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The best possible start: A qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders

Misty Pruner^{a,*}, Tracy Jirikowic^a, Kathryn M Yorkston^a, Heather Carmichael Olson^b^a School of Medicine, Department of Rehabilitation Medicine, Box 356490, University of Washington, Seattle, WA, 98195, USA^b Seattle Children's Research Institute, 2001 8th Ave, Seattle, WA, 98121, USA

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ABSTRACT

Background: The developmental outcomes and life course trajectories of young children with or at-risk for fetal alcohol spectrum disorders (FASD) can be optimized when individual and family needs are identified early and met with family-centered early intervention (EI) services. However, little is known about access to and quality of EI services with this high-needs population.

Method: Twenty-five biological or adoptive parents of children with or at high risk for FASD, living in the greater area of Seattle, Washington participated in this qualitative study. Three focus groups were conducted using a semi-structured interview guide. Participants described their experience with EI, as well as other supports and challenges faced in their child's first three years of life. Interviews were audio recorded, transcribed verbatim and coded using phenomenological methods. Themes that were consistent across participant groups emerged from the data, as well as themes that showed differences among participant experiences.

Results: Common EI supports and needs between biological and adoptive parent groups were identified. In addition, perspectives and needs unique to each parent group were revealed. Themes were identified and organized into three categories: (1) child needs; (2) parent needs and priorities; and (3) EI capacity. When parents talked about their child's cognitive, physical, communication or adaptive development, they all discussed how EI was meeting those needs. In contrast, when parents expressed concern for their child's social-emotional development, a description of how EI was supporting these needs was missing from the conversation. Parents appreciated when EI providers were truthful, provided anticipatory guidance, and connected them with supports for their own social-emotional well-being. Yet there were unmet needs for respite care, and parents expressed that support for basic needs related to child or family survival was not consistently recognized as a top priority for families. This high-risk group of young children and their parents also encountered a multitude of transitions in their child's early years and later. Parents wanted more support navigating these transitions as they entered or moved through different systems of care.

Conclusions: Parents appreciated and endorsed the importance of EI with its provision of individualized, family-centered supports and resources. Examination of the gaps and unmet needs that are common and distinct underscore the importance of an FASD-informed approach to EI.

* Corresponding author.

E-mail addresses: mpruner@uw.edu (M. Pruner), tracyj@uw.edu (T. Jirikowic), yorkston@uw.edu (K.M. Yorkston), heather.carmichaelolson@seattlechildrens.org (H.C. Olson).

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Study findings provide insight into areas for which EI enhancements could be developed in order to tailor supports for the complex needs of this diverse population of children and parents.

What this paper adds

This study highlights the converging and diverging needs of biological and adoptive parents raising young children with or at-risk for FASD.

In line with growing literature on infant and early childhood mental health, findings reinforce the need to advocate for EI approaches that prioritize and promote social-emotional development of young children in this population.

This study reinforces the importance of EI and its commitment to provision of family-centered supports and resources, but also draws attention to unmet needs given challenges raised by family circumstances in this vulnerable group.

1. Introduction

Young children with prenatal alcohol exposure (PAE), and those diagnosed with fetal alcohol spectrum disorders (FASD) are at increased risk for lifelong, neurodevelopmental disabilities (Cook et al., 2016). FASD is an umbrella term for the full range of conditions, including fetal alcohol syndrome, associated with the teratogenic impact of PAE (Mattson, Bernes, & Doyle, 2019). Damage to the developing fetus is permanent and extends into several domains of brain function including cognitive, communication, motor and social-emotional functioning (Reid et al., 2015). Developmental outcomes are further complicated by other prenatal substance exposures commonly found in children born with PAE (Astley, 2010), as well as postnatal environmental risk such as abuse, neglect and multiple home placements (Lander, Howsare, & Byrne, 2013; Olson, Jirikowic, Kartin, & Astley, 2007). Not surprisingly, children affected by FASD are likely to experience adverse life outcomes in adolescence and adulthood. These may include mental illness, disrupted school experiences, involvement with the law and alcohol and drug problems (Popova, Lange, Burd, Urbanoski, & Rehm, 2013; Streissguth et al., 2004). Moreover, current efforts to track the prevalence of FASD, which vary based on geography and method of diagnosis, indicate the significance of this public health problem. A recent systematic review and meta-analysis estimates global FASD prevalence at 7.7 per 1000 children in the general population (Lange et al., 2017). An alternate method for determining prevalence, active case ascertainment in schools, found prevalence rates in the U.S. general population are higher with the total rate of FASD estimated at 24–48 per 1000 children (May et al., 2014). Even more alarming are the especially high rates of FASD documented among children in foster care in the United States and Canada, where prevalence rates have been found to be 10–15 times higher than in the general population (Astley, Stachowiak, Clarren, & Clausen, 2002; Popova, Lange, Burd, & Rehm, 2014).

