EFFECT OF SIBLING RELATIONSHIPS ON WELL-BEING AND DEPRESSION IN ADULTS WITH AND WITHOUT DEVELOPMENTAL DISABILITIES

by

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Abstract

Siblings are an integral part of the support network for adults with a developmental disability (DD). However, little is known about the psychological stress of having a sibling with a DD in adulthood. This project had four main objectives: (1) to identify variables that predict and moderate psychological well-being and depressive symptoms in adults who have a sibling with a DD; (2) to examine differences in sibling relationship characteristics, psychological well-being, depressive symptoms, and support use in siblings of individuals with a DD alone versus siblings of individuals with a DD and symptoms of a mental illness; (3) to determine whether relationships with siblings with a DD differ from relationships with siblings without a DD; and (4) to explore the perspectives of adults with a DD regarding their sibling relationships and how these relationships affect their well-being.

One-hundred ninety six adult siblings of individuals with a DD completed online questionnaires about life events, relationship closeness, sibling contact, impact of having a sibling with a DD, family functioning, use of supports, symptoms of depression, and psychological well-being. Life events and having a sibling with a DD and behavioural or psychiatric symptoms predicted symptoms of depression and psychological well-being. However, the relationship between these predictor variables and psychological well-being was moderated by general family functioning. Additionally, siblings of individuals with a DD and behavioural or psychiatric symptoms reported less positive feelings about their sibling relationship, more symptoms of depression, and lower psychological well-being than siblings of individuals with a DD alone.
A subset of the participants \((n = 128)\) who also had a sibling without a DD completed questionnaires about their relationship closeness, sibling contact, and perceived impact of their sibling without a DD. Participants reported more in-person and telephone contact with siblings with a DD, more positive feelings about the sibling relationship, and greater perceived life impact as compared to their relationship with their sibling without a DD.

Seventeen adults with a DD also completed in-person interviews and answered questions about their sibling relationship closeness, shared activities, and support exchanged with siblings. Participants identified numerous activities they enjoyed doing with siblings and indicated a desire to spend more time with siblings. They also reported that they both provided support to and received support from their siblings.
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Statement of Originality

I hereby certify that all of the work described within this thesis is the original work of the author.

Any published (or unpublished) ideas and/or techniques from the work of others are fully acknowledged in accordance with the standard referencing practices.

(Julia Grace Burbidge)

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Chapter 1

General Introduction

Sibling relationships are often one of the longest lasting relationships in an individual’s life. Such relationships are unique in that they are ascribed rather than selected. Furthermore, siblings have a common history, including many shared experiences (Cicirelli, 1995), in addition to having a large proportion of shared genetic variance. Throughout the life course, intimacy and frequency of sibling contact waxes and wanes; however, strong sibling relationships are associated with greater well-being across all ages (Cicirelli, 1989; Sherman, Lansford, & Volling, 2006).

When one member of a sibling dyad has a developmental disability (DD), the nature of the sibling relationship is altered. The relationship often takes a more hierarchical form, and siblings may have fewer shared life experiences, particularly as disability severity increases (Stoneman, 2005). Despite these changes, siblings remain an integral component of the support network of individuals with a DD, particularly during adulthood (Krauss, Seltzer, & Goodman, 1992).

The deinstitutionalization movement and medical advancements have contributed to an increasing number of people with a DD living into later adulthood within the community. Often times, such individuals are at least partially dependent on family members, as opposed to the government, for support. Parents often provide the necessary support for individuals with a DD; however, with an aging DD population, parental
illness or death can prevent parents from fulfilling the role of caregiver for their adult child. Previous research on aging parents of adults with a DD shows that the majority of these parents experience significant concern related to accommodations and the provision of social and emotional support when they are no longer able to care for their child with a disability (Minnes & Woodford, 2004; Minnes, Woodford, & Passey, 2007). In many families, the siblings of the individual with a DD expect to and do take on part of the caregiving role once parents are no longer able (Bigby, 1997; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Krauss, Seltzer, Gordon, & Friedman, 1996). It is clear that siblings have an important role in the lives of adults with a DD; however, little is known about the nature of adult sibling relationships in this population.

Parents of Children with a DD

All parents face numerous challenges when raising their children; however, parents of children with a DD are faced with additional challenges above and beyond those typically experienced by parents of children without a DD. Children with a DD may have delays, in cognitive, language, and motor skills, which increase the caregiving demands placed on parents. Additionally, many children with a DD engage in more maladaptive behaviour than children without a DD (Baker et al., 2003; Stores, Stores, Fellows & Buckley, 1998), which can disrupt family functioning. Although many services exist to assist parents in raising a child with a DD, such services can place a financial burden on families (Doran et al., 2012; Fujiura, Roccuforte, & Braddock, 1994) and the process of navigating the service system can be frustrating and time consuming.
Given the significant stressors faced by parents of children with a DD, much research has focused on the psychological effect of parenting a child with a DD. Parents of children with a DD are at increased risk of experiencing depression and anxiety as compared to parents of children without a DD (Feldman et al., 2007; Gallagher, Phillips, Oliver, & Carroll, 2008; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; MacDonald, Hastings, & Fitzsimons, 2010; Olsson & Hwang, 2002; Singer, 2006; Weiss, 2002; White & Hastings, 2004). However, parents also report numerous positive effects of raising a child with a disability, such as increased compassion and tolerance, a changed perspective on life, and a greater sense of purpose in life (Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Taunt & Hastings, 2002).

Although parents bear the primary responsibility of caring for a child with a DD, many siblings, including young children, also take on a caregiver role for their brother or sister with a disability (Bigby, 1997; McHale & Gamble, 1989). Additionally, siblings of individuals with a DD often report that the majority of their parents’ attention was focused on the sibling with a disability during childhood (Ferraioli & Harris, 2010; Schuntermann, 2007). As a result, many siblings cope by acting out as a way to get attention, or they take on the role of the ‘good child’ and try to behave well and excel in all that they do so as not to place any additional stress on their parents (McMillan, 2005; Moyson & Roeyers, 2012; Schuntermann, 2007). Given that both parents and siblings face additional stressors when an individual in the family has a DD and that parents of children with a DD are at increased risk of mental health problems, it is important to
consider how siblings are psychologically impacted by growing up with a brother or sister with a DD.

**Child Siblings of Individuals with a DD**

Most previous sibling research focuses on the impact of having a sibling with a DD during childhood or adolescence, and the conclusions vary across outcome measures. Studies that have examined self-concept, social support, and perceptions of competence reveal that siblings of children with a DD do not differ from siblings of children without a DD (Dyson, 1999; Hannah & Midlarsky, 1999; Kaminsky & Dewey, 2002; Roeyers, & Mycke, 1995). In contrast, the findings from research focused on behaviour problems are equivocal. Many researchers have found that siblings of children with and without a DD do not differ in problem behaviours (Cuskelly, Chant, & Hayes, 1998; Dyson, 1999; Gold, 1993; Hannah & Midlarsky, 1999; Stores et al., 1998), whereas other studies show that siblings of children with a DD exhibit more internalizing and externalizing behaviour problems than children without a DD (Coleby, 1995; Nixon & Cummings, 1999). Şenel and Akkök (1996) found that siblings of children with a DD report more stress than siblings of children without a DD, and Gold (1993) reported more symptoms of depression among siblings of children with autism.

The effect on siblings may differ depending on the diagnosis of the child with a DD. Several studies show that siblings of children with autism have greater difficulty than siblings of children with other DDs or siblings of children without a DD, including more internalizing behaviour problems and less prosocial behaviour (Fisman et al., 1996;
Hastings, 2003; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009). Although the reasons for the increased problems in siblings of children with autism are unclear, the aforementioned authors posit several explanations, including increased parental stress and emotional difficulties that negatively affect the parents’ interactions with the sibling without a disability and the presence of autistic features in siblings (and parents) due to the shared autism endophenotype (Fisman et al., 1996; Hastings, 2003; Petalas et al., 2009). However, other studies have not found a difference between siblings of children with autism and siblings of children with other DDs or without a DD (Kaminsky & Dewey, 2002; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004).

Similar to parents, siblings also report benefits of having a brother or sister with a disability, including increased sensitivity to others, greater compassion, being able to get the most out of life, and development of significant relationships (Dyke, Mulroy, & Leonard, 2009; Findler & Vardi, 2009; Hodapp, Urbano, & Burke, 2010). Rossiter and Sharpe (2001) conducted a meta-analysis of sibling studies in the DD field, and they concluded that there is a negative, but small, effect of having a sibling with a DD and that overall, siblings are generally well-adjusted. However, they also highlight that in regards to psychological outcomes, the strength of the negative effect is greater, with siblings of people with a DD showing more symptoms of depression, and to a lesser extent more internalizing and externalizing behaviours and more symptoms of anxiety as compared to siblings of individuals without a DD.
Adult Siblings of Individuals with a DD

Although a considerable amount is known about childhood sibling relationships in the DD population, the developmental literature indicates that differences in familial structure and sibling relationship characteristics preclude the generalization of research findings from children and adolescents to the sibling experiences of adults (Orsmond & Seltzer, 2007; Rossiter & Sharpe, 2001). Thus, research focusing specifically on the experiences of having a sibling with a DD during adulthood is necessary. To date, much of the research related to adult sibling relationships in the DD field has focused on the current involvement of siblings in the lives of individuals with a DD, as well as siblings’ current and intended future care-giving roles (e.g., Bigby, 1997; Greenberg et al., 1999; Heller & Kramer, 2009; Krauss et al., 1996; Orsmond & Seltzer, 2000). Little emphasis has been placed on understanding the psychological and emotional outcomes related to the stress of having an adult sibling with a DD. Siblings of individuals with a DD may encounter many issues that are not present in non-disabled sibling dyads, including concerns about future care-giving roles, stigmatization, and atypical sibling relationship characteristics. Rossiter and Sharpe’s 2001 meta-analysis, which found a significant negative psychological effect of having a sibling with a DD, only included two studies that focused specifically on adult siblings, and few of such studies have been added to the literature in the past decade. Thus, at present there is limited information about whether having a sibling with a DD has an effect, either positive or negative, on the psychological well-being and mental health of adults.
Summary and Objectives

When one member of a sibling dyad has a DD, the nature of the sibling relationship is typically altered throughout the life course. Although siblings of individuals with a DD seem to be relatively well-adjusted, there is evidence that they experience some negative, as well as positive, psychological consequences of having a sibling with a DD. Much of the existing sibling literature focuses on the experiences of children, and the limited research that has focused on adult siblings has primarily examined their role as caregivers. Thus, there is a need for a more in-depth examination of the psychological experiences of adult siblings of individuals with a DD.

This project had four main objectives: (1) to identify variables that predict and moderate psychological well-being and depressive symptoms in adults who have a sibling with a DD; (2) to examine the impact of having a sibling with both a DD and symptoms of mental illness; (3) to determine whether relationships with siblings with a DD differ from relationships with siblings without a DD; and (4) to explore the perspectives of adults with a DD regarding their sibling relationships and how these relationships affect their well-being. The findings from this project add to the sibling literature by examining two areas that have not previously been explored: the perspectives of individuals with a DD and the impact of having a sibling with a DD and behavioural or psychiatric symptoms. Additionally, the application of Perry’s (2004) theoretical model to understand sibling stress provides important information about
factors that contribute to psychological well-being and symptoms of depression, as well as variables that moderate these relationships, in adult siblings of individuals with a DD. Finally, the comparison of participants’ relationships with their siblings with and without DDs enhances our understanding of which aspects of the sibling relationship are different when one sibling has a DD and which aspects do not differ from the typical sibling relationship. The results also suggest important areas for future research, and they offer information that may help clinicians and community agencies working in the DD field to recognize and understand the support needs of siblings, both with and without DDs.

**Definition of Developmental Disability**

The term *developmental disability* (DD) is used clinically to refer to a broad range of conditions, including intellectual disability, autism spectrum disorders, physical or motor impairments, speech or language impairments, and neurological disorders, among other conditions. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines developmental disabilities as ‘severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before age 22 and are likely to be lifelong’ (American Association on Intellectual and Developmental Disabilities, 2013). Developmental disabilities are typically diagnosed at birth or in early childhood; however, some children do not receive a proper diagnosis until later in life. The studies presented in this dissertation include adults who have a sibling with a DD, as well as adults who have a DD. Consistent with the AAIDD definition of developmental disabilities, I included participants and siblings who had a cognitive disability (i.e.,
primary diagnosis of intellectual disability or autism spectrum disorder) or both a
cognitive and physical disability. However, in contrast to the AAIDD definition, I used a
more narrow definition of physical disability alone and only included individuals who
had a nervous system disorder present from birth that affects multiple areas of
functioning (e.g., cerebral palsy). Thus, throughout this paper, the use of the term DD is
in reference to individuals who meet at least one of the latter three criteria.

*Intellectual disability* (ID) is the term currently used in the research literature to
represent the clinical diagnosis of mental retardation. The DSM-IV-TR diagnostic criteria
for mental retardation include having an IQ at or below 70, having impairments in at least
two areas of adaptive functioning (i.e., communication, self-care, home-living,
social/interpersonal skills, use of community resources, self-direction, functional
academic skills, work, leisure, health, and safety), and having an onset of these symptoms
prior to age 18 (American Psychiatric Association, 2000). There are many causes of ID,
including genetic disorders, neurological conditions, pre- or peri-natal trauma, traumatic
brain injuries that occur in childhood, and exposure to environmental toxins, among
others causes. Additionally, the cause of many people’s ID is unknown.

The term *autism spectrum disorder* (ASD) is used clinically and in research to
refer to a group of conditions, which include Autistic Disorder (i.e., autism), Asperger’s
Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).
These disorders all include deficits in reciprocal social interaction and the presence of
stereotyped patterns of behaviour, interests, and/or activities (American Psychiatric
Association, 2000). Autism is often associated with comorbid intellectual disability; however, Asperger’s Syndrome, by definition, is not associated with intellectual disability (American Psychiatric Association, 2000).
**Chapter 2**

**Psychological Well-being and Depressive Symptoms in Adults whose Siblings have a Developmental Disability**

Having a sibling with a DD can place additional burden on an individual. Oftentimes siblings are expected to take on more of a care-giving role than is typically expected of children whose siblings do not have a DD (Bigby, 1997; McHale & Gamble, 1989). Furthermore, children with a DD often demand more attention from their parents, thus leaving the sibling without a DD with less parental focus (Ferraioli & Harris, 2010; Schuntermann, 2007). In adulthood, siblings may be faced with the challenge of balancing their own family lives with providing support to the sibling with a DD and their aging parents. Additionally, throughout the life course, siblings can be faced with stigmatization from peers and other individuals who do not understand the behaviours and needs of their sibling with a DD.

Early sibling literature in the DD field tended to pathologize siblings of individuals with a DD, assuming that siblings were negatively impacted by having a brother or sister with a disability (see Rossiter & Sharpe, 2001 for a review). However, despite the added stressors experienced by siblings of individuals with a DD, many researchers have concluded that overall, siblings of individuals with a DD are well-adjusted. Additionally, many siblings experience benefits of having a brother or sister with a disability (Dyke et al., 2009; Findler & Vardi, 2009). Although having a sibling
with a disability may not in itself be a risk factor for poor psychosocial adjustment, there are some siblings of individuals with a DD who do experience negative psychological outcomes. Stoneman (2005) emphasized the importance of identifying specific factors that place some siblings at risk for negative outcomes when they have a brother or sister with a DD.

One such risk factor that has been identified in the sibling literature is disability type. Several studies have shown that both child and adult siblings of individuals with an ASD experience more problems than siblings of individuals with other DDs (Fisman et al., 1996; Hastings, 2003; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007; Petalas et al., 2009). However, this relationship has not been supported in all studies (Kaminsky & Dewey, 2002; Pilowsky et al., 2004). There is a need to further examine ASD, as well as additional characteristics of the sibling with a DD to determine if these characteristics are risk factors of negative psychological outcomes in adults who have a sibling with a DD. Additionally, it would be worthwhile to ascertain whether other factors (e.g., individual perceptions, family relationships, supports, etc.) can mitigate the negative effects of potential risk factors.

**Theoretical Framework**

In contrast to parent stress research in the DD field, Stoneman (2005) has described the sibling literature as “theory-free” (p. 339), and, thus, one of the aims of this study was to apply a theoretical model to further our understanding of the stress process experienced by adult siblings of individuals with a DD. The term stress represents a
complex concept that has been defined in three distinct ways across the general stress literature: (1) as a stimulus that brings about a response (i.e., a stressor); (2) as the physiological response that results from an external stimulus; and (3) as the overall interactive process between an external stimulus, an individual’s response to it, and the intervening factors (Monat, Lazarus, & Reevy, 2007). Consistent with much of the DD literature related to parental stress (see Hassall & Rose, 2005 for a review), I have defined stress using the latter definition, which describes stress as the overall interactive process between a stimulus, an individual’s response to the stimulus, and the intervening factors. Thus, sibling stress is conceptualized as the interactive process between having a sibling with a disability (i.e., the stressor), how the sibling responds to having a brother or sister with a disability, and what factors moderate the relationship between the stressor and the sibling’s response to the stressor.

Ecological systems theory (Bronfenbrenner, 1979) suggests that in order to fully understand an individual’s well-being, one must examine individual, family, and environmental level variables to determine their effect on well-being. To date, only one previous study has examined predictors of psychological well-being in adults who have a sibling with a DD. Seltzer and colleagues conducted a study comparing predictors of psychological well-being in adult siblings of individuals with a DD and adult siblings of individuals with mental illness (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). The examined predictors included demographic variables, problem behaviour in the individual with a DD, sibling perceptions of the impact (both quantity and direction) of
the individual with a DD on the sibling’s life, and sibling relationship closeness. The overall model predicted 22% of the variance in well-being. Seltzer and colleagues’ analysis included variables related to the non-disabled sibling’s perceptions and demographics (i.e., income, gender, and marital status), as well as characteristics of the individual with a DD; however, it did not include variables related to general life stressors or the supports and services (i.e., environmental factors) used by siblings of individuals with a DD. To date, no adult sibling studies have simultaneously examined variables at all three levels outlined by Bronfenbrenner.

This study examined predictors of well-being using a theoretical model of stress that stems, in part, from ecological theory but was developed specifically for the DD population (Perry, 2004). The model (Figure 1) posits that stressors (i.e., characteristics of the individual with a DD and other life stressors) predict both positive and negative outcomes in family members of individuals with a DD; however, the relationship between the stressors and the outcome variables is moderated by both resources (i.e., individual and family system) and supports (i.e., formal and informal).
Although there are several theoretical models of stress that have been applied to the DD literature (e.g., McCubbin and Patterson’s [1983] Double ABCX Model, Lazarus’ [1984] Transactional Model of Stress), I selected Perry’s (2004) model for four reasons. First, in their 2005 article outlining current challenges and future research directions related to siblings in the DD field, Hodapp, Glidden, and Kaiser highlight the need to include moderator variables when studying siblings. Perry’s model includes both resources and supports as moderator variables. Second, unlike the other stress models commonly used in the DD literature, Perry’s model includes ‘other life stressors’ (i.e., stressors that are unrelated to the individual with a DD). There is a wide body of literature outside of the DD field that demonstrates the relationship between general life stressors and negative outcome variables such as depression (e.g., Honkalampi et al., 2005; Monroe, Harkness, Simons, & Thase, 2001; Monroe et al., 2006; You & Conner, 2004).
and thus, it is reasonable to assume that general life stressors are also relevant for adults who have a sibling with a DD. Third, Perry’s model examines both individual resources (e.g., perceptions of the stressor) and family resources (e.g., family cohesion), whereas other models typically do not make this distinction (Perry, 2004). Fourth, other models of stress typically combine social supports and professional services and supports, whereas Perry’s model views these two types of supports separately. In the parent literature, studies consistently show that informal supports (e.g., friends and family) are linked to decreased stress and improved emotional well-being (White & Hastings, 2004; Hodapp, Fidler, & Smith, 1998); however, the findings related to formal services and supports are less consistent (e.g., King, King, Rosenbaum, & Goffin, 1999; White & Hastings, 2004). Therefore, it is worthwhile to examine these variables separately rather than as a single concept.

The following sections provide a brief review of the literature related to each component of Perry’s (2004) model. Due to the limited literature focused on adult siblings, findings related to child siblings and parents are included.

**Outcome Variables**

People can experience both distress and positive outcomes in response to a stressor, and these two types of outcome are not mutually exclusive (Dykens, 2005; Folkman & Moskowitz, 2000). Furthermore, Folkman and Moskowitz posit that the focus on negative outcomes has limited the progression of the stress and coping literature. Thus, Perry’s (2004) model includes both positive and negative outcome variables, which
I have defined as psychological well-being and symptoms of depression, respectively, for this study.

**Well-being.** Researchers in the DD field have recently begun to discuss the importance of examining positive outcome variables that result from the experience of stress (Findler & Vardi, 2009; Folkman & Moskowitz, 2000; Helff & Glidden, 1998). Well-being is often discussed as an outcome measure in research with parents and siblings of children with DD; however, it is often operationally defined as the absence of negative outcomes such as symptoms of depression, anxiety, and stress, rather than the presence of positive outcomes, such as happiness and sense of purpose in life (Dykens, 2005).

Ryff (1989; 1995) has developed a widely used model of well-being that is conceptualized as a combination of six dimensions: (1) self-acceptance (viewing the self and the life one has lived in a positive manner); (2) positive relations with others (having good quality, meaningful relationships with others); (3) autonomy (having a sense of independence and self-determination); (4) environmental mastery (the ability to successfully manage one's life); (5) purpose in life (having a sense of meaning in life); and (6) personal growth (having a sense of continued developmental and movement toward self-actualization).

Using Ryff’s (1989) conceptualization of well-being, Seltzer and colleagues (1997) examined whether demographic variables (income, gender, and marital status), stressors (maladaptive behaviours of siblings with a DD), and resources (closeness of the
sibling relationship and perceived impact the sibling has had on the participants life) predict well-being in adults who have a sibling with a DD. They found that income, marital status, and sibling relationship closeness predicted psychological well-being. Perceived impact of the sibling did not directly predict well-being; however, it significantly interacted with the valence of the impact. For participants who viewed their sibling as having little impact on their life, impact was not predictive of psychological well-being. In contrast, for participants who viewed their sibling with a DD as having a large impact on their life, the impact on well-being was dependent on whether this impact was positive or negative.

**Symptoms of Depression.** Several studies have examined depressive symptoms in family members of individuals with a DD, but findings are equivocal. Research on parents and siblings of children with a DD shows that these family members have higher depressive symptoms than parents and siblings of children without a DD (Gallagher et al., 2008; McHale & Gamble, 1989). In contrast, the depressive symptoms measured in a sample of aging parents of adult children with a DD were comparable to the severity of symptoms found in the general population of aging adults (Minnes & Woodford, 2004).

Fahey (2005) compared adult siblings of individuals with a DD to adult siblings of individuals without a DD and found, contrary to her hypothesis, that the former group had lower symptoms of depression than the latter group. However, despite the lower symptoms of depression scores for the siblings of individuals with a DD, 15% of Fahey’s participants had scores that were in the mild to severe range on the Beck Depression
Inventory-II. Thus, it appears that the mental health of adult siblings of individuals with a DD varies. Hodapp and Urbano (2007) compared adult siblings of individuals with Down syndrome to adult siblings of individuals with autism and found that having a sibling with autism was associated with more symptoms of depression. These findings highlight an important potential risk factor for increased symptoms of depression in adults who have a sibling with a DD. However, to date, few other variables have been examined to determine whether they relate to depressive symptoms in adult siblings.

**Stressors**

**Characteristics of the Individual with a DD.** Previous research has examined the impact of characteristics of the individual with a DD on the well-being and depressive symptoms of family members. There is some evidence that lower levels of adaptive functioning and higher levels of maladaptive behaviour are related to negative outcomes in mothers, including increased perceptions of stress and symptoms of depression (e.g., McIntyre, Blacher, & Baker, 2002; Minnes & Woodford, 2004). In contrast, Seltzer et al. (1997) found that maladaptive behaviour was not related to siblings’ psychological well-being.

One variable that has received little attention in the adult sibling literature is the diagnosis of an ASD. The characteristics of ASDs can make it more difficult for individuals with these diagnoses to connect with others, including siblings, and to form relationships. For example, individuals with an ASD often have difficulty understanding social nuances, engaging in reciprocal social interactions, and understanding others’
perspectives and emotions (Beyer, 2009). The findings related to siblings of individuals with an ASD in childhood are mixed, with some studies showing that children who have a sibling with an ASD are well-adjusted (e.g., Fisman et al., 1996; Hastings, 2003; Petalas, et al., 2009) and other studies showing that children are negatively impacted by having a sibling with an ASD (e.g., Kaminsky & Dewey, 2002; Pilowsky et al., 2004). The limited research on adults shows that siblings of individuals with an ASD tend to report less closeness in their sibling relationships and they spend less time with their brother or sister with an ASD as compared to siblings of individuals with other DDs such as Down syndrome (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). Additionally, adult siblings of individuals with an ASD report more symptoms of depression than adult siblings of individuals with Down syndrome (Hodapp & Urbano, 2007) Given this increased risk of symptoms of depression in siblings of individuals with an ASD, it is important to identify factors that can moderate the relationship between this stressor and negative outcome.

A second characteristic of individual’s with a DD that has received very little attention in the family stress literature is mental illness. The limited research in this area suggests that mental illness in individuals with a DD is related to decreased well-being and increased depressive symptoms in mothers (Esbensen, Seltzer, & Greenberg, 2006; McIntyre et al., 2002); however, this relationship has not yet been examined in siblings. There is a high prevalence of mental illness across the lifespan in the DD population, with point prevalence estimates of around 40% of the population (Cooper,
Smiley, Morrison, Williamson, & Allan, 2007; Emerson, 2003; Torr & Davis, 2007; Voelker, 2002). The presence of a mental illness in an individual with a DD has significant implications for both that individual and his or her family members. Mental illness is often accompanied by problematic behaviours and changes in an individual’s personality, which results in an increased need for support by family members. Furthermore, the diagnosis of a mental illness in an individual with a DD can place additional emotional stress on family members who have already undergone the difficult experience of having their child or sibling diagnosed with a developmental disability (Faust & Scior, 2008).

Little is known about the impact of having a sibling with both a DD and symptoms of a mental illness. The few studies that have examined differences between adults who have a sibling with a DD and adults who have a sibling with a mental illness show that siblings of adults with a DD provide more emotional support to their sibling and report greater amounts of contact, have increased relationship closeness, and express more positive feelings towards the sibling with a disability as compared to siblings of adults with mental illness (Greenberg et al., 1999; Seltzer et al., 1997). Siblings of adults with a DD also report greater well-being and lower lifetime incidence of depression as compared to siblings of adults with mental illness (Taylor, Greenberg, Seltzer, & Floyd, 2008).

The above findings suggest that having a sibling with a DD affects an individual differently than having a sibling with mental illness. Overall, it appears that the sibling
experience is more positive for siblings of adults with a DD than siblings of adults with mental illness. It is unclear whether this positive experience is maintained when a sibling with a DD develops symptoms of a mental illness, or whether the presence of a mental illness negatively affects the sibling relationship. Siblings of adults with mental illness have better psychological well-being when they are able to emotionally distance themselves from the mentally ill individual (Seltzer et al., 1997). It is unknown whether this also holds true for siblings of individuals who have both a DD and a mental illness. This is an important area for exploration because of the significance of siblings in the lives of individuals with a DD (Krauss et al., 1992). If the presence of a mental illness in an individual with a DD leads to emotional distance in the sibling relationship, the individual with a DD is at risk of losing a essential component of his or her social support network (i.e., their sibling). Furthermore, this could potentially decrease the likelihood of the sibling taking on future care-giving roles.

**Other Life Stressors.** A review of the family stress literature in the DD field will reveal that most studies have focused on the individual with a DD as the stressor for families, and the literature has largely ignored the effect of other life stressors unrelated to the individual with a DD. Outside of the DD field, there is a vast body of literature that links stressful life events to symptoms of depression (e.g., Honkalampi et al., 2005; Liu, Nagata, Shono, & Kitamura, 2009; Mazure, 1998; Meyer & Paul, 2011; Monroe et al., 2001; Monroe et al., 2006; You & Conner, 2009). Research shows that stressful life events from childhood predict symptoms of depression in adults (Meyer & Paul, 2011).
Additionally, current life stressors contribute to the onset of symptoms of depression and the failure to recover from such symptoms (Honkalampi et al., 2005), as well as triggering the recurrence of major depressive disorder (Monroe et al., 2006). In order to have a more complete understanding of the mental health of adult siblings of individuals with a DD, it is therefore worthwhile to consider general life stressors (e.g., difficulties with work, finances, marriage, illness, etc.) in addition to the stressors associated specifically with the sibling with a DD.

**Moderator Variables**

*Resources.* In Perry’s (2004) model of stress, resources are divided into the individual’s personal resources and family system resources. The former type of resource refers to an individual’s beliefs, perceptions, cognitions, coping styles, and personality features. The latter type of resource refers to family functioning and family demographic variables.

Numerous individual personal resources have been linked to well-being and symptoms of depression in parents of individuals with a DD, including appraisal of stress (Minnes & Woodford, 2004) and coping styles (Essex, Seltzer, & Krauss, 1999). There is also some evidence that personal resources are related to well-being in siblings of individuals with a DD. Seltzer and colleagues (1997) found that siblings who perceived their brother or sister with a DD as having had a large positive effect on their life had greater well-being than siblings who perceived that the individual with a DD had a large negative effect on their life.
Family functioning can also contribute to parents’ and siblings’ well-being and mental health (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Seltzer et al., 1997). In a review of the literature, Stoneman (2005) emphasized the strong effect that healthy family characteristics, such as family cohesion, effective coping strategies, and low disorganization can have on siblings of individuals with a DD. In childhood, self-concept and social competence are positively correlated with family functioning (e.g., family relationships and organization) and negatively correlated with parental stress (Dyson, 1999). The family environment appears to have a stronger influence on siblings of individuals with a DD than it does on adults who do not have a sibling with a disability (Lynch, Fay, Funk, & Nagel, 1993; Seltzer & Krauss, 1993).

**Supports.** The research examining the relationship between both formal and informal supports and well-being in families of individuals with disabilities has generally focused on the well-being of parents. Both a greater number of informal supports (e.g., friends and family) and increased satisfaction with these supports have been linked to decreased stress and improved emotional well-being in parents of individuals with disabilities (White & Hastings, 2004; Hodapp et al., 1998). The research related to formal supports (e.g., psychological services, support groups) is mixed, with some studies finding that use of formal supports leads to an increase in emotional well-being (e.g., King et al., 1999) and other studies failing to find a relationship between these variables (e.g., White & Hastings, 2004).
Previous research related to symptoms of depression and stress also demonstrates positive effects from increased availability of formal and informal supports in parents of children with a DD (Gallagher et al., 2008; Saloviita, Itälinna, & Leinonen, 2003). It is clear that both formal and informal supports can benefit parents of individuals with a DD; however, there is a paucity of research related to the effects of supports on well-being and depressive symptoms in siblings of individuals with disabilities. An examination of the effects of supports on psychological well-being and depressive symptoms will contribute to our understanding of the needs of siblings of adults with a DD and will hopefully encourage service providers to address these needs.

