

CORRELATES OF GUILT AMONG ADULT SIBLINGS OF INDIVIDUALS
WITH DEVELOPMENTAL DISABILITIES

By

Carolyn M. Shivers

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Approved:

Elisabeth Dykens

Robert Hodapp

Julie L. Taylor

Tedra Walden

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CHAPTER I

INTRODUCTION

Within the context of the family, guilt is a common emotion, especially among siblings. Children's desire to secure attention from their caregiver can lead to sibling rivalry and jealousy (Neubauer, 1983). However, once a sibling establishes perceived preferred status with their caregiver (e.g. the parent believes the sibling is more talented, intelligent, or attractive than their brother or sister), they can develop feelings of guilt.

If the sibling's brother or sister has a disability, this guilt may become even more pronounced because the discrepancy in ability or attractiveness is the result of an uncontrollable event – the brother or sister's disability – rather than effort on the part of the sibling (Moser, Jones, Zaorski, Mirsalimi, & Luchner, 2005). To better understand guilt in siblings of individuals with intellectual or developmental disabilities (ID/DD), it is important to understand first how these siblings differ from siblings of typically developing individuals and what factors influence these differences. Then one can begin to identify which factors influence guilt in this population.

Extant Adult Sibling Research

Effects of having a brother/sister with ID/DD

The extant sibling research covers a relatively wide variety of topics. Studies have found that siblings of individuals with ID/DD often report that their brother or sister had an impact on their life choices, such as their career or whether or not they pursue romantic relationships. In a series of focus groups, seven siblings of individuals with developmental disabilities reported that their experiences with their brother or sister influenced their decisions to enter into the field of special education (Marks, Matson, & Barraza, 2005). In contrast to siblings of individuals with mental illness, siblings of individuals with a disability were significantly more likely to report that their lives were somewhat or strongly affected by their brother or sister in the areas of career choice, whether to have children, choice of romantic relationships, plans for their future, and feelings about people with disabilities (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). Hodapp, Urbano, and Burke (2010) found that sisters of individuals with disabilities seem to be delaying the age of marriage and childbirth, in comparison to the national average. These sisters were also slightly less likely to divorce.

In contrast to the relatively few studies looking at life choices, more sibling researchers have examined broad classifications of outcomes such as whether having a brother or sister with ID/DD is a positive or negative event. In a study of 149 college-aged individuals, Grossman (1972) reported that 45% of siblings who grew up with a brother or sister with a disability were harmed by this experience,

while another 45% benefitted. Cleveland and Miller (1977) found that most adult siblings reported that they felt their family had coped successfully with having a child with a disability. Cleveland and Miller (1977) also pointed out, however, that siblings who regard their experience with their brother or sister as predominantly negative may have chosen not to participate in these studies. Also, earlier studies were likely to have broad definitions of disability, including in their samples siblings of children with cleft palate and similar physical disabilities together with siblings of individuals with developmental or intellectual disabilities (Lobato, 1983).

More recent studies reveal few differences between siblings of individuals with developmental disabilities and siblings of typically developing individuals in terms of negative psychological outcomes. Taylor, Greenberg, Seltzer, and Floyd (2008) found no differences between siblings of individuals with mild intellectual deficits and control siblings in levels of psychological distress or well-being. Burton and Parks (1994) found no increased vulnerability in either group for mental health problems.

Other studies, however, found that siblings differ markedly from control populations. Contrary to siblings of typically developing individuals, for example, Findler and Vardi (2009) found that siblings of individuals with a developmental disability reported significantly less personal, social, and spiritual growth. Meta-analysis found that these siblings, when compared to siblings of healthy controls, also show small negative effect sizes for depression, externalizing behavior, internalizing behavior, and anxiety, but also a small positive effect size for social functioning (Rossiter & Sharpe, 2001). Though researchers have theorized that

siblings of individuals with disabilities may experience more guilt than other siblings, no studies have empirically examined levels of guilt in this population (Moser, Jones, Zaorski, Mirsalimi, & Luchner, 2005).

Another area of sibling research concerns aspects of the relationship between the typically developing sibling and the brother or sister with a disability. In general, these relationships differ from those between nondisabled sibling pairs, with the typically developing sibling providing support to the brother or sister with a disability that may not be fully reciprocated (G.B. Seltzer, Begun, Seltzer, & Krauss, 1991). Siblings of individuals with mild intellectual deficits report feeling less emotionally close to their brother or sister and have fewer contacts per year than control pairs of siblings, despite being more likely to live in the same state (Taylor, Greenberg, Seltzer, & Floyd, 2008). However, siblings of individuals with intellectual disabilities have more face-to-face contact with their brother or sister than siblings of individuals with mental illness (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997).

Because siblings are a heterogeneous group, they are not all affected equally by having a brother or sister with a disability. If siblings may, in fact, be at risk for increased negative outcomes, researchers must determine which variables relate to said outcomes so that we can predict which siblings are more likely to be negatively affected (Hodapp, Glidden, & Kaiser, 2005).

Variables within the sibling population that affect sibling outcomes

When looking at characteristics of the sibling that play a role in sibling outcomes, gender has been frequently examined. Orsmond and Seltzer (2000) examined how sibling gender influences sibling interactions, with female (vs. male) siblings reporting more knowledge of their brother or sister's skills and needs, discussions with parents about their brother or sister, and joint activities. In comparison to male siblings, female siblings also reported higher levels of closeness with their brother or sister. G. Seltzer, Begun, Seltzer, and Krauss (1991) also found that, the sibling most involved with the brother or sister with a disability was more likely to be female. Krauss, Seltzer, Gordon, and Friedman (1996) found that female siblings were more likely than male siblings to co-reside with the brother or sister after their parents could no longer care for the brother or sister.

Individual differences in the quality of the sibling relationship can also predict psychological outcomes. Regardless of whether the sibling believes their experience with their brother or sister to be positive or negative, sibling closeness positively predicts well-being in siblings of individuals with intellectual disabilities (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997).

Within this sibling population, different characteristics of the brother or sister with a disability, such as the specific nature of their disability, may influence how much guilt the siblings feel. Compared to siblings of individuals with autism, siblings of individuals with Down syndrome report better overall perception of health and fewer depressive symptoms and have lower risk for psychiatric conditions (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2009). Within siblings of

individuals with autism, siblings reported more depressive symptoms, including guilt, if they were classified as having a broader autism phenotype (Orsmond & Seltzer, 2009). Based on parent report, the biggest issues that siblings of children with Down syndrome frequently have to deal with are peer acceptance of their brother or sister, while siblings of children with Rett syndrome more often have to deal with impaired family socialization. However, the parents of children with Rett syndrome also reported that their non-disabled children showed increases in compassion, caring, tolerance, and understanding relative to siblings of children with other disabilities (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008).

Beyond the brother or sister's disability diagnosis, siblings are also influenced by their brother or sister's level of behavioral problems (e.g. Hastings, 2003). Hastings (2007) found that the brother or sister's severity of behavior problems predicted sibling behavior problems at a later time point, beyond disability diagnosis and the siblings' initial level of behavior problems.

Each of the above factors (sibling gender, nature of the brother or sister's disability) influences the experience of the non-disabled sibling. It follows that such characteristics may also influence how siblings experience guilt as a factor of the sibling relationship, though few studies have looked at how such aspects correlate with feelings of guilt.

Sibling involvement with caring for their brother/sister with ID/DD

Research into how siblings are affected by having a brother or sister with ID/DD is becoming more salient as the lifespan of these brothers and sisters increase. By 2030, the U.S. is expected to have over 1.5 million individuals with disabilities over the age of 60 (National Center for Family Support, 2000). As these individuals start to outlive their parents, caregiving responsibility is often passed to nondisabled siblings (Hodapp, Glidden, & Kaiser, 2005). Because of the increasing life expectancy of individuals with developmental disabilities, more researchers are examining these sibling relationships in adulthood (Seltzer, Greenberg, Orsmond, & Lounds, 2005).

As parents age, siblings take over responsibilities such as guardianship, advocacy, and co-residency (Heller & Kramer, 2009). However, siblings are not equally likely to take over caregiving responsibilities. Heller and Kramer (2009) found that being female, having more contact with, and living closer to the brother or sister with ID/DD increased the likelihood of future caregiving. Greenberg, Seltzer, Orsmond, & Krauss (1999) found that siblings with their own children at home were less likely to provide both instrumental and emotional support to their brother or sister.

Extant research shows a strong link between guilt and responsibility, though theories on the directionality of this relationship are mixed (Berndsen & Manstead, 2007). While some psychologists believe that a greater sense of responsibility leads to higher levels of guilt (e.g. Izard, 1977; McGraw, 1987), others believe that greater feelings of guilt elicit more feelings of responsibility (e.g. Baumeister, Stillwell, &

Heatherton, 1994; Frijda, 1993). Berndsen and Manstead (2007) found perceptions of responsibility increased as a function of guilt. When researchers experimentally increased feelings of guilt, feelings of responsibility in subjects also increased. However, when researchers increased feelings of responsibility, there was no corresponding increase in guilt (Berndsen & Manstead, 2007). These findings support the theory that appraisals of responsibility arise from the emotion of guilt (e.g. Baumeister, Stillwell, & Heatherton, 1994). Other theorists believe that these views are not mutually exclusive; feelings of responsibility can lead to guilt, but emotion can also influence appraisals of responsibility (e.g. Keltner et al., Roseman & Evdokas, 2004). Regardless of theory, researchers agree that higher levels of guilt are related to more responsibility.

Among siblings of individuals with disabilities, these findings on guilt and responsibility may translate to more caregiving responsibilities. If a sibling feels guilt related to their brother or sister, they may feel responsible for caring for that individual to make up for any advantages the sibling has as the “better-off” child (Glenn, 1995). Thus, siblings of adults with ID/DD who plan to take over caregiving responsibilities for the brother or sister may have these plans because of higher levels of guilt.

