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ORIGINAL ARTICLE

Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: What has helped

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ABSTRACT

Background There is limited research investigating the lived experiences of parents raising children with fetal alcohol spectrum disorder (FASD). The aim of this paper is to use qualitative analysis to identify how parents have adapted to the experience of raising their child with FASD.

Method Eighty-four parents and caregivers of children with FASD in Ontario, Canada, participated in in-depth, semistructured interviews employing a basic interpretive approach.

Results Parents of children with FASD report a number of strategies, supports, and transformational outcomes. Using interpretative phenomenological analysis, 5 themes were identified: understanding FASD and advocating on their child's behalf, day-to-day adaptation, transformational outcomes, as well as the importance of informal and formal supports.

Conclusions Understanding what families do in order to facilitate adaptation is important when assisting families who may not be adapting as successfully. Continued research looking at the family experience of raising a child with a developmental disability, such as FASD, is necessary.

KEYWORDS

fetal alcohol spectrum disorder; families; adaptation; disability; parenting

Introduction

Despite a wealth of literature on the experience of raising a child with a developmental disability, there is a scarcity of research investigating the lived experiences of parents raising children with fetal alcohol spectrum disorder (FASD). In spite of the limited existing literature on families of children with FASD, many researchers have highlighted the importance of understanding the lived experiences of families who experience disability (Gardner, 2000; Sanders & Buck, 2010; Watson, Hayes, Coons, & Radford-Paz, 2013). The findings presented in this paper are part of a more expansive mixed methods study in Ontario, Canada. The focus of this paper was to identify how parents and caregivers have adapted to the experience of raising their child diagnosed with FASD using a qualitative interpretative approach.

Historically, researchers have approached the exploration of families of children with intellectual or developmental disabilities with the preconceived belief that families would unquestionably present with a pathological or dysfunctional profile (Maul & Singer, 2009). Parenting stress has been much of the focus in the family literature, and has highlighted the experience of stress in families raising children with various developmental disabilities (Abbeduto et al., 2004; Hastings, Daley, Burns, & Beck, 2006;

Johnston et al., 2003). However, family disability research has started to transition from traditionally negative, deficit-based models of coping to those that bring to light positive, strength-based aspects of family functioning, such as adaptation (Dykens, 2006; Helff & Glidden, 1998; Ylvén, Björck-Åkesson, & Granlund, 2006). Research into positive factors for families stemmed from an interest in discovering why some families facing adversity manage to function well, while other families facing a similar situation do not (Bayat, 2007; Patterson, 2002a; Walsh, 1998). A paradigm shift toward family resilience has emerged (Walsh, 1998), recognising that many families overcome crisis through the process of adaptation, resulting in more competent family functioning (Maul & Singer, 2009; Patterson, 2002a, 2002b). Additionally, many families of children with developmental disabilities clearly articulate positive contributions to their family's life and general wellbeing (e.g., Bayat, 2007; Scorgie, Wilgosh, Sobsey, & McDonald, 2001; Summers, Behr, & Turnbull, 1989). However, a major difficulty with the existing research on families' positive experiences is that the positive perceptions are not disability specific (Hastings, Allen, McDermott, & Still, 2002).

It is possible that a greater focus on the positives associated with their children can help parents focus

less on the negative aspects of their children and their perceived limitations as parents (Patterson, 1988, 1989, 1993). Despite the call for a strength-based approach to family research (Helff & Glidden, 1998; Stainton & Besser, 1998), researchers who seek to examine the relationships between parenting stress and adaptation often place a larger focus on the effects of increased caregiver stress or the demands that child behaviour problems often place on parents and caregivers. Adaptation is often discussed in a negative manner, defining adaptation as the absence of negative outcomes, rather than the presence of positive outcomes or positive contributions (Ylvén et al., 2006). However, one theoretical model, the family adjustment and adaptation response (FAAR) model (Patterson, 1988, 1989; Patterson & Garwick, 1994, 1998), posits that families who have adapted successfully to their child having a disability are likely able to demonstrate some positive perceptions and report positive experiences (Hastings & Taunt, 2002).

The family adjustment and adaptation response (FAAR) model

The FAAR model (Patterson, 1988, 1989; Patterson & Garwick, 1994, 1998; see Figure 1) is a two-phase interactional model that emphasises how families strive to attain stability or homeostasis in the face of stressful life events. The FAAR model is cyclical in nature, and individuals may return to a period of adjustment, from a period of adaptation, to deal with new crises that may arise within the family structure. The concept of adaptation is broader than cognitive coping (Patterson, 1993) and emphasises the importance of meaning making in the cognitive processes within the family system.

Given that the family is a social system, the child's disability and the family's overall functioning are continually interacting, thus adjustment and adaptation are ongoing processes (Patterson & Garwick, 1994). The adjustment phase of the model is an effort by the family to resist major disruption in its established patterns of behaviour and structure. Families may use avoidance coping strategies to deny or ignore the stressor or additional demands (Patterson & Garwick, 1994), which may lead to successful adjustment or to maladjustment or crisis if resistance efforts fail. However, it is important to note that crisis does not necessarily indicate a negative event, but simply represents a turning point where families are required to restructure and reestablish themselves. After a crisis, the adaptation phase is geared towards restoring homeostasis by acquiring new resources and coping behaviours,

decreasing the demands they must contend with, and changing the way they view their situation (e.g., situational and global meanings; Patterson, 1988). Adaptation is achieved through reciprocal relationships where the families' demands are met by their capabilities in order to achieve a balance at two crucial levels: between the individual and the family and between the family and the larger community (McCubbin & Patterson, 1983; Patterson, 1988, 1989; Patterson & Garwick, 1994). The way in which adaptation is achieved may vary based on the specific diagnosis, given that particular behavioural phenotypes are unique and predispose individuals to distinctive strengths and weaknesses (Dykens & Hodapp, 2001).

