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Caregiver Burden and Sibling Relationships in Families Raising
Children with Disabilities

Diane Allred

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Caregiver Burden and Sibling Relationships in Families Raising Children with Disabilities

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The purpose of this study was to examine sibling relationships and caregiver burden in families raising children with disabilities (CWD). In order to determine (a) are there differences in caregiver burden according to parent gender and types of disability (b) are there differences in sibling relationships according to parent gender and type of disability and (c) is there a relationship between caregiver burden and sibling relationships after controlling for CWD and sibling gender and age, and type of disability? After IRB approval, 166 families living in the west and raising typically developing children (TDC) or a CWD participated. Disabilities included autism; Down syndrome (DS); other disabilities (OD), which included orthopedic impairment, intellectual disabilities, emotional or physical disabilities, health impairment; and multiple disabilities (MD), which included both physical and intellectual disabilities. After consenting, both parents independently completed the 28-item Schaefer Sibling Inventory of Behavior. This inventory ranked sibling behaviors in relation to kindness, involvement, empathy, and avoidance. Additionally a revised version of the Caregiver Strain Index (Robinson, 1983) measuring hassle and frequency of burden was utilized. Mothers completed a demographic questionnaire. Analyses included descriptive statistics, a MANOVA, correlations, and multiple regressions. Results indicated mothers perceived more burden than fathers for all disability types. Parents of children with autism perceived the highest burden, and mothers of TDC and fathers of children with DS perceived the least amount burden. Mothers rated female siblings higher in kindness, involvement, and empathy than male siblings. Whereas, fathers rated siblings of children with OD as least avoidant; as did mothers of children with DS. The highest sibling relationship scores were fathers' rating of empathy in families raising children with DS and mothers' rating of empathy in families raising children with MD. There was a positive relationships between caregiver burden for both parents and between both parent's ratings of sibling empathy, kindness, and involvement. A negative relationship was found between parents' ratings of avoidance and empathy, kindness and involvement. All caregiver burden variables were positively related to avoidance. Siblings may benefit from information regarding a child's disability in order to decrease avoidance behavior. It would also be important to provide interventions/information about respite care and other appropriate community resources to parents of children with autism in order to help decrease the burden they experience. Finally, parents of CWD may benefit from information regarding the effect their perception of burden has on relationships between the child and siblings.

Keywords: Mothers; Fathers; Parenting stress; Caregiving; Disabilities; Sibling; Relationships

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Sibling Relationship and Caregiver Burden in Families Raising Children with Disabilities

The United States has a population of approximately 53.9 million school-aged children between 5-17 years of age; about 2.8 million are reported as having a disability (U.S. Disability Facts and Statistics of School Aged Children, 2011). Disabilities can be listed as mild to severe and may affect the child's development intellectually (Down syndrome and developmental delay), emotionally (autism and bipolar disorder), and physically (arthritis and orthopedic conditions (Nielsen et al., 2012). With no respect to race, age, gender or ethnic affiliation, increasing numbers of families face the possibility of raising a child with disabilities (CWD), since many of these children are now living longer and at home more than they did in the past.

Issues a parent faces in caring for a CWD continue to receive research and attention. Much of this research discusses how better health and social care have led to improved longevity within this population (Minnes & Woodford, 2005). This, combined with the growing numbers of CWD, suggests more people will be caregivers well into their old age (Minnes & Woodford). Consequently, as more family members are affected by this situation for longer periods of time, there is an increased interest in the well-being of families raising these children. Concerns related to these families include: quality of life; parenting practices and stress; caregiving demands; family support and satisfaction; and cultural differences (Sosbey & Calder, 2006), suggesting these families may be burdened by the care a CWD requires compared to families raising typically developing children (TDC) (Wang, Michaels, & Day, 2010; Weiss, 2002). In fact, Oelofsen and Richardson (2006) discovered up to 84% of families raising a CWD experienced stress due to the child's care needs which may lead to parental caregiver burden.

In addition to parents' caregiver burden, siblings are susceptible to unique stressors related to living in a family raising a CWD that include social impacts, parental time constraints,

and relationship difficulties (Mulroy, Robertson, Aiberti, & Bower, 2008; Waite-Jones & Madill, 2008). Even though there is added stress on these siblings, there is evidence of both positive and negative effects (Burke, 2010). For example, some studies indicate siblings of CWD seem to be well-adjusted (Hastings, 2003a, 2007; Kaminsky & Dewey, 2002; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shaley, 2004), while others report an increased potential for behavioral problems (Hastings, 2003b; Ross & Cuskelly, 2006; Verte, Roeyers, & Buysse, 2003). For example, Williams (1997) found 26 of 43 studies (61%) demonstrated siblings of CWD were at an increased risk of adjustment and other problems compared to siblings of TDC; whereas, the remaining studies reviewed identified either no risk or actual benefits to siblings.

Raising a CWD is clearly a stressor on parents and other caregivers. Likewise being a sibling of a CWD can add to the stress of the siblings' everyday life and affect relationships with others. Therefore, the purpose of this thesis was to explore parent perceptions of the sibling relationship including: kindness, avoidance, involvement, and empathy; and their own caregiver burden including: the amount of burden in families raising a CWD compared to families raising TDC.

Literature Review

Caregiver Burden

For nearly all parents, having children and caring for them is an experience with triumphs, joys and also challenges and stresses (Resch et al., 2010). Although parents expect to provide caregiving during the growth of a child, the caregiver role takes on a new significance when parents are raising a CWD (Raina et al., 2005), especially since recent practice supports caring for these children in the home. Related to this, Raina and colleagues discussed how duties and roles within the family unit may change when raising a CWD; caregivers are often faced

with the possibility the CWD may require long-term care well beyond the typical child raising years, as these parents remain in the caregiver role longer and are continually required to sacrifice their own needs over the child's needs (Nguyen, 2009). They therefore, may experience caregiver burden because of increased stress raising a CWD (Abbeduto et al. 2004; Dumas, Wolfe, Fisman, & Culligan, 1991; Rodrigue, Morgan, & Geffken, 1990; Warfield, 2005), and because parenting these children is extremely complex with challenging caregiver duties and pressures (Manor-Binyamini, 2011). In fact, many of these added stressors adversely affect caregivers' overall health (Oelsfsen & Richardson, 2006), and can lead to depression (Hasting, Daley, Burns, & Beck, 2006), marital conflict (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Suarez & Baker, 1997), less effective parenting (Baker & Heller, 1996), and increased behavior problems in their children (Baker et al. 2003).

