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Is approved by the final examining committee:

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THE PSYCHOSOCIAL OUTCOMES OF ADULT SIBLINGS OF ADULTS WITH AUTISM AND DOWN SYNDROME

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I would like to dedicate this study to my brother, Matthew. I would also like to thank Ben, my parents, and friends for their support and encouragement.

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ABSTRACT

Belkin, Teri M. M.S., Purdue University, December 2013. The Psychosocial Outcomes of Adult Siblings of Adults with Autism and Down Syndrome. Major Professor: John H. McGrew.

Little is known regarding the psychosocial outcomes of adult siblings of adults with autism. Accordingly, the current study sought to: (1) illuminate factors that predict health-related quality of life, caregiver burden, and reported benefits in adult siblings of adults with autism, using a stress and coping framework and (2) compare outcomes of siblings of adults with autism (n = 31) to siblings of adults with Down syndrome (DS) (n = 54). For the within subject hypotheses, analyses were repeated within the DS group and an overall Disability group (n = 97). The Disability group consisted of participants in the Autism and Down syndrome groups plus twelve individuals in a mixed group of adult siblings of adults with DS who presented with co-morbid symptoms of autism.

Variables were organized using The Adult Sibling Caregiver Conceptual Model (ASCCM) into three categories: antecedents (e.g., sibling relationship quality, problem behaviors of the disabled sibling), mediators (e.g., coping strategies, cognitive appraisal types), and psychosocial outcome variables (i.e., mental and physical health-related quality of life, caregiver burden, and reported benefits). For the within subject primary hypotheses, I posited a series of relationships between the antecedents and outcomes based on prior literature on demographic and individual difference predictors (e.g., siblings of adults with autism with fewer problem behaviors would have increased

health-related quality of life [HRQOL], decreased caregiver burden, and increased reported benefits) and on stress and coping factors related to the burden of providing care for an individual with autism (e.g., greater use of avoidant coping strategies would be related to lower HRQOL, increased caregiver burden, and decreased reports of benefits). Exploratory hypotheses also were examined (e.g., being married would be associated with increased HRQOL, decreased burden, and increased reported benefits).

The within-subject results indicated support for eight of the ten primary hypotheses and five of the six exploratory hypotheses when examined within at least one of the study groups: Autism, DS, or Disability. Overall, sibling caregivers, regardless of their sibling's disability, reported more favorable psychosocial outcomes when demands were lower (e.g., less severe levels of problem behaviors, fewer autism symptoms exhibited by their disabled sibling, decreased additional pile-up stress), when resources were available to cope with stress (e.g., social support, respite care), and when healthy responses to stress were reported (e.g., use of emotion focused vs. avoidant coping strategies, use of challenge vs. threat appraisal types). Of note, reported benefits, which have rarely been examined in the autism literature, were strongly related to the quality of a sibling relationship across all study groups, and with the helpfulness of received services and perceived social support within the Autism group.

The between subject hypotheses also were largely supported. As expected, compared to siblings of those with Down syndrome, siblings of those with autism demonstrated greater levels of caregiver burden and lower mental HRQOL. Moreover, there was a rank ordering in levels of caregiver burden across disability groups; siblings of adults with DS reported the lowest burden, siblings of adults with DS with symptoms of autism reported significantly higher levels of burden, and siblings of those with autism

reported the most burden. The results imply that autism, either alone or co-morbid with another diagnosis, presents an increased risk of stress and caregiver burden, not only in parent caregivers, but also in sibling caregivers. Interestingly, there was also evidence for higher levels of stress related growth within the Autism group compared to the DS group. Future research will be needed to generalize the results of this study to broader samples of adult siblings while taking a life course perspective to assess changes in non-disabled siblings' outcomes over time.

INTRODUCTION

As noted by more than one observer, “few disorders in children pose a greater threat to the psychosocial well-being of families than autism because the behavioral characteristics of this disorder tax even the strongest family systems” (Seltzer et al., 2005, p. 357). However, little is known regarding the psychosocial effects of autism on typically-developing adult brothers and sisters who have an adult sibling with autism spectrum disorder (ASD) (Orsmond & Seltzer, 2007). Even less is known regarding how these psychosocial effects change across the lifespan as both siblings in a dyad progress through stages of development in adulthood. For example, the sense of responsibility for one’s sibling with ASD is likely to increase as parents are no longer able to assist with caretaking responsibilities (Orsmond et al., 2009).

Because parent caregivers cannot expect to outlive their child or craft detailed plans sufficient to direct care for the entire span of their child’s life, they often turn to siblings and other relatives for support to fulfill the caregiving responsibilities (Bigby et al., 2011). It is important to understand how typically developing adult siblings of individuals with autism adjust and cope with these stressors. Accordingly, the current study examined the psychosocial outcomes associated with being the adult sibling of an adult with autism.

The study adopted a framework that built on the stress and coping model of Lazarus and Folkman (1984), the Double ABCX model of stress (McCubbin & Paterson, 1983), and the Family Caregiver Conceptual Model (McDonald et al., 1992) to identify the factors associated with psychosocial outcomes of adult siblings who may be providing care for their adult sibling with autism. In addition to examining these outcomes in adult siblings of adults with autism, to provide a reference point, the psychosocial outcomes of adult siblings of adults with Down syndrome were assessed (e.g., Orsmond & Seltzer, 2007; Hodapp & Urbano, 2007).

Autism Spectrum Disorders

Autism has been classified as a neurological disorder that results in communicative, sensory, behavioral, and social challenges (Centers for Disease Control and Prevention, 2011). Autism is one of three disorders subsumed under the category of autism spectrum disorder (ASD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994). ASD also includes Asperger syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS) (Ferraioli & Harris, 2010). If some, but not all, of the criteria required to diagnose autism is present, a child may be diagnosed with PDD-NOS. If a child’s language skills are developed and there is no intellectual disability, but autistic behaviors are present, Asperger syndrome may be diagnosed.

Autism was first proposed as a diagnostic syndrome in 1943 by Leo Kanner (1943). In 1966, the prevalence rate of autism in England and Wales, the United States, and Denmark was reported as 4.5 per 10,000 (Wazana et al., 2007). In 2004 and 2011, the Centers for Disease Control and Prevention (CDC) reported prevalence rates of 1 in 166 and 1 in 110 respectively, in the United States. In 2011, the CDC reported that 730,000 individuals under the age of 21 were classified with ASD. Given the dramatic increase in adults with ASD and children with ASD who will one day enter adulthood, together with the likelihood of lifelong disability and need for care, it is important to understand the stressors and psychosocial impacts on sibling caregivers.

Brief Synopsis of the Relevant Literature

Siblings of children with PDD tend to demonstrate more psychological adjustment difficulties over time than do siblings of children with Down syndrome or no disability (Fisman et al., 2000). For example, siblings of children with autism tend to have poorer social and emotional outcomes and display greater anxiety compared to children of typically developing siblings (Macks & Reeve, 2007). However, siblings of children with autism may display higher levels of self-concept and hold more positive views of their own behavior and intellect. A number of factors have been associated with adjustment difficulties in siblings of children with autism, including sibling, child, and family factors. For example, the severity of autistic siblings' symptoms, the amount of parents' involvement in siblings' education, stressful life events, and the quality of family climate all are significant predictors of sibling adjustment (Benson & Karlof, 2008).

Current research on the adjustment of siblings of children with ASD suffers from several methodological challenges (Hodapp et al., 2007). One challenge is small sample sizes. Some studies included as few as 20-50 participants per group, which may limit a study's power (Cohen, 2002). Another concern is the use of different control-contrast groups (e.g., typically developing vs. physical disability vs. intellectual disability), which makes it difficult to accurately cross-compare results across studies (Meadan et al., 2010). A further limitation is that few studies have examined siblings of individuals with autism as they leave their childhood homes to begin their adult lives and start families of their own. As parents of those with autism age, their non-disabled adult children may face new demands and caregiving responsibilities. Simultaneously, additional resources may become available to provide social and/or financial support and assist non-disabled siblings in coping with the stress of caregiving, resulting in positive adaptive outcomes.

In addition, potential problems with the sampling procedures of prior studies may limit the ability to generalize results to different populations. For example, the literature tends to be culturally homogenous. That is, most studies of siblings of adults with ASD have come from English-language journals and have targeted participants of European and American heritage (Heller & Arnold, 2010). A similar problem of restricted range is inherent in the increasingly common use of internet studies on sibling caregivers, which tend to draw from those with a higher socioeconomic status (SES) who have greater access to computers. It is also possible that siblings who are informants in these studies are typically the involved siblings in their family. This may leave out important information about the less-involved or less-educated siblings. These sample biases could result in inaccurate appraisals of the adult sibling relationship.

Theoretical Framework

The next section outlines three useful models for studying adult siblings who may be providing care for their disabled sibling. None has been explicitly formulated for the study of adult sibling caregivers. I will propose an adapted model, the "Adult Sibling Caregiver Conceptual Model," to study the outcomes of sibling caregivers in adulthood.

Three Stress and Coping Models in the Literature

The Stress and Coping Model: Lazarus and Folkman (1984)

According to this seminal model, stressful experiences are conceptualized as "person-environment transactions." External demands (stressors) are mediated by an individual's appraisal of the stressor (primary appraisal) and the resources that are available to him or her to cope with the stressor in determining whether an individual experiences stress (Glanz et al., 2002, p. 213). When stressors become chronic, they can affect one's sympathetic nervous system and endocrine functions, resulting in the progression of health problems such as cancer, infectious diseases, and HIV/AIDS (Robles et al., 2005).

Lazarus and Folkman's model has been used to study a number of populations including: individuals with HIV/AIDS and their caregivers, patients with post traumatic stress disorder (PTSD), cancer, and rheumatoid arthritis, nurses who work within an intensive care unit, caregivers and parents of preterm infants, children with disabilities, and dementia patients (Roesch et al., 2001).

The Double ABCX Model: McCubbin and Patterson (1983)

The Double ABCX Model expands on Hill's earlier models (1949, 1958) of family stress. The model examines the interaction between stress, coping, and adaptation. According to this model, a stressor event (Factor A), interacts with a family’s resources (Factor B), and the family’s interpretation of an event (Factor C) in determining whether a family will experience a “crisis” (Factor X) (McDonald et al., 1992). The Double ABCX Model of Family Adjustment and Adaptation states that stressors are unfolding events that accumulate across three stages: the initial event of a crisis, resulting changes in the family's life and experiences, and efforts expended by families to cope with their stress (McDonald et al., 1992, p. 9). The ABCX model has been utilized to study how family members adapt to the diagnosis of ASD and other developmental disorders. For example, the model has influenced studies that investigated the stress of parents of children with intellectual disabilities (ID; Salovilita et al., 2003) as well as parents of children who were recently diagnosed with ASD (Stuart & McGrew, 2009).

The Family Caregiver Conceptual Model: McDonald, Donner, and Poertner (1992)

McDonald and colleagues built on the work of Behr (1989) to develop the Family Caregiver Conceptual Model (McDonald et al., 1992). Their unpublished model was influenced by both the Cognitive Appraisal Model of Stress and Coping (Lazarus & Folkman, 1984) and the Double ABCX Model (McCubbin & Patterson, 1983). While the Cognitive Appraisal Model of Stress and Coping focuses on the individual and the Double ABCX Model focuses on families, McDonald and colleagues utilized aspects of both prior models to create a model to study the effects of providing care for children with disabilities or chronic illnesses. Their purpose was to fully explicate the constructs that impact the caregiving process.

As shown in Figure 1, the Family Caregiver Conceptual Model contains antecedents, mediators, and outcome variables. The model predicts that the familial characteristics of those with a chronic illness, including the characteristics of the primary caregiver and child with disability, will be mediated by coping skills and cognitive appraisal strategies to predict caregiving outcomes. Adaptive outcomes of both the primary caregiver as well as the child with the disability are examined in McDonald et al.'s model. Caregiver outcomes such as life satisfaction, somatic health, social functioning, financial security, and children's outcomes such as living arrangements, school attendance, and participation in the community may be assessed (see Figure 1).

The Adult Sibling Caregiver Conceptual Model

The current study will adapt the Family Caregiver Conceptual Model (McDonald et al., 1992) to examine the psychosocial outcomes of adult siblings of adults with autism and Down syndrome (see Figure 2). Although the core components of McDonald et al.'s conceptual model will remain the same, the specific variables included to assess antecedents, mediators, and outcome variables will be modified to be consistent with the current literature on autism and Down syndrome. The proposed Adult Sibling Caregiver Conceptual Model (ASCCM) will provide a framework for understanding and assessing the relationships between antecedent variables, their mediators, and the resulting psychosocial outcomes of typically developing adult siblings. As discussed in the following sections, to provide a more comprehensive assessment of impact, I proposed to examine 3 psychosocial outcomes: health-related quality of life, caregiver burden, and benefit finding (i.e., reported benefits of the sibling relationship or providing care for a disabled sibling). The next section briefly reviews the rationale and empirical data supporting the inclusion of each proposed model variable (see Tables 1 and 2 for a list of all ASCCM variables).

Adult Sibling Caregiver Conceptual Model Variables

Antecedent Variables

McDonald et al. (1992) included six antecedent categories in their model: Family Characteristics/Resources, Child (w/ Emotional Disability) Characteristics/Resources, Primary Caregiver Characteristics/Resources, Available Informal Supports (Services), Available Informal (Social) Services, and Other Community Characteristics/Resources. The Adult Sibling Caregiver Conceptual Model (ASCCM) proposes a total of five antecedent categories. In the ASCCM, the categories of “Available Informal Supports (Services)” and “Available Informal (Social) Services” were combined to create the category labeled “Caregiving (Caregiver) Resources”. Instead of assessing “Other Community Characteristics/Resources”, a new antecedent variable was added to the model: “Caregiving (Caregiver) Additional Demands”. The five antecedent categories of the ASCCM are comprised of 13 sub-components (antecedent variables), which are presented with their inclusion rationale in the following paragraphs. Ten of the antecedent variables were included in the ASCCM as primary hypotheses and three were incorporated into the model as exploratory hypotheses.

1) Family (Sibling Dyad) Characteristics

The ASCCM proposed that family characteristics such as having one or more additional non-disabled siblings in the family, quality of an adult sibling relationship, and sibling birth order would influence the psychosocial outcomes of non-disabled adult siblings in adulthood. The three Family (Sibling Dyad) Characteristics hypotheses (two primary and one exploratory) are listed in Tables 3 and 5, alongside the other primary and exploratory hypotheses (Tables 3, 4, and 5).

AH1.A) Number of Non-Disabled Siblings in the Family

There is little empirical data on whether having more non-disabled siblings in the family who are willing to take on caregiving responsibilities for an adult with autism affects a caregiver's psychosocial outcomes, although it is logical that demands should be reduced for an individual when they can be distributed across multiple persons. Consistent with this belief, it has been found that typically developing siblings view their relationship with their sibling with autism more positively when they are part of a larger family (McHale et al., 1986). Moreover, typically developing siblings seem to be at greater risk of maladjustment when their only sibling has ASD. In larger families, the burden may be more easily shared and attention from other siblings can also help to compensate for any reduction in parental attention (Howlin, 1988). The current study hypothesized that more non-disabled siblings in a family would increase a sibling caregiver's health-related quality of life and reported benefits, and decrease his/her caregiver burden.

AH1.B) Sibling Relationship Quality

Adults with chronic disabilities including autism and Down syndrome may lack functional life skills and cannot always perform activities of daily living (ADLs) independently. They may require help from sibling caregivers with their social, physical, and financial needs, which can result in unbalanced sibling relationships in adulthood. This inequality between siblings tends to increase as they age. Thus, when relationships between siblings of individuals with and without chronic disabilities were compared to one another, it was found that the sibling relationship becomes less reciprocal and more focused on the non-disabled sibling assuming some level of responsibility for the brother or sister with lifelong disability (Dallas et al., 1993). Other studies have replicated these results; typically developing siblings' provision of instrumental and emotional support in adulthood may not be fully reciprocated by their disabled sibling (Seltzer et al., 1991).

Studies also have compared the adult sibling relationships between siblings of individuals with intellectual disability (ID) and mental illness (MI). Adult siblings of individuals with ID tend to maintain high levels of involvement with their brothers and sisters across the life course (Orsmond & Seltzer, 2000; Pruchno, et al., 1996) and are more involved with their families of origin throughout their lives, while siblings of individuals with MI do not share this solidarity because their feelings of obligation towards their sibling do not usually begin in childhood (Taylor et al., 2008).

The current study explored if the quality of adult sibling relationships affected the psychosocial outcomes of typically developing adult siblings of individuals with autism and Down syndrome. Although there is little direct empirical evidence, theoretically, the quality of the relationship was thought to be related to caregivers' willingness to provide care and their felt sense of burden when providing care. Thus, it was hypothesized that a greater satisfaction with a sibling relationship would predict more positive psychosocial outcomes for a non-disabled adult sibling

EH.5) Sibling Birth Order

Research indicates that siblings of individuals with ASD are better adjusted if they are older than their affected siblings (Hastings, 2003b; McHale et al., 1986). Siblings who are younger than their impaired sibling may suffer more psychologically than siblings who are older, possibly because they do not get the "exclusive" caretaking time that should be reserved for them because parents are busy with their disabled sibling (Howlin, 1988). The current study sought to determine whether birth order affects typically developing adult siblings' psychosocial outcomes in adulthood. An exploratory hypothesis predicted that siblings who were older than their disabled sibling would report greater adjustment (which was measured using health-related quality of life as a proxy). No hypotheses were made regarding the affects of sibling birth order on reported benefits and caregiver burden.

2) Adult Sibling (Caregiver) Characteristics

The characteristics of typically developing adult sibling caregivers (e.g., gender, marital status, and age/developmental life stage) were predicted to influence caregiver outcomes and are discussed below. The one primary and two exploratory Adult Sibling (Caregiver) Characteristics hypotheses are listed in Tables 3 and 5.)

AH2.A) Gender of the Adult Sibling Caregiver

The gender of non-disabled adult sibling caregivers may predict their psychosocial adjustment. Sisters in particular, tend to play a more supportive role within their sibling relationship than brothers do (Orsmond & Seltzer, 2000; Seltzer et al., 1991) and are more likely to expect to provide future care for their adult sibling (Krauss et al., 1996, as cited by Seltzer et al., 2005). Seltzer and colleagues (2005) surveyed families and reported that sisters were more likely to expect to co-reside with their sibling who had a disability than were brothers.

There are also gender differences in levels of adjustment. A cross-sectional exploratory study compared the adjustment scores of child siblings of individuals with disabilities to scores of a normative sample (Hastings, 2003). Siblings of children with disabilities had greater adjustment problems and lower levels of pro-social behavior than the normative sibling group. Somewhat surprisingly, despite the increased caregiving roles, Hastings found that female siblings were better adjusted than male siblings. However, it was unclear if this result would still be obtained for siblings of adults with autism. Nevertheless, in the current study, it was hypothesized that adult sisters would report better psychosocial outcomes than would adult brothers.

EH.3) Age and Developmental Life Stage of the Adult Sibling Caregiver

The typically developing adult sibling's developmental life stage may impact his or her ability to provide care for his/her sibling with autism. For example, current demands (e.g., pile-up demands), as well as the social and financial resources present to cope with them, are likely dependent on one's developmental life stage.

In a large Taiwan-based study, it was demonstrated that the ages of caregivers of persons with ID (over the age of 55 or under the age of 55) influenced the caregivers' outcomes (Chou et al., 2009). Parent caregivers of older individuals with ID were more likely to have poor health, a low level of education, and to be a single parent (Chou et al., 2009). They also reported lower quality of life and less social support than younger caregivers did. The authors' conclusions were consistent with findings from studies conducted in Westernized cultures; older caregivers tended to have worse outcomes (Haveman et al., 1997; Hong et al., 2001; Krauss & Seltzer, 1993).

"Developmental life stage of the adult sibling caregiver" was an exploratory antecedent variable in the current study and was measured by using age as a proxy. I examined whether a caregiver's level of burden increases and his/her health-related quality of life decreases as he/she ages. The relationship between a caregiver's age and his/her level of reported benefits was also explored, although no a priori hypothesis was proposed.

EH.4) Marital Status of the Adult Sibling Caregiver

There is evidence that having a sibling with a disability may influence one's marital status. Women who are under the age of 45 and have a brother or sister with a developmental disability tend to marry and have children later than those in the typical population do (Hodapp & Urbano, 2007; 2010). However, they are just as likely to be married by mid and later adulthood. Seltzer and colleagues (2001) also reported that compared to siblings of individuals with Down syndrome, siblings of adults with autism are less likely to be married (Seltzer et al., 2001).

Although there is evidence that having a sibling with ASD or Down syndrome may influence the marital status of a non-disabled adult sibling, little is known concerning *how the marital status* of a non-disabled sibling will affect his/her psychosocial outcomes in adulthood. Given that married siblings have the additional support of a spouse, it is possible that when compared to unmarried adult siblings, married adult siblings will report increased quality of health, decreased caregiver burden, and increased benefits in their sibling relationship due to the additional support that may be provided by their life partner. These relationships were examined as exploratory hypotheses.

3) Adult with Autism/Down Syndrome (Caregivee) Characteristics

The four chosen characteristics of the disabled sibling (possible caregivee) with autism or Down syndrome (severity of autism symptoms, problem behavior, adaptive behavior, and age/developmental life stage) are discussed below. Three of the four variables (severity of autism symptoms, problem behaviors, and adaptive behavior) were hypothesized to affect a caregiver's psychosocial outcomes. (The three primary Adult with Autism/Down Syndrome (Caregivee) Characteristics hypotheses are listed in Table 3).

AH3.A) Severity of Autism Symptoms

The severity of one's autistic symptoms may impact the sibling relationship and a typically developing sibling's willingness to provide care. A study by Ingersoll and Hambrick (2011) found that child symptom severity was positively correlated with stress and depression in parents of children with ASD. Symptom severity has been associated with increased individual and family burden in a prior study (Stuart & McGrew, 2009). The current study hypothesized that an increase of autism symptoms would result in decreased health-related quality of life, fewer reported benefits, and increased caregiver burden in non-disabled adult siblings.

Problem Behavior (AH3.B) and Adaptive Behavior (AH3.C)

The amount of care that adults with autism or DS require depends to a large extent on their degree of adaptive behavior and functional independence, which may consequently affect caregivers' psychosocial outcomes. Adults with ASD have more unmet needs and behavior problems and are less likely to have residential independence than adults with Down syndrome are (Esbensen et al., 2010). Caregiving demands tend to increase with the number of problem behaviors (PBs) present and with greater limitations in functional independence (adaptive behavior). Problem behaviors such as self-injury or aggression tend to require more intensive monitoring and intervention, adding to overall caregiving demands. Similarly, depending on a disabled sibling's functional limitations, a caregiver may perform a hands-on duty (direct care) or arrange care using an external resource (indirect care). Deficits associated with autistic disorder are in areas of work, self-help, leisure, and hygiene (Matson et al., 2012). Thus, a non-disabled adult sibling may need to directly assist with activities of daily living (ADLs) and bathe, dress, cook for, or shop for his/her sibling with autism or DS. Similarly, if a disabled sibling cannot manage his/her household chores, cannot balance a checkbook, or cannot use public transportation, these tasks also become the responsibility of the sibling caregiver. In addition, a non-disabled sibling may need to assist his/her adult sibling in finding appropriate support services (i.e., speech, occupational, physical, and psychological therapy).

A study surveyed 280 spouses/partners and 243 adult/child caregivers of individuals with chronic illnesses to assess whether assisting with ADLs and PBs was related to levels of caregiver burden. Results found that assisting with ADLs was directly related with objective burden in both groups of caregivers. Moreover, assisting with PBs was related to all dimensions of burden: stress, relationship, and objective burden (Savundranayagam, 2011). In the current study, it was hypothesized that when a disabled sibling has more problem behaviors and fewer independent living skills (lower adaptive behavior) his/her non-disabled sibling would report a lower health-related quality of life, increased caregiver burden, and fewer benefits within the sibling relationship. Greater adaptive behavior was hypothesized to be related to better psychosocial outcomes.

Age/ Developmental Life Stage of the Sibling with Autism or Down Syndrome

Caregivers' outcomes may be associated with the developmental life stage of their sibling with autism. Particularly difficult challenges are likely to be encountered at vulnerable transitions along the disabled sibling's developmental pathway. The changes in available resources and/or the demands of adulthood may present new challenges for individuals with autism and DS and their caregivers. Services that were once provided free of charge for children with disabilities may now cost money, no longer be offered or be offered less often; finances may be stretched as caregivers are planning not only for their loved one's future, but for their own as well. Transitional periods may include: 1.) birth and early childhood, 2.) time of diagnosis, 3.) transition to elementary school, 4.) adolescence and transition to high school, and 5.) adulthood, postsecondary education, independent living, and entering the world of work (Turnbull et al., 2006). It has been recommended that future research explore the stresses of these transitional points and support systems over time in families who have children with autism (Gray, 2006 and Hare et al., 2004, as cited by Meadan et al., 2010). For example, while some children benefit strongly from educational opportunities and develop skill sets that enable them to enter the workplace and/or attend post-secondary school, individuals with more severe autism symptoms and behavior problems may have difficulty supporting themselves and often times become the responsibility of their family members during their adult years. Alternately, external residential placements and services including job coaches or day programs may be sought out when families have the financial resources or educational awareness to do so.

By using age as a proxy for developmental life stage, I explored whether health-related quality of life would decrease and caregiver burden would increase as a disabled sibling ages. Because caregivers' and caregivees' ages are highly correlated, only one exploratory hypothesis was proposed pertaining to age/developmental life stage (EH.3; see Table 5).

4) Caregiving (Caregiver) Resources

The presence or absence of caregiving resources may also impact caregiver outcomes. Three supports have been identified that can act as resources in a caregiving situation: social support, respite care, and formal supports (Meadan et al., 2010). Social supports are non-paid supports to the non-disabled adult sibling, including emotional and informational support. Respite and formal supports are typically paid services that provide therapeutic and financial assistance, as well as assistance with behavior problems. The three types of caregiving supports are discussed below and the two primary Caregiving (Caregiver) Resources hypotheses can be found in Table 4.

Social Supports for Adult Sibling Caregivers (AH4.A)

Social and emotional supports have been shown to lower stress levels in parents of children with autism (Turnbull et al., 2006). “Social support includes support from one's spouse, family and friends, availability of leisure time to participate in recreational activities, and availability of services and community programs for family members” (Siklos & Kerns, 2006, as cited by Meadan et al., 2010, p. 26). Informal support, which includes help from family and friends, significantly decreased depressed mood among parents of children with ASD (Benson, 2009). Additionally, satisfaction with social support (perceived support) may be more important than the actual number of supports (Meadan et al., 2010). Moreover, both general social support and autism-specific support may help to buffer the stress effects of caring for a child with autism (Stuart & McGrew, 2009). It was hypothesized that sibling caregivers who perceive general social support would have more positive psychosocial outcomes in adulthood: greater health-related quality of life and reported benefits, and decreased caregiver burden.

Respite Care (AH4.B)

Respite care is a support service in which a hired individual provides care for a child or adult with ASD for a specified period of time, on a consistent basis (Meadan et al. 2010). Unlike most services for ASD, respite care is targeted at families, rather than the person with ASD. Cowen and Reed (2002) expanded the definition of respite care to include additional supports and services including referrals for other types of assistance (Meadan et al., 2010). Spouses may also provide an informal source of respite by dividing the responsibilities of household management and sharing the role of disciplinarian (Meadan et al., 2010). Respite care has been shown to benefit parents of individuals with developmental disabilities. For example, on a short-term basis, respite care can reduce stress levels in parents of children with disabilities (Meadan et al., 2010). Moreover, in a study of 113 children with autism and their families, respite care was rated as the most helpful service in reducing caregiver, family, and financial stress out of all the possible interventions families typically receive (Ruble & McGrew, 2007). In the current study, it was hypothesized that caregivers receiving respite care would have increased health-related quality of life, decreased caregiver burden, and increased reported benefits in their sibling relationship.

Formal and Financial Supports (AH4.B)

Caregivers with greater financial resources have been shown to have better access to services and support groups. Mandell and Salzer (2007) found that parents of children with ASD who lived in poorer communities or in communities with a higher proportion of African American families had little access to parent support groups; thus, they had less access to the information and services that support groups provide.

Bromley et al. (2004) noted that when parents live in areas with greater wealth, they often have lower levels of stress than those who live in rural or inner-city areas where assistance is not as easily available. It is probable that the factors impacting the types of supports a person with autism receives will extend into their adulthood. Specifically, financial burdens may be placed upon a non-disabled adult sibling when parents are no longer able to provide financial support for their child with autism or when they have not set up measures to ensure the financial security of their disabled child. In this study it was predicted that non-disabled siblings (caregivers) with fewer financial supports would have greater caregiver burden, lower levels of health-related quality of life, and report fewer benefits in their sibling relationships.

Formal support services consist of support groups and professional services provided to both the individual with autism and his/her family members (Meadan et al., 2010). Supports include those provided to the individual with autism, directly reducing the demands on the caregiver, as well as supports provided to the caregiver, which may indirectly reduce or alleviate caregiver burden (e.g., support groups). For example, Sanders and Morgan (1997) suggested that supportive therapy allows parents to discuss issues and share their concerns (Meadan et al., 2010). By discussing matters including financial planning or the long-term care of their child with ASD, parents' quality of life may increase. Sibling support groups including "Sib Shops" have been shown to be effective in educating and providing support to siblings during childhood (Smith & Perry, 2005, as cited by Meadan et al., 2010). However, formal supports may not be equally available to all. A study by Thomas et al. (2007) found that minority families, those families whose members had little education, those who did not use mainstream treatment approaches, and/or those who lived in rural areas had less access to formal support services (Meadan et al., 2010). Moreover, direct supports, such as in home habilitation services, residential supports, and behavioral management, provide paid professional services for the individual with ASD and, thus, directly reduce caregiver demands and caregiver burden (Ruble & McGrew, 2007).

In the current study, I investigated the relationships between the helpfulness and number of financial and formal supports a family received and the psychosocial outcomes of non-disabled siblings. It was predicted that increased respite care, financial, and/or formal supports would be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits.

5) Adult Sibling (Caregiver) Additional Demands

The presence of additional demands placed upon the adult sibling caregiver (beyond his/her caregiving responsibilities) were predicted to affect his/her psychosocial outcomes. These additional caregiver demands, defined as “pile-up” demands, are discussed below. (The one Adult Sibling (Caregiver) Additional Demands hypotheses can be found in Table 4.

Pile-up Demands (AH5.A)

In adulthood, new demands may be placed upon an adult sibling (e.g., taking on the responsibilities of a new job, raising children, or caring for aging parents). These responsibilities deplete one’s energy and can be perceived as “pile-up demands” that may prevent or interfere with an adult sibling’s ability to perform his/her caregiving responsibilities for his/her disabled sibling.

Pile-up demands have been shown to be related to poorer family and caregiving outcomes (Bristol, 1987; Pakenham et al., 2005). Moreover, if the demands placed upon a caregiver are appraised to outweigh the resources that are available to manage those demands, then a caregiving situation may be viewed as stressful (Lazarus & Folkman, 1984). In the current study, it was hypothesized that increased pile-up demands would result in more negative outcomes for non-disabled adult siblings: decreased health-related quality of life, decreased reported benefits, and increased caregiver burden.

Mediating Variables

McDonald et al. (1992) included five mediating variables in their Family Caregiver Conceptual Model: primary appraisal, secondary appraisal, reactive emotion, active emotion, and coping behaviors. In the Adult Sibling Caregiver Conceptual Model, two mediating variables were assessed: cognitive appraisal and coping. Three types of cognitive appraisal were examined: threat, challenge, and centrality. Coping was subdivided into problem-focused, emotional approach, and avoidant strategies (see Table 1).

Cognitive Appraisal (EH.1)

As stated earlier, the 13 antecedent variables (discussed above) comprise the five antecedent categories of the ASCCM: 1.) Family (Sibling Dyad) Characteristics, 2.) Adult Sibling (Caregiver) Characteristics, 3.) Adult with Autism/DS (Caregivee) Characteristics, 4.) Caregiving (Caregiver) Resources, and 5.) Adult Sibling (Caregiver) Additional Demands (see Table 1). These antecedents helped to create and define the caregiving situation for a non-disabled adult sibling. According to Lazarus and Folkman (1984), a typically-developing adult sibling cognitively appraises his or her “stressor” (caregiving situation) and this cognitive appraisal mediates whether the stressor is experienced as stressful, as well as the corresponding psychosocial outcomes or emotions that result from the caregiving situation. Three kinds of cognitive appraisals have been identified in the literature: primary appraisal, secondary appraisal, and reappraisal (McDonald et al., 1992). In the current study, I was concerned with primary cognitive appraisal, which was referred to as “cognitive appraisal.” When a sibling caregiver appraises his/her caregiving situation, s/he makes a decision as to whether s/he perceives it as harmful or a loss, or a threat or a challenge (Lazarus & Folkman, 1984). Prior research examining caregivers’ perceptions of caring for a child with ASD indicate that a negative appraisal is associated with increased burden and distress (Stuart & McGrew, 2009). According to the Lazarus and Folkman model (1984), a challenge appraisal (e.g., viewing the stressor as an opportunity) is likely to lead to a reduced experience of stress and thus to more positive outcomes, whereas a threat appraisal (e.g., viewing the stressor as potentially harmful) is likely to lead to an increased experience of stress and more negative outcomes. Three appraisal types were examined in this study: threat, challenge, and centrality. I hypothesized that a positive cognitive appraisal of a caregiving situation (i.e., challenge) would be associated with increased health-related quality of life, decreased caregiver burden, and more reported benefits. In contrast, I hypothesized that a negative appraisal of a caregiving situation (i.e., threat) would result in the opposite relationship (see Table 5). I made no predictions for centrality appraisals.

