors. For example, children with FASD and children with ADHD may present quite similarly, and as such, children with FASD are often diagnosed with ADHD without taking into account their history of PAE. Raldiris, Bowers, and Towsey<sup>23</sup> find that children with FASD display more externalizing behaviors and greater cognitive impairments<sup>23</sup> when

compared to children diagnosed with ADHD, and have argued that on the basis of distinct differences between the neurological underpinnings of the two groups, early FASD-specific intervention is essential to “regain some cognitive function that was disrupted or damaged by prenatal alcohol exposure”.<sup>23</sup> Whether children with FASD require FASD-specific interventions or whether they can also be well-served by existing interventions that are adapted to meet their needs remains an ongoing discussion amongst both clinicians and researchers. However, obtaining a diagnosis to inform any kind of intervention has been shown to be challenging for practical reasons<sup>24</sup>, because of ethical concerns<sup>25,26</sup>, and because of physician’s fears of stigmatizing children and families<sup>27</sup>, reflecting the findings of Gahagan et al.<sup>20</sup> and Wedding et al.<sup>21</sup>

The diagnostic process is further complicated by:

- 1) the existence of different diagnostic guidelines<sup>28,29,30</sup>,
- 2) an evolving debate regarding whether the diagnosis should be viewed strictly as a medical condition or whether it should also be considered as a psychiatric diagnosis, as evidenced by the inclusion of Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure in Conditions for Further Study in DSM V<sup>31</sup>, and
- 3) concerns about if, when, and how to diagnose children who may be too young to be assessed in some of the very domains often impacted by PAE, such as executive function.<sup>32</sup>

In addition to (and perhaps partially as a result of) diagnostic challenges, there has been a lag in the development of evidence-based, efficacious interventions for FASD. In their examination of the state of interventions for this population, Premji, Benzies, Serrett, and Hayden<sup>33</sup> conclude that interventions guided by scientific evidence are few and far between, and that urgent, interdisciplinary collaboration is needed to address this sparseness. Over the last two decades there has been some progress in the development and evaluation of research-based interventions for children with FASD, such as the collaborative,

multi-site initiative supported by the Centers for Disease Control in the U.S.<sup>34</sup> More recent reviews have found that the interventions that have been studied focus primarily on improving school-aged children's performance in school and on school-related tasks<sup>35</sup> and that further research is needed to develop and refine interventions for younger children and adolescents and adults.<sup>36,37</sup>

Furthermore, although interventions aiming to address deficits resulting from other neurodevelopmental delays have been adapted for use with children with FASD (such as the Alert Program<sup>38</sup> implemented by both Wells, Chasnoff, Schmidt, Telford, and Schwartz<sup>39</sup> and Nash et al.<sup>40</sup>; and the utilization of the Zones of Regulation, an intervention for improving self-regulation among children with neurodevelopmental disorders<sup>41</sup>), few FASD-specific intervention options are available, particularly for infants and toddlers.

### **The Strategies for Enhancing Early Developmental Success Program (SEEDS)**

In response to the growing recognition of the profound challenges faced by children with FASD and their caregivers, there have been increased efforts to design interventions that address core impairments experienced by these children and to equip parents with the knowledge and skills needed to facilitate more optimal outcomes for their children. The Strategies for Enhancing Early Developmental Success Program for Infants and Toddlers (SEEDS-IT) is a prevention and early intervention program being evaluated for foster, adoptive, and kinship caregivers with children aged between 1 month and 24 months with PAE. SEEDS-IT is a 20 session intervention designed to improve self-regulation in young children affected by PAE and consists of three components: a project-developed Parent Education and Advocacy Module (PEAM), as well as two existing research-based programs: an attachment-based parenting intervention called Right From the Start (RFTS)<sup>42</sup>, and a music-based parent-child program, Music Together® (MT). The program is designed to be foundational, such that each component builds on the previous one. That is, PEAM aims to foster parents' basic knowledge and skills in caring for a child impacted by PAE, and then RFTS and MT provide opportunities for

parents to put their knowledge and skills into practice. Both RFTS and MT have been implemented for children with a range of challenges, but were considered to be good fits for this population given their focus on promoting more positive behavioral and socioemotional functioning.

Given the challenges that can arise in providing care for individuals with FASD, coupled with gaps in some professionals' knowledge about this disability, it is critical that caregivers are equipped with knowledge and skills to work collaboratively with professionals, educate others when needed, advocate for their children, and ensure that service providers render the appropriate services. The developers of SEEDS-IT have significant experience working with children with FASD and their families in both clinical<sup>45,46</sup> and research<sup>47,48</sup> contexts and thus sought to insure that SEEDS-IT would address many of the struggles these families encountered. In light of the need for parents and professionals to form strong partnerships on behalf of these children, we sought to understand and incorporate the perspectives of community-based professionals' regarding the challenges they observe in their work with children with FASD and their families. Exploration of those perspectives revealed a number of recurrent themes that were then used to inform the development of the PEAM component of SEEDS-IT (unpublished manual, 2011).