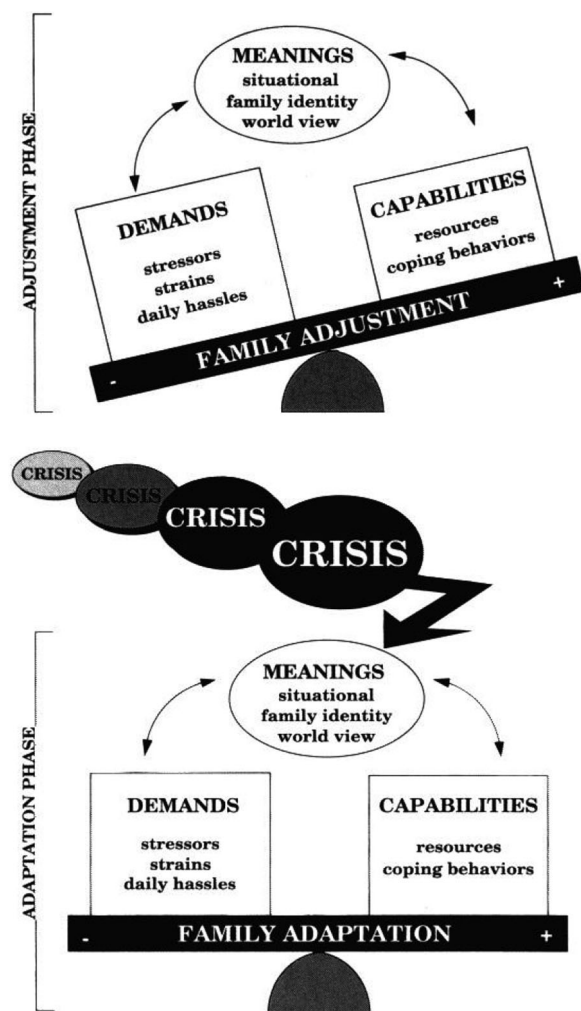


Figure 1. The Family Adjustment and Adaptation Response Model (Patterson & Garwick, 1994, 1998). From "Levels of Meaning in Family Stress Theory," by J. M. Patterson and A. W. Garwick, 1994, *Family Process*, 33, p. 290. Copyright 1994 by J. M. Patterson. Reprinted with permission.

Families of children with FASD

FASD is an umbrella term used to describe the range of effects caused by prenatal exposure to alcohol and is considered to be the leading cause of developmental disability in the Western World (Public Health Agency of Canada, 2005; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Families play a crucial role in the lives of individuals with FASD, yet little is known about how the experience of raising a child with FASD affects the family (Watson, Coons, & Hayes, 2013; Watson, Hayes, et al., 2013). It has been suggested that the caregiver stress of raising a child with FASD is likely different from that of other developmental disabilities (Olson, Jirikowic, Kartin, & Astley, 2007), and families of children with FASD may experience more stress than those with autism spectrum disorder (Watson, Coons, & Hayes, 2013).

Previous researchers have identified that families report a number of factors as valuable to maintaining placements, particularly foster placements, for their children (Brown, Sigvaldason, & Bednar, 2005). These factors include support from extended family, obtaining respite services, accessing assistance and supports for their child in school, maintaining a structured environment, respect and help from professionals, being aware of up-to-date information about FASD, and relationships and support from other parents of children with FASD (Brown et al., 2005). Furthermore, parents have identified seeing positive changes in the child (e.g., seeing the child's accomplishments, seeing their child succeed with difficult tasks) and wanting to make a difference in the child's life (e.g., seeing good things in the child with FASD) as crucial motivators for fostering a child with FASD (Brown, Rodger, George, Arnault, & Sintzel, 2008; Brown, Sigvaldason, & Bednar, 2007). Adoptive parents of children with FASD have indicated that they find the experience of raising a child with FASD both more rewarding and more difficult than they had initially anticipated (McCarty, Waterman, Burge, & Edelstein, 1999).

Gardner (2000) reported on the importance of coping with daily realities for caregivers raising children with FASD, including the necessity of providing consistency (e.g., the requirement of a structured schedule) and developing coping strategies (e.g., finding a support group) as important adaptive strategies. Additional studies from Olson, Oti, Gelo, and Beck (2009) and Sanders and Buck (2010) highlight the special benefits of raising a child with FASD, which include identifying their child as a teacher of important things in life and acknowledging their child's gifts.

Although some researchers have explored the overall experience of parents and caregivers from particular

family types (e.g., adoptive, foster, biological) raising children with FASD (Brown et al., 2005, 2007; Gardner, 2000; Olson et al., 2009; Sanders & Buck, 2010), the experience of family adaptation, in particular, remains largely unexplored. While unique differences do exist depending on family type, there are also a number of similarities across families in terms of family challenges, meaning making, and adaptation strategies. In this paper similarities between family types in terms of parenting strategies, family resources, and family adaptation are explored.

Method

As part of a larger mixed methods study examining the experience of raising a child with a developmental disability in Ontario, Canada, parents participated in qualitative interviews and completed a battery of quantitative questionnaires. The study incorporated qualitative research informed by basic interpretive inquiry (Merriam, 2002), conducted in the form of a semistructured interview. Drawn from phenomenology and symbolic interactionism, researchers utilising a basic interpretive approach assess how individuals understand their experiences, how they create their worlds, and what meaning they assign to their encounters (Merriam, 2002). This paper focuses on the qualitative component of this study to identify how parents and caregivers have adapted to the experience of raising their child diagnosed with FASD.

Consent and ethical issues

Ethical approval for this study was obtained from the Laurentian University Ethics Board, Ontario, Canada, and is in line with the Canadian Tri-Council Recommendations for Research with Human Participants. Informed consent was obtained from all participants, and was revisited throughout the research process. Prepaid envelopes were sent to all participants, containing a battery of quantitative questionnaires and two copies of a formal consent form for each participant (e.g., four consent forms in total for a mother and a father dyad). Participants were instructed to review the consent form, to determine if they were still willing to participate, to sign both copies of the consent form, and to keep one copy for their personal records. Informed consent was also obtained again from participants before participating in the semistructured interview. Participants were also repeatedly assured that they had the freedom to withdraw from the study at any time.

Participants

After receiving ethical approval, families in this study were accessed through disability support organisations from across Ontario, Canada. Emails were sent to numerous agencies, and participants were asked to phone or email the lead researchers if they were interested in partaking in the study. Respondent-driven sampling was also used (Salganik & Heckathorn, 2004), whereby individuals known to the investigators were contacted in the hopes of recognising families who would be willing to participate.

Participants included individuals who considered themselves primary caregivers to a child with FASD, such as biological parents, adoptive parents, foster parents, step-parents, custodial grandparents, great-grandparents, and a biological aunt (all referred to here as parents). Further information outlining participant demographics can be found in Table 1. Eighty-four parents of children with FASD from 59 families participated in the interview component of this study. In order to participate, parents had to have at least one child diagnosed with or suspected of having an FASD. The total number of children with a disability per family ranged from one to seven. The age of children with FASD ranged from one to 36, with a mean age of 14.29 ($SD = 7.65$). All participants in this study will be referred to by pseudonyms to protect their identities.