Coping Strategies (EH.2)

Coping involves consciously changing one's cognitive and behavioral efforts in order to manage external and/or internal demands that are appraised as taxing or exceeding the resources of an individual (McDonald, 1992, p. 15). Coping can be divided into problem-focused and emotion-focused coping styles. Problem-focused coping strategies such as seeking out information are used to actively solve and tackle problems. Emotion-focused coping strategies such as seeking social support are used to regulate or eliminate undesirable emotions that are associated with a problem (Carver et al., 1989). Emotion-focused coping strategies can be further divided into two categories: emotional-approach coping strategies (positive reappraisal) and avoidant coping strategies (denial or avoidance) (Meadan et al., 2010). One's choice of coping strategy has been shown to significantly predict caregiver burden (Stuart & McGrew, 2009).

Adolescents and adult siblings from 406 families were surveyed by Orsmond et al. (2009). Siblings who reported using problem-focused coping strategies also reported fewer negative impacts of the behavior problems of their siblings with ASD. Emotion-focused positive reframing techniques may also be effective when caring for an individual with autism when the stressor cannot be altered (Hastings et al., 2005). When using emotional-approach oriented strategies, a person seeks out information about a stressor, monitors it, and tries to resolve it.

However, caregivers who employ avoidant coping strategies have been shown to fair worse when dealing with chronic stressors (Stuart & McGrew, 2009). Parents of children with autism are more likely to use avoidant coping strategies such as distancing and escape compared to parents of typically-developing children (Sivberg, 2002).

Moreover, use of avoidant strategies has been related to increased depression, social isolation, and marital dissatisfaction in parents of children with ASD (Dunn et al., 2001). With respect to siblings, adolescent siblings of individuals with autism tend to use more emotion-focused than problem-focused coping strategies, but as they enter adulthood, they tend to use more problem-focused strategies when they are no longer living with their sibling. In adulthood, siblings may rely less on the support of their parents and friends and tackle their problems directly (Orsmond et al., 2009).

I explored whether the use of problem-focused or emotion-focused coping strategies by adult sibling caregivers would mediate their psychosocial outcomes. It was hypothesized that a problem-based or positive reframing emotion-focused style of coping would be associated with more positive psychosocial outcomes, while an avoidant, emotion-focused style of coping would be associated with more negative psychosocial outcomes (see Table 5).

Psychosocial Outcome Variables

The Family Caregiver Conceptual Model (McDonald et al., 1992) depicts outcomes for both the caregiver and the individual with a disability. In the current study, I was only concerned with the psychosocial outcomes of the non-disabled adult siblings. Three psychosocial outcomes were examined using the Adult Sibling Caregiving Conceptual Model: 1) health-related quality of life (HRQOL; mental and physical), 2) caregiver burden, and 3) reported benefits (see Table 2).

Health-Related Quality of Life (OH 6.A)

Health-related quality of life (HRQOL) includes physical health, personal beliefs, psychological well-being, functional roles, and satisfaction with social relationships and environmental events (Hawthorne et al., 1999). Mothers of children with Asperger syndrome and high functioning autism (AS/HFA) tended to have lower HRQOL compared to caregivers of typically developing children. Caregivers' HRQOL also tended to be lower when caring for children with a higher number of behavior problems. However, the study was limited by the small sample size and the exclusion of children who were not high functioning, such as those with autism or PDD (Allik et al., 2006). Similarly, compared to siblings of adults with DS, siblings of adults with autism had less warm sibling relationships, slightly worse health, and higher levels of depressive symptoms (Hodapp & Urbano, 2007).

In the current study, I used the Adult Sibling Caregiver Conceptual Model to predict individual variations in mental and physical HRQOL. It was hypothesized that a caregiver's HRQOL would be a function of antecedent variables and mediated by cognitive appraisal and one's use of coping strategies. Further, I predicted that a sibling caregiver of an adult with DS would have greater mental and physical HRQOL than would a sibling caregiver of an adult with autism (see Table 4).

Caregiver Burden (OH6.B)

Caregiver burden, as reported by the non-disabled adult sibling, is the subjective belief in his/her ability to successfully carry out caregiving responsibilities. Caregiver burden can include embarrassment or stigma and may overlap with both marital and family burden, although there is an independent effect on the individual (Stuart & McGrew, 2009). Caregiver burden can be defined as “the extent to which caregivers perceive that their emotional health, physical health, social life, and financial status has suffered as a result of providing care to the care recipient” (Khanna et al., 2012). In the current study, I used the Adult Sibling Caregiver Conceptual Model to predict levels of caregiver burden.

As noted earlier, caregiver burden tends to be higher for parents of persons with autism compared to parents caring for persons in other disability groups, including Down syndrome. Therefore, it was hypothesized that a similar pattern would be demonstrated in sibling caregivers; sibling caregivers of adults with autism were predicted to experience greater caregiver burden than were sibling caregivers of adults with DS (see Table 4).

Reported Benefits

The third psychosocial outcome variable is the benefits that a sibling caregiver may report from his/her relationship with his/her disabled sibling. That is, in addition to (or instead of) a caregiving situation being burdensome, it may be perceived as beneficial. For example, young caregivers of individuals with Multiple Sclerosis and Asperger syndrome have reported benefits in their caregiving relationships, including personal growth, strengthened relationships, and changes in their priorities (Pakenham et al., 2005).

Benefit finding has been examined in siblings of individuals with disabilities. Burton and Parks (1994) compared college-aged students who had a disabled sibling to college-aged siblings in a control group. Siblings who had disabled siblings reported that their siblings helped them to be more tolerant, responsible, and flexible. Siblings with disabled siblings also had a greater internal locus of control and more psychological strength. Some limitations to the study were that most participants were young adults and were not thinking about their future caregiving roles or how their lives would be years down the road.

In a study comparing siblings of adults with intellectual disability (ID) and mental illness (MI), most siblings of adults with ID believed their lives were greatly affected by their sibling, but saw those effects in a positive light (Seltzer et al., 2005). In contrast, adult siblings of individuals with MI were found to keep more of a psychological distance from their siblings than did siblings of individuals with ID. A literature review by Heller and Arnold (2010) summarized published studies from 1970–2008 that examined outcomes for adult siblings (over 21 years of age) of adults with intellectual and developmental disabilities. They reported mixed, but mostly positive psychosocial outcomes associated with having a sibling with a disability. In the current study, no a priori hypothesis was proposed regarding differences between groups in reported benefits.

Summary, Hypotheses, and Research Questions

The psychosocial outcomes of adult siblings who provide varying levels of care for their adult siblings with autism are not well understood. Suggestions from the extant literature on adult siblings of adults with intellectual disability, mental illness, physical disability, and ASD have been incorporated into the design of the current study. Prior research has been mostly exploratory and has largely been limited to examining sibling outcomes in childhood and adolescence. Little is known about the adult siblings who may provide care for their adult siblings with autism.

The current study proposed to use the Adult Sibling Caregiver Conceptual Model (ASCCM) to examine the associations between 13 antecedent variables and three psychosocial outcomes (health-related quality of life, caregiver burden, and reported benefits) within the adult sibling caregiving relationship. The relationships between the antecedent (predicting) factors of caregiving situations and outcomes were also predicted to be mediated by adult siblings' cognitive appraisals and/or coping strategies. All primary research questions and hypotheses are listed in Table 3 and 4. Secondary research questions and their related exploratory hypotheses can be found in Table 5. Table 6 provides detailed information about the elements of the ASCCM, lists all study variables, and the specific measures used to assess each one.

METHOD

Design

This study aimed to predict mental and physical health-related quality of life, caregiver burden, and reported benefits in adult siblings of adults with autism and Down syndrome. Data was collected via an electronic survey. Data were analyzed using SPSS, Version 20.

Recruitment Strategies

Adult siblings of adults with autism and Down syndrome were recruited by contacting non-profit and for-profit state and national organizations, as well by networking, using the first author’s personal contacts. The following organizations were contacted to recruit siblings of adults with autism: Autism Speaks, Easter Seals, The Indiana Institute on Disability, Indiana Resource Center for Autism, The ARC of Indiana, The ARC, USA, the National Sibling Research Consortium, Self Advocates Becoming Empowered (SABE), Don Meyer’s Sibling Network, The Sibling Leadership Network, and the Autism Society of Indiana. Also contacted were Noble of Indiana, the ARC of Greater Twin Cities, the Christian Sarkine Autism Center, SibNet, and InSource. The following organizations were contacted to recruit siblings of adults with Down syndrome:

the National Down Syndrome Society, the Bally Foundation, the National Down Syndrome Congress, and Ohio Sibs. To recruit siblings of adults with both autism and Down syndrome, AccessABILITY, Indiana Professional Management Group, and the Association of University Centers on Disability (AUCD) were contacted. The first author also advertised on two listservs, IUPUI's Jag News and the Association for Special Children and Families (ASCF). Emails with an IRB-approved description of the study were also distributed at local supermarkets, stores, and fundraising walks in Indianapolis (see Tables 7 and 8 for a list of all organizations that were contacted as well as whether a member of the organization was able to provide recruitment assistance).

Inclusion Criteria and Rationale

Study participants were over the age of 18 when completing the survey and had at least one disabled sibling who was also over the age of 18, with a reported diagnosis of autism or Down syndrome. A diagnosis of autism was confirmed by a non-disabled sibling's reported score of his/her sibling using the Gilliam Autism Rating Scale- Second Edition (GARS-2; Gilliam, 2006). A score of 85 or higher on the GARS-2 denoted the presence of autism. Consistent with the methods cited in the literature, siblings' reports were relied on to confirm the diagnosis of Down syndrome (Hodapp & Urbano, 2007). Sibling-reported confirmations of Down syndrome are considered valid because the phenotype is highly recognizable; the test to confirm the diagnosis is done perinatally, and it is very accurate and reliable, e.g., using amniocentesis, chorionic villus sampling

(CVS), percutaneous umbilical blood sampling (PUB), or a karyotype (genetics test) to assess for a third 21st chromosome (Mayo Clinic, 2012).

Participants in this study were familiar with their sibling to the extent that they could accurately report about his or her level of functioning and behavioral symptoms. Study participants could currently be performing caregiving duties as their sibling's primary caregiver, but it was not a requirement for the purposes of this study. That is, a sibling's degree of caregiving could range from providing no care at all, to being the guardian and sole caretaker for his/her sibling. Study participants must have been able to read and comprehend English and not be diagnosed with a physical or mental disability that would inhibit their participation in the study.

MEASURES

Screening Questionnaire (SQ)

A 4-item screening questionnaire (SQ) was administered to participants prior to assess study eligibility prior to completing the survey. The screening questions were designed to identify and exclude any non-disabled study participant who did not fulfill the inclusion criteria. Example screening questions included, “What is your sibling’s diagnosis?” and “Is he/she over the age of 18?”

Measures for Antecedent Variables

Demographic and Background Information

A Demographic and Background Information Questionnaire (DBIQ) assessed relevant demographic and background information about the non-disabled adult sibling and his/her family. Antecedent variables from the Adult Sibling Caregiver Conceptual Model were examined in this section, including: number of non-disabled siblings in the family and sibling birth order (Family (Sibling Dyad) Characteristics), gender of the adult sibling caregiver, marital status of the adult sibling caregiver, and the developmental life stage of the adult sibling caregiver -- using age as a proxy) (Adult Sibling (Caregiver) Characteristics). The gender, race, and age of the non-disabled and disabled siblings were assessed. Additional information including marital status, the state one resides in, employment and educational status were collected. Four of the 20 items on the DBIQ contained dichotomous answer choices (e.g., “What is the gender of your sibling with autism/DS?”), seven items used a single-response choice format (e.g., “What is your current relationship status?”), five items were fill-in-the-blank (e.g., “What is your age?”), and four items provided check-all-that-apply choices (e.g., “What is your race?”).

Sibling Relationship Quality

The Lifespan Sibling Relationship Scale (LSRS; Riggio, 2000) measured the quality of a sibling relationship across the lifespan. The LSRS is a self-report measure containing 6 eight-item subscales (Adult Affect, Adult Behavior, Adult Cognitions, Child Affect, Child Behavior, and Child Cognitions). Adult siblings will rate their sibling relationship on a 5-point Likert-type scale (1 = strongly disagree, 5 = strongly agree). Internal consistency reliability for the six scales ranges from .84 to .91. The total LSRS score has an alpha of .96 and a test-retest reliability of .91 after a one-month follow-up. The scale demonstrates a coherent factor structure and stable responses over time (Riggio, 2000). In the current study, Cronbach’s $\alpha = .97$.

Autism Diagnosis and Symptoms

The Gilliam Autism Rating Scale- 2nd Edition (GARS-2; Gilliam, 2006) was used to assess whether the adult siblings of study participants have a diagnosis of autism, as well as the severity of their autism symptoms. The GARS-2 is a revision of the original GARS and is comprised of 42 items. The GARS-2 has been normed on 1,107 individuals with ASD in the United States and can be taken by parents, teachers, or professionals (Norris & Lecavalier, 2010). Its internal consistency was found to be high ($\alpha = 0.94$) and its test-retest reliability is good ($r = 0.88$). The original GARS (1996) demonstrated a content-description validity of $r = 0.47$ and a criterion-related validity of $r = 0.64$. Recently it has been reported that the GARS-2 may have poor sensitivity, e.g., the test may underestimate (false negative) whether a person has autism (Norris & Lecavalier, 2010).

Items on the GARS-2 are organized into three subscales: Stereotyped Behaviors, Communication, and Social Interaction. Respondents (adult sibling caregivers) rated the frequencies of the corresponding behavior of their sibling on a four-point Likert scale (0 = never observed, 3 = frequently observed). Higher scores indicate a greater number of autism symptoms. Their item responses for each of the three subscales were added together to produce Raw scores. Raw scores were converted into standardized scores, which were then transformed into a standardized Autism Index score that has a mean of 100 and a standard deviation of 15 (Gilliam, 2006). Scores greater than or equal to 85 on the Autism Index suggested that there was a good likelihood that the disabled sibling has autism. This placed the non-disabled sibling into the “Autism” study group. GARS-2 scores between 70 and 84 indicate that an individual may have autism and scores below 70 imply that an individual is not likely to have autism (Gilliam, 2006).

For the purposes of the current study, a cut-off score of 85 was used, and individuals with scores below 85 were considered not to have autism. When the GARS-2 was taken by the current sample ($n = 97$), the mean and standard deviation were ($M = 71.60$, $SD = 9.47$). Internal consistency reliability was nearly identical to estimates for the normative sample (.94; Gilliam, 2006) at α = .96 for all 3 subscales. When examining the Stereotypical Behavior, Communication, and Social Interaction subscales alone, alphas were .86, .92, and .93 respectively.

Problem Behavior

The Problem Behavior Rating Scale (PBRS; Stone et al., 2010) was used to measure problematic behavior of adult siblings in the Autism, Down syndrome, Mixed, and Disability groups. The 30-item PBRS was initially normed on children and has an alpha of .88 when the informant is a teacher or a parent. The PBRS contains descriptors of problem behaviors typical for persons with autism or intellectual disabilities, e.g., “Having temper tantrums or meltdowns” to, “Having toileting accidents.” Items are rated on a four-point Likert type scale (1 = not at all problematic, to 4 = very problematic). Higher scores indicate a greater number and severity of problem behaviors. In the current study, the PBRS had an alpha of .93.

Adaptive Behavior

The Instrumental Activities of Daily Living Scale (IADL; Lawton & Brody, 1969) was used to assess the adaptive behavior of the disabled siblings of all study participants. The IADL was normed on elderly populations and its applicability as a screening tool for cognitive impairment has been confirmed (Lawton & Brody, 1969). It has also been recommended for use in community or hospital settings (Graf, 2007). Significant correlations have been found between the IADL and other measures of functional status (e.g., the Physical Classification, the Mental Status Questionnaire, the Behavior and Adjustment rating scales, and the PSMS) (Graf, 2007). The IADL has not been used to describe adults with autism. The internal consistency validity was adequate for the current study at $\alpha = .76$. The IADL scale assesses 8 domains of functional independence, including the ability to: 1) use the telephone, 2) shop, 3) prepare food, 4) keep house, 5) do laundry, 6) use transportation, 7) take medications, and 8) handle finances. Each domain contains 3-5 qualifying statements. The rater is required to circle the statement that best applies to his/her disabled sibling. For example, the "Ability to Handle Finances" domain contains three possible rating statements: a.) "Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income"; b.) "Manages day-to-day purchases, but needs help with banking, major purchases, etc."; c.) "Incapable if handling money" (Lawton & Brody, 1969).

Items are scored as either 1 (higher functioning) or 0 (low functioning). Total scores ranged from 0 (low functioning, dependent) to 8 (high functioning, independent).

Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988) was used to measure the social support of the adult sibling caregiver. The MSPSS was first developed using university students and then was validated on a range of samples including pregnant women, adolescents, older adults, doctor-trainees, and psychiatric patients (Edwards, 2004). The 12 items on the scale are rated on a 7-point Likert scale (1 = very strongly disagree to 7 = very strongly agree). Higher ratings indicate greater social support. Test-retest reliability (r = 0.85) and internal consistency reliability (α = 0.92) for the original MSPSS are good (Zimet, 1998). The MSPSS has been used previously to assess the social support present in caregivers of individuals with ASD (Stuart & McGrew, 2009). In the current study, Cronbach's α = .95.

Respite, Formal, and Financial Support Services

The Respite, Formal, and Financial Support Measure (RFFSM) was developed for this study to assess the amount of respite care, formal, and financial supports that an adult sibling caregiver and his/her disabled sibling receive. The 14-item measure was based on one used in a statewide survey to assess caregiver and family-related outcomes associated with receiving community-based services (Ruble & McGrew, 2007). The RFFSM asked caregivers what services they currently receive, the estimated number of hours each week they use the services, and to rate the helpfulness of services received on a 1-5 scale, with 1 being the least helpful and 5 being the most helpful. Examples of the services assessed are speech therapy, occupational therapy, and supported employment.

Pile-up Demands

The Social Readjustment Rating Scale (SRRS; Holmes & Rahe, 1967) was modified for this study (as per the guidelines of Stuart & McGrew, 2009) to measure the additional (pile-up) demands of non-disabled adult siblings. Participants were asked to rate each of the 43 items on the SRRS on a 6-point Likert type scale (0 = not experienced, 5 = experienced with extreme distress). A total score was calculated by adding the ratings across all items. When the SRRS was used with autism parent samples (Bristol, 1987; Pakenham et al., 2005) alpha was 0.82. The internal consistency reliability for a modified use of the SRRS found a slightly higher alpha of .87 (Stuart & McGrew, 2009). Consistent with prior findings, Cronbach's alpha was .83 in this study.

Measures for the Mediating Variables

Two variables were assessed as possible mediators in the ASCCM: cognitive appraisal types and coping strategies (see Table 5 for a list of the mediating variables, their associated hypotheses, and the measures used to assess them).

Cognitive Appraisal

The Stress Appraisal Measure (SAM) was used to measure primary cognitive appraisal. It is a 28-item questionnaire designed to measure dimensions of primary and secondary appraisal as they relate to anticipatory stress (Peacock & Wong, 1990, p. 228). The SAM produces scores for 7 appraisal dimensions: threat, challenge, centrality, control-self, control-others, uncontrollable, and stressfulness. In the current study, three of the seven appraisal dimensions, threat, challenge, and centrality, were used to determine a caregiver's primary appraisal of his/her caregiving situation.

Items were rated using a 5-point Likert type scale (1 = Not at all, 2 = Slightly, 3 = Moderately, 4 = Considerably, 5 = Extremely). The means of the three subscales were calculated as scale scores. The SAM has been tested on college students (Peacock & Wong, 1990) and on caregivers of severely ill persons (Kausar & Powell, 1999). Test-retest reliability is not appropriate for this measure because cognitive appraisals are expected to change over time (Peacock & Wong, 1990, p. 235). However, Cronbach alpha values have ranged from 0.71 to 0.90 (Kausar & Powell, 1999). In this study, alpha was .82 for all 3 subscales combined within the Disability group (n = 97). Alpha values for the subscales (threat, challenge, and centrality) respectively, were α = .88, .84, and .91.

Coping Strategies

The Brief COPE (Carver, 1997) was used to assess non-disabled adult sibling participants' coping strategies. The Brief COPE has 28 items, which are rated on a 4-point Likert type scale (1 = I haven't been doing this at all; 2 = I've been doing this a little bit, 3 = I've been doing this a medium amount, 4 = I've been doing this a lot). The items are coded into 14 coping strategies, which are then categorized into problem-focused, emotional approach, or passive avoidant subscales. The problem-focused subscale was calculated as the mean scores from the active coping, seeking instrumental support, and planning items. The emotional approach subscale was calculated as the mean scores from the seeking emotional support, positive reframing, humor, acceptance, and turning to religion items. The passive avoidant coping subscale was calculated as the mean scores from self-distraction, denial, substance use, behavioral disengagement, venting of emotions, and self-blame items.

The internal consistency estimates ranged from α = 0.50 to 0.90 for the three strategy subscales (Carver, 1997). When used in a prior study of caregivers of children with ASD, the internal consistency estimates were α = .81 for the problem-focused subscale, α = 0.60 for the emotional-approach subscale, and α = 0.79 for the passive avoidant subscale (Stuart & McGrew, 2009). In this study, α = .91 for the 28-item scale. Avoidant coping had an alpha of .87; problem-focused coping's alpha was .90 and emotional approach's alpha was .83.

Measures for Psychosocial Outcome Variables

To test the utility of the Adult Sibling Caregiver Conceptual Model, outcome variables were assessed in this study: mental and physical health-related quality of life (HRQOL), caregiver burden, and reported benefits. The adaptive outcomes listed by McDonald et al. (1992) and the prior study by Stuart and McGrew (2009) influenced the selection of these outcome variables.

Health-Related Quality of Life

The RAND Short-Form Health Survey (SF-12; Ware et al., 1996) was used to assess health-related quality of life (HRQOL) and is a subset of the SF-36. The SF-12's Physical component summary scale includes physical functioning, role physical, bodily pain, and general health subscales. The Mental component summary scale includes vitality, social functioning, role emotional, and mental health subscales. Some items are scored dichotomously (yes or no) and some items are rated using a 5-point scale (1 = excellent, to 5 = poor). The 2-week test-retest reliability is adequate for both the PCS ($r = 0.89$) and MCS subscales ($r = 0.76$) (Ware et al., 1996). The SF-12 has been used successfully to assess health-related quality of life outcomes in parents of children with ASD (Stuart & McGrew, 2009); internal consistency ratings of α = 0.65 for the PCS and α = 0.63 for the MCS were found. When the SF-12 was used in the current study the PCS had a rating of α = .75 and the MCS had a rating of α = .56.

Caregiver Burden

The Caregiver Strain Questionnaire (CGSQ; Brannan & Heflinger, 1997) measures the burden that an individual experiences when caring for a child with an emotional or behavioral disorder. It is considered to be a reliable and valid instrument to assess burden among caregivers of children with autism. The internal consistency for the scale is α = 0.93 and the test-retest reliability is r = 0.76 (Khanna et al., 2012). In the current study, the CGSQ was adapted to be used by adult siblings; the word “child” was replaced with the word “sibling”. When the CGSQ was used with adult siblings in the current study, alpha = .95.

The 21 items on the CGSQ are rated using a 5-point Likert type scale (1 = not at all a problem, to 5 = very much a problem). The responses were summed and divided by the number of items to obtain a mean rating. Higher scores indicate higher levels of caregiver burden (Brannan, & Heflinger, 1997).

Reported Benefits

The Benefit-Finding Scale (Tomich, & Helgeson, 2004a) was used to measure the possible benefits a non-disabled sibling may experience through his/her relationship with his/her disabled sibling. There are multiple versions of the Benefit-Finding Scale, which was initially developed to assess the benefits of having breast cancer (Tomich & Helgeson, 2002, 2004a, 2006; Helgeson, Snyder, & Seltman, 2004b; Tomich, Helgeson, & Vache, 2005).

For the current study, I used the 20-item version of the Benefit-Finding Scale (Tomich & Helgeson, 2004a). Example items include, “has taught me that everyone has a purpose in life”, and, “has helped me to budget my time better”. Study participants rated how much they agree or disagree with each of the 20 statements, using a 5-point Likert type scale: (1 = Not at all, to 5 = Extremely). For the current study, the wording of the first instructional paragraph of the scale was altered to apply toward adult siblings of persons with autism or Down syndrome. The wording of the 20 individual items remained the same. When the 20-item Benefit-Finding Scale was tested on patients with breast cancer, the alpha was .95 (Tomich & Helgeson, 2004a). In the current study, α = .96 (see Table 9 for a list of all study measures and their operationalization.)

PROCEDURE

Piloting the Survey

The survey was piloted on 5 individuals. Based on feedback, I re-formatted sentences, edited questions that were considered "confusing" (e.g., had both a number and a letter in their title, "A. 1. Ability to use telephone"), adjusted settings on multiple-choice items so that participants could only choose one answer, clarified instructions that were misleading, and reformatted questions so that anchors were more visible.

Data Collection

A link to the survey was made available to participants online. Survey data resided on a secure server (Survey Monkey) and data was downloaded into Microsoft Excel and then to an SPSS database. Participants were fully informed of the study's purpose and were asked to give their electronic consent prior to completing the survey. Participants were told that they could discontinue their participation in the study at any time. Upon completion of the survey, participants were thanked and given the contact information and phone number of the co-investigator, whom they could contact with any questions about the study. Participants also had the option of supplying their contact information to receive information about future studies conducted by the co-investigator.

Statistical Design and Data Analysis

Once the survey data was collected, it was transferred to the secure SPSS database, as previously mentioned. Missing data was replaced case wise, using weighted means for the completed items in the scale as long as more than 80% of the items were completed. If less than 80% of the data was present, a participant's data for a particular measure was not used in the analyses. All study variables were examined for normality, linearity, and homogeneity. The demographic information from the DBIQ was analyzed using "General Descriptives" (e.g., mean, standard deviation) and "Frequencies" on SPSS.

Hypothesis Testing

To control for alpha inflation, given the large number of tests required, within the DS and Disability groups, all analyses were conducted two-tailed using a $p < .01$ significance level. Within the Autism group, all hypothesized tests, both primary and exploratory, were conducted one-tailed using a $p < .05$ significance level.

Testing for Between-Group Differences

T-tests were used to test the a priori, between-group hypotheses (OH6.A and OH6.B) regarding HRQOL and caregiver burden between the Autism and DS groups. Exploratory ANOVAs were run to examine between-group differences among the Autism, DS, and Mixed groups. Differences in reported benefits between groups were also examined, but the ANOVA was considered exploratory because no a priori hypotheses were proposed. Post-hoc tests were run following all significant ANOVAs.

Testing for Mediation

Baron and Kenny's method was used to test for mediation (Baron & Kenny, 1986). If an antecedent variable was significantly associated with a dependent variable at the $p < .05$ or $p < .01$ level, then I tested for mediation within the Adult Sibling Caregiver Conceptual Model using a four-step process. 1) First, the outcome (Y) was entered into a regression equation as the criterion variable and the antecedent (X) was a predictor. 2) If that effect was significant, then, X was regressed to predict the possible mediators (M): coping strategies and cognitive appraisal. 3) Next, the mediators (M) were regressed onto the outcome variables (Y), while controlling for the antecedent variables (A). 4) Finally, if Steps #1-3 were significant, X and M were regressed simultaneously together onto Y. Mediation analyses were run for the Autism, DS, and Disability groups. I tested whether the proposed study mediators (cognitive appraisal and coping strategies) mediated specific antecedent variable-dependent variable correlations.

Power Analysis

Three power analyses were conducted to determine the number of participants needed in the two proposed study groups. After assessing the data, it was determined that some participants fell into a "Mixed" category, in which their sibling was reported to have Down syndrome, but their GARS-2 score was greater than/equal to 85. Twelve disabled siblings fell into the Mixed category. For that reason, a third study group, the Disability group, was developed, which comprised all participants in the Autism, DS, and Mixed groups. The first power analysis was run to test a regression with three predictors (the greatest number of variables in any antecedent category). The second power analysis tested a bivariate correlation between one of the antecedent variables and a psychosocial outcome. The third power analysis tested the between-group differences on a psychosocial outcome using a t-test. The analyses were conducted using G*power 3.1 (Faul et al., 2009).

To determine the sample size needed to run linear multiple regressions between blocks of variables within antecedent categories and the psychosocial outcome variables, an example antecedent category, “Adult Sibling (Caregiver) Characteristics” (which included three variables, the greatest of any antecedent category), and one psychosocial outcome variable (caregiver burden) were used. Because there is no prior research examining the relationship between the “Adult Sibling (Caregiver) Characteristics” and caregiver burden, a medium effect size of ($F^2 = .15$) was assumed for the purposes of this power analysis (Cohen, 1992). To run a linear multiple regression at an alpha of ($p < .05$), with a power of .8, and three predictor variables, a total sample size of 77 was needed.

To determine the sample size needed to test bivariate correlations (primary hypotheses) between antecedent variables (e.g., symptom severity) and psychosocial outcome variables (e.g., caregiver burden), as well as bivariate correlations (exploratory hypotheses) between mediating variables and psychosocial outcome variables within the Autism group, a medium effect size ($r = 0.3$), a one-tailed test, a power of .80, and an alpha of (p < .05) was assumed. The sample size needed to test the study's hypotheses within the Autism group was 67.

To determine the sample size needed to perform t-tests (between-group analyses) comparing the means of the psychosocial outcomes of the two study groups, a third power analysis was run with a one-tailed test, a power of .80, an alpha set at (p < .05), and a medium effect size (d = 0.5). This yielded the need for 51 participants in each group.

My goal was to recruit approximately 140 participants for this study: 70 adult siblings of adults with autism and 70 adult siblings of adults with Down syndrome, to accommodate the analyses with the largest sample-size requirements. Although I did not recruit 70 adult siblings of adults with autism or Down syndrome, I was able to use the Disability group (N = 97) to test analyses on adult sibling participants. As of 11/14/12, I was able to recruit 31 adult sibling respondents who met the criteria for the Autism group, 54 who met criteria for the DS group, and 12 who met criteria for the Mixed group (see Figure 3 for a monthly breakdown of when the surveys were completed). Together, the 97 sibling respondents were included in the Disability group. Given the nature of the analyses and the number of hypotheses being tested, a larger sample would have been preferred.

RESULTS

Study Participants

I recruited two groups, non-disabled adult siblings of adults with Down syndrome and non-disabled adult siblings of adults with autism. To participate, both members of the sibling dyad must have been over the age of 18 when the non-disabled sibling completed the survey. One hundred and eighty-four siblings attempted the research survey and 150 met the study inclusion criteria as operationalized in the Screening Questionnaire (SQ). Of the 150 participants who passed the SQ, 112 (75%) completed enough of the measures to be included in the analysis.

The 112 participants initially included in the analysis were sub-divided into three study groups: 1) adult siblings of adults with autism, 2) adult siblings of adults with Down syndrome, and 3) adult siblings of adults co-morbid for Down syndrome and significant autism symptoms. To be included in the Autism group, participants had to report that they had a sibling with autism and their siblings' scores on the GARS-2 had to be greater than or equal to 85 (n = 31). (See Figure 4 for the range of the participants' Autism Index Scale scores on the GARS-2). The 15 participants reporting that their siblings had autism, whose siblings' GARS-2 scores did not meet criteria for autism diagnosis, were placed into a "Self-Reported Autism" group. The Self-Reported Autism group was not included in the analyses; however, their demographic data is displayed in Tables 10, 11, and 12. To be included in the Down syndrome group, participants had to report that they had a sibling with Down syndrome and their siblings' scores on the GARS-2 had to be less than 85 (n = 54). A Mixed group emerged that had Down syndrome and also qualified as having autism on the GARS-2 scale (i.e., sibling-reported scores greater than or equal to 85; n = 12). Although the disabled siblings within the Mixed group had symptoms of autism sufficient to be diagnosable according to GARS-2 criteria, we could not independently confirm the autism diagnosis. Together, the Autism, DS, and Mixed groups comprised the Disability group (n = 97).

Demographic and Background Information of Non-disabled Study Participants

Tables 10, 11, and 12 display the demographic and background information of all participants. Study participants were drawn from 26 states within the United States and one participant resided in Quebec, Canada. Of the 97 non-disabled sibling participants within the Disability group, the majority were white/Caucasian (85.5%, n = 83) and the remaining were classified as non-white (7) or "mixed" (4). Eighty-seven non-disabled siblings were female (89.7%) and 10 were male. The sample consisted of 54 older sisters, 31 younger sisters, 2 older brothers, and 8 younger brothers. Forty-five percent (n = 44) of individuals were married, 41% (n = 40) were single, and 13% (n = 13) fell into the category of "other." The sample was highly educated; 40% (n = 39) obtained advanced/professional degrees, 32% (n = 31) were college graduates, and 22% (n = 21) were attending college. Fifty-seven percent reported working full-time (n = 55) and 7%

(n = 7) reported working part-time. An additional 9% reported being homemakers (n = 3), unemployed (n = 3) or retired (n = 3), 8% (n = 8) were full-time students, 1% (n = 1) was disabled, and 16% (n = 15) endorsed two or more categories.