FASD can have profound consequences for both the exposed individuals and their families. Parents of children with FASD experience a heavy burden as they try to manage the day-to-day challenges of their children's disabilities, obtain needed services, and cope with providers and community members that often have limited knowledge of FASD (Chamberlain, Reid, Warner, Shelton, & Dawe, 2017; Olson, Oti, Gelo, & Beck, 2009; Petrenko, Tahir, Mahoney, & Chin, 2014). A distinct set of challenges faced by families of children with FASD, including biological parents, adoptive, and foster caregivers, include high levels of parental stress, perceived lack of support within their community and, in general, being under-equipped to manage these lifelong deficits (Baskin, Delja, Mogil, Gorospe, & Paley, 2016; Jirikowic, Olson, & Astley, 2012; Paley, O'Conner, Frankel, & Marquardt, 2006). Given the far-reaching nature of this set of conditions and the widespread prevalence of FASD, it is essential that parents and providers from multiple systems of care work together to create the best possible start for this population.

What exactly does the best possible start look like for these families? A small but significant set of personal and environmental protective factors have been identified in the literature. Being reared in a nurturing, stable home environment, provision of an early and meaningful diagnosis and access to early intervention (EI) are of paramount importance for enhancing life outcomes for young children and families affected by PAE (Reid et al., 2015; Streissguth et al., 2004). Yet, putting these protective factors in place presents considerable challenges for the team of professionals supporting these families. For example, the quality of EI services being provided to young children at high risk for FASD due to PAE is variable, where many of these children are often being missed, misdiagnosed, or not treated at all (Chasnoff, Wells, & King, 2015). EI providers often do not recognize that young children are exposed or affected, and rarely provide care informed by knowledge about FASD or PAE (Olson et al., 2007; Petrenko, 2015). EI providers lack FASD-specific training to recognize the effects of PAE in young children, and this limits their ability to provide vital EI services tailored to the complex needs of these vulnerable children and families.

Determining how to improve training and service quality requires input from the groups of people to whom it matters most. There has been a call for the increased presence of key stakeholders' voices in educational decision-making involving children with FASD (Duquette, Stodel, Fullarton, & Hagglund, 2006), as well as more generally in FASD research (Brown, Harr, Morgan, Varga, & Fenrich, 2017). The value of an "insider perspective" has been emphasized, given useful findings derived from qualitative research with parents raising children with FASD. Themes related to prevention of secondary conditions, motives for fostering alcohol-exposed children and birth mothers' experiences related to systems of care (Brown, Sigvaldason, & Bednar, 2007; Petrenko, Tahir, Mahoney, & Chin, 2014; Salmon, 2008) have emerged, guiding researchers in development of holistic interventions. What remains to be explored, however, is the insider perspective on the vital EI system. Information is needed on how parents of children with or at risk for FASD

experience EI, and how child and parent needs are currently being addressed. By recognizing parents as experts, potential areas for program enhancement can be identified and FASD-informed approaches to EI can be created.

The purpose of this study was to: a) identify characteristics of EI practice that are both supportive and challenging for parents; b) identify gaps within the current EI system of care; and c) use findings to define training and competency needs for EI providers working with this high-needs population.

2. Methods

This qualitative inquiry utilized a phenomenological approach to gather the lived experiences of parents during their child's first three years of life. A phenomenological approach attempts to understand people's perceptions and experiences (Marshall & Rossman, 2014). In this case, the phenomenon of interest was the experience of EI from the parent's vantage point. A phenomenological research approach uses guided interviews with broad and open-ended questions, allowing participants to share information they deem most important. Researchers, using this approach, engage participants to describe and reflect on their reality by positioning themselves as experts. A phenomenological approach is an inductive process that focuses solely on the lived experience and is uncomplicated by clinical judgement or theory (Colaizzi, 1978).

2.1. Participants

Participants included adoptive or biological parents of children with or at high risk for FASD, residing in the greater Seattle, Washington area of the United States. Twenty-five parents were recruited from three settings, including a local EI agency, a family support group and a pregnant and parenting women (PPW) residential treatment program. Participant ages ranged from 19 to 63 years ($M = 36.8$, $SD = 11.6$).

