Comparison of Sibling Relationships in Families of Children with Autism Spectrum Disorder

and Fetal Alcohol Spectrum Disorder

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Author's Note

The following thesis was completed in partial fulfillment of an Honours Bachelor of Arts degree

in Psychology under the supervision of Dr. Shelley L. Watson. Please address any

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2015

Abstract

Employing a mixed methods approach, the purpose of this present study was to examine the lived experiences of siblings of children with autism spectrum disorder and fetal alcohol spectrum disorder. Participants participated in semi-structured interviews and completed two questionnaires. Interpretative phenomenological analysis was used to analyze interview transcripts and five main themes were identified: Positive Transformational Outcomes, Sibling Demands, Caregiving Roles, Awareness of Developmental Disabilities, and Supports. Questionnaire data from the Sibling Daily Hassles and Uplifts Scale and the Sibling Inventory of Behaviour Scale were also utilized and comparison findings between sibling groups from these questionnaires will be analyzed and discussed.

Acknowledgments

I would first and foremost like to thank the ten remarkable siblings who participated in this study. Thank you for being so open, willing, and honest in your accounts of your personal experiences. I can only hope by sharing your stories, we can help other families.

To my supervisor, Dr. Shelley L. Watson, thank you so much for your guidance, continued support, and positive reinforcement. This thesis could not have been completed in its present form without your expertise and constructive feedback. I have learned a great amount from you and I have enjoyed every minute of working with you. I look forward to your continued guidance during my masters.

I would also like to thank my second reader, lab mate, and mentor, Kelly Coons, for the time, effort, and invaluable input you provided. You are someone I look up to and it has been a great honor working with you. I hope to continue to do so throughout my education.

A special note of gratitude goes to my grandfather, Gary Hughes, for your endless support and encouragement, including being a sounding board during the writing of my thesis. Although we are miles apart, you have continued to push me to do great things and I am forever thankful.

Finally, I would like to thank all of my friends and family for believing in me and encouraging my dreams.

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CHAPTER ONE: INTRODUCTION

Much research has been undertaken exploring the impact of living with a child with a developmental disability (DD) on the family. However our understanding of the experiences of families with children with DDs is predominantly based on research carried out with parents and caregivers. This ongoing body of research has neglected another important group of family members, the siblings. Until the 1980's, sibling literature was extremely limited (Stoneman, 2005). As part of the family unit, the sibling subsystem is just as crucial to understand as the parents because the sibling relationship can be the first and most intense peer relationship, typically lasting the longest in one's life (Angell, Meadan, & Stoner, 2012; Doody, Hastings, O'Neil, & Grey, 2010; Heller & Kramer, 2009; Knott, Lewis, & Williams, 1995).

Interest in examining siblings of children with disabilities began for many researchers with the assumption that these siblings adjust negatively to growing up with a sibling with DD. However, a majority of the current literature has shifted away from these negative notions and has emphasized the successful adaptations and positive outcomes of siblings (Green, 2013; Stoneman, 2005). Despite this current shift, most research has tended to focus on "developmental disability" in general without addressing sibling adaptation in regards to a specific diagnosis of DD. Because siblings may adjust differently based on the child's specific disability, it is important to examine developmental disabilities separately (Hodapp, Fidler & Smith, 1998).

The purpose of this study is to explore the lived experiences of siblings living with brothers and sisters who have been diagnosed with DD, specifically with autism spectrum disorder (ASD) and fetal alcohol spectrum disorder (FASD). There is a paucity amount of research on siblings of children with ASD, and to the researcher's knowledge no current studies

have investigated siblings of children with FASD. Providing the lack of and inconsistent findings of sibling literature, the researcher hopes to contribute and to fill in existing gaps in the related literature from a sibling's point of view. Additionally, this study is both essential to understanding and improving research of the lived experience of siblings of children with ASD and FASD. If we can develop a better understanding of the lived experience of siblings, professionals can develop and implement appropriate supports and services to families and siblings (e.g., sibling support groups, respite services) which may differ based on sibling type.

Definitions

Developmental Disability. Developmental disability (DD) is an umbrella term used to encompass a large group of lifelong conditions that include, but are not limited to: autism spectrum disorder, mild, moderate or severe intellectual disability, attention deficit disorder, Down syndrome, and Cerebral Palsy. It is defined in terms of significant impairments in one or more of the following domains: cognitive and psychological processes, sensorimotor development, physical functioning, verbal and nonverbal communication, and social/adaptive behaviour (American Psychiatric Association [APA], 2014). The disability typically originates before the age of 22 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2010), and is likely to persist throughout one's life, making these the unique and significant markers to set DD apart from other disabilities.

Intellectual Disability. Intellectual disability (ID) is a revised term from the previous DSM-IV classification of mental retardation and falls under the DD umbrella (APA, 2014). The diagnostic criteria for ID includes having an IQ at or below 70, and having both intellectual and adaptive deficits in which are expressed in conceptual, practical and social situations. Onset of these symptoms typically originates prior to age 18 (AAIDD, 2010). There are many causes of

ID, including neurological conditions, genetic disorders, prenatal trauma, illness or injury. In some cases, causes of ID have been relatively unknown. The major difference between ID and DD is that ID refers to an individual's capability to think and reason. The estimated prevalence of I/DDs varies, depending on the degree of severity (e.g., mild, moderate, severe, and profound) and the population studied (e.g., ASD and FASD) but has been increasing in recent years with an average prevalence of 1 in 6 children (Centers for Disease Control and Prevention [CDC], 2014).

Autism Spectrum Disorder. Autism Spectrum Disorder (ASD) is a lifelong pervasive neurodevelopmental condition and is often associated with comorbid ID (e.g., IQ below 70); (Karst & Van Hecke, 2012). Previous epidemiological research has suggested that the prevalence for ASD was consistently rated at about 1 per 1000 persons (Bryson, Clark, & Smith, 1988); however, current research suggests that ASD is much more common, with a current prevalence of 1 in 68 children (CDC, 2014). Whether the increase is due to better recognition of the disorder, improved diagnostic criteria, or increased incidences of ASD is still unclear (Baird et al., 2006).

ASD is characterized by deficits in distinct areas of functioning such as social communication and by the presence of fixated and repetitive patterns of interests in activities and behaviours (APA, 2014; Heiman & Berger, 2008). Deficits of ASD usually manifest in early development, with onset occurring prior to age 3 and is reported to be more predominant in males than females, by a ratio of 4:1 (APA, 2014). Although these characteristics may not be immediately visible in early years, they gradually become more evident as a child becomes mobile (Lord & Bishop, 2010).

Individuals with ASD tend to also display a varied array of characteristic symptoms including, self-stimulating behaviours (e.g., flapping and rocking), self-injurious behaviours

(e.g., hair pulling), limited imagination and social repertoire (e.g., lack of imaginative play and empathy), and an inflexible persistence to routines and ritual (e.g. difficulties in dealing with change and managing transitions in everyday life). Children with ASD also have difficulty with "theory of mind", which is the ability to think about what another person might be thinking (Bauminger, 2002). Because of their significant difficulties, children with ASD are often unsuccessful at building developmentally appropriate relationships with their peers, which may lead to difficulties within the family system. Without the right support, these challenges may have a profound impact on individuals and families.

Fetal Alcohol Spectrum Disorder. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the spectrum of conditions that result from prenatal exposure to alcohol and is considered to be one of the most common non-hereditable causes of DDs and IDs in the Western population (Abel & Sokol, 1987; Chudley et al., 2005; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Estimates on the prevalence of these disorders are relatively unknown due to issues of diagnostic criteria; however, the CDC has currently estimated 300 000 cases of FASD in both the United States and Canada, with a prevalence of approximately 9 to 10 per 1000 live births. Furthermore, in regions such as South Africa, FASD has a prevalence of approximately 68 to 89 per 1000 live births, in Russia, 141 per 1000 live births, and in Italy, approximately 120 per 1000 live births (Nayak & Murthy, 2008). The estimated prevalence for FASD has also been shown to be even greater in high risk areas. For example, in an isolated Aboriginal community in British Columbia, the prevalence of FASD was 190 per 1000 live births (Robinson, Conry, & Conry, 1987). Determining the true prevalence of FASD can be a challenge. Some individuals may lack visible physical characteristics and mothers may also not feel comfortable admitting to drinking alcohol to avoid stigmatization of drinking during

pregnancy (May et al., 2009). Therefore, many children with FASD remain undetected (CDC, 2014; May et al., 2009; Riley, Infante, & Warren, 2011).

FASDs typically result in the following characteristics: a) central nervous system dysfunction; b) severe prenatal and/or postnatal growth restriction; and c) unique facial anomalies (Astley, 2006; Olson et al., 2009; Riley et al., 2011). Abnormal facial characteristics may include a small eye opening, thin upper lip, short palpebral fissures and a smooth philtrum (Senturias, 2014). Although facial and growth deficiencies are possible, they are not always observed in individuals with FASD. The most observable effects of the exposure to alcohol are on the developing brain (e.g., cognitive and behavioural difficulties; Chudley et al., 2005). These deficits, characterized as primary disabilities, can range from mild cognitive impairments to profound intellectual disability and can affect the individual's memory, attention, reasoning and adaptive functioning (Riley et al., 2011; Riley & McGee, 2005).

A significant percentage of affected individuals will also display adverse outcomes defined as secondary disabilities, which arise as a result of the primary disabilities. Because individuals may lack the visual signifiers associated with FASD, individuals may go undetected or be misdiagnosed, which can be extremely frustrating and distressing for the child and their families. The individual with FASD may then react to this frustration and produce problematic behaviours, such as substance abuse, addiction, unemployment, mental health issues and problems associated with the law (Chudley et al., 2005; Streissguth, Barr, Kogan, & Bookstein, 1996). Studies have shown that receiving an early diagnosis of FASD may minimize the chances of developing these "secondary disabilities", as an early diagnosis allows access to appropriate interventions and resources (Streissguth et al., 2004). Raising a child with FASD in a stable and nurturing home environment also serves as a protective factor; however, researchers have found

that a majority of children with FASD (80%) live with foster or adoptive parents, which may actually increase their risk of developing secondary disabilities (Streissguth et al., 1996; 2004).

The term FASD is relatively new in the literature. It was developed to acknowledge that those who fail to meet criteria for fetal alcohol syndrome (FAS) can still display negative outcomes caused by prenatal alcohol exposure (Olsen et al., 2009). Individuals with FAS are reported to lie towards one extreme end of the spectrum, being the most severe in terms of ID. It is then followed by partial FAS (p-FAS), alcohol-related neurodevelopmental disorder (ARND), fetal alcohol effects (FAE), and alcohol-related birth defects (ARBD) (Kyskan & Moore 2005; Riley et al., 2011). ARND is often used interchangeably with the term FAE and describes individuals with cognitive and behavioural impairments related to prenatal alcohol exposure; however, it does not meet the full criteria for a FAS diagnosis. Specifically, children with FAE and ARND may not present with any or all of the physical characteristics of prenatal alcohol exposure (Streissguth, 1997). The lack of the physical characteristics, as previously mentioned, may result in a non- or misdiagnoses, which may lead to a persistence of problem behaviours and others may also blame the parents for inadequate parenting (Graefe, 2004). Families may also find themselves struggling with regards to the overwhelming demands of the child with FASD, as well as not being able to understand what is causing their child's behaviour (Malbin, 2007). As we can see, early and accurate diagnosis is a crucial component for the welfare of individuals with FASD, which is only recently becoming recognized.

Research Questions

Following the main purpose of this study, to compare sibling relationships in families of children with ASD and FASD, the following research questions will be addressed:

1. What is the overall lived experience of having a sibling with ASD and FASD?

2. Are there similarities or differences of the lived experience between the two types of siblings?

Rationale

Disabilities are becoming increasingly prevalent (CDC, 2014), and like the general population, individuals with disabilities are also experiencing increased life expectancy due to medical advances and improved living conditions (Heller & Caldwell, 2006). In 2000, it was estimated that there were 641, 860 adults over the age of 60 with intellectual and developmental disabilities (I/DD) and is expected to almost double in 2030 (Boyle et al., 2011; Heller & Caldwell, 2006). Since the deinstitutionalization movement, 60 percent of individuals with DD are currently living at home with their parents and caregivers (Abrams, 2009; Hodapp, Urbano, & Burke, 2010), and due to this increased prevalence, future planning becomes imperative.

