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“I’m doing my part, I just need help from the community”: Intervention Implications of Foster and Adoptive Parents’ Experiences Raising Children and Young Adults with FASD

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Abstract

Individuals with fetal alcohol spectrum disorders (FASD) have high rates of health care service utilization. It is vital that health care professionals understand FASD and associated family experiences to strengthen their ability to respond to family needs and tailor family-focused interventions. This study included 24 foster and adoptive parents of children and adults (ages 3–33) with FASD. Data were collected via individual interviews and focus groups and analyzed thematically. Consistent with a developmental psychopathology perspective, parents’ experiences interacted with the individual (with FASD), family, and broader systems ecological levels. Parents undertook protective actions in an attempt to prevent secondary conditions, support their child and family, and mitigate systems barriers. They also experienced stressors at each level, and stress was increased by protective actions. The overall parenting experience was fueled by a protective parenting attitude. Findings can strengthen family focused care practices with individuals with FASD and their families and inform novel family interventions.

Keywords

fetal alcohol spectrum disorders; fetal alcohol syndrome; parenting; secondary conditions

Fetal alcohol spectrum disorders (FASD) affect 2 to 5 percent of children in the U.S. and other Western countries (May et al., 2018; Roozen et al., 2016); higher prevalence has been documented in certain regions of the world (May et al., 2013) and in special populations (Popova et al., 2019). Prenatal alcohol exposure has life-long effects on brain, behavior, and physical health (McGee Petrenko & Riley, 2011; Popova et al., 2016b). Although individuals vary, common areas affected include complex information processing, executive functioning,

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social communication, learning and memory, and self-regulation (Kodituwakku, 2009; Mattson, Crocker, & Nguyen, 2011). These primary disabilities are often associated with problems in social, behavioral, and adaptive functioning.

Children and adults with FASD are also at high risk for mental health problems and other secondary conditions, which can develop when individuals' primary disabilities are not well supported. Secondary conditions include school disruptions (e.g., drop out, suspensions), trouble with the law, confinement in legal and inpatient mental health systems, and substance use problems (Streissguth et al., 2004). Although rates of mental health problems are very high across the lifespan, the onset of other secondary conditions increases dramatically during adolescence and adulthood (Streissguth et al., 2004). Secondary conditions can be devastating to people with FASD and their families, and represent a large proportion of the health care and other costs associated with FASD (Popova, Lange, Burd, & Rehm, 2016a). Systematic data informing the development of family-focused interventions to prevent the onset or reduce the severity of secondary conditions is desperately needed (Olson, 2016).

Whether an individual with FASD develops secondary conditions is the result of the complex interplay of factors across the levels of the ecology (e.g., individual, family, systems of care, culture). These ecological levels are based on Bronfenbrenner's (1977) levels of the exosystem, microsystem, and Cicchetti's (1989) ontogenic level. The exosystem is defined as social structures that impact the child's immediate environment, including the availability of services. The microsystem refers to the immediate setting that contains the individual, including the family environment. Finally, the ontogenic level contains within-individual factors that influence development, including primary disabilities and secondary conditions. Risk factors are conditions that increase the likelihood of maladaptation and/or psychopathology (Cicchetti & Rizley, 1981), or in the case of FASD, secondary conditions. These risk factors are counterbalanced by protective factors that promote the development of competence, or adaptive functioning and the absence of secondary conditions. The incorporation of protective factors in developmental psychopathology is critical for considering a more comprehensive and nuanced course of individual development. As such, the hallmark of the developmental psychopathology theoretical framework is its shift away from risk and pathology to the transaction between risk and protective factors in an individual's developmental trajectory (e.g., Cicchetti & Toth, 2009).

Family environment plays a critical role in determining the developmental outcomes of children with FASD (Olson, Oti, Gelo, & Beck, 2009; Streissguth et al., 2004), making the family level of the ecology important to understand. Families need to balance the needs of the individual child and the primary disabilities associated with FASD with demands and interactions with systems of care. Unfortunately, families encounter numerous systems-level barriers, including others' misinterpretations of FASD-related behavior, lack of knowledge about FASD among providers and community members, delayed diagnosis, and poor availability and implementation of FASD-informed services (Petrenko, Tahir, Mahoney, & Chin, 2014b; Ryan, Bonnett, & Gass, 2006; Streissguth et al., 2004).

About two-thirds of children with FASD in the US are raised in out-of-home care (National Organization of Fetal Alcohol Syndrome, 2002), and rates of FASD are 17 to 19 times higher in child welfare systems than in the general population (Lange, Shield, Rehm, & Popova, 2013). The aim of the current study is to more fully understand the experiences of foster and adoptive parents raising a child with FASD. Understanding parents' experiences can identify family-level risk and protective factors that can help to inform family-focused interventions.

Given the high health care service utilization of individuals with FASD (Amendah, Gross, & Bertrand, 2011; Popova, Lange, Burd, & Rehm, 2012), it is vital that health care professionals understand FASD and its associated secondary conditions, as well as family experiences. To date, the vast majority of empirically studied interventions for individuals with FASD and their families have been designed for delivery by mental health clinicians, educators, or paraprofessional advocates or mentors; research on psychotropic interventions has been very limited (Petrenko & Alto, 2017). The field has yet to capitalize on interventions within primary or specialty care by nurses and other medical professionals (Caley, Shipkey, Winkelman, Dunlap, & Rivera, 2006). Nurses and other health care professionals encounter individuals with FASD and their families across their lifespan and have a critical role in the complex care of this population (Caley et al., 2006), which could expand as the roles of nurses and other allied health professionals in primary care, mental health care, and complex care coordination continue to increase. Understanding the experiences of foster and adoptive parents can inform the development of new interventions for FASD to prevent secondary conditions and will strengthen health care professionals' abilities to respond to family needs and tailor interventions appropriately for this population.

To accomplish the aims of this study, foster and adoptive parents raising children and adults with FASD in the US across a broad age range (birth to 35) were targeted to obtain diverse perspectives, including reflections on past, current, and anticipated future experiences caring for their children and managing secondary conditions. The aims of this study align with priorities in the field to identify targets for intervention to prevent or reduce the severity of secondary conditions in children and adults with FASD. Family-focused interventions are a critical component of prevention and treatment for this population (Olson et al., 2009; Petrenko, 2015).

