

LIVING WITH A SIBLING DIAGNOSED WITH FETAL  
ALCOHOL SPECTRUM DISORDER

by

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## Abstract

The following document is a two-paper manuscript-based thesis investigating the experiences of siblings of individuals with Fetal Alcohol Spectrum Disorder (FASD). According to the sibling literature, individuals are impacted by living with a brother or sister with a disability, but, much of the research has focused on siblings of individuals with Autism, Down Syndrome, or developmental disability in general. Thus, the purpose of this exploratory study was to examine both the positive and negative experiences associated with having a sibling diagnosed with FASD, along with what strategies these siblings are using to help them adapt. The first paper, which focused on the benefits and challenges when having a sibling diagnosed with FASD, used a mixed methods approach. The qualitative data consisted of semi-structured interviews, which were analyzed using Interpretative phenomenological analysis (IPA), and the quantitative data comprised the Sibling Inventory of Behaviour Scale (SIB) and the Daily Hassles and Uplifts Scale (DHUS), which were analyzed using descriptive statistical analysis. Siblings described feeling a number of emotions associated with their experience such as frustration, fear/worry, resentment, happiness, and personal growth. The second paper examined both coping behaviours and resources used by siblings to help facilitate adaptation. This qualitative study employed Thematic Analysis (TA) to analyze the semi-structured interview. Results indicated that siblings employ coping behaviours such as active and emotional avoidance, and access both informal and formal resources; however, understanding the complexities of FASD is important in perception of helpfulness of these resources. Implications for clinical interventions are discussed.

**Keywords:** fetal alcohol spectrum disorder, developmental disability, siblings, stressors, positive experience, negative experience, adaptation, mixed methods, qualitative, capabilities, coping, resources, services.

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## Chapter 1: Introduction

Many individuals are affected by developmental disabilities “a group of conditions due to an impairment in physical, learning, language, or behaviour areas” (CDC, 2015, p. 1).

Unfortunately, those affected by disabilities are not the only ones who are impacted by their condition. Often, family members such as parents, grandparents and siblings are very involved with caring for the individual with the disability. One such example where a strong family impact has been demonstrated is Fetal Alcohol Spectrum Disorder (FASD). The current-mixed methods study, approved by Laurentian University Research Ethics Board (REB; Appendix A), explores the experiences of siblings living with brothers and sisters who have been diagnosed with Fetal Alcohol Spectrum Disorder (FASD). In this study, siblings without FASD were asked to participate in semi-structured qualitative interviews. The questions provided relevant clinical information and allowed the researcher to gain insight into the relationship between the participants and their siblings with FASD. Additionally, siblings who are not diagnosed with FASD were asked to fill out two scales, the Sibling Inventory of Behaviour Scale (Hetherington, et al., 1999), and the Siblings Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006). These scales were used in conjunction with the interview to gain a better knowledge of their daily stressors, the benefits, as well as how siblings are trying to achieve adaptation in their environment. This mixed-methods approach allowed the gathering of thorough information, both positive and negative, about the experience that is lived by brothers and sisters of individuals with FASD.

The current study is a manuscript-based thesis and consists of four separate chapters. The current chapter explains in detail the literature review and provides an in-depth introduction to the thesis which is divided into two parts. Chapter 2 consists of the first research article which

focuses on what it is like to live with a sibling diagnosed with FASD. The following chapter, Chapter 3, is the second research article which provides insight into how the siblings are coping, and the supports they might need. Last, the final chapter is an overall discussion and conclusion to the entire manuscript.

### **1.1 Fetal Alcohol Spectrum Disorder**

Fetal Alcohol Spectrum Disorder is an umbrella term used to describe an individual affected by prenatal alcohol exposure. Under this umbrella is a range of disabilities that include fetal alcohol syndrome (FAS), partial FAS (p-FAS), alcohol-related neurodevelopmental disorder (ARND), fetal alcohol effects (FAE), and alcohol-related birth defects (ARBD; Davis, Desrocher, & Moore, 2011; Koren & Nulman, 2014; Kyskan & Moore 2005). Recently, changes to the Canadian Diagnostic Criteria for FASD were made to replace the aforementioned disorders with two categories, that is: (1) FASD with sentinel facial features; and (2) FASD without sentinel facial features (Cook et al., 2015). The prevalence rates of FASD are difficult to establish due to challenges in the diagnostic process, which include invisibility or lack of physical symptoms (Malbin, 2004) as well as the underreporting of maternal alcohol consumption due to the stigmatization of drinking during pregnancy (Ernhart, Morrow-Tlucak, Sokol, & Martier, 1988; Wilton & Plane, 2006). However, most recent prevalence rates estimate that 9.1 children per 1000 live births in both Canada and the United States are affected by FASD (Canada FASD Research Network, 2015; Chudley et al., 2005; Health Canada, 2006; Streissguth, 2007), with some rates as high as 25-190 per 1,000 live births in particular geographical locations (Chudley et al., 2005). FASD is considered to be the most preventable cause of congenital neurobehavioural impairment (Davis et al., 2011; Nash, et al., 2006) as well

as the leading cause of intellectual disability in the Western population (Floyd & Sidhu, 2004; Kyskan & Moore, 2005).

Individuals affected by prenatal alcohol exposure are characterized by physical growth deficiencies, which include small palpebral fissures, a smooth philtrum, and a thin upper lip (Clarke & Gibbard, 2003). Although these are noticeable features, the largest deficiencies that result from prenatal alcohol exposure are within the structural components of the brain. Nuñez, Roussotte, and Sowell (2011), in examining numerous studies, explain various structural abnormalities, such as a decrease in volume to the overall brain size, subcortical structure, cerebellum, frontal and parietal lobes, along with increased cortical thickness and excessive grey matter with a diminution in white matter. Consequently, these anomalies cause individuals with FASD to live with a number of neurological deficits that are categorized as primary disabilities, which include problems with adaptive functioning, language/learning, attention, reasoning, and memory (Clarke & Gibbard, 2003). Persons with FASD may then develop secondary disabilities, as highlighted by Streissguth, Barr, Kogan & Bookstein (1996), which are caused by the primary disabilities or the neurological deficits. Secondary disabilities are problems such as mental health disorders, disrupted school and employment experiences, trouble with the law, inappropriate sexual behaviour, and addictions (Clarke & Gibbard, 2003; Spohr, Willms, Steinhausen, 2007; Streissguth et al., 2004). With the wide array of disabilities and difficulties an individual with FASD is likely to experience, it is often important for them to have lifelong caretakers and a support system. However, given the nature of some of the problems faced by individuals with FASD, this is undoubtedly a difficult task and will have an impact on all of those who are involved in their lives.

Recently, Malbin, Boulding and Brooks (2010) redefined the behavioural symptoms associated with FASD by using the neuro-behavioural model. Just like the definition above, primary characteristics were also described as brain dysfunctions; however, the secondary behaviours are described as “defensive behaviors that develop over time where there is a chronic poor fit between person and environment” (p. 4). In this category, symptoms such as fatigue, anxiety, aggression and depression are described. Malbin et al. (2010) also introduced the term tertiary problems as “the net effect of chronic poor fit and patterns of secondary defensive symptoms” (p. 5). This category is essentially the result of not successfully dealing with the primary or secondary effects. Some of the common tertiary problems include mental health issues, trouble with the law, substance abuse, relationship issues, and the inability to hold a job. The description of the secondary disabilities is the main difference between both models presented. Whereas the Clarke and Gibbard (2003) model begins at the neurological disorders and proceeds to the issues these individuals experience on a societal level, the current model proposed by Malbin et al. (2010) included a category to explain the behaviours that result from the neurological impairments, which then leads to the broader issues individuals with FASD may experience in society. Regardless of the differences in categories, both of these models explain many of the impairments that individuals with FASD face on a daily basis. Furthermore, it is not only those diagnosed who are affected by the primary, secondary and tertiary disabilities, but rather, research has shown that families and support systems are also greatly affected by the disability.

## **1.2 History of Family Research**

**1.2.1 Families of Individuals with Developmental Disabilities.** Several studies have determined that raising a child with a disability can have numerous impacts on the family, in

which the major themes have consisted of family stress, family quality of life, coping, and a change in family dynamics (Families Special Interest Research Group of IASSIDD, 2013; Ha, Hong, Seltzer, & Greenberg, 2008; Hanson & Hanline, 1990; Poston et al., 2003). A major focus of the literature has been on the levels of stress that families experience. Researchers have found that families raising a child with a developmental disability have higher levels of maternal stress (Hanson & Hanline, 1990; Estes et al., 2009), and marital stress, potentially leading to higher divorce rates (Corman & Kaestner, 1992; Joesch & Smith, 1997; Reichman, Corman, & Noonan, 2004). Financial difficulties have also been reported in families raising a child with a disability, due to both the medical and specialized services required (Cuskelly, Pulman, & Hayes, 1998; Kuhlthau, Hill, Yucel, & Perrin, 2005; Newacheck & Kim, 2005), as well as the reduced hours of employment or ability to be employed due to the need for constant childcare (Freedman, Litchfield, & Warfield, 1995; Kuhlthau, Kahn, Hill, Gnanasekaran, & Ettner, 2010; Powers, 2003; Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). Ha et al. (2008) reported that parents of children with developmental disabilities experience significantly higher levels of negative affect, marginally poorer well-being, and more somatic symptoms than parents of children without disabilities. They also found that these negative experiences attenuate as parents get older, and that work status was the best predictor of well-being, which was defined by six different domains: autonomy, environmental mastery, purpose in life, positive relations with others, personal growth, and self-acceptance. Parents who were employed showed lower levels of negative affect and higher levels of psychological well-being; this increased functioning was evident for both the parents and the child with a developmental disability.

The focus on negative concepts such as stress is, unfortunately, a very large negative trend in family disability literature. In their study, Turnbull, Summers, Lee and Kyzar (2007)

analyzed 28 studies from 1999-2007, all of which focused on families with a child who has a developmental disability. Turnbull et al. (2007) included studies with one of the four outcomes: well-being, adaptation, family functioning, and family QOL. They discovered that within all of these 28 studies, the most frequent measures focused on depression, stress, burden, pessimism, and adaptability/cohesion. Thus, when researchers examined the constructs of these measures rather than focusing on positive dimensions as the studies portrayed, they focused almost exclusively on negative dimensions (Turnbull et al., 2007).

On the other hand, Scorgie and Sobsey (2000) examined parent transformations and found that although there are negative experiences, most parents of children with disabilities reported many positive changes such as personal growth, improved relations with others, and changes in philosophical or spiritual values, all as a result of parenting a child with a disability. Schall (2000) explored the experience of families raising a child with Autism Spectrum Disorder (ASD). Although parents reported various stressful situations such as negative behaviours, idiosyncrasies and troubles with diagnosis, they also reported a sense of commitment and passion for life, as well as “appreciation of the gifts of people that others take for granted” (p.420).

Positive aspects of raising a child with a developmental disability were also addressed in Taunt and Hastings’ (2002) study, where two samples of parents completed semi-structured interviews to gain knowledge about the parental experience. Based on the semi-structured interviews, six different categories indicating a positive impact on parents were developed. In the first sample, the first and second categories, positive aspects of their child (e.g., positive characteristics of the child, child’s achievement) as well as their changed perspective on life (e.g., not taking things for granted, new goals, valuing others more, changed life/career expectations) were spoken about in 80% of the interviews. The third and fourth concepts, which

were increased sensitivity (e.g., increased tolerance, awareness of others, improved sensitivity to child as a parent, increased patience), and support from other families (e.g., other parents have been through problems and can help, sharing information with other parents) were indicated in 60% and 50% of the interviews. The last two categories consisted of opportunities to learn (e.g., about children, disability, psychology, special education), and improved family dynamics (e.g., brought family closer together, spend more time together as a family) were in 30% and 10% of the interviews. Although the order changed slightly in the second sample, the top four categories, changed perspective on life, increased sensitivity, positive aspects of the child and opportunities to learn, were reported by at least 50% of the respondents. Thus, although there are many studies underlying the negative impacts on families raising a child with a disability, it is evident that a positive impact can exist as well.

**1.2.2 FASD Family Research.** Compared to other developmental disabilities such as Down Syndrome (DS) and ASD, there have been few studies addressing families who have children with FASD. It has been demonstrated however, that raising a child with FASD can be very demanding for various reasons. The first of these factors is the child's characteristics; more specifically, impaired executive functioning and higher levels of internalizing and externalizing behaviours have been found to be strong predictors of parents' levels of child-related stress (Paley, O'Connor, Frankel, & Marquardt, 2006). Researchers have also found that parents' stress levels increase when dealing with health professionals in having their child formally diagnosed (Sanders & Buck, 2010; Watson, Hayes, & Radford-Paz, 2011). Although the diagnostic process generates high stress levels, an accurate diagnosis is important in order to access services that have been found to be essential in raising a child with FASD (Jirikowic, Kartin & Olson, 2008).

It has been reported that different types of developmental disabilities (e.g ASD, down syndrome, etc.) yield different types of parenting experiences (Abbeduto, et al., 2004; Dabrowska & Pisula, 2010), and some researchers have compared parents of individuals with FASD to parents of individuals with ASD (Watson, Coons, & Hayes, 2013a; Olson, Jirikowic, Kartin, & Astley, 2007; Watson, Hayes, Coons, & Radford-Paz, 2013b). In comparing levels of stress in parents of children with ASD and FASD, Watson et al. (2013a) found that parents of children with FASD were experiencing significantly more stress as compared to parents of children with ASD, as measured by the PSI. In a follow-up qualitative study, Watson et al. (2013b) looked into the sources of stress within these two populations. They found that parents of children with FASD focused on their children's illegal behaviours, whereas parents of children with ASD struggled with their children's tantrums and anxieties.

Dicker and Gordon (2004) reported that approximately 80% of infants in foster care have been exposed to drugs and/or alcohol prior to birth, suggesting that there is a large population of individuals with FASD in the foster system, many of who go on to be adopted. When studying adoptive parents and their experiences, Williams, Dubovsky, and Merritt (2011) found that in the United-States, parents were often unaware of their child's disability due to laws of nondisclosure that existed until the the1980s and 1990s. Additionally, Williams et. al (2011) reported that when parents are unaware of their adopted child's disability, parents become psychologically affected in terms of frustration or anxiety, they second guess their own parenting skills, and become disappointed in their child, often leading to adoption disruption and dissolution (Nagler 2003; Williams et al., 2011).

With such a high percentage of individuals with FASD living with non-biological families, there has been a lack of studies looking specifically at biological parents. According to

the Hope for Women in Recovery Summit (2005), research has generally focused on biological mothers who unlike foster mothers, experience shame and guilt for having consumed alcohol during pregnancy. Additionally, Paley et al. (2006) examined the family characteristics of children with FASD to determine predictors of stress. They found that biological status and lower levels of resources were both associated with higher levels of the parent domain stress as measured by the Parenting Stress Index (PSI; Abidin, 1995). Elevated scores within this category “may reflect parenting stress associated with aspects of parents’ functioning (e.g. depressed mood) or their social network (e.g. an unsupportive spouse)” (p. 399), suggesting that biological parents may experience higher levels of stress than non-biological parents.

It is evident that research involving families and FASD has focused on the more stressful or negative experiences. There are very few studies that have looked at some of the positive aspects of raising a child with FASD. One of these studies, McCarty, Waterman, Burge, and Edelstein (1999) examined the experience of foster parents within the first year following the child’s placement. They found that parents generally felt good about their experience, with parents reporting that “caring for their children is challenging but a highly rewarding experience when they are provided with services tailored to their and their children’s needs” (pp. 576-577).

Given the literature and the testimonials of parenting a child with a developmental disability or a child with FASD, there is no doubt that families are faced with numerous challenges as well as positive experiences. Nevertheless, both the former and the latter are likely to affect not only the parents but the other children in the family as well who are faced with having a brother or sister with a disability.

### **1.3 Sibling Research**

**1.3.1 Siblings of Individuals with Developmental Disabilities.** It is evident that parents experience various kinds of stress when raising a child with a disability (Hanson & Hanline, 1990; Newacheck & Kim, 2005; Reichman, et al., 2004; Rosenzweig, et al., 2008). But as parents are members of a family, so too are siblings and they have also been shown to be affected in various ways by living with a brother or sister diagnosed with a developmental disability. However, some of the literature surrounding the impact that is made by living with a brother or sister with a developmental disability is both dated and inconsistent with many studies focus solely on positive or negative results. This is evidenced by the literature examining the psychosocial effects, the behavioural disturbances, emotional effects, as well as the individual differences reported in siblings living with a brother or sister diagnosed with a developmental disability.

**1.3.1.1 Psychosocial effects.** Bågenholm and Gillberg (1991) looked at the psychosocial effects on siblings of children with ASD and intellectual disabilities (ID). They found that the siblings of those with an intellectual disability reported more loneliness and concern about their sibling's future, and those who did not have any other siblings were more likely to see them as a burden. This study's findings are both congruent and incongruent with Kaminsky and Dewey (2002), who found that siblings of children with ASD reported low levels of loneliness and high levels of social support. But in accordance with the previous study, a larger family size seemed to play a role in the healthy adjustment of siblings of children with ASD. In terms of time spent with the sibling with a disability, McHale and Gamble (1989) looked at both siblings of typically developing individuals and siblings of individuals with a disability, and found that they both reported spending nearly the same amount of time together during sibling activities. Unlike the former group, both male and female siblings of children with ID's reported that they spent more

time in caregiving activities. In this study, siblings of children with IDs also reported more maternal negativity and poorer adjustment. Last, Wilson, McGillivray and Zetlin (1992) examined the attitudes of siblings who have a brother or sister with a disability. They found that adolescent siblings compared to adult siblings reported more embarrassment as well as more concern with both their own social stigma and being isolated by their peers because of their sibling with a disability.

**1.3.1.2 Behavioural disturbances.** LeClere and Kowalewski (1994) demonstrated that individuals who live with a family member who has a disability are more likely to experience behavioural problems than those who do not. In this study, African-Americans compared to Caucasians were at a higher risk of developing behavioural problems and also of “having experienced an accident, injury, or poisoning that required medical attention in the past 12 months” (p. 465). Additionally, Bågenholm and Gillberg (1991) used the Rutter’s scale to examine siblings of individuals with developmental disabilities ranging from 5-20 years of age. They reported that siblings of individuals with ASD scored higher on the inattention/hyperactivity and conduct problem scales. Although these scores were very similar to those with other developmental disabilities, they were still higher than typically developing siblings. When focusing on specific disabilities, numerous studies have reported that siblings of individuals with ASD experience heightened behavioural problems (Dunn, Slomkowski, Beardsall, & Rende, 1994; Orsmond & Seltzer, 2007). For siblings of individuals with DS, Cuskelly and Dadds (1992) revealed that their sisters were found to be more likely to have Conduct Disorder than their male counterparts and more than any other type of disorder.

**1.3.1.3 Emotional effects.** A meta-analysis by Rossiter and Sharpe (2001), integrated 25 different studies examining siblings of individuals with an intellectual disability. Result

demonstrated a significant but small negative effect on the functioning of the siblings, specifically with respect to depression and to a lesser extent anxiety. Additionally, Pollard, Barry, Freedman and Kotchick (2013) examined the relationship quality and its relation to anxiety in siblings of children with ASD or DS. This study demonstrated that, regardless of the disability type, individuals with more negative interchanges (e.g., conflict, antagonism) with their diagnosed sibling reported higher levels of anxiety. Also, McGinty, Worthington and Dennison (2008) examined siblings of individuals with comorbid mental illness and developmental disabilities and found that siblings are heavily impacted by their experience. Siblings in this situation may experience heightened levels of stress due to less time spent with parents who are trying to access services and meeting their child's needs, therefore making the main priority the sibling with a disability. As a result, parents may unintentionally reduce the resources that are available for the sibling's needs as they are being used by their brother or sister with a disability. Last, siblings are likely to have to deal with the stress of having to defend their siblings in public. Because their sibling is "different" from most other siblings, they may have to intervene or deal with their peers calling him/her names or making comments that are unkind. McGinty et al. (2008) discovered that there is an effect on the siblings and that they experienced a wide range of emotions, both positive and negative, towards their sibling with a disability. The authors emphasized the importance of asking families about the siblings to try and understand their experience, as they are faced with many unique challenges that can raise numerous concerns.

**1.3.1.4 Individual differences.** Research findings have demonstrated variability in experiences based on individual differences such as the type of disability, the sibling's gender, as well as the sibling's developmental stage. When examining specific types of disabilities, it has

been reported by Hodapp and Urbano (2007) that the siblings of individuals with DS, compared to ASD, had relationships that were closer and warmer with better health, lower levels of depression, and longer lengths of contact as measured by the Adult Sibling Relationship Questionnaire (Lanthier & Stocker, 1992). Similarly, Kaminsky and Dewey (2001) found that siblings of individuals with DS reported a greater admiration of their sibling and less sibling rivalry, while the relationships of individuals with ASD and their siblings were less intimate, with less prosocial behaviour and nurturance. This finding is not surprising given the behavioural issues that are commonly characteristic of children with ASD, in contrast to those with DS, which has been linked to poorer quality of sibling relationships (Dunn et al. 1994; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009).

Various studies have also shown differences in the sibling relationship based on gender. Siblings of individuals with DS were studied by Orsmond and Seltzer (2000). They discovered that sisters scored higher than brothers in caregiving, companionship and positive affect aspects of their relationship. Additionally, Orsmond and Seltzer (2000) found that for males, their emotional responses were more favourable when they had brothers with an intellectual disability compared to having a sister with an intellectual disability. Similarly, Orsmond et al. (2009) found that when looking at siblings of individuals with ASD, females with a sister with ASD reported the most positive affect in the sibling relationship, and males with a sister with ASD the least. Thus, it seems that sisters are generally closer and report more positive affect towards their sibling with a developmental disability than do brothers.

Last, sibling age is a factor that can impact a sibling's experience. Petalas et al. (2009) reported that siblings who were younger than the child with ASD, compared to those who were older, reported more conflict between siblings. Similarly, in Rossiter and Sharpe's (2001) meta-

analysis looking at the impact of having a sibling with an intellectual disability, results showed a small negative effect for depression, internalizing and externalizing behaviours, as well as anxiety. This negative effect was significant in childhood and less so in adolescence. Conversely, for adults, the results differed significantly from the childhood group, revealing more positive psychological functioning (e.g., attitudes towards individuals with DS), suggesting that the siblings' experiences may vary depending on their age and developmental stage. According to Rossiter and Sharpe (2001), this age difference may be attributable to both a diminished impact of their sibling with a disability and birth family in adulthood, and increased cognitive and social development leading to improved coping mechanisms and feeling of empathy towards their sibling with a disability.

Given the evidence provided by the above studies, it is clear that siblings are affected behaviourally, psychologically, and emotionally when being raised with a brother or sister with a disability. Based on research findings, their experiences may vary according to numerous variables such as family characteristics and age, but most importantly for the present study is the type of disability. Due to the characteristics of the diagnosis, siblings of individuals with FASD may not have the same experience as siblings of individuals with DS or ASD.

**1.3.2 Siblings of Individuals with FASD.** To date, there has been little research that has looked at the lived experience of siblings of individuals with FASD, and most findings have been based on parental accounts. One study by Brown, Sigvaldason, and Bednar (2005) entailed asking foster parents what they needed in order to successfully raise a child with FASD and the researchers created a concept map based on the participant responses. Within this concept map, two points derived by parents were directly related to other siblings in the household: "Support for biological children" and "Explain FASD to other children in the home". Although these

results are based on the parents' perspectives, providing siblings with help and knowledge about their brother or sister with FASD is something that will undoubtedly be beneficial in helping them cope with this unique situation (Conway & Meyer, 2008; McCullough & Simon, 2011). Olson et al. (2009) also expressed that siblings may be negatively impacted by their experience and therefore it would be beneficial to expand the literature on the siblings' experiences to identify the need and benefits of support.

It has been acknowledged that the type of disability (e.g., Down Syndrome, ASD) plays a role in the experience of the sibling (Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001). Seeing as though FASD is a distinct disorder, siblings may have unique or different experiences than those with ASD or DS. The strong likelihood that these experiences differ are evidenced in the parent data, whereby parents of individuals with FASD have reported higher stress levels, acceptance of many adversities such as teen pregnancy and jail time, and a lack of hope for their child's future, which was in contrast to the concerns of parents of individuals with ASD who were hopeful for the future of their children (Watson et al. 2013a; Watson et al. 2013b). Given these results, compared to other developmental disorders, the siblings of individuals with FASD may not only be subject to higher stress levels in the home, but they may also need more support when potentially considering the caretaking role in the future. However, as seen by the few studies that have been conducted in this field, in order to create theories more knowledge is to be gained in regards to the unique experience of siblings who have a brother or sister with FASD.

#### **1.4 Reflexivity**

As qualitative research relies on the researcher being the "research instrument" (Patton, 2002; Pezalla, Pettigrew, & Miller-Day, 2012), it is important to provide the readers with an overview of the filters and lenses that a researcher may use to view the world (Mansfield, 2006).

Offering an overview of the researcher's background gives the readers insight into what has influenced the researcher during their investigation (Malterud, 2001), and it also increases the trustworthiness of the study (Reid, Flowers, & Larkin, 2005). Thus, the following section will focus on my own self-reflection by examining how my ethnicity, gender, religion, and values may have influenced my interpretations and my research journey (Merriam, 2002).