Studies have shown that it is often a sibling who takes on the support and caregiving role in the life of a person with I/DD when the parent is no longer able to (Griffiths & Unger, 1994). However, there is little research on how siblings adapt to their brother or sister with I/DD. To date there is also limited examination in regards to siblings of children with ASD and to the researcher's knowledge, no studies investigating siblings of children with FASD.

Differences in the behavioural challenges posed by children with ASD and FASD are critical, and to the extent that those difficulties vary across diagnoses, differences in sibling reactions are possible. It is important to make clear why siblings' experiences would be expected to differ as a function of their sibling's diagnosis, and if researchers can determine where siblings of children with specific disabilities struggle, supports can be tailored to help lighten their experiences. Additionally, there has been limited examination comparing siblings of children with ASD to siblings of other types of DDs, and no current studies comparing ASD and FASD.

Therefore, the following study aims to compare the experiences of siblings of children with ASD and FASD.

Scope of the Paper

This study is both essential to understanding and improving research of the lived experience of siblings of children with ASD and FASD. The following paper will discuss the factors that have been noted in the literature to be associated with the lived experience of families raising a child with DD. I then review the few studies that have examined families of children with ASD and FASD in particular. In addition to summarizing the literature on families, I discuss how siblings adjust in regards to having a sibling with DD, ASD and FASD. An overview of the methodology used and the results of the present study are presented and the paper will conclude with a discussion of the implications of this research.

Literature Review

Theoretical Framework

The theoretical model that informed this study is the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988, 1999; Patterson & Garwick, 1994, 1998). The FAAR model posits that having a child in the family with a disability represents a major stressful life event for *all* family members (e.g., parents, siblings, grandparents). It is a two-phase interactional model, which proposes that families engage in processes to achieve homeostasis by meeting demands (stress and strains) with capabilities (resources and coping). According to Patterson (1988), the way in which families balance these demands and capabilities is mediated by how families interpret the events or 'crisis' that take place in their lives. Such interpretations, or meanings, can be developed individually, as well as shared by the family unit, and are often

constructed when family members talk with one another and begin to construct meanings about the pile-up of demands, as well as their way to manage them (i.e., capabilities). Furthermore, how a family responds to these interpreted crises will influence how they respond to succeeding events (McCubbin & Patterson, 1983).

Demands, as defined by the FAAR model, refer to all of the stressors, strains, and daily hassles that are experienced by family members that may disrupt normal family equilibrium. Stressors are the discrete life events that produce changes in the family system. In terms of disability research, stressors may include the challenges with navigating appropriate medical and behavioural services, or the emotional aspects (e.g., guilt, shame) of having a child with a disability in the family (Plant & Sanders, 2007). Strains, on the other hand, tend to be the unresolved and stealthy tensions that the family may experience as a result of the ongoing stressors (Patterson, 2002). Strains therefore do not necessarily have a discrete onset but emerge unconsciously in one's life and build up overtime. The minor disruptions in a family's day-to-day life are referred to as daily hassles in the FAAR model. Daily hassles include problematic behaviours that the child with the disability may display, multiple medical appointments, or having to repeatedly explain the child's disability to friends and family. All of these demands can cause an imbalance in the family unit, which may lead to a family crisis; however, by the use of the family's capabilities that balance may be restored. It is also important to note that 'crisis' does not necessarily mean a negative event, but a turning point, which leads to major changes in a families structure, interaction patterns, or both (Patterson, 2002).

According to the FAAR model, capabilities are defined by the way in which families utilize various tangible or psychosocial resources (what the family has) and coping behaviours (what the family does) (Patterson, 2002). Family resources may be at the individual level such as

a family member's personality traits (e.g., self-esteem and self-efficacy), experience, or their physical and/or emotional health. Resources may also be found within the family unit itself where decision-making and conflict resolution skills arise. Other types of resources, as described by the FAAR model, comprise resources that are available in the community. These resources include institutional supports, access to healthcare facilities, support groups, and other outside organizations families may use to meet their demands and provide them with the support they need (Patterson, 1988, 1989, 2002).

There are two phases a family may go through as described by the FAAR model: the adjustment phase and the adaptation phase. The adjustment phase is defined as a period of stability within the family, in the sense that the family's aim is to maintain routines, roles, and relationships as they existed before a turning point. This is the phase where families make only small changes to attempt to achieve balance between their demands and capabilities. However, there are times when the family's demands exceed their capabilities and an imbalance persists. This is when families experience a 'crisis' that often causes disorganization in the family (Patterson, 2002). Although a crisis may cause disorder in the family, it does not necessarily mean a negative event, as it often describes a turning point for a family that may ultimately lead to major changes in their structure or interaction patterns. In order to restore balance, the family must go through the second phase of the FAAR model, the adaptation phase. This phase is the outcome factor, which deals with the family's response to the crisis or transition. Furthermore, this phase leads to family adaptation on a continuum from bon-adaptation to maladaptation which is characterized by "a continued imbalance in family functioning" (Saloviita, Italinna, & Leinonen, 2003, p. 301). Figure 1 below shows the FAAR model.
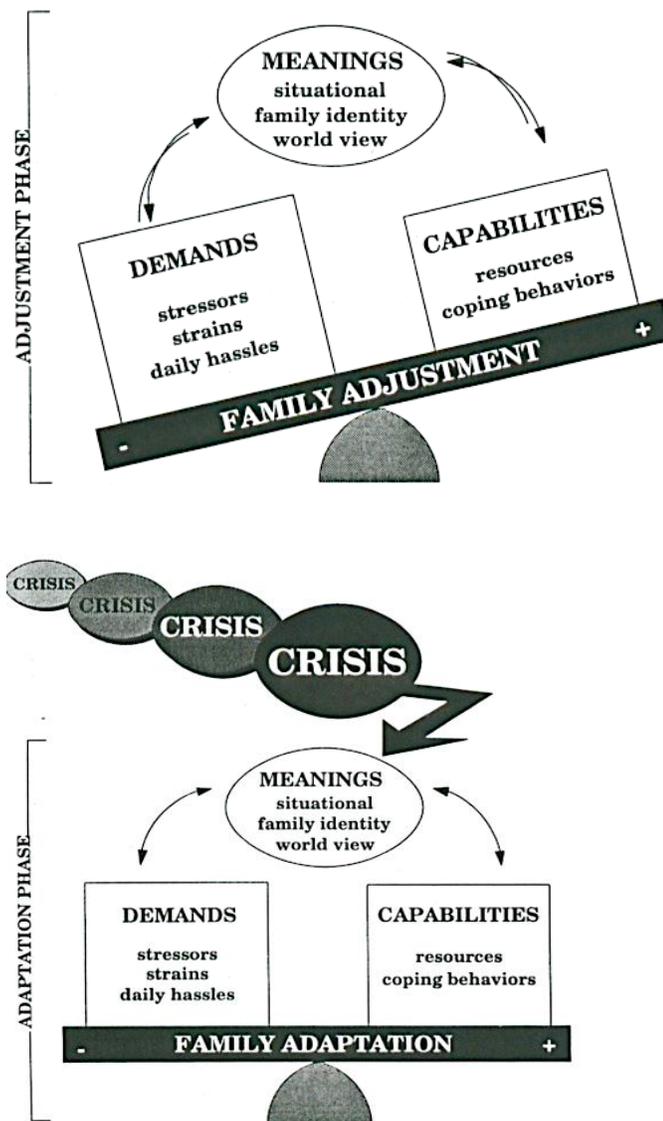
Figure 1. The Family Adjustment and Adaptation Response Model
(Patterson, 1988, 1989; Patterson & Garwick, 1994a, 1998)

Family Research

The impact of raising a child with a developmental disability (DD) has been a

predominant research focus for the last several decades, but the impression when reviewing the

literature around the experiences of families is one that is contradictory and perplex. Studies

comparing families of children with DD to typically developing children have been mixed in

regards to the psychological adaptation of families, suggesting both positive and negative

findings (e.g., see review by Stoneman, 2005). As these investigations have continued,

researchers have given specific attention to family stressors, family quality of life, and transformational outcomes (Brown et al., 2006; Donovan, 1988; Grant & Ramcharan, 2001; Ritzema & Sladeczek, 2011; Scorgie & Sobsey, 2000). The following section seeks to organize and summarize some of the key findings regarding parental adaptation to the challenges associated with raising a child with a DD, ASD and FASD.

Family-Related Stressors. The toddler years can be a particularly stressful time for parents and caregivers, however, parents of children with disabilities have an increased vulnerability to stressors during this time (Fidler, Hodapp, & Dykens, 2002; Hastings, 2002). Extensive evidence suggests parents of children with DD experience higher rates of stress than parents of children without a disability (e.g., Hastings, 2002; Rodrigue, Morgan, & Geffken, 1990; Roach, Orsmond, & Barratt, 1999). However, despite these broad findings, researchers acknowledge that the levels of stress that parents of children with DD experience vary considerably, and that these differences are accounted for by a wide range of variables (Baxter, Cummins, & Yiolitis, 2000).

For example, a large body of research suggests that the nature and severity of the child's disability is directly related to caregiver stress (Krstić & Oros, 2012; Minnes, 1998). Those diagnosed with severe or profound disabilities usually require lifelong assistance with daily care tasks, communication, as well as accessing and participating in community services and activities, all of which can be perceived as stressful by parents (Martin & Colbert, 1997). Challenging and unpredictable child behaviours (i.e., hitting, biting, self-injurious behaviours such as hair pulling, head banging), can also be a major source of stress for caregivers as these behaviours often require constant supervision to ensure the safety of the child and other members of the family. These findings are supported by Sanders and Morgan's (1997) study of comparing

stress levels in families of children with ASD, Down syndrome, and typically developing children. The results demonstrated that caregivers raising a child with ASD reported having higher levels of stress and, because ASD is often associated with more challenging behaviours, the results also support the clinical view in which the nature and severity of the child's condition is considered to be one of the major sources of the elevated levels of stress within the family system.

Family Quality of Life. The concept of family quality of life (FQOL) has only recently become an area of focus in family literature (Poston et al., 2003; Turnbull, Brown, & Turnbull, 2004). FQOL is defined as "conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" (Park et al., 2003, p. 368). Since the deinstitutionalization movement, a majority of individuals with DD (60%) are currently living at home with their parents and caregivers (Abrams, 2009; Hodapp et al., 2010). As individuals with DD have been removed from these facilities, the reliance on the family to fulfil the roles of service providers and advocates has increased significantly (Brown, Anand, Isaacs, Baum, & Fung, 2003; Cummins & Baxter, 1997). Researchers have suggested that these additional responsibilities of raising a child with DD may negatively impact FQOL (Wodehouse & McGill, 2009). Families with low socioeconomic status (SES; Park, Turnbull, & Turnbull, 2002) are families in particular that are suggested to have a negatively affected FQOL. Additionally, a study by Wang et al. (2004) revealed that the most significant predictor of FQOL being affected was severity of the child's disability. In contrast, families have also reported positive contributions that their child with DD has on their quality of life, such as improved relations with family members and increased levels of patience and compassion (Kausar et al., 2003).

Family Transformations. While there is a great deal of research on family stress (e.g., see review by Turnbull, Summers, Lee, & Kyzar, 2007) and how it may impact family quality of life (Turnbull et al., 2004), families also adjust quite positively (Jones & Passey, 2004). Summers, Behr, and Turnbull (1989) reviewed some of the positive transformations in the family literature and found that most parents reported many promising changes (e.g., increased awareness of inner strength, greater sense of satisfaction) as a result of parenting a child with a disability. Scorgie and Sobsey (2000) found similar findings in which parents reported in a qualitative interview many positive changes in their lives, such as personal growth, enhanced relations with others, and changes in their spiritual values. Families that employ adaptive coping strategies are also reported to feel a greater sense of satisfaction when raising a child with a disability and tend to experience lower levels of stress (Hastings & Johnson, 2001; Scorgie & Sobsey, 2000).

