Empirical Examination of Caregiver Empowerment, Appraisal, and Depressive Symptoms among Adult Siblings of Individuals with Intellectual and Developmental Disabilities

Mamta Saxena

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Empirical Examination of Caregiver Empowerment, Appraisal, and Depressive Symptoms among Adult Siblings of Individuals with Intellectual and Developmental Disabilities

Mamta Saxena Ph.D.

University of Connecticut

2013

Today, 72% of individuals with intellectual and developmental disabilities (IDDs) in the United States live with a caregiver (Braddock & Rizzolo, 2013). In many families, siblings of individuals with IDDs are the default long-term care providers (Heller et al., 2008). Despite the fact that research has begun to recognize and explore the roles of family members in care, little is known about sibling support providers (SSPs). Exploration and confirmation of the caregiving processes and outcomes of siblings can have implications for policy, research, and practice.

The purpose of this study was to examine a conceptual model of caregiving processes and outcomes for siblings of individuals with IDDs. Specifically, perceived social support, demand, appraisal of caregiving, depression, and empowerment were measured among 327 sibling caregivers recruited through disability organizations and social networking sites to complete a web-based survey. Most participants (35.7%) were 18-25 years old, female (85.4%) and White (83%). More than half (54%) lived within 10 miles of their siblings’ residence. The mean age of brother/sister with IDD was 32 years and 94.1% had co-occurring disabilities. A substantial number of individuals with IDDs (16.6%) did not engage in regular work or related daily activities. Few (2.4-9%) were fully independent on daily routine tasks.

The conceptual model consisted of five variables: Demand, perceived social support, appraisal of caregiving, depression, and empowerment. Demand consisted of the employment status of SSPs, functional abilities of the individual with IDDs, and the weekly duration of caregiving provided.
Other measures used were the Multidimensional Scale of Perceived Social Support (measured perceived social support; Zimet, Dahlem, Zimet, & Farley, 1988), the Appraisal of Caregiving Scale-Revised (measured appraisal of caregiving; Lawton, Moss, Hoffmann, & Perkinson, 2000), the Center for Epidemiologic Studies Depression Scale (measured depressive symptoms; Radloff, 1977) and Caregiver Empowerment Scale (measured empowerment; Degeneffe et al., 2011). The initial model did not converge and was revised. In the revised model, demand consisted of the summated scores of functional abilities of the individual with IDDs, and the weekly duration of caregiving provided. Employment status of SSPs formed the sixth variable in the model.

The analysis of the revised model suggested marginally good model fit \( \chi^2 = 12.2, df = 6, p = .057; \text{RMSEA} = .057 \) and significant associations between perceived social support, appraisal of caregiving, depression, and empowerment. SSP’s employment duration and demand did not significantly impact SSPs appraisal of caregiving. Tests of mediation (Sobel test) revealed appraisal of caregiving mediated perceived social support and depression and perceived social support and empowerment. The mediation findings hints at how sibling caregivers appraise caregiving (meaning they make) is an important factor in determining their depression scores and sense of empowerment.
Empirical Examination of Caregiver Empowerment, Appraisal, and Depressive Symptoms among Adult Siblings of Individuals with Intellectual and Developmental Disabilities

Mamta Saxena
M.S. University of Delhi, India, 1998

A Dissertation
Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy at the University of Connecticut 2013
Doctor of Philosophy Dissertation

Empirical Examination of Caregiver Empowerment, Appraisal, and Depressive Symptoms among Adult Siblings of Individuals with Intellectual and Developmental Disabilities

Presented by
Mamta Saxena, M.S.

Major Advisor: ____________________________
Anne F. Farrell, Ph.D.

Associate Advisor: ____________________________
Edna Brown, Ph.D.

Associate Advisor: ____________________________
Kari Adamsons, Ph.D.

University of Connecticut
2013
Acknowledgements

I would like to express my heartfelt gratitude to my major advisor, Dr. Anne F. Farrell, for providing me with excellent opportunities that have supported my professional and personal growth over the past five years and making graduate school such a positive experience. I would also like to thank my dissertation committee members, Dr. Kari Adamsons for her guidance on the methodology of the study and Dr. Edna Brown for her moral support throughout the dissertation process. Without their guidance and feedback, this study would have not evolved.

Many thanks to the Coordinators and Directors of all the agencies and organizations throughout the US who sent the information about the study to prospective participants and siblings of individuals with intellectual and developmental disabilities who volunteered to participate in the study. Without their help this study would not have been possible.

Most importantly, I am thankful to my family: my parents, who showed me the power of hard work, commitment, and integrity, my sister in-law for her unwavering support and encouragement throughout the years, my husband Manoj K. Saxena for believing in me and initiating the process of my doctoral program application six years ago, and my son Shreyus Saxena for making me smile on days when I felt low. I feel truly blessed.
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Chapter 1: Introduction

Statement of the Problem

Intellectual and developmental disabilities (IDDs) are characterized by significant limitations in intellectual functioning and adaptive behavior that originate before the age of 18 (AAIDD, 2010). The American Community Survey (2011) estimates that 12.1% of the civilian non-institutionalized U.S. population has disabilities, out of which 4.3% of the population has IDDs. It further estimates that 8 million individuals with IDDs are in the age range 18-64 years and 3 million are 65 years or older. The average life expectancy of individuals with IDDs has increased, and many are outliving their parents due to improved medical services and quality of life (American Community Survey; Factor, Heller & Janicki, 2012).

The increase in the number of and life expectancy of individuals with IDDs has an impact on three types of resources: family, state government, and federal government. First, aging individuals with IDDs experience accentuated deterioration in cognitive abilities and physical health that can be further worsened by delayed recognition of the problems (Smith, Hatfield, & Miller, 2000). Second, there is a shortage of adequate resources, and services for individuals with IDDs vary by state. Until the 1960s, individuals with IDDs lived in large institutions with largely custodial care and marginal efforts at rehabilitation and support. Positive efforts toward normalization and mainstreaming motivated by class action lawsuits (e.g., *Olmstead v. L.C.* decision), the Rehabilitation Act (1973), and the Americans with Disabilities Act (1990) mandated better living conditions, including improved access to community living. Consequently, a broad range of residential options developed, ranging from independent and assisted living to group homes (Kim & Dymond, 2012). Due to the increasing support needs of individuals with IDDs, these resources over time became inadequate, necessitating the need for
family caregiving (Talley & Crews, 2012). Today, 72% of the individuals with IDDs live with a caregiver, 13% live in a supervised residential setting, and 16% live alone or with a roommate (Braddock & Rizzolo, 2013).

Finally, in many families, after the death of the parents, siblings of individuals with IDDs are the default long-term support providers (Heller et al., 2008). Both during the parental lifespan and following their passing, families are challenged to provide adequate and appropriate care and support in the absence of adequate community resources.

**Statement of Significance**

The term sibling support providers (SSPs) refer to adult brothers/sisters of individuals with IDDs who provide any form of care and support. The term caregiving encompasses the expenditure of time and/or effort by SSPs in supporting the individuals with IDDs on a daily or intermittent basis. Some examples of caregiving include the following: scheduling their medical appointments, driving them places, and preparing meals for them. SSPs may or may not reside with their brother/sister with IDDs and they may be involved in their lives on a daily or intermittent basis. No formal demographics of SSPs are available, but their role in caregiving has been mentioned in previous studies such as in Fujiura (2010) and Easter Seals (2012).

Since there are about 11 million adults with IDDs, there are likely as many siblings. Therefore it is important to examine how they provide support to their brother/sister with IDDs in the context of their own lives, and its consequences. Despite the fact that research has begun to recognize and explore the roles of SSPs in long-term care (e.g., Heller et al., 2008; Heller & Arnold, 2010), little is known about this group. Studies completed by Fujiura (2010), Easter Seals (2012), and Burke, Taylor, Urbano, and Hodapp (2012) gave a very basic understanding of their about the demographics of sibling caregivers, such as their number and characteristics, yet
their caregiving processes, and outcomes (i.e., characteristics of care, their well-being, their caregiving tasks, and their perceptions of the overall experience), remain understudied. While siblings in general typically provide support to one another in adulthood, SSPs make a far greater commitment to their siblings (Heller & Factor, 1993). Therefore, exploration and confirmation of the caregiving processes and outcomes of SSPs can have implications for future research and practice.

**Research Questions**

The purpose of this study is to examine the caregiving processes and outcomes for SSPs. These processes and outcomes will be explored by examining perceived social support, demands, appraisal of caregiving, depression, and empowerment among SSPs of individuals with IDDs.

**Descriptive Research Questions**

1. What are the characteristics of SSPs who provide care to individuals with IDDs, and what are the characteristics of individuals with IDDs who receive this care?
2. What caretaking activities are associated with sibling caregiving, and on an average, how much time is spent on these activities monthly?

**Model-Related Research Questions**

1. Are perceived social support, demands, and appraisal of caregiving associated with depression among SSPs?
2. Are SSPs’ appraisal of caregiving associated with demands and perceived social support?
3. Are appraisal of caregiving and perceived social support associated with empowerment among SSPs?
Hypotheses

1. High perceived social support will be associated with low depression scores, positive appraisal of caregiving, and higher scores on empowerment.

2. Higher demands will be associated with higher depression scores and negative appraisal of caregiving.

3. Negative appraisal of caregiving will be associated with higher depression scores and lower empowerment scores.

Summary of Methodology

The section will provide a brief summary of data collection method, recruitment of the participants, measures used in the study, analysis of the data, and its limitations.

Data collection. The data for the study were collected through a web-based survey of SSPs. The study participants were adult siblings who are 18 years or older and who provided support to their brothers/sisters with IDDs. The developmental disabilities of the brother/sister were intellectual in nature, originated before 18 years of age, and could co-occur with other developmental disabilities such physical disabilities or language and sensory disabilities. In addition, participants were English speakers and U.S. residents.

Recruitment of participants. The study was IRB approved, before recruiting participants. To recruit participants, a web link to the survey used in this study was sent to 245 organizations and agencies throughout the US that work with individuals with IDDs and their families. These organizations include the following: The Sibling Leadership Network, The Sibling Network Project, The ARC, the Association of University Centers on Disabilities, Vanderbilt Kennedy Center Programs, the National Sibling Research Consortium, and the Tennessee Adult Brothers and Sisters. These organizations and agencies were requested to send
information about the study and a web link to their listserv members and post it on their Facebook and Twitter page. In addition, snowball recruiting was conducted through personal contacts, emails, and web postings on social networking and other sites.