After receiving my undergraduate degree in Psychology, I knew I wanted to pursue a post-graduate education in my field. Upon looking for supervisors, I was introduced to Dr. Shelley Watson, who informed me on her recent projects examining parents and grandparents of individuals with developmental disabilities, specifically fetal alcohol spectrum disorder (FASD) and autism spectrum disorder (ASD). Though I had sporadic involvement coaching or playing sports with Special Olympic organizations, I was very unfamiliar with the field of developmental disabilities, which made finding a research topic very challenging. My inspiration, however, came soon after when my sister, who is 8 years younger, began a rebellious phase. During this time, I could see not only that my parents were stressed and overwhelmed by her behaviours, but it also had a negative impact on myself and my younger brother. It was then that I began to research the sibling experience of living with a brother or sister diagnosed with a developmental disability. With no articles pertaining specifically to FASD, I was determined to begin a new path in the literature by giving these siblings a voice.

In the beginning, I had a predominantly negative view of the effects siblings can have based on my own personal experience. For myself, I constantly worried about the members in my family, my parents were constantly stressed, my brother was deeply hurt and concerned about his sister/ best friend, and for my sister who was engaging in self-destructive behaviours. Fortunately, both my values and education have taught me that there is always something

positive to be taken from any experience. This mindset is what encouraged me to examine both the positive and negative aspects of the sibling experience, allowing the research to reveal a more comprehensive outlook of their daily lives. During the data analysis process, however, the passion that some of the participants had in telling their story and their hardships made it very difficult at times to keep the positive moments in mind. Coming from an applied psychology background, and believing in therapy and supports, I too became passionate and wanted to help these siblings as best I could. This became evident for myself during the interviews where I made comments fit for therapy rather than asking more questions to gain more information on their experience. This was corrected by always having a print out of the interview guide and taking notes that directed me to questions rather than defaulting to my instinct of providing counselling. Despite having some emotional involvement, my supervisor continually stressed the importance of relying on the data and being objective rather than relying on how I felt when reading the transcripts. Keeping my objectivity entailed going back to the original transcripts and examining the contexts of the data and making sure that my analysis relied on the data rather than how the excerpts made me feel.

Growing up in a Caucasian, working class family, and gaining much success as a student-athlete, though I have faced numerous challenges, none have compared to what I heard from these participants. Thanks to these siblings of individuals with FASD, I have gained much awareness about the world of developmental disabilities during this research journey. First, though I had an idea of the hardships these siblings undergo on a daily basis, I was taken aback by the magnitude of the behaviours and the worries that these participants faced. Secondly, I was educated on the stigma surrounding disability and how for FASD, stigma is also extended to parents and families. I found it especially insulting for adoptive families who have opened their

homes and their hearts to raise these children as best they can. Last, as a catholic, my view of humanity has been upheld as the majority of siblings, despite the hardships, were able to find positive reasons for why these individuals have come into their lives. Though it may have been difficult at times, the participants were able to forgive their sibling without reason, accept their downfalls, and chose to love and embrace their sibling. Participants have undoubtedly inspired me to become more accepting of others, to cherish positive moments in my life, and to be an advocate and continue to help families of those with developmental disabilities.

### **1.5 Purpose**

The purpose of this research was to examine the experiences of the siblings in families that have children with FASD. Instead of asking parents about the sibling relationship resulting in assumptions and secondary data, this study aimed to gather primary data by interviewing the sibling about his/her own thoughts, feelings, frustrations, successes and reactions towards living with a brother or sister who has been diagnosed with FASD. A mixed-methods approach was employed in order to gain both quantitative as well as qualitative data, which helped to elicit a broader, more complete understanding of the impact of everyday life for siblings of children with FASD. All of the data gathered over the course of this study may enable researchers, as well as clinicians, to more fully understand siblings' lived experiences as well as how they are adapting to living with a brother or sister with a disability. Aside from gaining knowledge about the sibling's experiences, the goal of this study is to provide insight into how supports should be tailored in order to help this population.

### **1.6 Rationale of Research**

There is a gap in the literature in regards to siblings and how they are affected by their brother or sister diagnosed with FASD. Studies that have examined siblings' experiences for

other developmental disabilities have revealed inconsistent findings. The majority of these studies have also focused on secondary accounts, meaning the sibling's feelings/thoughts or opinions are derived from the parents rather than the sibling him- or herself.

In the early 1980s, a movement known as deinstitutionalization began in Canada (Smith, 1981). This movement consisted of closing institutions for individuals with mental health issues as well as developmental disabilities in order to promote community-based residential services (Lemay, 2009). The deinstitutionalization movement required families to have more of a presence in their child's life, whether it would be increased check-ins and phone calls to daily caretaking activities. Although community integration did pose some advantages for those diagnosed with developmental disability (Lemay, 2009), it also created disruptions in families who have to seek and plan long-term caretaking arrangements for when they are no longer able to care for their child. In a study by Watson et al. (2013), 98% of parents of individuals with FASD and 80% of parents of individuals with ASD responded "true" to the question "I worry about what will happen to \_\_\_\_ when I can no longer take care of him or her" which is an expression of concern for their child's caregiving future.

At the same time, it has also been documented that many siblings anticipate greater caregiving responsibilities for their sibling with a developmental disability as their parents age (Greenberg, Seltzer, Orsmond, & Kraus, 1999; Krauss, Seltzer, Gordon, & Friedman, 1996), and take on the role of primary caregivers once parents are no longer able to do so (Bigby, 1997). A study by Heller and Kramer (2009) examined siblings and some of the factors that influenced their involvement and future caregiving expectations. They found that very few families involved the siblings in the planning of their brother or sister's future. However, the siblings who were included in the planning were likely older, more involved in disability activities, and

provided more support to their sibling with disabilities. In this study, 38% of the siblings expected to be the primary caregivers at some point in their brother or sister's life. Within this 38%, the siblings' expectations of assuming the caregiving role was greater if they had more contact with their sibling with a developmental disability, provided them with more support, felt greater caregiving satisfaction, and if their sibling with a developmental disability lived close and was female.

As many siblings may have to take on this role at some point in their life, Heller and Kramer (2009) explained that siblings will likely need supports such as training on how to assume caregiving responsibility, financial support, and printed material on making future plans. In examining the experiences of both child and adult siblings, the present study hopes to gather information for researchers and clinicians to gain more knowledge about caregiving perceptions and what types of supports would facilitate this transition.

Additionally, when there is a disability in the family, it is not only the well-being of the one individual that is affected, but rather all members including the sibling (Conway & Meyer, 2008). It is important that each family member have a voice and can express concern in order to establish where siblings are struggling and where they are flourishing. That said, this study seeks to provide information that will enable clinicians to tailor supports and provide siblings with the tools to create mutual growth and development between them and their sibling.

## **1.7 Methodology**

The present study is part of a larger mixed-methods study examining families of individuals with FASD. The current manuscript-based study was completed using a mixed-methods design, as outlined by Teddlie and Tashakkori (2009), where both qualitative and quantitative data were integrated to provide a more complete understanding of the siblings'

experiences. The use of a mixed-methods approach, or rather multiple types of research methods, minimizes some of the limitations found in using a single type of method, as each model on its own presents disadvantages (Jick,1979). By employing different methods, it also allows the researcher to gain a better understanding of the social phenomena and all of its complexities, strengthening the nature of the study (Greene & Caracelli, 1997). In this present study, siblings were asked to participate in an in-depth semi-structured interview (qualitative data) and to complete two psychological questionnaires (quantitative data), which are described below.

For this study, the qualitative research was informed by a basic interpretive approach (Merriam, 2002), which was applied through the form of a semi-structured interview. According to Merriam (2002), the basic interpretive approach is used when “the researcher is interested in understanding how participants make meaning of a situation or phenomenon” (p. 6). This type of research is based on an inductive approach meaning rather than testing a theory, it aims to generate new theories. This approach will allow for the data of the present study to be gathered and used to build concepts, hypotheses or theories about the siblings and how they are affected by their brothers and/or sisters with FASD. The results obtained using the basic interpretive approach are descriptive, thus, using quotes and conveying the emotions of the participants, which allows the researcher to present a rich view of both the positive and negative experiences of the siblings. Using the basic interpretive approach in this specific study, the author is able to understand the process, perspectives and worldviews of siblings of individuals with FASD. With the methodology presented, this research study will answer the following questions:

What is the lived experience of a sibling living with a child who has FASD?

What are the benefits and drawbacks to having a sibling diagnosed with FASD?

What strategies of adaptation are used by the siblings living with a child with FASD?

### **1.7.1 Methods.**

*1.7.1.1 Procedure.* Individuals aged six years and older without a diagnosis of FASD but who had a sibling with FASD, based on self-report, were invited to participate the present study approved by the REB (Appendix A). Four different methods were used to recruit these siblings. The first was through an already existing pool of participants, whereby parents of individuals with FASD who had previously participated in the larger project were contacted to see if their non-diagnosed child would like to participate in the current study. The second method was through Facebook and other social media sites, where an advertisement was posted on a community agency page referring those who were interested to email the authors for additional details. Third, e-mails were sent to parent support groups, and last, respondent-driven sampling was used which is when the participants themselves refer individuals they know. There were 13 siblings who participated in the study, nine who completed both the interview and the questionnaires, one who only completed the interview, and three who only completed the questionnaires. Participant demographic information can be found in Table 1.

**Table 1. Participant Demographic Characteristics**

Demographic Characteristics	
Characteristics of Participant Siblings (N)	13
Average age (SD)	18.5 (7.8)
Age Range	11-37 Years
Gender	
Male (n)	6
Female (n)	7
Relationship to Sibling with FASD	
Biological (n)	0
Half-Sibling (n)	1
Adoptive (n)	12
Children in the Family	
Average number of children (SD)	3.6 (2.2)
Range of number of children	2-9
Siblings with FASD	
1 sibling with FASD (n)	10
2 siblings with FASD (n)	1
6 siblings with FASD (n)	1
7 siblings with FASD (n)	1
Average age of sibling with FASD (SD)	20.4 (7.6)
Range of age of sibling with FASD	12-42 Years

**1.7.1.2 Qualitative Interviews.** The interview guide consisted of approximately 19 questions, with some follow up questions if needed (See Appendix B for full interview guide). Based on the findings from studies that have examined parents raising children with FASD (Scorgie & Sobsey, 2000; Taunt & Hastings, 2002), researchers have acknowledged that it is important for parents participants to not only express their struggles but to shed some light on the positive aspects of their situation, and where they have benefited from their experience. In learning from these studies, the interview guide was developed so that siblings too could explain both the positive aspects as well as the more difficult areas of living with a sibling diagnosed with FASD. The questions that were developed were mostly open-ended, for example “How would you describe your sibling?” or “What is the best/most difficult parts of being a sibling to \_\_\_\_\_?” This style of open-ended questioning helped to prevent any single “yes” or “no”

answers, and was designed to encourage the siblings to provide an answer with as much information as possible. This approach also allowed room for dialogue and prompting questions. Finally, an open-ended format also prevented the researcher from leading the participant to answer in a specific way (e.g., positive or negative), ensuring that the experience was told from the participant's perspective. Interviews were conducted in-person, over the phone, or via Skype and lasted between 20 minutes and two hours.

All of the semi-structured interviews were digitally recorded and transcribed verbatim. Transcripts were then analyzed using interpretative phenomenological analysis (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith, Flowers, & Larkin, 2009). This form of analysis "is concerned with the examination of human lived experiences" (Smith et al., 2009, p. 32). During this analysis, the interview transcripts were reviewed several times to become familiar with their content. Notes pertaining to the ideas (e.g. tantrums, behaviours, caretaking, etc.) were then added in the margins in which reoccurring concepts were noted down for each and every interview. The researcher then compared each individual transcript and looked for common concepts across all interviews. From this process of comparison, themes and sub-themes were created, whereby similar concepts were grouped together (Smith & Osborn, 2008, while concepts that were not able to be grouped were either not included in the study or introduced in the discussion. Additionally, data that presented discrepancies, by not corresponding whether with the interviews or the quantitative data were explained in the chapters. To conclude the process, within each individual theme and sub-theme, original data or testimonials were incorporated to give the themes more depth, and the readers a better understanding of the experience. Ideas expressed by the majority of participants were explained in two separate chapters. Chapter one focused on the various emotions related to the siblings' experience and the

second chapter focused on sibling adaptation. It is important to note that a similar research project comparing FASD and ASD was conducted with the same transcripts, that said, both analyses were compared and found to be similar.

**1.7.1.3 Questionnaires** – Participants were asked to complete two questionnaires that were mailed to them either prior to or after the interview was conducted. The two questionnaires were selected for a few reasons. First, the measures are intended for use with children and youth, 6-16 years, which permitted the researcher to interview both younger and older siblings. Second, they both have been shown to have good psychometric properties; and last, the items in both questionnaires explored the negative and positive aspects of the siblings' experiences. As will be discussed later, these questionnaires were examined at the item level and used in conjunction with the qualitative interview to gain a better understanding of the siblings' relationship quality and their strategies to achieving adaptation.

*a) Sibling Inventory of Behaviour Scale (SIB, Hetherington, et al., 1999; Schaefer & Edgerton, 1981)* – The SIB is a 64-item questionnaire that assesses the relationship quality between a sibling and their brother or sister with a disability as seen in Appendix C. The first 32 items asks the child to rate their sibling's behaviour towards them, and the following 32 items to rate their behaviour towards their sibling. The 64 items are answered on a 5-point Likert scale that ranges from 1 (never) to 5 (always). All items are divided into six subscales. The positive involvement scale includes three subscales: Companionship (6 items), Empathy (5 items), and Teaching/Directiveness (4 items), and the negative involvement scale also includes three subscales: Rivalry (7 items), Aggression/Conflict (5 items) and Avoidance (5 items). Reports of Cronbach's alphas are acceptable and range from .67 to .88 across subscales (e.g., Hetherington et al., 1999).

*b) Daily Hassles and Uplifts Scale* (Giallo & Gavidia-Payne, 2006) – This questionnaire consists of 67 self-report items that measure the frequency and intensity of 43 hassles and 24 uplifts, as seen in Appendix D. All items are answered on a 5-point Likert-type scale, where higher scores on the hassle items indicate greater perceived stress; and greater positive affect for the uplift items. Some Hassle items include “When we go out, I don’t feel “normal” because people are staring or looking at us” and “In my family I worry that my mum and dad don’t get enough rest because of my brother or sister with a disability”. Uplift item examples are: “With my friends, they show an interest in my brother or sister with a disability” and “My brother or sister with a disability does cute things”. In Giallo and Gavidia-Payne’s (2006) study, they reported Cronbach’s  $\alpha$  coefficients for Hassles-Frequency ( $\alpha = 0.88$ ), Hassles-Intensity ( $\alpha = 0.92$ ), Uplifts-Frequency ( $\alpha = 0.88$ ), and Uplifts-Intensity ( $\alpha = 0.93$ ), all which demonstrate high internal consistency. This scale allowed the researchers to determine how siblings were affected on a daily basis, both negatively and positively, which minimizes a one-sided or biased image of sibling experiences.

All questionnaire data were entered into IBM SPSS Statistics software. Subscale scores from both questionnaires were calculated, along with descriptive statistics for each question. Because of the small sample size and in order to triangulate the qualitative data, questionnaires were evaluated at the item level and used to support the qualitative analysis. According to Creswell and Tashakkori (2007), the integration of two distinct strands of research findings, such as qualitative and quantitative data, while presenting analysis and interpretation of the results, are recommended in the creation of a good mixed-methods study. Thus, items whereby a clear majority of participants answered similarly were represented within the qualitative theme. These

additional data were used to demonstrate the themes and to better describe the siblings' overall experience of living with a brother or sister diagnosed with FASD.

## **1.8 Conclusion**

Living with a child who has FASD has been shown to impact a family in numerous ways. Although many families have experienced both positive and negative aspects of raising these children, the “family” studies that have been conducted have focused on the parents' experiences and not the other members of the family such as the siblings. Based on previous research of siblings of children with various developmental disabilities, siblings are significantly affected and do live a different daily life than other siblings who do not have someone with a disability in the household. Therefore, this exploratory study aims to first employ a mixed-methods analysis to identify how the siblings of individuals with FASD are affected, which will be presented in chapter two. Secondly, researchers will identify the facilitators to adaptation that siblings are employing, which will be described using Thematic Analysis in Chapter 3. Subsequently, a discussion encompassing both studies will portray how this study relates to the literature and recommendations will be made for both clinical implications and future research.

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## **Chapter 2**

**“He's fun to have around when he's in a good mood” The Experience of**

**Having an Adopted Sibling diagnosed with FASD**

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### Abstract

The purpose of this paper was to explore both positive and negative experiences of siblings living with an adopted brother or sister diagnosed with Fetal Alcohol Spectrum Disorder (FASD). The current study employed a mixed methods design, informed by Merriam's (2002) Basic Interpretive Approach. Thirteen siblings completed a semi-structured interview as well as two questionnaires, the Sibling Inventory of Behaviour Scale (SIB) and the Daily Hassles and Uplifts Scale (DHUS). The semi-structured interviews were analyzed using Interpretative Phenomenological Analysis (IPA), which generated five major themes: frustration, worry/fear, resentment, happiness, and personal growth. Each theme is discussed in detail and supported by the questionnaire results. The findings suggest that although siblings experience many stressors living with a sibling diagnosed with FASD, there are still many positive moments that shape their experience. Research considerations, clinical implications, and future direction for FASD sibling research are discussed.

**“He's fun to have around when he's in a good mood” The Experience of  
Having an Adopted Sibling diagnosed with FASD**

Many researchers have tried to gain a better understanding of the lived experiences of families raising a child diagnosed with a developmental disability. With the deinstitutionalization movement beginning in the 1960s, family studies on already existing developmental disabilities such as Autism and Down Syndrome began to emerge. Nevertheless, other disabilities such as FASD, which was officially recognized in 1973, have only recently begun to be investigated. That said, the following chapter will add to previous literature by studying the experience of siblings of individuals diagnosed with FASD. To date, this population has rarely been the focus of research studies in the field of psychology, and therefore there is much to learn, specifically in terms of both the challenges and benefits of being raised with a sibling diagnosed with FASD.

Studies report that regardless of diagnosis, families raising a child with a developmental disability are highly impacted by their experience, and show higher levels of maternal stress (Hanson & Hanline, 1990), overall stress on marriages (Corman & Kaestner, 1992; Joesch & Smith, 1997; Reichman, Corman, & Noonan, 2004), financial difficulties (Cuskelly, Pulman, & Hayes, 1998; Kuhlthau et al., 2005; Newacheck & Kim, 2005; Rosenzweig et al., 2008), significantly higher levels of negative affect, marginally poorer well-being, and more somatic symptoms than parents of children without disabilities (Ha, Hong, Seltzer, & Greenberg, 2008). When looking at family studies from 2000-2007, there is a trend where most studies have focused on the less favorable aspects of raising a child with a developmental disability (Turnbull, Summers, Lee, & Kyzar, 2007), but this trend is beginning to shift. Recently, numerous studies have examined the quality of life (QOL) of families raising children with a disability (Gardiner & Iarocci, 2012), where parents describe many positive changes such as personal growth,

improved relations with others, changes in philosophical or spiritual values (Scorgie & Sobsey, 2000), and an “appreciation of the gifts of people that others take for granted” (Schall, 2000, p. 420).

Researchers who have studied FASD have reported that these families’ stress levels increase with particular child characteristics, such as impaired executive functioning and higher levels of internalizing and externalizing behaviours (Paley, O’Connor, Frankel, & Marquardt, 2006), a lengthy diagnostic process (Sanders & Buck, 2010; Watson, Hayes, & Radford-Paz, 2011), as well as with family characteristics such as biological status and lower levels of resources (Paley et al., 2006). Watson, Coons, and Hayes (2013) found that parents of children with FASD were experiencing significantly more stress compared to parents of children with Autism, as measured by the Parenting Stress Index (PSI). In a follow up qualitative study, Watson, Hayes, Coons, and Radford-Paz (2013) reported that the parents of individuals with FASD focused on their children’s illegal behaviours as a specific stressor. Although there may be similarities between disabilities and their effect on the family, individual differences such as the type of disability as demonstrated above, is likely to yield a unique family experience (Gupta, 2007; Olson, Jirikowic, Kartin, & Astley, 2007), which emphasizes the importance of researching specific populations.

An important population to consider, and specific to the current study, is the adoption system. Studies have determined prevalence rates and estimated that 9.1 children per 1000 live births in both Canada and the United States are affected by FASD (Canada FASD Research Network, 2015; Chudley et al., 2005; Health Canada, 2006; Streissguth, 2007). However, Dicker and Gordon (2004) have suggested that approximately 80% of infants in foster care have been exposed to drugs and/or alcohol prior to birth. With such a high prenatal alcohol exposure rate, it

is likely that many children in the foster care system are affected by FASD, making these families and their experience of interest to researchers. Studies have shown that adoptive parents who are unaware of their child's disability can become frustrated, anxious, second guess their parenting skills, and become disappointed in their child (Nagler, 2003; Williams, Dubovsky, Merritt, 2011). Other adoptive or foster parents generally feel good about their experience, with parents reporting that "caring for their children is a challenging but highly rewarding experience when they are provided with services tailored to their and their children's needs" (McCarty, Waterman, Burge, & Edelstein, 1999, pp. 576-577).

### **2.1. Sibling Research**

A mother, a father and child(ren), is generally what constitutes a traditional family; however, most of the "family" studies cited above focus specifically on the mother, not including the father or the siblings. Despite the lack of siblings reporting in the family studies mentioned above, some researchers have addressed the sibling experience through both primary and secondary accounts. However, most sibling studies have focused on negative results such as stress levels, and there are many inconsistent findings. Specifically researchers have found that siblings reported spending more time in caregiving activities, experienced more maternal negativity, had poorer adjustment (McHale & Gamble, 1989), and showed higher levels of embarrassment and social stigma (Wilson, McGillivray & Zetlin, 1992). Due to the demands of parenting a child with a developmental disability, McGinty, Worthington and Dennison (2008) suggested that siblings are more likely to spend less time with parents and that a change in family priorities, such as fewer vacations and fewer resources allocated to the sibling's needs, is highly probable. Other research studies, although dated, have reported that siblings of individuals with developmental disabilities are more likely to have behavioural disturbances (Bågenholm &

Gillberg, 1991; Cuskelly & Dadds, 1992; LeClere & Kowalewski, 1994), and a higher prevalence of mental health issues than siblings of children without a disability (Pollard, Barry, Freedman & Kotchick, 2013; Rossiter & Sharpe, 2001). It is important to note however, that some of these studies (e.g., LeClere & Kowalewski, 1994; Cuskelly & Dadds, 1992) relied on secondary data, meaning that parents were the ones to report on their child's behaviours and attitudes in relation to their sibling with a developmental disability rather than the sibling themselves. It is therefore likely that the data presented in such studies may not reflect the true sibling experience, but rather, what parents believe their child's experience to be. By using both solely negatively-based constructs and reports from individuals other than the siblings themselves, it is likely that a skewed vision has been presented of what it is like to live, on a daily basis, with someone who has a developmental disability.

As is reported in the parent literature, there also appear to be different sibling experiences when comparing specific developmental disabilities (Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001). For example, when comparing both siblings of individuals with Down Syndrome and those of Autism, the former group is likely to have closer and warmer relationships with their siblings (Hodapp & Urbano, 2007), whereas in Autism, their relationships are characterized by less intimacy, less prosocial behaviour, and lower levels of nurturance when compared to the former group (Kaminsky & Dewey, 2001). Due to the greater focus on both Down Syndrome and Autism research, when searching the literature for the sibling perspectives of those living with a brother or sister with FASD, there is little research to review. Of the existing literature, a study by Brown, Sigvaldason, and Bednar (2005) asked foster parents what they needed in order to successfully raise a child with FASD and the researchers created a concept map based on the parents' answers. Within this concept map, two points were directly related to other siblings in

the household: “Support for biological children” was in the Other Foster Parent concept and “Explain FASD to other children in the home” was in the Understand FASD concept. Although siblings are discussed, it is a reflection of the parent’s experience and needs, not the siblings’ viewpoints. Even so, results suggested that having siblings acquire more knowledge about FASD may be beneficial to fostering a more positive experience and help them cope with their unique situation (Conway & Meyer, 2008; McCullough & Simon, 2011). Researchers have expressed that there is a need to expand the literature on siblings living with a brother or sister with FASD (Olson, Oti, Gelo, & Beck, 2009), which is the purpose of this study.

## **2.2 Methodology**

As part of a larger mixed-methods study examining families of individuals with FASD, the current study specifically studied the siblings’ experiences. In order to gain a better insight into their experiences, siblings participated in an in-depth semi-structured interview and completed two psychological questionnaires, described below. The integration of both qualitative and quantitative data (Teddlie & Tashakkori, 2009) sought to minimize the limitations caused by conducting a solely qualitative or quantitative study (Jick, 1979), and strengthened the research by examining all of the intricacies within this particular social phenomena (Greene & Caracelli, 1997). Incorporating both methods of data collection also provided more information, which allowed for a rich and detailed description of the sibling experience.

**2.2.1 Participants.** Individuals aged six and older without a diagnosis of FASD but who had a sibling with FASD, based on self-report, were invited to participate in the study. To recruit these siblings, researchers were able to access an already existing pool of parents of individuals with FASD, who had previously participated in the larger project. Messages were posted on social media sites, e-mails were sent to parent support groups, and respondent driven sampling

was also used. In total, 13 siblings participated in the study, nine who completed both the interview and the questionnaires, one who only completed the interview, and three who only completed the questionnaires. Though both adoptive and biological siblings were recruited, aside from one half-sibling, only participants with an adopted sibling with FASD sought participation in the study. Participant demographic information is presented in Table 1.