Even though many families have reported positive family transformations, it does not necessarily mean that there is a complete absence of stress. Positive transformational outcomes have often been shown to occur in the midst of stressful and difficult situations (Scorgie & Sobsey, 2000). In a comparison study investigating parents of children with ASD, cerebral palsy, Down syndrome, and sickle cell disease, Hall et al. (2012) found that stress was still present among caregivers, but parents also highlighted the positive adaptations associated with their difficulties.

Families of Children with ASD

ASD has been recognized to pose a range of distinct challenges for family members and has been found to affect most of the family's every day functioning (Hutton & Caron, 2005; Sobsey, 2004). Impairments in social communication (Davis & Carter, 2008) and the mental

inflexibility to adapt to changes in routines and rituals (Hutton & Carron, 2005) are difficulties that have been reported by families as remarkably challenging to handle. As a result of these issues, a large body of research suggests that the combined difficulties tend to place significant stress on family members of children with ASD (Hastings et al., 2005).

Various studies confirm that parents raising a child with ASD report having higher levels of stress compared to parents raising a child diagnosed with a different type of disability or raising a typically developing child (Dabrowska & Pisula, 2010; Dumas, Wolf, Fisman, & Culligan, 1991). For example, when parents of children with ASD were compared to parents of children with Down syndrome, the highest rates of stress and emotional exhaustion were reported in families of children with ASD (Dumas et al., 1991). Similar findings were reported by Benson and Dewey (2008), who measured parental stress in families of children with ASD using the Parenting Stress Index (PSI) and found that 60 percent of parents experienced higher levels of stress relative to the normative sample in their study.

Studies also indicate that stress is most prominent when children with ASD are classified as more severe and exhibit problematic behaviours (Abbeduto et al., 2004; Hastings & Brown, 2002; Hastings & Johnson, 2001). For example, Brobst, Clopton, and Hendrick (2009) found a positive relationship between maternal stress and the intensity of the child's behaviours. Parents who rated their child's ASD symptoms as more severe tended to report significantly higher levels of stress compared to parents of children with less severe symptoms. Consistent with this study, Tomanik, Harris, and Hawkins' (2004) findings also suggest that maternal stress levels increase as their child's behavioural problems increase.

Raising a child with ASD can also impact other areas of family functioning, such as marital relationships and family income (Hutton & Caron, 2005; Montes & Halterman, 2008).

Marital relationships are often reported as being problematic and dysfunctional (Sobsey, 2004),

for example, ensuring that the child with ASD lives in an environment suitable for their complex

needs requires a large effort and commitment from each member of the family, which can be

both emotionally and physically demanding (Hutton & Carron, 2005). Additionally,

approximately 85% of individuals with ASD require assistance (e.g., with self-care,

communication, mobility, cognitive tasks) from their caregivers for the entire duration of their

lives (Volkmar & Pauls, 2003).

With these additional caretaking responsibilities, parents often do not have time for one

another. Hutton and Carron (2005) found that the majority of primary caregivers of children with

ASD (66%) reported having less time for family activities and not having time to relax. Divorce

rates are also significantly higher in families of children with ASD compared to families with

typically developing children, with the risk of divorce being much higher when the child is

transitioning through infancy and early adulthood (Hartley et al., 2010). The risk of divorce

remained high into the child's early adulthood since children with ASD were often reported to

continue living at home and place high-levels of parenting demands (e.g., Smith et al., 2010) on

caregivers, which often led parents to continue to experience marital strain into their child's early

adulthood (Hartley et al., 2010).

It is evident that researchers tend to dwell on the more stressful and negative experiences

of raising a child with ASD. However, researchers also highlight the positive impacts of ASD on

family functioning, such as emotional strength and higher levels of empathy and patience (Davis

& Gavidia-Payne, 2009; Pakenham, Sofronoff, & Samios, 2011). Bayat (2007) investigated

resilience in families of children with ASD and found that parents had a more positive outlook

on life and had greater appreciation of personal accomplishments than parents of typically

developing children. Parents were also much more likely to have a closer connection with family members and reported gaining spiritual and personal strength. Additionally, parents that receive support from significant individuals in their lives (e.g., parents, friends, family) are reported to experience better psychological health than those with fewer social resources accessible to them (Benson & Dewey, 2008)

Families of Children with FASD

Compared to other types of DDs, such as ASD, Down syndrome, and Fragile X syndrome, there are very few studies directly examining the impact of raising a child with FASD on the family. However, existing literature suggests that parents of children with FASD also exhibit a significant amount of stress (e.g., Watson, Coons, & Hayes, 2013a). The primary and secondary disabilities associated with FASD are issues that have demonstrated to be directly related to parental stress (Brown & Bednar, 2003). For example, Paley, O'Conner, Kogan, and Findlay (2005) found a significant positive relationship between maternal stress and impairments in executive and adaptive functioning of children who were prenatally exposed to alcohol. Paley, O'Conner, Frankel, and Marquardt (2006) also found that stress was significantly higher in biological and adoptive parents if the child with FASD displayed higher levels of externalizing (e.g., hyperactivity) and internalizing (e.g., depression, or social withdrawal) behaviours.

In a second study examining the perceived stress experienced by parents of children with FASD and ASD, Watson et al., (2013a) found that both parent groups reported elevated levels of stress, but results from the Parenting Stress Index – Short Form (PSI-SF) indicated that parents of children with FASD experienced considerably more stress. In a follow-up qualitative study investigating the specific sources of stress, Watson, Hayes, Coons, and Radford-Paz (2013b) found that even though both parent groups experienced similar stressors (e.g., problems with

multi-tasking and dealing with behavioural issues), parents of children with FASD focused more on their child's illegal behaviours, demonstrating that the secondary disabilities associated with FASD contribute significantly to parental stress.

Families of children with FASD are also suggested to experience specific sources of stress associated with the child's unclear diagnosis (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013). Researchers have found that only 20% of children with FASD live with their biological mothers, highlighting that the remaining 80% live in foster care or with adoptive parents (Dicker & Gordon, 2004; Streissguth et al., 2004). When observing adoptive and foster parents' experiences of raising a child with FASD, Mukherjee et al. (2013) found that parents often reported being unaware of their child's disability as a result of professionals (e.g., doctors, social workers, and educators) not providing enough information to them. Because of the lack of information provided to parents, parents reported feeling blamed for inadequate parenting, which subsequently contributed to the parents' overall stress, feelings of isolation, and marital breakdown (Mukherjee et al., 2013).

Sibling Research

In addition to parents, siblings are also reported to be negatively affected (e.g., adjustment difficulties) by having a sibling with DD (Gold, 1993; McHale & Gamble, 1989; Ross & Cuskelly, 2006). However, some researchers suggest no effect on siblings (Bischoff & Tingstrom, 1991; Dyson, 2003), and some propose positive effects, such as developing compassion and growth (Hastings, 2003; Kaminsky & Dewey, 2002; Stoneman, 2005). Common themes in sibling literature have consisted of sibling stress (e.g., Pit-ten-Cate & Loots, 2000; Roeyers & Mycke, 1995), self-concept (e.g., Verté. Roeyers, & Buyssee, 2003), psychosocial adjustment (e.g., Bågenholm & Gillberg, 1991; Kaminsky & Dewey, 2002), behaviour

difficulties (e.g., Fisman, Wolf, Ellison, & Freeman, 2000; Hastings, 2003), and sibling relationship quality (e.g., Kaminsky & Dewey, 2001; McHale & Gamble, 1989). The findings of these trends are now summarized.

Previous research has demonstrated that siblings of children with DD feel stressed about their relationship with their brother and sister. Şenel and Akkök (1996) examined stress levels in 30 siblings of children with DD and 30 siblings of children without a disability and found a significant difference in stress levels, suggesting siblings of children with DD experience more stress. Similar findings were found in a study by Manor-Binyamini and Abu-Ajaj (2012) investigating siblings' self-esteem, stress, and growth. By comparing 100 siblings of children with DD and 100 siblings of children with typical development, they found that both sibling groups experienced similar degrees of self-esteem; however, siblings of children with DD reported higher levels of stress compared to the normative sample. Additionally, a negative correlation was found between perceptions of stress and growth amongst siblings of children with DD.

Sources of stress are also shown to differ based on the specific disability diagnosis. Roeyers and Mycke (1995) examined sibling relationship stressors by comparing 20 siblings of children with ASD, 20 siblings of children with Down syndrome, and 20 siblings of children with typical development. Results revealed that the three groups were similar in their ratings of the frequency of stressors; however, each sibling group reported different sources of their stress. For example, siblings of children with ASD reported that their siblings' behaviour was the major source of their stress, while siblings of children with Down syndrome reported the additional caretaking responsibilities to be accountable for their stress and siblings of typical developing children reported that verbal aggression was the most stressful event in their relationship.

It has often been assumed that siblings of children with disabilities display lower self-concept than those of typically developing children. Self-concept is the perception that individuals have of their own worth in terms of being capable, significant and successful. (Bellmore & Cillessen, 2006) Although several past studies have found that siblings of children with DD have a lower self-concept (e.g., Ayres, Cooley, & Dunn, 1990; Kistner & Osborne, 1987), other studies have shown consistent findings over the last decade, suggesting no differences in self-concept amongst siblings of children with and without DD (Dyson, 2003; Manor-Binyamini & Abu-Ajaj, 2012; Verté et al., 2003). In contrast, Dyson (1999) found that siblings who had a sibling with DD showed greater self-concept than siblings of typically developing children. They also found that siblings who reported higher levels of satisfaction with their sibling relationship revealed a more positive self-concept.

Findings regarding the psychosocial adjustment of siblings of children with DD have also been mixed. McHale and Gamble (1989) investigated the psychosocial well-being of siblings of children with ID and found that siblings scored higher on measures of depression and anxiety, and lower on social acceptance and conduct. Similarly, Bågenholm and Gillberg (1991) found that siblings of children with DD perceived their sibling as a burden, and in turn had lower levels of loneliness and increased problems with peers compared to a normative sample. In contrast, Kaminsky and Dewey (2002) also examined psychological adjustment in siblings of children with ASD, Down syndrome, and typically developing children and found that even though children with ASD reported feelings of loneliness; they were no more likely to have adjustment problems than comparison siblings.

Green (2013) reviewed the literature related to siblings' relationships when one sibling has ASD and suggested that the inconclusive findings may be due to several methodological

differences and confounding variables. Such factors include various methods (e.g., quantitative or qualitative), control-contrast groups (e.g., ASD vs. Down syndrome), different outcome measures (e.g., adjustment measures), and informants (e.g., parents vs. sibling). Variations in other factors (e.g., family environment or severity of the disability) could also explain the mixed results related to the siblings' relationships (Angell et al., 2012).

Studies investigating sibling's behaviours, either through externalizing (e.g., aggression, tantrums) or internalizing (e.g., anxiety, withdrawal) has also yielded inconsistent results. While a number of researchers have found no differences in behaviour problems within siblings of children with DD (e.g., Kaminsky & Dewey, 2002; McMahon, Noll, Michaud, & Johnson, 2001), others have found significantly different findings, suggesting an increase in difficulties amongst siblings (Hastings, 2003; Rodrigue, Geffken, & Morgan, 1993). Employing the Rutter Parent Questionnaire which measures behavioural difficulties in a child, Bågenholm and Gillberg (1991) found that siblings of children with ASD and ID exhibited significant difficulties in areas of inattention and hyperactivity compared to siblings of typically developing children. Similar findings were demonstrated in a study by Petalas, Hastings, Nash, Dowey, and Reilly (2009), who also found that behavioural and emotional difficulties were present in siblings of DD and the difficulties were found to be stable over an 18 month period of time.

Despite research addressing the negative impacts of having a sibling with DD, researchers acknowledge that having a sibling with DD may also be a positive experience for children (Stoneman, 2001, 2005; Turnbull et al., 2007). Some positive experiences include higher levels of empathy, increased sense of maturity and responsibility, as well as increased levels of tolerance and high acceptance of individual differences (Hastings, 2003; Kaminsky & Dewey, 2002). Evidence has also shown that in some cases sibling relationships in families of

DD may be more positive than siblings of children with typical development (Cuskelly & Gunn, 2003; Fisman et al., 2000; Royers & Mycke, 1995).