About one-third (n = 33; 34%) of siblings reported having no other siblings aside from their disabled sibling, another third reported having one additional sibling (n = 32; 33%), and about one fourth had two or more additional siblings (n=24, 24%) (8 individuals did not report number of siblings). The average age of the non-disabled study participant was 36.5 years (SD = 14.4). Thirty-one percent (n = 30) of siblings earned more than $90,000 each year, 20% (n = 19) earned $61-90,000/year, 22% (n = 21) earned $40,001-60,000/year, 17% (n = 16) earned $20,001-40,000, and 4% (n = 4) earned less than $20,000 each year. In addition, 12 percent (n = 12) reported that a portion of their family’s income comes from public assistance.

Siblings reported about the contact they have with their disabled sibling. Forty percent (n = 39) see their sibling more than 3 times each week, 25% (n = 24) see their sibling 1-3 times each week, 12% (n = 12) see their sibling more than once each month, 15% (n = 15) see him/her more than once every 3 months, 7% (n = 6) see him/her more than once a year, and 1% (n = 1) see him/her less than once a year. Forty-nine percent (n = 48) live within 0-30 miles from their disabled sibling, 21% (n = 20) live more than 500 miles away, and 30% (n = 29) live between 30 and 500 miles from their disabled sibling. A majority of siblings reported being very familiar (42%, n = 41) or mostly familiar (32%, n = 31) with their disabled sibling’s resources, with the remainder being somewhat (23%, n = 22) or not at all familiar (3%, n = 3).

Demographic and Background Information of Study Participants' Disabled Siblings

The demographic information for the disabled siblings, as reported by their non-disabled sibling, is also shown in Table 12. The Disability group consisted of 60 males (62%) and 37 females (38%). Of those, 26 males and 5 females were in the Autism group (n = 31), 30 males and 24 females were in the DS group (n = 54), and 4 males and 8 females were in the Mixed group (n = 12; total n = 97). Male-female ratios within the Autism (5.2:1) and DS groups (1.25:1) were close to the expected ratios (Autism: 4:1; Anello et al., 2009; DS: 1.24:1; Kovaleva et al., 2001). The "Mixed" group is more complex, thus the expected "correct" ratio is unclear relative to what was obtained (.5:1). Moreover, the sample may have been too small to obtain a reliable estimate of the male-female proportion. However, the data replicates prior work showing that ASD is not uncommon within the Down syndrome population. Kent et al. (1999) cited a 7% minimum prevalence of autism in DS and Lowenthal et al., (2007) reported frequencies of PDD in DS ranging from 1% to 11%. The average age of the disabled adult sibling was 31.3 (12.3) within the Autism group, 36.5 (14.3) within the DS group, and 36.1 (15.8) within the Mixed group. Similar to the non-disabled sibling member of the dyad, within the Disability group, 89% (n = 86) of the disabled siblings were white, 6% (n = 6) were non-white, and 3% (n = 3) reported mixed heritage.

Tests for Group Differences on Demographic Variables

Chi Square analyses and independent t-tests were used to compare information for participants included in the analysis (n = 112) with those not in the analysis (n = 38) on the available data (see Table 13). The groups were significantly different on three variables. Compared to those who did not finish the survey, completers tended to be slightly older (M = 35.3 vs. 29.9 years, t[47.6] = -2.22, p = .03), were more likely to rate themselves as being familiar with the resources their sibling received (1 = very familiar, 4 = not at all familiar; M = 1.89 vs. 2.31, t[136] = 2.16, p = .03), and their disabled siblings were less likely to be male (64% vs. 88%, $\chi^2[1] = 5.75$, p = .02).

ANOVA and Chi-square analyses were conducted to see if there were significant differences between the Autism, DS, and Mixed groups on any demographic variables for either the disabled or non-disabled sibling. With respect to the non-disabled sibling, the only significant difference was in the number of non-disabled siblings, F(2,86) = 3.82, p = .03. Using a follow-up Tukey's-B post-hoc test, the Autism group reported having fewer non-disabled siblings that the DS groups ($M[SD]_{Autism} = .62[.70]$, $M[SD]_{DS} = 1.49[1.58]$, p = .02) (see Table 8). With respect to the disabled sibling, as expected, there were differences in the number of male and female participants across the Autism, DS, and Mixed groups ($\chi^2[2] = 11.41$, p = .00). Follow up Chi Square analyses found significant gender differences between the Autism and DS groups ($\chi^2[1] = 7.03$, p = .01) and the Autism and Mixed groups ($\chi^2[1] = 10.48$, p = .00). There were no other significant group differences among the disabled siblings (see Table 14).

Testing the Study Hypotheses

Testing the Primary Hypotheses of the ASCCM

The primary hypotheses are listed in Tables 3 and 4. The first set of hypotheses, labeled antecedent hypotheses (AH), were designed to test the associations between antecedent variables (e.g., pile up demands) and psychosocial outcomes (e.g., caregiver burden) within the Autism group. Although not hypothesized, parallel tests were also conducted within the Down syndrome and total Disability groups. Thus, analyses were run separately within the following samples: 1) adult siblings of adults with autism, 2) adult siblings of adults with Down syndrome (DS), and 3) adult siblings of adults with any disability (i.e., autism, Down syndrome [DS], or Down syndrome with a GARS score > 85 [the Mixed group]). In each subsection below, the primary hypothesis is stated, followed by statistical evidence for its support (or lack thereof) for each of the three study groups. The means and standard deviations for all antecedent, mediating, and psychosocial outcome variables are shown in Tables 15, 16, and 17 respectively.

Table 18 presents correlations between the antecedent and outcome variables within all study groups. A priori primary hypotheses within the Autism group were examined as one-tailed bivariate correlations (p values < .05 were significant). Since no a priori hypotheses were made for the DS and disability group participants, primary hypotheses were examined as two-tailed bivariate correlations within the groups. To help protect against Type 1 error, only p values < .01 were considered significant.

Number of Non-Disabled Siblings (AH1.A)

Having more non-disabled siblings in a family was hypothesized to be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits within adult siblings of adults with autism. No relationships were found between the number of disabled siblings in a family and any of the psychosocial outcomes within any of the 3 study groups (see Table 18).

Sibling Relationship Quality (AH1.B)

It was hypothesized that better sibling relationship quality would be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits in adult siblings of adults with autism. As predicted, sibling relationship quality was associated with increased reports of benefits within the Autism group ($r = .55$, $p < 0.01$). Sibling relationship quality also was associated with decreased burden ($r = -.40$, $p < 0.01$ [DS]; $r = -.44$, $p < 0.01$) [Disability]), and increased reported benefits within the DS and Disability groups ($r = .66$, $p < 0.01$ [DS]; $r = .56$, $p < 0.01$ [Disability]; see Table 18)

An exploratory analysis of variance comparing the Autism, DS, and Mixed groups indicated that siblings of adults with DS reported significantly higher relationship quality than did siblings of adults with autism, $F(2,86) = 6.89$, $p = .00$. Post hoc analyses using Bonferroni adjustments indicated significant differences in relationship quality between the Autism ($M_{Autism} = 150.26$) and DS groups ($M_{DS} = 181.16$) (see Appendix Table B.1).

Gender of the Non-Disabled Sibling (AH.2)

Compared to male caregivers, female adult sibling caregivers were hypothesized to have increased health-related quality of life, decreased caregiver burden, and increased reports of benefits within the Autism group. No significant relationships were found between the gender of the non-disabled sibling and psychosocial outcomes within any of the study groups (Autism, DS, or Disability; see Table 18.)

Severity of Autism Symptoms (AH3.A)

More severe autism symptoms were hypothesized to be associated with decreased mental and physical health-related quality of life, increased caregiver burden, and decreased reports of benefits in non-disabled adult siblings. Within the Autism group, there was no relationship between the severity of the disabled sibling's symptoms and the psychosocial outcomes of the non-disabled sibling. However, within both the DS and Disability groups, increased autism symptoms were associated with decreased mental HRQOL ($r = -.38$, $p < 0.01$ [DS]; $r = -.28$, $p < 0.01$ [Disability]) and increased caregiver burden ($r = .42$, $p < 0.01$ [DS]; $r = .52$, $p < 0.01$ [Disability]; see Table 18.)

Problem Behavior (AH3.B)

It was hypothesized that the presence of more problem behaviors would be associated with lower health-related quality of life, greater caregiver burden, and fewer reported benefits within the Autism group. As predicted, problem behavior was correlated with greater caregiver burden ($r = .56$, $p < 0.01$) within the Autism group.

Problem behavior also was associated with increased caregiver burden within the DS and Disability groups (r = .47, $p < 0.01$ [DS]; r = .62, $p < 0.01$; [Disability]) and with decreased mental HRQOL within the Disability group (r = -.30, $p < 0.01$; see Table 18).

Adaptive Behavior (AH3.C)

More independent living skills, as measured by higher adaptive behavior, was predicted to be associated with higher HRQOL, lower caregiver burden, and more reported benefits within the Autism group. No significant correlations were found between adaptive behavior and any of the psychosocial outcomes within the Autism group. However, increased adaptive behavior was associated with decreased caregiver burden within the Disability group as a whole (r = -.35, $p < 0.01$; see Table 18).

Social Support (AH4.A)

Greater social support was hypothesized to be associated with increased HRQOL, decreased caregiver burden, and increased reports of benefits within the Autism group. As predicted, social support was associated with decreased caregiver burden (r = -.41, $p < 0.05$) and increased reported benefits (r = .41, $p < 0.05$) within the Autism group. Within the DS and Disability groups, social support was associated with increased mental HRQOL (r = .53, $p < 0.01$ [DS]; r = .43, $p < 0.01$ [Disability]) and decreased caregiver burden (r = -.59, $p < 0.01$ [DS]; r = -.52, $p < 0.01$ [Disability]; see Table 18.

Respite, Formal, and Financial Supports (AH4.B)

It was hypothesized that increased use of respite care services and increased use of financial and/or formal supports would be associated with increased mental and physical HRQOL, decreased caregiver burden, and increased reports of benefits. Two indices were used to measure services: ratings of the helpfulness of services (rated from 1 to 5) and the number of services received. As predicted, within the Autism group, mean helpfulness of services was correlated with increased mental HRQOL ($r = .33$, $p < .05$) and increased reported benefits ($r = .62$, $p < 0.01$). In contrast to predictions, however, number of services received was associated with *increased* caregiver burden ($r = .40$, $p < 0.05$) within the Autism group. However, the causal direction of this association likely runs from need for services (high burden) to receipt of services, and not vice versa. Helpfulness of services also was associated with increased mental HRQOL ($r = .38$, $p < 0.01$) within the DS group, and with decreased caregiver burden ($r = -.29$, $p < 0.01$) and increased benefits ($r = .45$, $p < 0.01$) within the overall Disability group (see Table 18).

An exploratory analysis was run to test whether the average helpfulness of services was correlated to the number of services received. Within the Autism group, the helpfulness of services and number of services received were correlated ($r = .52$, $p < .01$; See Appendix B2).

Pile-up Demands (AH.5)

Increased pile-up demands were hypothesized to be associated with decreased HRQOL, increased caregiver burden, and decreased reports of benefits. Within the

Autism group, pile-up demands were significantly associated with decreased physical HRQOL (r = -.33, p < .05). Within the DS and Disability groups, pile-up demands were associated with decreased mental HRQOL (r = -.46, p < 0.01 [DS]; r = -.29, p < 0.01 [Disability]; see Table 18.)

Between-Group Hypotheses

Two between-group hypotheses were proposed: compared to the DS group, siblings in the Autism group were expected to report lower HRQOL and more caregiver burden.

Mental Health-Related Quality of Life (OH6.A)

It was predicted that adult siblings of adults with autism would experience poorer HRQOL than would siblings of adults with DS. As predicted, those in the Autism group reported significantly worse mental HRQOL (M[SD] = 42.45[10.20]) than those in the DS group (M[SD] = 46.79[10.90]) (t(80)= -1.78, p = .04, one-tailed). An analysis of variance to examine other possible differences between the Autism, DS, and Mixed groups on mental HRQOL indicated a trend, *F*(2,91) = 2.86, *p* = .06. Because the ANOVA was not significant, follow-up post-hoc tests were not run (see Table 19).

Physical Health-Related Quality of Life (OH6.A)

There were no significant differences between the Autism (M[SD] = 51.35[10.89]) and DS groups (M[SD] = 54.50[7.15]) on physical HRQOL, although there was a trend toward significance (t(43.7) = 1.58, p = .08). The analysis of variance (ANOVA) comparing the Autism, DS, and Mixed groups on physical HRQOL also was not significant, *F*(2,91) = 1.34, *p* = .27; (see Table 19).

Caregiver Burden (OH6.B)

Hypothesis OH6.B predicted that siblings of adults with autism would report greater caregiver burden than would siblings of adults with Down syndrome. As predicted, non-disabled siblings in the Autism group (M[SD] = 2.37[.72]) reported significantly higher caregiver burden than those in the DS group (M[SD] = 1.61[.69]; t(76)= 4.65, p = .00). An analysis of variance comparing the Autism, DS, and Mixed groups also indicated significant differences in the level of caregiver burden between groups, *F*(2,86) = 12.96, *p* = .00. Post hoc analyses using Bonferroni adjustments indicated significantly greater caregiver burden in the Autism group compared to the DS group (M difference[SD] = .76[.18]; p < .01) and in the Mixed group compared to the DS group (M difference[SD] = -.97[.25]; p < .01) (see Table 19).

Reported Benefits

No between-group a priori hypothesis was proposed for reported benefits. However, an exploratory ANOVA examining differences in reported benefits between the three study groups was not significant (see Table 19).

Testing the Secondary Hypotheses of the ASCCM

The secondary hypotheses posited relationships between exploratory antecedent and mediating variables and the psychosocial outcomes within the Autism group. Similar to the primary hypotheses, relationships also were examined within the DS and Disability groups. Results of these analyses are shown in Tables 20, 21 and 22. As before, p values < .05, one-tailed, were considered significant within the Autism group, and p values < .01, two-tailed, were considered significant within the DS and Disability groups.

Cognitive Appraisal (EH.1)

It was hypothesized that a positive primary appraisal of the caregiving situation would be associated with increased HRQOL, decreased caregiver burden, and more reported benefits in adult siblings of adults with autism and, conversely, that a negative appraisal would be related to decreased HRQOL, increased caregiver burden, and fewer reported benefits. As noted earlier, cognitive appraisal was measured using three subscales of the Stress Appraisal Measure (SAM): threat, challenge, and centrality. The three subscales were analyzed separately. Threat was operationalized as a negative appraisal type, whereas challenge was operationalized as a positive appraisal type. A centrality appraisal type was operationalized as neutral, neither positive nor negative.

As predicted, a tendency toward using threat appraisals was associated with increased caregiver burden ($r = .58$, $p < 0.01$) within the Autism group. Within the DS and Disability groups, threat appraisals were also associated with increased caregiver burden ($r = .82$, $p < 0.01$ [DS]; $r = .75$, $p < 0.01$ [Disability]), as well as with decreased mental HRQOL ($r = -.56$, $p < 0.01$ [DS]; $r = -.43$, $p < 0.01$ [Disability]).

Also as predicted, a tendency to use a challenge appraisal was associated with increased reported benefits within the Autism group ($r = .33$, $p < .05$); this pattern was replicated within the DS and Disability groups ($r = .56$, $p < 0.01$ [DS]; $r = .54$, $p < 0.01$ [Disability]). Within the Disability group, a challenge appraisal type was also significantly associated with increased mental HRQOL ($r = .29$, $p < 0.01$) and decreased caregiver burden ($r = -.31$, $p < 0.01$ [Disability]).

Centrality was not correlated with psychosocial outcomes within the Autism subgroup, but was associated with increased caregiver burden within the DS and Disability groups ($r = .39$, $p < 0.01$ [DS]; $r = .30$, $p < 0.01$ [Disability]; see Table 20).

Coping Strategies (EH2.A & EH2.B)

Hypothesis EH2.A predicted that increased use of problem based and/or emotional-approach coping strategies would be associated with better psychosocial outcomes (i.e., increased mental and physical HRQOL, decreased caregiver burden, and increased reported benefits). Hypothesis EH2.B predicted that passive avoidant coping strategies would be associated with worse psychosocial outcomes within the Autism group.

In contrast to predictions, the use of problem-based coping strategies was uncorrelated to psychosocial outcome variables within the Autism group, although it was associated with decreased physical HRQOL ($r = -.46$, $p < 0.01$[DS]; $r = -.31$, $p < 0.01$ [Disability]) and increased caregiver burden within the DS and Disability groups ($r = .54$, $p < 0.01$ [DS]; $r = .37$, $p < 0.01$ [Disability]). However, as predicted, within the Autism group, emotional-approach coping was related to reported benefits ($r = .35$, $p < .05$) and increased use of avoidant coping was associated with decreased mental HRQOL ($r = -.66$, $p < 0.01$), increased caregiver burden ($r = .59$, $p < 0.01$) and decreased reported benefits ($r = -.47$, $p < 0.05$). Within the DS and Disability Groups, emotional-approach coping was unrelated to outcomes, and avoidant coping was associated with decreased mental HRQOL ($r = -.67$, $p < 0.01$ [DS]; $r = -.65$, $p < 0.01$ [Disability]) and increased caregiver burden ($r = .79$, $p < 0.01$ [DS]; $r = .72$, $p < 0.01$ [Disability]; see Table 20).

Age and Developmental Life Stage (EH.3)

Using age as a proxy for developmental life stage, it was hypothesized that mental and physical HRQOL would decrease and caregiver burden would increase for older caregivers (and caregivees). Consistent with predictions, within the Autism group, increased age of the non-disabled siblings was associated with decreased physical

HRQOL ($r = -.33$, $p < .05$). Increased sibling age was also associated with decreased physical HRQOL within the overall disability group ($r = -.31$, $p < 0.01$; see Table 20.)

Marital Status of Non-Disabled Sibling (EH.4)

Compared to single adult siblings of adults with autism, it was predicted that those who were married would have greater health-related quality of life, less caregiver burden, and more reported benefits. Within the Autism group, unmarried siblings experienced more caregiver burden M(SD) = 2.54(.75) than married siblings M(SD) = 2.03(.55), $t(27) = -1.89$, $p = .035$. Similar trends favoring married siblings were found for mental HRQOL within the Disability group ($M[SD]_{married} = 47.51[9.34]$ vs. $M[SD]_{unmarried} = 42.04[11.96]$; $t(91.9)= 2.49$, $p = .02$) and for reported benefits within the DS group ($M[SD]_{married} = 3.27[1.06]$ vs. $M[SD]_{unmarried} = 3.88[.80]$; $t(44)= -2.20$, $p = .03$; see Table 21, however, none were significant at the $p <.01$ level.

Sibling Birth Order (EH.5)

Hypothesis EH.5 predicted that siblings who were older than their disabled sibling would report greater HRQOL in adulthood. No specific hypotheses were made regarding the effects of sibling birth order on caregiver burden or reported benefits. Sibling birth order was unrelated to psychosocial outcomes across all study groups (see Table 22).

An additional exploratory analysis tested whether the distance a non-disabled sibling lived from one’s disabled sibling was associated with caregiver burden; no significant differences were found (see Appendix B3).

Testing for Mediation

I used Baron and Kenny's method (1986) to test whether cognitive appraisal, as operationalized using the three subscales of the SAM (threat, challenge, and centrality; Peacock & Wong, 1990) and coping style, as operationalized using the three subscales of the BRIEF-COPE (problem-focused, emotional approach, and avoidant; Carver, 1997) mediated any of the relationships between antecedent variables and caregiver burden within the Adult Sibling Caregiver Conceptual Model. Four antecedent variables were chosen for the mediation analyses (autism symptom severity, problem behavior, adaptive behavior, and pile-up demands) because they have been identified as useful predictors within a stress and coping framework (Lazarus and Folkman, 1984; McCubbin & Patterson, 1983). In Step 1, the four antecedents were correlated with caregiver burden (see Appendix Table B4 for Step 1 analyses). If an antecedent variable was determined to be significantly correlated with caregiver burden ($p < .05$, one-tailed within the Autism group and $p < .01$, two-tailed within the DS and Disability groups), it was used in Step 2 of the mediation analyses and correlated to the 6 mediating variables listed above. Step 2 demonstrated which antecedents were correlated to mediating variables as well as to caregiver burden (see Appendix Table B5.) A summary of Steps 1 and 2 can be found in Table B6 of the Appendix. Next, Step 3 was run, in which the mediators that were significantly correlated with antecedents in Step 2 were regressed onto caregiver burden, while controlling for the antecedent variables (see Appendix Tables B7 and B8). Finally, Step 4 was run, in which antecedents and mediating variables were simultaneously regressed onto caregiver burden, to determine whether there was actual mediation, either partial or complete (see Tables 23 and 24).

Results of the Mediation Analyses

Tables 23 and 24 present the results of the final step, Step 4, of the mediation analysis, separately for the Autism, DS and overall Disability groups. Based on Steps 1, 2 and 3, there was only one possible test of mediation within the Autism group. As shown, the relationship between problem behavior and caregiver burden was partially mediated by avoidant coping strategies. Specifically, the relationship between problem behavior and caregiver burden was no longer significant once avoidant coping was entered into the model (p = .07). Moreover, the beta weight between problem behavior and caregiver burden decreased from .50 to .31 (see Table 23).

Based on Steps 1, 2 and 3, there were three possible tests of mediation within the DS group. As shown in the table, threat appraisal mediated the relationship between caregiver burden and both severity of autism symptoms and problem behavior. Specifically, threat was significantly related to burden in both regressions and after entry into the regression, the relationship between caregiver burden and autism symptoms and caregiver burden and problem behavior was reduced to non-significance. In addition, after threat was entered into the regression, the beta weight between severity of symptoms and burden decreased from .38 to .08 (p = .40) and the beta weight between problem behavior and caregiver burden decreased from .44 to .17 (p = .07). The third test of mediation, which tested the impact of centrality on the relationship between severity of symptoms and caregiver burden, was inconclusive. Although the relationship between autism symptoms and caregiver burden was reduced below the significance threshold when centrality was entered into the regression, centrality also was not significantly related to burden in the regression. Thus, we could not confirm that centrality mediated the relationship between autism symptoms and caregiver burden (see Table 23).

Within the overall Disability group, based on Steps 1, 2 and 3, there were eight possible tests of mediation (see Table 24). Mediation was present in 5 of the 8 cases, as shown by a significant beta weight for the mediator when entered into the regression and a reduction in the beta weight between the antecedent and caregiver burden. That is, threat mediated the relationships between 1) severity of symptoms and caregiver burden (beta decreased from .50 to .21; p = .01), 2) problem behavior and caregiver burden (beta decreased from .57 to .31, p = .00), and 3) adaptive behavior and caregiver burden (beta decreased from -.33 to -.10; p = .19). However, for severity of symptoms and problem behavior the mediation was partial, because the residual beta weight was still significant. Only in the case of adaptive behavior did the relationship between the antecedent and caregiver burden reduce below significance once threat was entered into the regression.

In addition, 4) avoidant coping mediated the relationship between severity of symptoms and caregiver burden (beta decreased from .50 to .25; p = .00) and 5) problem behavior and caregiver burden (beta decreased from .57 to .31; p = .00). However, both relationships were partially mediated; the relationships between the antecedent and caregiver burden remained significant even after avoidant coping was entered into the regression equation.

Exploratory Analyses: Testing the Adult Sibling Caregiver Conceptual Model (ASCCM)

Stepwise regression was used to identify the best set of independent predictors of the four psychosocial outcomes (mental and physical HRQOL, caregiver burden, and reported benefits). This exploratory analysis was restricted to the Disability group because it had the largest sample size (n = 97). I conducted separate stepwise regression analyses using each of the four psychosocial outcomes as dependent variables. To control for the impact of autism diagnosis within the Disability group, a dichotomized dummy variable coded 1 for a GARS-2 score of 85 or higher and 0, otherwise, was entered first into the regression equation in Step 1. The antecedent and mediating variables from the overall ASCCM model found to be significant bivariately, were entered hierarchically as independent variables in Steps 2 and 3 of the regression. That is, the antecedent variables that were significantly correlated (at the $p < .05$ level) with the outcome variable were entered as the first block. Then, the mediating variables that were significantly correlated with the outcome variable were entered as the second block (see Tables 25, 26, 27 and 28).

For mental HRQOL, after controlling for autism diagnosis, of the 17 variables entered into the model, only one variable, avoidant coping, was a significant independent predictor of mental HRQOL, accounting for 43% of the variance ($R^2 = .43$, F[4,92] = 17.29 , p = .00; see Table 25.

For physical HRQOL, after controlling for autism diagnosis, age of non-disabled siblings and pile-up demands were significant independent predictors of physical HRQOL, accounting for 17% of the variance ($R^2 = .17$, F[3,93] = 6.35, p = .00); see Table 26).

For caregiver burden, after controlling for autism diagnosis, of the 17 variables entered into the model, three variables predicted caregiver burden. Problem behaviors, threat appraisal, and avoidant coping together accounted for 67% of the variance ($R^2 = .666$, F[5, 91] = 36.36 p = .00) (see Table 27).

For reported benefits, after controlling for autism diagnosis, of the 17 variables entered into the model, three variables autism diagnosis, sibling relationship quality, and challenge appraisal were significant independent predictors of reported benefits. Together, they accounted for 45% of the variance (R^2 = .45, F[4,92] = 18.99, p = .00; see Table 28).

DISCUSSION

This study is relatively unique in its focus and design in exploring psychosocial outcomes of adult siblings of adults with autism. Prior research in autism has typically focused on parent caregivers rather than sibling caregivers (Stuart & McGrew, 2009; Pakenham, 2005) and on the adjustment of siblings of children with autism rather than siblings of adults with autism (Hastings, 2003). Moreover, the few studies that have examined the outcomes of adult siblings of adults with intellectual disabilities or mental illness have not focused on autism specifically (e.g., Heller & Kramer, 2009; Heller & Arnold, 2010; Seltzer et al., 2005; Stoneman et al., 2005). In addition, the majority of studies on caregiver stress and burden within autism have tended to be atheoretical and limited to examining only one or two outcome variables.

In contrast, the current study focused on outcomes and predictors of outcomes for adult siblings of adults with autism with some caregiving role and incorporated a theoretical framework (ASCCM model) to organize the factors that were identified empirically and theoretically as potentially impacting the outcomes of adult siblings. The model utilizes a stress and coping framework to understand psychosocial outcomes and builds on the work of Lazarus and Folkman (1984), McCubbin and Patterson (1983) and McDonald, Donner, and Poertner (1992). Importantly, aspects of the stress and coping model were included that have tended not to be examined in prior work. For example, cognitive appraisal and coping strategies were examined as potential mediators of outcomes. Another relatively innovative design feature was the inclusion of multiple dependent variables that are not routinely included in studies of caregiver stress: mental and physical HRQOL and benefit finding.

The study hypotheses focused on three broad areas: 1) the expectation for poorer psychosocial outcomes for sibling caregivers of adults with autism vs. DS (between group differences), 2) within group predictors of these outcomes (within the Autism group), 3) and the role of mediating relationships between the antecedent predictors and outcomes. In general, there was support for the hypotheses within each of these three broad areas. (Table 29 summarizes the results for the primary hypotheses. See Figures 5, 6, 7, and 8 for visual depictions of the antecedent and mediating variables that were significantly associated with the four psychosocial outcome variables.)

As predicted, adult siblings of adults with autism exhibited greater levels of caregiver burden and lower health-related quality of life than did adult siblings of adults with DS. These findings for caregiver burden parallel those found previously for parent caregivers and extend these findings to sibling caregivers. That is, compared to other disability groups, caring for those with ASD was associated with significantly more reported burden for caregivers regardless of the specific relationship to the person with ASD (sibling, parent) (Mao, 2012, Xiong et al., 2011). Moreover, siblings of adults with DS reported less caregiver burden than both adult siblings of adults with autism and those displaying a mixed presentation of Down syndrome and autism, implying that symptoms of autism, either alone or co-morbid with another diagnosis, present an increased risk of stress and caregiver burden.

However, the negative impact of caring for a person with autism was not limited to a subjective feeling of burden. Compared to DS, caring for a sibling with autism also was associated with lower levels of mental HRQOL and nearly significantly to decreased physical HRQOL (p = .08). Although, there has been relatively less research on HRQOL, these findings are consistent with previous studies. Caregivers of children with autism were reported to have lower HRQOL scores than the general population (Khanna et al., 2011), as were mothers of adolescents and adults with autism (Barker et al., 2011). In addition, siblings of brothers/sisters with autism were found to have slightly worse health and higher levels of depressive symptoms than siblings of individuals with DS (Hodapp & Urbano, 2007). Moreover, in addition to self-reported health, compared to caregivers of typically developing children, caregivers of children with autism also may display elevated concentrations of the proinflammatory biomarker CRP and reported more frequent episodes of ill physical health (Lovell et al., 2012). Taken together these findings suggest that caring for a person with autism may produce real negative health impacts on the caregiver.

One unique component of this study is the exploration of reported benefits in adult siblings. Although reports of benefits have been examined in a number of populations including mothers of children with Asperger’s syndrome (Pakenham et al., 2005) and college age siblings of individuals with disabilities (Burton & Parks, 1994), to my knowledge, they have never been examined in adult siblings of adults with autism. Overall, compared to siblings of individuals with DS, siblings of adults with autism reported greater benefits in their relationship with their disabled sibling. This finding is particularly striking because siblings of adults with autism also reported lower HRQOL and more burden in those same relationships. Although it is not entirely clear why siblings of those with autism compared to siblings of those with DS would report more stress and more benefits within the same relationship, past literature provides some possible explanations. For example, Fletcher et al. (2012) noted that mothers of children with ASD were able to “rise above the negatives/costs associated with caring…and find silver linings”. That is, hope may be a key factor underlying these findings. For example, Schwartz and Hadar (2007) found that hope among parents who care for their adult child with physical disabilities leads to increased benefit finding. Similarly, in a meta-analysis of benefit finding generally, hope and optimism were found to moderate the relationships between benefit finding and adjustment outcomes (Hegelson et al., 2006). More specifically, vicarious futurity (VF), a component of hope that reflects both positive and negative attitudes, has been found to predict depressive symptoms and life satisfaction in parents of children with autism (Faso et al., 2013). Future research may usefully examine whether higher levels of VF also are present in adult siblings of adults with autism.

In addition to exploring the construct of hope, another reason for the increased reports of benefits in adult siblings of adults with autism may have stemmed from use of a more positive cognitive appraisal strategy. That is, their perception of having a sibling with a disability may have been more favorable, resulting in both a positive outlook and reported benefits. In general, increased use of positive appraisal (e.g., challenge) and decreased use of negative appraisal (e.g., threat) has been shown to predict better adjustment (Lazarus & Folkman, 1984; Peacock &Wong, 1990). Moreover, similar to the current study, findings from a large meta-analysis also reported that benefit finding is related to a positive reappraisal style (Helgeson et al., 2006). However, in the current study, compared to siblings of adults with DS, siblings of adults with autism did not use more challenge appraisal strategies and in fact, tended to use more threat appraisals ($M[SD]_{Autism} = 2.72[1.11]$; $M[SD]_{DS} = 1.80[.90]$, $t(74) = 3.91$, $p = .00$). It is worth noting, however, that the measures used in the current study, the Benefit Finding Scale (Tomich & Helgeson, 2004a) and the Stress Appraisal Measure (Peacock & Wong, 1990) did not necessarily focus on parallel aspects of having a disabled sibling. That is, the SAM focused on how a non-disabled sibling appraised caring for the sibling, not on how (s)he appraised his/her overall relationship with his/her sibling. In contrast, the BFS explored general benefits to having a sibling with autism and not the benefits (if any) of having to care for a sibling with autism. Future research is needed to explore whether, and in what circumstances adult siblings of adults with autism report benefits and positively appraise providing care for their disabled sibling in adulthood.

As stated earlier, another key focus of the study was to examine predictors of psychosocial outcomes within the Autism group, and separately, within the DS and Disability groups. Five of the ten hypothesized antecedent variables (relationship quality, problem behavior, social support, helpfulness of services, and pile-up demands) were consistent predictors of outcomes across all study groups, marking these as particularly important general predictors. Three other variables were predictive within one or more groups (severity of symptoms was a significant predictor within the DS and Disability groups, number of services received was a predictor within the Autism group, and adaptive behavior was a predictor within the Disability group), suggesting these predictors may be specific to a particular disability group. In contrast, two predictors, number of non-disabled siblings and gender of the non-disabled sibling failed to predict significantly within any of the groups, suggesting they may be only weakly related or non-predictors.

There are two caveats to the interpretation of the within group analyses, however. First, between groups differences in significance do not necessarily imply differences in effect size. Predictors may not have reached significance in the Autism and DS groups because the sample sizes were limited (low power), not because the effects were actually smaller. The inclusion of the Disability group (n = 97) helped to address this limitation. That is, effects were sometimes significant in the Disability group that were only trends in the other study groups. Second, because the larger Disability group is comprised of the participants in the Autism, DS, and Mixed groups, findings within the Disability group cannot be interpreted as independent replications. Nevertheless, the inclusion of the Disability group is helpful both for the increased power, and as a vehicle to include the Mixed group of participants (n = 12), a subgroup too small to be analyzed separately.

