

# A LONG JOURNEY: BIOLOGICAL AND NON-BIOLOGICAL PARENTS' EXPERIENCES RAISING CHILDREN WITH FASD

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## ABSTRACT

### Background

Research evaluating the experiences of birth and adoptive parents raising children with a fetal alcohol spectrum disorder (FASD) is needed to ascertain facilitating factors and barriers to successful family functioning. Qualitative approaches to parents' experiences can help us better understand in what ways families need support and can also be used to guide quantitative research in this area.

### Objectives

The present study is a qualitative, descriptive investigation of parents' experiences raising children with FASD in an Alberta city and environs.

### Methods

Eleven participants, consisting of biological (3), adoptive (7), and foster (1) parents were interviewed using an unstructured format in order to enable them to share their "as-is" experience. A phenomenological-hermeneutic approach and thematic analysis was used to analyze and organize the data into themes.

### Results

Nine central themes were derived from the interviews: 1) something's not right; 2) receiving a diagnosis; 3) attitudes toward birth parents; 4) living in a war zone; 5) understanding my child; 6) getting support; 7) re-defining success; 8) lifelong parenting; and 9) my child's gifts. Sub-themes were derived from several of these central themes. Descriptions of central and sub-themes are provided as data from each are presented.

### Conclusions

By better understanding parents' experiences, family members, teachers, professionals, support personnel, and the community can better support parents of children with FASD. This support is needed in order to promote stable environments for families raising children with FASD, which has been identified as a critical protective factor to promote lifelong successes for those living with the disorder.

**Key Words:** *Fetal Alcohol Spectrum Disorders (FASD), parenting, qualitative research*

A clinical description of the deleterious effects of fetal alcohol ingestion was first published by Lemoine et al, in 1968.<sup>1</sup> Five years later, Jones et al., a research team in Seattle, WA, provided a similar clinical description which they named fetal alcohol syndrome.<sup>2,3</sup> The classification of fetal alcohol spectrum disorders (FASD) is now used as an umbrella term identifying deficits related to all

degrees of prenatal alcohol exposure. Children with FASD can experience a number of neurocognitive difficulties<sup>4</sup> including deficits in intellectual ability<sup>5</sup>, executive functioning<sup>6</sup>, attention<sup>7</sup>, memory<sup>8</sup>, and social cognition.<sup>9</sup> Persons with FASD can have mild to serious cognitive challenges<sup>10</sup>, which can lead to secondary disabilities such as mental illness, addiction<sup>11</sup>, disrupted school experience,

inappropriate sexual behaviour, and trouble with the law.<sup>12</sup> Children with FASD who are diagnosed early and raised in stable home environments, however, have been shown to be more apt to avoid these devastating secondary disabilities.<sup>12</sup> It is therefore not surprising that Canadian Federal and Provincial governments consider addressing FASD to be an important priority.<sup>13</sup>

Children's cognitive deficits, behavioural difficulties, and secondary disabilities can create considerable challenge for parents raising children with FASD.<sup>14</sup> Research comparing the experiences of birth and adoptive parents raising children with FASD is needed to ascertain facilitating factors and barriers to successful family functioning.<sup>15</sup>

Frankel, Frankel, & Opie<sup>15</sup> interviewed parents who were perceived as successful in parenting children with FASD. In their study, the researchers described a plethora of challenges in caring for children with FASD, such as children's behavioural, cognitive, affective, physical, developmental, and social functioning. In addition, the researchers described several barriers to successfully accessing supports from educational and health care systems, and other external sources of stress such as racism and loss of culture among aboriginal children in non-aboriginal homes.

Brown & Bednar<sup>16</sup> evaluated parents' challenges raising children with FASD, and organized participants' responses into eight concepts. Parents expressed difficulty preventing the child's behaviour problems before they occur; making time for themselves; keeping plans for themselves and their families; collaborating with the school to maintain consistency for their child; keeping the FASD child involved in community activities; lacking support from professionals; keeping their child involved with peers; and coping with learning and behaviour problems. Challenges of parents raising children with FASD are varied, and multiple factors may accumulate to increase overall parenting challenge and stress.

Higher levels of stress may be experienced in families where children with prenatal alcohol exposure are raised. Paley et al.<sup>17</sup> evaluated predictors of stress in 100 children with FASD and their parents. In this study, the researchers compared children's cognitive, executive, adaptive, and behavioural functioning with child

and parent domain stress, accounting for demographic, diagnostic, and resource variables. Paley et al. found that delays in executive functioning, impaired adaptive functioning, behavior problems, and adoptive parent status were related to higher child domain stress. Parent domain stress was associated with biological parent status and fewer family resources.

Because a stable family environment is key to helping children with FASD attain positive outcomes<sup>12</sup>, additional supports for parents are needed. Supports needed by families raising children with FASD described by Brown<sup>18</sup>, include abroad support network of family and friends; helpful and compassionate professionals who have a good knowledge of prenatal alcohol effects; available community resources; good working relationship with the child's school; including staff with knowledge of FASD; appropriate strategies to promote learning; income support to assist with expenses such as medical costs and respite; and strengths-based approaches to parenting taking into account the individual child's unique abilities and challenges.