The biological parent group ($N = 15$) was comprised primarily of mothers who were receiving addiction treatment at the PPW program and had been in recovery for 6 months or less. As part of this comprehensive treatment program, children under the age of 5 years lived with their mothers at the residential center. Therapeutic childcare and parenting support was provided during their stay. Children of the biological parent group ranged in age between 1 month and 22 years old (mean = 6.44, standard deviation = 7.15). The adoptive parent group ($N = 10$) was comprised of eight adoptive parents and two close relatives of an adoptive child. There were three married couples in the adoptive group. With one exception, all members of the adoptive group had older children ranging in age

Table 1
Participant demographic characteristics.

Demographic Variable	
Parent Type, <i>n</i> (%)	
Biological parent	15 (60)
Adoptive parent	8 (32)
Relative of child	2 (8)
Parent Age, years (<i>SD</i>)	
Total mean age	36.8 (11.6)
Biological parent group	29.67 (8)
Adoptive parents group	47.4 (7.3)
Mean Age of Children, years (<i>SD</i>)	
Biological children	6.44 (7.15)
Adoptive children	22.44 (13.86)
Biological Sex, <i>n</i> (%)	
Female	21 (84)
Male	4 (16)
Mean # of children in family, <i>n</i> (<i>SD</i>)	
Biological parent group	2.2 (1.89)
Adoptive parent group	4.8 (5.16)
Race/Ethnicity (non-exclusive categories), <i>n</i> (%)	
Caucasian/White	23 (79)
African American/Black	1 (3.4)
Hispanic/Latinx	1 (3.4)
American Indian/Alaska Native	2 (6.9)
Other	2 (6.9)
Parent Partnership Status, <i>n</i> (%)	
Single	8 (32)
Married or in partnership	15 (60)
Separated or divorced	2 (8)

Table 2
Themes, sub-themes and examples of issues discussed by participants.

Theme	Sub-theme	Common to both parent types	Biological parents	Adoptive parents
Child Needs	Developmental concerns*	Diversity of developmental needs; EI is addressing these needs	Worried that their use "messed up" their child	Developmental gap continues to widen with age
	Social-emotional concerns	Child social-emotional concerns were raised	Concerns related to attachment and regulation were mentioned, however, a description of how EI was supporting these needs was noticeably absent in discussion	Some acknowledged that early adverse childhood experiences were not addressed by EI
Parent Needs & Priorities	Survival first	Parents not focused on child's unmet milestones; instead focused on survival	Self- and/or family-related survival is priority, given real-life stressors and problems of living	Child-related survival is priority, given early and intense medical needs
	Desperate for respite	Parents needed relief; Lack of respite and childcare	Need childcare to obtain and sustain employment	Limited options and long wait times for respite were discouraging
	Social emotional supports	Peer and family support is highly valued; Family supports not always available or welcome	Mothers in recovery value peer-support groups with supportive facilitators	Parents' social-emotional needs overlooked during EI period
EI Capacity	Truth and Guidance	Valued providers who shared the truth and helped manage expectations	Valued developmental guidance by trusted providers	Looking for a reality check from their provider
	Facilitating Transitions	Need help navigating systems of care	Do not know where to go or how to ask for help; some engaged in extreme behaviors in attempt to access help	Felt unprepared to advocate for their child

* other than social-emotional concerns.

between 6 and 56 years old (mean = 22.44, standard deviation = 13.86) and almost all had graduated from EI services. Consequently, participants in this group answered interview questions retrospectively. Demographic information, obtained from a participant questionnaire, is summarized in [Table 1](#).

When children “at high risk for FASD” are described within the context of this study, the authors are referencing the group of children living with their mothers at the PPW program. Because this group of mothers was seeking treatment for alcoholism and drug addiction, the exact type and nature of prenatal exposures was unclear, but clearly of clinical concern. Findings from a large clinical population document that a high proportion of children with PAE have co-occurring polysubstance exposure among other adversities ([Astley, 2010](#)) and for this reason, children of mothers at the PPW were considered “at high risk for FASD”.

2.2. Procedures

Data collection occurred over a 3-month period in 2017. Human Subjects Division approval for the study was obtained from the University of Washington Institutional Review Board. Three focus group meetings were conducted by authors MP and TJ. To ensure participants felt comfortable expressing their views, focus groups were exclusive to either biological parents or adoptive parents. Two biological parent focus groups took place in meeting rooms at the PPW residential center and one adoptive parent focus group was conducted at a community center where the support group met regularly. Group sessions averaged 90 min, although one group met for two hours. The pilot interview and adoptive parent focus group were conducted with one author in a lead role and one in a supporting role. The two focus groups of mothers at the PPW were carried out simultaneously; each conducted by one of the two interviewing authors.

