

**SIBLING RELATIONSHIPS IN FAMILIES OF CHILDREN WITH
AUTISM SPECTRUM DISORDER, DOWN SYNDROME, AND FETAL ALCOHOL
SPECTRUM
DISORDER**

by

Tara Hughes

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Hughes, Tara

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APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Shelley Watson
(Supervisor/Directrice de thèse)

Dr. Diana Urajnik
(Committee member/Membre du comité)

Dr. Daniel Côté
(Committee member/Membre du comité)

Dr. Monica Cuskelly
(External Examiner/Examineur externe)

Approved for the Faculty of Graduate Studies
Approuvé pour la Faculté des études supérieures
Dr. David Lesbarrères
Monsieur David Lesbarrères
Dean, Faculty of Graduate Studies
Doyen, Faculté des études supérieures

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Author's Note

The following thesis was completed in partial fulfillment of a Master of Arts degree in Interdisciplinary Health under the supervision of Dr. Shelley L. Watson. Please address any correspondence to thughes@laurentian.ca.

Tara Hughes

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Abstract

Background: Studies have shown that it is often a sibling who takes on the support and caregiving role in the life of a person with a developmental disability (DD) when the parent is no longer able to. However, very little research has examined how siblings adapt to their brother or sister with DD, specifically with autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), and Down syndrome (DS). Differences in the behavioural challenges posed by children with ASD, FASD, and DS are critical, and to the extent that those difficulties vary across diagnoses, differences in sibling reactions are possible.

Method: Siblings of children with ASD, FASD, and DS participated in in-depth qualitative interviews employing a basic interpretative approach.

Results: Thematic Analysis was used to analyze interview transcripts and three main themes were identified: Sibling Demands, Positive Transformational Outcomes, and Supports

Conclusions: Supports must be tailored to meet the specific needs of siblings of children with different types of disabilities

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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. As an integral part of the family unit, sibling relationships have been an underrepresented topic in the disability literature at large, and even more so for the autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), and Down syndrome (DS) populations (e.g., Meadan, Stoner, & Angell, 2010). 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 bond, typically lasting the longest in one's life (Angell, Meadan, & Stoner, 2012; Doody, Hastings, O'Neil, & Grey, 2010; Heller & Kramer, 2009).

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, much 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). Furthermore, despite the variability in sibling experiences reported in numerous studies, most research has tended to focus on "developmental disability" in general without addressing sibling adaptation in regards to a specific diagnosis associated with disabilities such as ASD, DS, or FASD. Because siblings may adjust differently based on the child's specific disability, it is important to examine developmental disabilities separately (i.e., ASD, DS, FASD, etc.) (Hodapp, Fidler & Smith, 1998; Mandlco & Webb, 2015).

1.1 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: ASD, mild, moderate or severe intellectual disability, attention deficit disorder, DS, 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 years (American Association on Intellectual and Developmental Disabilities [AAIDD], 2010), and is likely to persist throughout one's life, making its' associated impairments unique and significant markers that set DD apart from other disabilities.

1.2 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 that are expressed in conceptual, practical and social situations. Onset of these symptoms typically originates prior to age 18 years (AAIDD, 2013). 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 (i.e., mild, moderate, severe, and profound) and the

population studied (i.e., 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).

1.3 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong pervasive neurodevelopmental condition and is often associated with comorbid ID (i.e., IQ below 70; Karst & Van Hecke, 2012). Previous epidemiological research has consistently reported prevalence rates for ASD of 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 years, 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 the 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 (i.e., flapping and rocking), self-injurious behaviours (i.e., hair pulling), limited imagination and social repertoire (i.e., lack of imaginative play and empathy), and an inflexible persistence to routines and ritual (i.e. difficulties in dealing with change and managing transitions in everyday life; Rutter & Schopler, 1987). 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.

1.4 Down Syndrome

Down syndrome (DS) is the most common chromosomal condition that remains the single largest cause of ID (Sherman, Allen, Bean, & Freeman, 2007). DS is the result of a chromosomal abnormality and has an estimated incidence of 1 in 700 to 1000 live births worldwide (CDC, 2016; Cohen, 2005). In 95% of cases, DS, or Trisomy 21, is caused by the presence of a third chromosome 21 that is found in all cells (Bull et al., 2011; Cohen, 2005; Shin, Siffel, & Corre, 2010). The second form, translocation, affects approximately 4% of individuals with DS and develops when the extra chromosome 21 is “stuck” to another chromosome or attaches to chromosome 14 or 21. The remaining 1% of individuals with DS have a form called mosaicism, which occurs when only some cells have the extra chromosomal material (Bull et al., 2011; Cohen, 2005; Roizen, 2002; Shin, Siffel, & Corre, 2010).

Although phenotypes may vary, children with DS tend to display a variety of physical characteristics, such as a flat or depressed nasal bridge, poor tooth development, a protruding tongue, an upward slant of the eyes, epicanthal folds, small auricles and reduced rates of facial growth and size overall. Children born with DS are also inclined to having central hypotonia, manifested as decreased muscle tone and loose joints, resulting in delayed gross motor skills. As a result, individuals with DS are often unable to walk until the age of 4 years (Cohen, 2005).

According to the American Academy of Pediatrics (2011), children with DS are also more vulnerable to developing other health problems. Cardiovascular disorders are said to occur in about 50% of infants with DS (Bull et al., 2011), while many other children with DS may develop conditions such as gastrointestinal disorders, obstructive sleep apnea, epilepsy, and hypothyroidism (Bull et al., 2011; Goldberg-Stern, Strawsburg, & Patterson, 2001; Steingass, Chicoine, McGuire, & Roizen, 2011).

In addition to these health problems, most children with DS have mild to moderate ID, with IQ scores between 40 and 60 (Bull et al., 2011; Roizen, 2002). Other neurobehavioral disorders such as attention-deficit/hyperactivity disorder (ADHD), ASD, oppositional-defiant disorder (ODD), and disruptive disorder are also found to be more predominant in children with DS than in typically developing children (Capone, Goyal, Ares, & Lannigan, 2006). Problems with speech are also prominent, and many children with DS require speech therapy to assist with expressive (verbal) language (Bull et al., 2011; Cohen, 2005).

1.4 Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a spectrum of the conditions that result from prenatal exposure to alcohol, and is considered to be one of the most common non-hereditary causes of DDs in the Western population (Chudley et al., 2005; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Estimates on the prevalence of these disorders are relatively unknown due to past issues of diagnostic criteria; however, the most commonly cited estimate of individuals with FASD in Canada is 1 in 100 people, or approximately 1% of the population (Cook et al., 2016). 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).

Until recently, determining the true prevalence of FASD has been a challenge. Some individuals may lack the 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 undiagnosed (CDC, 2014; May et al., 2009; Riley, Infante, & Warren, 2011); however, since the publication of the last Canadian guideline for diagnosing individuals with FASD in 2005 (e.g., Chudley et al., 2005), research in this area has evolved significantly in hopes to prevent misdiagnoses (Cook et al., 2016).

According to the new Canadian guidelines, FASDs typically result in both central nervous system dysfunction and unique facial anomalies (Cook et al., 2016). The most observable effects of the exposure to alcohol are on the developing brain (i.e., cognitive and behavioural difficulties; Cook et al., 2016). 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).

Abnormal facial characteristics may include a thin upper lip, short palpebral fissures, and a smooth philtrum (Cook et al., 2016; Senturias, 2014). Although these facial features are possible, they are not always observed in individuals with FASD. Due to these issues, the new Canadian guidelines have introduced two criteria for the diagnosis of FASD: FASD with sentinel facial features and FASD without sentinel facial features. Thus, individuals who do not present facial features must therefore have evidence of neurodevelopmental impairments as well as a confirmation of prenatal exposure to alcohol (Cook et al., 2016).

A significant percentage of affected individuals will also display adverse outcomes, defined as secondary impacts, which arise as a result of the primary disabilities (i.e., substance abuse; Chudley et al., 2005). Because individuals may lack the visual signifiers associated with FASD, FASD itself 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 risks”, as an early diagnosis allows access to appropriate interventions and resources (Manitoba FASD Coalition, 2017; 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 challenges (Manitoba FASD Coalition, 2017; 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, can 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 has been demonstrated, an accurate diagnosis is a crucial component for the welfare of individuals with FASD, which has only recently been recognized.

When investigating sibling relationships, several theoretical frameworks of family functioning can be useful in understanding the various influences that can impact sibling's adjustment. Theory in family research can also help to conceptualize the processes that may be important for "bon-adaptation" (McCubbin & Patterson, 1987). Therefore, the following section describes the theoretical model informing this paper.

1.5 Theoretical Framework

The theoretical model informing this study is the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988; 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 (i.e., parents, siblings, grandparents). It is a two-phase interactional model, which proposes that families engage in processes to achieve homeostasis by meeting the demands of their environment (stress and strains) with the family's capability for handling those

demands (resources and coping). Given that the family is an interactive and interdependent system, the child's disability and the family's overall functioning are continually interacting.

Figure 1 below shows the FAAR model.

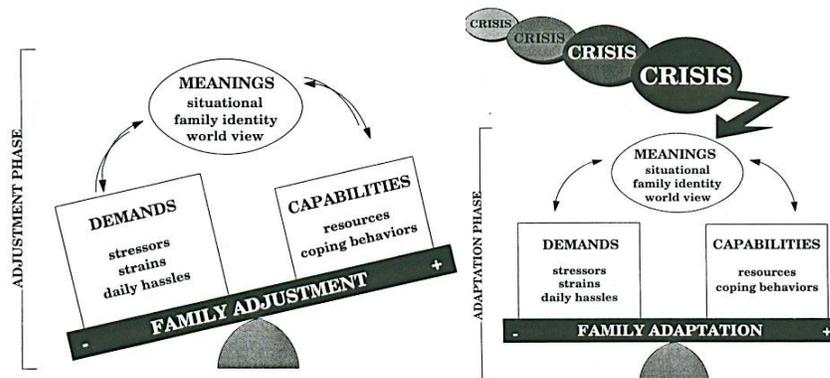


Figure 1. **The Family Adjustment and Adaptation Response Model (Patterson, 1988, 1989; Patterson & Garwick, 1994a, 1998)**

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. Families may use avoidance coping behaviours to deny or disregard the demands. Elimination strategies may be used to change or remove the stressor, and assimilation strategies are used to accept the demands into the family's existing patterns of interaction. These efforts may lead to successful adaptation; however, there are times when the family's demands exceed their capabilities and an imbalance persists. This imbalance often causes families to experience a 'crisis', which in turn causes disorganization in the family (Patterson, 2002). Although a crisis may cause disorder in the family, it may not necessarily be a negative event that precipitates disorder; a "crisis", 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 considered the outcome factor, which deals with the family's response to the crisis or transition and is geared towards re-establishing stability by making changes in the family structure and the patterns of interaction (i.e., rules, routines, relationships, roles, communication, and interactions with the community). Furthermore, this phase leads to family adaptation on a continuum from non-adaptation to maladaptation which is characterized by "a continued imbalance in family functioning" (Saloviita, Itälä, & Leinonen, 2003, p. 301).