***Table 1. Participant Demographic Characteristics***

<b>Demographic Characteristics</b>	
Characteristics of Participant Siblings (N)	13
Average age (SD)	18.5 (7.8)
Age Range	10-37 Years
Gender	
Male (n)	6
Female (n)	7
Relationship to Sibling with FASD	
Biological (n)	0
Half-sibling (n)	1
Adoptive (n)	12
Children in the Family	
Average number of children (SD)	3.6 (2.2)
Range of number of children	2-9
Siblings with FASD	
1 sibling with FASD (n)	10
2 siblings with FASD (n)	1
6 siblings with FASD (n)	1
7 siblings with FASD (n)	1
Average age of sibling with FASD (SD)	20.4 (7.6)
Range of age of sibling with FASD	12-42 Years

**2.2.2 Qualitative Interviews.** The qualitative component of the study was informed by the basic interpretive approach (Merriam, 2002), an inductive method which aims to understand “how participants make meaning of a situation or phenomenon” (p. 6). Due to the exploratory nature of this study, using an inductive approach allowed the researcher to generate main concepts outlining the siblings’ experiences based on the data provided during the interviews.

The semi-structured interviews, which were conducted in-person, over the phone, or via Skype, consisted of 19 questions with follow-up questions asked if needed, and lasted between

20 minutes and 2 hours. Given the importance of a wholesome view in a research study, that is incorporating both the positive and negative (Scorgie & Sobsey, 2000; Taunt & Hastings, 2002), siblings were asked to express their struggles and concerns as well as the benefits and positive moments associated with their unique experience. The questions that were asked during the interview were mostly open-ended, for example “How would you describe your sibling?” or “What is the best/most difficult parts of being a sibling to \_\_\_\_\_?”, ensuring that the experience was told from the participant’s perspective. This style of open-ended questioning encouraged the siblings to provide as much information as possible, allowed room for dialogue and follow-up questions, and prevented the researcher from leading the participant to answer in a specific way (e.g., positive or negative).

After digitally recording and transcribing the semi-structured interviews verbatim, transcripts were analyzed using interpretative phenomenological analysis. (IPA; Shaw, 2010; Smith & Eatough, 2008; Smith, Flowers, & Larkin, 2009). To begin, transcripts were reviewed and concepts were created within each individual interview. Subsequently, all transcripts were compared and similar concepts were grouped together to create themes and sub-themes (Smith & Osborn, 2008), while concepts that were not expressed by the majority were either mentioned in the discussion or not included in the analysis. The analysis was then conveyed to the reader descriptively with the incorporation of original data and quotes to add depth and provide a better understanding of the experience of living with a sibling diagnosed with FASD.

**2.2.3 Questionnaires.** Participants were asked to complete two separate psychological questionnaires pertaining to their relationship with their sibling diagnosed with FASD. The two questionnaires were selected due to the ages of normalization in which the age range was larger than other questionnaires (6-16 years), their strong psychometric properties, and item contents,

which explored both negative and positive aspects of sibling experiences. Due to the small number of participants, the questionnaire data were examined at the item level and were used in conjunction with the qualitative data to gain a better understanding of the siblings' relationship and their overall experience.

**2.2.3.1 Sibling Inventory of Behaviour Scale (SIB, Hetherington, et al., 1999; Schaefer & Edgerton, 1981).** The SIB is a 64-item questionnaire that assesses the relationship quality between a sibling and their brother or sister with a disability. The first 32 items ask the child to rate their sibling's behaviour towards them, and the following 32 items asks them to rate their behaviour towards their sibling. The 32 items are answered on a 5-point Likert scale that ranges from 1 (never) to 5 (always). Cronbach's alphas ranges from .67 to .88 across subscales, and are therefore, considered acceptable (Hetherington et al., 1999).

**2.2.3.2 Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006).** This questionnaire consists of 67 self-report items that measures the frequency and intensity of 43 hassles and 24 uplifts including: "When we go out, I don't feel "normal" because people are staring or looking at us" and "With my friends, they show an interest in my brother or sister with a disability". All items are answered on a 5-point Likert-type scale, where higher scores on the hassle items indicate greater perceived stress, and greater positive affect for the uplift items. Giallo and Gavidia-Payne (2006) reported Cronbach's  $\alpha$  coefficients ranging from 0.88-0.93, which demonstrates high internal consistency.

All data were entered into IBM SPSS Statistics Version 22.0. (IBM Corp., 2013). Single questionnaire items were analyzed, and percentages based on the responses were calculated. Given the calculations, we were able to determine if the majority of siblings responded in the middle of the scales or at the extremes. To maintain transparency, both items that did and did

not support the qualitative data were incorporated within the qualitative theme. The use of quantitative data was not only integrated to support the interview analysis and better describe the sibling's experience, but it was also used in order to triangulate the qualitative data and increase validity. Additionally, following the analysis, member checks were conducted, whereby a brief summary of the results were e-mailed to participants who completed the interview. During this exchange, researchers stressed the importance of properly conveying the sibling experience. That said participants, were asked to examine the results and provide feedback or propose changes if they disagreed with any of the material. Of the 10 participants who completed the interview, one e-mail was no longer in service, four of them did not respond, and the remaining five participants expressed no concerns and agreed with the information provided in the analysis.

### **2.3 Results**

Siblings, whose characteristics are presented in Table 2, were very open and eager to share their experience of what it is like to live with a brother or sister diagnosed with FASD. Throughout the semi-structured interviews, siblings were invited to share their whole experience with the researcher. That is, unlike some previous studies, participants were able to highlight the benefits or the “good” parts, as well as the downfalls or the “bad” parts of being a sibling to someone with FASD. During their interviews siblings described numerous feelings and emotions, which were categorized into five main themes using IPA. Siblings highlighted their frustrations (e.g., disability characteristics, society's lack of understanding), their constant worry (e.g., health and safety, future caregiving), their feelings of resentment (e.g. lack of resources, one- sided relationships), as well as happiness (e.g., bonding, success), and personal growth (e.g., building character, advocacy). Each of these themes is discussed next in further detail and illustrative quotes are used to demonstrate each theme.

**Table 2. Interview Participant Characteristics**

Pseudonym	Age	Number of Siblings with FASD
Sarah	10	1
Alyssa	11	1
Matthew	13	1
Zack	15	1
Bradley	17	1
Samantha	19	1
Katie	22	7
Brianne	25	6
Shawn	29	1
Sydney	37	2

It is important to note that throughout the interview some behaviours, such as their sibling's poor emotional control (i.e. tantrums), elicited numerous emotions depending on their situation and how they were viewed. For example, the poor emotional control caused frustration when they were towards the participants, and when their siblings were judged for them. These outbursts also elicited feelings of worry and fear for parents as they elevated their stress levels and could be physically hurt. As such, this particular behaviour is mentioned in various themes. That said, although the behaviours are similar, the emotions that are activated vary in nature and are thus described differently. Therefore, behaviours such as poor emotional control contributed to the sibling's experience in many different ways, and are described in different themes.

**2.3.1 Frustration.** Throughout the semi-structured interviews, participants reported feeling frustrated on numerous occasions, explaining that their anger is often triggered by their siblings' mood swings and subsequent behaviours, which they can experience on a weekly and sometimes daily basis. Siblings also spoke about being vexed by other people's reactions to their siblings, due to society's lack of understanding of FASD.

**2.3.1.1 "Walking on Eggshells" – Siblings with FASD and their mood.** All of the siblings who were interviewed made it clear that it can often be difficult to live with a sibling

diagnosed with FASD. For many siblings, their greatest frustration revolved around their sibling's mood and behaviours. On the SIB, two siblings reported *sometimes* and seven siblings reported *often/always* when it came to their siblings being mad at them; concurrently, five participants responded *sometimes* and five responded *often/always* to getting angry at their sibling with FASD. To demonstrate, 29 year-old sibling, Shawn, referred to his sibling's behaviour as a "lack of emotional control". In describing his childhood and reaction to his sister's tantrums he explains: "...it's really not easy to want to spend time with someone when you know, the slightest provocation will lead to an hour of yelling".

Numerous other participants described their frustration towards not knowing why their sibling's mood changed, as well as at their inability to resolve the issue or calm down their sibling. When asking 10-year old Sarah to describe the most difficult parts of being a sibling to someone with FASD, she explains that the motive behind the tantrums can be confusing. She elaborates, "sometimes she's not reasonable...when she gets mad at me for no reason I don't know how to fix it because I don't know why she's mad at me." Even after the tantrums have stopped, some participants still struggled with how their sibling's mood had affected their own. Due to the initial frustration that was felt by siblings during the outburst, when the tantrum suddenly stopped, these feelings of frustration had already had an impact on their mood, making it difficult to instantly forgive their now happy sibling and move on. Shawn describes this dilemma:

...she flips in terms of her mood so she can go from yelling at you, you know, three hours, and then something good happens and her mood shifts all the way back to the other side and so trying to balance that and not hold it against her when she's feeling good again and you still feel angry.

Thus, like Shawn mentions, the sudden shift in his sibling's mood, from angry to happy again, is very irritating as participants are left feeling frustrated towards their sibling while he or she is now happy. Although the struggle with their sibling's emotional regulation was frustrating to them, siblings did not believe that the individual with FASD should be judged for their behaviours stemming from the disability itself. In fact, there was much frustration towards society and the public's view of their brother or sister diagnosed with FASD.

**2.3.1.2 “She is just like the rest of us, she just has a disability!” – Public's lack of knowledge of FASD.** On the DHUS, 4 siblings responded *sometimes* and eight siblings answered *often/always* to “I can trust they [my friends] won't make fun of me or tease me because of my brother or sister with a disability”; also, two participants responded *sometimes* while seven participants reported *never/rarely* to “I have to talk about my brother or sister's disability or illness”. Although participants do not have to talk about their sibling's disability often, as results suggest, the semi-structured interviews revealed that many people simply do not understand the disability or why their siblings behave in such a way, which could explain why it is not a topic of conversation. Though two individuals in the interviews did report these tantrums to be embarrassing in public, on the DHUS, three of the siblings reported feeling upset *sometimes*, and six *often/always* to “when we go out...my brother or sister with a disability draws attention to us”. However, based on the interviews, the feeling “upset” does not seem to be towards the siblings but rather towards the public who responds to their sibling's behaviours by staring, by judging the siblings and their parents, and essentially by declaring that they are “not normal”. Despite sadness being a common emotional reaction to such judgements, these participants are frustrated because they know the truth, which is that it is not their sibling, it is not their parents, but rather it is the FASD. Thus instead of feeling sad and hurt they are angry,

and just want others to understand that it is the neurological disorder and that their sibling cannot help his or her behaviours; it is not their fault.

Participants who spoke about society's lack of knowledge referred to a large pool of individuals, such as the general public, peers, and even family members such as grandparents and other relatives. Although the scores were scattered across the DHUS scale, yielding mixed results for how often and how upset "People stare and look at us" made the participants feel, Sarah explained that when her sister with FASD would have a temper tantrum in public:

they stare, they react... they see that my mom's trying to calm her down so most of the parents know that she has a disability...but if they look at her strangely... I just want to, I feel mad because she is like the rest of us, she is, she just has a disability!

In Sarah's explanation she understands that people are going to look when her sibling is having a tantrum and many are aware of her sister's disability, but it is when they stare at her strangely that is offensive to her. Sarah knows that her sister is unable to control her behaviour and this is normal to her, and so it is puzzling to her that others would not understand and would give her sibling strange looks. Thus, instead of being embarrassed by her sister's behaviours, she is frustrated by other people's lack of caring and understanding.

Samantha, 19, who also spoke about the troubles of being in public or having people see her sister's tantrums, stated that even when she tries to educate others on FASD and how it affects her sister, they still cannot grasp it because they either do not care enough to listen or it is just difficult for them to understand FASD in general. Samantha explains how this lack of understanding and the fact that her sister is different has a major impact on both her and her sister's life at school:

...the only people she is friends with are like, not to put them down but the bad kids right?... They're all doing drugs and drinking in school...these are the kind of kids she's friends with and not because she wants to be, she doesn't even like them, it's because they're the only people that want to be friends with her...because she is just that small level of different that they [her peers] just kind of shun her which is, it's really sad to watch actually.

In her statement, Samantha feels terrible for her sibling and is frustrated at how her sister's peers reject her because she is different from them. They do not understand her disability and instead of trying to get to know her, they judge her. This shunning leaves her to befriend individuals who are likely poor influences, especially for an individual with FASD.

Similarly, 25 year-old Brianne, who has six siblings with FASD, explained her frustration towards her peers in high school because of their lack of understanding:

I knew what the other kids were thinking. They would come to me and be like why is your sister so weird? Like why doesn't she get this?... It takes her a few times for her, she has to go through these steps over and over again so I mean, you guys just have to chill out, you need to relax.

Although Brianne explained that it was difficult to watch others call her sisters "retarded", she stood firm and stated, "My sisters are not retarded! They might be slower but where they lack in certain things they are so much stronger in other things." This protective stance where siblings stick up and want to take care of their brother or sister with FASD was frequently seen throughout the interviews, and will be discussed later in further detail.

Whereas Sarah, Samantha, and Brianne's frustration stemmed from others judging their sibling, other participants went one step further and were frustrated with the judgments put on

their parents. Although his thoughts were speculative, Zack highlights his parents when talking about his sister's tantrums: "...it just gets annoying when people just stare at her then they stare at us because they think my mom and dad...taught her to be like that." Again, although the responses varied across the scale on the DHUS when referring to people staring at their sibling in public, this testimony highlights a discrepancy between the information gathered by both methods of data collection. In fact, this emphasizes the importance of incorporating both quantitative and qualitative data as methods of data collection, as it allows the researcher to detect these discrepancies and identify relevant information that may not be provided by the one or other method.

In relating the interviews with the previously mentioned scale items, it is not the "typically" developing siblings who are getting teased, it is those with FASD and their parents who are judged, endorsing much frustration towards the public. Additionally, although siblings may not have to talk about their brother or sister's disorder with peers, it is clear that they would like society to be more knowledgeable and understanding of individuals with FASD. By reducing the negative judgements made on their family, it would help to redirect their time and energy on helping their siblings with FASD, as many of their behaviours already cause frustration and a plethora of other emotions without the public's negative judgements.

**2.3.2 Worry/Fear.** During the interviews, participants often expressed worry when speaking about their experience of living with a brother or sister with FASD. In this study, one participant indicated *sometimes* and eight indicated *often/always* on the SIB that they are concerned for their sibling's welfare and happiness, and this worry was apparent in a variety of concerns that they raised during the interviews. Given that individuals with FASD are often impulsive and have difficulty following direction, for example, the majority of this fear stemmed

from their sibling's behaviours that threatened their well-being as well as the health and safety of their parents. These behaviours ranged from running away from home, to addiction, to physically assaulting those around them. Last, siblings reported worrying about their roles in the future caretaking of their brother(s) and/or sister(s) with FASD.

### ***2.3.2.1 "We worried about everything" – Health and Safety of Sibling with FASD.***

When speaking to some of the behaviours exhibited in individuals with FASD, participants described the mood swings along with a number of other distressing behaviours. Some participants reported that their brother or sister with FASD was involved in early sexual experiences, unwanted pregnancies, running away, depression and suicide, anxiety, addictions such as alcoholism and gambling, and refusing or continually forgetting to take medication causing serious damage to their physical health. Thus, the behaviours mentioned, and many others that were part of their sibling's conduct, caused participants to fear for their sibling's safety as well as the safety to those around them. With that, siblings maintained worrying on a daily basis about their sibling with FASD and what kind of trouble they were getting into or about to get into.

When it came to his sibling's health and safety, Zack explained that he was scared for his sister's well-being when she was out in public while his parents were not there to protect her from others or the law. He states: "Just being in public she may like have a tantrum and if she's an adult and she has a tantrum, in public, cops are probably going to put her in like a detention". As individuals with FASD have poor emotional regulation (Bjorkquist, Fryer, Reiss, Mattson, & Riley, 2010), they may lash out due to a misunderstanding or an inability to comprehend a specific situation. This inability to control their feelings paired with the public's lack of

knowledge could lead to a number of different situations, such as an arrest or an altercation if no one is there to defend them.

Siblings voiced concerns about their sibling's learning abilities both in general and also specifically to mathematics and their difficulty understanding finances and money. These participants were worried about how their sibling will not be able to find the "deals", and how difficult it will be for them to live on their own and manage money when they are older. For example when asking Bradley what he worries about, he replied "I worry... he's going to go become broke cause any dollar he has he spends it...he has no structure with money".

On top of their difficulty comprehending money, as reported by participants, the siblings with FASD are also very impulsive and have trouble considering the consequences of their actions, such as having a child as a result of sexual intercourse. The combination of these two issues caused siblings to worry about how their sibling would be able to support themselves and their families in the case of an unwanted pregnancy.

Moreover, siblings reported that their brother or sister with FASD engaged in many illegal behaviours, such as driving while impaired, stealing, and threatening or assaulting others. Although these behaviours are worrisome alone, when these types of actions are integrated with the intellectual disabilities, the severity of the outcome increases. For example, siblings worried about homelessness when pairing their sibling's addictions with their brother or sister's poor money management as adults. Other behaviours such as depression, and drinking and driving, elicited worry about their brother or sister being seriously injured, injuring others, or killing themselves or someone else. Not only did siblings fear the maladaptive behaviours mentioned above, but they were very confident in the occurrence of such events. In their interviews, participants had either already witnessed the maladaptive behaviours in the past and reminisced

about the worry they felt at the time, others spoke about the worry they currently feel seeing their siblings struggle with decision making, and some were looking into the future as they were sure unpleasant events would transpire at one point or another. The certainty of the maladaptive behaviours transpiring is extremely worrisome given the repercussions for their sibling (e.g., death, incarceration, homelessness) and for themselves and their family as well. Sydney, a 37 year-old explains her experience with these types of worries having grown up with two older brothers diagnosed with FASD:

...we worried about everything... Sam has a gambling addiction and he did go through a phase of alcoholism... there was a point where he was not able to keep a roof over his head...so that was really scary and with Frank it's always been scary because he's always been in trouble with the law, he's always gotten into fights, he's always had some new pregnant girl, he's always been in big kinds of trouble, the kind that you worry that, is he going to survive kind of thing.

Sibling participants, like Sydney, whose brothers exhibited numerous behavioural issues, were likely to be more severe cases of FASD. As such, she often worried about their behaviours leading to jail time and how they would survive in this kind of environment. However, due to their sibling with FASD's susceptibility towards risk-taking behaviours and poor decision making skills, the participants constantly worried about what kinds of situations their sibling would find themselves in or were going to engage in. If these behaviours were not occurring in the present, they worried about them happening in the future. Given their sibling's disability and the severity of the challenges they are faced with daily, participants continually wonder if their siblings will be able to overcome their adversities, beat the odds, graduate, or hold employment and live a long happy life. Unfortunately, they also pondered the harm that will be done to

others or be self-inflicted by their sibling, and the chances that their sibling will be a victim of their poor choices.

**2.3.2.2 “How much can I take?” – Siblings’ Future Role.** Eight of the siblings acknowledged that at some point their siblings will need help or have to be cared for by someone other than their parents. Although none of the siblings made any official plans for caretaking, two of the siblings stated that they would have their sibling live with them while one participant wanted his sibling to reside in an assisted living environment. Nevertheless, half of the participants showed much distress and concern about playing such a significant role in their sibling’s future. The worry that was elicited was demonstrated through their more assertive yet worried tone, and how much fear they expressed when faced with the question of their role in their siblings’ future. Those who expressed worry were passionate and had plenty to say about what they feared when it came to taking care of their sibling. These siblings were aware of the major responsibilities that came with taking on this role and had some big reservations. Katie and Brianne, who have seven and six siblings with FASD respectively, were particularly overwhelmed with the idea of having to take care of their siblings. Katie, as she is the only sibling in her family not diagnosed with FASD, is fully accepting of the fact that she will be responsible for her sibling’s caretaking and finances when she gets older, regardless of how overwhelming it is. Her fears of this position stem from her siblings’ negative reactions towards her for being her parents’ favourite and ultimately siding with her parents in most arguments. She explains that:

There’s going to be a point where my parents die and I’m going to be responsible for taking care of like finances and I will be there, I will do that. But, I’m actually more terrified of them refusing to come to me because they’re terrified I won’t do anything,

rather than how hard it will be to deal things out and take care of them in a reasonable manner.

Katie also stated that she has nightmares and worries about being the one having to make crucial decisions for health-related issues if or when they arise. On the other hand, Brianne constantly feared having to admit her position on her future role or lack thereof. She stated: “I just, I don’t want to be selfish and say I don’t want to be their caregiver when my parents pass, because I know I don’t. I just picked.... I just think of the amount of stress that I went through as a child...I don’t want to keep dealing with it.” Nonetheless, later on in the interview she says: “I see myself always being involved and voluntary I guess”. It is evident that Brianne is very conflicted; it would be much less stressful and less worrisome if she did not have to be the caretaker of her siblings. However, it is as if she does not feel as though she has a choice in the matter and must be responsible for them, as she is ultimately capable of taking care of them. Thus, contrary to what she would like, it is likely that she will be the one to take care of her siblings when her parents are no longer able to.

Both she and Katie mention that it is not only about their siblings, but their nieces and nephews too. As mentioned earlier, promiscuity or early sexual experiences exhibited by the siblings with FASD were feared by the participants as they can potentially lead to unplanned pregnancies. Given their siblings’ numerous problematic behaviours and cognitions, there is significant difficulty for individuals with FASD to be self-sufficient, let alone take care of a newborn child or even a family as Katie explains:

I worry, my one sister who has two children... the judge just granted the father over night privileges and the father is in the same situation as my sister is and I just, I worry... I know

it's not a safe place, I know it's not a safe environment. I know they won't be nourished as well as they would be if they're with my mother.

The stress of children living with a parent that may not be able to provide for them, teach them good habits, and be there for them as a stable role model, is what these participants and their families fear. That said, siblings like Brianne and Katie are prepared to take on this other role of caretaking if need be. In fact, they have been sensitised to these types of issues by their parents who also provided children with a more stable environment by adopting. When speaking about her nieces and nephews, Brianne states: "I see down the road my sister's two children possibly living with us, I would just love to take them into my home and be their aunt forever". Although the fear of their sibling having a child is worrisome, and taking care of their sibling with FASD might be a burden, this quote emphasizes that regardless of the challenges they would embrace raising their brother or sister's child.

When speaking about the future and caretaking, the remaining half of the participants did not mention it being stressful in their day-to-day life. Some of these participants, likely due to their younger age, admitted that they hadn't yet thought of their future while others stated that their parents were going to take care of their sibling, or that they were going to live in a home. While these participants did not portray themselves playing a caretaking role in their siblings' future at this point, a few others calmly stated that they will have their sibling live with them later on. Though these siblings may still worry or have concerns about the future, they did not express it, which for the latter group may be due a lack of knowledge on the stress that is likely to accompany a guardian role.

In summary, while some siblings expressed few concerns when speaking about future caretaking of their siblings with FASD, others viewed it as a burden and extremely worrisome.

Yet, out of those conveying worry or fear, these siblings still expressed that they will take on the role of caretaker, whether they want to or not. Although the participants expressed a will to raise their sibling with FASD's child, it is not something that they wished for.

**2.3.2.3 “It put a lot of stress on my parents” - Concerns for Parents.** In responding to the DHUS, two siblings responded *sometimes* and six *often/always* to “I worry that my mum and dad don't get enough rest because of my brother or sister with a disability”, showing ample concern for their parents. During the semi-structured interviews the majority of participants spoke about their parents and how difficult it must be to raise a child with FASD.

On a daily basis siblings witnessed their parents tackling the many unpleasant behaviours and experiences (e.g., stealing, substance use) caused by their sibling with FASD. Unfortunately, as a parent, it is difficult to simply walk away from your child or let someone else fix the problem for you, a responsibility that the siblings do not have to face. Thus, although the participants have experienced many difficult emotions as a sibling, they recognize that as a parent it must be an overwhelming and very stressful journey. The perceived parental impact was established in Shawn's interview where he spoke about the effect of the tantrums on his mother. He stated: “...[Tantrums] pushed my mom around to medical disability just from sort of the overall stress, she dealt with it the most” and later reiterates, “[FASD] took a tremendous emotional strain on her for years”. Unlike previous mentions of emotional instability eliciting frustration or worry regarding their sibling's health, this report shifts to how the tantrums lead sibling to worry about their parent's well-being. Shawn explained that he would leave when his sister was having a tantrum but his mother, who was the more involved parent, had to deal with it. He also added that his mother invested hundreds of hours trying to search for how to better deal with his sister. It was almost as if this disorder consumed her, her time, her energy, her

patience, and eventually she became sick. Similarly, Katie stated: “I think my parents feel very hopeless at times and helpless because they don’t know what to do.”

While Shawn and Katie recognized the emotional and psychological strain their parents undergo, Brianne and Katie also acknowledged the physical danger their family faced. When speaking about her sibling’s violent outbursts, Katie stated: “my mother often feels unsafe physically because of Terry’s temper tantrums, where he will threaten to hurt her or break her arm or break down a door and you know, or burn down the house.”

Although the siblings did not specifically use the word worry when speaking about their parents in the interview, their concerns were demonstrated by their behaviours towards them. For example, Samantha spoke about her childhood and explained: “When I was younger it put a lot of stress on my parents like I could see it even at young age. I think that I was probably a better child than I would have been if I had not had a sibling that was affected. Like I was just like I don’t want to cause trouble and I’m going to do my thing.” In this case, Samantha was clearly worried that her parents were under too much stress due to raising a daughter with FASD. In fear of adding to her parent’s stress, Samantha who could have rebelled to get attention, instead adopted positive behaviours to better accommodate her parents and their mental health. This meant being a “good” child and not causing trouble, all so that her parents did not have to worry about her as well. Nevertheless, the fact that Samantha maintained that she consciously thought about her parent’s stress levels during her childhood and subsequently altered her behaviours, demonstrates her worry and her actions to protect her parents.