In addition, researchers have found that siblings of children with DD tend to adjust better if they live in larger families with high SES, if the sibling with DD is younger than their siblings, and if the disability is less severe (Boyce & Barnett, 1993; Hastings, 2003; Kaminsky & Dewey, 2002; McHale, Sloan, & Simeonsson, 1986). Sibling gender has also been found to have an impact on overall adjustment. Verté et al. (2003) found that sisters of children with ASD had a more positive self-concept compared to brothers. Roeyers and Mycke (1995) also found that children with a greater understanding of their sibling's disability also had more positive sibling relationships.

Siblings of Children with ASD

Given the ways in which children with ASD have been demonstrated to affect their families, it seems reasonable to assume that these effects may also pertain to their siblings. However, the available literature on sibling relationships in families of children with ASD has yet to reach a consensus. Research revealed both positive and negative effects of growing up with a sibling with ASD, producing contradictory findings (Green, 2013; Orsmond & Seltzer, 2007). Some studies suggest that having a sibling with ASD in the family has negative effects on children's adjustment, such as increased levels of internalizing and externalizing behaviours (e.g., Hastings, 2003; Rodrigue et al., 1993; Ross & Cuskelly, 2006), psychosocial adjustment problems (e.g., Orsmond & Seltzer, 2007), as well as and depression and low self-concept (e.g., Gold, 1993). In contrast, some researchers reported that children experience positive effects, such as higher levels of self-concept and are emotionally well adjusted by having siblings with

ASD (e.g., Pilowsy et al., 2004). The following section discusses some of these inconsistent findings.

*Positive Relationships***.** Various studies have found that having a sibling with ASD in the family has a positive effect on children. Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004) found that siblings of children with ASD appear to be more socially and emotionally well-adjusted than siblings of children with developmental language disorders and ID. Moreover, Macks and Reeve (2007) compared psychosocial and emotional adjustment of 51 siblings with ASD and 36 siblings of typically developing children and found that siblings of children with ASD appeared to have a more positive self-concept compared to the normative sample. They also found that the siblings had positive attitudes towards their own behaviour and school performance (Macks & Reeve, 2007). In contrast, Verté et al. (2003) found no difference in behaviour or social problems in siblings of children with ASD and siblings of typically developing children, suggesting both were capable of adapting to the environmental demands of ASD.

Siblings of children with ASD have also reported less conflict (Fisman et al., 1996) and greater warmth (Kaminsky & Dewey, 2001) in the sibling relationship. Siblings are also reported to speak with pride in regards to teaching their sibling with ASD, and often score higher on self-esteem (Milevsky, 2005), empathy (Benderix & Sivberg, 2007) and maturity measurements (Smith & Elder, 2007). In a study by Kaminsky and Dewey (2001), siblings of children with ASD reported greater admiration of and less competition with their siblings than did siblings of typically developing children. In a qualitative study of 14 families of children with ASD, Mascha and Boucher (2006) found that most siblings reported mainly positive feelings about their sibling relationship, stating that they often had fun with their sibling and engaged in many activities

together, such as playing together, spending time outside and watching television. In a review focusing on sibling relationships and sibling well-being, Orsmond and Seltzer (2007) found that positive experiences in sibling relationships were often reported when the child with ASD displayed fewer problem behaviours. Furthermore, they suggested that siblings who employed effecting coping strategies had a more positive relationship.

In summary, siblings of children with ASD describe positive aspects of their sibling relationship, including greater admiration (Kaminsky & Dewey, 2001, pride (Milevsky, 2005), and less conflict (Orsmond & Seltzer, 2007). Further, indicators of a positive sibling relationship are when ASD symptoms are less problematic and coping strategies are used effectively (Orsmond & Seltzer, 2007).

Negative Relationships. Siblings of children with ASD have also reported to be negatively affected with regards to having a sibling with ASD. Increased levels of internalizing and externalizing behaviours (e.g., Hastings, 2003; Rodrigue et al., 1993; Ross & Cuskelly, 2006), psychosocial adjustment problems (e.g., Orsmond & Seltzer, 2007), hassles with sibling behaviours (e.g., Moyson & Roeyers, 2011) and displaying distressing emotions (e.g., such as shame, embarrassment, and guilt; Opperman & Alant, 2003) are a few concerns that have been noted in the literature.

In a sample of 25 siblings of children with ASD, Ross and Cuskelly (2006) concluded that siblings have an increased risk for developing internalizing behaviour problems. They also found that the majority of siblings in their study (84%) reported that their sibling with ASD exhibited an aggressive incident at least once, which was found to be the most common stressor in the sibling relationship. Lefkowitz, Crawford, and Dewey (2007) also found that the risk of developing behavioural or emotional problems, as well as difficulties in social competence, is

heightened in siblings of children with ASD compared to siblings of typically developing children.

A study by Bågenholm and Gillberg (1991) reported that siblings of children with ASD experience elevated levels of loneliness and difficulties with peers. The results of their study also demonstrated that siblings of children with ASD were generally more negative in their perceptions of their relationships, often describing their sibling as a burden and reporting more problems with their siblings' behaviours. Concerns about their siblings' future were also highlighted in this study. Another study by Gold (1993) measured depression, social adjustment and the amount of caretaking responsibilities in 22 male siblings of children with ASD and 34 siblings of typically developing children. Findings revealed significantly higher instances of depression in siblings of children with ASD than the comparison group, but no differences were found in relation to siblings' social adjustment.

Further, in comparison to children with Down syndrome and typically developing children, Orsmond and Seltzer (2007) found that siblings of children with ASD reported spending less time with their siblings. They also found that siblings' relationships with their parents were affected in families (e.g., spending less time together) of children with ASD compared to families of children with Down syndrome. Roeyers and Mycke (1995) found that siblings of children with ASD reported greater feelings of embarrassment than siblings of children without disabilities.

Thus, negative aspects of sibling relationships have been reported by siblings of children with ASD, such as an increased risk of internalizing behaviours (Ross & Cuskelly, 2006) and emotional problems (Lefkowitz et al., 2007), feeling of loneliness (Bågenholm & Gillberg,

1991), depression (Gold, 1993) embarrassment (Roeyers & Mycke, 1995), and concerns about the future of their sibling with ASD (Bågenholm & Gillberg, 1991).

Siblings of Children with FASD

To date, there is limited research investigating the lived experience of siblings of children with FASD. When looking at the overall experience of families of children with FASD, Olsen et al. (2009) stated that siblings may be negatively affected by a sibling with FASD and suggest this area as an avenue for future study in FASD family research. Similarly, Hollar (2012) also highlighted the importance of future investigations examining the overall impact a child with FASD may have on a sibling, and how the siblings themselves can "mitigate negative consequences for the individual with an FASD" (p.249). Additionally, families have often reported having substantial fear for their child's future in regards to future support (Olson, Oti, Gelo, & Beck, 2009; Sanders & Buck, 2010). Since siblings are often shown to support the child when the caregiver is no longer able to, it is particularly important to gather further research. The aim of this current study is to contribute to the FASD family literature.

Present Study

From the previous research, it is clear that families are affected by living with a child with DD. Families have been reported to adjust negatively, such as experiencing a significant amounts of stress (Dabrowska & Pisula, 2010; Hastings, 2002; Roach et al., 1999; Watson et al., 2013a). They have also been reported to adjust more positively, such as becoming closer with their family members and gaining personal and spiritual growth (Jones & Passey, 2004). Similar findings have also been reported in families of children with ASD and FASD. Although a large body of research has examined the impact a child with DD has on parents and caregivers, there is

a paucity of research looking at siblings' experiences in families of children with DD. There is

also a limited amount of research examining sibling relationships in families of children with

ASD, and to the researcher's knowledge, no studies examining sibling relationships in families

of children with FASD.

The few studies that have attempted to examine the lived experience of siblings of

children with ASD have produced contradictory findings. Researchers have looked at sibling

overall adjustment (Orsmond & Seltzer, 2007); sibling self-concept (Dyson, 1999); internalizing

and externalizing behaviours (Ross & Cuskelly, 2006); and the presence of stress and depression

in the typically developing sibling (Gold, 1993). Some studies indicate that many siblings report

positive reactions, such as pride and less conflict (Milevsky, 2005), while other children

experience feeling of loneliness (Bågenholm & Gillberg, 1991), depression (Gold, 1993), and

embarrassment (Roeyers & Mycke, 1995).

Because of the inconclusive findings, the aim of the current study was to look at the

overall adjustment of siblings of children with ASD and FASD in a mixed research design. In

addition to exploring the lived experience of having a sibling with ASD and FASD, the

researcher also wanted to see if there are any similarities or differences of the lived experience

between the two types of siblings and if there are any differences between the two types of

siblings based on what they report in terms of psychosocial adjustment, relationships, hassles and

uplifts.

CHAPTER TWO: METHODOLOGY

A mixed methods design (Teddlie & Tashakkori, 2009) was conducted, which involved collecting, analyzing, and integrating both qualitative and quantitative data in one single study. Although qualitative research methods seem to be neglected in sibling literature, they have grown increasingly popular. When qualitative and quantitative methods are combined, they complement each other, which enhance the quality of results (Greene et al., 1989). Mixed methods studies can also assist in answering an extensive and more complete range of research questions because they are not limited to a single method approach, which may lead to additional information that would not have otherwise come to light. For example, responses in a questionnaire may shed light on interview responses or interview answers may further clarify a participant's response on a close-ended questionnaire. Following the suggestions for mixed methods design outlined by Merriam (2002) and Teddlie and Tashakkori (2009), this study included a qualitative component informed by a basic interpretive approach (BIA; Merriam, 2002) (collected in a semi-structured interview), which allows researchers to explore the personal experiences of individuals, how they make sense of their subjective reality, and how they attach meaning to it, and a quantitative component (as measured by two psychometric assessments described below).

Participants

Families in this study were accessed through disability support organizations across North America. E-mails were sent to various agencies and participants were asked to phone or e-mail the lead researchers if they were interested in partaking in the study. Additionally, because

this study is part of a larger family project, siblings whose parents participated in previous interviews were also contacted via their parent or caregiver.

Participants included biological and adoptive siblings. Foster siblings were not invited to participate due to consent issues. Five siblings of children with ASD and five siblings of children with FASD participated in the interview component of this study. In order to participate, siblings must not have a diagnosis of ASD or FASD. The total number of children with ASD per family was one, and the total number of children with FASD per family ranged from one to seven. The age of siblings of children with ASD ranged from 14-24, with a mean age of 20 and the age of siblings of children with FASD ranged from 13-29, with a mean age of 21.2. In order to protect participant confidentiality all participants in this study will be referred to by pseudonyms. Table 1 below shows the demographics of the participant population (also see Appendix A).

Table 1

Participant Demographic Characteristics

Sibling	Diagnosis of brother or sister	Sibling type	Age of Sibling without disability	Age of Sibling with ASD/FASD
Lee	FASD	Adoptive	25	19, 20, 20, 24, 26, 26
Matt	FASD	Adoptive	13	14
Jason	FASD	Adoptive	29	26
Lacy	FASD	Adoptive	19	15
Bailey	FASD	Adoptive	20	15, 19
Linda	ASD	Biological	24	22
Gillian	ASD	Biological	22	19
Anna	ASD	Biological	19	25
Bradley	ASD	Biological	14	12
Alex	ASD	Biological	21	25

Qualitative Interviews

Following a basic interpretive approach (Merriam, 2002, 2009), and drawn from phenomenology and symbolic interactionism, a semi-structured interview was conducted with siblings of children with ASD and FASD. Based on previous research conducted with families of children with DDs (e.g., Watson et al., 2013b) and informed by the FAAR model (Patterson & Garwick, 1998), the primary researcher (SW) and I developed 21 open-ended questions with follow up prompts as required. Please see Appendix B for a full interview guide. For example, the question "what are some difficult parts of being a sibling to _____" attempts to identify demands placed on the sibling in regards to possible stressors or strains, whereas the questions "What helps you handle the difficult parts" and "when you worry, how do you cope?" addresses the sibling's capabilities and how they use appropriate coping strategies.

To ensure the participants were not guided by the researcher to describe their experience in a particular way (i.e, either positively or negatively), no close-ended questions were asked. Interviews were conducted by the researcher, who was trained by the primary researcher, and were done either by telephone, Skype or in-person. If the siblings were located within reasonable distance (e.g., in Ontario), interviews took place in-person at locations agreed upon by both the participant and the interviewer (e.g., the participant's home). Interviews lasted anywhere between 20 and 45 minutes.