In addition to the general challenge and pressure of raising a CWD, other factors are also linked to caregiver burden. For example, education is associated with the level of psychological stress (Al-Krenawi, Graham, & Gharaibeh, 2011; Cavallo, Feldman, Swaine, & Meshefedjian, 2008; Kumar, 2008). Specifically, educated mothers (those with post high school education) are more likely to seek help and provide appropriate and timely treatment for the child, which decreases the likelihood of medical crises (Kumar). However, parents who have low education levels (not completing high school) are much more dependent on medical staff and have little confidence in their ability to provide for their CWD (Cavallo et al.), and therefore, may experience more caregiver burden.

Parents also report increased caregiver burden when there are few resources available to help them find good healthcare and support for their child (McManus et al., 2011). In fact, parents of poor, minority, and uninsured children struggle to provide and coordinate their child's

health care because many do not have easy access to or knowledge of resources available. Without proper access to resources, financial burdens arise, the child's health care needs continue to go unmet, and parents spend prolonged time searching for help (McManus et al.). However, caregivers learn to deal with burden by using coping mechanisms that lower stress and strain. Some of these mechanisms include support received from social and familial relationships, as well as from health care professionals (Cavallo et al., 2008). On the other hand, when a CWD receives professional health care, the needs of the child are generally the focus rather than on how parents are coping with the situation. Consequently, if the family as a unit is the focus of care and support, caregiver burden can be relieved, especially during those difficult experiences when a child may be hospitalized or receiving therapy (Al-Krenawi et al., 2009; Resch et al., 2010).

Indeed, caregiver burden is experienced by parents raising a CWD. This added burden is linked to parents' well-being and can also lower the quality of care provided to the child. However, sibling relationships may also be affected if parents experience caregiver burden.

Sibling Relationships

A sibling's relationship with a brother or sister is complex, intensive, and has infinite variety (Nolbris, Enskar, & Hellstrom, 2007). It is also usually the longest relationship a person will experience in one's lifetime (Mandleco, Olsen, Dyches, & Marshall, 2003). In addition, siblings have emotional bonds which can fluctuate between warmth and sensitivity or negativity and filled with conflict (Nolbris et al., 2007). Accordingly, situations affecting one sibling will have some impact on other family members.

This is especially true when there is a CWD in the family; roles are altered and new ones must be defined (Branstetter, Domian, Graff, Piamjariyakul, & Williams, 2008), necessitating

changes in normal sibling interactions (Conger, Stocker, & McGuire, 2009). For example, if a CWD has developmental delays, there can be communication problems, differences in cognitive development, nonreciprocal behaviors, and other burdens (McHale & Harris, 1992). These changes in roles and added difficulties for the typically developing sibling have been termed “disability by association” (Burke, 2010, p. 1684), but may also be accepted by siblings as part of their own normality (Burke). Therefore, in looking at the quality of and roles between the CWD and the sibling, the relationship tends to progress less symmetrically over time, whereas for TDC the relationship tends to progress more symmetrically over time (Stoneman, 2005).

Research is mixed regarding how a CWD affects typically developing siblings. Some studies report a negative effect. For example, some siblings will have behavioral issues (Ishizaki et al., 2005; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009), social issues (Bagenholm & Gillberg, 1991; Sharpe & Rossiter, 2002), or academic issues (Sanders, 2004). Other studies suggest siblings can experience hardships related to disrupted or missed social experiences, constant worry about the CWD (Pineyard, 1983), and feel jealous because of uneven parental attention (Kiburz, 1994).

On the other hand, research also suggests positive outcomes related to being a sibling of a CWD. For example, these siblings often spend more time with the CWD compared to siblings of TDC, including playing together (Stoneman, 2005), helping parents care for the child (Benderix & Sivberg, 2007; Burke & Montgomery, 2000; Craft-Rosenberg, 2003; Lobato, Kow, & Plante, 2006; Sharp & Rossiter, 2002; Stoneman, 2001; 2005; Waite-Jones & Madill, 2008), and feeding or dressing the child (Sharpe & Rossiter). Because of these interactions, siblings of a CWD demonstrate more helping behaviors and greater than average self-respect (Kaminsky & Dewey,

2001); more empathy, kindness; are rarely and involvement avoidant (Nielsen et al., 2012); and exhibit more warmth (Cuskelly & Gunn, 2003).

Since little information exists between caregiver burden and sibling relationships in families raising a CWD, this research sought to answer three questions: (a) Are there differences in caregiver burden according to parent gender and type of disability? (b) Are there differences in sibling relationships according to parent gender and type of disability? (c) Is there a relationship between caregiver burden and sibling relationships after controlling for CWD and sibling gender and age, and type of disability?

Methods

Participants

A sample of 166 families (mother, father, target child, sibling) living in a Western state participated. Target children were either TDC ($n=32$) or a CWD ($n=134$). Participation was voluntary and families were recruited from conferences and education programs for families raising CWD as well as snowball sampling. The sample included parents raising children with the following disabilities or conditions: autism, which included any disability on the autism spectrum ($n = 43, 26.7%$); Down syndrome (DS) ($n = 30, 18.9 \%$); other disabilities (OD), which included orthopedic impairment, intellectual disabilities, emotional or physical disabilities, health impairment ($n = 36, 22.6%$); and multiple disabilities (MD), which included both physical and intellectual disabilities ($n = 25, 14.7%$). In this sample 62% of the CWD were male, and 42.2% of the siblings were male. The mean age of the CWD was 8.91 ($SD = 3.50$ years). The average age of siblings was 10.88 ($SD = 3.70$ years). The mean age of fathers was 41.99 ($SD = 7.73$ years), and the average age of mothers was 40.17 ($SD = 7.40$ years). Fathers averaged 15.91 years of education ($SD = 2.55$) and worked an average of 44.66 hours per week ($SD =$

11.48) with 95.5% working full time. Mothers mean years' of education was 15.14 ($SD = 2.05$), and they worked an average of 13.45 hours per week ($SD = 16.25$). Mothers working full-time were 16.8%, part-time 39.7%, and not working 43.6%. Most families earned more than \$50,000 annually (79.8%); the majority (94.7%) was Caucasian, and 91.0% were two-parent. The average number of children in the family was 3.98 ($SD = 1.96$).