**Variables and measures.** This study included the following variables and measures to examine the relationship between the variables in the conceptual model (such as perceived social support, burden, depression, appraisal of caregiving and empowerment among SSPs).

**Demands.** The variable demands is measured via three measures: employment status of SSPs, functional abilities of the individual with IDDs, and the duration of caregiving provided per week in hours. These three measures include information on the number of hours the participants work; the level of functional abilities of the individual with IDDs on day-to-day tasks such as preparation of meals, ability to self-administer medication, etc.; and the number of hours per week the SSP devotes to taking care of his or her brother/sister with IDDs. Two items from the scale are: On a scale of 1-5, with 1 being completely dependent to 5 being completely independent, “To what extent does your brother/sister with IDDs perform day-to-day routine tasks such as preparing meals?” “On an average, how much time per week, do you estimate to spend on performing tasks such as preparing meals for your brother/sister with IDDs?”

**Perceived social support.** The variable perceived social support is examined via the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), which is a measure of subjective assessment social support and the perceived adequacy of support from three sources: family, friends, and significant others. It is a 12-item, 7-point scale, and the responses can range from very strongly disagree to very strongly agree. Two examples of items from the scale are “I get the emotional help and support I need from my family” and “I have friends with whom I can share my joys and sorrows.”
Appraisal of caregiving. The Appraisal of caregiving” is assessed using the Appraisal of Caregiving Scale Revised (Lawton, Moss, Hoffmann, & Perkinson, 2000), which measures appraisals of caregiving in terms of subjective feelings related to caregiving stressors and the support providers’ ability to cope. It is a 27-item, 5-point Likert scale that has been tested among support providers of the elderly population. The Likert-type response format ranges from 1 to 5 (1 = strongly disagree, 5 = strongly agree. Two examples from the scale are “I get a sense of satisfaction from helping my brother or sister” and “My health has suffered because of the care I provide to my brother or sister.”

Depression. The occurrence of depressive symptoms among SSPs is assessed via the Center for Epidemiologic Studies Depression Scale (CES-D), an instrument designed to measure self-reported symptoms associated with depression experienced in the past week (Radloff, 1977). The scale includes 20 items that touch on moods, feelings, psychomotor retardation, and psychosomatic problems. Response categories indicate the frequency that each item occurs, and they are scored on a 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). An example of a scale item is: “I felt that I could not shake off the blues even with help from my family or friends.”

Empowerment. The variable empowerment among SSPs is measured through the Caregiver Empowerment Scale (Degeneffe et al., 2011). The instrument was developed as a measure of empowerment among family support providers of persons with traumatic brain injury. It is a 5-point Likert scale consisting of 30 items (see Appendix II). To adapt this tool for the current study, the phrase “relative with traumatic brain injury (TBI)” was replaced with “brother/sister with IDDs.” An example from the scale is: “I have a good sense of the
rehabilitation potential (i.e., work and independent living potential) of my brother or sister with
IDDs.”

**Data analysis.** A conceptual model was created based on the variables. Structural equation
modeling (SEM) was used to test the conceptual model and examine the proposed associations
among variables. SEM is a statistical technique that combines elements of multivariate models,
such as regression analysis, factor analyses, and simultaneous equation modeling (Kenny, 2012).
AMOS software was used to examine whether the data fit the conceptual model and to present
the standardized loadings of each path. Goodness-of-fit indices such as the chi square test, root
mean square error of approximation (RMSEA), comparative fit index (CFI), and standardized
root mean square residual (SRMR) were used to assess how well the data fit the conceptual
model. In addition, a Sobel test was used to test for mediating paths.
Chapter 2: Review of the Literature

Definition of Intellectual and Developmental Disabilities (IDDs)

Researchers, health care workers, and care providers have long discussed and debated accurate and appropriate definition of IDDs. Competing discourses on the definition and changing understanding of the nature, number, kind, level, and type of intellectual disabilities and the needs for services and supports have led the American Association of Intellectual and Developmental Disabilities (AAIDD) to revise the definition of intellectual disabilities several times. Each shift in definition has reflected an evolving worldview and the then-current understanding of the condition. This shift in definition began with the application of the social approach—individuals fail to adapt in the society—and then moved on to a clinical approach—labeling individuals based on hereditary abnormalities and/or brain injuries. Next came the intelligence approach, which emphasized intellectual functioning, as reflected by IQ score. This was followed by the dual-criteria approach with an emphasis on adaptive behavior in addition to intellectual functioning (Schalock et al., 2007). According to the AAIDD (2010), the latest definition includes age of onset and taking into account additional factors such as linguistic and cultural diversity and levels of available support to an individual in addition to intelligence and adaptive behavior. Interestingly, as definitions and world views have changed, the name of the AAIDD, the world’s largest and oldest organization of professionals working in the field of disabilities, has evolved as well. When it was founded in 1876, the organization was called the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons. Since then, the name has changed several times, from the American Association on Mental Deficiency to the American Association on Mental Retardation and now the American Association of Intellectual and Developmental Disabilities (Luckasson & Reeve, 2001).
Thus, IDDs are characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviors, such as social and practical skills. The disability must originate before the age of 18 (AAIDD, 2010). In defining and evaluating IDDs, the AAIDD stresses that intellectual functioning should not be the sole criteria for assessment; in fact, individuals must be assessed on limitations in adaptive behavior such as a) conceptual skills, defined as academics and self-direction; b) social skills, including interpersonal skills, responsible and appropriate behavior, and social problem solving; and c) practical skills such as activities of daily living, occupational skills, and use of healthcare, transportation, money, etc. Consequently, many IDDs such as cerebral palsy, autism spectrum disorder, epilepsy, significant learning disabilities, and other neurological conditions that begin in childhood are covered under the umbrella of IDDs. This study uses the AAIDD’s (2010) definition of individuals with IDDs.

Developing an accurate and appropriate definition for IDDs is important as it can have significant consequences for individuals, affecting eligibility for services such as entitlement to federal resources and services and protecting against discrimination.

**Increase in the Prevalence and Life Expectancy of Individuals with IDDs**

According to the Centers for Disease Control and Prevention (CDC; 2011), the number of individuals identified as having IDDs increased by 17.1% in 2006–2008 compared to a decade. For example, the prevalence of autism spectrum disorder increased by 289.5% and attention deficit-hyperactivity disorder by 33.0%. According to the recent estimates, 12.1% of the civilian non-institutionalized population has disabilities, out of which 4.3% of the population has IDDs (American Community Survey, 2011).
In addition to this upward trend in the number of people diagnosed with IDDs, individuals with IDDs are now surviving childhood and adolescence, and living into adulthood, owing to advancements in medical services and improved quality of life. The average life expectancy of individuals with IDDs increased from 33 years in the 1930s to 66 years in 1993, and today many individuals with IDDS are living into their 60s and 70s and outliving their parents (American Community Survey, 2011; Factor, Heller, & Janicki, 2012). It is estimated that 8 million individuals with IDDs are in the age range of 18-64 years and 3 million are 65 years or older (American Community Survey).

Living Options and Support for Adults with IDDs: Past and Contemporary Issues

Deinstitutionalization movement. In ancient times, children with disabilities were killed through active or passive euthanasia (Meisals & Shonkoff, 2000), and in the Middle Ages, although they were allowed to live, they were ridiculed and mocked. Most were either court jesters, street beggars, imprisoned, or institutionalized (Aries, 1962). In the 19th century Edouard Seguin, a pioneer of special education, developed a “physiological method of education” for children with IDDs in France (Meisals & Shonkoff, 2000, p. 9). After immigrating to the United States, he founded the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons to promote the education and training of children with IDDs. As mentioned earlier, this institution was the forerunner of today’s AAIDD.

By the middle of the 19th century, several asylums and special schools had been established in the United States to provide educational training, care, and behavior management for individuals with IDDs. These schools and asylums began with a mission of training and were supported by philanthropists and wealthy members of society. Gradually, these asylums turned into residential institutions for individuals with IDDs. At the start of 20th century, owing to
overcrowding and lack of resources, these residential institutions were transformed into institutions of custodial care (Meisals & Shonkoff, 2000) and exclusion with inhuman conditions. These residential changes, along with the eugenics movement spearheaded by Henry Goddard and Louis Terman, marked the beginning of the seclusion era in the United States. Intelligence testing movement and scientific studies predicting links between IDDs and criminal behavior were used to justify discrimination and compulsory sterilization procedures (Kamin, as cited in Meisals & Shonkoff, 2000). Parents were often advised against keeping their children at home (e.g., living with them), as IDDs were viewed as an unbearable burden and there as yet no community services. Parents and family members had no choice but to send their children with IDDs to institutions; however, many continued to visit and remain interested in the lives of their institutionalized children (Bagenstos, 2012).

In 1954, in *Brown v. Board of Education of Topeka, Kansas*, the U.S. Supreme Court supported racial inclusion in schools and the end of discrimination against a group of individuals for arbitrary reasons. This thinking became a precedent for mainstreaming children with disabilities. In addition, similar to U.S. Civil Rights Movement advocates who fought against discrimination and inequality, parents of individuals with disabilities pushed for equal rights and services for their children with IDDs and for better living conditions.

Parental activism and several lawsuits such as *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania* in 1972 and *Wyatt v. Stickney*, also in 1972, started the move toward deinstitutionalization (Gargiulo, 2008). The deinstitutionalization movement, which lasted from the early 1970s until the 1990s, focused on closing large state mental hospitals and facilities housing individuals with IDDs. The shift from institutionalization to deinstitutionalization was guided by a philosophy known as valorization—an ideology that
suggests that individuals with IDDs must have the same rights and similar life course experiences as their peers, such as leaving home, having an education, or obtaining a job (Wolfensburger, 1985). Consequently, individuals with IDDs moved out of large state institutions into private and public intermediate care facilities, adult care homes, and private nursing homes. Out of 354 large state-operated facilities operating between 1960 and 2008, only 162 facilities remained open in 2009 (Bagenstos, 2012). Similarly, 149,892 individuals with IDDs lived in institutions in 1977. By 2011, 29,574 lived in such facilities. Today, 14 states have no state-operated institutions for individuals with IDDs (Braddock & Rizzolo, 2013).