Analysis of Interviews

Semi-structured interviews were analyzed using Interpretative Phenomenological Analysis (IPA), which focuses on understanding how a person makes sense of a given phenomenon (Lyons & Coyle, 2007; Smith, Flowers, & Larkin, 2009). Following IPA

guidelines, all interviews were digitally recorded and transcribed verbatim. Each transcript and

their corresponding recordings were examined several times by the researcher to familiarize

herself with the data. After multiple reviews of the transcripts, notes and comments were made

throughout the document in the right margins. Comments were used to take note of any

observations that appeared significant and were analyzed again in order to convert the initial

remarks into more specific themes and phrases. The researcher then looked for connections

between the emerging themes and grouped them together according to their similarities. Once

themes came to light, inferences were made and the data were summarized. Refer to Appendix C

for a summary of themes and sub-themes.

Quantitative Measures

The quantitative component of this study involved the administration and analysis of two

survey questionnaires; the Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981;

Hetherington et al., 1999) and the Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-

Payne, 2002, 2006).

Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981; Hetherington et al.,

1999) – Siblings were asked to fill out a 64 item questionnaire that assessess the relationship

between siblings and their behaviour towards their sibling with ASD and FASD. The first 32

items is for the child to rate their sibling's behaviour towards them and the following 32 items is

to rate their own behaviour towards their sibling. All items are answered on a 5 point Likert scale

that ranges from 1 (never) to 5 (always) with high scores indicating a high level of behaviour

(See Appendix D). All items are divided into 6 subscales and a factor analysis indicated that the

scales formed two larger factors, positivity and negativity. The positive involvement scale

includes 3 of the subscales: Companionship (6 items), Empathy (5 items), Teaching/Directedness (4 items) and the negative involvement scale includes the last three subscales: Rivalry (7 items), Avoidance (5 items) and Aggression/Conflict (5 items). Cronbach's alphas were computed and ranged from .67 to .88 across subscales (Hetherington et al., 1999).

Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2002, 2006) – This questionnaire has 32 items assessing the substance and frequency of daily hassles and uplifts reported by siblings. It includes 22 hassles (e.g., "when my brother/sister with a disability does strange things) and 10 uplifting factors associated (e.g., "when my brother/sister with a disability does cute things") associated with having a sibling with a disability. The child is asked to rate each item along two dimensions: "how often does the good thing/problem happen" and "how happy/stressed does this make you feel?" The items are answered on a 5 point Likert scale that ranges from 1 (Never) to 5 (Always). High scores on the hassle subscale indicate high frequency and high intensity of affect associated with hassles. High scores on the uplifting subscale indicate high frequency and high intensity of affect associated with these positive events (See Appendix E). The Sibling Daily Hassles and Uplifts Scale has also been used in past research exploring stress and appraisal and coping in siblings with special needs (Orfus, 2008) in which items in the scale corresponded well with. Cronbach's coefficient was determined from the correlation among items and ranged from .88 to .9,3 indicating high internal consistency (Giallo & Gavidia-Payne, 2006).

Ethical Considerations

To protect the confidentiality of the data and the anonymity of the participants, I assigned pseudonyms to any names mentioned in the interviews. I also maintained the necessary ethical

standards by providing participants with the full disclosure of the nature and purpose of the research study. The participants were also given informed consent and because this study also involves children, parents were given all the information about the study and were asked to sign the consent form if the child was under the age of 16. Please see Appendix F for the sibling consent form. Furthermore, all siblings were informed that they could withdraw from the research at any time or not answer questions if they felt uncomfortable discussing that particular one.

CHAPTER THREE: RESULTS

Interview transcripts were analyzed using IPA (Lyons & Coyle, 2007; Smith et al., 2009).

Although siblings mentioned positive transformations such as sibling growth, patience and

acceptance, siblings also discussed several challenges associated with have a sibling with ASD

or FASD. During semi-structured interviews, siblings also identified a number of formal

supports that have helped and that could help them cope with the challenges they face. Using

IPA, five themes were identified from the interviews. These themes included positive

transformational outcomes, sibling demands, caregiving roles, awareness of developmental

disabilities, and formal supports (i.e., sibling support groups). Questionnaire data from the

Sibling Daily Hassles and Uplifts Scale and the Sibling Inventory of Behaviour Scale were also

utilized and comparison findings between sibling groups from these questionnaires will be

analyzed and discussed.

"It's definitely added to my character": Positive Transformational Outcomes

This theme title, taken from an interview with Gillian, a sibling to a child with ASD,

demonstrates that siblings have been able to positively adapt to having a sibling with a

developmental disability (Scorgie & Sobsey, 2000). Siblings also described the experience of

living with a sibling with ASD or FASD as valuable and an enriching one and discussed ways in

which they developed personal growth, gained patience, and have become more accepting of

others.

Growth. Siblings often elaborated on the ways in which they have personally grown

because of having a sibling with either ASD or FASD. Both sibling groups were very similar in

this aspect. For example, Jason, an adoptive sibling to a child with FASD, said that because his

parent's "put most of their energy into [his sibling]," he became more "self-sufficient". Siblings found that because of growing up independently, they have become more mature as adolescents. Additionally, siblings recognized that this experience helped them be more responsible and tolerant toward other people. Anna, a sibling to a child with ASD, discussed that because of having to constantly care for her sibling, she has become more responsible and caring with others. She also said that having her brother in her life has made her a more compassionate person and that because of this she sees her future as "better". Anna believes that she probably wouldn't be this way if she didn't have a sibling with a disability: "I see my future as… I have to say better. I see with having him in my life, it made a big change, it made me understand and have, I think, more compassion for people around me."

Alex, a sibling to a child with ASD also said that it's been a very uplifting experience: "I would never take it away for anything… it's been a really good experience in my life." He also said because of his brother being in his life, it has made his family close together and have all grown maturely from this experience. As Alex elaborated: "We probably wouldn't be as close as we are now… as a family. [We've] really grown maturely [and] we've learned a lot from him." Furthermore, Linda, a sibling to a child with ASD also said that having her sister in her life "made [her] grow up a lot faster" referring to the way in which she became a "second parent," as she often helped her mother with caregiving responsibilities in the household and by teaching her sister basic life skills.

Lee, a sibling to six children with FASD, shared similar experiences in regards to her personal growth. Lee found that she became an advocate for her siblings throughout her life by helping her siblings make good choices and by keeping them out of trouble at school (e.g., allowing her siblings to play with her). Lee believes these experiences have made her a better

person and even a "better mother". As Lee elaborated, "I've grown a lot because of it and I would never, ever, ever take any of it back. I would never because I feel like I'm a better person because of it." Siblings therefore expressed similar ways in which they have gained personal growth which has benefited them personally, with regards to being a more mature person, and has made them feel confident about their bright future ahead.

Patience. In addition to personal growth, siblings also discussed having gained more patience from their experiences. Lacy and Jason found that because their sibling with FASD threw many tantrums growing up, they often had to be on their best behaviour to avoid adding more stress in the family. Lacy said that she was "probably a better child than [she] would have been if [she] had not had a sibling that was affected [by FASD]." Jason also said that because he saw his sister with FASD push their mother to medical disability, which led her to unemployment, that he would often disappear and leave the household when his sister was acting out to avoid adding stress. He said that he "tried hard to be a good kid since there was already stress at home" and that he "left the house with his dad for hours when [his sister] was misbehaving."

Similar to siblings of children with FASD, Gillian, a sibling to a child with ASD, also found that she developed more patience as a result of having a sibling with a developmental disability. She found that her patience was tested the most when she would have to calm her brother if he was having a tantrum or when her brother would run away from home. However, Gillian said that even though her patience was always tested, that she still had to "learn and adapt in a peaceful way" which has "definitely added to [her] character because [she] feel[s] like it's made [her] very patient with others". As we can see, although both sibling groups discussed having to hold back with regards to always having to be on their best behaviour, they have

developed an increased tolerance level which they expressed with gratitude throughout the interviews.

Acceptance. In addition to sibling growth and patience, siblings of children with ASD and FASD also found that they are more understanding of others with regards to growing up with a sibling with a developmental disability. Some siblings, such as Lee, a sibling to six children with FASD, spoke about how she has become "more accepting" of other children with problem behaviours as she now sees that "it's not their fault". Lacy also elaborated on this as she described that even while working at her job she is more open-minded of others:

> She's taught me to be accepting like the most, no matter whether the person's special needs or not. If [someone is] 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.

Similar to siblings of children with FASD, siblings of children with ASD also found that they have become more accepting and understanding of others. Linda, a sibling of a child with ASD, said that the best part about being a sibling is how she has become "more understandable to other people, other families, and not even just people with disabilities." Sibling's found that when they are out in the community and see another child that displays similar behaviour characteristics as their sibling with ASD, such as throwing tantrums, they are more empathetic with regards to not making judgments. As we can see, both sibling groups have identified similar positive transformations as they both expressed gaining personal growth, have developed a higher tolerance, and are more accepting and understanding towards others.

"It's hard": Sibling Demands

Although siblings mentioned positive transformational outcomes, siblings also discussed several challenges associated with having a sibling with either ASD or FASD. Here is where interview analysis revealed a vast difference regarding what siblings found most difficult in their experiences. Siblings of children with ASD found that the most difficult part would be not being able to understand their sibling's needs whereas siblings of children with FASD found the safety and violence issues to be the most difficult. Additionally, siblings also expressed that they often find themselves worrying about the welfare of their sibling's future. These feelings of worry were expressed in a variety of ways between both sibling groups as siblings of children with FASD described the secondary disabilities that arise in children with FASD as something they worry about, whereas siblings of children with ASD tend to worry about their sibling's health issues and their siblings not being able to do what they love to do.

Difficult to understand needs: ASD. This subtheme that is found under the sibling demands reflects the challenges that siblings of children with ASD expressed as most difficult, specifically with the deficits in communication. Siblings found that because their siblings with ASD cannot verbally express their wants and needs that their siblings would resort to physical behaviour to express this. For example, Anna said "the difficult part would be not knowing what to do when he's not feeling good because he can't tell you". Anna described that in order for her brother to communicate that he's not feeling well, he would physically show it by banging his head on the wall or door. Similarly, Linda also expressed that "it's challenging in the sense of understanding everything she wants or she's asking for" with additionally stating that "it's also challenging to not hear her express herself to me - or tell me she loves me". While siblings expressed the deficits in communication a particular problem, they said that it was not anything they were too concerned about and that they have learned throughout the years to understand

their sibling's needs. Thus, learning how to communicate with children with ASD early in life has made understanding siblings needs much easier growing up.

Safety/violence issues: FASD. Although siblings of children with ASD found that the deficits in communication were most challenging, this did not seem to be a problem for siblings of children with FASD. Instead, siblings of children with FASD found that the secondary disabilities, as described by Streissguth et al. (1996; 2004), were the most challenging. Specifically, siblings described the violence, addictions, and problems associated with the law something difficult to manage. As Lee discussed:

> The cops came to my house dozens and dozens of times. The violence, that was hard. I was threatened by knife point several times growing up so imagine being an 11 year old girl being threatened with a knife by your sister. That was hard.

Consistent with findings from the Sibling Daily Hassles and Uplifts Scale, all of the siblings of children with FASD reported that their sibling sometimes or always "hurt, hits, pushes, scratches, or kicks [them] or others", stating that violent behaviour was sometimes or always prominent, whereas both siblings of children with ASD that completed the questionnaire, reported that their sibling only sometimes "hurts, hits, pushes, scratches, or kicks [them] or others," stating that it wasn't very often.

Because children with FASD are more vulnerable to developing secondary disabilities, these siblings also find themselves constantly trying to get their siblings out of bad crowds. Lacy described that her sister was hanging with the wrong crowd:

> They're all doing drugs and they're all drinking in school and one of her friends brought a gun to school. Like these are the kinds of kids she's friends with and not because she

wants to be… it's because they're the only people that want to be friends with her, so I constantly find myself bringing her with me and my friends.

