

THE BEAUTIFUL CHALLENGE: FAMILIES RAISING CHILDREN WITH FETAL
ALCOHOL SPECTRUM DISORDER IN ONTARIO

by

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Abstract

The current document is a paper-based thesis investigating the lived experiences of parents raising children with Fetal Alcohol Spectrum Disorder (FASD) in Ontario, Canada. Historically, researchers have approached the exploration of families with the notion that families of children with a developmental disability would present with a pathological profile. However, a recent paradigm shift has transitioned the focus from deficit-based outcomes to those that highlight positive outcomes. Therefore, the first paper included is a qualitative analysis of factors that facilitate family adaptation. Interpretative phenomenological analysis (IPA) was used to analyze semi-structured interviews with parents of children with FASD. Parents utilize a number of coping strategies, supports, and transformational outcomes that enable them to adapt to raising their child with FASD. The second paper included is also a qualitative analysis examining demands that hinder family adaptation. Parents discussed five stressors that hinder successful family adaptation. Recommendations from parents of children with FASD and implications for increasing knowledge and awareness of the disability are discussed.

Keywords

The following could be used to describe this thesis entitled “The Beautiful Challenge: Families Raising Children with Fetal Alcohol Spectrum Disorder in Ontario” which examines family adjustment and adaptation to the presence of a child with FASD: fetal alcohol spectrum disorder, developmental disability, families, parenting, family resilience, adjustment, adaptation, qualitative, Ontario, stressors, capabilities, meanings, positive psychology.

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Chapter 1: 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 of children with Fetal Alcohol Spectrum Disorders (FASD). There has been a long standing tradition investigating the impact of raising a child with a disability on the family (Helff & Glidden, 1998). For example, researchers have examined the parenting experiences of families of children with specific diagnoses, such as autism spectrum disorders (e.g., Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Fong, Wilgosh, & Sobsey, 1993; Smith et al., 2010), Down syndrome (e.g., Poehlmann, Clements, Abbeduto, & Farsad, 2005), and Fragile X syndrome (e.g., Carmichael, Pembrey, Turner, & Barnicoat, 1999). Researchers have often examined the experience of parents seeking a differential diagnosis for their child's disability (e.g., Carmichael et al., 1999; Graungaard & Skov, 2006; Watson, 2008a, 2008b), and the subsequent negative perceptions that parents often have when dealing with professionals (Poehlmann et al., 2005; Watson, 2008a). However, other scholars have commented on a number of areas across the life course, including parental stress and burden as a result of challenging child behaviours and early family experiences, such as the first awareness of their child's disability (e.g., Bilgin & Kucuk, 2010; Domingue, Cutler, & McTarnaghan, 2000).

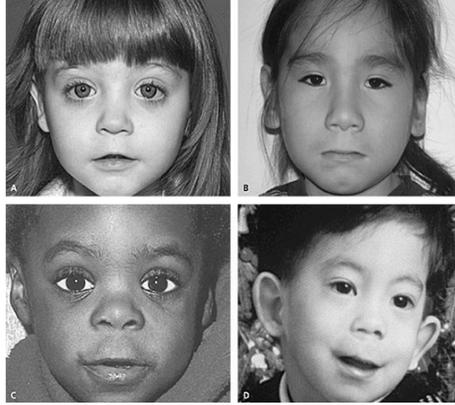
Despite the wealth of literature on other disabilities, and autism spectrum disorder in particular (e.g., Hutton & Caron, 2005; Luong, Yoder, & Canham, 2009; Meirsschaut, Roeyers, & Warreyn, 2010; Myers, Mackintosh, & Goin-Kochel, 2009), there is a paucity of research conducted with families of children with FASD (Watson, Coons, & Hayes, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013).

1.1 Fetal Alcohol Spectrum Disorder

Prenatal exposure to alcohol is a common, preventable cause of disability that is now considered to be the leading cause of developmental disability in the Western world (Connor & Streissguth, 1996; Public Health Agency of Canada, 2005, 2011; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008; Walker, Fisher, Sherman, Wybrecht, & Kyndely, 2005; Wilton & Plane, 2006). In recent years, FASD has been identified as a major public health concern. FASD is an umbrella term that is used to describe a wide range of possible outcomes associated with prenatal exposure to alcohol including: fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), fetal alcohol effects (FAE), and alcohol-related birth defects (ARBD) (Stade et al., 2009; Streissguth et al., 2004; Warren et al., 2004).

The original description and recognition of FAS came in 1973 by Jones and Smith, who identified a similar pattern of craniofacial, limb, and cardiovascular anomalies associated with prenatal onset growth deficiency and developmental delay. Although FASD is manifested in various levels of severity, FAS is generally considered the most severe presentation of FASD and is diagnosed when an individual meets three distinct criteria. Despite several suggested diagnostic schemas for FAS (Nguyen, Coppens, & Riley, 2011), all schemas require anomalies in three distinct areas: 1) growth deficiency, prenatally or postnally, for height or weight or both; 2) a specific pattern of anomalies that includes a characteristic face (e.g., a smooth or indistinct philtrum, a thin upper lip, and depressed nasal bridge; see Figure 1); and 3) central nervous system dysfunction (e.g., attention deficits, intellectual or cognitive impairment) (Astley & Clarren, 1997, 2000; Streissguth, 1997; Thomas, Warren, & Hewitt, 2010).

The terms FAE and ARND, sometimes used interchangeably, are reserved for individuals with functional or cognitive impairments linked to prenatal alcohol exposure, who do not meet the full criteria for an FAS diagnosis. Impairments may include decreased head size at birth, structural brain abnormalities, and a pattern of behavioural or cognitive anomalies (Streissguth, 1997). On average, individuals with FAE tend to have higher IQs than individuals with FAS (Jacobson & Jacobson, 2003). Individuals with FAS have IQs ranging from 29 to 120, with an average IQ of 79, but individuals with FAE have IQs ranging from 42 to 142, with an average IQ of 90 (Streissguth, Barr, Kogan, & Bookstein, 1996). Furthermore, clinicians are more likely to diagnose children with FAS or pFAS than they are to diagnose less dysmorphic or growth-retarded cases (Hoyme et al., 2005; May & Gossage, 2011; Stratton, Howe, & Battaglia, 1996). Since the original description of FAS, the spectrum of disabilities has remained diagnostically difficult and conceptually transitory (Devries & Waller, 2004) due to the changing recommendations for a medical diagnosis and the renaming of research terms (e.g., FAE to ARND). An incorrect diagnosis is therefore likely due to the fact that individuals with FAE or ARND do not present with the characteristic face exhibited by individuals with FAS and often do not experience a lack of growth deficiency. Because first-stage screening tools for FASD are based on dysmorphic features and physical growth retardation, individuals with less severe presentations of FASD may go undiagnosed (Astley & Clarren, 2000; Duquette, Stodel, Fullarton, & Hagglund, 2006).



**Figure 1: Facial Characteristics of Children with Fetal Alcohol Syndrome
Adopted from Wattendorf and Muenke (2005)**

Estimates on the prevalence of FASDs are relatively unknown due to challenges with the diagnostic process. Chandrasena, Mukherjee, and Turk (2009) identified “diagnostic dilemmas” that may have an impact on FASD prevalence rates, such as challenges with changing diagnostic criteria and changing facial characteristics over time (e.g., less pronounced facial characteristics over time), inconsistencies in the level of knowledge of the condition, as well as how to identify it, and the stigmatization of a label of FASD for families and children. For example, a study by Clark, Lutke, Minnes, and Ouellette-Kuntz (2004) found that less than 60% of professional respondents, a sample that included family doctors, pediatricians, midwives, and psychiatrists, correctly recognized that a combination of growth, brain, and facial feature abnormalities provided the most accurate diagnosis of FAS. Studies in the United States (e.g., Gahagan et al., 2006) and Australia (e.g., Elliot, Payne, Haan, & Bower, 2006) have also found that pediatricians in particular believe a diagnostic label of FASD to be stigmatizing for both the child and the family.

Researchers who have attempted to estimate the prevalence of FASD often comment that the numbers may be seriously underestimated (British Medical Association

Board of Science, 2007; May & Gossage, 2001; Olson, Oti, Gelo, & Beck, 2009) and large variation in prevalence rates may be due to differing diagnostic strategies and inconsistent applications of these methods (Burd, Klug, Li, Kerbashian, & Martsof, 2010; May & Gossage, 2001). However, the prevalence of FASD in the general population is believed to be approximately 1 to 6 per 1000 live births (Stade, Stevens, Ungar, Beyene, & Koren, 2006), with some estimates as high as 9.1 per 1000 live births in both Canada and the United States (Alberta Alcohol and Drug Abuse Commission, 2004; Bracken, 2008; Chudley et al., 2005). Even higher prevalence rates have been reported in other communities, such as in one isolated Aboriginal community in British Columbia, where the occurrence of FASD was reported to be as high as 190 per 1000 live births (Robinson, Conry, & Conry, 1987). Due to diagnostic challenges and lack of reliable and consistent data collection techniques, international incidence rates are not yet accurately known (Olson et al., 2009). However, FASD has also been identified as a major health problem internationally in cultures that have problems with alcohol. For example, South Africa, Italy, and Russia have estimated prevalence rates of 89, 120, and 141 per 1000 live births respectively (Nayak & Murthy, 2008).

Individuals with FASD face serious challenges due to cognitive and behavioural deficits, such as attention problems, cognitive impairments, and memory deficits. As a result of these primary impairments, individuals with FASD have serious vulnerabilities for further problems, termed “secondary disabilities” (Streissguth et al., 2004). These secondary disabilities include mental health issues, legal problems, disrupted school experiences, inappropriate sexual behaviour, and addiction or substance abuse problems

(Clark et al., 2004; Streissguth et al., 2004). Both primary and secondary disabilities can pose significant challenges for families raising these children.

An important protective factor that alleviates the consequences of secondary disabilities in FASD is living in a stable, nurturing home (Streissguth et al., 2004). However, a stable and nurturing home environment is not always the case for children with FASD, and these individuals often live in multiple foster houses throughout childhood. Additionally, research has found that only 20% of children with FASD live with their biological mothers (Astley, Bailey, Talbot, & Clarren, 2000; Streissguth et al., 2004). Foster and adoptive parents are often unaware of the birth mother's alcohol use during pregnancy, which may lead to confusion in understanding their child's behaviours. Prenatal alcohol exposure is therefore an early threat to the health of the child, which can cause issues related to personal temperament (e.g., poor bonding and making relationships), problems related to aggression or oppositional behaviours, and difficulties with poor or delayed social skills (Jones, 2004), and early bonding concerns may be particularly challenging for foster and adoptive parents. Despite the knowledge of difficulties associated with FASD, and the long history of family research, limited research has been conducted to examine these types of families.

1.2 History of Family Research: The Negative Impact of Disability on the Family

The experience of raising a child with an intellectual or developmental disability almost unavoidably has a substantial impact on the family system (Bailey Jr., 2007). However, families in general, and individuals within the family system (e.g., mothers, fathers, grandparents), vary in their response to the presence of a child with a disability. Despite the previously held belief that raising a child with a disability is a negative

experience for families (e.g., Fajardo, 1987; Solnit & Stark, 1961), the experience can in fact be positive in addition to challenging for families.

Historically, researchers have approached the exploration of families with the preconceived notion that families of children with intellectual or developmental disabilities would undeniably present with a pathological profile (Maul & Singer, 2009). Raising a child with a disability was thought to be a non-normative experience and was typically viewed as “burdensome, stressful, alienating, and frustrating” (Schilling, Gilchrist, & Schinke, 1984, p. 48). Until more recently, researchers have tended to focus on the notion of “developmental disability” in general, without examining issues related to specific differential diagnoses. Understanding family adaptation with regards to the child’s specific disability may be essential since family responses may differ based on the child’s unique disability and particular behavioural phenotype (Hodapp, Fidler, & Smith, 1998). However, regardless of disability diagnosis, researchers have suggested that having a child with a disability is unmistakably associated with the experience of increased parenting stress (see Watson, Hayes, & Radford-Paz, 2011).

The concept of parenting stress has been a predominant focus of family research with an abundance of literature examining the experience of stress faced by parents of children with intellectual disability (e.g., Hastings, Daley, Burns, & Beck, 2006; Hill & Rose, 2009), Down syndrome (e.g., Hodapp, Ly, Fidler, & Ricci, 2001; Hodapp, Ricci, Ly, & Fidler, 2003; Roach, Orsmond, & Barratt, 1999), Fragile X syndrome (e.g., Abbeduto et al., 2004, Johnston et al., 2003; McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006), and autism spectrum disorders (e.g., Abbeduto et al., 2004; Baker, Blacher, Crnic, & Edelbrock, 2002; Eisenhower, Baker, & Blacher, 2005). The vast

amount of existing research has concluded that raising a child with a developmental disability is significantly more stressful than raising a typically developing child (Baker et al., 2003; Gupta, 2007; Hastings, 2002; Hodapp et al., 1998; Johnston et al., 2003). The experience of increased parenting stress has commonly been attributed to the severity of the child's behavioural problems rather than the child's developmental delay, in addition to the increased demands placed upon family members required for the child's support needs (e.g., Baker et al., 2003; Fidler, Hodapp, & Dykens, 2000; Lessenberry & Rehfeldt, 2004; Weiss, Sullivan, & Diamond, 2003). However, in a recent article by Watson, Coons et al. (2013), the authors acknowledges that measures of parenting stress often over-rely on the presence of maladaptive child behaviours that may inflate reported parenting stress and do not capture the true subjective nature of stressful experiences.

Most literature regarding parenting stress has focused predominantly on mothers (e.g., Abbeduto et al., 2004; Estes et al., 2009; Hill & Rose, 2009; Lewis et al., 2006), but more recent studies have also found increased levels of parenting stress for both mothers and fathers of children with developmental disabilities (e.g., Baker et al., 2003; Davis & Carter, 2008; Hastings, Beck, & Hill, 2005; McCarthy et al., 2006). Elevated levels of reported parenting stress have also been found to be consistently higher across the lifespan for families of children with developmental disabilities compared to families with typically developing children (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). These identified levels of stress fluctuate over time according to the different developmental stages and demands parents face at each stage.

Particular stressors, such as difficulty obtaining services for their children, have also been reported by parents of children with various disabilities. More specifically,

parents frequently express their desire to obtain respite services in order to give both themselves and their child a break. However, rural and urban locations may play an important role with regards to both the quality and quantity of respite services. Yantzi, Rosenberg, and McKeever (2006) found that mothers caring for children with long-term care needs living in an urban area had greater access to out-of-home respite care in terms of availability and distance between their homes and the respite location. Although this same type of respite was available in the rural location, families often had to travel for more than one hour to get there. Wherry, Shema, Baltz, and Kelleher (1995) also compared urban and rural respondents on their belief and experiences related to respite care. Although the authors found no statistically significant differences between the groups, they noted that rural respondents were more likely to note that they had, or expected to have, difficulty in using respite care due to distance factors compared to their urban counterparts. Milligan (2001) also reported that the geographical context can have an impact because polity manifests itself in very different ways across urban and rural locations, and variations in both socio-political and demographic profiles of particular locations are likely to impact individuals receiving these services differently. Individuals therefore often face problems with the delivery of community-based services to widely dispersed populations. Additionally, parents often face challenges with access to services because some care supports may only be operated in main centres of population and choice for other services, such as locally based residential respite, may be limited (Milligan, 2001).

1.2.1 Parenting stress in families of children with FASD. Despite the wealth of literature on the experience of stress by parents of children with a variety of

developmental disabilities, there has been a limited examination of stress among families of children with FASD (Paley, O'Connor, Frankel, & Marquardt, 2006). Of the limited existing studies, researchers have in fact found increased levels of reported parenting stress, in addition to a number of experiences and challenges that are unique to FASD. Family characteristics may contribute to the experience of parenting stress for families of children with FASD (Olson et al., 2009; Paley et al., 2006; Paley, O'Connor, Kogan, & Findlay, 2005). Researchers have found that having fewer personal resources to advocate for and support a child with FASD was predictive of higher stress in biological mothers from low socioeconomic status families (Paley et al., 2005). In one study, being a biological parent and having fewer family resources were both predictors of Parent Domain stress on the Parenting Stress Index (PSI; Abidin, 1995), which measures stress associated to the parenting role, such as troubles with parent health and mood, as well as perception of parenting competence (Paley et al., 2006). However, adoptive and foster parents reported higher levels of child-related stress compared to biological parents, as measured by the Child Domain scale of the PSI, which gauges parenting stress resulting from difficult child behavioural characteristics. The differences found between these diverse types of families are particularly interesting, because it shows that different types of families may face diverse challenges (Olson et al., 2009). Unfortunately, children of adoptive and foster parents are often over-represented among those who experience earlier significant life stress, perhaps due to a lack of knowledge about potential exposure to alcohol, and therefore confusion regarding why their child may be behaving in a particular way. However, it is likely that all types of families face challenges at "turning points", such as when their child reaches adolescence (Olson et al., 2009).

In addition to family characteristics, child behaviour problems have also been implicated as particularly stressful for parents. Although family characteristics are important contributors to the experience of parenting stress, researchers have suggested that child characteristics, or child maladaptive behaviour problems, are a stronger predictor of parenting stress (Olson et al., 2009). For example, parents frequently report challenges in preventing setbacks in their children's behaviours (e.g., giving constant reminders, figuring out what is attributable to FASD and what is not), managing their children's behaviour problems (e.g., does not understand consequences, impulsive behaviour), making time for themselves, and keeping both their child and family involved in social activities (Brown & Bednar, 2004). Unfortunately for families, child behaviour problems are often blamed on what others perceive as poor parenting (Caley, Winkelman, & Mariano, 2009), contributing to larger family problems and difficulties in managing stress. Furthermore, child externalizing behaviour problems, such as hyperactivity, aggression, and rule-breaking behaviour, child internalizing behaviour problems, such as depression and anxiety, and poor executive and adaptive functioning, have been found to be predictive of higher total parenting stress and child-related stress, as well as increased stress on a variety of scales, on the PSI (Paley et al., 2005; Paley et al., 2006).

Further studies have also reported communication and educational barriers as particularly challenging for parents. Lack of knowledge of FASD by health professionals and service providers, in addition to being unaware of signs and symptoms associated with the disability, also appear to be particularly challenging for families (Brown & Bednar, 2004; Caley et al., 2009; Devries & Waller, 2004; Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Ryan, Bonnett, & Gass, 2006; Salmon, 2008). Parents frequently

report frustrations with being unable to receive a diagnosis of FASD for their child, because it prevents them from accessing appropriate services and supports (Caley et al., 2009; Watson, Hayes et al., 2013). Despite challenges in accessing formal diagnoses, the need for a diagnostic label is often reported in qualitative studies examining the lived experiences for parents (e.g., Sanders & Buck, 2010; Watson, Hayes et al., 2013).

What is particularly interesting with regards to the need for a diagnosis is that, although parents and caregivers strenuously seek a formal diagnosis for their child in order to access supports and services, parents often report the process of seeking support as frustrating or like “jumping through hoops” (Doig, McLennan, & Uricuk, 2009, p.236). Getting help for everyday activities (e.g., house cleaning, meal preparation), getting help so that other family responsibilities can be attended to, and getting help so that parents may have some personal time appear to be big challenges for families. According to the 2006 Participation and Activity Limitation Survey (PALS; Statistics Canada, 2008a), 29.7% of parents with a very young child with a severe disability experience challenges in these areas. Only about one fifth of parents (18.6%) reported having assistance from others and most parents who have a child with an activity limitation also report trouble finding and coordinating medical care. Parents stated that they often had a lack of time to coordinate care (63.1%), as well as conflicts with work schedules (60.2%). Parents frequently reported that help from family and friends was not available and 16% reported that their child was on a waiting list for needed help, but nearly three quarters (73.5%) of parents reported that obtaining extra help was too expensive.

Parents are often unsatisfied with the services, particularly respite that they receive (e.g., Hollingsworth, 1992; McGill, Papachristoforou, & Cooper, 2006). In particular, caregivers of children with disabilities often report being dissatisfied with strict eligibility requirements for some types of respite support (Benedict & Farel, 2003) and the overall lack of diversity or availability in the types of respite that are obtainable (Campbell, 1996; Floyd & Gallagher, 1997). Although respite care is the most prevalent type of family support offered (Freedman, Griffiths, Krauss, & Seltzer, 1999), parents often face lengthy wait times in gaining access to respite care and face difficulties obtaining respite due to lack of availability in their area (Caples & Sweeney, 2010).

Doig et al. (2009) examined 10 participants' experiences with respite care in Alberta, Canada, with the most frequently represented disability among the children being FASD. Parents often reported reaching their "breaking point" (p. 236), but respite allowed them to 'rest', 'refresh', and 'relax' (p. 236). However, the process of obtaining the necessary providers and services was challenging for families and parents often had difficulty "navigating the system" (p. 237). When parents were able to locate services they sometimes expressed frustrations around meeting the requirements, such as the ability of pay for respite. Parents in their study therefore expressed a need for more respite options, more flexibility, and better guidelines for providers (Doig et al., 2009). Although some aspects of respite care are likely universal, there may also be unique patterns of need that are associated with particular disabilities (Doig et al., 2009). However, given that in Canada respite care falls primarily under the jurisdiction of the provincial and territorial governments (Doig et al., 2009; Dunbrack 2003), it may be challenging to access supports that are specifically tailored to particular disabilities.

Therefore, gaining funding and acquiring respite services is likely to be highly variable, depending on where a family lives (Neufeld, Querby, & Drummond, 2001).