Eventually, the parent and family organizations that lobbied against deinstitutionalization of individuals with IDDs advocated for community services. The efforts of deinstitutionalization advocates turned to ensuring adequate and appropriate services in the community (Braddock & Rizzolo, 2013). The enactment of the Social Security and Supplemental Security Income program in 1972, the establishment of the right to a free public education for children with IDDs (Public Law 94-142, the Education for All Handicapped Children Act, 1975), the Individuals with Disabilities Education Act (1990), and the Americans with Disabilities Act (1990) reinforced community integration and provided funds and cash benefits to individuals with IDDs living in the community. In addition, these changes in social law and policy mandated education, vocational training, and employment, thereby enabling individuals with IDDs to successfully reside and thrive in a community that affirms their rights to full participation (Cook & Wright, 1995). Currently-available resources to support individuals with IDDs and their families include cash subsidies, federal funds and residential facilities with rehabilitative care (such as Supplemental Security Income, Social Services Block Grant), Medicaid Intermediate Care Facility, and the Home & Community-Based Waivers.
Growing demand for services, budget retrenchment, and the need for family caregiving. The demand for services for people with IDDs has conflicted with government budgetary troubles in recent years. On the one hand, the demand for new residential services has grown tremendously since 1980; Braddock (2010) projects that 725,300 individuals with IDDs will need residential services by 2020. On the other hand, state budgets moved toward retrenchment following the 2001 and 2007 recessions. In 2011, total IDD spending declined from $56.7 billion to $56.6 billion, and about half the states reduced IDD spending (Braddock & Rizzolo, 2013). Previously, in fiscal year 2009-2010, 22 states provided cash subsidies, and only 17% of the families with a member diagnosed with an IDD received agency support. During that year, Home & Community-Based Waivers provided the bulk (73%) of the support (Braddock, 2010). As state budgets have moved toward retrenchment, deinstitutionalization advocates are challenging cuts to the services on which families of individuals with IDDs have relied. The growing number of diagnosed individuals with IDDs, their increased average life expectancy, and recent state budget cuts have combined to cause the resources and services available to individuals with IDDs to become below par and inadequate (Braddock, Hemp, Rizzolo, Haffer, Tanis, & Wu, 2011), necessitating family caregiving (Talley & Crews, 2012). Today, the number of caregiving families far exceeds the number of families supported by state and federal resources (Braddock & Rizzolo, 2013).

Family Caregiving

Lifespan Perspectives on Family Caregiving

Family members have long supported and cared for individuals with disabilities and mental and physical illnesses (hereafter referred to as family caregiving). In the US, family caregiving started receiving most attention as a public health issue in the 1980s. Discussions on
its implications for public and family policy, long-term care, and research have ensued since then (Talley & Crews, 2007). Family support providers not only provide caregiving, but they also facilitate communication between formal providers and serve as an alternative to institutionalization. In his book *How Caregiving Affects Development*, Shifrin (2009) suggested that caregiving is a national issue and must be studied from a lifespan development perspective because becoming a caregiver at any point in the lifespan will affect the support providers’ current and future development.

**Theoretical Models of Family Caregiving**

Theoretical frameworks provide valuable roadmaps for organizing information, shape research, and have implications for practice. They can also offer descriptions and explanations of research findings and predict likely outcomes prior to research (Babbie, 2008). Research on siblings of children with IDDs has been argued to be “theory-free” (Stoneman, 2005, p. 339) and this is also true for adult sibling caregivers. Therefore, use of a theoretical framework to examine the caregiving processes and outcomes of support providers will assist in organizing and better understanding the field, as well as filling gaps in the literature.

Several theoretical frameworks have been applied to parents/support providers of children with IDDs. These include a cognitive phenomenological model of stress (Lazarus & Folkman, 1984), models of the caregiving process and caregiver burden (Raina, 2004), the ABCX model of family stress (Hill, 1949), and the Double ABCX model of family stress and adaptation (McCubbin & Patterson, 1983). Although each of these models has been used by researchers and professionals in the field of disabilities, and they have some applicability, they were not suitable for the current study because they are all based on the experiences of parents of young children with IDDs (e.g., Crnic, Friedrich, & Greenberg, 1983; Quine & Pahl, 1991) and
have not been applied to other family members such as SSPs and adults with IDDs. Second, none of these models adequately emphasize positive coping, adaptation, and outcomes, and psychological growth. These models provide only a small window into the experiences of support providers from a crisis resolution perspective. After a review of possible theoretical models for use in this study, the caregiver empowerment model (described below) was deemed best suited for this study’s objectives.

**The Caregiver Empowerment Model**

Jones, Winslow, Lee, Burns, and Zhang (2011) developed the caregiver empowerment model (CEM) to explain and predict positive caregiving outcomes (e.g., personal growth) among Asian American women who care for their elderly relatives with disabilities and mental health disorders (see Figure 1). The authors developed the model based on data collected in 1995, 1996, and 2002. The CEM is suitable as the guiding framework for the present study because, unlike the models listed in the previous section, this model was developed for use among adult support providers and because it explains and predicts positive outcomes of caregiving. Thus, the CEM provides a wider, enriched, and a holistic view of caregiving. The model employed in the current study is an adapted version of the CEM and will be referred to as the “conceptual model” throughout this dissertation.

According to Jones et al. (2012), background of the family support providers is determined by, but is not limited to, their demographics and level of acculturation and the nature of their relationship with the care recipient. Demographics of the support providers included their age, gender, race, ethnicity, prior relationship with the care recipient, and whether the care recipient is a close or a distant relative. In their work, acculturation referred to the number of
years for which the Asian American support providers’ had lived in the US, which could potentially have influenced their caregiving beliefs and values.

Jones et al. (2012) further asserted that the background of the participants influences filial values, caregiving demands, and the use of community resources. Filial values refers to personal and cultural beliefs about responsibility for one’s aging relative that can influence support providers’ motivation to provide care. Caregiving demands are the stressors—such as the care-recipients’ functional limitations, the duration and intensity of caregiving activities, and the competing role demands—that affect the functioning of caregivers, sometimes leading to negative health outcomes and dissatisfaction. Resources are the community factors that help in coping with caregiving demands. The filial values, intensity of caregiving demands, and resources together help predict the appraisal of caregiving, which encompasses the care provider’s subjective feelings about caregiving. The appraisal of caregiving, in turn, determines caregiving outcomes in terms of positive well-being, psychological growth, and empowerment.

Overall, CEM emphasizes that a) resources contribute to positive outcomes and buffer the negative effects of stress, and b) the positive appraisal of stressful situations leads to positive outcomes.
Sibling Caregiving of Individuals with IDDs

Siblings of Typically Developing Individuals: An Overview

In 1987, Bank and Kahn described their experiences with examining sibling development and relationships as “being in a foreign country, without a map” (p. 5). The field of human development does not provide a comprehensive view of siblings, and siblings’ influence on an individual is often considered a “fleeting influence” (p. 5). Despite this disregard, sibling relationships are one of the closest and most long-lasting relationships (Bank & Kahn, 1982; Cicirelli, 1982), and they are important at every stage of an individual’s development (Whiteman, Bernard, & Jensen, 2011). Evidence suggests that a person’s perception of the sibling relationship warmth can be a better predictor of self-esteem than perceptions of maternal warmth and responsiveness (Barnes & Austin, 1995). In fact, closeness to siblings can be the single most significant predictor of an individual’s adjustment in later life (Vaillant & Mukamal, 2001).

In early childhood, siblings can be transitional objects (siblings can use one another to make the transition away from the mother) or help to support object relations (psychological processes that all people use early in life to create internalized images of the self and other people) (Bank & Kahn, 1982). Older children gain social skills by interacting with their younger siblings, and the younger siblings gain cognitive skills by imitating the older ones (Teti, 1992). In addition, responsive and supportive interactions between siblings can be a source of secure attachment for the younger siblings (Ainsworth, Bleher, Waters, & Wall, 1978).

As children mature from childhood to adolescence, sibling conflict can increase (Brody, Stoneman, & McCoy, 1994). When siblings feel they are too alike, they behave different from one another (sibling deidentification) deliberately (Steinberg, 2011). Over the course of
adolescent development, sibling relationships become more egalitarian, but also more distant and less emotionally intense (Cole & Kern, 2001). Nevertheless, in adolescence, positive sibling interactions contribute to adolescents’ academic competence, sociability, autonomy, and self-worth (Kim, McHale, Crouter, & Osgood, 2007).

siblings play an important and unique role in adulthood and in later years, as well. Siblings in adulthood might serve as confidantes, teachers, role models, and friends to each other and provide help and support (Cicirelli, 1982). Many adults define themselves and measure their success in comparison to their siblings (Connidis & Campbell, 1995; Milevsky, 2005). In older years, as the longest survivors of the family of origin, siblings are often seen discussing family memories and become partners in shared reminiscences (Cicirelli, 1982).

**Sibling of Individuals with IDDs and Sibling Support Providers**

Today, 72% of individuals with IDDs live in their parents’ homes (Braddock & Rizzolo, 2013); after the death of the parents, adult siblings of individuals with IDDs (SSPs) are an option for their care in many families (Heller et al., 2008). As referred to in Chapter 1, studies completed by Fujiura (2010), Easter Seals (2012), and Burke, Taylor, Urbano, and Hodapp (2012) gave a very basic understanding of their about the demographics of sibling caregivers, such as their number and characteristics, yet their caregiving processes, and outcomes (i.e., characteristics of care, their well-being, their caregiving tasks, and their perceptions of the overall experience), remain understudied. For example, the findings of the Easter Seals Survey (2012) indicate that out of 351 siblings surveyed, 14% reported living with their brother/sister with IDDs and 23% reported that they were their brother/sister’s primary caregiver. Fujiura (2010) analyzed the American Community Survey (2007) data and reported that 8.74 million individuals with developmental disabilities need care and support. Four percent of these
individuals were being supported by siblings who were in need of financial support to cover out-of-pocket health care costs for their brother/sister with IDDs.

Siblings of typically developing individuals often provide support for one another in adulthood, but the caregiving demands and expectations for siblings of individuals with IDDs can be more extensive (Heller & Factor, 1993). In fact, some siblings may experience “compound caregiving,” having to provide care for both their brother/sister with IDDs and their aging parents (Perkins, 2011, p. 2).

Many individuals with IDDs eventually will be cared for by adult siblings either due to death/aging of their parents or because of diminishing state and federal funds for social services (Factor et al., 2012; Heller et al., 2008); thus, rigorous scientific exploration is needed to project the number of SSPs and their roles; their roles, needs, and perceptions; and the types of support they both provide and need. Scant research has examined adult sibling support providers of individuals with IDDs and their caregiving processes and outcomes. Therefore, this literature review draws from studies on a) caregiving and relationships between siblings and individuals with IDDs during childhood and adolescent years, b) predictors of future sibling caregiving of individuals with IDDs, c) adult sibling support providers of individuals with mental illnesses, and d) family support providers. Studies on adult siblings of individuals with mental illnesses and informal family support providers are also examined because they provide insights into linkages among decision making, caregiving processes, and outcomes that may be similar for SSPs of individuals with IDDs. Also, to establish future research and practice areas and to move the field of sibling caregiving of individuals with IDDs forward, we can draw from related areas, such as sibling support providers for individuals with disorders such as mental illnesses. As such,
this chapter discusses and distinguishes studies focusing on SSPs of individuals with mental illnesses and IDDs.