Several of the within group findings were noteworthy. As predicted, relationship quality, which has been rarely studied among siblings of those with autism or with disability, was positively associated with reported benefits in adult siblings of adults with autism and DS. That is, when siblings feel “close”, it may be easier to see the positive aspects of a relationship. The results are consistent with findings for siblings generally, in that the quality of sibling relationships in childhood are associated with the positive and negative feelings siblings hold for each other in adolescence (O’Laughlin, 2006). The results are also consistent with findings by Skotko et al. (2011) and Hodapp and Urbano (2007); siblings of individuals with a disability (DS or autism) who have greater contact with their disabled siblings, tend to express pride and affection towards their disabled siblings and feel more rewarded in their relationships.

Relationship quality also was negatively correlated with caregiver burden within the DS and Disability groups (in the direction consistent with expectations), but not within the autism group (the correlation was near zero, r = .04). That is, for the non-autism groups, relationship quality both predicted positive feelings (benefit finding) and provided some protection against negative outcomes, i.e., caregiver burden. Differences in the mean levels of burden and relationship quality in the autism and disability groups could help explain the lack of association within the autism group. For example, compared to the DS group, the Autism group displayed significantly higher levels of burden on the one hand (M_{Autism} = 2.37 vs. M_{DS} = 1.61, t = 4.65) and significantly lower relationship quality on the other hand (M_{Autism} = 150.26 vs. M_{DS} = 181.16, t = -3.95). Thus, those in the autism group reported both lower relationship quality and higher burden. One possible explanation for these group differences, then, may be that the relatively lower relationship quality in the autism group may not have been strong enough to outweigh the increased burden associated with caring for a sibling with autism. However, future research will be needed to more clearly understand these findings.

As expected, disability severity, as measured by several types of indicators (i.e., severity of symptoms, problem behaviors, and adaptive behavior), was a fairly consistent predictor of negative outcomes across all disability groups. However, there were some differences in the consistency and relative predictive power of the different indicators of severity. As mentioned earlier, problem behavior was a strong and consistent predictor of burden across disability groups. Moreover, of the severity variables, it was the only significant predictor of any outcome within the autism group. In addition, problem behavior was correlated significantly with decreased mental HRQOL within the DS and overall disability groups and at trend level within the Autism group. These findings are consistent with prior studies noting that problem behaviors are correlated with burden (Kring et al., 2010) and that depressive and anxious symptoms of mothers of adolescents and adults with autism fluctuate with their child's behavior problems (Barker et al., 2011). That is, dealing with problematic behaviors (e.g., tantrums, self-injury, etc.,) is one of the most difficult and challenging aspects of caregiving. One implication of these findings is that evidence-based services to effectively treat problem behaviors may be useful not only for the person with autism but also to help reduce the burden and mental health impact on caregivers of individuals with autism.

Interestingly, severity of autism symptoms was strongly related to decreased mental HRQOL and increased caregiver burden only in the DS and Disability groups, not in the autism group. In fact, within the autism group, the correlations were close to zero ($r = .12$ and $-.01$ respectively). One reason for the lack of association between symptoms and outcomes is limited variability in symptoms within the autism group. That is, symptoms of autism are already part of a diagnosis of autism and thus are common among all members of the autism group, creating a restriction of range that limits the ability to predict outcomes. In contrast, in the non-autism groups, where there is considerable variability in symptoms of autism, symptoms were strongly predictive. An important implication of these findings is that the apparent non-predictiveness of autism symptoms within the autism group may underestimate their true impact on outcomes. Even for those suffering from a major disability such as Down syndrome, having additional symptoms of autism adds measurably to the burden on caregivers. Thus, not only is burden higher for caregivers of those with autism compared to other disability groups, even within non-autistic disability groups, caring for an individual with autistic symptoms adds to the burden of care.

Similarly, adaptive behavior was significantly correlated with caregiver burden within the Disability group, trended towards significance within the DS group, but displayed a near zero relationship within the Autism group. According to Esbensen et al. (2010), adults with ASD as a group tend to have lower levels of adaptive behavior and are less likely to be classified as having high or moderate levels of independence in adult life, as compared to adults with DS. Thus, similar to autism symptoms, adaptive behavior may have a limited range concentrated at the lower end within the autism group, leading to reduced predictive power. Consistent with this observation, at the scale level in the current study, the modal number of tasks performed independently was 1 for the Autism group and 3 for the DS group, indicating more negative skew within the Autism group.

In addition, the Instrumental Activities of Daily Living (IADL) scale may not be a sensitive measure within the Autism group. The scale was developed originally for older adults in community, clinic, or hospital settings to assess changes in their functioning levels over time (Lawton & Brody, 1969), and, to my knowledge, has not been used to assess the functioning level of adults with autism. One possible problem is that range restriction and decreased sensitivity within the Autism group may have occurred at the item level because the IADL is scored on a dichotomous scale. If an individual could not complete a task independently, (s)he earned a score of "0" as opposed to a "1". Therefore, an individual who "needs to have meals prepared and served" and an individual who "prepares adequate meals if supplied with ingredients" would both receive a score of "0" because they are unable to "plan, prepare, and serve adequate meals independently." This dichotomous scoring system may not be appropriate for individuals with very low functioning, such as autism, and could restrict them to earn scores of "0" on items, even when they can perform a portion of a task.

Importantly, the availability of external resources and supports was associated with decreased burden across all disability groups. That is, siblings tended to report more favorable outcomes when they perceived or received some kind of outside supports, either social support or professional services. In addition, within the Autism group, increased social support was also related to increased reports of benefits, whereas, in the DS group, social support was also related to increased mental HRQOL. These findings for social support are consistent with studies showing that more social support and fewer unmet needs in social domains are related to decreased burden in parent caregivers of those with ASD (Cadman et al., 2012; Stuart & McGrew, 2009) and that smaller social networks are related to increased anxiety in mothers of adolescents and adults with autism (Barker et al., 2011).

The findings for services also are consistent with prior research that direct supports and paid services reduce caregiver burden (Ruble & McGrew, 2007). Specifically, the greater the perceived helpfulness of the services the better the mental HRQOL (Autism and DS groups), the lower the burden (overall Disability group), and the greater the perceived benefits (Autism and Disability groups). Interestingly, simple reception of services (i.e., number of services received) was a less sensitive predictor of outcomes than was sibling rated helpfulness of services. That is, what appears to be most critical, is not the number of services received, but the perceived helpfulness or quality of those services. Together with the results for social support, these findings suggest that having others to share or to help lift the load, can be an important factor in reducing negative outcomes. These findings also demonstrate the importance of developing evidence-based, quality care for adults with autism and are consistent with recommendations that empirically supported treatments be extended to additional (i.e., adult) age groups (Wilczynski et al., 2011).

Consistent with stress and coping theory (Lazarus & Folkman, 1984; McCubbin & Patterson, 1983), that stress is a function of the imbalance between demands and resources and that stress outcomes should worsen with increasing demands, additional pile-up demands were related to decreased mental or physical HRQOL across all three disability groups. These results parallel recent work on the stress effects of caregiving for individuals with disabilities. For example, Barker et al. (2011) noted that mothers of adolescents and adults with autism experienced increased anxiety when undergoing stressful life events, and younger mothers experienced greater depressive symptoms, suggesting that older mothers had learned coping strategies.

The current study also explored variables that are identified as important within stress-coping theory (i.e., appraisal and coping), but not typically examined in studies of caregiving for individuals with disabilities (Stuart & McGrew, 2009). For example, cognitive appraisal was consistently related to outcomes across all disability groups. In particular, threat appraisals were strongly related to increased caregiver burden (for all disability groups) and decreased mental HRQOL (DS and overall Disability groups) and challenge appraisals were related to increased benefit finding (all groups), increased mental HRQOL (Disability group) and decreased burden (DS and overall Disability groups). Thus, as predicted from theory, positive appraisals (challenge) were associated with better outcomes, and negative appraisals (threat) were associated with poorer outcomes. Importantly, this confirms the subjective and transactional nature of stress and the critical place of cognitive factors in explaining stress outcomes. That is, an individual's subjective experience, rather than an objective description of a stressor event tends to be the most critical to understanding the stress response. These findings also have treatment implications. In addition to attempting to change the stressor directly, teaching caregivers to try to view their circumstances as a challenge rather than a threat, may lead to better quality of life, decreased burden and a perception of increased benefits in their relationship with their disabled sibling. Future research may also usefully expand the exploration of appraisal to include secondary appraisal strategies, which focus on perceptions of control. For example, Peacock and Wong (1990) cited three relatively independent dimensions: the extent to which the situation is controllable-by-self, controllable by others, and uncontrollable-by-anyone, which may be associated with different types of coping strategies.

The results also supported the importance of coping style in explaining outcomes, as classified using Lazarus and Folkman’s (1984) functional categories of coping (i.e., problem focused, emotional approach, and avoidant). In particular, avoidant coping strategies were a strong predictor of negative outcomes across all disability groups. The use of avoidant coping strategies was associated with decreased Mental HRQOL and increased caregiver burden within all groups, and decreased reports of benefits within adult siblings of adults with autism. Moreover the sizes of the effects were very strong, highlighting the potentially large negative impact of avoidance as a coping style when dealing with stress. Importantly, these findings are consistent with theory (Lazarus & Folkman, 2001), with the general literature on the negative impact of avoidant coping on outcomes (Roth & Cohen, 1986) and with the literature on parent caregivers of children with ASD (Stuart & McGrew, 2009; Benson, 2010).

Somewhat surprisingly, however, problem-focused coping was unrelated to outcomes in the autism group and correlated in a direction opposite to the one hypothesized for both caregiver burden and Physical HRQOL within the DS and overall disability groups. Although the implied direction in the original hypothesis was that a helpful coping style, such as problem–focused coping would result in better outcomes (e.g., increased HRQOL and decreased burden), an alternate and more likely interpretation of these findings is that overall severity of the caregiving situation may lead both to increased burden and an increased need to problem solve. Additionally, goal-directed coping responses are believed to be most useful when an individual believes he/she has control over the stressor. In the case of autism or other chronic disabilities, it may be more difficult to problem-solve a chronic disability. When a stressor must be accepted, one may more usefully rely on non-problem focused strategies to regulate distress such as emotion-focused coping (O'Rourke & Cappeliez, 2002). This may explain why an emotional-approach style of coping was associated with increased reports of benefits within the Autism group and more positive outcomes at a trend level across all disability groups.

Three additional exploratory hypotheses were proposed to examine constructs that have rarely been studied in the literature: the ages of siblings in a dyad, the non-disabled sibling's marital status, and the order in which the siblings were born (see Table 30 for a summary of the results of the exploratory hypotheses). As predicted, being married was related to lower caregiver burden within the Autism group. However, in contrast to predictions, there was no association between birth order and any outcomes. Moreover, with respect to sibling age, in contrast to prediction, increased age of the non-disabled siblings was associated with decreased rather than increased physical HRQOL within the Autism and Disability groups. That is, caregiving does not necessarily result in a reduction in physical stress as one becomes a more experienced caregiver. However, the samples were relatively young ($M[SD]_{Autism} = 31.87[12.15]$; $M[SD]_{DS} = 36.49[14.40]$), which may have impacted the findings.

Tests of Mediation

Consistent with Lazarus and Folkman's model (Sweet et al., 1999) and with predictions from the Family Caregiver Conceptual Model (McDonald, Donner, & Poertner, 1992), cognitive appraisal type and coping strategies were tested as mediators of caregiver burden. Little evidence for mediation was found within the Autism group. Only avoidant coping mediated any relationship and that was limited to the relationship between problem behaviors and caregiver burden. There was more evidence for mediation within the DS and other disability groups. Within the DS group, perceiving a caregiving situation as threatening mediated the association between problem behavior and burden, and threat and centrality appraisals mediated the relationships between severity of autism symptoms and burden. Evidence for mediation was strongest within the Disability group, which had the largest sample size. Consistent with the mediation analyses for the autism and DS groups, the most reliable mediators within the Disability group were threat appraisal and avoidant coping strategies.

However, mediation was often partial in all study groups; that is, the significant relationships between antecedent and outcome variables (e.g., problem behaviors and caregiver burden) tended not to be solely accounted for by the hypothesized mediators. Regardless, the findings serve to highlight the potentially strong impact of cognitive appraisal and avoidant coping strategies on outcomes. Not only are coping and appraisal strongly and directly related to outcomes bivariately, their use by adult siblings tends to explain and mediate the relationship between external antecedents (e.g., problem behaviors) and outcomes. These results also have treatment implications. That is, as mentioned earlier, caregiver outcomes may be improved both by attempting to modify the antecedent variables directly (e.g., reducing problem behaviors), and by helping individuals to use more positive coping or appraisal strategies in response to their stressor.

Autism-Specific vs. Disability-General Effects on Outcomes

One key question is whether the relationships originally posited within the Autism group are specific to siblings of adults with autism or applicable more broadly to disability groups in general. As shown repeatedly above, the hypothesized relationships applied generally to all disability groups and were not limited to autism. In fact, in terms of significance and to a lesser extent in terms of effect size, the hypothesized relationships were more consistently supported within the larger Disability group and within the Down syndrome group than within the Autism group. This is likely due to the increased sample sizes in the other disability groups relative to the autism group, which only had 31 participants. Moreover, in several cases, the effect sizes within the Autism and other disability groups were similar, but failed to reach significance only within the Autism group. That is, it is likely that the study may be missing findings for the Autism group (Type II error), findings which were significant for the other disability groups. The implication is that the same factors that help explain burden, benefit finding, or HRQOL for sibling caregivers of those with autism work equally well to explain outcomes for sibling caregivers of those with disability generally.

Study Limitations

The study has several limitations. Sampling bias is a potential limitation. The study is limited to those who responded to the recruitment strategies, which may limit the study’s external validity and generalizability to other populations. Although the study was advertised on a national scale, it recruited heavily from sibling-group websites and listservs, which would tend to draw individuals with internet access, interest and skill. In addition to being highly educated, the participants also reported above average incomes, with approximately 1/3 of participants earning a household income greater than 90,000/year. Adult siblings also tended to represent a very limited range of racially, ethnically, and economically diverse individuals (117 white; 9 non-white; 9 mixed). In addition, participants were likely to be more involved in the life of their disabled sibling and may have been more knowledgeable about autism and DS than siblings who were less-involved or less-educated. Another limitation was the restriction to English speakers, adding to the already-existing English speaking bias in the disability literature (Heller & Arnold, 2010). A final sample limitation, common to many studies in autism, is that the majority of sibling participants were females/sisters (90%). Thus, the analysis of differences between male and female caregivers (exploratory hypothesis EH.3) was likely insensitive due to the very low number of male participants in the study. Taken together, these factors indicate that the sample may be unrepresentative of sibling caregivers generally and I cannot be confident the results would generalize to the larger population of sibling caregivers.

Social desirability may also have influenced siblings' reports. Some participants may have felt guilty about complaining about their caregiver role, and may have wished to present a positive picture in their reports. Another serious limitation, as already noted, is that the autism group was small, limiting the ability to detect smaller effects. Finally, several potential participants dropped out. Moreover, the individuals who did not complete the survey differed from those who did on several variables. Whether the results would change if the individuals who dropped out had been included is unknown, and further limits the generalizability of the findings.

Contributions, Implications for Clinical Interventions, and Summary

Few studies have examined the psychosocial outcomes of siblings of adults with disabilities, particularly adult siblings of adults with autism. To help address this gap, I surveyed adult siblings over the age of 18 from 26 states across the U.S. using an internet-based survey. The Adult Sibling Caregiver Conceptual Model (ASCCM) was proposed as a conceptual model to explore the relationships between antecedent, mediating and psychosocial outcome variables in non-disabled adult siblings. The ASCCM appeared to be a useful framework for organizing the potential relationships between antecedent factors, mediating factors, and psychosocial outcomes in adult siblings of adults with disabilities. Overall, some support was found for 10 of the 13 primary hypotheses and 5 of the 6 exploratory hypotheses based on the model. Of note, the findings were largely consistent with Lazarus and Folkman's stress and coping model

(1984), indicating the potential usefulness and importance of applying such models to understanding caregiver outcomes. Future research is needed to replicate the results of this study and to assess the usefulness of the ASCCM in other sibling disability groups.

One key finding is that adult siblings of adults with autism exhibited greater levels of caregiver burden and lower quality of life than did adult siblings of adults with DS. Moreover, siblings of adults with a mixed presentation of Down syndrome and autism symptoms also reported greater caregiver burden than adult siblings of those with Down syndrome alone. The results imply that autism, either alone or co-morbid with another diagnosis, presents an increased risk of stress and caregiver burden, not only in parent caregivers, but also in sibling caregivers.

Importantly, several findings had potential clinical implications. For example, use of more negative approaches to stress (e.g., negative cognitive appraisals—viewing events as a threat, and avoidant coping) led to poorer outcomes whereas use of more positive approaches to stress (e.g., positive cognitive appraisals—viewing events as a challenge, and emotion-focused coping) led to better outcomes. Future research should both replicate these findings in larger and more diverse samples and integrate the lessons learned into interventions developed to reduce the stress and burden of caregivers of those with disabilities.

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TABLES

Table 1

Study Variables: The Family Caregiver Conceptual Model v.s. The Adult Sibling Caregiver Conceptual Model

FAMILY CAREGIVER CONCEPTUAL MODEL	**ADULT SIBLING CAREGIVER CONCEPTUAL MODEL**
ANTECEDENT VARIABLES	**ANTECEDENT VARIABLES**
1) Family Characteristics/Resources	1) Family (Sibling Dyad) Characteristics: A) Number of Non-Disabled Siblings in the Family B) Sibling Relationship Quality C) Sibling Birth Order
2) Primary Caregiver Characteristics/Resources	2) Adult Sibling (Caregiver) Characteristics: A) Gender B) Age/ Developmental Life Stage C) Marital Status
3) Child (w/ Emotional Disability) Characteristics/Resources	3) Adult with Autism/DS (Caregivee) Characteristics: A) Severity of Autism Symptoms B) Problem Behavior C) Adaptive Behavior D) Age/ Developmental Life Stage
4) Available Informal Supports (Services) 5) Available Informal (Social) Services	4) Caregiving (Caregiver) Resources: A) Social Supports for the Adult Sibling Caregivers B) Respite, Financial, and Formal Supports for the Adult Sibling Caregiver
6) Other Community Characteristics/Resources	5) Adult Sibling (Caregiver) Additional Demands: A) Pile-Up Demands
MEDIATOR VARIABLES	**MEDIATOR VARIABLES**
1) Primary Appraisal 2) Secondary Appraisal 3) Reactive Emotion 4) Active Emotion	1) Cognitive Appraisal A) Threat B) Challenge C) Centrality
5) Coping Behaviors	2) Coping Strategies A) Problem-focused B) Emotional approach C) Avoidant

Table 1 Continued

Study Variables: The Family Caregiver Conceptual Model v.s. The Adult Sibling Caregiver Conceptual Model Continued

FAMILY CAREGIVER CONCEPTUAL MODEL	**ADULT SIBLING CAREGIVER CONCEPTUAL MODEL**
OUTCOME VARIABLES	**OUTCOME VARIABLES**
1) Primary Caregiver's: A) Life Satisfaction B) Somatic Health C) Social Functioning: I. General II. Family III. Work D) Financial Security	1.) Adult Sibling Caregiver's: A) Health-Related Quality of Life B) Caregiver Burden C) Reported Benefits
1) Child's A) Living Arrangements B) School Attendance Participation in the Community	N/A *We will not be concerned with the adult with ASD or DS' psychosocial outcomes in the current study.

Table 2

Primary Research Questions and Primary Hypotheses

Primary Research Questions: (PRQ)	**Antecedent Hypotheses: (AH)**	**Measure**
PRQ1) Do the *family (sibling dyad) characteristics* that are outlined in the proposed Adult Sibling Caregiver Conceptual Model significantly predict the typically-developing adult siblings' psychosocial outcomes?	AH.1.A) A *greater number of non-disabled siblings* in a family will be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits	Demographic and Background Information Questionnaire (DBIQ)
	AH.1.B) Having a higher *sibling relationship quality* will be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits.	Lifespan Sibling Relationship Scale (LSRS)
PRQ2) Do *the adult sibling (caregiver) characteristics* that are outlined in the proposed Adult Sibling Caregiver Conceptual Model significantly predict the typically-developing adult siblings' psychosocial outcomes?	AH.2) Compared to *male* caregivers, *female* adult sibling caregivers will have increased health-related quality of life, decreased caregiver burden, and increased reports of benefits.	DBIQ
PRQ3) Do the *adult with autism/DS (caregivee) characteristics* that are outlined in the proposed Adult Sibling Caregiver Conceptual Model significantly predict typically-developing adult siblings' psychosocial outcomes?	AH.3.A) More severe *autism symptoms* in adults with autism will be associated with decreased health-related quality of life, increased caregiver burden, and decreased reports of benefits in their adult sibling caregivers.	Gilliam Autism Rating Scale – Second Edition (GARS-2)
	AH.3.B. More *problem behaviors* in adults with autism will be associated with an adult sibling caregiver having increased caregiver burden, a lower health-related quality of life, and fewer reported benefits.	Problem Behavior Rating Scale (PBRS)
	AH.3.C *More independent living skills (a higher level of adaptive behavior)* will be associated with an adult sibling caregiver having a higher health-related quality of life, lower caregiver burden, and more reported benefits.	The Instrumental Activities of Daily Living Scale (IADL)

Table 2 Continued

Primary Research Questions and Primary Hypotheses Continued

Primary Research Questions: (PRQ)	**Antecedent Hypotheses: (AH)**	**Measure**
PRQ4) Do the *caregiving (caregiver) resources* that are outlined in the proposed Adult Sibling Caregiver Conceptual Model significantly predict typically-developing adult siblings' psychosocial outcomes?	AH.4.A) Increased *social support* will be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits.	Multidimensional Scale of Perceived Social Support (MSPSS)
	AH.4.B) Increased *respite care, financial, and/or formal supports* will be associated with increased health-related quality of life, decreased caregiver burden, and increased reports of benefits.	Respite, Formal, and Financial Support Measure (RFFSM)
PRQ5) Do the *adult sibling (caregiver) additional demands* that are outlined in the proposed Adult Sibling Caregiver Conceptual Model significantly predict typically-developing adult siblings' psychosocial outcomes?	AH.5) Increased *pile-up demands* will be associated with decreased health-related quality of life, increased caregiver burden, and decreased reports of benefits.	Social Readjustment Rating Scale (SRRS)
PRQ6) Are adult sibling caregivers' psychosocial outcomes associated with their siblings' diagnoses?	OH.6.A) Overall, sibling caregivers of adults with *autism* will experience *poorer health-related quality of life* than will sibling caregivers of adults with *Down syndrome*.	Short-Form Health Survey (SF-12)
	OH.6.B) Overall, sibling caregivers of adults with *autism* will experience *greater caregiver burden* than will sibling caregivers of adults with *Down syndrome.*	Caregiver Strain Questionnaire (CGSQ)

Table 3

Secondary Research Questions and Related Exploratory Hypotheses

Research Questions: (RQ)	Exploratory Hypotheses: (EH)	Measure
ERQ1) Do adult sibling caregivers' appraisal of their caregiving situations (i.e., as positive or negative) significantly influence their psychosocial outcomes (health-related quality of life, caregiver burden, and benefits reported)?	EH.1) A *positive appraisal* (i.e., challenge) of a caregiving situation will be associated with increased health-related quality of life, decreased caregiver burden, and more reported benefits. A *negative appraisal* (i.e., threat) of a caregiving situation will result in the opposite relationship.	The Stress Appraisal Measure (SAM)
ERQ2) Do adult sibling caregivers' coping styles (i.e., problem-focused, emotion-approach focused, or emotion- avoidant) significantly influence their psychosocial outcomes (health-related quality of life, caregiver burden, and benefits reported)?	EH.2.A) Using *problem-based and/or emotion approach* coping strategies will be associated with *better psychosocial outcomes* for adult sibling caregivers (i.e. increased health-related quality of life, decreased caregiver burden, and increased reported benefits).	The Brief COPE
	EH.2.B) *Passive avoidant* coping strategies will be associated with *fewer positive psychosocial outcomes* for adult sibling caregivers than problem-based and emotion-approach coping strategies will.	The Brief COPE
		DBIQ
ERQ3) Does a caregiver's developmental life stage significantly influence his or her psychosocial outcomes: levels of health-related quality of life, caregiver burden, and benefits reported?	EH.3) Using *age as a proxy for developmental life stage*, it is expected that health-related quality of life will decrease and caregiver burden will increase as a non-disabled sibling ages.	DBIQ
ERQ4) Does a caregiver's marital status significantly influence his or her psychosocial outcomes: levels of health-related quality of life, caregiver burden, and benefits reported?	EH.4) Compared to single adult sibling caregivers, those who are *married* will have increased health-related quality of life, decreased caregiver burden, and increased reports of benefits.	DBIQ
ERQ5) Does sibling birth order significantly influence a caregiver's level of caregiver burden or reported benefits?	EH.5) Compared to siblings who are younger than their sibling with autism or Down syndrome, siblings who are *older*, will have increased HRQOL.	

Note: DBIQ = Demographic and Background Information Questionnaire. HRQOL = Health-Related Quality of Life

Table 4

List of Measures and Internal Consistency Validity Values

MEASURE	AUTHOR	CONSTRUCT(S) ASSESSED	NUMBER OF ITEMS	INTERNAL CONSISTENCY VALIDITY
1) Demographic and Background Questionnaire (DBIQ)	Newly Created	1) Number of non-disabled siblings 2) Sibling Birth Order 3) Gender 4) Marital Status 5) Age/Developmental Life Stage		
2.) Lifespan Sibling Relationship Scale (LSRS)	*(Riggio, 2000)*	Sibling Relationship Quality	48	Cronbach's α = .97
3.) Gilliam Autism Rating Scale- Second Edition (GARS-2)	*(Gilliam, 2006)*	Autism Symptoms	42	Cronbach's α = .96 for all 3 subscales; Stereotypical behavior = Cronbach's α = .86; Communication = .92; Social Interaction = .93.
4.) Problem Behavior Rating Scale (PBRS)	(Stone et al., 2010)	Problem Behavior	30	Cronbach's α = .93
5.) Instrumental Activities of Daily Living Scale (IADL)	*(Lawton & Brody, 1969)*	Adaptive Behavior	8	Cronbach's α = .76
6.) Multidimensional Scale of Perceived Social Support (MSPSS)	*(Zimet, 1988)*	Perceived Social Support	12	Cronbach's α = .95
7) Respite, Formal, and Financial Support Measure	Newly Created	Respite, Formal, and Financial Supports	14	N/A
8.) Social Readjustment Rating Scale (SRRS)	*(Holmes & Rahe, 1967)*	Pile-up Demands	43	Cronbach's α = .83
9.) The Stress Appraisal Measure (SAM)	*(Peacock & Wong, 1990)*	Cognitive Appraisal	12	Cronbach's α = .82 for all 3 subscales; Threat = Cronbach's α = .88; Challenge = .84; Centrality = .91.
10.) Brief COPE	*(Carver, 1997)*	Coping Strategies	28	Cronbach's α = .91 for all 28 items; Problem-focused = .90; Emotional approach = .83; Avoidant = .87.
11.) Rand Short-Form Health Survey (SF-12)	*(Ware et al., 1996)*	Health-Related Quality of Life	12	PCS α = .75. MCS = .56.
12.) Caregiving Strain Questionnaire (CGSQ)	*(Brannan & Heflinger, 1997)*	Caregiver Burden	21	Cronbach's α = .95
13.) Benefit-Finding Scale (BFS)	*(Tomich, & Helgeson, 2004a)*	Reported Benefits	20	Cronbach's α = .96

Table 5

Recruitment Contacts

Organization	Assisted
Autism	
Acadian Autism Society	✓
Applied Behavior Center for Autism- Indianapolis-	✓
ARC of Greater Boone County	✓
The ARC of Indiana	✓
ARC of PA	
ARC of Tennessee	
ASCF	✓
Autism Indiana	✓
Autism Resource Network	✓
Autism Consulting	
Autism Cincinnati	
Autism Family resource center	✓
Autism Society of Indiana	✓
Autism Society in Nebraska	
Autism Speaks	✓
Christian Sarkine Center	
Emory Autism Center	
Howard County, Maryland Autism Society	
IAN Research Team	
IASF Indiana Autism Foundation Scholarship Foundation	
Indiana Institute on Disability, Indiana Resource Center for Autism, Indiana University	✓
Indiana Secondary Transition Resource Center	
Indiana Resource Center for Autism	✓
Indiana Resource Center for Autism	✓
Johnson county support group-	✓
New York Autism Society	✓
National Autism Society	✓
Pathfinders for Autism; Maryland	

Table 5 Continued

Recruitment Contacts Continued

Organization	Assisted
SABE Self Advocates of Indiana Board of Directors	
Sibling Leadership Network	
SibNet	✓
TACA	✓
Down Syndrome	✓
AccessABILITY- Center for Independent Living (CIL)- Indianapolis	
Indiana Professional Management Group	
National Down Syndrome Congress	
National Down Syndrome Society	✓
Parent at Indianapolis Conference- September, 2012	✓
Personal contacts in Boston	✓
Personal contacts in Indiana	✓
Personal contacts in NJ	✓
Personal Contacts in Washington state	✓
The Bally Foundation	✓
Autism and Down Syndrome	✓
ARC of Greater Twin Cities	
Easter Seals	
Facebook: Listservs	✓
Insource Indiana	✓
IUPUI- Jag News to faculty and students	✓
Jespy House	✓
Noble of Indiana	
Research and Family Partnership	✓
The Friendship Circle	✓

Table 6

Adult Sibling Caregiver Conceptual Model Variables, Measures Used, and Operational Definitions

ASCCM Variable	Measure	Operational Definition
Antecedent Variables:		
1) Number of non-disabled siblings in the family	DBIQ	Measured background and demographic information.
2) Sibling Birth Order	DBIQ	
3) Relationship Quality	LSRS	Higher scores indicated a better relationship quality.
4) Gender of the Non-disabled Adult Sibling Participant	DBIQ	
5) Marital Status of the Non-disabled Adult Sibling Participant	DBIQ	
6) Developmental Lifestage/Age of Both Siblings in the Dyad	DBIQ	
7) Severity of Autism Symptoms	GARS-2	Higher scores indicated greater autism symptoms.
8) Problem Behaviors	PBRS	Higher scores indicated the presence of more problematic behaviors.
9) Adaptive Behavior	IADL	Higher scores indicated more adaptive behavior.
10) Perceived Social Support	MSPSS	Higher scores indicated more perceived social support from one's family, friends, and acquaintances.
11) Number of Respite, Formal and Financial Services	RFFSM	Higher scores indicated more services were received.
12) Helpfulness of Services	RFFSM	Higher scores indicated the services received are helpful.
13) Pile-up Demands	SRRS	Higher scores indicated more additional demands.
Mediating Variables:		
1) Cognitive Appraisal	SAM	Higher scores indicated a greater appraisal in the positive or negative direction.
2) Coping Strategies	Brief COPE	Higher scores indicated the use of more coping strategies.
Outcome Variables:		
1) Health-Related Quality of Life	SF-12	Higher scores indicated more Mental and Physical HRQOL.
2) Caregiver Burden	CGSQ	Higher scores indicated more burden
3) Reported Benefits	BFS	Higher scores indicated more reported benefits

Note. DBIQ = Demographic & Background Information Questionnaire. LSRS = Lifespan Sibling Relationship Scale. GARS-2 = Gilliam Autism Rating Scale-2. PBRS = Problem Behavior Rating Scale. IADL = The Instrumental Activities of Daily Living Scale. MSPSS = Multidimensional Scale of Perceived Social Support. RFFSM = Respite, Formal, and Financial Services Measure. SRRS = Social Readjustment Rating Scale. SAM = The Stress Appraisal Measure. Brief COPE = The Brief Cope. SF-12 = RAND Short-Form Health Survey. CGSQ = Caregiver Strain Questionnaire. BFS = The Benefit Finding Scale.