Procedure

This research is part of a larger, ongoing study examining how families adapt when raising a CWD or chronic condition. During a home visit, parents individually filled out questionnaires related to caregiver burden (Appendix A) and sibling relationships (Appendix B). One parent (generally mothers) also completed a demographic questionnaire (Appendix C). Families received a \$20 gift card for participating.

Measures

Caregiver burden. Adapted from Robinson's (1983) Caregiver Strain Index (CSI), the caregiver burden instrument contained 13 items related to the burdens of caring for children (e.g., feeling that caring for my children is an inconvenience). Parents related how often they feel this way (1 = rarely, 4 = constantly) and how much of a hassle the feeling was to them (1 = no hassle, 4 = big hassle). For each subscale, items were summed and a mean score calculated. In this study, only the amount of hassle was used. Reliabilities for this sample were: 0.86 for both fathers and mothers.

Sibling relationship. Parents individually completed the 28-item Sibling Inventory of Behavior (Schaefer & Edgerton, 1981) developed to evaluate relationships between a typically developing sibling and a CWD in four areas: kindness (9 items), empathy (6 items), involvement (7 items), and avoidance (6 items). Parents ranked the relationship between typically developing

sibling and the CWD on a Likert scale (1 = never, 5 = always). Sample questions included: tries to comfort him/her when she is unhappy or upset (kindness), shows sympathy when things are hard for him/her (empathy), makes plans that include him/her (involvement), and tries to avoid being seen with him/her (avoidance). For each subscale, items were summed and a mean score calculated. Reliabilities for this sample were empathy: 0.89 (fathers), 0.90 (mothers); kindness: 0.87 (fathers), 0.89 (mothers); involvement: 0.92 (fathers), 0.91 (mothers); and avoidance: 0.83 (fathers), 0.83 (mother).

Demographic variables. Mothers completed a demographic questionnaire that included questions regarding the age and gender of the CWD and sibling, as well as the child's type of disability, and other family variables.

Analysis

Initially, descriptive statistics were calculated including a mean and standard deviation for all variables (mothers' and fathers' ratings of hassle of burden and mothers' and fathers' ratings on sibling kindness, empathy, involvement, and avoidance according to the type of disability). MANOVAs were then calculated to determine if there were differences in caregiver burden and sibling relationship variables according to parent gender and type of disability. Bivariate correlations were performed to discover if there were significant relationships between caregiver burden and the sibling relationship variables.

Finally, hierarchical multiple regression analyses were performed to identify if type of disability and caregiver burden predicted sibling relationships, even in the presence of demographic variables (CWD age, sibling age, and sibling gender). Interaction effects between caregiver burden and disability were also tested. In the multiple regression analyses, caregiver burden was centered to reduce multicollinearity (Preacher, 2009). In Model 1 the centered

caregiver burden variable and the control variables were entered. Dummy variables were created for child gender and disability. Interaction effects between the centered caregiver burden variable and disability were tested in Model 2. The interaction was calculated to determine if the magnitude of the effect of caregiver burden on the sibling relationship variables varied according to disability (Preacher, 2009)

Aiken and West's (1991) step-down approach was used to interpret regression results. This strategy assesses the presence of significant interaction effects before testing for the effects of control variables and main effects. When interaction effects were not significant, the previous step of the equation was interpreted (Model 1). When interactions were significant, the mean plus or minus the standard deviation of the predictor variables was used to plot the regression lines (Preacher, 2009).

Results

Descriptive Statistics

For caregiver burden, the mean for parents' ratings (no hassle to big hassle) ranged from 1.56 to 2.16 (Table 2). The lowest scores (least likely to experience burden) were for fathers of children with DS and mothers of TDC. The highest scores (most likely to experience burden) were for mothers and fathers of children with autism.

For sibling relationship variables, the mean for parents' rating (never to always) ranged from 1.64 to 4.24 (Table 2). The lowest scores were fathers' rating of avoidance in families of children with OD and mothers' rating of avoidance in families of children with DS. The highest scores were fathers' rating of empathy in families raising children with DS and mothers' rating of empathy in families raising children with DS and MD.

MANOVAs

We calculated a 2 x 5 MANOVA with parent gender (mother, father) as one independent variable and disability type as a second independent variable (TDC, autism, DS, OD, MD). Mother and father ratings of caregiver burden were the dependent variables. There were significant multivariate effects for both parent gender (Wilks' Lambda = 20.22; $p < .001$) and type of disability (Wilks' Lambda = 3.49; $p < .001$). There was also a significant parent x disability interaction (Wilks' Lambda = 2.56; $p < .01$).

We conducted two follow up univariate analyses. The first univariate analyses were conducted to examine differences in caregiver burden by parent gender; mothers ($M = 2.00$; $p < .001$) scored significantly higher than fathers ($M = 1.73$; $p < .001$). The second univariate analyses were conducted to examine differences in caregiver burden by disability type. Parents of children with autism rated burden higher than parents of TDC and parents of children with DS.

When we tested the interaction effect of burden, mothers of children with all types of disabilities perceived higher burden than fathers. However, there was no significant difference between mothers and fathers of TDC (Table 2).

We calculated another 2 x 5 MANOVA with parent gender (mother, father) as one independent variable and disability type as a second independent variable (TDC, autism, DS, MD, and OD). Mother and father ratings of sibling relationships were the dependent variables (kindness, empathy, involvement, and avoidance). There were significant multivariate effects for both type of disability (Wilks' Lambda = 4.84; $p < .001$) and parent gender (Wilks' Lambda = 4.58; $p < .001$), but no significant interaction effect (Wilks' Lambda = 1.15; $p = .31$).

Follow up univariate analyses were conducted to examine differences in sibling relationships by parent gender. Although the multivariate effect was significant, there were no significant univariate differences in sibling relationships by parent gender.

Additional follow up univariate analyses were then conducted to examine differences in sibling relationships by type of disability. There was a significant univariate effect for disability and sibling kindness ($F = 6.35; p < .001$). Parents raising TDC rated sibling kindness significantly lower than parents raising children with MD, DS, or autism. However, parents of children with DS or MD rated sibling kindness significantly higher than parents of children with OD.

Correlations

Bivariate correlations were calculated to examine the relationships between study variables (Table 3). There was a negative relationship between fathers' and mothers' rating of sibling avoidance and the other three sibling relationship variables; empathy, kindness and involvement. On the other hand, parents' perceptions of empathy, kindness and involvement were positively related.

Bivariate correlations also were calculated for caregiver burden and sibling relationship variables (Table 4). All caregiver burden variables were positively related to parents' rating of avoidance. In addition, burden for both parents was negatively related to empathy, kindness, and involvement.