A few comparable qualitative studies using an unstructured interview approach were retrieved from the literature. Granitsas<sup>19</sup> conducted interviews with four adoptive parents living in Massachusetts, USA, who were currently caring for children or adolescents with FASD in their homes. Using a phenomenological-hermeneutic approach for data analysis, six essential themes emerged from the interviews: Feeling Delight Upon Adoption; Not Knowing, where parents explained that they were given no information, or incomplete information about their child's diagnosis; Identifying Problems, Concerns, and Difficulties common to FAS; Feeling Frustrated given difficulties raising a child with FAS; Feeling Pride in children's accomplishments despite medical, learning, and behavioural challenges; and Feeling Devoted despite incomplete knowledge, frustration, and coping with difficulties. Granitsas, who adopted four children with FAS, then compared and validated the participants' experiences with her own. Recommendations for nurse practitioners serving parents of children with FAS include reviewing maternal alcohol consumption for prevention of FAS, serving as resources for parents, being

empathic advocates, and assisting with individual educational plans and parent advocacy.

Gardner<sup>20</sup> described experiences of eight married, middle-class foster parents of children with FAS living in the United States, also using an unstructured interview format. Using content analysis, Gardner described three topic areas: Cognitive concerns, Behavioural management, and Coping with daily realities. Gardner recommended that nurses help parents create realistic expectations for their children, and to assist parents in recognizing that misbehaviour is best thought of resulting from brain dysfunction rather than maliciousness.

Salmon<sup>21</sup> interviewed eight birth mothers from New Zealand from a feminist paradigm. The themes derived from these interviews emphasized prejudices and oppressions experienced by these mothers, consistent with the feminist approach, with less emphasis on parenting children. This study correctly recognizes the burdens and injustices that many biological mothers experience and emphasizes support for families and educating communities on the adverse effects of prenatal alcohol exposure.

These researchers have provided a starting point to better understanding the experiences of parents of children with FASD. Research studies of these types have not been uncovered from a Canadian context. Because of the small sample sizes and geographical restrictions inherent in qualitative research, further research of this nature is needed better understand parents' experiences. In this study, parents' subjective experiences are emphasized, resulting in extensive quotes from participants, with the intent that their stories (as they would share them) are conveyed.

## METHOD

### Design

To explore biological and non-biological parents' experiences raising children with FASD, a

phenomenological-hermeneutic approach was utilized.<sup>22</sup> Rehorick & Taylor<sup>23</sup> articulated the need to understand human experience "as-is" which, in terms of parenting, may include parenting expectations and stresses, as well as coping with children's behavioural and cognitive challenges. The "as-is" experiences of parents are not restricted to positivistic, observable incidences and experiences. Rather, un-observable cognitive processes permeate human experience.<sup>24</sup> In order to prevent leading participants to share particular experiences and to enable the sharing of "as-is" experience, an unstructured interview format was followed.

### Participants

Parents were eligible to participate in the study if they presently, or had previously, raised a child with FASD in their home, and could speak English. In total, eleven participants, consisting of biological (3), adoptive (7), and foster (1) parents were recruited through community agencies and word of mouth in an urban Alberta city and environs. Three adoptive parents and one biological parent cared for children who now live out-of-home. Only about half of the parents (6) were in a marital relationship at the time of the interview. Participants' spouses were not actively recruited to avoid "parenting team" dynamics in order to allow participants' subjective experiences to be shared more freely. All participants were Caucasian except for Lorraine who was Native American. Age range of the participants was 32-59 years, with a mean age of 45.8.

Table 1 contains demographic information on the parents, including age, marital, and parental status, and the ages of their children with FASD. Identifying information of participants has been removed, and the names of parents and children appearing herein are pseudonyms.

**TABLE 1** Participant Demographics

Participant (pseudonym)	Age	Marital status	Parental status	FASD child(ren) (pseudonyms)
Allison	52	Separated	Adoptive	Andrew (age 16)
Bob	59	Married	Foster	Becky (age 14), Beth (age 12), Brianne (age 11)
Christine	33	Married	Adoptive/Step-parent	Chad (age 6)
Deidre	32	Divorced	Biological	Dylan (age 15)
Ellen	50	Divorced	Adoptive	Elizabeth (age 21)
Frances	57	Divorced	Adoptive	Fraser (age 18)
Gloria	47	Married	Adoptive	Gavin (age 12)
Jane	46	Married	Adoptive	Jeremy (age 18)
Karen	33	Single	Adoptive	Kevin (age 5)
Lorraine	56	Married	Biological	Larry (age 20)
Mark	39	Married	Biological	Mary (age 11), Makayla (age 10)

**Data Collection**

Participants in this study were recruited through an FASD newsletter received by approximately 1,300 Albertans, through community agencies, and through personal contacts. Once a participant demonstrated interest in the study, the researcher arranged an appointment at a private location of the participants' choosing. An explanation of the study was provided, and informed consent was obtained. The participant was instructed that the interview would be audio recorded, and that the interviewer was not looking for specific themes, but sought to hear parents' experiences from their perspectives. Participants were asked to share thoughts and experience important to them. At the conclusion of the interview, the interviewer asked the parents to sum up their experiences "in a phrase or two." These interviews were then transcribed verbatim for analysis.

**Data Analysis**

The researcher examined the interview transcriptions for emerging themes.<sup>22</sup> QSR Nvivo 7® qualitative data analysis software was used to help identify, categorize and compare the themes.