Qualitative studies examining the lived experiences of families of children with FASD have also addressed the overwhelming financial burden (e.g., Brown, Sigvaldason, & Bednar, 2005; Caley et al., 2009; Gelo & O'Malley, 2003), as well as parents' concerns for their child's future (Mukherjee et al., 2013; Watson, Coons, Hayes, & Radford-Paz, in press). Research on parents and caregivers of children with FASD reveals that birth, foster, and adoptive parents have considerable fear for the future (Gardner, 2000; Morrisette, 2001; Olson et al., 2009; Salmon, 2008; Sanders & Buck, 2010; Watson et al., in press). Parents and caregivers must often accept the reality that their children will be reliant on some form of support throughout their lives, and that their role as caregiver does not end when their children turn 18 years old (Olson et al., 2009; Sanders & Buck, 2010). Parents and caregivers therefore often see themselves in the role of the 'lifelong parent' (Sanders & Buck, 2010), because they are faced with a lifelong commitment to taking care of their children.

It is therefore clear that parents of children with FASD face enormous challenges physically, socially, emotionally, and financially (Gelo & O'Malley, 2003).

Understanding the particular stressors and strains that these families face is essential, because the experience of caregiver stress of raising a child with FASD is different from that of other developmental disabilities (Olson, Jirikowic, Kartin, & Astley, 2007).

Furthermore, findings in the field clearly point out that risks can vary by family type, because birth, foster, kinship, and non-kinship adoptive families appear to respond differently to the presence of a child with FASD. Qualitative studies have also pointed

out the social isolation, stigmatization, and strong attitudes that some individuals hold towards biological mothers of children with FASD (e.g., Brown & Bednar, 2004; Salmon, 2008; Sanders & Buck, 2010). Biological parents often indicate feelings of guilt or shame due to their drinking during pregnancy (Salmon, 2008; Sanders & Buck, 2010). However, foster and adoptive parents may unknowingly look after a child who was prenatally exposed to alcohol and may therefore face confusion and frustration with child rearing later in life if they are unable to properly identify the behaviours. Individuals with FASD are often removed from their birth parents and foster parents are seldom made aware of the circumstances of the separation or the possibility of alcohol exposure (Spohr & Steinhausen, 2008). Therefore, it is important to understand how the experience differs for different family compositions since they may face a wide range of challenges and react differently to the presence of a child with FASD (Olson et al., 2009).

In summary, parents of children with FASD share a number of similar stressors and strains with parents of children with developmental disabilities in general. For example, parents and caregivers of children with FASD and developmental disabilities in general express difficulties in making time for themselves (e.g., having time to partake in personal activities, constantly advocating on behalf of their child); obtaining a formal diagnosis for their child; managing their child's challenging behaviours; receiving support from formal support groups; and dealing with professionals (Brown & Bednar, 2004; Graungaard & Skov, 2006; Poehlmann et al., 2005; Watson, 2008b; Watson, Hayes et al., 2013; Weiss et al., 2003). However, clear differences exist for families of children with FASD, especially pertaining to knowledge of the disability (Brown & Bednar, 2004; Ryan et al., 2006; Salmon, 2008). Families of children with FASD vehemently report that

individuals in all facets of their lives are not properly educated on the realities of FASD, ranging from respite workers (e.g., impossible to find workers who know how to look after their child), to teachers and educators (e.g., do not understand FASD behaviours), and extended family members (e.g., lack of social support or family members to help out). Furthermore, social isolation appears to be a particularly unique aspect to the experience of raising FASD as many individuals in society hold a strong stigma towards the disability and biological mothers (Salmon, 2008; Sanders & Buck, 2010).

1.3 History of Family Research: Changing Perceptions

Despite the focus on negative outcomes, such as stress, burden, and parental depression, increasing evidence has demonstrated that families of children with disabilities articulate positive contributions of their child with a disability to their family's life and general well-being (Bayat, 2007; Hastings, Allen, McDermott, & Still, 2002; Hastings et al., 2005; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, Sobsey, & McDonald, 2001; Skinner, Rodriguez, & Bailey Jr., 1999; Summers, Behr, & Turnbull, 1989; Taunt & Hastings, 2002). Elevated parenting stress, distress, or difficulties in family functioning are not inevitably associated with having a child with a developmental disability, and there is a wide variation in families' responses to raising a child with a disability (Byrne & Cunningham, 1985; Hastings et al., 2002; Scorgie & Sobsey, 2000). A literature review conducted by Helff and Glidden (1998) found that a shift took place from a less negative to a more positive portrayal of families between the 1970s and the 1980s/1990s. Although this change was not significant, it reflected a paradigm change over time, showing a shift to a more positive and strength-based approach to families.

Parents often express a number of positive benefits associated with raising their child with a disability, including connectedness and closeness (e.g., a unified family or marriage) (Bayat, 2007; Greer, Grey, & McClean, 2006; Hastings et al., 2002; Maul & Singer, 2009; Scallan, Senior, & Reilly, 2011; Taunt & Hastings, 2002), growing experience in learning humility, patience, compassion, and acceptance of others (Kausar, Jevne, & Sobsey, 2003; Scorgie, 1996; Summers et al., 1989; Taunt & Hastings, 2002), expanded social and community networks (Kausar et al., 2003; Scallan et al., 2011; Stainton & Besser, 1998; Taunt & Hastings, 2002), and an opportunity for personal growth and transformation (Greer et al., 2006; Hastings et al., 2002; Kearney & Griffin, 2001; Scorgie, 1996; Scorgie & Sobsey, 2000; Scorgie et al., 2001; Stainton & Besser, 1998; Taunt & Hastings, 2002). A particularly intriguing finding comes from research from Hastings and colleagues (2002), where mothers in their study who reported higher levels of caregiving demand for their child with an intellectual disability also reported higher levels of personal growth and maturity. The presence of both stress and positive outcomes may be due to the fact that children with more severe disabilities may provide mothers with more opportunities for personal growth and developing a mature outlook of the world. The results of this study differ from other findings that have demonstrated that both mothers and fathers of children with autism who report more positive experiences also report lower levels of parenting stress (e.g., Kayfitz, Gragg, & Orr, 2010). The interpretation of these results suggests that a greater focus on positive aspects of their child can help parents to focus less on the negative aspects (e.g., challenging behaviours) and their perceived limitations as parents (Kayfitz et al., 2010).

Parents frequently report a changed perspective on life involving not taking things for granted, making new goals or priorities, and having an overall increased appreciation for life (Taunt & Hastings, 2002). Positive meaning making of the disability appears to be an important component of acknowledging positive benefits and showing evidence of family resilience. For example, in Bayat's (2007) study, he found that 63% of his sample identified themselves as believing they had become more compassionate, less selfish and more caring, more mindful of individual differences, and better at finding healthier perspectives in life (e.g., becoming less judgmental), as a result of raising their child with a disability. Acknowledging positive contributions and maintaining a positive outlook on life is therefore likely associated with family resilience, effective coping, and adaptation to the experience of raising a child with a disability. Recognizing positive aspects of children with disabilities, and in particular FASD, may be an essential component in family functioning. A positive emphasis may ease the burden or feelings of stress parents face because they can focus on their children's strengths rather than their weaknesses. Despite a negative focus and emphasis of parenting stress, families do successfully cope and find positive meaning in their experiences of raising their child with a disability.

1.3.1 Positives of raising a child with FASD. Notwithstanding the relatively plentiful literature presented above on positive aspects of raising children with developmental disabilities, only two studies have been published that reflect on the positive aspects associated with parenting a child with FASD (Brown, Rodger, George, St. Arnault, & Sintzel, 2008; McCarty, Waterman, Burge, & Edelstein, 1999). McCarty and colleagues (1999) found that adoptive parents of children with alcohol-related disabilities described the experience to be both more rewarding and more difficult than

they had imagined. Similarly, Brown et al. (2008) examined the rewards of parenting a child with FASD on birth, foster, and adoptive parents. Parents often reported that they were proud of their child's strength in succeeding with difficult tasks. Parents also described their child's gains in self-confidence in their own abilities and gains in independence as particularly rewarding. However, this finding regarding independence differs from other research conducted on families of children with FASD (e.g., Watson et al., in press), where parents of children with FASD were often concerned for the future and believed that their child would never become fully independent.

In spite of the abundance of literature in the field reviewed here, the majority of existing studies are not grounded in theory (Turnball, Summers, Lee, & Kyzar, 2007). Furthermore, of the studies that do include a guiding theoretical framework, many of the studies have inconsistencies with regards to the definition and operationalization of key terms and concepts (Turnball et al., 2007). In order for a concept to be scientifically meaningful, it must be part of an implicit or explicit theoretical framework (Pedhazur & Schmelkin, 1991). In the case of family research, a parents' ability to assign meaning to their situation significantly influences their experience and families tend to fare better when they are able to make meaning of their child's disability (Pakenham, Sofronoff, & Samios, 2004). Researchers have therefore called for substantial work in the field to define family outcomes and move definitions to conceptual frameworks and theory. By basing research within an appropriate theoretical framework, researchers can obtain findings that are relevant to families, as well as facilitate the operational definitions of terminology (Turnball et al., 2007; Watson et al., 2011).

1.4 Family Adjustment and Adaptation Response (FAAR) Model

The Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988, 1989; Patterson & Garwick, 1994a, 1998) is a two-phase interactional model that focuses on how families strive to achieve stability or homeostasis in the face of stressful life events. Moreover, the FAAR model attempts to identify the variables that account for the observed differences among families in their adaptations to these stressful circumstances. Given that the family is a social system, the child's disability and the family's overall functioning are continually interacting. The adjustment phase of the model is an attempt 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 and other demands. Elimination strategies are used to change or remove the stressor. Alternatively, assimilation strategies are used to accept the demands into the existing patterns of interaction. These efforts may lead to successful adjustment, or if resistance efforts fail, may lead to maladjustment or crisis (Patterson & Garwick, 1994a, 1998). However, it is important to note that "crisis" does not necessarily mean a negative event, but simply a turning point where families are forced to restructure and reestablish themselves. After the crisis, the adaptation phase is geared towards reestablishing stability by making changes in the family structure, altering its established patterns of interaction, and uniting the new patterns to achieve a new balance. Adaptation is conceptualized as a continuum ranging from adaptation (i.e. bonadaptation) to maladaptation

Despite the emergence of other theoretical frameworks that attempt to explain the process of adaptation (e.g., Fiske, 2004; Perry, 1989, 2004), the FAAR model was specifically conceptualized to explain the cognitive factors that influence the adaptation

of families to stressful experiences living with a child with a disability or chronic illness (Patterson, 1993). Furthermore, the main components of the model (i.e. demands, capabilities, meanings) are based on variables that have been the foundation of family stress theory for decades. Hill (1949, 1958) was a major contributor to the field of family research and proposed the earliest conceptual foundation of family adaptation (Manning, Wainwright, & Bennett, 2011). Hill examined the family's response to war separation and reunion and formulated the ABCX model, which has since become the center of family stress theory. According to Hill's formula, A (the stressor event) interacting with B (the family's crisis-meeting resources) interacting with C (the definition the family makes of the event) produces X (the crisis) (Hill, 1949). Further development of the ABCX framework came from the work of McCubbin and Patterson (1982) that expanded the ABCX model into the Double ABCX model. According to McCubbin and Patterson (1982), aA is the pile-up of demands, bB is the family's adaptive resources, cC is the family's perception of the stressful events, and xX is family adaptation. A further shift in the development of family stress theory emerged during the mid 1980s, which saw a shift in the approach of understanding family adaptation by changing the focus to family processes, shared family meanings, culture, and contexts, as well as family strengths.

The FAAR model is one of the models to emerge during this postmodern era (Weber, 2010) that focuses on shared meaning created through family member interactions. Despite being an older model, many scholars still utilize this model in family research (e.g., Abery, 2006; Carnes & Quinn, 2005; Murray, Kelley-Soderholm, & Murray, 2007; Watson, 2008a, 2008b). The FAAR model provides a more elaborate

framework compared to earlier models of adaptation, such as the ABCX and Double ABCX models, and is therefore the theoretical model chosen for the current study.

The FAAR highlights three important contributing factors to adjustment and adaptation: demands, capabilities, and meanings. Demands are conditions that call for a change in the family system, but because stress is subjective (Lazarus, 1991), what one family deems stressful is facilitated by the meaning they make of that stressor. Demands are also balanced by the family's resources and coping behaviours. Families attempt to maintain a balanced functioning by using their capabilities to meet their demands. The meanings the family attributes to what is happening to them (i.e., demands) and to what they have for responding to them (i.e., resources) are critical in achieving a balanced functioning (Patterson, 1988). Each of these components of the FAAR model (e.g., demands, meanings, and capabilities) will be discussed in detail. Figure 2 below shows the FAAR model.

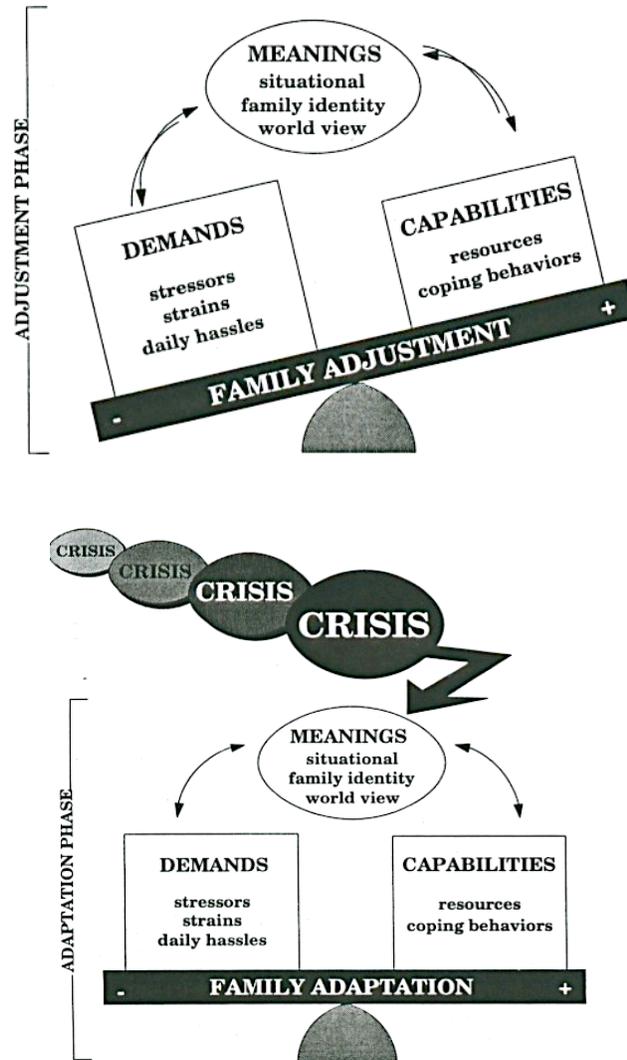


Figure 2: The Family Adjustment and Adaptation Response Model (Patterson & Garwick, 1994a, 1994b)

1.4.1 Demands: Stressors, strains, and daily hassles. According to the FAAR model (Patterson, 1988, 2002; Patterson & Garwick, 1994a, 1994b, 1998), three kinds of demands exist, including stressors, strains, and daily hassles. Stressors are life events that occur at a discrete period of time and a family's adaptation to a stressor may take a great deal of time. With regards to disability research, an example of a stressor may be going to a doctor's appointment.

Strains, on the other hand, are conditions of felt tension that are the result of a pile-up of demands and are associated with a need or desire to change something. Strains therefore do not usually have a discrete onset, but emerge more stealthily within the family (Patterson, 1988). According to McCubbin and Patterson (1983), how a family responds to one stressor will influence how they respond to succeeding stressors. Individuals will vary in how they respond to the same events that occur in their lives (Ferguson, 2002) and what may be a stressor for one family could be considered a strain for another. An example of a strain for parents raising a child with a disability could be when a parent has to take their child to a multitude of doctor's appointments.

Daily hassles are minor irritants that we confront throughout our day-to-day functioning (Ferguson, 2002), such as waiting in traffic on the way to an appointment. It is important to remember that all three kinds of demands are highly subjective and individuals may appraise a stressor, strain, or daily hassle differently. Similarly, the demands associated with a child diagnosed with a disability may vary based on the specific diagnosis, such as autism or FASD, given that particular behavioural phenotypes predispose individuals to unique behaviours and are associated with distinguishing diagnostic processes (Watson, Hayes et al., 2013; Watson et al., 2011).

1.4.2 Capabilities: Resources and coping behaviours. According to the FAAR model, capabilities are defined as the potentiality the family has available for meeting its demands (Patterson, 1988, 1989). There are two major types of capabilities: resources (i.e., what a family has) and coping behaviours (i.e., what the family does). Similar to the three sources of demands, the FAAR model presents three potential sources of resources: individual family members (personal resources), the family unit (family resources), and

the larger community (community resources). Personal resources may include knowledge and skills acquired from education, training, or experience, or personality traits, such as a good sense of humour, self-esteem, and self-efficacy (Patterson & Garwick, 1994a). Family resources include unity (i.e., bonds of harmony between family members) and adaptability (i.e., the family's capacity to meet obstacles and shift course). Community based resources are defined as characteristics, competencies, and means of persons, groups, and institutions outside the family that they may call upon, access, and use to meet their demands (Patterson, 1988, 1989) and provide families with social support. Three broad categories of social support also exist, including emotional support (e.g., words of love and care), informational support (e.g., advice and suggestions), and instrumental support (e.g., financial support). According to Patterson and Garwick (1994a), when families are successful in maintaining their existing networks and in developing new friendships, such as with other families of children with disabilities, they are better able to adapt and show better individual and family outcomes.

1.4.3 Meanings: Family world view, situational, and family identity. For families, a major part of the adaptation process is defining the situation, or attributing meaning, to the event that has been inflicted on their lives (e.g., raising a child with a disability) (Patterson & Garwick, 1994a, 1994b). Meanings can be held individually, as well as shared by members of a group who coexist, such as the family unit or members of the community. For example, family members who are part of specific community organizations or support groups may find shared meaning from expressing the trials and tribulations they face as parents. According to the FAAR model, three levels of meaning

are important when considering family adaptation to stressful life experiences: family world view, situational meanings, and family identity.

Family world view is the most abstract level of family meaning and focuses on the family members' orientation toward the world outside the family. Meanings at this level focus on how the individual interprets reality, what their fundamental assumptions are about the environment, and their existential viewpoints about the family's purpose in life (Patterson & Garwick, 1994b, 1998). Although families are often not able to articulate or describe their world view if asked, qualitative analysis of language used in interviews may give insights into this construction (e.g., discussion of issues with one another regarding the impact of their child with a disability on their lives). Stigmatization and isolation within the community is unfortunately an experience for some families with a child with a disability, which may be exceptionally evident for families of children with FASD. This stigmatization and isolation may lead to a new, and often negative, view of the larger community.

Situational meanings are constructed when family members talk with one another and begin to construct meanings about the stressful event or pile-up of demands, as well as their ability to manage them (i.e., capabilities). Family members do not necessarily have to have a shared construction or shared meaning regarding their child with a disability, but families may often have a shared definition after interactions over time (Patterson & Garwick, 1994b, 1998).

Finally, family identity is a more global view about the family relationships and indicates how a family views themselves. Family identities are more stable than situational meanings about demands and capabilities (Patterson & Garwick, 1994b,

1998). According to the FAAR, how a family defines itself is reflected by who is in the family, as well as how the family functions (e.g., patterns of relationships linking members to one another). Family identity is constructed through routines and rituals that are developed and maintained, and it is through observation that one may gain insight about a family's identity. Routines and rituals provide a sense of stability for a family and can serve as an "anchoring point and a sense of balance when stressful events happen," (Patterson & Garwick, 1994b, p. 6).

1.5 Purpose

As part of a larger study examining the full range of experiences associated with family adjustment and adaptation to the diagnosis of a developmental disability, the purpose of the current study is therefore to identify what it is like to live with a child with FASD in Ontario, Canada, as well as to further contribute to the existing literature regarding the lived experiences of families raising children with FASD. Only two studies have examined the lived experiences of Canadian families; the first study conducted by Sanders and Buck (2010) in Alberta, and the second study conducted by Watson, Hayes et al. (2013) examining families in Northern Ontario. The larger project addresses the experiences of family resiliency and challenges associated with raising a child diagnosed with ASD or FASD in Ontario. Informed by the FAAR model, the larger project is a mixed methods study that includes the administration of a battery of quantitative questionnaires as well as a semi-structured interview aimed at capturing the full range of experiences for parents. The Laurentian University Research Fund (LURF), the Consortium National de Formation en Santé (CNFS), the Social Sciences and Humanities Research Council of Canada (SSHRC), and the Ontario Graduate Scholarship (OGS)

funded part of the larger research project. Funding for this thesis was obtained from SSHRC. Therefore, as a smaller portion of the larger project, and based on the limited existing literature highlighting the experiences of family adjustment and adaptation to rearing a child diagnosed with FASD, the aim of this thesis is to contribute to and further our understanding of the adjustment and adaptation processes of families raising children diagnosed with FASD.

1.5.1 Research context. Before discussing the research aims of the current study, it is important to acknowledge the cultural, rural, and Northern Ontario issues that frame the research context. When families have a child with a disability, in this case FASD, the cultural context into which one is born profoundly influences how one interprets stress (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). With specific regards to FASD, cultural context plays an essential role in what behaviours are deemed acceptable. For example, rates of FAS are highly variable between different cultural groups, and the variations appear to be based on normative patterns of drinking (Whitehurst, 2011).