Qualitative interviews

Based on previous interview research conducted with families of children with disabilities (e.g., Watson,

2008) and informed by the FAAR model (Patterson & Garwick, 1998), the primary researcher (the second author) developed 22 open-ended questions with follow-up prompts if required (see Appendix). For example, the questions “How do you manage all of your responsibilities?” and “Is there anyone to whom you turned to for support during this process?” sought to identify capabilities and resources, such as particular resources or supports that families draw upon. The question “In what ways have you changed or do you see yourself differently as a result of your child having FASD?” addressed a major part of the adaptation process in defining the situation, or attributing meaning, to raising a child with FASD. Interviews were conducted by the lead researcher, who has several years’ experience conducting qualitative research, as well as by three graduate students, who were trained by the primary researcher. Interviews took place at locations agreed upon by both the participant and the interviewer, such as the participant’s home or a local coffee shop. In most instances, when more than one parent participated, they preferred to be interviewed together.

Data analysis

All interviews were digitally recorded and transcribed word for word. All transcripts were examined several times by the researchers to familiarise themselves with the content of the interviews. Repeated close and detailed readings of the interviews allowed the researchers to ensure that future interpretations of the data remained grounded within the participant’s account. After manual transcription and multiple reviews of the transcripts, notes and comments were made throughout the document in the margins and interviews were reread to convert original remarks and ideas into more specific themes and phrases using interpretative phenomenological analysis (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith, Flowers, & Larkin, 2009). IPA is associated with a detailed examination of personal and lived experiences of the individual and how that individual makes sense and forms meaning of that particular experience (Merriam, 2002; Smith & Eatough, 2008). IPA is also idiographic and is conducted at the level of the individual case so that the researcher is able to make specific claims about the individuals being studied (Forrester, 2010). Therefore, the goal of IPA is to understand what it is like to walk in another’s shoes and make analytic interpretations about those experiences and about the person as the “experiencer.”

During the data analysis process, an audit trail was kept to track detailed responses regarding thoughts and

Table 1. Participant demographic characteristics.

Demographic characteristics	
Characteristics of mothers (<i>n</i>)	
Average age (<i>SD</i>)	50.74 (11.27)
Age range	27–71
Relationship to child with disability	
Biological ^a (<i>n</i>)	12
Step-parent ^b (<i>n</i>)	2
Adoptive ^c (<i>n</i>)	39
Foster (<i>n</i>)	5
Married (%)	67.2
Characteristics of fathers (<i>n</i>)	
Average age (<i>SD</i>)	54.35 (11.39)
Age range	32–71
Relationship to child with disability	
Biological ^d (<i>n</i>)	4
Step-parent ^e (<i>n</i>)	3
Adoptive ^f (<i>n</i>)	16
Foster (<i>n</i>)	3
Married (%)	80.8

^aBiological relationship to child including aunt, grandmother, and great-grandmother.

^bStepmother relationship to child including step-grandmother.

^cAdoptive relationship to child including adoptive grandmother.

^dBiological relationship to child including grandfather and great-grandfather.

^eStepfather relationship to child including step-grandfather.

^fAdoptive relationship to child including adoptive grandfather.

comments about the content, the coding method, inclusion and exclusion criteria for themes, and examples of quotes for each determined theme. Once themes emerged, inferences were made and the data were summarised. Following Ryan and Bernard's (2003) recommendation for looking for repetitions in the data, themes were identified and further reduced by establishing connections between preliminary themes and clustering them appropriately (Shaw, 2010). Clusters were given a descriptive label, which conveyed the conceptual nature of the theme. Participant quotations are included in the text as they support congruence and integrity in relation to the identification of themes and subthemes. Each member of the research team conducted their own independent analysis of the data, and themes were then compared to check for consistency and negotiated by a group consensus, thus supporting triangulation of the data. Reliability and validity of the themes were ensured through investigator and methodological triangulation, as well as member checking (Shenton, 2004).

Results

Although parents and caregivers raising children with FASD experience a great deal of parenting stress (e.g., Watson, Coons, & Hayes, 2013; Watson, Hayes, et al., 2013), during the semistructured interviews family members also reported a number of strategies, supports, and transformational outcomes that enable them to adapt to raising a child with FASD. Using IPA, five themes were identified from the interviews: understanding FASD and advocating on their child's behalf, day-to-day adaptation, transformational outcomes, informal supports (e.g., extended family members, friends, church members), and formal supports (e.g., organisations designed to help families, professionals). Each of these themes is discussed in detail (see Table 2 for a summary of themes and subthemes).

Understanding FASD: "Get educated, get involved"

This theme title, taken from an interview with Gabrielle, an adoptive mother to a now adult daughter with FASD, demonstrates two important aspects of learning about and becoming involved with FASD. Parents discussed the need to learn more about the disability if their child was diagnosed with or suspected of having FASD, as well as the need to advocate for their children, particularly in the school system.

Table 2. Summary of themes.

Theme and subtheme name
1. Understanding FASD: "Get educated, get involved"
1.1 Learning about FASD: "Get as much information and knowledge as you can"
1.2 Becoming advocates: "You have to fight for everything for these children"
2. Day-to-day adaptation: "I take it day to day, I don't think about tomorrow"
2.1 Maintaining routines: "Everyday it's like the movie <i>Groundhog Day</i> "
2.2 Picking the right fight: "Choose your battles"
3. Transformational outcomes: "I wouldn't change it for the world"
3.1 Reframed worldview: "Life is one big adventure"
3.2 Positive outlook: "Our life is far richer"
4. Informal supports: "I have good support around me"
4.1 Significant others: "Luckily we sort of balance each other"
4.2 Family and friends: "A lot of insightful friends that just know how to be friends"
5. Formal supports: "It's nice to know you're not alone"
5.1 FASD support groups: "It was a lifesaver, the FASD group"
5.2 Help from professionals: "She listened and she tried to get other people to"

Learning about FASD: "Get as much information and knowledge as you can"