The FAAR highlights three important concepts to adjustment and adaptation: demands, capabilities, and meanings. Each of the components of the FAAR model are described in detail as follows:

1.5.1 Demands: Stressors, strains, and daily hassles. Demands, as defined by the FAAR model, refer to all of the stressors, strains, and daily hassles that are experienced by family members, and 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 (i.e., guilt, shame) of having a child with a disability in the family (Patterson & Garwick, 1994a).

Strains, on the other hand, tend to be the unresolved 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 over time. Individual family members will vary in the ways in which they respond to the event that occurs in their lives (Ferguson, 2002), and what may be considered a stressor for one family could be considered a strain for another. An example of a strain for a sibling of a child with a disability could be the additional caretaking responsibilities that persist 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 important to emphasize that individuals will vary in how they respond to similar events that occur in their lives, and what may be a daily hassle for one person, may be a strain for another (Ferguson, 2002).

1.5.2 Capabilities: Coping and resources. According to the FAAR model, capabilities are defined by the way in which families utilize various tangible or psychosocial resources (i.e., what the family has) and coping behaviours (i.e., what the family does; Patterson, 2002). Similar to the three sources of demands, the FAAR model describes three potential sources of resources: individual family members (personal resources), the family unit (family resources), and the larger community (community resources).

Family resources may be at the individual level such as a family member's personality traits (i.e., good sense of humour, self-esteem and self-efficacy), knowledge, and skills acquired from education and experience, or their physical and/or emotional health. Siblings that grew up

with their brother or sister with a disability may have gained an abundance of knowledge from watching their parents raise the child, which may act as a resource and ultimately shed light on their experiences.

Resources may also be found within the family unit itself where decision making and conflict resolution skills arise. This is when families often talk to one another and combine their thoughts to create an ultimate solution for a problem. 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).

1.5.3 Meanings: Family world view, situational, and family identity. According to Patterson (1988), the way in which families balance demands and capabilities is mediated by how families interpret the events or ‘crises’ 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 developed 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 later events (McCubbin & Patterson, 1983). For example, siblings who are part of specific community organizations or sibling support groups may find shared meaning from expressing their personal experiences and various challenges they face as siblings. According to the FAAR model, three levels of meaning are important when considering family adaptation to stressful events: situational meanings, family identity, and family world view.

Situational meanings develop when family members talk with one another about the stressor or pile-up of demands, and their ability to manage them (capabilities). As this type of interaction occurs, new meanings are constructed (Patterson & Garwick, 1994b, 1998). For example, when a family discusses the child's diagnosis and how the disability will affect the family system, family members will interpret the event in their own unique way.

The second level of meaning is family identity. Family identity is an overall view or perspective about the family's relationships and functioning, and indicates how a family views themselves. At this level, family identities are more stable than situational meanings (Patterson & Garwick, 1994b, 1998). According to the FAAR, how a family defines itself is reflected by who is in the family, as well as how the family interacts and functions. Family identity is constructed through routines, roles, and rituals that are developed and maintained, as these sets of patterns provide a sense of stability for a family and can serve as an "anchoring point and a sense of balance when stressful events happen," (Patterson & Garwick, 1994, p. 6). It is thus through observation of these patterns that one may get an idea about a family's identity.

The third level of family meaning, family world view, involves the family members' orientation to the world outside the family unit and how the family members understand reality, their fundamental assumptions about their environment, and also existential beliefs (i.e., the family's purpose in life; Patterson & Garwick, 1994b, 1998). This level of meaning is the most abstract, and families are most often unable to articulate or describe their world view if asked. However, through qualitative research, questions may be tailored to gain insight on a family's world view (i.e., discussing how their sibling with ASD, FASD, or DS has impacted their lives).

In summary, the FAAR model demonstrates how families are able to adjust and adapt with the demands that they are faced with. When families have appropriate supports and resources, their ability to adapt is high, which allows the family to achieve homeostasis within the family system. If resources and coping mechanisms are not utilized or have not yet been implemented, families may experience an imbalance which in turn causes a crisis in the family. The FAAR model not only describes the different cognitive factors that may influence family adaptation with regards to raising a child with a disability, but also illustrates positive adaptation, and highlights the importance of utilizing appropriate resources when demands are high. Researchers have found that models like these are needed to understand the complex relationship between having a child with a disability and successful family adaptation, especially with regards to supports and intervention development (Manning, Wainwright, & Bennett, 2011). If researchers can determine where siblings of children with ASD, FASD, or Down syndrome struggle (demands), supports can be tailored to help lighten their experiences (capabilities).

1.6 Family Research

The impact of raising a child with a 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. Research findings 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 quality of life, family stressors, 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, DS, and FASD.

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, in which all longstay psychiatric institutions were replaced with less isolated community mental health services for those diagnosed with DD (Stroman, 2003), a majority of individuals with DD (60%) are currently living at home with their parents and caregivers (Abrams, 2009; Hodapp, Urbano, & Burke, 2010). As individuals with DD have been removed from these facilities, the reliance on the family to fill 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) are families in particular that are found to have poorer FQOL (Park, Turnbull, & Turnbull, 2002). Additionally, a study by Wang et al. (2004) revealed that the most significant predictor of FQOL was severity of the child’s disability. In contrast, families have also reported positive contributions that their child with DD has had on their quality of life, such as improved relations with family members and increased levels of patience and compassion (Kausar et al., 2003).

Family-Related Stressors. 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 (i.e., the severity of the disability; Baxter, Cummins, & Yiolitis, 2000). Raising a child can be stressful 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). 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 results of Sanders and Morgan's (1997) study of comparing stress levels in families of children with ASD, DS, and typically developing children. The findings 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 that 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 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 to having a child with DD (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 (i.e., increased awareness of inner strength, greater sense of satisfaction) as a result of parenting a child with a disability. In an interview study, Scorgie and Sobsey (2000) found similar findings in which parents reported many positive changes in their lives, such as personal growth, enhanced relations with others, and changes in their spiritual values. Within a FAAR framework, families that employ adaptive coping strategies are also reported to experience 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).

However, it is important to note that 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, DS, 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. Ultimately, as we will see, various disabilities present different

challenges and opportunities for families, which are discussed in further detail in the following sections.

1.6.2 Families of Children with ASD. ASD has been known 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 the 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 (i.e., FASD) or raising a typically developing child (Dabrowska & Pisula, 2010; Dumas, Wolf, Fisman, & Culligan, 1991; Hayes & Watson, 2013; Watson, Coons, & Hayes, 2013a). For example, when parents of children with ASD were compared to parents of children with DS, 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% 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 having a more severe disability and exhibit problematic behaviours (Abbeduto et al., 2004;

Hastings & Brown, 2002; Hastings & Johnson, 2001). For example, Brobst, Clopton, and Hendrick (2009) found a positive correlation 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 for those raising a child with DD (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 (i.e., 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 or the marital relationship. 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 remains high into the child's early adulthood because children with ASD often continue to live at home and therefore place high-levels of parenting demands (e.g., Smith & Elder, 2010) on caregivers, which often leads parents to continue to experience marital strain into their child's early adulthood (Hartley et al., 2010).

It is evident that research tends 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 (i.e., parents, friends, family) are reported to experience better psychological health than those with fewer social resources accessible to them (Benson & Dewey, 2008)

1.6.3 Families of Children with DS. Raising a child with DS has been described to have a substantial impact on the family system (Betz & Nehring, 2010). However, like many families of children with DD's, families vary in response to the presence of a child with DS. Where some studies reveal that families spend less time in social activities (Rodrigue, Morgan, & Geffken, 1992), have difficulties in pursuing careers and employment and may experience financial burden (Cuskelly, Hauser-Cram, & Van Riper, 2009), others have discovered positive adaptations, such as family growth (King et al., 2006) and resilience (Van Riper, 2007). The

biggest discrepancy in findings has mostly been found when families of children with DS are compared to other family types. When families of children with DS are compared to families of other types of DD's (i.e., ASD, fragile X syndrome), researchers tend to find that families of children with DS fare better (e.g., Hastings & Beck, 2004; Hodapp, 2007), whereas the opposite (i.e., poorer functioning) is found when compared to a sample of families without a child who has a DD (e.g., Sanders & Morgan, 1997).

When families of children with DS are compared to families of children with typical development, these families are reported to have higher instances of stress and anxiety than do families of typically developing children (Hodapp, 2007; Sanders & Morgan, 1997). For example, if the child with DS displays the behavioural phenotype that is considered to be typical of children with DS, families are more vulnerable to increased stress levels (Fidler, Hepburn, & Rogers, 2006; Hastings & Beck, 2004). Furthermore, if the child has comorbid psychiatric conditions that are often found in children with DS (i.e., ADHD, ODD), it often enhances the risk of externalizing behaviours (i.e., impulsivity, inattention, stubbornness) and internalizing behaviours (i.e., social withdrawal; Feeley & Jones, 2006). Because children with DS are also at an increased risk of developing a number of health conditions, they often require extra medical care than children with typical development, in which parents must devote extra time to their child with DS (Schieve, Boulet, Kogan, Van Naarden-Braun, & Boyle, 2011). As a result, families of children with DS have reported less family participation in social activities, experience dissatisfaction with caregiving roles, and have greater financial burden when compared to parents of typically developing children (Cuskelly, Hauser-Cram, Van Riper, 2009; Rodrigue et al., 1992; Sanders & Morgan 1997).

In a study examining stress and adjustment in parents of children with ASD, DS and typically developing children, Sanders and Morgan (1997) found that compared to families of children without a disability, families of children with ASD and DS had higher levels of stress. The mothers in this study were particularly more stressed, and had reported that most of their time was directed to the child with DD and less time with other family members. However, when the parents of children with ASD and DS were compared, parents of children with DS were found to experience less stress. Similarly, in a study looking at parental perceptions, stress, and involvement in parents of children with DS compared to parents of other types of IDs, results indicated that parents of children with DS have higher levels of well-being (Ricci & Hodapp, 2003).