As themes emerged they were organized into central themes and sub-themes. Quotes were identified that seemed best to describe these themes. To assist with the identification and coding process, some themes were named after a quote provided by a participant. In this way, interpretation and organization of themes remained close to the data, and allowed the data to "speak for itself".<sup>25</sup> To improve trustworthiness of the data analysis, themes were shared with three of the participants to determine if interpretations were congruent with their perspectives. These three parents expressed that they felt the themes were accurate.

**Findings and Discussion**

Nine central themes were derived from the interviews: 1) something's not right; 2) receiving a diagnosis; 3) attitudes toward birth parents; 4) living in a war zone; 5) understanding my child; 6) getting support; 7) re-defining success; 8) lifelong parenting; and 9) my child's gifts. Sub-themes were derived from several of these central themes.

### **1) “Something’s not right”**

Except for Karen, all non-biological parents in this study had taken their children into their homes prior to a diagnosis of an FASD. Some of these parents were unaware that their child’s birth mother consumed alcohol during pregnancy. Other parents, while aware that alcohol was consumed during pregnancy, were uninformed of the potential impact on their child’s cognitive, learning, and behavioural functioning. Allison recounted she found out Andrew’s birth mother used substances after she already signed the adoption papers:

After we signed the adoption papers, the social worker says ‘by the way, we found out that his mom used to drink and do drugs’, and that was it. That is all she mentioned. I didn’t have a clue what FASD was.

Parents’ journeys to obtaining a FASD diagnosis began as they perceived that “something was not right” with their children. Frances described how Fraser seemed “out of character” when he was seven years-old:

Well that's when things started falling apart when he was 7...he just became very aggressive and he became quite delusional...he became extremely impulsive...he also made this suicidal gesture that he had a tensor bandage and he kind of wrapped it around his neck and it wouldn't have worked but at 7 years old I don't think he necessarily knew that. So he was in a lot of distress and he was aggressive it was totally out of character and that's when we really knew there was something wrong...It was really stressful because we really didn't know what was happening. We had no real explanation of any kind. It just didn't seem to make sense.

#### **1a) Seeking answers**

Several parents started seeking answers as they perceived that “something was not right” with their children. For some of these parents, investigating the possibility of prenatal alcohol exposure was a self-directed exploration. Jane read material on FASD provided by her employer and explained that, “it was like reading our story in a lot of ways.” Gloria

suspected that FASD may have been a factor in Gavin’s life and initiated the process of diagnosis:

We started to have some extreme behaviours after he moved in. In my mind, I thought ‘is this fetal alcohol?’ Because he was exposed prenatal to alcohol and all kinds of drugs. We had that documentation so I started to think maybe this is what it is, so I got him in the [hospital] to get the diagnosis.”

#### **1b) “Not on the radar”**

Some parents encountered barriers as they were seeking answers to their children’s apparent deficits. Several participants indicated that prenatal alcohol exposure was “not on (the doctor’s) radar screen”, and that aberrations in behaviour and development were dismissed as “nothing to worry about.” Frances expressed frustration with the lack of awareness of FASD exhibited by some mental health professionals:

Nobody seemed to be cognizant of fetal alcohol...It's really frustrating for parents because for the most part you're dealing with mental health professionals who are absolutely clueless about fetal alcohol. It's not on their radar screen.

### **2) Receiving a diagnosis**

Receiving a diagnosis of FASD seemed like a double-edged sword for many parents in this study. Birth mothers experienced grief and guilt for drinking during pregnancy. In addition, biological and non-biological parents expressed regret for “mishandling” situations before they were aware that their children were impacted by prenatal alcohol exposure. However, obtaining a diagnosis provided relief and validation as parents came to understand their children’s challenges. Finally, several parents explained that an FASD diagnosis was not the only identified concern, and that they were faced with a “double whammy”; having to cope with multiple disabilities.

#### **2a) Grief and guilt**

Ellen explained that she felt “incredible guilt” for assuming her daughter was purposefully misbehaving. Deidre described the terrible guilt she felt when she learned that Dylan’s deficits were the result of drinking during pregnancy:

I had a lot of guilt for many years...very much depressed, knowing that my drinking caused this damage. Like I said, that just threw me over the edge. I cried a lot. I felt bad that I did this damage to Dylan. I thought what kind of a parent am I to do that to my own kid.

Jane experienced a grieving process as her hopes and dreams for Jeremy were spoiled:

There was a prolonged grieving stage because you have all these hopes and expectations for your child that they're going to grow up and be successful and have relationships, and you can certainly never expect that at 15 you're going to be moving your child out of your home, and you're going to be dealing with the justice system and professionals and ultimately having your 18 year-old son go to jail, having to talk to street people in order to find out where he is. All of those things were not hopes and dreams you have when you have a small baby.

### **2b) Relief and validation**

Although parents experienced feelings of regret and grief, receiving a diagnosis also provided relief and validation as they came to understand the source of their children's challenges better. Ellen felt "a great comfort" when she received the diagnosis. Allison said that receiving a diagnosis provided insight regarding what to expect of Andrew:

At first I figured we were doing something wrong because he is not listening. Then after he was diagnosed and we went to the [hospital] and they said he also has oppositional defiant disorder, then we kind of realized where he was coming from. And then the more we learned about his diagnosis and the impact of what to expect and what not to expect, then it was easier to a certain degree...At least we knew what we were in for!