**Variables That Influence Sibling Caregiving**

**Age and stage of development of sibling support providers.** Shifrin (2009) discussed how caregiving affects family support providers during four periods: young adulthood (18–25 years old), adulthood (26–40 years old), middle age (40–65 years old), and older adult years (age 65 and older). The young adult years are marked by the making of life-changing decisions and several developmental processes and goals such as differentiating from parents, forming intimate relationships, exploring fields of study, and establishing economic and residential independence. Individuals in this stage form stable structures and basic foundations of future life, and all of these tasks are crucial in the development of a unique personal identity (Arnett, 2000). Previous studies have proposed that lifelong experiences with brothers/sisters with IDDs could make siblings curious to learn about disabilities and therefore might affect their vocational plans, with many choosing careers in special education (Burton & Parks, 2004; Marks, Matson, & Barraza, 2005). While providing support, young adults have the cognitive capacity to understand the needs of the care recipient, but they may not be able to solve many of the problems due to their limited contextual experiences (Shifren, 2009) and therefore might get easily frustrated. In addition, time spent on caregiving responsibilities can conflict with SSPs’ focus on developmental goals such as dating and social activities (Horwitz, Tessler, Fisher, & Gamache, 1992).

By their 30s to early 40s, support providers are able to think through issues and can recognize more than one solution to a problem. However, similar to young adults, adult providers are contemplating and struggling with their own life issues such as full-time
employment, maintaining romantic relationships or marriage, and raising children (Shifren, 2009). Individuals at this age have a sense of “filial responsibilities and obligations,” i.e., an attitude about a set of responsibilities or obligations that they must assume (Stein, 2009, p. 122). The sense of filial responsibilities and obligations encourage consistent contact and provision of support to the relative who needs help. If given too many caregiving responsibilities, support providers may have to compromise on some of these developmental tasks; for example, they may hesitate to marry and have a family (Horwitz et al., 1992). In contrast, support providers with larger support networks may seek and get emotional and physical support from others and have positive experiences (Shifren, 2009).

Middle-aged adult support providers face a number of responsibilities, including raising their own children, working, maintaining family relationships, and participating in work- and community-related activities as well as possibly caring for their aging parents. In addition, support providers in this life stage may experience some decline in health and biological changes that can compete with the caregiving role. Consequently, support providers may express stress, interpersonal conflict, and poor psychological well-being, especially when the care recipient is demanding, unresponsive, or uncooperative. Generally, individuals in middle adulthood years have the largest convoys (network of friends and family members) to provide emotional and social support (Stephens, Franks, Martire, Norton, & Atienza, 2009).

Support providers who are 65 years and older experience significant physical and cognitive changes that could affect their ability to provide appropriate support and care. Since effective caregiving includes being able to perform multiple tasks, providers above 65 years of age might find it difficult to perform strenuous and heavy caregiving tasks (Patrick & Goedereis, 2009).
Gender and birth order of the sibling. Gender plays a significant role in caretaking activities and has been reported to be the most influential variable influencing allocation of caregiving tasks (Stoneman, Brody, Davis, & Crapps, 1991). Females are expected to be kinkeepers and nurturers, and they grow up with the expectation of taking on the future caregiving responsibilities of their brother/sister (Marks et al., 2005). Research findings suggest that the most involved sibling is a female who provides greater care and companionship to the brother/sister with mental illnesses and has a greater positive affect than males during childhood and adult years (Bigby, 1997; Greenberg, Seltzer, Orsmond, & Krauss, 1999). Similar findings have been reported among siblings of individuals with IDDs (e.g., Orsmond & Seltzer, 2000). In a recent survey, Burke et al. (2012) found that more female than male siblings reported the desire to co-reside and take care of their brother/sister with IDDs in the future.

Orsmond and Seltzer (2000) proposed the “same sex dyad” principle (p. 489). The authors suggested that sister-sister dyads engage in significantly more shared activities than brother-brother dyads who, in turn, engage in more than brother–sister dyads. However, a later study found this principle to be true only during early childhood and not during the adolescent or adulthood years (Orsmond, Kuo, & Seltzer, 2009).

Other studies have noted the differential effect of birth order among siblings in terms of their emotional and behavioral adjustment (Petelas, Hastings, Nash, Lloyd, & Dowey, 2009) and caregiving expectations (Schuntermann, 2009). Older siblings are usually more involved (Ormond et al., 2009; Schuntermann, 2009), perhaps due to parental expectations. In addition, being a lone sibling is found to be strongly associated with expectations for future caregiving (Burke et al., 2012). In terms of the interaction of birth order and gender, Orsmond and Seltzer (2000) found that being an older female sibling often results in a heavier caregiving role.
**Residential proximity and co-residence.** During adulthood years, the geographic/residential closeness of siblings can be associated with greater involvement in the lives of their brother/sister with IDDs (Pruchno, Patrick, & Burant, 1996; Rimmerman & Raif, 2001). Siblings who live closer are expected to provide more caregiving (Burke et al., 2012), report more emotional involvement (Seltzer, Greenberg, Orsmond, & Lounds, 2005), and provide greater instrumental and affective support (Greenberg et al., 1999). Nonetheless, Orsmond and Seltzer (2007) speculated that even though living closer is associated with greater contact and support, it might not mean a better relationship.

Among SSPs of individuals with mental illnesses, co-residence is related to higher levels of caregiving burden. Reinhard and Horwitz (1996) found that co-residing family members (N=163 family members, 86 parents and 77 siblings) who provided intensive care (more than 35 hours per week) were less likely to be employed and more likely to be on public assistance. In contrast, Carpentier, Lesage, Lalonde, Goulet, and Renaud (1992) suggested that providing care to individuals with mental illnesses from a distance could be more stressful: siblings who live with the person needing care can incorporate responsibilities into their daily lives, but siblings who live further away might not be able to do so. The differential impact of co-residence and moving away on siblings of individuals with IDDs is not well-understood. Recent findings from the Easter Seals Survey (2012) suggested that 14% (n=351) of the siblings surveyed live with their brother/sister with IDDs. How and why that decision was made is not indicated. Once fully understood, decision making processes and outcomes can provide evidence for supporting SSPs with diverse needs and for understanding how residential proximity influences caregiving.

**Disability of the Brother/Sister.** In many ways, the type and level of the disability of the brother/sister can create a state of confusion for SSPs therefore, further analysis of the
complexity of interactions between variables is critical. On the one hand, perceptions of higher needs owing to severe IDDs can induce SSPs to become more involved in caregiving (Pruchno et al., 1996), regardless of the current and past sibling relationship quality (Jewell & Stein, 2002). On the other hand, if the sibling’s needs are significant, SSPs might not want to get involved (Rimmerman & Raif, 2001). For example, studies have found that siblings of a brother/sister with Down syndrome who have less severe behavioral problems report closer and warmer relationships (Hodapp & Urbano, 2007), positive feelings about their relationship, more contact, and more involvement in their sibling’s future than siblings of a brother/sister with autism spectrum disorder (Krauss, Seltzer, Gordon, & Friedman, 1996; Orsmond & Seltzer, 2007).

Likewise, Greenberg et al. (1999) found that two-thirds of siblings who had a brother/sister with IDDs expected to assume future caregiving responsibilities, whereas only one-third of siblings of individuals with mental illnesses (who have more behavioral problems and require more support) expected to do so. Similarly, in another study, severity of aggression was found to be a moderate predictor of caregiver burden (n=44 support providers of individuals with IDDs, r=.61, p<.001) (Unwin & Deb, 2011).

In addition to behavioral problems, higher support needs and cognitive challenges can also affect the daily routines of individuals with IDDs. Taylor and Hodapp (2012) examined the relationship between the absence of daytime activities for an individual with IDDs and the well-being and health of their adult sibling caregiver. Individuals with IDDs who did not participate in any daytime activity due to their low functional abilities and health and behavioral problems had SSPs who were more likely to have significant negative health outcomes compared with SSPs whose brother/sister were involved in a daytime activity.
There are two main interpretations of the above findings. First, in the case of a brother/sister with autism spectrum disorder or mental illness, the demands associated with caregiving might become difficult to manage due to the higher problem behaviors of their brother/sister. Therefore, higher caregiving demands might influence SSPs involvement negatively. Second, the brother/sister with moderate levels of IDDs might be able to be cared for by their siblings, but for the brother/sister with severe IDDs, it becomes necessary to seek support from formal services (Pruchno et al., 1996).

**Family, race, and ethnic values related to the caregiving.** The cultural meaning of caregiving can have a direct influence on the health, beliefs, and practices of the caregiver (Hoffmann & Mitchell, 1998). Cultural and ethnic values influence family values and determine elements such as norms of a family member’s responsibility, the value placed on familism (valuing family over individual needs and interests), perceptions of the caregiving burden (Goldner & Drentea, 2009), and the use of community resources (Jones et al., 2011).

Culture and ethnic values shape perceptions of caregiving so much that terms like caregiving burden are not universally recognized. The impact of family values and culture has not been studied among sibling of individuals with IDDs. Studies on Latino and African American individuals with mental illnesses suggest that SSPs do not consider caregiving to be burdensome. They, therefore, readily accept the responsibility and perform more caregiving duties (objective burden) and yet report less caregiving burden (subjective burden) than Caucasian SSPs (Reinhard & Horwitz, 1995). In another study, African American siblings were two times more likely than Caucasian siblings of individuals with mental illnesses (32% vs. 15%) to co-reside with their brother/sister with mental illnesses (Jewell & Stein, 2002). Hence, families that believe in family caregiving and/or value familism expect siblings to provide future
support and may begin delegating age-appropriate caregiving tasks from a younger age. Consequently, Smith, Greenberg, and Seltzer (2007) found that siblings who expressed a stronger sense of family responsibility for care reported being more involved in providing future assistance for their brother/sister with mental illnesses.

Ethnicity can also influence caregiving. For example, Asian American support providers of the elderly with health problems do not like to access support services despite engaging in intensive caregiving. In Asian cultures, accessing outside help can mean that the family is unable to support the elderly family member, which is considered disgraceful. Values such as these can put support providers at risk for emotional consequences due to intensive caregiving and underutilization of professional services.