## **METHOD**

### **Participants**

Nineteen participants were recruited for two focus groups using a snowball sampling technique. Snowball sampling refers to the use of an initial set of participants as a source of additional research participants through the initial participants' social networks.<sup>49</sup> In this case, those networks consisted of professional or collegial relationships. These focus groups were exclusively for Los Angeles County-based professionals who work with young children with PAE and / or young children in out-of-home care (i.e., in the care of foster parents, adoptive parents, or kinship caregivers). Potential participants were told that the focus group would

ask them to identify common challenges and needs of foster, adoptive, and relative parents and caregivers of young children with PAE in order to inform a pilot prevention and early intervention program for this population.

The two focus groups included professionals from the following disciplines: psychology (n = 9), social work (n = 4), marriage and family therapy (n = 4), occupational therapy (n = 1), and developmental pediatrics (n = 1). Years of experience ranged from one year to over 30 years, with the majority of participants falling towards either end of the range. Eleven participants worked in community mental health settings, whereas a smaller number worked in county social service agencies.

### Setting

Each focus group was conducted for two hours in a conference room at a university-based medical center. One focus group had 8 participants while the other had 11 participants. Group size varied between the groups because the investigators over-recruited to account for an estimated 20% no-show rate.<sup>50</sup> The larger group had full attendance.

### Data Collection

The lead investigator, a licensed clinical psychologist with expertise in FASD, facilitated both focus groups. A trained research assistant took a detailed written record of the group, including verbatim responses and observational notes. The facilitator followed a semi-structured topic guide<sup>50</sup> that included the following prompts:

- *What do you think are some of the biggest challenges faced by parents or caregivers who are raising young children with prenatal alcohol exposure?*
- *What kinds of information do you think would be helpful for parents or caregivers of a young child with prenatal alcohol exposure to have?*
- *What is your perspective regarding whether parents or caregivers should share an FASD-related diagnosis with schools and teachers?*

Participants were also provided with a brief overview of the components of the proposed intervention (i.e., PEAM, MT, RFTS). Parents were then asked to respond to a project-developed eight-item questionnaire that included five Likert-scale questions (e.g., “I believe that the SEEDS-IT Parent Education and Advocacy Module could be helpful to families that I work with in my agency.”) and three open-ended questions related to the participants’ perceptions regarding how helpful they anticipated the different components of SEEDS-IT would be to impacted families, what they considered to be the most and least appealing aspects of the program, and any additional areas or domains that they felt should be addressed by the intervention (e.g., “Please note anything you think that should be addressed in SEEDS-IT, but is not.”).

### Data Analysis

The three opening prompts and the questionnaire encouraged participants to engage in lengthy discussions about their perspectives on parents’ and caregivers’ experiences receiving an FASD diagnosis, subsequent needs and challenges, and what prospective interventions should include to effectively support caregivers and their children. These data were transcribed, coded, categorized, and further subcategorized manually to reflect major themes informed by a grounded theory approach: a qualitative methodology that seeks to facilitate the inductive cultivation of theoretical accounts of observed phenomena (in this case, the perceptions of clinicians about their clients’ needs, capabilities, and skills).<sup>49,51</sup> The process was later repeated by a second investigator to ensure that codes and thematic findings accurately and reliably represented both the opinions of the participants and their perspectives about experiences of parents and caregivers. Codes were chosen and assigned by consensus, and any disagreements about codes were discussed until consensus between the two investigators was achieved. Investigators paid particular attention to opinions that were not clearly encapsulated by the identified categories in order to more comprehensively understand nuanced aspects of the issues covered by the groups.

## RESULTS

Discussions in the two focus groups highlighted a set of challenges that professionals working with families of children with FASD believe caregivers face as they care for a child with FASD. Participants' responses suggested that as caregivers face these challenges, the needs and capacities of caregivers evolve. Participants broadly felt that the proposed intervention should facilitate the cultivation and refinement of capacities to address these challenges in order to prepare caregivers to confidently and effectively engage schools, medical and mental health providers, and other human service systems as informed advocates so as to meet the unique needs of their children.