Frustrating and constantly worrying. Both sibling groups spoke in great detail about how they would constantly worry about their sibling. Siblings of children with FASD expressed that they constantly worry about their sibling's future in terms of their secondary disabilities with regards to having addiction problems or getting in trouble with the law. Lee said that she didn't want to see her brothers go to jail and that this was definitely a possibility as they often get in trouble with the law: "my brother's in high school now… and he's doing things he shouldn't be doing and I know if he gets caught he could potentially go to jail… I don't ever want to see him go to jail!" Because of this constant worry, Lee also expressed that it was frustrating because it has affected her in her personal life; Lee says "I worry a lot… a lot! And in the past it's affected my relationship with my husband… I mean, I'm always constantly in my head… Is somebody hurt? Is somebody in trouble?" Bailey, also a sibling to two children with FASD, discussed her sibling's addiction as something she often worries about with regards to their future: "Addiction… I don't want that to be their future."

Siblings of children with ASD on the other hand discussed worrying about issues such as health problems, being alone, and their sibling not being able to do what they want to do. Anna said that she was most concerned regarding her sibling's seizures persisting throughout his life and not being able to get them controlled: "the only worries with him would be not being able to get his seizures under control and the anxiety he has." Additionally, Linda described being concerned for her sibling in terms of her being alone and depressed: "I'm kind of scared for her future because there's not a lot of things out there for her right now… just her being bored or alone." Gillian said that she worries a lot about her brother being able to do the things that he

love to do (i.e., travel). She says: "I think physically going to where he wants to go because he loves to travel… I think that's one of the biggest things that I would worry about."

These findings were also consistent with sibling's responses on the Sibling Inventory of Behaviour questionnaire as 5 out of 6 siblings that completed the questionnaire said that they are often or always "concerned for his/her [sibling's] welfare and happiness."

"She's probably going to end up living with me": Caregiving Role

Siblings spoke in great detail about their thoughts regarding potentially being a caregiver for their sibling with ASD or FASD; however, there were very mixed results between both sibling types. Most siblings of children with ASD said that they have thought of being a potential caregiver and it was definitely a possibility in their future; whereas some sibling of children with ASD said that even though they will still be highly involved in their sibling's future, their sibling was most likely going to move to a residential setting. On the other hand, most siblings of children with FASD said that being a caregiver for their sibling was not something that they foresee in their future, but that they would most likely be involved in managing their sibling's finances. Most siblings discussed that their siblings were irresponsible with money and that because of this carelessness; their siblings would always need to be monitored with regards to their finances.

Potential caregiving in the future: Although none of the siblings of children with ASD or FASD was the primary caregiver for their sibling, they reported being involved in a number of caretaking tasks such as responding to their siblings' physical and emotional needs, taking care of them when their parent was away, and teaching them appropriate behaviours. Some siblings of children with ASD said that they found pleasure in taking care of their sibling with ASD and that

this would be something they would like to do in their future. For example, Anna had discussed that because of her sibling, she went into a program in college related to ASD to further educate herself on the condition, which she seemed very excited about. When asked where she sees herself in the future of her brother she said: "I can see possibly having to take care of him if my parents never could." Additionally, Bradley, a sibling to a child with ASD, said that even though it may take a lot to take care of his brother, as he refers back to the current behaviours (e.g., tantrums), he sees that being a potential caregiver a possibility in his future: "…I feel like I'll be able to do it, it might just take a lot."

Although most siblings of children with FASD said that they would not be a potential caregiver, those siblings that did not experience a lot of stress growing up, such as the excessive violence that some siblings experienced, said that this would be a possibility. For example, Lacy said that even though she is hopeful her sister will be able to live on her own, she believes that her sister is "probably going to end up living with [her] when she gets older." Lacy's comment with regards to possibly being a caregiver was consistent with the quantitative findings on the Sibling Inventory of Behaviour questionnaire, as Lacy was the only sibling of a child with FASD to report that she always "babysits and cares for [her sibling]" with FASD.

Not wanting to be a future caregiver. For most siblings of children with FASD, being a potential caregiver is not something they see in their future. Most siblings referred back to the stresses they experienced growing up and that they did not want that stress to be carried forward in their future. For example, Lee said "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 think of the amount of stress that I went through as a child." Though Lee was adamant about this statement, throughout the

interview she expressed emotions such as shame and guilt for not wanting to be a caregiver for her siblings which was very evident to the researcher.

While most of the siblings of children with FASD said that they did not want to be a potential caregiver in the future of their sibling, they would most likely be involved in their sibling's future in regards to their sibling's financial situations, as this was an area in particular that siblings described their siblings as being most irresponsible in. For example, Jason said that "[he will] do her taxes for a few years… [Because] things like that she needs help with." Lacy also said that "if she doesn't live with me I'm going to be in charge of her finances" and that she's "kind of accepted [being a guardian] as [her] future." Although siblings described concerns with regards to their sibling's problem behaviours, and with whether or not they would like to be a potential caregiver, siblings also expressed concerns with the community and their opinions, which are discussed in the next emergent theme.

"They didn't understand": Awareness of Disabilities

Many siblings found that because their sibling looks "normal", individuals in the community have trouble understanding that the child has organic brain damage. Both sibling groups were similar in this aspect and vocalized that it was hard growing up having other people constantly staring at them when they are in public or making rude comments to them in regards to their siblings problem behaviours. Some sibling said that if their sibling was throwing a tantrum, people in the community would come up to them and tell them to control their sibling, which was expressed as humiliating to siblings. As a result of a lack of understanding and negative attitudes and opinions of other people, siblings often experienced a range of emotions in which they said they often felt angry, embarrassed or irritated towards others. Thus, the overwhelming

emotions that have been reported to arise from the lack of knowledge in people in the community resulted in often having to provide explanations to stranger and friends. Additionally, some sibling's also said that they would withdrawal from being around peers or strangers in the community to simply avoid explaining their sibling's problem behaviours.

Other people's opinions and their knowledge on disabilities. Some siblings spoke about other people's attitudes toward their siblings with ASD or FASD, and the difficulties associated with reactions from peers. For example, Linda, a sibling of a child with ASD, said that "a difficult part would be not so much her but dealing with other people and how they view her or look, stare… because not everyone understands." Brandon, a sibling of a child with ASD, also said that he only enjoyed going to the movies if there were events that were specifically for children with ASD. He said that this experience would be more pleasant for him since there were other people of the same type of disorder and that there would not be other people staring or walking over to their support dog.

To some other siblings, social awkwardness and embarrassment were also a regular occurrence. Lacy, a sibling of a child with FASD describes an event when she felt most embarrassed in public with her sibling: "When I was a child it could sometimes be kind of embarrassing to go out with her… I remember one time we went to a fair and she pressed the emergency on the fire truck… it attracted everyone and I just wanted to crawl into a hole just faraway."

Although siblings identified feelings of embarrassment throughout the semi-structured interviews, findings from the Sibling Inventory of Behaviour questionnaire, revealed that all of the siblings who completed the questionnaires said that they were only seldom "embarrassed to

be with [their sibling] in public." This response may be due to social desirability, because as we can see, sibling's expressed very different feelings throughout the interview, reporting that they often feel humiliated in public when their sibling is displaying problematic behaviours, such as tantrums.

In addition, the attitudes of others led some siblings to withdraw from friends and remain silent with regards to their sibling's behaviour. Sibling's felt that they were constantly questioned about their sibling's behaviour and that it essentially became a hassle to constantly explain. Jason, a sibling to a child FASD, for example, said that he often would not invite anyone new over and would only have the same few friends over so that he wouldn't have to continuously explain his sibling's behaviour to them.

For one sibling of a child with FASD, Lee, having to always explain her sibling's disorder to others often made her feel frustrated and angry. These feelings of frustration and anger often occurred in situations where Lee believed that children at school were displaying discriminating behaviour towards their sibling with the disability, such as making fun of their sibling for not understanding how to play a sport like basketball, or not being able to solve simple math equations. Lee perceived these individuals as lacking the necessary understanding required when a child with FASD acts in a way that is out-of-the-ordinary. As Lee elaborated: "The other kids didn't get it, they didn't understand, they thought they were weird, they thought that… I mean they used the word retarded all the time… They're not retarded!"

As we can gather, siblings have found that people make quick judgments with regards to their sibling's behaviours. Educating others on ASD and FASD is something that may be beneficial for sibling's which has often been expressed throughout the interviews. Additionally,

siblings have stated that having someone to talk to about these problems would help with eliminating some of the negative emotions that arise from their siblings problem behaviours and other people's opinions, which is discussed in the next theme.

"Siblings need it just as much if not more": Supports

The last theme identified, supports, refers to what has and what can help siblings cope with the challenges they face. Subthemes under supports include: supports have made life easier for siblings of children with ASD and need more support groups for siblings of children with FASD. As we can see in the titles themselves, this is a particular area of need for siblings of children with FASD. Siblings of children with ASD have discussed some of the formal supports, such as having personal aids, group homes, and support dogs as beneficial to the family. On the other hand, siblings of children with FASD spoke about the lack of formal supports, such as support groups for siblings of children with FASD, which has been expressed as a significant area of need. Siblings of children with FASD did, however, resort to informal supports such as friends and family, which they said helped a little bit.

Need more support groups for siblings of children with FASD. Siblings discussed in great detail about the lack of formal supports available for siblings of children with FASD. Most siblings said that having formal supports would have been extremely beneficial growing up as they did not have anyone else to confide in with regards to their experience of having a sibling with FASD. For example, Lee said that she often had to leave her house because she did not have anyone to talk to: "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… so I would leave… I didn't want to be around it and I know it would take a few days for [my siblings] to digress and calm down",

stating that having support would have been something helpful when she was younger. Additionally, siblings also spoke about the fact that there were numerous support groups available for parents and that siblings need it just as much: "I think just having support groups for siblings, like there were so many support groups for my mom, there's so many support groups for my sister, and then there was me and I was like hello?? The siblings need it just as much if not more than those affected."

Because of the lack of supports available to this sibling group, siblings also discussed their interest in starting their own support groups. As Lee elaborated:

I want to get a group together for siblings of people with FASD just so those people have somebody to talk to because I knew only now recently that I've had problems… I know that there are people out there that don't understand why they're always fearful and why they're always worried, and why they're stressed all the time… I just want to set that up for other people who would like just to talk to somebody about it.

Lacy also said because her mother runs a support group for parents of children with FASD, that this would be something she would be interested in doing as well: "I definitely want to help her."

Consistent with findings from the Sibling Daily Hassles and Uplifts Scale, 3 out of 4 siblings of children with FASD who complete the questionnaires, reported that they never or sometimes "get to be part of different groups because of [their] brother or sister with a disability", whereas the one sibling that said their mother runs a support group for parents, said that she always "get[s] to be a part of different groups because of [their] brother or sister with a disability."

Supports have made life easier for siblings of children with ASD. According to the interviews, it appears there are many supports available for siblings of children with ASD, who found it much easier to positively adapt to the difficulties associated with their sibling's condition. Having formal supports, such as support dogs, personal aids, and group homes have been said to be helpful to siblings that has allowed them to have a more positive experience with regards to having a sibling with ASD. Bradley, for example, discussed his brother's support dog being a huge help, and not only for him but for his entire family: "Ever since the [support] dog came two years ago it's been better because he's not as violent and he's not yelling as much." Bradley said that now that the support dog was in the family, his parents were not as stressed which has shed a lot of light within their family dynamic. Linda, on the other hand, said that having "residence", a group home that her sister would stay at 5 days a week as extremely beneficial for her and her family. Linda also said that because she has been staying in residents that she didn't have to worry as much for her future: "If she didn't have ["residence"] she'd be living with me for the rest of her life and that would kind of hinder my own family and relationships. So basically having "residence" is the biggest support ever." In addition, Alex discussed having an aid come by daily to take care of his sibling. He said that this was refreshing because it allowed everyone in the family to take a break from having to constantly take care of his sibling's high needs (i.e., having to keep him occupied in order to avoid tantrums).

As we can see, and to sum up the findings of this present study, both sibling types experience similar challenges but have distinct differences in some areas. Specifically, siblings of children with FASD tend to face more struggles in terms of their sibling's violence and behavioural challenges; whereas siblings of children with ASD face more challenges with understanding their sibling's needs. There are also no existing support groups for siblings of

children with FASD which has been described as an area of need. This does not appear to be a problem for siblings of children with ASD as they discussed numerous supports and resources already available to them. Although many challenges have been discussed across both sibling groups, siblings also discuss positive transformations in which they have grown from the experience, and have gained increased levels of tolerance and patience and have become more accepting and understanding to others.