When families of children with DS are compared to families of children with DD, they are reported to have a “DS advantage” (Seltzer & Ryff, 1994; Hodapp, 2007). The DS advantage refers to the consistent findings that when compared to families of other types of DDs, families of children with DS experience lower levels of stress (Griffith, Hastings, Nash & Hill, 2010), feel more optimistic about their child’s future (Fidler, Hodapp, & Dykens, 2000), and have more satisfying and harmonious family relationships than do families of children with other types of DDs (Abbeduto et al., 2004; Urbano & Hodapp 2007). It is important to note, that not all results support this expectation, but a majority of the literature does favor the DS advantage (Esbenson & Seltzer, 2011).

In summary, the literature on families of children with DS suggests that the whole family structure can be altered in both positive and negative ways by a child with DS. Like any other family, families of children with DS experience a mix of hassles and uplifts, displeasures and

gratifications, and stresses and growth. It has been shown that parents of children with DS have overwhelmingly reported love for their child with DS, and do not have any regrets for their birth (Skotko, Levine, & Goldstein (2011), which is why future research should emphasize the positive adaptations and not dwell on the negative aspects of family life. Despite a wealth of literature on families of children with DD, ASD, and DS, limited research has examined families of children with FASD.

1.6.4 Families of Children with FASD. Compared to other types of DDs, such as ASD, DS, and Fragile X syndrome, there are very few studies that have 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 et al., 2013a). The primary and secondary risks 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 (i.e., hyperactivity) and internalizing (i.e., 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 (i.e., 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 challenges associated with FASD contribute significantly to parental stress.

Additionally, if the child's diagnosis is unclear or uncertain, families of children with FASD are suggested to experience higher instances of stress. (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 (i.e., 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).

1.7 Sibling Research

In addition to parents, siblings are also reported to be negatively affected (i.e., 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), 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 research in these areas or themes are summarized below.

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.

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 DS, and 20 siblings of children with typical development. Results revealed that the three groups were similar in their ratings of the frequency of stressors, yet each sibling group reported different sources for their stress. For example, siblings of children with ASD reported that their sibling's behaviour was the major source of their stress, while siblings of children with DS reported that additional caretaking responsibilities

accounted for their stress, and siblings of typically developing children reported that verbal aggression was the most stressful event in their relationship.

In regards to self-concept, 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 that suggest 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 brother or sister 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 wellbeing 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, DS, 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 (i.e., quantitative or qualitative), control-contrast groups (i.e., ASD vs. DS), different outcome measures (i.e., adjustment measures), and type of informant (i.e., parents vs. sibling). Variations in other factors (i.e., family environment or severity of the disability) may also explain the mixed results related to the siblings' relationships (Angell et al., 2012).

Studies investigating sibling's behaviours, either externalizing (i.e., aggression, tantrums) or internalizing (i.e., anxiety, withdrawal), have also yielded inconsistent results. While a number of researchers have found no differences in behaviour problems between siblings of children with DD and those without (e.g., Kaminsky & Dewey, 2002), others have found greater levels of behaviour problems for those with DD 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 also 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; Roeyers & 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 had more positive sibling relationships.

In summary, siblings of children with DD describe both positive and negative aspects of their sibling relationship. Researchers have reported mixed findings on sibling self-concept (Ayres, Cooley, & Dunn, 1990; Dyson, 2003), psychosocial adjustment (Kaminsky and Dewey, 2002), behaviour problems (Hastings, 2003); and the quality of sibling relationships (Kaminsky & Dewey, 2001; McHale & Gamble, 1989). Furthermore, living in families with higher SES, being older than the affected sibling, and having a sibling with a less severe disability, have been

shown to be indicators of a positive sibling relationship in families of children with DD (Hastings, 2003; Kaminsky & Dewey, 2002). In the following sections, sibling experiences are discussed in regards to their specific disability (i.e., ASD, DS, and FASD)

1.7.1 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 has 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 depression and poor self-concept (e.g., Gold, 1993). In contrast, some researchers reported that children experience positive effects, such as having higher levels of self-concept and personal growth by having siblings with ASD (e.g., Pilowsky 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 the psychosocial and emotional adjustment of 51 siblings of children 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 have spoken with pride in regards to teaching their sibling with ASD, and are often found to score higher on self-esteem (Milevsky, 2005), empathy (Benderix & Sivberg, 2007) and maturity measurements (Smith & Elder, 2010). In a study by Kaminsky and Dewey (2001), siblings of children with ASD reported greater admiration for 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, 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 effective 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 (i.e., 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 emphasized 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 DS 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 (i.e., spending less time together) of children with ASD compared to families of children with DS. 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).

1.7.3 Siblings of Children with DS. Although there have been many studies suggesting that siblings of children with DS may be negatively affected by having a brother or sister with DS (e.g., Cuskelly and Dadds, 1992), recent studies suggest that siblings are in fact more inclined to be positively impacted (e.g., Bagenholm & Gillberg 1991; Hodapp, 2007; Kaminsky & Dewey 2001; Orsmond & Seltzer, 2007, Skotko & Levine, 2006). When reviewing the

literature, most studies have tended to dwell on the negative effects of having a sibling with DS and have mostly focused on adjustment and behavioural problems, stress, and the overall relationship in the sibling dyad (e.g., Cuskelly & Gunn 2006; Kaminsky & Dewey, 2001). However, when compared to siblings of other types of DDs (i.e., ASD and fragile x syndrome), and typically developing children, siblings who have a brother or sister with DS report having closer sibling relationships (Bagenholm & Gillberg 1991; Kaminsky & Dewey 2001), describe spending more time with their sibling (Knott, Lewis, & Williams, 1995), less conflict and more warmth in their relationship (Fisman et al., 2000), feel more understanding for their siblings (Hodapp and Urbano, 2007), and are more optimistic about their brother or sister's future (Bagenholm & Gillberg 1991; Orsmond, 2007).

Skotko and Levine (2006) suggested that although siblings of children with DS experienced a range of emotions, the positive emotions typically outweigh the negative, and siblings often describe their journey as one filled with pride and joy. In a larger cross-cultural study, Skotko et al. (2011) collected data from 822 siblings of children with DS. Skotko et al. (2011) administered questionnaires that measured siblings' feelings toward their brother or sister with DS, as well as how having their sibling in their life has directly impacted them. The researchers found that the majority of siblings expressed feelings of pride and love for their sibling with DS, while only 10% had negative feelings toward their sibling (i.e., feelings of embarrassment), and less than 5 % expressed their sibling as a burden (Skotko et al., 2011). They also found that siblings felt that having their sibling in their life was an enhancing and positive experience, as siblings reported being able to develop compassion and personal growth.

Researchers have also suggested that there are significant differences between siblings of children with DS when compared to siblings of children with other types of DDs. In a study comparing the psychological adjustment of siblings of children with ASD, DS, and typically developing children, Kaminsky and Dewey (2001) found that siblings of children with DS reported significantly higher levels of admiration, closeness and nurturance compared to the other two sibling groups. Furthermore, siblings of children with DS were found to be more prosocial towards their sibling and did not exhibit internalizing behaviour problems as compared to the other two comparison groups (Kaminsky & Dewey, 2001).

Cuskelly and Gunn (2003) also found a trend toward more positive interactions within the sibling dyad if siblings of children with DS were compared to siblings of typically developing children. In their study comparing 53 siblings of children with DS with 53 siblings of typically developing children, Cuskelly and Gunn (2006) found that having a sibling with DS did not have an impact on the likelihood of developing future adjustment problems. They also found that siblings of children with DS had higher levels of empathy and kindness towards their sibling with DS (Cuskelly & Gunn, 2006).

Although the literature on siblings of children with DS tends to dwell on sibling maladaptation, it is evident that siblings of children with DS are more prone to having a pleasant experience, whether they are compared to siblings of children with other types of DDs or typically developing children. Siblings of brothers and sisters with DS have reported feelings of warmth (Cuskelly & Gunn, 2006), less conflict with their sibling (Fisman et al., 2000), and an overall pleasant sibling experience (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007).

1.7.4 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). Because siblings are often shown to support the child when the caregiver is no longer able to, it is particularly important to expand further research. A primary aim of this current study is to contribute to the FASD family literature and how having a child with FASD compares to other disabilities.

1.8 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, FASD, and DS. 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 DS, and to the researcher's knowledge, no studies examining sibling relationships in families of children with FASD.

The few studies that have examined the lived experience of siblings of children with ASD and DS 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 examine the overall adjustment of siblings of children with ASD, DS, and FASD by way of a qualitative research design. In addition to exploring the lived experience of having a sibling with ASD, DS, and FASD, the researcher sought to determine if there are any similarities or differences in the lived experiences of the three types of siblings, and if there are any differences within the three types of siblings based on what they report in terms of psychosocial adjustment, relationships, hassles and uplifts.

1.8.1 Research Questions. Following the main purpose of this study, to compare sibling relationships in families of children with ASD, DS, and FASD, the following research questions were addressed:

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

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

1.9 Reflexivity

A fundamental underpinning of qualitative research is the process of reflexivity (Finlay, 2002). In order to be self-reflective, one must demonstrate “thoughtful, self aware analysis of the intersubjective dynamics between [the] researcher and the researched” (Finlay & Gough, 2003 p. ix). Without reflexivity and self-examination, there is a risk of generating research that contains personal preconceptions and biases (Finlay, 2003). However, rather than eliminating these subjectivities, Merriam (2002) proposes that we as researchers must identify our biases, and monitor them in order to accurately collect, shape, and interpret our data. Thus, reflexive tools have been used in the current research. The following is a description of my personal and professional experiences, and how they may have influenced the conclusions made in this research.

Over the past six years I have been involved in the field of disabilities as a student, volunteer, and employee. I have volunteer experience as an educational assistant in a life skills classroom, and have worked as a behavioural counsellor at a drug and alcohol rehabilitation center for youth. In these roles, I worked with individuals with a variety of different diagnoses (i.e., ASD, FASD, DS, ID, and physical disabilities), and created programs, presented lessons, and assisted with their individual needs.

Throughout my entire life I have always found myself helping individuals with varied needs. As early as my elementary years, I made fast friends with a young girl who was blind. At that time, I spent a majority of my free time accompanying this girl. Little did I know that

friendship, and helping her with everyday tasks and school work, would ultimately fuel a deep desire to help people in need. During high school, my volunteer hours were spent organizing events for life skills classrooms, organizing daily breakfast clubs and I have also received credit for peer tutoring in an applied classroom designated for providing assistance to teens with ID/DDs. Unbeknownst to me, it appears, I had developed and began to nurture a strong desire to work with individuals with special needs.