Discrepancies between urban and rural health issues are also relevant because findings from Shields and Tremblay (2002) found that individuals living in northern, remote communities were the least healthy of individuals in their study. Smoking, obesity, and alcohol consumption rates in these northern communities were above the Canadian averages, and higher daily smoking and heavy drinking rates were associated with shorter life expectancies. Conversely, individuals living in large metropolitan areas

and urban centers had longer life expectancies and disability-free life expectations (Shields & Tremblay, 2002). Despite the expressed concern for the health of rural Canadians, more recent findings from Gauthier, Lariviere, Pong, Snelling, and Young (2012) indicate that geographic location alone may not be the only important determinant in health status, as geographic location was not a significant determinant of physical activity in their study. However, little is known about individuals with intellectual or developmental disabilities in rural regions (Ouellette-Kuntz, 2012). One study conducted in Manitoba (MacTavish, Mahon, Lutifyya, 2000) attempted to understand the social integration of individuals with intellectual disabilities and participants were recruited from large, urban centers in Western Canada, as well as a collection of small towns and rural settings. Although the focus of the study was not urban/rural distinctions, the authors noted that in urban settings families tended to be more actively involved in the lives of their children well into their mid-30s, whereas rural participants typically had less contact with their families by the time they were in their early 20s. Although it has been noted that a stronger sense of community belonging may be a protective factor for those living in rural regions, particularly for depression (Romans, Cohen, & Forte, 2011), individuals with intellectual disabilities may not feel the same social integration as those in urban centers (MacTavish et al., 2000). It is therefore clear that the experience of rural health is complex, and it is unclear if and how these factors influence families raising children with FASD.

Furthermore, because there is a high prevalence of Native and Aboriginal individuals in Northern Ontario, issues surrounding FASD may be more concerning and more prevalent in northern regions of Ontario compared to more southern regions of

Ontario. Northern Ontario comprises 106 First Nations and has an Aboriginal population of 97,930 (Ministry of Northern Development, Mines and Forestry, 2010). Aboriginal individuals bear a disproportionate burden of illness compared to those in the general population and are at a greater risk for a range of health and social problems, including infectious diseases, diabetes, cervical cancer, suicide, unemployment, family violence, and substance abuse (MacMillan, MacMillan, Offord, & Dingle, 1996; Tookenay, 1996). Due to the significantly high population of Aboriginal people in Northern Ontario, and the high prevalence rate of FASD among these populations, FASD may be a particularly evident problem in the North.

Rural and urban differences may also be important for families of children with FASD because prevalence rates of FAS have been found to be highest in rural and remote communities (Robinson et al., 1987; Sampson et al., 1997; Tough, Ediger, Hicks, & Clarke, 2008; Viljoen, Croxford, Gossage, Kodituwakku, & May, 2002; Williams, Odaibo, & McGee, 1999). Tough and colleagues (2008) examined differences between rural and urban health care providers in Canada with regards to their knowledge of, attitudes about, and awareness of FASD and preconception counseling practices. Despite few differences between rural and urban care providers' general knowledge and diagnostic knowledge of FASD, rural providers are in fact more prepared to access resources for women with addiction issues and are more likely to care for patients with a FASD (Tough et al., 2008). However, rural providers were also shown to be significantly less likely to believe it was the physician's role to manage problems in the area of alcohol abuse. Rural providers were also significantly more likely to gain knowledge about FASD through parents or patients, likely due to the fact that rural providers have more

exposure to individuals with FASD attributable to the higher prevalence rates, as well as the fact they see more patients than their urban counterparts. Tough et al. (2008) in fact found that rural providers were significantly more likely to report caring for patients with FAS and to have referred a patient for diagnosis.

Despite the knowledge of FASD in rural and remote communities, families of children with FASD in Northern Ontario frequently report challenges associated with being required to travel to Southern Ontario, specifically Toronto, or out of province in order to access a diagnosis for their child (Watson, Hayes et al., 2013). Until more recently, families with children suspected of having FASD had to make the trip down south to St. Michael's Hospital in Toronto due to struggles developing FASD services in the north (Carmichael, 2011). Seeing as Northern Ontario constitutes nearly 90% of Ontario's land area but only holds 6% of the total population (Ministry of Northern Development, Mines and Forestry, 2010), families may face specific issues in terms of accessing doctors, because many specialists may not be living in Northern regions (McFarlane, 2011; McFarlane & Rajani, 2007; Wenghofer, Timony, & Pong, 2011). Furthermore, Northern Ontario's large land area and relatively small population results in a density of approximately one person per square kilometer, compared to 115 persons per square kilometer in Southern Ontario (Ministry of Northern Development, Mines and Forestry, 2010). One third of Northern Ontario's population lives in a rural location, compared to only 11% of Southern Ontario's population (Ministry of Northern Development, Mines and Forestry, 2010).

Additionally, families living in more rural locations, both in Northern and Southern regions of Ontario, may face similar challenges in locating appropriate

specialists. However, families living in more urban locations, such as in the Greater Toronto Area (GTA), may be at an advantage because they are better able to locate doctors and services, such as Surrey Place Centre in downtown Toronto. Researchers have examined the diagnostic process in general for families with regards to specific disabilities in various areas of the world (e.g., Chamak et al., 2011; Graungaard & Skov, 2006; Hutton & Caron, 2005), as well as reasons for why families seek a differential diagnosis (e.g., Watson, 2008b). However, no studies appear to have examined the challenges in the diagnostic process due to geographic location, particularly for FASD. Travel distances may restrict some people's access to health services and geographic proximity to physicians is part of the health care challenge facing residents' outside of urban areas (Ng, Wilkins, Pole, & Adams, 1997). Individuals living in urban centers are generally not far from a doctor (Ng et al., 1997), and individuals in more urban areas may therefore have easier access to diagnosticians or FASD specialists. Difficulties stemming from longer distances to doctors may also be further compounded by a lack of transportation, as the availability of public transit tends to be more limited in rural locations compared to urban (Ng et al., 1997). Therefore, it is noteworthy to examine whether families of children in Southern or Southeastern Ontario experience some of the same diagnostic challenges or if particular issues, such as the challenges in receiving a diagnosis, arise as a result of location.

1.5.2 Research questions. The current study therefore seeks to answer the following three research questions:

1. What is the lived experience for parents raising children with FASD in Ontario, and is this experience consistent with the limited existing literature?

2. What are the differences in the lived experience between parents with regards to the type of family structure (e.g., biological parents, foster/adoptive parents, kinship caregivers)?
3. How does the lived experience for parents of children with FASD differ based on region (e.g., Northern Ontario, Southeastern Ontario, etc.)?

1.6 Reflexivity

“The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008, p. 53). A fundamental part of conducting qualitative research is the idea of the ‘human researcher as instrument’ (Denzin & Lincoln, 2000; Pezalla, Pettigrew, & Miller-Day, 2012). The experience of subjectivity is inextricably connected with self-reflexivity and positionality (Denzin & Lincoln, 2000). In order to be self-reflexive, one must essentially come clean as a researcher about how their own race, class, gender, religion, and personal or social values influence their understanding of the research setting and the phenomena under investigation (Merriam, 2002). Because the researcher is the central figure and the lens through which the data is collected, selected, analyzed, and interpreted, exercising self-awareness and critical evaluation of one’s role in the research process is essential (Finlay, 2002; Holloway, 2005; Merriam, 2009). What follows is therefore a description of my personal background and reflections on this project as to how my perspective may have influenced my interpretations contained herein.

The starting point of my reflexivity stems from a question and a comment I was posed on many occasions by a number of participants in this study: “So why are you doing this research? I don’t really know what you’re looking for.” Going into most of my

interviews, I experienced a very similar dialogue before the interview even began. Most of my participants wondered whether their experiences could possibly be useful to me and questioned why I was interested in their lives. A number of them asked me questions I now pose to myself. How did I come to be involved in their lives? What brought me to this point and why was I interested in learning about FASD? I initially wondered if I would even be able to relate to the families in my study. I do not have any family members, close or extended, with a disability, let alone someone with FASD. I come from a middle class family and had what many would consider a privileged upbringing. My evolution into the realm of family research seemed strange at best. So why did I care so much about families raising children with FASD?

My first real involvement with individuals with disabilities and families raising children with disabilities began the summer after my third year of my undergraduate degree in Sport Psychology. Growing up, I had limited exposure to individuals with disabilities, as in both my elementary and high school experiences these individuals were often placed in a segregated classroom and only partially integrated for classes, such as physical education. My initial interest in the area of disabilities began after taking several courses during my undergraduate degree that discussed topics related to developmental disabilities. As I needed to complete a fourth year thesis, I approached Dr. Shelley Watson to see if she would be willing to supervise me as a fourth year student. I was fortunate enough to also obtain a research assistant position with her for that same summer, which provided me the opportunity to become involved with her on-going research looking at the experiences of families raising children with various developmental disabilities in Northern Ontario, mainly Autism Spectrum Disorder (ASD)

and FASD. Since beginning this position as a research assistant, and subsequently continuing on as her student, I have been immensely influenced by my supervisor and mentor, Dr. Shelley Watson. Two of her major areas of interest include families of children with disabilities and human rights of people with intellectual disabilities, both of which have hugely impacted not only my research, but also my worldview. As her undergraduate research assistant, I had the opportunity to transcribe a number of qualitative interviews, of both families of children with ASD and FASD, as well as to participate in initial qualitative data analysis.

At the same time, as a fourth year undergraduate Sport Psychology student, I was required to complete a 60 hour internship placement. Based on the recommendation of my mentor, I chose to complete my internship at the Independent Living Sudbury/Manitoulin working on goal setting and team building exercises with individuals with a variety of disabilities, both intellectual and physical. This was a profound moment for me, as the independent living movement is based on the philosophy that individuals with disabilities are the best experts on their own needs, and therefore must take the initiative in designing and promoting better solutions for themselves in their communities. The independent living viewpoint emphasizes working towards self-determination, self-respect, and equal opportunities for individuals with disabilities.

I felt as though my personal experience working with individuals with various disabilities both echoed and conflicted many of the comments I was hearing, and transcribing, from families who were participating in the on-going research project. Despite the philosophy of the independent living movement that focuses on the strengths of the individual with the disability that I was exposed to through my placement, parents

of children with ASD and FASD were expressing their sadness that their children did not fit into their larger communities. Many parents of children with FASD in particular discussed their fears for their child's adult life and future community integration. A phrase that remains in my mind to this day is that children with FASD are 'square pegs' that fit within their immediate family unit, but they do not fit in the outside world as it is now.

These beliefs were even further established from my more recent work experience as a research assistant for the MultiDimensional Assessment of Providers and Systems (MAPS) project based out of Queen's University. I was involved with a portion of the project examining the productivity involvements of people with intellectual disabilities in Ontario. I had the opportunity to conduct qualitative interviews with individuals with intellectual and developmental disabilities, as well as their caregivers, and again assist in preliminary qualitative data analysis. Preliminary data from this study seemed to further reinforce findings in my own on-going work and I could see connections between individuals' struggles obtaining meaningful employment and being integrated in their communities in the MAPS project and what concerns caregivers of children with FASD were sharing about their child's future (e.g., fear that they would have difficulty obtaining or keeping employment; Watson et al., in press). Although I maintain that if you seek out parenting stress you are going to find it, it seemed hard to ignore the fact that caregivers of both children and adults with various disabilities were expressing many of the same concerns and stressors. I found myself wondering why so much of the family literature and my own research experience seemed to be focusing on the challenges and stressors of

raising a child with a disability. What about the positive aspects of raising a child with a disability?

While completing my undergraduate thesis comparing the stressors and strains faced by families raising children with ASD and FASD, I found myself drawn to the families that were raising children with FASD. Although I was interested in ASD, I found the topic of FASD to be fascinating. I also felt more connected to the families raising children with FASD and I shared in their frustrations with the lack of knowledge and awareness of FASD in Ontario. After all, I had never heard of FASD myself until my third year of university. While transcribing and reading the interview transcripts, I often felt emotionally drained after reading them. The families' words were so powerful and I found many of their experiences to be immensely sad. However, at the same time, I was astounded by the resilience displayed by these parents. They expressed such hardship, yet were determined to do anything necessary for their child and seemingly had the ability to bounce back. While I am sure all parents of any child can share both sad and happy memories of their child, these families stories seemed different to me in a way that I found gripping and has since stuck with me. While examining the experience of parenting stress, I found it compelling that parents of children with FASD were reporting more parenting stress compared to parents of children with ASD (Watson, Coons et al., 2013). This finding is noteworthy as much of the existing family literature has concluded that parenting a child with ASD is significantly more stressful compared to children with typical development or other development disabilities (e.g., Down syndrome or Fragile X syndrome; Griffith, Hastings, Nash, & Hill, 2010; Wolf, Noh, Fisman, & Speechley, 1989). I therefore felt compelled to continue investigating the experiences of families

raising children with FASD in particular. I realize that my research experiences listening to and talking with families about their children's challenges drove me to focus on the positives of raising a child with FASD and much of the focus of this document surrounds the factors that both facilitate and hinder family adaptation.

I have also been influenced by the Human Development (DEVE) program. The DEVE program integrates knowledge from a number of fields, including psychology, sociology, and human kinetics, to provide a broader understanding of human development across the lifespan. Much of my individual work (e.g., Coons, in press) and research interests have been shaped by the courses I have taken in the past two years, especially my courses on theoretical perspectives and qualitative methods. The DEVE program has fostered my comprehension of the significance of understanding the human experience across the lifespan, a focus that is particularly important for this research study at hand. I have come to understand the value of exploring family adjustment and adaptation as on-going, as different stressors at different points across a family's life course can alter their patterns of functioning and can create new developmental trajectories. I therefore acknowledge that the results presented in this document represent family adaptation at this discrete point in time.

My early career experience has provided me with the knowledge that individuals with disabilities and their families often face a number of unmet needs and sometimes feel alienated by their larger communities. Although I feel strongly that focusing on the strengths of individuals and their families is essential, at times I struggled with maintaining my positive lens. I sometimes found myself trying to report positive-based facilitators to adaptation, which really seemed to be better addressed as challenges or

problems for families; this subsequently led to the development of my second manuscript included herein. By doing this research, and being involved in various research projects, I have realized that I want to remain in Ontario so that I can try to meet some of the needs discussed by families in this study, including increasing the knowledge and awareness of FASD. Dr. Shelley Watson has been instrumental in encouraging me along the way and showing me the importance of listening to families in order to understand their experience and individual needs. I now turn my attention to specific reflections on the researcher-participant relationship during the current research study.

1.6.1 Navigating the researcher-participant relationship. During the research process, I attempted to bear in mind a number of factors that would likely influence my thinking about the research findings: my attachment to the participants, my liking (or disliking) of my participants, and their words from the interviews that would remain in my head for days, if not weeks, afterwards. I found the process of navigating the researcher-participant relationship to be challenging at times. Specifically, learning about interviewing and actually *doing* interviews are different tasks (Pezalla et al., 2012), which was an on-going educational process for me. As described above, I had specific topics in mind going into the qualitative interviews. These topics and their relation to the families' experiences were covered naturally during the course of the interview with very little probing from me, as many of the questions on the semi-structured interview guide lent themselves towards these specific topics. However, learning when to speak and when to step back and allow the participants to talk was a valuable lesson for me. It seemed to be a delicate balance between remaining somewhat removed as an interviewer and providing suggestions or comments based on the experiences I had heard from other families. Many

participants wanted to be reminded that they were not alone in their experiences and I found that a lot of them asked me what other families had said during their interviews or if I had found any connections between my data thus far. I worked hard to refrain from stepping outside of my role as an interviewer, but I was also cautious not to damage the rapport that I was trying to build with these families.

Another important experience during the interview process was learning when and how much information to divulge about myself. It seemed unfair to me that these participants were opening intricate and very personal details about their lives to me, yet I was trying to hold back to keep the focus on them and their experiences as much as possible. I understood what Mosselson (2010) described in her reflexivity, whereby the researcher holds the power and can choose how much information to reveal about themselves and when to disclose this information. There were several instances during interviews when participants would pose questions back to me. On one occasion, a participant in fact used my answer to her question as a way to better explain her meaning (e.g., my use of “I try”). I was also cognizant of what other researchers, such as Tanggaard (2007) and Abell, Locke, Condor, Gibson, and Stevenson (2006) have discussed, that empathy and self-disclosure may in fact be dangerous interviewer qualities that could distance the interviewer from the participant.

I also refrained from divulging personal information about myself, specifically with regard to my (lack of) spiritual or religious beliefs. Spiritual coping was an important factor for many families who participated in my study. Although I struggled to relate to them when they spoke about turning to God for support, I felt it was important to include the subtheme “*We look at it as a real blessing*” because it was integral to how

parents adapted to their experience of raising their child with FASD. Even though I may not share the same beliefs about their method of adaptation, it was essential for me to keep my point of view in check and remember that I was telling the story of how these families adapt.

Because the interviews were a learning process for me, I found it was important to take notes not only on the content of the interview, but also on my reactions to the interview, as well as my mood for the day or how I was feeling. I learned early on that how I was feeling could have a direct impact on how I interpreted what families were telling me in the moment, as well as the way in which I asked questions or responded to participants' comments. Understanding how my influence could have impacted the interview was integral when it came to interpreting what families were saying and understanding their attributed meanings. I acknowledge my role in the decision of what quotes to use, and subsequently not use, from these interviews in my interpretations of the families' experiences when it came to determining which quotes best represented each theme. I also accept that the relationships I have developed with these families drive me to see that this study produces meaningful findings and provides some return to the participants for their personal investment of time and information.

1.7 Methodology

As part of a larger project examining the full range of experiences associated with raising a child with a developmental disability, a mixed methods study (Teddlie & Tashakkori, 2009), informed by the Family Adjustment and Adaptation Response Model (FAAR; Patterson, 1988, 1989, 2002; Patterson & Garwick, 1994a, 1994b, 1998), was conducted to enhance the quality of results in the larger project. Research in this field has

predominantly been qualitative in nature (e.g., Gardner, 2000; Salmon, 2008; Sanders & Buck, 2010). However, by employing both quantitative and qualitative methods, researchers can obtain an understanding of what families are experiencing, because narratives can improve and add meaning to numbers resulting from quantitative measures. Mixed methods studies allow parents or caregivers to tell their stories, providing a well-rounded understanding of the family experience of raising a child with a developmental disability, specifically with FASD in Ontario. Additionally, mixed methods research can assist in answering a broad and more complex range of research questions, because the research is not restricted to one approach (Johnson & Onweugbuzie, 2004). Following the guidelines for mixed methods research, the larger study incorporated qualitative research informed by basic interpretive inquiry (Merriam, 2002), conducted in the form of a semi-structured interview, and quantitative research, as measured by six psychometric assessments. Psychometric questionnaires were mailed to participants in pre-paid envelopes and were returned to the researcher upon completion. Participants were also asked to complete a short demographic questionnaire to obtain information regarding the age of the participant, the number of children in the family, the number of children in the family who have or are suspected of having FASD, the age of their child or children with FASD, and the family's annual income to determine socioeconomic status. However, the focus of this thesis pertains to the qualitative component of this larger study and quantitative results have been presented elsewhere (e.g., Coons & Watson, 2013; Watson, Coons et al., 2013). Ethics approval for this study was obtained from the Laurentian University Research Ethics Board (see Appendix A).

Following the guidelines from the Canadian Tourism Commission (2010), participants were recruited from seven different regions of Ontario; region one was Northern Ontario, region two was the Ottawa region, region three was Eastern Ontario, region four was Central Ontario, region five was the Greater Toronto Area (GTA), region six was Niagara Falls and region, and region seven was Southwestern Ontario. A figure showing the different divisions of Ontario can be found in Figure 3 below.



**Figure 3: Regions of Ontario
Canadian Tourism Commission (2010)**

Participants were also recruited from both rural and urban locales. Canada’s rural demography consists of approximately six million people. However, stronger growth among large urban centres has meant that these six million individuals represent a smaller share of Canada’s total population (Statistics Canada, 2008b). Urban generally refers to a concentration of population at a high density, whereas rural refers to population that is not concentrated, but rather dispersed at a low density (Statistics Canada, 2011). There are a number of proposed definitions for the term “rural” (Statistics Canada, 2001). For the purposes of this study, “rural” and “small town” refer to those areas outside of urban

centres and the main commuting zone of larger urban areas. An urban area is defined as having a population of at least 1,000 and a density of 400 or more people per square kilometer; all territory outside of an urban area was defined as rural (Statistics Canada, 2011). Urban centres were also broken down into three categories, following the recent changes from Statistics Canada regarding a population centre, formerly referred to as an urban area. A small population centre consists of a population between 1,000 and 29,999. A medium population centre refers to a population between 30,000 and 99,999. A large population centre refers to a population between 100,000 and over (Statistics Canada, 2011). Rural and urban locales were differentiated across Ontario as a whole. Because of a small sample size within each group (i.e., residents in rural locations in Northern Ontario, residents in rural locations in Southwestern Ontario, etc.), rural and urban centers were not distinguished and compared across the seven regions of Ontario. The seven different regions of Ontario were utilized to examine similarities and differences across Ontario.

1.7.1 Participants. Families in this study were accessed through disability support organizations, such as the FASD Network Sudbury/Manitoulin, Surrey Place Centre, Fetal Alcohol Support and Information Centre, FASD Group Ottawa, FASworld Family FASD Support Group, the Association for Community Living, FASD Caregiver Support Group, FASD ONE, and FASD Stakeholders for Ontario, throughout Ontario, Canada. E-mails were sent to various agencies and organizations and participants who were interested in participating were asked to phone or e-mail the lead researchers. Respondent driven sampling was also used (Salganik & Heckathorn, 2004), whereby individuals known to the researcher were contacted in the hopes of identifying families

who would be willing to participate. Word of mouth was also used, where individuals interested in participating in the study contacted the researcher.