Table 7

Demographic Characteristics of Study Participants and Their Disabled Adult Siblings

	Autism	DS	Mixed	Disability	Self Reported Autism	Complete Data	Incomplete Data	Total Passed SQ
	N = 31	N = 54	N = 12	N = 97	N = 15	N = 112	N = 38	N = 150
Characteristics of the Non-Disabled Adult Sibling Participant:								
Gender[1]								
Male	3	6	1	10	1	11	0	11
Female	28	48	11	87	14	101	26	127
Race[1]								
White	25	46	12	83	12	95	22	117
Non-White	3	4	0	7	1	8	1	9
Mixed	1	3	0	4	2	6	3	9
Other Siblings with a Mental or Physical Disability?[1]								
No	28	48	12	88	13	101	35	136
Yes	3	6	0	9	2	11	3	14
Do you have a mental or physical disability?[1]								
No	27	52	11	90	12	102	25	127
Yes	4	1	1	6	3	9	1	10
Number of Non-Disabled Siblings[1]								
0	13	16	4	33	5	38	13	51
1	10	17	5	32	3	35	3	38
2	3	6	1	10	3	13	4	17
3	0	6	2	8	2	10	1	11
4	0	2	0	2	0	2	1	3
5	0	3	0	3	0	3	0	3
6	0	1	0	1	0	1	0	1
Relationship to Sibling[1]								
Older Sister	20	27	7	54	10	64	13	77
Younger Sister	8	19	4	31	4	35	12	47
Older Brother	0	1	1	2	0	2	0	2
Younger Brother	2	6	0	8	1	9	0	9
Relationship Status[1]								
Married	10	28	6	44	4	48	7	55
Single	19	16	5	40	7	47	14	61
Other	2	10	1	13	4	17	5	22

Table 7 Continued

Demographic Characteristics of Study Participants and Their Disabled Adult Siblings Continued

	Autism	DS	Mixed	Disability	Self-Reported Autism	Complete Data	Incomplete Data	Total Passed SQ
	N = 31	N = 54	N = 12	N = 97	N = 15	N = 112	N = 38	N = 150
Characteristics of the Non-Disabled Adult Sibling Participant:								
Level of Education [1]								
High school graduate or GED	0	3	1	4	0	4	2	6
Technical or trade school	1	1	0	2	0	2	1	3
Some college	9	10	2	21	5	26	5	31
College graduate	12	15	4	31	5	36	9	45
Advanced/Professional degree	9	25	5	39	5	44	9	53
Employment status [1]								
Working full-time	14	34	7	55	7	62	13	75
Working part-time	0	5	2	7	2	9	4	13
Homemaker	0	2	1	3	0	3	1	4
Unemployed	1	2	0	3	0	3	0	3
Disabled	1	0	0	1	0	1	0	1
Retired	1	2	0	3	0	3	0	3
Full-time student	5	2	1	8	3	11	4	15
Endorses two or more	8	6	1	15	2	17	4	21
Income [1]								
Less than or equal to $20,000	3	1	0	4	0	4	3	7
$20,001 - $40,000	5	9	2	16	2	18	7	25
$40,001 - $60,000	8	8	5	21	2	23	3	26
$60,001 - $90,000	8	10	1	19	2	21	4	25
More than $90,000	6	20	4	30	9	39	9	48
Public assistance [1]								
Yes	7	3	2	12	0	12	5	17
No	24	48	10	82	15	97	21	118
Contact [1]								
More than 3x/week	9	25	5	39	5	44	10	54
1-3x/week	8	13	3	24	6	30	6	36
More than 1x/month	4	7	1	12	3	15	6	21
More than 1x/3 months	5	8	2	15	1	16	2	18
More than once a year	4	1	1	6	0	6	2	8
Less than once a year	1	0	0	1	0	1	0	1
Resources [1]								
Very Familiar	15	20	6	41	4	45	7	52
Mostly Familiar	7	21	3	31	6	37	6	43
Somewhat familiar	8	12	2	22	5	27	11	38
Not at all familiar	1	1	1	3	0	3	2	5

Note. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined. Self-Reported Autism (SR) = non-disabled sibling reported their sibling had autism, but GARS-2 score was </= 85. Complete Data = all study participants who completed the GARS-2 and enough data to have their results analyzed. Incomplete Data = participants who passed the screening questionnaire, but did not provide enough data for their results to be analyzed. Total Passed SQ = total participants who passed the screening questionnaire (data may or may not have been analyzed). [1] = data within a given category may not add up to the total value (N) for that category due to missing data.

Table 7 Continued

Demographic Characteristics of Study Participants and Their Disabled Adult Siblings Continued

	Autism	DS	Mixed	Disability	Self Reported Autism	Complete Data	Incomplete Data	Total Passed SQ
	N = 31	N = 54	N = 12	N = 97	N = 15	N = 112	N = 38	N = 150
Characteristics of the Non-Disabled Adult Sibling Participant:								
Number of Miles[1]								
0-30	16	27	5	48	6	54	13	67
30-60	0	5	0	5	1	6	2	8
60-100 miles	1	3	0	4	0	4	1	5
100-300 miles	6	5	1	12	5	17	5	22
300-500 miles	1	5	2	8	0	8	1	9
More than 500 miles	7	9	4	20	3	23	4	27
Number of people in household besides you[1]								
1	11	28	6	45	5	50	8	58
2	4	10	1	15	4	19	6	25
3	7	6	2	15	3	18	6	24
4	3	3	1	7	0	7	2	9
5	0	2	0	2	1	3	0	3
8	0	0	0	0	0	0	1	1
Number of States Represented	16	21	8	25	8	25	11	26
Number of Countries Represented	1	1	1	1	2	2	2	3
Age (years): (M(SD))	31.87 (12.15)	38.2 (4.75)	40.50 (16.31)	36.49 (14.40)	27.60 (5.12)	35.30 (13.85)	29.90 (10.48) [7]	34.29 (13.42) [9]
Characteristics of the Disabled Sibling								
	N = 31	N = 54	N = 12	N = 97	N = 15	N = 112	N = 38	N = 150
Age (years):	31.32 (12.31)	36.52 (14.36) [2]	36.18 (15.79)[3]	34.77 (13.95) [4]	27.93 (7.91)[5]	33.62 (13.62)[6]	28.76 (11.12)[8]	32.71 (13.29)[10]
Gender[1]								
Male	26	30	4	60	12	72	23	95
Female	5	24	8	37	3	40	3	43
Race (Total): [1]								
White/Caucasian	26	48	12	86	12	98	24	122
Non-White/Caucasian	2	4	0	6	2	8	1	9
Mixed	1	2	0	3	1	4	1	5

Note. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined. Self-Reported Autism (SR) = non-disabled sibling reported their sibling had autism, but GARS-2 score was </= 85. Complete Data = all study participants who completed the GARS-2 and enough data to have their results analyzed. Incomplete data = participants who passed the screening questionnaire, but did not provide enough data for their results to be analyzed. Total Passed SQ = total participants who passed the screening questionnaire (data may or may not have been analyzed). [1] Data within a given category may not add up to the total value (N) for that category due to missing data.
[2] n = 52. [3] n = 11. [4] n = 94. [5] n = 14. [6] n = 108. [7] n = 26. [8] n = 25. [9] n =138. [10] n = 133.

Table 8

Tests of Differences in Demographic Characteristics of Study Participants

	Autism (n = 31) vs. DS (n = 54) vs. Mixed (n = 12)				Complete Data (n = 112) vs. Incomplete Data (n = 38)
Non-Disabled Adult Sibling Participant	Initial Test	Post-Hoc tests			
Gender					χ^2(1) = 2.78, p = .10
Male	χ^2 (2) = 1.02, p = .95				
Female	χ^2(2) = 1.83, p = .40				
Race					χ^2(1) = .12, p = .73[12]
White					
Non-White					
Other Siblings with a Mental or Physical Disability	χ^2(2) = 1.45, p = .49				χ^2(1) = .12, p = .72[3]
No					
Yes					
Do you have a mental or physical disability?	χ^2(2) = 4.15, p = .13				χ^2(1) = .57, p = .45
No					
Yes		Autism vs. DS	Autism vs. Mixed	DS vs. Mixed	
Number of Non-Disabled Siblings	F(2,86) = 3.82, p = .03*	M(SD) Autism = .62(.70), p = .02*	M(SD) DS = 1.49 (1.58), p = .57	M(SD) Mixed = 1.08 (1.08), p = .60	t(122) = -1.17, p = .25
Relationship to Sibling	N/A[1]				N/A[1]
Sister					
Brother					
Relationship Status					χ^2(1) = 2.24, p = .14
Married	χ^2(2) = 3.17, p = .21				
Not Married					
Level of Education					χ^2(1) = .05, p = .82
College graduate or higher	χ^2(2) = .45, p = .80				
Less than college graduate					
Employment status					χ^2(1) = .05, p = .83
Working	χ^2(2) = 2.11, p = .35				
Not Working					
Income					χ^2(1) = .43, p = .51
Less than 60K	χ^2(2) = 2.78, p = .25				
More than 60K					
Public assistance					χ^2(1) = 1.29, p = .26
Yes	χ^2(2) = 5.02, p = .08				
No					
Contact					χ^2(1) = .36, p = .55
More than once a month	χ^2(2) = 2.77, p = .25				
Less than once a month					
Resources					t(136) = 2.16, p = .03
Very Familiar	F(2,94) = .04, p = .96				
Mostly Familiar					
Somewhat familiar					
Not at all familiar					

Note. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Complete Data = all study participants who completed the GARS-2 and enough data to have their results analyzed. Incomplete Data = participants who passed the screening questionnaire, but did not provide enough data for their results to be analyzed. 1 = Chi Square was not run because "sisters vs. brothers" is the same as gender.

Table 8 Continued

Tests of Differences in Demographic Characteristics of Study Participants and Their Disabled Siblings Continued

	Autism vs. DS vs. Mixed	Autism vs. DS	Autism vs. Mixed	DS vs. Mixed	Complete Data (n = 112) vs. Incomplete Data (n = 38)
Non-Disabled Adult Sibling	Initial test		Post-hoc tests		
Number of Miles	$\chi^2(2) = 2.46$, p = .29				$\chi^2(1) = .17$, p = .68
More than 100					
Less than 100					
Number of people in household besides you	$\chi^2(2) = .062$, p = .97				χ2(1) = .14, p = .70
More than 3					
Less than 3					
Age (years):	F(2,94) = 2.55, p = .08				t(47.65) = -2.22, p = .03
Characteristics of the Disabled Sibling					
Age (years):	F(2,91) = 1.43, p = .25				χ2(131) = -1.67, p = .10
Gender					
Male	$\chi^2(2) = 11.41$, p =.00**	$\chi^2(1) = 7.03$, p = .01**	$\chi^2(1) = 10.48$, p = .00**	χ2(1) = 1.94, p = .16	χ2(1) = 5.75, p = .02
Female					
Race (Total):					
White	χ2(2) = 1.45, p = .48				χ2(1) = .24, p = .63
Non-White					

Note. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Complete Data = all study participants who completed the GARS-2 and enough data to have their results analyzed. Incomplete Data = participants who passed the screening questionnaire, but did not provide enough data for their results to be analyzed.

Table 9

Means and Standard Deviations of the Antecedent Variables

	Autism (N = 31) Mean (SD)	DS (N = 54) Mean (SD)	Mixed (N = 12) Mean (SD)	Disability (N = 97) Mean (SD)	Self Report Autism (N = 15) Mean (SD)	Total Analyzed (N = 112) Mean (SD)
Number of Non-Disabled Siblings[1]	-	-	-	-	-	-
Birth Order[1]	-	-	-	-	-	-
Sibling Relationship	150.26 (38.47)	181.16 (30.09)	165.56 (49.70)	169.17 (38.02)	144.90 (22.71)	165.87 (37.18)
Severity of Autism Symptoms	101.87 (10.01)	61.54 (11.90)	99.83 (14.25)	79.16 (22.96)	71.60 (9.47)	78.15 (21.77)
Problem Behaviors	2.28 (.38)	1.34 (.30)	2.18 (.47)	1.76 (.57)	1.80 (.40)	1.76 (.55)
Adaptive Behavior	2.61 (1.95)	3.31 (1.79)	1.55 (1.57)	2.86 (1.90)	5.21 (3.47)	3.18 (2.30)
Social Support	5.26 (1.26)	5.50 (1.47)	4.92 (1.68)	5.35 (1.43)	5.40 (1.48)	5.36 (1.43)
Helpfulness of Services	3.34 (1.13)	3.60 (.85)	3.08 (1.52)	3.44 (1.06)	3.15 (1.04)	3.40 (1.06)
Number of Services	3.55 (1.07)	2.79 (.99)	3.00 (1.00)	3.06 (1.06)	3.11 (1.28)	3.07 (1.09)
Pile-up Demands	40.79 (55.49)	23.07 (14.7)	23.82 (14.91)	28.93 (34.50)	21.56 (19.52)	27.96 (32.94)

Note. For all scales, higher scores indicate more of a construct. [1] = see Table 7 for demographic information regarding this variable. Sibling Relationship is measured by the Lifespan Sibling Relationship Scale. Severity of Autism Symptoms is measured by the Gilliam Autism Rating Scale-2. Problem Behaviors are measured by the Problem Behavior Rating Scale. Adaptive behavior is measured by the Instrumental Activities of Daily Living Scale. Social Support is measured by the Multidimensional Scale of Perceived Social Support. Helpfulness of Services is measured by the Respite, Formal, and Financial Support Measure. Number of Services is measured by the Respite, Formal, and Financial Support Measure. Pile-up Demands are measured by the Social Readjustment Rating Scale. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined. Self-Reported Autism = non-disabled sibling reported their sibling had autism, but GARS-2 score was </= 85. Total Analyzed = all study participants who completed the GARS-2 and enough data to have their results analyzed.

Table 10

Means and Standard Deviations of the Mediating Variables

	Autism (N = 31)	DS (N = 54)	Mixed (N = 12)	Disability (N = 97)	Self Report Autism (N = 15)	Total Analyzed (N = 112)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Cognitive Appraisal						
Threat	2.72 (1.11)	1.80 (.90)	2.70 (1.17)	2.20 (1.09)	2.52 (1.28)	2.24 (1.11)
Challenge	3.26 (1.07)	3.30 (1.05)	2.56 (1.20)	3.19 (1.09)	2.29 (.99)	3.07 (1.12)
Centrality	4.21 (1.10)	3.64 (1.19)	4.16 (.82)	3.88 (1.15)	3.33 (1.40)	3.80 (1.19)
Coping Strategies						
Problem-focused	2.51 (.74)	2.09 (.94)	2.13 (.84)	2.22 (.88)	2.02 (.70)	2.19 (.86)
Emotional App.	2.47 (.64)	2.01 (.65)	2.08 (.44)	2.16 (.65)	1.94 (.49)	2.13 (.64)
Avoidant	1.79 (.56)	1.28 (.41)	1.69 (.56)	1.49 (.53)	1.58 (.50)	1.50 (.52)

Note. For all scales, higher scores indicate more of a construct. Cognitive Appraisal is measured by the Stress Appraisal Measure. Coping Strategies are measured by the Brief COPE. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined. Self-Reported Autism (SR) = non-disabled sibling reported their sibling had autism, but GARS-2 score was </= 85. Total Analyzed = all study participants who completed the GARS-2 and enough data to have their results analyzed. Emotional App. = emotional approach coping.

Table 11

Means and Standard Deviations of the Outcome Variables

	Autism (N = 31) Mean (SD)	DS (N = 54) Mean (SD)	Mixed (N = 12) Mean (SD)	Disability (N = 97) Mean (SD)	Self Report Autism (N = 15) Mean (SD)	Total Analyzed (N = 112) Mean (SD)
Mental HRQOL	42.45 (10.20)	46.79 (10.90)	39.61 (12.84)	44.49 (11.16)	49.11 (8.28)	45.09 (10.91)
Physical HRQOL	51.35 (10.89)	54.50 (7.15)	51.48 (11.98)	53.11 (9.19)	51.40 (7.62)	52.88 (8.99)
Caregiver Burden	2.37 (.72)	1.61 (.69)	2.58 (1.13)	1.98 (.86)	2.26 (.85)	2.01 (.86)
Benefits	3.69 (1.07)	3.59 (.97)	3.17 (1.11)	3.57 (1.03)	2.68 (.78)	3.45 (1.04)

Note. For all scales, higher scores indicate more of a construct. Caregiver Burden = Caregiver Strain Questionnaire. HRQOL = health-related quality of life; RAND Short-Form Health Survey. Benefits = reported benefits; Benefit Finding Scale. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined. Self-Reported Autism (SR) = non-disabled sibling reported their sibling had autism, but GARS-2 score was </= 85. Total Analyzed = all study participants who completed the GARS-2 and enough data to have their results analyzed. Emotional App. = emotional approach coping.

Table 12

Primary Hypotheses: Pearson (r) Correlations Between Antecedent and Outcome Variables

Hypothesis	Antecedent Variable	Autism (N = 31) Outcome Variables				DS (N = 54) Outcome Variables				Disability (N = 97) Outcome Variables			
		HRQOL M. / P.		Burden	Benefits	HRQOL Benefits		Burden M. / P.		HRQOL M. / P.		Burden	Benefits
AH1.A	Number of Non-Disabled Siblings	-.21	.09	.13	-.15	.18	-.16	-.12	-.23	.18	-.03	-.28^t	-.13
AH1.C	Relationship Quality	.22	-.32	.04	.55 ††	.12	.11	-.40**	.66**	.17	.01	-.44**	.56**
AH2	Gender of Non-Disabled Sibling	.15	.01	.00	-.10	-.05	-.02	.10	.11	.04	-.06	.05	.08
AH3.A	Severity of Symptoms	.12	.19	-.01	.11	-.38**	-.14	.42**	-.03	-.28**	-.17	.52**	-.01
AH3.B	Problem Behavior	-.27	-.02	.56 ††	-.21	-.33^t	-.17	.47**	-.03	-.30**	-.16	.62**	-.08
AH3.C	Adaptive Behavior	.01	-.12	-.02	-.14	.22	.23	-.34^t	.09	.20	.14	-.35**	.06
AH4.A	Social Support	.13	.07	-.41†	.41†	.53**	.15	-.59**	.11	.43**	.12	-.52**	.24^t
AH4.B	Helpfulness of Services/	.33†	-.06	-.23	.62 ††	.38**	-.11	-.37^t	.31	.20	-.06	-.29**	.45**
	Number of Services	.02	-.01	.40†	.21	.01	.00	-.18	.19	-.02	-.05	.15	.20
AH.5	Pile-up Demands	-.28	-.33†	.36	.08	-.46**	.01	.24	-.05	-.29**	-.22^t	.27^t	.08

Note. For all scales, higher scores indicate more of a construct. Autism group: † = p < .05; †† = p < .01 (one-tailed). DS and Disability groups: ** = p < .01 (two-tailed); ^{t} = trend towards significance, (p < .05, two-tailed). Relationship Quality = Lifespan Sibling Relationship Scale. Severity of Symptoms = Gilliam Autism Rating Scale-2. Problem Behaviors = Problem Behavior Rating Scale. Adaptive Behavior = Instrumental Activities of Daily Living Scale. Social Support = Multidimensional Scale of Perceived Social Support. Helpfulness of Services/ Number of Services = Respite, Formal, and Financial Support Measure. Pile-up Demands = Social Readjustment Rating Scale. HRQOL = health-related quality of life; RAND Short-Form Health Survey. Burden = Caregiver Strain Questionnaire. Benefits = reported benefits; Benefit Finding Scale. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Disability Group = Autism + DS + Mixed groups combined

Table 13

Primary Hypotheses Continued: Tests of Differences Between Autism, DS, and Mixed Groups on Psychosocial Outcomes

Hypothesis	Variable	Autism	DS	Mixed	Autism vs. DS	ANOVA	Autism vs. DS	Autism vs. Mixed	DS vs. Mixed
		x(SD)	x(SD)	x(SD)					
OH6.A	Mental HRQOL	42.45 (10.20)	46.79 (10.90)	39.61 (12.84)	t(80) = -1.78, p = .04†	F(2,91) = 2.86, p = .06^t	-	-	-
OH6.A	Physical HRQOL	51.35 (10.89)	54.50 (7.15)	51.48 (11.98)	t(43.7) = -1.42, p = .08^t	F(2,91) = 1.34, p = .27	-	-	-
OH6.B	Caregiver Burden	2.37 (.72)	1.61 (.69)	2.58 (1.13)	t(76) = 4.65, p = .00††	F(2, 86) = 12.96, p = 0.00**	.76 (.18), p = .00**	- .21 (.27), p = 1.00	-.97 (.25), p = .00**
	Reported Benefits	3.69 (1.07)	3.59 (.97)	3.17 (1.11)	t(73) = .44, p = .66	-	-	-	-

Note. For all scales, higher scores indicate more of a construct. † = p < .05, one-tailed. †† = p < .01, one-tailed. * = p < .05, two tailed. ** = p < .01, two tailed. ^{t} = trend towards significance, p > .05, two-tailed. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined.

Table 14

Exploratory Hypotheses (EH.1 – EH.3): Pearson (r) Correlations

Antecedent Variable	Autism (N = 31)				DS (N = 54)				Disability Group (N = 97)			
	Outcome Variables				Outcome Variables				Outcome Variables			
	HRQOL Mental /	Physical	Burden	Benefits	HRQOL Mental /	Physical	Burden	Benefits	HRQOL Mental /	Physical	Burden	Benefits
(EH.1) SAM												
Threat	-.12	-.02	.58† †	-.22	-.56**	-.20	.82**	-.29^{t}	-.43**	-.25^{t}	.75**	-.26^{t}
Challenge	.29	.11	.02	.33†	.33^{t}	.12	-.34^{t}	.56**	.29**	.18	-.31**	.54**
Centrality	. 25	.17	.29	.08	-.31^{t}	-.20	.39**	-.02	-.19	-.15	.30**	.06
(EH.2) COPE												
EH2.A												
Problem Based	.15	-.20	.21	.31	-.22	-.46**	.54**	-.11	-.14	-.31**	.37**	.08
Emotional Approach	.17	-.13	-.03	.35†	-.29^{t}	-.35^{t}	.28	.08	-.17	-.22^{t}	.14	.26^{t}
EH2.B												
Avoidant	-.66† †	.09	.59† †	-.47††	-.67**	-.25	.79**	-.20	-.65**	-.17	.72**	-.24^{t}
(EH.3) Age / Developmental Life Stage of Non-Disabled Sibling	.09	-.33†	-.28	.13	.13	-.26	.21	-.37^{t}	.13	-.31**	.00	-.17

Note. For all scales, higher scores indicate more of a construct. Autism group: † p < .05; †† p < .01 (one-tailed). DS and Disability groups: ** p < .01 (two-tailed); ^{t} = trend towards significance (p < .05, two-tailed). HRQOL = RAND Short-Form Health Survey. Burden = Caregiver Strain Questionnaire. Benefits = Benefit Finding Scale. SAM = Stress Appraisal Measure. COPE = The Brief COPE. Autism group = disabled sibling's score on GARS-2 is >/= 85. DS group = non-disabled sibling reported a diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed group = non-disabled sibling reported a diagnosis of Down Syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability Group = Autism + DS + Mixed groups combined.

Table 15

The Associations Between Marital Status and Non-Disabled Siblings' Psychosocial Outcomes (EH.4)

Variable	Married	Unmarried	Unmarried Siblings
	Mean (SD)	Mean (SD)	
Mental HRQOL			
Disability (N = 94)	47.51 (9.34)	42.04 (11.96)	t(91.9) = 2.49, p = .02^{t}
Autism (N = 30)	44.87 (9.44)	41.24 (10.59)	t(28) = .92, p = .19
DS (N = 52)	49.10 (8.65)	44.10 (12.34)	t(44.7) = 1.82, p = .08^{t}
Physical HRQOL			
Disability (N = 94)	52.61 (9.68)	53.51 (8.84)	t(92) = -.47, p = .64
Autism (N = 30)	51.52 (12.16)	51.27 (10.54)	t(28) = .06, p = .48
DS (N = 52)	53.99 (6.73)	55.01 (7.64)	t(50) = -.51, p = .61
Caregiver Burden			
Disability (N = 89)	1.82 (.82)	2.10 (.88)	t(87) = -1.53, p = .13
Autism (N = 29)	2.03 (.55)	2.54 (.75)	t(27) = -1.89, p = .04†
DS (N = 49)	1.56 (.61)	1.66 (.76)	t(47) = -.49, p = .63
Reported Benefits			
Disability (N = 86)	3.43 (1.09)	3.68 (.97)	t(84) = -1.11, p = .27
Autism (N = 29)	4.01 (.88)	3.53 (1.14)	t(27) = 1.16, p = .13
DS (N = 46)	3.27 (1.06)	3.88 (.80)	t(44) = 2.20, p = .03^{t}

Note. Autism group: † = p < .05; †† = p < .01 (one-tailed). DS and Disability group: ** = p < .01; t = trend towards significance (p < .05; two-tailed).

Table 16

The Associations Between Birth Order and Non-Disabled Siblings' Psychosocial Outcomes (EH.5)

Variable	Older Than Disabled Sibling	Younger Than Disabled Sibling	t	df	p
	Mean (SD)	Mean (SD)			
Mental HRQOL					
Disability (N = 92)	43.64 (11.23)	46.32 (10.91)	-1.14	90	0.26
Autism (N = 29)	43.40 (10.33)	41.93 (9.80)	0.36	27	0.72
DS (N = 51)	44.56 (11.89)	49.50 (9.38)	-1.65	47.2	0.11
Physical HRQOL					
Disability (N = 92)	52.96 (9.82)	53.82 (8.03)	-0.44	90	0.66
Autism (N = 29)	50.43 (11.20)	53.29 (11.21)	-0.64	27	0.53
DS (N = 51)	54.96 (7.42)	54.81 (5.90)	0.08	49	0.94
Caregiver Burden					
Disability (N = 87)	2.05 (.77)	1.89 (.99)	0.82	85	0.41
Autism (N = 28)	2.35 (.66)	2.42 (.93)	-0.2	26	0.84
DS (N = 48)	1.67 (.60)	1.57 (.78)	0.48	46	0.63
Reported Benefits					
Disability (N = 85)	3.58 (1.00)	3.57 (1.01)	0.05	83	0.96
Autism (N = 28)	3.87 (1.00)	3.41 (1.23)	1.06	26	0.30
DS (N = 46)	3.50 (1.01)	3.69 (.95)	-0.64	44	0.52

Note. Autism group: † = $p < .05$; †† = $p < .01$ (one-tailed). DS and Disability group: ** = $p < .01$; ^{t} = trend towards significance ($p < .05$; two-tailed).

Table 17

Mediation Analysis Step #4: Summary of Regression Analyses When Antecedents and Mediators are Entered Simultaneously to Predict Caregiver Burden

	Variable	B	p	R	R^2	Model p
Within Autism Group						
1) Step 1	Problem Behaviors	.50	.00**			
Step 2	Avoidant (Coping)	0.44	0.01*	0.64	0.41	0.00**
	Problem Behaviors	0.31	0.07			
	Variable	β	P	R	R^2	Model p
Within Down Syndrome Group						
1) Step 1	Severity of Symptoms	.38	.01*			
Step 2	Threat (Appraisal)	0.78	0.00**	0.81	0.66	0.00**
	Severity of Symptoms	0.08	0.40			
2) Step 1	Severity of Symptoms	.38	.01			
Step 2	Centrality (Appraisal)	0.25	0.07	0.44	0.20	0.00**
	Severity of Symptoms	0.27	0.06			
3) Step 1	Problem Behaviors	.44	.00**			
Step 2	Threat (Appraisal)	0.75	0.00**	0.82	0.68	0.00**
	Problem Behaviors	0.17	0.07			

Note: * = $p < .05$. ** = $p < .01$. ^{t} = trend towards significance.

Table 17 Continued

Mediation Analysis Step #4: Summary of Regression Analyses When Antecedents and Mediators are Entered Simultaneously to Predict Caregiver Burden Continued

	Variable	β	p	R	R^2	Model p
Within Disability Group						
1) Step 1	Severity of Symptoms	.50	.00**			
Step 2	Threat (Appraisal)	0.61	0.00**	0.74	0.54	0.00**
	Severity of Symptoms	0.21	0.01^t			
2) Step 1	Severity of Symptoms	.50	.00**			
Step 2	Centrality (Appraisal)	0.13	0.17	0.52	0.27	0.00**
	Severity of Symptoms	0.46	0.00**			
3) Step 1	Severity of Symptoms	.50	.00**			
Step 2	Avoidant (Coping)	.59	.00**	.73	.53	.00**
	Severity of Symptoms	.25	.00**			
4) Step 1	Severity of Symptoms	.50	.00**			
Step 2	Emotional Approach (Coping)	-.01	.88	.50	.25	.00**
	Severity of Symptoms	.51	.00**			
5) Step 1	Adaptive Behavior	-.33	.00**			
Step 2	Threat (Appraisal)	0.68	0.00**	0.72	0.52	0.00**
	Adaptive Behavior	-0.10	0.19			
6) Step 1	Adaptive Behavior	-.33	.00**			
Step 2	Challenge (Appraisal)	-0.23	0.02^t	0.40	0.16	0.00**
	Adaptive Behavior	-0.27	0.01^t			
7) Step 1	Problem Behaviors	.57	.00**			
Step 2	Threat (Appraisal)	0.57	0.00**	0.77	0.59	0.00**
	Problem Behaviors	0.32	0.00**			
8) Step 1	Problem Behaviors	.57	.00**			
Step 2	Avoidant (Coping)	0.54	0.00**	0.74	0.55	0.00**
	Problem Behaviors	0.31	0.00**			

Note: * = $p < .05$. ** = $p < .01$. ^{t} = trend towards significance.

Table 18

Summary of Regression Analysis for Variables Predicting Mental Health-Related Quality of Life Within the Disability Group

Variable	β	p	R	R^2	Model p
Step 1					
Autism Diagnosis	-0.12	0.23	0.12	0.02	0.23
Step 2					
Autism Diagnosis	-0.05	0.59	0.49	0.24	.00**
Social Support	0.40	0.00**			
Pile-up demands	-0.25	0.01*			
Step 3					
Autism Diagnosis	.10	0.24	.66	.43	.00**
Social Support	0.15	0.12			
Pile-up demands	-.12	.18			
Avoidant Coping	-.56	.00**			

Note: N = 97. * = p < .05. ** = p < .01. ^{t} = trend towards significance. Autism Diagnosis has been dichotomized (yes/no).

Table 19

Summary of Regression Analysis for Variables Predicting Physical Health-Related Quality of Life Within the Disability Group

Variable	β	p	R	R^2	Model p
Step 1					
Autism Diagnosis	-.13	.21	.13	.02	.21
Step 2					
Autism Diagnosis	-.16	.11	.41	.17	.00**
Age of ND Sibling	-.36	.00**			
Pile-up Demands	-.22	.03*			

Note: N = 97. * p < .05. ** p < .01. ^{t} = trend towards significance. Autism Diagnosis has been dichotomized (yes/no).

Table 20

Summary of Regression Analysis Predicting Caregiver Burden Within the Disability Group

Variable	β	p	R	R^2	Model p
Step 1					
Autism Diagnosis	.31	0.00**	.31	.10	.00**
Step 2					
Autism Diagnosis	-.01	.90	.68	.47	.00**
Problem Behaviors	.49	.00**			
Social Support	-.38	.00**			
Step 3					
Autism Diagnosis	-.09	.24	.82	.67	.00**
Problem Behaviors	.29	.00**			
Social Support	-.10	.16			
Threat	.38	.00**			
Avoidant Coping	.31	.00**			

Note: N = 97. * = $p < .05$. ** = $p < .01$. ^{t} = trend towards significance. Autism Diagnosis has been dichotomized (yes/no).

Table 21

Summary of Regression Analysis Predicting Reported Benefits Within the Disability Group

Variable	β	p	R	R^2	Model p
Step 1					
Autism Diagnosis	.08	.42	.08	.01	.42
Step 2					
Autism Diagnosis	.28	.00**	.64	.41	.00**
Sibling Relationship Quality	.56	.00**			
Helpfulness of Services	.21	.02*			
Step 3					
Autism Diagnosis	.23	.01*	.67	.45	.01^t
Sibling Relationship Quality	.44	.00**			
Helpfulness of Services	.17	.05^t			
Challenge Appraisal	.24	.01*			

Note: N = 97. * p < .05. ** p < .01. ^{t} = trend towards significance. Autism Diagnosis has been dichotomized (yes/no).

Table 22

Summary of the Results of the Primary Antecedent Hypotheses

	Study Group	Autism	Autism	Autism	Autism	DS	DS	DS	DS	Disability	Disability	Disability	Disability
Primary Hypotheses	Psychosocial Outcome	Mental (M.) HRQOL	Physical (P.) HRQOL	Burden	Benefits	M. HRQOL	P. HRQOL	Burden	Benefits	M. HRQOL	P. HRQOL	Burden	Benefits
		Pred./Found	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F
AH1.A.	No. Non-disabled siblings	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / -	+ / 0
AH1.C.	Relationship quality	+ / 0	+ / ++	- / 0	+ / +++	+ / 0	+ / 0	- / --	+ / +++	+ / 0	+ / 0	- / ---	+ / +++ R
AH2.	Gender of Non-disabled Sibling	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / 0	+ / 0
AH3.A.	Symptom severity	- / 0	- / 0	+ / 0	- / 0	- / --	- / 0	+ / ++	- / 0	- / ---	- / 0	+ / +++	- / 0
AH3.B.	Problem Behaviors	- / -	- / 0	+ / +++	- / 0	- / +	- / 0	+ / +++	- / 0	- / --	- / 0	+ / +++ R	- / 0
AH3.C.	Adaptive Behavior	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / --	+ / 0	+ / +	+ / 0	- / --	+ / 0
AH4.A.	Social support	+ / 0	+ / 0	- / --	+ / ++	+ / +++	+ / 0	- / ---	+ / 0	+ / +++	+ / 0	- / ---	+ / +
AH4.B.	Helpfulness of Services	+ / ++	+ / 0	- / 0	+ / +++	+ / +	+ / 0	- / -	+ / +	+ / +	+ / 0	- / --	+ / +++
AH4.B.	No. of services	+ / 0	+ / 0	- / ++	+ / 0	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / 0	+ / +
AH.5.	Pile-up demands	- / 0	- / -	+ / 0	- / 0	- / ---	- / 0	+ / 0	- / 0	- / --	- / -- R	+ / +	- / 0

Note. P = direction of the relationship predicted. F = direction and type of relationship found during analyses. All analyses within the Autism group are 1-tailed. All analyses within the DS and Disability groups are 2-tailed. Within the Autism group: 0 = no relationship (p > .10 or p < -.10); trend = + or – (p < .10 or p > -.10); significant at the p < .05 level = ++ or -- (p < .05 or p > -.05); significant at the p < .01 level = +++ or --- (p < .01 or p > -.01). Within the DS and Disability groups: No relationship = 0 (p > .05 and p < -.05); trend = + or – (p < .05 or p > -.05); significant at the p < .01 level = ++ or – (p < .01 or p > -.01); significant at the p < .001 level = +++ or --- (p < .001 or p > -.001). R = variable was significant in the regression analysis within the Disability group.