However, it was not until after high school when I opted to take a two-year hiatus from education that a true appreciation evolved of where I wanted to develop my life career goal. This was a time when I really did not know what to pursue. A time when I truly began to think of behavioural sciences as an ultimate goal. During the summer of 2012 I realized working with individuals with DD has and always will be a passion of mine. Not long after thinking this through, I applied to enter the Developmental Services Worker (DSW) program at Cambrian College. As reflected in my grades, I thoroughly enjoyed this program as it helped me gain a heightened awareness of my passion for this field.

My first true introduction to the behavioural arts came in an applied behaviour analysis (ABA) class I took in the DSW program. As I listened to a guest speaker enlighten us about his chosen career, I was captivated by his enthusiasm and compassion for the people he assisted. Keeping this career option in mind, I continued with my studies. It was not until my last week of college that my professor pulled me aside and mentioned that I should further my education in this particular field. It was mentioned with a clear admonition that it may be something I should consider and pursue. Later that evening, I did some research and knew that this was something

for me as the fit with my growing desire was seemingly a perfect match. That spring, I applied for acceptance to the Honours Psychology program at Laurentian University.

The subsequent years spent pursuing my bachelor's degree was the most pivotal period of my life, and it has significantly helped me both shape and understand my chosen career path. While there have not been many courses offered in the psychology program directly related to my field of interest, I thought that doing research in the field would perhaps keep me motivated and open new doors. In fact, during my first couple of weeks at Laurentian University, I did some research on the faculty members in the psychology department which subsequently led to my meeting Dr. Shelley Watson. I recall telling her at that time that in my final year, "I want to write my Honours thesis under your supervision as I want it to be related to disability studies".

Three years later, I found myself in her office discussing potential thesis topics. Dr. Watson had mentioned to me that she would like for me to be a part of her large and ongoing research project examining the experiences of families raising children with various DDs, mainly ASD and FASD. I thought this would be an excellent idea, as I was familiar with both disabilities through my work and volunteer experience. I did a review of the literature and thought that it would be interesting to examine the sibling experience. Little did I know, much research was needed in this particular field which led to the approval of this topic. This then began my first mixed methods study looking at the overall lived experiences of siblings of children with ASD and FASD.

Having worked in the field prior to this research, I always viewed families of individuals with DD through a conflicting lens. Looking back, I feel like I used to think that being a sibling was a bright and positive experience. It was not; however, until I conducted interviews with

individuals with FASD that I realized that there were many challenges that siblings face. I was not aware of the difficulties that siblings of children with DD go through, and this was something I had to accept, particularly when interpreting the data. Since then, I have continued my interviews with an open mind, and although many siblings did speak to the positive aspects, I was able to balance my perspective as a researcher.

To this day, I am still fortunate to be involved with Dr. Watson's ongoing research project in my master's research, to which I have now added a third disability type or group of siblings (i.e., DS). One of the reasons for choosing DS as my third study group is because I have worked with many children with this diagnosis, and I also have a two-year-old sister with DS. As a sibling myself, I will describe my personal experience in the following section.

1.9.1 Navigating the researcher-participant relationship. It is significant to mention that when I began this study, I was not yet a sibling to a child with DD. My perspective on being a sibling to a child with a DD ultimately comes from the knowledge I have gained through the literature and my own personal experience working with individuals with various DD. My sibling with DS has also yet to reach her primal toddler years, meaning that I have yet to perhaps experience some of the events that the current participants have expressed to me in their interviews. During the interviews, siblings did however, discuss some of the health issues which I could relate to my personal experience. My sibling with DS had been in the hospital for the first three months of her life which was a very difficult time. Hearing the emotions and concerns from the siblings did spark an emotional response at times. Furthermore, I did not share with the siblings that I had a sister with DS as I did not want to influence their experience.

On the other hand, siblings did discuss many uplifting memories and experiences in which I felt excited for my upcoming journey as a sibling. While listening to their stories, the siblings said overall their sibling has been the best thing to ever happen to them which made me feel a sense of pride and relief. Thus, while conducting the interviews, I attempted to bear in mind the fact that siblings do face significant challenges and that it is not always a happy-go-lucky experience. I remained as open minded as possible and listened to the siblings in this research as they described their experience because ultimately they were the experts of their lives.

Overall, I found the process of navigating the researcher-participant relationship to be challenging at times. Specifically, learning about interviewing and actually conducting the interviews is something that was new to me, which was an ongoing educational process. I was also encouraged by Dr. Watson to keep notes of my own emotions as well as my perception of the siblings' emotions. While analyzing the interviews, I also made notes of why I chose particular themes and subthemes, and often questioned myself about why I chose to use certain quotes in the final product. By keeping this open mind and letting siblings tell their story, during both the collection and analysis of the interview data, and I am so grateful for this wonderful experience. The following section will now discuss the methodology and methods I have chosen and utilized in the current study.

CHAPTER TWO: METHODOLOGY AND METHODS

As part of a larger, ongoing study examining the experience of families of individuals with DD (Watson, Coons, et al., 2013; 2016), this study employed a qualitative research design specifically studying the siblings' experiences. To gain a better understanding of their experience, siblings participated in in-depth semi-structured interviews informed by a basic interpretive approach (BIA; Merriam, 2002). The BIA allows researchers to explore the personal experiences of individuals, how they make sense of their subjective reality, and how they attach meaning to it. Due to the exploratory nature of the current study, using an inductive approach allowed the researcher to generate concepts on the sibling's experiences and make generalized conclusions on how these siblings try to adjust and adapt to their brother or sister with DD.

2.1 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. A total of 33 siblings participated for this thesis; 14 siblings with a brother or sister with ASD, 12 siblings of children with FASD, and 7 siblings who have a sibling diagnosed with DS. In order to protect participant confidentiality all participants in this study will be referred to by pseudonyms. Table 1 below shows the demographic characteristics of the participants (see Appendix A for the study demographic questionnaire).

Table 1

Participant Demographic Characteristics

Demographic Characteristics	
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Characteristics of siblings of children with ASD (<i>n</i>)	14
Average age (<i>SD</i>)	25.91
Age range	11-43
Relation to child with disability Biological (<i>n</i>)	14
Adoptive (<i>n</i>)	-
<hr/>	
Characteristics of siblings of children with FASD (<i>n</i>)	12
Average age (<i>SD</i>)	20.33
Age range	10-37
Relation to child with disability Biological (<i>n</i>)	-
Adoptive (<i>n</i>)	12
<hr/>	
Characteristics of siblings of children with DS (<i>n</i>)	7
Average age (<i>SD</i>)	26.88
Age range	16-39
Relation to child with disability Biological (<i>n</i>)	7
Adoptive (<i>n</i>)	-
<hr/>	

2.2 Qualitative Interviews. Following a basic interpretive approach (Merriam, 2002), semi-structured interviews were conducted with siblings of children with ASD, FASD, and DS. 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 (see Appendix B for a full version of the semi-structured 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 closed-ended questions were asked. As part of a larger ongoing study, the interviews were administered by three other researchers, including the lead researcher, and two other graduate students. I personally conducted 17 complete interviews and corresponding batteries of questionnaires to the larger project. Further, interviews were completed either by telephone, Skype or in-person. If the siblings were located within reasonable distance (i.e., in Ontario), interviews took place in-person at locations agreed upon by both the participant and the interviewer (i.e., the participant’s home). The interviews took approximately 20 and 45 minutes to complete.

2.3 Analysis of Interviews. The semi-structured interviews were analyzed using Thematic Analysis, whereby researchers search for recurrent patterns of meaning across a data set (Braun & Clarke, 2006). 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. In addition, an audit trail was kept to keep track of the phases of research and all the decisions that were made with regards to the research design, data collection, and the steps that were taken to manage, analyze and report 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 interviews were analyzed multiple times 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 were developed, inferences were made and the data were summarized. Finally, a member check was also conducted during the analysis of interviews to ensure the accuracy of the themes, and if they were representative of the participants' experiences.

2.4 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. Informed consent was obtained from participants and because this study also involved children, the parents of the children were provided with information about the study and were asked to sign the consent form if the child was under the age of 16 years (see Appendix C 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 in discussing particular questions. Ethics approval for this study was obtained from the Laurentian University Research Ethics Board (see Appendix D).

CHAPTER THREE: RESULTS

The results of the semi-structured interviews yielded a number of similar, yet unique experiences as articulated by the siblings of children with ASD, DS, and FASD. Although the siblings mentioned positive transformations such as sibling growth, patience and acceptance, they also discussed several challenges associated with have a sibling with ASD, DS, or FASD. During the interviews, siblings also identified a number of formal supports that have helped and that could help them cope with the challenges they face as a result of their experience. Through the Thematic Analysis (Braun & Clarke, 2006)., three main themes were identified from the interviews. These themes included sibling demands, positive transformational outcomes, and supports (i.e., sibling support groups). Each of these themes is discussed in further detail, and illustrative quotes are used to demonstrate each theme.

3.1 “It’s hard”: Sibling Demands

Siblings discussed several challenges associated with having a sibling with either ASD, DS, or FASD. The interview analysis revealed some similarities as well as some vast differences regarding what siblings found most difficult in their experiences. Siblings of children with ASD, DS, and FASD found that the most difficult parts were the extra responsibilities with regards to caring for their sibling with DD as well as other people’s opinions and judgments of their sibling. Additionally, siblings also expressed that they often found themselves worrying about the welfare of their sibling’s future. These feelings of worry were expressed in different ways by the three sibling groups; the siblings of children with FASD described the secondary challenges that arise in children with FASD as something that they worry about, whereas siblings of children

with DS tend to worry about their sibling's health issues and siblings of children with ASD worried most about their siblings not being able to do what they love to do.

3.1.1 “I don’t always want to be the one that... takes care of him”: **Extra responsibilities.** During the interviews, all siblings made it clear that it is difficult having to take on extra responsibilities because of their brother or sister with DD. Most siblings of children with ASD, DS, and FASD reported being involved in several caretaking roles, including responding to their siblings’ physical and emotional needs, taking care of their brother or sister when their parents were away, and teaching their sibling skills or appropriate behaviours, such as learning to make breakfast or learning to control tantrums. While all three sibling groups expressed having to take on these additional tasks at some point in their lives, interview findings revealed certain differences regarding what participants found to be the most challenging.