A total of 84 parents of children with FASD from 59 families participated in this study. Sixty-four parents participated in both the quantitative and qualitative component. Eighteen parents participated in only the qualitative component and two participants participated in only the quantitative component. These participants included biological parents, adoptive parents, foster parents, step-parents, custodial grandparents and great-grandparents, and a biological aunt. In order to participate, parents or caregivers had to have at least one child with FASD. The number of children with disabilities ranged from 1 to 7. Children in this study ranged from the ages of 1 to 36. Participants in this study will be referred to by pseudonyms. Table 1 below shows the demographics of the participant population of this study. Appendix B shows participant pseudonyms by family, including age(s) of diagnosed child(ren).

Table 1: Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of mothers (<i>n</i>)	58
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
Region of Ontario (% Southern Ontario)	53.4
Characteristics of fathers (<i>n</i>)	26
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
Region of Ontario (% Southern Ontario)	57.7
Characteristics of children (<i>n</i>)	94
Gender (% female)	55.3
Average age (<i>SD</i>)	14.29 (7.65)

Note: ^a = biological relationship to child including aunt, grandmother, and great-grandmother, ^b = step mother relationship to child including step-grandmother, ^c = adoptive relationship to child including adoptive grandmother, ^d = biological relationship to child including grandfather and great-grandfather, ^e = step father relationship to child including step-grandfather, ^f = adoptive relationship to child including adoptive grandfather

1.7.2 Qualitative interviews. Following a basic interpretive approach (Merriam, 2002), semi-structured interviews were conducted with parents. Drawn from phenomenology and symbolic interactionism, researchers utilizing a basic interpretive approach assess how individuals understand their experiences, how they construct their worlds, and what meaning they ascribe to their encounters (Merriam, 2002). The interview consisted of approximately 22 questions and participants were given prompting

questions as needed (refer to Appendix C for full interview guide). All questions were open-ended, such as “Describe your child to me”, “Please talk about how you are doing right now”, and “Please describe your diagnostic experience.” Examples of prompting questions included “Can you please run me through the morning routine” and “When did you suspect he had a developmental disability?” No close-ended questions were asked to ensure that participants were not guided by the researcher to describe their experience in a particular way (e.g., either positively or negatively). Because this study is part of a larger mixed methods study that has been on-going, interviews were conducted by myself (n=27), as well as by the lead researcher (n=25), and two other graduate students at locations agreed upon by both the participant and the interviewer, such as the participant’s home or a coffee shop. Interviews lasted between 40 minutes and two hours and participants were asked follow up questions through e-mail or over the phone.

1.7.3 Researcher experience. Given that this project is part of a larger mixed-methods study, four individuals conducted interviews in this study: two other graduate students, the lead researcher, and me. The lead researcher has several years of experience conducting qualitative research. Both myself, and the two other graduate students, have two years of experience conducting qualitative research. Myself, and the other graduate students, were all trained by the primary researcher with regard to appropriate interview techniques, analyzing and interpreting qualitative data, and ways to write-up the findings. The training first involved sitting in on several interviews to observe the lead researcher. Notes were taken about how the lead researcher asked questions, how and when the lead researcher followed-up with particular participant responses, and how the researcher engaged with the participants during the interview. Debriefing sessions were held after

the observing interviews to discuss how the interview went and to ask questions. I then conducted an interview myself with the lead researcher present to provide feedback afterwards. At the same time, meetings were frequently held with the lead researcher and the other graduate students to discuss the on-going project and to identify preliminary findings. All parties involved conducted their own analysis of the qualitative interviews and we frequently came together to discuss results and re-work emerging themes. Samples of theme tables were provided by the lead researcher to demonstrate the appropriate way to summarize the themes. Additionally, the initial training involved reading a number of resources to familiarize myself with the data analysis process, as well as transcribing and reading the already collected data to acquaint myself with the content of the project.

1.7.4 Analysis of interviews. All semi-structured interviews were digitally recorded and transcribed word for word. As part of the larger project, I personally conducted a total of 27 interviews and transcribed 43 of the interviews. However, I analyzed all 56 interview transcripts for this thesis. Transcripts were reviewed several times to acquaint myself with the content of the interviews. Repeated close and detailed readings of the interviews allowed me as the researcher to ensure that future interpretations of the data remained grounded within the participant's account. After transcription and multiple reviews of the transcripts, notes and comments were made throughout the document in the margins and interviews were re-read to convert original remarks and ideas into more specific themes and phrases. Comments were used to take note of anything that appeared significant or of interest, as well as to summarize the interview. Initial remarks and ideas from all semi-structured interviews were transformed

into more specific themes and phrases using Interpretative Phenomenological Analysis (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith, Flowers, & Larkin, 2009).

IPA focuses on wanting to understand the meaning of a human experience. 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 (Creswell, 1998; Fossey, Harvey, McDermott, & Davidson, 2002; 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'.

Following Seidel's (1998) recommendation for looking for patterns, and Ryan and Bernard's (2003) recommendation for looking for repetitions in the data, themes were identified using these strategies. Data was further reduced by establishing connections between preliminary themes and clustering them appropriately (Shaw, 2010). Clusters of themes were assigned a descriptive label that communicated the nature of the theme, using direct quotations from the interview transcripts.

During the data analysis process, an audit trail was kept to maintain a track of detailed responses regarding my thoughts and comments of the content, coding method, inclusion and exclusion criteria for themes, and examples of quotes for each determined theme. As previously mentioned, each transcript was read several times and the margins were used to make note of anything that appeared significant or of interest. Establishing connections between preliminary themes and clustering them as appropriate further

reduced data. Once themes emerged, inferences were made and the data was summarized. A summary table with illustrative quotes was produced to show each superordinate theme and the subthemes which it comprises (see Appendices D and E). Clusters were given a descriptive label, which conveyed the conceptual nature of the theme.

1.8 Conclusion and Overview of Subsequent Chapters

As part of a larger project examining the experience of parents of children diagnosed with a developmental disability, based upon the theoretical framework of the FAAR model, this paper-based thesis examines factors that both facilitate and hinder successful family adaptation in families raising children with FASD. Using mixed methods, a basic interpretive approach (Merriam, 2002) was applied to qualitative, semi-structured interviews that were analyzed using IPA (Shaw, 2010; Smith & Eatough, 2008; Smith et al., 2009) to encapsulate the story of parents and caregivers raising children with FASD in Ontario. Incorporating both quantitative and qualitative data provides for a rich, thick description of the experience of families (Merriam, 2002; Teddlie & Tashakkori, 2009). However, despite the use of mixed methods for the larger project, the two papers that follow both employ a qualitative approach. Previous research has tended to neglect the use of qualitative research, leading to an overuse of quantitative measures to evaluate the experiences of families. By allowing parents and caregivers to tell their stories, researchers can answer a broader, more complete, and more complex range of research questions.

The first paper included is a qualitative analysis of factors that contribute to successful family adaptation. The results suggest that despite the experience of increased parenting stress for parents of children with FASD, families are able to employ a number

of coping strategies, supports, and transformational outcomes that enable them to adapt to raising their child. Findings suggest that adoptive, foster, and biological parents utilize many of the same strategies when raising their child, although some unique differences exist depending on family type. Future research is needed to explore the differences between mothers and fathers with regards to the adaptation process. Additionally, despite attempts to account for socio-economic status (SES), cultural status and SES was an issue in this study. Future research should attempt to account for SES to determine its impact on the experience of family adaptation.

The second paper included is also a qualitative analysis examining demands that hamper successful family adaptation. Parents identified five stressors that hinder successful family adaptation. Each stressor is explored in turn and recommendations from parents of children with FASD are discussed. Implications for increasing knowledge and awareness of the disability are also addressed.

Following the two papers, a final chapter summarizes the two studies and provides concluding remarks about the larger project and research questions contained herein. Limitations, future research, and practical and clinical implications are also discussed.

Facilitators of Adaptation in Families Raising Children with Fetal Alcohol

Spectrum Disorder Part I: What Has Helped

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Abstract

As part of a larger, mixed-methods study examining the experience of raising a child with a developmental disability, the purpose of this paper is to identify how parents and caregivers have adapted to the experience of raising a child diagnosed with Fetal Alcohol Spectrum Disorder (FASD). Informed by the Family Adjustment and Adaptation Response (FAAR) Model, and following a basic interpretive approach, eighty-two parents of children with FASD in Ontario, Canada participated in semi-structured interviews. Findings from the qualitative component of this study suggest that parents report a number of coping strategies, support networks, and transformational outcomes that enable them to successfully adapt to raising their child with FASD. Using interpretative phenomenological analysis (IPA), five themes were identified from the interviews comprising: understanding FASD and advocating on their child's behalf, the need for routine and choosing appropriate battles, focusing on the positives of their child, informal supports, and formal supports. Each theme is discussed in detail. The findings are further discussed in relation to the existing literature on families raising children with FASD and limitations and considerations are examined.

Facilitators of Adaptation in Families Raising Children with Fetal Alcohol

Spectrum Disorder Part I: What Has Helped

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 these families (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 current aim is to use qualitative analysis to identify how parents and caregivers have adapted to the experience of raising their child diagnosed with FASD.

Historically, researchers have approached the exploration of families with the preconceived belief that families of children with intellectual or developmental disabilities would unquestionably present with a pathological or dysfunctional profile (Maul & Singer, 2009). Much of the focus of family literature has surrounded the experience of parenting stress in families raising children with various developmental disabilities (e.g., 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). This paradigm shift has subsequently led to the field of family resilience (Walsh, 1998), recognizing that many

families overcome crisis through the process of adaptation, resulting in more competent family functioning (Maul & Singer, 2009; Patterson, 2002).

Research into positive factors for families stemmed from an interest in discovering why some families facing privation manage to function well, while other families facing a similar situation do not (Bayat, 2007; Patterson, 2002; Walsh, 1998). This recent paradigm shift demonstrates that the majority of families are able to adjust, adapt, and experience positive transformations as a result of having a child with a disability (Dykens, 2006; Hodapp, 2002; Risdal & Singer, 2004). Additionally, many families articulate positive contributions associated with raising a child with a developmental disability to their family's life and general well-being (e.g., Bayat, 2007; Scorgie, Wilgosh, Sobsey, & McDonald, 2001; Summers, Behr, & Turnbull, 1989). One important finding from this field is that although families of children with disabilities report more stress, they do not report fewer positive feelings (Hastings & Taunt, 2002). 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).

The implication of theoretical models, such as the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988, 1989; Patterson & Garwick, 1994, 1998), is 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). Additionally, 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, interpretations that fit within existing

theoretical models (e.g., Patterson, 1988, 1989, 1993). Despite the call for a strength-based approach to family research, studies that seek to examine the relationships between parenting stress and adaptation inevitably end up discussing only the implications 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.

Models of Family Adaptation

Before discussing the ways in which families of children with FASD successfully adapt to the experience of raising their child, it is important to clarify what is meant by the term adaptation. McCubbin and Patterson (1983) established the frequently used Double ABCX model (1983) and the T-double ABCX model (1987), which demonstrate that the stress of raising a child with a disability (X) is a consequence of the child's characteristics (A), parental perceptions of the child's disability (B), and the family's resources (C). Building on the ABCX framework, the FAAR model (Patterson, 1988, 1989; Patterson & Garwick, 1994, 1998) is a two-phase interactional model that emphasizes how families strive to attain stability or homeostasis in the face of stressful life events.

Given that the family is a social system, the child's disability, in this instance FASD, and the family's overall functioning are continually interacting. 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. These efforts may lead to successful

adjustment or, if resistance efforts fail, may lead to maladjustment or crisis (Patterson & Garwick, 1994). 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 re-establish themselves. After a crisis, the adaptation phase is geared towards re-establishing stability by making changes in the family structure, altering its established patterns of interaction, and uniting the patterns of behaviour to achieve a new balance. During the adaptation phase, families attempt to restore 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, such as FASD, given that particular behavioural phenotypes are unique and predispose individuals to distinctive strengths and weaknesses (Dykens & Hodapp, 2001).

Families of Children with FASD

FASD is an umbrella term used to describe the continuum 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, 2011; 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 et al., 2013).

Prior research has identified that families report a number of factors as valuable to maintaining positive placements for their children. 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, Sigvaldason, & Bednar, 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, St. 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 in 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 research 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.

Methodology

As part of a greater 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 semi-structured interview. 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. Quantitative findings have been presented elsewhere (see Watson, Coons et al., 2013).

Participants

Families in this study were accessed through disability support organizations across Ontario, Canada. E-mails were sent to numerous agencies and participants were asked to phone or e-mail 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 recognizing families who would be willing to participate.

Participants included biological parents, adoptive parents, foster parents, stepparents, custodial grandparents, great-grandparents, and a biological aunt (all referred to here as parents). Eighty-two parents of children with FASD 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 1 to 36, with a mean age of 14.29. All participants in this study will be referred to by pseudonyms.

Qualitative Interviews

Following a basic interpretive approach (Merriam, 2002, 2009) a semi-structured interview was conducted with parents. Drawn from phenomenology and symbolic interactionism, researchers utilizing a basic interpretive approach assess how individuals understand their experiences, how they construct their worlds, and what meaning they ascribe to their encounters (Merriam, 2002). 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 (SW) developed 22 open-ended questions with follow-up prompts if required. For example, the questions “How do you manage all of your responsibilities?” and “Is there anyone whom you turn to for support?” sought to identify capabilities, in particular resources and supports that families utilize, whereas 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. No close-ended questions were asked to ensure that participants were not guided by the researchers to describe their experience in a particular way (e.g., either positively or negatively). 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, and interviews lasted between 40 minutes and 4 hours.

Data Analysis

All interviews were digitally recorded and transcribed word for word. All transcripts were examined several times by the researchers to familiarize 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 transcription and multiple reviews of the transcripts, notes and comments were made throughout the document in the margins and interviews were re-read to convert original remarks and ideas into more specific themes and phrases. Comments were used to take note of anything that appeared significant or of interest, as well as to summarize the interview. Initial remarks and ideas from all interviews were transformed into more specific themes and phrases using interpretative phenomenological analysis (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith, Flowers, & Larkin, 2009). 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).

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

Clusters were given a descriptive label, which conveyed the conceptual nature of the theme. Participant quotations are used to maintain accuracy and integrity in terms of the naming of themes and sub-themes. Each member of the research team conducted their own independent analysis of the data, and themes were then compared to check for consistency. Reliability and validity of the themes were ensured through investigator and methodological triangulation and member checking (Shenton, 2004).

Results

Although parents and caregivers raising children with FASD experience a great deal of parenting stress (e.g., Watson, Coons et al., 2013; Watson, Hayes et al., 2013), family members also report a number of coping strategies, supports, and transformational outcomes that enable them to adapt to raising a child with FASD. During semi-structured interviews, parents identified a number of coping strategies that have helped them in raising their children, as well as informal and formal supports that they have accessed, and changes to their general outlook on life. Using IPA, five themes were identified from the interviews. These themes include understanding FASD and advocating on their child's behalf, the need for routine and choosing appropriate battles, focusing on the positives of their child, informal supports (e.g., extended family members, friends, church members), and formal supports (e.g., organizations designed to help families, professionals). Each of these themes is discussed in detail.

“Get Educated, Get Involved”: Understanding FASD

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.

“Get as much information and knowledge as you can”: **Learning about FASD.** 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 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 re-think her approach to her individual parenting strategies:

Absolutely learn as much as you can. Knowledge is power and if you have the knowledge, at least you can see why the behaviours are happening, you can see why the child’s acting like this...But absolutely you need education on FAS and supports.

Carmen and Robyn also shared similar sentiments about the importance of learning about FASD to better understand their child’s behaviour, because having more knowledge of the disability allowed parents to understand their own thought processes and comprehend why their children acted in a particular manner. For example, Carmen discussed the importance of learning about FASD to recognize what she refers to as a ‘disconnect’ in her granddaughter Angelica,

This is her daily: “you’re trying to get me in trouble.”... You start to feel crazy after a while because you don’t understand and finally her therapist said to me “stop going to the why and go to the what needs to happen.”.... So it stops that

insanity, but the insanity was my insanity because she really believes she didn't do it because of the disconnect. And so I had to learn about fetal alcohol and I had to learn about that disconnect.

Other parents talked about the importance of attending conferences, seminars, and workshops focused on FASD. Annie and Jason, foster parents to Nicholas, discussed their experiences in learning about FASD at conferences,

That's where we first began to learn about how you could do things in the environment to help them with memory and...this kind of stuff. This is just, 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."

“You have to fight for everything for these children”: **Becoming advocates.** 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, I've given talks. So you take on more – and I talk about alcohol use with, you know, during pregnancy to teenagers. Whenever I have a chance I'll be mouthing off about it (*laughs*)."

However, 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 other parents, such as Tracey, Denise, Leslie, and Kevin, also discussed the need to advocate for their children's sake. For example, Leslie and Kevin communicated having to push for supports for their two sons, Jace and Jared. As Leslie stated,

I would also tell parents to be their kid's biggest advocate because they're not going to get anywhere if they don't push for supports. People aren't going to offer support. You have to go out and get it. And if that means you have to spend hours on the weekend on the phone or on the computer then that's what you do to find what's out there and what's available.

Many parents, such as Veronica, Carmen, and Pauline, discussed their advocacy role in relation to the school system. Veronica talked about educating the teachers on her daughter Irene, particularly in terms of tangible resources,

I've gone out and I've printed off, like 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, so hopefully they're using some of those strategies.

Although parents were often annoyed at having to continually advocate, parents such as Denise discussed the rewards that are the result of their advocacy, including a better understanding from teachers:

I worked hand in hand with the teacher last year, I gave him all the information, the pamphlets, everything, and he said that, you know, 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 Individualized Education Plans (IEPs).

"I Take It Day-to-Day, I Don't Think About Tomorrow": Day-to-Day Management

The title theme, spoken by several parents, emphasizes 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.

“Everyday it’s like the movie Groundhog Day”: Maintaining routines. In order to manage their children’s behaviours, parents often 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 exact 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 becomes stuck in a time loop and is forced to re-live 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.

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 to, you know, 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,

So like, she’s in the bathroom right now, she’ll see a sign that says “Did you wash your teeth? Did you flush the toilet?” and she’ll go through that list every time

soon as she sees them, soon as she's in there to remind, help her remember what to do.

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."

"Choose your battles": Picking the right fight. Many parents found that when they learned to choose the appropriate conflicts with their children, it improved their relationship with their children tremendously. For example, Melanie, an adoptive mother to one son, found that when she stopped fighting 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."

Jade and Kimberly shared specific examples of struggles they decided to avoid or discontinue with their children related to what they refer to as "rages" or "meltdowns". For many parents, allowing their children to continue with certain non-harmful 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. Kimberly also discussed her occasional internal struggle between balancing whether or not her daughter could continue to participate in something she found

inappropriate against the risk of her daughter, Bernadette, having a “meltdown”, such as not allowing her daughter to watch PG-13 movies because it was not age appropriate.

“I Wouldn’t Change it for the World”: Transformational Outcomes

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. 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. Many parents also mentioned the importance of spirituality, and that their faith and belief in God provided them with a strong sense that their child was meant to be in their family.

“Life is one big adventure”: Focusing on the positives. 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. For example, many families discussed that their life was often unpredictable, but this provided them with a sense of excitement. Similarly, several parents believed that raising a child with FASD provided them with a rewarding, one of a kind learning opportunity. For example, Kimberly and Veronica both referred to their adoptive daughters as “teachers” and to themselves as “students”. Other parents, like Kimberly and Veronica, shared that raising a child with FASD allowed them to not only learn more

about the disability itself, but also to learn about families raising child with various disabilities, providing parents and caregivers with an opportunity to change their worldviews.

Some caregivers also acknowledged the unique personal feelings that raising their child with FASD had for them. 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 also shared a parallel 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 emphasized that despite their frustrations and challenges that they “would do this a million times over.”

“We look at it as a real blessing”: **Spiritual outlook.** In addition to holding a positive outlook, several parents identified a sense of spirituality as an important factor in their adaptation. Bailey, an adoptive mother to Benjamin, discussed her recent personal journey and reflection over her son’s death,

I mean, you can “why me?” over a whole lot of things. You know, you really can’t second-guess, so you kind of have to trust your own journey. Know that somewhere there’s a point and a purpose to all of this...Maybe I was this strong person that could handle that. Who’s to say? All I know is that I hope I don’t remember the frustrations when I get in front of the good Lord and offer to kick him in the leg (*laughs*).

However, not all families felt their child with FASD was a blessing from God. Gabrielle, an adoptive mother, felt that God would never purposefully place a child with FASD in her home. However, she still acknowledged a purpose to her experience,

Like I can look back and say well it was tragic and it destroyed a family as it was, but it’s not going, it’s not gone to waste. I mean I can still see there was a reason, I mean I don’t believe God would ever say “This is going to happen so you can help other families.” I don’t believe that. But...it happened...Try to see the good in it.

“You Can’t Do It on Your Own”: Informal Supports

In addition to a changed worldview, families remarked upon the importance of obtaining support. This theme identifies the importance of having people to turn to for support. 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.

“Luckily we sort of balance each other”: **Significant others.** Parents frequently discussed turning to their significant other on a daily basis to ensure that they were on the same page, as well as to reassure one another of their parenting skills. 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.

More importantly, some families discussed the need to have someone to lean on. For example, Kevin shared a comment about his wife, Leslie: “We lean on each other. We do. 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 can help to be a source of balance for them. Celine further 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.’”

“I have good support around me”: **Family and friends.** In addition to having a strong spousal relationship, parents also discussed receiving support from other family members and close friends. Parents referred to a number of informal sources of support, including sisters, grandparents, other parents of children with FASD, friends from church, and close personal friends. Close friends and family provided parents with someone to talk to about a number of issues. 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. 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...she’s a mental health worker...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.