Multiple Regressions

Four hierarchical multiple regressions were calculated with each of the sibling relationship variables (kindness, involvement, empathy, and avoidance) as the outcome variables. Regressions were calculated for both mothers' and fathers' ratings of sibling

relationships. In the first model, the following variables were entered: caregiver burden, age of the child with a disability, age and gender of the sibling (0 = male; 1 = female), and dummy variables for autism, DS, OD, and MD (TDC was the comparison group). In the second model, the interactions between each of the disability variables and caregiver burden were added.

Mothers. In the first equation kindness was the outcome variable (Table 5). We interpreted the results from Model 1 because no interactions were statistically significant (Aiken & West, 1991). In Model 1 caregiver burden was negatively related to kindness; the higher the mothers' burden, the lower she rated the sibling on kindness. However, female siblings were rated higher on kindness than male siblings, and siblings of children with DS were rated higher on kindness than siblings of TDC; 16% of the variance was explained by the predictor variables.

In the second equation empathy was the outcome variable. There were no significant disability x caregiver burden interactions, so we interpreted Model 1. Again, caregiver burden was negatively related to empathy; the higher the mothers' burden, the lower she rated the sibling on empathy. Female siblings were rated higher on empathy than male siblings and 14% of the variance was explained by the predictor variables.

In the third equation involvement was the outcome variable, and in the second model 20% of the variance was explained by the predictor variables. Caregiver burden was negatively related to involvement; the higher the mother's burden, the lower she rated the sibling on involvement. Female siblings were rated higher on involvement than male siblings, and there was a significant interaction between OD x caregiver burden. As seen in Figure 1, in families of TDC, there was little difference in sibling involvement, regardless of the level of burden. However, siblings of children with OD were less involved with the child when mothers experienced higher burden.

In the fourth equation avoidance was the outcome variable. There were no significant disability x caregiver burden interactions, so we interpreted Model 1. In this equation, caregiver burden was positively related to avoidance; the higher the mothers' burden, the higher she rated the sibling on avoidance. In addition, the older the siblings, the higher they were rated on avoidance and 30% of the variance was explained by the predictor variables.

Fathers. In the first equation kindness was the outcome variable (Table 6). There were no significant disability x caregiver burden interactions, so we interpreted Model 1. In the first model caregiver burden was negatively related to kindness; the higher the fathers' burden, the lower he rated the sibling on kindness. No other relationships were statistically significant, and only 13% of the variance was explained by the predictor variables.

In the second equation empathy was the outcome variable. There were no significant disability x caregiver burden interactions, so Model 1 was interpreted. Caregiver burden was negatively related to empathy; the higher the fathers' burden, the lower he rated the sibling on empathy. In addition, the older the CWD, the lower he rated the sibling on empathy, and female siblings were rated higher on empathy than male siblings; 26% of the variance was explained by the predictor variables.

In the third equation involvement was the outcome variable. There were no significant disability x caregiver burden interactions, so Model 1 was interpreted. Caregiver burden was negatively related to involvement; the higher the fathers' burden the lower he rated the sibling on involvement. In addition, the older the sibling, the lower the sibling was rated on involvement, and 19% of the variance was explained by the predictor variables.

In the fourth equation avoidance was the outcome variable and 20% of the variance was explained by the predictor variables. In the second model, caregiver burden was positively

related to avoidance; the higher the fathers' burden, the higher he rated the sibling on avoidance. There was also a significant interaction between autism and caregiver burden. As seen in Figure 2, in families raising children with autism, sibling avoidance was similar, regardless of the level of burden. However, in families of TDC, fathers who had higher levels of burden rated siblings higher on avoidance than fathers with lower levels of burden.

Discussion

Parents caring for a CWD have greater levels of stress and demands placed on them daily (Abbeduto et al. 2004; Dumas et al., 1991; Rodrigue et al., 1990; Warfield, 2005) than parents raising TDC. This burden may have a negative impact on these parents which can extend to the entire family, including siblings and their relationship with each other and the CWD (Blair, 2003; Resch et al., 2010). Indeed, sibling relationships are an important part of a child's experiences, affecting how other relationships develop and how one learns to interact with others (Abrams, 2009).

Research has examined both caregiver burden (Wade et al., 2010) and sibling relationships (Hastings, Kovshoff, Espinosa, Brown, & Remington, 2005) separately, but minimal research has examined how the two variables are related. In addition, most prior research obtained data from mothers rather than fathers or combined perceptions of both parents (Guite, Lobato, Kao, & Plant, 2004; Hollidage, 2001; Masood, Turner, & Baxter, 2007). However, this study focused on parent gender separately, looking for differences between mothers' and fathers' perception of caregiver burden and sibling relationships and addresses this gap in the literature.

Specifically, three research questions were asked: (a) Are there differences in caregiver burden according to parent gender and type of disability? (b) Are there differences in sibling

relationships according parent gender and type of disability? (c) Is there a relationship between caregiver burden and sibling relationships even in the presence of sibling and CWD gender and age, and type of disability? These questions will be discussed in the following paragraphs.

Differences in Caregiver Burden by Parent Gender and Type of Disability

When examining caregiver burden and parent gender, mothers of children with all types of disabilities perceived higher levels of burden than fathers. This could be because most mothers in our sample (83.3%) are at home at least part of the day, and consequently, may be more involved in child care and experienced higher stress, as they provide most care for the CWD (Tehee, Honan, & Hevey, 2008). In addition, research shows mothers' stress also increases over time whereas fathers' stress tends to remain constant (Gerstein, Crinic, Blacher & Baker, 2009). Fathers may also have lower levels of burden because they have lower stress levels than mothers, especially when raising a child with intellectual disabilities (Herring et al., 2006). The majority of fathers in our sample (95%) worked full-time and may have fewer responsibilities caring for the CWD, perhaps impacting why they perceive lower burden than mothers.

Our study found significant differences in caregiver burden by type of disability. Parents of children with autism rated burden higher than parents of TDC or parents of children with DS. This finding could be because children with DS have fewer behavior problems compared with children with autism (Dykens & Kasari, 1997; Ricci & Hodapp, 2003; Stores, Stores, Fellows, & Buckley, 1998), thereby contributing to less perceived burden. Children with autism also have more behavioral problems as well as intellectual problems, compared to other CWD (Griffith, Hastings, Nash, & Hill, 2009), and TDC (Baker et al., (2003), which can lead to parental stress, especially if these behaviors occur often (Griffith et al.). Research also suggests parents of

children with autism experience a higher level of stress because these children require more monitoring than children with OD (Hastings, 2007).