**Perspectives of Individuals with DD**

By their very nature, sibling relationships are bi-directional, and thus, they affect both members of the sibling dyad. For over a decade, researchers have highlighted the need to include adults with a disability as participants in sibling research (e.g., Heller & Kramer, 2009; Seltzer & Krauss, 1993; Stoneman, 2005), yet to date, this recommendation has not been actualized. Siblings are one of the primary members of the support network for many adults with a DD (Krauss et al., 1992), and, therefore, strong sibling relationships are of considerable importance. An exploration of the sibling relationship from the perspective of the non-disabled sibling is underway in the research literature (e.g., Hodapp & Urbano, 2007; Seltzer et al., 1997); however, in order to obtain a complete understanding of this relationship, an exploration of the perspectives of siblings with a DD is warranted. Sibling research in the non-disabled population has
demonstrated that sibling relationship quality is associated with psychological well-being across the lifespan (Cicirelli, 1989; Sherman et al., 2006). Likewise, when one member of the sibling dyad has a DD, greater sibling relationship quality is related to better psychological well-being in the sibling without a disability (Seltzer et al., 1997). It is unknown whether the relationship between sibling relationship quality and well-being is present in adults with a DD.

Limitations of Previous Research and Objectives of the Current Study

The existing research that examines the psychological outcomes of having a brother or sister with a DD in adulthood is scarce. The few studies that have examined factors related to psychological outcomes in siblings have not employed a theoretical framework to guide the selection of variables to examine. Additionally, there is a paucity of information about the perspectives of adults with a DD themselves. Sibling relationships are inherently bi-directional, and thus, in order to fully understand the sibling experience when one member of the sibling dyad has a DD, it is imperative to include the perspectives of the siblings both with and without a DD.

Based on the above limitations, I conducted two studies to examine the experiences of adults with and without a DD. In the first study, I sought to apply a comprehensive theoretical model, which includes stressors, resources, and supports, to predict both positive and negative psychological outcomes in adult siblings of individuals with a DD. I predicted that both characteristics of the individual with a DD and life stressors not related to the sibling with a DD would predict psychological well-being and
depressive symptoms in adult siblings. Additionally, I expected that these relationships would be moderated by the individual and family resources available to the sibling and the formal and informal supports used by the sibling.

In the second study, I aimed to determine whether sibling relationship closeness is related to well-being in adults with a DD. I hypothesized that closer sibling relationships would predict greater well-being reported by the adults with a DD.

**Study 1**

**Method**

**Participants.** The original dataset included 196 participants; however, I excluded 14 participants due to missing data. For a description of the demographic characteristics of the total 196 participants, see the study described in Chapter 3.

This study included data from 182 adults (154 women and 28 men), aged 19 to 63 years ($M = 38.03$, $SD = 11.65$), who had at least one living adult sibling with DD. Adults whose siblings with a DD were children or were deceased were not included.

Most participants lived in Canada ($n = 84$; 46.2%) or the United States ($n = 89$; 48.9%); however, 9 participants (4.9%) lived in other countries. The majority of participants were married or in a common-law relationship ($n = 116$; 63.7%), and the remainder were single ($n = 54$; 29.7%) or separated / divorced ($n = 12$; 6.6%). Overall, the participants had completed a high level of education: 58 (31.9%) had a graduate or professional degree; 67 (36.8%) had an undergraduate degree; 24 (13.2%) had a college certificate; 22 (12.1%) had partial college or university; and 11 (6.0%) had a high school
diploma. The median reported annual household income was $75,000, and 149 (81.9%) of the participants were employed.

The participants’ siblings included 67 women and 115 men aged 17 to 70 years ($M = 36.35; SD = 12.22$). They had a variety of diagnoses: Down syndrome ($n = 62; 34.1%$); ASD ($n = 35; 19.2%$); cerebral palsy ($n = 20; 11.0%$); brain injury ($n = 6; 3.3%$); other syndromes/disorders ($n = 18; 9.9%$). Additionally, 34 (18.7%) siblings had an intellectual disability due to an unknown cause, and 7 (3.8%) had ASD and a comorbid disorder that causes intellectual disability. The comorbid disorders included Down syndrome ($n = 1$); tuberous sclerosis ($n = 1$); Fragile X syndrome ($n = 2$); cerebral palsy ($n = 1$); fetal alcohol spectrum disorder ($n = 1$); both fetal alcohol spectrum disorder and cerebral palsy ($n = 1$). The adaptive functioning of the participants’ siblings was measured using the Scales of Independent Behavior-Revised Short Form (see description below). Siblings’ total scores ranged from 3 to 117 ($M = 75.73, SD = 24.43$), which represent age equivalent scores that range from 0 to 31 years of age ($M = 8.05, SD = 5.21$).

**Measures.** The adults who had a sibling with DD completed the following questionnaires to measure stressors, resources, supports and services, and outcome variables. If the participant had more than one sibling with a disability, the instructions directed them to complete sibling-related questionnaires based on the sibling with a disability with whom they had the closest relationship.
The *Demographic Questionnaire* (Appendix A) asked participants about their gender, age, marital status, employment status, annual household income, the highest level of education they have achieved, the number of children they have, their country of origin, and the country in which they currently live.

**Sibling Characteristics.** The *Information about Siblings Questionnaire* (Appendix B) was used to collect demographic data about the participants’ sibling with a disability. Participants provided information about their siblings’ gender; age; and psychiatric issues, including both diagnosed psychiatric conditions (e.g., ‘obsessive-compulsive disorder’) and undiagnosed psychiatric symptoms (e.g., ‘serious anxiety problems but not a diagnosed disorder’). Additionally, participants identified the cause of their sibling’s disability, their sibling’s level of intellectual ability, their sibling’s physical or medical impairments, and where their sibling lives (e.g., ‘with parents’).

The *Scales of Independent Behavior-Revised Short Form* (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) assesses an individual’s everyday living skills. This scale measures adaptive behaviour including motor, social interaction, communication, and personal living skills, as well as maladaptive behaviour. This study only included the adaptive behaviour scale, which consists of 40 tasks that are progressively more difficult (e.g., ‘Washes and dries dishes and puts them away’ and ‘Makes purchases with a check’). Respondents rate the ability of the individual with a DD to do each of the tasks using a 4-point scale ranging from 0 (*never or rarely*) to 3 (*does very well*). Total raw scores on the adaptive behaviour scale range from 0 to 120,
and higher scores indicate higher adaptive functioning. The SIB-R Short Form has good test-retest reliability .86, and construct validity ranges from .67 to .96 being .95 overall (Bruininks et al., 1996).

Other Life Stressors. A modified version of the Life Events Inventory (LEI; Cochrane & Robertson, 1973; Appendix C) was used to measure stressful life events that participants had experienced over the past year. The original LEI contains 55 life events (e.g., ‘divorce’). Eight items were eliminated due to redundancy because the original version of the questionnaire includes separate sections for individuals who are ‘ever-married only’ and those who are ‘never-married only,’ and I did not make this distinction in my study. Thus, I used 47 of the original LEI items. For this study, participants indicated whether each event had occurred in the previous year (yes/no), and if it had occurred, they rated the extent to which they viewed the event as having either a positive or negative impact on their life at the time the event occurred using a 7-point scale ranging from -3 (extremely negative) to 3 (extremely positive). A score of 0 indicated that the event had no impact on the individual’s life. I computed a total LEI score by summing the 47 items. Thus, total possible scores ranged from -141 to 141. Positive total scores (i.e., greater than 0) indicate that the perceived net impact of life events was positive, with higher scores reflecting a greater number of positive life events. In contrast, negative total scores (i.e., less than 0) indicate that the perceived net impact of life events was negative, with lower scores reflecting a greater number of negative life events.
**Individual’s Personal Resources.** The *Life Domains Questionnaire* (Seltzer et al., 1997; Appendix D) asked participants to rate the extent that their sibling with a DD had affected 11 areas of their life, including career choice, where to live, whether to have children, religious beliefs, feelings about self, choice of romantic relationship, relationship with spouse, relationship with children, plans for own future, political views, and feelings about people with disabilities. Responses were made on a 4-point scale ranging from 0 (*not at all affected*) to 3 (*strongly affected*), and participants had the option to select ‘*not applicable*’ for items that were not relevant to them (e.g., ‘relationship with children’ for participants who did not have children). I then computed a mean score of the 11 items, with higher scores corresponding to the perception that siblings had a greater impact on participants’ lives. The Cronbach’s alpha for this study indicated that the scale had good internal consistency (*α* = .82).

**Family System Resources.** The *Family Assessment Device – General Functioning Scale* (FAD; Epstein, Baldwin, & Bishop, 2005) is a 12-item scale that measures overall family functioning (e.g., ‘we confide in each other’). Although this measure has previously been used with parents of individuals with a DD (e.g., Al-Krenawi, Graham, & Al Gharaibeh, 2011; Herring et al., 2006), it has not been used in the DD sibling literature. I asked participants to answer the questions based on their relationships with their parents and their siblings (rather than their spouse and their children). Participants rated each item using a 4-point scale ranging from 1 (*strongly agree*) to 4 (*strongly disagree*). I computed a mean score of the 12 items with higher scores corresponding to
greater family dysfunction. Previous research shows that the FAD General Functioning Scale has acceptable test-retest reliability (.71; Miller, Epstein, Bishop, & Keitner, 1985) and good internal consistency with a non-clinical sample (Cronbach’s α = .83; Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). The Cronbach’s alpha for this study indicated that the FAD General Functioning Scale had excellent internal consistency (α = .94).

**Informal Social Support.** The *Family Support Scale* (FSS; Dunst, Trivette, & Hamby, 1994; Appendix E) measures the perceived helpfulness of 18 types of formal (e.g., professional helpers such as therapists) and informal (e.g., spouse or partner) supports used over the past 6 months. I deleted two of the 18 items from the scale for this study because they pertain only to children (i.e., ‘early childhood intervention program’ and ‘school/day-care center’). Participants rated each type of support on a scale ranging from 1 (*not at all helpful*) to 5 (*extremely helpful*). They also had the option of selecting NA (*not available*). The FSS has good psychometric properties, including adequate internal consistency (Cronbach’s α = .79; r = .77 for split-half reliability) and good test-retest reliability (r = .91 for the total scale score when repeated after 1 month; Dunst et al., 1994). Based on the theoretical model used in this study, I divided the FSS items into informal supports (parents; spouse or partner’s parents; relatives/kin; spouse or partner’s relatives/kin; spouse or partner; friends; spouse or partner’s friends; own children; other siblings of people with DD; co-workers; sibling groups; social groups/clubs; and church groups/religious affiliations) and formal services (family physician; professional helpers such as social workers, therapists, etc.; and professional agencies). I used the 13 informal
supports to calculate a mean helpfulness of informal supports score. First, I re-coded the items by subtracting 1 from the participants’ responses on each item. Thus, the lowest score (not at all helpful) was represented by 0 rather than 1 and the highest score (extremely helpful) was represented by 4 rather than 5. Items rated as NA (not available) received scores of 0. I then summed the items to get a total score that reflected both the number of supports a person received and their satisfaction with these supports. The possible total scores ranged from 0 to 52, with higher scores corresponding to greater perceived helpfulness. The three formal services were added to the items measured in the Community Supports questionnaire described below.

**Formal Services.** The Community Supports Questionnaire (Appendix F) was designed for this study and it measured participants’ knowledge and use of formal community services (i.e., support groups, online support groups, education groups/workshops, and other Internet supports). Each category asked about services designed specifically for siblings of people with a DD and about supports designed for families of people with a DD in general, which resulted in a total of eight types of service. Participants indicated whether they were aware of the specific type of support (yes/no), whether they were currently using it or if they had used it in the past (yes/no), and how helpful they found the service, with the latter question being rated on a 5-point scale ranging from 1 (not at all helpful) to 5 (extremely helpful). If not using the named service, participants were asked the reason why not. I combined the helpfulness ratings from the 8 formal services with the helpfulness ratings from the three formal services on
the Family Support Scale (as described above) to create a mean helpfulness score. First, I re-coded the items by subtracting 1 from the participants’ responses on each item. Thus, the lowest score (not at all helpful) was represented by 0 rather than 1 and the highest score (extremely helpful) was represented by 4 rather than 5. If participants were not using a service, it received a score of 0. I then summed the items to get a total score that reflected both the number of supports a person received and their satisfaction with these supports. The possible total scores ranged from 0 to 44, higher scores corresponding to greater perceived helpfulness of the formal services.

**Outcomes.** The Scales of Psychological Well-Being (Ryff, 1989; Appendix G) consists of six scales that measure various aspects of an individual’s well-being, including Autonomy (e.g., ‘My decisions are not usually influenced by what everyone else is doing’), Environmental Mastery (e.g., ‘I am good at juggling my time so that I can fit everything in that needs to get done’), Personal Growth (e.g., ‘I have the sense that I have developed a lot as a person over time’), Positive Relations with Others (e.g., ‘Most people see me as loving and affectionate’), Purpose in Life (e.g., ‘I enjoy making plans for the future and working to make them a reality’), and Self-Acceptance (e.g., ‘In general, I feel confident and positive about myself’). Several versions of this measure exist, which vary in item length. I used a shortened version of the measure, which contains nine items on each scale (54 items in total). Participants rated each item on a 6-point scale ranging from 1 (strongly disagree) to 6 (strongly agree). Higher scores represent greater psychological well-being. The scales have good internal consistency.
(Cronbach’s $\alpha$ range from .83 to .91; Ryff, 1989). For this study, I created a total score by summing all 54 items (maximum total score = 324). This total score had excellent internal consistency (Cronbach’s $\alpha = .96$).

The *Center for Epidemiologic Studies Depression Scale* (CES-D; Radloff, 1977; Appendix H) was used to measure depressive symptoms. This 20-item scale assesses cognitive, affective, and somatic symptoms of depression over the previous week (e.g., “I had crying spells”). Participants rated each item on a scale from 0 (*less than 1 day*) to 3 (*5-7 days*); total scale scores range from 0-60, with higher scores indicating more depressive symptoms. The CES-D has good internal validity (Cronbach’s $\alpha$s = .84 to .90; split-half reliability $r = .76$ to .85). The Cronbach’s alpha for this study indicated that the CES-D had excellent internal consistency ($\alpha = .93$).

**Procedure.** This study consisted of a set of online questionnaires that took approximately 60 minutes to complete. I recruited participants through a variety of methods. First, I used email to contact staff and volunteer coordinators from organizations across Canada and the United States that support people with disabilities and their family members. In my initial contact emails, I provided the recipients with information about the study and inquired whether they would be interested in assisting me with recruitment. Those who agreed to assist me distributed information about my study in one or more of the following ways depending on which method worked best for the individual organization: 1) distributed an email to organization members through a listserv, 2) posted an online advertisement on the organization website or social media
Second, I posted online notifications about the study on several public websites that are targeted towards family members of individuals with disabilities through the social media sites facebook.com and yahoo.com. Third, I posted paper advertisements around a university campus and in community agencies for people with DDs in Kingston, Ontario. Each of the aforementioned types of recruitment communication provided potential participants with a brief description of the study, a link to access the online questionnaires, and my contact information.

Participants completed the questionnaires using one of two methods. Most participants (97.0%) completed the questionnaires online using Survey Monkey, a confidential database designed for the purpose of data collection. Upon entering the online database, participants read an information letter and they were informed that should they choose to continue with the study, it would be assumed that they were providing their consent to participate in the study (see Appendix I). Upon the completion of the questionnaires, participants read an online debriefing letter (see Appendix J). If a participant only completed a portion of the questionnaires, I sent them one reminder email requesting that they complete the remainder of the questionnaires.

Participants who preferred to complete the questionnaires in a paper format instead of online were asked to contact the researcher via email, telephone, or mail. I then mailed a paper copy of the information letter, questionnaires, and debriefing letter, as
well as a pre-addressed, stamped, return envelope to the participant. Six participants (3.0%)
chose to complete paper copies of the questionnaires.

As a thank you for their participation, individuals had the option of entering their name into a draw to win one of four $25 gift certificates to the Amazon website.

Results

Data Preparation. Prior to analyzing the data, I examined the variables for outliers, normality, and multicollinearity. I examined the z-scores and histograms for each continuous variable to identify univariate outliers. I replaced z-scores greater than 3.29 with a score one unit higher or lower than the next most extreme value in order to decrease the effect of the outlier (Tabachnick & Fidell, 2007). Next, I reviewed the skewness and kurtosis values, as well as histograms for each variable. All variables were normally distributed except the Formal Services scores (i.e., scores on the Community Supports questionnaire) and the CES-D scores, both of which were positively skewed. Therefore, I transformed these two variables using a square-root transformation (Tabachnick & Fidell, 2007). The transformations resulted in normal distributions for both variables. I then examined the variables for multivariate outliers using Mahalanobis distance (Tabachnick & Fidell, 2007), and did not find any such cases. Finally, there was no evidence of multicollinearity or singularity.

Descriptive Statistics. Tables 1 and 2 provide the descriptive statistics for each of the variables included in the moderated regression analyses.
Table 1

*Frequencies for Dichotomous Regression Variables*

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural/psychiatric symptoms</td>
<td>115 (58.7)</td>
</tr>
<tr>
<td>ASD diagnosis</td>
<td>45 (23.0)</td>
</tr>
</tbody>
</table>

*Note. ASD = autism spectrum disorder.*

Table 2

*Descriptive Statistics for Continuous Regression Variables*

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>Range of Possible Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total life events</td>
<td>-0.13</td>
<td>6.34</td>
<td>-22 – 14</td>
<td>-141 – 141</td>
</tr>
<tr>
<td>Mean life domain impact</td>
<td>1.41</td>
<td>0.73</td>
<td>0 – 3</td>
<td>0 – 3</td>
</tr>
<tr>
<td>Family functioning</td>
<td>2.03</td>
<td>0.70</td>
<td>1 – 4</td>
<td>1 – 4</td>
</tr>
<tr>
<td>Total helpfulness of informal supports</td>
<td>14.14</td>
<td>8.50</td>
<td>0 – 40</td>
<td>0 – 52</td>
</tr>
<tr>
<td>Total helpfulness of formal services(^a)</td>
<td>5.23</td>
<td>5.82</td>
<td>0 – 28</td>
<td>0 – 44</td>
</tr>
<tr>
<td>Symptoms of depression(^a)</td>
<td>11.79</td>
<td>11.13</td>
<td>0 – 48</td>
<td>0 – 60</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>244.63</td>
<td>38.51</td>
<td>151 – 311</td>
<td>54 – 324</td>
</tr>
</tbody>
</table>

\(^a\)Values were calculated using non-transformed data.

**Moderated Regression Analyses.** I computed Pearson correlations to determine whether demographic characteristics were related to CES-D or PWB scores. Gender was significantly correlated with CES-D scores, \(r = .16, p = .04\), with women reporting greater symptoms of depression than men on average. Likewise, age was correlated with CES-D scores, \(r = -.20, p = .009\), with younger participants reporting higher CES-D
scores. Additionally, PWB scores were significantly correlated with both age, $r = .16, p = .04$, and income, $r = .15, p = .05$. Greater psychological well-being was associated with increased age and greater income. In order to control for the effects of the significant demographic characteristics in the final regression models, I conducted two preliminary linear regression analyses: CES-D scores were regressed on gender and age, and PWB scores were regressed on age and income. The standardized residuals of these two regression analyses were saved.

In order to determine whether resources and stressors moderated the relationships between the stressor variables and the outcome variables, I conducted two linear regression analyses. The dependent variable for one regression was the standardized residual scores from the CES-D regression described above, and the dependent variable for the other regression was the standardized residual scores from the PWB regression described above. In order to facilitate the interpretation of significant interaction terms, I standardized all continuous variables prior to running the regression analyses. Additionally, I effects coded the two dichotomous variables (sibling has ASD diagnosis: -1 = no, 1 = yes; sibling has behavioural or psychiatric symptoms: -1 = no; 1 = yes). I created interaction terms by multiplying each standardized or effects coded stressor variable with each standardized resources/supports variable (e.g., life events * informal supports). Table 3 shows the results of the regression analyses. The overall models accounted for 30% of the variance in CES-D scores (adjusted $R^2 = .30$) and 37% of the variance in PWB scores (adjusted $R^2 = .37$).
Table 3

Results of Moderated Regression Analyses

<table>
<thead>
<tr>
<th></th>
<th>CES-D</th>
<th></th>
<th></th>
<th>PWB</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β</td>
<td>t</td>
<td>p</td>
<td>β</td>
<td>t</td>
<td>p</td>
</tr>
<tr>
<td>Life Events</td>
<td>-0.29</td>
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<td>&lt;.001</td>
<td>0.18</td>
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<td>.002</td>
<td>-0.31</td>
<td>4.59</td>
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<td>1.59</td>
<td>.12</td>
<td>-0.06</td>
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<td>.47</td>
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<td>Life Domain Impact</td>
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<td>.71</td>
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*Note.* CES-D = Center for Epidemiologic Studies Depression Scale; PWB = Scales of Psychological Well-being; ASD = autism spectrum disorder.
The results of the CES-D regression show that none of the interaction terms was significant; however, the conditional (simple) effects for life events scores and behavioural/psychiatric symptoms were significant. Thus, when the moderator variables have values of zero (i.e., they have a mean score because they are standardized) and the other predictor variables are held constant, participants who experienced more negative life events had higher symptoms of depression scores and participants whose sibling had behavioural/psychiatric symptoms had higher symptoms of depression scores.

The results of the PWB regression show that the life events by family dysfunction interaction was significant and the behavioural/psychiatric symptoms by family dysfunction interaction was significant. Figures 2 and 3 depict these interactions. In order to further explore the interactions, I conducted simple slopes analyses by examining the effect of life events and behavioural/psychiatric symptoms on PWB at low (1 SD below the standardized mean = -1.00) and high (1 SD above the standardized mean = 1.00) values of family dysfunction. I also used the Johnson-Neyman (J-N) technique based on the suggestions and SPSS script provided by Hayes & Matthes (2009). The J-N technique identifies the transition points in the range of values of the moderator variable where the effect of the predictor variable on the outcome variable changes from being significant to non-significant or vice versa (Hayes & Matthes, 2009).

For the life events by family dysfunction interaction, the simple slopes analysis showed a significant positive relationship between life events and psychological well-being when family dysfunction scores were one standard deviation below the mean. In
contrast, when family dysfunction scores were one standard deviation above the mean, the relationship between life events and psychological well-being was not significant.

*Figure 2.* Life events by family dysfunction (FAD) interaction for personal well-being.

*Figure 3.* Behavioural/psychiatric symptoms by family dysfunction (FAD) interaction for personal well-being.
The results of the J-N analysis show that the point of transition between significance and non-significance was at a family dysfunction standardized score of 0.14, $\beta = 0.15$, $t = 1.97$, $p = .05$. When participants had a standardized family dysfunction score of slightly above the mean or lower (which corresponds to lower amounts of family dysfunction) there was a significant positive relationship between life events and psychological well-being. Thus, the more positive life events the participant experienced, the greater their psychological well-being, and the more negative life events they experienced, the lower their psychological well-being. For participants whose standardized family dysfunction score was greater than 0.14 (which corresponds to higher amounts of family dysfunction), the relationship between life events and psychological well-being was not significant.

For the behavioural/psychiatric symptoms * family dysfunction interaction, the simple slopes analysis showed a significant negative relationship between behavioural/psychiatric symptoms and psychological well-being when family dysfunction scores were one standard deviation above the mean. In contrast, when family dysfunction scores were one standard deviation below the mean, the relationship between behavioural/psychiatric symptoms and psychological well-being was not significant. The results of the J-N analysis show that the point of transition between significance and non-significance was at a family dysfunction standardized score of -0.71, $\beta = -0.17$, $t = 1.97$, $p = .05$. When participants had a standardized family dysfunction score of nearly one standard deviation below the mean or higher (which corresponds to higher amounts of
family dysfunction) there was a significant negative relationship between having a sibling with behavioural/psychiatric symptoms and the participants’ psychological well-being. Participants whose sibling had behavioural/psychiatric symptoms had lower psychological well-being than those participants whose siblings did not have behavioural/psychiatric symptoms. For participants whose standardized family dysfunction score was lower than -0.71 (which corresponds to lower amounts of family dysfunction), the relationship between having a sibling with behavioural/psychiatric symptoms and participants’ psychological well-being was not significant.

**Study 2**

**Method**

**Participants.** This study included data from 17 adults with a DD (7 men and 10 women) and their parent/guardian. An additional parent completed the parent interview; however, her adult child did not want to participate in the study, so this parent’s data were not included. The adults with a DD ranged in age from 22 to 66 years ($M = 35.88$, $SD = 12.96$). Their parents/guardians provided information about the adults with a DD’s diagnoses. Of the 17 adults with a DD, 4 had an intellectual disability due to an unknown cause, 8 had Down syndrome, 1 had an autism spectrum disorder, 2 had an intellectual disability caused by birth trauma, and 2 had other syndromes.

The parents/guardians (1 man and 16 women) included 10 biological parents, 1 adoptive parent, 5 siblings, and 1 caregiver who had known the adult with a DD for 7
years. They ranged in age from 31 to 78 years ($M = 58.12$, $SD = 13.82$). Eight of the parents/guardians lived with the adult with a DD, two lived with them part-time, and seven did not currently live with the adult with a DD.

Measures. The adults with a DD and their parents completed the following questionnaires to measure their sibling relationship characteristics and their well-being.

Sibling Relationship Characteristics. The Lifespan Sibling Relationship Scale (LSRS; Riggio, 2000) measures feelings, behaviours, and thoughts related to sibling relationships in both adulthood and childhood. For this study, the LSRS was modified for use with the participants with a DD (Appendix K). I collaborated with my supervisor to modify the language of the measure to a level that was appropriate for use with adults with mild to moderate intellectual disability. To reduce the complexity of this measure, participants completed the questions related to their relationship during adulthood but not the questions related to their relationship during childhood. The three scales used in this study were Adult Affect (e.g., “My sibling makes me happy”), Adult Behaviour (e.g., “My sibling and I share things with each other”), and Adult Cognition (e.g., “My sibling thinks I am important”). Participants made responses using one of two scales: (1) a 2-point scale (1 = no; 2 = yes) or (2) a 3-point scale (1 = no; 2 = sometimes; 3 = yes). The response scale used for each participant was determined using the criteria outlined in the Personal Wellbeing Index – Intellectual Disability (described below). This measure includes instructions for determining a participant’s level of understanding of rating scales. Thus, if a participant was deemed able to use a 3-point scale according to the
Personal Wellbeing Index, a 3-point scale was also used for the LSRS, etcetera. In order to examine the test-retest reliability of this measure, participants completed the measure at two time points – once during the initial interview and a second time 2 weeks later. The psychometric properties of this scale are described in the Results section below.

**Well-being.** The *Personal Wellbeing Index – Intellectual Disability* (PWI-ID; Cummins & Lau, 2005; Appendix L) is a measure of well-being designed specifically for use with people with DD, and it consists of two parts. Part I is a single item that asks respondents about how happy they are with their life as a whole. Part II includes seven items and asks respondents how happy they feel about each item (e.g., “how things will be later on in your life”). For both parts of the scale items are rated on a multi-point scale. The PWI-ID has a detailed manual that includes instructions to determine whether participants are acquiescing and whether they are able to understand a multi-point scale. Prior to starting Part I of the measure, a series of questions are asked to determine whether the participant is able to use an 11-point, 5-point, 3-point, or 2-point scale to answer the questions. Previous research shows that the PWI-ID has adequate internal reliability (Cronbach’s $\alpha = 0.76$); however, it has limited test-retest reliability ($r = .57$; McGillivray, Lau, Cummins, & Davey, 2009).

**Parent Information.** The parent/guardian of the adults with a DD in Study 2 completed the *Information about Adults with an Intellectual Disability* (Appendix M) in a telephone interview. This questionnaire was designed for this study, and it was used to collect further information about the adults with a DD who participated in the study. The
questionnaire included demographic information about the parent/guardian (i.e., gender, birth year, and relationship to adult with DD). Parents/guardians also provided information about with whom the adult with a DD lives, how long the parent/guardian has known the adult with a DD (if the parent/guardian is not a biological parent), and about the siblings of the adult with a DD (gender, age, and frequency of contact). Finally, parent/guardian was asked about the cause(s) of the adult with a DD’s disability, who made the diagnosis, when the diagnosis was made, and whether the adult with a DD has any other diagnoses (e.g., epilepsy, psychiatric disorder, etc.).

Procedure. I recruited adults with developmental disabilities through various community organizations that support individuals with DD in Kingston and Ottawa, Ontario. First, I contacted the agencies and informed them about my study. If they were interested in assisting me with recruitment, then we agreed upon an approach to recruitment. One organization requested that I speak to the adults with DD first about my project and then contact the parents if the adult with DD was interested in participating. The remainder of the organizations requested that they pass along my recruitment information (e.g., email, fliers) to the parents of the adults with DD. Then, those families who were interested in participating contacted me via telephone or email. I obtained consent from the parent/guardian for both the parent/guardian to participate and for the adult with DD to participate (Appendix N). Additionally, I obtained verbal assent from the adults with DD prior to participation (Appendix O).
Once I obtained consent, I communicated with the individual with DD and his/her parent/guardian and/or the supporting agency to arrange a time to complete an individual, in-person interview that took approximately 20 minutes to complete. I conducted interviews in locations that were convenient for the participant (e.g., at the agency where the participant was recruited or at a local fast-food restaurant). Prior to commencing the questionnaires, I asked participants a series of questions from the PWI-ID to determine whether they were prone to acquiescing and if they were able to understand and use a multi-point scale.

In order to evaluate the test-retest reliability of the modified LSRS used in this study, the adults with DD completed this measure twice – once during the initial interview and a second time two weeks later. The second interview only included the LSRS and took approximately 5 minutes to complete.

I also conducted a telephone interview with the parent/guardian of the adult with DD that took about 15 minutes. During the interview, I completed the Information about Adults with an Intellectual Disability – Parent Version questionnaire with the parent, and I made arrangements to interview the adult with DD if necessary.

As a thank you for their participation, individuals with a DD had the opportunity to enter their name into a draw to win a $10 gift certificate. The parents/guardians of the adults with DD did not receive any form of compensation for their participation.
Results

The adults with a DD completed the PWI-ID as a measure of their overall well-being. The scoring manual of the PWI-ID indicates that data from participants who score the maximum possible score on the PWI-ID should be excluded from data analysis because it is not possible to determine whether this high score is an accurate reflection of their perceptions or whether it is due to acquiescence, which is a common issue when working with individuals with intellectual disability (Cummins & Lau, 2005). In my sample, five of the first eight participants (63%) who completed interviews scored the maximum possible score. Given this disproportionately large number of people who would therefore be excluded from the data analyses, I decided to discontinue using the PWI-ID as I deemed it unethical to continue to administer a measure that would knowingly not be included in the final analyses. Therefore, no analyses were conducted to determine whether closer sibling relationships were related to greater well-being in adults with a DD.

I did continue to complete the LSRS with all participants in order to examine the psychometric properties of this modified version of the scale. Of the 17 participants who completed the LSRS, 14 were able to use a 3-point response scale, and the other three used a 2-point response scale. The internal consistency of the Behaviour scale was good (Cronbach’s $\alpha = .88$); however, the internal consistency of the Affect and Cognition scales was unacceptably low (Cronbach’s $\alpha = .38$ and .49, respectively). The test-retest
reliability was in the acceptable range for the Behaviour and Cognition scales \( r = .79 \) and \( .78 \), respectively); however, it was in the poor range for the Affect scale \( r = .52 \).

**Discussion**

The two main foci of these studies were to examine how specific characteristics of siblings with a DD affect psychological outcomes in adult siblings without a DD and to determine whether sibling relationship quality relates to well-being in adults with a DD. A theoretical model was used to identify the stressors that contribute to the psychological well-being and symptoms of depression in adults who have a sibling with a DD. Additionally, the structure of this model allowed me to identify the variables that moderate the relationship between the stressors and the psychological outcomes. I predicted that both characteristics of the individual with a DD and life stressors not related to the sibling with a DD would predict psychological well-being and depressive symptoms in adult siblings. This hypothesis was supported. Both the presence of behavioural or psychiatric symptoms in the sibling with a DD and general life stressors were related to psychological well-being and depressive symptoms. Additionally, I expected that the relationships between the stressors and outcome variables would be moderated by the individual and family resources available to the sibling and the formal and informal supports used by the sibling. This hypothesis was only partially supported. Family dysfunction moderated the relationship between behavioural or psychiatric symptoms and psychological well-being and between general life stressors and
psychological well-being. In contrast, none of the variables moderated the relationship between the stressors and symptoms of depression.