CHAPTER FOUR: DISCUSSION

Research findings' examining the lived experiences of siblings of children with DD has

been shown to be inconsistent, making interpretation a challenge. According to Green (2013), the

discrepancy in findings across studies may be accounted for by several methodological

differences and confounding variables such as family environment (e.g, age, gender), the severity

of the disability, differences in the populations sampled (e.g., Down Syndrome, ASD, FASD),

the use of different outcome measures (e.g., adjustment measures), and the lack of comparison

groups. In an attempt to clarify research findings to date, the present study explored the lived

experiences of siblings of children with ASD and FASD. In addition, the author also sought to

examine similarities and differences between the two sibling types.

The ten siblings in this study expressed five super-ordinate themes: Positive

Transformational Outcomes, Sibling Demands, Caregiving Roles, Awareness of Developmental

Disabilities, and Formal Supports. These themes represent a variety of underlining experiences,

which were further detailed by subthemes and direct quotations from semi-structured interviews.

In addition, quantitative questionnaire data was collected as a supplementary piece to the

qualitative data; however, the researcher was unable to meet this objective due to complications

with the questionnaires selected for this study, a limitation that is discussed in the limitations

section of the study. Additionally, the structure of the FAAR model allowed the researcher to

identify the variables that moderate the relationship between the demands and the capabilities

(i.e., coping and resources).

According to some previous studies, siblings of children with DD often perceived their

sibling as a burden (Bågenholm & Gillberg, 1991), spent less time with their sibling with DD

(Orsmond & Seltzer, 2007), and experienced psychological maladjustment (Kaminsky & Dewey,

2002). On the other hand, some studies suggest no differences in behaviour problems amongst siblings (McMahon et al., 2001). Although mixed results are prevalent in most sibling research with regards to siblings having a positive or negative experience (e.g., see review by Green, 2013), the current findings are consistent with some results from other studies, indicating that siblings have positively adapted to having a sibling with ASD or FASD (Stoneman, 2001, 2005; Turnbull et al., 2007).

According to Scorgie and Sobsey (2000), families often undergo positive transformations and life changing experiences when they live with a child with DD. Both sibling groups who participated in the present study identified a number of positive factors associated with transformational outcomes, including having a greater sense of personal growth and that because of their positive relationships they were able to foster positive perceptions of their siblings which increased tolerance and acceptance of others and of their siblings' more challenging behaviours (Hastings, 2003; Kaminsky & Dewey, 2002).

Most siblings in this study experienced positive transformations when they took on additional responsibilities at home (i.e., caretaking tasks) or if their family worked well together and as a team. Byat (2007), investigating family resilience in families of children with ASD, also found that if families worked together as a unit, communicated well with one another, and were able to utilize their resources well, they reported having a greater sense of satisfaction and even expressed being more compassionate and understanding to others. Furthermore, siblings in this study referred to the stress that they observed in their parents, which was something that they did not want to add on to, resulting in being more self-sufficient and staying out of trouble (Hastings, 2002). Having become so independent at a young age made them more mature and facilitated personal growth. Although the researcher did not address SES within families; studies have also

shown that siblings of children with DD tend to adjust better if they live in larger families with high SES, if the sibling with DD is younger than their siblings, and if the disability is less severe (Boyce & Barnett, 1993; Hastings, 2003; Kaminsky & Dewey, 2002; McHale et al., 1986). Future research examining siblings of children with ASD and FASD should take SES factors into consideration.

While siblings expressed a number of positive adaptations, both sibling groups also discussed the unique challenges they face in terms of their sibling's specific diagnosis. Siblings of children with ASD founds deficits in communication most difficult (Heiman & Berger, 2008), whereas siblings of children with FASD found the secondary disabilities that arise in children with FASD an extraordinary challenge (Chudley et al., 2005; Streissguth et al., 1996). Siblings of children with ASD said that they found not being able to understand their sibling's needs to be challenging because they were not able to accommodate those needs. For example, these siblings said that when their sibling with ASD was not feeling well they would resort to physical behaviours (i.e., banging head on wall). Siblings also found this to be a challenge because they are unable to hear their sibling express their emotions towards them (i.e., tell them that they love them). According to the literature, deficits in communication have not been found to be a concern for siblings of children with ASD. Instead, the behaviour problems (i.e., aggression) have been identified as a challenge for siblings (e.g., Ross & Cuskelly, 2006).

Although deficits in communication are also common in children with FASD (Church & Kaltenbach, 1997), siblings with this condition did not find this to be their main concern. In past studies, the primary and secondary disabilities associated with FASD are issues that have been demonstrated to be directly related to family stress (Brown & Bednar, 2003). In a qualitative study investigating specific sources of stress reported by parents of children with FASD, they

found parents were more stressed in terms of their child's illegal behaviours, demonstrating that the secondary disabilities associated with FASD were a significant contributor to family stress (Watson et al., 2013b). It is no surprise that siblings have also expressed this to be their main concern. Among a sample of 253 individuals with FASD, 60 percent reported being charged, convicted, or in trouble with the law (i.e., trouble with authority). Siblings said that they were most afraid of their sibling going to jail whether it was because of violence or drug or alcohol abuse. Although siblings expressed such concerns, they also described protective factors that have been implemented (i.e., early diagnosis and adoption), which unfortunately has not helped.

Because of the challenges associated with having a sibling with ASD and FASD siblings had mixed feelings regarding whether or not they saw themselves as a potential caregiver in the future. Considering it has been reported that it is often a sibling who takes on the support and caregiving role of a child with a disability (Griffiths & Unger, 1994), this response was quite interesting.

Siblings of children with ASD reported that they have thought of being a potential caregiver and it was definitely a possibility for them in their future. Mascha and Boucher's (2006) findings revealed that most siblings of children with ASD reported mainly positive feelings about their sibling relationship, stating that they spent a lot of time with their sibling. Because siblings of children with ASD in this study discussed spending a lot of time with their sibling and that caretaking was almost a second nature to them growing up, caretaking did not seem to be a big concern.

Although siblings of children with FASD also reported taking on extra responsibilities in terms of taking care of their siblings, this was something they did not want in their future.

Siblings of children with FASD discussed the stress they went through growing up and that they did not want that stress to be carried forward in their future. However, siblings of children with FASD did say that they were concerned about the welfare of their sibling in terms of them staying out of trouble and that they would most likely be in their lives "involuntary." According to Orsmond and Seltzer (2007), the responsibility of caring for one's sibling with DD has been shown to result in excessive worrying in which they have suggested that siblings should be provided with support to relieve these worries.

Previous studies have also mentioned that siblings are typically faced with issues like peer issues and embarrassment (Conway & Meyer, 2008). According to both interview and questionnaire responses in the present study, siblings discussed other people's opinions towards their sibling with ASD and FASD as a challenge. Because of the lack of awareness and knowledge of DD in the community, siblings found that going out in public was something stressful for them as they were often shunned by the public or received rude remarks in regards to their sibling's problem behaviour (Chudley et al., 2005; Heiman & Berger, 2008). These stares and comments seemed to be a challenge for both sibling types, as they said that because their siblings looked "normal," individuals in the community had a difficult time understanding that the child has organic brain damage. Siblings found themselves often having to explain themselves, which was somewhat frustrating for them.

Finally, siblings described the importance of receiving adequate formal support. Siblings of children with ASD discussed numerous supports and resources already available to them which was said to be very beneficial for siblings.

Siblings of children with FASD; however, stated that this was a significant area of need. Because ASD is much more common than FASD (CDC, 2014), supports have been available for siblings of children with ASD for quite some time. Siblings identified having supports such as support dogs, in-home aids, or group homes available for their sibling with ASD as being helpful for them and their family in terms of putting less pressure on the sibling and parents. Previous studies have indicated the importance of supports, and how they play a vital role in helping families of children with DD to cope with stresses they may experience (Pilowsky et al., 2004). Additionally, Schunterman (2007) found that siblings often report more positive behaviours when they are provided with formal supports. Conway and Meyer (2008) also stated that it is important to implement supports for siblings at an early age to avoid problems in the future. Consistent with findings from this study is that siblings often report having support at a young age would have been invaluable.

Relating back to the FAAR model, demands and capabilities were addressed in the semi-structured, qualitative interviews, as the questions were informed by the FAAR model (Patterson, 1988). Siblings of children with ASD were found to experience demands such as not understanding their sibling's needs. This was a challenge for most siblings in this study; however, because siblings of children with ASD had a number of resources available to them, they were able to achieve homeostasis, as they were able to meet their demands with their current capabilities.

Siblings of children with FASD, on the other hand, had a difficult time achieving stability in the family unit; which ultimately led to crisis. The crisis that siblings of children with FASD experience is strongly related to the failure to obtain external resources. By improving resources and capabilities for siblings of children with FASD, such as the development of sibling support

groups, professionals can help facilitate family adaptation processes to stabilize and balance the sibling's demands with their capabilities.

Limitations and Considerations

Although this study used credible qualitative research methods (Patton, 2002), the researcher recognizes that the validity of the findings may be affected by some limitations. The first limitation of this study is the sample size. Although the sample size of 10 is typical of those recruited generally for qualitative research (Starks & Trinidad, 2007); findings do need to be treated with caution and should not be generalized across developmental stages (i.e., early childhood or adolescents). The second limitation is the age of the participants. The participants ranged in age from 7-29 years and therefore the generalizability of the findings may be limited. Future research should ideally focus on particular age ranges to further investigate sibling's experiences (i.e., early childhood, adolescents and adulthood). A third limitation of this study is that the all of the siblings of children with ASD were biological, whereas all siblings of children with FASD were adoptive. Unfortunately, this is difficult to manage because according to the literature 80% of children with FASD live in foster care or are adopted (Dicker & Gordon, 2004; Streissguth et al., 2004). However, future research of sibling experiences in families of children with FASD should more comprehensively compare the specific differences between biological siblings and foster/adoptive siblings.

Furthermore, another limitation of this study relates to the quantitative measures employed. The Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2002, 2006) is designed to assess the substance and frequency of daily hassles and uplifts reported by siblings, whereas the Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981; Hetherington et al., 1999) is

designed to assess the relationship between siblings and their behaviour towards their sibling with a disability, such as ASD or FASD. Although both measures are intended to examine the relationships of siblings of children with DD; the researcher found their use is limited in regards to the overall lived experience of having a sibling with ASD or FASD. Additionally, because not all of the questionnaires were received back from the participants, the researcher was not able to fully determine whether the lived experiences of siblings that was expressed in the semi-structured interview was consistent with what they responded on the questionnaires.

Strengths of the Study

Despite the limitations already discussed, the present study used a number of strategies to ensure the reliability and validity of this study. Trustworthiness in qualitative studies has been defined as how well a particular study does what it is supposed to do and if it accurately represents the experiences of participants (Merriam, 1995). Therefore, in order to judge the reliability and validity of qualitative research, a number of strategies have been utilized.

First, the researcher ensured credibility by allowing the participants to validate the reported findings represents their experiences, by the use of member checks (Mertens & McLaughlin, 2004). Member checks involves relating the accuracy of data "on the spot" (during the interview itself) to clarify information (Shenton, 2004), as well as verification of emerging themes with participants (Brewer & Hunter, 1989). Member checks were therefore conducted with participants in this study throughout the entire data collection process. During the interview itself, siblings were asked to clarify their experiences and were given the opportunity to add anything else that seemed relevant at the end of the interview. After themes emerged during data analysis, siblings were contacted, and were asked to ensure that the emerging themes were

representative of what was discussed during the interviews. In addition to ensure reliability and validity of the present study, triangulation was employed, which consisted of combining both qualitative and quantitative methods. In the present study, the quantitative measures were used as supplementary data to the qualitative findings to support emerging themes. According to Patton (2002), combining both qualitative and quantitative methods often strengthen a study, which was done in the current study. Finally, because a majority of research relies on parental reports, a final strength of this study would by the fact that the researcher was able to collect data directly from the siblings themselves. Parent reports often appear to produce different information from what emerges from self-reports and are also found to be more negative (e.g., Lobato, Barbour, Hall, & Miller, 1987), therefore it is important to gather self-report data from siblings as well in order to capture a valid experience (Macks & Reeve, 2007).