### Caregiver Challenges

The investigators found that a set of recurrent themes emerged from the discussions, suggesting five distinct but related challenges faced by caregivers, each with its own demands and difficulties: (1) seeking and possibly receiving a diagnosis; (2) processing emotions and coming to terms with the child's FASD; (3) seeking social support and belonging within a knowledgeable community; (4) developing a new understanding of the child's behavior; and (5) becoming an educator, advocate, and expert on the child and FASD.

#### *Seeking and potentially receiving a diagnosis*

The diagnostic process is complex for caregivers and service providers alike. Participants reflected upon reservations that caregivers may express about seeking diagnosis, recognizing, for example, that there has been "push back on evaluating children for FASD because the diagnosis would put a label on the child, as if the child doesn't have it bad enough." Such attitudes reflect concerns that participants raised about broader social and cultural issues. One participant suggested that "every culture has its own level of trust in doctors, belief in the benefits of testing and evaluation, and even explanations of why physical or psychological symptoms occur." As such, according to another participant, it is important for professionals who are giving a diagnosis of an FASD to "be sensitive to families'

cultural beliefs, while also helping parents and caregivers parse out the neurological effects of prenatal alcohol exposure."

Participants also discussed the effect that receiving the diagnosis of an FASD may have on caregivers and families. Given the perceived gravity of a diagnosis, one participant felt that families need to be given ample time to process diagnostic information and to understand how the diagnosis may potentially impact the child, the parents and caregivers and the entire family. Another pointed out that the "biggest challenge for some is accepting the diagnosis" and that "the ability to take in the information and follow through with the intervention is contingent upon accepting the diagnosis." One participant pointed out a potential misconception that caregivers may have upon receiving the diagnosis: "some parents accept the diagnosis to such an extent that they say they cannot change certain behaviors because they are biological in nature" and so participants recognized a "fine line to walk in explaining the impact on brain development and explaining that [certain behaviors] are not immutable." Such perceptions suggest that helping families arrive at a balanced perspective wherein they have a realistic understanding of the challenges their child faces but can also maintain a sense of hope that their child will be able to make progress in meeting some of these challenges is an important part of discussing the disability. For this participant, clearing up such a misconception entails explaining facts about brain plasticity to caregivers and the possibility for children to overcome or to adapt to what may appear at first to be permanent impairments.

#### *Processing emotions and coming to terms with the child's difficulties*

Coming to an understanding of how their child has been impacted by PAE and possibly receiving a diagnosis can be an intense, emotionally laden experience. An important challenge that participants identified centers on the range of possible emotional reactions caregivers may experience and their potential attendant needs. One participant referred to the importance of a "reframing process" for caregivers in which it may "take months or years for parents to see that this is how their child is going to be and to

understand that the child will not meet their expectations and to realize that [caregivers] have to change and that they have to change the environment." Another echoed this sentiment, pointing out that "adopting parents have different expectations-often academic" and so may need "help [to] find things that the child is good at or passionate about." Such needs suggested to one participant that service providers ought to "help parents nurture these interests instead of what they have hopes for." In the face of disappointed expectations, participants suggested that addressing caregivers' hopelessness may be integral, and that "validation" and affirmation of caregivers' emotional experience may play a role in this aspect of work, as well. Participants also pointed out that addressing caregivers' shame and guilt may be a significant aspect of any focus on emotional reactions to their coming to terms with how their child has been impacted by PAE.

#### ***Seeking social support and belonging within a knowledgeable community***

As caregivers engage with their personal emotional reactions to their child's diagnosis and begin to grasp the demands they may face moving forward, participants recognized the value that a supportive, knowledgeable group of peers who have faced or are facing similar circumstances may have for caregivers. One participant stated that being part of "a group of parents who have also gone through it" is a way for caregivers to feel that they belong and are understood, especially since participants also felt that "parents feel isolated [and that] others cannot deal with their kids." Another agreed, noting that it is "important to have developed a support group with other parents who have common experiences." In written response to questionnaire item 7 ("Please note what you think might be the most appealing aspects of the program for parents."), 8 out of 19 (42%) participants listed having group support, highlighting the importance of addressing this need for caregivers.

#### ***Developing a new understanding of the child's behaviors***

Participants felt that through a process of learning and reframing, caregivers may also transition into a different mode of understanding and responding

to their children's behaviors. Participants perceived that initially, "to many parents who don't know what [FASD] is, don't know what the terms are, the children are just 'bad kids.'" In facing this challenge, caregivers may come to understand, explain, and ultimately respond to their children's behaviors differently. One participant emphasized the importance of "training parents on how to deal with behaviors, anger, and aggression" that may be largely a result of the child's PAE. Every participant replied in the written questionnaire that education for caregivers specifically about the diagnosis and appropriate parenting practices was among the most appealing aspects of the proposed pilot intervention, strongly reinforcing participants' perceived importance of learning and understanding the disability and how it may affect children's behavior.