Siblings of a child with DS, for example, found that there was a lot of pressure from their parents to take on extra household tasks, such as cooking, as well as taking care of their brother or sister when their parents were busy. Nineteen-year-old Sara spoke to the fact that she often had to be more grown up for her age and that her parents expected much more from her compared to her sibling with DD. To demonstrate, Sara said that her parents would often push her to take care of her brother and said that they would often tell her to “go hang out with [her] brother, [and] go do things with [her] brother” and she simply “didn’t want to”. As Sara elaborated:

It’s kind of hard at times because it’s like I... feel like I have to be a grown up more because I... have to help my parents take care of him. I hated it because I don’t want to be the one that always takes care of him... I felt really pressured.

Twenty-eight-year-old Samara also said that because of her brother with DS' "health issues" he "can't be left alone all the time", which required Samara to help her parents to take care of her brother if needed. Because her sibling was unable to be alone, Samara and her siblings were often having to regularly "change [their] schedules to accommodate for each other," which was not necessarily a strain or stress to Sam but a daily hassle, as it often conflicted with her daily plans. For example, Samara said that if one of her sibling's had to "go out," one would have to stay behind to watch their brother with DS.

Similarly, siblings of children with FASD also elaborated on the ways in which they had to be more responsible and independent. For example, Mary, a 37-year-old adoptive sibling to a child with FASD said that she and her typically developing sister would often have to take care of her two siblings with FASD because "neither of [her siblings] are self-sufficient" and that it was "an additional burden." Mary explained that she felt as though she had to be "the more responsible, mature, capable" one... since she "[isn't the one that has] organic brain damage." Mary said that it was also difficult being a sibling because she felt that her brothers and sisters could never return the favour, and that it was very "stressful having two members of the family taking a lot more than they can give to you." Similarly, Jason, a 29-year-old adoptive sibling to a child with FASD, said that because his parents "put most of their energy into [his sibling]," he became more "self-sufficient," as he often had to do things on his own growing up (i.e., getting himself ready for school). Siblings found that because of growing up independently, they had become much more mature as adolescents, which was something they described as unfair and lonely.

Siblings of children with ASD, on the other hand, described their experiences with extra responsibilities as a challenge because of their sibling's autism symptoms (i.e., aggressive behaviours). Participants said that because their sibling would often require constant care and supervision due to their behaviours, that they would regularly have to babysit and tend to their sibling. For example, Jenna, a thirty-two-year-old sibling to a child with ASD said that because her brother needs 24-hour supervision, she noticed that her “parents were burning out,” and unable to tend to their child with ASD, and she eventually “took [on] a lot more responsibility.” Although Jenna offered to help, she had described this time in her life as “challenging,” as she felt less like a sibling and more like a parent. In fact, Jenna had stated that because her brother was so used to her parenting him, he started to “resist [her] support and interaction... to the point where [she] couldn't eat dinner upstairs with everybody.” Ella, a 24-year-old sibling to a child with ASD, also had a similar experience, and said that because she had to “take care of [her brother] a lot of the time” it had “shift[ed] the[ir] dynamic,” as she feels that she is playing the older sibling role, and does not feel like the younger sibling. Ella believes that the older sibling should be the more responsible sibling, and that the younger one should be looking up to the eldest, which in Ella's relationship is not the situation. Thus, it appears that Ella is struggling determining her ‘family identity’ as described by the FAAR model (Patterson & Garwick, 1994), in which she feels that she is now playing the role of her parent.

Therefore, all three sibling groups have identified similar yet distinct challenges associated with the additional caretaking tasks and responsibilities of having a sibling with DD. Most siblings of children with DS and FASD said that they had to be more independent growing up, while siblings of children with ASD spoke to the strains with regards to supervising and

managing their sibling's aggressive behaviours. Although siblings mentioned the difficulties associated with the extra caretaking responsibilities, many siblings also expressed concerns with the community and their opinions, which are discussed in the next subtheme.

3.1.2 “They didn’t understand”: Awareness of disabilities. Many participants in the ASD, FASD, and DS groups perceived there to be a lack of knowledge and awareness of DDs, and felt that individuals in the community tended to have negative impressions of their brother or sister. All three sibling groups were similar in this aspect and vocalized that it was hard growing up having other people constantly staring at them when they were in public, or making rude comments to them in regards to their siblings problem behaviours. Some participants 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 they described as humiliating. Linda, a 26-year-old sibling of a child with ASD, said that the “difficult part would be not so much her sibling with ASD but dealing with other people and how they view her or look, stare... because not everyone understands.” Because of this lack of understanding and negative opinions of other people, siblings experienced a range of emotions, such as often being angry, embarrassed or irritated towards others. Siblings expressed these emotions in a number of situations, for example, Santana, a 15-year-old sibling to a child with FASD spoke to being out in the community with her sibling. Santana had said that it was a “little awkward” when her sibling “goes in public and makes a tantrum” because “people star[ed] at [her]”, which made Santana feel uncomfortable in the community.

Siblings of children with FASD found that because their siblings look “normal”, individuals in the community have trouble comprehending that their sibling has organic brain

damage. Participants in the FASD group described that many times, people in the community would comment on their sibling's behaviour and tell them to "control" it, not realizing that their brother or sister has a disability. For example, 22-year-old Beth, an adopted sibling to seven children with FASD said "my siblings present normal, which causes a lot of issues...[people] are just oh... you're just not a good family." Beth said that because she and her parents need to be strict with all of her siblings, that people think her family is "harsh" and "abusive." When asked how she reacts to these comments, Beth said "a lot of frustration" and said that she "often take[s] it upon [herself] to educate people" by explaining her sibling's disability, in order to reduce these negative judgments.

Furthermore, Lee, a 28-year-old adoptive sibling to six children with FASD, said that having to always explain her siblings' disorder to others often made her feel irritated and angry. These feelings of frustration often occurred in situations where Lee believed that children at school were displaying discriminating behaviour towards her siblings with the disability, such as making fun of her siblings 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... they thought that... I mean they used the word retarded all the time... They're not retarded!"

Siblings of children with ASD also described negative judgments towards their families; however, participants in the ASD group spoke more to the negative comments coming from their own friends and extended family, and not the community. Siblings of children with ASD often said that their friends and family did not know how to react around their brother or sister due to

the lack of knowledge, which was “embarrassing” and “awkward” at times. For example, Marissa, a 26-year-old sibling to a child with ASD said:

When my friends would come over from school... they didn't know how to react to [my brother] because he [would] jump all over the place and make strange noises... they would just act awkward around him because they [didn't] know [how].

Twenty-two-year-old Julia described similar experiences, and said that some of her family members “don't necessarily get it” and that “they think it's weird [her brother with ASD] acts a certain way.” Most siblings of children with ASD said that they would have to constantly explain their sibling's disorder, and it was frustrating having to do so. They said that regardless of how many times they explain, they would still not understand. Even after explaining their siblings' behaviours, some participants still struggled with erroneous judgments, which had even led a lot of siblings to withdraw from the public (i.e., staying in their room all day), as they did not want to be around people with negative attitudes or deal with judgmental comments. In fact, one sibling of a child with ASD said that he only enjoyed going to social events if there were events that were specifically for children with ASD. He said that this experience would be more pleasant for him because there were other people of the same type of disorder and that there would not be other people staring who were not familiar with ASD. Noah, a 14-year-old sibling elaborated, “we normally go to the movies when there's an autism event. So it's okay, there's not other people that are staring. It's a little but more calm...[than] if we were with normal people”

Siblings of children with DS, on the other hand, said that because of their sibling's facial phenotypes, people in the community treated them differently and at times would even reject them from restaurants and stores. As Sara elaborated:

I hate seeing people stare and... a lot of times we'll go to McDonalds or Tim Horton's and people refuse to serve him... I won't go there because I went with my brother when he came to visit and [the employee] said 'I'm not serving a retarded kid.'"

Brenda, a sibling to a child with DS, also said that when she would be at a restaurant, servers would ask her what her sibling wants to order, not understanding that her sibling could order himself. This reaction from the community caused a lot of frustration for siblings of children with DS as they, like anyone else, believe that their siblings should be treated with respect regardless of their disability. Most participants in the DS group said that because people were not treating them properly, that they would have to be their sibling's voice, and speak up when people were not treating them appropriately. Brenda elaborated:

My biggest thing is that I'm always on the lookout that everybody is treating him well because there are so many people out there in the general public that I find aren't educated about Down syndrome and other disabilities... I will speak up if I see anything that's not kind or... if someone's staring...that's probably the biggest thing that frustrates me.

As can be seen, siblings noted that people often make quick judgments with regards to their siblings' behaviours. Although siblings described many times to find it frustrating having to constantly explain their siblings disorder to peers, it is clear that they would like the community to be more informed and understanding of their sibling's condition. In the next subtheme, siblings discussed further challenges, specifically concerns about their brother or sister's future.

3.1.3 “The hardest part is sort of thinking about the future and thinking about what life is going to be like for him”: Concerns about sibling’s future. Although siblings mentioned the extra responsibilities and other people’s opinions to be difficult, all three sibling groups spoke about how they would constantly worry about their sibling’s future. These feelings of concern were expressed in a variety of ways for siblings of children with ASD, DS, and FASD. For example, siblings of children with FASD described the secondary challenges that arise as something they frequently worry about, whereas siblings of children with ASD and DS found their siblings’ health issues to be their biggest concern.

During the interviews, siblings of children with FASD said that they were constantly concerned about their sibling’s future in terms of their secondary challenges (Manitoba FASD Coalition, 2017; Streissguth et al., 1996; 2004). Specifically, siblings described the violence, addictions, and problems associated with the law as something they feared. Because many siblings had already observed their brother or sister’s delinquent activities over the years, participants in the FASD group expressed being worried that these behaviours would lead to jail time. Lee, an adoptive sibling to seven children with FASD stressed: “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 stated that it was frustrating because being concerned all of the time 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?”

Participants in the FASD group also stated that some of the issues around illegal behaviour were often caused by their sibling’s tendency to hang out with the “wrong crowd”.

Lacy, a 19-year-old adoptive sibling, identified her sibling's social activities as particularly alarming:

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.

Given the daily hassles and stressors siblings of children with FASD are faced with, participants continually worry and stress if their siblings will ever be able to live on their own. For example, when asking Mindy what she worries about, she replied

I really fear for the financial implications like how will he have a roof over his head? He's very much at risk of being homeless and the psychological implications of him not being able to do that work anymore. He's a fairly high-functioning alcoholic, so what happens when the high-functioning part goes away and all that's left is the alcoholic part? I don't think that will turn out well.