Two other participants in the study explained how they felt the need to defend their parents to their siblings. Brianne specifically stated: “my sister always yells at my mom so it’s like sis you need to – go step back, step back and just think, this is why she’s asking you this,

these questions... I have to defend my mother, and I have to kind of like calm everybody down". Thus, when disagreements occurred between Brianne's parents and her sibling with FASD, instead of retreating from the situation, she chose to help her parents by calming her sibling down and further explaining their point-of-view. In turn, if she was able to calm them down and get the point across, it would increase cooperation and reduce the stress and tension between both parties. Note that Brianne did not state that she worried about her parents in this quote, but her actions say otherwise. To defend her mother means that she perceived a threat to her at some point, and therefore worried about the outcome such as added stress, and so Brianne came to her aid to appease the situation. Thus, in both of these examples siblings worried about the impact of parenting a child with FASD, and as a result, actively tried to alleviate or diminish their parent's stress levels by not creating more issues or by helping to settle the issues with their sibling.

When asking the participants about coping skills and whom they can talk to, although the majority stated that they are able to talk to their parents, three of the siblings expressed that they limit their approaches or do not want to speak to their parents about FASD because they do not want to add to their stress. Brianne explains: "I don't want to talk to my parents about it because they already have so much to worry about". Similarly, Zack stated that he does not like to speak to his parents because "they know what the frustration is and they deal with it every day so like it's still not equal, they obviously have more of the stuff put onto them because they ultimately have to deal with her in the end". Given these examples, it is evident that the siblings' concern for their parents' stress levels led them to develop other ways of coping instead of talking to their parents.

In all of the examples mentioned above, siblings have verbally expressed concern or altered their behaviours to diminish the burden put on their parents. The messages provided by siblings conveyed their worry about their parent's health and burdens as well as their solutions as they actively seek to reduce their stress levels. Overall the participants worried about their sibling with FASD, themselves, and their parents, making worry a very common emotion that is felt among these participants. In fact, siblings expressed that they did not like worrying about everything all the time. From the researcher's perspective, it was evidently both difficult and challenging to have to worry so often about their sibling. Evidently, the siblings felt similarly as they expressed many concerns with the fairness in the household, and the sacrifices they have had to make for their sibling with FASD.

**2.3.3 Resentment.** In the SIB, five of siblings responded *never* to resenting their sibling while two responded *seldom*, three *sometimes*, and one answered *often* and *always* respectively on the quantitative questionnaire. That said, though five participants indicated they did not feel resentment towards their sibling, the remaining seven siblings indicated that at times they do feel resentment, which was also supported by the semi-structured interviews. While speaking with the participants, many siblings brought to light how their parents expended a significant amount of time, energy, and money on their sibling with FASD, leaving less for the participants. They also maintained that they too sacrificed a lot of time and effort in trying to bond with and care for their sibling. Despite their efforts towards building and maintaining a relationship with their sibling, participants explained that their efforts were rarely reciprocated. It is important to note that siblings never said "I resent my sibling for..." in the interviews, but rather it was their tone, and expression which suggested that there were ill-feelings towards their sibling for the unequal treatment they received at some point or another. Thus, both sub-themes presented below

focused on how they perceived to be treated unfairly in their family as a result of growing up with a sibling diagnosed with FASD.

### ***2.3.3.1 “What about me?” – The siblings with FASD received all of the attention.***

Throughout the interviews, siblings maintained various situations as being unjust, specifically the greater amount of attention directed to their siblings with FASD. The participants’ lack of allocated time and resources from parents was evidenced not only in the interview, but also in the Daily Hassles and Uplifts Scale. In this questionnaire, on the item “I get to spend time alone with my mom and dad while my sib is being looked after by someone else”, seven of the participants responded on the lower half of the Likert scale (Never, Seldom), and four in the middle (Sometimes). These results indicate that the majority of siblings perceived that they are not spending enough alone time with their parents. To add, while drawing from previous themes, if they are always in the presence of their sibling with FASD, then it is possible that they have little time to relax with their parents and instead may continue to experience frustration or worry about parents when their sibling is acting out. Although the time spent with parents was an issue, so was the allocation of resources and the psychological and emotional difficulties they faced that resulted from being raised with a sibling who has FASD.

As discussed in the theme of worry/fear, siblings showed much empathy towards their siblings and their parents. However, participants stressed that there were many hardships to sharing the spotlight with their sibling. Sydney explains her difficulties in terms of resources:

It’s really stressful having two members of the family taking a lot more than they can ever give...my parents are very depleted psychologically, emotionally, financially, and I could use that, those resources myself. You know, there’s only so many resources in a family and there are a couple of family members who get the majority of those resources.

Here, Sydney reveals that her parents spent a lot of what they had on her brothers with FASD, leaving very little time and energy for her. This statement clearly shows that Sydney would have liked to share more experiences with her parents, maybe spend more time or receive more help but was unable to because of her sibling with FASD. Although she clarifies that this was not always the case, she follows up by saying “it’s definitely there”, emphasizing that it is a major part of her life, a stressful part. These circumstances, that is, not being able to receive the care she needed or not being provided with the same opportunities as her sibling with FASD and also seeing her parents in a depleted state, may have fostered feelings of resentment. Samantha too, had to push for what she wanted. She states:

I had to fight for things that I wanted more, like we put a lot of our time and money into all this stuff for her and I asked when I was younger if I could dance and the answer was “no” because we couldn’t afford it. But I kept pushing and pushing and pushing and then for 5-6 years I did dance...

In both of these examples, their parents had to spend more of their resources on their siblings with FASD instead of them, noticeably affecting the participants. This kind of discrepancy where the siblings diagnosed with FASD got more than the others was also explained in terms of “getting away with things”. For example, Samantha explains that although it is easier to comprehend now, when she was younger it was difficult to understand why her sibling did not get repercussions when acting out, but she would. As adults, siblings are able to rationalize their brother or sister’s behaviours as it being the disability, and are able to tell themselves as their sibling is acting out “It’s because of the FASD”. However, as a child this is something that it very difficult to do. Although they may know that their sibling is different at a young age, when their sibling with FASD is receiving special treatment and he or she is not, it is

conceivable that a child think it incredibly unfair, regardless of their sibling's difference. This unequal dispersion of attention, in turn, may foster feelings of resentment towards both their parents and their sibling. Despite growing older and being able to direct the anger and resentment towards the FASD itself, it is unavoidable that they will at times be angry at their sibling with FASD as they are the ones committing the problematic actions. That being said, although the siblings did not explicitly say "resent" in their interviews, they have nonetheless explained feelings of resentment, that is, an ill feeling for being treated unfairly. This bitter indignation was conveyed towards their parents for not being able to give them more time and energy, and towards their siblings with FASD for taking all of those resources away from them. Although they understand how and why this unjust allocation of attention has occurred, they still are not happy with the little attention they have received.

#### ***2.3.3.2 "Giving back or lack thereof" – Relationship dynamics between siblings.***

Participants identified that the effort put into the relationship between them and their sibling with FASD was unfair. Participants felt that they suffered for their sibling's behaviours, evidenced by the six individuals who answered *sometimes*, one individual who reported in the middle of *sometimes* and *often* and three participants who reported *often* to "we have to stop what we are doing because of my brother or sister with a disability" on the DHUS. Having to miss out on events is supported by testimonies such as Zack's, 15, who explained how his sister ruins his family visits at the museum, an activity he loves to do: "She hates museums and if we go to a museum and she's forced to go she'll just scream the whole time and everyone's going to be staring and it's not cool so we have to leave... We never have fun if we're at a museum, that's basically it. That's the gist of it because we have to leave..."

Siblings expressed feeling as though the relationship with their sibling diagnosed with FASD was very one-sided with all members of the family. Sydney explains: “the investment is not the kind that there will ever really be a return on...[it] didn’t feel like it was adding up to anything.” She went on to explain that for parents, they take many financial resources and as a sibling she states: “... it’s really stressful having two members of the family taking a lot more than they can ever give you”. Many participants felt similarly; that the sibling with FASD takes away time spent with parents, the financial resources, the love and help given to them by participants, and yet due to the many impairments these siblings face, they continue to behave poorly, and cannot return the help when participants need it.

Bradley, 17, also really struggled with his brother not making an effort to interact with Bradley. On numerous occasions throughout the interview he opined that there was a lack of “giving back”: “whenever I try giving him love he doesn’t appreciate it”, “I would try everything just to connect with him”, “it’s sad I’ll listen to his conversations and he won’t have the same appreciation for me”. For Bradley, feeling unappreciated affected him so much that when talking about the future of his sibling, he felt as though he had put enough effort in the relationship thus far, he stated: “It’s more what he can do to come close to me. I don’t know, if he cares, then I’d be happy to help him, but if he doesn’t care then he is on his own.” The idea of being hurt and not being appreciated again in this type of situation clearly weighed heavily on him, impacting his decision to play a role in his sibling’s future. Unfortunately, Bradley was not the only participant giving their time, advice, or extending out invitations, while often receiving nothing in return or being turned down by their siblings. In response to this emotional roller coaster described by the participants, a couple of the siblings reported keeping an “emotional distance” with their sibling, to avoid being hurt. After all, it was very difficult for the participants to keep

helping their sibling with FASD when they may not be able to develop the empathy or insight to return favors and change their behaviours for the better.

This theme of resentment, specific to how the participants do much more for their siblings than what they get in return, is supported by the results from the SIB questionnaire as seen in Table 3. On the questions that are provided: “Teaches you new skills”, “Gets ideas for things the two of you can do together”, “Helps you adjust to a new situation”, and “Babysits and cares for you”, “Makes plans that include you” and “Tries to comfort you when you are unhappy or upset”, siblings indicated they were likely to engage in these behaviours towards their sibling, but were unlikely to receive these behaviours from their sibling. These specific results suggest that according to the participants, their brothers or sisters with FASD spend little time helping or caring for them. Although this data could be biased in favour of the participants, as they could be presenting themselves in more of a positive light or their siblings with FASD in a more negative one, the information presented clearly suggests that the majority of the siblings feel as though they help, care for, and give more to their sibling with FASD than they get in return. Combining the qualitative and quantitative data for this particular theme has demonstrated that participants believe the expenditure of energy on their siblings is unfair and leaves them resenting their brother or sister for their lack of involvement.

**Table 3. SIB Resentment Questionnaire Items.**

SIB Questionnaire Items	Participant to Sibling with FASD		Sibling with FASD to Participant	
Teaches ____ new skills	2 <i>Sometimes</i>	7 <i>Often/Always</i>	4 <i>Sometimes</i>	7 <i>Never/Seldom</i>
Gets ideas for things the two of you can do together	5 <i>Sometimes</i>	3 <i>Often/Always</i>	0 <i>Sometimes</i>	11 <i>Never/Seldom</i>
Helps ____ adjust to a new situation	6 <i>Sometimes</i>	4 <i>Often/Always</i>	1 <i>Sometimes</i>	10 <i>Never/Seldom</i>
Babysits and cares for ____	1 <i>Sometimes</i>	7 <i>Often/Always</i>	1 <i>Sometimes</i>	10 <i>Never/Seldom</i>
Makes plans that include ____	6 <i>Sometimes</i>	5 <i>Often/Always</i>	2 <i>Sometimes</i>	6 <i>Never/Seldom</i>
Tries to comfort ____ when ____ are unhappy or upset	4 <i>Sometimes</i>	7 <i>Often/Always</i>	3 <i>Sometimes</i>	7 <i>Never/Seldom</i>

Given the time and energy the participants gave to their siblings, some resented the fact that after everything they have sacrificed for their siblings, and the plethora of emotions they felt on a daily basis, prompted the development of mental health issues. Three of the participants maintained that growing up with a brother or sister with a disability is beyond difficult, and has played a role in the fact that they have developed anxiety and/or depression, or needed to see a counsellor. Katie, who struggled with depression since childhood, also reported having difficulty forming and maintaining relationships “because they found that they could not deal with the extent of what’s going on with my family” and as much as “we want companionship... you know asking someone to sign on for all of that is huge”. Ultimately, what Katie was saying was that it is not fair that she has made many sacrifices to help them, but has herself, ended up with relationship and mental health issues because of them. She was afraid to have a relationship because she is afraid to invite others into her chaotic life.

Encompassing all of these issues in her interview with the frustrations, the worry/fear, and resentment, Sydney states “We are better for them, than they are for us”, undoubtedly a painful truth to admit. Given the frustration, the worry, fear and resentment that siblings described, there is no denying the whirlwind that can occur when living with a sibling diagnosed with FASD. Despite all of the challenging emotions, siblings, as will be presented, were still able to appreciate the better parts of their experience of having a sibling with FASD. In fact, they did not only appreciate the positive moments, they embraced them.

**2.3.4 Happiness.** Throughout the semi-structured interviews, although participants described many difficult experiences, they also reported numerous benefits and positive aspects to having a brother or sister diagnosed with FASD. All of the siblings’ favourite memories revolved around their sibling’s happiness, times where they bonded or when they saw them succeed. Siblings also spoke at length about their appreciation of this experience and how it has made them a better person, more patient and understanding, better parents, and advocates for their sibling’s cause.

**2.3.4.1 “She was really happy, and I was happy” – The sibling under the FASD.**

Happiness was often reported in the participants’ favourite memories or the best part of being a sibling to an individual with FASD. In their testimonies, participants spoke about family vacations, bike rides and other sporting events where their siblings were able to laugh, play and simply be themselves without the tantrums. Matthew, a 13 year-old, who was particularly shy during his interview, stressed how much of a great person his sister was when she was happy: “probably the best part is when she is happy, she’ll like move my hair, it’s weird when she does that”. In the instance that Matthew described, when referring to his sister’s happiness he associates it with moments of affection. He also stated that he enjoyed playing board games and

sports with his sister. Matthew went on to explain that now that his sister is maturing, getting older, and has more control over her emotions, they get along much better. Shawn seconds the idea of maturity playing a big role in his and his sister's happiness: "she doesn't really throw tantrums anymore so much um, so, so the later periods of her life have been the ones that I've enjoyed spending with her the most um, just because... even if she's five or six years behind she still has the emotional I guess maturity of it you know at least a 16 year-old."

Brianne, whose family members are very involved in sports, recalled times where her whole family would get together and have baseball games. She recounts: "I just remember playing and just being children like not worrying about the disability, not worrying about all the other stuff that was going on cause when we were playing, we were playing and everyone plays the same." This was a time for her where everyone was on the same level and having fun together as a family rather than having to worry about the complexity and chaotic nature of their situation.

Likewise, when asking Zack about his favourite memory, it was nothing extravagant such as a trip, but simply an activity that they did together. Zack states: "...there was one time we had a bike ride... we were racing each other... she won... she was really happy, and I was happy...I mean it's fun to be around her when she's happy or nice and there's... there are good memories and there's not... but I don't know my favourite it's probably just if she's nice we'll go bike, like we'll just bike". This last part "we'll go bike, like we'll just bike" resonated more than any other of the statements. Although Zack was not overly happy when saying this, his favourite part of being a sibling was knowing that she can be happy and they can be normal and get along like they do on the days where they just bike. The reason the statement was so powerful is that it highlighted a moment that is so simple, just a normal activity that they can do together like

“typical” siblings do, as if there was no FASD at all. This statement is one that a typical family without an individual with a disability may not understand, and an experience that most siblings may take for granted. It is clear that moments like these, where the FASD was invisible, were moments of happiness.

**2.3.4.2 “I can actually help her” – Making Connections.** Other favourable moments that meant a lot to the siblings were moments where they were able to bond and help their siblings diagnosed with FASD. Bradley, when asked what his favourite memory of his brother was, explained that bonding for them is rare and so it is special when they do. He goes on to describe a time when they went fishing, he says:

He loves to go fishing, he never likes to take my advice he always wants to do it on his own. It was really funny, I told him how to fish better, he didn't listen to me then when I went away he listened to me and started to do the things I said and I thought it was pretty funny, I really appreciated that he actually was listening to me.

Although Bradley believed that his brother was not paying attention to him, he surprised him by using the information, meaning that his brother was in fact listening to him and valued his opinion, a subtle but very rewarding experience. He was finally heard by his sibling and able to give him some brotherly advice, to be helpful and make a difference.

Samantha's favourite part was also when her sibling wanted to bond with her. She explains:

When we were younger we used to share a room and we had bunk beds and I had the bottom bunk and she had the top... she was probably about six or so um, in the mornings she would wake up super early and she'd come wake me and then she would just ask me to read her a book and we'd lay there for hours in the morning and I'd just be reading to

her so, in those like calm moments when it's just one on one it's just, it's really good, like this is my little sister it's good kind of memories.

In this testimony, Samantha stresses the calmness as compared to the chaos that can occur, and just engaging in normal sibling interactions and how amazing that was, even if it was something small and simple. Both of these narratives exemplify the bonding that occurs when siblings do not have to contend with their brother or sister's poor mood and externalizing behaviours.

Contrary to the happiness felt by participants, primarily when the FASD was not playing a role in their mood or behaviours, two of the younger participants claimed that there are benefits to having a sibling with impairments caused by FASD. In the following examples, the younger siblings are able to connect and bond with their older siblings due to the FASD. Specifically, these two siblings talk about how their siblings have slower maturation rates and intellectual delays which makes them think and act at a younger age than they really are, shortening the age gap between them and their sibling. The first example is from Alyssa, 11, who when asked what the best part of having a sibling with FASD replied:

I have to say that I really like that um... he doesn't really mature as fast as other kids so he'll do stuff that's like younger than um... younger kids would do so it's nice to have someone who's like acting more around my age cause we have like a three year difference.

Therefore, whereas a typical older brother would likely go off and do his own thing and hang out with his friends, Alyssa's brother still enjoys activities with his younger sister due to his mental age. When Sarah was asked what is the best part of being a siblings to her sister with FASD, she stated: "When she needs help I can actually help her with her schoolwork, so if she was a normal teenager I couldn't help her with her homework at all." Thus, again, if Sarah's sister was a

typically developing child, she would be much more advanced intellectually than Sarah, but because her sister has a trouble understanding mathematics, Sarah is able to help her big sister. These unique bonding experiences for these two younger siblings is one that they clearly cherish, and brings them happiness.

**2.3.4.3 “I am so proud of her” - Watching them succeed.** During the interviews, many siblings mentioned that seeing their sibling succeed or grow up and mature made them incredibly happy and proud. These moments of bliss are justified by the SIB questionnaire, where five participants reported *sometimes* and seven *often/always to always* being pleased by the progress their sibling made. Additionally, two siblings reported that seeing their sibling learn something new made them *a little bit happy* and eight reported *happy/very happy*, on the DHUS. Katie who had seven siblings with FASD, was particularly excited to tell me all about her one sister Janice because of her success: “Janice is my one success story, so Janice is the most hard-working little person ever and I am so proud of her so I’m going to ramble here about all that good stuff and that’s so she works really hard in school and so she’s at the local community college.” Katie went on to describe many other accomplishments, like her sister Janice also being able to hold a steady job and the high hopes for her future. When asking Shawn about the best part of being a sibling to his sister, his reply was: “the excitement that comes out of seeing her succeed, especially when she was younger there was significant questions, you know would she ever be able to hold a job? But she can actually hold a job, and make money which, you know, is a fairly major accomplishment for someone in that position.” In both of these testimonies and many others, it brought them great joy and happiness to see their siblings overcome their challenges and watch them succeed in life. However, they were not the only ones to overcome challenges

and flourish in their environment. Siblings too, given all of their sacrifices, gained a lot from their experience of having a sibling with FASD.

**2.3.5 Personal Growth.** Regardless of the negative emotions felt by the participants, interviews revealed that siblings were able to maintain positivity towards their experience as they also expressed the advantages of growing up with a brother or sister with FASD. Siblings discussed how having a sibling with FASD built character and made them better people as they developed more patience, acceptance, empathy, and other interpersonal skills. Siblings also explained how they became very aware of FASD and its effect on others, so much so that some of the siblings hope to advocate for FASD, a cause they hold very close to their hearts.

**2.3.5.1 “I’m a better person because of it” – Building Character.** The majority of the siblings, when talking about the benefits of their experience and how it has impacted them said that they became better people, more accepting, patient, aware and caring because of their sibling with FASD. On the DHUS questionnaire, three siblings indicated *sometimes* and nine indicated *often/always* when asked “I know and understand a lot about disability”. When talking about some of the benefits that came out of having a sibling with FASD, consistent with the questionnaire, Kyle mentions “Learning, I gained a lot of knowledge from how to deal with his behaviour and his reactions... I was able to apply that to, to just regular life especially dealing with like little kids or other kids that have problems, it’s definitely been a huge plus to be able to understand”. A couple siblings spoke about gaining a better awareness about disability like Kyle did. For example Brienne stated, “I’m a better person because of it... I’m more willing and more accepting and I’m more educated on those situations than other people”. Samantha has a similar opinion about what her experience has taught her:

She's just taught me to be accepting... no matter whether the person's special needs or not what – if they're not understanding just take a second and help them understand because there's a reason they're not understanding. You don't have to get mad at them for not understanding and definitely acceptance and patience... I still have those instincts in me obviously but they were definitely brought out a lot more.

The interviews really highlighted how the participants have become more sensitive to developmental disabilities as well as the injustices that surround them, as Sydney explains:

The gift that it gave all of us is that it made us all way more sensitive empathetic people because from early on in childhood I had an awareness of the issues around prejudices in our culture and you know ongoing racism and some of the barriers that they faced...I think a lot of that comes from having them in our family.

Overall, the siblings felt as though they had truly grown in a positive way both personally in terms of patience and understanding, and generally in becoming better members of society due to living with a sibling with FASD.

In adding to the list of qualities, half of the participants in this study either described or specifically talked about how they had developed a better caregiving instinct because of the many hours they spent helping their parents and their sibling. Thus, it was no surprise when the results from the DHUS revealed that two siblings reported *sometimes* and eight *often/always* to “my mum/dad tells me that I am being a big help around the home.” Alyssa, 11, who worked hard on her farm, expressed her caregiving instincts by wanting to make sure her brother had a shelter when he grew up. She also aspired to become a doctor to take care of others. Similarly, Sarah who is only 10 stated: “sometimes when she's hungry I make her stuff if she's not feeling well”, expressing how she likes to care for her sister. The older female siblings who were better

able to communicate some of the benefits of living with a sibling diagnosed with FASD were able to talk about their increased maternal instincts, like in the case of Brianne:

I'm a better mother than any of my friends will ever ever be. I've learned how to change a diaper when I was 5 years old and I knew when a baby was in distress....at 5 years old I knew I had to change a diaper, and I would I would go and would pick the babies up and I'd change them while my mom is dealing with my older siblings and... So ya, I've grown a lot because of it and I would never ever ever take any of it back.

Although Brianne was already a mother, there was no doubt in both Samantha and Katie's minds that they would make great parents with the tools they have learned over the years. That said, siblings gained much caregiving experience and took pride in how they have developed into patient, caring and understanding individuals, due in part to their sibling(s) with FASD.

**2.3.5.2 “I definitely want to inform as many people as possible” – Increasing awareness of FASD.** In the interviews, Samantha, Brianne, Katie and Sydney were on the path to educating the world by wanting to advocate for siblings and individuals with FASD. The methods in which these individuals wanted to help varied. For example, Brianne stated: “it's just like it's really hard for me not to see someone like who's pregnant or who are thinking about having a kid, and not being like you have to know you can't have drink, you can't have drink, you can't”. In her case, Brianne, when she would see someone who was pregnant felt obligated to give gentle reminders about not consuming alcohol in fear of having another child in this world born with FASD.

Another way of reaching others and informing them about FASD, Sydney whose mother has been an advocate for FASD for years, explained how she and her mother “would travel and... go to a whole bunch of um, FASD conventions just to educate people”. Similarly, Samantha,

whose mother was also an advocate, describes helping her mother who works for FAS World.

She states:

I've offered to help her next year because she did it for the first time in St. Catherine's this year and it was kind of like a smaller turn out... Like I definitely want to help her and I definitely want to inform as many people as possible about this because my biggest anger about fetal alcohol is that it is preventable.

Thus, regardless of the technique that is used, they were still whole-heartedly invested in making a difference and educating others in hopes that others do not have to go through what they and their siblings did. For Katie, this meant stopping FASD at the source and not consuming alcohol when pregnant. If there is no alcohol consumption, then there is no FASD. For Sydney and Samantha, it was about sharing knowledge on how to improve behaviours, decrease the tantrums, how to cope and sharing resources to make the experience of having a child with FASD in the home easier. Regardless of the approach or motive, both of these methods to educate the public are crucial to society and to families with individuals with FASD. Educating the public will not only prevent children from being born with FASD, but it will also reduce the stigma and in turn, the frustration that siblings feel towards society and their lack of understanding.