### **2c) "Double whammy"**

Several parents explained that their children had other disabilities and disorders in addition to FASD. As noted in the quote above, Andrew was

diagnosed with Oppositional Defiant Disorder in addition to FASD. Elizabeth was previously diagnosed with Generalized Anxiety Disorder, and Fraser also experienced significant concerns with anxiety. Chad was diagnosed with ADHD prior to FASD, and also experienced separation anxiety. Kevin was not responding to family members and was diagnosed with Reactive Attachment Disorder. Becky was given an additional diagnosis of ADHD, and Beth demonstrated obsessive/compulsive tendencies. Gavin has Cerebral Palsy and Post-Traumatic Stress Disorder in addition to FASD, and Larry was diagnosed with Klinefelter's Disorder. These factors, in relation with FASD, create complex profiles for these children.

### **3) Attitudes toward birth parents**

Several non-biological parents, and a biological father, shared their feelings and perceptions toward their children's birth mothers. Although this topic was not anticipated at the commencement of the study, it does provide important insight into the feelings and perceptions of adoptive/foster parents of children with FASD. Some parents expressed anger toward their child's birth mother for "ruining" their child's life. They were frustrated that some mothers drink alcohol during multiple pregnancies with impunity. Other parents withheld judgment and acknowledge probable challenges in the birth mother's life that may have contributed to her drinking. They suggest that FASD is a greater social issue than a woman's individual choice to drink, and suggest that these birth mothers do not set out to intentionally harm their children.

### **4) "Living in a war zone"**

Many children with FASD demonstrate severe behavioural challenges, including tantrums, aggression, and destructiveness.<sup>10</sup> In this theme, parents describe their experiences living and coping with their children's tantrums, aggression, and destructive behaviour. For several families, coping with these significant challenges have impacted family members' mental health and relationships, and are described in the sub-theme *4a) "Collateral Damage"*. In addition, chaos in the home is further fuelled in some cases when parents are "not on the same page", which is described in the sub-theme *4b) "Two Generals,*

*One Army*” Jane explained that living with Jeremy was “like living in a war zone.” She further noted that, “Anything could trigger him, and he would go on a rampage, and he would break things, and if anybody got in his way even the slightest little bit he became violent.” Gloria shared an experience where seven year-old Gavin tantrummed for 11 hours:

My husband and I took turns restraining him. So you go have supper and I'll hold him down, and then you, that's how we did it. This time it was 11 hours, and it was 11 at night and we were so tired...My husband had to put Plexiglas up over the window because we were afraid he was going to smash the window. We hear this huge crash, so we go up, and he'd managed to get the Plexiglas out of the window, and he'd broken it into 100 little pieces.

Challenges in learning and memory associated with FASD may impact contingency learning.<sup>26</sup> For this reason, behavioural strategies, such as natural and logical consequences, are often ineffective in modifying behaviour. Karen explained how implementing natural consequences did nothing to reduce Kevin's hitting:

He's had so much behaviour management and work put into him...I don't even think it's to the point that he's gotten better. I think we've learned to not set him off...He'd hit constantly. Before I had any formal training in FAS I would try natural consequences. So he would hit me and I would put him in timeout on a chair. And I even taught Kevin, you hit you sit. That was the rule. I trained him to sit down after he finished hitting. So it's all he did, I just trained him. So he would hit and he would go sit down in the chair, but the consequence didn't stop the hitting.

#### **4a) Collateral Damage**

“Living in a war zone” can create a chaotic home environment where “it's very hard to make a family seem like a family” (Frances). In the theme *Collateral Damage*, parents describe the impacts of this environment on family members' feelings, mental health, and relationships. Bob shared that

fostering children with FASD has impacted his “social life significantly.” Jane explains that her daughter was diagnosed with Post-Traumatic Stress Disorder as a result of Jeremy's violence in the home. Frances noted that her experience raising Fraser has tainted her perspective toward people affected by prenatal alcohol exposure: “I can't even say I can learn how to get along with a fetal alcohol kid because sometimes when he gets really aggressive, it's really hard to accept the behaviour. It's influenced my attitude.”

#### **4b) Two Generals, One Army**

This theme describes the turmoil that can result when two parents raising their child with FASD are not “on the same page.” At times, one of the parents seemed to have difficulty accepting their child's limitations which, according to some participants, created additional strain on the marital relationship. Jane indicated that her husband, Jeremy's step-father, is not “used to living with somebody with FAS, and it's very chaotic.” Allison, who has been separated from her husband for 10 years, described the impact these challenges had on her marriage, which eventually contributed to their breakup:

We worked together when we adopted Andrew, and once all his behaviours started we couldn't take it anymore. So [my ex-husband] said either Andrew goes or he goes. So I had a tough choice to make. I couldn't get rid of him because he was already disposed of once. I couldn't do that again.

#### **5) “Understanding my child”**

Parents reported that their abilities to care for their children improved as they learned about the behavioural, cognitive, and developmental impacts of prenatal alcohol exposure. However, learning about FASD was only one step toward more successful parenting. Because of the spectrum of deficits associated with FASD, the impacts of prenatal alcohol exposure are unique to each child, and deficits associated with the disorder will not manifest in all cases. In addition, parents related that even when well-versed in knowledge of FASD, appropriate strategies were difficult to implement when coping with parenting stresses and “losing patience” (Gloria). Bob

explained that “real learning” about FASD children doesn't come in a book, but in hands-on experience: “You can read about fetal alcohol. You see the images and you can understand that they're affected physiologically and intellectually and, whatever. But your real learning is about how you deal with these children.”