Guilt in Siblings of Individuals with ID/DD

Guilt as a risk factor for poor physical and mental health

As Erikson (1950) predicted, not all feelings of guilt lead to positive outcomes. High levels of guilt, can become maladaptive (O'Connor, Berry, & Weiss, 1999). High levels of guilt are positively associated with receiving disapproval from others, loss of control, self-aggression, and self-criticism (Luyten, Fontaine, & Corveleyn, 2002). Maladaptive guilt (high levels of guilt with no opportunity to fix the causal event) can also lead to distress, inhibitions, psychopathology, loneliness, and alienation (O'Conner, Berry & Weiss, 1999; Bruno, Lutwick & Agin, 2009). These negative consequences are more likely to occur when one cannot fix the situation (i.e. siblings cannot cure their brother or sister's disability) (Luyten, Fontaine, & Corveleyn, 2002). Nelissen and Zeelenberg (2009) found that when individuals felt guilt related to a situation they could not fix, they were more likely to punish themselves through denial of pleasure activities. Because siblings of individuals with disabilities cannot fix their brother or sister's disability, they are at higher risk for negative outcomes associated with guilt. It is important to identify which siblings are more likely to feel guilt so that we can better prevent such outcomes.

Why might siblings of individuals with ID/DD experience guilt?

Although researchers have developed theories about guilt in siblings of individuals with disabilities, only one study has specifically recorded siblings'

reports of guilt (Fleitas, 2000). Martino and Newman (1974) hypothesized that siblings feel guilty for fulfilling their own goals while their sibling does not have the same opportunity. Featherstone (1980) reported that this population may feel anger toward their parents who pay more attention to their brother or sister with disabilities, at their brother or sister with a disability for being the beneficiaries of this extra attention, or at the world in general for not understanding their experience. They may then feel guilty for these angry feelings, realizing that their brother or sister's disability is no one's "fault" (Seligman, 1983). As siblings often have more caregiving responsibilities for their brother or sister, they may also feel guilty and responsible when something happens to that brother or sister (Hayden, 1974).

While siblings participate in caring for their brother or sister with a disability, many families also rely on outside sources to provide services. Unfortunately, many of these families report unmet services needs regarding the individuals with a disability (e.g. Hayden & DePaepe, 1994). These deficits in needed services may highlight the discrepancy in quality of life between siblings, thus increasing sibling guilt.

In the sole study examining sibling guilt, Fleitas (2000) interviewed siblings of children with disabilities to determine what emotions they felt in regards to their siblings disability. Siblings of children with a disability report feeling guilty for their own stress, considering it to be petty in comparison to what their parents and brother or sister were going through. In very young siblings, feelings of guilt may

arise because they believe they somehow “caused” their brother or sister’s disability by wishing them ill in moments of childhood anger (Fleitas, 2000).

Possible correlates of guilt in siblings of individuals with ID/DD

By understanding how guilt operates in individuals who do not have a brother or sister with a disability, one can better conceptualize how individuals within the target population might experience guilt. Many correlates of guilt found in previous studies may also play a role in how siblings of adults with ID/DD feel guilt.

Previous studies examined guilt in siblings of individuals with chronic illness, physical disability, mental illness, as well as siblings who have a brother or sister who has died. Such studies seem analogous to the developmental disability literature, as each describes cases in which one sibling is somehow “better off” than another. Whether this sibling suffers the death of a brother or sister, or the brother/sister has chronic illness, mental illness, or developmental disabilities, the siblings are often able to do many things that their brother or sister cannot. This concept of being the better-off sibling is especially salient when the perception of being more able than a sibling is shared by the parents (Glenn, 1995). Siblings in an advantaged position sense that the sibling experience is not fair and balanced, leading to a sense of guilt for being the beneficiary of this perceived injustice (Glenn, 1995).

Freud first described sibling guilt in relation to his own feelings after the death of his infant brother (Freud, 1900). Siblings experiencing such guilt typically feel as if they have no right to live the kind of happy life that was denied to their brother or sister (Modell, 1971). In extreme cases, guilt from the death of a brother or sister can manifest physically, causing headaches, stomach pain, or fainting (Christian, 2007). For both siblings of individuals with disabilities and siblings of individuals who have died, the event that causes sibling guilt (death or disability) is beyond the sibling's control.

Studies of family members of individuals with chronic illness look at familial guilt in the context of caregiving by adult family members (e.g. Tangney & Dearing, 2002). Among cancer caregivers, how the caregiver experiences guilt is related to characteristics of the caregiver and the affected individual (Spillers, Wellisch, Kim, Matthews & Baker, 2008). Younger caregivers felt more guilt than older caregivers, as did caregivers who were employed in addition to carrying out their caregiving duties. Caregivers who felt more competent in their role felt lower levels of guilt. Such patient characteristics as higher levels of both physical and mental functioning predicted lower levels of caregiver stress (Spillers, Wellisch, Kim, Matthews & Baker, 2008). Guilt in siblings of individuals with disabilities, therefore, may be related to their brother or sister's level of functional abilities.

In the general population as well, studies have examined causes and correlates of guilt as well as descriptions of how guilt operates. Many studies have looked at how gender relates to guilt. Starting in adolescence, females (compared to males) report more intense feelings of guilt (Evans, 1984). Females are more likely

to feel guilt over violations of compassion and trust and are also more likely than males to report guilt when the perceived transgression involves intimate relationships (i.e. parents and extended family) (Williams & Bybee, 1994).

Aspects of the family environment also have a large impact on the development of guilt (Baumeister, 1998). In a study of adolescents with typically-developing brothers and sisters, Walter and Burnaford (2006) found that sibling closeness was related to guilt, with siblings who reported higher levels of closeness also reporting more guilt. They suggest that, because guilt can rise from a desire to amend a problematic situation, it can be classified as a positive affect and is therefore related to higher levels of sibling closeness (Walter & Burnaford, 2006). However, Seltzer et al. (1997) found that better sibling relationship quality is related to better psychological well-being in sibling pairs in which one individual has a disability. Because guilt as a result of having a brother or sister with a disability cannot be alleviated by amending the situation, it is more likely to be related to negative outcomes. Therefore, guilt in siblings of individuals with a disability may be related to poorer quality of sibling relationship.

Guilt as a result of having advantages over others has also been studied in general populations. When studying advantaged groups, researchers found that members of a better-off group are more likely to feel guilt when they perceive their advantage as unfair or undeserved (Harth, Kessler, & Leach, 2008). If siblings of individuals with disabilities also feel that the nature of their brother or sister's disability is unfair (i.e. 'Why them and not me?'), such siblings may feel more guilt as the result of their privileged status over their brother or sister.

The Current Study

The present study examines correlates of guilt in adult siblings of individuals with developmental disabilities. Analyses will examine differences in guilt related to four categories: aspects of the sibling relationship, characteristics of the brother/sister with a disability, characteristics of the sibling, and future caregiving for the brother/sister with a disability.

The present sample includes information from over 1,000 adult siblings of individuals with disabilities. Because the sample is not limited to siblings of individuals with one type of disability (e.g. autism), we can obtain a broader view of the correlates of guilt in adult siblings. Additionally, the survey specifically addresses guilt as a result of growing up with a brother or sister with a disability. By wording the item in this manner, the survey controls for any other guilt siblings may experience that do not directly relate to the questions at hand.

Based on the existing research, we have developed the following hypotheses:

Sibling Relationship

Siblings who are closer to their brother or sister will report less guilt.

Siblings who have less contact and knowledge of their brother or sister will report more guilt.

Characteristic of the Brother/Sister with a Disability

Siblings of individuals with autism or emotional disturbances, as well as siblings of individuals with poorer physical health and fewer functional abilities will

report higher levels of guilt than siblings of individuals with other developmental disabilities. Siblings who have brothers or sisters with a large amount of needed but not in place services will report more guilt.

Sibling Characteristics

Siblings who report more guilt will have lower levels of mental health, physical health, and well-being. Additionally, female siblings will report more guilt than male siblings.

Future Caregiving

Siblings who report high amounts of expected future caregiving will report more guilt.

CHAPTER II

METHOD

Participants

The original sample included 1,166 adult siblings of individuals with intellectual and developmental disabilities. Respondents who did not indicate an answer to the question regarding guilt were not included, leaving, 1,150 participants in the final sample. The sample was largely female and primarily Caucasian. Compared to the overall U.S. population, participants were relatively well-educated, with 28.3% (n=326) of the sample having received at least one degree beyond their bachelor's degree. The age range in the sample was 18 to 85, with over 100 respondents in each 5-year age category between 20 and 49 years. There were respondents from all 50 states and the District of Columbia, with 29 states featuring at least 10 respondents. Further characteristics of the siblings in the present sample can be found in Table 1.

When looking at characteristics of the brother or sister with a disability, there were more males than females in the survey (58.6% and 41.4%, respectively).

Table 1

Sibling Demographic Variables

	N	Percentage of Sample
Gender		
Female	899	78.4%
Male	247	21.6%
Age		
<20	68	5.9%
20-29	398	34.9%
30-39	225	19.7%
40-49	210	18.3%
50-59	177	15.5%
>60	65	5.7%
Ethnicity		
White non-Hispanic	1034	89.9%
African-American	23	2.0%
Hispanic	33	2.9%
Native American	3	.3%
Asian or Pacific Islander	11	1.0%
Other	28	2.4%
Education Level		
High School	350	30.9%
Bachelors	447	38.8%
Masters	268	23.3%
Doctorate	58	5.0%
Marital Status		
Never Married	466	40.5%
Married	567	49.3%
Separated	10	.9%
Divorced	81	7.0%
Widowed	16	1.4%
Employment		
Unemployed	196	17.0%
Employed, Part-time	197	17.1%
Employed, Full-time	730	63.5%
Employed, seasonally	34	3.0%

The age range of persons with a disability was broader than the age range of the siblings, from the age of 1 to 81, with a mean age of 34. Disabilities included MR/DD (n=543, 47.2%), Down syndrome (n=282, 24.5%), Fragile X syndrome (n=9, .8%), Prader-Willi syndrome (n=6, .5%), autism (n=181, 15.7%), emotional disturbance or condition (n=86, 7.5%), sensory impairment (n=61, 5.3%), cerebral palsy (n=146, 12.7%), Williams syndrome (n=13, 1.1%), health condition (n=81, 7.0%), or unspecified developmental disability (n=55, 4.8%). Siblings could indicate more than one disability; 27.8% (n=320) of the sample marked at least two categories of disability.