Methods

Study Design

Data presented in the current study are from a larger investigation of contributing factors to secondary conditions in individuals with FASD and needed intervention strategies to prevent them (Petrenko et al., 2014a; Petrenko et al., 2014b). Based on stakeholder input prior to study implementation, two data collection methods were selected: individual interviews and focus groups. The use of these two methods capitalizes on the strengths of each approach, permits comparisons of findings across methods, accommodates varying participant comfort levels, and reduces logistical barriers. Individual interviews allow for the collection of rich detailed information from the perspectives of particular individuals, while the explicit use of group interaction in focus groups often produces insights that would be less accessible in an

individual interview format (Liamputtong, 2009; Morgan, 1997). Parents were able to select which data collection method they preferred.

Participants

Data from 24 foster and adoptive parents living in Upstate New York were included. Parents were recruited if they were raising a child or young adult (birth to age 35) with an FASD. Recruitment methods included provider referrals, FASD parent support groups, posted flyers and brochures, and presentations at family-oriented conferences. Table 1 provides selected demographic information. The mean age of participants was 53.71 years ($SD = 8.41$; range 30–65). Twenty-one parents identified as Caucasian (87.5%) and three identified as African American (12.5%), which is consistent with the region. Education levels were reported: 4.2% diploma/GED, 56% some college/associates degree, 29.2% bachelor's degree, and 12.5% master's degree.

Data Collection

This study was approved by the University of Rochester Institutional Review Board and each participant provided written informed consent. The first author conducted all interviews and focus groups. Similar questioning routes were used in both interview and focus group formats and covered the following topics: 1) strengths and challenges of children and adults with FASD and their families; 2) key areas to target in an intervention; 3) ideal age range for the intervention; 4) intervention length; and 5) perceived incentives and obstacles.

Data were collected in 2012. Sixteen caregivers elected to participate in focus groups. Two groups were held, each with 8 caregivers. Eight caregivers completed interviews (a total of 5 interviews; 3 included both parents). Individual and focus group interviews were of similar length and lasted an average of 74 minutes ($SD = 12.5$; interviews ranged 52–82, focus groups range 81–87). They were audio recorded and transcribed verbatim for later analysis. All participants received a small financial incentive (US \$20) for their participation.

Preliminary analyses were also presented to the majority of parents in the sample in a second round of focus groups (3 focus groups, 21 total participants, 5–9 per group) as part of participant verification to ensure data were presented accurately. Focus groups lasted on average 80 minutes ($SD=17.1$, range 66–99).

Data Analysis

The research team approached the current study from a developmental psychopathology perspective, which influenced the development of the questioning route (i.e., asking about sources of strength or resilience and risk), the consideration of an ecological model when analyzing and organizing the data, and the interpretation of findings and implications for intervention. A thematic analysis was undertaken to understand how parents' experiences of raising children and adults with FASD relate with the development of secondary conditions in this population. Thematic analysis focuses on identifying patterns or themes within the data (Liamputtong, 2009; Miles, Huberman, & Saldana, 2014). After familiarization with the data, the research team iteratively reviewed each transcript and assigned initial codes. Codes were discussed and defined by the research team and interrelationships among themes

were identified. During the iterative analysis process, parents in the second round of focus groups were presented with a preliminary model showing parents' Protective Actions and Stressors on two ends of a balance. Parents responded to this model by acknowledging the Protective Actions, but they focused most on reiterating the Stressors experienced and emphasizing the context of systems-level barriers that contributed to these. This feedback informed further revisions to the analytic model that reflected transactions with systems-level barriers and across levels of the ecology.

Several matrix displays also assisted with analysis (Miles et al., 2014). A participant matrix display that listed evidence for each of the major themes by participant revealed moderate to high consistency across participants and no differences by data collection method (interview vs. focus group). Data were also examined for each participant (or couple) to determine whether the themes that emerged from each individual's experience were consistent with final analyses. There was concordance between the themes and the model for nearly all participants except one foster parent who did not report any current systems barriers.

Results

Overview

The major themes identified in this study and their interrelationships attributed by parents are illustrated in Figure 1. Consistent with a developmental psychopathology perspective, the experiences of parents raising children and adults with FASD related to factors at the individual (with FASD), family, and systems levels of the ecology. Parent experiences across ecological levels were categorized into two major themes reflecting: 1) **Protective Actions**, which involve attitudes and behaviors parents implement to prevent secondary conditions, support their children and families, and mitigate systems-level barriers; and 2) **Stressors** parents experience relating to managing their children's disabilities, navigating interpersonal relationships, and coping with systems barriers. Although parents acknowledged their Protective Actions mitigated some of the risk associated with the development of secondary conditions in their child with FASD, they also eloquently described how these actions increased Stressors. Parents were motivated by **Protective Parenting Attitudes** that cut across all levels of the ecology. Evidence for each of these themes and sub-themes and their transactions with the ecological levels are detailed in the following sections. Table 1 provides selected contextual information for participants linked to quotes within the text by a code signifying family unit and participant.

Individual (with FASD) Level

Although parents identified a number of strengths in their children (e.g., compassionate, resilient, vigilant, verbal skills, funny, athletic, creative), parents more clearly attributed their Protective Actions and Stressors to their children's primary disabilities (e.g., differences in social, adaptive, executive functioning, and self-regulation) and their efforts to prevent or mitigate secondary conditions. All parents identified concerns about secondary conditions, and many reported their children had experienced secondary problems relating to their primary disabilities not being well supported. School disruptions (e.g., detentions, suspensions, drop out) and mental health problems (e.g., anxiety, depression, low self-

esteem) were the most commonly reported problems. Several teenagers and young adults had also had received inpatient mental health treatment or had trouble with the law. Parents attributed secondary conditions to systems-level barriers relating to teachers' and providers' lack of knowledge about FASD and difficulties obtaining the appropriate services for their children (discussed in more detail below in the Systems Level section).

Protective actions.—Due to the developmental immaturity and challenging behavior displayed by their children, parents emphasized the need for constant monitoring to protect and support their children. Parents described a high level of monitoring and vigilance at all developmental periods. For example, one adoptive mother (F7P1) stated about her son when he was younger that:

You couldn't leave him alone in a playground, I mean not for a second. And you could tell him twenty-five times before he went up that slide "don't you touch anyone up there," and he'd get up there and you'd hear some shrieking.

An adoptive father (F1P2) of teenagers similarly stated: "They're easily swayed by their peers so I think you have to watch them a lot more than maybe you would a normal 15-year-old."

In addition to a high level of monitoring, parents described providing their children with frequent prompts and reminders to support memory and executive functioning problems. One foster mother (F14P1) iterated that "everything's a step by step by step by step" process. Multiple parents described the need to develop patience to be able to provide the necessary prompts and support for their children. For example, an adoptive mother (F1P1) of 15-year-old sons explained, "If you give orders, you have to give one line commands and kind of repeat things over and over and over. ... You have to have great patience and just accept what the disability is."