Six sub-themes were identified as part of parents' learning about their children: 5a) *here today, gone tomorrow*; 5b) *an invisible disability*; 5c) *trouble maintaining school/employment*; 5d) *taken advantage of*; 5e) *in the wrong crowd*; and 5f) *creating a bubble*.

#### **5a) “Here Today, Gone Tomorrow”**

Ellen described Elizabeth's tendency to forget simple tasks, such as putting on socks, as “here today, gone tomorrow.” This theme describes parents' perceptions of the learning and memory challenges their children experience. Several of these children often require frequent cueing, reminding, and re-learning of even simple tasks. Parents shared their frustrations with their children's memory and learning, how they came to understand these challenges in relation to FASD, and how it has altered the way they parent their children. Christine was baffled by her son's apparent inability to learn:

It's a really hard thing to get your head around when you realize that he really doesn't understand. You're telling him this and he really doesn't get it. But he understood it yesterday...He got it. Then today it's like you've never told him at all because he doesn't remember. That's really hard to understand how come, well you knew yesterday, why don't you know today?

Coping with such memory and learning challenges can be wearisome even when the parent knows that their child is experiencing a memory or learning deficit. Christine explained that, “it's frustrating because you get mad telling your kid the same thing a million and one times but you know he doesn't remember.” Although well-versed in understanding the deficits associated with FASD, Gloria sometimes loses her patience with Gavin's inability to complete simple tasks:

Just understanding for the umpteenth time. Sometimes I am telling him things 7 times! Pick your shoes up! He'll go to pick his shoes up, but then see something else. And I say pick your shoes up. And then the phone will ring and he'll get it. It's like I'm going to scream! I'm really going to lose it. So it's hard even for me sometimes to keep my patience.

#### **5b) “An invisible disability”**

Many people with FASD do not demonstrate the growth deficiencies and facial dysmorphism associated with FAS, yet can still demonstrate significant learning and behavioural challenges.<sup>27</sup> In some cases, people with FASD demonstrate average or above average IQ.<sup>28</sup> The invisibility of disability in these cases of FASD can lead to unrealistic assumptions and expectations about their social, learning, and behavioural functioning. Ellen explains that people expect too much of Elizabeth, partly because she is not visibly disabled:

I think in many ways she would have had an easier life if she looked more disabled...So her biggest issue is that people expect too much of her, because she looks like she (understood) and should be able to do it. That's what gets her in trouble. She does a lot of masking. She tries really hard to make it look like she knows what's going on, and half the time she doesn't.”

In contrast, Gloria feels that Gavin, who also has cerebral palsy, will be advantaged throughout his life because he looks disabled, “I think in that way people will look after him a little bit more, he'll be a little more protected than someone with FASD that has an IQ of 100, who looks like he doesn't have a disability.”

#### **5c) Trouble maintaining school/employment**

Research indicates that people with FASD are at-risk of school drop-out and tend to have difficulty maintaining employment.<sup>12</sup> Such struggles were demonstrated in this study as parents described their children's challenges with maintaining school attendance and finding and maintaining employment. Jane related that Jeremy was kicked out of multiple school districts and several



parents, such as Deidre, had to deal with multiple suspensions and sought out specialized school programs to meet their children's educational needs.

Of the 4 adult children in this study, only Elizabeth graduated high school. Although she spent some time unemployed and receiving provincial funding from AISH (Assured Income for the Severely Handicapped), Elizabeth has successfully maintained employment:

She also had approval for assured income, and she used assured income until the last year. She really needed it. She wasn't working any kind of regular shifts, she wouldn't accept any employment help as in going with an agency. So she'd get these jobs, one of them was a cashier, and there is no way. She can't count money. Not at the speed that you need to do it as a cashier. Within a week or two that job was over. I'm sure one of the supervisors was just frustrated, like why can't you get it? She can't do it. So some unrealistic jobs...Now she's working for a hotel, she's the housekeeper. It's the same job pretty well everyday, you clean the hotel rooms, and you need to do it to this standard, and they check the standards intermittently so you never know which rooms they will check. And that's the best way for Elizabeth, is to know exactly what it should look like when it is done, so she is good at the job and is well paid.

Gloria described her perception of what 12 year-old Gavin needs to be successful in employment:

He can't pack groceries. What is light, and what's heavy? That's a judgment call. He can put things in a bag but you know that watermelon is going to go on top of the eggs every time. Well the eggs are heavy! (Laughs). No, they're fragile. He couldn't do janitorial work...He could do like assembly line work, same thing same way every time, no judgment. There is something out there for him. There will be. Maybe it will be paid employment or maybe it won't.

#### ***5d) Taken advantage of***

Related to challenges creating and maintaining friendships, children with FASD in this study were often "taken advantage of" by peers. Some parents explained that their children had no "true" friends, while other children became connected with negative peer relationships. Jane described how Jeremy created friendships, "He started to steal money and buy friends. He would buy cigarettes for his friends and that's how he made friends." Gloria described Gavin's social immaturity at school:

He loves people, but he's so naïve. We won't let him take valuable things to school, but he really wanted to take a basketball to school, and then it got 'lost', and then he got a book that was stolen. I think the other kids know that he is, you know. But he just loves everybody in his class. So as a boy he was being bullied, and the strategy is just to stay away from [the bully]. So if he's in line, you just wait for someone else to line up, don't stand beside him in line. And if he comes behind you leave the line and go to the back of the line. We tried to teach him these things, well this boy talked to him one day and was nice to him. Well he's my friend. Now he's the nice boy.