Table 23

Summary of the Results of the Exploratory Hypotheses

	Study Group	Autism	Autism	Autism	Autism	DS	DS	DS	DS	Disability	Disability	Disability	Disability
Secondary Hypothesis	Psychosocial Outcome	Mental (M.) HRQOL	Physical (P.) HRQOL	Burden	Benefits	M. HRQOL	P. HRQOL	Burden	Benefits	M. HRQOL	P. HRQOL	Burden	Benefits
		P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F	P / F
EH1	Threat Appraisal	- / 0	- / 0	+ / +++	- / 0	- / --	- / 0	+ / ++	- / -	- / --	- / -	+ / ++ R	- / -
EH1	Challenge Appraisal	+ / +	+ / 0	- / 0	+ / ++	+ / 0	+ / 0	- / -	+ / ++	+ / ++	+ / 0	- / --	+ / ++ R
EH1	Centrality Appraisal	0 / +	0 / 0	0 / +	0 / 0	0 / 0	0 / 0	0 / ++	0 / 0	0 / 0	0 / 0	0 / ++	0 / 0
EH2.A.	Problem Based Coping	+ / 0	+ / 0	- / +	+ / 0	+ / 0	+ / --	- / ++	+ / 0	+ / 0	+ / --	- / ++	+ / 0
EH2.A.	Emotional Approach Coping	+ / 0	+ / 0	- / 0	+ / +	+ / -	+ / 0	- / 0	+ / 0	+ / 0	+ / -	- / 0	+ / +
EH2.B.	Passive Avoidant Coping	- / ---	- / 0	+ / +++	- / --	- / --	- / 0	+ / ++	- / 0	- / -- R	- / -	+ / ++ R	- / -
EH.3	Age of non-disabled sibling	- / 0	- / --	+ / -	0 / 0	- / 0	- / 0	+ / 0	0 / -	- / 0	- / -- R	+ / 0	0 / 0
EH.4	Marital Status	+ / 0	+ / 0	- / -	+ / 0	+ / 0	+ / 0	- / 0	+ / 0	+ / 0	+ / 0	- / 0	+ / 0
EH.5	Birth Order	+ / 0	+ / 0	0 / 0	0 / 0	+ / 0	+ / 0	0 / 0	0 / 0	+ / 0	+ / 0	0 / 0	0 / 0

Note. P = direction of the relationship predicted. F = direction and type of relationship found during analyses. All analyses within the Autism group are 1-tailed. All analyses within the DS and Disability groups are 2-tailed. Within the Autism group: 0 = no relationship (p > .10 or p < -.10); trend = + or – (p < .10 or p > -.10); significant at the p < .05 level = ++ or -- (p < .05 or p > -.05); significant at the p < .01 level = +++ or --- (p < .01 or p > -.01). Within the DS and Disability groups: No relationship = 0 (p > .05 and p < -.05); trend = + or – (p < .05 or p > -.05); significant at the p < .01 level = ++ or – (p < .01 or p > -.01); significant at the p < .001 level = +++ or --- (p < .001 or p > -.001). R = variable was significant in the regression analysis within the Disability group.

FIGURES

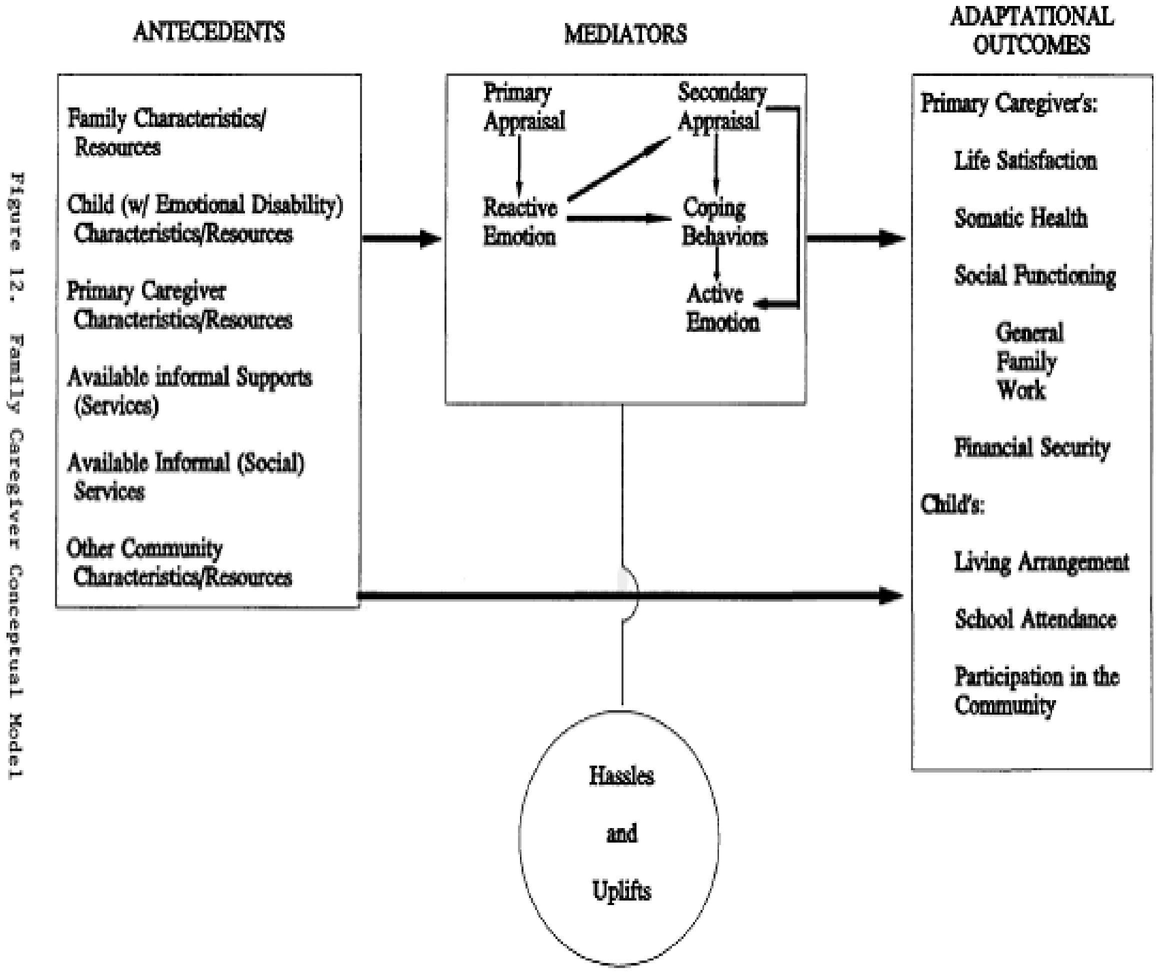


Figure 1. *The Family Caregiver Conceptual Model (McDonald et al., 1992)*

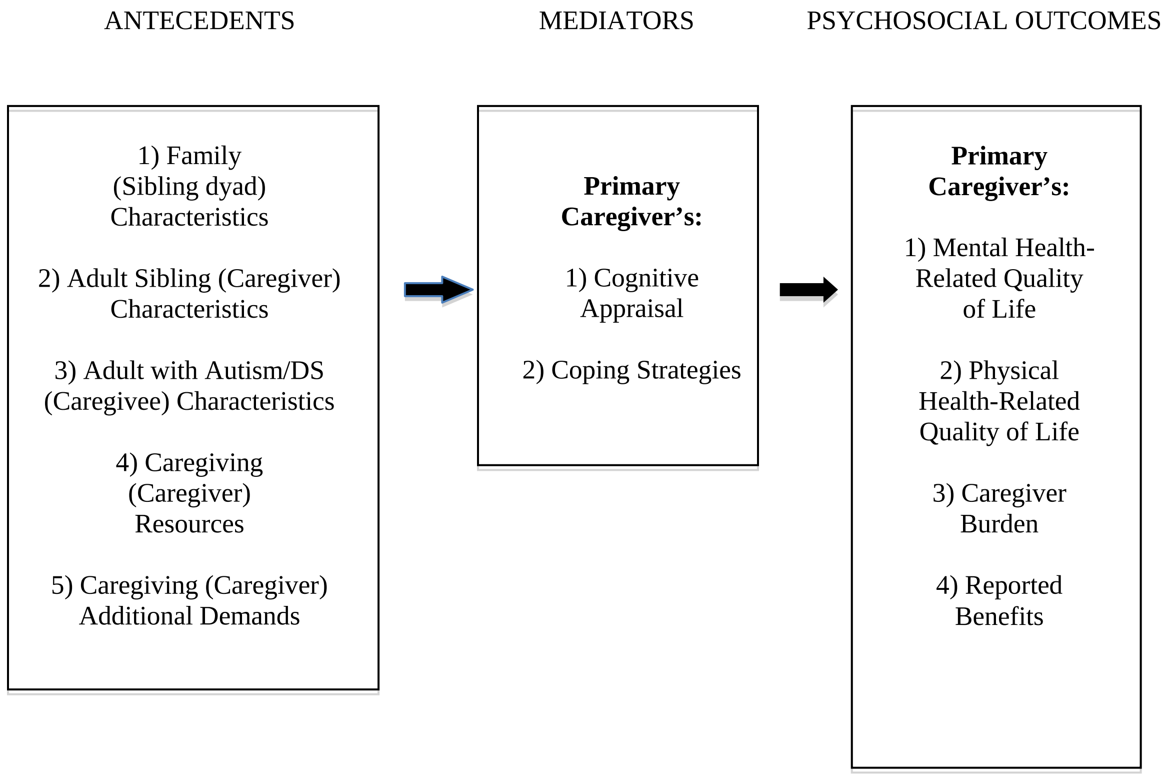


Figure 2. *The Adult Sibling Caregiver Conceptual Model (ASCCM)*

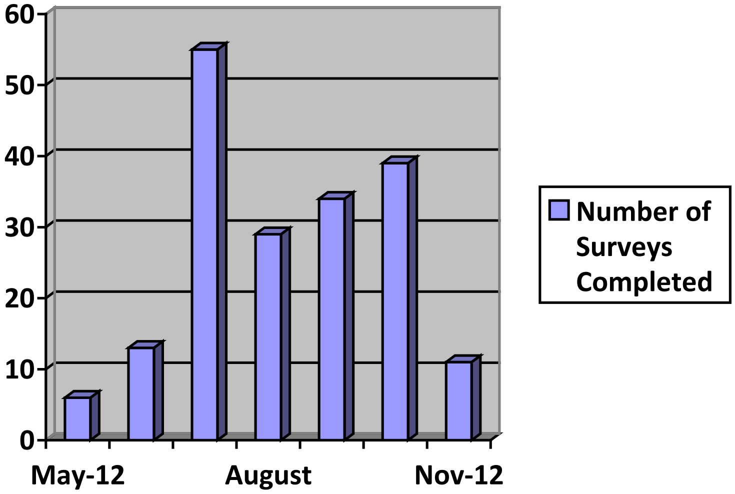
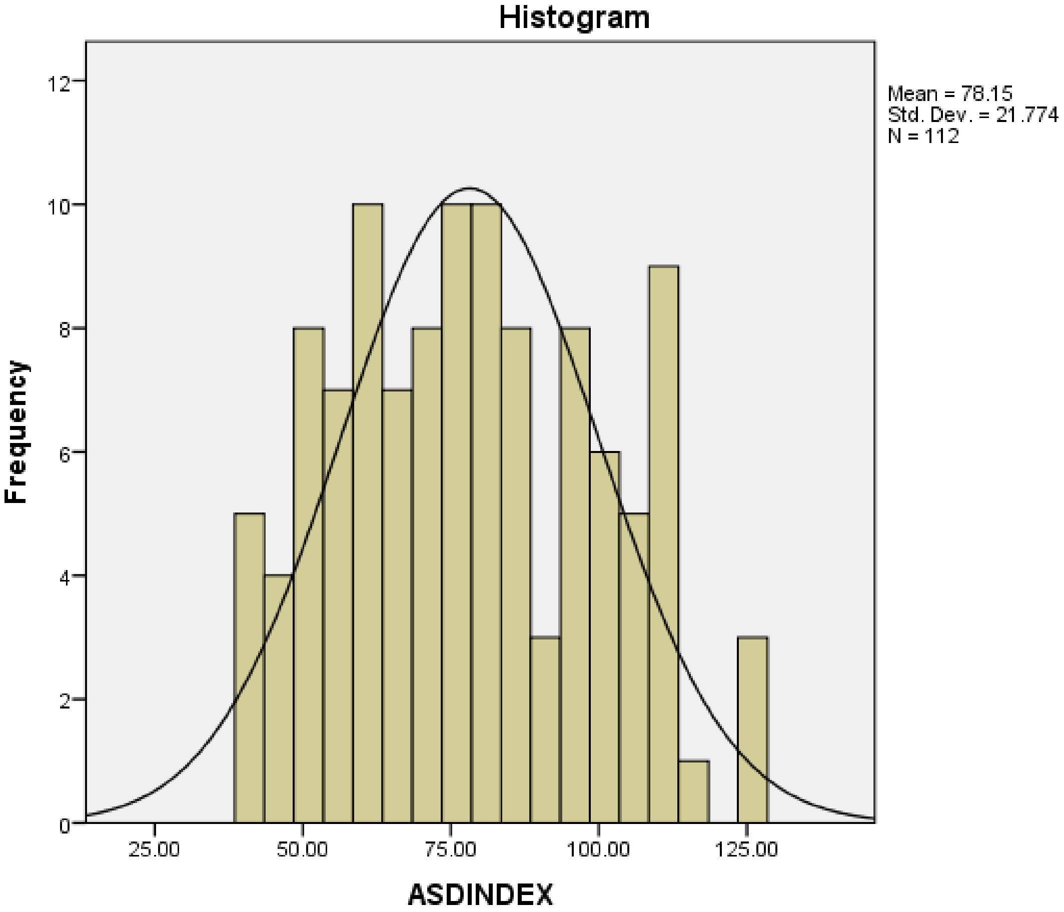
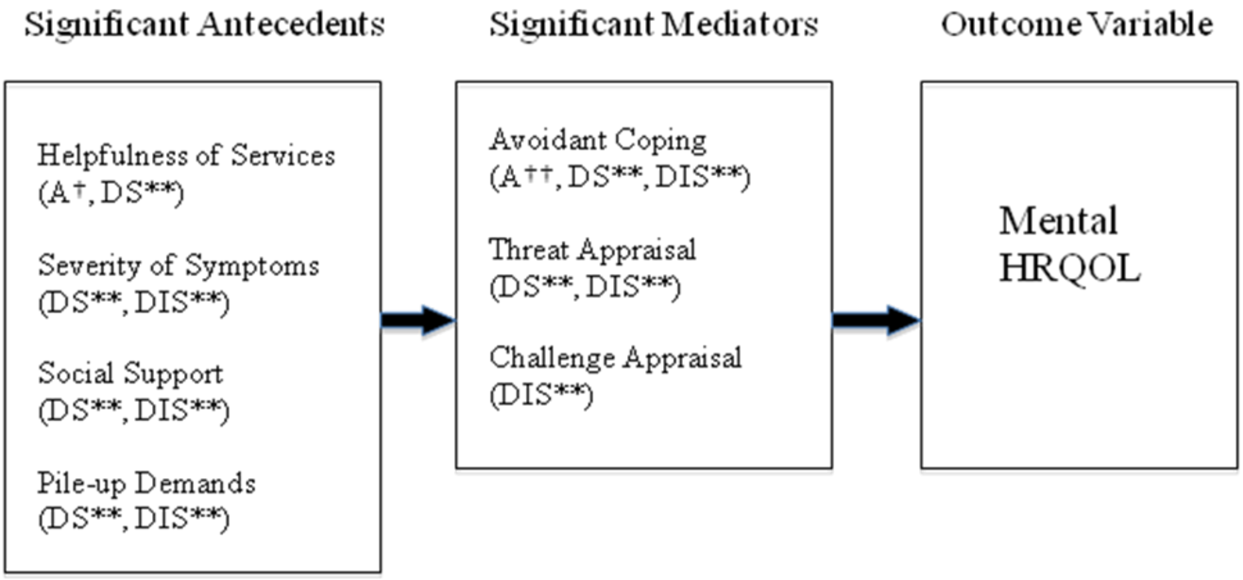


Figure 3. *Time Frame for Survey Completions*



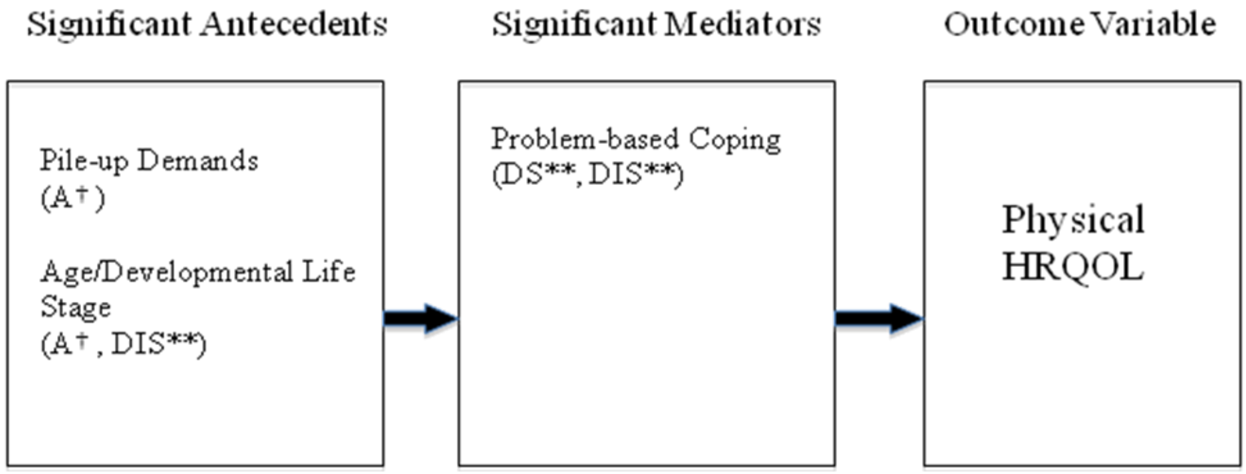
Note: GARS-2 Autism Index Scale: Mean = 100; SD = 15. A diagnosis of Autism is likely when score is >/= 85.

Figure 4. *Range of Autism Index Scale Scores on the GARS-2 for Study Participants with Analyzed Data (N = 112)*



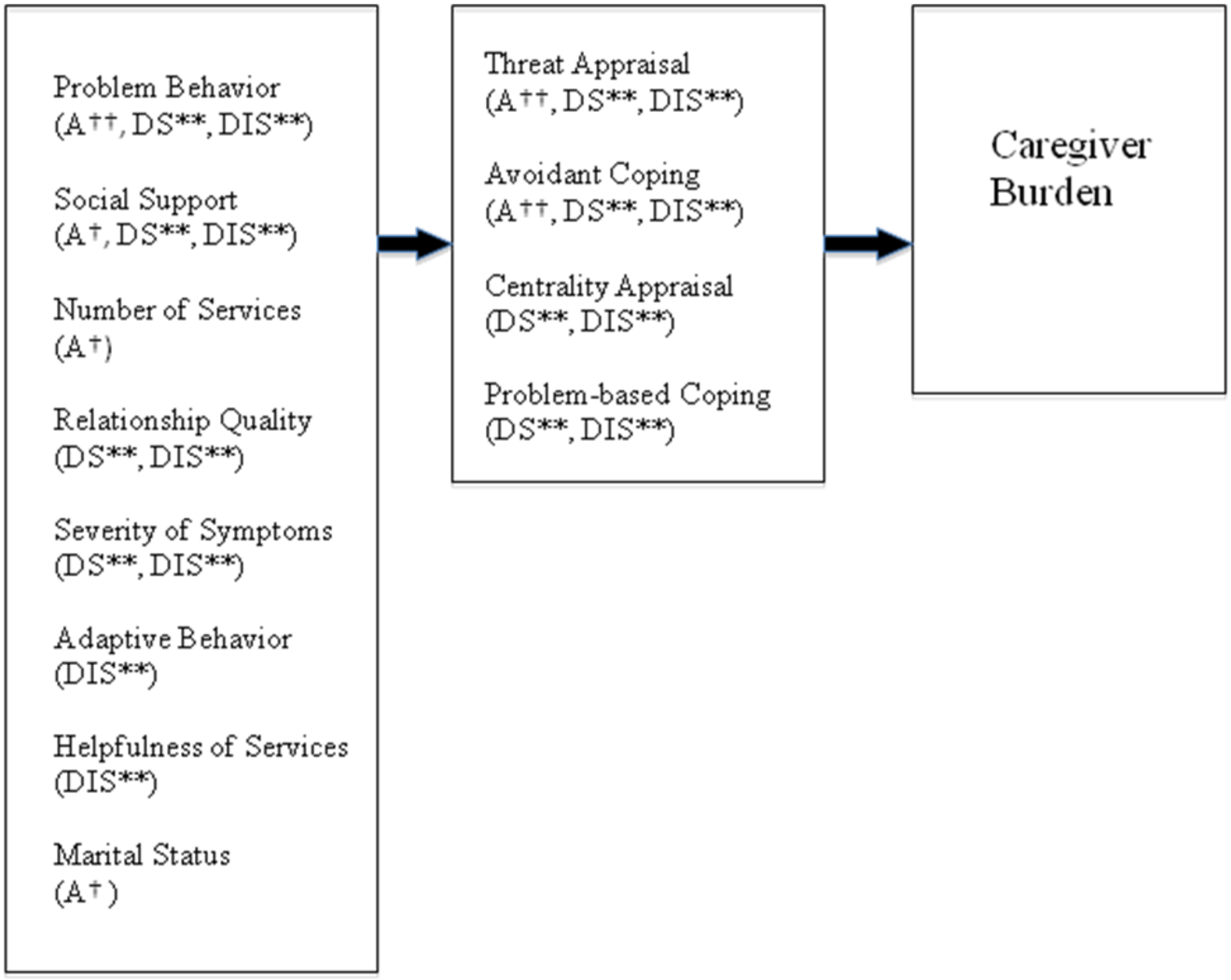
Note: A = Autism group. DS = Down syndrome group. DIS = Disability group. * = p < .05, two-tailed. ** = p < .01, two-tailed. † = p < .05, 1-tailed. †† = p < .01, 1-tailed.

Figure 5. *The ASCCM with Variables Significantly Associated with Mental HRQOL*



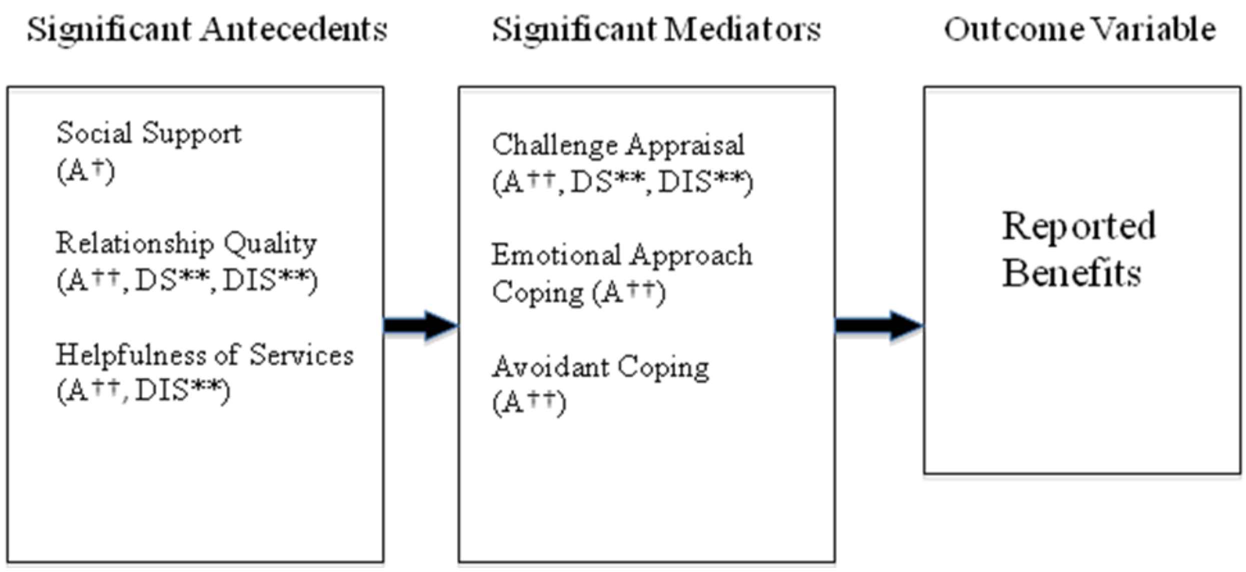
Note: A = Autism group. DS = Down syndrome group. DIS = Disability group. * = p < .05, two-tailed. ** = p < .01, two-tailed. † = p < .05, 1-tailed. †† = p < .01, 1-tailed.

Figure 6. *The ASCCM with Variables Significantly Associated with Physical HRQOL*



Note: A = Autism group. DS = Down syndrome group. DIS = Disability group. * = $p < .05$, two-tailed. ** = $p < .01$, two-tailed. † = $p < .05$, 1-tailed. †† = $p < .01$, 1-tailed.

Figure 7. *The ASCCM with Variables Significantly Associated with Caregiver Burden*



Note: A = Autism group. DS = Down syndrome group. DIS = Disability group. * = $p < .05$, two-tailed. ** = $p < .01$, two-tailed. † = $p < .05$, 1-tailed. †† = $p < .01$, 1-tailed.

Figure 8. *The ASCCM with Variables Significantly Associated with Reported Benefits*

APPENDICES

Appendix A. The Survey

CAREGIVER BURDEN, HEALTH-RELATED QUALITY OF LIFE, AND REPORTED BENEFITS IN ADULT SIBLING CAREGIVERS OF ADULTS WITH AUTISM AND DOWN SYNDROME

Survey Packet

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INFORMED CONSENT DOCUMENT

You are invited to participate in a research study that will investigate how adult siblings of adults with autism and Down Syndrome respond to the stress of having a disabled sibling in adulthood. You were selected as a possible subject because you have a sibling with autism or Down Syndrome and both of you are over the age of 18. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by John McGrew, Ph.D., and Teri Belkin, B.A. of the Psychology Department of Indiana University- Purdue University- Indianapolis (IUPUI).

STUDY PURPOSE

The purpose of this study is to examine the factors that may be associated with psychosocial outcomes of adult siblings of adults with autism or Down Syndrome.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things: Complete an online survey which will take approximately 45 minutes. The survey includes questions about your sibling's behaviors and core characteristics, his/her caregiving needs, and the demands that are placed on you as his/her sibling, as a potential caregiver, and in other domains of your life. You will also be asked to mention any resources that are available to you, including social supports, respite care, and financial/formal assistance. Your coping strategies and your appraisal of your caregiving situation will be examined as well. Finally, your health-related quality of life, caregiving burden, and any benefits you find in your relationship with your disabled sibling will be assessed.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. Information exchanged by emails or phone calls to the co-investigator will be deleted/destroyed once your questions have been answered. The survey that is submitted will not be associated with your name. Your identity will be confidential in reports in which the study may be published, and databases in which the results may be stored.

Organizations that may inspect and/or copy the confidential survey information for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP).

PAYMENT

With your consent, at the end of the survey, you can be entered into a raffle for a chance to win a $50 gift card to Target.

SCREENING QUESTIONNAIRE (SQ)

1. Do you have a mental or physical disability? If Yes, please indicate your diagnosis:

☐No ☐Yes________________________________

2.) Are you over the age of 18?

☐No ☐Yes________________________________

3.) Do you have a sibling with autism or Down syndrome?

☐No ☐Yes________________________________

4.) What is your sibling's diagnosis? (Please check only one):

☐Autism	☐Asperger's Syndrome
☐PDD-NOS	☐Down Syndrome
☐None	☐Other_____________________

5.) Is your sibling over the age of 18?

☐No ☐Yes________________________________

6.) Do you have any other siblings with a mental or physical disability? If Yes, please indicate their diagnosis:

☐No ☐Yes________________________________

7.) How often do you have contact (in person or long-distance) with your disabled sibling?

☐	☐	☐	☐	☐	☐
> 3x/week	1-3x/week	>1x/month	> 1x every 3 months	> once a year	< once a year

8.) To what degree are you familiar with the resources (respite, formal, and financial supports) that your sibling with autism or Down syndrome receives?

☐1. Very familiar
☐2. Mostly familiar
☐3. Somewhat familiar
☐4. Not at all familiar

DEMOGRAPHIC & BACKGROUND INFORMATION QUESTIONNAIRE (DBIQ)

1.) Number of non-disabled siblings that you have:

____

2.) What is your relationship to your sibling with autism/DS? (Check one)
"I am his/her ____."

____	Older Sister
____	Younger Sister
____	Older Brother
____	Younger Brother
____	Other (what:______________________)

3.) What is your sibling with autism/DS's gender? (Check one)

☐Male ☐Female

4.) What is your sibling with autism/DS's age?

____

5.) What is your sibling with autism/DS's race? (Check all that apply)
☐1. White
☐2. Black or African American
☐3. Asian
☐4. American Indian or Alaska Native
☐5. Native Hawaiian or Other Pacific Islander
☐6. Hispanic or Latino
☐7. Other________________________________

6.) What is your gender?

☐Male ☐Female

7.) What is your age?

____

8.) What is your race? (Check all that apply)
☐1. White
☐2. Black or African American
☐3. Asian
☐4. American Indian or Alaska Native
☐5. Native Hawaiian or Other Pacific Islander
☐6. Hispanic or Latino
☐7. Other________________________________

9.) Who currently lives in your household?

Age
Gender
Relationship to <u>you:</u> (spouse, son, daughter, etc.)

10.) In what state or province do you currently live?
____

11.) What is your current relationship status? (Check one)
☐Married ☐Single ☐Divorced
☐Widowed ☐Separated ☐Cohabitating

12.) What is your current employment status? (Check all that apply)
☐1. Working full time (35+ hours per week)
☐2. Working part time
☐3. Homemaker
☐4. Unemployed, looking for work
☐5. Unemployed, not looking for work
☐6. Disabled
☐7. Retired
☐8. Student, full time
☐9. Student, part time
☐10. Other___________________________________

13.) What is your highest level of education? (Check one)
☐1. Eighth grade or less
☐2. Some high school
☐3. High school graduate or GED
☐4. Some college
☐5. Technical or trade school
☐6. College graduate
☐7. Advanced graduate or professional degree
☐8. Other

14.) Does any part of your family's income come from public assistance?
☐Yes ☐No

15.) Annual household income:
☐1. Less than or equal to $20,000
☐2. $20,001 - $40,000
☐3. $40,001 - $60,000
☐4. $60,001 - $90,000
☐5. More than $90,000

LIFESPAN SIBLING RELATIONSHIP SCALE (LSRS)

Lifespan Sibling Relationship Scale Items

1 Strongly Disagree
2 Disagree
3 Neither Agree or Disagree
4 Agree
5 Strongly Agree

1. My sibling makes me happy. 1 2 3 4 5
2. My sibling's feelings are very important to me. 1 2 3 4 5
3. I enjoy my relationship with my sibling. 1 2 3 4 5
4. I am proud of my sibling. 1 2 3 4 5
5. My sibling and I have a lot of fun together. 1 2 3 4 5

6.* My sibling frequently makes me very angry. 1 2 3 4 5

7. I admire my sibling. 1 2 3 4 5
8. I like to spend time with my sibling. 1 2 3 4 5
9. I presently spend a lot of time with my sibling. 1 2 3 4 5
10. I call my sibling on the telephone frequently. 1 2 3 4 5
11. My sibling and I share secrets. 1 2 3 4 5
12. My sibling and I do a lot of things together. 1 2 3 4 5

13.* I never talk about my problems with my sibling. 1 2 3 4 5

14. My sibling and I borrow things from each other. 1 2 3 4 5
15. My sibling and I 'hang out' together. 1 2 3 4 5
16. My sibling talks to me about personal problems. 1 2 3 4 5

LIFESPAN SIBLING RELATIONSHIP SCALE (LSRS)

17. My sibling is a good friend. 1 2 3 4 5

18. My sibling is very important in my life. 1 2 3 4 5

19.* My sibling and I are not very close. 1 2 3 4 5

20. My sibling is one of my best friends. 1 2 3 4 5

21. My sibling and I have a lot in common. 1 2 3 4 5

22. I believe I am very important to my sibling. 1 2 3 4 5

23. I know that I am one of my sibling's best friends. 1 2 3 4 5

24. My sibling is proud of me. 1 2 3 4 5

25.* My sibling bothered me a lot when we were children. 1 2 3 4 5

26. I remember loving my sibling very much when I was a child. 1 2 3 4 5

27.* My sibling made me miserable when we were children. 1 2 3 4 5

28.* I was frequently angry at my sibling when we were children. 1 2 3 4 5

29. I was proud of my sibling when I was a child. 1 2 3 4 5

30. I enjoyed spending time with my sibling as a child. 1 2 3 4 5

31. I remember feeling very close to my sibling when we were children. 1 2 3 4 5

32. I remember having a lot of fun with my sibling when we were children. 1 2 3 4 5

33. My sibling and I often had the same friends as children. 1 2 3 4 5

34. My sibling and I shared secrets as children. 1 2 3 4 5

35. My sibling and I often helped each other as children. 1 2 3 4 5

LIFESPAN SIBLING RELATIONSHIP SCALE (LSRS)

36. My sibling looked after me (OR I looked after my sibling) when we were children.

1 2 3 4 5

37. My sibling and I often played together as children.

1 2 3 4 5

38.* My sibling and I did not spend a lot of time together when we were children

1 2 3 4 5

39. My sibling and I spent time together after school as children.

1 2 3 4 5

40. I talked to my sibling about my problems when we were children.

1 2 3 4 5

41. My sibling and I were 'buddies' as children.

1 2 3 4 5

42.* My sibling did not like to play with me when we were children.