Many parents mentioned increasing structure and routine in their children's environment as being essential to their child or young adult's success. For example, one adoptive mother (F6P1) of a 5-year-old described that her daughter "requires a lot of one-to-one, especially during unsupervised times, like lunch and the bus. Those were a nightmare in the beginning, but once we structured them a little more for her, she did better." Another adoptive mother (F12P1) of a 16-year-old daughter stated the benefits of structure and routine as: "They feel like they can accomplish it, because they do it over and over and over again."

Parents also discovered that they needed to develop "outside of the box" parenting strategies that went "above and beyond basic parenting." Many learned to adjust their behavior management strategies to best suit each child's needs, saying, "don't try harder, try differently." Parents iterated the need to approach problems creatively and with flexibility. An adoptive father (F9P2) of a 12-year-old boy stressed the importance of creativity: "You know how to be creative - solutions - instead of doing what works for other children may not work for your FAS child."

Another common theme was the importance of supporting the child's strengths and interests. One adoptive mother (F4P1) of 32- and 33-year-old daughters stated:

I think you need to look and see what their strengths are going to be, because they're not going to be able to perform like a regular child, in school, academically. ... Each child is different and each child does have a gift and find out what that is, what they're good at, and try to capitalize on that.

Parents viewed targeting strengths as important to helping the child or adult feel successful and reducing secondary problems.

Stressors.—Parents were very open and articulate about how their challenging realities were related to their children's disabilities and efforts to prevent or mitigate secondary conditions. The emotional impact of these challenging realities on parents was particularly notable. Parents reported a great deal of sadness, particularly at seeing the gap widening between their child and his or her peers and the social consequences. For example, one adoptive mother (F10P1) of a 20-year-old stated: "It's really sad because she loves to do things with [our granddaughters who are 12 and 15], but we've seen the older one kind of pulling away because she's going beyond years of really where [daughter's name] is." Many detailed how their children were aware of the differences between themselves and their peers, and often stated how they 'just wanted to be normal.' For example, an adoptive mother (F11P1) described the impact on her 13-year-old son's self-esteem:

Ours sometimes just wants to be a regular kid. "Why can't I be a regular kid?" And I mean, he will be up in his room and he will just cry. ... He'll say, "I don't know why I'm like this, I don't know why I do the things I do. I don't want to do the things I do." ... And it breaks my heart when he does that, because he knows he's not like everybody else.

Fears about their children's safety were also commonly reported. One foster mother (F14P1) of young children reported concerns of her boys going off with strangers or engaging in unsafe behaviors suggested by peers: "He will do anything to get a friend. You know anybody could take them and do what they want with them, but as long as they can get a friend." An adoptive father (F2P2) of an almost 12-year-old girl described multiple fears relating to the gap in his daughter's age and developmental level, such as concerns about being bullied on the bus, being taken advantage of sexually, and how her behavioral meltdowns are interpreted by law enforcement and community members:

She's maturing physically and at a rapid rate, and mentally she is not keeping up with that at all. You're looking at somebody who is biologically 12, she could physically pass for 14 or 15, and socially and in her mind she could be sometimes 5 or 7 years old. Which is very dangerous, very scary, about how you have to handle her, and how people perceive her, and what they see.

Parents also reported a lot of fears about their child's future, particularly as the child aged and social interactions were not as easily supervised or controlled. Many parents had read about or heard from other families the experiences of secondary conditions in people with FASD. All parents expressed concerns about secondary conditions, even those of young children. These concerns became increasingly salient for parents of teens and young adults who were seeing their children continue to display the same problem behaviors, but with more significant consequences. One adoptive mother (F4P1) stated:

[The challenges] are consistent, they just get bigger. Well if a child is small, and they're stealing, you can kind of control the environment, but as they get older, you can't control the environment if they're stealing. Or lying... Everything is easier when they are smaller, and when they get older those lies get bigger. Those lies get more deadly.

Parents also reported struggling with balancing their child's desire to have increased independence while recognizing their child was not developmentally ready for it. For example, one adoptive mother (F4P1) described:

As they get older, they want more independence, of course. But, the parent has a challenge of how much, how much independence can I give them? ... So that concern of, well, what parameters are you going to put around them, because personally for me, the bottom line was safety. And so sometimes that puts me at odds with my daughter because she's 32 years old, but her reasoning is of a 7-year-old.

Parents described feeling exhausted and overwhelmed, often relating to the efforts required to manage their children's disabilities and mitigating risk for secondary conditions on an everyday basis. One adoptive mother (F2P1) stated "you have to be totally vigilant. It's exhausting at times." Similarly, another adoptive mother (F10P1) of a 20-year-old daughter echoed this point and also emphasized how this exhaustion contributes to social isolation, explaining "We find that we don't have the energy to do a lot of things with other people because it seems like it takes so much energy, the relationship, you know. Our daughter takes a lot of energy. So we're tired."

Feelings of confusion about the causes or management of the behavior of children and adults with FASD were also described. This confusion was attributed to having a delayed diagnosis, the gap between chronological age and developmental functioning, and variability in behavior from day to day. One adoptive mother (F4P1) whose daughter received a diagnosis at age 21, described: "We adopted her at three years of age, so we had gone what 17–18 years with just so much gambit of things, and not really understanding what she could do, what she couldn't do. It was so confusing." Parents described often feeling confused on what to do to help their child. For example, one adoptive mother (F3P1) said, "I'm not sure what she needs sometimes, because one day she can be completely fine and the next day everything is wrong."

Family Level

Parents described Protective Actions and Stressors at the family level of the ecology that pertain to social influences that affect the family unit. General factors include the presence or absence of social supports and family or marital dynamics. Parents engage in Protective Actions such as working together as a family and seeking support from families with similar experiences in order to bolster these family-level factors. When social supports are insufficient, or there are negative family and marital dynamics, parents described higher levels of stressors, including a greater sense of isolation, struggles with stigma, and strains on family relationships.

Protective actions.—Working together as a family was an important theme raised by several two-parent families. For example, one adoptive father (F9P2) stated: “[the parents] both have to be a team first and then you can help your child... You need to get together and talk about stuff before you go and do things.” Being “on the same page” and responding to the child or adult with an FASD in a similar manner was viewed as especially helpful given the nature of the individual’s disabilities (e.g., difficulty adapting to change, processing, self-regulation).