**Financial resources and socioeconomic status.** Houser and Gibson (2008) estimated the economic value of family support providers (if they were to be paid for the services they voluntarily undertake) to be $375 billion. Research shows that adult SSPs of individuals with mental illnesses who are primary support providers (i.e. who provide higher intensity and frequency of support consistently) incur greater costs than other temporary support providers (Lohrer et al., 2007). Although, some SSPs report involvement in caregiving to be gratifying and fulfilling, they face economic strains associated with providing support (Easter Seals, 2012; Greenberg et al., 1999). For example, 60% (n=351) of the SSPs of individuals with IDDs surveyed in the Easter Seals study reported concerns about meeting their long-term financial goals, and 40% reported that they were currently facing financial stress.

The economic impacts of caregiving need to be examined for two primary reasons: a) expenses associated with caregiving reduces the available income of SSPs, and b) SSPs or their spouses might not seek full-time employment, leading to lower earnings. Both of these financial
issues, in addition to the time devoted to caregiving, can affect the quality of life of support providers (Clark & Drake, 1994).

Another factor that is related to financial resources and can complicate caregiving is the socioeconomic status of the SSP’s family. Parish, Seltzer, Greenberg, and Floyd (2004) reported that the families of individuals with IDDs have nearly 27% lower savings than families (n=73) without individuals with IDDs (n=73). A later study found that in families of individuals with IDDs, mothers were more likely to be employed part time and to earn less than mothers with typically developing children (Stabile & Allin, 2012). Lower savings and earnings of the family can further complicate sibling caregiving—when parents are unable to help financially, siblings might be deterred from providing care.

**Conceptual Model and Constructs**

The following section presents literature review of the constructs in the model and their relationship with each other (See figure 4). The constructs and their definitions are as follows. Perceived social support is defined as the subjective assessment of adequacy of social support from family, friends and significant others (Zimet, Dahlem, Zimet & Farley, 1988). Demands refer to the cumulative effect of physical stressors such as functional limitations of the individual with IDDs, the weekly duration of caregiving, and the employment status of SSPs. Appraisals of caregiving are the subjective feelings related to caregiving. These subjective feelings are based on caregiving challenges encountered and extent of utilization of available resources to cope with those challenges (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Depression is defined as feelings of hopelessness, guilt, worthlessness, and irritability accompanied by loss of interest in activities, fatigue, difficulty in concentrating, insomnia, and thoughts of suicide. For a diagnosis of depression, these signs should be present most of the day either daily or nearly daily
for at least two weeks (Centers for Disease Control & Prevention, 2012). Finally empowerment among SSPs’ is the perception of caregiving efficacy i.e. their confidence in successfully navigating through all the hurdles, perceptions of being in control, and the ability to rise above the challenges of caregiving processes (Degeneffe, Chan, Dunlap, Man, & Sung, 2011).

**Perceived Social Support**

**Perceived social support and depression.** Depression among support providers is a widely researched topic. Researchers have noted that family support providers of individuals with IDDs and mental illnesses become more stressed as they face additional challenges in their day-to-day routines (Baker, Seltzer, & Greenberg, 2011; Orsmond, Kuo, & Seltzer, 2009; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Radloff, 1991). Notably, across studies, depressive symptoms have been reported mostly by females, perhaps for two main reasons. First, studies have found that in families of individuals with IDDs, the most commonly involved person is a female (either a mother or a sister) who provides a major portion of the caregiving (Burke et al., 2012; Greenberg et al., 1999; & Orsmond & Seltzer, 2000). Second, females are more likely than males to co-reside with the individual with IDDs (Krauss, Seltzer, Gordon, & Friedman, 1996).

In comparison, other studies have found the strong association between caregiving and depression to be buffered in the presence of higher social support. For example, Demirtepe-Saygili and Bozo (2011) interviewed parents of children with cancer. They found that parents (n=100 mothers of children with cancer) who perceived higher support from their own partners, families, and friends reported less negative psychological outcomes such as depressive symptoms. Umberson and Montez (2010) examined the negative association between social support and depressive symptoms and suggested that the “emotionally sustaining qualities of
relationships (e.g., a sense that one is loved, cared for, and listened to)” benefits mental and physical health and fosters a sense of meaning and purpose in the life of a support provider (p. 3).

**Perceived social support, appraisal of caregiving, and depression.** Similar to depression, the appraisal of caregiving is another highly researched topic, perhaps due to its implications for mental health. In a 2011 study, support providers of individuals with dementia (n=302) reported negative appraisals of caregiving in terms of feeling burdened (hereafter, “caregiving burden”) and dissatisfied with their life (Kim, Chang, Rose & Kim, 2011). Hsiao (2010) noted similar results among family support providers of individuals with mental illnesses (n=43), finding that those who perceived lower social support reported significantly higher caregiving burdens. Martin, Rodriguez, Gomez, Villa, and Caro (2011) reported that the support providers (n=102) of individuals with dementia who experienced an intense level of caregiving burden reported more depressive symptoms. Notably, SSPs of individuals with traumatic brain injury (n=60) experienced stress, dissatisfaction, and feelings of burden, yet their negative appraisals and stress levels were buffered by higher levels of perceived social support. In fact, a higher level of perceived social support was found to be the strongest factor predicting positive appraisal of caregiving (Hanks, Rapport, & Vangel, 2007).

**Demands**

Demands are the physical stressors caused by the employment status of the support providers, care-recipients’ functional limitations, and the duration of caregiving. They can influence the caregiving processes and outcomes by influencing depression and the appraisal of caregiving. Research to date on SSPs has not examined the complexity of the interactions between these constructs. The sections that follow provide a brief discussion of the influence of
employment status, the functional level of the sibling with IDDs, and the duration of caregiving activities on level of demand experienced by SSPs. These sections are followed by a discussion of the associations among demands, appraisal of caregiving, and mood.

**Employment status.** Having a career is one of the most prominent adult life goals. The National Alliance for Caregiving and AARP (2009) surveyed family support providers of a general elderly population (n=1480) and found that 57% of family support providers were employed. Of these, 46% worked full time and 11% worked part time. The employment rate among family support providers was significantly lower than among the civilian non-institutionalized population (57% vs. 65.7%, respectively) (U.S. Bureau of Labor Statistics, 2009). The authors speculated that caregiving activities could lead to imbalance and conflict between work and caregiving responsibilities; therefore, support providers may feel compelled to take unfavorable steps such as cutting back on their working hours, change jobs, leave the workforce permanently, or take a leave of absence. Similar findings were noted in studies of mothers of children with IDDs; such mothers were more likely to be employed part-time and earned less than women without children with IDDs (Parish, Seltzer, Greenberg, & Floyd, 2004; Stabile & Allin, 2012). As these various studies show, support providers such as SSPs can experience frequent life-work imbalances and unsatisfactory fulfillment of work obligations due to higher demands.

**Functional level of individuals with IDDs.** Lower functional levels of individuals with IDDs or mental illnesses and higher levels of support needs have been found to complicate caregiving. Higher support needs owing to lower functional level can induce some SSPs to become more heavily involved in caregiving (Pruchno, Patrick, & Burant, 1996), but can discourage others from getting involved completely (Rimmerman & Raif, 2001). If SSPs choose
to become involved, over the years, growing support needs and functional limitations of the individuals with IDDs might become excessive and might lead to higher perceptions of demands as higher functional limitations among individuals with IDDs restrict the number and/or duration of daytime activities in which they participate (Taylor & Hodapp, 2012). These daytime activities can be a respite from caregiving and potentially lower the demands they face. The lack of respite opportunities among mothers of children with IDDs has been shown to contribute to feelings of isolation and helplessness and greater caregiving demands (Talley & Crews, 2012).

**Duration of caregiving.** The duration of caregiving is not a well-researched among SSPs, however if SSPs are co-residing with their brother/sister with IDDs, they are perhaps full-time support providers. According to the Easter Seals Survey (2013) 14% (n=351) reported that their brother/sister with IDDs lives with them and another 23% reported that they are the primary caregiver (a caregiver that provides the most caregiving and is responsible for making medical and legal decisions for the individuals with IDDS). Of these 14%, 75% of SSPs reported it to be a full-time job. It remains to be examined how duration of caregiving impacts demands of the caregivers.

**Demands, appraisal of caregiving, and depression.** Strong associations among demands, appraisal of caregiving, and depression have been reported frequently among support providers. The National Alliance for Caregiving and AARP (2009) suggested that family support providers of individuals with negative health outcomes such as Alzheimer, dementia, cancer, heart disease and stroke (n=1480) who provided care for 20+ hours/week (reflecting higher demands) reported higher negative appraisals of caregiving in terms of dissatisfaction, feelings of isolation, and caregiving burden. In the field of developmental disabilities, Gerstein, Crnic, Blacher, and Baker (2009) found that mothers of children with IDDs reported higher levels of...
isolation, resentment, bitterness, and frustration with caregiving and depression. Moreover, this negative appraisal of caregiving and depressive symptoms has been found to increase over time due to an increasing amount of time spent on caregiving. Among SSPs, greater time spent on caregiving tasks can mean fewer hours to relax or exercise and the inability to keep health maintenance appointments for continued preventive medical care (Raver, Michalek, & Gillespie, 2011). This may further contribute to feeling burdened and to depressive symptoms.

**Perceived Social Support, Appraisal of Caregiving, and Empowerment**

Kyzar, Turnbull, Summers, and Gomez (2012) completed a research synthesis of 23 studies published between 1990 and 2010 on the relationship between family support and family outcomes among children with severe IDDs. The authors found that family support had a positive effect on family outcomes across studies, including an improved sense of satisfaction among participants in their caregiving role (reflecting empowerment) and improved family functioning.

Similar to perceived social support, positive appraisal of caregiving is associated with higher levels of caregiving efficacy and a sense of empowerment among support providers. Bookwala and Schulz (1998) showed that spouses (n=300 individuals with dementia) who felt and reported a positive appraisal of caregiving also reported a higher sense of caregiving efficacy and empowerment. In the study, empowerment was reported in terms of support providers’ ability to successfully face caregiving challenges and solve problems when necessary. Park (1998) suggested that approaching any stressful event as a challenge and a learning opportunity can lead to positive outcomes such as personal and psychological growth and a higher sense of efficacy and empowerment. On the other hand, negative appraisal of caregiving such as higher
perceived levels of caregiving burden and dissatisfaction can result in feelings of not being in control and a lowered sense of caregiving efficacy and empowerment.