The second component of the study focused on the perspectives of adults with a DD and aimed to determine whether closer sibling relationships predict greater well-being. Unfortunately, I was unable to meet this objective due to complications with the measurement tools selected for this study.

**Experiences of Adult Siblings who do not have a DD**

This study used a theoretical model of stress developed by Perry (2004) for predicting positive and negative outcomes in parents of children with a DD. The model suggests that characteristics of the individual with a DD and general life stressors predict positive and negative outcomes; however, these relationships are moderated by individual and family resources and formal and informal supports. Consistent with previous research outside of the DD field, which shows that stressful life events predicts symptoms of depression (Honkalampi et al., 2005; Liu et al., 2009; Mazure, 1998; Meyer & Paul, 2011; Monroe, et al., 2001; Monroe et al., 2006; You & Conner, 2009), I found that general life stressors predicted symptoms of depression and psychological well-being in adult siblings of individuals with a DD. Participants reported lower psychological well-being and higher symptoms of depression when they experienced more negative life events. Additionally, I found that having a sibling with a DD and behavioural or psychiatric symptoms was related to higher reported symptoms of depression and lower psychological well-being as compared to having a sibling with a DD alone. These
findings are consistent with those of Esbensen et al. (2006) who found that symptoms of depression in adult children with an intellectual disability were predictive of symptoms of depression in mothers.

However, family dysfunction moderated the relationships between the significant stressor variables and psychological well-being. Specifically, participants who had low levels of family dysfunction reported lower psychological well-being when they experienced more negative life events. In contrast, life events were not related to psychological well-being for participants who reported high levels of family dysfunction. These findings suggest a possible resilience that develops from having a family that is more dysfunctional. In other words, individuals who come from well functioning families may not be accustomed to experiencing negative life events. Thus, when such events occur, these individuals may be less well equipped to deal with the events, which therefore results in a negative impact on their psychological well-being. In contrast, when individuals come from more dysfunctional families, they are likely exposed to a greater number of stressors on a regular basis. Thus, when more significant negative life events do occur, these individuals may apply more effective strategies for coping with them.

Additionally, participants who had moderate to high levels of family dysfunction reported lower psychological well-being if their sibling with a DD also had behavioural or psychiatric symptoms as compared to participants whose siblings had a DD alone. In contrast, for participants who reported very low levels of family dysfunction (i.e., scores close to one standard deviation below the mean), having a sibling with a DD and
behavioural or psychiatric symptoms was unrelated to the participant’s well-being. The significant moderation effect of family dysfunction is consistent with previous research that highlights the importance of family functioning in relation to the outcomes of siblings of individuals with a DD (Stoneman, 2005). When an individual with a DD experiences mental health problems, it places an added burden on family members (Faust & Scior, 2008). Families that act cohesively, communicate well, and address problems effectively will likely adapt to this added burden better than families that are more dysfunctional. Well-adjusted families may be more open to discussing the need for assessment and treatment and seeking these services for individuals with a DD and behavioural or psychiatric symptoms, thus reducing the likelihood of siblings being in conflict with other family members regarding the care of the individual with a DD. Additionally, in well-adjusted families, siblings who are caregivers of a brother or sister with a DD and behavioural or psychiatric problems may receive more support from other family members than those siblings from families that are more poorly adjusted. Thus, the added stress of having a sibling with a DD and behavioural or psychiatric symptoms appears to have a weaker relationship with psychological well-being when siblings have a family that is well-equipped to manage this stressor.

In contrast to psychological well-being, none of the resources or support variables moderated the relationship between the stressor variables and symptoms of depression. These findings contradict some previous research with the general population that shows resources (Spence, Sheffield, & Donovan, 2002) and supports (Chou & Chi, 2001) do
moderate the relationship between negative life events and symptoms of depression. However, other studies have found that resources (e.g., self-perceived competence, sense of control) act as a mediator between life events and symptoms of depression, rather than as a moderator (Chou & Chi, 2001; Tram & Cole, 2000). Thus, the lack of a moderation effect found in my study may be because the variables included have a mediational relationship (i.e., they account for the relationship between the stressor variables and depressive symptoms; Baron & Kenny, 1986), rather than a moderational relationship (i.e., they affect the direction or strength of the relationship between the stressor variables and depressive symptoms; Baron & Kenny, 1986). Additionally, the participants’ use of supports was low in this study and their depression scores were highly skewed. Therefore, a restricted range of scores for the supports variables and the depression variable may have impeded the ability to detect a significant moderator effect. Furthermore, both of the support measures used in this study examined actual use of specific supports as opposed to perceived availability of supports. Measures such as the Interpersonal Support Evaluation List (ISEL; Cohen & Hoberman, 1983), which assess the perceived availability of non-specific informal support, might yield different results than those found in my study.

Having a sibling with an ASD was not a significant predictor of either psychological well-being or symptoms of depression. These findings contradict some previous research that shows siblings are negatively impacted by having a brother or sister with an ASD (Fisman et al., 1996; Hastings, 2003; Hodapp & Urbano, 2007;
One explanation for this finding is that a large portion of the individuals with an ASD also had behavioural or psychiatric symptoms, and therefore, this may have decreased the amount of unique variance that ASD contributed to the regression model.

**Experiences of Adult Siblings who have a DD**

Due to difficulty with the measure of well-being used in this study, I was not able to determine whether sibling relationship closeness predicted well-being in adults with a DD. Although the measure of well-being was specifically designed for adults with a DD, its use is limited to those who are functioning at a higher cognitive level than the majority of participants who volunteered for my study. I am unaware of any alternative measures of well-being that have been designed for use with individuals with a DD; however, future research could include measures of quality of life that have been designed for individuals with a DD (see Townsend-White, Pham, & Vassos, 2012 for a review).

Despite the complications with the well-being measure, I was able to evaluate some of the psychometric properties of the Lifespan Sibling Relationship Scale that was modified for use with adults with a DD in this study. Examination of the internal consistency and the test-retest reliability of this measure revealed that only the Adult Behaviour scale had adequate psychometric properties. The internal consistency of the Adult Affect and Adult Cognition scales and the test-retest reliability of the Adult Affect Scale were in the poor to unacceptable ranges. Thus, the version of the LSRS used in this
study requires further modification before it can be considered an acceptable measure of sibling relationship quality for use with adults with a DD.

There is a growing awareness of the need to include the perspectives of adults with a DD in research (Seltzer, Greenberg, Orsmond, & Lounds, 2005). This is of particular importance when examining sibling relationships, which are inherently bidirectional, and therefore cannot be fully understood without the perspective of both members of a sibling dyad. However, as this study demonstrates, there are additional challenges with measuring variables when working with individuals with a DD. It will be important for researchers to continue to develop psychometrically sound quantitative measurement tools that can be used to measure sibling relationship characteristics in adults with a DD who have a range of cognitive abilities. Additionally, qualitative research designs may provide useful information about sibling relationships, particularly when working with adults who struggle with rating scales commonly used on quantitative measures. Finally, the use of observational research could provide greater insight into how adults with a DD communicate with and interact with their siblings.

Limitations and Directions for Future Research

There are some important limitations to these studies. The theoretical model used in Study 1 identifies eight categories, and within each of these is a wide range of variables that could be examined. Due to the limited sample size in this study, I was limited in the number of variables that could be included in each category. Thus, it is possible that the variables selected were not the best possible measures, although their
selection was based on findings from previous research and their statistically significant relationship to the dependent variables. Additionally, the use of supports was particularly low amongst the participants. Thus, the restricted range of scores for formal supports may have limited the ability to detect a moderation effect of supports. It will be worthwhile for future research to examine alternative moderator variables (e.g., coping style, self-efficacy, locus of control, etc.) to determine whether they impact the relationship between stressors and both positive and negative psychological outcomes in adult siblings of individuals with a DD. Further research is also needed to compare different theoretical models to determine whether Perry’s (2004) model is the most appropriate model for understanding stress in adult siblings.

A second limitation of the measures used in this study is the potential for response bias in self-reporting. Participants were aware of the general purpose of the study, and thus, it is possible that some participants responded in a socially desirable manner, particularly on the measures of psychological well-being and depressive symptoms, so as to avoid implicating their sibling with a disability. Although it is difficult to avoid response bias in self-report measures, future studies could incorporate more objective measures, such as clinician evaluation of depressive symptoms.

The characteristics of the participants’ siblings could also have impacted the findings of this study. As described above, a large portion of the participants who had behavioural or psychiatric symptoms also had an ASD diagnosis. Thus, the shared variance between these two variables may have impacted the results of the regression
analyses. To clarify the relationship between ASD and psychiatric symptoms, and how these relate to siblings’ depression and well-being, future research could compare siblings of individuals with an ASD and limited or no behavioural problems to siblings of individuals with an ASD who have a clear psychiatric diagnosis. This would further clarify whether the effect of having a sibling with an ASD and psychiatric symptoms is different from having a sibling with an ASD alone. Additionally, a replication of my study with the exclusion of individuals with an ASD diagnosis would further clarify the relationship between having a sibling with a DD (other than ASD) in addition to behavioural or psychiatric symptoms and the psychological well-being and depressive symptoms of siblings without a DD.

As described above, Study 2 was limited by the measure used to determine well-being in adults with a DD. Despite being designed specifically for use with individuals who have a DD the majority of participants’ responses to this measure were invalid because they reached the maximum score on the Likert-type rating scale. It is not possible to determine whether these high scores were an accurate reflection of participants’ perceptions, a result of acquiescence, or a result of the limited response options because most participants were only able to understand how to use a 2- or 3-point scales. Due to the limitations of the well-being measure, I was not able to determine whether sibling relationship closeness predicted well-being in adults with a DD. Further research is necessary to develop measures of well-being and sibling relationship closeness that can be used reliably with adults with DDs who have a range of cognitive
abilities. Given the issues related to the use of the Likert-type scale in my study, it would be useful to employ alternative methods of measurement. The literature on social support may offer useful directions for determining a more effective way to examine sibling relationship closeness. For example, in a study focused on the social support of adults with mild intellectual disabilities, Lunsky and Neely (2002) used a measure that involved identifying individuals in one’s life who provide social support by placing them in concentric circles (i.e., people who provide the most support are placed in the closest circle and those who provide the least support are placed in the farthest circle). Additionally, Lunsky and Neely asked participants questions about who provides various types of support (e.g., ‘Is there someone you can count on for pleasant companionship? Who?’). Such approaches could provide information about perceived closeness in the sibling relationship without requiring the use of rating scales.

**Theoretical Implications**

To date, the literature on sibling relationships in the DD field has not examined any specific theoretical models to determine their utility in understanding how people are affected by having a sibling with a DD (Stoneman, 2005). This study used a theoretical model adapted from the parenting stress literature, which provided a framework for selecting stressor variables, moderator variables, and both a positive and negative outcome variable. The model was chosen for several reasons. First, it includes both positive and negative outcome variables. For many years, researchers have highlighted the need to increase our focus on the positive outcomes in the DD field (Findler & Vardi,
Second, it includes characteristics of the individual with a DD as a stressor variable, but it also incorporates general life stressors. Outside of the DD field, general life stressors are often included when examining symptoms depression as an outcome variable (e.g., Andrews & Wilding, 2004; Honkalampi et al., 2005; Monroe et al., 2001; Monroe et al., 2006; You & Conner, 2009). However, within the DD field the tendency has been to focus solely on the individual with a DD as the stressor and to ignore other life stressors. Third, this model includes moderator variables, which allows for a more complex analysis of the relationship between the stressor variables and the outcome variables. To date, limited focus has been given to examining mediator or moderator variables in the sibling literature (Stoneman, 2005).

The statistically significant stressor variables (i.e., life events and having a sibling with a DD and behavioural or psychiatric symptoms) were the same for the positive outcome, psychological well-being, and for the negative outcome, symptoms of depression. However, family dysfunction was a significant moderator for psychological well-being, whereas none of the moderator variables showed a significant interaction with the stressor variables for symptoms of depression. This highlights the importance of including both positive and negative variables as separate outcomes when doing research with adult siblings of individuals with a DD. Additionally, the results of this study support the inclusion of general life stressors when examining outcomes for siblings.
Thus, the focus should not be solely on the stressors related to the brother or sister with a disability.

For psychological well-being, the only significant moderator variable was family dysfunction, which represented the family system resources component of the model. The variables that represented the individual’s personal resources, informal social supports, and formal supports and services were not significant moderators. This finding suggests that the relationships and interactions within the family of origin contribute to how siblings adapt to both general life stressors and the stressors associated with having a brother or sister with a disability. In contrast, the individual’s own resources (e.g., perceptions) and their use of services and supports outside of the family of origin did not contribute to the effect that the stressors had on the siblings’ psychological well-being.

Because this study is the first to utilize Perry’s (2004) model with siblings, it would be premature to conclude that an individual’s personal resources and their use of informal and formal services and supports are unrelated to their psychological well-being and symptoms of depression. Future research that examines other types of personal resources (e.g., coping style) is warranted. Additionally, the use of both formal and informal supports was relatively low for participants in this study. Thus, the restricted range of scores may have impacted the results of the regression analyses. The low use of supports, especially formal services and supports, may relate to the paucity of resources that are available specifically for adults who have a sibling with a DD. Replication of this study with a participant sample that uses a broader range of supports would be beneficial;
however, such a sample may be difficult to obtain given the lack of existing sibling services. Therefore, a more realistic approach at this time may be to focus on clinical research that examines whether new and existing services and supports have an impact on the psychological well-being of adults who have a sibling with a DD. For example, qualitative research could be used to investigate the experiences of adults who participate in adult sibling workshops or are members of online sibling support networks to determine why they use these supports, what benefits they gain, and whether they perceive these supports as having impacted their well-being.

In contrast to the psychological well-being findings, none of the moderator variables used in this study was significant for the symptoms of depression variable. Again, it would be premature to conclude from this study alone that Perry’s (2004) model is not appropriate for examining symptoms of depression in adults who have a sibling with a DD. Prior to drawing such conclusions, it would be pertinent for future research to examine alternative resource (e.g., coping style, sibling relationship quality, marital satisfaction) and support variables to determine whether these may in fact act as moderators between the stressors and depressive symptoms in adults who have a sibling with a DD. Additionally, the issues related to restricted range, discussed above, may have impacted the findings related to use of formal and informal supports.

Clinical Implications

Having a family member with a DD can be challenging for both parents and siblings. Oftentimes, in both research and clinical practice, professionals focus on the
impact of the individual with a DD and how to change that individual (e.g., decrease maladaptive behaviour) when other family members are being affected by the individual with a DD. The findings from this study suggest that although the characteristics of the individual with a DD can affect the psychological well-being of siblings, this effect is moderated by family dysfunction. Therefore, support, education, and therapy that focus on the family as a whole may be an important approach for fostering healthy psychological well-being in adult siblings of individuals with a DD.

The findings from this study also show that the presence of behavioural or psychiatric symptoms in individuals with a DD is related to higher symptoms of depression in some adult siblings. Although a causal relationship cannot be determined from this study, the findings do suggest that clinicians working with adults with a DD who have behavioural or psychiatric symptoms should be aware that siblings may also be at increased risk of mental health issues. Thus, these siblings may need additional supports and resources such as referrals for individual or group counseling, information about stress management techniques, or assistance with navigating the challenges associated with having a sibling with a DD (e.g., simultaneously caring for the sibling, aging parents, and the individual’s own children; communicating with other family members about future caregiver roles; managing familial conflict regarding issues related to the individual with a DD, etc.).
Conclusions

The primary objective of this study was to evaluate the utility of a theoretical model of stress adapted from the DD parent literature for predicting positive and negative psychological outcomes in adult siblings of individuals with a DD. Being the first study to apply a theoretical model of stress with adult siblings in the DD literature, this study provides several important findings. First, the relationship between the stressor variables and moderator variables differed for the positive (psychological well-being) and the negative (symptoms of depression) outcome variables. This highlights the importance of including both positive and negative outcomes as separate constructs when studying siblings, rather than defining positive outcomes as the absence of negative symptoms (e.g., symptoms of depression, anxiety). Second, this study identified two variables that predict psychological well-being and depressive symptoms that have not been previously examined in adult siblings: general life stressors and having a sibling with both a DD and serious behavioural or psychiatric symptoms. There is a need for future research to further examine how siblings and sibling relationships are affected when individuals with a DD also develop symptoms of a mental illness. Third, the findings from this study demonstrate that family dynamics play an important role in moderating the negative effect of general life stressors and having a sibling with a DD and behavioural or psychiatric symptoms on siblings’ psychological well-being. Additional research is necessary to identify other moderators for adult siblings of individuals with a DD.
Chapter 3

How are Siblings affected when their Brother or Sister with a Developmental Disability has Symptoms of a Mental Illness?

Serious mental illness can have a significant impact on family members, including siblings. Many adult siblings report experiencing a multitude of emotions in response to their brother or sister’s mental illness, including feelings of anger, sadness, guilt, and fear (Lively, Friedrich, & Buckwalter, 1995; Lukens, Thorning, & Lohrer, 2004; Riebschleger, 1991). Because of the timing of onset of mental illness, many siblings (and parents) feel an intense sense of loss as the previously ‘normal’ sibling undergoes changes in their personality, motivations, behaviours, and cognitive abilities (Stein & Wemmerus, 2001). This loss can result in a prolonged period of grieving for the family members of the individual with a mental illness (Riebschleger, 1991).

In addition to their emotional response to the individual with a mental illness, some siblings report a negative impact of the mental illness on their own relationships. Friends or spouses/intimate partners may struggle to understand siblings’ experiences and needs (Lively et al., 1995; Lukens et al., 2004), and some siblings report a significant decrease in relationship closeness with their brother or sister after the onset of his or her mental illness (Gerace, Camilleri, & Ayres, 1993; Lively et al., 1995). Additionally, the stressors associated with having a family member with a mental illness can negatively affect siblings’ physical and mental health (Lively et al., 1995).
Despite the negative effects described above, Chen and Lukens (2011) found that adult siblings of individuals with serious mental illness report greater emotional well-being and fewer symptoms of depression than their parents. Moreover, some siblings are able to maintain a strong, healthy relationship with their brother or sister with a mental illness (Gerace et al., 1993), and many siblings also report an intention to provide emotional support to their brother or sister with a mental illness when their parents are no longer able (Hatfield & Lefley, 2005).

**Sibling Relationship Comparisons: Developmental Disability versus Mental Illness**

Siblings of individuals with a DD share a number of experiences with siblings of individuals with a mental illness. For example, Seltzer et al. (1997) highlight that both groups of siblings are aware of having to potentially take on a caregiver role for the sibling with a disability when parents are no longer able, both groups are faced with the challenge of balancing the increased needs of their sibling with a disability with their own personal lives, and both groups may have fears related to their own children and the heritability of the disability. Despite these similarities, a number of key differences exist between the experiences of these two groups of siblings.

First, the timing of diagnosis differs between these two groups (Greenberg et al., 1999; Seltzer et al., 1997). Developmental disabilities are typically diagnosed at birth or in early childhood, and thus, siblings grow up always knowing that their brother or sister has a disability. From an early age, the sibling relationship is often less egalitarian than a typical sibling relationship, and the sibling without a disability is often expected to take
more of a caregiver role than is expected in typical sibling relationships. In contrast, mental illness is typically diagnosed in adolescence or early adulthood. Thus, siblings would develop a typical sibling relationship throughout childhood that is then altered at a later point in life when the symptoms of mental illness begin to present.

A second factor that distinguishes between the experience of having a sibling with a DD and having a sibling with a mental illness is the course of the disorder (Greenberg et al., 1999; Seltzer et al., 1997; Taylor et al., 2008). Developmental disabilities, although associated with deficits in adaptive behaviour and often problem behaviours as well, tend to be relatively stable throughout the life span. Thus, the siblings of individuals with a DD know what they can expect from their brother or sister regarding their personality characteristics and their abilities in daily living skills, communication skills, and interpersonal relationship skills. In contrast, the course of a mental illness is often much less predictable. An individual’s ability to participate in activities of daily living and engage in interpersonal relationships can vary greatly depending on life stressors, medication use and effectiveness, and receipt of appropriate psychological treatment when they have a mental illness.

Third, Taylor et al. (2008) posit that families of individuals with a DD may have higher levels of solidarity compared to families that do not include a child with a disability, which results in siblings sharing a belief from a young age that they play an important role in the care of their brother or sister with a DD. In contrast, because mental illness is typically not diagnosed until later in life, siblings of individuals with mental
illness would likely not grow up experiencing the higher level of family solidarity that is present in families of individuals with a DD (Taylor et al., 2008).

The differences in the onset and course of DDs versus mental illness, and the differences in the age at which siblings identify their role as a caregiver, likely contribute to the differences that exist in the sibling relationship characteristics and relationship quality between sibling dyads that include an individual with a DD and sibling dyads that include an individual with a mental illness. Adult siblings of individuals with a DD provide more emotional support to their sibling with a disability and are more likely to expect to take on a caregiver role when parents are no longer able as compared to adult siblings of individuals with a mental illness (Greenberg et al., 1999). These differences may relate to the increased family solidarity and caregiver expectation that is present from a young age in families of individuals with a DD.

Seltzer et al. (1997) found that compared to adult siblings of individuals with a mental illness, adult siblings of individuals with a DD perceived their brother or sister with a disability as having a greater impact on numerous aspects of their lives, including their career choice, whether to have children, their choice of romantic relationships, their plans for their own future, and their feelings about people with disabilities. The authors attributed these differences to the differential onset of the disability. DDs have an onset in early childhood and therefore affect the sibling throughout their entire development. In contrast, mental illnesses typically have an onset in late adolescence or early adulthood, and therefore, siblings may have made many of their decisions about career, romantic
relationships, etcetera by the time their brother or sister is diagnosed with a mental illness. Furthermore, Seltzer et al. found that adult siblings of individuals with a DD reported more frequent face-to-face contact with their sibling with a disability and greater perceptions of sibling relationship closeness than adult siblings of individuals with a mental illness.

Taylor and colleagues (2008) compared the experiences of siblings of individuals with a DD (mild intellectual disability), siblings of individuals with a mental illness, and a control group of siblings of individuals who had neither a DD nor a mental illness. They found that both siblings of individuals with a DD and siblings of individuals with a mental illness had less contact with their brother or sister than siblings of people in the control group. Unfortunately, Taylor et al. used post hoc tests that did not include direct comparisons between the siblings of individuals with a DD and siblings of individuals with a mental illness; however, the mean scores suggest that siblings of individuals with a mental illness may have less contact with their brother or sister than siblings of individuals with a DD (mean number of contacts per year were 27 and 35, respectively). Additionally, the siblings of individuals with mental illness were more likely to have had a depressive episode and they reported lower psychological well-being than the control group. In contrast, siblings of individuals with a DD did not differ from the control group in history of previous depressive episodes or psychological well-being.

In summary, the limited research comparing the experiences of siblings of individuals with a DD and siblings of individuals with a mental illness shows that overall,
sibling relationships tend to be more positive when the sibling has a DD as compared to when the sibling has a mental illness.

**Prevalence of Psychiatric Disorders in the DD Population**

The prevalence rates of psychiatric disorders are higher in the DD population than they are in the general population. Although the estimates vary across studies, in part due to methodological differences, most studies report a prevalence rate of between 30% to 50% of individuals with a developmental disability having a psychiatric disorder (e.g., Cooper et al., 2007; Emerson, 2003; Morgan, Leonard, Bourke, & Jablenesky, 2008).

One factor that can complicate the study of psychiatric disorders in the DD population is the increased difficulty of accurately diagnosing these disorders in individuals with a DD. Oftentimes, symptoms of a psychiatric disorder are overlooked as being symptoms of the developmental disability itself – a phenomenon called ‘diagnostic overshadowing’. Furthermore, the criteria laid out in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) may not always be appropriate or easily measurable for individuals with DD. For example, identifying delusions, disorganized speech, and feelings of worthlessness or excessive guilt becomes increasingly difficult when working with individuals with a DD who are non-verbal. Lack of access to mental health professionals with specialized training in DDs can also result in psychiatric conditions being undiagnosed in individuals with a DD.

Despite the high prevalence of mental illness in the DD population, to date no previous studies have examined the impact of the co-occurrence of these two conditions,
commonly referred to as dual diagnosis, on adult siblings and their relationships with their sibling with a DD. However, the literature related to sibling relationships in the DD population and in the mental illness population suggests that an examination of the effects of a dual diagnosis on the sibling relationship is warranted.

Effects of Dual Diagnosis on Mothers

Although no previous studies examined dual diagnosis in siblings, the limited research related to the impact of dual diagnosis on mothers may offer some insight into how siblings might be affected. The studies that have examined family burden as an outcome show that having a child or adult child with a dual diagnosis is related to mothers reporting increased family burden as compared to mothers of children with intellectual disability alone (Irazábal et al., 2012; Maes, Broekman, Došen, & Nauts, 2003; Martorell, Gutiérrez-Recacha, Irazábal, Marsà, & García, 2011), behaviour disorders alone (Maes et al., 2003; Martorell et al., 2011) and schizophrenia alone (Martorell et al., 2011). Additionally, Esbensen et al. (2006) found that higher self-reported symptoms of depression in adult children with intellectual disability predicted higher symptoms of depression scores in mothers. However, symptoms of depression scores were not related to relationship quality. The presence of dual diagnosis appears to be more closely related to negative outcomes for parents rather than positive outcomes (e.g., perceived positive impact of the child with a dual diagnosis on the family), which may not be directly impacted by the child having a dual diagnosis (McIntyre et al., 2002).
Limitations of Previous Research and Objectives of the Current Study

Although previous research has examined the impact of dual diagnosis on parents, to date, no studies have examined the impact of dual diagnosis on siblings. Previous research shows that parents of children with dual diagnosis experience more negative outcomes than parents of children with a DD alone (Esbensen et al., 2006; Irazábal et al., 2012; Maes et al., 2003; Martorell et al., 2011; McIntyre et al., 2002). However, the experiences of siblings are not always consistent with those of parents (Chen & Lukens, 2011), and thus, it is unclear whether siblings of individuals with a dual diagnosis also experience more negative outcomes than siblings of individuals with a DD alone. There is evidence that adult siblings of individuals with mental illness have more negative perspectives about various aspects of their sibling relationship as compared to adult siblings of individuals with a DD alone (Greenberg et al., 1999; Seltzer et al., 1997). However, the effect of having a sibling with both conditions is unknown. Given that the prevalence rates of mental illness in the DD population are significantly higher than the typical population (Cooper et al., 2007; Emerson, 2003; Morgan et al., 2008), and that adult siblings are an important source of support for individuals with a DD (Seltzer et al., 2005), an examination of how dual diagnosis affects siblings and sibling relationship quality is warranted.

Thus, the focus of this study was a comparison of adults who have a sibling with a DD alone to adults who have a sibling with both a DD and either a diagnosed mental illness or serious behavioural or psychiatric symptoms to determine how the presence of
a mental illness affects sibling relationships. As described above, psychiatric disorders can be difficult to diagnose in individuals with a DD. Additionally, there is relatively high correlation between behavioural problems and psychiatric conditions in individuals with a DD (Myrbakk & von Tetzchner, 2008). Therefore, because the aim of this study was to examine sibling experiences rather than to provide accurate diagnostic information, siblings of individuals with a diagnosed mental illness and siblings of individuals with serious behavioural symptoms without a formal diagnosis or serious psychiatric symptoms without a formal diagnosis were included in the same group.

This study had four objectives. First, I aimed to determine whether siblings of adults with a DD and behavioural or psychiatric problems differ from siblings of adults with a DD alone in the extent that they perceive their sibling as having impacted various aspects of their life. Seltzer et al. (1997) found that siblings of adults with a DD reported greater life impact than siblings of adults with a mental illness. Seltzer and colleagues concluded that this difference related to the timing of onset of DD versus mental illness. Thus, consistent with the findings from the Seltzer et al. study, I predicted that the two groups in my study would not differ in the impact they perceived their brother or sister as having had on their life.

Second, I sought to compare the frequency of sibling contact and sibling relationship closeness between siblings of adults with a DD and behavioural or psychiatric problems and siblings of adults with a DD alone. Seltzer et al. (1997) reported that siblings of adults with a DD had more contact with their brother or sister than
siblings of adults with a mental illness. The findings from Taylor et al. (2008) also offer some support for this conclusion. Thus, I expected that when individuals had both a DD and behavioural or psychiatric problems, their siblings would spend less time with them as compared to siblings of individuals who had a DD alone. Additionally, Seltzer and colleagues found that siblings of individuals with a mental illness reported less relationship closeness than siblings of adults with a DD alone. Therefore, I expected that siblings of adults with a DD and behavioural or psychiatric problems would report less relationship closeness than siblings of adults with a DD alone.

Third, I examined whether siblings of adults with a DD and behavioural or psychiatric problems and siblings of adults with a DD alone differed in their psychological well-being and symptoms of depression. Based on the findings presented in the study described in Chapter 2 and Taylor et al.’s (2008) finding that siblings of individuals with mental illness were more likely to have a history of depression and reported lower psychological well-being, I predicted that siblings of individuals with a DD and behavioural or psychiatric symptoms would report higher symptoms of depression and lower psychological well-being than siblings of individuals with a DD alone.

Fourth, I examined the use of services and supports in siblings of adults with a DD and behavioural or psychiatric problems and siblings of adults with a DD alone. No previous research has examined service use in adult siblings of individuals with a DD or
a dual diagnosis. Thus, this objective was exploratory and did not involve specific hypotheses.