#### ***Becoming an educator, advocate, and expert on the child and FASD***

Participants advocated that the prospective intervention should to inform, educate, and ultimately empower caregivers. One participant felt that "parents should be empowered to build networks and learn information [about FASD]," while another thought that "parents should be able to teach others and share their valuable experiences." Participants believed that parents and caregivers must take the lead in supporting their child's development, particularly with respect to the child's education, including advocacy during the IEP<sup>1</sup> process. Participants emphasized the need for parents to develop and cultivate positive parent-professional relationships that serve to benefit their child's development. Participants also noted that being the expert on their child and on PAE/FASD more generally brings with it an added responsibility for parents and caregivers: they need to continually build up their own knowledge base of effective services and strategies for children with PAE and FASD.

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<sup>1</sup>In the United States, the Individuals with Disabilities Act mandates that children with certain types of disabilities receive an Individual Education Program (IEP). This document stipulates education goals and techniques used by teachers to help children achieve those goals. In Canada, an Individual Education Plan (IEP) serves the same purpose. In both countries, caregivers and professionals collaborate with administrators and teachers to forge a detailed plan for the child's learning.

Parents and caregivers also need to learn to “communicate effectively” and “be able to teach others.”

### **Caregivers of Children with FASD and Human Service Systems**

A significant amount of time in focus groups was spent discussing how caregivers who cultivate the capacities to address these challenges may engage (or struggle to engage) different human service systems to meet their child's needs. Participants largely focused these discussions on the education, medical, and mental health systems.

#### ***The American public education system***

For participants, the cultivation of the capacities to cope with the challenges outlined above equips caregivers to engage with the educational and social service systems that they and their child will inevitably encounter. With an understanding of their child's history, disability, and difficult behaviors, one participant encouraged caregivers not to “hide what it is, [but instead] to educate” since people “tend to discriminate against that which [they] don't understand.” However, some participants disagreed about the utility of sharing the child's diagnosis with educators, as they perceived some educators might lack the knowledge and/or skills to work with caregivers.

While participants recognized the utility of a diagnosis for caregivers' understanding of their child, some felt strongly that disclosing a diagnosis carries considerable risks and insufficient benefits in the context of school systems. One participant observed that “parents think diagnosis is the ‘magic key,’ but having the diagnosis is not an automatic opening door key” with respect to receiving support from teachers and administrators. In light of that perceived reality, other participants believed that caregivers ought not to “tell the school about [prenatal alcohol exposure]” because “telling the school about [PAE] is stigmatizing and damaging.” On the other hand, the same participant said “that it may be different for [disclosing the diagnosis of full] FAS,” ostensibly because of the readily apparent physical features (facial dysmorphology and growth deficiencies) of FAS. Yet another claimed nonetheless that disclosing even the FAS

diagnosis may bring “negative consequences as a result.”

Participants elaborated on different reasons for their concerns about sharing a child's diagnosis with educators. One stated that caregivers “can explain to teachers without diagnosing or telling them that the child has PAE” since, if teachers and administrators have that information, “some people write off the child.” Another participant wondered aloud about “what should be done while the discriminatory attitude is still occurring,” while yet another articulated the perception that “schools are not a controlled environment; teachers have contact with each other, talk, and tell others at school.” These sentiments reflect a concern on the part of participants about the capacity of educators and administrators to effectively meet the needs of children with FASD, even after they have been made aware of the child's diagnosis. Furthermore, participants worried about children being stigmatized or treated differently in school settings upon the disclosure of their diagnosis.

Participants' acute concern for negative outcomes appeared to reflect perceptions that many school environments may not be adequately equipped to understand and support children with FASD and their caregivers. One participant felt that “most teachers don't know what [FASD are], and sometimes families are going to get teachers that just don't know what to do [with a child with PAE].” Another recounted a story of an adoptive mother who felt ostracized by the school when administrators initially thought that she was the birth mother of the child and had caused her child's difficulties by consuming alcohol during pregnancy. Yet another participant stated that “if the diagnosis just goes into a file and is duplicated year after year, but information about what it means is not provided, it could be detrimental [to the child].”

Other participants outlined ways in which caregivers could adapt to schools' perceived shortcomings without disclosing diagnostic details. One explained that “diagnosis may not be exactly helpful” and that “looking for other delays can get IEPs without [disclosing the] diagnosis” of an FASD. Another instructs caregivers to “just describe the symptoms and tell [educators] what



to do about it since there may be kids without PAE who have similar symptoms” and to tell educators “how to deal with [those symptoms], otherwise, [the diagnosis is] in the record, passed on from year to year.”