Siblings of children with ASD, on the other hand, discussed worrying about issues such as their sibling being alone, and not being able to do what they want to do in the future. For example, Anna, a 19-year-old sibling to a child with ASD said that because her sibling has a lot of health issues, such as seizures, she is unable to do a lot of things on her own. She stated: "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." It was evident that Anna was emotional during this statement, as she seemed truly concerned that her sibling would be by herself and depressed in the future. Julia, a

21-year-old sibling to a child with ASD, also said that she worries a lot about her brother not being able to do the things that he loves such as travelling, which is something he always wanted to do. 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 worry about.”

Finally, siblings of children with DS discussed their brother or sister’s health problems as being an ultimate concern. Most participants in the DS group spoke about their sibling being in the hospital many times, and often fear that they may not survive. Brenda said that “it’s scary when he goes to the hospital because you never know what’s going to happen. He’s had a lot of times when his heart actually stopped and they’ve had to resuscitate him”. Suzanne also discussed her brother being in the hospital many times and said “I hate that I’m worried beyond belief. Watching my brother in a hospital bed time after time... that part is obviously awful and I wouldn’t wish that on anyone.” During the semi-structured interviews, it was very evident that siblings had a difficult time speaking about their siblings’ health issues, as they expressed a lot of emotions such as sadness and distress when discussing these specific concerns. Some siblings even teared up, as they often feared the worst. As Samara stated: “...the older you get...you realize [death]...is a possibility. That was always hard.”

As can be seen, all three sibling groups experience similar challenges but have distinct differences in some areas. Specifically, it appears that siblings of children with DS and FASD have difficulties with the pressures from their caregivers of taking on extra responsibility; whereas siblings of children with ASD have challenges with supervising and managing their sibling’s aggressive behaviours. Furthermore, while all three sibling groups discussed the difficulties with regards to other people’s opinions, siblings of children with DS found the

judgments challenging because of their sibling's physical phenotypes, such as their facial abnormalities; whereas siblings of children with ASD and FASD struggled with people judging their brother or sister based solely on their behaviours. All three sibling groups also discussed having many concerns with regards to their sibling's future. Siblings of children with FASD tend to struggle in terms of their sibling's secondary impacts, whereas siblings of children with ASD and DS are concerned about their brother or sister's health condition. Furthermore, all three sibling groups had fears about whether or not their sibling will be independent in the future, or even survive.

3.2 “I’m a better person because of it”: Positive Transformational Outcomes

Although siblings mentioned negative outcomes, siblings also discussed some of the positives associated with having a sibling with either ASD, DS, or FASD. This theme title, taken from an interview with Gillian, a sibling to a child with ASD, demonstrates that siblings had good experiences with regards to having a sibling with a developmental disability. Siblings also described the experience of living with a sibling with ASD, DS, or FASD as valuable and an enriching one and discussed ways in which they developed personal growth and have become more educated an understanding of those with DD.

3.2.1 “We learned a lot from him”: Growth. Siblings often elaborated on the ways in which they have personally grown because of having a sibling with either ASD, DS, or FASD. All three sibling groups were very similar in this respect. For example, during the interviews when discussing some of the best parts of being a sibling to their brother or sister, participants

often said that overall, regardless of the challenges they have faced, it has been an uplifting experience.

Siblings of children with ASD specifically spoke about how they learned a lot from their sibling, which made them grow up faster and mature earlier. For instance, Alex, a 21-year-old sibling to a child with ASD said that because of his brother being in his life, he has “really grown maturely [and]... learned a lot from him,” which he then described as being “a really good experience in [his] life.” During the interview, Alex also discussed that because of taking care of his brother and having to be more mature as a child, that he has now began working with his brother as his personal-aid. Alex was very excited to talk about his responsibilities and said that his life would not have been the same if it wasn’t for his brother shaping Alex’s character.

Laura, a 31-year-old sibling to a child with ASD also said that when she was younger, that she had “a lot of growing up to do” because of her brother. Laura said because of being mature at such a young age, that: “[her brother had] really taught [her] what it means to be different and how to care for people who are different and to, sort of be above and beyond in compassion.” Laura then concluded by expressing her gratitude for her brother in her life, and said that overall the experience really influenced her in a “good way, [and] very positive way”.

Siblings of children with DS also discussed their growth in character, and said that their sibling shaped them to be “compassionate” and “empathetic”. For example, Samara, a 27-year-old sibling to a child with DS really highlighted the positives in her experiences and said that she would not be “her” if it wasn’t for her brother. Sam said:

It's really good [being a sibling]. I think he's kind of shaped me into who I am today, made me like a very empathetic person naturally, and made me see the world a bit differently... Just like a more gentle sort of way of looking at things, looking at people... especially a different way of looking at people who have differences. Just more empathetic mainly... Compassionate, empathetic and understanding.”

Furthermore, Erica a 35-year-old sibling to a child with DS also spoke about how her brother has shaped her character, and said that her brother has been nothing but a “positive influence on [her] personal growth and development”. She stated: “he probably makes me more effective and probably thoughtful about how I am and my behaviours in other people,” really expressing the positive impact her brother has had on her personal growth. This sibling in particular also said that because of how “amazing” the experience has been and how close she now is to her brother, that she is now raising her brother with DS in her own home and that the experience has continued to be elevating and inspiring. Erica also said that now her kids and husband volunteer with her brother, which has also been shaping their personal growth.

Finally, siblings of children with FASD discussed the ways in which they have now become better people. For instance, Lacy a 19-year-old sibling to a child with FASD 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].” She said that she had a lot of responsibility growing up, and that she kind of had to grow up quick. Lee, a sibling to six children with FASD, shared similar experiences in regards to her personal growth. Lee said 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 (i.e., allowing her siblings to play with her) and said because of this, she had

“grown up a lot because of it” and that she feels like she is a “better person because of it.”

Siblings therefore expressed similar ways in which they have gained personal growth that has benefited them personally and within their family, with regards to being a more mature person, and has made them feel confident about their bright future ahead.

3.2.2 “No matter whether the person’s special needs or not”: Accepting and Educated. In addition to sibling growth, siblings of children with ASD, DS, and FASD also found that they are now more understanding of others with regards to growing up with a sibling with a DD. For example, siblings of children with ASD and DS discussed being more educated about DD, which has made them develop patience and consideration towards those with individual differences. For example, when asked to sum up her overall experience of being a sibling to a child with DS, Sara said: “[It has been] VERY educational. I got to learn a lot of things that a lot of people never would learn in their life,” referring to the ways in which she now understands other people with differences, and that she too can apply her newfound knowledge to her everyday life. Sara also said that because of learning about DD at such a young age, it has guided her to her current career path as an early childhood educator.

Sam, a sibling to a child with DS also spoke about currently working in the field as a teacher, and said that other teachers often compliment her patience and skills with people with DD. Sam elaborated:

[I’d] get a call to a special education class [and] all the EAs would be like “wow, you’re oddly really good with them” you know, because it’s not something for everyone sort of

deal, unfortunately. So I'm like "oh yeah my brother has Down syndrome." They'll be like "oh that makes sense"

Linda, a 26-year-old sibling of a child with ASD, also spoke about how she has become more accepting and understanding of others, which led her to her current career. Linda, 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." She also said that because of her sister with ASD, that she (Linda) wanted to further her education so that she can have a better understanding of DD and took a Developmental Services Worker program at a local college. Because of this program, Linda decided to work in the field which she loves to do.

Finally, while siblings of children with FASD did not discuss working in the field of DD, this sibling group did discuss how growing up with their sibling has taught them how to accept other people's behaviours, especially if they have a disability. For example, 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," and that she is now "more willing and more accepting and more educated on those situations than other people." Lacy, a 19-yearold sibling to a child with FASD elaborated on this as she described an event while working at her telemarketing 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.

Alex, a 21-year-old sibling to a child with ASD also stated that he has “gained a lot of knowledge from how to deal with [his brothers] behaviours and his reactions...” He continued discussing how he has now applied that newfound knowledge in his life and said: “I [am] able to apply that to just regular life especially deal with like kids or other kids that have problems, it’s definitely been a huge plus to be able to understand.”

Therefore, siblings found that because of growing up with a sibling with DD, they can apply that knowledge to everyday life and feel happy about being more accepting to others. Furthermore, when siblings are out in the community and see another child that displays similar behavioural characteristics as their sibling with FASD, such as throwing tantrums, they are more empathetic with regards to not making judgments. In sum, siblings of children with ASD, DS, and FASD have identified similar positive transformations as they all expressed gaining personal growth, have developed a higher tolerance, and are more accepting and understanding towards others.

3.3 “Siblings need it just as much if not more”: Supports

The last theme identified, supports, refers to what has and what can help siblings deal with the challenges they face as a result of having a sibling with DD. For the current study, informal supports refer to individuals who are part of the sibling’s personal social network. For example, some siblings discussed having family members (i.e., parents or typically developing siblings), friends, neighbours, colleagues, or members of a faith-based community as someone they would talk to. Some siblings on the other hand discussed formal supports as something helpful to deal with their experience, and these include organizations or agencies that have

provided help or a service to the family (i.e., sibling support groups, group homes, physicians, or social service workers). Subthemes under supports include: supports have made life easier for siblings of children with ASD and DS, and more support groups are needed for siblings of children with FASD.

3.3.1 “Its just nice to know that other people feel the same things: Supports have made life easier for siblings of children with ASD and DS. According to the interviews, it appears there are many supports available for siblings of children with ASD and DS, who found it easy to adapt to the difficulties associated with their sibling’s condition. Having formal supports, such as support animals (i.e., support dogs and therapeutic horses), personal aids, group homes, and sibling groups, as well as informal supports, such as family and peers, have been said to be helpful to siblings. Furthermore, siblings discussed how these supports have made for a more positive experience with their sibling.

Noah, for example, a 14-year-old sibling of a child with ASD, 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.” Noah said that now that the support dog was in the family, his parents were not as stressed, which has lessened the tension in the family. Similarly, Brenda, a 31-year-old sibling to a child with DS, said that ever since her brother has been going to a therapeutic program that includes horses, her brother has been experiencing less depression and anxiety, which has made their relationship much better and has also made Brenda less worried about her sibling’s wellbeing. Brenda said:

He's been going there for about 2 years now and it just worked out, it was kind of fate that it worked out... He goes for rides and he's not scared or anything and he's so calm and [the horses are] very calm around him as well because they can sense your behaviour and emotions and all that so I think it's like it's very therapeutic for him, so, I love just taking him out there... He gets a kick out of it so that's probably our favourite thing to do.