**Conclusion**

This literature review defined examined and reviewed the relationships among social support, demands, appraisal of caregiving, depression, and empowerment among family support providers. The nature and extent of associations among these variables remain largely unexplored among SSPs of individuals with IDDs. Because SSPs are often next in line after parents for providing support to individuals with IDDs, and with the growing numbers of individuals diagnosed with IDDs and their increased life expectancy, attention to SSPs in research, practice, and social policies is necessary.

The current study employed a conceptual model (Figure 4) to examine the following constructs among SSPs: perceived social support, demands, appraisal of caregiving, depression, and empowerment. The conceptual model proposes that perceived social support and demands directly predict depression. Demands are predicted by the employment status of SSPs, the weekly duration of caregiving, and the functional level of the individual with IDDs. In addition to the direct association with depression, demands when mediated by appraisal of caregiving also predict depression. Finally, perceived social support and appraisal of caregiving predict empowerment among SSPs.

Overall, the literature review above establishes the relationship between social support, demands, appraisal of caregiving, depression and empowerment among family support providers. It is evident that these associations remain unexplored among SSPs of individuals with IDDs. In view of the fact that SSPs are next in line to provide support to individuals with IDDs,
and with the growing numbers of individuals with IDDs and their increased life expectancy, attention to SSPs in research, practice, and social policies is necessary.

To initiate the examination of the constructs such as perceived social support, demands, appraisal of caregiving, depression, and empowerment among SSPs, a conceptual model (see figure 4) for the study is being proposed. In the conceptual model, it is proposed that perceived social support and demands directly predict depression. Demands are predicted by the employment status of SSPs, the weekly duration of caregiving, and the functional level of the individual with IDDs. In addition to the direct association with depression, demands when mediated by appraisal of caregiving also predict depression. Finally, perceived social support and appraisal of caregiving predict empowerment among SSPs. Based on the conceptual model and the gaps in the literature, the proposed research questions and hypotheses are as follows.

**Research Questions**

The purpose of this study is to examine the caregiving processes and outcomes for SSPs. These processes and outcomes will be explored by examining perceived social support, demands, appraisal of caregiving, depression, and empowerment among SSPs of individuals with IDDs.

**Descriptive Research Questions**

3. What are the characteristics of SSPs who provide care to individuals with IDDs, and what are the characteristics of individuals with IDDs who receive this care?

4. What caretaking activities are associated with sibling caregiving, and on an average, how much time is spent on these activities monthly?

**Model-Related Research Questions**

4. Are perceived social support, demands, and appraisal of caregiving associated with depression among SSPs?
5. Are SSPs’ appraisal of caregiving associated with demands and perceived social support?

6. Are appraisal of caregiving and perceived social support associated with empowerment among SSPs?

**Hypotheses**

4. High perceived social support will be associated with low depression scores, positive appraisal of caregiving, and higher scores on empowerment.

5. Higher demands will be associated with higher depression scores and negative appraisal of caregiving.

6. Negative appraisal of caregiving will be associated with higher depression scores and lower empowerment scores.
Chapter 3: Method

Given that the caregiving aspects of SSPs remain understudied and theoretical models have not been applied, the purpose of the current proposal is to test the conceptual model and examine relationships between perceived social support, demands, appraisal of caregiving, depression, and empowerment among SSPs. The section begins with a discussion of the method of data collection, followed by details of the participants, inclusion criteria, sample size, recruitment of participants, variables and measures, and data analysis.

Method of Data Collection

Web-based survey is being used in this study for its significant advantages. These advantages are faster response at less cost and potential to reach out to a large number of individuals across large geographical area (Cobanoglu, Warde, & Moreo, 2001). However, web-based surveys can have a coverage bias as some prospective participants might not have access or choose not to use the internet may be left out.

Participants

Adults 18 years or older who are sibling support providers of individuals with intellectual and developmental disabilities.

Inclusion Criteria

To be eligible to participate in the survey, participants need to be self identified as

1) 18 years old or more
2) Have a brother or sister with intellectual disabilities such as Down syndrome, fragile X, autism spectrum disorders that may co-occur with physical, sensory or language disabilities.
3) A support provider of their brother or sister with developmental disabilities
4) An English speaker and residing in the US

Sample Size

In structural equation modeling, a minimum of 200 participants is recommended (Preacher & Coffman, 2006). In the study, a total of 350 participants were recruited.

Recruitment of Participants

The study was IRB approved, before recruiting participants. To recruit participants, a web link to the survey used in this study was sent to 245 organizations and agencies throughout the US that work with individuals with IDDs and their families. Some of these organizations include the following: The Sibling Leadership Network and its state chapters, The Sibling Network Project, The ARC of the United States and its state and local chapters, the Association of University Centers on Disabilities, Vanderbilt Kennedy Center Programs. The organizations and agencies were requested to send information about the study and a web link to their listserv members and post the study information on their Facebook and Twitter page. In addition, snowball recruiting was conducted through personal contacts, emails, and web postings on social networking and other sites.

Variables and Measures

To examine variables in the conceptual model such as perceived social support, burden, depression, appraisal of caregiving and empowerment among SSPs, the following measures have been selected.

Demands. The latent construct demands is measured via three observed variables: number of hours the participants work; the level of functional abilities of the individual with IDDs on day-to-day tasks such as preparation of meals, ability to self-administer medication, etc.; and the number of hours per week the SSP devotes to taking care of his or her brother/sister.
with IDDs. (Refer to Appendix II, section A, Question 8 and section C). The total scores can range between 23 and 111, with lower scores suggesting lower demands on SSPs. In the current sample $\alpha$ for demand = .912.

*Employment status.* The variable seeks information on the number of hours for which participants are employed. The variable is a categorical item with 5 options and responses ranging from 0 to more than 30+ hours/week. The total scores can range between 1 and 5 with lower scores suggesting lower demands on SSPs. Two items from the scale are: On a scale of 1-5, with 1 being completely dependent to 5 being completely independent, “To what extent does your brother/sister with IDDs perform day-to-day routine tasks such as preparing meals?” “On an average, how much time per week, do you estimate to spend on performing tasks such as preparing meals for your brother/sister with IDDs?”

*Functional ability of the care recipient.* This variable is assessed through an 11-item scale with responses ranging from 1 (completely dependent) to 5 (completely independent). The scale collects information on the level of functional abilities of the individual with IDDs on the day-to-day tasks such as preparation of meals, ability to self-administer medication etc. The total scores can range between 11 and 55 with lower scores reflective of lower functional abilities of the individual with IDDs and higher demands on SSPs. A sample item includes “On a scale of 1-5, with 1 being completely dependent to 5 being completely independent, “To what extent does your brother/sister with IDDs perform day-to-day routine tasks such as preparing meals?”

*Duration of caregiving provided/week.* It is an 11-item, 5-point scale, and seeks information on the number of hours/week SSPs spend on taking care of individuals with IDDs. The number of hours per week can range from 0 to more than 10 hours. The total scores can range between 11 and 55 with lower scores reflective of lower duration and lower demands on
SSPs. One of the items from the scale is, “On an average, how much time per week, do you estimate you spend on performing tasks such as preparing meals for your brother/sister with IDDs?”

**Perceived social support.** The variable perceived social support is examined via the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), which is a measure of subjective assessment social support and the perceived adequacy of support from three sources: family, friends, and significant others. It is a 12-item, 7-point scale and the response format ranges from very strongly disagree to very strongly agree. The total scores can range between 12 and 84. Higher scores indicate higher perceived social support (refer to Appendix II, section E). A Cronbach’s coefficient alpha value was reported previously as being .84 for the total scale (Zimet, Powell, Farley, & Werkman, 1990). For the current sample $\alpha = .934$. Two sample items from the scale are a) “I get the emotional help and support I need from my family” and b) “I have friends with whom I can share my joys and sorrows.”

**Appraisal of caregiving.** The Appraisal of caregiving” is assessed using the Appraisal of Caregiving Scale Revised (Lawton, Moss, Hoffmann, & Perkinson, 2000), which measures appraisals of caregiving in terms of subjective feelings related to caregiving stressors and the support providers’ ability to cope. It is a 27 item, five-point Likert scale that has been tested on support providers of the elderly population. The Likert-type response format ranges from 1 to 5 (1 = strongly disagree, 5 = strongly agree) and the total scores can range from 27 to 135. The higher the total score, the more positive is the appraisal (refer to Appendix II, section E). The Cronbach’s alpha for the total scale is 0.86 (Lawton et al., 2000). For the current sample $\alpha = .911$. Two sample items from the scale are a) “I get a sense of satisfaction from helping my
brother or sister” and b) “My health has suffered because of the care I provide to my brother or sister.”

**Depression.** The occurrence of depressive symptoms among SSPs is assessed via the Center for Epidemiologic Studies Depression Scale (CES-D), an instrument designed to measure self-reported symptoms associated with depression experienced in the past week (Radloff, 1977). Since its development, it has been used to diagnose depression among support providers of individuals with mental illnesses and physical disabilities (Talley and Crews, 2012). The scale includes 20 items on depressed mood, feelings of guilt, worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbances. Response categories indicate the frequency of occurrence of each item and are scored on a 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Total scores can range from 0 to 60 (refer to Appendix II). Higher scores (both item and total scores) indicate more depressive symptoms. The CES-D has been demonstrated to be a reliable measure of depression across racial, gender, and age categories. A high internal consistency was noted with Cronbach’s alpha coefficients ranging from .85 to .91 across studies, the test-retest stability was acceptable (.40) and there was excellent concurrent validity by clinical and self-report criteria (Radloff, 1977; 1991; Zumbo, Gelin, & Hubley, 2001). For the current sample $\alpha = .915$. A sample item from the scale is- “I felt that I could not shake off the blues even with help from my family or friends” (refer to Appendix II, section D).

**Empowerment.** The variable empowerment among SSPs is measured through the Caregiver Empowerment Scale (Degeneffe et al., 2011). The instrument was developed as a measure of empowerment among family support providers of persons with traumatic brain injury. It is a 5-point Likert scale consisting of 30 items (see Appendix II). The total score can
range from 30 to 150 with higher scores indicating that the caregiver possesses self-confidence and has capacity to respond to the demands of being a caregiver. Estimates of the Cronbach’s alpha coefficients of the whole scale are not available, but estimates of internal consistency for each of the subscales are .76, .88, .84, and .92 indicating acceptable levels of internal consistency. Tests of concurrent validity established a moderate association between CES factors and financial, social, and physical well-being (Degeneffe et al, 2011). For the current sample $\alpha = .947$. To adapt this tool in the current study, the phrase “relative with traumatic brain injury (TBI)” was replaced by brother or sister with IDDs. A sample item from the scale is – “I have a good sense of the rehabilitation potential (i.e., work and independent living potential) of my brother or sister with IDDs” (refer to II, section F).