There is no doubt that this experience, although sometimes positive, has taken or may take its toll on these siblings. However, even if the thought of never having adopted their siblings has crossed their minds, at the end of the day, no matter the stressors or pain that they may experience, their brother(s) and/or sister(s) are family and they would not change it for the world. Katie seconds this as she states: "I've grown a lot because of it and I would never ever ever take any of it back. Sometimes I feel like I would or want to, but I don't. I would never, because I feel like I'm a better person because of it." After mentioning all of the worst parts of being a sibling

to someone with FASD, Katie was asked about the benefits and rewards, and although at first she was stumped she later replied “I tell everyone, and I say this genuinely that the day they were adopted was the best day of my life, I wanted siblings so bad”. They love their siblings, and this statement is why the majority will no matter what, take care of their siblings even if it is an incredible burden; they will do just about anything for them. The love they feel for their sibling will lead them to continue feeling frustrated, worried, and resentful, all while making more sacrifices of their own, as their parents did. However, along the way, they will surely embrace and not take for granted the happy moments and they will continue to fight to ameliorate the circumstances of families like theirs.

## **2.4 Discussion**

The current study explored the thoughts, feelings and attitudes of individuals living with a brother or sister diagnosed with FASD. Interview and questionnaire analysis revealed five main themes: frustration, worry/fear, resentment, happiness and personal growth, each of which were accompanied by sub-themes to describe the siblings’ reported experience.

In the first theme, frustration, siblings described the hardships of dealing with their sibling’s mood swings and tantrums which was often unwarranted and difficult to manage. Siblings also expressed frustration towards society’s reaction to their sibling’s tantrums and how their lack of understanding and perceived judgements led to participants trying or wanting to defend their siblings as well as their parents. Similarly, in establishing a family-centered care approach, McGinty, Worthington and Dennison’s (2008) described how siblings may be impacted by having to defend or seeing others make negative remarks about their brother or sister with a developmental disability and a mental illness in public. Although in the SIB many siblings reported being upset when in public and “my brother or sister with a disability draws

attention to us”, these results were attributed to society’s lack of knowledge as they stare, eliciting frustration in the participants.

In the second theme, worry/fear, siblings expressed their daily concerns towards the health and safety of their sibling. Due to the numerous behavioural problems experienced by individuals with FASD (Malbin, Boulding & Brooks, 2010), siblings worried about their brother or sister receiving jail time, running away, becoming pregnant, or suffering a number of health-related issues such as alcoholism and even death. Siblings’ illegal behaviours were reported as being one of the main sources of stress for parents by Watson et. al. (2013). Although we cannot determine the most prominent emotion felt by siblings in this study, we can however conclude that they did have a great amount of stress attributable to the problem behaviours. Siblings also voiced concern for their parents and the amount of stress they had undergone raising a child with FASD. Their apprehension was evidenced not only by participants voicing their worry, but also in how they changed their behaviours and reported being “better children” to accommodate their parents and decrease their levels of stress. This particular finding is in contrast to both Bågenholm and Gillberg (1991) and LeClere and Kowalewski (1994), who reported that siblings of individuals with a developmental disability had increased behavioural disturbances such as peer conflicts, hyperactivity, etc. Some siblings, though it was rare, did report peer conflicts in order to protect their sibling, however the overall difference in behaviour may be attributable to different experiences based on the sibling’s disability. Given that criminal behaviour seems to play a large role in parent’s stress levels (Watson et. al. 2013), which were also reported to be higher than parents of individuals with ASD (Watson et al., 2013), this difference in results could also be attributed to the higher levels of criminal behaviour exhibited by individuals with FASD. To expand, individuals with FASD do experience a number of neurological deficits that leads to

poor decision making and being easily persuaded. Because FASD is an invisible disability, it can be difficult for them to access services, unlike for example, Down Syndrome. The lack of support from health professionals as well as their ability to act autonomously in public, allows individuals with FASD to engage in a wide range of delinquent behaviours. This is evidenced by the few studies who claim that there is high prevalence rate of individuals with FASD in the criminal justice system (Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011). As a result, their siblings, who themselves experience the worry and frustration towards their sibling with FASD's behaviours, do not want to replicate them, in fear of adding too much stress on their parents. Though this is one possible explanation and could account for a portion of the population, a second explanation could be that siblings or potential participants who externalize their behaviours were less likely to participate in this study. In order to gather more information on the behavioural adjustments of siblings with individuals with FASD, a quantitative measure examining behaviour would have to be administered.

Last, within this theme was the worry and fear siblings experienced when thinking about their future role. Many of the siblings explained that it will be their responsibility to take care of their sibling, whether they want to or not, once their parents are no longer able to. The worry regarding the uncertainty of the future was also demonstrated in a study by Burke, Fish and Lawton (2015), whereby 47% of anticipated caregivers spoke about the challenges regarding the uncertainty of their future as a caregiver. Among the challenges faced by both anticipated and current caregivers, 19% of the siblings mentioned the difficulty with addressing their sibling's problem behaviours, a worry that was emphasized in the current study as well. In this study, current caregivers also felt as though they were alone in the process and had little support. In the current study, having little support was especially true for the participants whose only sibling(s)

was diagnosed with FASD, thus not having typically developing siblings to share the task, and for participants who's typically developing siblings were not likely to help in caregiving activities. Given, the results presented by Burke, et al. (2015), that not only verify that other siblings are also worried about the future, but they also justify fearing being alone in the caregiving process, as current sibling caregivers find it challenging to have little support in caring for their sibling with a developmental disability.

The third theme focused on feelings of resentment whereby older siblings explained, with reluctance, how the energy, time and resources spent by their parents was mostly on their sibling(s) with FASD. Similar issues were also revealed in Fleitas (2000) and in an article published by McGinty et al. (2008) which educated therapists on the stress faced by families of individuals with developmental disabilities. The authors explained that siblings may experience heightened levels of stress due to less time spent with parents who are trying to access services and meeting their child's needs and making the main priority the sibling with a disability. In congruency with the aforementioned results, many of the participants expressed a lack of attention from parents and an uneven allocation of resources, leaving the participants really having to fight for some of the things they wanted. Participants also felt some resentment towards their sibling with FASD in terms of how much they did for them and received nothing in return. Some demonstrations of this theme included the tantrums during fun activities forcing them to leave, not appreciating the time spent helping them or caring for them, etc. Instead, siblings reported having anxiety, depression or needing to see a therapist because of their brothers or sisters with FASD. Similarly, numerous studies have found that siblings of individuals with developmental disabilities are at a higher risk than siblings of typically developing individuals of developing psychological problems and mental health issues (Leclere

& Kowalewski, 1994; Orsmond & Seltzer 2007; Rossiter & Sharpe, 2001). However, contradicting these findings is a more current study by Neely-Barnes and Graff (2011) who discovered that the elevation of mental health visits by siblings were attributed to co-occurring risk factors such as living in a lower income household or single-parent families, rather than to being a sibling to an individual with a developmental disability. Although the present study did not take into account these other risk factors, siblings were greatly impacted by the behaviours of their sibling with FASD. Thus, future research should focus on sorting out the potential cause of psychological concerns, specifically in the families of individuals of FASD, who exhibit higher levels of stress than most other developmental disabilities.

It is important to note that throughout the interviews, siblings did not want to speak negatively about their parents or siblings. They showed great hesitation, distress and guilt when referring to how it has affected them personally. Unlike the “survivor guilt” that has been researched (Moser, Jones, Zaorski, Mirsalimi, & Luchner, 2005; Siegel, Elliott & Silverstein, 2001), whereby siblings feel guilty for being “spared” of the disability, siblings simply felt guilty admitting to the unpleasant parts of their experience. This was the case when talking about the their own and their parents’ investments and when siblings spoke about their caretaking role in the future; some participants felt bad acknowledging that their siblings were difficult to manage, and one even felt selfish and identified feeling guilty admitting that she did not want to take on the task. That said, often times participants seemed to disregard many of their emotions such as anger towards their siblings with FASD, or their parents. Instead participants often stated that they understood and accepted the reasons behind their parents’ and siblings’ actions and tried to take a logical stance (e.g. “It’s not their fault”) instead of validating their emotional response. Though these explanations are valid, so too are the emotions that participants feel in response to

these events. However if their feelings are repressed or invalidated it can also be damaging to participants as their emotions are not properly managed using coping mechanisms such as counselling.

Next siblings described moments of happiness, which occurred when their brother or sister was happy, while doing activities together, connecting with each other or when they finally appreciated or gave back to the participants. Due to their intellectual delays and their poor executive functioning, their sibling's success was also very important. Siblings maintained that it is an amazing feeling when they see their sibling "beat the odds", which for some meant holding a job or graduating high school and even college. The emphasis on success can be related to a study by Schall (2000), who explored the experience of families raising a child with Autism. In this study parents did identify numerous stressful situations, but they also reported an "appreciation of the gifts of people that others take for granted" (p.420). Participants in this study did just that: they gave examples of simple events or accomplishments that the average person may not think to consider because they are taken for granted. Unfortunately, endeavors such as a high school graduation is an accomplishment that individuals with FASD have to put so much work into, as learning the material does not come easily to them, which is also true for holding employment. Thus, although there are many unfavourable parts of living with a sibling with FASD, there are many positive ones. Given their unique experience, the participants learned to truly cherish these simple happy moments with their siblings, as they may be few and far in between.

The final theme was that of personal growth, where in the interviews siblings described being proud of their experience as it allowed them to grow into better people. Because of their experience they are more accepting, caring, and understanding of others, which are similar to

Scorgie and Sobsey's (2000) findings of parent transformations. Siblings also expressed that they will be or are better parents as they have developed a caregiving instinct due to having helped their parents with their brother or sister with FASD. The improved caregiving abilities supported the findings from McHale and Gamble (1989), who highlighted increased caretaking by the siblings of individuals with a disability. Lastly, the siblings explained that they are more aware of the issues surrounding disabilities and FASD in particular. Some have even taken a pledge or expressed wanting to help others and advocate for FASD.

## **2.5 Limitations and Considerations**

While this exploratory study did identify many themes involved in the experience of living with individuals with FASD, there are still many limitations to consider. The first limitation to this study was the sample size. Although using a minimum of six participants is often recommended when conducting qualitative interviews using a phenomenological approach (Denzin & Lincoln, 1994; Kuzel, 1999; Morse, 2000), because this study is mixed methods, it was the quantitative portion that posed limitations. First, the sample size was too small to detect statistically significant differences or relationships (Cohen 1992; Schmidt, 1996; Schmidt & Hunter, 1997), and second, the use of a non-random sample limits the generalization of results to the larger sibling population (Onwuegbuzie, Jiao, & Bostick, 2004). The latter is especially true as this sample sought to include all siblings, both adoptive and biological, however, aside from one half-sibling, only adoptive siblings asked to participate in the current study, limiting generalizations to biological siblings of individuals with FASD. The small sample size also limited the ability to expand on population sub-groups such as age differences in the sample. With three participants in their early teens, three in their mid-late teens and four above 20 years, qualitatively the sample size was not big enough to make specific generalizations to each sub-

group. However, it is important to convey that age differences did exist within this sample. This was especially evident when asking the participants about future caretaking, where the older population did report more stress associated with future caregiving than did the younger individuals. As individuals got older they were better able to highlight some of the more complex emotions such as resentment, they highlighted issues with mental health, better explain the strain their parents faced. Interestingly, older participants were able to raise the issue of role reversal/confusion which focused on having to play a parent role to their sibling or act as an older sibling although they were younger. Nevertheless, it would be beneficial to examine the specific experience of both young and older siblings of individuals with FASD to gain knowledge on their stressors and outlook over time.

Despite the downfalls, the greatest benefit to this study is the integration of both the quantitative and qualitative data across the conceptualization, experiential and inferential stages, as suggested by Teddlie and Tashakkori (2009). The combination of both methods, in turn increased the depth, strengthened the themes and provided a greater degree of trustworthiness, more so than what either method could have provided alone (Creswell, 2014; Guest, MacQueen, & Namey, 2012; Teddlie & Tashakkori, 2009).

Transparency was also a key factor in improving the degree of trustworthiness in the qualitative analysis (Guest et al., 2012). As mentioned, the incongruities between the qualitative and quantitative data were included and presented by the researcher. For example, some questions pertaining to the public's reactions on the DHUS indicated that the public stared sometimes or less so, causing siblings to be only a little bit upset, according to the majority of the participants. But, in the interviews, many siblings commented on the public giving strange looks, suggesting that this type of experience was more impactful among siblings than previously

indicated in the quantitative measures. It was discrepancies like these that were included, increasing the reciprocity of information between the researcher and the audience. These inconsistencies across methods of data collection also highlighted the importance of including more than one method of gathering information as one may be able to identify information that the other may not. Additionally, the member checks which were conducted, ensured that participants perspectives were honoured and accurately conveyed, increasing the trustworthiness of the study.

Given that all of the siblings diagnosed with FASD were adopted, this study is representative of the adoptive population, which makes up approximately 80% of infants in foster care (Dicker & Gordon, 2004). Although these results are generalizable, knowing if the themes are reflective of either the disability or the adoptive status is difficult to identify as it is challenging to separate genetic and environmental factors. In order to gain more knowledge on the matter, future research should consider studying and comparing the presence of a family member with FASD in biological families. Though this type of study would be ideal it may be challenging to gather biological siblings without FASD due to the many siblings that are likely to be affected by FASD.

Last, the questionnaires that were used during this study were normed for individuals between the ages of 6-16 years. However, in the current study, participants from the ages of 11-37 used these measures. To be specific, almost half of our sample used questionnaires that were not normed for their age. The problem this posed was that participants who were older and out of their childhood setting had to think back to how they thought and felt during this time, which decreased the validity of the questionnaires. Self-report measures also present a number of biases such as social desirability bias whereby the participants will answer questions in a way that

makes them look favorable to the researchers. For example in the present study, the Sibling Inventory of Behaviour asked participants to rate their sibling's behaviour towards them on a number of items and vice versa. In many of the items, the siblings recorded themselves as helping and caring much more than their siblings with FASD. Thus, there is a possibility that they made themselves look much more favourable to the researcher or maybe, due to the feelings of resentment discussed, they made their sibling look worse.

Another type of bias in a questionnaire is end aversion, where participants will avoid the ends of the scales and respond in the middle section to be conservative (Choi & Pak, 2005). Though social desirability may also play a role in this bias, there were numerous items in the questionnaires where siblings responded in the middle, selecting "sometimes", and avoided using the ends of the scales. Additionally, some siblings also felt guilty about saying anything bad about their sibling with FASD evidenced by the participant's hesitation, worrisome tone, or them following up with a positive statement about their love for their sibling. Thus, avoiding the ends may have made them look favourable as well. Despite the potential biases, the results presented in this study are likely a valid representation of the population as they were congruent with the themes and supported by the qualitative data.

## **2.6 Implications for Service**

Although a strength of this study was including the positive experiences of living with an adopted sibling with FASD, it is also important to address the obstacles. Reporting the difficulties will not only help in future research but will allow practitioners to establish a plan on how we can assist the participants and other siblings just like them overcome the challenges. This study identified numerous areas of concern for siblings raised with a child diagnosed with FASD. First, there is a wide range of emotions that have been associated with the lack of

emotional stability exemplified by the siblings with FASD. According to Nash et al. (2015), individuals with FASD who participated in the Alert Program for Self-Regulation in the immediate treatment group reported significant improvements in inhibitory control and social cognition, improved behavioral and emotional regulation, as well as reduced externalizing behavior problems. Having their siblings complete this 12-week program may be beneficial to their siblings and family in reducing frustration in the home. Although information about tantrums and how to handle them should be recommended, the literature that surrounds this information is geared towards parents and/or specific to Autism. Despite this shortcoming, siblings should receive more education on strategies, techniques and proper communication to help alleviate their sibling's emotional state.

Second, siblings emphasized that living with a sibling diagnosed with FASD caused heightened levels of worry, fear, and frustration. Experiencing these emotions for prolonged periods of time are likely to cause depression, anxiety, or other mental health problems, as some siblings did point out. It is therefore important for siblings to receive therapy to treat these issues. For both anxiety and depression, Cognitive Behavioural Therapy (CBT) is highly recommended (APA, 2010; Hollon & Ponniah, 2010). The analysis of both quantitative and qualitative data revealed that many siblings also felt resentment. Despite the fact that participants gave examples of this experience rather than specifically using the term "resentment" in the interviews, over one third of participants expressed feeling resentment towards their sibling at one point or another as indicated in the questionnaires. To strengthen this argument, resentment has been reported by individuals living with a brother or sister diagnosed with a developmental disability (Featherstone, 1980; Fleitas, 2000; Pompeo, 2007; Seligman 1983). Despite being able to rationalize the allocation of resources and attention due to the FASD, being able to open up

about their emotions, in a safe, non-judgemental environment and be able to tease out their feelings and know that they are “normal” would benefit the siblings greatly. Additionally, siblings did admit that they did not want to speak to their parents because they already had too much to deal with, thus the action of engaging in a conversation with someone who is knowledgeable in the matter would prove to be valuable. In fact, resources such as groups for siblings of individuals with developmental disabilities have been found to be both beneficial (Giallo & Gavidia-Payne, 2008; Kinsella, Anderson, & Anderson, 1996; Lobato & Kao, 2005; Phillips, 1999; Roberts, Ejova, Giallo, Strohm, Lollie & Fuss, 2015; Williams et al., 2003) and a strong predictor of adjustment and adaptation (Choi & Van Riper, 2013).

To conclude, seeing as though future caretaking is worrisome for many of the participants, information on how to prepare themselves and plan for their future caregiving role would be beneficial. Fortunately, there is a program called The Future Is Now, a peer support intervention developed to support aging caregivers and adults with developmental disabilities in planning for the future (Heller & Caldwell, 2006). This program offers legal and financial training, explores residential planning, and other important options to facilitate the transfer of caregivers. Families who completed this program reported a significant decrease in caregiver burden and an increase in choice-making from the individuals with a developmental disability.

## **2.7 Conclusion**

This mixed-methods study investigated the experience of having a brother or sister diagnosed with FASD. In this exploratory research, five themes emerged from the siblings’ interviews: frustration, worry/fear, resentment, happiness and personal growth, each having many sub themes which helped to gain a better understanding of how the participants give

meaning to their unique situations. Participants were able to provide both negative and positive testimonies, which provided an unbiased picture of their daily lives.

Despite the numerous negative emotions that were presented, participants were still very expressive of their love for their sibling and not knowing what it is like to live otherwise because this is their “normal”. The stress, the worry, the resentment but also the happiness, joy and pride is what they feel on a day-to-day basis, they do now know anything else. However, the idea that they can imagine a life with their siblings as not having the FASD is seen in bits and pieces throughout the interviews, mostly in the positive feelings where the tantrums and negative behaviours are hidden, and the success that “normal” individuals would achieve are present.

As this is one of the first studies to explore this field, continued research looking into siblings experience and their creation of meanings surrounding their experience is crucial in order to establish resources for their well-being. Given the emotions that have been presented in this article and the potential impact (worry, anxiety, mental health issues), researchers need to gain a better understanding of each of these elements. Due to the deinstitutionalization movement, whereby individuals with disabilities are integrated into the community rather than residing in a specific establishment, siblings beginning at a young age and through to adulthood are thinking about how they will have to take care of their sibling when their parents are no longer able to. Although to some it does not seem to be of worry, many others do realize the difficulties the caretaking role poses, causing much worry and stress. Further knowledge about the siblings’ experience would help to create resources in hopes of decreasing the stress on siblings, increasing the benefits, and facilitating this transition into the caregiving role.

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### **Chapter 3**

#### **The Need for Support: Coping Behaviours and Resources**

#### **Employed by Siblings of Individuals with Fetal Alcohol Spectrum Disorder**

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### Abstract

The purpose of this paper was to identify the coping behaviours and resources used by siblings of individuals with FASD. The current study is a qualitative study informed by Merriam's (2002) Basic Interpretive Approach. Ten siblings across North America completed a semi-structured interview, which was analyzed using Thematic Analysis (Braun & Clarke, 2006). Two main themes resulted from the analysis, the first was the need for space and highlighted both the active and emotional avoidance coping behaviours employed by siblings. The second theme was the need for understanding, which revealed both the successful interactions with resources along with the challenges they present to siblings of individuals with FASD. The findings suggest that siblings are in need of more education and support in order to manage the stressors associated with having a sibling diagnosed with FASD. Research considerations, clinical implications, and future direction for FASD sibling research are discussed.

## **The Need for Support – Coping Behaviours and Resources Employed by Siblings of Individuals with Fetal Alcohol Spectrum Disorder**

Researchers have established that living with a child diagnosed with a developmental disability (DD) comes with many stressors and challenges. Despite the increased prevalence of positive literature on families and disabilities (Blacher, Begum, Marcoulides, & Baker, 2013; Thompson, Hiebert-Murphy, & Trute, 2013), many studies have highlighted the difficulties associated with living with someone with a disability such as depression, stress, burden, pessimism and adaptability/cohesion (Turnbull, Summers, Lee & Kyzar, 2007). Although parents have been the focus of most family research (Families Special Interest Research Group of IASSIDD, 2013; Ha, Hong, Seltzer, & Greenberg, 2008), siblings are gaining attention in the literature as they too have been reported to be affected by living with a sibling diagnosed with a disability.

When examining the impact of individuals with DD on siblings, studies have reported that compared to siblings of individuals without a DD, siblings with a brother or sister with a disability experience greater psychosocial issues such as loneliness, maternal negativity, poorer adjustment, and isolation (Kaminsky & Dewey, 2002; Wilson, McGillivray & Zetlin, 1992), more behavioural disturbances (Orsmond & Seltzer, 2007a) as well as greater stress and mental health problems (McGinty, Worthington, & Dennison, 2008; Pollard, Barry, Freedman & Kotchick, 2013) than siblings of individuals without a DD. These results suggest that siblings may have difficulty coping and adapting to the strains and stressors associated with having a sibling diagnosed with a DD. With limited literature surrounding siblings of individuals with Fetal Alcohol Spectrum (FASD), the current study investigated the adaptation of siblings of

individuals with FASD. Specifically, capabilities, coping strategies, and resources are investigated, as well as supports that would help siblings of individuals with FASD.

### **3.1 Fetal Alcohol Spectrum Disorder**

FASD is a DD caused by prenatal alcohol exposure and is cited as the most preventable cause of congenital neurobehavioural impairment (O’Leary et al., 2013). Although prevalence rates are difficult to determine (May et al., 2009), the most recent estimates propose that approximately 9.1 children per 1000 live births in Canada and the United States have FASD (Canada FASD Research Network, 2015). These rates have also been found to increase up to 60 per 1000 children in child-care systems (e.g., orphanage, foster care, child welfare system; Lange, Shield, Rehm, & Popova, 2013), and 105 to 520 per 1000 in foster care settings specifically (Ospina & Dennett, 2013). Prenatal alcohol exposure leads to alterations in the structural components of the brain (Nuñez, Roussotte, & Sowell, 2011), causing various neurological deficits such as adaptive functioning, language/learning, attention, reasoning, and memory deficiencies (Clarke & Gibbard, 2003). These neurological deficits also lead to problems such as mental health disorders, disrupted school and employment experiences, trouble with the law, inappropriate sexual behaviour, and addictions (Dörrie, Föcker, Freunsch, & Hebebrand, 2014; Spohr, Willms, & Steinhausen, 2007), which have significant impacts on the family.

Unfortunately, there is little research surrounding FASD and its effects on the family, as FASD was only officially recognized in 1973. However, it is clear that great demands are placed upon families who manage the daily problems experienced by individuals with FASD. In fact, many challenges have been reported by parents, that begin with their experience of having their child formally diagnosed (Sanders & Buck, 2010; Watson, Hayes, & Radford-Paz, 2011).

Additionally, Paley, O'Connor, Frankel, and Marquardt (2006) examined child and parent related factors and their association with child and parent domain stress. Results revealed that the child with FASD's impaired executive functioning, poorer adaptive functioning, higher levels of externalizing and internalizing behaviours, as well as adoptive parent status, were strong predictors of higher levels of child domain stress. Also, results revealed that biological parent status and fewer family resources were associated with higher levels of parent domain stress. When comparing parents of children with FASD to those with Autism (ASD), Watson, Coons, and Hayes (2013) revealed that the former group reported significantly higher stress levels than the latter, as measured by the results on the Parenting Stress Index – Short Form. In a follow-up qualitative study, they found that the parental stress was mostly associated with their children's illegal behaviours rather than the tantrums and anxieties reported by the parents of children with Autism (Watson, Hayes, Coons, & Radford-Paz, 2013).

When directing attention to siblings specifically, one study has examined both the stresses and benefits of having a sibling diagnosed with FASD. Belanger and Watson (2016) conducted a mixed-method study that revealed that siblings of individuals with FASD experience a wide range of emotions, both positive and negative. Results indicated that participants felt frustrated with their siblings' emotional dysregulation and the public's lack of understanding. They worried and feared for their sibling's safety due to their illegal behaviours, their parents' health, as well as their own role in future caretaking. Participants also expressed resentment as their sibling often received all of the family resources (e.g., financial, emotional), and despite their efforts in helping their sibling, their actions were rarely reciprocated. Though many negative emotions were associated with their experience, participants also reported feeling happy during times of

bonding and when watching their sibling succeed. They also maintained that living with a sibling diagnosed with FASD had helped them grow and become a better person.

Though siblings are able to report positive experiences, there is evidence in both the parent literature (Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013) and the sibling literature (Belanger & Watson, 2016) that suggest that siblings are faced with numerous demands. Given their unique experience, siblings are presented with a variety of challenges that pose a threat to their psychological and emotional well-being, which is why it is important to examine both their coping behaviours and resources as steps towards adaptation.

### **3.2 Coping Behaviours and Resources**

Capability as defined by Patterson and Garwick in the Family Adjustment and Adaptation Response (FAAR) Model is the “potentiality the family has for meeting demands” (Patterson, 1988, p.216). According to the model, capabilities are divided into both coping behaviours and resources, two components that influence the individual’s ability to reach adaptation and both central themes in the current thesis. In operationally defining these themes, coping behaviours are “efforts by which an individual or group attempts to reduce or manage a demand” (p. 218) such as exercise and maintaining an optimistic outlook. As for the second factor, resources, they are separated into both informal resources (e.g., family and friends) as well as formal resources (e.g. therapy and support groups); medical facilities are also known as community resources.