Procedures

In collaboration with the National Sibling Consortium, a small group of sibling researchers, the Adult Sibling Survey was developed and revised. The questionnaire and procedures for distribution were approved by the Vanderbilt University IRB and then presented to the Board of Directors of The Arc, U.S. The final questionnaire was uploaded to a secure website of the Vanderbilt Kennedy Center. The SurveyGold program (Golden Hills Software, Inc., 2006) was used to store survey responses, which were then downloaded periodically into SPSS analysis data sets.

As the web-based survey was finalized, recruitment of potential subjects began. Beginning in late February of 2006, news of the survey was disseminated through The Arc's list-serves and other computer-based information dissemination networks. In early May, a short article about the survey appeared in *InSight*, the

national newsletter of The Arc. Other methods for dissemination included the website of the Association of University Centers on Disability (AUCD; a network of 67 centers across the country), Don Meyer's Sibnet network, and several state Developmental Disability networks and newsletters.

Though the majority of participants responded via computer, they also had the option to fill out and return paper versions of the survey. Researchers responded to both phone and e-mail requests, mailing over 100 paper surveys to individual siblings and 250 to several professionals who ran sibling workshops or had access to families who did not have access to high-speed internet. Using the included self-addressed, stamped envelopes, approximately 80 participants returned completed surveys, which were then entered onto the website.

The Adult Sibling Survey took approximately 20-25 minutes to fill out. Upon going to the address of the survey website, participants first saw a screen describing the study. After agreeing to participate, the respondent was then directed to the second screen, which contained a brief description of the survey as well as the survey itself. Once they completed the survey, the respondent was thanked and asked to push a button indicating their completion. By pushing that button, they then submitted the survey to the website. A third screen then appeared, asking respondents if they wanted to receive a summary of the questionnaire results or if they would be willing to participate in future research. If they responded "yes" to either question, they then filled out their name, address, phone number, and e-mail address. Throughout the process, all responses remained anonymous. Provided

contact information was not linked to earlier survey responses. The full survey can be found in Appendix A.

Adult Sibling Questionnaire

Specifically designed for this study, the Adult Sibling Questionnaire was comprised of 163 questions divided into 8 distinct sections: 1) respondent demographic information, 2) information about the brother/sister with disabilities, 3) information about the parents and family of origin, 4) joint activities and involvement with the brother/sister with disabilities, 5) major transitions over the past year occurring to the respondent, the brother/sister with disabilities, or the parents, 6) sibling relationship and effects of that relationship, 7) respondent health and depression, and 8) caregiving responsibilities for the brother/sister with disabilities. Responses involved clicking on (or marking, in the paper surveys) one of the questions' options. Questions involved responses that were either categorical (e.g. gender) or on a Likert-like scale (e.g. '1=never or not at all true' to '4=always or completely true'). The only exception was a set of final, open-ended questions that asked respondents to reflect on various aspects of their experience as a sibling of an individual with a disability (e.g. "What would help you now to make it easier to support your sibling with disabilities?"). Certain questions were borrowed from existing short-form measures; these are indicated in the appropriate section.

Dependent Variable

Guilt. Using the question ‘As a result of having grown up with a brother/sister with disabilities, do you think that you have less, the same, or more of the following characteristics: Feelings of guilt?’, we created 4 categories of sibling guilt. The first category was created by combining the responses of “somewhat less guilt” and “less guilt” into “Decreased guilt,” (=0) due to the small number of individuals endorsing each response. The remaining three categories corresponded directly to possible answers from the survey: same guilt (guilt has not changed as the result of having a brother or sister with a disability, =1), slightly more guilt (sibling has somewhat more guilt as the result of having a brother or sister with a disability, =2), and a lot more guilt (sibling has more guilt as the result of having a brother or sister with a disability, =3).

Independent Variables

Respondent Demographics. The age and gender of the respondent were included in analyses.

Sibling relationship. Participants responded to questions derived from the Positive Affect Index of relationship quality (Bengston & Black, 1973). Respondents rated the degree to which they understand, trust, respect, love, feel close to and positive towards their brother or sister with disabilities using a 6-point scale

ranging from “not at all” to “extremely” (Cronbach’s alpha=.90 for this sample). Responses from the Bengston scale were summed, creating one score of the quality of the sibling relationship (min=7, max=42), with higher scores indicating a more positive sibling relationship,

Amount of contact. One question was used to assess the amount of sibling contact, with answers ranging from 1=less than once a year to 8=daily. This included all types of contact (i.e. in person, phone, e-mail).

Knowledge of brother/sister. Scores were summed from 8 questions indicating how well-informed respondents are about eight aspects of their brother/sister’s lives: ability to perform daily living skills, interpersonal skills, financial needs, residential needs, vocational needs, social/recreational activity needs, physical health needs, and mental health needs. Responses options were 1=not at all informed, 2=not very well informed, 3=fairly well informed, 4=very well informed. Possible total scores ranged from 8 to 32, with higher scores indicating greater knowledge.

Characteristics of the Brother/Sister with a Disability

Nature of brother/sister’s disability. Responses to each disability were dichotomous (1=my brother/sister does have this disability, 0=my brother/sister does not have this disability). Disability categories included mental

retardation/developmental disability, Down syndrome, Fragile X syndrome, Prader-Willi syndrome, autism, emotional disturbance or condition, sensory impairment, cerebral palsy, Williams syndrome, health condition, unspecified developmental disability, and other condition. Siblings could indicate more than one disability.

Brother/Sister functional abilities. The survey included 15 functional abilities of the brother/sister with disabilities (e.g. walking, eating, performing household tasks) taken from the Activities of Daily Living scale (ADL; Seltzer & Li, 1996). These responses were then summed into one score of total abilities. Individual answers were scaled from 1 (brother or sister can not do this skill at all) to 5 (brother or sister can do this skill very well). Scores ranged from 15 to 75, with higher scores indicating higher levels of functioning. Cronbach's alpha for this sample was .91.

Brother/Sister health problems. Siblings were asked to rate the extent to which their brother or sister has significant health problems and significant emotional/behavior problems. Both questions were scaled from 1 (not a problem) to 5 (very much a problem).

In Place Services. Siblings indicated their brother or sister's need for support in 16 different areas: case management, job counseling-assessment, job placement, job coach, residential placement, respite care, transportation, medical care, dental care, occupational therapy, physical therapy, speech therapy, psychotherapy, behavioral intervention, social security benefits, and money for personal expenses.

Response options to the above items included: in place, needed but not in place, and not needed. Researchers counted how many items were marked as “in place” for each respondent to find the total number of in place services for each brother or sister. Totals ranged from 0 (no services in place) to 16 (all 16 services in place).

Needed but not In Place Services Using the same items that were used to create the In Place Services variable, researchers counted how many items were marked as “needed but not in place.” This total was entered as the number of services that were needed but not in place for each brother or sister. Totals ranged from 0 (no services needed but not in place) to 16 (all 16 services needed, but none in place).

Total Needed Services The total number of needed services was found by adding the number of in place services to the number of needed but not in place services. Totals ranged from 0 (no services needed) to 16 (all 16 services needed, either in place or not in place).

Percentage of Unmet Service Needs This variable was created by taking the ratio of needed but not in place services to total needed services. Ratios ranged from 0 (all service needs-if any-are currently being met) to 1.00 (all service needs are currently unmet).

Siblings Characteristics

Sibling physical health. Participants were asked to rate the general quality of their physical health by responding to the question “How would you say this in general your health is?” Responses ranged from 1 (poor) to 5 (excellent). Self-rated health has been found to be a strong predictor of lifespan (Idler & Benjamini, 1997).

Sibling depressive symptoms Siblings’ level of depressive symptoms was calculated using five questions taken from the Center for Epidemiological Studies Depression scale or CES-D (Radloff, 1977). Respondents indicated how often in the past week they had experienced the following: felt depressed, had restless sleep, felt lonely, could not ‘get going’, and had crying spells. Response options were coded from 1 (rarely or none of the time – less than 1 day) to 4 (most or all of the time – 5-7 days). These measures have been previously used in studies of families of children with disabilities (Greenberg, Seltzer, Orsmond, & Krauss, 1999). Total depression scores were created by summing responses to the 5 CES-D questions (min=5, max=20), with higher scores indicating more depressive symptoms. For this study, Cronbach’s alpha for the CES-D equaled .79.

Sibling well-being. Sum scores were created from 18 items of well-being taken from Ryff’s (1989) Psychological Well-Being measure. Respondents were asked to indicate their level of agreement with various statements such as “I am quite good at managing the many responsibilities of my daily life” and “I like most

aspects of my personality” on Likert-like scale from 1 (strongly disagree) to 6 (strong agree). Five of these items were reverse coded, so that total scores ranged from 18 to 108, with higher scores indicating higher levels of well-being. Ryff’s original measure divides questions into six subscales (self acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth) which were not used in the present study. Cronbach’s alpha for this sample equaled .82.