Differences in Sibling Relationships by Parent Gender and Type of Disability

There were no significant differences in sibling relationships by parent gender, however, when examining the differences between sibling relationships and type of disability, parents of TDC rated sibling kindness lower than did parents of children with MD, DS, and autism. This is not surprising since past research shows siblings living with a CWD are kinder than siblings of TDC (Kaminsky & Dewey, 2001; Mandlaco et al., 2003; Pilowsky et al., 2004; Skotko & Levine, 2006; Stoneman, 2001). In addition, parents of children with DS rated siblings kinder than did parents of siblings of children with OD, perhaps because children with DS are known to have positive and charming characteristics. Therefore, siblings might enjoy being around and helping this child. In addition, siblings often benefit from the child's upbeat personality characteristics (Skotko & Levine), which may positively impact the sibling, resulting in more kindness than is seen in siblings of children with other disabilities (Mulroy et al., 2008). Finally, parents of children with OD rated sibling kindness lower than parents of children with MD. In this sample, children with MD had both cognitive and physical disabilities compared to children in the OD category. Meeting the needs of these children can be difficult; in fact, research shows some mothers of children with MD spent up to eighteen hours a day devoted to the child's care (Hassall, Rose, & McDonald, 2005). Meeting the needs of a child with MD is intensive, requiring large amounts of time and effort especially related to activities of daily living compared to children with all other disabilities (Tadema & Vlaskamp, 2009). Siblings of children with MD may participate in addressing some of the increased care needs of the child, which can translate into kinder interactions with the child.

Relationship between Caregiver Burden and Sibling Relationships

Parents face extra burdens when caring for a CWD and research suggests this can contribute to difficulties for siblings (Stoneman, 2005). Even though siblings of a CWD can be empathetic, kind, and involved, and rarely avoidant (Nielsen et al., 2012), our research shows when parents are burdened some sibling relationships seem to be negatively affected and these relationships may be perceived differently by each parent (Berge, Patterson, & Rueter, 2005; Hastings et al., 2005).

Mothers' perception. When mothers' burden increased, we found siblings of CWD show less empathy, kindness, and involvement. This could be attributed to increased caregiver needs the CWD requires, and her limited time to provide that care (Mulroy et al., 2008). Mothers with higher burden also perceived higher levels of sibling avoidance. One reason for this might be the negative stigma associated with living with a CWD and difficulty accepting the child's differences (Meyer & Vadasy, 1996). These siblings may also be embarrassed by the CWD and be reacting to strangers' perception of the child (Pit-ten Cate & Loots, 2000). Mothers also perceived sisters showed more kindness, empathy, and involvement than brothers. This may be because as Cuskelly and Gunn (2003) suggested, female siblings spend more time with the CWD than male siblings, and therefore may be perceived as kinder by mothers who observe sibling interactions more often than fathers. Female children may also be expected to be more kind, involved, and nurturing whereas male children might not have this expectation (Cuskelly & Gunn, 2003, 2006; Wisdom, Rees, Riley & Weis, 2007).

We discovered when mothers' burden increases, involvement of siblings of children with OD decreases. Siblings of children with OD might not have the skills necessary to provide the type of care the child needs, especially if the child with OD requires mechanical equipment (e.g.

wheelchairs, braces, feeding tubes). Interestingly, involvement of siblings of TDC showed little difference regardless of the burden amount, perhaps because they were rarely involved in caring for the TDC.

Fathers' perception. Even after controlling for the type of disability and child and sibling characteristics, when father's burden increases, we found siblings of CWD showed less empathy, kindness, and involvement and more avoidance. In addition, we discovered father's perceived female siblings were more empathetic, again perhaps attributed to females generally showing more empathy than males. For example, Labay and Walco, (2004) found higher levels of empathy, especially in sisters of children with cancer. Our results found siblings of older CWD were perceived as less empathetic and less involved. These findings were similar to Bischoff and Tingstrom (1991), who discovered more negative behaviors in older siblings because of the increase in responsibility and higher parental expectations and demands when there is a CWD in the home compared to families with TDC.

We also discovered that when raising a child with autism, no matter the level of fathers' burden, the level of sibling avoidance did not change. However, in families of TDC, fathers with higher levels of burden rated siblings higher on avoidance than did fathers with lower level of burden. Perhaps children with autism generally require more care compared to TDC, so no matter how burdened a father may be, sibling avoidance stayed the same; whereas, in families of TDC, the higher the father's burden, the more siblings avoided the TDC because they were affected by the fathers' burden. These findings support previous research suggesting when parents are stressed (burdened); siblings demonstrate negative behaviors (Emerson, 2003; Neece & Baker, 2009), and excessive levels of parent distress adversely affect the well-child (Plant & Sander, 2007).

Conclusion

In summary, mothers of CWD experienced more burden than fathers, although no differences were found for parents of TDC, perhaps because fathers spend less time caring for the CWD than mothers. Mothers felt female siblings showed more kindness and involvement than male siblings and perceived older siblings as having more avoidant relationships with the CWD than younger siblings. Fathers' perceived older siblings as being less involved, and the older the CWD, the less empathetic the sibling was. Both parents rated female siblings as more empathetic than male siblings, and the older the sibling, the less involved they were.

There were differences in sibling relationships according to type of disability. Parents raising children with MD, DS, or autism rated sibling kindness significantly higher than parents of TDC. However, parents of children with OD rated sibling kindness significantly lower than parents of DS or MD.

There were also differences in sibling relationships, depending on the amount of caregiver burden and type of disability. When mothers rated themselves as having higher levels of burden, sibling involvement with children with OD was lower; however, levels of involvement of siblings with TDC was about the same at higher and lower levels of burden. For fathers, when caregiver burden was higher, the level of sibling avoidance in children with autism was about the same as when caregiver burden was lower. However, fathers rated avoidance higher in siblings of TDC when levels of burden were higher.

Finally, even after controlling for a number of variables, we discovered a relationship between caregiver burden and sibling relationships. For both parents, caregiver burden was negatively related to sibling kindness, empathy, and involvement, but was positively related to avoidance.