There is little research looking at the experience of siblings of individuals with FASD, but other disability groups have been studied. Although some factors that influence adaptation are similar across disabilities (e.g., age, gender, severity of disability; Choi & Van Riper; 2013; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004), previous researchers have identified differences in the sibling experience based on the specific diagnosis of the sibling. Some of the

factors that vary depending on the DD include the types of relationships, physical health, mental health (Hodapp & Urbano, 2007), sibling rivalry (Kaminsky & Dewey, 2001), and the amount of time interacting with one another (Knott, Lewis, & Williams, 1995). That said, despite the similarities across factors that may increase or decrease a sibling's ability to adapt, the stressors they face differ based on the disability of their brother or sister.

**3.2.1 Coping Behaviours.** Coping behaviours are one of the two capability components that play a role in the family's ability to adapt; according to Folkman and Lazarus (1984), problem-focused coping (i.e., active coping, planning, suppression of competing activities, as well as positive reinterpretation and growth) directly addresses the problem. This method has been found to be generally adaptive (Folkman & Lazarus, 1984) and has been associated with closer sibling relationships (Orsmond & Seltzer, 2007b). However, emotion-focused coping (i.e., denial, focusing on and venting of emotions, behavioural disengagement and mental disengagement) is when an individual either avoids or emotionalizes the experience, which is generally maladaptive (Folkman & Lazarus, 1984).

Gamble and McHale (1989), on the other hand, coined the term "other directed cognitions", a coping behaviour (e.g., blaming someone else) that was found to be associated with poorer scores on adjustment measures such as well-being, as well as attitudes and behaviours of one towards the sibling with a disability. One can argue however that directing their cognitions outwardly also avoids or emotionalizes the experience as presented by Folkman and Lazarus (1980). Interestingly, siblings of individuals with a disability and females of non-disabled siblings (Gamble & McHale, 1989), as well as siblings of individuals with ASD (Roeyers & Mycke, 1995), have been most likely to use "other directed cognitions." However, more recent literature contradicts these findings. Instead Ross and Cuskelly (2006) found that

siblings of individuals with ASD use emotional regulation and wishful thinking. These findings may suggest that siblings of individuals with ASD are actively controlling their emotions to reduce the anger caused by aggressive incidences, and that they also have a strong desire for their situation to be different (Ross & Cuskelly, 2006). Additionally, Angell, Meadan, and Stoner (2012), highlighted that siblings of individuals with ASD reported restricting their boundaries (i.e., isolation), along with broadening their personal boundaries (e.g., obtaining support, educating others) as coping behaviours.

These results first identify that there is a distinction between which coping mechanisms are adaptive and which are maladaptive, and second, coping behaviours used by siblings may vary based on their brother or sister's disability. Such claims place an emphasis on the need to identify what coping behaviours are being used by siblings of individuals with specific disabilities such as FASD.

**3.2.2 Resources.** Many researchers have acknowledged that siblings of individuals with a disability are not only impacted by their experience but that they are also in need of support (McCullough & Simon, 2011; McGinty, Worthington, Dennison, 2008). In fact, resources that are available to a family and to siblings are strong predictors of adjustment and adaptation (Choi & Van Riper, 2013). For example, Van Riper (2000) examined family resources, demands, problem-solving, communication, coping, and sibling well-being in families of individuals with Down Syndrome (DS), and found that family resources were significantly correlated with sibling social competence and self-concept. Additionally, Kinsella et al. (1996) reported that siblings of individuals with a mental illness (e.g., Schizophrenia, Bipolar, Major Depression) who used resources outside of the family were "perceived to decrease the use of isolation as a means of

coping, promote normalization through the sharing of experiences, reduce stigma, and provide an excellent source of information” (p.30).

When examining sibling support groups, the literature is scarce. However, studies have identified that support groups do improve participants’ knowledge of their siblings’ disorder, their sense of connectedness with other children in similar family circumstances, and their perceptions of self-competence (Lobato & Kao, 2005). In addition, siblings reportedly experience fewer emotional and behavioural difficulties compared to waitlist controls (Roberts et. al., 2015), experience increased positive effect on their feelings towards their sibling, and learn new coping strategies (Johnson & Sandall, 2005).

Unfortunately, not all of the resource literature is positive. Giallo and Gavidia-Payne (2006) studied the adjustment of siblings of individuals with a disability and found both parent stress and previous attendance at a sibling support group were significant predictors of adjustment difficulties. Several other studies have shown that accessing professional support can have a negative impact not only on the families of children with a disability, such as financial pressure, sleep disturbances, and family job changes for parents (Rogers & Hogan, 2003), but it can also have a negative effect on the sibling relationship (Rivers & Stoneman, 2003). Explanations for the negative impact of attending support groups have been speculated to increase family stress (Rivers & Stoneman, 2003), and if siblings are sensitive to the negative experiences of others they may increase their negativity towards their own experience (Giallo & Gavidia-Payne, 2006).

It is clear that the literature has yielded inconsistent findings in regards to the effect of resources and sibling groups on the well-being of siblings of individuals with a DD. Despite these varying results, it is evident that the type of disorder plays a role in the siblings’ use of

resources and coping behaviours. That said, it is important to study each disability separately to identify stressors as well as factors that influence adaptation that are specific to each disability. With FASD prevalence rates ranging from 9.1- 520 children per 1000 live births depending on the population being examined in North America (FASD Research Network, 2015; Ospina & Dennett, 2013), it is likely that there are many siblings of individuals with FASD. With little knowledge about these siblings, the recognition of such factors will, in turn, allow those in the clinical field to tailor supports specifically for these siblings.

### **3.3 Methodology and Methods**

The current research is part of a larger mixed-methods study that examined families of individuals with FASD (Hughes, 2015; Watson, Coons et al. 2013; Watson, Hayes et al., 2013). The present qualitative study is informed by Merriam's (2002) basic interpretive approach, whereby "the researcher is interested in understanding how participants make meaning of a situation or phenomenon" (p. 6). With the use of the basic interpretive approach, semi-structured interviews were designed and conducted in order to explore the adaptation strategies of individuals with siblings diagnosed with FASD. Given the exploratory nature of this study, the inductive reasoning that is characteristic of the basic interpretive approach allows for concepts to be built and generalized conclusions to be made about how these siblings try to adapt. Additionally, using such an approach allowed for a descriptive explanation of the perspectives and worldviews of these siblings of individuals diagnosed with FASD. In the current study, interviews were conducted by the lead researcher and a graduate student who were both trained by an experienced researcher. However, the data analyzed solely by the lead researcher.

**3.3.1 Participants.** Siblings were recruited through disability support organizations across Ontario, Canada. These organizations were sent e-mails and individuals interested in the

study were asked to contact a member of our research team for more information.

Advertisements for the current study were also posted on social media sites such as Facebook.

Respondent driven sampling was also employed, whereby individuals known by the members of the research team were approached with hopes of recruiting more participants. Respondent-driven sampling is a technique that has been documented to help gain access to hard-to-reach populations (Salganik & Heckathorn, 2004).

Ten siblings of individuals diagnosed with FASD, as confirmed through self-report, from nine families participated in the semi-structured interviews. In order to participate in the study, siblings could not have a diagnosis of FASD, which may have had an impact on the sample demographics. Participants ranged in age from 10 to 37 years, with an average age of 19.8 years, and though they were all biological children, their siblings with FASD were adopted. With many biological siblings also having an FASD diagnosis, it is likely that the inclusion criteria deterred biological siblings from participating in the current study. The participant demographic information can be seen in Table 4.

**Table 4. Participant Demographic Information**

Demographic Characteristics	
Characteristics of Participant Siblings (N)	10
Average age (SD)	19.8 (8.5)
Age Range	10-37 years
Gender	
Male (n)	4
Female (n)	6
Relationship to Sibling with FASD	
Biological (n)	0
Adoptive (n)	10
Children in the Family	
Average number of children (SD)	2.2 (2.2)
Range of number of children	2-9
Siblings with FASD	
1 sibling with FASD (n)	7
2 siblings with FASD (n)	1
6 siblings with FASD (n)	1
7 siblings with FASD (n)	1
Average age of sibling with FASD (SD)	21.9 (7.4)
Range of age of sibling with FASD	14-42 Years

**3.3.2 Qualitative Interviews.** All participants were invited to participate in a semi-structured interview in person, over the phone or on Skype, which lasted between 20 minutes and 2 hours. During the semi-structured interviews, the researchers used an interview guide that consisted of approximately 20 questions, with some follow up questions if needed, as well as adapted language or clarifications for the younger participants. Many of the questions were open-ended, which helped to gain as much information as possible and avoided any yes or no answers. Examples of these questions included: “What helps you handle the difficult parts?” and “How do you think (insert name of sibling with FASD) has affected your family dynamic?” This approach allowed room for dialogue and ensured that participants answered the questions honestly rather than being led by the researcher to answer in a specific way.

During the interviews, each participant gave consent to digitally record their session, and interviews were transcribed verbatim. Subsequently, transcripts were analyzed using Thematic Analysis (TA; Braun & Clarke, 2014), which is used for “systematically identifying, organizing and offering insight into patterns of meaning across the data set” (p. 57). Specifically, TA allows the researcher to distinguish what is common between the interviews and then proceed to make sense of what is both common and meaningful. The TA process includes six stages which began by transcribing the interviews and then becoming familiar with the data by reviewing the transcripts several times. Secondly, initial codes were generated for the data that are relevant to the research question. Thus, this deductive approach focused on extracting and categorizing data that was relevant to both coping behaviours and the use of formal and informal resources. Next, in the third and fourth steps, themes were explored by “reviewing the coded data to identify areas of similarity and overlap between codes” (Braun & Clarke, 2014, p. 63), and reviewed by generating a thematic map to ensure there was no overlap between themes and sub-themes. Once the themes accurately described the data, the themes were then defined “the need for space”, and “the need for support”. Lastly, the report was produced whereby original data was selected to convey a better and deeper understanding of participants’ experiences. Such data included sibling testimonials and excerpts from the interview transcripts which provided the reader with concrete examples and promoted a better and deeper understanding of the participants’ experience. In this step, “the story” that is told is also compared to the already existing literature.

### **3.4 Results**

After analyzing all of the transcripts using Thematic Analysis (Braun & Clarke, 2014), two main themes were created. The first theme focused on the participants’ need for space,

which consisted of coping behaviours employed by siblings (e.g., active avoidance, emotional avoidance). The second theme highlighted the need for understanding, which comprised the effectiveness of resources (i.e., successful experiences, challenges) that siblings used to help them adapt. In order to give context to the reader when referring to specific participants, each sibling's pseudonym, age, and the number of siblings they have are presented in Table 2.

***Table 2. Interview Participant Characteristics***

Pseudonym	Age	Number of Siblings with FASD
Sarah	10	1
Alyssa	11	1
Matthew	13	1
Zack	15	1
Bradley	17	1
Samantha	19	1
Katie	22	7
Brianne	25	6
Shawn	29	1
Sydney	37	2

### ***3.4.1. The Need for Space – Coping Behaviours.***

As reported in Belanger and Watson (2016), participants in this study reported feeling frustrated, worried, and resentful, due to the numerous negative behaviours exemplified by their brother or sister with FASD. That said, throughout the interviews, the participants were often asked how they dealt or coped with the undesirable behaviours demonstrated by their sibling with FASD. The analysis of the semi-structured interviews revealed two main categories of coping behaviours, physical or active avoidance and emotional avoidance. The physical or active avoidance primarily focused on participants separating themselves physically from their sibling to avoid altercations, to calm down, and to escape. Emotional avoidance, however, highlighted how siblings avoid being emotionally attached to their sibling or suppress thoughts and feelings during times of distress. The coping behaviours reported by participants exemplify how they are

behaving in order to manage or reduce the demands put on themselves and their families by needing both physical and emotional space from their sibling.

**3.4.1.1 “I would leave...” – Active Avoidance as a Coping Behaviour.** Upon analyzing the transcripts, separation was one of the most common ways that siblings dealt with their brother or sister’s tantrums and stressful behaviours. During the interviews, eight participants maintained that they engaged in other activities away from their sibling to either avoid the chaos or to calm themselves down following altercations. For example, when asking Zack, 15, what kind of activities he likes to do with his sister with FASD, he responded by saying biking and watching TV, but then added “that’s kind of not a lot cause... she’s downstairs a lot, but most of the time we’re all separate so there’s no like fighting...and it goes on a lot because she’ll start crap that doesn’t need to be started...” Zack, who also found it difficult to calm his sister down, decided to adapt to his sister’s poor emotional regulation by spending time apart, reducing the chances of sparking an argument. The physical separation that Zack decided to put between the two of them sought to decrease their interactions, which in turn, minimized the number of demands faced by his family.

Participants also used physical distance as a coping behaviour in order to calm themselves down following an outburst with their sibling diagnosed with FASD. Going to their rooms to read or to listen to music, or going outside for a long walk or a bike ride were some of the ways that participants increased time apart from their sibling with FASD when they were frustrated or worried. Brianne, 25, who has six siblings with FASD, explains:

I would leave... I had a friend that lived eight houses down from me so I would leave and I would go to her house and I’d spend a few days there just because I didn’t want to be around it and I know it would take a few days for them to digress and calm down....

most of my childhood um, once I was able to walk to her house I did it almost weekend, I left almost every weekend just because...

Brianne, like many other participants, often needed time away from their siblings to calm down and avoid the chaos that occurred at the home. That said, the use of physical separation and distancing served as an escape from the chaotic environment. In fact, changing environments to be separated from her siblings became routine, as she automatically returned to her friend's house on weekends. Given the daily stressors reported by participants, having a specific area away from her sibling with FASD sought to eliminate or minimize these stressors, thus allowing them to de-stress and enjoy themselves rather than be frustrated or worried about their sibling. Having a refuge, away from their sibling was echoed by Samantha, 19, who spent her time dancing to circumvent the worry she so often felt. She explains:

Dance was really nice for me because it was just somewhere I could go, I didn't have to worry about my sister... I was there my whole week like Monday, Tuesday, Wednesday, Thursday, Saturday and it was, it was fantastic because I'd be there for hours at a time...just go to dance and not have to worry about anything else and it was, it was really nice.

As Samantha explains, leaving the house to do activities such as dance was extremely liberating. In fact, she chose to engage in such an activity five of seven days because it allowed her to be away from her sister, in a separate environment whereby she could redirect her focus onto her bodily movements rather than worrying about her sister and the troubles associated with her diagnosis. Just like Brianne, Samantha routinely placed physical distance between herself and her sister, as incorporating happiness, rather than worry, was essential to her mental health.

### *3.4.1.2 “I cope with emotional distance” – Emotional Avoidance as a Coping*

*Behaviour.* While many siblings sought to avoid problems by physically avoiding their sibling, seven participants also used emotional avoidance as a coping behaviour. Unlike physical avoidance, participants who used emotional avoidance could be physically near their siblings, and would even continue to interact with their siblings; however, instead of changing their physical boundaries, siblings who used emotional avoidance changed their boundaries by deciding not to emotionally engage with their sibling. Four participants described actively choosing not to emotionally engage with their sibling by either becoming less interactive or by reframing their thoughts to redirect their emotions away from their sibling. For example, Sydney, 37, changed her emotional boundaries when interacting with her two brothers with FASD to protect herself from the emotional turmoil caused by their behaviours. When asking Sydney how she copes, she explained:

I think that I cope with emotional distance, I think that I often feel guilty that I'm less involved in their lives... but I think that that's what keeps me from getting too hurt is that I just keep, I keep a fair amount of distance.

In her experience, just like many of the participants, Sydney had seen her brothers go through many hardships, such as being incarcerated, dealing with depression, alcoholism, suicidal behaviour, and an unplanned pregnancy. Not only did Sydney help her brothers during these times and was disappointed with the occurrence of other negative behaviours after her help, but she was also in a constant worry of “what is next?” That said, Sydney explained how she tried to retreat from the drama not by physical distance but by being less involved. Thus, setting her relationship with her brothers aside rather than entering their chaotic lifestyle diminished her

chances of being hurt emotionally either by disappointment, fear, or frustration with her siblings' behaviours.

Another way siblings chose to become less emotionally involved was through the reframing of their thoughts. For Shawn, 29, and other participants, not releasing their emotions was attributed to not knowing exactly where to direct their emotion. To be specific, the siblings often felt anger due to their sibling's behaviours but they did not want to direct their anger towards their sibling, as it is the FASD itself that is ultimately driving their behaviours. Shawn, who tried to spare his sister of his anger, stated: "you know just with an understanding that you know it's not necessarily her fault she's just doing, you know what she's doing... and that you know, as irritating as it is to be yelled at for an hour or two hours, it will pass...". Thus, instead of feeling angry at their sibling, these individuals reframed their thoughts to blame the behaviours on the FASD. This type of emotional regulation reduced their negative emotions and avoided negative expression of emotions directed to the sibling which could lead to bigger and prolonged altercations. In turn, the redirection of their anger towards the FASD itself may have fostered a better relationship between siblings by reducing the time they spent arguing. It is clear that participants who minimized their engagement or reframed their thoughts as coping behaviours realized that worrying or becoming angry is not helpful to their situation. Thus, employing these types of coping behaviours may indicate that they are in fact adapting to their situation. Nevertheless, for these participants, along with others, coping with their sibling's behaviours is about trying to stay positive by not becoming angry and "powering through" the chaos.

Other participants in the study simply tried to suppress their emotions completely. In fact, at least three of the participants described stopping themselves from feeling or thinking as a

coping behaviour. For example, when speaking with Alyssa, 11, about what she does when she worries about her brother she stated “I just try and take it out of my mind”. It was clear that for Alyssa, she feared the future and was scared to think about what could happen. However, for Zack, 15, who explained “I just don’t like thinking about when she’s having a tantrum”, he feared his inability to regulate his emotions which would escalate the situation. Thus, whether it was removing the negative thoughts from one’s mind to try and reduce the negative feelings, or “bottling up” the emotions, as expressed by Shawn, these siblings chose to avoid their emotions all together rather than accepting the potential outcomes, and the emotions that arise from them.

### ***3.4.2. The Need for Understanding – Resources.***

During the interviews, participants were asked about accessing both informal and formal resources. Results revealed that six of the siblings did confide in someone about the hardships of living with a sibling diagnosed with FASD. Some participants reported speaking with informal resources such as parents and friends, and others accessed formal resources such as therapy or support groups. Interestingly, one of the main components participants focused on when speaking about positive and negative experiences with resources was feeling understood. It was clear that good experiences were shaped by open communication with their parents, someone who believes what they are saying, someone who is educated and can provide them with information, and someone who shares the same experience. On the other hand, some of the challenges with resources included: not wanting to bother their parents, a lack of understanding of friends and family, and lack of knowledge, along with being the only sibling of an individual with FASD in a sibling support group.

***3.4.2.1 “She’s probably the only person that actually believes me and understands” – Successful Experiences when Accessing Formal and Informal Resources.*** Results revealed that

half of the participants expressed speaking to their parents in regards to the problems they have with their sibling with FASD. Sydney, whose parents brought her to see a psychologist as a child, stated “I don’t remember confiding in that therapist and I could talk with my parents, my parents really had an open-door policy and it wasn’t like taboo to talk about anything really...” Given that her parents were aware of and shared many of her struggles, they made sure that Sydney felt comfortable speaking with them about the hardships of living with two brothers with FASD. Like Sydney, other participants such as Bradley, Sarah, Zack, and Katie all said that speaking with their parents was helpful. These participants maintained that they would talk to their parents about issues and “get advice” about how to handle problems with their sibling. Katie, who lived separate from her family, would often “check-in” by calling her parents on a weekly or daily basis when she was bothered by her siblings with FASD or something they did.

When asking the participants about other informal supports that they may access, only three participants, Zack, Katie and Samantha, reported confiding in specific friends. These closest friends provided them with an outlet to vent as they were capable of listening and accepted the problems that occurred as a result of the disability, rather than questioning its validity. When speaking with Samantha, she explained how it is only her closest friend who really believes her when she is speaking about the issues that occur with her sibling with FASD:

Like one of my [friends] she actually lives across the road...we’ve been inseparable ever since and like she’s seen everything in my sister’s life so she knows that I’m not just making stuff up and she knows that these things actually happen for a reason and so she’s probably the only person that actually believes me and understands when I tell her which is, its kind of nice to have at least one person.

As Samantha points out, her closest friend is the only friend that has witnessed the effects of FASD over time. Having been in Samantha's life for many years, her best friend was present during both good and bad times, and has become aware of the extent and frequency of the behaviours exemplified by Samantha's sister. With this knowledge, Samantha's friend is able to believe her when she is talking about her sister, which is not only a relief but also very validating.

When examining formal resources, four participants expressed having seen and benefitted from speaking with health professionals about the stress and anxiety of living with a sibling diagnosed with FASD. For Brianne, she explained that when she was young "I didn't have anyone to talk to, I didn't have the resources as a sibling, I didn't have those resources just to go and talk to somebody." However, now that she has the ability to speak with someone, she has gained education on managing her experience, and she stated "She's been very helpful, um, just being able to give me different strategies to cope." Given her reported feelings of solitude, her therapist was the one person that she felt she could speak with; the one person who had the knowledge to be able to understand her issues and who she knew she was not bothering by venting about her feelings. Additionally, all three of these participants maintained that they struggled with depression, as well as anxiety due to the frequent amounts of worrying about their sibling with FASD (Belanger & Watson, 2016). Therefore, therapists also provided a space where they could safely vent about the emotions they felt which improved their mental health.

Samantha, on the other hand, had the chance to speak with other siblings of individuals with FASD when attending her mother's support group. When talking about her experience she stated:

“She’d [her mother] let me go and talk to the other siblings because there’s no one else and it’s so great to just even just talk to them. To realize you’re not alone with having a crazy sibling like... it’s fantastic.”

As Samantha explains, this experience was very rewarding as she no longer felt alone, and she could share her feelings, which were validated by the other siblings at the group. Additionally, her last statement “to realize you’re not alone with having a crazy sibling like... its fantastic”, is exactly what many siblings were searching for. In fact, the majority of siblings reported wanting to partake in such an experience which would allow them to be validated, to be part of a group of people who share the same concerns and feelings about their sibling, as well as to share information that will help one another. With the overwhelming amount of emotions (Belanger & Watson, 2016), utilizing poor coping strategies, and the challenges with resources, feeling alone is likely very common for siblings of individuals with FASD. Therefore, addressing and conquering these feelings of solitude are very important for siblings of individuals with FASD.

Given the examples provided above, it is clear that participants are able to and do speak with both informal and formal resources successfully. However, successful experiences with these resources is highly mediated by the resource’s level of understanding. Thus, this notion of being “understood”, that is, someone who understands the disability, someone who believes their story and someone who validates their thoughts and feelings, is very important for siblings of individuals with FASD. Despite the positive experiences shared by some of the participants, it was evident throughout the interviews that there were many barriers when it came to speaking to others about their sibling with FASD.

**3.4.2.2 “No one got it” – Challenges with Resources.** The interviews revealed that participants had many challenges when accessing informal and formal resources. When looking

at the informal resources, three individuals felt as though they could not or did not want to speak to their parents. For example, Brianne explains: “I don’t want to talk to my parents about it because they already have so much to worry about.” Brianne, along with the other participants, was certain that her parents are likely already aware of the problems associated with her siblings and have enough to deal with raising a child with FASD. That said, it was important for siblings not to increase their parents’ demands by venting about their own frustrations. As siblings already reported having little support, opting not to speak with their parents continues to limit the number of resources they feel they can approach. In fact, Brianne, Shawn, and Zack all reported that there was no one to speak with while growing up with a sibling diagnosed with FASD.

Another challenge was the lack of understanding demonstrated by informal resources. Despite participants having friends and family, when it came to confiding in them, some participants expressed that they simply could not comprehend their experiences. In fact, the idea of no one understanding was echoed by the majority of the participants throughout the interviews, such as Sydney, who explained:

I don’t think it’s the kind of thing I could really talk to friends about or even family right like I have a couple of very beloved aunts but even then, I don’t think even they understood... so I don’t think I had anyone to confide in really um... I think I had to keep that really within the family and not because anyone was telling me to, but because just no one got it.

Given the extent of the behaviours displayed by persons with FASD, many onlookers have difficulty grasping the extent of the disability and the strain that accompanies living with an individual with this diagnosis. The questions asked by individuals discouraged participants from speaking to them about their feelings. Thus, because their social network (i.e., friends and

extended family) was unaware of the nature of the disability, they would likely spend their time questioning rather than listening to and understanding the participants. Secondly, if participants were to speak with friends or family, it would likely be an invalidating experience, as these informal resources could not begin to comprehend the plethora of emotions that siblings experience daily as a result of living with a brother or sister diagnosed with FASD. Speaking about their experiences made it challenging for some who felt as though they could only open-up to their immediate family (e.g., parents, siblings).

When examining the challenges that participants have faced while accessing formal resources, a lack of understanding from professionals this time, was reported by Katie. In her experience, it was the little knowledge her therapist demonstrated about FASD that sparked an issue, as she felt as though she was not being fully understood. Although Katie still saw a therapist weekly she stated:

There's just not enough information... when I started going to counselling... I had seen a couple different people over the last several years you know. I have to explain to them the severity even though they have the DSM-V right there and like they have Ph.D.s and it's like I know... this is new information, but I need you to know this is really important.