**Method**

**Participants**

This study included 196 adults who had at least one living adult sibling with DD. I excluded adults whose siblings with a DD were children or were deceased. I divided participants into two groups: (1) concurrent behavioural/psychiatric symptoms and a DD (2) DD alone. There is a strong relationship between psychiatric symptoms and problem behaviours in people with DD (Holden & Gitlesen, 2003; Moss et al., 2000; Myrbakk & von Tetzchner, 2008). Additionally, psychiatric disorders can be difficult to diagnose in people with DD (Myrbakk & von Tetzchner, 2008). Thus, participants who reported that their sibling with a DD had a psychiatric diagnosis or serious behavioural or psychiatric symptoms without a formal diagnosis were combined to form the behavioural/psychiatric symptoms group (n = 115). This group included 51 participants who reported that their siblings had behavioural or psychiatric symptoms without a formal diagnosis, 41 participants whose siblings had a formal psychiatric diagnosis, and an additional 23 participants whose siblings had both a formal psychiatric diagnosis and other undiagnosed psychiatric symptoms (e.g., formal diagnosis of major depressive disorder plus symptoms of anxiety that were not formally diagnosed). All other participants were assigned to the DD alone group (n = 81). Tables 4 and 5 provide demographic information about participants and their siblings, respectively.
Table 4

**Participant Demographic Information**

<table>
<thead>
<tr>
<th></th>
<th>Behavioural/psychiatric symptoms group (n = 115)</th>
<th>DD alone group (n = 81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of women (%)</td>
<td>98 (85.2)</td>
<td>67 (82.7)</td>
</tr>
<tr>
<td>Mean age in years (SD)</td>
<td>38.5 (11.8)</td>
<td>38.2 (11.9)</td>
</tr>
<tr>
<td>Age range in years</td>
<td>19 - 63</td>
<td>19 - 67</td>
</tr>
<tr>
<td>Country of residence n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>52 (45.2)</td>
<td>37 (45.7)</td>
</tr>
<tr>
<td>United States</td>
<td>56 (48.7)</td>
<td>41 (50.6)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (6.1)</td>
<td>3 (3.7)</td>
</tr>
<tr>
<td>Marital status n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/common law</td>
<td>71 (61.8)</td>
<td>56 (69.2)</td>
</tr>
<tr>
<td>Single</td>
<td>36 (31.3)</td>
<td>21 (25.9)</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>8 (6.9)</td>
<td>4 (4.9)</td>
</tr>
<tr>
<td>Mean number children living at home (SD)</td>
<td>0.6 (0.9)</td>
<td>0.6 (0.9)</td>
</tr>
<tr>
<td>Level of Education n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma</td>
<td>4 (3.5)</td>
<td>8 (9.9)</td>
</tr>
<tr>
<td>Some college/university</td>
<td>15 (13.0)</td>
<td>8 (9.9)</td>
</tr>
<tr>
<td>College certificate</td>
<td>14 (12.2)</td>
<td>10 (12.3)</td>
</tr>
<tr>
<td>Undergraduate degree</td>
<td>45 (39.2)</td>
<td>27 (33.3)</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>37 (32.2)</td>
<td>28 (34.6)</td>
</tr>
<tr>
<td>Currently employed n (%)</td>
<td>95 (82.6)</td>
<td>68 (84.0)</td>
</tr>
<tr>
<td>Median household income</td>
<td>$75,000</td>
<td>$75,000</td>
</tr>
</tbody>
</table>
Table 5

**Demographic Information for Participants’ Siblings with a DD**

<table>
<thead>
<tr>
<th></th>
<th>Behavioural/psychiatric symptoms group (n = 115)</th>
<th>DD alone group (n = 81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of women (%)</td>
<td>40 (34.8)</td>
<td>32 (39.5)</td>
</tr>
<tr>
<td>Mean age in years (SD)</td>
<td>37.1 (12.5)</td>
<td>35.8 (11.9)</td>
</tr>
<tr>
<td>Age range in years</td>
<td>17 - 70</td>
<td>21 - 69</td>
</tr>
<tr>
<td>Primary diagnosis n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Down syndrome</td>
<td>27 (23.5)</td>
<td>38 (46.9)</td>
</tr>
<tr>
<td>ASD</td>
<td>31 (27.0)</td>
<td>6 (7.4)</td>
</tr>
<tr>
<td>ASD + other diagnosis</td>
<td>6 (5.2)$^a$</td>
<td>2 (2.5)$^b$</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>9 (7.8)</td>
<td>12 (14.8)</td>
</tr>
<tr>
<td>Intellectual disability due to unknown cause</td>
<td>22 (19.1)</td>
<td>15 (18.5)</td>
</tr>
<tr>
<td>Brain injury</td>
<td>7 (6.1)</td>
<td>2 (2.5)</td>
</tr>
<tr>
<td>Other syndrome or disorder</td>
<td>13 (11.3)</td>
<td>6 (7.4)</td>
</tr>
<tr>
<td>Behavioural/psychiatric symptoms n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood disorder/symptoms</td>
<td>61 (53.0)</td>
<td></td>
</tr>
<tr>
<td>Anxiety disorder/symptoms</td>
<td>81 (70.4)</td>
<td></td>
</tr>
<tr>
<td>Psychotic disorder/symptoms</td>
<td>8 (6.9)</td>
<td></td>
</tr>
<tr>
<td>Serious behavioural symptoms</td>
<td>29 (25.2)</td>
<td></td>
</tr>
<tr>
<td>Other psychiatric diagnosis</td>
<td>14 (12.2)</td>
<td></td>
</tr>
<tr>
<td>Level of ID n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No impairment</td>
<td>5 (4.3)</td>
<td>4 (4.9)</td>
</tr>
<tr>
<td>Mild/borderline ID</td>
<td>19 (16.5)</td>
<td>13 (16.0)</td>
</tr>
<tr>
<td>Moderate ID</td>
<td>55 (47.8)</td>
<td>40 (49.4)</td>
</tr>
<tr>
<td>Severe ID</td>
<td>26 (22.6)</td>
<td>15 (18.5)</td>
</tr>
<tr>
<td>Profound ID</td>
<td>4 (3.5)</td>
<td>5 (6.2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>6 (5.2)</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td>SIB-R adaptive behaviour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean score (SD)</td>
<td>78.2 (20.5)</td>
<td>72.7 (29.1)</td>
</tr>
<tr>
<td>Range of scores$^d$</td>
<td>7 - 117</td>
<td>3 – 115</td>
</tr>
<tr>
<td>Mean age equivalent in years (SD)</td>
<td>8.2 (5.3)</td>
<td>7.8 (5.1)</td>
</tr>
<tr>
<td>Place of residence</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>With participant</td>
<td>13 (11.3)</td>
<td>6 (7.4)</td>
</tr>
<tr>
<td>With parents</td>
<td>52 (45.2)</td>
<td>43 (53.1)</td>
</tr>
<tr>
<td>With other family member</td>
<td>3 (2.6)</td>
<td>2 (2.5)</td>
</tr>
<tr>
<td>Group home/assisted living</td>
<td>26 (22.6)</td>
<td>18 (22.2)</td>
</tr>
<tr>
<td>Alone/roommates/partner</td>
<td>15 (13.0)</td>
<td>7 (8.6)</td>
</tr>
<tr>
<td>With other caregiver</td>
<td>6 (5.2)</td>
<td>5 (6.2)</td>
</tr>
</tbody>
</table>

Note. ASD = autism spectrum disorder; ID = intellectual disability.

a Other diagnoses include Down syndrome (n = 2); Fragile X syndrome (n = 2); tuberous sclerosis (n = 1); cerebral palsy (n = 1).
b Other diagnoses include Fetal Alcohol Spectrum Disorder (n = 1); Fetal Alcohol Spectrum Disorder + cerebral palsy (n = 1).
c The conditions listed under this heading are not mutually exclusive.
d Possible scores range from 0 to 120.

Measures

The Demographic Questionnaire (Appendix A) asked participants about their gender, age, marital status, employment status, annual household income, highest level of education achieved, number of children, country of origin, and country of current residence.

The Information about Siblings Questionnaire (Appendix B) was used to collect demographic data about the participants’ sibling with a disability. Participants provided information about their siblings’ gender; age; and psychiatric issues, including both diagnosed psychiatric conditions (e.g., ‘obsessive-compulsive disorder’) and undiagnosed psychiatric symptoms (e.g., ‘serious anxiety problems but not a diagnosed disorder’). Additionally, participants identified the cause of their sibling’s disability, their sibling’s level of intellectual ability, their sibling’s physical or medical impairments, and sibling’s place of residence (e.g., ‘with parents’).
The *Scales of Independent Behavior-Revised Short Form* (SIB-R; Bruininks et al., 1996) assesses an individual’s everyday living skills. This scale measures adaptive behaviour including motor, social interaction, communication, and personal living skills, as well as maladaptive behaviour. This study only included the adaptive behaviour scale, which consists of 40 tasks that are progressively more difficult (e.g., ‘Washes and dries dishes and puts them away’ and ‘Makes purchases with a check’). Respondents rate the ability of the individual with DD to do each of the tasks using a 4-point scale ranging from 0 (*never or rarely*) to 3 (*does very well*). Total raw scores on the adaptive behaviour scale range from 0 to 120, and higher scores indicate higher adaptive functioning. The SIB-R Short Form has good test-retest reliability .86, and construct validity ranges from .67 to .96 being .95 overall (Bruininks et al., 1996).

The *Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist – Revised* (PAS-ADD; Moss et al., 1998) is a screening tool for psychiatric symptoms in adults with DD that is designed to be completed by a caregiver or family member of the adult with DD. It includes a list of 25 symptom descriptions (e.g., ‘irritable or bad tempered’) and respondents rate each item by indicating the frequency with which the individual with a disability displayed the symptoms in the previous four weeks. Response options include *has not happened, or has always been like this; happened occasionally or present in a mild form; happened frequently, or present in a moderate form; present in a severe form for much of the time*. A scoring algorithm is then used to calculate three scores: Possible Organic Condition; Affective or Neurotic
Disorder; and Psychotic Disorder. Thresholds are provided to identify scores that suggest the need for further psychiatric assessment.

The *Life Domains Questionnaire* (Seltzer et al., 1997; Appendix D) asked participants to rate the extent that their sibling with DD has affected 11 areas of their life, including: career choice, where to live, whether to have children, religious beliefs, feelings about self, choice of romantic relationship, relationship with spouse, relationship with children, plans for own future, political views, and feelings about people with disabilities. Responses were made on a 4-point scale ranging from 0 (*not at all affected*) to 3 (*strongly affected*), with higher scores corresponding to the perception that siblings had a greater impact on participants’ lives. Participants had the option to select ‘*not applicable*’ for items that were not relevant to them (e.g., ‘relationship with children’ for participants who did not have children). Consistent with the approach used by Seltzer et al., scores on each item were dichotomized by collapsing scores of 0 and 1 (*not at all affected* and *not very affected*) and by collapsing scores of 2 and 3 (*somewhat affected* and *strongly affected*). The Cronbach’s alpha for this study indicated that the scale had good internal consistency (*α* = .83).

The *Sibling Contact Questionnaire* (Appendix P) was designed for this study. It contains six items asking participants about the type, frequency, and quality of contact they have with their siblings. The first three items ask about frequency of three types of contact: face-to-face, telephone, and other contact (e.g., email, letters, text message, etc.). Participants rate each item using a 6-point scale (0 = *never*; 1 = *less than once per month*;
2 = 1 to 3 times per month; 3 = 1 to 3 times per week; 4 = 4 to 6 times per week; 5 = daily). If the participant indicates that they never have a certain type of contact with their sibling, they are asked to indicate the reason. The fourth item asks participants whether they have had any changes in contact with their sibling over the past two years, and if yes they are asked to describe the change and the reason for it. The fifth item asks how long it takes for participants to get to their sibling’s home, and responses were made on a 6-point scale (0 = N/A, my sibling lives with me; 1 = less than 30 minutes; 2 = 30 to 60 minutes; 3 = 1 to 2 hours; 4 = 2 to 3 hours; 5 = more than 3 hours). The final question asks participants to provide a qualitative response describing their quality of contact with their sibling.

The Lifespan Sibling Relationship Scale (LSRS; Riggio, 2000; Appendix Q) measures an adult’s perceptions about their sibling relationship quality. It consists of six scales containing eight items each; three of the scales focus on childhood and three focus on adulthood. The childhood scales were not included because the focus of this study was on understanding experiences in adulthood when a sibling with a DD has behavioural/psychiatric problems. Serious psychiatric problems are less common during childhood than adulthood, and without information about the time of onset of the psychiatric problems, I am unable to determine whether the participants’ siblings presented with psychiatric problems during childhood. The scales that focus on adulthood measure each of the following: affect towards the sibling and sibling relationship (e.g., ‘My sibling makes me happy’); behaviour with and toward the sibling (e.g., ‘I presently
spend a lot of time with my sibling’); and cognitions about the sibling and sibling relationship (e.g., ‘My sibling is a good friend’). Items are rated on a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree), with higher scores representing more positive perceptions about the sibling relationship. The LSRS has good psychometric properties, including high internal consistency (Cronbach’s $\alpha = .96$ for the total LSRS and ranges from .87 to .91 for the three adult scales) and good test-retest reliability (Riggio, 2000). Consistent with Riggio’s findings, the LSRS demonstrated good internal consistency for this study (Cronbach’s $\alpha = .90$ for Adult Affect; Cronbach’s $\alpha = .84$ for Adult Behaviour; Cronbach’s $\alpha = .90$ for Adult Cognition).

The Scales of Psychological Well-Being (Ryff, 1989; Appendix G) consists of six scales that measure various aspects of an individual’s well-being, including Autonomy (e.g., ‘My decisions are not usually influenced by what everyone else is doing’), Environmental Mastery (e.g., ‘I am good at juggling my time so that I can fit everything in that needs to get done’), Personal Growth (e.g., ‘I have the sense that I have developed a lot as a person over time’), Positive Relations with Others (e.g., ‘Most people see me as loving and affectionate’), Purpose in Life (e.g., ‘I enjoy making plans for the future and working to make them a reality’), and Self-Acceptance (e.g., ‘In general, I feel confident and positive about myself’). Several versions of this measure exist, which vary in item length. I used a shortened version of the measure, which contains nine items on each scale (54 items in total). Participants rated each item on a 6-point scale ranging from 1 (strongly disagree) to 6 (strongly agree). Higher scores represent greater psychological
well-being. The scales have good internal consistency (Cronbach’s $\alpha$ range from .83 to .91; Ryff, 1989). For this study, I created a total score by summing all 54 items (maximum total score = 324). This total score had excellent internal consistency (Cronbach’s $\alpha = .96$).

The Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977; Appendix H) was used to measure depressive symptoms. This 20-item scale assesses cognitive, affective, and somatic symptoms of depression over the previous week (e.g., “I had crying spells”). Participants rated each item on a scale from 0 (less than 1 day) to 3 (5-7 days); total scale scores range from 0-60, with higher scores indicating more depressive symptoms. The CES-D has good internal validity (Cronbach’s $\alpha$s = .84 to .90; split-half reliability $r = .76$ to .85). The Cronbach’s alpha for this study indicated that the CES-D had excellent internal consistency ($\alpha = .93$).

The Community Supports Questionnaire (Appendix F) was designed for this study and it measured participants’ knowledge and use of formal community services (i.e., support groups, online support groups, education groups/workshops, and other Internet supports). Each category asked about services designed specifically for siblings of people with DD and about supports designed for families of people with DD in general, which resulted in a total of 8 types of service. Participants indicated whether they were aware of the specific type of support (yes/no), whether they were currently using it or if they have used it in the past (yes/no), and how helpful they found the service, with the latter question being rated on a 5-point scale ranging from 1 (not at all helpful) to 5 (extremely helpful).
helpful). If not using the named service, participants were asked the reason why not. I combined the helpfulness ratings from the 8 formal services with the helpfulness ratings from the three formal services on the Family Support Scale (as described above) to create a mean helpfulness score. First, I re-coded the items by subtracting 1 from the participants’ responses on each item. Thus, the lowest score (not at all helpful) was represented by 0 rather than 1 and the highest score (extremely helpful) was represented by 4 rather than 5. If participants were not using a service, it received a score of 0. I then summed the items to obtain a total score that reflected both the number of supports a person received and their satisfaction with these supports. Higher scores corresponded to greater perceived helpfulness of the formal services.

**Procedure**

The data used in this study were collected at the same time as the data described in Study 1 in Chapter 2, and thus, I refer the reader to the Procedure section of Chapter 2 for full details regarding the recruitment process and procedure used for this study. Data for this study were collected using some of the measures described in Chapter 2 as well as some additional measures that were not included in Chapter 2. If the participant had more than one sibling with a disability (n = 22; 11.3%), the instructions directed them to complete all sibling-related questionnaires based on the sibling with a disability whom they had the closest relationship.
Results

Data Preparation

The PAS-ADD was included as a screening tool for psychiatric symptoms; however, 65 (33.9%) of the participants indicated that they ‘can’t answer’ one or more of the items on the PAS-ADD. The primary reason for not answering was due to lack of knowledge of whether their sibling had experienced the specific symptoms. Based on the high frequency of ‘can’t answer’ responses, I excluded this measure from all analyses.

Prior to analyzing the data, I examined the variables for outliers and normality. I examined the z-scores and histograms for each continuous variable to identify univariate outliers. I replaced z-scores greater than 3.29 with a score one unit higher or lower than the next most extreme value in order to decrease the effect of the outlier (Tabachnick & Fidell, 2007). I also reviewed the skewness and kurtosis values, as well as histograms for each variable. All variables were normally distributed except the total number of services score from the Community Supports questionnaires and the CES-D scores, both of which were positively skewed. Therefore, I transformed these two variables using a square-root transformation (Tabachnick & Fidell, 2007). The transformations resulted in normal distributions for both variables.

Demographic Information

Next, I conducted independent samples t-tests and chi-square tests of independence to determine whether the two sibling groups differed based on their demographic characteristics. The groups did not differ in participants’ age, gender,
marital status, annual household income, highest level of education completed, current employment status, or country of residence ($ps > .05$). Additionally, the groups did not differ in the age, gender, level of adaptive behaviour, or level of intellectual disability of the participants’ siblings ($ps > .05$). However, the chi-square test of independence comparing behavioural/psychiatric symptoms to autism spectrum disorder (ASD) diagnosis was significant, $\chi^2(1, N = 196) = 13.36, p < .001$. When the participants’ siblings had an ASD diagnosis, a significantly greater proportion of them also had behavioural/psychiatric symptoms (82.2% vs. 17.8%). In contrast, when the participants’ siblings did not have an ASD diagnosis, approximately equal proportions had behavioural/psychiatric symptoms (51.7%) and did not have such symptoms (48.3%).

**Life Domain Impact**

In order to determine whether the group differences in frequency of ASD diagnosis affected Life Domain Impact scores for each life domain item, I conducted Spearman’s correlations. None of the correlations between the life domain items and ASD diagnosis was significant, $ps > .05$. Thus, ASD diagnosis was not controlled for in the following analyses.

I conducted chi-square tests of independence to determine whether the presence of behavioural/psychiatric symptoms was related to the degree of perceived life domain impact for each of the 11 life domain items. None of the chi-square tests was significant, $ps > .05$ (see Table 6).
Table 6

**Chi-square Tests of Independence for Life Domain Items**

<table>
<thead>
<tr>
<th></th>
<th>B/PS</th>
<th>DD</th>
<th>N</th>
<th>Pearson’s $\chi^2$</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career choice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not At All / Not Very Affected</td>
<td>44.3</td>
<td>45.0</td>
<td>195</td>
<td>0.01</td>
<td>.93</td>
</tr>
<tr>
<td>Somewhat / Very Affected</td>
<td>55.7</td>
<td>55.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Where to live</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>43.0</td>
<td>51.2</td>
<td>194</td>
<td>1.29</td>
<td>.26</td>
</tr>
<tr>
<td>DD</td>
<td>57.0</td>
<td>48.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whether to have children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>65.8</td>
<td>73.1</td>
<td>192</td>
<td>1.14</td>
<td>.29</td>
</tr>
<tr>
<td>DD</td>
<td>34.2</td>
<td>26.9</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Religious beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>78.8</td>
<td>85.0</td>
<td>193</td>
<td>1.20</td>
<td>.27</td>
</tr>
<tr>
<td>DD</td>
<td>21.2</td>
<td>15.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings about yourself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>34.8</td>
<td>40.7</td>
<td>196</td>
<td>0.72</td>
<td>.40</td>
</tr>
<tr>
<td>DD</td>
<td>65.2</td>
<td>59.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Choice of romantic relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>52.2</td>
<td>62.5</td>
<td>195</td>
<td>2.05</td>
<td>.15</td>
</tr>
<tr>
<td>DD</td>
<td>47.8</td>
<td>37.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship with spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>48.6</td>
<td>57.3</td>
<td>182</td>
<td>1.35</td>
<td>.25</td>
</tr>
<tr>
<td>DD</td>
<td>51.4</td>
<td>42.7</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Relationship with children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>64.0</td>
<td>75.4</td>
<td>146</td>
<td>2.09</td>
<td>.15</td>
</tr>
<tr>
<td>DD</td>
<td>36.0</td>
<td>24.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plan for own future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>21.1</td>
<td>29.1</td>
<td>193</td>
<td>1.65</td>
<td>.20</td>
</tr>
<tr>
<td>DD</td>
<td>78.9</td>
<td>70.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Political views</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>60.9</td>
<td>62.3</td>
<td>187</td>
<td>0.04</td>
<td>.84</td>
</tr>
<tr>
<td>DD</td>
<td>39.1</td>
<td>37.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings about people with disabilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B/PS</td>
<td>13.0</td>
<td>10.1</td>
<td>194</td>
<td>0.38</td>
<td>.54</td>
</tr>
<tr>
<td>DD</td>
<td>87.0</td>
<td>89.9</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: BP/S denotes the behavioural/psychiatric symptoms group; DD denotes the DD alone group.

**Sibling Contact and Relationship Closeness**

I examined two aspects of participants’ contact with their sibling with a disability: frequency of face-to-face contact and frequency of telephone contact (see Table 7). For
these analyses, I excluded participants who currently lived with their sibling with DD ($n = 14$ for the behavioural/psychiatric symptoms group and $n = 5$ for the DD alone group), which resulted in sample sizes of 101 for the behavioural/psychiatric symptoms group and 76 for the DD alone group. In order to determine whether the group differences in frequency of ASD diagnosis affected each type of contact, I conducted point-biserial correlations. The correlation between frequency of face-to-face contact and ASD diagnosis was not significant, $r = .03$, $p = .71$. However, the correlation between frequency of telephone contact and ASD diagnosis was significant, $r = -.17$, $p = .03$, and therefore ASD diagnosis was included as a covariate in subsequent telephone contact analyses.

Table 7

<table>
<thead>
<tr>
<th>Frequency of Contact with Siblings with a DD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face</td>
</tr>
<tr>
<td>Weekly or more</td>
</tr>
<tr>
<td>1-3 times per month</td>
</tr>
<tr>
<td>Several times per year or less</td>
</tr>
<tr>
<td>Telephone</td>
</tr>
<tr>
<td>Weekly or more</td>
</tr>
<tr>
<td>1-3 times per month</td>
</tr>
<tr>
<td>Several times per year or less</td>
</tr>
</tbody>
</table>

I conducted an independent samples t-test to compare frequency of face-to-face contact between siblings in the behavioural/psychiatric symptoms group and siblings in the DD alone group. The t-test was not significant, $t(175) = 0.98$, $p = .33$, which indicated
that the frequency of face-to-face contact of siblings in the behavioural/psychiatric symptoms group ($M = 2.07; SD = 1.06$) did not differ from the frequency of such contact for siblings in the DD alone group ($M = 2.24; SD = 1.20$).

To examine frequency of telephone contact, I conducted a one-way analysis of covariance (ANCOVA) with telephone contact as the dependent variable, sibling group (i.e., behavioural/psychiatric symptoms vs. DD alone) as the independent variable, and ASD diagnosis as a dummy coded covariate. Prior to running the final ANCOVA, I tested the homogeneity of slopes assumption and found that this assumption was met. The results of the ANCOVA showed that the main effect of sibling group was not significant, $F(1, 174) = 0.15, p = .70$, partial $\eta^2 = .001$. Frequency of telephone contact of siblings in the behavioural/psychiatric symptoms group ($M = 2.13; SD = 1.34$) did not differ from the frequency of such contact for siblings in the DD alone group ($M = 2.33; SD = 1.37$).

Sibling relationship closeness was evaluated using the three adult scales of the LSRS. In order to determine whether the group differences in frequency of ASD diagnosis affected each LSRS scale, I conducted point-biserial correlations. All three correlations were significant (Adult Affect: $r = -.20, p = .01$; Adult Behaviour: $r = -.17, p = .02$; Adult Cognition: $r = -.19, p = .01$), and therefore, ASD diagnosis was included as a covariate in subsequent LSRS analyses.

I conducted three one-way ANCOVAs (one for each LSRS adult scale as the dependent variable), each with sibling group (i.e., behavioural/psychiatric symptoms vs. DD alone) as the independent variable, and ASD diagnosis as the covariate.
DD alone) as the independent variable and ASD diagnosis as a dummy coded covariate. Prior to running the final ANCOVAs, I tested the homogeneity of slopes assumption and found that this assumption was met for all three dependent variables. Table 8 presents the findings from the three ANCOVAs. In order to decrease the risk of type I error due to conducting multiple tests, Holm’s Sequential Bonferroni correction was used.

Participants in the DD alone group reported more positive feelings (affect) toward their sibling with a disability as compared to participants in the behavioural/psychiatric symptoms group; however, when the Bonferroni correction was applied, this difference was not significant. There were no differences between the two groups in the behaviours with or cognitions towards siblings with a disability.

Table 8

<table>
<thead>
<tr>
<th></th>
<th>B/PS</th>
<th>DD</th>
<th>F-test</th>
<th>α(^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Affect</td>
<td>31.59 (6.34)</td>
<td>34.20 (4.90)</td>
<td>(F(1, 182) = 5.48, p = .02)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>partial (\eta^2 = .03)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Behaviour</td>
<td>21.57 (6.91)</td>
<td>23.24 (7.04)</td>
<td>(F(1, 182) = 1.03, p = .31)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>partial (\eta^2 &lt; .01)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Cognition</td>
<td>29.40 (6.70)</td>
<td>31.30 (6.37)</td>
<td>(F(1, 182) = 1.64, p = .20)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>partial (\eta^2 &lt; .01)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: B/P/S denotes the behavioural/psychiatric symptoms group; DD denotes the DD alone group.
\(^a\)Alpha values were computed using Holm’s Sequential Bonferroni correction.

Mental Health

Two aspects of participants’ mental health were examined: psychological well-being, as measured by the total score on the PWB, and symptoms of depression, as measured by the total score on the CES-D. In order to determine whether the group
differences in frequency of ASD diagnosis affected psychological well-being and symptoms of depression, I conducted point-biserial correlations. Both correlations were significant (psychological well-being: \( r = -.19, p = .01 \); symptoms of depression: \( r = .25, p = .001 \)), and therefore, ASD diagnosis was included as a covariate in subsequent analyses.

To examine psychological well-being and symptoms of depression, I conducted one-way ANCOVAs. The homogeneity of slopes assumption was met for both analyses. For the psychological well-being ANCOVA, ASD diagnosis was entered as a covariate; however, it was not a significant covariate, \( F(1, 180) = 2.40, p = .12 \). Therefore, I removed it from the analysis and conducted an independent samples t-test to determine whether differences in psychological well-being exist between siblings in the behavioural/psychiatric symptoms group and siblings in the DD alone group. The t-test was significant, \( t(181) = 4.73, p < .001 \), Cohen’s \( d = 0.72 \). Participants in the DD alone group (\( M = 259.92; SD = 30.14 \)) had significantly higher psychological well-being scores than participants in the behavioural/psychiatric symptoms group (\( M = 234.01; SD = 40.21 \)).

For the symptoms of depression dependent variable, I conducted a one-way ANCOVA with sibling group (behavioural/psychiatric symptoms vs. DD alone) as the independent variable and ASD diagnosis as a dummy coded covariate. The results of the ANCOVA showed that the main effect of sibling was significant, \( F(1, 180) = 8.78, p = .003 \), partial \( \eta^2 = .05 \). Participants in the behavioural/psychiatric symptoms group (\( M = 91 \))
14.22, \(SD = 8.31\); \(M_{\text{transformed}} = 3.37, SD_{\text{transformed}} = 1.70\) had significantly higher symptoms of depression scores than participants in the DD alone group \((M = 8.22, SD = 12.14; M_{\text{transformed}} = 2.48, SD_{\text{transformed}} = 1.45)\). Radloff (1977) identified an arbitrary cut-off score of 16 that is now used commonly in the literature to identify people who have clinically significant symptoms of depression. A chi-square test of independence was also conducted to determine whether exceeding the cut-off score on the CES-D was related to having a sibling with a DD and behavioural/psychiatric symptoms. The chi-square test was significant, \(\chi^2(1, N = 183)\). The proportion of participants in the behavioural/psychiatric symptoms group who exceeded the CES-D cut-off score (33.0%) was greater than the proportion of participants in the DD alone group who exceeded the cut-off score (14.9%).

**Services and Supports**

I examined eight types of formal supports to determine what supports siblings were currently using or had used in the past and how helpful they perceived these supports as being. Tables 9 and 10 provide the descriptive information for the use of these supports. Overall, siblings were using few supports currently or in the past, and their mean helpfulness scores indicated that on average, participants found most of the services they used to be ‘generally helpful’.

In order to determine whether participants in the DD alone group differed from participants in the behavioural/psychiatric symptoms group in terms of the total number of supports used and the perceived helpfulness of the supports, I conducted two
Table 9

Use and Perceived Helpfulness of Services and Supports

<table>
<thead>
<tr>
<th></th>
<th>Current Use n (%)</th>
<th>Past Use n (%)</th>
<th>Helpfulness M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling support groups</td>
<td>B/PS 9 (8.2)</td>
<td>20 (18.2)</td>
<td>3.55 (1.29)</td>
</tr>
<tr>
<td></td>
<td>DD 8 (10.7)</td>
<td>15 (20.0)</td>
<td>3.88 (1.25)</td>
</tr>
<tr>
<td>Family support groups</td>
<td>B/PS 10 (9.1)</td>
<td>21 (19.1)</td>
<td>3.69 (0.95)</td>
</tr>
<tr>
<td></td>
<td>DD 2 (2.7)</td>
<td>9 (12.0)</td>
<td>3.75 (1.26)</td>
</tr>
<tr>
<td>Online sibling support groups</td>
<td>B/PS 15 (13.6)</td>
<td>18 (16.4)</td>
<td>3.00 (1.37)</td>
</tr>
<tr>
<td></td>
<td>DD 9 (12.0)</td>
<td>9 (12.0)</td>
<td>3.88 (1.25)</td>
</tr>
<tr>
<td>Online family support groups</td>
<td>B/PS 2 (1.8)</td>
<td>3 (2.7)</td>
<td>3.00 (1.00)</td>
</tr>
<tr>
<td></td>
<td>DD 3 (4.0)</td>
<td>4 (5.3)</td>
<td>3.20 (1.64)</td>
</tr>
<tr>
<td>Educational groups/</td>
<td>B/PS 11 (10.0)</td>
<td>20 (18.2)</td>
<td>3.71 (0.99)</td>
</tr>
<tr>
<td>workshops for siblings</td>
<td>DD 6 (8.0)</td>
<td>15 (20.0)</td>
<td>4.00 (1.31)</td>
</tr>
<tr>
<td>Educational groups/</td>
<td>B/PS 9 (8.2)</td>
<td>20 (18.2)</td>
<td>3.40 (1.06)</td>
</tr>
<tr>
<td>workshops for families</td>
<td>DD 2 (2.7)</td>
<td>8 (10.7)</td>
<td>3.25 (1.26)</td>
</tr>
<tr>
<td>Other online sibling resources</td>
<td>B/PS 8 (7.3)</td>
<td>16 (14.5)</td>
<td>2.77 (0.83)</td>
</tr>
<tr>
<td></td>
<td>DD 6 (8.0)</td>
<td>9 (12.0)</td>
<td>3.57 (1.40)</td>
</tr>
<tr>
<td>Other online family resources</td>
<td>B/PS 13 (11.8)</td>
<td>29 (26.4)</td>
<td>2.63 (0.90)</td>
</tr>
<tr>
<td></td>
<td>DD 7 (9.3)</td>
<td>8 (10.7)</td>
<td>3.29 (0.95)</td>
</tr>
</tbody>
</table>

Note: For the DD group, n = 75 for current use and past use. For the B/PS group, n = 110. For both groups, helpfulness ratings were only provided by participants who were currently using the service or who had used the service within the past 6 months. Helpfulness was rated on a scale from 1 to 5 with higher scores corresponding to greater perceived helpfulness.

independent samples t-tests. The dependent variables for the two analyses were the total number of services used and the mean helpfulness ratings. The independent variable for both analyses was sibling group. Prior to conducting the t-tests, I used point-biserial correlations to determine whether the group differences in frequency of ASD diagnosis affected the number of supports used or the helpfulness ratings. Neither of the
Table 10

*Frequencies of Number of Supports Used – Past and PresentCombined*

<table>
<thead>
<tr>
<th>Total Number of Supports Used</th>
<th>B/PS Group</th>
<th>DD Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>41 (37.6)</td>
<td>39 (53.4)</td>
</tr>
<tr>
<td>1</td>
<td>25 (22.9)</td>
<td>17 (23.3)</td>
</tr>
<tr>
<td>2</td>
<td>20 (18.3)</td>
<td>4 (5.5)</td>
</tr>
<tr>
<td>3</td>
<td>11 (10.1)</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>4</td>
<td>6 (5.5)</td>
<td>5 (6.8)</td>
</tr>
<tr>
<td>5</td>
<td>2 (1.8)</td>
<td>4 (5.5)</td>
</tr>
<tr>
<td>6</td>
<td>3 (2.8)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>7</td>
<td>0 (0.0)</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>8</td>
<td>1 (0.9)</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

correlations was significant (ps > .05), and therefore, ASD diagnosis was not included as a covariate in the subsequent analyses. The results of the first t-test showed that there was a trend towards a greater number of services used by the siblings in the behavioural/psychiatric symptoms group (M = 1.45, SD = 1.65; M(transformed) = 0.91, SD = 0.79) as compared to the siblings in the DD alone group (M = 1.11, SD = 1.66; M(transformed) = 0.68; SD = 0.81); however, this difference was not statistically significant, t(180) = 1.90, p = .058. The results of the second t-test showed that siblings in the DD alone group (M = 3.42, SD = 1.02) did not differ from siblings in the behavioural/psychiatric symptoms group (M = 3.08, SD = 1.00) on the helpfulness ratings, t(61) = 1.22, p = .23.