Parents also described seeking support from families with similar experiences to reduce isolation and to get new ideas of how best to support their children. One adoptive mother (F11P1) stated, “I feel so much better talking to other parents [who have children with FAS] knowing it’s not just my child. It’s not just us.” Another adoptive mother (F10P1) emphasized the value of networking with other parents to find new ideas and resources:

You network at the parent support group like we go to. It really does help. You can tell someone, “oh, did you know that there is this program that’s run by [name of agency], and my son really loves it, and it might be something that your daughter might like.” Networking I think is very important.

Parents also expressed satisfaction in being able to share what they’ve learned with others.

Stressors.—Family-level stressors included social isolation, stigma, and strains on family relationships. Parents reported feeling very isolated as a result of their child’s disorder. For some, a lack of knowledge about FASD in the general community could exacerbate this isolation, especially if the parent did not know any families in similar situations with whom they could share their experiences. One adoptive mother (F2P1) of an 11-year-old daughter stated: “The isolation at times ... I felt I was the only one with a child with this kind of disability because it is not talked about.” Others reported that their child’s behavior issues prevented them from socializing, whether in public or private settings where other people may not understand the child’s behavior. An adoptive mother (F6P1) of a 5-year-old daughter stated, “I have problems socially. Going out and being social and doing things. Even a simple doctor’s appointment, depending on her day can be a struggle. Or going to the playground.” Although speaking about shared experiences with other parents may buffer against the stress of isolation, many parents reported that they did not have such a support system in place. For example, an adoptive father (F1P2) stated: “we really don’t have anybody we can call and say ‘hey, how did you handle this matter?’ I don’t think there’s enough support groups.”

Although foster and adoptive parents noted that biological parents were likely to experience higher levels of stigma, they also felt stigma due to their child’s disability as well as the behavior problems their children often displayed. One adoptive mother (F4P1) stated:

I wouldn’t just go around saying my girls are adopted, but the doctor and the counselor advised that I should do that because people would look at me like ‘you’re the one that did this.’ ... They said whenever you’re talking to someone advocating for her you need to be upfront and say this is my adopted daughter so that you’ll just release all the antagonism that’s going to be thrown at you.

This concern about the negative reactions of others emphasizes the struggle parents face against uneducated providers and community members. Another adoptive mother (F2P1) shared an example of when her daughter had a meltdown in a store:

Society isn't really well educated either... Long story short, the customers called the police. Thought we had done something to our daughter. ... And, I'm explaining the situation, and I said, "My daughter has FAS." "What's FAS?" a policeman asked me, and I said, "Fetal Alcohol." And I had to be sure to say I'm the adoptive mother, because then I'm thinking he's going to think I'm an alcoholic or something. That was scary. ... So since then I've got a letter on me from the pediatrician ...that states her diagnosis, and I have an attorney business card in my wallet if I needed to call someone too.

Parents experienced mixed emotions relating to the stigma of FASD including fear, discomfort, anger and frustration at the situation, and urgency to protect themselves and their child.

Parents described how managing their children's disabilities and advocating for them could put strain on marital and sibling relationships. For example, one adoptive father (F1P2) commented, "These families going through it have economic, financial pressures, between the spouses, between the family, the dynamic, and that's where all of this - its all one thing. Many pressures coming from all different angles, for different things." For some families, the pressure becomes too much; two adoptive mothers in the current study reported that their first marriages had ended in divorce after adopting their children. In families with multiple children, participants reported struggling to balance differential treatment between siblings. For example, an adoptive mother (F9P1) described how her daughters resented their brother at times due to all the time and efforts the parents put into implementing interventions for him: "The other girls would also resent him for that. He was getting a lot more attention than they would have been getting."

Larger Systems Level

The larger systems level was characterized by a number of barriers, which were previously described by Petrenko and colleagues (2014b). The overarching barrier identified by parents was a pervasive lack of knowledge about FASD throughout multiple systems. This lack of knowledge contributes to delayed diagnosis, unavailability of services, and difficulty qualifying for, implementing, and maintaining services. This study contributes novel findings regarding how foster and adoptive parents experience these barriers. Parents described specific Protective Actions they undertake as a direct response to the systems-level barriers they encounter. They also attributed increased Stressors to the constant need for these Protective Actions.

Protective actions.—Most families identified that due to a lack of awareness about FASD, parents needed to be constant advocates for their children with teachers, health care providers, and community members to obtain necessary services. Advocacy was often described as a "fight" against the system. An adoptive mother (F11P1) of a 13-year-old son stated:

You have to fight for your child. You cannot sit back and let the teachers tell you, “Well this is what we’re going to do.” You have to be willing to fight constantly to get your child what he needs and to get them to listen to you. Because a lot of times they won’t listen to you.

Key aspects of being an effective advocate mentioned by parents included knowing your rights, maintaining records, and keeping up to date and monitoring the quality of implementation of the child’s services. For example, an adoptive father (F2P2) of an 11-year-old daughter stated: “it’s just how it is going to be. It’s a constant being on top of things, knowing your rights, knowing what you can do, what you need to do.”

To be an effective advocate, parents described the importance of educating themselves about FASD. One adoptive mother (F3P1) of a 7-year-old daughter stated, “I had to do my own research, trying to find something somewhere because nobody seemed to know anything that would help.” Some parents were able to find classes to help them learn new parenting strategies or advocacy skills. For example, one foster mother (F14P1) stated:

I did all of it myself. ... I went out and talked to different people. I came to groups. I went down to [name of program] and took classes, and me and my husband, we took classes and classes and *classes*... I said, “I need to know everything about Fetal Alcohol.”

Other parents described reading books, finding information online, or going to conferences. In addition to educating themselves about FASD, many parents found that they had to repeatedly educate others, such as residential facility workers, health care providers, and therapists, who were responsible for their child’s care. For example, one adoptive father (F9P2) of a 12-year-old boy stated: “Your pediatrician, your doctor ... We have to educate everyone we come in contact with what is FAS, how does this exhibit? I mean it can be from a Sunday school teacher, to a coach, to anybody, you know?” Some families were able to engage professional and community advocates to help support them in advocating for their child. Parents who used advocacy services found them quite helpful.

Another common theme expressed by parents was the willingness to take advantage of available services in an effort to find something that would help their son or daughter. For example, adoptive parents (F5P1 and F5P2) of a 28-year-old son stated: “Anything that was offered I would take ... We are trying to do the best we can for our son.” Another adoptive father (F2P2) reiterated that: “Whatever we find, whatever anyone offers us we’ll take... We hear about something in an article or whatever we see, we’ll look into it; we’ll see if it’s possible, if it can help her, help us, something.”