2.3. Pilot and Focus group interviews

A semi-structured interview guide, created for this study, was first piloted with parents of a child with FASD. Data collected from the pilot interview was included in the data analysis. Focus group interviews with parent groups were conducted within the next three months. Each focus group interview began with a definition of EI to ensure a shared interpretation of the term. EI was described as “services or therapies provided to a child in their first three years of life that support motor, speech and language, cognitive and/or social emotional development”. Once the study purpose was explained, participants were recognized for their expertise as parents and informed that their input would guide decision-making for improvement of EI services. Participants signed a written agreement consenting to the interviews and were told they could end their participation at any time.

Using open-ended questions, the interview began with the grand tour question: (1) What has been your experience, if any, with early intervention and your child? Next, participants were asked: (2) Can you talk about any of the supports or challenges your family may have faced in your child’s first three years of life; (3) Do you feel like your child’s developmental needs were met; and (4) Do you feel like your needs as a parent were met? Interviewers provided prompts, as necessary, to obtain a rich description of parents’ perspective on their experiences during the EI period.

2.4. Data analysis

Focus group interviews were audio recorded and transcribed verbatim. All transcripts were independently reviewed by two members (MP, TJ) of the research team. Grounded in participant responses, a coding scheme emerged based on the transcripts themselves. The transcripts were uploaded and coded in Dedoose ([Dedoose Version 6.1.18, 2017](#)). To ensure trustworthiness of the data, all interviews were coded by the first author (MP), while the second author (TJ) coded ~ 40 % of the interviews using a constant comparison technique ([Anderson, 2010](#)). For example, each coded excerpt was compared to previously coded excerpts and necessary changes to the coding scheme or interpretation were made. The rare occurrences of disagreements were resolved by

Table 3
Participant Characteristics.

	Participant ID	Sex	Child with FASD diagnosis*		Participant ID	Sex	Child with FASD diagnosis*
Adoptive	VO	F	+	Birth	UE	M	+
	UF	F	+		PP	F	-
	MJ	M	+		YV	F	-
	LC	F	+		FV	F	-
	EK	F	+		YL	F	-
	WP	M	+		BF	F	-
	FC	F	+		TZ	F	-
	WN	F	+		LF	F	-
Relative	KP	M	-	GC	F	-	
	HU	F	-	JK	F	-	
				VI	F	-	
				PN	F	-	

M = Male; F = Female.

* Per parent report; children without an FASD diagnoses are considered at high risk for FASD.

consensus. Together, the authors organized the coded excerpts into meaningful clusters and identified emerging themes. Analysis in this manner aims to provide an honest and accurate representation of participant perspectives, while establishing rigor within a qualitative framework.

3. Results

Three primary themes and eight sub-themes emerged (see Table 2). Biological and adoptive parents expressed converging and diverging perspectives on their experiences with EI. Themes common to both groups, as well as those exclusive to each parent group, were explored. Direct quotations were used to illustrate participant perspectives in support of the derived themes. Randomly-generated initials were assigned to participants and then linked to participant quotations (see Table 3).

3.1. Theme 1: child needs

The first theme, *child needs*, reflected parental experiences and perceptions of their child's early development and incorporated two sub-themes: *developmental concerns (other than social-emotional concerns)* and *social-emotional concerns*.

Developmental concerns (other than social-emotional concerns)

Participants from both parent groups reported a wide range of developmental concerns. Some parents worried about delayed motor milestones such as learning to crawl, walk or point at objects of interest. Other parents were concerned about their child's expressive or receptive communication. For example, FV commented about her toddler: *"She'll sit there and babble to me, and she's trying to say something but I'm just like, 'huh?'...she's trying to communicate but I just don't understand her."* Concerns for vision, hearing, sensory processing, sleep and school readiness also emerged.

When parents talked about their child's cognitive, physical, communication or adaptive development, they jointly discussed how some type of EI or early childhood programming was adequately addressing those needs. For example, one parent explained how her child's delays were addressed by the therapeutic childcare provided at the recovery center. YV said *"...when my baby came here, she wasn't crawling. Now she's crawling. She can point, she picks up food and feeds herself. She dances, and that's all stuff she does downstairs."* Another participant, FC, described the many services involved in her son's care: *"We had social workers, we did [occupational therapy] and [physical therapy] and everything you could think from the whole get go...we had every intervention from the very beginning."* These examples highlight the positive impact and availability of early supports experienced by some families from both parent groups.