“It’s Nice to Know You’re Not Alone”: **Formal 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.

“It was a lifesaver, the FASD group”: **Support groups.** Formal support groups appeared to be the most important source of support for parents because it provided them with a sense of community and a sense of belonging. For example, when discussing their

local support group, Stephanie and Chad, adoptive parents to Victor, stated, “We belong with that. 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?

Understanding that challenging behaviours and family struggles also occurred in other families of children with FASD proved to be extremely helpful for Ashleigh and Shawn, who discussed how their struggles with their son almost resulted in multiple adoption disruptions,

But the good thing that came out of the diagnosis was we hooked up with the FASD group, so that helped us through because we were very close to three adoption disruptions I would say. Like... we almost said you know what? Take him back. We didn’t sign up for this. Thank goodness for the FASD group, right? We found that oh, you know what? A lot of people with FASD behave in such and such a manner and my kid did that too at such and such an age and nods around the table and snickers around the table and so it was, it was a lifesaver, the FASD group.

Caregivers also found the practicality of having a form of online support from families that was easily accessible extremely helpful. 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 e-mails from her support group when she feared her 16 year-old granddaughter with FASD might be pregnant. Claire discussed one specific example of how having support from her friends online helped her through a crisis,

...I still keep in contact with them, even though I've never met them... Know their kids from all our stories, will e-mail them in a crisis. I had my one friend the night she tried to kill me, it was like four hours of her out-bursting and my friend would just send me e-mails – are you okay? What's going on? And she lives in Nova Scotia. She kept me sane that night and I have never met her.

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

In addition to turning to formal support groups for assistance, some parents also reported going to a variety of professionals for help. Aid from professionals included support from psychiatrists, counsellors, social workers, teachers, and doctors or pediatricians. Barbara, a biological mother to Austin, commented on support she received from numerous professionals, such as a counsellor and psychiatrist. Denise, a biological grandmother, and Jade, an adoptive grandmother, also found their counsellors to be a tremendous form of support. As Jade elaborated,

And 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 because, you know, she laughs at my resiliency skills, and my take on life, and that sort of thing. But that really... that really helps too.

Of the professional supports discussed, a minority of families found doctors to be an important source of support. By providing support for their children, these professionals were in fact also providing better support for the parents. For example, Annie and Jason found their family doctor extremely helpful since she would make an attempt to understand FASD,

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?

Families were very appreciative of doctors who made an effort, either to educate themselves about FASD or to refer them to the appropriate service or individual. However, many participants felt that doctors and teachers lacked knowledge of FASD and were therefore not very helpful.

Discussion

The authors of this qualitative study found that parents identify a number of factors that help them adapt to the experience of raising their child with FASD. For instance, families spoke in great detail about the importance of 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 organization, family, or individual (Bernheimer & Weisner, 2007).

Families also identified the experience of raising their child with FASD as positive, although challenging. Individuals who perceive a situation as a challenge also

often regard it as a chance 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). Families in this study identified a number of positive factors associated with transformational outcomes including: acquiring new roles, such as being an advocate for their child or an educator about FASD; a greater sense of personal strength and patience; determining what is really important and valuable in life; stronger spiritual convictions; and improved family relationships, particularly supportive marriages (Scorgie & Sobsey, 2000; Scorgie et al., 2001). Parents and caregivers further expressed that their children had been influential in changing their lives. Researchers have previously identified that some parents hold the perception of their child's disability as a mission or a duty, as well as a gift from God (Pelchat, Levert, & Bourgeois-Guérin, 2009). Families may therefore, through a sense of spirituality, seek to fulfill their mission or test their strength, giving meaning to their experience as a parent of a child with a disability and promoting adaptation. Affirming personal strength, keeping a positive outlook, and having a sense of spirituality or maintaining a belief system, are important contributors to family resilience (Kearney & Griffin, 2001; Walsh, 1998), all of which were demonstrated by the participants in this study. Encouraging parents to recognize the positive aspects of life with their child with FASD is needed, since focusing on positive outcomes may help to alleviate the influence of child-related stress (e.g., behavioural or emotional problems) on parental well being (Hastings & Taunt, 2002; Kayfitz, Gragg, & Orr, 2010).

Families also emphasized how essential having a form of social support was, particularly when it came to formalized support groups. The link between social support

and a family's well being and the parents' ability to parent has been discussed in the literature (Armstrong, Birnie-Lefcovitch, & Ungar, 2005) and qualitative findings have revealed that parent to parent support is vital because it creates a sense of a "reliable ally" (Ainbinder et al., 1998, p. 103). As was demonstrated in the current study, parent to parent support fosters a sense of community, because others in a similar situation can 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) and as a critical element in the coping 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 FASD is essential in aiding families who are not adapting as successfully. Although the results presented here reflect a large proportion of families in this study, not all parents reported facilitators of successful adaptation. Several families referred to their life as living in a constant crisis. 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 maladaptation 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.

Understanding adaptation and maladaptation in families raising children with FASD is essential, as the way in which adaptation is achieved may be unique for families of children with FASD. 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 a coping behaviour and as acquiring a new resource, as families are better able to mobilize 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). 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 serve to reduce their demands.

A number of these families spoke in detail about their personal difficulties balancing their adult child's difficulties with other family roles and responsibilities, particularly when it came to caring for their aging parents or a sick spouse. Previous researchers have shown that aging parents may sometimes find themselves sandwiched between the needs of two generations, as their parent or spouse may become ill and

require care in addition to their adult child with a disability (Seltzer, Greenberg, & Krauss, 1995). Interestingly, a similar concept may apply to grandparents who are raising a second-generation child with FASD, because they may find themselves experiencing challenges raising their grandchild with FASD, as well as their middle generation. Therefore, identifying strategies that foster successful adaptation is essential in helping families facing maladaptation.

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 socio-economic status (SES) was also an issue. Most participants came from Caucasian, affluent families, and therefore generalizing results to other cultures and lower SES families is impossible. 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 stress (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.

SES differences and family backgrounds may also play a particularly important role with regards to family type, mainly in differences between biological, foster, and adoptive families. Adoptive families may be more likely to come from middle to upper class families that take on a child with FASD in order to provide them with what they hope will be a better life (Brown et al., 2005). Unfortunately, many biological mothers of children with FASD tend to come from low-income families who lack proper education regarding alcohol consumption and pregnancy. Although women of any SES can bear children with FASD, the more severe forms of FASD (e.g., Fetal Alcohol Syndrome [FAS] and partial-Fetal Alcohol Syndrome [p-FAS]) have been most frequently found in lower SES categories across various countries (May & Gossage, 2011). For example, one study conducted by Bignol et al. (1987) in the United States found that the risk of bearing a child with FAS was 15.8 times higher for women of lower SES. Because alcohol consumption during pregnancy is part of a damaging lifestyle, biological parents raising children with FASD may face additional struggles that impede resilience (Rowbottom, Merali, & Pei, 2010). However, lower SES may not in and of itself cause this increased risk for FASD; co-factors of risk likely also put forth a cumulative effect, such as poor

living conditions, inadequate nutrition, and high levels of stress on childbearing (Coons, in press; May & Gossage, 2011).

Conclusion

This study revealed that although the experience of raising a child with FASD can be challenging for families, parents and caregivers find ways to successfully adapt. The five themes provide evidence that families ascribe meaning and gain understanding from their experiences associated with raising their children with FASD. 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). Families tend to fare better when they are able to make meaning of their child's disability (Pakenham, Sofronoff, & Samios, 2004), 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.

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Facilitators of Adaptation in Families Raising Children with Fetal Alcohol

Spectrum Disorder Part II: What Would Help

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Abstract

Despite a wealth of literature on the experience of stress faced by parents of children with an intellectual or developmental disability, there is a scarcity of research examining the stress faced by parents of children with Fetal Alcohol Spectrum Disorder (FASD). However, understanding the unique experience of parenting stress and adaptation with regards to the child's specific formal diagnosis is essential as demands may vary and family responses differ based on the child's specific disability and corresponding behavioural phenotype. Therefore, as part of a larger, mixed-methods project investigating the family experience of raising a child with a developmental disability, the aim of this paper is to identify and explore the unique stressors experienced by parents of children with FASD, as well as to provide recommendations for lessening the impact of these stressors. Informed by the Family Adjustment and Adaptation Response (FAAR) model and following a basic interpretive approach, eighty-two parents of children with FASD participated in semi-structured interviews. Semi-structured interviews were analyzed using interpretative phenomenological analysis (IPA). Five themes were identified from the interviews comprising: more training for professionals, early knowledge of the disability, support for the child, support for the family, and more knowledge and awareness of FASD. Each theme is discussed in detail and recommendations from parents of children with FASD are explored. Furthermore, implications for increasing knowledge and awareness of the disability are discussed.

Facilitators of Adaptation in Families Raising Children with Fetal Alcohol Spectrum Disorder Part II: What Would Help

Despite a wealth of literature on the experience of stress faced by parents of children with an intellectual or developmental disability (e.g., Abbeduto et al., 2004; Johnston et al., 2003; Smith et al., 2010), there is a scarcity of research investigating the stress faced by parents of children with Fetal Alcohol Spectrum Disorder (FASD; Watson, Coons, & Hayes, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). Regardless of disability diagnosis, researchers have suggested that having a child with a disability is associated with the experience of increased parenting stress (see Watson, Hayes, & Radford-Paz, 2011). However, understanding the unique experience of parenting stress and adaptation with regards to the particular formal diagnosis is important as demands may vary and family responses may differ based on the child's specific disability (Hodapp, Fidler, & Smith, 1998). Predominantly, behavioural phenotypes predispose individuals to distinctive strengths and weaknesses (Dykens & Hodapp, 2001; Watson et al., 2011). If researchers can establish in what ways families of children with specific disabilities, such as FASD, are struggling, supports can be tailored to help alleviate those stressors. Therefore, the aim of this paper is to identify and explore unique stressors experienced by parents of children with FASD, as well as to provide recommendations for lessening the impact of these particular stressors.

Parenting Stress Theory and Family Adaptation

According to McCubbin and Patterson (1983), how a family responds to one stressor will inevitably influence how they respond to successive stressors. Individuals will vary in how they respond to the same events (Ferguson, 2002) and what may be a

stressor for one family could be viewed as a strain for another. The Family Adjustment and Adaptation Response (FAAR) Model (Patterson & Garwick, 1994) reveals how families raising a child with a disability attempt to deal with the stressors and strains placed upon them. A number of variations of the model have been developed and expanded (e.g., McCubbin & McCubbin, 1991; McCubbin, McCubbin, Thompson, & Thompson, 1995; McCubbin, Thompson, & McCubbin, 2001), but the original FAAR model progressed from the ABCX model (McCubbin & Patterson, 1987) in an attempt to explain how families adjust and adapt to the demands placed upon them. The model is an interactional view of stress (Patterson, 1989) that focuses on three levels of system: the individual, the family, and the community (Patterson, 1988). Furthermore, the FAAR model highlights three contributing factors to adjustment and adaptation: demands, meanings, and capabilities.

According to the FAAR model (Patterson, 2002; Patterson & Garwick, 1994, 1998), three kinds of demands exist: stressors, strains, and daily hassles. A stressor is defined as a life event that occurs at a discrete period of time, such as a transition into school. Stressors may subsequently turn into strains if the stressor is continuous and the pile up of demands increases, such as negative community encounters as a result of lack of knowledge of their child's disability. Because stress is a subjective experience (Lazarus, 1991), what a family considers stressful is facilitated by the meaning they make of that stressor. The meaning that a family attributes to what is happening to them (i.e., their demands) and to what they have for responding to them (i.e., their resources or capabilities) are critical in achieving a balanced functioning (Patterson, 1988). The FAAR model and the stressors that impact families are of particular interest to the current

study because the focus of the model is on a family's efforts to manage the demands placed upon them (Patterson, 1989) and subsequently *how* families manage these demands, leading to successful adaptation.

Families of Children with FASD

To develop effective family-level interventions for those affected by FASD, it is essential to understand the unique stressors that these families experience. Researchers have identified a number of challenges reported by families including: obtaining a formal diagnosis (Brown & Bednar, 2004; Caley, Winkelman, & Mariano, 2009; Ryan, Bonnett, & Gass, 2006; Watson, Hayes et al., 2013); social isolation (Brown & Bednar, 2004; Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Salmon, 2008); lack of understanding from family members (Brown & Bednar, 2004); feeling unsupported by medical and health professionals (Mukherjee et al., 2013; Ryan et al., 2006; Salmon, 2008; Sanders & Buck, 2010; Watson, Hayes et al., 2013); receiving respite when it is convenient and having a worker who is properly trained (Brown & Bednar, 2004; Caley et al., 2009; Ryan et al., 2006); and home-school relationships (e.g., expectations too high in school, not many teachers who are educated about FASD; Brown & Bednar, 2004).

Insufficient knowledge of FASD by health professionals and service providers, in addition to being unaware of signs and symptoms associated with the disability, also appear to be challenging for families (Brown & Bednar, 2004; Caley et al., 2009; Devries & Waller, 2004; Mukherjee et al., 2013; Ryan et al., 2006; Salmon, 2008). Because of this lack of knowledge, families feel as if they have nowhere to turn to for answers about how to best support their children. Awareness and understanding of FASD remains low, and individuals who are affected by FASD are seriously underserved (Ryan et al.,

2006). Parents frequently report frustrations with being unable to receive a diagnosis of FASD for their child, as it prevents them from accessing appropriate services and supports (Caley et al., 2009; Watson, Hayes et al., 2013). Even with a formal diagnosis, families report a lack of appropriate services and trouble accessing existing services (Ryan et al., 2006). Furthermore, as a result of lack of knowledge of the disability, families often feel misunderstood and blamed by those in the larger community and their child's behavioural problems are often attributed to poor parenting (Brown & Bednar, 2004; Caley et al., 2009).

One major concern is that families often report confusion when it comes to obtaining formal services and supports for their child with FASD. Children and families raising children with FASD are often reported to be falling through the cracks due to a lack of support. For example, parents and caregivers discuss not even knowing what services they can receive (Brown & Bednar, 2004). When families are able to obtain support for their child, such as an occupational or physical therapist, parents often express their dismay at being discharged from the service once their child demonstrates some achievement or improvement (Brown & Bednar, 2004). Furthermore, families express their desire to obtain help in dealing with FASD itself, but are most often provided with solutions for managing symptoms of the disability (e.g., medications to manage a particular aspect of their child's behaviour). Children with FASD display complex mental health needs and may be prescribed with a variety of medications (Gelo & O'Malley, 2003). Researchers have acknowledged that services for families and children with FASD are scarce. For services that do exist, families often report being unable to obtain them due to strict eligibility criteria, such as an IQ below 70 (Ryan et al.,

2006; Watson, Hayes et al., 2013). Therefore, although families desperately want to obtain help for their child with FASD, there appears to be a lack of appropriate or existing services.

Methodology

As part of a larger mixed methods study examining the experience of family adjustment and adaptation to the diagnosis of developmental disability in Ontario, Canada, parents participated in qualitative, semi-structured interviews, in addition to completing a number of questionnaires. The purpose of this study was to explore the dynamics that contribute to successful family adaptation while raising a child with FASD. This study incorporated qualitative research informed by basic interpretive inquiry (Merriam, 2002, 2009). This article presents findings based on the qualitative component of this study; quantitative findings have been presented elsewhere (see Watson, Coons et al., 2013).

Participants

Eighty-four parents of children with FASD from 59 families participated in this study. Eighty-two parents and caregivers of children with FASD participated in the interview component of this study, predominantly biological, adoptive, and foster parents and caregivers. Participants also included stepparents, custodial grandparents, great-grandparents, and one biological aunt (all referred to here as parents). Participants in this study were recruited from organizations, disability agencies, and support groups across Ontario, Canada. Respondent driven sampling (Salganik & Heckathorn, 2004) was also used, where individuals interested in participating contacted the researcher. For

confidentiality purposes, all participants' names and identifying information have been changed.

Semi-Structured Qualitative Interviews

Following a basic interpretive approach, semi-structured interviews were conducted with parents and caregivers in order to understand how parents make sense of their lives and their experiences (Merriam, 2002). A basic interpretive approach, or what Merriam (2009) also refers to as basic qualitative research, seeks to understand the constructed meaning a phenomenon has for those involved. Although all qualitative research is interested in how meaning is constructed, the primary goal of a basic qualitative study is to uncover and interpret these meanings (Merriam, 2009). 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 developed an interview guide, which consisted of 22 open-ended questions. For example, two questions were: "What is it like for you to be his/her parent?" and "How has having a name for the disability changed the experience for you?" Participants were also given prompting questions if needed. For example, "Why did you want a formal diagnosis?" was a prompt for the question "What meaning did you think a formal/differential diagnosis would provide?" Because this project is part of a larger research project, 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. Semi-structured interviews were conducted at locations agreed upon by the participant and the interviewer, such as participant's

homes and local coffee shops. Follow-up questions were asked of the participants, using e-mail and telephone conversations.

Data Analysis

Semi-structured interviews were analyzed using interpretative phenomenological analysis (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith, Flowers, & Larkin, 2009), which is associated with a detailed examination of personal and lived experiences of the individual, and how that individual makes sense of their lived experience (Creswell, 1998; Fossey, Harvey, McDermott, & Davidson, 2002; Merriam, 2002). Although we assume and accept that events ‘actually exist’, we grasp that our only access to those experiences is through a specific lens (e.g., through the eyes of parents of children with FASD) (Shaw, 2010). IPA aims to capture and explore the meanings that participants ascribe to their experiences and is coupled with the subjective and reflective processes of interpretations of the researcher (Eatough & Smith, 2006; Reid, Flowers, & Larkin, 2005). The inductive procedure of IPA allows the researcher to develop an initial “insider’s perspective” (Reid et al., 2005, p. 22) into the topic of interest, in this case the experience of parents raising children with FASD. IPA is therefore a powerful tool as it provides a balance between the ‘emic’ (i.e. insider position, participant) and the ‘etic’ (i.e. outsider position, interpreter) as the researcher begins by hearing the stories of participants and then attempts to make sense of the participant’s accounts to explain their lived experiences in a way that answers a particular research question (Reid et al., 2005).

All interviews were digitally recorded and transcribed verbatim. Transcripts were read, and then re-read multiple times, in order for the researchers to familiarize themselves with the content of the interviews. Detailed notes and comments were made

in the margins of the transcript regarding initial remarks and thoughts, which were re-read to transform these initial notes into more specific themes and phrases (Shaw, 2010). Following recommendations to look for patterns and repetitions in the data (Ryan & Bernard, 2003), more specific labels were identified. Establishing connections between preliminary themes further reduced the data. The reduced data were then clustered into themes (Shaw, 2010) and clusters of themes were given a descriptive label that communicated the nature of the theme using direct quotation from the interviews. During the data analysis process, an audit trail was kept to maintain a record of coding methods, including inclusion and exclusion criteria for themes, and examples of quotes for each determined theme and sub-theme.

Results

Families raising children with FASD identified a number of coping strategies, supports, and transformational outcomes, which enable them to adapt to raising a child with FASD (see Coons, 2013a for Part I). However, families also highlighted areas of concern when caring for their children. During semi-structured interviews, parents and caregivers expressed that support in a number of areas would help in adapting to raising their children with FASD. Using IPA, five themes emerged from the interviews. These themes include more training for professionals, early knowledge of the disability, support for the child, support for the family, and more knowledge and awareness of FASD.

“Doctors and Nurses and Teachers All Need to be Educated”: More Training for Professionals

Although parents acknowledged that professionals were sometimes important sources of formal support (see Coons, 2013a), families frequently remarked that medical

professionals, educators, and law enforcement officers often lacked knowledge of FASD. A number of parents cited experiences of being around doctors who encouraged drinking during pregnancy. As Adrianna, a biological grandmother, stated, “Both my girls have fetal alcohol. I listened to what the doctor said, I never drank, the doctor said have a drink each night, it’ll help the baby sleep and you’ll get a better sleep. So I produced two fetal alcohol children. Those two have produced eleven fetal alcohol children.”

In addition to the promotion of consuming alcohol during pregnancy for relaxation purposes, some families discussed their experiences with doctors who did not understand the implications of FASD or did not believe in the diagnosis of FASD. As Patricia conferred in her interview, her daughter’s doctor never listens to her about Adelle’s strengths or weaknesses:

[The GP] always argues with me...“No, no, no. You know what? This does not apply. She does not have FASD.” Despite the diagnosis, every time I go in...“She is way too smart for this...this report card indicates that she has an A in this. She cannot have FASD.”...But...literally that was the fourth in town that I went to and he was the closest to understanding FASD.

Carmen also had a similar experience with a lack of professional knowledge from a doctor who refused to diagnose her granddaughter with FASD when Carmen first began exploring the possibility that Angelica might have FASD:

And so I took her to the doctor...and he just yelled at me. He said to me “look at her face!” And he had her do about three little things, motor skill things, and then he said, “Look at her face! This child is perfect. There is nothing wrong with this child. What’s the matter with you?”

In addition to difficulties with medical practitioners, parents noted a serious lack of knowledge amongst teachers and school professionals. Caitlin commented that she has to home school her daughter because educators “don’t know” about FASD. Caitlin went on to say, “I don’t know if it’s they don’t know or if they just don’t want to know or how to deal with it properly. To them it’s just a personality disorder, conduct disorder.” Along a similar line, many families remarked that teachers often perceived their children to be lazy or assumed they were being disobedient on purpose. For example, Robyn discussed her step-grandson Alexander’s difficulties in school once he reached the high school years,

Teachers really didn’t have any understanding of FAS and issues around that. He was...smoking dope, he was defiant, to say he was...threatening me with sharp objects...I mean, I talked to the principal, I talked to the teacher...I put together...an “Alexander operating manual” with information about FAS. I mean the teacher just thought he was being lazy and a goofball. They truly, truly didn’t get it.