Parents often discussed the need to learn about FASD in order to better understand their child's disability and to better inform others. For example, Kaylee, an adoptive mother to two adult children with FASD, discussed the need to "get as much information and knowledge as you can ... so that you can understand and share that with whoever is dealing with your kid." Karen also referred to having "knowledge [of FASD] as power," as it allowed her to both understand her child's behaviour and modify her parenting strategies. For example, many parents discussed the work of Diane Malbin (2002) and highlighted the importance of "trying differently" rather than "trying harder" to change their child's behaviours. For Patricia, an adoptive mother to 8-year-old Adelle with FASD, one example of trying differently included altering the home environment. This included choosing a "calming" paint colour for Adelle's bedroom to soothe her, as well as keeping her room, and the house in general, uncluttered to prevent any feelings of overstimulation. Patricia elaborated that everything in their home is "maintained with an eye to calming Adelle." Other parents, such as Julie and Rob, a biological mother and stepfather, emphasised the importance of trying differently by enrolling their teenage sons in recreational sports leagues as a way to expend their extra energy. Furthermore, parents discussed obtaining education about FASD as a critical necessity in their lives to support them in better understanding the disability, their child's behaviour problems, and the reasons why traditional parenting strategies, such as punishment, did not work. For many parents, obtaining education about FASD allowed them to reevaluate their approaches to parenting, as they started understanding FASD as a brain injury.

Other parents talked also about the importance of attending conferences, seminars, and workshops focused on FASD as a method to obtain this knowledge of FASD. For many parents, attending conferences and workshops was often a first step in learning about, and understanding, FASD. Annie and Jason, foster parents to Nicholas, who is now an adult living with FASD, discussed their experiences in learning about FASD at conferences when Nicholas was younger:

That's where we first began to learn about how you could do things in the environment to help them with memory and ... This is such important information to have, we have to get out there and help out people.

Jade also discussed how important obtaining information regarding FASD was: "Educate yourself as much as possible – if you have a speaker coming in ... Even an hour away, go to the workshops on FAS."

Becoming advocates: "You have to fight for everything for these children"

In addition to educating themselves about FASD, parents also identified having to take on the role of advocate for their children's sake, particularly within the school system. Some parents, such as Sally, talked broadly about what it meant to be an advocate, which she identified as talking to anyone who would listen about FASD or could potentially help her two sons:

I have become more of an advocate. Like writing the MP, writing letters to the editor and stuff like that. And giving talks ... So you take on more – and I talk about alcohol use ... during pregnancy to teenagers. Whenever I have a chance I'll be mouthing off about it (*laughs*).

Like Sally, several parents utilised evocative words or phrases during their interviews that spoke to their challenges and persistence as advocates. For example, Leslie and Kevin repeatedly used the phrase "push for supports" to describe their advocacy for their sons, Jace and Jared. For them, advocacy often meant hours spent on the phone or on the internet to locate available supports and obtain access to them for their sons. Other parents, such as Robyn, identified her role as an advocate as being able to think ahead and "being a pain in the ass" to ensure her step-grandson was enrolled in a number of programs that she believed would be beneficial to his wellbeing. Many parents discussed their advocacy role as "a fight" on their children's behalf, because their children are often unable to advocate for themselves. Kimberly used the analogy of having to "fight like a bulldog" because she often had to become heavily involved on her daughter's behalf when she was not being properly supported:

I'm a very loud advocate and I don't let things go, my mom refers to me as a bulldog (*laughs*). I sink my teeth and I don't let go until I get what I'm after, and that's partly why I started the support group.

Several parents, such as Veronica, Carmen, and Pauline, discussed their advocacy role in relation to the school system. Many parents reflected that their children's teachers, school staff, and principals were often unaware or uneducated about FASD. Some parents, such as Patricia and Lacey, worried that their children's schooling would be disrupted as a result of this lack of knowledge. For example, Patricia argued that her daughter would "be a lot worse off if I wasn't as strong an advocate as I already am. She would be suspended because they wouldn't understand why she acts out." Parents therefore provided tangible resources for their children's teachers to ensure that they received some educational material on FASD. For example, Veronica talked about educating the teachers about her daughter Irene:

I found British Columbia had an excellent resource on kids who have FASD and strategies and suggestions for teachers. So I printed that off and gave them a copy. And then I found out that SickKids through Motherisk, they published a book as well for FAS and I ordered two copies, one for myself and one for her school.

For many parents, like Veronica, advocating for their child to receive additional support in school and educating teachers about FASD was often a challenge because there was no way to ensure that the teachers were employing the strategies suggested in the educational materials. However, in some instances, despite often being annoyed at having to continually advocate, some parents discussed the rewards of their continued advocacy. For example, Denise touched upon her experience with her daughter's teacher that culminated in both a better understanding of FASD from the teacher, as well as validation for Denise:

I worked hand in hand with the teacher last year, I gave him all the information, the pamphlets, everything, and he said ... "At first, Denise, I thought maybe it was just Hayley not wanting to listen and not wanting to ..." But he said, "After reading all the stuff, you know, I understand better."

It was important for parents to advocate for their children's schooling to ensure that they received a proper education and stay in school. Many parents refused to allow the school to make decisions without consulting them, especially when it came to matters such as suspensions or individualised education plans (IEPs). This advocacy work benefits both the caregivers and the child with FASD, as an improved understanding of

their child's disability and better supports in school settings provide a sense of reassurance for parents that their child is obtaining an education and is attended to by informed teachers and staff while at school and out of their direct care.

Day-to-day adaptation: "I take it day to day, I don't think about tomorrow"

This title theme, spoken by several parents, emphasises the importance of having strategies to manage the everyday tasks and challenges that arise in their lives. For example, Allan stated that, "It's just kind of going with the flow ... just, day to day, kind of dealing with the challenges." Other parents, such as Adrianna and Paul, grandparents to four children with FASD, and Caitlin, an adoptive mother to one daughter with FASD, mentioned that on the days where you cannot go day to day, you may have to go hour by hour. Parents discussed two main strategies that they used to aid with the challenges of everyday life: maintaining routine and choosing appropriate battles.

Maintaining routines: "Everyday it's like the movie Groundhog Day"

In order to manage their children's behaviours, parents discussed the importance of keeping routine, consistency, and repetition in their everyday lives. Although this theme name came from an interview with Louis, a biological father to a teenage son with FASD, several parents used the same phrase to describe their parenting routines. For example, Rob, a stepfather to two sons with FASD, compared his life to the movie *Groundhog Day*, where Bill Murray's character becomes stuck in a time loop and is forced to relive the same day over and over:

Living with them, it's like, ever see that movie Groundhog Day? Reminds me of that because these children ... like normally any kids you have to tell them so many times so it sinks into their head. But these kids here, it's like every day you tell them and like, got erased during the night. Next day start over. Tell him again.