Stressors.—Families described a number of practical stressors relating to systems-level factors, including resource, time, and organizational demands, as well as challenges with finances and securing childcare. Parents talked about the high resource needs of children and adults with FASD. For example, one adoptive father (F9P2) of a 12-year-old boy commented: “They are high maintenance you know ... A lot of resources, emotional and physical resources you need for that one child is equal to at least two or three normal kids.” Others described how some of the protective actions they took to support their children’s

needs added extra burden and work for them. For example, an adoptive mother (F1P1) shared: “When they were riding the bus there were problems. We ended up picking them up every day. There again, there’s the extra work. Otherwise you get all kinds of problems.”

Parents also discussed the stress of juggling multiple demands and time-intensive services. Many parents had participated in behavioral management programs due to their children’s challenging behaviors. Keeping consistent with a behavioral management program could be time consuming and emotionally draining, and many parents reiterated the need for constant, patient instruction. Families also emphasized the struggle of having to juggle services in multiple systems of care. One adoptive father (F9P2) stated, “I think that’s where we struggle. This is so fragmented that I gotta go here for this, gotta go here for this, gotta go here for this.” Another adoptive father (F2P2) commented that, “you have to find the time to juggle that [social skills program] with school and homework and you know some of the things are good, but there’s also having to find the time to do all this.” Although parents emphasized the importance of the protective actions they were undertaking to help their children to be successful, they also acknowledged the emotional and physical drain it had on them.

Additionally, parents reported struggling with financial stress in providing their child with the services they needed. For example, one adoptive mother (F3P1) described challenges of securing mental health services for her child: “They wanted to see her weekly and we were trying to budget that out and we just couldn’t.” Even activities common to childhood, such as swimming, became a struggle for a child with FASD who may need to be removed from group lessons for expensive private instruction. While government assistance is available, many parents reported struggling to qualify. For those able to access such funds, they found their allowances being cut, which forced the family to pick up the remaining balance or remove their child from the activity.

Parents reported that finding a childcare provider was a major challenge. One foster mother (F14P1) noted that “You have to be careful who your kids are with. Who you leave them with, who watches them.” For many, this need exacerbated social isolation, as caregivers were unable to find someone appropriately qualified or willing to watch the child. For example, one adoptive mother (F3P1) noted: “A lot of it is child care because my husband works second shift. I don’t have anybody really that will watch them for any length of time.”

Many parents described feeling unsupported by existing services and schools. One adoptive mother (F2P1) stated:

I’m doing my part, I just need help from the community and so far we’ve got it in bits and pieces and spurts. And I don’t want to see [child’s name] or any of these other children just lost out on the street or in a group home, when they can be a little more functioning if they were given the supports they need from an early age.

Access to services was a main factor for parents feeling unsupported. An adoptive mother (F3P1) of a 7-year-old described:

We’ve had to go to [city name], which is an hour and 20 minutes away or an hour and a half just to get some of what I feel would be the basic services. A lot of lack

of knowledge with the psychologist, the psychiatrist, and mental health. They're usually flipping the book open as you are saying what she has. It's like ugh!

Parents also described feeling frustrated by protective actions not yielding the desired results. For example, an adoptive mother (F5P1) of a 28-year old described her frustration in relation to her son's difficulty making inferences: "Not being able to generalize or making inferences from one set of circumstances to another, everything has to be explained more than once. ... It becomes frustrating because you think, 'Why aren't they getting it?' He's a bright guy." Encountering systems barriers and having to advocate for their children was one of the greatest sources of frustration and stress for parents. Repeatedly, participants emphasized having to advocate every time their child interacted with someone new, or risk letting them miss out on available help. Parents reported that the constant struggle of educating themselves and disseminating this information to others exacerbated their already high levels of stress and fatigue. For example, one adoptive mother (F10P1) stated: "You feel like you're just starting out and you're getting some place and then somebody else you got to explain it to, and then somebody else." The high level of provider turnover was a common source of frustration in this regard.

Parents also emphasized that FASD is an "invisible disability" and articulated how FASD is treated differently than other developmental disabilities. Being treated differently was largely attributed to a lack of knowledge or awareness about FASD by community members and providers. One adoptive mother (F7P1) gave an example of her experience of sending her child to a camp for children with disabilities: "They do real well with the kid who is in a wheelchair or has cerebral palsy... [Children with FASD] look like the typical kid, and yet their behavior is ... unexpected. ... They're not like the other kids with disabilities." Parents emphasized the need for education on FASD, just "like other disabilities." However, parents acknowledged that increasing awareness about FASD is complicated by stigma. One adoptive mother (F1P1) stated:

We have to get them to talk about it the way they talk about Downs Syndrome and autism. ... Everybody is aware of it because you've got a star in Hollywood who has child with that. ... They're never going to say I have a child with FAS, and I was the cause of it or whatever... So this is going to probably always be something that'll never get its due.

A sense of unfairness was palpable in some interviews and focus groups as parents described their perceptions that qualifying and maintaining services was harder than for other disabilities. For example, one adoptive father (F5P2) stated, "You need to have FASD classified or recognized as a categorical developmental disability so it can get status, so that people can become eligible for Medicaid funded services at the same level as people with autism or any developmental disabilities."

Protective Parenting Attitudes

Parents expressed several common attitudes that aided them in implementing protective actions. Parents spoke openly about their devotion and unconditional love for their children. For example, one adoptive mother (F11P1) of a 13-year-old boy said, "...unconditional love,

...even on their worst day... I said, 'I may not like what you did, but I will always love you.' ... Just that reassurance of love. We're going to love you no matter what."

Understanding and accepting the diagnosis were identified as critical processes in being able to cope with the child or adult's disabilities and effectively advocate for them across systems. For example, one adoptive mother (F11P1) stated:

When we originally found out and knew, okay, life is not going to be a typical childhood for him, it was almost like a grieving process for us ... once we accepted it and said, "Okay, this is the way he is," it was much easier.

Several parents talked about how reframing their understanding of their children's behavior was helpful and to recognize that it is not willful. One adoptive mother (F7P1) expressed: "you need to remember too it's not their fault... You can get so angry at them for something they did, but you have to remember all the time it's not their fault."

Other parents described a strong motivation and a feeling of responsibility to fill the gaps left by the "broken system." For example, one adoptive father (F11P2) stated, "It's survival, because if you don't – if you listen to everybody else - your child is going to get pushed under the rug." This feeling of responsibility and need to protect their children helped families overcome many uncomfortable and distressing situations. For example, one adoptive mother (F4P1) of young adults described the process of obtaining legal guardianship of one of her adult daughters: "I had to present the piece that she could not do it on her own. Which was, you know, you don't want to have to say that, but you have to if you want to protect them."