Future Caregiving

Future caregiving. Siblings responded to five items indicating how much responsibility they will have for supporting their brother/sister with disabilities in various areas (residential arrangement, financial arrangements, legal guardianship, interacting with service system, companionship-emotional support). For each of these items, siblings could choose one of the following responses: I will have primary responsibility (1), Another sibling and I will share responsibility (2), Other sibling(s) will have responsibility (3), Other family member will have responsibility (4), I will share responsibility equally with another family member (5), Professional or agency will have responsibility (6). These items were recoded into three categories: 0=no planned responsibility (responses 3, 4, or 6), 1-some planned responsibility (responses 2 or 5), 2=most or all planned responsibility (response 1). These scores were then summed into one total future responsibility score, ranging from 0-10. Higher scores indicate more planned future responsibility.

Analysis

One-way ANOVAs were used to analyze group differences in outcomes variables based on amount of change in guilt. For categorical variables (i.e. gender and nature of brother/sister's disability), chi-squares were used to assess group differences. Post-hoc analyses were used to determine which levels of guilt significantly differed from other levels.

Variables found to be significant in the ANOVA and chi-square analyses were entered into an ordinal regression analysis to determine which variables contributed independently to variation in sibling guilt. Because the service variables were so highly correlated (see Table 3), only the Percentage of Unmet Service Needs variable was used. This variable was chosen because it is a combination of both the total number of services and the number of unmet service needs. Ordinal regression was used because, while the guilt variable is not continuous, the responses indicate quantitative differences in amount of guilt felt by siblings.

CHAPTER III

RESULTS

Preliminary Findings

The responses to the question regarding guilt showed much variability. Over half of the sample (54.5%) indicated an increase in guilt as a result of having a brother or sister with a disability. The smallest number of individuals reported that they have less guilt (n=143, 12.4% of the sample). Additionally, 33.0% (n=380) responded that their guilt has not changed as a result of having a brother or sister with disabilities, 24.6% (n=283) reported a slight increase in guilt, and the remaining 29.9% (n=344) reported that they have a lot more guilt as the result of having a brother or sister with disabilities.

The mean values of the continuous dependent variables can be found in Table 2. On average, siblings contacted their brother or sister slightly less than once per week and were fairly to very well informed about their brother or sister's needs and abilities. The brothers and sisters with ID/DD had physical and emotional/behavioral problems that were "somewhat of a problem." These brothers and sisters received an average of 6-7 services, with an additional 2 unmet service needs. This is equivalent to an average of 23% of their service needs that are not currently being met. Siblings, an average, reported that their physical health is "very good."

Table 2

Independent Variable Means and Standard Deviations

	Mean	SD	N	Range
Total Sibling Relationship	35.48	6.99	1150	1-46
Sibling Contact	5.71	1.85	1148	1-8
Total Knowledge of Brother/Sister with Disabilities	26.27	5.17	1142	8-32
Brother/Sister Functional Abilities	42.65	12.48	1015	15-75
Brother/Sister Physical Health Problems	2.60	1.34	1147	1-5
Brother/Sister Emotional Health Problems	2.68	1.38	1145	1-5
Needed but not In Place Services	2.00	2.64	1150	0-16
In Place Services	6.74	3.42	1150	0-16
Total Needed Services	8.73	3.36	1150	0-16
Percentage of Unmet Service Needs	.23	.28	1119	0-1
Sibling Physical Health	3.87	.96	1149	1-5
Sibling Depression	7.68	2.95	1146	1-20
Sibling Well-being	83.48	11.53	1149	5-108
Total Future Care	6.54	3.27	1123	0-10

Correlations between the independent variables can be found in Table 3. The highest correlations were among the service variables (Needed but not In Place Services, Total Needed Services, Percentage of Unmet Service Needs). Sibling depression was also moderately negatively correlated with sibling physical health and well-being.

Sibling Relationship

Table 4 shows the means for each guilt category of variables related to the sibling relationship. Only the quality of the sibling relationship differed by guilt category. Siblings who reported a worse overall relationship with their brother or sister were more likely to report increased levels of guilt. Siblings who reported the highest increase in guilt had sibling relationship scores that were approximately one-half standard deviation lower than siblings who reported decreased guilt. Follow-up tests show that siblings reporting the least guilt have better sibling relationships than all other groups ($t(1146)=2.05, 2.66, \text{ and } 4.92$, for no change, a little more guilt, and a lot more guilt, respectively, $p<.05$). Siblings who reported the largest increase in guilt reported worse sibling relationships than those who reported a slight increase in guilt or no change in guilt ($t(1146)=3.87 \text{ and } 2.69$ for no change in guilt and slight increase in guilt, respectively, $p<.01$). In sum, it appears that better sibling relationship quality is related to lower levels of guilt. Siblings showed no differences in amount of contact with their brother or sister or knowledge of their brother or sister based on guilt.

Table 3

Dependent Variable Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Gender															
2. Total Relationship	.01														
3. Total Contact	.09	.36													
4. Total Knowledge	.13	.37	.28												
5. Functional Abilities	.02	.10	.10	-.02											
6. Brother/Sister Health Problems	.08	-.09	-.07	.00	-.20										
7. Brother/ Sister Emotional Problems	.08	-.37	-.11	-.13	-.06	.20									
8. Needed but not in Place Services	.10	-.20	.10	-.14	.02	.06	.25								
9. In Place Services	.03	.14	-.09	.21	-.17	.08	.02	-.41							
10. Total Needed Services	.11	-.02	-.01	.11	-.16	.12	.22	.37	.70						
11. Percentage of Unmet Service Needs	.09	-.21	.08	-.18	-.12	.01	.20	.85	-.69	.01					
12. Sibling Health	-.08	.10	.01	.06	.09	-.13	-.17	.09	.03	-.04	-.08				
13. Sibling Well-Being	.01	.25	.02	-.17	.11	-.10	-.18	-.16	.11	-.01	-.15	.33			
14. Sibling Depression	.09	-.12	.05	-.05	-.10	.13	.25	.20	-.08	.07	.17	-.39	-.53		
15. Total Future Care	.12	.12	.32	.23	-.03	-.04	-.06	.04	.03	.07	.00	-.02	-.02	.09	
16. Guilt	.12	-.15	.01	-.04	-.06	.05	.16	.18	-.05	.10	.17	-.04	-.21	.25	.12

Note: All correlations > |.06| are significant (p>.05)

Table 4

Means and standard deviations of sibling relationship variables by guilt category

	Less Guilt (0)	Same Guilt (1)	Slightly More Guilt (2)	A Lot More Guilt (3)	F value	Group Differences
Total Sibling Relationship	37.42 (6.28)	36.03 (6.91)	35.53 (6.39)	34.03 (7.57)	9.55***	3>2,1>0
Amount of Sibling Contact	3.14 (1.86)	3.36 (1.87)	3.29 (1.82)	3.28 (1.84)	.49	
Knowledge of Brother/Sister with Disabilities	26.77 (5.38)	26.33 (4.88)	26.08 (5.24)	26.14 (5.34)	.67	

Characteristics of the Brother/Sister with Disabilities

Table 5 shows the mean values of characteristics of the brother or sister with disabilities based on amount of sibling guilt. While brother/sister functional abilities and physical health were not related to sibling guilt, emotional health and amount of needed supports differed significantly based on guilt. Siblings who reported more guilt also reported that their brother or sister had more emotional/behavioral problems, and those reporting the greatest increase in guilt had a brother or sister with significantly more emotional/behavioral problems than siblings in each of the other categories ($t(1141) = -3.04, -5.44, \text{ and } -4.05$ for slight increase in guilt, no change in guilt, and decreased guilt, respectively, $p < .01$). These results indicate that more sibling guilt is related to the severity of the brother or sister's emotional and behavioral problems.

Table 5

Means and standard deviations of brother/sister characteristics by sibling guilt category

	Less Guilt (0)	Same Guilt (1)	Slightly More Guilt (2)	A Lot More Guilt (3)	F or χ^2	Group Differences
Functional Abilities	42.56 (13.51)	43.83 (12.35)	42.96 (12.21)	41.19 (12.30)	2.45	
Emotional Health Problems	2.46 (1.33)	2.46 (1.32)	2.68 (1.34)	3.01 (1.44)	11.30***	3>2,1,0 2>1
Physical Health Problems	2.64 (1.38)	2.48 (1.32)	2.60 (1.30)	2.73 (1.36)	2.09	
In Place Services	7.05 (3.56)	6.86 (3.27)	6.64 (3.43)	6.55 (3.52)	.96	
Needed but not In Place Services	1.32 (2.19)	1.59 (2.34)	2.08 (2.58)	2.65 (3.02)	13.69***	3>2>1,0
Total Needed Services	8.37 (3.64)	8.45 (3.23)	8.72 (3.18)	9.21 (3.47)	3.76*	3>1
Percentage of Unmet Service Needs	.15 (.23)	.19 (.27)	.25 (.30)	.28 (.28)	10.67***	3,2>1,0

Sibling guilt was found to be related to both the number of needed but not in place services, as well as the total number of needed services for the brother or sister with disabilities. Brothers or sisters of siblings who reported the greatest increase in guilt had more unmet service needs than brothers or sisters of all other siblings ($t(1146) = -5.15, -5.49, \text{ and } -2.76$ for decreased guilt, no change, and slightly increased guilt, respectively, $p < .01$). Brothers or sisters of siblings with slightly

increased guilt had more unmet service needs than brothers or sisters of siblings with no change in guilt or decreased guilt ($t(1146) = -2.38$ and -2.83 , respectively, $p < .05$). In terms of total needed services, brothers or sisters of siblings with the greatest increase in guilt had more total service needs than brothers or sisters of siblings with no change in guilt or decreased guilt ($t(1146) = -3.04$ and -2.51 , respectively, $p < .05$).