While parents discussed experiencing their everyday lives like the movie *Groundhog Day* in the sense that their children may often have memory deficits, there was also a sense of desperation for parents in terms of finding strategies that would make their daily lives easier. In the movie, as the time loop continues, Bill Murray's character tries increasingly more drastically to end the time loop and, ultimately, he succeeds through positive change and learning experiences. One theme from the movie includes the idea of self-improvement and the need to live the day correctly. For parents, using the

phrase "groundhog day" may not only reflect their child's memory processes, but also their hope to find an everyday routine that works for their family. The double meaning behind the idea of groundhog day is important, as it is as much about the parents as it is about the children. For many parents, finally getting the daily routine correct may pave the way for the best possible day for their children.

Parents, such as Tamara, found that by maintaining a routine, they were better able to predict their children's challenging behaviours: "They have to stay on their routine all the time, 'cause it's very structured for them and it's very easy for them ... their behaviours are predictable." Some parents also discussed using alternative methods to maintain routine in their home. For example, Kendra, a biological mother to Audrey, discussed how she uses visual prompts and signs for her daughter to remind her to complete all the steps of particular tasks, such as brushing her teeth before bed or using the washroom. Parents also found that following a routine made their lives simpler and easier. For example, Allan, an adoptive father to Jessica, stated:

It's taken us a while to adapt to having these kids ... so now that we're on a routine and understand that kids need that routine, it's easier for us now as well ... If you have everything as a routine, it's very simple.

Picking the right fight: "Choose your battles"

Many parents found that when they adapted to picking what they perceived to be an appropriate conflict (e.g., inappropriate choices of friends or significant others, engagement in illegal activities) with their children, it improved their relationship with their children tremendously. For example, Melanie, an adoptive mother to one son with FASD, found that when she stopped arguing with her son about some of his behaviours, his outbursts began to stop: "I mean, it's just, his little quirks that we finally decided to accept and that we're not gonna battle about it anymore. The rages, I think that all happened because we were battling all the wrong things."

For many parents, allowing their children to continue with certain nonharmful behaviours or quirks made life easier on them because they were able to put their energy into other areas or activities. For example, Jade discussed conserving her energy when dealing with her granddaughter Leona's outbreaks when she came off the bus from school, and Kimberly discussed her occasional internal struggle between allowing her daughter Bernadette to watch "inappropriate" movies (e.g., movies that were rated as PG 13 or higher) or risking Bernadette having a "meltdown." Many parents reflected that you have

to “pick your battles” and that many of them “are not worth picking.” Although quirks or certain behaviours could sometimes become irritating or problematic for some families, many parents felt that the day-to-day quirks were not as important as the “bigger things that need to be tackled.” For many parents, dealing with serious behaviour problems, such as aggression or depression, or planning for their children’s futures were more critical than daily issues that may arise.

Transformational outcomes: “I wouldn’t change it for the world”

In addition to the strategies parents employed to deal with the day-to-day management of their children, parents also showed evidence of a changed worldview. As will be demonstrated, parents often reflected that despite the challenges and struggles associated with raising their child with FASD, if provided with the opportunity, they would choose to raise that child again. A number of parents discussed the positives that their child had brought to their lives.

Reframed worldview: “Life is one big adventure”

This subtheme reflects the feelings that many parents held regarding their outlook on raising their child with FASD. Families found the experience of raising their children to be enriching and focused on the positive contributions that their children brought to their lives. Many parents referred to their parenting experience as “an adventure” and several parents remarked that they would be bored without their child’s unique contributions to their family life. A number of families discussed that their life was often unpredictable, but this provided them with a sense of excitement. For example, Kimberly remarked that life with her daughter Bernadette is “an adventure ... it’s scary ‘cause I never know what she’s going to do, it’s unpredictable (*laughs*). I don’t ever worry about being bored.” Nicoletta and Geoffrey also described their lives with their six adopted children with FASD as erratic, but observed that there is “never a dull moment” in their household.

Positive outlook: “Our life is far richer”

Some caregivers also acknowledged the unique personal changes that resulted from raising their child with FASD, such as feelings of gratitude, personal strength, and patience. For example, several adoptive parents, such as Jennifer, expressed that their child brought a sense of joy to their lives because they could not have a biological child of their own. As Jennifer elaborated, “everyone says ‘oh, you saved Mackenzie’s life!’ He’s saved ours because at one time we couldn’t have kids ...

And he filled that gap that we needed and ... that’s the joy that Mackenzie brings.” Several biological mothers shared a similar outlook regarding the pleasure that their child brought to their life, although some parents, such as Kendra, a biological mother to Audrey, had their own unique situations:

I am sober; she gives me a reason to stay sober. I don’t think I would have managed to stay 10 years sober right now, had it not been for her. I’d probably be dead by now if I was still drinking so ... I can honestly say she saved my life.

Parents therefore were able to identify the positive and rewarding aspects of raising their child with FASD and, as discussed by Mina, a biological aunt to Emma, they emphasised that despite their frustrations and challenges that they “would do this a million times over.”

Informal supports: “I have good support around me”

In addition to a changed worldview, families remarked upon the importance of obtaining support from family and friends. Tracey, a biological great-grandmother to Leah, stated:

It takes a community to raise a child [with FASD]. And I believe it, I really believe it now. There’s nobody. I don’t care where you come from or where they go, there’s nobody that can do it on their own.

Parents discussed the support they received from informal sources, particularly from significant others, family members, and close personal friends.

Significant others: “Luckily we sort of balance each other”

Many families discussed the need to have someone, particularly their spouse or partner, to “lean on” for support. For example, Kevin shared a comment about his wife, Leslie: “We lean on each other ... We support each other a ton. We really have to team up (*laughs*) ... So ... everything we do, we always run it by each other.” Kaylee, an adoptive mother to two children, and Celine, an adoptive and foster mother to two sons, talked about how their husbands could “balance” them when they were having a bad day and could take on more of the parenting responsibilities if someone in the relationship needed a break.