1 2 3 4 5

43. My sibling and I were very close when we were children.

1 2 3 4 5

44. My sibling and I were important to each other when we were children.

1 2 3 4 5

45. My sibling had an important and positive effect on my childhood.

1 2 3 4 5

46. My sibling knew everything about me when we were children.

1 2 3 4 5

47. My sibling and I liked all the same things when we were children.

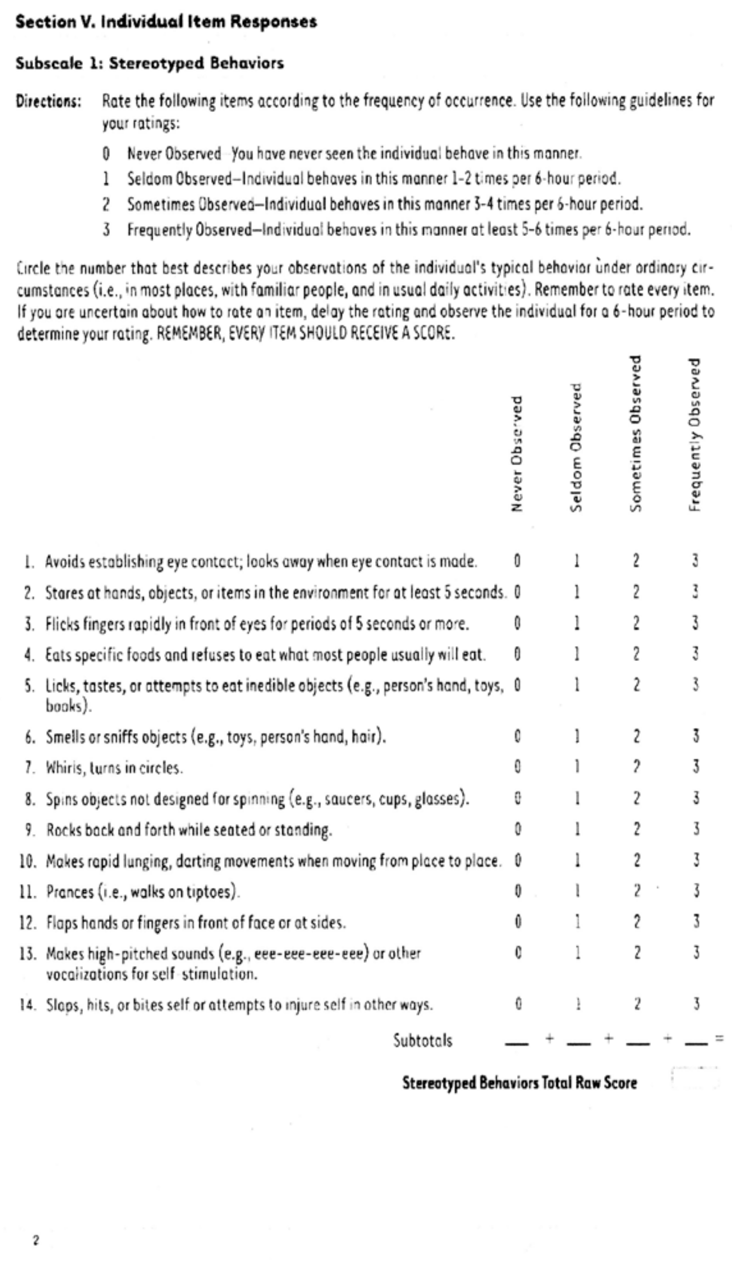
1 2 3 4 5

48. My sibling and I had a lot in common as children.

1 2 3 4 5

*Note.** Reverse scored item. Items 1-8 reflect Adult Affect; 9-16 reflect Adult Behavior; 17-24 reflect Adult Cognitions; 25-32 reflect Child Affect; 33-40 reflect Child Behavior; and 41-48 reflect Child Cognition.

GILLIAM AUTISM RATING SCALE SECOND EDITION (GARS-2)



Section V. Individual Item Responses

Subscale 1: Stereotyped Behaviors

Directions: Rate the following items according to the frequency of occurrence. Use the following guidelines for your ratings:

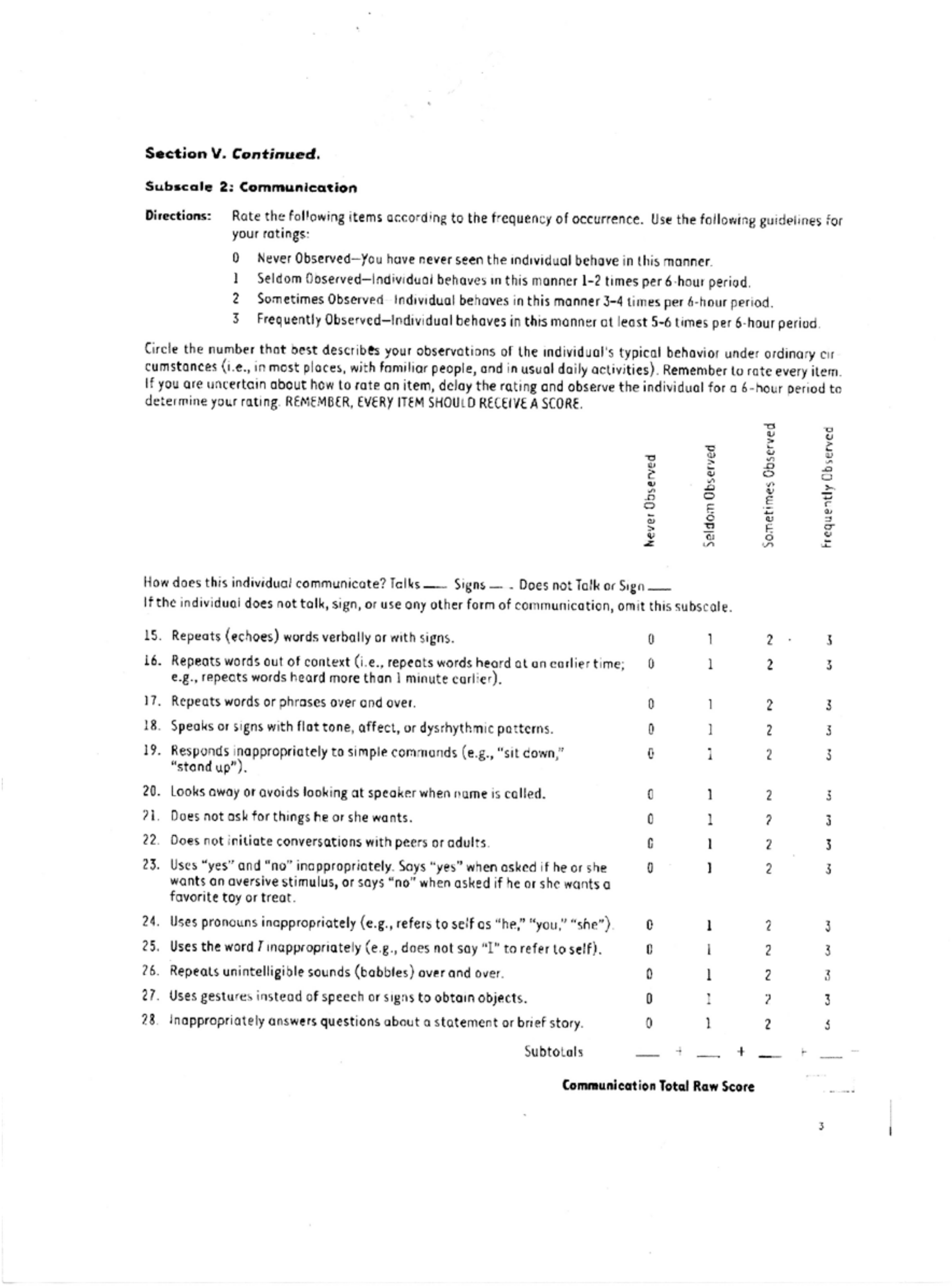
0 Never Observed You have never seen the individual behave in this manner.
1 Seldom Observed—Individual behaves in this manner 1–2 times per 6-hour period.
2 Sometimes Observed—Individual behaves in this manner 3–4 times per 6-hour period.
3 Frequently Observed—Individual behaves in this manner at least 5–6 times per 6-hour period.

Circle the number that best describes your observations of the individual's typical behavior under ordinary circumstances (i.e., in most places, with familiar people, and in usual daily activities). Remember to rate every item. If you are uncertain about how to rate an item, delay the rating and observe the individual for a 6-hour period to determine your rating. REMEMBER, EVERY ITEM SHOULD RECEIVE A SCORE.

	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed
1. Avoids establishing eye contact; looks away when eye contact is made.	0	1	2	3
2. Stares at hands, objects, or items in the environment for at least 5 seconds.	0	1	2	3
3. Flicks fingers rapidly in front of eyes for periods of 5 seconds or more.	0	1	2	3
4. Eats specific foods and refuses to eat what most people usually will eat.	0	1	2	3
5. Licks, tastes, or attempts to eat inedible objects (e.g., person's hand, toys, books).	0	1	2	3
6. Smells or sniffs objects (e.g., toys, person's hand, hair).	0	1	2	3
7. Whirls, turns in circles.	0	1	2	3
8. Spins objects not designed for spinning (e.g., saucers, cups, glasses).	0	1	2	3
9. Rocks back and forth while seated or standing.	0	1	2	3
10. Makes rapid lunging, darting movements when moving from place to place.	0	1	2	3
11. Prances (i.e., walks on tiptoes).	0	1	2	3
12. Flaps hands or fingers in front of face or at sides.	0	1	2	3
13. Makes high-pitched sounds (e.g., eee-eee-eee-eee) or other vocalizations for self stimulation.	0	1	2	3
14. Slaps, hits, or bites self or attempts to injure self in other ways.	0	1	2	3
Subtotals	___ +	___ +	___ +	___ =

Stereotyped Behaviors Total Raw Score ☐

GILLIAM AUTISM RATING SCALE SECOND EDITION (GARS-2)



Section V. *Continued.*

Subscale 2: Communication

Directions: Rate the following items according to the frequency of occurrence. Use the following guidelines for your ratings:

0 Never Observed—You have never seen the individual behave in this manner.
1 Seldom Observed—Individual behaves in this manner 1–2 times per 6-hour period.
2 Sometimes Observed—Individual behaves in this manner 3–4 times per 6-hour period.
3 Frequently Observed—Individual behaves in this manner at least 5–6 times per 6-hour period.

Circle the number that best describes your observations of the individual's typical behavior under ordinary circumstances (i.e., in most places, with familiar people, and in usual daily activities). Remember to rate every item. If you are uncertain about how to rate an item, delay the rating and observe the individual for a 6-hour period to determine your rating. REMEMBER, EVERY ITEM SHOULD RECEIVE A SCORE.

How does this individual communicate? Talks ___ Signs ___ Does not Talk or Sign ___
If the individual does not talk, sign, or use any other form of communication, omit this subscale.

	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed
15. Repeats (echoes) words verbally or with signs.	0	1	2	3
16. Repeats words out of context (i.e., repeats words heard at an earlier time; e.g., repeats words heard more than 1 minute earlier).	0	1	2	3
17. Repeats words or phrases over and over.	0	1	2	3
18. Speaks or signs with flat tone, affect, or dysrhythmic patterns.	0	1	2	3
19. Responds inappropriately to simple commands (e.g., "sit down," "stand up").	0	1	2	3
20. Looks away or avoids looking at speaker when name is called.	0	1	2	3
21. Does not ask for things he or she wants.	0	1	2	3
22. Does not initiate conversations with peers or adults.	0	1	2	3
23. Uses "yes" and "no" inappropriately. Says "yes" when asked if he or she wants an aversive stimulus, or says "no" when asked if he or she wants a favorite toy or treat.	0	1	2	3
24. Uses pronouns inappropriately (e.g., refers to self as "he," "you," "she").	0	1	2	3
25. Uses the word *I* inappropriately (e.g., does not say "I" to refer to self).	0	1	2	3
26. Repeats unintelligible sounds (babbles) over and over.	0	1	2	3
27. Uses gestures instead of speech or signs to obtain objects.	0	1	2	3
28. Inappropriately answers questions about a statement or brief story.	0	1	2	3
Subtotals	___ +	___ +	___ +	___ =

Communication Total Raw Score ___

Section V. *Continued.*

Subscale 3: Social Interaction

Directions: Rate the following items according to the frequency of occurrence. Use the following guidelines for your ratings:

0 Never Observed—You have never seen the individual behave in this manner.
1 Seldom Observed—Individual behaves in this manner 1–2 times per 6-hour period.
2 Sometimes Observed—Individual behaves in this manner 3–4 times per 6-hour period.
3 Frequently Observed—Individual behaves in this manner at least 5–6 times per 6-hour period.

Circle the number that best describes your observations of the individual's typical behavior under ordinary circumstances (i.e., in most places, with familiar people, and in usual daily activities). Remember to rate every item. If you are uncertain about how to rate an item, delay the rating and observe the individual for a 6-hour period to determine your rating. REMEMBER, EVERY ITEM SHOULD RECEIVE A SCORE.

	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed
29. Avoids eye contact; looks away when someone looks at him or her.	0	1	2	3
30. Stares or looks unhappy or unexcited when praised, humored, or entertained.	0	1	2	3
31. Resists physical contact from others (e.g., hugs, pats, being held affectionately).	0	1	2	3
32. Does not imitate other people when imitation is required or desirable, such as in games or learning activities.	0	1	2	3
33. Withdraws, remains aloof, or acts standoffish in group situations.	0	1	2	3
34. Behaves in an unreasonably fearful, frightened manner.	0	1	2	3
35. Is unaffectionate; does not give affectionate responses (e.g., hugs and kisses).	0	1	2	3
36. Shows no recognition that a person is present (i.e., looks through people).	0	1	2	3
37. Laughs, giggles, cries inappropriately.	0	1	2	3
38. Uses toys or objects inappropriately (e.g., spins toy cars, takes action toys apart).	0	1	2	3
39. Does certain things repetitively, ritualistically.	0	1	2	3
40. Becomes upset when routines are changed.	0	1	2	3
41. Responds negatively or with temper tantrums when given commands, requests, or directions.	0	1	2	3
42. Lines up objects in precise, orderly fashion and becomes upset when the order is disturbed.	0	1	2	3
Subtotals	___ +	___ +	___ +	___ =

Social Interaction Total Raw Score ☐

PROBLEM BEHAVIOR RATING SCALE (PBRS)

A. Please use the following scale to indicate which of the following behaviors are problematic for your sibling:

1	2	3	4
Not at all problematic		Very problematic	

1. Acting impulsively or carelessly, without regard for consequences

1 2 3 4

2. Hitting or hurting others

1 2 3 4

3. Teasing or bullying others

1 2 3 4

4. Damaging or breaking things that belong to others

1 2 3 4

5. Screaming or yelling

1 2 3 4

6. Having sudden mood changes; demonstrating mood swings

1 2 3 4

7. Having temper tantrums or meltdowns

1 2 3 4

8. Being overly bossy or stubborn; needing to have his/her own way

1 2 3 4

9. Having a low frustration tolerance; becoming easily angered or upset

1 2 3 4

10. Crying easily with minor provocation

1 2 3 4

11. Making negative statements about him/herself

1 2 3 4

12. Being overly quiet, shy, or withdrawn

1 2 3 4

PROBLEM BEHAVIOR RATING SCALE (PBRS)

13. Acting sulky or sad

1 2 3 4

14. Being underactive or lacking in energy; sedentary

1 2 3 4

15. Expressing worry about many things

1 2 3 4

16. Engaging in behaviors that may be distasteful to others, such as nose-picking or spitting

1 2 3 4

17. Touching him/herself inappropriately

1 2 3 4

18. Engaging in compulsive behaviors; repeating certain acts over and over; having to do the same behavior in a specified way many times

1 2 3 4

19. Being overly concerned with making mistakes; being a perfectionist

1 2 3 4

20. Having toileting accidents

1 2 3 4

PROBLEM BEHAVIOR RATING SCALE (PBRS)

21. Hitting or hurting him/herself

1 2 3 4

22. Becoming overly upset when others touch or move his/her belongings

1 2 3 4

23. Laughing or giggling at inappropriate times (e.g., when others are hurt or upset)

1 2 3 4

24. Ignoring or walking away from others during interactions or play

1 2 3 4

25. Becoming upset if routines are changed

1 2 3 4

26. Touching others inappropriately

1 2 3 4

27. Asking the same questions over and over

1 2 3 4

28. Engaging in unusual mannerisms such as hand-flapping or spinning

1 2 3 4

29. Having to play or do things in the same exact way each time

1 2 3 4

30. Having difficulty calming him/herself down when upset or excited

1 2 3 4

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)

A. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers, etc.	1
2. Dials a few well-known numbers	
3. Answers telephone but does not dial	
4. Does not use telephone at all.	1
	1
	0

B. Shopping

1. Takes care of all shopping needs independently	1
2. Shops independently for small purchases	0
3. Needs to be accompanied on any shopping trip.	0
4. Completely unable to shop.	0

C. Food Preparation

1. Plans, prepares and serves adequate meals independently	1
2. Prepares adequate meals if supplied with ingredients	0
3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet.	0
4. Needs to have meals prepared and served.	0

D. Housekeeping

1. Maintains house alone or with occasional assistance (e.g. “heavy work domestic help”)	1
2. Performs light daily tasks such as dish-washing, bed making	1
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.	1
4. Needs help with all home maintenance tasks.	1
5. Does not participate in any housekeeping tasks.	0

Source: Lawton, M.P., and Brody, E.M. “Assessment of older people: Self-maintaining and instrumental activities of daily living.” Gerontologist 9:179-186, (1969).

E. Laundry

1. Does personal laundry completely	1
2. Launders small items; rinses stockings, etc.	1
3. All laundry must be done by others.	0

F. Mode of Transportation

1. Travels independently on public transportation or drives own car.	1
2. Arranges own travel via taxi, but does not otherwise use public transportation.	1
3. Travels on public transportation when accompanied by another.	1
4. Travel limited to taxi or automobile with assistance of another.	0
5. Does not travel at all.	0

G. Responsibility for own medications

1. Is responsible for taking medication in correct dosages at correct time.	1
2. Takes responsibility if medication is prepared in advance in separate dosage.	0
3. Is not capable of dispensing own medication.	0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income.	1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	1
3. Incapable if handling money)	0

MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (MSPSS)

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

1, 2, 5, 10 = SO
3, 4, 8, 11 = Fam
6, 7, 9, 12 = Fri

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life that cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

RESPITE, FORMAL, AND FINANCIAL SUPPORT MEASURE (RFFSM)

Please indicate whether, and how often, you, your family, and your sibling receive the following services. Then please rate the item's helpfulness on a scale of 1-5.

Service		Receive: Yes / No / Don't Know (DK)	Estimated # of Hours/Week	Helpfulness on a Scale of 1-5, with 1 being the least helpful and 5 being the most helpful.
1.)	Respite	Yes / No / DK	______hours.	1 2 3 4 5
2.)	Occupational Therapy	Yes / No / DK	______hours.	1 2 3 4 5
3.)	Physical Therapy	Yes / No / DK	______hours.	1 2 3 4 5
4.)	Speech Therapy	Yes / No / DK	______hours.	1 2 3 4 5
5.)	Behavior Therapy	Yes / No / DK	______hours.	1 2 3 4 5
6.)	Psychology Services	Yes / No / DK	______hours.	1 2 3 4 5
7.)	Day Program Placement	Yes / No / DK	______hours.	1 2 3 4 5
8.)	Group Home Placement	Yes / No / DK	______hours.	1 2 3 4 5
9.)	Supported Living	Yes / No / DK	______hours.	1 2 3 4 5
10.)	Supported Employment	Yes / No / DK	______hours.	1 2 3 4 5
11.)	Assistance From Other Family Members	Yes / No / DK	______hours.	1 2 3 4 5
12.)	Other (please type/write in below):	Yes / No / DK	______hours.	1 2 3 4 5

SOCIAL READJUSTMENT RATING SCALE (SRRS)

For each of the events listed below, please indicate whether you have experienced the event within the past ***12 months*** and how stressful the event was for you.

	Not Experienced	Experienced:				
		with No Distress	with Mild Distress	with Moderate Distress	with Great Distress	with Extreme Distress
1. Death of spouse	0	1	2	3	4	5
2. Divorce	0	1	2	3	4	5
3. Marital Separation	0	1	2	3	4	5
4. Jail term	0	1	2	3	4	5
5. Death of a close family member	0	1	2	3	4	5
6. Personal injury/illness	0	1	2	3	4	5
7. Marriage	0	1	2	3	4	5
8. Fired at work	0	1	2	3	4	5
9. Marital reconciliation	0	1	2	3	4	5
10. Retirement	0	1	2	3	4	5
11. Change in health of family member	0	1	2	3	4	5
12. Pregnancy	0	1	2	3	4	5
13. Sex differences	0	1	2	3	4	5
14. Gain of a new family member	0	1	2	3	4	5
15. Business readjustments	0	1	2	3	4	5
16. Change in financial state	0	1	2	3	4	5
17. Death of a close friend	0	1	2	3	4	5
18. Change to different line of work	0	1	2	3	4	5
19. Change in number of arguments with spouse	0	1	2	3	4	5
20. Mortgage over $50,000	0	1	2	3	4	5
21. Foreclosure of Mortgage	0	1	2	3	4	5

SOCIAL READJUSTMENT RATING SCALE (SRRS)

22. Change in responsibilities at work	0	1	2	3	4	5
23. Son/daughter leaving home (other than subject child)	0	1	2	3	4	5
24. Trouble with in-laws	0	1	2	3	4	5
25. Outstanding personal achievements	0	1	2	3	4	5
26. Spouse begins/stops work	0	1	2	3	4	5
27. Begin or end school	0	1	2	3	4	5
28. Change in living conditions	0	1	2	3	4	5
29. Revision of personal habits (diet, exercise)	0	1	2	3	4	5
30. Trouble with boss	0	1	2	3	4	5
31. Change in work hours or conditions	0	1	2	3	4	5
32. Change in residence	0	1	2	3	4	5
33. Change in school	0	1	2	3	4	5
34. Change in recreation	0	1	2	3	4	5
35. Change in religious activities	0	1	2	3	4	5
36. Change in social activities	0	1	2	3	4	5
37. Loan less than $50,000	0	1	2	3	4	5
38. Change in sleeping habits	0	1	2	3	4	5
39. Change in number of family get-togethers	0	1	2	3	4	5
40. Change in eating habits	0	1	2	3	4	5
41. Vacation	0	1	2	3	4	5
42. Holidays	0	1	2	3	4	5
43. Minor violation of laws	0	1	2	3	4	5
27. Begin or end school	0	1	2	3	4	5
28. Change in living conditions	0	1	2	3	4	5
29. Revision of personal habits (diet, exercise)	0	1	2	3	4	5
30. Trouble with boss	0	1	2	3	4	5
31. Change in work hours or conditions	0	1	2	3	4	5
32. Change in residence	0	1	2	3	4	5
33. Change in school	0	1	2	3	4	5
34. Change in recreation	0	1	2	3	4	5

35. Change in religious activities	0	1	2	3	4	5
36. Change in social activities	0	1	2	3	4	5
37. Loan less than $50,000	0	1	2	3	4	5
38. Change in sleeping habits	0	1	2	3	4	5
39. Change in number of family get-togethers	0	1	2	3	4	5
40. Change in eating habits	0	1	2	3	4	5
41. Vacation	0	1	2	3	4	5
42. Holidays	0	1	2	3	4	5
43. Minor violation of laws	0	1	2	3	4	5

THE STRESS APPRAISAL MEASURE (SAM)

The Stress Appraisal Measure
(SAM)

Edward J. Peacock & Paul T.P. Wong

This questionnaire is concerned with your thoughts about various aspects of the situation identified previously. There are no right or wrong answers. Please respond according to how you view this situation right **NOW.** Please answer ALL questions. Answer each question by CIRCLING the appropriate number corresponding to the following scale.

1 = Not At All, 2 = Slightly, 3 = Moderately, 4 = Considerably, 5 = Extremely

1. Is this a totally hopeless situation? 1 2 3 4 5
2. Does this situation create tension in me? 1 2 3 4 5
3. Is the outcome of this situation uncontrollable by anyone? 1 2 3 4 5
4. Is there someone or some agency I can turn to for help if I need it? 1 2 3 4 5
5. Does this situation make me feel anxious? 1 2 3 4 5
6. Does this situation have important consequences for me? 1 2 3 4 5
7. Is this going to have a positive impact on me? 1 2 3 4 5
8. How eager am I to tackle this problem? 1 2 3 4 5
9. How much will I be affected by the outcome of this situation? 1 2 3 4 5

10. To what extent can I become a stronger person because of this problem
1 2 3 4 5

11. Will the outcome of this situation be negative?
1 2 3 4 5

12. Do I have the ability to do well in this situation?
1 2 3 4 5

13. Does this situation have serious implications for me?
1 2 3 4 5

14. Do I have what it takes to do well in this situation?
1 2 3 4 5

THE STRESS APPRAISAL MEASURE (SAM)

15. Is there help available to me for dealing with this problem? 1 2 3 4 5
16. Does this situation tax or exceed my coping resources? 1 2 3 4 5
17. Are there sufficient resources available to help me in dealing with this situation? 1 2 3 4 5
18. Is it beyond anyone's power to do anything about this situation? 1 2 3 4 5
19. To what extent am I excited thinking about the outcome of this situation? 1 2 3 4 5
20. How threatening is this situation? 1 2 3 4 5
21. Is the problem unresolvable by anyone? 1 2 3 4 5
22. Will I be able to overcome the problem? 1 2 3 4 5
23. Is there anyone who can help me to manage this problem? 1 2 3 4 5
24. To what extent do I perceive this situation as stressful? 1 2 3 4 5
25. Do I have the skills necessary to achieve a successful outcome to this situation? 1 2 3 4 5
26. To what extent does this event require coping efforts on my part? 1 2 3 4 5
27. Does this situation have long-term consequences for me? 1 2 3 4 5
28. Is this going to have a negative impact on me? 1 2 3 4 5

Scoring Key For The Stress Appraisal Measure (SAM).
Edward J. Peacock & Paul T. P. Wong

SAM SCALE	SAM ITEM NUMBERS
Threat	5, 11, 20, 28
Challenge	7, 8, 10, 19
Centrality	6, 9, 13, 27
Control-Self	12, 14, 22, 25
Control-Others	4, 15, 17, 23
Uncontrollable	1, 3, 18, 21

BRIEF COPE

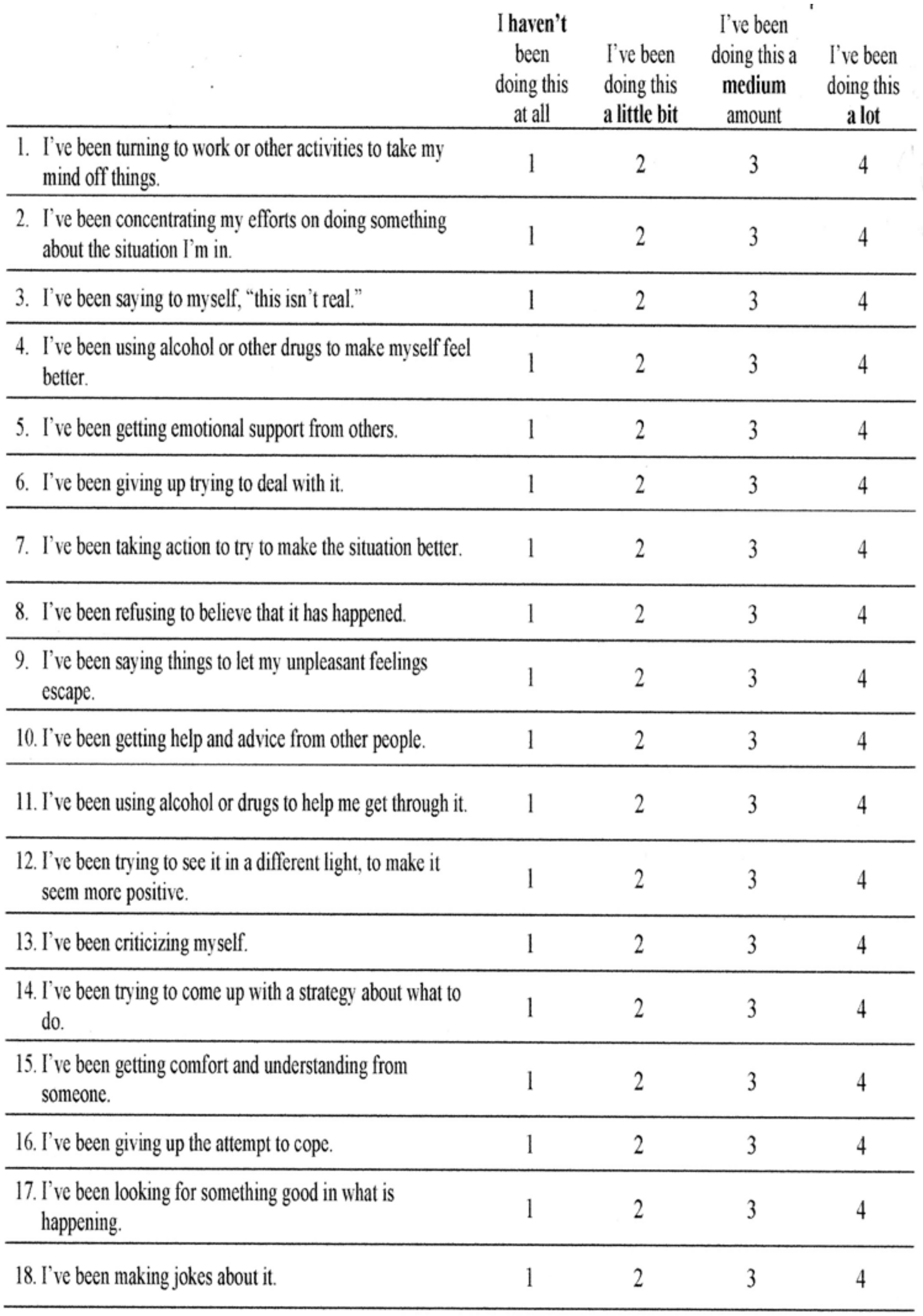
These items deal with ways you've been coping with the stress in your life due to having a sibling with autism or Down syndrome. There are many ways to try to deal with stresses. These items ask what you've been doing to cope with this stress. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

“Following is the BRIEF COPE as we are now administering it, with the instructional orientation for a presurgery interview (the first time the COPE is given in this particular study). Please feel free to adapt the instructions as needed for your application. Scales are computed as follows (with no reversals of coding):”

Self-distraction, items 1 and 19
Active coping, items 2 and 7
Denial, items 3 and 8
Substance use, items 4 and 11
Use of emotional support, items 5 and 15
Use of instrumental support, items 10 and 23
Behavioral disengagement, items 6 and 16
Venting, items 9 and 21
Positive reframing, items 12 and 17
Planning, items 14 and 25
Humor, items 18 and 28
Acceptance, items 20 and 24
Religion, items 22 and 27
Self-blame, items 13 and 26

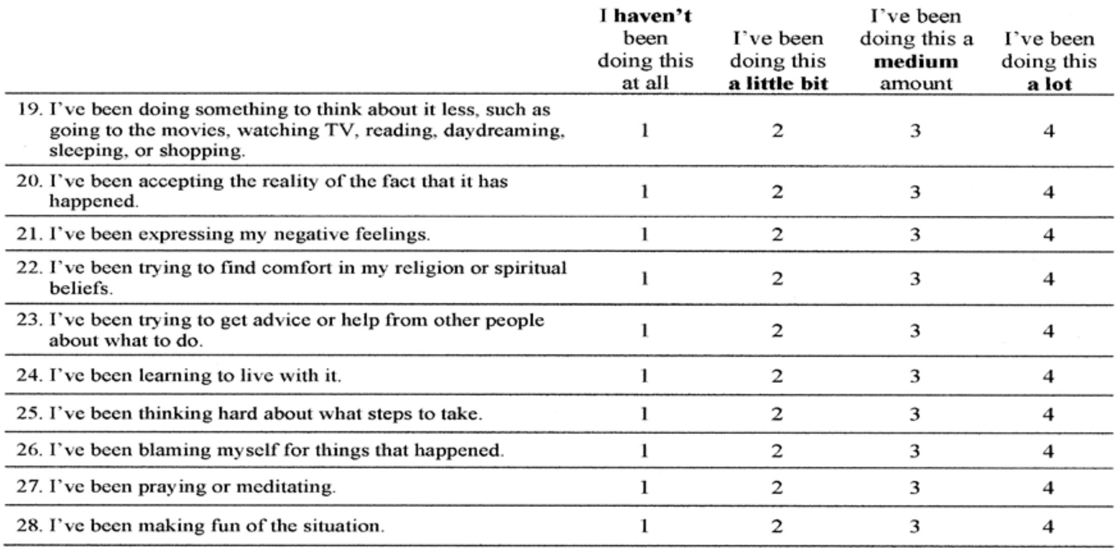
1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