Finally, I used chi-square tests of independence to examine differences between the two sibling groups in the reasons for not using services. I coded participants’

responses into three categories: (1) no need for the service; (2) unaware of the service /
the service was not available to the participant / the service was available but it did not meet the participant’s needs; and (3) ‘other’ reasons (e.g., lack of time). None of the chi-square tests was significant (see Table 11), which suggests that there were no significant differences in the reasons for not using services between siblings in the DD alone group and the siblings in the behavioural/psychiatric symptoms group.

Table 11

Reasons for Not Using Services and Supports

<table>
<thead>
<tr>
<th></th>
<th>B/PS</th>
<th>DD</th>
<th>B/PS</th>
<th>DD</th>
<th>B/PS</th>
<th>DD</th>
<th>B/PS</th>
<th>DD</th>
<th>Pearson’s chi-squarea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling support groups</td>
<td>41 (40.6)</td>
<td>39 (56.5)</td>
<td>48 (47.5)</td>
<td>23 (33.3)</td>
<td>12 (11.9)</td>
<td>7 (10.1)</td>
<td>48 (47.5)</td>
<td>23 (32.4)</td>
<td>χ² = 4.30 p = .12</td>
</tr>
<tr>
<td>Family support groups</td>
<td>47 (47.5)</td>
<td>38 (53.5)</td>
<td>31 (31.3)</td>
<td>23 (32.4)</td>
<td>21 (21.2)</td>
<td>10 (14.1)</td>
<td>47 (47.5)</td>
<td>23 (34.3)</td>
<td>χ² = 1.47 p = .48</td>
</tr>
<tr>
<td>Online sibling support groups</td>
<td>36 (39.6)</td>
<td>37 (58.7)</td>
<td>41 (45.1)</td>
<td>18 (28.6)</td>
<td>14 (15.4)</td>
<td>8 (12.7)</td>
<td>36 (39.6)</td>
<td>18 (34.3)</td>
<td>χ² = 5.71 p = .06</td>
</tr>
<tr>
<td>Online family support groups</td>
<td>45 (42.1)</td>
<td>37 (54.4)</td>
<td>40 (37.4)</td>
<td>21 (30.9)</td>
<td>22 (20.6)</td>
<td>10 (14.7)</td>
<td>45 (42.1)</td>
<td>21 (34.3)</td>
<td>χ² = 2.64 p = .27</td>
</tr>
<tr>
<td>Educational groups/</td>
<td>36 (36.7)</td>
<td>36 (53.7)</td>
<td>44 (44.9)</td>
<td>23 (34.3)</td>
<td>18 (18.4)</td>
<td>8 (11.9)</td>
<td>36 (36.7)</td>
<td>23 (34.3)</td>
<td>χ² = 4.77 p = .09</td>
</tr>
<tr>
<td>workshops for siblings</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational groups/</td>
<td>42 (42.0)</td>
<td>39 (54.9)</td>
<td>35 (35.0)</td>
<td>21 (29.6)</td>
<td>23 (23.0)</td>
<td>11 (15.5)</td>
<td>42 (42.0)</td>
<td>21 (29.6)</td>
<td>χ² = 3.02 p = .22</td>
</tr>
<tr>
<td>workshops for families</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other online sibling</td>
<td>47 (47.0)</td>
<td>38 (56.7)</td>
<td>35 (35.0)</td>
<td>19 (28.4)</td>
<td>18 (18.0)</td>
<td>10 (14.9)</td>
<td>47 (47.0)</td>
<td>19 (28.4)</td>
<td>χ² = 1.52 p = .47</td>
</tr>
<tr>
<td>resources</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other online family</td>
<td>49 (50.5)</td>
<td>39 (57.4)</td>
<td>29 (29.9)</td>
<td>17 (25.0)</td>
<td>19 (19.6)</td>
<td>12 (17.6)</td>
<td>49 (50.5)</td>
<td>17 (25.0)</td>
<td>χ² = 0.77 p = .68</td>
</tr>
<tr>
<td>resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Note: The sample size varied for each type of support because only those siblings not using a specific type of support responded to the question about the reason for not using the support.

aThe degrees of freedom for all chi-square tests was 2.
Discussion

The overall aim of this study was to examine the effect of mental illness on siblings and sibling relationships in adults whose brother or sister had a DD. I divided participants into two groups: 1) participants who had a sibling with a DD alone and 2) participants who had a sibling with a DD and either a diagnosed mental illness or serious behavioural or psychiatric symptoms without a formal diagnosis.

I addressed four main research questions with this study. First, I aimed to determine whether siblings of adults with a DD and behavioural or psychiatric problems differ from siblings of adults with a DD alone in the extent that they perceive their sibling as having impacted various aspects of their life. Consistent with my hypothesis, I found no significant differences between the two groups in perceived impact on any of the life domain items.

Second, I sought to compare the frequency of sibling contact and sibling relationship closeness between siblings of adults with a DD and behavioural or psychiatric problems and siblings of adults with a DD alone. I hypothesized that when individuals had both a DD and behavioural or psychiatric problems, their siblings would spend less time with them as compared to siblings of individuals who have a DD alone. Contrary to my hypothesis, I did not find a significant difference in frequency of either face-to-face contact or telephone contact between the two sibling groups. I also predicted that siblings of adults with a DD and behavioural or psychiatric problems would report less relationship closeness than siblings of adults with a DD alone. This hypothesis was
not supported. Siblings of individuals with both a DD and behavioural or psychiatric problems reported less positive feelings toward their brother or sister than siblings of individuals with a DD alone; however, this difference was not significant when corrections were applied to control for risk of type I error. The two groups did not differ in their thoughts about their sibling relationship or their behaviours.

Third, I examined whether siblings of adults with a DD and behavioural or psychiatric problems and siblings of adults with a DD alone differed in their psychological well-being and symptoms of depression. Consistent with my hypotheses, siblings of individuals with a DD and behavioural or psychiatric symptoms reported higher symptoms of depression and lower psychological well-being than siblings of individuals with a DD alone.

Fourth, I examined the use of services and supports in siblings of adults with a DD and behavioural or psychiatric problems and siblings of adults with a DD alone. This objective was exploratory and did not involve specific hypotheses. However, the results indicated that overall, formal service use was low in both groups. Additionally, the two sibling groups did not differ in the number of supports used or in the reasons for not using formal supports.

**Life Domains**

I did not find any significant differences between siblings in the DD group and siblings in the behavioural or psychiatric symptoms group in the amount of impact that they reported their sibling with a DD had on the various life domains (e.g., career choice,
where to live, etc). In contrast, Seltzer et al. (1997) used the same Life Domains Questionnaire to compare siblings of adults with a DD to siblings of adults with a mental illness. They found that compared to siblings of adults with a mental illness, siblings of adults with a DD reported that their brother or sister had a greater impact on several domains of their life: career choice, whether to have children, feelings about self, plans for own future, and feelings about people with disabilities. Seltzer and colleagues concluded that the differences between siblings in the DD group and siblings in the mental illness group were likely related to the timing of the onset of the two types of disability. DDs are present from birth or are diagnosed in early childhood. In contrast, symptoms of mental illness usually have a much later onset. Thus, Seltzer et al. posit that having a sibling with a mental illness does not have a large impact on people’s life domains because the symptoms of the mental illness are often not present during the earlier formative years. To support this conclusion, Seltzer and colleagues compared siblings of adults with a DD to siblings of adults with a mental illness who had an onset of the mental illness prior to age 19. Indeed, they found that these two groups were quite similar.

In my study, both groups of participants had siblings with a DD; however, the siblings in one group also had behavioural or psychiatric symptoms. Based on the findings of the Seltzer et al. (1997) study, it is likely that participants in both groups were equally affected by their sibling during the formative years, because the siblings’ DDs would have been present from birth or early childhood in both groups. Unfortunately, I
did not collect information about the siblings’ age of onset for the symptoms of a mental illness. If these symptoms occurred later in life, then they may not have contributed additional influence on the siblings’ life domains, nor detracted from the perceived effect the sibling had on the life domains.

**Sibling Contact and Relationship Closeness**

The majority of siblings reported that they spent face-to-face time with or talked on the phone to their sibling on a monthly or more frequent basis, with approximately one-third of these participants having at least weekly contact with their sibling with a DD. However, I did not find any differences in frequency of contact between the two sibling groups. Seltzer et al. (1997) found that adults who have a sibling with a mental illness spend less time with their brother or sister than do adults who have a sibling with a DD. Additionally, Taylor et al. (2008) compared siblings of individuals with a mental illness to siblings of individuals without a disability, and found that the former group spent less time with their brother or sister with a mental illness. Although the presence of a mental illness in individuals without a DD seems to have a negative effect on frequency of sibling contact, this does not appear to hold true when the individual with symptoms of a mental illness also has a DD. The difference in findings between my study and those of Seltzer et al. and Taylor et al. could relate to differences in demographic characteristics. For example, I had a greater percentage of women participants than the other two studies and my participants were younger on average than those in the Taylor et al. study.
Alternatively, having a DD may act as a protective factor in the sibling relationship when mental illness is also present.

Family solidarity may explain why the presence of a mental illness does not result in decreased contact with the sibling with a DD. In their theory of family solidarity, Bengtson and Roberts (1991) define normative solidarity, or familism, as the “strength of commitment to performance of familial roles and to meeting family obligations” (p. 857). They found that greater normative solidarity is associated with more positive feelings about family relationships and increased contact between family members (Bengtson & Roberts, 1991). In families that include an individual with a DD, children are often taught from an early age that they share some of the responsibility of caring for their sibling with a disability (McHale & Gamble, 1989; Stoneman, 2005). Taylor et al. (2008) suggest that these increased expectations from an early age result in a heightened sense of family solidarity for siblings of individuals with a DD as compared to siblings of children without DDs, which in turn leads to greater sibling contact throughout the life course. In my study, the siblings in both groups would have presumably developed similar levels of family solidarity while growing up with a sibling with a DD. Thus, when siblings with a DD later developed a mental illness, the strength of the pre-existing family solidarity may have protected against the decreased sibling contact that seems to result in other sibling dyads that include an individual with a mental illness. Further research is necessary to confirm the relationship between mental illness, family solidarity, and sibling contact.
Similar to sibling contact, I did not find a difference between the two sibling
groups in sibling relationship closeness. In contrast, Seltzer et al. (1997) found that adult
siblings of individuals with a DD reported significantly greater relationship closeness
with their brother or sister with a disability than did adult siblings of individuals with a
mental illness. The lack of a negative effect of mental illness on these aspects of sibling
relationship closeness in my study may again be related to family solidarity. The Adult
Behaviours scale and the Adult Cognition scale measure the ways that participants
behave with their siblings (e.g., spending time with them) and the way they think about
their sibling (e.g., importance of sibling, being proud of sibling), respectively. As
described above, siblings of individuals with a DD are often raised with the family
expectation that the siblings without a DD participate in the lives of the individual with a
DD and that they value them as an important member of the family (McHale & Gamble,
1989; Stoneman, 2005). Thus, these early-established family beliefs and attitudes may
prevent any negative changes in behaviours towards or thoughts about the sibling with a
DD when a mental illness develops later in life.

The Adult Affect scale measures feelings about one’s siblings. Although the
siblings of individuals with a DD alone reported more positive feelings about the sibling
relationship than siblings of individuals with a DD and behavioural or psychiatric
symptoms, this difference was not significant after applying a statistical correction to
control for increased risk of type I error. Previous research does show that mental illness
can have a negative effect on sibling relationship closeness (Gerace et al., 1993; Lively et
al., 1995; Seltzer et al., 1997); and therefore, a replication of the findings related to Adult Affect would be beneficial before concluding that having a sibling with a DD and behavioural or psychiatric symptoms is unrelated to people’s feelings about their sibling. Additionally, future research that distinguishes between adults whose sibling with a DD has an acute mental illness (e.g., single major depressive episode) versus those whose sibling with a DD has a more chronic mental illness (e.g., schizophrenia) could provide further clarification about how the presence of mental illness impacts sibling relationship quality.

**Psychological Well-being and Symptoms of Depression**

Siblings of individuals with a DD and behavioural or psychiatric symptoms had lower psychological well-being scores and more symptoms of depression than siblings of individuals with a DD alone. Additionally, a greater proportion of siblings in the former group exceeded the clinical cut-off score on the measure of depressive symptoms. Taken together, these findings suggest that siblings of individuals with a DD are at increased risk of mental health problems when their brother or sister also has symptoms of a mental illness. However, because this study did not use an experimental design, I cannot draw causal conclusions about the relationship between the variables of interest.

To date, no previous studies have examined symptoms of depression or psychological well-being in adults who have a brother or sister with a DD and behavioural or psychiatric symptoms. However, my findings are consistent with those of Esbensen et al. (2006) who found higher symptoms of depression in parents of adult
children with a DD and mental health problems as compared to parents of adult children
with a DD alone. Additionally, Taylor et al. (2008) found that brothers of individuals
with a mental illness had lower psychological well-being than siblings of individuals with
a DD. In contrast to my findings, Taylor and colleagues did not find a difference in
depressive symptoms between siblings of individuals with a DD, those with a mental
illness, or those with a sibling without a disability. Thus, it may be the combined effect of
both the DD and mental illness that relates to siblings and parents (Esbensen et al., 2006)
having higher symptoms of depression.

Despite the lack of previous research on siblings of individuals with a DD and
behavioural or psychiatric symptoms, there are several possible conclusions one can
make based on other literature. One possible explanation for the differences between the
two groups in this study is that the stress of having a brother or sister with a DD and
behavioural or psychiatric symptoms causes siblings to have poorer mental health. When
an individual has a mental illness their behaviour is typically less predictable, they may
become lethargic and withdrawn, and they often exhibit changes in their personality.
Additionally, due to the difficulty of diagnosing mental illness in individuals with a DD
(Einfeld et al., 2007), families may be left uncertain about the cause of the changes in
their family member with a DD for long periods of time while the individual goes
undiagnosed and untreated (Faust & Scior, 2008). Thus, the onset of a mental illness will
likely lead to an increase in the number of stressors experienced by family members,
including siblings, of individuals with a DD. Previous research demonstrates a causal relationship between life stressors and the onset of depression (Monroe et al., 2006).

However, because the stressors identified above are related to a sibling, it is possible that the poorer mental health in adults who have a sibling with a DD and behavioural or psychiatric symptoms is related to shared genetic factors or shared environmental factors such as negative life events, family dysfunction, or growing up in an impoverished environment (Esbensen, 2011; Wallander, Dekker, & Koot, 2006). Studies in both the DD population and the general population show that family history of mental illness is a risk factor for the development of psychiatric symptoms (Ghaziuddin & Greden, 1998; Weissman et al., 2005).

Finally, it is possible that poorer mental health in the adult without a DD causes behavioural or psychiatric symptoms in the sibling with a DD. Siblings are an important source of instrumental and emotional support for adults with a DD (Bigby, 1997; Seltzer, Begun, Seltzer, & Krauss, 1991). Thus, if the sibling without a DD develops symptoms of depression, he or she may have decreased contact with the sibling with a DD or exhibit less positive emotions toward the sibling with a DD. This in turn could have negative consequences for the mental health of the sibling with a DD. Longitudinal research that controls for the effects of shared genes and environment and that examines the timing of onset of symptoms of depression in siblings without a DD relative to the onset of behavioural or psychiatric symptoms in the sibling with a DD is necessary to enhance our understanding of why siblings of individuals with a DD have poorer psychological
well-being and greater symptoms of depression when their brother or sister also has
behavioural or psychiatric symptoms.

**Service Use**

I did not find any significant differences between the two sibling groups in their
use of services, their perceived helpfulness of services, and their reasons for not using
services. However, overall, participants’ use of formal services in this study was low.
Over one-third of the siblings of individuals with a DD and behavioural or psychiatric
symptoms and over one-half of the siblings of individuals with a DD alone reported that
they had never used any of the services included in this study. The participants who had
used services, either currently or in the past 6 months, reported that overall the services
were ‘generally helpful’, with average helpfulness scores ranging from about 3 to 4 on a
5-point scale (1 = ‘not at all helpful’, 5 = ‘extremely helpful’). Although many
participants reported that they did not feel a need for the use of services, approximately
one-third to one-half of siblings reported that their reason for not using services was due
to lack of awareness of the service or lack of access to a service that met their specific
needs. Taken together, these findings suggest that the provision of appropriate services
for adult siblings of individuals with a DD is unsatisfactory at present. In a recent study,
Arnold, Heller, and Kramer (2012) used a qualitative approach to examine the perceived
support needs of adult siblings of individuals with a DD. Some of the needs highlighted
by their participants included sibling-specific supports that offer opportunities for siblings
to connect with one another, share information, and receive support. Siblings also
reported a need for more formal educational opportunities (e.g., workshops, conferences),
information about future planning, and assistance with navigating service systems.

An examination of the broader literature also provides some useful information
about how to possibly improve the current state of adult sibling supports. Dyke et al.
(2009) put forward several recommendations for professionals working with siblings of
children with a DD. They highlight the importance of providing siblings with information
to better understand their brother or sister’s disability. Although this may not be
necessary for many adults who have spent their whole life with their sibling with a
disability, this suggestion may be of particular importance for adults whose siblings
develop symptoms of a mental illness later in life. Despite the existence of many
websites, books, and other resources that provide information about mental illness, the
resources that provide information about how mental illness manifests in individuals with
a DD is far more limited.

Previous research shows that many family members of individuals with chronic
conditions benefit from the opportunity to talk to others who have shared experiences,
including adult siblings of individuals with mental illness (Friedrich, Lively, &
Rubenstein, 2008; Lukens, Thorning, & Lohrer, 2002), children whose siblings have a
DD (Moyson & Roeyers, 2012), and parents of children with autism (Clifford, 2011).
Such opportunities often come in the form of support groups or self-help groups. As
mentioned above, Arnold et al. (2012) also found that adult siblings of individuals with a
DD report a desire for more opportunities to connect and talk with one another. It would
be beneficial for future research to examine the most effective types of support groups for adult siblings of individuals with a DD. Such groups could target siblings of individuals with specific diagnoses (e.g., ASD or a dual diagnosis), siblings in specific life stages (e.g., those planning to undertake future caregiver roles), or just adult siblings in general. Additional qualitative research that examines what siblings want in a support group could offer further direction on types of support groups to develop. The use of program evaluation questionnaires and pre- post-measures could also provide clinicians with a better understanding of the specific aspects of support groups that are most beneficial for siblings. Finally, given that many siblings appear to be well-adjusted and do not report a need for services designed for individuals who are experiencing distress or maladaptation, it would be worthwhile to further explore the potential benefits of sibling groups that focus on enjoyable sibling activities and social connections.

There is a growing awareness of the beneficial role of the Internet in providing support to family members of individuals with a disability (see Perkins & LaMartin, 2012 for a review). For example, Clifford (2011) found that parents of children with autism benefitted from participation in an online support group, and Dyke et al. (2009) mention the benefits of online ‘chat rooms’ for family members of individuals with a DD. Currently, the Sibling Support Project in the United States is one of the few organizations that offer Internet-based support for adult siblings of individuals with a DD in the form of online groups designed for siblings to share information and to provide each other with support. Although the Sibling Support Project is accessible to siblings world-wide, 45%
of the siblings of individuals with a DD and behavioural or psychiatric symptoms and 29% of the siblings of individuals with a DD alone who participated in my study were either unaware of this, and similar services, or they did not feel that these services met their specific needs.

Limitations and Directions for Future Research

Although this study offers useful information about how behavioural or psychiatric symptoms can affect adult siblings of individuals with a DD, it does have some limitations. First, I did not have a means of confirming that the participants’ siblings had mental illness symptoms or diagnoses. Ideally, a psychologist or psychiatrist specializing in dual diagnosis would assess each participant’s sibling to confirm whether the person meets criteria for a mental illness. Based on the methodology in this study, it is possible that participants whose siblings did not actually meet criteria for a mental illness were included in the behavioural/psychiatric symptoms group. However, it is likely that it is not the formal diagnosis, but rather the presence of perceived psychiatric symptoms that the sibling perceives to be problematic that may have a negative effect on the sibling relationship.

Second, because this study used a correlational design, conclusions about causality are not warranted. I cannot conclude that having a sibling with behavioural/psychiatric symptoms causes people to have more negative feelings about the sibling relationship, greater symptoms of depression, and lower psychological well-being. Instead, I am limited to highlighting the fact that individuals who have a sibling
with behavioural/psychiatric symptoms also appear to be at increased risk and therefore may require additional support. It will be important for future research to utilize methodological designs that enable conclusions related to causality. For example, longitudinal studies that measure changes in siblings’ relationship closeness, psychological well-being, and depressive symptoms before and after the onset of psychiatric symptoms in the sibling with a DD would further clarify whether a dual diagnosis negatively affects siblings without a DD. Additionally, there is a need to control for genetic factors and shared life experiences that may contribute to symptoms of depression and lower psychological well-being in both the sibling with and without a DD.

The measure used to assess symptoms of depression in this study is widely used in research; however, it is a screening tool rather than a psychodiagnostic measure of clinical depression. A greater proportion of siblings of individuals with a DD and behavioural or psychiatric symptoms, as compared to siblings of individuals with a DD alone, exceeded the commonly used clinical cut-off score on the CES-D in this study. However, further research is needed to determine whether there are more siblings of individuals with a DD and behavioural or psychiatric symptoms who meet diagnostic criteria for major depressive disorder. This would facilitate clinicians’ understanding of the type of supports these siblings need.

**Clinical Implications**

A significant body of research has focused on the psychological outcomes of parenting a child with a DD (e.g., Baker, Blacher, & Olsson, 2005; Emerson, Robertson,
& Wood, 2004; Feldman et al., 2007; Gallagher et al., 2008; Herman & Marcenko, 1997; MacDonald et al., 2010; Minnes & Woodford, 2004); however, relatively little attention has been focused on the psychological impact of growing up with a sibling with a DD. Additionally, despite the high prevalence of mental illness in the DD population, to date, no previous studies have examined the psychological impact of having a brother or sister with both a DD and symptoms of a mental illness.

The findings from this study show that adult siblings of individuals with both a DD and serious behavioural or psychiatric symptoms are at greater risk of experiencing symptoms of depression, and they experience lower psychological well-being as compared to adult siblings of individuals with a DD alone. Thus, this group of siblings may benefit from additional professional support to assist in coping with having a sibling with a DD. Based on the findings from the study presented in Chapter 2, it appears that a family-focused approach would benefit siblings of adults with a DD and behavioural/psychiatric symptoms. Thus, in addition to providing these siblings with supports that focus on directly meeting their own needs, it will be important to assist the family as a whole in operating as a cohesive, cooperative unit.

There are many community supports available to meet the needs of individuals with a DD and their parents, and the number of resources available for children who have a sibling with a DD is growing. However, there are far fewer resources available for adult siblings. Overall, the sample in this study reported using few formal supports, and approximately one out of every three participants not using supports reported they were
unaware that this type of support existed or there was a lack of access to support that met their needs. These findings suggest that there is a significant need for more formal services that specifically address the needs of adult siblings of individuals with a DD. Future research is needed to determine the most effective approaches to providing support for adult siblings (e.g., online resources, support groups, etc.). Additionally, it will be important to identify strategies for making siblings aware of existing resources, especially those siblings who may not currently be actively involved with agencies that support individuals with a DD.

**Conclusions**

This study offers new information about the experiences of siblings whose brother or sister with a DD develops symptoms of a mental illness. Although previous research has examined the relationship between mental illness and sibling experiences outside of the DD field, this study is the first to examine this topic within the DD field. By comparing various aspects of the sibling relationship and the mental health of the sibling without a disability, this study showed that having a sibling with a DD and behavioural or psychiatric symptoms is related to greater symptoms of depression and lower psychological well-being in the sibling without a DD. However, behavioural or psychiatric symptoms do not negatively affect all aspects of the sibling relationship. Siblings in this study did not report any difference in sibling contact, thoughts about or behaviours affecting the sibling relationship, or perceptions of life impact based on whether or not their sibling with a DD also had behavioural or psychiatric symptoms.
The finding that siblings of individuals with a DD and behavioural or psychiatric symptoms experience greater symptoms of depression and lower psychological well-being suggests that these individuals may be in greater need of community supports and resources. The use of supports by siblings in this study was low across both groups, and one of the main reasons for not using supports was a lack of awareness of or access to appropriate supports. Thus, these findings highlight the need for future research about what supports are needed by adult siblings, how to make these supports more accessible, and how to address the specific needs of adults whose sibling with a DD also develops symptoms of a mental illness.
Chapter 4

Relationships with Siblings with and without Disabilities – Do They Differ?

Siblings play an important role in the lives of individuals with and without disabilities. Cicirelli (1995) outlined five characteristics of sibling relationships that make them unique relative to other relationships. First, sibling relationships are often the longest relationships people will have in their lifetime as they typically start at birth or in the early childhood years and last until the death of one of the siblings. Second, unlike relationships with friends or intimate partners that are purposely selected, the relationship with the sibling is automatically created at birth (or in early childhood if a sibling is adopted). Regardless of whether siblings maintain contact with one another, they will always maintain the status of siblings. Third, sibling relationships tend to follow a pattern of closeness that changes over the life course. In childhood, most siblings live together and interact on a daily basis, whereas adulthood is characterized by decreased frequency of contact. Fourth, despite differences in age, sibling relationships tend to be relatively egalitarian with both siblings having mutual feelings toward one another. Finally, siblings have both shared and non-shared life experiences, and both types of experiences can influence the personal development of each sibling and can affect the sibling relationship.
Sibling Relationships across the Lifespan

As mentioned above, the characteristics of sibling relationships evolve over the life course. In childhood, siblings provide each other with companionship and emotional support, and they often spend considerable time engaging with one another through play (Cicirelli, 1995; Goetting, 1986). Additionally, older siblings may participate in caregiving tasks for younger siblings (Bryant, 1982; Cicirelli, 1995; Goetting, 1986). As siblings enter early adolescence, their relationship becomes increasingly egalitarian; however, rivalry and conflict may peak during this time period (Cicirelli, 1995). During late adolescence, more time is spent with friends and sibling involvement tends to decrease (Cicirelli, 1995). Once siblings reach early adulthood, they again undergo changes in the sibling relationship as they face significant transition points such as leaving the parental home, embarking on post-secondary education or a career, and starting a family of their own (Conger & Little, 2010; Corti, 2009; Riggio, 2006; Ross & Milgram, 1982).

Many adults report strong feelings of affection toward their sibling, despite the decreased frequency of contact with siblings that is characteristic of this age group (Cicirelli, 1991, 1995; Goetting, 1986). Adult siblings often provide each other with companionship and are viewed as friends; however, a small percentage of adults report no contact or emotional closeness with siblings during adulthood (Cicirelli, 1995). Siblings tend to provide each other with support throughout adulthood; however, this support may be more frequent in later adulthood (Cicirelli, 1991; Conger & Little, 2010).
Additionally, emotional support seems to be more common than instrumental support (Cicirelli, 1991; Goetting, 1986). Siblings report a number of reasons for maintaining their relationships in adulthood, with some of the most common being because they are family, they provide each other with support, they share common interests, they are friends, and they love each other (Myers, 2011).

**Relationships with Siblings with a DD versus Siblings without a DD**

When one member of a sibling dyad has a DD, two aspects of the unique sibling relationship as outlined above by Cicirelli (1995) may change. First, the relationship may be less egalitarian and more hierarchical, especially during adolescence and adulthood as the disparity in the siblings’ cognitive abilities and adaptive functioning grows. Second, there may be fewer shared life experiences, particularly during adulthood, as many individuals with a DD do not have the opportunity to attend post secondary education, have a career, and start a family the way their siblings without a disability do. In light of these differences in the sibling relationship as compared to sibling dyads that do not include an individual with a DD, very little is known about how adult sibling relationships that include an individual with a DD differ from sibling relationships that do not include an individual with a DD.

Many adult siblings of individuals with a DD live closer to their brother or sister than do siblings of individuals without a disability (Doody, Hastings, O’Neill, & Grey, 2010; Taylor et al., 2008). Studies that only include siblings of individuals with a DD report that these individuals have close sibling relationships (Hodapp et al., 2010) and
have regular in-person and telephone contact with their brother or sister with a disability (Hodapp et al., 2010; Krauss et al., 1996). Additionally, qualitative research with siblings shows that individuals with a DD can have significant impacts on various aspects of their siblings’ lives, such as career choice, relationships, and where siblings choose to live (Flaton, 2006; Marks, Matson, & Barraza, 2005). Despite the positive feelings about the sibling relationship and the regular contact, studies that include siblings of individuals without a DD show that siblings of individuals with a DD may have less closeness and contact than siblings of individuals without a DD. Taylor et al. (2008) found that siblings of individuals with a mild ID reported less sibling relationship closeness than siblings of individuals without a DD. Doody et al. (2010) also found less relationship closeness for siblings of individuals with a DD, but this was only true when the sibling had a severe or profound level of ID. Additionally, Taylor et al. reported that siblings of individuals with a mild ID had fewer annual contacts with their brother or sister with a disability than did siblings of individuals without a disability. Doody et al. also found that individuals with a DD phoned their sibling less than individuals without a DD; however, in contrast to the findings of Taylor et al., Doody and colleagues did not find a difference in frequency of in-person contact or frequency of participants’ (i.e., individuals without a DD) phone calls made to siblings. Taken together, this literature suggests that siblings do have close relationships with their brother or sister with a DD; however, these relationships may differ from those of siblings who do not have a disability.
Perspectives of Adults with a DD

There is an increasing interest in understanding the effect of sibling relationships during adulthood in the DD field; however, to date, this research has focused on how siblings without a DD are affected by their sibling with a DD. Despite the awareness that it is also necessary to include adults with a disability as participants in sibling research (e.g., Heller & Kramer, 2009; Seltzer & Krauss, 1993; Stoneman, 2005) little has been done to understand how adults with a DD are affected by their siblings from the perspective of adults with a DD themselves. In addition to broadening our knowledge of sibling relationships, Stoneman (2005) posited that the inclusion of individuals with a DD in sibling research may also assist in directing sibling research towards focusing on the positive aspects of sibling relationships rather than emphasizing the negative aspects of these relationships. To date, no research has examined sibling relationship characteristics and quality from the perspective of adults with a DD.