Data Analysis

A conceptual model was created based on the variables. Structural equation modeling (SEM) was used to test the conceptual model and examine the proposed associations among variables. SEM is a statistical technique that combines elements of multivariate model, such as regression analysis, factor analyses and simultaneous equation modeling (Kenny, 2012). SEM can be helpful in examining the patterns of interrelationships among variables, estimate the effects of latent variables on observed variables, and allow for more accurate estimates of the effects of the predictor on the criterion (Kline, 2010).

AMOS software was used to examine whether the data fit the conceptual model and to present the standardized loadings of each path. Goodness-of-fit indices such as the chi square test, root mean square error of approximation (RMSEA), comparative fit index (CFI), and standardized root mean square residual (SRMR) were used to assess how well the data fit the conceptual model. Indicators of a good fit of the model are insignificant chi square test ($p > .05$),
less than or equal to .05 value of RMSEA, CFI greater than or equal to .95 and less than .08 SRMR value. In addition, Sobel tests will be used to test for mediating paths.

Data was screened for missing values and to ascertain patterns in missingness such as missing at random, missing completely at random and missing not at random. It is important to consider patterns in missingness as it can lead to substantial biases in analyses. Since AMOS uses full information maximum likelihood (FIML) estimation, it was used to estimate missing data. FIML has been shown to outperform most common methods of handling missing data, including listwise and pairwise data deletion, and mean substitution (Arbuckle, 1996).
Chapter 4 Results

Descriptive Analysis and Findings

A total of 363 SSPs participated in the online survey. Of these, 322 are part of the analysis. In the remainder, either the data were completely missing (n= 20), participants were less than 18 years old (n= 20), or the SSPs brother/sister with IDD were no longer alive (n=1) and therefore participant was an ex-caregiver. The chapter begins with descriptions of SSPs who participated in the study, followed by an overview of the sibling characteristics (e.g., how respondents describe their brother/sister with IDD), and the weekly duration of caregiving on selected tasks. Finally, the results of tests of the model and mediation related are presented along with related information. As indicated in the Method section, information regarding the characteristics of participants and their siblings is drawn solely from survey responses.

Demographics of the Participants

The participants in the study were all adult siblings of individuals with IDDs (see Table 1). Most participants (35.7%) were relatively young, falling in the age range of 18-25 years. As was expected with a sample of caregivers and survey respondents, a majority of participants were female (85.4%). The participants were largely White (83%) and resided all cross the United States. Nearly half (44.8%) of the participants had more than 4 years of college education and 22.3% had a 2-year degree. More than half of the participants (51.1%) were employed for 30 hours/week or more and approximately a quarter of the participants (24.2%) reported their average household income to be in the range of $50,000-$74,000. Thirty-nine percent of the participants reported their average household income to be lower than the average household income of $50,000 in the US (US Census Bureau, 2010). Most participants were married (36.9%)
It was interesting to note that approximately one-third of the participants (32.3%) lived with their brother or sister with IDDs and another 21.7% lived within 10 miles of their brother/sister’s residence. The mean distance was reported to be 152.3 miles.

**Demographics of the Brother/Sister with IDDs**

Table 2 presents the reported characteristics of brother/sisters with disabilities. The mean age was 32 years ($s=14.2$) and their ages ranged between 4 and 76 years. A majority of the brother/sister with IDDs were males (63.3%). In addition to intellectual difficulties, majority (94.1%) had additional co-occurring disabilities. The most commonly-reported concomitant disabilities were learning disabilities (42.5%) followed by language and communication disorders (38.5%) and behavior problems (32.3%). The least reported disability was sensory impairment (18.3%). Even though majority of the brother/sister with IDDs were in school or in training program (36.5%), a substantial number of individuals with IDDs (16.6%) did not work and/or had any kind of daytime activities. Only a small percent of brothers/sisters with IDDs (5%) worked independently and held a paid position. The majority of the individuals with IDDs who were either employed, in school, in training program or had other day time activities were reported to be engaged for 20-39 hours in these activities. In terms of their functional level on selected tasks (see Figure 2), it was found that most brother/sisters with IDDs can walk independently (63.6%). Nearly half were verbal (44%) and less than quarter (21%) could read. The data on tasks such as taking medications, preparing meals, taking public transport suggested that a very small portion of individuals with IDDs (2.4-9%) were completely independent and therefore need extensive support and assistance from others.
SSPs Caregiving Tasks and their Weekly Duration

The findings on SSPs caregiving tasks and their weekly duration suggested that, on an average, SSPs spent nearly 18 hours per week on caregiving ($\bar{x} = 17.81; s = 8.7$). The task on which most SSPs spent their time is preparing meals (56%), followed by driving the individuals with IDDs or commuting with them in public transportation (52.9%) (See figure 3). The task on which least percentage of SSPs spends time was helping them to walk, not surprising because most siblings with IDDs (63.6%) are completely independent on those tasks (for example, walk). The amount of caregiving provided to individuals with IDDs was significantly correlated with their functional level ($r = .351, p = .000$). Thus, SSPs provided greater duration of caregiving if their brothers/sisters with IDDs had higher functional needs.

Model Related Analysis and Findings

Initial Model identification. Per Figure 4, the initial model had seven observed variables, seven unobserved variables, and therefore 14 parameters to be estimated. Observed variables included perceived social support, SSPs employment duration, functional level of individuals with IDDs, weekly duration of caregiving, appraisal of caregiving, depression, and empowerment. Unobserved variables included demand, the errors, and the disturbances.

Initial model estimation. The initial model was estimated using maximum likelihood estimation (MLE). MLE derives estimates that maximize the likelihood that the data from the sample came from the population of interest. Amos's full information maximum likelihood (FIML) estimation was used to handle missing data. FIML uses all information of the observed data and requires no data imputation. Since there were missing data in the sample, many fit indices such as SRMR and modification indices could not be computed automatically in AMOS.
**Model fit indices.** Researchers have suggested viewing and reporting multiple measures when examining model fit (Kline, 2005). Accordingly, during each step of the process, the model fit was examined using measures of goodness of fit. For this study, the selected measures included chi square, the Normed fit index (NFI), and root mean square of error approximation (RMSEA). Chi square measures the magnitude of the difference between the covariance matrices. Because a significant chi square suggests a meaningful difference between the covariance matrices, a good model fit results in a non-significant chi-square result (Hooper et al., 2008). Chi square is the most commonly used measure of fit; however, it is affected by sample size (Hooper et al., 2008). The comparative Fit Index (CFI: Bentler, 1990) performs well even when sample size is small. A value of CFI \( \geq 0.95 \) is presently recognized as indicative of good fit (Hu and Bentler, 1999). RMSEA is a measure of how well the model would fit the population covariance matrix if it had optimal parameter estimates. This measure is often selected because it is sensitive to the number of parameter estimates, and it favors the best fit but also the most parsimonious model (Hooper et al., 2008). For purposes of this study, values of the RMSEA were examined and the cutoff used was 0.05.

**Initial model findings.** Once the initial model was estimated, the parameter estimates and model-fit measure needs are examined to determine if the model fit the data (Hooper, Coughlan, & Mullen, 2008). The initial model failed to converge despite increasing the iteration limit from 50 to 5000.

To further investigate the problem, all observed variables of demand (weekly caregiving duration and employment duration of SSPs and functional level of individuals with IDDs) were examined. Cronbach's alpha for the scale and its items were calculated for functional level of individuals with IDDs and weekly caregiving duration. Cronbach’s alpha is a measure of internal
consistency, that is, how closely related a set of items are as a group. The finding suggested possible reason behind issues with the convergence of the initial model. Functional level and weekly caregiving duration had a very high Cronbach’s alpha (\(\alpha = 0.94\)) and therefore may be acting as one scale rather than two different scales.

**Model Revisions and Respecifications**

For any set of multivariate data, more than one potential model can fit the data. Therefore, theory, rather than pure statistics must guide decisions surrounding what is plausible or nonplausible (Kenny, 1999; Kline, 2005). The possibilities for model revision include altering the number of factors, altering the relationships between the indicators and the factors, and correlating measurement error (Kline, 2005). However, it is also important that revisions in the model are guided by the theory (Kline, 2005). As indicated earlier, an examination of each scale and specific items within each scale suggested the potential theoretical rationale for the revision. Since functional level and weekly caregiving duration had very high Cronbach’s alpha’s, their summated scores were added to form one new exogenous variable named “demand”. In other words, the variable employment duration was used to create a second exogenous variable (See figure 5). After these changes, the model converged without increasing the iteration limit, yet the model fit after first revision of the model was marginally good (\(\chi^2 (6) = 12.2, \ p = .057; \ \text{RMSEA} = .057; \ \text{CFI} = .968\)) (See Table 3 & 4).

Weekly caregiving duration and employment duration of SSPs and functional level of B/S with IDDs did not impact siblings’ appraisal of caregiving significantly. The implications of these non significant findings are discussed in Chapter 5.

Negative regression weights in the pathways of the final model suggest inverse associations between variables. For example, a pathway from social support and depression has
negative regression weight (B=.216, \( p < .001 \)). This suggests that as social support increases by one unit, depression decreases significantly by .216 units. Similarly, pathway from appraisal of caregiving and empowerment has negative regression weight (B= -.574, \( p < .001 \)). This suggests that as negative appraisal of caregiving decreases by one unit, empowerment increases significantly by .574 units.

Positive regression weights in the pathways of the final model suggest positive associations between variables. For example, a pathway between social support and empowerment has a significant regression weight (B=.281, \( p < .001 \)). This suggests that as social support increases by one unit, empowerment increases significantly by .281 units. Similarly, pathway between appraisal of caregiving and depression has regression weight (B= .161, \( p < .001 \)). This suggests that as negative appraisal of caregiving increases by one unit, depression increases significantly by .161 units.

**Test of Mediation**

In the final model, appraisal of caregiving was noted to be the partial mediator between perceived social support and depression and between perceived social support and empowerment. The Sobel test was used to test the significance of the mediation effect. If there is a significant mediation, the relationship between the independent variable and the dependent variable is an indirect effect of a third variable (the mediator). Hence, on including the mediator in analysis, the effect of the independent variable is reduced and the effect of the mediator remains significant. The Sobel test helps to determine whether the reduction in the effect of the independent variable, after including the mediator is a significant reduction and therefore whether the mediation effect is statistically significant (Preacher and Hayes, 2004).