### ***The public medical and mental health system***

While participants expressed concerns about the education system that highlighted their perceptions of its lack of preparedness to support, understand, and teach children with FASD, their reservations about the medical and public mental health systems focused primarily on their perceptions that these systems are large, complex, and often fragmented, and hence challenging to navigate. Insofar as the scale of these institutions necessitates an explicit set of organizational structures, rules, and policies, participants expressed concerns having to do with the ways in which these attributes make communication and coordination within and across these systems cumbersome. Referring to the integration of services, one participant reported that a public mental health services agency “doesn’t allow coordination” while, along similar lines, another pointed to a “struggle to coordinate.” Another participant described the effects of this lack of coordination: “life happens; children with FAS have physical ailments so parents have inconsistent attendance due to appointments at [multiple service providers], which leads to the exhaustion of parents.” In other words, participants felt that services are scattered and provided by an array of service providers who may not always communicate with each other about their clients. This burdens caregivers as they are inevitably forced to act as the go-between for service providers who are not centrally coordinated.

## **DISCUSSION**

The present study aimed to understand the experiences of professionals who work with families of children with FASD and their perceptions regarding the challenges faced by these caregivers in order to inform the development of SEEDS-IT, a preventive intervention for young children with PAE.

### **Perceptions of Caregivers and Systems**

The professionals participating in our focus groups identified a number of specific challenges commonly experienced by caregivers of children with FASD: (1) seeking and potentially receiving a diagnosis for their child; (2) dealing with their emotional responses as they come to terms with how their child has been impacted by PAE; (3) reducing feelings of isolation by finding social support and belonging within a knowledgeable community; (4) coming to a new understanding of their child’s behaviors and learning to effectively manage and sensitively respond to challenging behaviors; and (5) developing their capacity to be their child’s advocate in their local human service systems by building the confidence, knowledge, and skills to educate others, including educational, medical, and mental health professionals, about their child’s condition and related needs. At the same time, participants were cognizant of the many barriers that caregivers face as they attempt to navigate these challenges. On the one hand are practical issues such as lack of time, money, and energy, and on the other, even if caregivers are able to rise to these challenges, different systems of care may not be well-equipped to meet the needs of children with FASD. Thus, we aimed to design SEEDS-IT to equip parents with the knowledge and skills to address many of the challenges commonly faced by families of children with FASD, as well as with strategies for developing more effective partnerships with service providers, as described below.

With these findings in mind, the PEAM component of SEEDS-IT consists of the following sessions: (1) the early developmental effects of PAE; (2) the importance of a stable and nurturing family environment for infants and toddlers with PAE; (3) parenting strategies to support the development of self-regulation in infants and toddlers with PAE; and (4) strategies for effectively accessing and advocating for early intervention services for infants and toddlers with PAE. Each session is a combination of didactic content, parent discussion, and interactive and hands-on activities. As noted earlier, SEEDS-IT is a multi-component, foundational intervention, and the primary aim of PEAM is to lay the groundwork for parents to learn new perspectives, knowledge, and skills regarding PAE and FASD,

which they can then put into practice in RFTS, an attachment-based parenting program, and MT, a music-based, parent-child play group.

### **Understanding and Navigating the Diagnostic Process**

Participants' sentiments about diagnosis in this study are similar to concerns that Duquette, Stodel, Fullarton, and Hagglund raise. They suggest that disclosing a diagnosis "often provided the false hope of a legitimate claim when discussing accommodations [for children with FASD] with school personnel".<sup>52</sup> For those children who receive a diagnosis, this process may help parents better understand their children's difficulties. However, disclosure of the diagnosis to educators does not necessarily impart that same understanding, and as such may not bring about extra supports for the child. When the diagnosis does not yield appropriate supports and services in school, and when educators are not adequately trained to naturally provide them in the classroom environment, the onus is shifted back to parents. In school systems that are routinely stretched to the limits of their available financial and personnel resources, disclosure of a diagnosis and a request for further support may strain these limited and dwindling resources even further. Most teachers and schools likely have the best interests of their students in mind; increased demands on parents may in large part be a function of resource-scarce operating environments and the absence of FASD-specific modalities and interventions to support children with the disability. On the other hand, some participants expressed support for the idea of disclosing the diagnosis under the auspices of informing and educating the educators of their children. For these participants, disclosing the diagnosis was a way to engage educators as collaborative allies by providing detailed, informative explanations about the child's educational and behavioral challenges. The mixed perceptions about disclosing an FASD diagnosis underscore another challenge caregivers may face: receiving variable and at times conflicting guidance from different professionals. Moreover, given the inevitable variability across teachers, schools, and school systems in terms of resources, expertise, and receptivity to collaboration, each parent ventures into unique