Diverging perspectives among parent groups were also expressed. Some biological parents, for example, found it difficult to acknowledge their child's delay in light of their prenatal substance use. GC felt worried when her son qualified for EI services and admitted that the *"biggest fear is that you messed up your kid from your use"*. Many mothers staying at the PPW program were concerned about making mistakes in their parenting as expressed in this statement from PN: *"This little child is special and I just don't want to get nothing wrong. You know? It's hard."* Comparatively, many adoptive parents described how the developmental gap continued to widen as their child got older, especially when compared to typical siblings or peers. For example, MJ recalled thinking there was a trend in which his child's developmental age *"was half of his chronological age...when he was one, we realized he was six months behind...and when he was five, we realized he was two and half years behind...the trigger goes off when you see another kid the same age."*

3.1.1. Social-emotional concerns

To build rapport with participants at the beginning of the focus groups, parents were asked to describe what they enjoyed most about their child. All parents eagerly shared positive and loving qualities about their child(ren) including qualities that centered on relationships. For example, many parents affectionately described the bond between siblings or cherished moments of cuddling with their child. One mother, FV valued moments of laughter with her daughter: *"Yeah I love everything about my daughter...the best things is when we are just sitting there and laughing together. She'll bump her head on the wall and I'll chuckle, and she'll start cracking up. Things like that, like I'm laughing with her like she's a friend."* Likewise, some parents valued qualities in their child that centered on regulation. BF appreciated her child's ability to self-soothe: *"I like how she can already soothe herself and she can put herself to sleep. I can put her in her crib and she'll just play...and flop around and then all of a sudden, I'll look over and she's sleeping. I'm like cool, that was easy."*

In addition to parents finding value in their child's social-emotional attainments, they also expressed concern for their child's social-emotional well-being. For example, some adoptive parents believed that adverse childhood experiences, occurring prior to the child's arrival in their foster or adoptive home, were not addressed by intervention services. UF shared the following experience about her two-year-old son's behaviors: *"early on, what would've been most helpful is just respite and [parenting] support to help with [son's challenging behaviors]. Of course, all the [challenging behaviors] were developed before we got him. They were horrible. There were multiple placements."* Some biological parents, on the other hand, worried about their child's maladaptive coping when child protective services (CPS) was involved. VI explained, *"He would just scream and I thought it was... just the case I had going on with CPS and being in foster care. Then he would be really, just like the weirdest things, like he'd be put down, he'd freak out. Pick him up, he'd freak out."* When statements like this were made, suggestive of insecure attachment or trauma-related behaviors, it was notable that the conversation lacked a description of how EI was supporting the child's social-emotional needs. This was not the case when parents talked about their child's other developmental needs.

3.2. Theme 2: Parent needs and priorities

The second primary theme was *parent needs and priorities*, which revealed unmet needs and first priorities for parents during the EI

period. The three sub-themes that fell under this category included *survival first*, *desperate for respite*, and *social-emotional supports*.

3.2.1. Survival first

All parents talked about how overwhelmed they felt in the early days, months and years of their child's life. Equally noticeable was each group's focus on "survival" during the EI period, however experiences between parent groups looked very different. For example, parents from the adoptive group recounted intense experiences of their child's complex medical conditions; conditions that included chronic heart problems, gastroesophageal reflux disease, and necrotizing enterocolitis. Traumatic stories of early and extended hospitalizations were also shared. WP reflected back on his child's health during the EI period: *"He wasn't really thriving. He was dying"*. During these stressful times, parents were clearly focused on their child's survival rather than their child's unmet milestones. An excerpt from EK details this experience: *"To have him be so intense for so long, you just sort of get numb...now we feel like we're doing ok. No, he can't talk and he can't do all this stuff, but look it, he's alive!"*

Biological parents, on the other hand, emphasized the enormous pressures of meeting everyday demands of living such as homelessness, unemployment and securing childcare. Maintaining sobriety only compounded their stress. EK admitted that *"if I had to go back to living like I was [homeless], there's no way I could do it sober...and I couldn't do it with kids either"*. Another cause for concern was how one parent linked her family's negative life consequences with a lack of housing. LF commented: *"because of my choices, and the fact that I was still living an addict life, the situation I have with my son, I have with my son. But I feel like it could've been prevented if I had more resources for housing."* Given the real-life stressors and problems of living encountered by this biological parent group, self- or family-related survival was of primary focus.

3.2.2. Desperate for respite

Participants expressed feelings of stress and exhaustion when describing the day-to-day challenges of managing their child's behaviors and needs. In the case of biological parents, respite often took the form of childcare so that employment could be obtained and sustained. This was especially true for single mothers. FV explained: *"I didn't have babysitters. My son was under a year old...I don't have family support to...watch my son...I can't go back to work and get a house myself. If I could go back to work, then I'd be able to pay my bills by myself"*.