For siblings who already feel as though no one understands them or the disability, help-seeking might be a natural inclination. However, to think that because a therapist is a professional he or she should be knowledgeable about the disorder and its symptoms, is an assumption that is often made. As Katie discovered first hand, there is a lack of information and education of health professionals on FASD which can be very frustrating and even discouraging for siblings of individuals with FASD.

With no sibling support groups specific to FASD reported in the literature, siblings who want support are encouraged to participate in support groups which include a wide range of disabilities (e.g., DS, ASD). Sarah, who had the chance to participate in such a sibling support group, expressed discontent in regards to her experience receiving formal support. When asking her if the group was beneficial she said “A little bit of the time because, they don’t have the, their siblings don’t have the same disorders”, she continued to say and she continued to say “It would be better if ... kids the same age as me that had a brother or sister who had FAS because most of them have Down Syndrome or other types, they don’t have FAS.” She also added that the groups “were all very much geared towards... people who are younger” and she was only 10 years of age. Thus, despite having gained some broad knowledge about disabilities, she still felt isolated from the group as everyone else only understood what it was like to have a sibling with Autism or Down Syndrome, not FASD.

In summary, participants reported that they needed space in order to cope with their experience of having a sibling with FASD. They achieved space by using both active and emotional avoidance to distance themselves from the stressors associated with their sibling and his or her behaviours. Additionally, many of the participants were successfully able to access resources to speak with others about the problems and the stress associated with having a sibling diagnosed with FASD. However, siblings maintained that there are various challenges to confiding in others. When asking siblings what they need for support it was no wonder they all wanted someone who will truly listen rather than question, as well as individuals who will be able to validate their emotions. Ultimately, siblings wanted people who will make them feel like they are not alone in going through this unique experience of living with a sibling diagnosed with FASD.

### 3.5 Discussion

After analyzing the transcripts with the use of TA, two main themes were identified: the need for space and the need for understanding, which highlighted the siblings' use of coping behaviours and resources. In the first theme, both active avoidance and emotional avoidance were identified as the most commonly employed coping behaviours. Active avoidance was when participants engaged in pleasurable activities (e.g., visiting friends, dance, etc.) to minimize the occurrence of altercations, to escape their sibling's presence or their chaotic environment, and to digress or calm down. Kinsella et. al. (1996) described these behaviours as "constructive escape" which "allowed for successful management of adaptation to adverse circumstances without secondary repercussions" (p. 26). Similarly, Lyons et al. (2010) and Pottie and Ingram (2008) referred to such behaviours as distraction, which yielded positive effects when employed by parents of individuals with a DD. Though the current study did not examine the effectiveness of active avoidance as a coping behaviour, the behaviours involved are consistent with positive strategies of adaptation as discussed in the literature.

Emotional avoidance, on the other hand, was characterized by participants reframing their thoughts and minimizing their involvement with their sibling in order to protect themselves from being hurt both emotionally and/or psychologically, along with the suppression of their emotions. Though there were a few participants who were unable to regulate their emotions, the current results are congruent with Ross and Cuskelly's (2006) study, whose findings revealed that siblings of individuals with ASD most commonly used emotional regulation rather than suppression or avoidance and rarely placed the blame on others. In the current study, emotional regulation was evidenced by the participants' acceptance of their circumstances and thus siblings were able to choose to minimize their engagement with their siblings and reframe their thoughts

by placing the blame on FASD itself, rather than their sibling. In fact, these findings are in contrast to Gamble and McHale (1989) and Roeyers and Mycke's (1995) results who found that siblings blamed others as a coping behaviour. Nonetheless, although many siblings of individuals with FASD are using adaptive or active coping skills, there are still siblings who are avoiding their emotions, which is likely detrimental to their adaptation as well as to their relationship with their sibling (Folkman & Lazarus, 1984).

The second theme, the need to be understood, was comprised of the siblings' positive experience with informal and formal resources, along with their challenges. When examining informal resources, Opperman and Alant (2003) highlighted the feelings of loneliness and isolation that are present within siblings of individuals with a disability. In the current study, the majority of participants reported open communication between them and their parents, while others expressed not wanting to approach them as it may add to their parents' stress. Additionally, not speaking with extended family due to their inability to understand was also reported by participants in the current study. In fact, Opperman and Alant (2003) reported that only 5% of the participants felt as though they were well-supported by their parents, and 32% by their extended family, suggesting a lack of support from family members. Additionally, only close friends were accessed as an informal resource by a few of the participants in the current study, which does not coincide with the 74% of adolescent siblings that reported speaking with friends (Opperman & Alant, 2003). Though there is a discrepancy in participant ages between studies, no adolescents in the current sample reported speaking with friends. However, both Opperman and Alant, (2003) and the current study did report that siblings may only have one or two friends to speak with, if none at all, as many friends of those with a DD struggle to believe that there is disability, or cannot grasp the issues regarding a sibling with a disability.

Participants also expressed accessing formal resources such as receiving therapy (Neely-Barnes and Graff, 2011) or attending a support group, but this was reported by less than half of the sample. Positive aspects of receiving therapy were having someone who is knowledgeable and learning about either the disability or about coping (Johnson & Sandall, 2005; Lobato & Kao, 2002, 2005). However, a barrier that was presented was the therapist's lack of knowledge of FASD, a finding that has also been supported in the literature (Tough, Hicks, & Clarke, 2008; Wedding et al., 2007). Additionally, participants either enjoyed or maintained wanting to speak with other siblings of individuals with FASD, as these individuals would "understand." A challenge however, was that isolation was increased, as most groups include a variety of disorders and are geared towards the younger population (Lobato & Kao, 2002, 2005; Roberts et al., 2015; Tudor & Lerner, 2015). Nonetheless, validation, which is used to communicate acceptance and understanding, has been associated with alleviating pain and distress (Greville-Harris, 2013). Thus, sharing validating experiences with other siblings of individuals with FASD, would be beneficial to siblings' well-being.

### **3.6 Limitations and Considerations**

Though this qualitative study explored the capability strategies used by siblings of individuals with FASD, it should be interpreted within its limitations. With many challenges throughout the process, the first consisted of the wide age range of the participants. Siblings had a mean age of 19.8 years, however this varied from 10-37 years. Therefore, siblings may have reported coping behaviours or resources specifically associated with their age. For example, younger participants would walk, go to their rooms, and they were the ones to attend support groups, while older siblings were more likely to see therapists, call their parents to check-in, or

become less involved in their siblings' lives. Future research should examine the strategies used by siblings of different developmental stages (e.g., childhood, adolescence, adulthood).

Another consideration is the adopted status of all participants in the current study. Although both adoptive and biological siblings were invited to participate in the study, only adopted siblings sought participation. Thus, the sample is representative of the adoptive population, as approximately 80% of infants in foster care have FASD (Dicker & Gordon, 2004). A possible explanation to the sole participation of adopted siblings could be attributed to the study's exclusion criteria. As siblings with FASD were excluded to participate, this may have discouraged biological siblings, who often share the FASD diagnosis, to participate. However, adoptive status may have an effect on coping or resources that is different from those of biological status, and thus results may not generalize to this population. For example, previous literature has found that biological mothers of individuals with FASD reported guilt (Sanders & Buck, 2010), or being at fault (Salmon, 2008). With adopted siblings feeling as though they do not want to burden their parents, this may be exacerbated in biological families or have other effects on sibling coping strategies or resources. Thus, more knowledge on the capability strategies used by the biological population would ensure that supports are tailored appropriately.

As Braun and Clarke (2006) highlighted, Thematic Analysis (TA) has, in the past, been a poorly defined method in the field of psychology. Nevertheless, they argued that with clarification and direction on employing TA, it should be seen as a foundational method of qualitative analysis. Though the limitations associated with employing TA “depend more on poorly conducted analyses or inappropriate research questions, than on the method itself” (Braun & Clarke, 2006; p.27), what counts as “accurate representation” depends on your theoretical and analytic approach (p.22). In other words, the data-set and analysis can be subject to the

researcher's biases. In order to reduce such biases, the sample size did surpass the required minimum of six participants in a qualitative study (Kuzel, 1999; Morse, 2000), which may have enhanced reliability in the current study. To ensure trustworthiness, both member checks and triangulation was conducted (Shenton, 2004). As it was important to accurately convey the experience of siblings diagnosed with FASD, member checks were conducted, whereby a summary of the themes were sent to the participants for their review and accuracy prior to the completion of the document (Shenton, 2004). All participants who responded indicated that the thematic analysis reflected their experiences and that no adjustments to themes needed to be made. Additionally, as the current transcripts were employed in another research project, investigator triangulation was also employed by having another researcher analyze the transcripts, which ensured that similar interpretations were made by all researchers (Tuckett, 2005). Despite these limitations, TA, as proposed by Braun and Clarke (2006), is a rigorous process that ensures flexibility and allows results to educate the general public as well as to inform policy development (Braun & Clarke, 2006).

### **3.7 Implications for Service**

Given the results of the current study, there are many recommendations to be made. First, to ease the process for families raising a child with FASD, health service providers of all kinds, such as general practitioners and psychologists, need more education on FASD (Tough, Hicks, & Clarke, 2008; Wedding et al., 2007). A confident and informed health service provider could help siblings feel understood, and they can educate the family or refer them to an organization, increasing the family's resources.

Knowing that parents of individuals diagnosed with a DD are concerned for their non-diagnosed children (Kresak, Gallagher, & Rhodes, 2009), educating them on the sibling's

perspective would help address the communication issues reported by participants. Though guidelines, which outline how to communicate with your child, have been proposed by Harris and Glasberg (2003), they are specific to siblings of individuals with ASD. Thus, sharing information about repetitive behaviours and nonverbal communication, which are characteristic of ASD, may be different than sharing information about illegal behaviours as seen in FASD, highlighting the need for FASD specific material. Additionally, as siblings of individuals with FASD are requesting more information, it would be beneficial for parents to help them learn about the disability, and the management, resources, and adaptive coping mechanisms that are associated with FASD. Given that parents are likely to receive helpful information and tactics to rearing a child with FASD from support groups or therapy, sharing some helpful skills with their non-diagnosed child that they may use, could help foster a closer relationship between siblings.

Increasing accessibility and the use of formal resources could help to alleviate siblings' feelings of loneliness and isolation, and promote the creation of a network of continued support for siblings of individuals with FASD. With siblings expressing a strong desire to speak with others in the same situation, providing them with the opportunity to share their story and learn about FASD from someone who has lived the full experience (e.g., siblings and caregiver) could fill the void that siblings face with the reported lack of understanding. Additionally, with some of the participants maintaining that they suppressed their emotions or avoided them, formal resources could provide siblings with information on adaptive strategies (e.g., problem-focused) along with maladaptive strategies (e.g., emotion-focused) and their psychological effect (e.g., anxiety, depression). With the use of problem-focused coping being correlated with closer sibling relationships in individuals with a DD (Orsmond & Seltzer, 2007b), insight on how to directly address the problem by taking control, information seeking, and evaluating the pros and cons

(Folkman & Lazarus, 1984) would likely be beneficial to this population. As per the request from participants, more education around the management of their siblings' behaviours and attitudes, as well as creating a plan of action towards adopting the caregiver role of a brother or sister with FASD for the older participant, would benefit them greatly.

### **3.8 Conclusion**

The current qualitative study explored the coping behaviours and resources utilized by siblings of individuals with FASD. With the use of Thematic Analysis, two main themes were generated: the need for space and the need for understanding. It was determined that though siblings are employing effective capabilities (e.g., physical avoidance, the use of informal and formal resources), there are still many challenges to their ability to successfully adapt (e.g., emotional avoidance, lack of understanding). Nonetheless, many recommendations have been made to help develop their adaptive capabilities, such as increasing knowledge in health practitioners, parents and siblings as well as decreasing their feelings of isolation by connecting with formal and informal supports.

Given that this was the first study to explore the capabilities and support needs of individuals with FASD, the need for more research in this particular area has been established. Specifically, more attention must be placed on the effectiveness of coping strategies and resources within this population. Also, research on accessibility and tailoring of support specific to siblings of individuals with FASD is essential to their adaptation. Increasing the literature in this field will help with a plethora of issues, such as reducing the siblings' stressors, their feelings of isolation, provide them with help to manage their emotions, ease the transition into the caregiving role, and ultimately foster a better closer relationship with their sibling diagnosed with FASD.

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## **Chapter 4: Conclusion**

The current manuscript-based thesis intended to add to the literature of siblings of individuals with Fetal Alcohol Spectrum Disorder (FASD), a population that has been understudied in the field of developmental disability. Two research articles were included in the present thesis, the first of which explored the experiences of siblings of individuals with FASD as described by the emotions they felt. The second paper explored the facilitators to adaptation and the support siblings need to increase adaptability in their unique situation. In this final chapter, the results of both studies are summarized, plus the author discusses the trustworthiness of the study, considerations and recommendations for future research, knowledge translation, as well as the clinical implications.

### **4.1 Summary of Findings**

There is extensive research in the field of developmental disabilities that specifically focuses on the impact a child with a developmental disability has on the family (Hanson & Hanline, 1990; Newacheck & Kim, 2005; Reichman, et al., 2004; Rosenzweig, et al., 2008). Though much of the research has focused on parental experiences (Families Special Interest Research Group of IASSIDD, 2013; Ha, Hong, Seltzer, & Greenberg, 2008; Hanson & Hanline, 1990; Poston et al., 2003), there are several studies that have indicated a negative impact on the siblings of individuals with developmental disabilities (Kaminsky & Dewey, 2002; McGinty, Worthington and Dennison, 2008; Orsmond & Seltzer, 2007ab; Pollard, Barry, Freedman & Kotchick, 2013). However, upon close examination of these studies, it becomes evident that very little research in the field of developmental disabilities includes and/or focuses on the experiences of siblings of individuals diagnosed with FASD. Despite foster parents of children with FASD indicating a need for support and education for their biological children (Brown,

Sigvaldason, & Bednar, 2005), and other researchers stating the need to explore this population (Conway & Meyer, 2008; McCullough & Simon, 2011; Olson et al. 2009), no scientific research has examined the unaffected siblings of individuals with FASD. That said, the current study sought to explore this population and answer two research questions: 1. What are the benefits and drawbacks to having a sibling diagnosed with FASD? and 2. What strategies of adaptation are used by the siblings living with a child with FASD?

With many studies in the field focusing on the negative impact of having a child with a developmental disability on the family (Turnbull, Summers, Lee, & Kyzar, 2007), the first research question explored both positive and negative aspects of living with a child with FASD to gain a more comprehensive understanding of their experiences. In answering this first research question, 13 siblings of individuals with FASD participated in a mixed-methods study (Teddlie & Tashakkori, 2009). Thus, participants completed two self-report measures, the Sibling Inventory of Behaviour Scale (SIB, Hetherington, et al., 1999; Schaefer & Edgerton, 1981) and the Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006), which were analyzed using descriptive statistics and integrated with the qualitative data. The siblings also participated in a semi-structured interview in which questions were derived using a basic interpretive approach (Merriam, 2002) and analyzed using Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009). Results of the analyses identified five major themes including, frustration, worry/fear, resentment, happiness, and personal growth. These results indicate that although there are positive aspects to being a sibling to someone with FASD, these siblings are also dealing with significant strains and stressors that require support and attention.

With siblings of individuals reporting great demands, the second research question examined their capabilities, as guided by the FAAR model (Patterson & Garwick, 1994a;

Patterson, 1988). Thus, researchers re-analyzed the same 10 semi-structured interview transcripts from the first study, however this time Thematic Analysis (TA; Braun & Clarke, 2006) was employed. The use of TA, rather than IPA, allowed the researcher to focus solely on the support topics that siblings identified. The analysis revealed two main categories, which included coping behaviours and resources. The second article revealed that siblings are employing healthy coping skills, but they also face many barriers to adaptation due to some of their coping behaviours as well as the minimal knowledge and understanding exemplified by their resources.

#### **4.2 Ensuring Quality of Research**

Many steps were taken to ensure the quality of the current study. However, in avoiding positivist ideas proposed by quantitative methodologies (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991; Lincoln & Guba, 1985) and the use of terms such as reliability and validity, qualitative researchers employ the term trustworthiness, which is, as Merriam (1998) describes it, how efficaciously a study does what it was originally designed to do. In verifying the quality of the research, trustworthiness is achieved by applying rigorous standards to establish credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985). The techniques employed by the researcher throughout the analysis (i.e., Interpretative Phenomenological Analysis and Thematic Analysis) to establish the four criteria above, and by extension to achieve trustworthiness of the study, are described below.

Credibility is consistent with internal validity (Shenton, 2004) and thus refers to “how congruent are the findings with reality?” (Merriam, 1998, p.201). Numerous techniques were involved in establishing credibility in the current study, which began with choosing the proper operational measures for the concepts being studied (Yin, 1994). Thus, each document involved in the larger project, which examined the experience of families of individuals with FASD and/or

Autism Spectrum Disorder (ASD), employed both mixed-method and qualitative approaches (Hughes, 2015; Pepper, 2016; Watson, Coons, & Hayes, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). Prolonged engagement, whereby the researcher became familiar with the topic and culture of participating organizations (Shenton, 2004), added credibility by virtue of thorough literature reviews and networking with the authors of the larger project who have done research with families of individuals with FASD. Immersion in the topic and networking activities allowed the researcher to gain an understanding of FASD and their families prior to beginning the study.

A third technique undertaken to establish credibility in the current study was the use of triangulation. Specifically, the first study employed methodological triangulation by combining dissimilar techniques for data collection (Tuckett, 2005). The combination of both methods increased the depth and strengthened the themes more so than what either method could have provided alone (Creswell, 2014; Guest, MacQueen, & Namey, 2012; Teddlie & Tashakkori, 2009). Also, as part of the larger project, the current data were analyzed for a separate project, comparing siblings of FASD with those of children with Autism (ASD). Thus, both the research supervisor and the graduate researcher who helped with data collection participated in investigator triangulation, which is using multiple observers to analyze the data (Denzin, 1989). Thus, credibility was strengthened when each observer generated similar themes from the participant transcripts.

Steps to ensure the quality of the research also included much peer debriefing, whereby analytical probing occurred not only to test hypotheses about the data, but to also uncover potential biases, thereby seeking to ensure that the participants' perspectives were conveyed and not the researcher's (Lincoln & Guba, 1985). Last, member checks were conducted, whereby the

results were sent to participants via e-mail for review and to bring forth any concerns about the results. Making sure that participants were satisfied with the results sought to ensure that the findings accurately described the participants' experiences, which would serve to increase the credibility and trustworthiness of the findings obtained in the current study.

Transferability refers to the external validity of the study, thus demonstrating that the current findings can be applied to a wider population (Shenton, 2004). One of the methods to increase transferability of a study is by providing a thick description of the phenomenon. Including sufficient detail of the results allows the readers to transfer the conclusions to other populations and settings. In this way, the current study provided a thick description of concepts presented, participant information (e.g., demographics), and credible interpretation (Tuckett, 2005). The researcher has also set forth potential limitations of the current study, which readers can take into account before attempting transference (Shenton, 2004).

Dependability shows that the findings are consistent and thus can be repeated. It is however argued that dependability and credibility are very similar, therefore ensuring the former, to some extent, ensures the latter (Lincoln & Guba, 1985). The use of overlapping methods is one way to achieve dependability, such as administering both questionnaires and conducting individual interviews, as was done in the current study. Second, ensuring that the study's procedures are explained in detail, so that any future researcher can reproduce the study, can address the issue of dependability. Readers were provided with detail regarding the research design, the operational detail of data gathering, and reflecting on the process, as done in the current chapter (Shenton, 2004).

The final method to achieving dependability is through external audits, whereby a researcher who is not involved in the research process examines the procedures and research

study. That said, the current document was reviewed not only by the research supervisor, but also by two committee members and a designated external auditor. Thus, the evaluation of the findings and interpretations by external auditors has been maintained, improving the dependability of the study.

The final step towards ensuring trustworthiness of a study is confirmability, which certifies that the findings are yielded objectively rather than by the researcher's biases (Lincoln & Guba, 1985). In order to maintain objectivity in the analysis, triangulation as mentioned above was employed, which minimizes the effects of investigator bias (Shenton, 2004). Additionally, an audit trail (Tuckett, 2005) was kept, which begins with the notes that were made on the transcripts and the coding of data on separate documents that were individualized by colour for each participant making it easier to trace the data back to its origin for review. Last, the lead researcher provided the readers with a reflexivity section, which is a detailed description of the researcher's demographic information, education, experience, and world views. Including this information allows for a critical evaluation of the role the researcher and her background played in the research process (Merriam, 2009). Though including a reflexivity section does not eliminate research biases from the results herein, it does however increase transparency of the results, and provides a good indication that the guidelines for "good practice" proposed by Elliott, Fischer, and Rennie (1999) were followed (Reid, Flowers, & Larkin, 2005). Overall, using the aforementioned methods to demonstrate credibility, transferability, dependability, and confirmability, has strengthened the trustworthiness of the study.

### **4.3 Considerations and Recommendations for Future Research**

Despite trying to achieve good quality in both of the current studies, it is equally important to note and reflect upon the many considerations that have been generated throughout

the research process. Issues pertaining to recruitment methods and the sample size are discussed. Additionally, recommendations for future research are made in order to address the limitations of the current studies and to expand on the findings.

The current study recruited siblings primarily by informing parents of individuals with FASD regarding the study. Sparking parental interest then lead to sibling notification and eventual participation. However, two considerations must be brought to light with such a recruitment method. First, the majority of parents were accessed through an already existing pool of parent participants who were recruited primarily through support groups. Participation in support groups could suggest that parents are having a difficult time adapting to rearing a child diagnosed with FASD. On the other hand, social support has been positively correlated with adaptation (Greeff, Vansteenwegen, & Gillard, 2012) and has been found to increase adaptive coping skills (Clifford & Minnes, 2013). In fact, the size of the support system has been found to be the best predictor of lower stress and fewer family difficulties in families of individuals with Smith-Magenis syndrome (Hodapp, Fidler, & Smith, 1998). That said, the current sample of siblings may have had more resources and social supports than others within the population, therefore limiting the generalization of results to the greater sibling population.

Last, many of the participants' parents receive support for their child with FASD, which may highlight a selection bias, a common downfall of snowball sampling (Atkinson & Flint, 2001). In the current study the selection bias includes individuals who may be more resourceful, which may miss isolated siblings whose families may not have access to supports or resources. Despite the possibility of such a bias, to increase transparency, siblings were asked about the resources and supports they may receive or attend. Though the impact of parental resources was not measured, many siblings explained that they themselves did not have much social support.

The minimal support reported by siblings demonstrates that parental support may not have increased the participants' access to supports, which in turn preserves the study's credibility.

A second area under consideration was the sample size. Despite meeting the minimum recommendation of six participants for a qualitative study (Denzin & Lincoln, 1994; Kuzel, 1999; Morse, 2000), with only 13 individuals completing the questionnaires, the sample size impeded the ability to conduct more sophisticated statistical analysis for the data derived from the quantitative measures used in the first study (Cohen 1992; Schmidt, 1996; Schmidt & Hunter, 1997). Thus, future research should include a larger sample size to have the ability to yield conclusions that can be applied to the greater population within this context.

One of the advantages to the current thesis was the use of a mixed-methods approach in the first research article. By integrating both questionnaires (quantitative data) and semi-structured interviews (qualitative data), and as highlighted by Teddlie and Tashakkori (2009), the analysis revealed a comprehensive, in-depth view of the sibling experience. Not only were the themes better supported and strengthened with two types of data, the degree of trustworthiness of the study was enhanced (Creswell, 2014; Guest, MacQueen, & Namey, 2012; Teddlie & Tashakkori, 2009).

As the literature pertaining to healthy siblings of individuals with FASD is very scarce, both current studies highlighted areas in need of further research. In addressing some of the considerations stated above, the need for a larger sample and the inclusion of quantitative and qualitative data are noteworthy elements to include if conducting research with this population. Studies should continue to examine factors that are involved in the sibling experience such as stress levels, levels of externalizing and internalizing behaviours, and other factors that may contribute to their daily demands. Knowing the impact of such demands could initiate problem

solving on how to help siblings minimize specific stressors, and in turn foster a closer relationship between affected and unaffected siblings.

Continued research is also needed with regard to sibling adaptation. With both the limited resources and the ongoing worry reported by siblings, future studies should focus on how siblings are adjusting behaviourally and psychologically. If siblings are greatly affected by the experience of having a sibling with FASD, further research could provide empirical evidence that emphasizes the need for support. Future studies should also examine the coping strategies, resources, and adaptiveness towards living with a sibling diagnosed with FASD. Further information on how siblings are currently adapting (or not) is an important factor, as supports should be tailored to provide specific strategies to help these siblings achieve adaptation. Providing siblings with tools to help them adapt could promote a healthy sibling relationship and facilitate the potential future caregiving role.

Another area to focus on when considering future research is on comparison studies, both between and across groups. Comparison studies would allow researchers to examine similarities and differences in the experiences and adaptation of siblings within this population, by considering how characteristics such as gender, age, and especially biological and adoptive status may influence their perspectives. When examining gender of participants in the current study, female siblings reported wanting to bring awareness of FASD, felt the need for more resources, and engaged in caregiving activities more did their male counterparts, a trend that has been reported in the literature (Orsmond & Seltzer, 2000). Also, when examining the age of the participants, given that many were older, they often provided the researcher with a retrospective account of their experience, which could have changed as they developed more awareness, insight, and maturity. However, many of their childhood recollections were conceptually

grouped with the younger population, suggesting a mostly accurate reflection of a younger sibling's experience. The four oldest participants also lived in separate households. However, aside from fear of caretaking reported in the older participants, no differences were noted in the data due to their physical separation. It is possible though that both physical and emotional distance were easier to achieve for these participants, given that they are already separated from their sibling (s). Both gender and age are thus factors that play a role in the sibling experience and should be examined further.