Limitations and Directions for Future Research

Study results verify that caregiver burden is associated with sibling relationships; however, several limitations need consideration. First, parents volunteered to participate, were from the same geographic area, primarily Caucasian, mostly middle class, well-educated, and from two-parent families. The project was also cross sectional rather than longitudinal. Consequently, we were unable to determine if caregiver burden and sibling relationships change over time. We were also unable to determine the direction of effect since sibling relationships may in fact impact caregiver burden.

Although this research is informative, future work should use a more ethnically diverse sample from a different geographic area and follow them longitudinally. It would also be helpful to gather information on how many hours per day each parent spends with siblings and the CWD and what each does during these interactions. It would be important to gather qualitative data from parents and siblings and then compare perceptions about living with or raising a CWD regarding sibling relationship and caregiver burden across disability type. Finally, future research is needed to untangle the direction of effects: does caregiver burden affect sibling relationships or do sibling relationships affect caregiver burden?

Implications

Information attained from this study can be helpful for families raising a CWD by providing education about sibling relationships in these families and their relationship with caregiver burden. It would also be important to educate parents about relieving their caregiver stress, including resources available, to help them provide care for the CWD. For the most part, sibling relationships in families raising a CWD can be positive, but parents need to be aware that as siblings age, they may be less involved and empathetic toward the CWD because they may

spend more time in school activities and with friends. Finally, since mothers experience the most burden from raising a CWD, they should be relieved of these responsibilities periodically to help decrease stress, and fathers encouraged to participate in care more often, since when fathers are involved in care, mothers experience less emotional distress and family functioning improves (Gavin & Wysocki, 2006).

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Table 1***Participant Characteristic***

<u>Variable</u>	<u>Mean</u>	<u>Standard Deviation</u>	<u>Range</u>
Mothers' age in years	40.17	7.40	26-66
Fathers' age in years	41.99	7.73	29-67
Child with disability age in years	8.91	3.50	0-22
Sibling age in years	10.88	3.70	4-25
Mothers' years of education	15.14	2.05	11-15
Fathers' years of education	15.91	2.55	5-26
Mother's hours work per week	13.45	16.25	0-80
Fathers' hours work per week	44.66	11.48	0-80
Number of children in family	3.98	1.96	1-13

Table 2

Descriptive Statistics

	Typically Developing	Autism	Down Syndrome	Other Disabilities	Multiple Disabilities
	Mean (<i>SD</i>)	Mean (<i>SD</i>)	Mean (<i>SD</i>)	Mean (<i>SD</i>)	Mean (<i>SD</i>)
Caregiver burden					
Hassle					
Father	1.76 (.44)	1.92 (.49)	1.56 (.42)	1.77 (.46)	1.63 (.53)
Mother	1.82 (.39)	2.16 (.61)	1.93 (.52)	1.98 (.53)	2.11 (.69)
Sibling relationship					
Kindness					
Father	3.21 (.56)	3.56 (.73)	3.73 (.44)	3.38 (.46)	3.95 (.55)
Mother	3.15 (.57)	3.59 (.73)	3.76 (.54)	3.33 (.61)	3.78 (.53)
Avoidance					
Father	1.79 (.59)	1.94 (.70)	1.70 (.52)	1.64 (.43)	1.66 (.44)
Mother	1.79 (.54)	2.01 (.78)	1.68 (.56)	1.77 (.51)	1.75 (.60)
Involvement					
Father	3.42 (.56)	3.40 (.79)	3.70 (.74)	3.35 (.62)	3.52 (.79)
Mother	3.44 (.64)	3.28 (.96)	3.52 (.55)	3.51 (.64)	3.32 (.77)
Empathy					
Father	3.29 (.69)	3.79 (.86)	4.24 (.58)	3.81 (.56)	4.22 (.59)
Mother	3.97 (.73)	3.99 (.86)	4.38 (.49)	3.90 (.70)	4.24 (.61)

Table 3*Correlations Among Sibling Relationship Subscales for Mothers and Fathers*

	Avoidance	Empathy	Kindness	Involvement
Avoidance		-0.62	-0.65	-0.55
Empathy	-0.54		0.74	0.73
Kindness	-0.64	0.73		0.64
Involvement	-0.57	0.64	0.48	

All correlations significant at $p < .001$ level

Mothers' ratings below the diagonal; Fathers' ratings above the diagonal

Table 4*Correlations Between Caregiver Burden and Sibling Relationships*

	Kindness	Empathy	Involvement	Avoidance
<i>Fathers</i>				
Hassle Of Burden	-.27 ^a	-.40 ^a	-.29 ^a	0.23 ^a
<i>Mothers</i>				
Hassle Of Burden	-.25 ^a	-.17 ^b	-.19 ^b	0.32 ^a

a < .01. *b* < .05.

Table 5

Mothers' Ratings of Caregiver Burden and Sibling Outcomes

Model 1												
	Kindness			Empathy			Involvement			Avoidance		
	<i>B</i>	β	<i>R</i> ²	<i>B</i>	β	<i>R</i> ²	<i>B</i>	β	<i>R</i> ²	<i>B</i>	β	<i>R</i> ²
Burden	-.31	-.27 ^a	.16	-.22	-.17 ^c	.14	-.27	-.21 ^b	.17	.34	.31 ^a	.30
CWD age	-.03	-.15		-.03	-.17		-.03	-.14		.02	.12	
Sibling age	-.01	-.04		.01	.02		-.04	-.15		.07	.34 ^a	
Sibling sex	.25	.19 ^c		.39	.27 ^a		.39	.26 ^a		-.09	-.07	
Aut	.21	.14		-.07	-.04		-.03	-.02		.11	.08	
DS	.32	.18 ^c		.24	.12		.21	.10		-.13	-.08	
MD	-.45	-.13		-.15	-.04		-.45	-.12		.45	.14	
Other	.08	.05		-.07	-.04		.16	.09		-.14	-.09	
Model 2												
Burden	-.07	-.06	.19	-.19	-.15	.15	-.10	-.08	.20	.29	.27 ^c	.30
CWD age	-.03	-.18		-.04	-.19 ^c		-.04	-.18 ^c		.02	.13	
Sibling age	-.01	-.04		.01	.03		-.03	-.14		.07	.34 ^a	
Sibling sex	.23	.18 ^c		.40	.28 ^a		.43	.29 ^a		-.09	-.08	
Aut	.21	.14		-.07	-.04		-.05	-.03		.12	.08	
DS	.30	.16		.25	.12		.20	.10		-.13	-.07	
MD	-.44	-.13		-.17	-.05		-.51	-.13		.45	.14	
Other	.07	.04		-.03	-.02		.22	.12		-.15	-.10	
Aut x Burden	-.43	-.20		-.03	-.01		-.02	-.01		.06	.03	
DS x Burden	-.38	-.13		.18	.05		-.36	-.10		.08	.03	
MD x Burden	.12	.02		.32	.05		.58	.09		-.18	-.03	
Other x Burden	-.37	-.13		-.36	-.12		-.77	-.25 ^c		.16	.06	

a < .001, b < .01, c < .05

Aut = Autism; DS = Down Syndrome; MD = Multiple Disabilities; Other = Other Disabilities