In contrast, adoptive parents wanted respite because it brought relief from the continuous support and care of their child(ren). One couple revealed the intensity of their child's behaviors and their need for a break: *"We were being hit, kicked, spit on, all these things going on and you just need a break from that"* (UF & WP). One parent was so exhausted that she knowingly sent her child to preschool with an ear infection. The two-hour preschool day was this mother's only option for a much-needed break. Other adoptive parents expressed a desire for more time to connect with their spouse. Finally, many parents in the adoptive group conveyed how difficult it was to acquire respite care. WN recalled the extremely long wait time for respite and said this of her husband's experience: *"He didn't even fill out the paperwork, he was just so discouraged. It feels so far out there and you kind of want that relief now. When you're looking for respite, you need it."*

3.2.3. Social-emotional supports

Both parent groups valued connection with other parents that had been through a similar journey. These connections were often made during support groups, where parents explained that they could talk freely without fear of being judged. Adoptive parent LC explained: *"I think if it wasn't for this group, [where] we could sit and laugh about our crazy lives, I don't know where I would be."* Several parents in the biological parent group appreciated the exchange of ideas between more experienced parents and parents new to the group: *"So it is just nice to have people here who have been through it, when you don't know what you're in for"* (YL). Another parent discovered that sharing ideas with others helped process her own thoughts and expectations for her child.

Social-emotional supports for the parent were especially important when family supports were not available or welcomed, a sentiment heard repeatedly from both parent groups. For instance, one biological parent revealed the generational differences that existed between herself and her parents. When BF discussed her child's need for therapy services with her parents, she did not feel supported: *"But my parents looked at it like...she doesn't need none of that. She'll be fine. I wasn't fine. I'm not fine."*

Interestingly, many adoptive parents felt that their own emotional needs had been overlooked during the EI period. To illustrate this point, VO suggested *"one of the most valuable things...that [intervention] could help with, would be building a support network, family to family, where kids could meet other kids that were like them, especially as they get older, and where parents could meet other parents, and where apologies wouldn't necessarily be necessary."* In contrast, many of the mothers in recovery recognized the importance of their early support: *"Dealing with recovery...on top of being a mom, and pretty much all of us are on our own...those are three huge things, and I feel like early intervention and the support we get here, all the different resources and each other is key"* (TZ).

3.3. Theme 3: EI capacity

The third primary theme, *EI capacity* identifies what caregivers needed or expected from providers, and thus potential areas for practice enhancement. In this category, two sub-themes emerged including *truth & guidance* and *facilitating transitions*.

3.3.1. Truth & guidance

All parents valued providers who shared the truth and helped to manage their expectations accordingly. This looked different for each parent group. In the case of the adoptive group, parents were looking for a reality check from their providers. For example, MJ felt misguided when providers did not explain the full implications of his son's diagnosis: *"Nobody explained to me early on...your loved*

one has FAS, but they didn't explain what that meant. I would sit there and think, so that just means I have to work extra hard at doing what I did for my typical children?" Adoptive parents also wanted anticipatory guidance from their EI team as powerfully articulated by VO: "As parents, I would rather know that this is going to be the hardest job that I'm ever going to have to do, than to tell me that this is all going to be fine, because then I go home that day and it's not fine, then I feel like a loser. I feel like I'm the one that's not making it." When guidance was offered by providers who listened and maintained an empathic stance, adoptive parents felt a sense of relief and hope. One mother, LC, appreciated when her provider recognized her many roles and responsibilities: "and she told me, you're the mom. Be the mom. Let us take care of the other stuff. Best advice, because I don't think I could've done it all". Not surprisingly, biological parents felt defeated when they sensed judgement or lack of appreciation for family circumstance from their providers. EK admitted: "when you feel that as a parent, it depresses you. You feel beaten."

Discussions with biological parent groups focused on the value of developmental guidance when delivered by a trusted provider. Parents appreciated when child behaviors were framed in the context of early experiences. One parent, VI, felt more capable of managing her son's challenging behaviors when she understood them in the context of his early adverse experiences: "it wasn't necessarily that [child] had an issue...with his sensory, but that he had a problem with...the situation and circumstance."

3.3.2. Facilitating transitions

A wide range of transitions was discussed by both parent types including leaving the recovery center, baby's hospital to home transition, preparing for and accepting an FASD diagnosis, changing providers, and moving from birth to three services to the education system. As a general rule, parents did not feel adequately prepared as they moved between systems of care.

In particular, biological parents struggled with accessing systems of care for their child and themselves, not knowing where to go or what kind of help to ask for. One mother, JK, was so desperate for help that she called CPS for herself: "I had to go to get services with CPS from January to April just so that I could get help, because we were homeless and I didn't know what else to do, and there was nothing out there." Another mother felt like her behaviors had to be extreme before supports would be available to her: "Like I have to go out and use drugs and be a problem before somebody will help me"(PP).