Gloria further described that, in social relationships, Gavin "has no insight." Allison explained that Andrew is a "follower." Frances said that Fraser is "associated with a fairly negative peer group because they're the ones that accept him." Lorraine noted that 20 year-old Larry is "so easily led astray" by negative influences. Because several children in this study were prone to negative social relationships, many ended up getting in the wrong crowd.

#### ***5e) In the wrong crowd***

People with FASD are at much greater risk of getting into trouble with the law.<sup>12</sup> Parents of adult children with FASD in the present study were concerned about potential for criminal and gang involvement. Jane shares her story of rescuing Jeremy from "gang hits", where he was at-risk of being killed:

He's been involved in gangs, we know that. But because he doesn't understand things the way other people do, they will give him drugs to sell, and he'll sell the drugs and then spend the money himself. So we've had several instances where there have been gang hits on him, so it's either we pay the debt and free him up, or we risk having him killed...I've been able to, through the police, make some contacts with some of the higher profile older gang members who maybe aren't necessarily involved in criminal activities anymore, but are still considered to be part of the gang, and suggest to them that Jeremy isn't a good risk. He has a history of basically stealing from the gang, so they might want to not consider him, and as far as I can tell that's having some effect...We had to get really creative to figure out how we were going to stop this cycle from happening because he just doesn't understand...and if we kept rescuing him there's no deterrent, and yet if we don't rescue him it likely will mean death, so I had to figure something out. I can't control him so I have to control the environment.

#### **5f) *Creating a Bubble***

By "controlling" Jeremy's environment, Jane was able to help prevent her son being seriously hurt or killed. Because of their children's risk of social problems and learning deficits, many parents needed to find ways to control their children's environments to keep them from harm.

In response to the death threats placed on her son, Jane has "infiltrated his life" to try to prevent his involvement with gangs. To prevent Dylan from "going down the wrong path", Deidre has "sheltered" him for most of his life. Frances tried to put "controls" on Fraser's life such as restricting activity with inappropriate friends. Jane described that controlling Jeremy's environment was necessary for promoting success, "I can't control what he does. I just have to figure out how to control the environment as much as possible to allow him the most success."

#### **6) *Getting Support***

Parents reported barriers and successes in getting help from support networks, medical and mental

health professionals, schools, government agencies, and community organizations. Frances felt that involvement with the medical system was detrimental to Fraser's mental health at present:

Looking back, I really think that it would have been better if I had not gone through the mental health system...after two years of Risperdal he put on a ton of weight and he was very sedated. It had a lot of negative effects and it really didn't do anything positive for him. At best, the anti-psychotics helped him with his agitation, but it went way beyond agitation to the point where he was actually sedated. I can't get him back (to the doctor) now because of this experience and he says that he found it damaging going through the mental health system, because he always felt he had something wrong with him so he just saw that as a negative. Now he won't take medications. He won't go see a psychiatrist even though he has significant depressive symptoms. He's had psychotic breaks. But he has zero confidence in the mental health. So and he probably would benefit from some medications even if it's just antidepressants, anti-anxiety medications. He just won't go and I think it's because of his experience with the mental health system.

Ellen recognized that many children with FASD are not adequately accommodated in school. She described that successful school supports for Elizabeth may be in part due to Ellen's work in the disabilities field and her efforts in advocating for Elizabeth:

She had great support through school, terrific support. Maybe that's [the school board], maybe it's what people thought I might know or who I might know in this kind of work, but she got terrific support. I felt kind of guilty because sometimes you see kids and they are struggling and they're not getting that support. Her siblings never got it either because nobody fought for them. I felt guilty that Elizabeth got more than anyone else, but I can't do anything about their kids.

FASD specific strategies provided by personal and professional supports were beneficial for parents raising their children. Some strategies shared by these parents include warnings for upcoming transitions (i.e. leaving the store), repeating instructions, structure and routine, using visuals to outline routines and instructions, and recognizing sensory issues such as sensitivity to light or clothing. In addition, parents emphasized that in using these strategies, remaining patient is paramount because, as Christine observed, "I'm going to have to tell (him) twenty-five times. It's normal."

Some parents felt unsupported as they indicated they felt blamed for their children's behavioural challenges attributable to FASD. Christine elaborates on how many people "don't understand" what it is like raising a child with FASD:

It's a really hard thing to deal with people because they don't understand. Until you've actually had to raise a kid (with FASD) or look after a kid that has it, they don't get it and they can tell you they do but they don't get it. They had parenting groups at my daughter's school and they have all these solutions and life fixes. "Well try this because this works really well" and you just get to the point you're like, whatever. They hand you all these life fixes and all this information and it's like okay, you don't get it. It's not going to work. They say "Well you just didn't try hard enough." No it's not going to work, okay? He's not going to do it because it doesn't work like that. Then it's usually, "well you didn't try hard enough" or "if you would've done this with him", and "well he gets away with too many things." Well it's not that he gets away with it, he doesn't know better. He doesn't understand. You can't make him get what he isn't going to get. People have a hard time with that...Parents look at you like you're a freak because you're really strict with him. They look at you like you're a mean ass and its like, no, you don't get it. If I tell him nicely in twenty words, he's lost.