Table 6

Fathers' Ratings of Caregiver Burden and Sibling Outcomes

Model 1	Kindness			Empathy			Involvement			Avoidance		
	<i>B</i>	β	<i>R</i> ²	<i>B</i>	β	<i>R</i> ²	<i>B</i>	β	<i>R</i> ²	<i>B</i>	β	<i>R</i> ²
Burden	-.40	-.29 ^a	.13	-.60	-.39 ^a	.26	-.46	-.30 ^a	.19	.31	.25 ^b	.16
CWD age	-.03	-.15		-.04	-.22 ^c		-.03	-.16		.02	.14	
Sibling age	-.01	-.01		.01	.04		-.05	-.19 ^c		.03	.13	
Sibling sex	.11	.09		.26	.18 ^c		.23	.16		.03	.03	
Aut	.18	.13		-.03	-.02		.12	.08		.07	.06	
DS	.24	.14		.28	.14		.29	.15		-.11	-.07	
MD	-.12	-.03		-.04	-.01		-.33	-.08		.39	.12	
Other	-.03	-.02		-.07	-.04		.04	.02		-.24	-.16	
Model 2												
Burden	-.66	-.49 ^a	.16	-.77	-.49 ^a	.27	-.62	-.41 ^b	.22	.54	.43 ^b	.20
CWD age	-.03	-.17		-.05	-.24 ^c		-.03	-.17		.03	.16	
Sibling age	-.01	-.01		.01	.05		-.05	-.19		.02	.12	
Sibling sex	.10	.08		.27	.19 ^c		.23	.16		.03	.03	
Aut	.16	.11		-.05	-.03		.07	.05		.10	.08	
DS	.25	.14		.32	.16		.26	.13		-.13	-.08	
MD	-.12	-.04		-.05	-.01		-.35	-.09		.40	.12	
Other	-.01	-.01		-.04	-.02		.07	.04		-.27	-.19	
Aut x Burden	.55	.24		.36	.13		.49	.19		-.52	-.24 ^c	
DS x Burden	.12	.03		.26	.06		-.19	-.04		-.14	-.04	
MD x Burden	.67	.07		.31	.03		.63	.06		-.83	-.10	
Other x Burden	.30	.08		.07	.02		.06	.01		-.16	-.05	

a < .001, b < .01, c < .05

Aut = Autism; DS = Down Syndrome; MD = Multiple Disabilities; Other = Other disabilities

Figure 1

Interaction between Caregiver Burden and Disability for Mother Ratings of Sibling Involvement

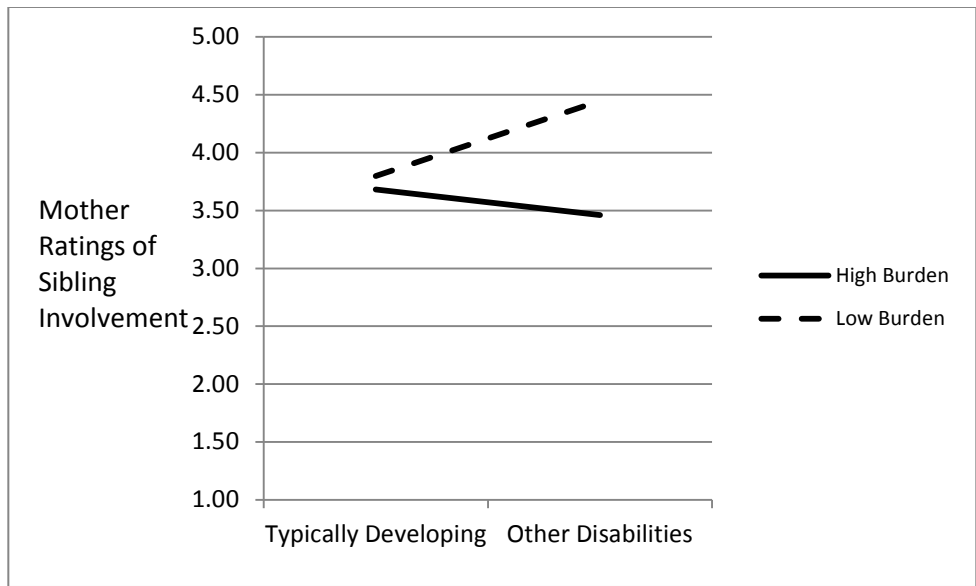
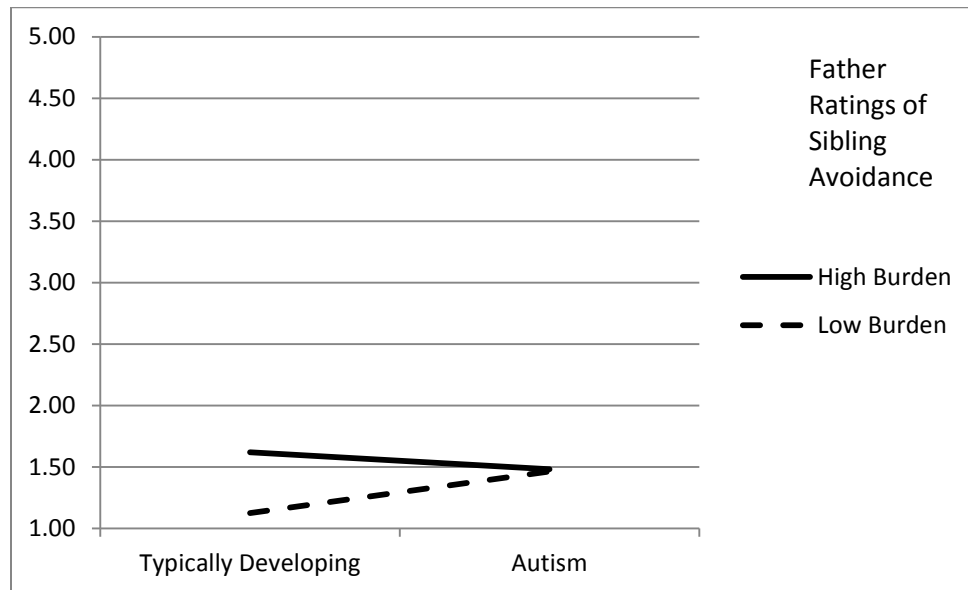


Figure 2

Interaction between Caregiver Burden and Disability for Father Ratings of Sibling Avoidance



Appendix A: Caregiver Burden Questionnaire

Parent Part I

Mother ID#_____

Below is a list of typical everyday events that parents may encounter: Thinking of what it takes to raise all the children in your family, for each item, circle how frequently this generally occurs and then how much of a hassle you find it.