On the other hand, adoptive parents spoke about feeling overwhelmed by too many resources. This was especially true when lists of resources were handed to parents after receiving a diagnosis for their child. There was mounting stress as parents struggled with navigating, pacing and prioritizing action steps following a diagnosis. Adoptive parents also felt unprepared to advocate for their child. One parent advised: "You need to kind of be a loud voice. I think just giving parents that expectation to be ready to fight, because you might need to" (TZ).

4. Discussion

The life course trajectories of children born prenatally exposed to alcohol can be enhanced when interventions occur early in life and take advantage of plasticity in the developing brain (Hannigan et al., 2007; O'Leary-Moore, & Berman, 2007; Reid et al., 2015). To alter life course trajectories in a positive direction, participation in EI services is crucial. Through personal stories and reflection, the strengths and challenges of EI services, as perceived by parents of young children with or at high risk for FASD, were explored. Results from this study highlight components of EI practice that are supportive for this population, while also uncovering an array of unmet needs that deserve acknowledgment and attention.

Parents described how formal EI services or other early childhood programs addressed important developmental concerns about their child's motor, language, sensory, cognitive and adaptive functioning. The children raised by adoptive parents had all participated in EI. In contrast, it was unclear how many birth parents had engaged in formal EI services, beyond the supports provided by the PPW program. Building capacity for EI systems of care that are FASD-informed and shaped by referral guidelines outlined in Bertrand, Floyd and Weber (2005), which include acknowledgement of social and family factors associated with parental substance abuse and adversity, are a high priority to ensure that more children at high-risk for FASD are identified and receive targeted interventions within this critical window of neurobehavioral and social-emotional development.

Importantly, parents described how child social-emotional needs were not fully or clearly addressed. Findings revealed parents' tendency to discuss their child's developmental progress in the context of intervention supports. However, EI system responses to their child's social-emotional needs and supports were rarely mentioned. Growing evidence from the field of infant mental health demonstrates the crucial role of early attachment relationships in young children's emotional, social and cognitive development (Osofsky & Thomas, 2012; Schore, 2001), and the positive influence of secure attachment on parental behaviors and emotions (Jones, Cassidy, & Shaver, 2015). Indeed, research with children impacted by complex trauma suggests developmental competencies can only be built when a foundation of safe and secure attachment exists (Arvidson et al., 2011). The Attachment, Self-Regulation and Competency (ARC) Framework (Arvidson et al., 2011; Kinniburgh, Blaustein, Spinazzola, & Van der Kolk, 2017) suggests that intervention for vulnerable populations should progress in a stepwise fashion, in which building a safe attachment system is prioritized ahead of acquiring age-appropriate competencies. Taken together, developmental science highlights the importance of promoting social and emotional well-being, in partnership with parents, that should precede the focus on developing age-appropriate competencies.

Understanding why parents did not clearly acknowledge specific interventions associated with social-emotional development requires further inquiry. One possibility is that social-emotional needs were not directly addressed. Given that many of the adoptive parents were reflecting on their experience with EI retrospectively, our findings may not reflect current or evolving EI practices that emphasize relationship-focused interventions (Auerbach, 2015). A second possibility is that child and parent social-emotional needs were supported by EI services, but were not explicitly recognized as such by the parents, or that these needs were so complex that

more supports were needed. Further research should examine the degree of comfort and competency EI providers have in providing direct support for social and emotional development of families with complex needs that are related to substance abuse.

Parents from both groups expressed common needs and worries, in tandem with diverging needs and sources of strain. Both sets of parents were immersed in turmoil related to child or family survival during the EI period. Biological parents faced significant socioeconomic stressors such as obtaining housing, employment, and fulfilling material needs essential to physical and psychological well-being. A large part of focus group discussions centered on these problems of living, suggesting that, for biological parents, these issues were foremost in their minds. Along these lines, many adoptive parents admitted to feeling all-consumed by their child's intense medical needs and survival during those early years. It follows that a parent's capacity to support their child's development will be undermined when they lack support for their own circumstances and well-being (Lieberman, Ippen, & Van Horn, 2015). This line of reasoning runs parallel to Maslow's "hierarchy of needs" theory which proposes an individual can only realize personal potential once lower level needs have been satisfied (McLeod, 2018). Further compounding these problems were unmet needs for respite and lack of support in navigating systems of care, which appear to be prevailing needs over time (Olson et al., 2009). These findings support the assumption that parents find it difficult to remain attuned to their child's development when personal resources are depleted. Our findings support interventions that are family-centered, teach advocacy, and provide concrete assistance for family circumstances and parent well-being. EI models and services that are flexible and responsive to complex family needs, as well as anticipate changing priorities and multiple transitions, are additional features that may support FASD-informed EI on a broader level. Further research is needed to examine ease of access, as well as the availability and usefulness of resources for this vulnerable population.