Limitations of Previous Research and Objectives of the Current Study

There is a paucity of literature that examines whether adult sibling relationships differ when one member of the sibling dyad has a DD as compared to when neither sibling has a DD. Additionally, most previous sibling research in the DD field that has used comparison groups has focused on comparing siblings of children with a DD to siblings of children without a DD, and when differences are found, they are attributed to the child with a DD. Stoneman (2005) argues that this methodology is flawed because group differences between siblings or their families that could affect the sibling
relationship are rarely controlled. For example, rates of disability are higher among low socioeconomic families and they vary across ethnic groups (Fujiura, Yamaki, & Czechowicz, 1998). In order to avoid these confounding factors, I compared participants’ relationships with their sibling with a DD to their relationship with their sibling without a DD, thus eliminating the effect of differences in demographic or family variables between the two comparison groups.

A second significant limitation of the existing literature is the failure to include the perspectives of adults with a DD. Previous studies have relied on proxy reports, often provided by mothers. However, in order to fully understand how adults with a DD are impacted by their sibling relationships, it is necessary to include them as research participants.

I conducted two studies to examine sibling relationship characteristics from the perspective of adults with and without a DD. In the first study, I aimed to compare two types of sibling dyads: (1) those that included an adult sibling without a DD and an adult sibling with a DD and (2) those that included two adult siblings without a DD. Based on the previous findings that siblings’ choice about career, relationships, and where to live are related to their brother or sister with a DD (Flaton, 2006; Marks et al., 2005), I predicted that participants would report a greater impact on all life domains from their sibling with a DD than from their sibling without a DD. Additionally, I expected that participants would report less relationship closeness with their sibling with a DD than with their sibling without a DD, consistent with the findings of Taylor et al. (2008) and
Finally, I predicted that participants would spend less time talking on the telephone with their sibling with a DD or using other forms of technology-based communication as compared to their sibling without a DD, but I did not expect participants to differ on the amount of time spent with each type of sibling (Doody et al., 2010).

In the second study, I sought to examine the sibling relationship from the perspective of adults with a DD. Due to a lack of existing research from which to formulate hypotheses, this objective was exploratory in nature. I examined perceptions of sibling relationship closeness, types of sibling contact, shared activities between siblings, and the exchange of helping behaviours between siblings. I expected that adults with a DD would perceive their sibling relationships as beneficial and important.

**Study 1**

**Method**

**Participants.** This study included 128 adults (108 women and 20 men), aged 19 to 63 years ($M = 39.82, SD = 11.86$), who had at least one living adult sibling with DD and at least one living adult sibling without DD. I excluded adults whose siblings were children or were deceased.

Most participants lived in Canada ($n = 58; 45.3\%$) or the United States ($n = 65; 50.8\%$); however, 5 participants (3.9\%) lived in other countries from around the world. The majority of participants were married or in common-law relationships ($n = 84; 65.6\%$), and the remainder were single ($n = 35; 27.3\%$) or separated / divorced ($n = 9$;
7.0%). Overall, the participants had completed a high level of education: 41 (31.8%) had a graduate or professional degree; 46 (35.9%) had an undergraduate degree; 16 (12.5%) had a college certificate; 13 (10.2%) had partial college or university; and 12 (9.4%) had a high school diploma. The median reported annual household income was $75,000, and 105 (82.0%) of the participants were employed.

Table 12 includes the demographic information about the participants’ siblings with and without DD.

**Measures.** The *Demographic Questionnaire* (Appendix A) asked participants about their gender, age, marital status, employment status, annual household income, the highest level of education they have achieved, the number of children they have, their country of origin, and the country in which they currently live.

The *Information about Siblings Questionnaire* (Appendix B) was used to collect demographic data about the participants’ sibling with a disability. Participants provided information about their siblings’ gender; age; and psychiatric issues, including both diagnosed psychiatric conditions (e.g., ‘obsessive-compulsive disorder’) and undiagnosed psychiatric symptoms (e.g., ‘serious anxiety problems but not a diagnosed disorder’). Additionally, participants identified the cause of their sibling’s disability, their sibling’s level of intellectual ability, their sibling’s physical or medical impairments, and where their sibling lives (e.g., ‘with parents’). This measure also asked about the demographic characteristics of the participants’ sibling without a disability, including their age, gender, and whether they had any diagnosed psychiatric conditions.
### Table 12

**Sibling Demographic Information**

<table>
<thead>
<tr>
<th></th>
<th>Siblings with DD (n = 128)</th>
<th>Siblings without DD (n = 128)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of women (%)</td>
<td>47 (36.7)</td>
<td>57 (44.5)</td>
</tr>
<tr>
<td>Mean age in years ((SD))</td>
<td>37.76 (12.17)</td>
<td>40.34 (14.54)</td>
</tr>
<tr>
<td>Age range in years</td>
<td>17 - 69</td>
<td>17 - 82</td>
</tr>
<tr>
<td>Primary diagnosis (n (%))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Down syndrome</td>
<td>49 (38.3)</td>
<td></td>
</tr>
<tr>
<td>ASD</td>
<td>14 (10.9)</td>
<td></td>
</tr>
<tr>
<td>ASD + other diagnosis</td>
<td>7 (5.5)&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>15 (11.7)</td>
<td></td>
</tr>
<tr>
<td>Intellectual disability due to</td>
<td>28 (21.9)</td>
<td></td>
</tr>
<tr>
<td>unknown cause</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain injury</td>
<td>6 (4.7)</td>
<td></td>
</tr>
<tr>
<td>Other syndrome or disorder</td>
<td>9 (7.0)</td>
<td></td>
</tr>
<tr>
<td>Level of ID (n (%))&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No impairment</td>
<td>3 (2.4)</td>
<td></td>
</tr>
<tr>
<td>Mild/borderline ID</td>
<td>19 (15.0)</td>
<td></td>
</tr>
<tr>
<td>Moderate ID</td>
<td>64 (50.4)</td>
<td></td>
</tr>
<tr>
<td>Severe ID</td>
<td>28 (22.0)</td>
<td></td>
</tr>
<tr>
<td>Profound ID</td>
<td>6 (4.7)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>7 (5.5)</td>
<td></td>
</tr>
<tr>
<td>SIB-R adaptive behaviour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean score ((SD))</td>
<td>76.82 (21.54)</td>
<td></td>
</tr>
<tr>
<td>Range of scores&lt;sup&gt;b&lt;/sup&gt;</td>
<td>4 - 110</td>
<td></td>
</tr>
<tr>
<td>Mean age equivalent in years</td>
<td>7.86 (4.25)</td>
<td></td>
</tr>
<tr>
<td>((SD))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age equivalent range in years</td>
<td>0 - 18</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* DD = developmental disabilities; ASD = autism spectrum disorder.

<sup>a</sup>Other diagnoses include Down syndrome \((n = 1)\); Fragile X syndrome \((n = 2)\); tuberous sclerosis \((n = 1)\); cerebral palsy \((n = 1)\); Fetal Alcohol Spectrum Disorder \((n = 1)\); Fetal Alcohol Spectrum Disorder + cerebral palsy \((n = 1)\).

<sup>b</sup>\(n = 127\). *Possible scores range from 0 to 120.*
The *Scales of Independent Behavior-Revised Short Form* (SIB-R; Bruininks et al., 1996) assesses an individual’s everyday living skills. Participants only completed this scale based on their sibling with a disability, not on their sibling without a disability. The SIB-R measures adaptive behaviour including motor, social interaction, communication, and personal living skills, as well as maladaptive behaviour. This study only included the adaptive behaviour scale, which consists of 40 tasks that are progressively more difficult (e.g., ‘Washes and dries dishes and puts them away’ and ‘Makes purchases with a check’). Respondents rate the ability of the individual with DD to do each of the tasks using a 4-point scale ranging from 0 (*never or rarely*) to 3 (*does very well*). Total raw scores on the adaptive behaviour scale range from 0 to 120, and higher scores indicate higher adaptive functioning. The SIB-R Short Form has good test-retest reliability .86, and construct validity ranges from .67 to .96 being .95 overall (Bruininks et al., 1996).

The *Sibling Contact Questionnaire* (Appendix P) was designed for this study. It contains six items and asks participants about the type, frequency, and quality of contact they have with their siblings. The first three items ask about frequency of three types of contact: face-to-face, telephone, and other contact (e.g., email, letters, text message, etc.). Participants rate each item using a 6-point scale (0 = *never*; 1 = *less than once per month*; 2 = *1 to 3 times per month*; 3 = *1 to 3 times per week*; 4 = *4 to 6 times per week*; 5 = *daily*). If the participant indicates that they never have a certain type of contact with their sibling, they are asked to indicate the reason. The fourth item asks participants whether they have had any changes contact with their sibling over the past two years, and if yes
they are asked to describe the change and the reason for it. The fifth item asks about how long it takes for participants to get to their sibling’s home, and responses were made on a 6-point scale (0 = N/A, my sibling lives with me; 1 = less than 30 minutes; 2 = 30 to 60 minutes; 3 = 1 to 2 hours; 4 = 2 to 3 hours; 5 = more than 3 hours). The final question asks participants to provide a qualitative response that describes the quality of contact they have with their sibling. Participants completed this measure twice – once based on their relationship with their sibling with a disability and once based on their relationship with their sibling without a disability.

The Life Domains Questionnaire (Seltzer et al., 1997; Appendix D) asked participants to rate the extent that their sibling with DD has affected 11 areas of their life, including: career choice, where to live, whether to have children, religious beliefs, feelings about self, choice of romantic relationship, relationship with spouse, relationship with children, plans for own future, political views, and feelings about people with disabilities. Responses were made on a 4-point scale ranging from 0 (not at all affected) to 3 (strongly affected), with higher scores corresponding to the perception that siblings had a greater impact on participants’ lives. Participants had the option to select ‘not applicable’ for items that were not relevant to them (e.g., ‘relationship with children’ for participants who did not have children). Participants completed this measure twice – once based on their relationship with their sibling with a disability and once based on their relationship with their sibling without a disability. The Cronbach’s alpha for this study
indicated that the scale had good internal consistency for the scores based on both
siblings with a disability ($\alpha = .84$) and siblings without a disability ($\alpha = .87$).

The *Lifespan Sibling Relationship Scale* (LSRS; Riggio, 2000; Appendix Q) measures an adult’s perceptions about the sibling relationship. It consists of six scales containing eight items each. Three of the scales focus on childhood and three focus on adulthood. For both childhood and adulthood there is a scale that measures each of the following: affect towards the sibling and sibling relationship (e.g., ‘My sibling makes me happy’); behaviour with and toward the sibling (e.g., ‘I presently spend a lot of time with my sibling’); and cognitions about the sibling and sibling relationship (e.g., ‘My sibling is a good friend’). Items are rated on a 5-point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*), which higher scores representing more positive perceptions about the sibling relationship. The LSRS has good psychometric properties, including high internal consistency (Cronbach’s $\alpha = .96$ for the total LSRS and ranges from .84 to .91 for the six scales) and good test-retest reliability (Riggio, 2000). Consistent with Riggio’s findings, the LSRS demonstrated good internal consistency for this study. When the LSRS was completed based on the relationship with the sibling with a disability, Cronbach’s $\alpha$ was .96 for the total score and it ranged from .82 to .89 for the six scales. When the LSRS was completed based on the relationship with the sibling without a disability, Cronbach’s $\alpha$ was .96 for the total score and it ranged from .87 to .92 for the six scales.

**Procedure.** Participants completed a set of online questionnaires that took approximately 60 minutes to complete. If the participant had more than one sibling with a
disability ($n = 14; 10.9\%$), the instructions directed them to complete sibling-related
quionnaires based on the sibling with a disability with whom they had the closest
relationship. Likewise, participants who had more than one sibling who did not have a
disability ($n = 63; 49.2\%$) were asked to complete the sibling-related questionnaires
based on the sibling without a disability with whom they had the closest relationship.
This study used the same set of data that was collected for Study 1 described in Chapter
2. Thus, I refer the reader to the Procedure section of Chapter 2 for full details regarding
the recruitment process and procedure used for this study.

Results

Data Preparation. Prior to analyzing the data, I examined the variables for
outliers and normality. I examined the z-scores for each continuous variable to identify
univariate outliers. I replaced z-scores greater than 3.29 with a score one unit higher or
lower than the next most extreme value in order to decrease the effect of the outlier
(Tabachnick & Fidell, 2007). I reviewed the skewness and kurtosis values, as well as
histograms for each variable and all variables were normally distributed. I also examined
the variables for multivariate outliers, and did not find any such cases.

Next, I compared the demographic characteristics of the siblings with and without
a DD. I used a paired samples t-test to compare the age of the siblings with a DD to the
age of the siblings without a DD. The results showed that the siblings without a DD were
significantly older ($M = 40.34, SD = 14.54$) than the siblings with a DD ($M = 37.76, SD =
12.17$), $t(127) = 4.08, p < .001$. I also conducted a McNemar test to determine whether
the proportion of men and women differed between the two types of siblings and the results of this test were not significant, \( \chi^2(2, N = 128) = 1.31, \ p = .25. \)

Due to the significant difference in age between the siblings with and without a DD, I conducted Pearson correlations to determine whether the age of either sibling group was significantly correlated with any of the dependent variables of interest in this study. Frequency of contact with siblings with a DD using technology other than a telephone was significantly correlated with both the age of the sibling with a DD, \( r = -.24, p = .006 \), and with the age of the sibling without a DD, \( r = -.26, p = .003 \). Younger age was correlated with greater frequency of contact. Likewise, the frequency of contact with siblings without a DD using other technology was significantly correlated with the age of the sibling with a DD, \( r = -.22, p = .01 \), with younger age being associated with greater frequency of contact. The correlations between sibling ages and the following dependent variables were not significant: Life Domain Impact scores; LSRS Adult Affect, Adult Behaviour, and Adult Cognition scores; frequency of face-to-face contact; and frequency of telephone contact.

**Life Domain Impact.** I conducted McNemar tests to determine whether the siblings’ disability status (i.e., had a DD vs. did not have a DD) was related to the degree of perceived life domain impact for each of the 11 life domain items. To control for the increased risk of type I error, a Bonferroni correction was used, which resulted in an \( \alpha \)-value of .005. All of the McNemar tests were significant (see Table 13). For each of the 11 life domains, there were a greater proportion of participants who were somewhat /
Table 13

*McNemar Tests for Life Domain Items*

<table>
<thead>
<tr>
<th>Siblings with a Disability – Amount Affected</th>
<th>Siblings without a Disability – Amount Affected</th>
<th>N</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career choice Not at All / Not Very Somewhat / Very</td>
<td>63 1 127</td>
<td>46.17</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Where to live Not at All / Not Very Somewhat / Very</td>
<td>57 3 127</td>
<td>42.88</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Whether to have children Not at All / Not Very Somewhat / Very</td>
<td>94 2 125</td>
<td>16.96</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Religious beliefs Not at All / Not Very Somewhat / Very</td>
<td>103 2 126</td>
<td>6 p = .001$^a$</td>
<td></td>
</tr>
<tr>
<td>Feelings about yourself Not at All / Not Very Somewhat / Very</td>
<td>53 6 127</td>
<td>17.33</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Choice of romantic relationships Not at All / Not Very Somewhat / Very</td>
<td>74 2 127</td>
<td>31.61</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Relationship with spouse Not at All / Not Very Somewhat / Very</td>
<td>61 4 122</td>
<td>35.58</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Relationship with children Not at All / Not Very Somewhat / Very</td>
<td>69 3 105</td>
<td>16.69</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Plan for own future Not at All / Not Very Somewhat / Very</td>
<td>33 3 125</td>
<td>61.65</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Political views Not at All / Not Very Somewhat / Very</td>
<td>79 0 121</td>
<td>35.03</td>
<td>$p &lt; .001$</td>
</tr>
<tr>
<td>Feelings about people with disabilities Not at All / Not Very Somewhat / Very</td>
<td>17 1 126</td>
<td>82.10</td>
<td>$p &lt; .001$</td>
</tr>
</tbody>
</table>

$^a$Due to the distribution of the responses for this item, the binomial distribution was used, and thus, a chi-square value was not produced.
very affected by their sibling with a DD but not at all / not very affected by their sibling without a DD as compared to the proportion of participants who were somewhat / very affected by their sibling without a DD but not at all / not very affected by their sibling with a DD.

**Frequency of Contact.** I examined three aspects of participants’ contact with their sibling with a disability: frequency of face-to-face contact, frequency of telephone contact, and frequency of contact through other forms of technology (e.g., text messaging, email, etc.; Table 14).

Table 14

*Frequency of Contact with Siblings with a DD*

<table>
<thead>
<tr>
<th></th>
<th>Siblings with a DD</th>
<th>Siblings without a DD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Face-to-face</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly or more</td>
<td>54 (42.2%)</td>
<td>28 (21.9%)</td>
</tr>
<tr>
<td>1-3 times per month</td>
<td>30 (23.4%)</td>
<td>29 (22.7%)</td>
</tr>
<tr>
<td>Several times per year or less</td>
<td>44 (34.4%)</td>
<td>71 (55.5%)</td>
</tr>
<tr>
<td><strong>Telephone</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly or more</td>
<td>56 (43.7%)</td>
<td>36 (28.1%)</td>
</tr>
<tr>
<td>1-3 times per month</td>
<td>39 (30.5%)</td>
<td>52 (40.6%)</td>
</tr>
<tr>
<td>Several times per year or less</td>
<td>33 (25.8%)</td>
<td>40 (31.3%)</td>
</tr>
<tr>
<td><strong>Other Technology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly or more</td>
<td>19 (14.8%)</td>
<td>66 (51.6%)</td>
</tr>
<tr>
<td>1-3 times per month</td>
<td>15 (11.7%)</td>
<td>32 (25.0%)</td>
</tr>
<tr>
<td>Several times per year or less</td>
<td>94 (73.4%)</td>
<td>30 (23.4%)</td>
</tr>
</tbody>
</table>

To compare the frequency of face-to-face contact and telephone contact that participants had with their siblings with a DD versus their siblings without a DD, I
conducted two paired samples t-tests. I used Holm’s Sequential Bonferroni correction to control for increased risk of type I error in the three contact analyses. The t-test related to frequency of face-to-face contact was significant, $t(127) = 5.06, p < .001 (\alpha = .016)$; participants reported a greater frequency of face-to-face contact with their sibling with a DD ($M = 2.36; SD = 1.34$) as compared to their sibling without a DD ($M = 1.71; SD = 1.17$). Likewise, the t-test related to frequency of telephone contact was significant, $t(127) = 2.14, p = .03 (\alpha = .05)$; participants reported a greater frequency of telephone contact with their sibling with a DD ($M = 2.36; SD = 1.43$) as compared to their sibling without a DD ($M = 2.05; SD = 1.18$).

Due to the significant correlation between sibling age and frequency of other technology-based forms of communication, I conducted a repeated measures analysis of covariance (ANCOVA) with sibling age as a covariate to compare frequency of this type of contact between the two sibling types. There was a significant main effect of sibling type, Wilk’s $\Lambda = 0.94, F(1, 125) = 8.31, p = .005 (\alpha = .025)$. After controlling for the age of both the sibling with a DD and the sibling without a DD, participants reported a significantly greater frequency of other technology-based forms of contact with their sibling without a DD ($M = 2.55; SD = 1.40$) than with their sibling with a DD ($M = 0.93; SD = 1.31$).

**Sibling Relationship Closeness.** Sibling relationship closeness was evaluated using the three adult scales of the LSRS. I conducted three paired samples t-tests (one for each LSRS adult scale) to determine whether relationship closeness with the sibling with
a DD differed from relationship closeness with the sibling without a DD. I used Holm’s Sequential Bonferroni correction to control for increased risk of type I error. The t-test for Adult Affect was significant, \( t(118) = 3.33, p = .001 (\alpha = .025) \). Participants reported more positive feelings toward their sibling with a DD (\( M = 33.55, SD = 5.34 \)) than they did toward their sibling without a DD (\( M = 31.29, SD = 6.59 \)). The t-test for Adult Behaviour was also significant, \( t(118) = 3.58, p < .001 (\alpha = .017) \); however, the participants reported less closeness in their behaviours toward their sibling with a DD (\( M = 22.80, SD = 6.67 \)) as compared to their sibling without a DD (\( M = 25.46, SD = 7.08 \)). The t-test for Adult Cognition was not significant, \( t(118) = 1.42, p = .16 (\alpha = .05) \). The participants’ thoughts about the closeness of their relationship with their sibling with a DD (\( M = 30.82, SD = 5.93 \)) did not differ from their thoughts about the closeness of their relationship with their sibling without a DD (\( M = 29.82, SD = 7.33 \)).

**Study 2**

**Method**

**Participants.** This study included data from 17 adults with a DD (7 men and 10 women) and their parent/guardian. An additional parent completed the parent interview; however, her adult child did not want to participate in the study, so this parent’s data were not included. The adults with a DD ranged in age from 22 to 66 years (\( M = 35.88, SD = 12.96 \)). Their parent/guardian provided information about the adults with a DD’s diagnoses. Of the 17 adults with a DD, 4 had an intellectual disability due to an unknown
cause, 8 had Down syndrome, 1 had an autism spectrum disorder, 2 had an intellectual disability caused by birth trauma, and 2 had other syndromes.

The parents/guardians (1 man and 16 women) included 10 biological parents, 1 adoptive parent, 5 siblings, and 1 caregiver who had known the adult with a DD for 7 years. They ranged in age from 31 to 78 years ($M = 58.12, SD = 13.82$). Eight of the parents/guardians lived with the adult with a DD, two lived with them part-time, and seven did not currently live with the adult with a DD.

**Measures.** The *Sibling Contact Interview for People with Disabilities* (Appendix R) was designed for this study, and it included demographic information about participants including their age, gender, and with whom they lived. It was also used to collect information from the adults with DD about their number of brothers and sisters, whether the siblings were older or younger, how often the participant saw their siblings, and how often the participant communicated with their siblings by telephone, email, msn, or other forms of communication. Participants were also asked a series of questions about both the sibling they saw most often and the sibling they saw least often (if they had more than one sibling). These questions asked about what the participant liked to do with the sibling, whether there were things that they wanted to do with the sibling but did not, and if so, why not. Additionally, participants were asked about the ways that their sibling helped them, the ways that they helped their sibling, whether they would like to spend more time with their sibling, and why they did not spend more time with their sibling.
The *Lifespan Sibling Relationship Scale* (LSRS; Riggio, 2000) measures feelings, behaviours, and thoughts related to sibling relationships in both adulthood and childhood. For this study, the LSRS was modified for use with the participants with DD (Appendix K). I collaborated with my supervisor to modify the language of the measure to a level that was appropriate for use with adults with mild to moderate intellectual disability. To reduce the complexity of this measure, participants completed the questions related to their relationship during adulthood but not the questions related to their relationship during childhood. The three scales used in this study were Adult Affect (e.g., “My sibling makes me happy”), Adult Behaviour (e.g., “My sibling and I share things with each other”), and Adult Cognition (e.g., “My sibling thinks I am important”). Participants made responses using one of two scales: (1) a 2-point scale (1 = no; 2 = yes) or (2) a 3-point scale (1 = no; 2 = sometimes; 3 = yes). The response scale used for each participant was determined using the criteria outlined in the *Personal Wellbeing Index – Intellectual Disability* (described below). This measure includes instructions for determining a participant’s level of understanding of rating scales. Thus, if a participant was deemed able to use a 3-point scale according to the Personal Wellbeing Index, a 3-point scale was also used for the LSRS, etcetera. In order to examine the test-retest reliability of this measure, participants completed the measure at two time points – once during the initial interview and a second time 2 weeks later. As described in the Results section of Chapter 2, the internal consistency of the Behaviour scale was good (Cronbach’s $\alpha = .88$); however, the internal consistency of the Affect and Cognition scales was unacceptably
low (Cronbach’s $\alpha = .38$ and .49, respectively). The test-retest reliability was in the acceptable range for the Behaviour and Cognition scales ($r = .79$ and .78, respectively); however, it was in the poor range for the Affect scale ($r = .52$).

The parent/guardian of the adults with DD in Study 2 completed the Information about Adults with an Intellectual Disability – Parent Version (Appendix M) in a telephone interview. This questionnaire was designed for this study, and it was used to collect further information about the adults with DD who participated in the study. The questionnaire included demographic information about the parent/guardian (i.e., gender, birth year, and relationship to adult with DD). Parents/guardians also provided information about with whom the adult with DD lived, how long the parent/guardian had known the adult with DD (if the parent/guardian was not a biological parent), and about the siblings of the adult with DD (gender, age, and frequency of contact). Finally, the parent/guardian was asked about the cause(s) of the adult with DD’s disability, who made the diagnosis, when the diagnosis was made, and whether the adult with DD has any other diagnoses (e.g., epilepsy, psychiatric disorder, etc.).

**Procedure.** Participants completed in-person interviews and their parent/guardian completed a telephone interview. This study used the same set of data that was collected for Study 2 described in Chapter 2. Thus, I refer the reader to the Procedure section of Chapter 2 for full details regarding the recruitment process and procedure used for this study.
Results

To determine whether the adults with a DD differed in their feelings, behaviours, and thoughts towards their siblings, a one-way repeated-measures ANOVA was conducted to compare the Affect, Behaviour, and Cognition scores of the LSRS. There was a significant main effect, Wilk’s $\Lambda = .36$, $F(2, 15) = 13.24$, $p < .001$, partial $\eta^2 = .64$. Pairwise comparisons showed that the scores on the Affect ($M = 15.24$, $SD = 1.09$) and Cognition ($M = 14.71$, $SD = 1.83$) scales were both significantly higher than scores on the Behaviour scale ($M = 9.29$, $SD = 5.18$). The Affect and Cognition scale scores did not significantly differ from one another.

I also explored sibling contact. All of the adults with a DD reported that they spent face-to-face time with their brothers and sisters. Additionally, 15 (88.2%) participants said they spent time talking with their sibling on the telephone and 9 (60.0%) reported using other forms of technology to communicate with their siblings. Such communication included email, text messaging, online video (e.g., skype), online chat (e.g., msn), and social media websites (e.g., facebook).

Participants also provided descriptive information about the activities they did with their sibling. If participants had more than one sibling, they were asked to provide information about the sibling with whom they felt closest. Table 15 provides information about the types of activities that participants reported that they enjoyed doing with their sibling. Twelve (70.6%) participants also reported that they would like to spend more time with their sibling than they currently did. The main reasons for not spending more
time with siblings included the distance between where the participant and the sibling lived ($n = 7; 58.3\%$) and the sibling being too busy to spend more time with the participant ($n = 4; 33.3\%$).

Table 15

Activities Participants Enjoy Doing with their Siblings

<table>
<thead>
<tr>
<th>Activity</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaging in physical activity (e.g., swimming, bowling)</td>
<td>6 (35.3)</td>
</tr>
<tr>
<td>Going shopping</td>
<td>5 (29.4)</td>
</tr>
<tr>
<td>Eating in restaurants</td>
<td>4 (23.5)</td>
</tr>
<tr>
<td>Going to movies</td>
<td>4 (23.5)</td>
</tr>
<tr>
<td>Talking/visiting</td>
<td>4 (23.5)</td>
</tr>
<tr>
<td>Watching TV / playing videogames / listening to music</td>
<td>3 (17.6)</td>
</tr>
<tr>
<td>Playing games</td>
<td>2 (11.8)</td>
</tr>
<tr>
<td>Going to a cottage</td>
<td>2 (11.8)</td>
</tr>
<tr>
<td>Other activities</td>
<td>5 (29.4)</td>
</tr>
</tbody>
</table>

*Note: Activities are not mutually exclusive.*

Finally, I asked participants about helping behaviours in their sibling relationship.

Twelve (70.6\%) of the participants indicated that their sibling provided them with help and 12 (70.6\%) of the participants reported that they provided help to their siblings (see Table 16).
Table 16

*Activities in which Participants and Siblings Help Each Other*

<table>
<thead>
<tr>
<th></th>
<th>Sibling Helps</th>
<th>Participant Helps</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Chores / household tasks</td>
<td>3 (25.0)</td>
<td>6 (50.0)</td>
</tr>
<tr>
<td>Going places in the community</td>
<td>4 (33.3)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Use of technology</td>
<td>2 (16.7)</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td>Cooking</td>
<td>2 (16.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Finances</td>
<td>2 (16.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (25.0)</td>
<td>3 (25.0)</td>
</tr>
</tbody>
</table>

*Note:* Activities are not mutually exclusive.

**Discussion**

Through these two studies, I sought to examine various aspects of the sibling relationship from both the perspectives of siblings with and without a DD. Consistent with my hypothesis participants reported that their sibling with a DD had a greater impact on all 11 domains of their life than their sibling without a DD. In terms of sibling contact, I predicted that participants would have a greater frequency of telephone contact with their sibling without a DD and that there would be no difference between sibling types in face-to-face contact. Contrary to these predictions, participants reported a greater frequency of both face-to-face contact and telephone contact with their sibling with a DD as compared to their sibling without a DD. However, consistent with my hypothesis, participants reported less use of technology based forms of contact such as email and text messaging for communicating with their sibling with a DD as compared to their sibling with a DD. Finally, my hypothesis that siblings would report less relationship closeness
with their sibling with a DD was only partially supported. Participants did report less
closeness in their behaviours toward their sibling with a DD; however, their feelings
about their relationship with their sibling with a DD were reported to be more positive
than their feelings about their relationship with their sibling without a disability. I did not
find a difference in thoughts about the relationship between the two types of siblings.

I did not propose any specific hypotheses for Study 2; however, I did anticipate
that adults with a DD would perceive their sibling relationships as beneficial and
important. Indeed, participants identified numerous activities they enjoyed doing with
siblings, they indicated that they exchanged instrumental support with their sibling, and
many reported that they would like to spend more time with their siblings.

**Relationships with Siblings with a DD versus Relationships with Siblings without a DD**

This study examined three aspects of sibling relationships, including the amount
of perceived impact that siblings with a DD had on various domains of participants’ lives,
the frequency of various types of sibling contact, and sibling relationship closeness.
Consistent with previous research (Flaton, 2006; Marks, Matson, & Barraza, 2005), I
found that participants perceived their sibling with a DD as having a greater impact on all
life domains than their sibling without a DD. The domains that showed the greatest
discrepancy were career choice, where to live, relationship with spouse, plans for the
future, and feelings about people with a disability. Many siblings of individuals with a
DD plan to partake in care giving for their sibling when their parents are no longer able to
do so (Bigby, 1997; Greenberg et al., 1999; Krauss et al., 1996). This expectation likely relates to the greater impact on life domains such as where to live, spousal relationships, and future plans.

Previous research on frequency of sibling contact indicates that siblings report regular in-person and telephone contact with their brother or sister with a DD. For example, Krauss et al. (1996) found that 30% of siblings in their study spoke to their brother or sister with a DD on the phone at least weekly and 41% visited their sibling at least weekly. However, Taylor et al. (2008) found that in comparison to siblings of individuals without a DD, siblings of individuals with a DD had less frequent contact. In contrast, the findings from my study and a study by Doody et al. (2010) show greater frequency of contact for sibling pairs that include an individual with and one without a DD as compared to sibling dyads that only include individuals without a disability. The discrepancy in findings between these studies may be related to differences in demographic characteristics, as the participants in Taylor et al.’s study included a larger proportion of brothers than the other two studies and on average, Taylor et al.’s participants were approximately 25 to 30 years older than the participants in the other two studies.

One reason that participants in my study may have reported more contact with their siblings with a DD as compared to their siblings without a DD may be due to the increased instrumental support provided to siblings with a DD. Doody et al. (2010) conducted a second analysis that involved excluding siblings who had care giving
responsibilities for their brother or sister with a DD. After removing these participants, they found no difference in frequency of in-person or telephone contact between siblings of individuals with a DD and siblings of individuals without a DD. However, Doody et al. (2010) did not ask participants about care giving responsibilities for siblings without a DD. Although this may occur less frequently, there are numerous circumstances in which a sibling may act as a caregiver for a brother or sister without a DD, such as in the case of chronic illness, physical disability, and age-related physical or cognitive decline. Unfortunately, I did not ask participants about their care giving responsibilities and therefore was unable to compare sibling contact after removing time spent care giving. Further research is needed to clarify whether there are differences in frequency of sibling contact that is not related to care giving activities in sibling pairs that include an individual with a DD and pairs that do not include an individual with a DD.