A number of couples also viewed themselves as a team who worked in constant collaboration, providing feedback on parenting, discussing strengths and weaknesses of everyday life, and reassuring one another when needed. For example, Celine expressed how her husband reassures her of her parenting skills, which makes her feel confident in her abilities and creates a positive

home experience: “Like just yesterday he said ‘Geez, you’re a good mom.’ I said, ‘Why do you say that?’ He goes, ‘Because you are.’” Many parents discussed the importance of talking to one another about the struggles they face, as well as strategies that have been effective, in order to ensure that they are parenting in the same way. Geoffrey, an adoptive father to six children with FASD, stated that he and his wife are often the only form of support for one another because no one else really understands what they are going through:

There are days when I can’t do it or I can’t get it through to one of the kids and I say “you gotta talk to them” or “you gotta do something” or whatever ... Really, nobody ... nobody else knows what we’re going through. ... I don’t like burdening other people because they have problems of their own, why would they want to listen to my problems, right? So a lot of times it’s just the two of us that vent.

Family and friends: “A lot of insightful friends that just know how to be friends”

In addition to having a strong spousal relationship, parents also discussed receiving support from other informal sources, including sisters, grandparents, other parents of children with disabilities, friends from church, and close personal friends. Parents, such as Emily, felt that having close friends to talk to allowed her to discuss her daughter without being judged: “I had a few close friends that I could trust, that I could tell them anything about Lisa and they wouldn’t judge her or myself. And ... that made me feel good that ... I had that outlet.” Whitney, a biological mother to Randall, expressed similar feelings of finding one good friend who did not judge her:

I have a really good friend ... and she was the only one that acknowledged that this is my reality now, but didn’t judge me for it. She was very supportive and I could pretty much talk to her about anything.

Formal supports: “It’s nice to know you’re not alone”

In addition to informal supports, families talked in great detail about the amount of support they received from formal sources. During their interviews, most parents discussed the importance of support groups and help from professionals as particularly important in their lives.

FASD support groups: “It was a lifesaver, the FASD group”

Formal support groups, such as parent-to-parent FASD support groups, appeared to be the most important source of formal support for parents because it provided them with a sense of community and a sense of

belonging as a family unit. For example, when discussing their local support group, Stephanie and Chad, adoptive parents to Victor, stated, “We belong with them.” Claire, an adoptive mother to Stella, shared a similar comment about having people around who understood her daughter’s behaviour:

I have a support group I go to ... That is probably the only place where you can be like “sooo, my daughter brought a knife to school today” and everybody’s like “oh yeah! How’d that go?” Like ... absolutely feeling normal. And everybody goes “how old is she?” She’s eleven. “Huh ... the next two years are gonna be really bad.” (*Laughs*) You know?

Talking to other parents, especially parents who have children with similar challenges, allowed families to exchange stories or vent about current frustrations, providing them with a sense of relief. For Claire, having people who understood, and did not judge, her daughter’s violent behaviour was a tremendous form of comfort and validation. She discussed how support group meetings always tended to have “snickers around the table” where parents of children with FASD could share a laugh over what many other people would find absurd, allowing Claire to feel understood among a group of peers who share similar experiences and challenges.

Caregivers also appreciated the practicality of having a form of online support from families that was easily accessible. In particular, families discussed FASlink as a key resource, as well as online friends they had made through various FASD resources and Facebook groups. For example, Adrianna shared a personal anecdote about receiving emails from her support group when she feared her 16-year-old granddaughter with FASD might be pregnant. Claire also discussed one specific example of how having support from her friends online helped her through a crisis when she believed her daughter was going to kill her in her sleep. Claire elaborated on how one fellow parent in particular would constantly check in to see how things were going and would be there at any time to provide her with support. As Claire stated, “she kept me sane that night and I have never met her.”

Help from professionals: “She listened and she tried to get other people to”

In addition to turning to existing formal FASD support groups for assistance, some parents also reported going to a variety of professionals for help. Aid from professionals included support from psychiatrists, counselors, social workers, teachers, and doctors or paediatricians. Denise, a biological grandmother, and

Jade, an adoptive grandmother, also found their counselors to be a tremendous form of support, because of their ability to listen to their weekly experiences at home with their children with FASD. As Jade elaborated:

I still go once every six weeks ... And we joke that she's going to retire and I'm still going to be in counselling. Sometimes I go and bawl for the whole hour because I'm so stressed out, other times we just laugh for the whole hour ... she laughs at my resiliency skills, and my take on life ... That really helps too.

Of the professional supports discussed, a minority of families found doctors to be an important source of support. By helping their children, these professionals were in fact also providing better assistance to the parents, as interventions for the child can be an extension of aid for the parents, and is thus perceived as a form of tangible support to parents. For example, Annie and Jason found their family doctor extremely helpful because this physician would make an attempt to understand FASD at a time when many other individuals, including several medical professionals in their lives, were unwilling to learn about their child's challenges:

That was kind of the breakthrough point as far as finally getting a doctor who got it and was willing to work with us and Nicholas. She listened and she tried to get other people to ... provide the proper supports for him and everything ... Any help that she could offer us, she would, you know?

A minority of families were very appreciative of physicians who made an effort, either to educate themselves about FASD or to refer them to the appropriate service or individual. Unfortunately, the majority of participants felt that doctors lacked knowledge of FASD and were therefore not very helpful.

Discussion

The authors of this qualitative study found that parents identified a number of factors that helped them adapt to the experience of raising their child with FASD. Although new family crises may continually arise, prompting a renewed period of adjustment, many families in this study described their unique strategies to enable positive family adaptation. Patterson and Garwick's (1994) FAAR model explains how families balance their demands with their resources and coping behaviours in order to achieve homeostasis and thus adaptation. This adaptation was recognised or recounted by the families of children with FASD in this study as acquiring new skills or supports, which in turn helped them lessen the demands they must contend with and change the way they view a particular situation. Families

demonstrated evidence of adaptation in a number of ways, for instance, maintaining a strict routine to help alleviate their child's difficult behaviours. Planning and implementing interventions that will better support the family's daily routine is important because interventions will not be effective if they are not integrated into the daily routine of an organisation, family, or individual (Bernheimer & Weisner, 2007).