### 7) *Re-defining success*

Several parents described a transformation in their expectations of their children as they have come to learn about the cognitive, learning, and

behavioural challenges associated with FASD. Re-defining success involves setting more realistic expectations for their children in light of their deficits. Bob explained the need to accept his children's limitations:

You always want them to be better than they are but you have to realize all the love and nurturing in the world is not going to get them from point A to point B. You have to come to terms with their limitations. Build them up where you can and leave the rest alone. Don't keep fighting it.

### 8) *The lifelong parent*

The lifelong parent represents parents' perceptions of lifelong challenges associated with their children's disabilities. It is suggested by them that their children will be dependent on some sort of support throughout their lives, and that their role as caregiver does not end when their children turn 18 years old. Interestingly, Jane's 18 year-old son Jeremy and Lorraine's 20 year-old son Larry telephoned their mothers during the interviews because they were in need of assistance. Lorraine explained the "lifetime commitment" of raising a child with FASD:

There's no saying you're 18 now they can go, or they can be home and you don't have to worry about them. You always have to worry about them, and it's hard because you never know what they're going to do. They could end up with a gang, they could get hurt easily drinking and being in a crowd. They're so easily led astray...Yeah, it's a lifetime of worrying about them.

### 9) *Gifts*

Although participants primarily emphasized their challenges raising children with FASD, many parents also discussed their children's gifts. Mary and Becky are gifted artistically. Jeremy is "an amazing musician, a gifted athlete, a loyal friend." Gavin is "warm and friendly. He always tries his best, and he wants to make others happy." Makayla is "a little ham." Andrew can be "a real kind and sweet person", and Dylan is "compassionate and forgiving." Karen explained that although the effects of prenatal alcohol

exposure have negatively impacted Kevin's behaviour, having FAS is part of "who he is":

I don't know how to explain it without sounding really horrible. In a way, Kevin wouldn't be who he is without his FAS. And I guess that part of that is his impulsivity...I think in a way that his traits in FAS make him who he is, and I love who he is. I don't want to say I'm glad he's affected or that I wouldn't want him not to be affected, but I like the spunk, and I like everything about him. It's not that I love that my son has FAS, but all the personality traits and everything that comes along with it is such a blessing, a gift for him.

## DISCUSSION

The themes derived from the interviews are largely in line with research on parenting children with FASD. In feeling that "something's not right" with their children, parents in this study related similar feelings to those parents interviewed by Granitsas<sup>19</sup>, who explained that they had been given incomplete information, if any, about their children's diagnoses. In addition, Frankel, Frankel, & Opie<sup>15</sup> also found that the adoptive parents in their study were not fully informed of the possible consequences of prenatal alcohol exposure, despite the knowledge or suspicion that their children were exposed to alcohol prenatally. Informing adoptive/foster parents of the possibility or likelihood of prenatal alcohol exposure does little to empower them if information on the effects of FASD, appropriate strategies, and access to additional supports are not provided as well. Like participants in other studies, parents were challenged by not knowing where to seek out information about FASD. In addition, parents expressed frustration as they dealt with educational and health professionals who lacked knowledge of the effects of prenatal alcohol. Nevin et al.<sup>29</sup> surveyed 75 physicians in Toronto, Ontario, half of whom had very little confidence in their ability to diagnose FAS, and none of whom were aware of the accepted screening method for alcohol use in pregnancy. In many areas that seem to experience higher prevalence of FASD, such as rural areas of Northern Canada, clinicians have few professional

resources available to them.<sup>30</sup> It seems that there are few practitioners in health, education, social services, and justice systems that have a working knowledge of the effects of FASD.<sup>18</sup> In addition, many parents feel that their knowledge of FASD is not regarded or utilized by professionals.<sup>16</sup>

Receiving a diagnosis of FASD early in a child's life may be a crucial step to preventing future social problems. It was apparent in this study that receiving a diagnosis elicited strong emotional reactions from parents, including grief over dashed hopes for their children, guilt over alcohol consumption or prior parenting practices, relief for the explanation and normalization of their children's challenges, and validation that children's troubles were not caused by bad parenting. Physicians shared in interviews that an appropriate FASD diagnosis can provide relief and explanation to parents living with the disorder<sup>31</sup>. Although there is research regarding the importance of obtaining a diagnosis for families who have children with other developmental disabilities<sup>32</sup>, little research was found focusing on the experiences of parents receiving their children's diagnoses of an FASD. One exception is Ryan & Ferguson's<sup>33</sup> qualitative study of 5 families of children with FAS, where parents expressed, "If I knew then what I know now" (pg. 372), their parenting strategies and expectations of their children would have been different. Reactions to a diagnosis of FASD may differ from developmental disabilities because the deficits of FASD are different, and blame can be allocated to birth mothers. Because a diagnosis has the potential to alleviate family tensions, research evaluating parents' experiences receiving diagnoses of FASD for their children is needed.

"The FAS label has the power to both apportion blame and erase it".<sup>31</sup> Although attitudes toward birth mothers were not anticipated at the commencement of the study, it does provide important insight into the feelings and perceptions of adoptive/foster parents of children with FASD. Like parents in this study, participants in Gardner's<sup>20</sup> study of foster parents expressed feelings of anger and frustration toward birth mothers for drinking during pregnancy. The result of such intense feelings may negatively impact family functioning.<sup>34</sup> Practitioners consulting with adoptive and foster parents of children with FASD should be aware that parents may hold harsh

feelings toward birth parents. Helping parents cope with anger and resentment may be an important step in promoting healthy family functioning.