territory when attempting to make decisions regarding what information to share in order to best serve the educational needs of their child. Thus, PEAM focuses on enhancing parents' understanding of the FASD diagnostic continuum as well as the evaluation process, and equipping them with information that allows them to be "smart consumers" of diagnostic and evaluation services. Parents are also engaged in interactive discussions about the potential benefits and risks of sharing a diagnosis, as well as strategies for how to share a diagnosis with professionals (e.g., teachers, therapists, etc.) -if they choose to do so- in ways that are more likely to yield benefits for their child (e.g., being prepared to share FASD resources with their child's provider). Rather than presuming to tell parents whether or not they should share a diagnosis, the goal is to empower parents to make informed and thoughtful decisions about if, when, and how to share information about their child with service providers.

### **Managing the Emotional Terrain of Prenatal Alcohol Exposure**

The emotional impact of caring for a child with PAE, whether or not they have a formal diagnosis, is likely a function of a multitude of factors. Focus group participants highlighted that some parents may need support in processing feelings of disappointment when they realize their child cannot meet their expectations, or hopelessness regarding their child's prospects for making progress in overcoming their challenges. Participants also anticipated that some parents might be contending with feelings of guilt and shame. Olson et al.<sup>12,15</sup> have noted that FASD often carry an additional stigma and emotional burden for families beyond other types of developmental disabilities, since the developmental costs of PAE could have been prevented.

The importance of supporting parents and caregivers in dealing with the emotional toll of these disabilities is not only relevant to their own well-being, but also to the family climate in which these children are raised. Previous research has demonstrated that a stable, nurturing caregiving environment is one of the strongest predictors of a better prognosis for children with FASD<sup>2</sup>, but

parents who are stressed, demoralized, and/or ashamed are likely to be compromised in their ability to provide such an environment. Moreover, as some focus group participants noted, some parents may come to view adverse outcomes for their children with a certain degree of inevitability and thus believe there is little they can do as caregivers to set their child on a more positive developmental trajectory. However, Olson et al.<sup>15</sup> have highlighted the critical role that parents can play as change agents in outcomes for children with FASD.

Guided by such findings, an important component of SEEDS-IT is to provide parents with the space and opportunity to reflect on and share the challenges of raising a child impacted by PAE. However, it is important-while validating these struggles-to also help parents develop a sense of efficacy and confidence that they can help their children overcome some of the limitations they are facing. In planning the different topics and activities for PEAM, we believed it was important to strike a balance between acknowledging the very genuine struggles that these families experience, but also empowering them to move forward in productive ways. Thus, we also include discussions and hands-on exercises related to increasing parents' understanding of the importance of the family environment in supporting their children's development, learning strategies for self-care, and recognizing and mobilizing their family's unique set of strengths.

### **Creating a Network of Support**

Focus group participants expressed that the opportunity to connect and share common experiences with other parents would be a critical component of SEEDS-IT. This perspective is consistent with findings<sup>15</sup> that in a sample of parents of school-aged children with FASD and behavior problems, almost 70% of parents reported that their top unmet need was to "discuss feelings about my child with someone who has gone through the same experience." While most parents of children with developmental disabilities would likely benefit from connection with other parents facing similar challenges, this need may be especially heightened among parents of children with FASD given the often "hidden"

nature of this disability, as well as the stigmatization that may accompany the diagnosis.<sup>53</sup> Consequently, the format of SEEDS-IT is designed to promote interactions and connections among parents, and this priority is evident from the outset of the PEAM. Although each session entails a facilitator providing didactic content, there is also a strong emphasis on activities in which parents have opportunities to identify challenges and then collaborate to problem-solve and share their own expertise with one another. Facilitators utilize hands-on exercises in which parents work together in large groups, small groups, and pairs to allow parents to connect in a variety of ways. At times, facilitators allow these connections to form organically, while at other times, they may deliberately seek to encourage interactions between certain parents. For example, they may pair a parent who is relatively new to the world of FASD with a more knowledgeable parent, whereas at other times they may pair up two relatively inexperienced parents who may bond as they tackle unfamiliar ground together.