Linda, a 26 year-old sibling to a child with ASD, discussed having "residence", a group home that her sister would stay at 5 days a week, was extremely beneficial for her and her family. Linda also said that because she has been staying in residence that she did not 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, a 21-year-old sibling to a child with ASD, 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).

Organizations such as sibling support groups were also discussed several times throughout the interviews. Both siblings of children with ASD and DS said that talking to other siblings had been a huge help when they were younger, as it made them understand their sibling better, and also made them feel less resentment towards their sibling. For example, Jenna, a 32-year-old sibling to a child with ASD said:

It was so nice when I actually joined the sibling support group a handful of years ago... the adult one... Just being able to talk to other sibling's other than my sister, to have similar experiences who can sit there and be like, 'wow yeah! Like let's celebrate that your brother,

he learned how to write his signature and he's 17 years old!' You know, and that's something that if you talk to your typical friends about that and say oh you know my brother, he learned how to do his signature... they may not have the same understanding as when you're in a group of other people who have siblings with special needs.

Similarly, Samara, a 28-year-old sibling of a child with DS said "It was always nice, like I said, at the Down Syndrome Association functions and stuff when all the siblings were invited... I still kept in touch with some. It's just nice to know that other people feel the same things and it's not just my sister, so it's nice when you meet that."

Finally, while both sibling groups discussed a number of formal supports that have been helpful, siblings of children with ASD and DS also discussed informal supports such as family members and peers as being valuable to their experience. Amanda, for instance, a 39-year-old sibling to a child with DS, said that when she was growing up she did not "feel like there was an issue or that [she] needed support in any way". She said that if anything, she would speak to her sister if she needed to talk to someone. Similarly, Brenda, a 31-year old sibling to a child with DS, said that with her parents and sister, she really "lucked out" as she spoke highly about her family "[sticking] together as a support system". Brenda also said that her family often talks to each other if they are stressed and would also be a shoulder to cry on if needed.

Anna, a 19-year-old sibling of a child with ASD spoke highly about the teamwork with her other siblings. She said that having three other brothers was helpful because they would all share the responsibility, but were also there to lean on if they had any frustrations. Anna said: "since I have four siblings, especially two that really help out, they all share it so like if any of us want to do stuff one of us will volunteer to keep an eye on [our brother] or whatever – just to here and there

sort of let them do things. Same thing with my parents, we'll often do stuff so they can go out and do things". Shannon a 43-year-old sibling to a child with ASD said that she too has a big support system at home. Shannon elaborates: "I have my husband, I have my sister, I have my friends that know my brother and they understood... his situation.

3.3.2 "I didn't have anyone": Need more support groups for siblings of children with FASD. Siblings of children with ASD and DS have discussed some of the formal and informal supports, such as having personal aids and group homes, as well as peer supports as being beneficial to the family. Siblings of children with FASD, on the other hand, had 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 and that she did not have the resources as a sibling to her with her experiences. Lee said: "I didn't have those resources just to go and talk to somebody", 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, but 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 of children with FASD also discussed their interest in starting their own support groups. Lacy and Lee were two examples of this, and 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.

In summary, the findings of the present study demonstrated that all three sibling groups experience similar experiences but have distinct differences in some areas. Specifically, while all three sibling groups discussed having positive transformational outcomes such as a developing growth, knowledge, and acceptance towards others, siblings also discussed some of the challenges they face. For example, siblings of children with DS and FASD said they struggle with the pressures from their caregivers of taking on extra responsibility; whereas siblings of children with ASD find it challenging to supervise and manage their sibling's aggressive behaviours. Furthermore, while all three sibling groups discussed the difficulties with regards to other people's opinions, siblings of children with DS found it difficult because of their sibling's physical phenotypes, such as their facial abnormalities; whereas siblings of children with ASD and FASD struggled with people judging their brother or sister based solely on their behaviours. All three sibling groups also discussed having many concerns with regards to their sibling's future. Siblings of children with FASD tend to worry about their sibling's secondary impacts, whereas siblings of children with ASD and DS are concerned about their brother or sister's health condition. Furthermore, all three sibling groups had fears about whether or not their sibling will be independent in the future, or even survive.

Finally, participants mentioned no existing support groups for siblings of children with FASD which has been described by siblings as an area of need. Supports do not appear to be a problem for siblings of children with ASD and DS as they discussed numerous supports and resources already available to them. Although many challenges have been discussed across the three sibling groups, siblings also discuss positive transformations in which they have grown from the experience, and have gained knowledge and have become more accepting and understanding to others.

CHAPTER FOUR: DISCUSSION

To the author's knowledge, this is the first study to compare siblings of children with ASD, DS, and FASD. Research findings examining the lived experiences of siblings of children with DD have 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 (i.e., age, gender), the severity of the disability, differences in the populations sampled (i.e., DS, ASD, FASD), the use of different outcome measures (i.e., 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, DS, and FASD. In addition, the author also sought to examine similarities and differences in the experiences of the three types of siblings.

The participants in this study expressed three super-ordinate themes: sibling demands, positive transformational outcomes, and supports. These themes represent a variety of underlying experiences, which were further detailed by subthemes and direct quotations from semistructured interviews. 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).

Under the theme, "sibling demands", all three sibling groups discussed some of the unique challenges they face in terms of being a brother or sister to a child with DD. Subthemes

included: extra responsibilities, people's opinions and awareness of disabilities, and concerns about their sibling's future.

In the first subtheme, extra responsibilities, participants in this study expressed that they have additional tasks and priorities that are very different compared to families raising typically developing children. Because there is a tendency for siblings to take on extra caretaking and household tasks when there is a child in the family with a disability (Cuskelly & Gunn, 2003), siblings may be subject to pileup demands (i.e., stressors and strains), which may in turn cause resentment towards their brother or sister (Van Riper, 2007). All three sibling groups felt burdened at some point in their lives by the extra chores and caretaking responsibilities that they were asked to perform by their parents. While they found these tasks to be a challenge at times, there was a difference in what siblings found most difficult. For example, siblings of children with DS and FASD said that the burdens from their parents were the most trying. Both sibling groups said that because there was a lot of pressure to help their parents with their brother or sister, they felt that being more mature was expected, causing a bitterness towards their sibling. Although sibling's in the current study discussed the caretaking responsibilities as a burden, a study by Skotko and Levine (2006) suggests otherwise. According to Skotko and Levine (2006), siblings of children with DS reported feelings of being helpful and capable when doing tasks such as teaching, babysitting and applying discipline. The researchers do however state that parents and caregivers should limit caregiving tasks, as they are found to be overwhelming for siblings. The researchers found that siblings often take these pressures quite seriously and often blame themselves, which in turn produces feelings such as guilt and anger (Skotko & Levine,

2006). Thus the researchers suggest that parents ask the child first whether they are able to help, rather than expecting that they always will.

Although siblings of children with ASD also said that they experienced a lot of pressure with regards to having to be more responsible, siblings with this condition were concerned with additional responsibilities such as having to constantly manage their siblings' behaviours. In a quantitative study investigating psychological adjustment in siblings of children with ASD, Ross and Cuskelly (2007) found that sibling stress was often associated with their siblings' aggressive behaviours. Most of the siblings in the present study said that they were constantly having to control their sibling with regards to constantly telling them not to hit, bite, or yell, and trying to minimize the work for their caregivers, which was found to be very difficult to do. Furthermore, siblings of children with ASD also referred to the stress that they observed in their parents, which was something that they did not want to add on to, resulting in becoming more self-sufficient and helpful (Hastings, 2002).

In the second subtheme, people's opinions and awareness of disabilities, siblings of children with ASD, DS, and FASD, described the difficulties of dealing with society's reaction to their brother or sister's disability. Because of the lack of awareness and knowledge of DD in the community, siblings found that being in public was something stressful for them as they often had to deal with misunderstandings, biases, and insults towards themselves and their sibling with DD, which they described as embarrassing (Mascha & Boucher, 2006). For example, siblings discussed times where people in the community would come up to them and tell them to control their sibling's inappropriate behaviours. According to interview responses in

the present study, siblings of children with ASD and FASD experienced difficulties with regards to stares and comments as a result of their sibling not having the distinctive facial features.

Siblings in both the ASD and FASD group described often having to explain that their sibling has a disability, which when referring to the FAAR model (Patterson, 1988), was considered a daily hassle. Siblings of children with DS on the other hand said that because of their brother or sister's facial phenotypes, they were often rejected from society, and were treated very poorly. Most siblings spoke about how they would often have to defend their sibling, which was sometimes aggravating and uncomfortable.

Lastly, while siblings expressed the challenges associated with the additional caretaking responsibilities and other people's opinions, all three participant groups also discussed what they worry about the most is their brother or sister's future. Siblings of children with ASD and DS, for example, found that they were often concerned about their sibling's health problems (Heiman & Berger, 2008). Participants in both the ASD and DS groups said that because their sibling was often ill, they frequently worried if their sibling would have a good quality of life in their future, or perhaps even survive into adulthood. Although problems with health 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 challenges 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, Watson et al. (2013b) found that parents were more stressed in terms of their child's illegal behaviours, demonstrating that the secondary impacts associated with FASD were a significant contributor to family stress. It is no surprise that siblings have also expressed

behaviours such as troubles with the law or drug and alcohol addictions to be their main concern. Siblings said that because of these secondary challenges, they were most afraid of their sibling going to jail, or heading down a dark and negative path in the future.

As described previously, demands, as defined by the FAAR model, refer to all of the stressors, strains, and daily hassles that family members may experience and that may disrupt normal family equilibrium (Patterson & Garwick, 1994a). In the current study, demands were addressed in the semi-structured, qualitative interviews, as the interview questions were informed by the FAAR model (Patterson, 1988). Siblings of children with ASD, DS, and FASD were found to experience many challenges; however, there were some unique differences and similarities in what siblings found most difficult. Specifically, siblings discussed extra responsibilities as a challenge, difficulties with regards to other people's opinions, and siblings also discussed having many concerns with regards to their sibling's future.

Although siblings mentioned some of the challenges they had experienced, 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. All three sibling groups who participated in the present study identified 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 more knowledge and positive perceptions of their siblings which increased tolerance and acceptance of others and of their siblings' more challenging behaviours.

While participants described having extra responsibilities as a challenge, participants in this study did express experiencing positive transformations when they took on these additional tasks 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 the current 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. Having become so independent at a young age made them more knowledgeable and mature, and also facilitated personal growth. Although the current study 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, DS, and FASD should take SES factors into consideration.