Furthermore, Kendra and Nicoletta discussed the lack of knowledge of FASD in the legal system. Kendra, whose daughter Audrey had been arrested three times, mentioned the lack of knowledge from police officers in her region, particularly with regards to comprehending the implications of brain damage in individuals with FASD. For example, Kendra felt that the police in her region had no understanding of the discrepancy individuals with FASD often have between their receptive and expressive language abilities, which subsequently resulted in her daughter being arrested:

The police...don't really understand Fetal Alcohol Syndrome and how it can make them impulsive and instead they went into these situations going "Oh, it's a 12 year old and she's badly behaved so we're going to arrest her..." When the police deal with her, they see a child who can talk really, really well and use big words but they don't realize that she...doesn't understand what she's saying so she ends up getting arrested....They see her as some kid that's being bad.

Consequently, parents often reported feeling unsupported by professionals, because they felt as though professionals had nothing to offer in terms of practical solutions or appropriate interventions due to their lack of knowledge of the disability.

Because of this lack of knowledge, parents called for the education of professionals. As Stacey stated, "Doctors and nurses and teachers all need to be educated. And even if they think they don't need to be educated, they need to be re-educated. And that's such a big deficit. *Such* a big deficit." Parents also discussed the need to introduce the topic of FASD into school curricula. For example, Pauline stated that she wished to have more training offered in schools and Gabrielle argued for the need for more education, specifically in the medical school curriculum, "We need education. We need doctors to learn about it at medical school instead of the patient having to say, 'Well have you ever heard of it?' And him saying, 'Oh, you don't have to worry about it, it's only the first trimester so you don't have to worry.'" In addition to increasing the level of knowledge of FASD within the professional community, parents also expressed the importance of obtaining an early diagnosis of FASD. However, because of the lack of knowledge of the disability, obtaining an early diagnosis is often incredibly difficult for parents.

“If Kids are Intervened Early They Have a Better Chance”: Early Identification of FASD

Families expressed that it was not only important to receive the right diagnosis of FASD at an early age, but it was also essential to obtain early knowledge of the disability in order to implement appropriate interventions and promote understanding of the issues associated with FASD. Parents discussed in great detail the negative life outcomes associated with not receiving an early diagnosis. For example, Kimberly discussed individuals in her life that she has come across in her work with other families of children with FASD and was saddened by the negative life outcomes that occur as a result of lack of early intervention. Kimberly had exhibited first hand that without appropriate intervention, individuals with FASD and their families often experience hardship: “Without the support, and without the early intervention, and the early diagnosis, that’s the key. Without that, the older they get, the worse it is. The worse the outcome really, really is.”

The lack of appropriate early intervention was a reality for many parents in this study who now have adult children with FASD. Their children struggle with a number of secondary disabilities including severe mental health issues, alcohol and drug addiction, and involvement with the criminal justice system. Sally and Peter reflected on their experience of raising their two teenage sons with FASD and wondered about their parenting skills over the years, “But, that’s what it’s like now. It’s like feeling did you do the right thing? Were you a good parent? You know, you look at what you’re supposed to do...if kids are intervened early they have a better chance.” Jocelyn also described her feelings when she found out about her daughter’s FASD quite late in life and explained

that the damage was already done because it was too late to go back and employ appropriate interventions for Abigail:

I cried for a couple weeks after I read that article [on FASD] because the girl's expression on the face...all the ways that she acted, it just...made you feel sick because we had been barking up the wrong tree for such a long time and frustrating ourselves and Abigail all that time and she was then, I think she was almost 16...Very late [to get a diagnosis], yeah. Pretty hard to back pedal at that point.

Families therefore deemed early diagnosis and intervention as essential factors in improving outcomes for their children later in life and believed early diagnosis was critical in preventing the occurrence of many secondary disabilities. As Patricia remarked, obtaining the diagnosis of FASD early on is an important facilitator of identifying parenting strategies that work:

If I'd had [the diagnosis] from the beginning, we could have parented her properly from the beginning...So instead of punishing and doing stupid reward charts and things like that she's never gonna get anyways, what a waste of energy!...It also helps you to parent her, like I said,...it helps me to parent her because it's totally different. It's parenting apples versus oranges, right?

Caitlin also felt that having the diagnosis was essential to understanding her daughter's issues because, "When you understand what they're going through, then you're more receptive and accommodating to their needs."

“Nobody Really Knows What Our Kids Can Do When They’re Properly Supported Because Nobody’s Done it Right”: Support for the Child

Families also discussed the importance of having supports that were directly beneficial to their children. Families felt that if their children were properly supported, the family would also be supported. However, families frequently cited that actually obtaining appropriate supports for their child was a challenge. Whitney, a biological mother, described her experience of trying to navigate services for her son, Memphis, as being brushed off by a number of existing services whose employees felt that dealing with FASD was not part of their mandate:

So there’s no supports that we can access...everybody says it’s somebody else’s problem...Developmental services say no it’s not a developmental concern ‘cause most kids are not in the first percentile. And they say it’s a mental health issue.

And then mental health people say well no, it’s not. It’s...developmental.

When parents were asked what supports they would like, parents often responded that better supports for their children would be helpful for the family. Specifically, families believed that three supports would be essential for their children: help either obtaining or keeping a job, having a mentor, and having an assisted living arrangement or a safe place to live.

Many parents, especially of adult children with FASD, spoke of their child’s difficulty in maintaining employment. Parents found employers were often not willing to train or supervise their child. As Stacey described, employers often told parents that dealing with their children at work was more like babysitting than employment: “We’ve had one person after he was fired who just said to me ‘I’m not gonna babysit someone.’”

So...there has to be...some way that you can actually find work for these people and find out who are the employers who will do that.” Jocelyn also discussed her daughter

Abigail’s trouble with employers:

She is more than willing to work and there are many, many things that she can do....But there are factors in FASD, behavioural factors, which render a lot of people affected unable to keep their work....So if somebody can stock shelves and they can clean dishes and they can waitress...but they have a hair trigger or they occasionally let loose with a string of expletives that would turn your hair blue, at the wrong time, in the presence of the public that you’re supposed to be polite to or if they steal...they cannot be employed.

In addition to obtaining employment, parents identified the need to have someone around their child who was trustworthy and could serve as a role model. Many parents wanted their child to have more friends, especially good quality friends who would help to keep them out of trouble. As Gabrielle stated, individuals with FASD need positive influences in their lives who will help them make better decisions: “They need one-on-one support. She needs a really good best friend that would say ‘No Brigit, we’re not going to go to Bingo tonight and spend that kind of money...She needs a good example. She needs a good role model. All her role models are druggies and people with all kinds of kids with different fathers...That’s her life.” Parents, such as Faith, wished there was someone who could help their child find a job: “So it would be nice if there was an agency that you could call and say ‘She’s looking for a job, just a part-time job, just to help her to get into the work, to understand what working life is like.’ That I would love to have right now.”

Parents and caregivers further wished that there could be some sort of semi-independent housing situation where their child could reside in adulthood. Although many parents of adult children with FASD discussed this issue, several parents of young children with FASD also expressed their hope that these arrangements would be in place once their child reached young adulthood. Robyn believed an assisted living arrangement would be perfect for her step-grandson, especially if there could be someone around who was knowledgeable about FASD and could assist with the everyday sort of tasks, “The perfect thing for Alexander...would be some kind of low level assisted living...But something where there’s help...doing those boring, basic things...I asked him to change a light bulb in his room. Well what did he do? (*Laughs*) Tried to unscrew the whole fixture.” Sally and Peter also agreed that a semi-independent living arrangement would be perfect for their two teenage sons as they progress into adulthood, and hoped that the situation would involve some kind of an independent room within a larger apartment where staff could check in and ensure that their sons took their medications, kept up with personal hygiene, and contributed meaningfully to society.

“Safe, Appropriate Respite”: Support for the Family

In addition to the need to put supports in place for their child, parents also indicated the need for family support, particularly respite. As Joseph, an adoptive father to Jewel, remarked, “you can’t just give a child with FASD to anybody to babysit! They gotta know about FASD themselves.” This was a widespread sentiment among families in this study, who indicated that it was almost impossible to find someone they felt comfortable leaving their children with. For example, Lacey discussed her experience in trying to find someone who was properly trained to provide respite for her two adoptive

children as incredibly challenging, because most individuals she came across were not educated about FASD:

Finding respite, people who can do respite, is incredibly challenging....You can't just have the 15 year old down the street come and hang out, even with Chantelle, you can't do that. You know she'll be up and into the scissors and cutting her hair or slicing off her fingers because she wants to cut her own fingernails...like it just can't be a normal teenager down the street. And so getting any time to have a break is pretty much impossible.

Like Lacey, many parents expressed difficulties in obtaining respite services. Parents, such as Ashleigh, were adamant that they should receive respite because "it's the only way to survive." Some caregivers, such as Patricia and Claire, who had limited respite available to them, also commented that they wished their worker could be available more often. Finding workers who were "trained, consistent, and committed" was important to families, especially to Nicoletta, who commented that you need a respite worker who is capable of dealing with the realities of a child with FASD:

You want somebody who is better trained or can be trained or knows your kids and you want to pay them for doing a job that is not babysitting....You need somebody that has a clue. You need somebody that's gonna know how to react in situations that your kids are gonna throw at them because your kids are gonna throw everything they can think of at them!

“When People Understand, Their Attitudes Change”: More Knowledge and Awareness of FASD

Families spoke in great detail about the lack of knowledge and understanding of FASD from those in the general public. Although this theme shares several similarities to the first theme regarding lack of knowledge amongst health care providers, families attributed different meanings to their encounters with the general public. Families expressed feelings of frustration with health care professionals because they expected practical solutions and support when dealing with their child. Families of children with FASD anticipated that their child’s doctors and teachers would be knowledgeable about FASD because of their extensive training and education. However, when it came to their interactions with their larger community, families discussed feeling isolated and unsupported. Families expressed feeling judged by those in their communities, and expressed their desire to have more education and awareness about the disability. Families shared many stories of encounters with neighbours who believed that their child was willfully being bad. Families also recited examples of receiving glowering looks from individuals in public if their child had an outburst at a restaurant or a grocery store. Additionally, families talked about the importance of education and awareness to promote prevention of the disability.

“Education is what it boils down to”: The need for education about FASD.

Education regarding FASD was an important topic to all participants in this study. Families frequently expressed that people around them did not even know what FASD was. For example, Kristen talked about a group of her friends, who are all mothers, and were all ignorant about FASD until she informed them what it was:

I want changes and these kids deserve that... You know, the awareness and prevention and all that. Like my friends, they didn't know. They all have kids, they were pregnant.... Nobody knows about FAS. "What's FASD?" And these are all mothers!

Adrianna, a biological grandmother, also reflected on the lack of information about FASD in her community, "And it's sad because there's not enough information out there. When the alcohol board came out with that poster about drinking and being pregnant, I wanted to do cartwheels."

Furthermore, many families found that because their child looks "normal", individuals in the community have trouble understanding that their child has organic brain damage. As Mandy and Joseph stated, "she looks normal. You expect her to be normal." Several parents compared FASD to autism spectrum disorder or Down's syndrome, highlighting the fact that many individuals on the spectrum do not look like they have a disability. As Stefanie, an adoptive mother to two teenage sons, argued, "I mean people just don't know enough about fetal alcohol and because it's such a wide spectrum, there's not one picture of it like you might get for Down syndrome." Lacey, an adoptive mother to two young children with FASD, also expressed a similar comment,

I hate using it, but if you say to somebody that your kid has autism, there's a sense of recognition of what that means, and a sense of "oh, so that's why he flips out sometimes." Or... "That's why he doesn't have any friends"... If you say to someone "my kid has fetal alcohol" they're like "what? What's that?" if they ask. And... even after you explain it there's still such a stigma attached to it and... such

an ignorance. You can explain it to the same person 5 times but they still don't know what it means, they still don't know what it's like to live with.

In order to better educate those in the larger community about FASD, participants such as Nicoletta identified the need to teach adolescents as early as elementary school about FASD in order to foster early learning, "More education as far as FASD goes, both from the beginning, like this is why you shouldn't drink when you get pregnant and starting in...grade 8 rather than grade 12." Several parents also discussed the implications of deterring women who may have problems with alcohol from drinking. As many parents argued, encouraging knowledge about the disability was an important step towards prevention of the disability. As Louis, a biological father, stated education is the most important thing:

Education, education, education is what it boils down to. I'd like to see it completely blanked out, but probably won't be. It's worldwide, you know...More awareness, more understanding of it. More deterrents to the pregnant women or alcoholics for them not to drink is the number one thing.

Kendra also discussed in great detail the need to promote an understanding of addiction issues. As a biological mother, she highlighted the importance of helping those in need rather than hindering them from coming forward:

A lot of my issues with FAS come from society in general. People need to stop judging those who made a mistake and drank when pregnant, as people that are horrible. They need to realize that drinking's an addiction; nobody sets out to harm their child. It's just the way it is and instead of judging them, offer them help...I see a lot of people talk about "Throw those in jail who drank when they

were pregnant.” That’s not going to help women... That’s going to make women hide their drinking and be even less likely to tell their doctors. There needs to be more, not telling a women it’s okay to drink when you’re pregnant, but more acceptance so that the women will feel safe to tell the doctor.

In addition to educating society on the implications of FASD and increasing the amount of existing information on FASD, families expressed the need to promote awareness of the disability.

“FASD is the white elephant”: A call for awareness. Similar to educating those in the general public about FASD, families articulated their desire to have those around them understand the disability. Many families shared that individuals around them often perceive their children to be acting poorly on purpose, or assume that their child is being “lazy”. Many parents also expressed feeling judged because people in the general community assumed their child was acting out of control as a result of their poor parenting skills. As Alyssa conversed, having a greater understanding of the disability would allow families and the individual with FASD to feel better supported: “Just a greater understanding [from people everywhere] so that they know people have this kind of a disability and it’s not their fault and it’s not... a blaming thing, it’s just how we better help them.”

In particular, many parents expressed that they wished those around them were aware of the behaviours that often accompany a diagnosis of FASD. Jade, an adoptive grandmother, shared, “The ordinary Joe on the street doesn’t understand, they look at Leona and think she’s a brat. So it’s difficult to find support from your neighbours for instance, people that don’t understand FAS or... children with neurological problems.”

Because of these multiple challenges, families called for a greater amount of support in their everyday lives and increased education about FASD.

Discussion

The authors of this qualitative study found that parents of children with FASD face a number of unmet needs, which contribute to their experience of parenting stress. Despite identifying strategies that enable families to successfully adapt to raising their child (Coons, 2013a), families appear to face additional stressors that are often out of their control, such as a lack of knowledge of the disability amongst health professionals. Despite the Public Health Agency of Canada's framework for action, in which they identify increasing public and professional awareness and understanding of FASD, as well as the impact of alcohol use during pregnancy, as their number one broad goal (Public Health Agency of Canada, 2003), awareness of FASD still remains low in the general population (Walker, Fisher, Sherman, Wybrecht, & Kyndely, 2005). Because of this lack of knowledge of FASD, many parents recommended the need for first hand and contextualized education of professionals. Particularly, families emphasized how critical it was to beginning educating individuals about FASD early and proposed adding more information about FASD to university and medical school curriculums. These recommendations are not surprising, given that they mirror existing findings in the FASD literature. Families frequently report barriers in getting help from support networks, medical and mental health professionals, schools, government agencies, and community organizations (Sanders & Buck, 2010). Furthermore, families report that the stressors of raising a child with FASD do not originate internally within

the family, but rather are often the result of limited support in their community (Sanders & Buck, 2010).

Given the rise in average class sizes and the lack of funds in education, providing training for teachers to properly deal with children with FASD or other neurological disabilities may pose a challenge. However, low-cost options may be feasible, such as reading Internet resources or existing published documents from many FASD organizations. Additionally, many families who view themselves as their child's advocates discussed their willingness to go into the schools and educate both teachers and students on the implications of FASD. In fact, several parents in this study described giving lectures about FASD and printing and providing their child's teachers and principal with information on FASD.

Furthermore, researchers have indicated mixed results regarding level of knowledge of FASD amongst health care providers, with some studies demonstrating that professionals, such as psychologists and general practitioners, tend to have limited knowledge of FASD (e.g., Nevin, Parshuram, Nulman, Koren, & Einarson, 2002; Peadon, O'Leary, Bower, & Elliot, 2007; Wedding et al., 2007; Whitehurst, 2011). However, other researchers have identified that health care professionals do have knowledge of FASD (e.g., Anderson et al., 2010; Gahagan et al., 2006; Zoorob, Aliyu, & Hayes, 2010), but this level of knowledge of FASD varies depending on the type of health care provider group (Brems, Boschma-Wynn, Dewane, Edwards, & Robinson, 2010). This lack of knowledge is disturbing, given that health care providers are crucial in harm reduction and identification of women who may be at risk of having a child with FASD or may need interventions beyond primary prevention (FASD Regional Training

Centers Consortium, 2007; Peadon et al., 2007; Sarkar et al., 2009). It is therefore imperative that professionals increase their knowledge and understanding of FASD, including the physical, neurological, and behavioural features of FASD, in addition to the collective family experience. The findings from this study contribute to the understanding that professionals still demonstrate a lack of knowledge about FASD. However, the families in this study are the most qualified and knowledgeable individuals about the realities of raising a child with FASD and professionals can be educated by listening to their stories. This study therefore highlights the importance of listening to families of children with FASD in order to capture the complexity of their lived experience and furthers the findings that families of children with FASD often feel unsupported and underserved.

Families also described the importance of obtaining support for their child and for themselves. Families shared their concerns about their child's future, and hoped that there would be resources in place to help their child live in a safe, supported living environment. Adults with FASD require tremendous support to be part of their community; however, most have few supports other than family members or friends (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008). Not surprisingly, adults with FASD who have a history of addictions, sexually inappropriate behaviour, and confinement in prison or a psychiatric hospital often have difficulty with community integration (Clark et al., 2008). With appropriate supports throughout the lifespan, individuals with FASD may be able to avoid the development of these secondary disabilities.

Additionally, in order to effectively support a child with FASD, parents and caregivers need considerable support of their own (Rowbottom, Merali, & Pei, 2010).

Regardless of the type of respite families preferred, all families expressed a strong desire to obtain “safe, appropriate respite.”

Research has indicated that families are often unsatisfied with the services, particularly respite, that they receive (Caples & Sweeney, 2010; Doig, McLennan, & Urichuk, 2009; McGill, Papachristoforou, & Cooper, 2006) and providing families with respite care, especially those of children with FASD, is often lacking (Olson, Oti, Gelo, & Beck, 2009). However, providing families with respite is likely to help in reducing caregiver stress by promoting parent self-care.

Early knowledge of the disability was also essential in order to understand the behaviours associated with FASD, and therefore adapt appropriate strategies for parenting. The development of the ability to both understand and care for individuals affected by FASD begins with obtaining a diagnosis (Devries & Waller, 2004). One of the main purposes of receiving a formal diagnosis is to develop an appropriate intervention strategy, but many families, especially adoptive families, are often unaware of their child’s disability. Furthermore, without early knowledge of the disability, many families report employing parenting strategies that simply do not work, as individuals with FASD have a number of executive functioning deficits (Rasmussen, 2005). Acquiring a formal diagnosis before the age of 6 is often critical in preventing the development of secondary disabilities (Chudley et al., 2005; Streissguth et al., 2004), but many families in this study, particularly those with now adult children, discovered that their child likely had FASD in their teenage years. Furthermore, similar to families in this study, Ryan and Ferguson (2006) found that parents expressed the sentiment that “If I

knew then what I know now” (p. 371), their parenting strategies and expectations would have been altered.

Finally, all families in this study expressed their concern that those in the general public were not informed about FASD. Furthermore, many biological parents discussed additional stressors that were associated with the lack of community knowledge and awareness of the disability. For example, many biological mothers shared their experiences of being blamed by those in the general public who deemed them as bad people because of their alcohol consumption during pregnancy. Multiple biological mothers shared their stories about their struggles with addiction and reflected that those around them had very little understanding of issues encompassing addiction. An important implication with regard to biological mothers is the lack of understanding of addiction issues. Many mothers who may struggle with addiction cannot stop themselves from drinking during pregnancy, regardless of how much they may know about FASD, and need help from trained professionals. Moreover, women who drink during pregnancy are not a homogenous group, and include women who are alcohol dependent, women who use alcohol on an episodic basis, and women who drink infrequently or regularly at low amounts (Coons, 2013b; Public Health Agency of Canada, 2007). Social, psychological, and biological factors all contribute to a woman’s risk of drinking during pregnancy, and may include genetic factors, familial and demographic factors, and cultural influences (see Coons, 2013b for a review).

When parents were asked what would be helpful to them, many parents expressed that they would like education. Breanne stated, “That’s what I want, I want education...Educating everybody about this is what I [want], magic wand, everybody

knows about it!” Percy, an adoptive father, also summed it up nicely when he said, “Understanding is the key. Education is the answer.”

However, previous research has identified a gap between general awareness of drinking during pregnancy and knowledge of FASD. Salmon (2008) found that although there may be a general awareness in the public of adverse effects of alcohol consumption during pregnancy, very few people know specifically about FASD. Additionally, public awareness campaigns have been designed to raise knowledge about the risks of using alcohol during pregnancy. For example, the Best Start Resource Centre launched an awareness campaign called “Be Safe” in Ontario in 2004 that was successful in raising awareness to stop alcohol use during pregnancy (Burgoyne, Willet, & Armstrong, 2006).