	<u>How Frequently</u>				<u>How Much of A Hassle</u>			
	1	2	3	4	1	2	3	4
1. Feeling that my time is not my own. Care of my children interferes with house work, employment, family life, hobbies, or other outside interests, etc.	1	2	3	4	1	2	3	4
2. Feeling overwhelmed at all there is to do in caring for my children.	1	2	3	4	1	2	3	4
3. Feeling financial strain involved in caring for my children.	1	2	3	4	1	2	3	4
4. Feeling that I need to change my plans in order to fulfill my children's needs.	1	2	3	4	1	2	3	4
5. Feeling that my children are a source of joy to me.	1	2	3	4	1	2	3	4
6. Feeling that I don't have time to maintain my physical health due to caring for my children (e.g., exercise, eat right).	1	2	3	4	1	2	3	4
7. Feeling that rearing my children brings me closer to my spouse (or ex-spouse where applicable.)	1	2	3	4	1	2	3	4
8. Feeling that my children provide stimulation and learning for me.	1	2	3	4	1	2	3	4
9. Feeling emotionally drained due to caring for my children-- emotionally frazzled and worn out.	1	2	3	4	1	2	3	4

- | | | | | | | | | |
|--|---|---|---|---|---|---|---|---|
| 10. Feeling that rearing my children created more conflict and arguments with significant others (e.g., my parents, friend, etc.). | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 11. Feelings of isolation—No one understands what I am going through in raising my children. | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 12. Feeling that my children teach me wonderful and worthwhile things. | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 13. Feeling that my children get along with each other well (in cases where there is more than one child). | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 14. Experiencing loss of sleep due to meeting my children's needs. | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 15. Feeling physically drained by caring for my children (e.g., bathing, feeding, cleaning, etc.). | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 16. Feeling that caring for my children is an inconvenience. | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 17. Feeling that my personal growth is enhanced because of caring for my children. | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 18. Feeling that rearing my children creates more conflicts with my spouse (or ex-spouse where applicable). | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 19. Feeling that rearing my children brings me closer to significant others (e.g., my parents, friends, etc.). | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 20. Feeling that my children don't get along with each other well (in cases where there is more than one child). | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |

Appendix B: Sibling Relationships Questionnaire

Think about the behavior of one of your children who does not have a disability.

Please write the number that indicates how often the *CHILD WITHOUT A DISABILITY* behaves toward the child with the disability in the way described.

1	2	3	4	5
Never	Seldom	Sometimes	Often	Always
____(1)	Is pleased by progress he/she makes.			
____(2)	Shows or tells him/her interesting things.			
____(3)	Teases or annoys him/her.			
____(4)	Helps him/her in any way possible.			
____(5)	Gets angry with him/her.			
____(6)	Accepts him/her as a playmate.			
____(7)	Is embarrassed to be with him/her in public.			
____(8)	Wants him/her to succeed.			
____(9)	Stays away from him/her if possible.			
____(10)	Gets ideas for things they can do together.			
____(11)	Does things to please him/her.			
____(12)	Fusses and argues with him/her.			
____(13)	Has fun at home with him/her.			
____(14)	Acts shamed of him/her.			
____(15)	Shows sympathy when things are hard for him/her.			
____(16)	Frowns or pouts when he/she has to be with him/her.			
____(17)	Teaches him/her new skills.			
____(18)	Says unkind things to him/her.			

- ____(19) Helps him/her adjust to new situations.
- ____(20) Treats him/her as a good friend.
- ____(21) Tries to avoid being seen with him/her.
- ____(22) Is concerned for his/her welfare and happiness.
- ____(23) Would rather be alone than to play with him/her.
- ____(24) Makes plans that include him/her.
- ____(25) Hurts his/her feelings.
- ____(26) Tries to comfort him/her when he/she is unhappy or upset.
- ____(27) Complains about the trouble he/she makes.
- ____(28) Is glad to have him/her in the family.

Appendix C: Demographic questionnaire

1. Today's Date _____
2. Family ethnicity _____
3. How/where family was recruited _____
4. Ethnicity of child with disability/chronic condition (if different from family) _____
5. Child with disability/chronic condition's birth date _____ Age _____ Gender _____
6. Name of sibling who is participating in the study _____
7. Sibling's birth date _____ Age _____ Gender _____

First names of all other children in your family (do not include sibling listed above or child with a disability/chronic condition).

<u>Name</u>	<u>Male/Female</u>	<u>Age</u>	<u>Birth date (Month/Day/Year)</u>

8. Family composition: (circle one)
 - a. Two Parent Family
 - d. Other Family Type _____
 - b. Single Parent Family
 - e. Other adults besides parent living at home? Yes No
 - c. Step Parent Family
 - f. If yes, who? _____
9. Age of parents: _____ Father _____ Mother
10. How many years of education has husband completed? _____ years
11. How many years of education has wife completed? _____ years
12. What is husband's current occupation? (job title) _____

Please briefly describe husband's duties _____

13. What is wife's current occupation? (job title) _____

Please briefly describe wife's duties _____

14. If husband has been employed outside of the home during this past year, has the employment generally been full time or part time? _____

15. _____ Number of hours husband works per week.

16. If wife has been employed outside of the home during this past year, has the employment generally been full time or part time? _____

17. _____ Number of hours wife works per week.

18. _____ Husband's religious preference.

19. _____ Wife's religious preference

20. What is your total family income?

- a. Under \$7,000
- b. \$7,000-\$15,000
- c. \$15,001-\$25,000
- d. \$25,001-\$35,000
- e. \$35,001-\$50,000
- f. \$50,001-\$75,000
- g. \$75,000-\$100,000
- h. Over \$100,000

Please describe your child's disability