Families also identified the experience of raising their child with FASD as positive, although difficult. Individuals who perceive a situation as a challenge often regard an obstacle as an opportunity to gain something beneficial from the experience and to better cope with their environment, as well as an opportunity for personal growth (Lazarus & Folkman, 1984; Scorgie & Sobsey, 2000). Scorgie and colleagues (Scorgie & Sobsey, 2000; Scorgie et al., 2001) identified a number of positive factors associated with transformational outcomes in families raising children with developmental disabilities that are very similar to the many positive factors associated with raising a child with FASD presented in this study. For example, Scorgie et al. (2001) identified acquiring new roles (e.g., being an advocate for their child), a greater sense of personal strength and patience, determining what is really important and valuable in life, and improved family relationships, particularly supportive marriages, as influential transformational outcomes. Parents in our study highlighted many of the same positives, particularly in relation to new roles (e.g., advocate, educator about FASD) and improved family relationships (e.g., improved communication between spouses, closer family unit).

Parents and caregivers further expressed that their children had been influential in changing their lives. A positive outlook, feeling some sense of affirmation despite the struggles, and finding the strength to keep going are important contributors to family resilience (Kearney & Griffin, 2001; Walsh, 1998). These attributes were clearly demonstrated by the participants in this study. Resilience is a construct in family research that focuses on the positive factors that contribute to a family's ability to recover from crisis (Watson, Hayes, & Radford-Paz, 2011). Other researchers, such as Walsh (1998), have conceptualised resilience as the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful. Patterson (2002b) contends that the FAAR is a model of family resilience because it emphasises the dynamic progression by which families experience periods of adjustment and adaptation to a crisis. Patterson (2002b) further argues that resiliency theory extends family stress theory by recognising that many families overcome crisis through the process of adaptation, resulting in more competent

family functioning. Parental wellbeing is also a critical construct that is important in caring for children with FASD. In an examination of child behaviour and its influence on parental wellbeing, Hastings and Taunt (2002) indicate that experiencing positive outcomes may support stress reduction in relation to the child with behavioural or emotional concerns (Kayfitz, Gragg, & Orr, 2010).

Families also emphasised how essential having a form of social support was, particularly when it came to formalised and structured support groups either in person at their monthly community meetings or online. The link between social support and a family's wellbeing and the caregivers' abilities to parent has been discussed in the literature (Armstrong, Birnie-Lefcovitch, & Ungar, 2005). Further, qualitative findings have also revealed that parent-to-parent support is vital because it creates a sense of a "reliable ally" (Ainbinder et al., 1998, p. 103). In the current study, parent-to-parent support fostered a sense of community, because other families could relate to the same daily challenges and behaviours. Research examining families of children with FASD has demonstrated that families identify social support as a foremost factor in maintaining successful placements of children with FASD in foster home environments (Brown et al., 2005). Further, social support is a critical element in the adaptation process (Gardner, 2000; Sanders & Buck, 2010). Encouraging access to social supports may also be critical in helping families avoid feelings of social isolation or stigma, a common experience reported by parents of children with FASD from all family types (Brown & Bednar, 2004; Salmon, 2008; Sanders & Buck, 2010; Watson, Hayes, et al., 2013).

Furthermore, understanding what families do in order to effectively adapt to raising their child with a FASD diagnosis is essential in aiding families who are not adapting successfully to their child's needs. The findings generally indicate that most families in this study are adapting on a day-to-day basis and this adaptation is influenced by a number of factors (e.g., age of the child, single- or two-parent family, family type). However, parenting children with a FASD diagnosis is stressful and several families in the study did indicate that they were living in a constant crisis, thus not moving from adjustment to adaptation. For example, Sally and Peter, adoptive parents to two teenage sons with FASD, stated, "Well, we're not doing well. Our life is like we can't sleep. You are in crisis ... You drive around the corner and your stomach, you feel nauseous 'cause you wonder 'what's happened? What will have happened? Will the kids be home?'" Peter further went on to refer to himself as a parent who has "post-traumatic stress disorder ... I'm battle weary. That's parenting [a child with

FASD]." It is worth noting that several of the families who experienced difficulties with adaptation were parents of *adult* children with FASD, many of whom received a diagnosis quite late in their child's life or received an incorrect diagnosis, typically attention-deficit/hyperactivity disorder (ADHD) or conduct disorder. These families' demands exceeded their current capabilities, and thus they did not find it easy to meet the needs of their child, accommodate an environment that would support their child's needs, or adapt to the often very challenging needs of their child. The fact that these children received an inaccurate diagnosis is critical, as the lack of an appropriate diagnosis led to challenges in adaptation. Parents did not know or understand how they needed to structure their child's environment, an important coping behaviour.

Understanding how families adapt or do not adapt to raising children living with FASD is essential to constructing a home environment that meets the child's as well as the parents' needs. The ways in which adaptation is achieved may be unique for families of children with FASD, as compared to other intellectual or developmental disabilities. By employing a theoretical model of family adjustment and adaptation, such as the FAAR, we can better understand the ways in which families achieve a balanced functioning. For example, parents in this study cited the importance of obtaining information about FASD in terms of better understanding their children's behaviour. Seeking out information about the disability could be viewed as both an adaptation behaviour and as acquiring a new resource, as families are better able to mobilise and obtain information that is critical to their daily functioning and parenting. Furthermore, by obtaining information about the disability themselves, families are also able to relay that information to professionals who may be dealing with their children (e.g., educate and advocate on their child's behalf) and thus receive appropriate interventions, which can lessen the demands on the family. Additionally, families developed a number of strategies to aid in their day-to-day functioning (e.g., maintaining a consistent routine, choosing their battles) that served to reduce their stressors and strains, and thus facilitate family adaptation.

A number of these families spoke in detail about their personal difficulties balancing the demands of their adult child's difficulties with other family roles and responsibilities, particularly when it came to caring for their ageing parents or a sick spouse. A study by Seltzer, Greenberg, and Krauss (1995) indicated that ageing parents may sometimes find themselves sandwiched between the needs of two generations, such as their parent(s) or even a spouse who becomes ill and

requires care in addition to their adult child with a disability. A similar concept may apply to grandparents who are raising a second-generation child with FASD (e.g., their biological or adoptive grandchild), because they may find themselves experiencing challenges raising their grandchild with FASD (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013), as well as their middle generation (Clement, Coons, & Watson, 2013). Therefore, identifying strategies that foster successful adaptation is essential in helping families face the challenges in caring for the needs of a child with a FASD diagnosis. It is important to consider those factors that are perceived as supportive and their influence on helping families adapt and maintain balance in caring for a child with often complex needs and demands.