Conclusion

Understanding the particular issues and challenges that families of children with FASD face is essential in developing, improving, and implementing appropriate and effective services for parents and their child with a disability. It is worth noting that although families of children with FASD discuss specific stressors, increased parenting stress does not necessarily indicate family pathology or maladaptation (Keller & Honig, 2004), but rather alerts experts to situations that may need attention, including assistance in obtaining medical, health, or educational services for both themselves and their child. The current study displays a clear need for more supports for families, particularly in the areas of receiving respite and increasing public and professional knowledge about the realities of raising a child with FASD. Despite acknowledgment that drinking during pregnancy has lifelong negative outcomes, parents reported that doctors and midwives in Ontario still affirmed that it was acceptable to drink while pregnant and one adoptive

mother reported, "...Doctors, even now, some of them say 'oh, well, a sip or two is okay.' And...it isn't, any amount is not okay." Until families are provided with adequate supports and knowledge of FASD amongst professionals and the larger community increases, successful adaptation will still be a gravely difficult task for families raising a child with FASD.

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Chapter 4: Conclusion

The aim of this paper-based thesis was to contribute to our understanding of the lived experiences of parenting a child with Fetal Alcohol Spectrum Disorder (FASD), with a particular focus on family adaptation. In this chapter, findings from the two studies contained herein are summarized and framed within the larger project of which they are a small part. The three research questions presented in chapter one are discussed and the application of a theoretical model of family resilience, such as the Family Adjustment and Adaptation Response Model (FAAR; Patterson, 1988; 2002; Patterson & Garwick, 1994a, 1994b), is discussed. This chapter concludes with suggestions for future research as well as clinical and practical implications.

4.1 Summary of Findings

The first article titled “Facilitators of adaptation in families raising children with fetal alcohol spectrum disorder part I: What has helped” employed a qualitative analysis to examine the experience of successful family adaptation. Families of children with FASD play a vital role in the lives of individuals affected by FASD, yet little is known about how the experience of raising a child with FASD affects the family (Watson, Coons et al., 2013; Watson, Hayes et al., 2013). Researchers have called for systematic investigations that address the factors that are critical for family adaptation (Olson et al., 2009). Informed by the FAAR model (Patterson, 1988, 1989; Patterson & Garwick, 1994a), and following a basic interpretive approach (Merriam, 2002), drawn from phenomenology and symbolic interactionism, semi-structured interviews were conducted with 82 parents and caregivers of children with FASD. Interview transcripts were

analyzed using interpretative phenomenological analysis (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith et al., 2009). The findings from this study indicate that although parents and caregivers raising children with FASD experience a great deal of parenting stress, family members also report a number of coping strategies, supports, and transformational outcomes. Five themes were identified from the analysis comprising: understanding FASD and advocating on their child's behalf, the need for routine and choosing appropriate battles during the daily management of their child's FASD, focusing on the positives of their child, informal supports, and formal supports.

Understanding what parents do in order to successfully adapt to rearing their child with FASD is pivotal in aiding families who are not adapting as effectively. Although the results presented in this article focused on strength-based, positive outcomes for families, not all participants in the current study displayed characteristics of successful family adaptation. Furthermore, although this study addressed the need to inspect specific facilitators of adaptation, a number of limitations presented, including the fact that caregiving couples were interviewed together and many participating families were from Caucasian, affluent families. Therefore, the author of this thesis cautions about the transferability of these findings to other parents of children with FASD and suggests that more research is warranted to examine differences between mothers and fathers, as well as amongst different ethnic and socioeconomic status groups.

With regard to parenting and family adaptation differences between mothers and fathers, it is also important to acknowledge differences in the gendered experience of care responsibilities in the home. Fathers of children with developmental disabilities have a long history of being perceived as a 'peripheral parent' (Herbert & Carpenter, 1994), an

‘invisible parent’ (Ballard, Bray, Shelton, & Clarkson, 1997), or a ‘distant dad’ (Barker, 2011). Because of these long standing beliefs, fathers have often been overlooked and excluded from research examining the lived experiences of families raising children with developmental disabilities (MacDonald & Hastings, 2010). However, shifts in social and societal beliefs have meant that fathers are even more involved and affected by the nurturing and caring roles for their child with a developmental disability.

Increased labor force participation of women and loosening expectations that mothers will automatically assume the role of primary caregiver has meant that fathers are more involved in the rearing of their child. Furthermore, the deinstitutionalization movement of individuals with developmental disabilities saw the return of care for children and young adults with developmental disabilities to their families (Braddock, Emerson, Felce, & Stancliffe, 2001). While progress has been made in acknowledging that father’s experiences are likely different from mother’s experiences, advancement in the field is still needed to clarify and reach a consensus on how fathers and the fathering roles are defined in research (MacDonald & Hastings, 2010).

Early work by Lillie (1993) suggests that a number of factors mitigate father involvement in the care of their child with a developmental disability. For example, fathers were often uncomfortable with female-dominated services and role differentiation between parents did not facilitate contact between the child and the father. Furthermore, because most programs or meetings took place during daytime hours, fathers were often excluded due to conflicts with their working lives. Trouble being involved with their children during the day is not surprising, given that researchers have shown that fathers are much more likely to work full time compared to mothers. For example, Warfield

(2005) demonstrated that 94.1% of fathers worked full time or more compared to only 23.5% of mothers, meaning that mother's careers are disproportionately affected by having a child with a developmental disability (Baker & Drapela, 2010). Expectations of mothers are typically focused on the internal dynamics of the family, whereas fathers are more likely to focus their expectations on the wider world, primarily through their work (Pelchat, Lefebvre, & Perreault, 2003).

While family members frequently look to the father for support, the father's own needs often go unrecognized or are seen as less of a priority than those of the child or the mother (MacDonald & Hastings, 2010). Findings from Trute and Hiebert-Murphy (2005) indicate specific experiences for father adjustment and parenting stress over time. One unique finding in their study was that parenting stress over time for fathers was associated with their parenting morale (e.g., enthusiasm or confidence regarding a specific parenting function or task; Trute & Hiebert-Murphy, 2005). Therefore, the authors caution the interpretation that the process of adaptation is the same for both mothers and fathers of children with FASD.

The second article titled "Facilitators of adaptation in families raising children with fetal alcohol spectrum disorder part II: What would help" is a continuation of the first article presented. While the first article focuses on the factors that families report as helpful in their experience of raising their child with FASD, the second article discusses stressors that hinder family adaptation. Employing the same methodology as the first article, five themes were identified including: the need for more training for professionals, early knowledge of the disability, support for the child, support for the family, and more knowledge and awareness of FASD in the general population.

This article was an effort to frame parenting stress within the broader context of the family experience, particularly with regard to family adaptation. Although families discussed these five themes as stressors, families also provided recommendations as to how the impact of said stressors could be alleviated. Researchers have concluded for decades that the experience of increased parenting stress is a direct cause of the child's challenging behavioural characteristics. These findings have been demonstrated in the FASD literature (e.g., Paley et al., 2006); however, families of children with FASD also report that the stressors of raising their child do not originate internally within the family, but rather are often the result of limited support in their community (Sanders & Buck, 2010). The current study provides further evidence that individuals in both the professional community and the general population are often ignorant about the implications of FASD.

In summary, the findings presented here have addressed two of the research questions by contributing the following results: 1) The lived experience of parenting a child with FASD is complex for families living in Ontario, Canada. Families experience significant parenting stress, but cite that many of their stressors are caused by a lack of understanding of the disability in their communities. Despite the unique aspects of the disability and the experience of parenting stress, families are able to employ a number of strategies to aid them in raising their child with FASD. Most families are clearly able to balance their demands (e.g., stressors) with their capabilities (e.g., educating themselves about FASD, becoming advocates, managing day-to-day, focusing on the positives of their child, maintaining a spiritual outlook, and accessing informal and formal supports), in order to bring about successful family adaptation. 2) The problems faced by families,

as well as the strategies they utilize, were very similar regardless of family structure (e.g., adoptive, foster, biological). However, unique differences exist with regard to the meaning parents ascribe. For example, when discussing the theme “I wouldn’t change it for the world”, divergences existed between adoptive and biological families. Kendra, a biological mother, discussed that she felt her daughter had saved her life because she had kept her sober, whereas Jennifer, an adoptive mother, felt her son had saved her life because she was unable to have a biological child of her own. Although both parents used the phrase “I wouldn’t change it for the world”, there were different meanings behind the use of that phrase. A similar difference was also evident within the theme “When people understand, their attitudes change.” Biological parents, and biological mothers in particular, faced additional challenges when it came to obtaining understanding from the community. Biological mothers often reported feeling judged and demonized by those around them because they were the ones who drank during their pregnancy. Along the same lines, biological parents often had to contend with additional feelings of guilt and self-blame as a result of their child’s disability. However, adoptive parents often described their own sense of mourning over the child they thought they may have had at the time of adoption. The third research question, which was not addressed in either article, is discussed below.

4.2 Regional Differences Impact on the Lived Experiences of Families

This project also examined regional differences in Ontario, Canada. The availability of services, particularly in rural regions, has been described as a challenge. Research investigating rural and urban differences in services across Canada have identified that many areas that experience higher prevalence rates of FASD, such as rural

areas of Northern Canada, often have few professional services available (McFarlane, 2011; Nevin, Parshuram, Nulman, Koren, & Einarson, 2002; Sanders & Buck, 2010). Despite recommendations encouraging early identification to prevent the development of secondary disabilities, many individuals affected by FASD do not receive a diagnosis (Chudley et al., 2005; Rowbottom, Merali, & Pei, 2010). This deficit in obtaining a diagnosis is largely due to the lack of clinicians available in Canada, as well as the lack of multi-disciplinary diagnostic professionals and services (e.g., medical, neurodevelopmental assessments, behavioural assessments, and psychological assessments) in rural and remote regions (McFarlane & Rajani, 2007). Additionally, families report travelling great distances to obtain a formal diagnosis for their child (McFarlane, 2011; McFarlane & Rajani, 2007; Watson, Hayes et al., 2013). Furthermore, even where services might exist, coverage and access is uneven and often does not extend to rural or remote communities (Salmon, 2008).

Investigators in the field of FASD have stated that it is important to provide parents with information about specific local resources and services that they can access for their child's health care, social needs, and academic needs (Rowbottom et al., 2010). However, as was found in this study, parents of children with FASD in Ontario report tremendous difficulties in locating and obtaining services for both themselves and their children. Families across Ontario discussed the lack of services available to them, indicating that it is not just rural regions that are reporting being underserved. Many parents shared observations similar to Mabel, an adoptive mother to Rachelle, in that "they're better out West than they are here. Ontario's about the slowest province there is." Many parents wished for the knowledge and awareness of the disability that other

provinces, particularly British Columbia, Alberta, and Manitoba, have regarding FASD, as all of these provinces have provincial mandates for dealing with FASD (Koren, 2012). Koren (2012) has argued that it is a myth that Ontario is far behind other provinces; the reality being that the difference is simply that Ontario does not have a formal strategy for dealing with FASD which subsequently contributes to the misuse of services and resources. Nonetheless, parents reported feeling as though Ontario is struggling in its initiatives regarding FASD.

In addition to challenges obtaining services across Ontario, parents reported personal challenges that did not differ based on their regional location. Parents in rural and urban locations cited examples of both strengths and weaknesses of their area. For example, many participants in rural locations believed that it was easier to keep their child with FASD out of trouble. Because their community was smaller, parents felt that they could keep a closer eye on their child to ensure they did not run away or get in with the wrong crowd. For example, as Robyn discussed,

I think one of the factors that's really been significant for Alexander doing as well as he is, is the fact that we do live in a...small community....Limited range of things to get into trouble doing. Everyone knows you. It's a tight knit community; it's 700 people. It's like a small town.

However, smaller communities were also an issue for some families, such as Lily and Stefan, adoptive parents to Molly:

I think we're in such a down period of our lives because...we live in a small community, she had had altercations in two small communities, and so...the

police [were] involved and there were a lot of people phoning us about her behaviour...and the school had been constantly phoning about her behaviour. Lily and Stefan went on to elaborate about how their daughter's escalating behaviours in the community caused issues with their community, predominantly with their neighbours. Families who shared experiences comparable to Lily and Stefan's discussed feeling ostracized and judged by those in their communities because of their children's behaviours. The central finding here is that parents and caregivers of children with FASD share many of the same common issues, regardless of their rural or urban location, as well as their regional location (e.g., Northern Ontario, Ottawa region, Central Ontario, etc.) across the province.

4.3 The Larger Project: A Discussion of the FAAR and the Importance of Theory

This thesis was a small part of a larger project examining the experience of family resilience and the challenges associated with raising a child diagnosed with a developmental disability, specifically FASD or autism spectrum disorder (ASD). The project was a mixed methods application of the FAAR, and included the administration of five questionnaires as well as a semi-structured interview. The five questionnaires included: the Parenting Stress Index, Short Form (PSI-SF; Abidin, 1995), the Questionnaire on Resources and Stress, Friedrich's version (QRS-F; Friedrich, Greenberg, & Crnic, 1983), the Family Crisis Oriented Personal Scale (F-COPES; McCubbin, Olson, & Larsen, 1991), the Family Resource Scale (FRS; Dunst & Leet, 1987), and the Hope Scale (Snyder et al., 1991). Findings from this thesis mirror findings from the on-going larger project, indicating that despite the presence of parenting stress, many families are in fact resilient. What follows here is a discussion of the

conceptualization of family resilience and adaptation, as well as an argument for the importance of theory in family research.

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 et al., 2011). Other researchers, such as Walsh (1998), have conceptualized resilience as the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful. Furthermore, resiliency can be viewed in different ways, such as the interaction of risk and protective factors (Rutter, 1987) or as a flexible process indicating the family's strength at different points during the lifespan and within different circumstances (Walsh, 2003). Patterson (2002) contends that the FAAR is a model of family resilience because it emphasizes the dynamic progression by which families experience periods of adjustment and adaptation to a crisis. Patterson (2002) further argues that resiliency theory extends family stress theory, by recognizing that many families overcome crisis through the process of adaptation, resulting in more competent family functioning. However, it is impossible to discuss family resilience without also discussing family stress, as well as the theoretical conceptions of what these terms mean.

According to Lavee, McCubbin, and Patterson (1985), the relationship between the stressful event, the outcome of stress, and the intervening factors between the two (e.g., coping resources and the utilization of resources) are the three basic phenomena that have been used to explain a family's response to stressful situations. The FAAR model has been described as 'the best of both worlds' because it encapsulates elements of both crisis theory and family stress theory. The family is a dynamic system of interdependent parts, and the family system is constantly characterized by change (Head

& Abbeduto, 2007). Within this family system there exists family structure (e.g., organizational patterns and boundaries) and family functioning (e.g., connections between members, level of cohesion and flexibility, problem-solving style). When families experience stress, the homeostasis of the system is interrupted, forcing togetherness and individuality to come into contact, and perhaps conflict. The manner by which parents adapt to the experience of caring for a child with a disability is generally thought to depend upon a range of variables, typically conceptualized within multi-dimensional models (Hassall & Rose, 2005) such as the FAAR.

Excessive demands deplete parents' resources, creating a pile-up of demands. Following in line with the conceptualizing 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 were optimistic, tended to show 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 regards to intervention development (Manning et al., 2011; Orr, Cameron, & Day, 1991).

However, much of the literature on families has not been grounded within a theoretical framework (Turnball et al., 2007). Of the studies that include a guiding theoretical framework, many of the studies have inconsistencies with regard to the definition and operationalization of key terms and concepts (Turnball et al., 2007). In order for a concept to be scientifically meaningful, it must be part of an implicit or explicit theoretical framework (Pedhazur & Schmelkin, 1991). In the case of family

research, a parents' ability to ascribe meaning to their situation significantly influences their experience. Turnball and colleagues (2007) published one of the most relevant studies regarding the use of theory and family research and found that studies that used the terms well-being, adaptation, and family functioning in their title often use the terms interchangeably throughout the article. For example, synonyms for well-being included adjustment, adaptation, family functioning, and psychological distress. Only 25.0% of studies focusing on well-being described a conceptual framework and the conceptual definitions were typically implied by the focus of the variables and the instrumentation applied in the study.

Furthermore, the literature has yet to provide a concrete definition for the terms coping, resilience, and adaptation, and the three are often used interchangeably to refer to the same concept. A review of the literature by Ylvén, Björck-Åkesson, and Granlund (2006) indicated that previous studies investigating problem solving, family sense of coherence, and positive coping have conceptual roots in different sets of theories, with a high level of consensus among researchers as to how the concepts should be defined. However, no similar agreement or strict definition for adaptation was noted. Therefore, researchers have called for substantial work in the field to define family outcomes and move these definitions to conceptual frameworks and theory. By basing research within an appropriate theoretical framework, researchers can obtain findings that are relevant to families, as well as facilitate the operational definitions of terminology (Turnball et al., 2007; Watson et al., 2011).

The FAAR model provided the overarching framework for the investigation of the experience of families of children with developmental disabilities in Ontario. Based

on the three components of the FAAR, demands were measured by the experience of parenting stress (e.g., PSI-SF, QRS-F), capabilities were measured by presence of family resources (e.g., FRS) and the coping behaviours utilized (F-COPES), and meanings were assessed by the experience of hope (the Hope Scale; Hayes, 2012). As part of this thesis, demands were also measured by the presence of challenging behaviours (Child Behavior Checklist; Achenbach, 1991; Achenbach & Rescorla, 2001) and capabilities were measured by the ability to which a family's needs were met (Family Needs Scale; Dunst, Cooper, Weedldreyer, Snyder, & Chase, 1988; Dunst, Trivette, & Deal, 1988). Demands, capabilities, and meanings were also addressed in the semi-structured, qualitative interviews, as the questions were informed by the FAAR model. Therefore, the application of the FAAR as an overarching theoretical framework in this study is a strength as it unites the investigation of both family stress and family resilience. By combining the study of family adjustment and adaptation within a theoretical framework, researchers can generate findings that are relevant for parents. Applying a theoretical framework facilitates the operational definition of key terms, which is particularly important when it comes to explaining family adaptation, as researchers have still not agreed upon a strict definition for adaptation (Ylvén et al., 2006).

However, a potential limitation of using the FAAR is that (almost) all of the families included in this project could be defined as successful families because most of them displayed evidence of achieving family adaptation as demonstrated in the two papers included herein. Recruiting strong and resilient families is not uncommon in research pertaining to human participants, as it is often difficult to access hidden populations (Salganik & Heckathorn, 2004) and those parents who choose to participate

are likely not experiencing additional demands that would prevent them from participating. Although a potential limitation, researchers have discussed that investigations of successful family resilience would benefit from examining well-functioning families in order to identify strengths (Patterson, 2002).

4.4 Summary and Future Directions: Fetal Alcohol Spectrum Disorder and Family Adaptation

As an application of the FAAR model to the experience of families raising children diagnosed with FASD in Ontario, Canada, this thesis has provided evidence for the factors that facilitate and hinder successful family adaptation. This study has addressed identified gaps in the literature, examining both the common experiences and special benefits of parenting a child with FASD, the crucial factors and qualities that promote positive adaptation, and regional differences in the experience of parenting a child with FASD (Morrissette, 2001; Olson et al., 2009). Moreover, this study has also provided additional evidence that families frequently express their frustrations with the lack of knowledge of FASD outside of the FASD community. Unfortunately, even though significant advances have been made in knowledge acquisition, education, and prevention, prevalence rates of FASD are little changed and surprising amounts of misinformation regarding alcohol consumption and pregnancy still exist (Gearing, McNeill, & Lozier, 2005; Paley, 2009).

A point that warrants further discussion is the presence of multiple children with FASD in 23 of the 59 families that participated in this project. Eighteen families had at least two children with FASD; one family was raising three children, one family raising five children, one family raising six children, and two families raising seven children

affected by FASD. Furthermore, two families also reported caring for over 20 and 100 children respectively at various times over the years. The majority of families raising multiple children with FASD were adoptive or foster families (or both). However, two of these families were adoptive families that were also biological grandparents to the children with FASD who expressed the importance of keeping their grandchildren in their family. The capability of so many families to choose to raise multiple children with FASD speaks to their aptitude to transform into a successful, fully functioning family, achieving adaptation. As June, a biological grandmother, stated “I mean, I look at Shyanne now and she’s come such a long way and...it’s positive...I think now, with Shyanne at the stage she’s at right now, we want to open our home to more children.” Although larger families are typically thought of as a risk factor in developmental research for those with typical development, the presence of multiple children with a disability may actually be a protective factor and facilitator of adaptation in families raising children with disabilities, such as FASD (Olson et al., 2009). Families raising multiple children with FASD may in fact serve to promote peer support and facilitate the accumulation of family resources.

4.5 Ensuring the Quality of Qualitative Research

Researchers have argued for the need to move beyond the ‘need to explain’ qualitative methodologies and shift away from the influence of positivist ideas (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2011). However, it is important to acknowledge the value of listening to families and compiling common experiences (Devries & Waller, 2004). The research study contained herein provides evidence for the power of listening to the stories of families. Families who participated in this study were

very excited to share their stories. Having families discuss their experiences is important because a vital source of knowledge on the importance of family affairs are the thoughts of families affected by FASD themselves, which often provide direction for future research (Olson et al., 2009). Furthermore, understanding the needs of families is critical in developing appropriate interventions that will be useful for families. As Orr and colleagues (1991) affirmed, all too often interventions for families of children with disabilities become “a case of putting the cart before the horse, or, in this instance, putting the resources before the need,” (p. 449). They strongly believe the solution to be listening to families and exploring their perceptions of their child, the disability, and how it affects the family. Once this has been accomplished, then family and professionals can discuss the use of resources that appear warranted, increasing the effective use of resources and adaptation in families (Devries & Waller, 2004; Orr et al., 1991).