Parents were also motivated by a desire to see their children happy and successful. One adoptive mother (F2P1) of an 11-year-old daughter commented, "I never thought that I could have done all of this. You know it's become my career now. I gave up my career for this and I won't give up the fight until she's happily settled somewhere."

Discussion

The aim of the current study is to understand the experiences of foster and adoptive parents of children and adults with FASD to inform family-focused interventions. Results document parents' perspectives on how factors at different levels of the ecology (individual with FASD, family, systems) influence their experience. Parents undertake Protective Actions at each ecological level to prevent secondary conditions, support their child and family, and mitigate systems barriers. Parents also describe how these Protective Actions increase Stressors at levels of the ecology. The overall parenting experience is fueled by Protective Parenting Attitudes. These interactive risk and protective factors at multiple ecological levels are characteristic of the developmental psychopathology perspective.

Replication and Extension of Findings Relative to FASD Samples

Although many of the specific themes identified in the current study have been documented in prior research on FASD (see Table 2) and other developmental disabilities, the application of the developmental psychopathology perspective and comprehensiveness of the model

offer novel contributions to the field. Replication of findings also suggests the likely transferability of current results to other foster and adoptive parents raising children and adults with FASD. The developed model provides a useful conceptualization that has implications for future research directions and clinical interventions.

In addition, several original themes have been identified. Specifically, the sense of sadness that caregivers feel at seeing their child's widening gap relative to their peers has not been explicitly documented in prior FASD studies, although it has been noted as "chronic sorrow" in literature on other developmental disabilities (e.g., Copley & Bodensteiner, 1987). With respect to family-level factors, positive actions such as working together as a family and seeking interpersonal supports are novel in the context of the overall model. At a systems level, findings highlighted parents' resourcefulness and willingness to take advantage of any available resources, and how this was both protective and stressful for families. Other novel stressors at the systems-level include the high resource needs, the time-intensive demands parents are forced to juggle, the sense of frustration parents experience when their protective actions do not yield the desired results, and the lack of childcare and respite. Notably, parents in the current study also observed how the systems barriers encountered for FASD are different from those encountered for other developmental disabilities, due in part to a lack of awareness and stigma among providers and the general population. Relatedly, parents also commented on how stigma and lack of awareness lead to different perceptions of FASD compared to other developmental disabilities, like autism and Downs Syndrome. As a result, foster and adoptive parents feel they need to specify their caregiving status (or have been advised to do so) in order to protect themselves and their children.

Less attention has been given to protective characteristics of parents' attitudes towards caring for their children with FASD. Swart, Hall, McKee, and Ford (2014) noted the importance of reframing child behavior as a part of understanding the diagnosis and a sense of responsibility for securing services. However, the unconditional love these parents feel, their need to accept the child's diagnosis, and a strong desire to see the child succeed have not been explicitly stated in prior FASD research, although these themes are documented in parents of children with other disabilities (e.g., Hastings & Taunt, 2002; Heiman, 2002). Understanding this positive perspective is important for future intervention research to support parents in their protective actions and capitalize on their pre-existing motivation to help their children.

Comparison of Developed Model to Literature on Other Developmental Disabilities

Literature on the experiences of parents raising children with other developmental disabilities has shown similar barriers to services and factors that negatively impact parent wellbeing, including limited access to information and services, financial barriers, restricted school and community inclusion, and lack of family support (Resch et al., 2010). In addition, the tension between positive and negative aspects of the parenting experience has been highlighted among parents of children with other developmental disabilities (Kearney & Griffin, 2001).

Watson, Hayes, Coons, and Radford-Paz (2013) have conducted one of the few studies that have directly compared the experiences of parents raising children with FASD to those of

parents raising children with other developmental disabilities, specifically Autism Spectrum Disorder (ASD). This study focused specifically on stress, and found stress levels were quantitatively higher in the FASD group. In depth interviews revealed some similar stressors for both groups including the diagnostic process, dealing with behavioral issues, and the need for advocacy. However, the nature of these stressors was different in a number of ways between groups. For example, the ASD diagnostic process was characterized by doctors minimizing parents' concerns, long waitlists, and having to see multiple providers. In contrast, the FASD diagnostic process involved significant barriers including needing to travel long distances to see a provider, difficulties verifying maternal drinking, and getting a diagnosis in the absence of characteristic facial features. Similarly, the nature of challenging behaviors differed: The ASD group emphasized meltdowns due to anxiety and rigidity whereas the FASD group focused on secondary conditions, such as trouble with the law. Parents in both groups described the need for advocacy, but the FASD group reported having to educate doctors about the condition, which was not the case for ASD.

Collectively, the findings of this study document that foster and adoptive parents of children with FASD experience significant stressors at multiple levels of the ecology. Some of these stressors are similar to those reported for parents of children with other disabilities, while others have unique features relating to the pervasive lack of knowledge about FASD and stigma associated with this condition. It is also notable that although foster and adoptive parents are connected to some services and systems as a result of their caregiving status, they still have difficulty accessing developmental disability services and experience similar caregiving stressors as biological parents raising a child with a developmental disability (Kearny & Griffin, 2001; Resch et al., 2010; Watson et al., 2013). Thus, it is important for health care professionals to recognize the need for intervention among these families.

Implications for Intervention

The current study, as well as prior research and theory (for a review see Petrenko, 2015), support the need for multi-component interventions directly targeting multiple levels of the ecology, including the primary disabilities of the individual with FASD, family functioning, systems-level knowledge about FASD, and infrastructure to permit access to appropriate services and supports. A model illustrating the types of services and supports that would be beneficial for families, systems, and affected individuals across the lifespan to prevent secondary conditions can be found in Petrenko, Tahir, Mahoney, and Chin (2014a). This model is consistent with the movement toward health homes advocated by the Substance Abuse and Mental Health Systems Administration (SAMHSA, 2013).

Several interventions have been developed for families raising children with FASD (predominately in the preschool to school-age period) that address some or many of the themes identified in this study (Petrenko, 2015). For example, the Families Moving Forward (FMF) Program (Bertrand, 2009; Olson & Montague, 2011) is a parent consultation program that targets individual and transactional family-level risk and protective factors including parent-child interaction patterns, caregiver cognitive appraisal, parenting self-efficacy, caregiving stress, family resource needs, and a factor central to family adaptation: child behavior problems. It also targets systems-level factors by including targeted consultation

with the child's school and other community providers, and efforts to link families with appropriate community services and supports. A recent study has also piloted the FMF Program in combination with a child intervention, and demonstrated promising outcomes (Petrenko, Pandolfino, & Robinson, 2017).