Last, though biological siblings would be difficult to access given that many biological dyads share the FASD diagnosis, with many siblings reporting worry for their parents, it is a population that may be challenged with different stressors. According to the literature mothers have been found to experience guilt (Sanders & Buck, 2010) or report being at fault (Salmon, 2008), thus they may experience different personal stressors than do adoptive mothers. As participants in the current study were concerned about their parents' stresses and needs, the guilt experienced by mothers or the fact that they consumed alcohol during pregnancy is likely to elicit different emotions towards their biological mother. Examining these groups specifically in the realm of adaptation could reveal what subgroups are more at risk for psychological difficulties. Additionally, comparing the perspectives of siblings of children with FASD to those of children with other DD's such as Autism and Down Syndrome, could help to differentiate the sibling experiences between these disorders, and lead to tailored supports depending on type of disability.

When looking at the support system specifically, more research on resource or support group accessibility, quality, and efficiency should be considered as the literature pertaining to support groups shows great variability (Tudor & Lerner, 2014). In adding to the support

literature, FASD-specific groups should be an area of focus for both clinical and empirical purposes. With many participants wanting more education, more research on FASD, and more people to speak with, adding to the literature will not only address some of their needs, but it will also provide decision-makers with the information they need to support the implementation of tailored programs for siblings of individuals with FASD.

Last, research should address the experience and adaptation of siblings over time. Differences were noted in the experiences of subgroups, such as older siblings reporting more fear and distress about future caretaking; and their use of therapists. The subtle age differences found in both the current work, and in the developmental disability literature (Choi & Van Riper, 2013; Orsmond, Kuo, & Seltzer, 2009; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009; Wilson, McGillivray & Zetlin, 1992), indicates that siblings' experiences and adaptation may change over time (Patterson, 1988). Longitudinal research could help shed light not only on the changes that occur in family adaptation (Patterson, 2002a; Pederson et al., 2015), but could address issues such as caretaking, whereby the role of becoming a caretaker may yield higher stress as siblings age and are more likely to assume a caretaker role.

#### **4.4 Knowledge Translation**

In order for the current studies' results to have an impact on the targeted population, knowledge translation is crucial. According to the Canadian Institutes for Health Research (2016), knowledge translation is “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, and provide more effective health services...” (§ 4). Conducting such a process with the results of the current thesis would be beneficial for knowledge users such as disability researchers, siblings and parents of individuals with FASD, FASD organizations and support

groups, as well as mental health clinicians. In mending the gap between researchers and knowledge users, the information obtained in this thesis will be dispersed through conference presentations, providing formal resources with summaries of the study's findings, and empirical publications.

As knowledge users vary in background, methods such as presentations and reports are useful for reaching various sectors associated with developmental disabilities. That said, conferences can attract a wide array of individuals from researchers to professionals to families of an individual with a developmental disability. To increase knowledge translation, the current study has been presented at conferences such as a Research Special Interest Group, Laurentian University's Research Week, and the FASD Matters Conference: Across the Life Span. In addition to conferences, in order to reach a large population, knowledge users such as Sibshops, FASD ONE, FASworld, FAS link, and the Canadian Association of Mental Health, along with other institutions that provide services for individuals with FASD and their families, will be sent a brief report containing the results of the current studies. In fact, to begin this process, throughout the research project, each participant or their parents were asked if they wanted to receive a copy of the study once completed. Of 13 individuals, nine individuals indicated wanting to receive the results, which will promote the sharing of information within families of individuals with FASD.

A third method of knowledge translation is the publication of research. Thus, thesis authors will seek to publish the current research in peer-reviewed journal articles. Translating knowledge through publication will not only add to the body of disability literature, but it will also be viewed by the academic community and those who have access to academic journals. With many participants reporting a lack of resources or support, employing methods such as

presentations, reports and publications will hopefully inform policy-makers and help tailor and facilitate supports for siblings of individuals with FASD. Though this may help the service sector, we also aim to increase the overall awareness of FASD in society. Participants made it clear that many individuals do not understand the disorder and therefore, educating the public, could lead to more knowledge about FASD and how to prevent it.

#### **4.5 Clinical Implications**

As the current thesis goes towards earning a master's degree in applied psychology, there is an inherent need to discuss the role that health care professionals can play in the lives of siblings of individuals diagnosed with FASD. Based on the study findings, it is evident that siblings of individuals diagnosed with FASD face numerous daily stressors and could benefit from receiving support. Specifically, the siblings' transcripts revealed a need for validation and education.

Validation refers to “the recognition and acceptance of another person's thoughts, feelings, sensations, and behaviors as understandable” (Hall, 2012; p.1). In their experience, participants often witnessed their siblings engage in a wide range of socially unaccepted behaviours (e.g., tantrums, eating a goldfish, criminal behaviour, and substance abuse). Nonetheless, when participants chose to confide in others about these behaviours, it was clear that the resources that they approached were not understanding and/or accepting of their testaments, as evidenced by the questions that followed. Thus, because resource/helping providers were not educated on FASD, they focused on the validity of the sibling's statements, rather than on how the participant felt. As questions about the participants' siblings and their behaviours were continually made by these providers, the participants' emotions were subsequently invalidated which heightened their feelings of solitude. Empirically, invalidating

responses, as experienced by siblings, have been found to increase physiological and psychological arousal and decrease social engagement behaviours (Greville-Harris, et al., 2016; Shenk, & Fruzzetti, 2011), all of which are detrimental to one's well-being. Therefore, clinically speaking, it would benefit participants to speak with someone who can validate their thoughts and experiences, such as a helping/health practitioner who is familiar with FASD or another sibling of someone with FASD (e.g., FASD sibling support group). Both resources would allow siblings to not only be accepted but to speak about their experiences in a safe place. Whereas a helping practitioner may be more helpful in attending to their feelings and help siblings with acceptance, speaking with other siblings who also have a brother or sister with FASD may yield or provide siblings with a true understanding of their experiences. Additionally, accessing support groups could increase the sibling's social network, such as the building of friendships with others like them, which could promote longevity in their support system. Thus, increasing access and promoting discussions with both types of resources could help siblings decrease physiological arousal due to invalidation or misunderstanding, and promote psychological well-being through sociability and the discussion of issues that would otherwise remain unresolved.

The second clinical implication for these siblings is to provide them with information and education on tools that can help them adapt to their experience. For example, tantrums were one of the most frequently reported behaviours to elicit negative emotions among participants. However, participants often reported escaping the environment when tantrums occurred. Though this could be viewed as an adaptive way of coping, it could also indicate that they may not know what to do in this situation, and are thus not using adaptive coping behaviours. Nonetheless, to help siblings adapt, learning about sensory dysfunction, impulse control and calming techniques as proposed by the Edmonton and Area Fetal Alcohol Network (2007), could provide siblings

with the tools to help reduce the occurrence of tantrums or to actively alleviate their sibling's anger.

Another emotionally-charged topic discussed by participants was their siblings' future. The worry that was expressed, particularly from the older participants, revolved around their role in taking care of their sibling with FASD when their parents were no longer able. Although some participants were clear on their intent to play a small role and others planned to take full responsibility of their sibling with FASD, not many participants had information on their options or the logistics involved in making this transition. In fact, their lack of knowledge only added to their worry and concern for their future and their siblings' future. With 80% of adults with FASD being unable to live independently (Streissguth, Bar, Kogan, & Bookstein, 1996), this means siblings would not only be caring for their brother or sister with FASD, but their aging parents as well. Another option is to place their sibling in a group home. However, with many homes unable to meet the unique needs of individuals with FASD, organizations have begun to examine FASD-specific housing (Brownstone, 2005; Burns, 2008). As these are only a few of the many considerations to be made, siblings reported feeling very overwhelmed and scared when considering becoming their sibling's caregiver. Nonetheless, to alleviate some of their fear, becoming educated on the process and issues as mentioned above, along with preparing and planning with their parents, could make for a smoother and more confident transition.

Last, results showed that siblings are in need of strategies to help them adapt, such as coping mechanisms and resources. Thus, it would be beneficial for participants to learn how to cope with their siblings' behaviours and the many emotions they feel as a result of their unique experiences. Being aware of the adaptive and maladaptive coping techniques would allow siblings to monitor their own behaviours in order for them to take a proactive role towards

adaptation. It is important to note, however, that none of the implications can be made without educating siblings on resources that are available. Thus, healthcare providers, along with parents, should be informed of the struggles that siblings may face so that they can be prepared and have information on the resources (e.g., counselling, support groups) that are available to siblings of individuals with FASD.

In a broader sense, with siblings worrying not only about their sibling with FASD but also about their parents, they made it clear that helping the members in their family would also be helping them. Siblings spoke about more resources, more funding and more help for their family, but they also wished for the world to be a more understanding place. Participants maintained that their siblings and parents did not deserve the judgments that were made by community members, and with a better understanding of disability in society, their experiences would be much more pleasant. However, by educating communities with their story, they hoped to not only help other siblings and families of individuals with FASD, but to also prevent future mothers from consuming alcohol during their pregnancy. Despite all of the challenges these participants faced, they love their sibling(s) with FASD, and they made it clear that all they wanted was for society to love them as well, but it was important for them to help others not have to endure the demands that they have faced due to their unique experience.

To conclude, this exploratory study is one of the first to examine siblings of adopted individuals with FASD, and has expanded on the knowledge gathered in the larger project examining families of individuals with FASD and ASD (Hughes, 2015; Pepper, 2016; Watson, Coons, & Hayes, 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). Specifically, this thesis provided researchers with a better understanding of the challenges and the benefits of having a sibling diagnosed with FASD, along with the strategies siblings are using to adapt to their unique

situation. Gaining an understanding of the sibling experience can serve to inform policy-makers, support providers, and other individuals who work with families of individuals with FASD, and who can ultimately provide siblings with the services they may require.

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## Appendix A



## 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 / Modifications to project X / Time extension	
<b>Name of Principal Investigator and school/department</b>	Josee Belanger, Psychology, supervisor Shelley Watson, Psychology
<b>Title of Project</b>	Living with a Sibling Diagnosed with Fetal Alcohol Spectrum Disorder
<b>REB file number</b>	2014-12-08
<b>Date of original approval of project</b>	December, 2014
<b>Date of approval of project modifications or extension (if applicable)</b>	March 16, 2015
<b>Final/Interim report due on:</b> <i>(You may request an extension)</i>	April, 2016
<b>Conditions placed on project</b>	

During the course of your research, no deviations from, 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 refer to the Research Ethics website to 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 LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, Laurentian University Research Ethics Board

**Appendix B**  
Semi-Structured Interview Guide

1. How old are you?
2. How many siblings do you have?
3. How old are they?
  - a. How old is (insert name of sibling with FASD)?
4. Did your sibling grow-up in the same home as you?
5. Was your sibling adopted?
6. How did you find out that your sibling has FASD?
7. How would you describe (insert name of sibling with FASD)?
8. What is it like to be (insert name of sibling with FASD)'s sibling?
9. Tell me about a typical day in your household.
10. How do you think (insert name of sibling with FASD) has affected your family dynamic?
11. What is a favourite memory you have with him/her?
12. What are some of your favourite activities to do with (insert name of sibling with FASD)?
13. What is the best part of being a sibling to (insert name of sibling with FASD)?
14. What are some difficult parts of being a sibling to (insert name of sibling with FASD)?
  - a. What helps you handle the difficult parts (insert name of sibling with FASD)?
  - b. How often do you engage in these activities?
15. How do other children/classmates act towards you and your sibling?
  - a. How do you react to this?
16. How do you see the future for your sibling?
  - a. What do you worry about?
  - b. When you worry, how do you cope?
  - c. Who do you talk to when you are worried?
17. How do you see your future?
18. Are there any supports you would like or is there anything that would help you in your relationship with your sibling (insert name of sibling with FASD)?
19. Is there anything else you think I should know about your relationship with your sibling?

## Appendix C

### Sibling Inventory of Behaviour Scale

In this section, we are asking you to describe how you and \_\_\_\_\_ (brother or sister) behave toward each other.

First we ask you to describe how \_\_\_\_\_ (brother or sister) behaves towards you. For each item, please circle the number that shows how often \_\_\_\_\_ (brother or sister) behaves in the way described.

\_\_\_\_\_ (Brother or Sister)

	<u>Never</u>	<u>Seldom</u>	<u>Sometimes</u>	<u>Often</u>	<u>Always</u>
1. Is pleased by progress you make	1	2	3	4	5
2. Teases or annoys you	1	2	3	4	5
3. Gets angry with you	1	2	3	4	5
4. Accepts you as a playmate	1	2	3	4	5
5. Is embarrassed to be with you in public	1	2	3	4	5
6. Wants you to succeed	1	2	3	4	5
7. Stays away from you if possible	1	2	3	4	5
8. Gets ideas for things the two of you can do together	1	2	3	4	5
9. Fusses and argues with you	1	2	3	4	5
10. Has fun at home with you	1	2	3	4	5
11. Acts ashamed of you	1	2	3	4	5
12. Shows sympathy when things are hard for you	1	2	3	4	5
13. Frowns or pouts when he/she has to be with you	1	2	3	4	5
14. Teaches you new skills	1	2	3	4	5
15. Helps you adjust to a new situation	1	2	3	4	5
16. Treats you as a good friend	1	2	3	4	5
17. Tries to avoid being seen with you	1	2	3	4	5
18. Is concerned for your welfare and happiness	1	2	3	4	5
19. Makes plans that include you	1	2	3	4	5
20. Hurts your feelings	1	2	3	4	5
21. Tries to comfort you when you are unhappy or upset	1	2	3	4	5

22. Shares secrets with you	1	2	3	4	5
23. Babysits and cares for you	1	2	3	4	5
24. Tattles on you	1	2	3	4	5
25. Is jealous of you	1	2	3	4	5
26. Has physical fights with you (not just for fun)	1	2	3	4	5
27. Is nosey and has to know everything about you	1	2	3	4	5
28. Tries to teach you how to behave	1	2	3	4	5
29. Takes advantage of you	1	2	3	4	5
30. Blames you when something goes wrong	1	2	3	4	5
31. Is very competitive against you	1	2	3	4	5
32. Resents you	1	2	3	4	5

Now describe how you behave towards \_\_\_\_\_ (brother or sister). For each item, please circle the number that shows how often you behave towards him/her in the way described.

	<u>Never</u>	<u>Seldom</u>	<u>Sometimes</u>	<u>Often</u>	<u>Always</u>
1. Are pleased by progress he/she makes	1	2	3	4	5
2. Tease or annoy him/her	1	2	3	4	5
3. Gets angry with him/her	1	2	3	4	5
4. Accepts him/her as a playmate	1	2	3	4	5
5. Is embarrassed to be with him/her in public	1	2	3	4	5
6. Want him/her to succeed	1	2	3	4	5
7. Stays away from him/her if possible	1	2	3	4	5
8. Gets ideas for things the two of you can do together	1	2	3	4	5
9. Fuss and argue with him/her	1	2	3	4	5
10. Have fun at home with him/her	1	2	3	4	5
11. Act ashamed of him/her	1	2	3	4	5
12. Show sympathy when things are hard for him/her	1	2	3	4	5

13. Frown or pout when you have to be with him/her	1	2	3	4	5
14. Teach him/her new skills	1	2	3	4	5
15. Help him/her adjust to a new situation	1	2	3	4	5
16. Treat him/her as a good friend	1	2	3	4	5
17. Try to avoid being seen with him/her	1	2	3	4	5
18. Are concerned for his/her welfare and happiness	1	2	3	4	5
19. Make plans that include him/her	1	2	3	4	5
20. Hurt his/her feelings	1	2	3	4	5
21. Try to comfort him/her when he/she is unhappy or upset	1	2	3	4	5
22. Share secrets with him/her	1	2	3	4	5
23. Babysit and care for him/her	1	2	3	4	5
24. Tattle on him/her	1	2	3	4	5
25. Are jealous of him/her	1	2	3	4	5
26. Have physical fights with him/her (not just for fun)	1	2	3	4	5
27. Are nosey and have to know everything about him/her	1	2	3	4	5
28. Try to teach him/her how to behave	1	2	3	4	5
29. Take advantage of him/her	1	2	3	4	5
30. Blame him/her when something goes wrong	1	2	3	4	5
31. Are very competitive against him/her	1	2	3	4	5
32. Resents him/her	1	2	3	4	5

**Appendix D**  
Daily Hassles and Uplifts Scale

Me and My Sib: The Daily Experience Scale for Siblings of Children  
with Disabilities....

**Things that Make Me Happy: Experiences about Growing up with a  
Brother or Sister with a Disability**

There are good things that happen in our lives that make us happy. Below are some things that can make you feel happy. For each event, we would like to know:

1. How often does the good thing happen?
2. How happy does this make you feel?

This is how to fill it out:

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes	Always			Not very happy	A little bit happy		Very happy	
	1	2	3	4	5	1	2	3	4	5
My friends get along and play nicely with my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5

In the example, this person feels that their friends sometimes get along and play nicely with their brother/sister with a disability and it makes them very happy

**WHEN WE GO OUT....**

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes	Always			Not very happy	A little bit happy		Very happy	
	1	2	3	4	5	1	2	3	4	5
1. I get to be part of different groups (e.g. Down Syndrome Victoria, Autism Victoria, Early Intervention Centres) because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5

<b>2. I know and understand a lot about disability</b>	1	2	3	4	5	1	2	3	4	5
<b>3. My brother or sister with a disability is happy</b>	1	2	3	4	5	1	2	3	4	5

**IN MY FAMILY...**

How often does this happen?

How happy does this make you feel?

Never      Sometimes      Always

Not very happy      A little bit happy      Very happy

4. I get to spend time alone with my mum and dad while my brother or sister with a disability is being looked after by somebody else	1	2	3	4	5	1	2	3	4	5
<b>5. I get to share experiences and do things with my family (for example., go on a holiday, go on bike rides)</b>	1	2	3	4	5	1	2	3	4	5
6. My mum/dad are in a good mood	1	2	3	4	5	1	2	3	4	5
<b>7. My mum/dad tell me that I am being a big help around the home</b>	1	2	3	4	5	1	2	3	4	5
8. My mum and dad tell me how happy they are of me (for example., for getting a good grade at school)	1	2	3	4	5	1	2	3	4	5

**WITH MY FRIENDS....**

How often does this happen?

How happy does this make you feel?

Never    Sometimes    Always

Not very happy    A little bit happy    Very happy

9. They understand my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
<b>10. They get along and play nicely with my brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5
11. I can trust they won't make fun of me because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
<b>12. They don't treat me differently because I have a brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5
13. I get to spend time along with them without my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
14. They show an interest in my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
15. They make me feel special because I know how to manage my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
16. I go to their house and I am able to feel 'normal' with another family	1	2	3	4	5	1	2	3	4	5

**AT SCHOOL... If you do not go to the same school as your brother or sister with a disability please go to the next section – ‘my brother/sister with a disability’**

How often does this happen?

How happy does this make you feel?

Never    Sometimes    Always

Not very happy    A little bit happy    Very happy

17. My brother or sister with a disability is good fun and is entertaining (for example, does funny things)	1	2	3	4	5	1	2	3	4	5
<b>18. My brother or sister with a disability gives me time to play alone with my friends</b>	1	2	3	4	5	1	2	3	4	5
19. I am able to be there and look after my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5

**MY BROTHER/SISTER WITH A DISABILITY...**

How often does this happen?

How happy does this make you feel?

Never    Sometimes    Always

Not very happy    A little bit happy    Very happy

20. Learns something new (e.g., a new word, good math or writing)	1	2	3	4	5	1	2	3	4	5
<b>21. Does cute things</b>	1	2	3	4	5	1	2	3	4	5
22. Is in a good mood and smiling	1	2	3	4	5	1	2	3	4	5
<b>23. Plays with me like other brothers and sisters</b>	1	2	3	4	5	1	2	3	4	5

**Things that Bother, Upset or Stress Me out: Experiences about Growing up with a Brother or Sister with a Disability**

Everyone has problems or hassles that bother them from time to time. Below are some things that can make you feel upset, bothered or stressed out. For each problem, we would like to know:

1. How often does this problem happen?
2. How bothered, upset or stressed out does the problem make you feel?

This is how to fill it out:

	How often does this happen?	How bothered or upset does this make you feel?
	Never    Sometimes    Always	Not        A little bit        Very bothered   bothered   bothered or upset    or upset    or upset

When we go out people stare or look at us

1	2	3	4	5	1	2	3	4	5
---	---	---	---	---	---	---	---	---	---

In the example, this person feels that people are always staring or looking at them and it bothers them a little bit

**WHEN WE GO OUT....**

	How often does this happen?	How bothered or upset does this make you feel?
	Never    Sometimes    Always	Not        A little bit        Very bothered   bothered   bothered or upset    or upset    or upset

24. My brother or sister with a disability does strange things	1    2    3    4    5	1    2    3    4    5
<b>25. My brother or sister with a disability runs away</b>	1    2    3    4    5	1    2    3    4    5
26. My brother or sister with a disability draws attention to us	1    2    3    4    5	1    2    3    4    5

<b>27. People stare or look at us</b>	1	2	3	4	5	1	2	3	4	5
28. I don't feel 'normal' because people are staring or looking at us	1	2	3	4	5	1	2	3	4	5
<b>29. We have to stop what we are doing (for example, leave the supermarket) because of my brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5
30. My brother or sister with a disability takes things from the shelves (for example, a DVD)	1	2	3	4	5	1	2	3	4	5

**IN MY FAMILY....**

How often does this happen?

How bothered or upset does this make you feel?

Never    Sometimes    Always

Not            A little bit            Very  
bothered    bothered            bothered  
or upset    or upset            or upset

31. We can't do things that other families can do (for example, go to the movies as a family) because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
<b>32. I have to do more jobs/chores around the home because of my brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5
33. I worry that my mum and dad don't get enough rest because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
<b>34. We miss out on things (for example, getting a pet) because of my brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5

35. We have to change our plans all the time because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
<b>36. I feel like I don't have time for myself because of my brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5
37. My parents won't let me do things that my brother or sister with a disability can't do	1	2	3	4	5	1	2	3	4	5

**WITH MY FRIENDS...**

How often does this happen?

How bothered or upset does this make you feel?

Never      Sometimes      Always

Not      A little bit      Very  
bothered   bothered   bothered  
or upset   or upset   or upset

38. I have to talk about my brother or sister's disability or illness	1	2	3	4	5	1	2	3	4	5
<b>39. My brother or sister with a disability does embarrassing things</b>	1	2	3	4	5	1	2	3	4	5
40. I don't invite them over because of the way my brother or sister with a disability will behave	1	2	3	4	5	1	2	3	4	5
<b>41. I worry that they will tell other people about my brother or sister with a disability</b>	1	2	3	4	5	1	2	3	4	5
42. I worry that they won't want to come back and play if they come over and see my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
<b>43. I get sad when they say mean things about people with disabilities (for example, he runs like someone with Down Syndrome)</b>	1	2	3	4	5	1	2	3	4	5

**AT SCHOOL... If you do not go to the same school as your brother or sister with a disability please go to the next section**

How often does this happen?

How bothered or upset does this make you feel?

Never    Sometimes    Always

Not            A little bit            Very  
bothered    bothered    bothered  
or upset    or upset    or upset

44. I worry that my brother or sister with a disability is going to run away	1	2	3	4	5	1	2	3	4	5
<b>45. I worry that my brother or sister may get hurt if he/she runs away and no one would know</b>	1	2	3	4	5	1	2	3	4	5
46. My brother or sister with a disability is clingy and wants to be around me all the time	1	2	3	4	5	1	2	3	4	5
<b>47. My brother or sister with a disability comes and finds me for help (for example, can you show me how to climb up the monkey bars? How to dig in the sand?)</b>	1	2	3	4	5	1	2	3	4	5
48. Teachers ask me how to manage the behaviour of my brother or sister with a disability at school	1	2	3	4	5	1	2	3	4	5
<b>49. Other students come to get me because they know my brother or sister with a disability is looking for me in the school yard</b>	1	2	3	4	5	1	2	3	4	5
50. I worry about what new people will think about my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5

**MY BROTHER/SISTER WITH A DISABILITY...**

How often does this happen?

How bothered or upset does this  
make you feel?

Never    Sometimes    Always

Not            A little bit            Very  
bothered    bothered    bothered  
or upset    or upset    or upset

51. Hurts, hits, pushes, scratches or kicks me or others	1	2	3	4	5	1	2	3	4	5
<b>52. Touches or takes my things</b>	1	2	3	4	5	1	2	3	4	5
53. Always gets his/her own way in order to stop a tantrum	1	2	3	4	5	1	2	3	4	5
<b>54. Doesn't know how to talk properly so I don't know what he/she needs</b>	1	2	3	4	5	1	2	3	4	5
55. Does annoying things (for example, bites his/her hands or bangs on the wall) until he/she gets what they want	1	2	3	4	5	1	2	3	4	5
<b>56. Wakes me up early in the morning</b>	1	2	3	4	5	1	2	3	4	5
57. Makes me feel like I don't have a 'real' brother or sister because they have a disability	1	2	3	4	5	1	2	3	4	5
<b>58. Makes me miss out on things (for example, being able to play football) that other brothers and sisters can do because he/she has a disability</b>	1	2	3	4	5	1	2	3	4	5