Important variables associated with the parent-provider relationship were also highlighted, including those that compromise the quality and effectiveness of the partnership. Negative or blaming judgement towards a parent, for example, caused parents to feel defeated. In contrast, parents who received empathic support from their provider felt reassured and hopeful. A study of pregnant and parenting women using substances and their young children revealed that a multilevel relational approach to service, where providers model relationships that are safe, and demonstrate empathy, kindness and compassion, was associated with improved parent, child and dyadic outcomes (Andrews, Motz, Pepler, Jeong, & Khoury, 2018). Speaking truth about the lifelong struggles associated with FASD was something parents also wanted and expected from their EI providers. Providers offering accurate developmental and anticipatory guidance allowed parents to establish realistic expectations for their child. Findings point to the value inherent in providers clearly understanding potential long term outcomes for this clinical population, and appreciating how risk and protective factors influence development over time. A lack of knowledge and understanding of FASD has been reported among trainees and professionals across multiple systems of care (Eyal & O'Connor, 2011; Payne et al., 2005; Petrenko et al., 2014a), but this may be only part of the problem. Discussing sensitive topics (e.g., the risk for developing alcohol and drug problems later in life) can be uncomfortable for providers and emotionally laden for parents. It is possible that providers find it easier to talk about resiliency and positive outcomes, rather than risk offending a parent when talking about potential adverse life consequences (Substance Abuse & Mental Health Services Administration, 2014). Offering training opportunities and ongoing reflective supervision may promote provider competence and confidence for handling these difficult conversations.

Findings from this study should be interpreted with the following limitations in mind. First, this study was based on a small, convenience sample of biological and adoptive parents. The participants, however, were chosen to reflect the types of parents who typically raise children affected by PAE, and to reveal perspectives that may be under-represented. This included the voices of biological mothers living with their young children at the PPW program to ensure that children whose diagnosis may be delayed, overlooked or misdiagnosed were accounted for in the sample. Likewise, including a group of foster and adoptive parents with older children provided an opportunity to hear from parents who could reflect on their experiences during the EI period, free from the acute stressors that often accompany the early years. This sampling method also resulted in groups with notable age differences, and the perspectives of newer adoptive or foster parents currently raising young children may be underrepresented in this sample. Second, data collected retrospectively from the adoptive parents introduces the possibility of recall bias, since some parents were remembering events from as many as 16 years ago. Third, mothers from the PPW were in early stages of recovery and may not represent the views of all biological parents raising children with PAE or FASD. Fourth, this study included parents of children at various levels of risk for FASD, since not all children had been screened for or received a diagnosis of FASD. This was especially true of mothers from the PPW program. Given the difficult life circumstances that compelled the biological mothers to seek treatment, there is a high likelihood of alcohol use during pregnancy (and prenatal substance exposure to their children). Hence, the pattern of results is likely consistent with perspectives from parents raising children with confirmed prenatal alcohol exposure. A fifth and final limitation is that respondent validation, a method for assessing validity of research findings, was not carried out for feasibility reasons. Inviting participants to provide feedback on final themes in the future would ensure a shared interpretation of the data. In light of noted limitations, future research could compare and contrast different caregiver perspectives to parse out potential differences and/or unique needs of the range of different caregivers who raise children affected by PAE such as grandparents, foster parents and fathers to ensure theme saturation and to increase generalizations of findings.

4.1. Conclusions

Study results highlight the importance of EI services in the lives of families impacted by PAE and FASD, and help to define FASD-informed care for young children. Findings reveal the need for enhancements to early intervention that are specific to this clinical population, based on empirical data. Evidence from this study documents the compelling truth that these young children and their families have complex, unmet and enduring needs that intersect with multiple systems of care: health care; social service; substance

abuse treatment; and child welfare. Beyond this, study data reveal the actual lived experiences of these families and, through this, describe the specific services and supports they require. Adding the perspectives of EI providers to those of families informs the training needs of EI providers working with families made vulnerable by substance abuse, PAE and FASD. Broader policy implications are that adequate funding is needed for multifaceted resources, careful service coordination, and FASD-informed systems of care during the vital period of early development. EI supports are needed for young children diagnosed with FASD. But they are also essential for the high-needs group of infants and young children with PAE who are at very high risk for FASD—and who often go unrecognized and untreated until the time for early intervention has passed.

Declaration of Competing Interest

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