Siblings who reported increased guilt had brothers or sisters who needed significantly more support services than they were currently receiving. Specifically, siblings who reported increased guilt had brothers or sisters who were only having 72-75% of their service needs met, while brothers and sisters of siblings who reported decreased guilt or no change in guilt had 81-85% of their service needs met. Siblings who reported slight increases in guilt had brothers or sisters with a higher percentage of unmet services than siblings who reported no change in guilt or decreased guilt ($t(1115) = -2.76$ and -3.38 for no change and decreased guilt, respectively, $p < .01$). Siblings with the most guilt also reported a higher percentage of unmet service needs when compared to siblings with no change in guilt or less guilt ($t(1115) = -4.44$ and -4.62 for no change and decreased guilt, respectively, $p < .001$). These results indicate that more sibling guilt is related to their brother or sister's service needs. Siblings showed no difference in guilt based on how many services their brother or sister was currently receiving.

Although the nature of the brother/sister's disability was largely unrelated to guilt, there were two exceptions: emotional disturbance or condition and Down syndrome. Siblings of individuals with Down syndrome were less likely to indicate

that they had a lot more guilt than siblings of individuals who do not have Down syndrome (22.7% vs. 32.3%; $\chi^2=10.987$, $p<.05$, $df=3$). The difference between siblings of individuals with and without an emotional disturbance was even more striking; siblings who had a brother or sister with an emotional disturbance or condition were more likely to report having a lot more guilt (51.2% vs. 28.2%) and less likely to report no change in guilt (17.4% vs. 34.3%; $\chi^2= 21.85$, $p<.001$, $df=3$).

This comparison is illustrated in Figure 1.

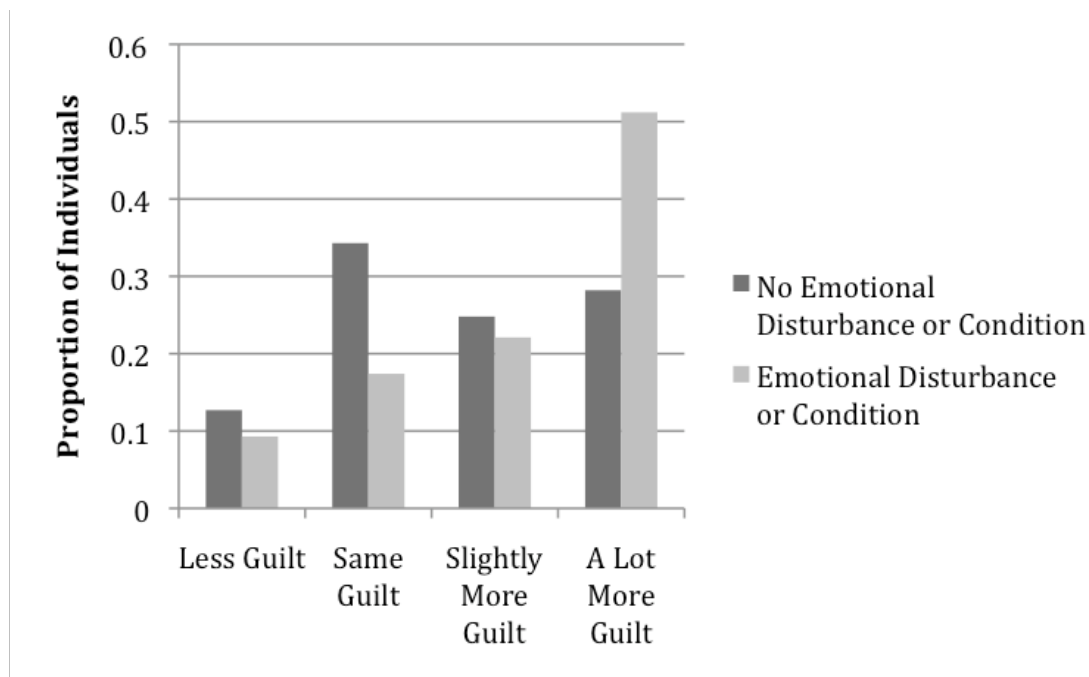


Figure 1: Percentage of respondents indicating each level of guilt by nature of brother or sister’s disability. The figure depicts the percentages of guilt responses by siblings of individuals with an emotional disturbance/condition vs. siblings of individuals who do not have an emotional disturbance/condition.

Characteristics of the Sibling

Figure 2 shows the percentages of each gender reporting a given level of change in guilt. Compared to males, females reported higher levels of guilt, with a greater percentage reporting “a lot more” guilt (32.7% vs. 19.8%), and fewer reporting no change in guilt (42.9% vs. 30.3%; $\chi^2=20.71$, $p<.001$, $df=3,1$). Guilt was not significantly related to sibling age.

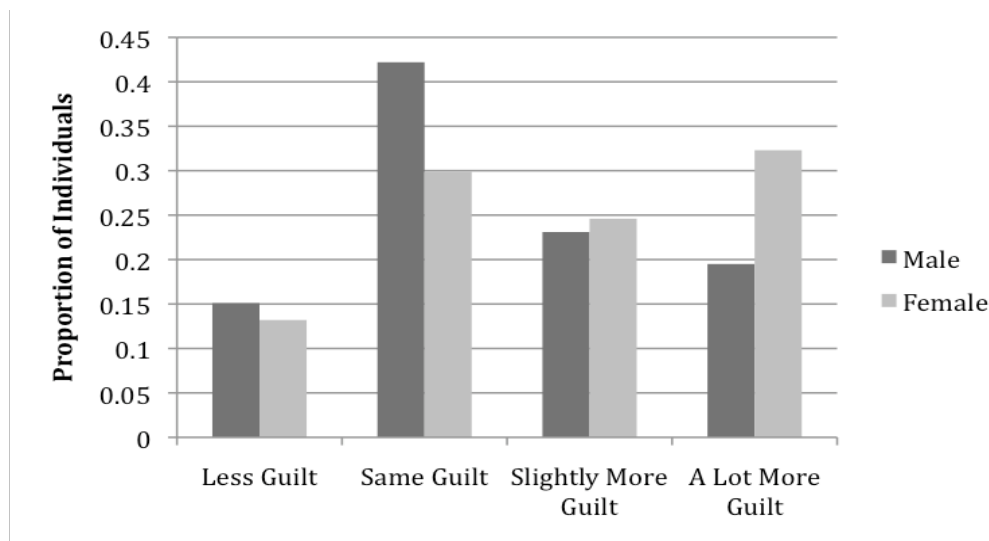


Figure 2: Percentage of respondents indicating each level of guilt by gender.

Table 6 shows mean amounts of sibling mental and physical health and well-being by guilt. Siblings who report increased levels of guilt report significantly lower well-being scores. Well-being differed significantly among all groups, with well-being decreasing as guilt increased. Siblings who reported the largest increase in

guilt had lower levels of well-being than all other siblings ($t(1145)=2.84, 5.71,$ and 6.21 for slightly increased guilt, no change, and decreased guilt, respectively, $p<.01$), Siblings with slightly increase guilt had lower levels of well-being than siblings with no change in guilt and decreased guilt ($t(1145)=2.51$ and 3.80 , respectively, $p<.05$) Siblings who reported no change in guilt had lower levels of well-being than siblings who reported decreased guilt ($t(1145)=1.96, p=.05$). Together, these findings indicate that well-being decreases as guilt increases.

Table 6

Means and standard deviations of sibling health and well-being by sibling guilt

	Less Guilt (0)	Same Guilt (1)	Slightly More Guilt (2)	A Lot More Guilt (3)	F or χ^2	Group Differences
Total Depression	6.72 (2.09)	7.05 (2.51)	7.74 (2.99)	8.71 (3.35)	26.25***	3>2>1,0
Total Well-Being	87.37 (10.08)	85.20 (10.77)	82.97 (10.63)	80.40 (12.77)	17.33***	3<2<1<0
Physical Health	3.96 (.98)	3.90 (.94)	3.82 (.96)	3.85 (.98)	.807	

Siblings who reported the most guilt had significantly more depressive symptoms than all other siblings ($t(1142)=-4.20, -7.77,$ and -6.97 for slightly

increased guilt, no change, and decreased guilt, respectively, $p < .001$). Siblings who reported a slight increase in guilt also reported more depressive symptoms than siblings who reported no change in guilt or less guilt ($t(1142) = -3.07$ and -3.47 , respectively, $p < .01$). These findings suggest that siblings depressive symptoms increase as guilt increases. Siblings show no differences, however, in self-reported physically health based on guilt.

Future Caregiving

As Figure 3 shows, siblings who report an increase in guilt expect to be significantly more involved in caregiving than siblings who report decreased guilt or no change in guilt ($F = 5.91$, $p < .05$). Siblings who report the most guilt plan to do more caregiving than siblings with no change in guilt and decreased guilt ($t(1119) = -3.31$ and -3.37 , respectively, $p = .001$). Siblings who report a slight increase in guilt also report more planned caregiving than siblings with no change in guilt and decreased guilt ($t(1119) = -2.19$ and -2.55 , respectively, $p < .05$). Together, these results suggest that that siblings who feel guilt as the result of having a brother or sister with a disability plan to be more involved in caregiving for their brother or sister than siblings who do not feel guilty as the result of having a brother or sister with a disability.