Finally, siblings described the importance of receiving adequate support. Siblings of children with ASD and DS discussed numerous supports and resources already available to them, which they said to be very beneficial for them and their sibling. Siblings of children with FASD, however, stated that this was a significant area of need. Because there is a wealth of

literature on ASD and DS, supports have been available for siblings with these disorders for quite some time.

Siblings identified having informal supports such as family members, friends, and peers as well as formal supports including support dogs, in-home aids, group homes, and sibling support groups available for their sibling with ASD or DS which were described as helpful for siblings and their family as there was less pressure on the family unit. 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 the 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 these findings, siblings in the current study often reported that having support at a young age would have been vital as it would have made their relationship with their sibling much stronger.

Although there are a number of theories that attempt to explain the different processes of adaptation (e.g., Hill, 1949; McCubbin & Patterson, 1983; Perry, 2004), the FAAR model was specifically designed to explain the various factors that influence family adaptation to the experience of raising a child with a disability (Patterson, 1993). In addition, the main concepts of the model (i.e., demands, capabilities, meanings) are based on variables that have been the basis of family stress theory for years (e.g., ABCX Family Stress Model; Hill, 1949). The FAAR also emphasizes the interactional patterns of adaptations and addresses a variety of intrapersonal factors, such as the interpretation of an event, and external factors, such as resources and social

support. Furthermore, despite being an older model, many scholars still utilize this model in family research (e.g., Abery, 2006; Murray, Kelley-Soderholm, & Murray, 2007; Watson et al., 2013a; Watson et al., 2013b), and has been especially useful since it includes aspects regarding positive adaptation and functioning.

For example, Watson et al. (2013a, 2013b) used this model to inform their study looking at parents of children with ASD and FASD, and found that by using the FAAR model, they were able to better understand the ways in which families achieve a balanced functioning. Watson et al. (2013a, 2013b) had found that parents emphasized the importance of obtaining information about the disabilities in terms to better understand their children's behaviour. Seeking information about their child's disability was seen as a coping behaviour and as acquiring a new resource. Additionally, the researchers found that many families developed a number of strategies to help with their day-to-day functioning (e.g., maintaining a consistent routine) that served to reduce their demands.

Abery (2006) also examined the experience of raising a child Down syndrome and stated that many families take the experience in a slow and steady pace, and allow for adjustment overtime, where they were able to adapt to higher demands and grow as individuals and families. Furthermore, Murray et al. (2007) grounded part of their qualitative study in the theoretical foundations of the FAAR model to examine the various challenges and strengths in families of children with congenital upper limb differences. In this study, the researchers utilized both the family systems theory and the FAAR model, where they were able to view the family as an interactive system and also attempted to explain how families responded to stressors.

Although the FAAR model has many advantages over other family theoretical frameworks, this model may be affected by some limitations. First, the FAAR model should

take into consideration how demands, capabilities, and adaptation might operate within developmental frameworks (e.g., the family life cycle) and how family members' experiences vary across different life stages (e.g., adolescents, adults). When looking at siblings specifically, they may have different views and understandings at one point in their lives; however, they may alter the way in which they cope and utilize resources when they, or when the child with the disability, ages. Further, siblings that are younger may not have access to certain resources, which may seem like they are not utilizing appropriate coping behaviours, and are not able to balance their demands with their capabilities. Sibling gender has also been found to have an impact on overall adjustment. Verté et al. (2003) found that brothers of children with ASD had lower self-concept compared to sisters. This may be the result of male siblings not seeking or utilizing appropriate resources and coping strategies, in which they are ultimately no able to balance their demands with their capabilities.

Further, the FAAR model should also look at specific diagnosis or the severity of the child's behaviour. 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). Individuals with severe disabilities require lifelong assistance with daily care tasks, communication, as well as accessing and partaking in community services and events, all of which can be perceived as stressful by parents (Martin & Colbert, 1997). Families may have a difficult time balancing their demands and capabilities because of constantly being strained with additional caretaking responsibilities, whereas families with higher functioning children may be able adapt much easier.

Geographic location may also be an important concept to take into consideration in the FAAR model, especially when it requires accessing resources. The availability of services,

particularly in rural regions, has been described as a challenge as they often have fewer professional services available (Sanders & Buck, 2010). Again, this may seem like families are not utilizing appropriate coping strategies; however, in reality, they are restricted on what they can and cannot do due to services not being accessible.

Finally, the FAAR model does not speak to family adjustment and adaptation over time. The model only posits that a family may either fall within a continuum of bonadaptation or maladaptation, and does not state if adaptation persists or declines over a period of time. The FAAR model should perhaps have more than one phase, such as a baseline phase where families go back to if adjustment is not stable, or a period going back to the adjustment phase, where there is a continuum of adjustment and adaption occurring.

In sum, the FAAR model demonstrates how families are able to adjust and adapt with the demands that they are faced with. When families have appropriate supports and resources, their ability to adapt is high, which allows the family to achieve homeostasis within the family system. If resources and coping mechanisms are not utilized or have not yet been implemented, families may experience an imbalance which in turn causes a crisis in the family. The FAAR model not only describes the different cognitive factors that may influence family adaptation with regards to raising a child with a disability, but also illustrates positive adaptation, and highlights the importance of utilizing appropriate resources when demands are high.

4.1. Considerations and Future Directions

Although this study used credible qualitative research methods (Patton, 2002), the researcher recognizes that the trustworthiness of the findings may be affected by some limitations. The first limitation of this study is the sample size. Although the sample size of six to 10 participants is typical of those recruited generally for qualitative research (Starks & Trinidad,

2007), findings do need to be treated with caution as results may not be generalized to the entire sibling population of siblings of children with DD. The second limitation is the age of the participants. The participants ranged in age from 10 to 43 years and therefore the generalizability of the findings may be limited and should not be generalized across developmental stages (i.e., early childhood or adolescents). Future research should ideally focus on a particular age range to further investigate siblings' experiences (i.e., early childhood, adolescents and adulthood). For example, younger participants discussed demands such as their sibling not sharing toys or being "mean" to them; whereas older siblings said that their biggest concern was their sibling getting into trouble or their siblings health issues. Younger participants also said that they would walk away or get mad at their siblings in order to cope with the stressors or strains in the household. Older siblings, on the other hand, would discuss resources such as going to see a therapist or become less involved in their siblings lives in order to cope with the challenges they had faced. Furthermore, older siblings discussed living with their sibling as their parent is no longer able to. The fact that the older siblings were currently "parenting" their sibling, may have affected their experience and sibling bond, and may have also shifted the family dynamic as many sibling's expressed feeling more of a parent and less as a sibling. This was not the case for the younger siblings as they have no yet reached the developmental milestone.

A third limitation of this study is that all siblings of children with ASD and DS were biological, whereas all siblings of children with FASD were adoptive. Unfortunately, it is difficult to recruit biological siblings because according to the literature, 80% of children with FASD live in foster care or are adopted (Dicker & Gordon, 2004; Streissguth et al., 2004). 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. However, while this type of study would be ideal in order to clarify the role of genetic and environmental factors, it may be difficult to gather biological siblings without FASD, as biological siblings may also be likely to be affected by FASD.

Despite the limitations already discussed, the present study used a number of strategies to ensure trustworthiness 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 trustworthiness of qualitative research, a number of strategies were employed.

First, the researcher ensured trustworthiness 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. All siblings agreed to the analysis and also added anything that was missing.

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, DS, or FASD. Employing a self-report interview not only allowed for more 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, DS, 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.

The findings from this study indicate a number of implications for clinical professionals and services. Understanding the particular challenges that siblings of children with ASD, DS, and FASD face is essential to developing, implementing, and improving appropriate services for siblings. Having formal supports and resources available to siblings could help alleviate some the stressors and strains they experience. Most siblings in the current study stated that they would benefit largely from speaking with other siblings of children with DD, as it would provide them with the opportunity to share their story and also understand that they are not alone. There is also a need to promote knowledge and awareness of ASD, DS, 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, DS, and FASD may help lessen the stigma around those individuals affected by DD which essentially may make life easier for families. Furthermore, having increased knowledge may also be helpful in preventing secondary impacts that are shown to arise in children with FASD and create stress in family members.

4.2 Conclusion

The results of the present study provide new insights regarding sibling relationships in families of children with ASD, DS, and FASD. In line with past research (Hastings, 2003; Rivers & Stoneman, 2003), the researcher found that siblings who participated in the present study demonstrated different and unique challenges associated with having a sibling with these DD. In the exploratory research, three themes emerged from the siblings' interviews: sibling demands, positive transformational outcomes, and supports.

Because previous studies suggest that when siblings of children with ASD are compared with siblings of other types of DD, such as DS, siblings of children with ASD tend to show a greater risk for negative outcomes (Hastings, 2003; Rivers & Stoneman, 2003). In the current study, 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. Providing supports to those who have sibling with FASD will lead to more positive life outcomes, and facilitate family adaptation as they progress through their lifetime.

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Appendix A

Demographic Questionnaire

Family Research Project Demographic Form

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/DS)?
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/DS?
7. How would you describe (insert name of sibling with FASD/ASD/DS)?
8. What is it like to be (insert name of sibling with FASD/ASD/DS)'s sibling?
9. Tell me about a typical day in your household.
10. How do you think [insert name of sibling]'s FASD/ASD/DS 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/DS)?
13. What is the best part of being a sibling to (insert name of sibling with FASD/ASD/DS)?
14. What are some difficult parts of being a sibling to (insert name of sibling with FASD/ASD/DS)?
 - a. What helps you handle the difficult parts (insert name of sibling with FASD/ASD/DS)?
 - 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/DS)

19. Is there anything else you think I should know about your relationship with your sibling?

Appendix C

Sibling Consent Form



Laurentian University
Université Laurentienne

Fax/Télé. : 705-675-4889

Department of Psychology
Département de psychologie
Tel/Tél.: 705-675-1151, 4250

I agree to participate in the research project entitled “Comparison of Sibling Relationships in Families of Children with Autism Spectrum Disorder, Down Syndrome 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), Down Syndrome (DS) 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 or 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

Appendix C

Ethics Approval

**APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS**

Research Ethics Board – Laurentian University

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

TYPE OF APPROVAL / New X / Modifications to project / Time extension	
Name of Principal Investigator and school/department	Tara Hughes, Rural & Northern Health, supervisor Shelley Watson, Psychology
Title of Project	Comparison of Sibling Relationships in Families of Children with Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder and Down Syndrome
REB file number	2015-07-05
Date of original approval of project	Sept 22, 2015
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on: <i>(You may request an extension)</i>	September, 2016
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

A handwritten signature in blue ink that reads "Rosanna Langer". The signature is written in a cursive, flowing style.

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