Limitations and considerations

Although this study addressed the need to examine specific facilitators to adaptation in families raising children with FASD, a number of limitations presented, including the fact that caregiving couples were interviewed together. Hastings, Beck, and Hill (2005) have suggested that mothers report more positive perceptions compared to fathers of their child's contributions to their family and themselves. However, due to their busy schedules, mothers and fathers from the same family in this study often expressed the desire to be interviewed simultaneously. Although being interviewed together may have potentially limited what families divulged, this seems unlikely as the researchers were often struck by the amount of personal information families discussed. Furthermore, being interviewed together allowed the researchers to access participants who would not have otherwise participated.

Cultural and socioeconomic status (SES) was also an issue. Most participants came from Caucasian, affluent families, and therefore generalising results to other cultures and lower SES families is not possible. Although we attempted to obtain information regarding family SES, not all families felt comfortable divulging that information. The cultural context into which one is born profoundly influences how one interprets stressors (Chun, Moos, & Cronkite, 2006; Lazarus & Folkman, 1984). Diverse racial and ethnic backgrounds influence what events are perceived as stressful, what coping strategies are available or acceptable, and what support systems families need (Cardoso, Padilla, & Sampson, 2010). Because families in this study came from relatively affluent homes, they may not have faced additional stressors that could have made adaptation more challenging.

Conclusion

This study revealed that although the experience of raising a child with FASD can be challenging for families, most parents and caregivers find ways to successfully adapt. The themes provide evidence that families ascribe meaning and gain understanding from their experiences associated with raising their children with FASD. To reiterate, the five major themes emerging from this study were understanding FASD and becoming their child's advocate, implementing day-to-day adaptation, promoting transformational outcomes by focusing on the positives of their child, utilising informal supports such as their significant other, additional family members, and friends, and accessing formal supports such as parent-to-parent FASD support groups and helpful professionals.

According to the FAAR model (Patterson & Garwick, 1994, 1998), families attempt to maintain a balanced functioning, or homeostasis, by using their resources to meet their added demands. Meanings that families assign to these added demands, as well as meanings they assign to their capabilities, are critical features in achieving this balanced functioning (Patterson & Garwick, 1994; Olson et al., 2009; Sanders & Buck, 2010). Families tend to fare better when they are able to make meaning of their child's disability (Pakenham, Sofronoff, & Samios, 2004; Olson et al., 2009; Watson, Hayes, et al., 2013), therefore continued research looking at the family experience and the meanings families place on raising a child with a developmental disability, such as FASD, is necessary. Excessive demands deplete parents' resources, creating a pile-up of demands. In line with the conceptualisation of positive functioning and successful adaptation, Jones and Passey (2005) noted that parents who believed their lives were not controlled by their child with a disability, and who coped by focusing on family integration, cooperation, and optimism, tended to report lower overall levels of stress and better family functioning. Many authors contend that models like the FAAR are needed to understand the complex relationship between having a child with a disability and successful family adaptation, especially with regard to intervention development (e.g., Manning, Wainwright, & Bennett, 2011). Further research examining the family experience of raising a child with FASD in relation to both family strengths and stressors, including internal and external sources, is warranted (see Coons, Watson, Yantzi, & Schinke, 2016).

In order to enhance the findings reported herein, future researchers should seek to examine the experience of family adaptation over time for parents of children with FASD. It would be advantageous for future researchers to conduct longitudinal studies on the

experience of families (Dykens, 2006; Patterson, 2002a), as adaptation is an ongoing, cyclical process, describing transformation over time. To date, limited longitudinal research has investigated the life-course outlook for individuals with FASD and their families (see Coons, 2013). However, it is important to understand the longitudinal process of family adaptation as there are different considerations across the life course, such as when a family first discovers that they have a child with FASD, managing the development and emergence of secondary disabilities, and when ageing parents must consider the future of their child with FASD (Gardner, 2000; Olson et al., 2009; Watson, Hayes, et al., 2013). Furthermore, researchers should investigate the level of awareness that both professionals and the larger community (e.g., women of childbearing age) have regarding FASD. Findings from the current study reveal that parents do not feel supported by those from whom they expect help, particularly healthcare providers and teachers. Existing research has demonstrated conflicting evidence regarding how much knowledge and awareness professionals have of FASD. For example, researchers have shown that very few practitioners in the health, education, social services, and justice systems have a working knowledge of the effects of FASD (Nevin, Parshuram, Nulman, Koren, & Einarson, 2002). Understanding how much knowledge and awareness individuals have regarding FASD is an important step in developing appropriate educational strategies, understanding the high prevalence rates of the disability, and creating targeted prevention initiatives.

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Appendix. Semistructured interview guide for parents

- (1) Describe your child. What is he/she like? Favourite memories?
- (2) What is it like for you to be his/her parent?
- (3) Please describe a typical day in your home. (*Prompt: Can you please run me through the morning routine, etc.?*)
- (4) How did you find out about your child's disability (or suspected disability)? (*Prompt: When did you suspect he/she had a developmental disability?*)
- (5) How did you feel when you received the diagnosis of FASD? (*Prompt: For parents who have not received a diagnosis: How did you feel when you were unable to receive a diagnosis?*)
- (6) What prompted you to initiate the diagnostic process?
- (7) What meaning did you think a formal/differential diagnosis would provide? (*Prompt: Why did you want a formal diagnosis?*)
- (8) Please describe, in as much detail as possible, the story of your diagnostic experience, giving particular attention to the critical events and challenges you have faced along the way.
- (9) What was the most helpful during this process? What was the most difficult part of the process?
- (10) How did your child cope with the testing? What about other family members?
- (11) Is there anyone to whom you turned to for support during this process?
- (12) How has having a name for the disability changed the experience for you?
- (13) Please talk about how you are doing right now.
 - (i) Whom do you turn to for support?
 - (ii) How do you manage all of your responsibilities?
- (14) Tell me how you manage your child's FASD at home.
- (15) If applicable, tell me about how school personnel manage your child's FASD.
- (16) How do your child's doctors manage your child's FASD?
- (17) What has worked to facilitate effective management of your child's FASD? Why?
- (18) How do you think family dynamics are different having a child with FASD? (*Prompt: If applicable, does one child get more attention than another? Have your vocational choices been influenced by your child's disability?*)
- (19) In what ways have you changed and in what ways do you see yourself differently as a result of your child having FASD?
- (20) When you think about the future, what do you see?
- (21) If you could wave a magic wand, what supports would you like?
- (22) If you could give advice to another parent of a child with FASD, what would you tell them?