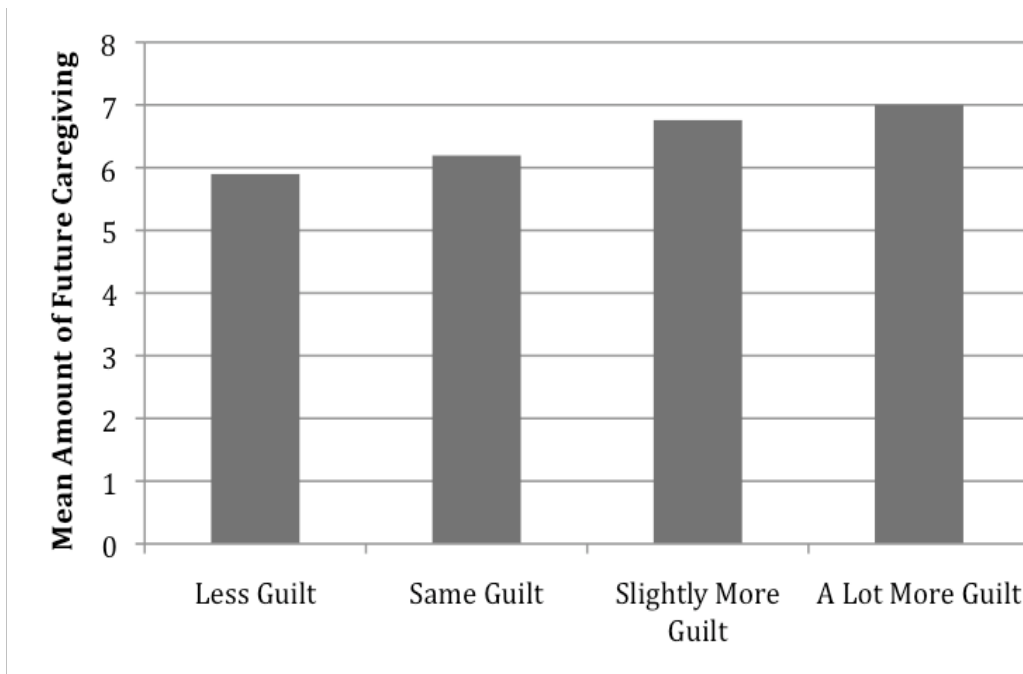


Figure 3: Mean amount of expected future sibling caregiving by level of guilt.

Ordinal Regression

Sibling gender, brother/sister diagnosis of Down syndrome, brother/sister diagnosis of an emotional disturbance or condition, sibling well-being, sibling depression, brother/sister severity of emotional problems, percentage of unmet service needs, and sibling future caregiving, all of which were found to be significant in previous analyses, were entered into an ordinal regression analysis. Overall, the model with predictors was significantly better than the model without ($\chi^2= 122.61$, $p<.001$). The model accounted for 11% of the variability in sibling guilt.

Regression also revealed four independently significant predictors of guilt: total sibling well-being ($\beta=-.015$, $p=.01$), total sibling depression ($\beta=.095$, $p<.001$), percentage of unmet service needs ($\beta=.612$, $p<.01$), and total future caregiving

($\beta=.066$, $p<.001$). Lower levels of sibling well-being predicted increases in sibling guilt. Higher levels of sibling depressive symptoms, brother/sister unmet service needs, and sibling expectations for future caregiving all predicted increased guilt.

CHAPTER IV

DISCUSSION

Though siblings of individuals may be prone to higher levels of guilt, no studies have yet examined the potential correlates of such feelings (Moser, Zaorski, Mirsalimi, & Luchner, 2005). The present study used a large online survey of adult siblings to determine which factors are related to higher levels of guilt in siblings of individuals with developmental disabilities. By asking siblings to rate their change in guilt as a result of having a brother or sister with a disability, this study was able to examine correlates that relate directly to the experience of growing up with a brother or sister with ID/DD, rather than guilt siblings may feel as a result of other life events.

This study has four main findings. The first relates to the overall level of guilt. Over half of the sample of siblings reported an increase in guilt, with nearly 30% reporting that their guilt has increased a lot as the result of having a brother or sister with a disability. This finding both supports previous speculation about sibling guilt and provides a quantitative basis for further studies. The reasons for this guilt in siblings are difficult to determine. Siblings may feel the burden of being the “better-off sibling” (Glenn, 1995), feeling guilty for the advantages they have over their brother or sister. They may also feel guilty for any negative feelings they have toward their brother or sister (Featherstone, 1980).

In addition to the prevalence of guilt, findings from the present study show that the guilt felt by these siblings is related to negative psychological outcomes. Siblings reporting increased guilt had more depressive symptoms as well as lower levels of well-being. These findings suggest that the guilt felt by these siblings is maladaptive (e.g. Lutwick & Agin, 2009). Luyten, Fontaine, and Corveleyn suggest that negative consequences of guilt are more likely when the offending situation cannot be rectified. With no opportunity to “fix” their brother or sister’s disability, siblings cannot alleviate the cause of their guilt, increasing their chances of experiencing negative outcomes such as distress and psychopathology (O’Connor, Berry & Weiss, 1999).

Of particular interest is the relationship between guilt and sibling well-being. Not only did lower levels of well-being predict increased guilt, but each incremental increase in guilt corresponded to significantly lower well-being. The siblings who reported decreased guilt had the highest levels of well-being, and the siblings who reported the largest increase in guilt had the lowest levels of well-being. This finding specifically suggests that any increase in guilt at all may significantly relate to poorer outcomes for the sibling. Therefore, it is important to determine not only which siblings are at risk for guilt, but how much guilt siblings feel.

The final two findings relate to care for the brother or sister with disabilities. Siblings who reported increased guilt plan to be more involved in caring for their brother or sister than siblings who reported decreased guilt or no change in guilt. There are many possible reasons for this finding. Siblings may feel an increased sense of responsibility toward their brother or sister because of their increased guilt

(e.g. Berndsen & Manstead, 2007). Caring for their brother or sister may provide siblings with an opportunity to decrease the discrepancy they feel as the “better-off sibling” (Glenn, 1995) by improving their brother or sister’s living circumstances.

The last finding also relates to care for the brother or sister. Brothers and sisters of siblings who reported increased guilt had a greater percentage of unmet service needs than brothers and sisters of siblings who reported decreased guilt or no change in guilt. If these brothers and sisters are having fewer of their needs met, they are presumably worse off, increasing the perception of the sibling being “better-off” (Glenn, 1995), thereby increasing sibling guilt.

Together, these findings paint a specific picture of siblings who feel increased guilt. These siblings plan to be more involved in caring for their brother or sister. This care could possibly be more difficult, as their brothers and sisters have a greater percentage of unmet service needs. On top of this increased caregiving, these siblings have more depressive symptoms and lower levels of well-being. This combination is not a pleasant one. Clearly, there are both practical and theoretical implications for these findings.

First, more research is needed to further determine the causes and implications of sibling guilt. As the first study to quantify levels of sibling guilt and the correlates thereof, this study provides a starting point for research of sibling guilt. However, future studies are needed to expand on the present findings. It is still unclear why siblings who report increased guilt plan to be more involved in caring for their brother or sister. The present study only addressed plans for future caregiving. Siblings who are currently playing a role in caring for their brother or

sister may show different patterns of guilt than siblings who are not yet at that point. Additionally, the finding regarding unmet service needs warrants more study. There may be specific unmet needs (e.g. medical care or job placement) that have a greater impact on guilt than others. These findings may also vary by state, as different states have different services available for persons with disabilities. Finally, developmental studies are needed to determine whether or not these levels of guilt are specific to adults. Child siblings may also feel increased guilt as the result of having a brother or sister with a disability.

Similarly, our findings have practical implications. Because we found guilt to be related to increased depressive symptoms and well-being, supports and therapies designed to lessen guilt could lead to better overall psychological health. Increased well-being would benefit not only the siblings, but the brothers and sisters, as the siblings with increased guilt are also more involved in caring for their brothers and sisters. Decreased guilt could also lead to a better sibling relationship, which has been shown to be related to better sibling well-being as well (Seltzer et al., 1997).

Though the present study is an important first step, it has certain limitations. First, the Adult Sibling Survey only has one question pertaining to guilt. It is unknown whether this question relates to established measures of guilt; the question possibly only measures sibling distress. Additionally, as mentioned above, the survey only addressed future caregiving, despite the fact that many respondents may currently be responsible for some care for their brother or sister. This

distinction between present caregiving and expectations for future caregiving may be important and deserves further study.

The nature of the present sample also provides limitations. Though the survey obtained a large number of participants, the sample was predominantly white, well-educated, and middle class. It is unclear whether our findings generalize to other siblings of individuals with disabilities. Similarly, the cross-sectional nature of the survey limits the generalizability of the findings. Some siblings in the sample have brothers or sisters who were born in the 1950s, when the life expectancy for a person with Down syndrome was 25-30 years (Yang et al., 2002). Cohort differences such as life expectancy, available services, and cultural expectations for individuals with disabilities are worthy of more in-depth study than the present sample can provide.

Despite these limitations, the present study has many strengths and provides important findings. Though there is only one question addressing guilt, the question specifically asks about guilt as it relates to growing up with a brother or sister with a disability. This distinction is important, as it potentially removes variability from guilt that siblings may feel as the result of other events. Additionally, the large and geographically varied sample allows us to examine guilt in adult siblings of a variety of ages from all over the United States. By not limiting the sample to one or two specific disabilities, we were able to explore guilt in siblings of individuals with many types of developmental disability, rather than simply Down syndrome or autism. The findings from this study give important insight into siblings' experience of guilt, confirming early speculation that these siblings may feel guilt toward their

brother or sister (e.g. Martino & Newman, 1974). It is important to further study this phenomenon to ensure that siblings of individuals with disabilities are receiving all the support they need to ensure both their own well-being and the well-being of their brothers and sisters.

APPENDIX A

ADULT SIBLING SURVEY

Instructions

Of all family ties, our relationships with our siblings last the longest. We would like your help in understanding the lifelong relationship of adult siblings to their brother or sister with disabilities. To reach this understanding, we have developed the questionnaire that follows. This questionnaire is divided into 5 parts. After providing basic information about yourself, your sibling and family in Part 1, the next 3 sections ask about your and your brother/sister with disabilities' joint activities and involvement; your brother/sister's support needs (both now and in the future); and your own health and well-being. We end by asking you to write your thoughts about your overall relationship with your brother/sister with disabilities. We ask that you fill out this survey only if you are 18 years or older, and that only one non-disabled sibling per family participate in this study.