Empirically-validated interventions for individuals with FASD have yet to capitalize on the skillset of nurses and other allied health professionals. These providers have unique opportunities to utilize information on family experience to intervene to support families in the prevention of secondary conditions. Nurses and other health care providers should acknowledge that although families of individuals with FASD may experience similar or greater levels of stress as families of children with other developmental disabilities (Watson, Coons, & Hayes, 2013), the source of that stress may be different (Watson, Hayes, et al., 2013) and may therefore require different kinds of intervention. Recommendations for health care professionals consistent with the findings of this study and other published guidance (Caley et al., 2006; Williams, Smith, & the Committee on Substance Abuse, 2015) are listed in Table 3.

The results of this study also emphasize the need for systems-level interventions to alleviate the stress created by parents' advocacy responsibilities. Improved education and training on FASD for educational and health professionals appears a clear priority based on parents' experiences of having difficulty finding knowledgeable providers. Prior survey-based studies of health professionals have documented insufficient knowledge about FASD and lack of perceived competency in serving individuals with FASD (e.g., Eyal & O'Connor, 2011; Gahagan, Sharpe, & Briacombe, 2006; Payne et al., 2005). Increased awareness among professionals is also an important step toward modifying policies and other systems-barriers (e.g., delayed diagnosis, access and availability of services) that compromise the success of individuals with FASD.

Implications for Future Research

Future research is needed to evaluate the transferability of the current findings and further elucidate pathways and associations implicated in the model. The results from the current study may not entirely transfer to foster and adoptive families whose children have not been diagnosed or who are not actively engaged in advocacy and securing services, or to other types of families raising children with FASD, such as biological parents or relative caregivers. The families in this study had also been caring for the children or adults in their homes for at least a year, and many much longer. Families newer to fostering or adopting might have different experiences. The experiences of these families may also not be generalizable outside of this region of the United States, or to countries with different systems barriers and cultural perceptions of drinking during pregnancy. Additional studies are needed to capture the experiences of more diverse family types and determine the extent of the transferability of results. Although there are advantages to having multiple data collection methods and there was a solid rationale for the methods selected, parents were able to self-select their method of participation. Results did not differ by data collection method, but allowing self-selection may have introduced some bias in findings.

The transactions in the current study were identified from parents' attributions based on their lived experience. Future quantitative studies could further empirically test these transactions. Longitudinal studies testing the associations found in the current study would provide important evidence for identified pathways over time. For example, specific risk and protective factors (e.g., parental skill in protective actions, parent distress, number of systems barriers, level of impairment) could be examined to determine their influence on different developmental trajectories for affected individuals and family adaptation. The model could also be empirically tested within the context of a randomized controlled trial of an intervention program directly targeting primary variables. Randomized controlled trials are an optimal design with which to evaluate existing theory, as they allow for a true test of causality, which may not be possible otherwise (Toth, Petrenko, Gravner-Davis, & Handley, 2016). Mixed-method designs may be advantageous, as existing quantitative measures may not adequately capture the experiences of parents raising children and adults with FASD.

Conclusions

This study adds to the literature by examining the transactions between parent experiences (including protective actions and stressors) and factors at multiple ecological levels from a developmental psychopathology perspective. The analytic model has important clinical and research implications that emphasize the need for multicomponent interventions and empirical evaluation of these protective action and stress-related processes. Findings from this study can be utilized to strengthen family focused care practices with individuals with FASD and their families and can inform the development of novel interventions to promote effective family adaptation to the diagnosis and optimal developmental outcomes for affected individuals.

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Biography

Christie L. M. Petrenko, PhD, is a clinical psychologist and researcher who has been conducting research with individuals with fetal alcohol spectrum disorders (FASD) since 2003. In 2011, she joined the faculty of Mt. Hope Family Center, University of Rochester, New York, USA, as a research associate and assistant professor. Her current lines of research emphasize the development and evaluation of novel intervention packages, investigating both efficacy and implementation parameters, to improve access and outcomes for children with FASD and their families in the community. Dr. Petrenko also provides diagnostic and intervention services to children and families through the multidisciplinary FASD Clinic at the University of Rochester Medical Center. Recent publications include:

Petrenko, C. L. M., Pandolfino, M. E., & Robinson, L. K. (2017). Findings from the Families on Track intervention pilot trial with children with fetal alcohol spectrum disorders and their families. *Alcoholism: Clinical and Experimental Research*, 41, 1340–1351. <https://doi.org/10.1111/acer.13408>

Petrenko, C. L. M., Pandolfino, M. E., & Roddenbery, R. (2016). The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: A mixed-methods study. *Research in Developmental Disabilities*, 20, 255–267. <https://doi.org/10.1016/j.ridd.2016.09.005>

Petrenko, C. L. M., Tahir, N., Mahoney, E. C., & Chin, N. P. (2014). Prevention of secondary conditions in fetal alcohol spectrum disorders: Identification of systems-level barriers. *Maternal and Child Health Journal*, 18, 1496–1505. <https://doi.org/10.1007/s10995-013-1390-y>

Michelle E. Alto, MA, is a doctoral candidate in clinical psychology at the University of Rochester, New York, USA. Her research examines interpersonal mechanisms of intervention in the treatment of trauma in children from diverse cultural and economic backgrounds. Her clinical experience includes diagnostic, individual, and family-based intervention work with children with FASD and children who have experienced trauma and maltreatment. Recent publications include:

Alto, M. E., Handley, E., Rogosch, F. A., Toth, S. L., & Cicchetti, D. (2018). Maternal relationship quality and peer social acceptance as mediators between childhood maltreatment and adolescent depressive symptoms: Gender differences. *Journal of Adolescence*, 63, 19–28. <https://doi.org/10.1016/j.adolescence.2017.12.004>

Alto, M. E. & Petrenko, C. M. (2017). Fostering secure attachment to promote resilience in low- and middle-income countries: Suggestions for evidence-based interventions. *Evaluation and Program Planning*, 60, 151–165 <https://doi.org/10.1016/j.evalprogplan.2016.11.003>

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Andrea R. Hart, BS, is a research coordinator with the Department of Obstetrics and Gynecology at the University of Rochester, New York, USA. Her research focuses and maternal and child health and childhood development, with particular interest in the use of technology to improve outcomes.