Several researchers have addressed the issue of judging reliability and validity in qualitative research (Guba & Lincoln, 1989; Lincoln & Guba, 1985), but many researchers have differed on the definitions of these concepts. Seeing as the terms reliability and validity refer to criteria for quantitative researchers, qualitative paradigm terms such as rigor, trustworthiness, credibility, consistency/dependency, and transferability have been proposed as terms for judging the quality of qualitative research (Davies & Dodd, 2002; Healy & Perry, 2000; Lincoln & Guba, 1985; Mishler, 2000; Seale, 1999; Stenbacka, 2001). Without rigor, research becomes “worthless, becomes fiction, and loses its utility” (Morse, Barrett, Mayan, Olson, & Spiers, 2002, p. 14). Trustworthiness has been defined as how well a particular study does what it is supposed to do (Merriam, 1995). Principle issues related to trustworthiness include authenticity

(i.e., representation of the findings), coherence (i.e., how the findings are presented), and permeability (i.e., contribution of the researcher's perspective to the interpretation) (Fossey et al., 2002). Therefore, a number of strategies were undertaken to ensure the trustworthiness of the current study.

Reliability and validity of the semi-structured interviews was ensured through triangulation (Golafshani, 2003; Mathison, 1988; Shenton, 2004) and member checking (Brewer & Hunter, 1989; Lincoln & Guba, 1985; Shenton, 2004). Patton (2002) suggests that triangulation strengthens qualitative studies by combining methods (both qualitative and quantitative), as was done in the current study. Involving the participants in member checks also allowed the researchers to ensure honesty in the informants' responses (Guba, 1981; Shenton, 2004). Member checks involved relating the accuracy of data "on the spot" (during the interview itself) to clarify information (Shenton, 2004), as well as verification of emerging themes with participants (Brewer & Hunter, 1989). Frequent debriefing sessions between myself and my supervisor also allowed for recurrent discussions regarding the study since collaborative discussions can allow the vision of the investigator to be widened as others bring their experiences and perceptions to the table (Shenton, 2004). Discussion meetings allowed for reflections and discussions of flaws in the proposed courses of actions, and these meetings therefore further contribute to the credibility of this research study.

Furthermore, when using IPA, a successful analysis is interpretative (i.e., subjective) so that the results are not given the status of fact and transparent (i.e., grounded in examples from the data) as was done in the two manuscripts included herein (Reid, Flowers, & Larkin, 2005). Transparency of the results and reflexivity in the

interpretation process have been suggested as good benchmarks for judging the quality of the research (Elliott, Fischer, & Rennie, 1999; Reid et al., 2005), and I strived to meet these criteria while completing this project.

4.6 Suggestions for Future Research

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, 2002), as adaptation is an on-going, cyclical process, describing transformation over time. Because the family is a social system, the child's disability and the family's overall functioning are continually interacting, and families may need to alter their established patterns of behaviour and capabilities over time when new demands arise (Patterson, 1988, 1989; Patterson & Garwick, 1994a, 1998). To date, limited longitudinal research has investigated the life course outlook for individuals affected by FASD and their families (see Coons, in press). However, it is important to understand the process of family adaptation over time for families raising children with FASD as there are different considerations across the life course, such as when a family first discovers that they have a child with FASD, contending with the development and emergence of secondary disabilities, and when parents are aging and must consider the future of their child with FASD (Gardner, 2000; Olson et al., 2009; Ryan et al., 2006; Watson et al., in press; Watson, Hayes et al., 2013).

Future research should also examine the shared experience of different family structures raising children with FASD. As was found in this study, many of the stressors and strategies that parents from various family types discuss are often the same or

similar. However, previous research has often looked at the experience of adoptive parents, foster parents, and biological parents of children with FASD separately (Brown et al., 2005; Brown, Sigvaldason, & Bednar, 2007; Morrissette, 2001; Salmon, 2008). While it is important to acknowledge that unique differences do exist, especially for biological parents, it is also important to identify common experiences of parents of children with FASD. Biological parents of children with FASD frequently express feelings of isolation, and identifying shared experiences may be an important step in providing more parent to parent support for biological parents.

In addition to identifying shared experiences for parents, future research should seek to uncover the experience of grandparents raising grandchildren with FASD. Increasing numbers of children with disabilities are being raised by grandparents in the absence of the parental generation (Heller & Ganguly, 2002), yet these families remain underrepresented in the literature (Force, Botsford, Pisano, & Holbert, 2000). Raising children with FASD clearly poses difficulties to any family; however, grandparent caregivers likely experience specific challenges associated with raising multiple generations suspected of having FASD (Clement, Coons, & Watson, 2013). To the author's knowledge, no published study has identified the experience of grandparents raising grandchildren with FASD.

Finally, future research should seek to determine the level of knowledge that both professionals and the larger community (e.g., individuals who are 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, such as doctors, mental health practitioners, and teachers. Existing research in the field has demonstrated conflicting

evidence regarding how much knowledge professionals have of FASD (e.g., Anderson et al., 2010; Brems, Boschma-Wynn, Dewane, Edwards, & Robinson, 2010; Peadon, O’Leary, Bower, & Elliot, 2007; Wedding et al., 2007). For example, researchers have demonstrated that very few practitioners in the health, education, social services, and justice systems have a working knowledge of the effects of FASD (Nevin et al., 2002). Understanding how much knowledge 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.

4.7 Knowledge Translation and Mobilization

An important component of conducting research is also the process of knowledge mobilization, whereby researchers move available knowledge (e.g., findings from formal research) into active use by bridging the gap between research, policy, and practice. An important part of this process is building relationships between research producers and the users through the use of networks, informal and formal events (e.g., conference presentations), and collaboration of resources. Although the results of this thesis will be published in an academic journal to facilitate and enable the accessibility of the impact of the research amongst researchers and professionals, knowledge translation must go beyond the use of academic publications. According to the National Institute on Disability and Rehabilitation (NIDRR, 2005) knowledge translation and mobilization refers to “the multidimensional, active process of ensuring that new knowledge gained through the course of research ultimately improves the lives of people with disabilities, and furthers their participation in society.” Therefore, dissemination of the research findings goes well beyond simply making research available through the traditional

methods of journal publication and academic conference presentations and involves a process of extracting the main messages and key implications from the research results.

Findings from this study will also be exchanged with colleagues and collaborative research project members who are stakeholders in the implications of this work.

Furthermore, the widespread use of the internet has provided a vehicle for dissemination of research to many individuals, including the families who participated in this project, who are vastly invested in the outcomes of these types of projects. By sharing the findings with FASD organizations, community leaders, and FASD advocates, research connections can facilitate reciprocal relationships between researchers and invested parties.

4.8 Clinical and Practical Implications

Understanding the particular strengths and challenges that families of children with FASD face is essential in developing, improving, and implementing appropriate and effective services for parents, as well as for the child with FASD. For the individual affected by FASD, implementing appropriate services as young as possible is extremely helpful in preventing secondary disabilities later in life (Chudley et al., 2005). By listening to families' struggles in fostering early identification of the disability and implementing interventions for their child, appropriate modifications can hopefully be made to ensure that children receive a diagnosis at an early age, specifically before the age of six years old (Streissguth et al., 2004). As families in this study reflected, obtaining knowledge of the disability earlier in their child's life would have been critical in educating themselves about appropriate parenting strategies.

Emphasizing the importance of focusing on the present and dealing with the day-to-day challenges is also essential. Professionals working with families should assist in making the reality of the day-to-day challenges more manageable for families and should provide specific recommendations and interventions that may make daily living easier for both the child and the parent.

There is also a need to promote knowledge of the positive benefits that their child with the disability brings to their lives for parents facing crisis (Helff & Glidden, 1998; Kayfitz et al., 2010; Scorgie & Sobsey, 2000; Scorgie et al., 2001). Professionals working with families should emphasize for parents the various types of positive benefits of raising the individual with FASD, helping to promote positive parenting views, and positive cognitive appraisal especially for parents experiencing clinical levels of parenting stress (Olson et al., 2009). Individuals working with families of children with FASD should be also aware of the meaning making process in order to help families make these processes clear and hopefully more adaptive. Furthermore, professionals and service providers should adopt a family-centered approach to providing services, using collaborative and strengths-based methods that view the family as central to the child's well-being. While families report that the needs of their children can be challenging, and have even been described as endless by other researchers (Jones, 2004), helping families develop a strong and protective bond with their children is essential in promoting family resilience.

The current study also shows a clear need for an increase in the knowledge and awareness of FASD across Ontario in both the professional and general communities. Parents found it extremely frustrating to constantly educate those around them about their

child's issues. Better training for professionals is critical in providing more appropriate support for families, which they report as lacking. Parents in the current study often reported that, despite research indicating the negative outcomes of prenatal alcohol exposure (e.g., see Rasmussen, 2005 for a review), many medical professionals still advocated for the use of alcohol during pregnancy. Professionals and service providers therefore need to be trained about what FASD is and how it impacts the brain and materials containing practical strategies, resources, and information about the disability should be made available to those working with individuals affected by FASD and their families (e.g., pediatricians, teachers, principals, social workers). If service providers are properly educated about FASD, they may be able to provide families with the assistance and support they are looking for. Service providers should be knowledgeable about parenting approaches and coping strategies to recommend to parents, including opportunities to promote family togetherness and mutual aid through parental support groups.

In conclusion, this study has furthered our understanding of the lived experiences of families raising children diagnosed with FASD. The current study has provided evidence that the FAAR model can be applied to understanding the demands, capabilities, and meanings that come from parenting a child with FASD. Awareness of what meaning parents ascribe to their experience and understanding what strategies parents employ to cope with their demands (e.g., stressors, strains, or daily hassles) is valuable knowledge for professionals working with families of children with FASD. Understanding what successful families do in order to transform from a family in crisis to a fully functioning family assists in the development of family support programs to help families who may

be facing maladaptation. The families in this study are the most qualified and knowledgeable individuals about the realities of raising a child with FASD and professionals can be educated by listening to their stories. This study therefore highlights the importance of listening to families of children with FASD in order to capture the complexity of their lived experience.

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Appendix A

Laurentian University Research Ethics Board Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL	New	X	Modifications to project	Time extension
Name of Principal Investigator and school/department	Kelly Coons (Dr. Shelley Watson; supervisor) — Human Development (Laurentian University)			
Title of Project	<i>The Beautiful Challenge: Families Raising Children with Fetal Alcohol Spectrum Disorder in Ontario</i>			
REB file number	2012-02-02			
Date of original approval of project	February 29 th 2012			
Date of approval of project modifications or extension (if applicable)				
Final/Interim report due on	March 1 st 2013			
Conditions placed on project	Final or interim report on March 1 st 2013			

During the course of your research, no deviations or changes to the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please complete the appropriate [REB form](#).

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB FORM](#).

In all cases, please ensure that your research complies with the [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations, and best of luck in conducting your research.

Jean Dragon Ph.D. (Ethics officer LU) for Susan James Ph.D.
Acting Chair of the *Laurentian University Research Ethics Board*
Laurentian University

Appendix B

Participant Pseudonyms by Family, Including Age(s) of Diagnosed Child(ren)

Participant Pseudonym		Family Type	Name(s) and Age(s) of Diagnosed Child(ren)
Mother	Father		
Annie	Jason	Adoptive	Nicholas (35)
Karen		Foster	Patrick (9), Stephen (6)
Stephanie	Chad	Adoptive	Victor (27)
Julie	Rob	Biological	Jonathan (19), Arthur (15)
Donna	Steve	Adoptive	Katie (14), Erik (11)
Gabrielle		Adoptive	Brigit (36)
Natalie		Adoptive	Elizabeth (9), Susan (7)
Faith		Adoptive	Grace (16)
Kaylee		Adoptive	William (33), Allison (30)
	Louis	Biological	Pierre (15)
Melanie		Adoptive	Robert (37)
Tracey	Bernie	Biological	Leah (8)
Sharon		Adoptive	Cassandra (17)
Emily		Adoptive	Lisa (23), Penelope (21)
Nina	Shane	Adoptive	Annabelle (7)
Tamara	Allan	Adoptive	Jessica (9)
Denise	Barry	Biological/Step-parent	Hayley (7)
Jane		Adoptive	Luke (17)
Shannon	Jake	Foster	Darcey (21), Jamie (18), Taylor (16), Rachel (14), Devin (12), Wendy (10), Chase (4)
Sarah		Biological	Abigail (10), Emma (7), Hannah (6), Brooke (5), Olivia (1)
Katherine		Biological	Jacqueline (23)
Pauline	Marc	Foster	Benjamin (13)
Barbara		Biological	Austin (19)
Marianne		Adoptive	Daniella (15)
Celine		Adoptive/Foster	Anthony (8), Manfred (3)
Robyn		Step-grandparent	Alexander (21)
Caitlin		Adoptive	Carolyn (8)
Carmen		Biological/Foster	Angelica (18), Jocie (18)
Veronica		Adoptive	Irene (8)
Patricia		Adoptive	Adelle (8), Paige (10)

Leslie	Kevin	Adoptive	Jace (7), Jared (6)
Ashleigh	Shawn	Adoptive	Jackson (11)
Daphnie		Adoptive	Kristi (21)
Bailey	Trevor	Adoptive/Step-parent	Benjamin (23)
Mabel	Percy	Adoptive	Rachelle (17)
Breanne	Cole	Adoptive	Ian (14), Alexia (9)
Lily	Stefan	Adoptive	Molly (16)
Nicoletta	Geoffrey	Adoptive	Jack (19), Tanya (17), Chris (16), Simon (15), Eliza (14), Cheryl (10)
Adrianna	Paul	Biological	Abby (16), Evan (12), Joey (10), Adam (8)
Kimberly		Adoptive	Bernadette (12)
Stacey	Ivan	Adoptive	Jared (21)
Lacey		Adoptive	Randy (10), Chantelle (7)
Sally	Peter	Adoptive	Tye (18), Daryl (17)
Whitney		Biological	Randall (8)
Jennifer		Adoptive	Mackenzie (11)
Allison		Adoptive	Maya (15)
Claire		Adoptive	Stella (12)
Jocelyn		Adoptive	Abigail (30)
Beverly	Drew	Adoptive	William (30)
Kristen		Adoptive	Casey (11), Hailey (7)
Stefanie		Adoptive	Scott (19), Corey (15)
Jade	Devin	Adoptive	Leona (9)
Jodi	Marcus	Step-parent/Biological	Memphis (10)
Kendra		Biological	Audrey (12)
Alyssa		Biological	Kyle (16)
Olivia	Joshua	Adoptive/Foster	Charlene (8), Taylor (8), Alec (7)
Angie		Adoptive	Rebekkah (10)
Mandy	Joseph	Adoptive	Jewel (29)
Mina		Biological	Emma (6)

Appendix C

Semi-Structured 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 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 with FASD, what would you tell them?

Appendix D

Summary of Themes and Sub-themes Presented in Chapter Two

Superordinate theme	Sub-themes	Example of illustrative quotation
Theme 1: “Get educated, get involved”	Learning more about FASD	Get as much information and knowledge as you can...So that you can share that with whoever is dealing with your kid. – <i>Kaylee</i>
	Becoming advocates	You have to fight for everything for those children. And you have to be on top of everything for them. – <i>Tracey</i>
Theme 2: “I take it day-to-day, I don’t think about tomorrow” (Day-to-day management)		I take it day-to-day. That’s all I do, day-to-day, I don’t think about tomorrow, I do what comes. – <i>Natalie</i>
	“Every day it’s like the movie Groundhog Day”	I mean some days are like Groundhog Day, you wake up and you have to repeat everything over and over and do it exactly the same and if you wear your hair up instead of down, that’s the difference that’s gonna send her into a meltdown that morning. – <i>Patricia</i>
	“Choose your battles”	When she would get off the bus at about 3:15 she would have a two or three hour, what I call, ‘meltdown’. Like she would go into a rage – be kicking the walls, she’d stand in the corner like peeing her pants... Well we try to deal with it when it comes, when she goes in a rage, we try to ignore it as best we can because we’ve discovered that if you pay attention it lasts about an hour – if you ignore it, it lasts about an hour. Basically it doesn’t really matter what you do, it lasts about an hour. – <i>Jade</i>

Theme 3: “I wouldn’t change it for the world” (Transformational Outcomes)	Focusing on the positives	It’s honestly awesome [to be her mom]. I would not change it for the world. Normal kids are boring, so she makes life interesting...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 right now if I was still drinking, so I can honestly say she saved my life. – <i>Kendra</i>
	“We look at it as a real blessing” (Child is meant to be there)	I guess, I’d say we’re doing okay, like, I’m- we have a strong faith and I know that God’s in control, and I know that we’re raising these girls because that’s how it’s supposed to be. – <i>Jade</i>
Theme 4: “You can’t do it on your own” (Informal Supports)		They say it takes a community to raise a child [with a disability]. And I believe it, I really believe it now. Because you can’t do it on your own. 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. – <i>Tracey</i>
	Significant Others	Well, luckily we sort of balance each other off, like if I’m having a really down time, he’ll be sort of up and vice-versa. – <i>Kaylee</i>
	Family members/Friends	I have some friends, and I have my sister, so like I have good support around me. – <i>Marianne</i>
Theme 5: “It’s nice to know you’re not alone” (Formal support)	Support groups	I have a support group that 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?’

Helpful
professionals

She's 11. 'Huh...the next two years are gonna be really bad.' (Laughs) You know? It's pretty funny! – *Claire*

And 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 because, you know, she laughs at my resiliency skills, and my take on life, and that sort of thing. But that really...that really helps too. – *Jade*

Appendix E

Summary of Themes and Sub-themes Presented in Chapter Three

Superordinate themes	Sub-themes	Example of illustrative quotation
Theme 1: “Doctors and nurses and teachers all need to be educated”	More training and education for professionals (Medical practitioners, school professionals, psychologists)	But the more people that know...two years ago I was in a gynecologist’s office, OB/GYN, and I’m sitting there waiting for my appointment, my first appointment, she comes out and walking a patient out that looked to be probably close to term...and told her to go ahead and have a glass of wine at night to relax. It’s much better for the baby...Like...I’m giving the glare and the doctor’s looking at me and I’m just giving her the glare...so I kind of blasted that doctor and anytime somebody tells me that they’re going to see this particular doctor I say walk away now. Go to this other one. And I tell them why. – <i>Caitlin</i>
Theme 2: “Nobody really knows what our kids can do when they’re properly supported because nobody’s done it right” (Support for the child)	Help obtaining a job/in the workplace Mentoring programs/friends Assisted housing/safe place to live	So, the judicial system, the school system...there’s nothing for them. They’re floundering. Everybody’s mandate, well not accommodating, we have gone around case conferences with health teams, ‘Well it’s not my mandate, it’s not my mandate.’ And the dad has his head down on the desk and he’s crying ‘I want help for my son.’ – <i>Gabrielle</i>
Theme 3: “Safe, appropriate respite” (Support for the family)	Need for respite/individuals who are properly trained to provide respite	And there’s no other supports. Finding respite, people who can do respite, is incredibly challenging and...we have funding available to us...But like I said to them, ‘you could give us a million

Theme 4: “If kids are intervened early they have a better chance”	Receiving and early diagnosis of FASD and getting the <i>right</i> diagnosis	dollars but if there’s no workers than it does nothing for us.’ And, you can’t just have the 15 year old down the street come and hang out, even with Chantelle you can’t do that. You know, she’ll be up and into the scissors and cutting her hair or slicing off her fingers because she wants to cut her own fingernails or whatever, like you can’t, it just can’t be a normal teenager down the street. And so getting any time to have a break is pretty much impossible. – <i>Lacey</i>
	Early knowledge of the disability in order to implement interventions and understand their issues	And without the support, and without the early intervention, and early diagnosis, that’s the key. Without that, the older they get, the worse it is, the worse the outcome really, really is. – <i>Kimberly</i>
		And I was a little bit mad, like, if I’d had [the diagnosis] from the beginning, we could have parented her properly from the beginning, do you know what I mean? So instead of punishing and doing stupid reward charts and things like that she’s never gonna get anyways, what a waste of energy!...It also helps you to parent her, like I said, you know, it helps me to parent her because it’s totally different. It’s parenting apples versus oranges, right? Sounds funny but you can’t, you can’t do the same things. – <i>Patricia</i>
Theme 5: “When people understand, their attitudes change”	More information and education about FASD	Education, education, education is what it boils down to. I’d like to see it completely blanked out, but probably won’t be. It’s worldwide, you know...More awareness, more understanding of it. More deterrents to the pregnant women or alcoholics for

them not to drink is the number one thing. – *Louis*

More knowledge and awareness of FASD

FASD is the white elephant in the social service system...If you don't, I didn't write that on that one, that if you don't have power you need to manipulate. That's how a lot of them have to live and they, they become very good manipulators a lot of times because they, they need to survive. They find a way to survive. They don't understand why they don't know what they did wrong. That is another, such a true, true fact for them. They really don't know why, they don't know why they can't think it. It's going around in their head, they don't know why they can't get it to hear. They know it up here so then they start feeling stupid and they start feeling like a failure and they start feeling like they're, they're no good. People tell them they're no good. The teachers tell them they're stupid 'cause you know it yesterday Johnny, how come you can't do it today? He's just being lazy. If I hear that one more time. He know it yesterday, well his brain was connecting yesterday. His synapses were connecting, they aren't today. Try to get that across to somebody before they know what FASD is. – *Karen*