Your responses to this questionnaire are entirely voluntary and will be used, anonymously, in our ongoing research on adult siblings of individuals with disabilities. In addition, you may withdraw your participation at any time and may choose to skip any questions that you wish. A check in the box below indicates that you have read and understand these conditions and that you authorize the use of your information in the questionnaire for research purposes.

By filling out this questionnaire, you agree to be in our study. For our part, we agree to report findings only in group form.

About You	
1. I have read and understand the terms of this agreement, and agree to be part of this study.	
<input type="checkbox"/> Yes	
	2. Age
	3. Gender
<input type="checkbox"/> Male	
<input type="checkbox"/> Female	
	4. What state do you live in?

5. What is your zip code?

6. Please select the one ethnicity category that best describes you.

(Select only one.)

- White non-Hispanic
- African-American
- Hispanic
- Native American
- Asian or Pacific Islander
- Other:

7. What is the highest grade of school you completed? (12=High school, 16=College Graduate, 18=Masters level, 20=Doctoral level)

8. Are you currently a student?

- No
- Yes - Working on Associated Degree
- Yes - Working on Bachelor's Degree
- Yes - Working on post Bachelor's Degree but not graduate degree
- Yes - Graduate Degree
- Yes-Grad. Area:

9. Are you currently employed?

- No
- Yes, part-time
- Yes, full-time
- Yes, Seasonally/temporarily

10. What is your occupation?

11. What is your current marital status?

- never married
- married
- separated
- divorced
- widowed

12. With whom do you currently live?

- no one else
- spouse/significant other
- parents
- other relative(s)
- other non-relatives

13. How many children do you have?

- None
- 1
- 2
- 3
- 4

- 5
- 6
- > 6

14. Do any of your children have a disability and/or major health problem?

- Yes
- No

15. If yes, how many children have a disability and/or health problem?

**16. If yes, what disabilities and/or major health problems do your children have?
Please put each disability or major health problem on a separate line.**

Please rate the CURRENT IMPORTANCE of the following roles in your life on a five point scale 1-Less Important, 2-Somewhat Important, 3-Very Important, 4 Most Important, NA-not applicable to my situation

17. Parent

- 1 Less important
- 2 Somewhat important
- 3 Very important
- 4 Most important
- NA - not applicable to my situation

18. Spouse

- 1 Less important
- 2 Somewhat important
- 3 Very important
- 4 Most important
- NA - not applicable to my situation

19. Sibling of Brother/Sister with Disability

- 1 Less important
- 2 Somewhat important
- 3 Very important
- 4 Most important
- NA - not applicable to my situation

20. Son/Daughter

- 1 Less important
- 2 Somewhat important
- 3 Very important
- 4 Most important
- NA - not applicable to my situation

About Your Brother/Sister with Disabilities

If you have more than one brother/sister with disabilities, please complete the questionnaire as it concerns that sibling who is closest to you in age.

21. Age of brother/sister with disabilities

22. Gender

- Male
- Female

23. Which of the following disability conditions does your brother/sister have?

- Mental retardation/Developmental disability
- Down syndrome
- Fragile X syndrome
- Prader-Willi syndrome
- Autism
- Emotional Disturbance or Condition
- Sensory Impairment (Hearing, vision)
- Cerebral Palsy
- Williams syndrome
- Health Condition
- Unspecified developmental disability
- Other Condition:

24. Where does brother/sister with disabilities live? If there are multiple living arrangements, please select the one where your sibling spends the most time.

(Select only one.)

- family home with parents
- family home with another relative
- your home
- group home
- supervised apartment
- Lives with spouse/significant other/friend
- by self (in home or apartment)
- larger facility
- residential school
- Other:

25. How long has your sibling lived in this residence (in years)

26. About how long does it take you to get to your brother's/sister's current residence?

(Select only one.)

- less than 15 minutes
- 15-30 minutes
- 31-60 minutes
- more than 60 minutes

27. Which of the following best describes your brother or sister with disabilities' daily work or activities? (Check all that apply.)

(Select all that apply.)

- Works in paid job within the community
- Works in paid job with some assistance (e.g., a job coach)
- Works in a paid job, with modifications

- Supervised workshop
- In school or training for future job
- Volunteer activities
- Prevocational setting
- Activity setting/day program
- Does not work or has no activity setting.

28. All together, how many hours per week are spent in these work/activity settings?

(Select only one.)

- 40 hours/week or more
- 20 - 39 hours/week
- 10 - 19 hours/week
- 5 - 9 hours/week
- 1 - 4 hours/week
- 0 hours/week

Functional Abilities

To what extent can your brother/sister with disabilities perform the following activities.

29. Walking

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

30. Speaking

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

31. Reading

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

32. Eating

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4

- 5 Very Well

33. Preparing meals

(Select only one.)

- 1 Not at all
 2
 3 Somewhat/Sometimes
 4
 5 Very Well

34. Taking medications (if applicable)

(Select only one.)

- 1 Not at all
 2
 3 Somewhat/Sometimes
 4
 5 Very Well

35. Grooming/personal hygiene

(Select only one.)

- 1 Not at all
 2
 3 Somewhat/Sometimes
 4
 5 Very Well

36. Performing household tasks

(Select only one.)

- 1 Not at all
 2
 3 Somewhat/Sometimes
 4
 5 Very Well

37. Running errands

(Select only one.)

- 1 Not at all
 2
 3 Somewhat/Sometimes
 4
 5 Very Well

38. Performing basic financial tasks (e.g., balance checkbook)

(Select only one.)

- 1 Not at all
 2
 3 Somewhat/Sometimes
 4
 5 Very Well

39. Participating in leisure activities

(Select only one.)

- 1 Not at all

- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

40. Living independently

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

41. Working at a job

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

42. Maintaining friendships

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

43. Maintaining intimate relationships

(Select only one.)

- 1 Not at all
- 2
- 3 Somewhat/Sometimes
- 4
- 5 Very Well

Problem Areas

To what extent does your brother/sister with disabilities have problems with the following activities.

44. has significant health problems

(Select only one.)

- 1 Not a problem
- 2
- 3 Somewhat of a Problem
- 4
- 5 Very much a Problem

45. has significant emotional/behavior problems

(Select only one.)

- 1 Not a problem

- 2
- 3 Somewhat of a Problem
- 4
- 5 Very much a Problem

About Your Parents

46. Mother is living?

(Select only one.)

- Alive
- Deceased

47. If alive, your mother's marital status is?

(Select only one.)

- Married
- Divorced and remarried
- Divorced, not remarried
- Never married
- Widowed

48. If mother is deceased -- At what age?

49. If mother is deceased -- In what year (1990,2000,etc) did it occur?

50. Father is living?

(Select only one.)

- Alive (Skip to Q. 53)
- Deceased

51. If father is deceased -- At what age?

52. If father is deceased -- In what year (1990,2000,etc) did it occur?

53. Ability of your parents to care for your brother/sister with disabilities

(Select only one.)

- 0 Both parents deceased
- 1 Poor
- 2 Fair
- 3 Moderate
- 4 Good
- 5 Excellent

About Your Family Constellation

Please fill in information about all members of your family of origin.
Check all that apply.

54. Child 1 (Oldest)

(Select all that apply.)

- You (Respondent)
- Male
- Female
- living at home
- Person with disability

55. Child 2

(Select all that apply.)

- You (Respondent)
- Male
- Female
- living at home
- Person with disability

56. Child 3

(Select all that apply.)

- You (Respondent)
- Male
- Female
- living at home
- Person with disability

57. Child 4

(Select all that apply.)

- You (Respondent)
- Male
- Female
- living at home
- Person with disability

58. Child 5

(Select all that apply.)

- You (Respondent)
- Male
- Female
- living at home
- Person with disability

59. Child 6 (youngest)

(Select all that apply.)

- You (Respondent)
- Male
- Female
- living at home
- Person with disability

About Your Family Constellation (continued)

60. Child 1 (Oldest) Age

61. Child 2 Age

62. Child 3 Age

63. Child 4 Age

64. Child 5 Age

65. Child 6 (youngest) Age

About Your Family Constellation (continued.)

66. Are there more than six children in your family?

(Select only one.)

No Yes

67. If more than six children, how many children in family?

68. If more than six children, what is the AGE of the youngest child?

69. Is the child with a disability among the first six?

Yes No

70. age

71. gender

Male Female

72. birth order

(Select only one.)

- 7
- 8
- 9
- 10
- 11
- 12
- 13 or higher

Joint Activities and Involvement

73. Considering all forms of contact (visits, outings, telephone calls, emails), how often are you in contact with your brother/sister with disabilities

(Select only one.)

- Daily
- Several times a week
- Weekly
- Biweekly

- Once a month
- Once every 2-3 months
- Once a year
- Less than once a year

74. Which of the following is your main mode of contact?

(Select only one.)

- Personal visit to brother/sister's residence or to your home
- Outings into community
- Phone calls
- E-mails
- Other:

75. How much time, per month, do you estimate that you spend with your brother/sister with disabilities (add up all modes of contact)?

(Select only one.)

- 10+ hours
- 5 - 9 hours
- 3 - 4 hours
- 1 - 2 hours
- Less than 1 - 2 hours

76. In your opinion, this time commitment is ...

(Select only one.)

- 1 Too much time
- 2 Somewhat too much time
- 3 About the right amount of time
- 4 Somewhat not enough time
- 5 Not enough time

77. If the time that you generally spend together is not enough (Answer 4 or 5 to prior question), to what extent is the following the reason?

(Select all that apply.)

- Lives too far away (not easy to visit)
- Brother/sister is hard to be with
- My own family commitments
- My work commitments
- Other:

Transitions

During the LAST 12 MONTHS have any of the following EVENTS occurred to you, your brother/sister with disabilities, or parents.

78. Divorce or Separation

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

79. Marriage

(Select all that apply.)