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Lynn L. Cole, MS, PNP, leads the clinical services of a large center for children with intellectual and developmental disabilities, including FASD. In collaboration with Christie

L. M. Petrenko, PhD, she led the development of the primary diagnostic and treatment program for children affected by FASD in upstate NY. Her research interests include shared decision making and identification and treatment of co-occurring physical and behavioral health in pediatric disabilities. Recent publications include:

Ameis, S. H., Kasse, C., Corbett-Dick, P., Cole, L., Dadhwal, S., Lai, M. C.,...Correll, C. U. (2018). Systematic review and guide to management of core and psychiatric symptoms in youth with autism. *Acta Psychiatrica Scandinavica*, 138, 379–400. <https://doi.org/10.1111/acps.12918>

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Figure 1. Thematic model. This figure illustrates the transactions between foster and adoptive parents' Protective Actions and Stressors related to raising an individual with FASD across multiple levels of the ecology (individual with FASD, family, systems). Parents' Protective Parenting Attitude was central to their experience and transcended ecological levels.

Table 1

Demographic Characteristics of Participants

ID	Participation	Parent Sex	Child Age(s)	Status	Constellation
F1P1	Interview	Female	15, 15	International adoption	2 parent
F1P2		Male			
F2P1	Interview	Female	11	International adoption	2 parent
F2P2		Male			
F3P1	Interview	Female	7	Adopted from foster care	2 parent
F4P1	Interview	Female	32, 33	Adopted from foster care	2 parent
F5P1	Interview	Female	28	Private adoption	2 parent
F5P2		Male			
F6P1	Focus Group	Female	5	Adopted from foster care	2 parent
F7P1	Focus Group	Female	14	International adoption	2 parent
F7P2		Male			
F8P1	Focus Group	Female	18	Adopted from foster care	2 parent
F9P1	Focus Group	Female	12	Adopted from foster care	2 parent
F9P2		Male			
F10P1	Focus Group	Female	20	Adopted from foster care	2 parent
F10P2		Male			
F11P1	Focus Group	Female	13	Adopted from foster care	2 parent
F11P2		Male			
F12P1	Focus Group	Female	16	Adopted from foster care	2 parent
F13P1	Focus Group	Male	21, 22	Adopted from foster care	2 parent
F14P1	Focus Group	Female	3, 8	Foster care	2 parent
F14P2		Male			
F15P1	Focus Group	Female	14	Adopted from foster care	1 parent
F16P1	Focus Group	Female	12	Foster care	1 parent

Table 2

Replication of Themes Identified In Prior Studies and New Themes Not Explicitly Stated in Prior FASD Literature

	Protective Actions	Citation(s)	Stressors	Citation(s)
Individual with FASD	Constant monitoring	Morrisette, 2001	Sadness	New in FASD
	Frequent prompts/reminders	Green et al., 2014	Fear for safety	Gardner, 2000
	Structure/ routine	Gardner, 2000; Green et al., 2014; Watson, Hayes, Coons, & Radford-Paz, 2013	Fear for future	Morisette, 2001; Mukherjee et al., 2013; Ryan, Bonnett, & Gas, 2006; Gardner, 2000
	Outside-the-box parenting strategies	Brown, Bednar, & Sigvaldason, 2007; Green et al., 2014; Kapasi & Brown, 2017	Exhausted/overwhelmed	Brown, Bednar, & Sigvaldason, 2007; Kapasi, 2015; Swart et al., 2014
	Supporting strengths/interests	Brown, Sigvaldason, & Bednar, 2007	Confused about causes/management of child behavior	Green et al., 2014
Family Level	Working together as a family	New in FASD	Isolation	Kapasi, 2015; Mukherjee et al., 2013; Swart et al., 2014
	Seeking support from families with similar experiences	New in FASD	Stigma	Brown, Bednar, & Sigvaldason, 2007; Kapasi, 2015; Mukherjee et al., 2013; Swart et al., 2014
Systems Level			Strains on family relationships	Green et al., 2014; Morrisette, 2001
	Constant advocacy	Brown, Sigvaldason, & Bednar, 2007; Duquette & Stodel, 2005; Green et al., 2014; Kapasi & Brown, 2017; Mukherjee et al., 2013; Swart et al., 2014	High resource needs	New in FASD
	Self-education on FASD	Brown, Sigvaldason, & Bednar, 2007; Gardner, 2000	Multiple demands/time-intensive services	New in FASD
	Repeatedly educating others about FASD	Swart, Hall, McKee, & Ford, 2014	Financial stress	Paley, O'Connor, Frankel, & Marquardt, 2006; Ryan, Bonnett, & Gas, 2006; Swart et al., 2014
	Taking advantage of any available services	New in FASD	Securing childcare	New in FASD
			Feeling unsupported by services/schools	Green et al., 2014; Kapasi, 2015; Morrisette, 2001; Ryan & Ferguson, 2006; Ryan, Bonnett, & Gas, 2006
			Frustrated that protective actions not yielding results	New in FASD
Protective Parenting Attitude			Treated differently than other developmental disabilities	New in FASD
	Unconditional love	New in FASD		
	Understand and accept diagnosis	New in FASD		
	Feeling of responsibility	New in FASD		
	Desire to see child happy and successful	New in FASD		

Table 3**FASD-Specific Implications for Health Professionals**

Self-Education	
•	Recognize FASD as a developmental disability
•	Increase personal knowledge about FASD through trainings and conferences <ul style="list-style-type: none"> – Free Online Trainings (with continuing education credits) for health care professionals through CDC's Collaborative for Alcohol-Free Pregnancy: https://nccd.cdc.gov/FASD/
•	Be aware that foster and adoptive parents have trouble accessing supports
FASD-Informed Care	
•	Utilize existing FASD resources, such as the American Academy of Pediatrics' FASD Toolkit
•	Provide health teaching: <ul style="list-style-type: none"> – FASD psychoeducation for parents, school staff, pediatric providers, and mental health providers – FASD-informed parenting strategies
•	Provide referrals and case management support
•	Provide support for caregivers' emotional and interpersonal stress and make referrals as needed
•	Adapt evidence-based interventions for people with FASD
•	Develop and evaluate novel nursing interventions for FASD
Advocacy & Systems Change	
•	Connect with local, state, regional, or national FASD organizations: <ul style="list-style-type: none"> – National Organization for FAS (NOFAS): www.nofas.org
•	Address FASD systems barriers through advocacy and support
•	Provide education and training to colleagues and trainees <ul style="list-style-type: none"> – Access the FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice through the Mountain Plains FASD Practice & Implementation Center: http://www.mpfasdpic.org/causes/competency-based-curriculum-development-guide/
•	Address Stigma <ul style="list-style-type: none"> – Join NOFAS's Stamp Out Stigma Campaign: www.nofas.org/stigma – Acknowledge stigma affecting parents and caregivers of all types and people with FASD – Use non-stigmatizing (e.g., "prenatal alcohol exposure" rather than "maternal alcohol exposure") and person-first language – Speak up when someone says something shaming or insensitive about women, families, or individuals with FASD