Violence, antisocial behaviour, and conduct-related disorders can be associated with prenatal alcohol exposure.<sup>35</sup> Living with an FASD child with externalizing behaviour problems, such as hyperactivity, aggression, and destructiveness, can be stressful and discouraging for parents. Coping with these externalizing problems can be demanding on parents and interfere with self-care<sup>16</sup>, which can then spiral into further stress.<sup>17</sup> Parents need to be encouraged to adopt self-care practices, and be empowered to do so through community support and respite services.

Children with FASD can experience significant cognitive, memory, and executive difficulties<sup>10</sup> that can impact their school, home, and social functioning. Because of problems with short-term memory, organization, learning, retention, regulation, and social awareness, these cognitive concerns may permeate most or all of the secondary challenges of FASD described by Streissguth et al.<sup>12</sup> Coping with learning and memory challenges was frustrating and disheartening for parents in this study, and many felt guilty for assuming that their children were “forgetting” purposefully or maliciously.

Caregivers' assumptions of what their children should know and remember may be confounded by the invisibility of FASD in many cases. Chudley et al.<sup>13</sup> suggested that the facial dysmorphology associated with FAS is relatively unimportant when compared with the central nervous system dysfunction caused by prenatal alcohol. In fact, absence of facial dysmorphology, compared to the presence of facial dysmorphology, has been shown to be associated with gaps in services and more unfavourable life outcomes.<sup>12</sup>

Like the participants in this study, parents in Gardner<sup>20</sup> expressed that they were worried about their children because they were “naïve” and would be “taken advantage of”. As children grow into adolescence, their social lives become increasingly complex, and the gap in social ability widens between adolescents with FASD and their peers.<sup>36</sup> This seems to relate to parents' responses in this study, in that their children were “so easily manipulated” and had no social “insight”. Their lags in social development, perhaps in conjunction with

other cognitive abilities and mental health concerns, may put adolescents and adults with FASD at greater risk of gang involvement, as was noted in this study as well.

Children with FASD need to be “protect(ed) from the hazardous straits into which they are born”.<sup>12</sup> Because of their cognitive disabilities, patients with FASD can be vulnerable to being manipulated by others. Parents in this study encountered the same need to protect their children from untoward peer associations and from being “taken advantage of”. In “Creating a bubble” of protection, parents seemed to be cognizant of their children's “hazardous straits”, and intervened in the hopes of promoting success for them. For Jane, “Creating a bubble”, worked to save Jeremy's life without him knowing.

Parents in this study seemed to internalize the importance of creating realistic expectations for their children. Changing expectations may be an important coping strategy for parents<sup>20</sup>, and may be a characteristic of successful families.<sup>15</sup> The importance of “under-reacting” is emphasized when children with FASD misbehave because behaviour that seems malicious may be due to learning, memory, or processing deficits. Information about realistic expectations should be frankly shared with parents, and more research about parental expectations is needed.

The consequences of prenatal alcohol exposure “appear to persist throughout life and to require lifelong supports”.<sup>33</sup> This can be troubling for parents, who may become lifelong caregivers to some extent for their children. Although some of their children may achieve a degree of independence (i.e. Elizabeth in this study), others will likely require support to some degree. Because of the invisibility of disability and because average IQs for FASD populations typically exceed cut-offs for adult support, much of this burden will likely fall on parents. Fears for not knowing their children's future were expressed by parents in other research<sup>19,20</sup>, but literature examining actual experiences of parents of adult children with FASD was not located. Because of the lifelong need for support and advocacy, further research is needed in this area.

While recognizing the deficits characteristic of FASD, it is also important to recognize these children's strengths, skills, and gifts. Each child is more than a case of FASD.<sup>26</sup> Parents in Granitsas'<sup>19</sup> study explained that they felt pride in their children,

and recognized their children's abilities, which for many was in music. Parents in this study also recognized their children's gifts amidst a myriad of social, cognitive, and behavioural deficits. In working with families, clinicians and educators should recognize children's gifts to create strength-based intervention programs<sup>18</sup> and to work empathically with parents.<sup>30</sup>

In this light, it seems appropriate to expand research on this topic to obtain more generalizable findings. Individual themes and subthemes arising from this study can be further explored using larger samples of participants and quantitative methodologies. For example, parenting expectations can be explored using quantitative measures comparing parents of children with FASD, other disabilities, and typically developing children. Doing so can further clarify our understanding of parents' general experiences, leading to targeted interventions. Findings from exploratory qualitative studies on parenting children with FASD to date have laid the groundwork for further research into the lives of parents, and obtaining additional generalizable findings may lead to positive changes in the prevention of FASD and how families access support.

At the conclusion of interviews, parents were asked to sum up their experience in a phrase or two. Although the parents expressed significant challenges, they also experienced personal growth and unity with their children. Mark expressed satisfaction for his "journey" raising his two biological children with FASD:

I think I've been blessed that I have these two girls in my life; they are very special in their own way. I don't know what I would do without them if they weren't in my life. It was a long journey! But it was worth it...I could be helping them the rest of their lives...They probably remember all the things I helped them on and what I did for them. I think they will appreciate all things I did. I give myself a pat on the back!

Certainly, many parents of children with FASD deserve "a pat on the back". By providing these families with the supports they need, family members, teachers, professionals, support personnel, and the community can help promote successful family functioning for families raising children with

FASD, which can help promote lifelong successes for those living with the disorder.

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