### **Reframing the Child's Behavior and Supportive More Positive Parenting Practices**

Participants' emphasis on the importance of reframing the behavioral and cognitive difficulties and helping parents to develop more positive and effective parenting practices is a theme frequently highlighted by researchers and clinicians<sup>54,55</sup> working with this population. Parents and caregivers of children affected by PAE have reported finding externalizing and disruptive behaviors, as well as cognitive and social difficulties, particularly stressful to manage.<sup>16,17,56</sup>

Helping them understand that some, if not many, of these challenging behaviors are a function of the impact of PAE on brain development may allow them to respond more patiently and less punitively. At the same time, however, these challenges are real and it is not enough for parents to simply make more benign attributions about their child's behavior. They must also be equipped with concrete skills they can implement to address these challenges. Olson and colleagues developed an intensive behavioral consultant intervention, Families Moving Forward<sup>34</sup> (FMF), for school-aged children with

FASD that has successfully integrated these components. FMF provides both psychoeducation, so that parents come to understand the brain-based nature of their children's difficulties, while also teaching them positive behavior support strategies. We aimed to strike a similar balance in SEEDS-IT, including psychoeducation and interactive discussions on how PAE can impact children's development across all domains, with a particular focus on helping parents understand the early signs of dysregulation that might be seen in their infants and toddlers as a result of alcohol's effect on their children's brains, including irritability, sleep difficulties, impulsivity, and difficulty tolerating frustration. Parents participate in hands-on exercises to help them recognize the importance of considering whether a child's behavioral difficulties might reflect a lack of skill or ability rather than noncompliance, a critical distinction that Malbin has so astutely made about this population<sup>54</sup>, as well as a home activity to better understand what might trigger periods of dysregulation in their children.

In addition to shifting parents' perspectives on their children, a central component of SEEDS-IT is to support parents in developing more effective and positive parenting practices. The foundation for these skills is initially laid in SEEDS-IT PEAM with psychoeducation, interactive discussions, and hands-on exercises. There is a focus on establishing a trusting parent-child relationship and increasing parents' understanding that a critical role for them is to serve as a source of external regulation for their child. Consistent with Green's findings<sup>56</sup> on parents' perspectives regarding helpful parenting practices with this population, SEEDS-IT is designed to teach parents how to create supportive environments for their children, including establishing consistent routines and schedules, and creating organized physical spaces with modulated sensory inputs. SEEDS-IT also includes discussions and opportunities to practice strategies for coaching and supporting young children as they learn to master various developmental tasks.

### **Building Partnerships within Human Service Systems**

Although there has been some progress over the last decade with respect to the capacity of human service systems to care for children affected by PAE and their families, significant challenges remain, as strongly voiced by the participants in our focus groups and as evidenced by other recent studies. One such challenge is the ability of medical professionals to make a diagnosis when appropriate or to even just consider that PAE might account for some of a child's presenting difficulties.<sup>24,27</sup> In a sample from a clinic serving high-risk children and adolescents, especially those in the child welfare system, 86.5% of the children with FASD had either never been diagnosed or had been misdiagnosed.<sup>24</sup> As such mistakes can have important implications for the treatment and services children and their families receive<sup>24</sup>, parents and caregivers will continue to have to push systems to do more to "get it right." Consistent with these findings, clinicians from across Canada with expertise in FASD reported that parents of affected children expressed that among their biggest challenges was the "lack of knowledge, awareness, and training" within "the education system and by service providers" which often led to parents being marginalized or blamed for their children's difficulties.<sup>56</sup> In this same study, clinicians reported their own frustrations regarding the lack of cohesion across services, echoing the concerns of our focus group participants regarding the poor coordination of services across different systems. Thus clinicians within both Canada and the U.S. highlight the necessity for parents and caregivers to proactively engage and build collaborative partnerships with and among the systems and providers who serve their children. However, even if successful partnerships are established, the wide variability in cross-province (or cross-state) and cross-national availability and scope of FASD-related services may pose additional obstacles for caregivers seeking competent providers. Moreover, financial considerations in terms of how the costs for a wide range of services might be covered further complicates this issue, as well, and is compounded in the U.S. as a result of the burden sometimes placed upon caregivers to cover the costs of a range of services.

The fragmentation of care families often experience highlights that it is not enough for parents just to know *that* they need to advocate for their children—they must also know *how* to advocate within complex systems and with different service providers who may vary in their receptivity to collaborating with parents. This priority led to ensuring that SEEDS-IT focuses on equipping parents with the necessary knowledge so that they are better positioned to educate and share information with providers who might have limited experience with this population, including instructional strategies, environmental supports, or teaching resources that might be helpful in working with a child impacted by PAE. Parents in SEEDS-IT are also equipped with the knowledge to refute some of the common misconceptions that parents encounter, such as the assumption that a child must show physical sequelae (e.g., facial dysmorphism) to be affected by PAE. In addition to building their knowledge of PAE and FASD, parents in SEEDS-IT learn concrete strategies for engaging service providers in a more proactive and organized manner, including preparing sets of questions ahead of assessment and therapy appointments, creating systems for organizing their child's records, and developing initial treatment goals for their child and their family that they refine in collaboration with their service provider.