Technology based forms of communication such as email, text messaging, and social media websites are commonly used to maintain contact with siblings (Corti, 2009). However, participants in my study reported less use of these technology based forms of communication for contacting siblings with a DD as compared to siblings without a DD. This finding is consistent with research by Hodapp and colleagues (2010) who found that very few siblings of individuals with a DD used email as a primary form of contact with their sibling with a disability. This finding may be due in part to the decreased access to technology for individuals with a DD as compared to the general population (Palmer, Wehmeyer, Davies, & Stock, 2012; Tanis et al., 2012). Additionally, the limitations of
some individuals with a DD, such as an inability to read or write, may further contribute to the decreased use of technology for sibling communication.

The final aspect of sibling relationships that I examined was relationship closeness, which included feelings about the sibling relationship (affect), behaviours in the relationship, and thoughts about the relationship (cognitions). Although I found no difference in cognitions between the two types of sibling relationships, I did find that participants reported more positive feelings but less close behaviours toward their relationship with their sibling with a DD as compared to their sibling without a DD. The lack of difference in cognitions is consistent with the results of Doody et al. (2010) who found no difference in relationship closeness between adult siblings of individuals with a DD and adult siblings of individuals without a disability. However, my findings related to affect and behaviours contradict Doody et al.’s results, as well as the findings of Taylor et al. (2008) who found that siblings of individuals with a mild ID reported lower relationship closeness than siblings of individuals without an ID. The discrepancy between the findings may relate in part to differences in the measures used. Doody et al. examined the Warmth factor of the Adult Sibling Relationship Questionnaire, which is a combination of scales that include questions about affect, behaviours, cognitions, and other aspects of the sibling relationship. Thus, Doody et al. did not examine differences in the specific aspects of these relationships as I did in my study. Taylor et al. used a single item question asking participants to rate their closeness with their sibling on a 4-
point scale ranging from ‘not at all close’ to ‘very close’. Again, this approach did not allow for comparison of more subtle aspects of the sibling relationship.

Interestingly, participants in my study reported having more face-to-face contact with their sibling with a DD but lower behaviour scores on the measure of relationship closeness. The Adult Behaviour scale measures behaviours such as hanging out with siblings and talking about problems with siblings. The fact that participants engaged in less of these types of behaviours with their sibling with a DD, yet they spent more time with these siblings could indicate that time spent with siblings with a DD is less often spent in a social context or focused on providing emotional support and instead is more focused on providing instrumental support as compared to time spent with siblings without a DD. This explanation is supported by the previously mentioned findings of Doody et al. (2010) who reported that siblings of individuals with a DD spent more time with their brother or sister than siblings of individuals without a DD; however, when care giving time was controlled for, there was no difference in frequency of contact between the two groups.

**Perspectives of Adults with a DD**

The adults with a DD in this study had higher scores on the Affect and Cognition scales of the LSRS than they did on the Behaviour scale. This finding suggests that the participants had positive feelings about their siblings and they thought of their relationship with their sibling as being close and important. However, the behaviours exhibited in the sibling relationship (e.g., time spent together, talking about problems,
etc.) did not reflect the same level of closeness as was suggested by the feelings and thoughts about the sibling relationship.

There are several possible explanations for the differences between the Affect and Cognition scales and the Behaviour scale. First, the internal consistency of the Affect and Cognition scales was low, whereas the Behaviour scale had good internal consistency. Therefore, discrepancies between the scales found in this study could be partly attributable to their poor psychometric properties, and thus, the findings should be interpreted with caution until they are replicated using a psychometrically sound measure.

Second, an examination of each participant’s scores on the LSRS revealed that five participants had particularly low scores on the Behaviour scale, although they did not meet the criteria for being statistical outliers. Four of these participants reported that they would like to spend more time with their sibling; however, they were unable to do so because their sibling lived too far away or their sibling was too busy. Thus, despite having positive feelings and thoughts about the sibling relationship, these participants were not able to engage in the relationship behaviours (e.g., spending time together) that they would like to engage in due to other factors.

A third explanation of the discrepancy between the affect and cognition scores and the behaviour scores relates to the findings from Study 1, in which adults without a DD reported more positive feelings toward their sibling with a DD than toward their sibling without a DD but less close behaviours with their sibling with a DD than with their sibling without a DD. A follow-up analysis revealed that, on average, these
participants lived closer to their sibling with a DD than they did to their siblings without a DD, and therefore, greater distance is not a sufficient explanation for the decreased behaviour scores. Rather, this difference may be due to the items included on the Adult Behaviour scale (e.g., discussing problems with the sibling) and the specific deficits of people with a DD (e.g., intellectual disability, communication impairments). Further research is needed to determine the specific cause(s) for the discrepancy reported by adults with a DD between their feelings, thoughts, and behaviours towards their siblings.

Despite the lower scores related to sibling relationship behaviour, all of the participants reported spending face-to-face time with their brother or sister, and they identified numerous activities that they enjoyed doing with their sibling. Similar to studies of adult siblings without disabilities (Scott, 1983, as cited in Cicirelli, 1995) and the reports of adults who have a sibling with a DD (Krauss et al., 1996), the most commonly enjoyed activities included engaging in physical activity, going shopping, eating in restaurants, going to movies, and visiting. In a qualitative study with children who had a brother or sister with a DD, Moyson and Roeyers (2012) found that siblings without a DD enjoyed spending time doing ‘normal’ activities (i.e., activities that they would do with a sibling who does not have a DD) with their siblings with a DD. The findings from this study suggest that individuals with a DD shared this perspective and enjoyed doing activities that siblings without disabilities would do.

Participants in this study also reported interacting with their siblings using a variety of forms of technology. Nearly all participants reported that they talked to their
sibling on the phone, and 60% also used cellular telephones (e.g., text messaging) and internet-based forms of communication (e.g., email, msn, skype) to interact with their siblings. These forms of communication are widely used tools for maintaining social contact with siblings (Corti, 2009), other family members, and friends in the general population (see Tee, Brush, & Inkpen, 2009 for a review). Unfortunately, many people with a DD still have less access to social communication technology than people without a DD (Palmer et al., 2012; Tanis et al., 2012). In this study, 40% of adults with a DD did not use any type of computer-based communication to stay in contact with their siblings. This is consistent with the findings of Tanis and colleagues who found that 34% of adults with a DD in their study reported that they did not have an email address. There are many barriers to technology use for adults with a DD, including lack of training on how to use computers, cost, lack of assistance with maintenance (Palmer et al., 2012; Tanis et al., 2012), group home staff attitudes that online communication is not a desirable form of social contact for individuals with a DD (Parsons, Daniels, Porter, & Robertson, 2008), and cognitive and physical impairments that make the use of technology more difficult. Technology-based communication appears to be an important method of maintaining contact with siblings for adults with a DD, and therefore, future research examining ways to overcome the aforementioned barriers may have positive benefits for sibling relationships.

In addition to spending time with siblings, most participants reported that their sibling provided them with help with various tasks. Most of the helping behaviours that
the participants identified reflected instrumental support such as siblings taking the participants places in the community (e.g., stores, doctor appointments, etc.), helping them with household chores and cooking, assisting them with finances, and helping them to operate technology. Previous research shows that when adults with a DD live with their parents, siblings typically provide little instrumental support (Seltzer et al., 1991), whereas when adults with a DD live with siblings or in settings other than the parental home, siblings provide a greater amount of instrumental support (Bigby, 1997). Twelve of the 17 participants in this study lived either with siblings or outside of the parental home, and therefore, the focus on instrumental support provided by the siblings in this study is supported by previous research. However, regardless of where individuals with a DD live, previous research also shows that most siblings provide emotional support as well (Bigby, 1997; Seltzer et al., 1991). The adults in this study made little mention of emotional support provided by siblings. It is possible that this omission was due to the wording of the interview question, which asked the participant if the sibling ‘helped them with anything’. Such wording may have primed the adults to think of instrumental rather than emotional forms of support. It would be beneficial for future research to examine perceptions of instrumental and emotional support from the perspectives of adults with a DD using a better form of questioning. For example, providing explicit examples or cues may elicit more detailed information about emotional support received from siblings.

Finally, this study examined the ways that adults with a DD help their siblings. Most of the participants reported that they provide instrumental support to their brother or
sister, and this primarily involved assistance with household tasks (e.g., cleaning, caring for pets when siblings were away, etc.). Research on helping behaviour of adult siblings in the general population shows that during early and middle adulthood, most siblings do provide each other with some instrumental support, including coordinated care of elderly parents and occasional assistance with finances, babysitting, sharing possessions, and other tasks (Goetting, 1986). Although the adults with a DD provided help to their siblings, the specific tasks they help with appear to differ somewhat from the tasks in which siblings without a DD may assist one another. The provision of emotional support is also common for siblings in early and middle adulthood (Goetting, 1986); however, only one participant in my study mentioned a form of emotional support – she said she listens to her brother. Seltzer et al. (1991) used information collected from mothers to examine emotional support provided by adults with a DD to their siblings and found that these individuals did provide emotional support; however, the frequency of support they provided was lower than the frequency of support they received from their sibling. Seltzer and colleagues did not examine instrumental support provided by adults with a DD. Again, this study may have failed to identify the emotional support that adults with a DD provide to their siblings due to the wording of the interview questions.

**Limitations and Directions for Future Research**

The two studies presented in this paper offer useful insight into the nature of adult sibling relationships when one member of the sibling dyad has a DD; however, there are several limitations that must be considered when interpreting the results. First,
participants who had more than one sibling with a DD (or without a DD) were asked to respond to the questionnaires based on their relationship with the sibling with whom they had the closest relationship. Only about 10% of participants had more than one sibling with a DD, whereas approximately half of participants had more than one sibling without a DD. The large portion of individuals who had more than one sibling without a DD suggests that the results may not be generalizable to all sibling relationships. In other words, if the relationships of participants and their sibling with a DD were compared to the relationships of participants and their siblings with whom they were less close, the characteristics and differences in these relationships may differ from those found in this study. Further research is needed to examine relationship patterns among siblings of varying degrees of emotional closeness.

Second, although I was able to determine that participants perceived that their sibling with a DD had a significantly greater impact on the 11 life domains as compared to their sibling without a DD, I did not have information about whether the perceived impact was positive or negative. Seltzer et al. (1997) found that siblings of adults with a DD reported more positive impact than siblings of adults with a mental illness; however, it is unclear from the findings of my study whether the differences in impact between siblings with and without a DD are related to perceptions that the sibling with a DD had a beneficial or detrimental impact on the participants’ lives.

Another limitation of Study 1 is the focus on frequency of contact rather than duration or type of activities engaged in during contact. Although participants spent more
face-to-face time with their sibling with a DD than their sibling without a DD, it is unclear whether this time was spent in activities that were enjoyable and fostered the sibling relationship or whether the increased time was due to participants providing instrumental support to their siblings with a DD (e.g., taking them to appointments, assisting with shopping or banking, etc.). Further research is needed to conduct a more in-depth examination of the specific types of activities that adults engage in with their siblings with and without a DD and the duration of these activities.

The study that focused on the perspectives of adults with a DD was limited by the measure of sibling relationship closeness, which was an adapted version of the LSRS. To date, there are no existing measures of sibling relationship closeness designed specifically for individuals with an intellectual disability. Thus, I adapted a measure of sibling relationship closeness from the general literature and used it for this study. Several of the psychometric properties of this measure were in the unacceptable range. Thus, the findings related to sibling relationship closeness in this study must be interpreted with caution. There is growing interest in studying sibling relationships in the DD field, and there is also an increasing awareness of the importance of including individuals with a DD in sibling research. Therefore, it will be important for future research to focus on developing psychometrically sound measures that can be used with adults with a DD in order to enhance our understanding of how sibling relationships impact the lives of these individuals. As outlined in Chapter 2, the literature related to the availability of social
supports for adults with a DD may provide useful direction for how to best measure sibling relationship closeness in adults with a DD.

The general sibling literature shows that sibling relationships change over time depending on the life stage and transition points of siblings (Dana, 1996). My two studies included siblings with and without a DD who covered a broad range of ages, and thus, were at very different life stages. Some of the participants (both with and without a DD) were in early adulthood and still living at home with their parents, whereas others had retired and already experienced the death of their parents. It will be worthwhile for future research to examine whether adult siblings with and without a DD perceive their sibling relationships differently at different points in their lives (e.g., young adults versus older adults). Additionally, an exploration of how the sibling relationship changes at various transition points (e.g., when the sibling without a DD leaves the parental home, gets married, and has children; when the parents die, etc.) would provide insight into when siblings provide each other with increased or decreased support.

Finally, the research designs of the two studies presented in this chapter are limited in that both studies only included the perspective of one sibling in the sibling dyad. Future research that included sibling pairs in which one sibling has a DD and the other does not would enable comparisons of the perspectives of each sibling. Such an approach would allow researchers to determine which aspects of the sibling relationship are perceived as mutually positive (or negative), and it could enable researchers to identify factors that lead to discrepant perceptions about the sibling relationship.
Clinical Implications

It is clear from the results of these studies that siblings are important in the lives of both individuals with and without a DD. Therefore, it is important to encourage sibling connections. New forms of technology such as text messaging, email, social media websites, etcetera, appear to be important means of communication for siblings. The siblings in Study 1 reported that they had fewer contacts with their sibling with a DD using these forms of communication as compared to their siblings without a DD. Likewise, a large portion of the participants in Study 2 did not use technology, other than the telephone, to communicate with their siblings. Given the importance of this form of communication for siblings, it would be worthwhile to investigate ways of facilitating the use of technology for adults with a DD. This may involve training on how to use technology or trouble shoot problems, as well as the development of equipment and programs that are user-friendly for individuals with a DD.

Conclusions

The goal of these two studies was to examine various sibling relationship characteristics from the perspectives of both siblings without a DD and siblings with a DD. Study 1 used an approach not previously used in the existing literature, which involved comparing participants relationships with their sibling with a DD to their relationships with their siblings without a DD. Overall, siblings with a DD appeared to have a greater impact on participants’ lives than their siblings without a DD. Participants reported that they spent more time in face-to-face and telephone contact with their sibling
with a DD and that their sibling with a DD had a greater impact on all aspects of their life, such as their career, relationships, political and religious views, plans for the future, and etcetera. Additionally, participants reported more positive feelings about their relationship with their sibling with a DD as compared to their sibling without a DD. In contrast, participants reported less closeness in their sibling relationship behaviours and a lower frequency of technology-based communication (e.g., email, text message) with their sibling with a DD as compared to their sibling without a DD. These differences may be due to the cognitive and physical limitations of the siblings with a DD.

Study 2 provided new information in that it is the first known study to ask adults with a DD about their perspectives of the sibling relationship. Overall, the participants seemed to value their relationship with their siblings. They reported numerous enjoyable activities that they did with their sibling as well as identifying various ways that they gave and received support from their siblings. Additionally, most of the adults with a DD reported positive thoughts and feelings about their sibling relationship, and they indicated that they would like to spend more time with their sibling. Given the small sample size in this study, further research is needed to confirm these findings and expand our knowledge of the perspectives of adults with a DD on their sibling relationships.
Chapter 5

General Discussion

Through these three studies, I aimed to further our understanding of sibling relationships in adults with and without a DD. To achieve this, I applied a theoretical framework to facilitate our understanding of the stress process experienced by siblings of individuals with a DD. I also examined the experiences of siblings with both a DD and serious behavioural or psychiatric symptoms, and I compared participants’ relationship with their sibling with a DD to their relationship with their sibling without a DD. Finally, I interviewed adults with a DD to gain their unique perspective on sibling interactions.

Taken together, the findings of these studies show that sibling relationships are important for both adults with and without a DD. For adults without a DD, their relationship with their brother or sister with a disability seems to be more prominent in their life than their relationship with their other siblings. The adults without a DD reported that they had more contact with their sibling with a DD, had more positive feelings about their sibling relationship, and were more impacted by their sibling with a DD across numerous life domains as compared to their siblings without a DD. However, the experiences of participants varied. Those whose siblings had both a DD and serious behavioural or psychiatric symptoms reported poorer mental health and less close relationships with their sibling with a DD. However, family functioning played an important role in determining whether siblings’ psychological well-being would be negatively impacted when their brother or sister had both a DD and behavioural or
psychiatric symptoms. Despite the increased risk of negative mental health outcomes in siblings of individuals with a DD and behavioural or psychiatric symptoms, these siblings, and in fact, all of the siblings, were using very few community services and supports designed to assist family members of individuals with a DD.

The participants with a DD identified numerous benefits of their sibling relationships, including engaging in enjoyable activities with their siblings and both providing help to and receiving help from their siblings without a DD. Although all participants spent face-to-face time with their siblings and most also talked on the phone with their siblings, the majority of participants indicated that they would like to spend more time with their siblings than they did currently. Thus, overall, the results of these studies suggest that the adults with a DD perceived their sibling relationships as an important and positive aspect of their life.

**Theoretical Implications**

To date, this study was the first to apply a theoretical model to guide understanding of the psychological impact of having a sibling with a DD in adulthood. Specifically, the Perry (2004) model posits that both general life stressors and characteristics of the individual with a DD predict positive and negative outcomes in siblings; however, the relationships between the stressors and the outcome variables are moderated by individual and family resources and by formal and informal supports (Perry, 2004). This study provided some support for the model’s utility in identifying predictors and moderators of psychological well-being. General life stressors and having
a sibling with both a DD and behavioural/psychiatric symptoms predicted psychological well-being; however, these relationships were moderated by family dysfunction. These findings suggest that when examining the effect of having a sibling with a DD, it is important to consider factors other than just the sibling; life stressors experienced by all adults, as well as general family functioning, are both related to the well-being of the adult siblings of individuals with a DD.

The relationship between the stressor variables and depressive symptoms was not moderated by any of the resources or supports variables. There are two possible explanations for this finding. First, resources and supports may in fact not affect the relationship between stressors and negative outcome variables, in which case, the model used in this study does not provide a useful framework for understanding how adult siblings of individuals with a DD might be negatively affected by their brother or sister with a disability. Second, the variables selected to represent the constructs in the model may not have been appropriate. Given that this was the first study to apply this model to adult siblings, it would be worthwhile for further research to examine alternative moderator variables (e.g., coping style, sibling relationship closeness, etc.) before concluding that this model is not useful in understanding the negative outcomes of sibling relationships.

Clinical Implications

The findings from this study have several important implications for clinicians. We know from the results of these studies and from previous research that siblings are an
important source of both emotional and instrumental support for adults with a DD (Bigby, 1997; Seltzer et al., 1991) and some siblings also act as primary caregivers when parents are no longer able to do so (Bigby, 1997; Greenberg et al., 1999; Krauss et al., 1996). Additionally, siblings who are emotionally close tend to desire a greater frequency of contact with one another (Scott, 1990). Thus, strong sibling relationships can have a positive impact on adults with a DD and may have the potential to lower the need for formal services and supports used by the adult with a DD. Moreover, many adults without a DD experience important benefits from their relationship with their sibling with a DD. Therefore, clinicians working with individuals with a DD and their family members should strive to promote strong sibling relationships in adulthood.

Although there is increased recognition that siblings of individuals with a DD may benefit from supports specifically designed to meet their unique needs, much of the focus to date has been on providing supports to siblings in childhood. Many adults in my studies reported that they did not feel a need for formal supports; however, a large portion also indicated that the necessary supports were not available to them. Thus, there is a need for clinicians and community agencies to develop and implement supports targeted at adult siblings that address issues unique to this demographic, such as maintaining sibling relationships when living in different cities; balancing the care of the sibling with a DD, aging parents, and one’s own family; and providing support for siblings with a DD when parents are deceased or no longer able to provide care. Additionally, the siblings who are well adjusted may still be able to benefit from formal supports such as
workshops or educational resources that focus on promoting healthy sibling relationships rather than addressing problems that siblings may experience.

Finally, these studies highlight that siblings of individuals with a DD and behavioural or psychiatric symptoms are at risk of having more symptoms of depression and lower psychological well-being. Thus, these siblings may require additional supports to cope with the stressors associated with their siblings’ mental illness and their own general life stressors. Given the moderating effect of family dysfunction, another avenue of support for this group may be family-focused interventions that address overall family functioning.

**General Limitations**

There are several limitations that apply to all of the studies presented in this dissertation. First, the characteristics of the participants without a DD may limit the generalizability of the results. These participants were primarily women (i.e., sisters). Previous research shows that sisters are more likely to provide instrumental and emotional support to their sibling with a disability and they tend to report more positive feelings about the sibling relationship than brothers (Ormond & Seltzer, 2000; Seltzer et al., 1991). Given these gender differences it is unclear whether the relationships between the presence of behavioural or psychiatric symptoms in siblings and the variables examined in this study hold true for brothers, especially those who are less involved with the sibling with a DD. Furthermore, sisters report more frequent contact with their sibling with a DD than brothers report (Hodapp et al., 2010). Thus, my finding that participants
reported more frequent contact with their sibling with a DD as compared to their sibling without a DD may not generalize to brothers of individuals with a DD.

Additional demographic factors that may affect the generalizability of the results are the education level and household income of the siblings without a DD in this study. The majority of these participants were well-educated with approximately 70% having an undergraduate university degree and about 30% of those also having a graduate degree. According to Statistics Canada (2010), only 22.9% of Canadians aged 25 to 64 had a university degree or higher in 2006. Therefore, the mean education level of the participants in these studies was higher than the general population. Orsmond and Seltzer (2007) found that lower levels of education were related to closer sibling relationships reported by adult siblings of individuals with autism. Additionally, the median income of participants was approximately $10,000 higher than the median Canadian household income of $65,500 (Statistics Canada, 2012). It is possible that individuals with higher income and more education are better able to access resources and supports to cope with their own life stressors and to understand and meet the support needs of their sibling with a DD. Such factors could have contributed to greater psychological well-being, lower symptoms of depression, and closer sibling relationships in my sample compared to the general population. It would be worthwhile for future research to determine whether the findings from my studies are relevant to siblings who are less educated and who have a lower household income.
The majority of participants in these studies were also employed (82%) and 64% were married or in a common-law relationship. Although these demographic characteristics may limit the generalizability of the findings to siblings who are single or unemployed, Greenberg et al. (1999) found that marital status and employment were not related to the provision of instrumental or emotional support or expectations of future care-giving in adult siblings of individuals with a DD. Thus, these sample characteristics likely had limited impact on the findings related to sibling relationship characteristics.

Furthermore, all of the participants without a DD had at least some contact with their siblings with a disability. One could assume that individuals who are closer to their brother or sister with a DD may be more likely to take the time to participate in a study related to sibling relationships. Further research is needed to determine if the experiences of siblings who no longer have contact with their brother or sister with a disability are different from the experiences reported by the participants in this study.

Finally, the information about the siblings of the participants without a DD was not verified. The participants provided information about their siblings’ disability diagnoses, level of intellectual ability, and behavioural/psychiatric symptoms; however, some siblings may have had incorrect or incomplete information due to receiving inaccurate information through secondary sources or having parents who withheld information. Ideally, diagnoses would be confirmed through medical or psychiatric reports or parent report and siblings’ intellectual and adaptive functioning would be measured using psychometric tests. Unfortunately, such procedures exceeded the
resources available for these studies. However, because this research focused largely on siblings’ perspectives and subjective experiences, their understanding of their brother or sister’s diagnoses and abilities may be more relevant than ensuring accurate diagnostic information.

The two studies that included adults with a DD also have some important limitations. First, the sample size for these studies was small, and therefore, the results should be replicated before drawing firm conclusions. Second, nearly half of the participants had a diagnosis of Down syndrome, whereas only one participant had a diagnosis of autism. Although no other studies to date have examined sibling relationships from the perspective of adults with autism and Down syndrome, studies that have compared adult siblings of individuals with autism to adult siblings of individuals with Down syndrome show that siblings of people with autism had less contact with their brother or sister and they reported less positive feelings about the sibling relationship as compared to siblings of people with Down syndrome (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). Thus, given the differences between diagnostic groups in terms of the experiences of siblings without a DD, it will be important to determine whether the perspectives of adults with autism also differ from the perspectives of adults with Down syndrome or other disorders.

A final limitation relates to the method of recruitment used for these studies. The majority of the participants, both with and without a DD, were recruited through community agencies that support individuals with a DD and their family members. Thus,
the findings may not generalize to families that are not connected with resources in their communities.

**Directions for Future Research**

The literature related to adult siblings in the DD field is limited; however, there appears to be an increasing awareness that this is an important area of study. As we move forward, it will be important to incorporate theory into the study of adult siblings both with and without a DD. The findings from my research show that it may be useful to draw on models of stress from the parent literature. Additionally, the use of theoretical models facilitates the exploration of more complex relationships between variables, such as the effects of mediators and moderators.

It is evident that there is significant variation in the experiences of adult siblings of individuals with a DD. However, given the many confounding factors (e.g., shared genetics, shared developmental and familial environment, etc.) it is difficult to determine whether the differences experienced by siblings are caused by the specific characteristics of their brother or sister with a DD or by other factors. Longitudinal research may help to clarify issues of causality. Additionally, it will continue to be important to identify both protective and risk factors for adults who have a sibling with a DD. My studies examined a variable that has not previously been studied – symptoms of mental illness in the sibling with a DD – and found that siblings of individuals with mental health problems are at greater risk of poor psychological outcomes themselves as compared to siblings of individuals with a DD alone. Once a risk factor or a protective factor is identified, it will
be important for further research to examine how the risks can be mitigated (e.g., identifying variables that moderate the relationship between the risk factor and the outcome) or the protective factors can be promoted. Clinically based research will also be of great benefit in examining how different forms of services and supports can assist in decreasing risks and increasing protective factors for siblings.

Finally, this study was the first of its kind to examine characteristics of the sibling relationship from the perspective of adults with a DD. The importance of including individuals with a DD in sibling research is clear; however, we are currently faced with challenges in realizing this goal. In order to enhance our understanding of how siblings impact the lives of adults with a DD, researchers may need to utilize various methodological approaches such as observational or case studies. Additionally, the development of psychometrically sound qualitative measures that can be used with adults with a DD who have a range of cognitive abilities would further our ability to understand sibling relationships from the perspective of individuals with a DD and how these relationships contribute to well-being. In developing these measures, it may be worthwhile to draw on the existing literature in other areas such as measures used with young children, and measures of social support and quality of life that do not use Likert-type rating scales.

**Summary and Conclusions**

These studies offer new information about the relatively under-researched area of adult siblings of individuals with a DD. In particular, these studies offer insight into the
experiences of individuals who have a sibling with both a DD and mental health symptoms, the perspectives of adults with a DD on their sibling relationships, and the utility of a theoretical model for understanding the stress process in adult siblings. Taken together, the findings of these studies show that many of the siblings of adults with a DD were well-adjusted and benefited from their relationship with their sibling. However, a subset of siblings, namely those whose siblings also had behavioural or psychiatric symptoms, appeared to be at increased risk for negative mental health outcomes. These siblings may benefit from additional supports and resources. Unfortunately, many siblings of adults with a DD in this study reported that they were not aware of accessible services that met their specific needs. Thus, further research is needed to determine how to improve service access for adult siblings and to ascertain whether siblings of individuals with both a DD and mental health problems have unique support needs.

Adults with a DD also reported many benefits of their sibling relationship; however, further research is needed to develop appropriate measurement tools for understanding the experiences of siblings with a DD. The more we understand sibling relationships in adults with and without disabilities, the better we will able to foster long-lasting, healthy sibling relationships that offer mutual benefit to both members of the sibling dyad.
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Appendix A
Demographic Questionnaire

Please answer the following questions about yourself.

1) Gender: ____________________

2) Age: _____

3) What is your marital status? _____________________________

4) How many children do you have? _____
   How many of your children currently live in your home? _____

5) What is the highest level of education that you have completed? __________________

6) Are you currently employed?
   _____ Yes     Occupational title if employed: ____________________________
   _____ No

7) What is your approximate annual household income? ____________________________

8) What country were you born in? _____________________________

9) What country do you currently live in? ____________________________
Appendix B

Information about Siblings Questionnaire

The following questions are about your sibling with a developmental disability (DD).

1) Gender: ___________________
2) Age: _____

3) Below are some of the specific diagnoses that may be associated with developmental disabilities. Please check all of the disorders that your sibling has been diagnosed with as they can co-occur:
   ______ Down syndrome
   ______ Autism, Pervasive Developmental Disorder, (PDD), or Autism Spectrum Disorder (ASD)
   ______ Asperger syndrome
   ______ Prader-Willi syndrome
   ______ Fragile X syndrome
   ______ Rett syndrome
   ______ PKU (Phenylketonuria)
   ______ Cerebral Palsy
   ______ Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Spectrum Disorder (FASD)
   ______ Other syndrome or diagnosis (please specify) _____________________
   ______ My sibling has not received a specific diagnosis (i.e., cause is unknown)
   ______ I do not know whether or not my sibling has a specific diagnosis

4) Does your sibling have any of the following (please check all that apply)
   ______ Problems using his/her legs (e.g., walking, running, standing)
   ______ Problems using his/her hands (e.g., picking things up, holding a pencil)
   ______ Other problems with motor control/coordinat ion (e.g., very clumsy)
   ______ Feeding or eating difficulties (gastro-intestinal problems, feeding tubes, major allergies and sensitivities, etc.)
   ______ Heart problems
   ______ Physical dysmorphology (unusual looking face, head, eyes, ears, fingers, toes)
   ______ Other (please specify) _____________________
   ______ I do not know whether or not my sibling has any of the above conditions

5) Which of the following best describes your sibling’s level of ability?
   ______ No intellectual disability
   ______ Mild or borderline intellectual disability
   ______ Moderate intellectual disability
   ______ Severe intellectual disability
   ______ Profound intellectual disability
   ______ I do not know my sibling’s level of intellectual ability

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6) Does your sibling have any of the following Psychiatric Diagnoses (select all that apply)?:
   _____ Major Depression
   _____ Bipolar Disorder (Manic Depression)
   _____ Anxiety Disorder
   _____ Phobia
   _____ Obsessive Compulsive Disorder (OCD)
   _____ Tourette’s Disorder or other tic disorder
   _____ Schizophrenia or other psychotic disorder
   _____ Anorexia or Bulimia
   _____ I do not know if my sibling has any of the above diagnoses
   _____ None
   _____ Other Psychiatric Illness (please specify): ____________________

7) Does your sibling have any of the following symptoms (select all that apply)?
   _____ Serious anxiety problems but not a diagnosed disorder
   _____ Serious mood problems but not a diagnosed disorder
   _____ Serious behaviour problems but not a diagnosed disorder
   _____ Other psychiatric or psychological problems (please specify) _____________

8) Where does your sibling currently live?
   _____ With parents
   _____ My sibling lives with me
   _____ With another family member (please specify): ______________________
   _____ In a group home
   _____ Alone or with roommates

Please answer the following questions about your sibling who does not have a DD.

1) Gender: _____________________

2) Age: _____

3) Does your sibling have any of the following Psychiatric Diagnoses (select all that apply)?:
   _____ Major Depression
   _____ Bipolar Disorder (Manic Depression)
   _____ Anxiety Disorder
   _____ Phobia
   _____ Obsessive Compulsive Disorder (OCD)
   _____ Tourette’s Disorder or other tic disorder
   _____ Schizophrenia or other psychotic disorder
   _____ Anorexia or Bulimia
   _____ Other Psychiatric Illness (please specify): _____________________
Appendix C

Life Events Inventory

**Instructions:** Please indicate whether you have experienced each of the following life events in the past year. If you have experienced the event, please rate how much turmoil, upheaval, and social readjustment it caused in your life. If an event is not applicable to you, please select N/A (for example “son or daughter left home” is not applicable if you do not have any children).