BRIEF COPE CONTINUED



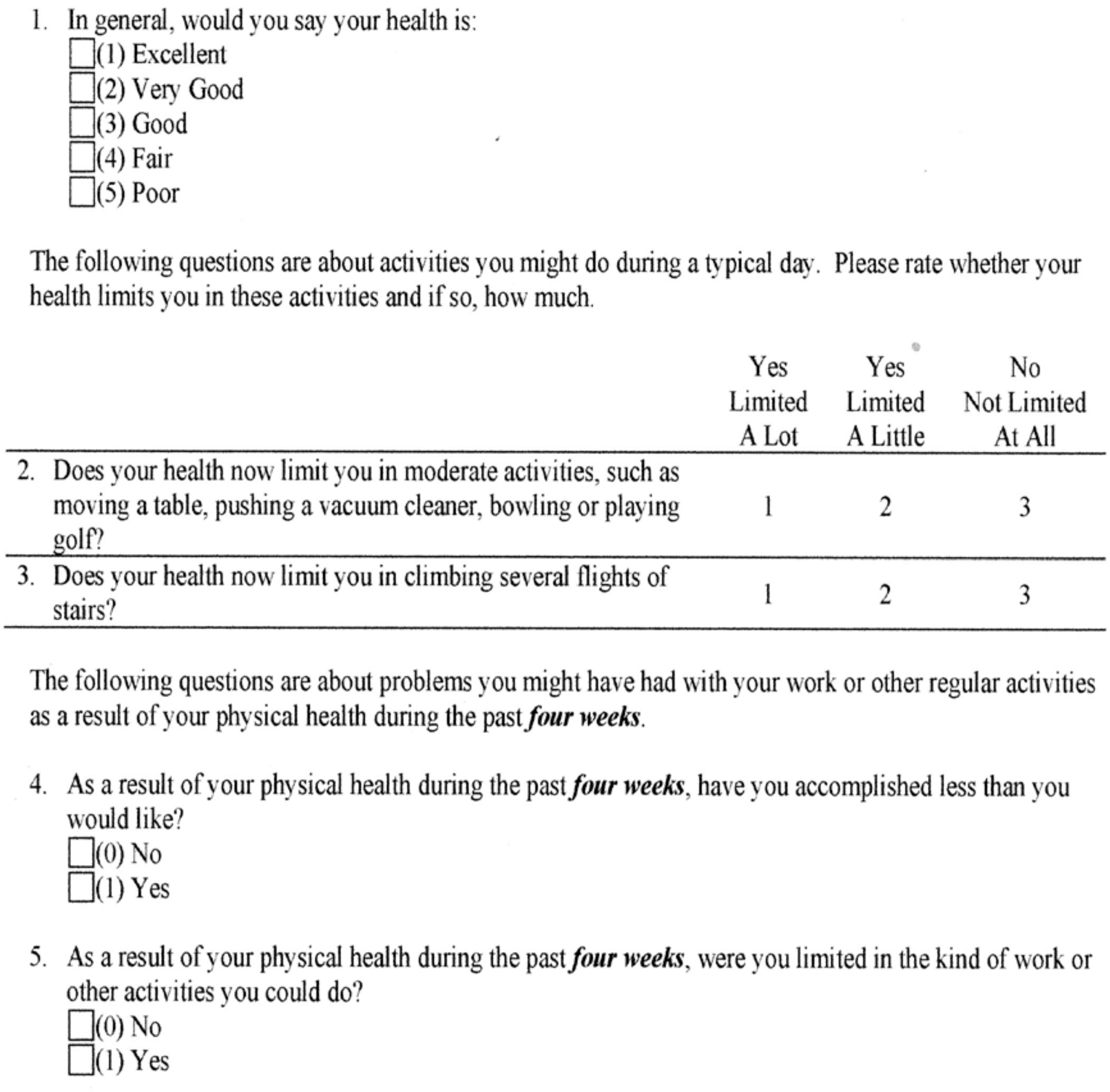
	I **haven't** been doing this at all	I've been doing this **a little bit**	I've been doing this a **medium** amount	I've been doing this **a lot**
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself, "this isn't real."	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I've been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4

BRIEF COPE CONTINUED



	I **haven't** been doing this at all	I've been doing this **a little bit**	I've been doing this a **medium** amount	I've been doing this **a lot**
19. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

RAND SHORT FORM HEALTH SURVEY (SF-12)



1. In general, would you say your health is:
   ☐(1) Excellent
   ☐(2) Very Good
   ☐(3) Good
   ☐(4) Fair
   ☐(5) Poor

The following questions are about activities you might do during a typical day. Please rate whether your health limits you in these activities and if so, how much.

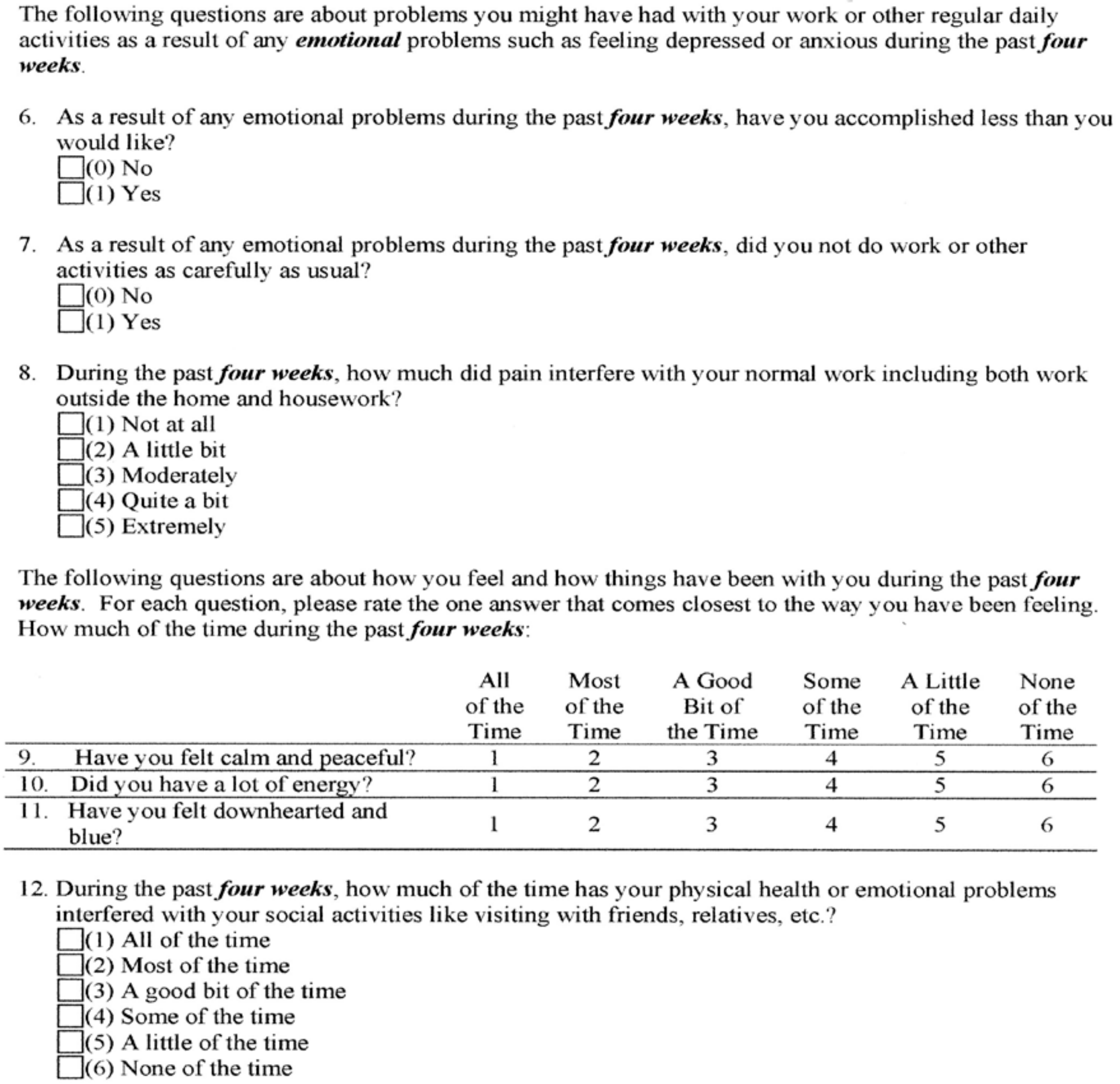
	Yes Limited A Lot	Yes Limited A Little	No Not Limited At All
2. Does your health now limit you in moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf?	1	2	3
3. Does your health now limit you in climbing several flights of stairs?	1	2	3

The following questions are about problems you might have had with your work or other regular activities as a result of your physical health during the past ***four weeks***.

4. As a result of your physical health during the past ***four weeks***, have you accomplished less than you would like?
   ☐(0) No
   ☐(1) Yes

5. As a result of your physical health during the past ***four weeks***, were you limited in the kind of work or other activities you could do?
   ☐(0) No
   ☐(1) Yes

RAND SHORT FORM HEALTH SURVEY (SF-12) CONTINUED



The following questions are about problems you might have had with your work or other regular daily activities as a result of any ***emotional*** problems such as feeling depressed or anxious during the past ***four weeks***.

6. As a result of any emotional problems during the past ***four weeks***, have you accomplished less than you would like?
   ☐(0) No
   ☐(1) Yes

7. As a result of any emotional problems during the past ***four weeks***, did you not do work or other activities as carefully as usual?
   ☐(0) No
   ☐(1) Yes

8. During the past ***four weeks***, how much did pain interfere with your normal work including both work outside the home and housework?
   ☐(1) Not at all
   ☐(2) A little bit
   ☐(3) Moderately
   ☐(4) Quite a bit
   ☐(5) Extremely

The following questions are about how you feel and how things have been with you during the past ***four weeks***. For each question, please rate the one answer that comes closest to the way you have been feeling. How much of the time during the past ***four weeks***:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
9. Have you felt calm and peaceful?	1	2	3	4	5	6
10. Did you have a lot of energy?	1	2	3	4	5	6
11. Have you felt downhearted and blue?	1	2	3	4	5	6

12. During the past ***four weeks***, how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends, relatives, etc.?
   ☐(1) All of the time
   ☐(2) Most of the time
   ☐(3) A good bit of the time
   ☐(4) Some of the time
   ☐(5) A little of the time
   ☐(6) None of the time

CAREGIVING STRAIN QUESTIONNAIRE (CGSQ)

Please indicate how much of a problem each of the statements below has been to you, with respect to your sibling with autism or Down syndrome.

	Not at all a problem	A little of a	A problem problem	A lot of a	Very much a problem problem
1.) Interruption of personal time	1	2	3	4	5
2.) Missing work or neglecting other duties	1	2	3	4	5
3.) Disruption of family routines	1	2	3	4	5
4.) Family member having to do without things	1	2	3	4	5
5.) Family member suffering mental/physical health effects	1	2	3	4	5
6.) Sibling having trouble with neighbors or law	1	2	3	4	5
7.) Financial Strain	1	2	3	4	5
8.) Less attention paid to other family members	1	2	3	4	5
9.) Disruption of family relationships	1	2	3	4	5
10.) Disruption of family's social activities	1	2	3	4	5
11.) Feeling socially isolated	1	2	3	4	5
12.) Feeling sad or unhappy	1	2	3	4	5
13.) Feeling embarrassed	1	2	3	4	5
14.) Relating well to sibling	1	2	3	4	5
15.) Feeling angry towards siblings	1	2	3	4	5
16.) Feeling worry about sibling's future	1	2	3	4	5
17.) Feeling worry about family's future	1	2	3	4	5
18.) Feeling guilty about sibling's illness	1	2	3	4	5
19.) Feeling resentful towards sibling	1	2	3	4	5
20.) Feeling tired or strained	1	2	3	4	5
21.) Toll taken on family	1	2	3	4	5

BENEFIT-FINDING SCALE

Please indicate the number with the answer that best reflects your response to the following statements.

Providing care for my adult sibling:

1	2	3	4	5
Not at All	**A Little**	**Moderately**	**Quite a bit**	**Extremely**

1. has shown me that all people need to be loved.

1_____ 2_____ 3_____ 4_____ 5_____

2. has made me more sensitive to family issues.

1_____ 2_____ 3_____ 4_____ 5_____

3. has led me to be more accepting of things.

1_____ 2_____ 3_____ 4_____ 5_____

4. has taught me that everyone has a purpose in life.

1_____ 2_____ 3_____ 4_____ 5_____

5. has made us more in charge of ourselves as a family

1_____ 2_____ 3_____ 4_____ 5_____

6. has made me more aware and concerned for the future of humankind.

1_____ 2_____ 3_____ 4_____ 5_____

7. has taught me how to adjust to things I cannot change.

1_____ 2_____ 3_____ 4_____ 5_____

8. has given my family a sense of continuity, a sense of history.

1_____ 2_____ 3_____ 4_____ 5_____

BENEFIT-FINDING SCALE

9. has made me a more responsible person.

1_____ 2_____ 3_____ 4_____ 5_____

10. has made me realize the importance of planning for my family’s future.

1_____ 2_____ 3_____ 4_____ 5_____

11. has given my life better structure.

1_____ 2_____ 3_____ 4_____ 5_____

12. has brought my family closer together.

1_____ 2_____ 3_____ 4_____ 5_____

13. has made me more productive.

1_____ 2_____ 3_____ 4_____ 5_____

14. has helped me take things as they come.

1_____ 2_____ 3_____ 4_____ 5_____

15. has helped me to budget my time better.

1_____ 2_____ 3_____ 4_____ 5_____

16. has made me more grateful for each day.

1_____ 2_____ 3_____ 4_____ 5_____

17. has taught me to be patient.

1_____ 2_____ 3_____ 4_____ 5_____

18. has taught me to control my temper.

1_____ 2_____ 3_____ 4_____ 5_____

19. has renewed my interest in participating in different activities.

1_____ 2_____ 3_____ 4_____ 5_____

20. has led me to cope better with stress and problems.

1_____ 2_____ 3_____ 4_____ 5_____

Appendix B. Additional Analyses

Appendix Table B1

Exploratory Tests of Differences Between Autism and DS Groups on Sibling Relationship Quality

ASD	DS	Autism vs DS	ANOVA	Autism vs DS	Autism vs Mixed	DS vs Mixed
x(SD)	x(SD)					
150.262 (38.50)	181.16 (30.09)	t(76) = -3.95, p = .00**	F(4,109) = 6.10, p = .00**	-30.90(8.23), p = .00**	-15.29(12.43), p = .73	15.60(11.71), p = .67

Note. For all scales, higher scores indicate more of a construct. * = p < .05, two-tailed. ** = p < .01, two-tailed. Autism = disabled sibling's score on GARS-2 is >/= 85. DS = Non-disabled sibling reported diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed = non-disabled sibling reported diagnosis of Down syndrome and a possible co-morbidity of autism (GARS score >/= 85). Disability = Autism + DS + Mixed.

Appendix Table B2

Exploratory Test of Correlations Between Average Helpfulness of Services and Number of Services Received

Autism	DS	Disability
.52 ††	.12	.27*

Note. For all scales, higher scores indicate more of a construct. * = $p < .05$, two-tailed. †† = $p < .01$, one tailed. Autism = disabled sibling's score on GARS-2 is >/= 85. DS = Non-disabled sibling reported diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed = non-disabled sibling reported diagnosis of Down syndrome and a possible co-morbidity of autism (GARS score >/= 85). Disability = Autism + DS + Mixed.

Appendix Table B3

Exploratory Test of Correlations Between Distance Away From Disabled Sibling and Caregiver Burden

Autism	DS	Disability
-.15	-.27	-.06

Note. For all scales, higher scores indicate more of a construct. * = p < .05, two-tailed. ** = p < .01, two tailed. Autism = disabled sibling's score on GARS-2 is >/= 85. DS = Non-disabled sibling reported diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Mixed = non disabled sibling reported diagnosis of Down syndrome and a possible comorbidity of autism (GARS score >/= 85). Disability = Autism + DS + Mixed.

Appendix Table B4

Step #1 of Mediation Analysis: Pearson (r) Correlations Between Antecedent and Outcome Variables

Antecedent Variable	Autism (N = 31) Outcome Variables	DS (N = 54) Outcome Variables	Disability (N = 97) Outcome Variables
	Burden	Burden	Burden
Severity of Symptoms	-.01	.42**	.52**
Adaptive Behavior	-.02	-.34^t	-.35**
Problem Behaviors	.56††	.47**	.62**
Pile-up Demands	.36	.24	.27^t

Note. For all scales, higher scores indicate more of a construct. Autism: † p < .05, one-tailed. † † p < .01, one-tailed. DS and Disability: ** p < .01; ^{t} = trend towards significance. Severity of Symptoms = Gilliam Autism Rating Scale-2. Adaptive Behavior = Instrumental Activities of Daily Living Scale. Problem Behaviors = Problem Behavior Rating Scale. Pile-up Demands = additional demands. HRQOL = health-related quality of life; RAND Short-Form Health Survey. Burden = Caregiver Strain Questionnaire. Benefits = Benefit Finding Scale. Autism = disabled sibling's score on GARS-2 is >/= 85. DS = Non-disabled sibling reported diagnosis of Down syndrome, excluding a comorbid diagnosis of autism. Disability = Autism + DS + Mixed.

Appendix Table B5

Step #2: Pearson (r) Correlations Between Antecedent and Mediating Variables (Coping Strategies and Cognitive Appraisal)

	Autism (N = 31)			DS (N = 54)			Disability(N = 97)		
Antecedents									
Symptom Severity	-.02	-.07	-.06	.21	.33^{t}	.30^{t}	.24^{t}	.31**	.45**
Adaptive Behaviors	.45*	.63**	.35*	-.15	-.24	-.28	-.01	.03	-.12
Problem Behaviors	.18	.11	.51**	.05	.20	.35^{t}	.15	.28^{t}	.51**
Pile-up Demands	.00	-.00	.34*	.16	.22	.19	.12	.15	.32**

	Autism (N = 31)			DS (N = 54)			Disability (N = 97)		
Antecedents	Cognitive Appraisal			Cognitive Appraisal			Cognitive Appraisal		
	Th.	Ch.	Cent.	Th.	Ch.	Cent.	Th.	Ch.	Cent.
Symptom Severity	.08	.02	-.00	.42**	-.08	.47**	.49**	-.12	.35**
Adaptive Behaviors	-.22	.06	.15	-.27	.29^{t}	-.28	-.34**	.28**	-.17
Problem Behaviors	.31	.03	.15	.39**	-.12	.29^{t}	.47**	-.11	.27^{t}
Pile-up Demands	.06	.09	-.32	.22	-.02	.21	.16	.06	-.04

Note. Prob. = Problem focused coping. E.A. = Emotional approach coping. Av. = Avoidant coping. Th. = Threat. Ch. = Challenge. Cent. = Centrality. Autism = disabled sibling's score on GARS-2 is >/= 85. DS = diagnosis of Down Syndrome excluding a co-morbid diagnosis of autism. Disability = diagnoses of Autism, DS, and Mixed combined.

Appendix Table B6

Summary of Steps 1 & 2

Antecedents are significantly correlated with the following mediators and outcome variables:

Antecedents	Mediators	Psychosocial Outcomes
Autism (p < .05)		
1) Problem behaviors	Avoidant	Caregiver Burden
DS (p < .01)		
1) Severity of Symptoms	Threat	Caregiver Burden
	Centrality	
2) Problem behaviors	Threat	Caregiver Burden
Disability (p < .01)		
1) Severity of Symptoms	Threat Centrality Avoidant Emotional Approach	Caregiver Burden
2) Adaptive behavior	Threat Challenge	Caregiver Burden
3) Problem behaviors	Threat Avoidant	Caregiver Burden

Appendix Table B7

Step #3: Summary of Regression Analyses of Mediators Predicting Caregiver Burden When Controlling for the Antecedents

	Variable	β	p	R	R^2	Model p
Within Autism Group						
1) Step 1	Avoidant (Coping)	0.58	0.00**	0.58	0.33	0.00**
Step 2	Avoidant (Coping)	0.44	0.01*	0.64	0.41	0.00**
	Problem Behaviors	0.31	0.07			
2) Step 1	Avoidant (Coping)	.58	.00**	.58	.33	.00**
Step 2	Avoidant (Coping)	.52	.00**	.60	.36	.00**
	Pile-up Demands	.18	.29			
	Variable	β	P	R	R^2	Model p
Within Down Syndrome Group						
1) Step 1	Threat (Appraisal)	0.81	0.00**	0.81	0.65	0.00**
Step 2	Threat (Appraisal)	0.78	0.00**	0.81	0.66	0.00**
	Severity of Symptoms	0.08	0.40			
2) Step 1	Centrality (Appraisal)	0.37	0.01	0.37	0.14	0.01^t
Step 2	Centrality (Appraisal)	0.25	0.07	0.44	0.20	0.00**
	Severity of Symptoms	0.27	0.06			
3) Step 1	Threat (Apprasial)	0.81	0.00**	0.81	0.65	0.00**
Step 2	Threat (Apprasial)	0.75	0.00**	0.82	0.68	0.00**
	Problem Behaviors	0.17	0.07			

Note: * $p < .05$. ** $p < .01$. ^{t} = trend towards significance.

Appendix Table B7 Continued

Step #3: Summary of Regression Analyses of Mediators Predicting Caregiver Burden When Controlling for the Antecedents Continued

	Variable	β	p	R	R^2	Model p
Within Disability Group						
1) Step 1	Threat (Appraisal)	0.71	0.00**	0.71	0.51	0.00**
Step 2	Threat (Appraisal)	0.61	0.00**	0.74	0.54	0.00**
	Severity of Symptoms	0.21	0.01[t]			
2) Step 1	Centrality (Appraisal)	0.29	0.01[t]	0.29	0.08	0.01[t]
Step 2	Centrality (Appraisal)	0.13	0.17	0.52	0.27	0.00**
	Severity of Symptoms	0.46	0.00**			
3) Step 1	Avoidant (Coping)	.69	.00**	.69	.48	.00**
Step 2	Avoidant (Coping)	.59	.00**	.73	.53	.00**
	Severity of Symptoms	.25	.00**			
4) Step 1	Emotional Approach (Coping)	.14	.18	.14	.02	.18
Step 2	Emotional Approach (Coping)	-.01	.88	.50	.25	.00**
	Severity of Symptoms	.51	.00**			
5) Step 1	Threat (Appraisal)	0.71	0.00**	0.71	0.51	0.00**
Step 2	Threat (Appraisal)	0.68	0.00**	0.72	0.52	0.00**
	Adaptive Behavior	-0.10	0.19			
6) Step 1	Challenge (Appraisal)	-0.31	0.00**	0.31	0.09	0.00**
Step 2	Challenge (Appraisal)	-0.23	0.02[t]	0.40	0.16	0.00**
	Adaptive Behavior	-0.27	0.01[t]			
7) Step 1	Threat (Appraisal)	0.71	0.00**	0.71	0.51	0.00**
Step 2	Threat (Appraisal)	0.57	0.00**	0.77	0.59	0.00**
	Problem Behaviors	0.32	0.00**			
8) Step 1	Avoidant (Coping)	0.69	0.00**	0.69	0.48	0.00**
Step 2	Avoidant (Coping)	0.54	0.00**	0.74	0.55	0.00**
	Problem Behaviors	0.31	0.00**			

Note: * $p < .05$. ** $p < .01$. [t] = trend towards significance.

Testing the Antecedent Categories within the Adult Sibling Caregiver Conceptual Model (ASCCM)

The 13 antecedent variables in the ASCCM are organized into 5 blocks: Family (Sibling Dyad) Characteristics, Adult Sibling (Caregiver) Characteristics, Adult With Autism/DS (Caregivee) Characteristics, Caregiving (Caregiver) Resources, and Caregiving Demands. The variables within each of the 5 categories of the ASCCM were regressed as individual blocks onto the 4 psychosocial outcome variables within each of the 3 study groups (Autism, DS, and Disability) to test the utility of the 5 categories within the ASCCM. The findings are discussed below (see Table B.5).

Predicting Mental Health-Related Quality of Life Using the Five Antecedent Categories

Three antecedent categories significantly predicted Mental HRQOL within the Disability group: 1) Adult With Autism/DS (Caregivee) Characteristics (F = 2.82, p = .03; R = .33, R^2 = .12), 2) Caregiving (Caregiver) Resources (F = 6.78, p = .00; R = .43, R^2 = .19), and 3) Caregiving Demands (F = 7.68, p = .01; R = .28, R^2 = .08). Three antecedent categories significantly predicted Mental HRQOL within the DS group: 1) Adult With Autism/DS (Caregivee) Characteristics (F = 2.75, p = .04; R = .43, R^2 = .18), 2) Caregiving (Caregiver) Resources (F = 7.35, p = .00; R = .56, R^2 = .32), and 3) Caregiving Demands (F = 12.15, p = .00; R = .44, R^2 = .20). No antecedent categories significantly predicted Mental HRQOL within the Autism group.

Predicting Physical Health-Related Quality of Life Using the Five Antecedent Categories

Three antecedent categories significantly predicted physical HRQOL within the Disability group: 1) Adult Sibling (Caregiver) Characteristics, ($F = 3.05$, $p = .03$; $R = .30$, $R^2 = .09$), 2) Adult With Autism/DS (Caregivee) Characteristics ($F = 3.83$, $p = .01$; $R = .38$, $R^2 = .14$), and 3) Caregiving Demands ($F = 4.24$, $p = .04$; $R = .21$, $R^2 = .04$). No antecedent categories predicted physical HRQOL within the DS or Autism groups.

Predicting Caregiver Burden Using the Five Antecedent Categories

Four antecedent categories significantly predicted caregiver burden within the Disability group: 1) Family (Sibling Dyad) Characteristics ($F = 9.52$, $p = .00$; $R = .49$, $R^2 = .24$), 2) Adult With Autism/DS (Caregivee) Characteristics ($F = 12.80$, $p = .00$; $R = .60$, $R^2 = .36$), 3) Caregiving (Caregiver) Resources ($F = 12.76$, $p = .00$; $R = .55$, $R^2 = .30$), and 4) Caregiving Demands ($F = 6.68$, $p = .01$; $R = .26$, $R^2 = .07$).

Three antecedent categories significantly predicted caregiver burden within the DS group: 1) Family (Sibling Dyad) Characteristics ($F = 3.42$, $p = .02$; $R = .41$, $R^2 = .17$), 2) Adult With Autism/DS (Caregivee) Characteristics ($F = 3.60$, $p = .01$; $R = .48$, $R^2 = .23$), 3) Caregiving (Caregiver) Resources ($F = 7.75$, $p = .00$; $R = .58$, $R^2 = .34$).

Two antecedent categories significantly predicted caregiver burden within the Autism group: 1) Adult With Autism/DS (Caregivee) Characteristics ($F = 3.12$, $p = .03$; $R = .57$, $R^2 = .33$), 2) Caregiving (Caregiver) Resources ($F = 4.17$, $p = .02$; $R = .57$, $R^2 = .33$). A third category, Caregiving Demands ($F = 3.93$, $p = .06$; $R = .35$, $R^2 = .12$) displayed a trend toward significance.

Predicting Reported Benefits Using the Five Antecedent Categories

Two antecedent categories significantly predicted reported benefits within the Disability and Autism groups: 1) Family (Sibling Dyad) Characteristics (Disability: $F = 15.23$, $p = .00$; $R = .58$, $R^2 = .33$; Autism: $F = 3.84$, $p = .02$; $R = .55$, $R^2 = .30$) and 2) Caregiving (Caregiver) Resources (Disability: $F = 6.66$, $p = .00$; $R = .43$, $R^2 = .19$; Autism: $F = 5.47$, $p = .01$; $R = .63$, $R^2 = .40$).

Within the DS group, two antecedent categories significantly predicted reported benefits: 1) Family (Sibling Dyad) Characteristics ($F = 11.75$ $p = .00$; $R = .65$, $R^2 = .42$) and 2) Adult Sibling (Caregiver) Characteristics ($F = 3.09$, $p = .04$; $R = .40$, $R^2 = .16$).

Appendix Table B8

Adult Sibling Caregiver Conceptual Model Antecedent Categories Regressed Onto Psychosocial Outcomes for Autism, DS, and Disability Groups

		Mental HRQOL	Physical HRQOL	Caregiver Burden	Benefits
	WITHIN DISABILITY GROUP				
1	Family (sibling dyad) characteristics	F = 1.78, p = .16; R = .23, R^2 = .05	F = .33, p = .81; R = .10, R^2 = .01	F = 9.52, p = .00; R = .49, R^2 = .24	F = 15.23, p = .00; R = .58, R^2 = .33
2	Adult sibling (caregiver) characteristics	F = 2.00, p = .12; R = .25, R^2 = .06	F = 3.05, p = .03; R = .30, R^2 = .09	F = .93, p = .43; R = .17, R^2 = .03	F = 1.13, p = .34; R = .19, R^2 = .04
3	Adult with autism/DS (caregivee) characteristics	F = 2.82, p = .03; R = .33, R^2 = .12	F = 3.83, p = .01; R = .38, R^2 = .14	F = 12.80, p = .00; R = .60, R^2 = .36	F = .59, p = .67; R = .16, R^2 = .03
4	Caregiving (caregiver) resources	F = 6.78, p = .00; R = .43, R^2 = .19	F = .81, p = .49; R = .16, R^2 = .03	F = 12.76, p = .00; R = .55, R^2 = .30	F = 6.66, p = .00; R = .43, R^2 = .19
5	Caregiving demands	F = 7.68, p = .01; R = .28, R^2 = .08	F = 4.24, p = .04; R = .21, R^2 = .04	F = 6.68, p = .01; R = .26, R^2 = .07	F = .48, p = .49; R = .08, R^2 = .01
	WITHIN AUTISM GROUP				
1	Family (sibling dyad) characteristics	F = .77, p = .52; R = .28, R^2 = .08	F = 1.13, p = .35; R = .33, R^2 = .11	F = .27, p = .85; R = .17, R^2 = .03	F = 3.84, p = .02; R = .55, R^2 = .30
2	Adult sibling (caregiver) characteristics	F = .34, p = .80; R = .19, R^2 = .04	F = 1.58, p = .22; R = .39, R^2 = .15	F = 1.41, p = .26; R = .37, R^2 = .14	F = .62, p = .61; R = .25, R^2 = .06
3	Adult with autism/DS (caregivee) characteristics	F = .74, p = .57; R = .32, R^2 = .10	F = .69, p = .60; R = .31, R^2 = .10	F = 3.12, p = .03; R = .57, R^2 = .33	F = .47, p = .76; R = .26, R^2 = .07
4	Caregiving (caregiver) resources	F = 1.29, p = .30; R = .36, R^2 = .13	F = .16, p = .92; R = .13, R^2 = .09	F = 4.17, p = .02; R = .57, R^2 = .33	F = 5.47, p = .01; R = .63, R^2 = .40
5	Caregiving demands	F = 2.13, p = .16; R = .27, R^2 = .07	F = 3.21, p = .08; R = .32, R^2 = .10	F = 3.93, p = .06; R = .35, R^2 = .12	F = .18, p = .68; R = .08, R^2 = .01
	WITHIN DS GROUP				
1	Family (sibling dyad) characteristics	F = 1.20, p = .32; R = .26, R^2 = .07	F = .45, p = .72; R = .16, R^2 = .03	F = 3.42, p = .02; R = .41, R^2 = .17	F = 11.75 p = .00; R = .65, R^2 = .42
2	Adult sibling (caregiver) characteristics	F = 1.14, p = .34; R = .25, R^2 = .06	F = .97, p = .41; R = .24, R^2 = .01	F = .93, p = .43; R = .23, R^2 = .05	F = 3.09, p = .04; R = .40, R^2 = .16
3	Adult with autism/DS (caregivee) characteristics	F = 2.75, p = .04; R = .43, R^2 = .18	F = 1.34, p = .27; R = .31, R^2 = .10	F = 3.60, p = .01; R = .48, R^2 = .23	F = .38, p = .82; R = .17, R^2 = .03
4	Caregiving (caregiver) resources	F = 7.35, p = .00; R = .56, R^2 = .32	F = .73, p = .54; R = .21, R^2 = .04	F = 7.75, p = .00; R = .58, R^2 = .34	F = 1.74, p = .17; R = .32, R^2 = .10
5	Caregiving demands	F = 12.15, p = .00; R = .44, R^2 = .20	F = .00, p = .97; R = .01, R^2 = .00	F = 2.69, p = .11; R = .23, R^2 = .05	F = .12, p = .74; R = .05, R^2 = .00

Note: HRQOL = Health-related quality of life. DS = Down syndrome group.