In line with the concerns expressed by our focus group participants about the capacity of educational systems to support children with FASD, other research has documented a dearth of training, awareness, and resources within schools to assess and accommodate children, and more broadly, the constant effort required to ensure that children with FASD do not fall through the cracks in the public school system.<sup>57</sup> In a qualitative examination of the advocacy practices of adoptive parents of children with FASD, Duquette et al. point out that “parents... commented that advocacy is required because their children's disability is usually invisible and teachers attributed weak academic performance and inappropriate behavior to poor parenting and not the disability”.<sup>52</sup> In a series of focus groups with educators, caregivers, and other professionals, Job et al.<sup>58</sup> found that educators' knowledge of the issues associated with FASD falls short of the

available information, and proposed that being under-trained in effective teaching methods for children with FASD will constrain educators' ability to collaborate with families and provide appropriate teaching. In a study conducted of Toronto's school system, Koren, Fantus, and Nulman<sup>59</sup> observe similar issues: educators were uninformed about the effects of PAE, confirmed that a formal diagnosis did little to garner additional support, and were unsure how to effectively teach children with FASD. While there may be some differences between the education systems of the U.S. and Canada, there are also clearly some similarities in the issues faced by children with FASD as they move through education systems.

Such findings highlight the need for parents to advocate for their children throughout their school experiences, and we believed it would be important to prepare parents in SEEDS-IT for the challenges ahead of them as their children enter formal schooling. However, we also anticipated that parents of infants and toddlers impacted by PAE would face a distinct set of challenges that may be less salient for parents of school-aged children. That is, parents and caregivers of young children affected by PAE may be attempting to transform into strong advocates at the same time they are just beginning to understand that their children may be facing serious developmental challenges, and they may be relatively early in the process of grieving or coming to terms with the reality of their child's limitations. Some parents—especially first-time parents or those who have not parented young children for many years (e.g., grandparents)—might have limited knowledge of typical versus atypical development, and may be wrestling with questions about whether certain behaviors are normative or should be viewed with concern. Additionally, these parents more often face uncertain futures with the young children they are caring for since custody issues are often not resolved, and issues of potential loss might loom large. Consequently, in designing SEEDS-IT, we aimed to strike a balance in preparing parents for some of the future hurdles they will face, while also supporting them in dealing with the challenges that they may confront more immediately. Thus, one focus of SEEDS-IT is to

educate parents about the process when their children transition from the services provided by state-funded developmental disability centers to the supports provided through school, including special education services and ways in which their children might qualify for such services (since a diagnosis along the FASD continuum is not typically a qualifying diagnosis). However, we have also designed SEEDS-IT to promote a better understanding of typical development across domains (e.g., cognitive, language, socioemotional, motor), how PAE might affect development across those domains, and how those developmental challenges might manifest in daycare or early education settings. Parents are also provided with written materials regarding how to access early education or intervention services, how to navigate the special education process, as well as resources they can share with early childhood educators. Although we anticipated that such practical content would be valuable, we also believed it would be important to provide opportunities for parents to share strategies for dealing with some of the educational challenges parents of children this age commonly encounter, including daycare or early education staff having limited (or no) understanding of PAE, and for foster and adoptive parents, having limited rights to pursue early education or intervention services but recognizing the importance of getting the child services as early as possible.

## CONCLUSION

This study's focus groups generated important perspectives about the challenges caregivers for children with FASD may face in caring for their children and navigating human service systems.

These perspectives were offered by professionals and service providers who work with families of children with FASD, and thus represent their observations of the kinds of challenges parents or caregivers face. However, it is important to note that parents themselves have identified many of the same challenges in other studies. While the participants in this study were affiliated with a range of service agencies, the possibility remains that the results of this study were influenced by the small geographic scope of recruitment, the particular demographics of the

participants, or by idiosyncratic facets of their own experiences, among other possible variables. Indeed, each participant had their own unique vantage point, but in the analysis, consistent themes emerged. Focus groups participants shed light on barriers across the landscape of human service systems, and identified how such barriers may circumscribe caregivers' expectations, needs, and experiences. The themes reflecting these perceptions that arose in our analysis directly informed the conceptualization and development of SEEDS-IT, and the PEAM component, in particular. Given our findings, it is clear that new interventions for children and families affected by FASD must prepare caregivers to efficaciously engage providers and systems to insure that children receive appropriate care.

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