<table>
<thead>
<tr>
<th>Event</th>
<th>Happen in Previous Year</th>
<th>Extreme Negative</th>
<th>Moderate Negative</th>
<th>Slightly Negative</th>
<th>No Impact</th>
<th>Slightly Positive</th>
<th>Moderate Positive</th>
<th>Extreme Positive</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployment</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Trouble with superiors at work</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>New job in same line of work</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>New job in new line of work</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Change in hours or conditions in present job</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Promotion or change of responsibilities at work</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Retirement</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Move to a different location</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Purchasing own house (taking out mortgage)</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>New neighbours</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Quarrel with neighbours</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Income increased substantially (25 %)</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Income decreased substantially (25 %)</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Getting into debt beyond means of</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Event</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
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<td>----------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Repayment</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Going on holiday</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Conviction for minor violation (e.g. speeding or drunkenness)</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Jail sentence</td>
<td>Y or N</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
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<td>2</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Involvement in fight</td>
<td>Y or N</td>
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<td>Y or N</td>
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<td>with spouse or</td>
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<td>(e.g. in-laws)</td>
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<tr>
<td>Son or daughter left</td>
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<tr>
<td>home</td>
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<td>2</td>
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<tr>
<td>Death of spouse or</td>
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<td>-1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
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<tr>
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<td>3</td>
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<td>Separation from</td>
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<td>3</td>
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<tr>
<td>spouse or partner</td>
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<td>Extra-marital</td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td>N/A</td>
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<tr>
<td>sexual affair</td>
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Appendix D
Life Domains Questionnaire

Use the scale below to rate the extent that your sibling with a developmental disability has had an effect on each of the following areas of your life.

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<thead>
<tr>
<th></th>
<th>0 Not at All Affected</th>
<th>1 Not Very Affected</th>
<th>2 Somewhat Affected</th>
<th>3 Strongly Affected</th>
<th>N/A Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career choice</td>
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<tr>
<td>Where to live</td>
<td></td>
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<tr>
<td>Whether to have children</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Religious beliefs</td>
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<td></td>
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<tr>
<td>Feelings about self</td>
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<tr>
<td>Choice of romantic relationships</td>
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<td></td>
</tr>
<tr>
<td>Relationship with spouse</td>
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<td></td>
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<td>N/A</td>
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<tr>
<td>Relationship with children</td>
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<td></td>
<td>N/A</td>
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<tr>
<td>Plans for own future</td>
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<tr>
<td>Political views</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Feelings about people with disabilities</td>
<td></td>
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</tbody>
</table>

Now, please use the scale below to rate the extent that your sibling who does not have a developmental disability has had an effect on each of the following areas of your life.

<table>
<thead>
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<th></th>
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<th>1 Not Very Affected</th>
<th>2 Somewhat Affected</th>
<th>3 Strongly Affected</th>
<th>N/A Not Applicable</th>
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<tr>
<td>Career choice</td>
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<tr>
<td>Where to live</td>
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</tr>
<tr>
<td>Whether to have children</td>
<td></td>
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</tr>
<tr>
<td>Religious beliefs</td>
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<tr>
<td>Feelings about self</td>
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</tr>
<tr>
<td>Choice of romantic relationships</td>
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<tr>
<td>Relationship with spouse</td>
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<td>Relationship with children</td>
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<tr>
<td>Plans for own future</td>
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</tr>
<tr>
<td>Political views</td>
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<td>Feelings about people with disabilities</td>
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Appendix E

Family Support Scale

**Instructions:** Listed below are people and groups that are often times helpful to family members of individuals with developmental disabilities (DD). This questionnaire asks you to indicate how helpful each source is to you. Please select the response that best describes how helpful the sources have been to you during the past 3 to 6 months. If a source of help has not been available to you during this period of time, select NA (Not Available) response.

How helpful have each of the following been to you in terms of dealing with issues related to your sibling with DD?

<table>
<thead>
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<th>Source</th>
<th>Not Available</th>
<th>Not at All Helpful</th>
<th>Sometimes Helpful</th>
<th>Generally Helpful</th>
<th>Very Helpful</th>
<th>Extremely Helpful</th>
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<td>My parents</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My spouse or partner’s parents</td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My relatives/kin</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My spouse or partner’s relatives/kin</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My spouse or partner</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My friends</td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My spouse or partner’s friends</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My own children</td>
<td>NA</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>Co-workers</td>
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<tr>
<td>Social groups/clubs</td>
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<td>Church groups/religious officials</td>
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<tr>
<td>My family physician</td>
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<tr>
<td>Professional helpers (social workers, therapists, etc.)</td>
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<td>2</td>
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<tr>
<td>Professional agencies (public health, social services, mental health, etc.)</td>
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</table>
Appendix F
Community Supports Questionnaire

The following questions are about services and supports that might be available to you. Please answer the following questions by selecting the appropriate response.

1) Are you aware of any support groups in your community specifically for siblings of people with a developmental disability (DD)?
   _____ No (If no, skip to question 2)
   _____ Yes
   Are you currently using this service? _____ Yes
   _____ No – if no, why not? ________________

   Have you used this type of service in the past? _____ Yes _____ No

   If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

   Not at all helpful    Sometimes helpful    Generally helpful    Very helpful    Extremely helpful

2) Are you aware of any support groups in your community for family members in general?
   _____ No (If no, skip to question 2)
   _____ Yes
   Are you currently using this service? _____ Yes
   _____ No – if no, why not? ________________

   Have you used this type of service in the past? _____ Yes _____ No

   If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

   Not at all helpful    Sometimes helpful    Generally helpful    Very helpful    Extremely helpful

3) Are you aware of any online support groups specifically for siblings of people with a developmental disability (DD)?
   _____ No (If no, skip to question 2)
   _____ Yes
   Are you currently using this service? _____ Yes
   _____ No – if no, why not? ________________

   Have you used this type of service in the past? _____ Yes _____ No
If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

**Not at all helpful**  **Sometimes helpful**  **Generally helpful**  **Very helpful**  **Extremely helpful**

4) Are you aware of any **online support groups** for family members in general?
   ____ No (If no, skip to question 2)
   ____ Yes
   Are you currently using this service?  ____ Yes
   ____ No – if no, why not? ________________

Have you used this type of service in the past?  ____ Yes  ____ No

If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

**Not at all helpful**  **Sometimes helpful**  **Generally helpful**  **Very helpful**  **Extremely helpful**

5) Are you aware of any **education groups/workshops** in your community specifically for **siblings** of people with a developmental disability (DD)?
   ____ No (If no, skip to question 2)
   ____ Yes
   Are you currently using this service?  ____ Yes
   ____ No – if no, why not? ________________

Have you used this type of service in the past?  ____ Yes  ____ No

If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

**Not at all helpful**  **Sometimes helpful**  **Generally helpful**  **Very helpful**  **Extremely helpful**

6) Are you aware of any **education groups/workshops** for family members in general?
   ____ No (If no, skip to question 2)
   ____ Yes
   Are you currently using this service?  ____ Yes
   ____ No – if no, why not? ________________

Have you used this type of service in the past?  ____ Yes  ____ No

If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:
7) Are you aware of any other internet supports (e.g., informational websites) specifically for siblings of people with a developmental disability (DD)?
   _____ No (If no, skip to question 2)
   _____ Yes
   Are you currently using this service?   _____ Yes
                  _____ No – if no, why not? __________________________
   Have you used this type of service in the past?   _____ Yes       _____ No

If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

Not at all helpful      Sometimes helpful      Generally helpful      Very helpful
Extremely helpful

8) Are you aware of any other internet supports (e.g., informational websites) for family members in general?
   _____ No (If no, skip to question 2)
   _____ Yes
   Are you currently using this service?   _____ Yes
                  _____ No – if no, why not? __________________________
   Have you used this type of service in the past?   _____ Yes       _____ No

If you have used this service in the past 6 months, please rate how helpful the service has been to you in terms of dealing with issues related to your sibling with DD:

Not at all helpful      Sometimes helpful      Generally helpful      Very helpful
Extremely helpful

If you are using any other supports not mention above, please describe them here:

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

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Appendix G
Scales of Psychological Well-being

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers.

<table>
<thead>
<tr>
<th>Circle the number that best describes your present agreement or disagreement with each statement.</th>
<th>Strongly Disagree</th>
<th>Disagree Somewhat</th>
<th>Disagree Slightly</th>
<th>Agree Slightly</th>
<th>Agree Somewhat</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most people see me as loving and affectionate.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>In general, I feel I am in charge of the situation in which I live.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I am not interested in activities that will expand my horizons.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>When I look at the story of my life, I am pleased with how things have turned out.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Maintaining close relationships has been difficult and frustrating for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>The demands of everyday life often get me down.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I live life one day at a time and don’t really think about the future.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>In general, I feel confident and positive about myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I often feel lonely because I have few close friends with whom to share my concerns.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>My decisions are not usually influenced by what everyone else is doing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I do not fit very well with the people and the community around me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I tend to focus on the present, because the future nearly always brings me problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I feel like many of the people I know have gotten more out of life than I have.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I enjoy personal and mutual conversations with family members or friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I tend to worry about what other people think of me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I am quite good at managing the many responsibilities of my daily life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I don’t want to try new ways of doing things - my life is fine the way it is.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Being happy with myself is more important to me than having others approve of me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I often feel overwhelmed by my responsibilities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I think it is important to have new experiences that challenge how you think about yourself and the world.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>My daily activities often seem trivial and unimportant to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I like most aspects of my personality.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I don’t have many people who want to listen when I need to talk.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I tend to be influenced by people with strong opinions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>When I think about it, I haven’t really improved much as a person over the years.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I don’t have a good sense of what it is I’m trying to accomplish in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I made some mistakes in the past, but I feel that all in all everything has worked out for the best.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I generally do a good job of taking care of my personal finances and affairs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I used to set goals for myself, but that now seems like a waste of time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>In many ways, I feel disappointed about my achievements in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>It seems to me that most other people have more friends than I do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I enjoy making plans for the future and working to make them a reality.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>People would describe me as a giving person, willing to share my time with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have confidence in my opinions, even if they are contrary to the general consensus.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I am good at juggling my time so that I can fit everything in that needs to be done.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have a sense that I have developed a lot as a person over time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I am an active person in carrying out the plans I set for myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have not experienced many warm and trusting relationships with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>It’s difficult for me to voice my own opinions on controversial matters.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I do not enjoy being in new situations that require me to change my old familiar ways of doing things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Some people wander aimlessly through life, but I am not one of them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>My attitude about myself is probably not as positive as most people feel about themselves.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I often change my mind about decisions if my friends or family disagree.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>For me, life has been a continuous process of learning, changing, and growth.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I sometimes feel as if I’ve done all there is to do in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I know that I can trust my friends, and they know they can trust me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>The past had its ups and downs, but in general, I wouldn’t want to change it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have difficulty arranging my life in a way that is satisfying to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I gave up trying to make big improvements or changes in my life a long time ago.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>When I compare myself to friends and acquaintances, it makes me feel good about who I am.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I judge myself by what I think is important, not by the values of what others think is important.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>I have been able to build a home and a lifestyle for myself that is much to my liking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>There is truth to the saying that you can’t teach an old dog new tricks.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
Appendix H

Center for Epidemiologic Studies Depression Scale

**Instructions:** Below is a list of the ways you might have felt or behaved. Please select the category that shows how often you have felt this way during the past week.

<table>
<thead>
<tr>
<th>During the past week:</th>
<th>Rarely or none of the time (Less than 1 day)</th>
<th>Some or a little of the time (1-2 days)</th>
<th>Occasionally or a moderate amount of time (3-4 days)</th>
<th>Most or all of the time (5-7 days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was bothered by things that usually don’t bother me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I did not feel like eating; my appetite was poor.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that I could not shake off the blues even with help from my family or friends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that I was just as good as other people.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I had trouble keeping my mind on what I was doing.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt depressed.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that everything I did was an effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt hopeful about the future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I thought my life had been a failure.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt fearful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My sleep was restless.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I was happy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I talked less than usual.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt lonely.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>People were unfriendly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I enjoyed life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I had crying spells.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt sad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I felt that people dislike me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I could not get “going.”</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix I

Letter of Information for Participants without a DD

Effect of Sibling Relationships on Well-Being and Depression in Adults with and without Developmental Disabilities

You are invited to participate in a research study being conducted by Julia Burbidge, a graduate student working with Dr. Patricia Minnes in the Psychology Department at Queen's University in Kingston, Ontario, Canada. This study was granted clearance by the Health Sciences Research Ethics Board for compliance with the TCPS: Ethical Conduct of Research Involving Humans, and Queen's Policies.

What is this study about?
This study will examine the effect of sibling relationships and supports on well-being and depressive symptoms in adults who have a sibling with a developmental disability.

Who is eligible to participate in this study?
You are eligible if:

• You are aged 18 to 70 years old,
• You do not have a developmental disability,
• You have at least one living adult sibling with a developmental disability (e.g., intellectual disability, Down syndrome, Fragile X syndrome, autism spectrum disorder, Asperger's syndrome, cerebral palsy, fetal alcohol syndrome/spectrum disorder, etc.)
• You have regular contact with your disabled sibling (i.e., any type of contact at least twice per month) to ensure that you have sufficient knowledge about the sibling to answer questions in the survey.

What will you be asked to do?
You will be asked to fill in the attached surveys, which ask about:

• Relationship characteristics
• Well-being
• Depressive symptoms
• Support use
• Your sibling with a developmental disability (e.g., diagnosis and level of ability)

How long will it take?
• Approximately 45 - 60 minutes if you do not have any non-disabled siblings
• Approximately 1 hour if you have one or more non-disabled siblings

What will happen to the information?
There are no known risks associated with your participation in this study. Participation is completely voluntary. You are free to withdraw at any time for whatever reason without penalty by just not completing the surveys. You will not be identified in any way if the results are published, and nothing will connect you to your responses. All data will be stored in a secure computer file accessible only to the researchers.

As a thank you for your participation, you will be given the opportunity to enter your name into a draw to win one of four $25 CAD gift certificates to Amazon.com (or a similar online website if you live in a country that is not serviced by Amazon.com). If you are the recipient of one of the gift certificates, you will be contacted via email.

If you have any complaints, concerns, or questions about this research, please feel free to contact:

• Julia Burbidge, Primary Investigator, email: 5jgb@queensu.ca

• Dr. Patricia Minnes, Supervisor, email: patricia.minnes@queensu.ca or telephone: 613-533-2885

• Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081

Thanks you for your interest in this study,

Julia Burbidge - Graduate Student
Dr. Patricia Minnes - Faculty Supervisor

If you complete this survey, it implies that you understand and agree to the following statements:

• I have read, and I understand the above information. I understand that:
  o My participation in this study is voluntary
  o I may withdraw from this study at any time without penalty
  o If I choose to withdraw, I may do so by not returning the questionnaires to the researcher
  o My answers will be kept confidential

• I would like to participate in this study.
Appendix J
Debriefing Form

Thank you for completing this survey!

The purpose of this study is to identify factors that are related to well-being and symptoms of depression in adults who have a sibling with a developmental disability. We are expecting that characteristics of disabled siblings (e.g., level of disability), family relationships, and support use will all be related to well-being and depression.

Additionally, we plan to examine how the presence of a mental illness in individuals with developmental disabilities affects sibling relationships and their siblings’ well-being.

Finally, we are interested in whether there are relationship differences between sibling pairs that include a disabled and a non-disabled sibling and sibling pairs that include two non-disabled siblings.

If you have any questions or comments about this study, please email the primary investigator, Julie Burbidge, at 5jgb@queensu.ca. When the study is complete, you will receive a summary of the findings via email.
Appendix K
Lifespan Sibling Relationship Scale - Modified

For these questions, I want you to think about your brother or sister who you are closest to.
What is his/her name? __________________

**Response Options for Different Rating Scale Lengths**
*3-point scale: 1 = No; 2 = Sometimes; 3 = Yes*
*2-point scale: 1 = No; 2 = Yes*

**Type of Scale Used:** ______________________

| 1. I spend a lot of time with ________. | Response |
| 2. ________ makes me happy. | |
| 3. ________ is my good friend. | |
| 4. I tell ________ about my problems. | |
| 5. I enjoy my relationship with _________. | |
| 6. ________ is very important in my life. | |
| 7. I call _________ on the telephone often. | |
| 8. I am proud of _________. | |
| 9. ________ and I have a very close relationship. | |
| 10. ________ and I share things with each other. | |
| 11. I care a lot about the way ________ feels. | |
| 12. ________ is proud of me. | |
| 13. ________ tells me about his/her problems. | |
| 14. I have a lot of fun with _________. | |
| 15. ________ thinks I am one of his/her best friends. | |
| 16. ________ and I hang out together. | |
| 17. I like to spend time with _________. | |
| 18. ________ and I like a lot of the same things. | |
| 19. I do a lot of things with _________. | |
| 20. ________ often makes me feel very angry. | |
| 21. ________ thinks I am important. | |
| 22. ________ and I tell each other our secrets. | |
| 23. I look up to _________. | |
| 24. ________ is one of my best friends. | |
Appendix L

Personal Wellbeing Index – Intellectual Disability

Respondent’s Rating

<table>
<thead>
<tr>
<th>2-pt (0-1)</th>
<th>3-pt (0-2)</th>
<th>5-pt (0-4)</th>
</tr>
</thead>
</table>

Part 1: Happy with life as a whole [optional].
How happy do you feel about your life as a whole?

Part 2: Personal Well-being Index – ID

How happy do you feel about...

1. the things you have? Like the money you have and the things you own?

2. how healthy you are?

3. the things you make or the things you learn?

4. the way you get along with people you know?

5. how safe you feel?

6. doing things outside your home?

7. how things will be later in your life?
Appendix M

Information about Adults with an Intellectual Disability

1) Parent/guardian Gender: _____
2) Parent’s/guardian’s Birth Year: _____
3) Relationship to adult with ID: ________________________________

4) Does [adult with DD’s name] currently live with you? _____ Yes _____ No
   a. If yes, how long has he/she lived with you? _____________
   b. If no, where does [adult with DD’s name] currently live? ______________________

5) If respondent is not a parent or other family member: How long have you known [adult with DD’s name]? _______________

Now I would like to ask you some questions about [adult with DD’s name].

6) How old is [adult with DD’s name]? ______

7) Do you know the cause of [adult with DD’s name] developmental disability?
   a. _____ No, the cause is unknown (go to item 11)
   b. _____ No, he/she might have a diagnosis but I do not know about it (go to item 11)
   c. _____ Yes

8) If yes to item 7: What is the cause of [adult with DD’s name] developmental disability?
   ____________________________________________
   a. Who made this diagnosis? _____________________________
   b. When was this diagnosis made? _____________________________

9) Does [adult with DD’s name] have any additional diagnoses that you are aware of (e.g., cerebral palsy, epilepsy, depression, anxiety disorder, ADHD, etc.)?
   a. _____ No, he/she does not have any other diagnoses
   b. _____ No, he/she might have other diagnoses but I am not aware of any
   c. _____ Yes – if so, what diagnoses _____________________________

10) How many siblings does [adult with DD’s name] have? Sisters or brothers? Age of siblings?

11) How often does [adult with DD’s name] see each of his/her siblings?

12) Which sibling would you say that [adult with DD’s name] has the closest relationship with?
Appendix N

Information Sheet for Parents/Guardians

Effect of Sibling Relationships on Well-being and Depression in Adults with and without Developmental Disabilities

What is this study about? You are invited to participate in a research study through Queen’s University. The purpose of this research is to look at the effect of sibling relationships on the well-being of adults with developmental disabilities. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Who would we like to talk to?
• Adults, aged 18 or older, with a developmental disability and their parent or guardian

What will your son/daughter be asked to do?
• Answer questions about his/her siblings (e.g., number, gender, and age of siblings; frequency of contact with siblings) and his/her sibling relationship
• Answer questions about his/her happiness with different parts of life (e.g., his/her health, relationships with others, learning, etc.)

How long will it take?
There are two parts to this study for your son/daughter.
• First, we would like to do a 30-minute interview with your son/daughter at a location that is convenient for him/her (e.g., at a community agency, day program, group home, etc.).
• Second, we would like to return to the same location and ask your son/daughter some of the same questions 2 weeks later. This will take about 10 minutes. The reason we would like to ask some of the same questions twice is because from previous research, we know that sometimes people with disabilities can have difficulty with answering questions in research studies. One way that we can check if participants in this study understand our questions is to ask them twice at different time points.

How long will it take you?
• We request that you complete a brief telephone interview, which will take 5-10 minutes.

What will you be asked to do?
• Answer basic questions about yourself (e.g., birth year) and questions about your son/daughter’s disability diagnoses
• Answer questions about your son/daughter’s siblings (e.g., number and age of siblings).
**What will happen to the information?** The information we gather is private. We will keep all of the information confidential. No one will see your answers except members of the research team. ID numbers will be used to identify participants so your name will not appear on any of the questionnaires. The information will be kept in a locked filing cabinet. When the information is put in the computer there will be no names with it and the information will require a password to be accessed. No information about your child or yourself will be given to anyone without your written permission, unless this information is required by law. It is the law that professionals must report a suspicion of child abuse.

After gathering all of the information we will write a report to give to the adults with a developmental disability, their parents/guardians, and other people involved in the study. Your name will not be in any of the information and no one will know your answers to the questions.

Your participation and your son/daughter’s participation in this study are voluntary. You and your son/daughter do not have to answer all the questions if you don’t want to. Also, you and/or your son/daughter can withdraw from the study at any time without any penalty.

**How can you and your son/daughter become part of this study?**
- If you would like to be a part of this study, you will need to fill out the consent form on the next page.
- You or your son/daughter can return one copy to the researcher prior to the interview and you can keep one copy for yourself.
- The researcher will also read through a similar information sheet with your son/daughter to get his/her assent to participate.
Effect of Sibling Relationships on Well-being and Depression in Adults with and without Developmental Disabilities: Consent Form

I have read and I understand the information sheet about the Effect of Sibling Relationships on Well-being and Depression in Adults with and without Developmental Disabilities project. I have had the study explained to my satisfaction. I have had my questions about the study answered. I understand that I may refuse to participate or withdraw at any time without any penalties of any kind. I understand that my information will be kept confidential. I will receive a copy of this consent form for my information.

If at any time I have further questions or if I have problems related to participation in this study, I can contact:

- Julie Burbidge, Project Leader: (613) 533-3059
- Dr. Patricia Minnes, Project Supervisor: (613) 533-2885
- Dr. Richard Beninger, Department Head of Psychology, Queen’s University: (613) 533-2486

If I have questions regarding my rights as a research subject I can contact:

- Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board: (613) 533-6081

By signing this consent form, I am indicating that I agree to participate in this study. I am also giving permission for my son/daughter ____________________________ to participate in this study.

(print son/daughter’s full name)

_______________________________________
Name (please print)            Signature of Parent/Guardian            Date

Please provide your telephone number so the researcher can contact you for the telephone interview. ____________________________

STATEMENT OF INVESTIGATOR:

The nature of the above research study has been explained to the participant. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_______________________________________  ____________________________
Signature of Principal Investigator            Date

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Appendix O

Information Sheet for Adults with Disabilities

Effect of Sibling Relationships on Well-being and Depression in Adults with and without Developmental Disabilities

- This project is being done by a student in the Department of Psychology at Queen’s University named Julie Burbidge.
- Dr. Patricia Minnes is supervising this project.
- This project has been approved by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

What is this study about?

- How well people get along with their brothers and sisters
- How happy people are with different parts of their life

Who would we like to talk to?

- Adults (age 18 or older) with a disability who have a brother or sister
- The parents or guardians of the adults with a disability

What will we ask you to do?

- Answer questions about your brothers and sisters, like how old they are and how often you see them
- Answer questions about how well you get along with your brothers and sisters
- Answer questions about how happy you are with different things in your life like your health and things you do during the day

How long will it take?

- We would like to talk to you two different times
- First day: 30 minutes
- Second day: 10 minutes
- We will talk to you somewhere that is convenient for you, like a place that you go to often during the day

What will we ask your parent or guardian to do?

- Answer some questions about your health and your disability
- Answer some questions about your brothers and sisters
- We will talk to them for about 10 minutes on the telephone
What will happen to the information?

- The information you and your parent tell us is private. We will not tell your parent or guardian or brother or sister anything you say. We also won’t tell anyone else anything you say.
- No one will see your answers except people who are working on this project.
- Your name will not be written on your answers.
- Your answers will be kept in a locked filing cabinet.
- When your answers are put on a computer, your name won’t be on your answers.
- We won’t tell anyone your answers unless you tell us about a child that is being hurt. If you tell us about a child that is being hurt, we have to tell the police about it.
- After we talk to all of the people in the project, we will write a report to give to everyone who did the project. Your name will not be in any of the information and no one will know your answers to the questions.
- You do not have to do this project if you don’t want to.
- If you want to do the project, you can say pass if there are any questions that you don’t want to answer.
- If you want to stop doing the project at any time, you can say ‘I want to stop.’ You will not get in trouble if you say you want to stop.

How can you become part of this study?

- If you want to do this project, you can tell the researcher that you want to do it. Then you will need to write your name on the next page.
- You will also need to give a letter to your parent or guardian. They should sign the letter to say that it is OK for you to do the project.
Effect of Sibling Relationships on Well-being and Depression in Adults with and without Developmental Disabilities: Assent Form

- The researcher has read me the information sheet about the Effect of Sibling Relationships on Well-being and Depression in Adults with and without Developmental Disabilities project.
- I understand the information about the project.
- The researcher answered my questions about the project.
- I know that:
  - I don’t have to do this project if I don’t want to.
  - I can quit this project at any time and I won’t get in trouble.
  - The researcher will not tell anyone my answers.
  - I will get a copy of this form to keep.

If at any time I have questions or problems I can contact:

- Julie Burbidge, Project Leader: (613) 533-3059
- Dr. Patricia Minnes, Project Supervisor: (613) 533-2885
- Dr. Richard Beninger, Department Head of Psychology, Queen’s University: (613) 533-2486

If I have questions about my rights when I do a project, I can contact:

- Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board: (613) 533-6081

By signing this assent form, I am saying that I want to do this project.

_______________________________  _______________
Signature of Participant                   Date

STATEMENT OF INVESTIGATOR:

The nature of the above research study has been explained to the participant. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_______________________________  _______________
Signature of Principal Investigator               Date
Appendix P

Sibling Contact Questionnaire

The following questions are about the contact you have with your sibling with a developmental disability. Please think about the average amount of contact you have had with your sibling over the past year and indicate your answer by selecting the appropriate response option.

1) How often do you speak to your sibling on the telephone?
    ______ daily
    ______ 4-6 times per week
    ______ 1-3 times per week
    ______ 1-3 times per month
    ______ less than once per month
    ______ never – if never, why not ________________________________

2) How often do you communicate with your sibling through email, letters, online instant messaging, text messages or other modes of communication (please do not include telephone contact here)?
    ______ daily
    ______ 4-6 times per week
    ______ 1-3 times per week
    ______ 1-3 times per month
    ______ less than once per month
    ______ never – if never, why not ________________________________

3) How often do you spend face to face time with your sibling?
    ______ daily
    ______ 4-6 times per week
    ______ 1-3 times per week
    ______ 1-3 times per month
    ______ less than once per month
    ______ never – if never, why not ________________________________

4) Have there been any changes in your amount of contact or communication with your sibling in the last 5 years?
    ______ No
    ______ Yes – if yes, please briefly describe: 1) the type of contact/communication that has changed (e.g., face to face, telephone, etc.), 2) whether the change was an increase or a decrease in contact/communication, and 3) the reason for the change in contact/communication

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
5) How long does it take you to get from your home to your sibling’s home?
   _____ less than 30 minutes
   _____ 30 to 60 minutes
   _____ 1 – 2 hours
   _____ 2 – 3 hours
   _____ more than 3 hours
   _____ not applicable – my sibling lives in my home

6) In general, how would you describe the quality of the time you spend in contact with your sibling, including face to face contact and communications via alternative methods (e.g., telephone, email, etc.)?
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

The following questions are about the contact you have with your sibling who does not have a developmental disability. Please think about the average amount of contact you have had with your sibling over the past year and indicate your answer by selecting the appropriate response option.

(NOTE: The same 6 questions as above were repeated here.)
Appendix Q

Lifespan Sibling Relationship Scale

*Please answer the following questions about your sibling with a developmental disability.*

<table>
<thead>
<tr>
<th>Sibling Interaction/Feelings</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I presently spend a lot of time with my sibling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I were “buddies” as children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling makes me happy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I spent time together after school as children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling is a good friend.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I remember having a lot of fun with my sibling when we were children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I never talk about my problems with my sibling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling did not like to play with me when we were kids.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I enjoy my relationship with my sibling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I often helped each other as children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling is very important in my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I was frequently angry at my sibling when we were children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I call my sibling on the telephone frequently.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I were important to each other when we were children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am proud of my sibling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I often had the same friends as children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I are not very close.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I enjoyed spending time with my sibling as a child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I borrow things from each other.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling knew everything about me when we were kids.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling’s feelings are very important to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling and I did not spend a lot of time together when we were children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My sibling is proud of me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
I remember feeling very close to my sibling when we were children.
My sibling talks to me about personal problems.
My sibling had an important and positive effect on my childhood.
My sibling and I have a lot of fun together.
My sibling and I shared secrets as children.
I know that I am one of my sibling’s best friends.
My sibling bothered me a lot when we were children.
My sibling and I “hang out” together.
My sibling and I liked all the same things when we were children.
I like to spend time with my siblings.
My sibling looked after me (OR I looked after my sibling) when we were children.
My sibling and I have a lot in common.
I was proud of my sibling when I was a child.
My sibling and I do a lot of things together.
My sibling and I were very close when we were children.
My sibling frequently makes me very angry.
My sibling and I often played together as children.
I believe I am very important to my sibling.
I remember loving my sibling very much when I was a child.
My sibling and I share secrets.
My sibling and I had a lot in common as children.
I admire my sibling.
I talked to my sibling about my problems when we were children.
My sibling is one of my best friends.
My sibling made me miserable when we were children.

Now, please answer the questions about your sibling who does not have a developmental disability.

(NOTE: The same questions as above were repeated here.)
Appendix R
Sibling Contact Interview for People with Disabilities

Gender: _______________  Age: _______  Date: _________________

Who do you live with right now? __________________________________________________

1) How many brothers do you have? _____________ (if none, skip to question 2)
   Are they older than you or younger than you? _________________________________
   How many of your brothers live with you right now? __________________________

2) How many sisters do you have? ______________ (if none, skip to question 3)
   Are they older than you or younger than you? _________________________________
   How many of your sisters live with you right now? ____________________________

3) How often do you see each of your brothers and sisters? _______________________
   __________________________________________________

4) How often do you talk to each of your brothers and sisters on the phone? _______
   __________________________________________________

5) Do you talk to your brothers and sisters in any other way like by email or on msn? If so, how often? __________________________

Think about which of your brothers or sisters you are closest to (if participant only has one sibling, think about that sibling). For the next few questions, I want you to give answers about the brother or sister you are closest to.

6) Tell me a little bit about (sibling’s name). _____________________________________
   Gender: _______________  Age: (younger or older): ______________

7) What do you like to do with (sibling’s name)? __________________________________

8) Are there things that you want to do with (sibling’s name) but you don’t do them? ______
   What types of things? _________________________________________________
   Why don’t you do them? _____________________________________________

9) Would you like to spend more time with (sibling’s name)? __________________________

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10) Why don’t you spend more time with (sibling’s name)? ____________________________

11) Does (sibling’s name) help you with anything? If yes, what? _________________________

12) Do you help (sibling’s name) with anything? If yes, what? __________________________