Implications of the Study

The findings from this study indicate a number of implications for clinical professionals and services. Understanding the particular positive adaptations and challenges that siblings of children with ASD and FASD face is essential to developing, implementing, and improving appropriate services for siblings. Although supports have been discussed as helpful to siblings of children with ASD, this is a particular area of need for siblings of children with FASD. Therefore, support, therapy, and education that focuses specifically on siblings of children with FASD is a vital approach for fostering healthy psychological well-being in siblings.

There is also a need to promote knowledge and awareness of ASD and FASD in both the community and with professionals. Siblings found it extremely frustrating to constantly educate those around them about their sibling's issues and problem behaviours. Promoting knowledge

and awareness of ASD and FASD may help lessen the stigma around those individuals affected by ASD and FASD which essentially may make life easier for families. This increased knowledge may also be helpful in preventing secondary disabilities that are shown to arise in children with FASD and create stress in family members.

Furthermore, during the recruitment of participants, as well as the interviews, siblings often demonstrated excitement and pride when given the opportunity to discuss their experiences with a sibling with ASD or FASD. Employing a self-report interview not only allowed for more accurate data, but it also provided opportunities for siblings to express themselves and tell their story. According to Murray (2003), qualitative interviews are found to be therapeutic for participants. Thus, the findings have implication for providing a strength-based approach (Hammond, 2010) for siblings of children with ASD or FASD. It is important to not only provide crisis intervention services for the challenges siblings' face, but to acknowledge their strengths and capabilities, which may ultimately give siblings a more positive outlook and hope.

Conclusion

The results of the present study provide new insights regarding sibling relationships in families of children with ASD and FASD. In line with past research (Stoneman, 2001, 2005; Turnbull et al., 2007), the researcher found that siblings who participated in the present study have been able to positively adapt to having a sibling with these conditions and have been able to gain personal growth and develop increased levels of tolerance and high acceptance of individual differences. Also consistent with past research (Bågenholm & Gillberg, 1991; Kaminsky & Dewey, 2002), siblings demonstrated different and unique challenges associated with having a sibling with these conditions, and have identified what has helped with these challenges, and

what could help. Although previous studies suggest that when siblings of children with ASD are compared with siblings of other types of DD, siblings of children with ASD tend to show a greater risk for negative outcomes (Hastings, 2003; Rivers & Stoneman, 2003), it appears that siblings of children with FASD are associated with more sibling challenges. Given that siblings of children with FASD tend to face more sibling difficulties and have reported that support is a significant area of need, research should further investigate this sibling group.

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Appendix A

Demographic Questionnaire

<u>Family Research Project Demographic Form</u>

Name: _____

Age: _____

E-mail Address: _____

Phone Number: _____

Number of Children in the Family: _____

Number of Child(ren) who have FASD: _____

Number of adopted children who have FASD: _____

Age of adopted Child(ren) with FASD: _____

Appendix B

Interview Guide for Siblings

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/ASD)?
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/ASD?
7. How would you describe (insert name of sibling with FASD/ASD)?
8. What is it like to be (insert name of sibling with FASD/ASD)'s sibling?
9. Tell me about a typical day in your household.
10. How do you think [insert name of sibling]'s FASD /ASD 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/ASD)?
13. What is the best part of being a sibling to (insert name of sibling with FASD/ASD)?
14. What are some difficult parts of being a sibling to (insert name of sibling with FASD/ASD)?
    a. What helps you handle the difficult parts (insert name of sibling with FASD/ASD)?
    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?
    a. Where do you see yourself in the future of your sibling?
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/ASD)
19. Is there anything else you think I should know about your relationship with your sibling?

Appendix C

Summary of Themes and Sub-themes Presented in Chapter Two

Superordinate Themes	Sub-themes	Example of illustrative quotation
Theme 1: "It's definitely added to my character" (Positive transformational outcomes)	Growth	I see my future as… I have to say better. I see with having him in my life, it made a big change, it made me understand and have, I think, more compassion for people around me. – *Anna (ASD)*
	Patience	I feel like it's definitely added to my character because I feel like it's made me very patient with others. – *Gillian (ASD)*
	Acceptance	She's just taught me to be accepting like the most, no matter whether the person's special needs or not. – *Lacy (FASD)*
Theme 2: "It's hard" (Sibling Demands)	Difficult to understand needs	It's hard because like we could hear him bang or something and we can go up and ask him what's going on and he won't know how to explain it…The difficult part would be not knowing what to do when he's not feeling good because he can't tell you – *Anna (ASD)*
	Safety/Violence issues	The violence, that was hard. I was threatened by knife point several times growing up. – *Lee (FASD)*
	Frustrating and constantly worrying	I worry a lot. I come home from school and the cops are at my house. What's happening? What's going on? Is somebody in trouble? – *Lee (FASD)*
Theme 3: "She's probably going to end up living with me" (Caregiving Role)	Not wanting to be a future caregiver	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 think of the amount of stress that I went through as a child. – *Lee (FASD)*
	Potential caregiving in the future	I can see possibly having to take care of him if my parents never could or could

		see one of the siblings to chip in – *Anna (ASD)*
		I know the reality is she's probably going to end up living with me when she gets older. That's just kind of something that I've been like ok, ya. – *Lacy (FASD)*
Theme 4: "They didn't understand" (Awareness of disabilities)	Other people's opinions and their knowledge on disabilities	A difficult part would be not so much her but dealing with other people and how they view her or look, stare, - which is a given, you know? Because not everyone understands… just dealing with other people and their opinions and stuff. - *Linda (ASD)*
		"The other kids didn't get it, they didn't understand" – *Lee (FASD)*
Theme 5: "Siblings need it just as much if not more" (Supports)	Need more support groups for siblings of children with FASD	I think just having support groups for siblings, like there were so many support groups for my mom, there's so many support groups for my sister, and then there was me and I was like hello?? The siblings need it just as much if not more than those affected– *Lacy (FASD)*
		I want to get a group together for siblings of people with FASD just so those people have somebody to talk to because I knew only recently that I've had problems. – *Lee (FASD)*
	Supports have made life easier for siblings of children with ASD	Ever since the [support] dog came two years ago it's been better because he's not as violent and he's not yelling as much. – *Bradley (ASD)*

Appendix D

Sibling Inventory of Behaviour Scale

*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) <u>behaves</u> 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	1	2	3	4	5

new situation					
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.

	Never	Seldom	Sometimes	Often	Always
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 E

Sibling Daily Uplifts and Hassles 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**		**A little bit**		**Very happy**
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**		**A little bit**		**Very happy**
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
2. I know and understand a lot about disability	1	2	3	4	5	1	2	3	4	5
3. My brother or sister with a disability is happy	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		A little bit		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
5.I get to share experiences and do things with my family (for example., go on a holiday, go on bike rides)	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
7.My mum/dad tell me that I am being a big help around the home.	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		A little bit		Very happy
9.They understand my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
10. They get along and play nicely with my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
11. I can trust they won't make fun of me or tease me because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5

12. They don't treat me differently because I have a brother or sister with a	1	2	3	4	5		1	2	3	4	5	
13. I get to spend time alone 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		A little bit		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	
18. My brother or sister with a disability gives me time to play alone with my friends	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	A little bit	Very happy

	How often does this happen?					How bothered or upset does this make you feel?				
20. Learns something new (e.g., a new word, good math or writing)	1	2	3	4	5	1	2	3	4	5
21. Does cute things.	1	2	3	4	5	1	2	3	4	5
22. Is in a good mood and is smiling.	1	2	3	4	5	1	2	3	4	5
23. Plays with me like other brother and sisters.	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 the 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?				
						Not bothered		A little bit bothered		Very bothered
	Never		Sometimes		Always					
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?				
						Not bothered		A little bit bothered		Very bothered
	Never		Sometimes		Always					
24. My brother or sister with a disability does strange things.	1	2	3	4	5	1	2	3	4	5
25. My brother or sister with a disability runs away.	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
27. People stare or look at us.	1	2	3	4	5	1	2	3	4	5

	How often does this happen?					How bothered or upset does this make you feel?				
28. I don't feel 'normal' because people are staring or looking at us.	1	2	3	4	5	1	2	3	4	5
29. We have to stop what we are doing (for example, leave the supermarket) because of my brother or sister with a disability.	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 bothered		A little bit bothered		Very bothered
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
32. I have to do more jobs/chores around the home because of my brother or sister with a disability	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
34. We miss out on things (for example, getting a pet) because of my brother or sister with a disability.	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
36. I feel like I don't have time to myself because of my brother or sister with a disability.	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 bothered		A little bit bothered		Very bothered
38. I have to talk about my brother or sister's disability or illness	1	2	3	4	5	1	2	3	4	5
39. My brother or sister with a disability does embarrassing things	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
41. I worry that they will tell other people about my brother or sister with a disability and I will get teased.	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
43. I get sad when they say mean things about people with disabilities (for example, he runs like someone with Down Syndrome)	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 bothered or upset does this make you feel?				
	Never		Sometimes		Always	Not bothered		A little bit bothered		Very bothered
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
45. I worry that my brother or sister may get hurt if he/she runs away and no one would know.	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

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 pit?)	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
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.	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 bothered		A little bit bothered		Very bothered
51. Hurts, hits, pushes, scratches or kicks me or others	1	2	3	4	5	1	2	3	4	5
52. Touches or takes my things	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
54. Doesn't know how to talk properly so I don't know what he/she wants or needs	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 get what they want.	1	2	3	4	5	1	2	3	4	5
56. Wakes me up early in the morning.	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

| 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. | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5 |

Appendix F

Sibling Consent Form

LaurentianUniversity
Université**Laurentienne**

Department of Psychology
Departement de psychologie
Tel/Tél.: 705-675-1151, 4250
Fax/Téléc. : 705-675-4889

I agree to participate in the research project entitled "Comparison of Sibling Relationships in Families of Children with Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder".

I understand that the goals of this research are to find out what it's like to live with a brother or sister who has been diagnosed with either Autism Spectrum Disorder (ASD) or Fetal Alcohol Spectrum Disorder (FASD). The study is looking only at siblings who are not diagnosed with ASD or FASD. If we can find out how siblings of individuals with ASD ir FASD are coping, services can be changed to better help brothers and sisters who have similar experiences. Therefore we can look to reduce the problems that are arising.

I understand that I will be asked to participate in an interview. This interview will take place either in my home or in a public place (i.e. library) and will last approximately one hour; with the chance of follow-up questions. During this interview I will fill out two questionnaires called Sibling Inventory of Behaviour and the Daily Hassles and Uplifts scale, which will take approximately 15 minutes to complete.

I understand that I do not have to participate in this study. I may stop participating at any time. I understand that the interview may bring up times in my life that were hard. I can choose not to answer any questions. If I feel uncomfortable, I can take a break or stop the interview. If I experience distress, support services will be provided to me.

I understand that all information collected will be used for research purposes only. I understand that my anonymity will be protected. Personal information collected during the study will be scanned or typed and encrypted for confidentiality purposes unless any abuse or neglect is reported. In this case the examiner will be required to contact Children's Aid Society. I understand that all consent forms, interview transcripts, audio recordings and questionnaires will be destroyed 5 years after the end of this project. I also understand that I will have a chance to look at my interview transcript to make sure it shows what I have said. If I want, I may receive a copy of the results at the end of the study (please check below).

If I have any questions regarding the purpose or nature of the study, I can call Shelley Watson, Ph.D. at XXXX or Tara Hughes at XXXX. If I have concerns regarding the ethics of the study, I may contact, Laurentian University Research Office, via telephone at 705-675-1151 ext. 3213, 2436, toll free at 1-800-461-4030, or email: ethics@laurentian.ca.

PARTICIPANT : _____   _____
                          (Print)   (Signature)
PARENT/GUARDIAN: _____   _____
 (6-16 years)   (Print)   (Signature)
DATE: _____

Name: _____   **Daytime phone number:** _____

Email address: _____

_____ I would like to receive a copy of the results at the end of this study