- You

- Your brother/sister with disabilities
- Parents

80. Pregnancy

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

81. Other relative moved into household

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

82. Death of family member or close friend

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

83. Financial or legal problems

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

84. Health problems

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

85. Major change in residence

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

86. Major change in employment

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

87. Loss of services or supports

(Select all that apply.)

- You
- Your brother/sister with disabilities
- Parents

Relationship

How would you rate your relationship with your brother/sister with disabilities on the following dimensions? (1=Not at all, 2=Not much, 3=Some, 4=Pretty much, 5=Very much, 6=Extremely)

88. How much do you UNDERSTAND your brother/sister?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

89. How much do you TRUST your brother/sister?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

90. How FAIR do you feel you are toward your brother/sister?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

91. How much do you RESPECT your brother/sister?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

92. How much AFFECTION do you have toward your brother/sister?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

93. Taking everything into consideration, how CLOSE do you feel in the relationship between you and your brother/sister?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

94. In general, to what extent do you think that your relationship with your brother/sister with disabilities has been mostly POSITIVE?

(Select only one.)

- 1 Not at all
- 2 Not much
- 3 Somewhat
- 4 Pretty much
- 5 Very much
- 6 Extremely

Relationship (continued)

95. Compared to your brothers/sisters without disabilities, how close are you to your brother/sister with disabilities?

(Select only one.)

- I am the only other child
- I am the closest with my brother/sister with disabilities
- I am close, but probably not the closest
- I am not very close

Your Strengths

As a result of having grown up with a brother/sister with disabilities, do you think that you have less, the same, or more of the following characteristics?

96. Empathy

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

97. Understanding of differences

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More

- 5 More

98. Open to opportunities to learn

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

99. Compassion

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

100. Aware of family interactions/dynamics

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

101. A responsible person

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

102. Feelings of guilt

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

103. Aware of injustices

(Select only one.)

- 1 Less
- 2 Somewhat Less
- 3 Same
- 4 Somewhat More
- 5 More

Your Physical Health

104. How would you say that in general your health is

(Select only one.)

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very Good
- 5 Excellent

Your Mental Health

Below is a list of ways you may have felt or behaved.
Please tell us how you have felt during the past week.

105. I felt depressed

(Select only one.)

- Rarely or none of the time (less than 1 day)
- Some or little of the time (1-2 days)
- Occasionally or moderate amount of time (3-4 days)
- Most or all of the time (5-7 days)

106. My sleep was restless

(Select only one.)

- Rarely or none of the time (less than 1 day)
- Some or little of the time (1-2 days)
- Occasionally or moderate amount of time (3-4 days)
- Most or all of the time (5-7 days)

107. I felt lonely

(Select only one.)

- Rarely or none of the time (less than 1 day)
- Some or little of the time (1-2 days)
- Occasionally or moderate amount of time (3-4 days)
- Most or all of the time (5-7 days)

108. I could not 'get going'

(Select only one.)

- Rarely or none of the time (less than 1 day)
- Some or little of the time (1-2 days)
- Occasionally or moderate amount of time (3-4 days)
- Most or all of the time (5-7 days)

109. I had crying spells

(Select only one.)

- Rarely or none of the time (less than 1 day)
- Some or little of the time (1-2 days)
- Occasionally or moderate amount of time (3-4 days)
- Most or all of the time (5-7 days)

Well-being

In this section there are statements about well-being. Please rate your AGREEMENT with each statement on a six point scale where 1=STRONGLY AGREE AND 6=STRONGLY DISAGREE.

110. I tend to be influenced by people with strong opinions.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

111. I have confidence in my own opinions, even if they are contrary to the general consensus

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

112. I judge myself by what I think is important, not by the values of what others think is important.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

113. In general, I feel I am in charge of the situation in which I live.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

114. The demands of everyday life often get me down.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5

6 Strongly Agree

115. I am quite good at managing the many responsibilities of my daily life.

(Select only one.)

1 Strongly Disagree

2

3

4

5

6 Strongly Agree

116. I think it is important to have new experiences that challenge how you think about yourself and the world.

(Select only one.)

1 Strongly Disagree

2

3

4

5

6 Strongly Agree

117. For me, life has been a continuous process of learning, changing, and growth.

(Select only one.)

1 Strongly Disagree

2

3

4

5

6 Strongly Agree

118. I gave up trying to make big improvements or changes in my life a long time ago.

(Select only one.)

1 Strongly Disagree

2

3

4

5

6 Strongly Agree

119. Maintaining close relationships has been difficult and frustrating for me.

(Select only one.)

1 Strongly Disagree

2

3

4

5

6 Strongly Agree

120. People would describe me as a giving person, willing to share my time with others.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

121. I have not experienced many warm and trusting relationships with others.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

122. I live life one day at a time and don't really think about the future.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

123. Some people wander aimlessly through life, but I am not one of them.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

124. I sometimes feel as if I've done all there is to do in life.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

125. When I look at the story of my life, I am pleased with how things have turned out.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5

- 6 Strongly Agree

126. I like most aspects of my personality.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

127. In many ways, I feel disappointed with my achievements in life.

(Select only one.)

- 1 Strongly Disagree
- 2
- 3
- 4
- 5
- 6 Strongly Agree

Current Supports

To what extent does your brother/sister now RECEIVE and NEED each of the following supports? Check all that apply.

128. Case Management

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

129. Job Counseling-Assessment

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

130. Job Placement

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

131. Job Coach

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

132. Residential placement

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

133. Respite Care

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

134. Transportation

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

135. Medical Care

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

136. Dental Care

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

137. Occupational Therapy

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

138. Physical Therapy

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

139. Speech Therapy

(Select only one.)

- In Place
- Needed, But not in place

- Not needed
- Don't Know

140. Psychotherapy

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

141. Behavioral Intervention

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

142. Social Security Benefits

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

143. Money for Personal Expenses

(Select only one.)

- In Place
- Needed, But not in place
- Not needed
- Don't Know

Knowledge of Skills/Needs

How much do you feel you know about the following skills and needs of your brother/sister with disabilities?

144. ...ability to perform daily living skills

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

145. ...interpersonal skills

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

146. ...financial needs

(Select only one.)

- Not at all informed
- Not very well informed

- Fairly well informed
- Very well informed

147. ...residential needs

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

148. ...vocational needs

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

149. ...social/recreational activity needs

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

150. ...physical health needs

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

151. ...mental health needs

(Select only one.)

- Not at all informed
- Not very well informed
- Fairly well informed
- Very well informed

Roles

Sometimes a particular family member or close family friend assumes each of several different roles for the adult individual with disabilities. Whom do you think will play each of the following roles when your parent(s) are no longer able to do this?

152. Residential arrangements

(Select only one.)

- I will have primary responsibility
- Another sibling and I will share responsibility
- Other sibling(s) will have responsibility
- Other family member will have responsibility
- I will share responsibility equally with another family member

- Professional or agency will have responsibility

153. Financial arrangements

(Select only one.)

- I will have primary responsibility
- Another sibling and I will share responsibility
- Other sibling(s) will have responsibility
- Other family member will have responsibility
- I will share responsibility equally with another family member
- Professional or agency will have responsibility

154. Legal guardianship

(Select only one.)

- I will have primary responsibility
- Another sibling and I will share responsibility
- Other sibling(s) will have responsibility
- Other family member will have responsibility
- I will share responsibility equally with another family member
- Professional or agency will have responsibility

155. Interacting with service system

(Select only one.)

- I will have primary responsibility
- Another sibling and I will share responsibility
- Other sibling(s) will have responsibility
- Other family member will have responsibility
- I will share responsibility equally with another family member
- Professional or agency will have responsibility

156. Providing companionship-emotional support.

(Select only one.)

- I will have primary responsibility
- Another sibling and I will share responsibility
- Other sibling(s) will have responsibility
- Other family member will have responsibility
- I will share responsibility equally with another family member
- Professional or agency will have responsibility

Roles (continued)

157. I am currently my brother/sister with disabilities' legal guardian

(Select only one.)

- Yes
- No

158. When your parents die or are no longer able to care for your brother/sister with disabilities, who will take on the responsibility for his/her care? If you select "Other", and a person will be responsible, please give their relationship to your brother/sister.

(Select only one.)

- I will be mainly responsible
- One of my other brothers/sistes will be responsible

- I will jointly be responsible with one (or more) brothers/sisters
- Not clear due to an ongoing discussions
- Not clear--we've never discussed this issue
- Other:

Reflections

In the space below, please tell us in your own words your thoughts about the following (Use the back of the page if you need additional space.)

159. What is your relationship like with your brother/sister with disabilities?

160. How has your relationship changed in the last 5 years

161. What do you expect your relationship to be like in 5 years' time?

162. What would help you now to make it easier to support your sibling with disabilities?

163. What would have helped you growing up as a sibling of a child with disabilities?

164. Is there anything else you would like to tell us?

165. What advice would you give parents of children with disabilities?

Thank you for taking time to complete this survey.

Your answers to this survey will be anonymous with no personal identifying information.

If you would like to receive a summary of the results of this study, please complete and submit the registration form included with the questionnaire. In addition, you may request to be contacted for future studies.

Registration forms will be separated from when received and no attempt will be made to match questionnaires with registration information.

register

Instructions

Participation in future studies

You are free to decide to participate in any particular study. You may request to have your name taken off the contact list at any time. If you have any questions, you may contact us at email:FamilyResearch@vanderbilt.edu or phone:1.888-xxxx

Contact Information

1. I would like to be contacted to participate in future family research studies.

- yes
- no

2. First Name

3. Last Name

4. Street Address

5. Street Address (second line)

6. City

7. State

8. Zip Code

9. email address

10. Home phone number (optional)

11. Work phone number (optional)

Our postal address is:

Family Research Group
Vanderbilt Kennedy Center

Vanderbilt University
230 Appleton Place, Box 40
Nashville TN 37203

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