To calculate Sobel test statistics and its significance value, regression weights and their standard errors between perceived social support and appraisal of caregiving (\( B = -.410; SE = \))
and between appraisal of caregiving and depression ($B = .161; SE = .042$) were supplied to
an online Sobel test calculator. The process was repeated to test another mediation in the final
model between perceived social support and appraisal of caregiving ($B = -.410; SE = .066$) and
appraisal of caregiving and empowerment ($B = .574; SE = .079$). The tests of mediation among
perceived social support, appraisal of caregiving and depression suggested significant partial
mediation (Sobel test statistics = -3.26, one tailed $p = .000$ and two tailed $p = .000$). Similarly, the
test of mediation among perceived social support, appraisal of caregiving and empowerment also
suggested significant partial mediation (Sobel test statistics = 4.721, one tailed $p < .001$ and two
tailed $p < .001$). The significant mediation by appraisal of caregiving hints at - how sibling
caregivers appraise caregiving (meaning they make) is an important factor in determining their
depressive symptoms and their sense of empowerment or being in control, yet their direct effects
remain.

On the contrary, since the direct paths between demands and depression ($B = .066, p = .118$) were insignificant, the mediation by Appraisal of caregiving was noted to be insignificant
as well (Sobel test statistics = -0.42, one tailed $p = .33$ and two tailed $p = .6$
Chapter Five: Discussion

The purpose of the current study was to examine via structural equation modeling caregiving processes and outcomes for SSPs of individuals with IDDs and explore relationships among perceived social support, demands, appraisal of caregiving, depression, and empowerment among this population. This chapter begins with a summative review of descriptive and model-related findings that compares the current findings with the extant but small and scattered body of research. It concludes, and includes a discussion of study limitations and implications.

Summary: Characteristics of SSPs

Ages and stages of sibling development are important, as each stage fosters new capacities, goals, and social expectations (Berk, 2012). In the case of SSPs, the age and stage of development relates to the family context, individual cognitive-developmental functioning, lived experiences and demands, and ultimately, understanding of their siblings’ disabilities and the roles and responsibilities they undertake. Whereas it is long known that siblings have critical roles as support providers, very little is known about their demographic composition, their intentions and experiences of caregiving, and the effects of these roles within and across their lives.

In this study, more than one third of the SSPs were young adults aged 18-25 years. Less than 10% were in the age–range of 36-45 years. These findings diverge from the sample characteristics noted by Taylor and Hoddapp (2012). The authors surveyed 796 siblings of adults with intellectual and developmental disabilities who responded to a web-based survey and their mean age of siblings was 40.2 years (s = 12.81). Similarly, 45% of the siblings in Easter Seals Survey (2012) were in the age range of 35-54 years old.
In the current study, SSPs were predominantly White, female, married, well-educated, had full-time employment. These findings are consistent with the earlier studies of siblings of individuals with IDDs and mental illnesses (Burke et al., 2012; Easter Seals, 2012; Taylor & Hoddapp, 2012). Researchers have often reported on the gendered nature of caregiving and that the most involved sibling at any stage of life was a sister who provided care, companionship, and had a positive affect (Bigby, 1997; Easter Seals, 2012; Greenberg et al., 1999; Orsmond & Seltzer, 2000; Pruchno et al., 1996; Taylor & Hoddapp, 2012). As described in Chapter 2, females are expected to fulfill the roles of a kin-keeper and caregiver more often than men (Moen & Wethington, 1999) and therefore they grow up with an expectation that they will take on additional caregiving and household responsibilities for their sibling in the future (McHale & Gamble 1989; Mark, 2005; Stoneman et al. 1991). However, before drawing any conclusions, future studies need to further investigate whether a male sibling is actually hesitant to provide long-term care to his brother/sister with IDDs or is it that more females than males respond to surveys in the field of social sciences.

Residential proximity and co-residence. Residential proximity has been shown by researchers to determine the intensity and frequency of caregiving provided. During adulthood, the geographic/residential closeness of siblings predicts greater involvement in the lives of their brothers/sisters with IDD(s) (Rimmerman, 2001; Seltzer et al., 1991; Seltzer et al., 2001; Zetlin, 1986). Siblings of individuals with IDDs and mental illnesses who lived closer reported more emotional involvement (Seltzer et al., 2001) and provision of greater instrumental and affective support (Greenberg et al., 1999) than siblings who moved away. In addition to involvement, residential proximity has been shown to determine caregiving burden among SSPs of individuals with mental illnesses. Cook, (1988), Pickett, Cook, Cohler, and Solomon (1997), Tessler &
Gamache, (1994) suggested that co-residence is related to higher levels of caregiving burden. Co-residence increased the burden of caregiving and supervision and the individual with mental illnesses had less impact on the family when he/she lived apart. Although the impact of residential proximity on appraisal or weekly duration of caregiving, depression, and empowerment were not examined in the current study, yet this finding can have implications for future studies and strengthens the evidence that most SSPs continue to live closer to their brothers/sisters with IDDs in adulthood years. In the current study, approximately one-third of the SSPs lived with their brother or sister with IDDs and another 21.7% lived within 10 miles of their brother/sister’s residence. Thus, 54% of the SSPs lived either with their brother/sister or within 10 miles of the residences of their brothers/sisters with IDDs.

**Characteristics of brothers/sisters with IDDs**

Participant report indicates that, a majority of individuals with IDDs (siblings) were males (63.3%) and had additional co-occurring disabilities (94.1%). The most commonly-reported concomitant disabilities were learning disabilities (42.5%) followed by language and communication disorders (38.5%) and behavior problems (32.3%). The finding on individuals with IDDs being predominantly male is consistent with a higher prevalence of intellectual disabilities among males than females in the population. Males have about a 1.5-fold greater prevalence in intellectual disabilities such as autism spectrum disorder, attention deficit and hyperactivity disorder, behavior problems, and learning disabilities (Maulik & Harbour, 2010).

Similar to Taylor and Hoddapp (2012), a majority of the brothers/sisters with IDDs in this study were reported to be in school or a training program (36.5%) and substantial number of individuals with IDDs (16.6%) do not work or have any daily activities. These day-time activities can be opportunities of respite for SSPs and therefore the role of no day time activities
on appraisal of caregiving can be investigated in future research. Examining the reported functional level of brothers/sisters with IDDs on selected tasks, it appears that a very small portion of individuals with IDDs (2.4-9%) are completely independent and therefore needed extensive support and assistance from others. These findings are inconsistent with the Easter Seals Survey (2012) wherein one-third (n=351) of the siblings reported that their brothers/sisters with IDDs were able to complete activities of daily living on their own. Since the Easter Seals survey did not specify tasks or activities of daily living, comparisons between the two findings cannot be drawn. Replication of the findings on the functional level of brothers/sisters with IDDs in future studies may provide strong evidence for caregiving support and population-based studies are needed.

**Sibling Caregiving Tasks and their Weekly Duration**

Findings on sibling caregiving tasks and their weekly duration suggested that on an average siblings spend nearly 18 hours weekly on caregiving (\( \bar{x} = 17.81; s = 8.7 \)). The minimum duration of time spent by SSPs was reported to be 10 hours/week and the maximum duration was 50 hours/week. The finding confirms the role of SSPs in caregiving and further indicated that taking care of their brothers/sisters with IDDs is either a part time or a full-time job for many. The task on which most SSPs spend their time was preparing meals (56%), followed by driving them to places or commuting with them in a public transport (52.9%). The task on which least percentage of SSPs spent time was helping them to walk. One reason for this may be that most individuals with IDDs (63.6%) were completely independent on those tasks (for example, walking). In addition, it was noted that the amount of caregiving provided to the individuals with IDDs is moderately correlated with their functional level (\( r = .351, p \text{ value} = .000 \)). The findings related to specific sibling caregiving tasks have not been examined earlier.
and therefore need replication and further investigation to draw implications for support programs for SSPs.

**Model-Related Findings and Discussion**

**Perceived social support, appraisal of caregiving, and depression.** Consistent with study hypotheses, results indicated a significant relationship between perceived social support and depression (-.219, \( p < .001 \)) and perceived social support and appraisal of caregiving (-.411, \( p < .001 \)). The negative regression weights indicated that the higher scores on perceived social support are associated with lower depressive symptoms and lower negative appraisal of caregiving.

The findings of the study are consistent with existing research on SSPs of individuals with mental illnesses. It has often been suggested that SSPs of individuals with IDDs and mental illnesses experience more stress than individuals of typically developing brother/sisters (Baker, Seltzer, & Greenberg, 2011; Orsmond, Kuo, & Seltzer, 2009; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Radloff, 1991); therefore, it follows that SSPs of individuals with IDDs may report more caregiving burden and dissatisfaction with their life (Kim, Chang, Rose & Kim, 2011). However, the negative impact of caregiving has been noted to diminish in the presence of higher social support (Demirtepe-Saygili & Bozo, 2011; Hanks, Rapport, & Vangel, 2007; Martin et al., 2011). This suggests that social support, including the individual’s belief that they are loved, cared for, and are listened to by their family, friends or significant others, positively influences mental health. Even though specific aspects of social support were not examined, one might speculate that perhaps supportive family, friends and significant others deter the sense of loneliness and/or enhance the sense of self-worth and feelings of security and comfort, potentially leading to resiliency. Researchers have also noted that social support
attenuates the reaction to the stressful event by attenuating negative appraisal response (House, Landies, Umberson, 1988). It is likely that the perception that others will help if one turns to them, might have encouraged SSPs to positively reframe the danger posed by the stress and perhaps bolstered their sense of coping ability resulting in negative association with depressive symptoms and negative appraisal of caregiving. Additionally, perspectives on caregiving that focus largely on stress fails to consider potentially salutatory effects of caregiving (Jones et al., 2012).

**Perceived social support, appraisal of caregiving, and empowerment.** Consistent with study hypotheses, analyses revealed a significant relationship between perceived social support and empowerment (.282, p<.001) and between negative appraisals of caregiving and empowerment (-.572, p<.001). The significant relationships between perceived social support and empowerment indicate that higher scores on perceived social support are associated with a higher sense of empowerment. Empowerment includes individual's perceived sense of control and ability to navigate life demands; as such, it follows that supportive friend, family member and significant other might bolster the sense of control, caregiving mastery, and independence. While the data do not provide an explanation of the specific mechanisms by which friends, families, and significant others help to create a sense of empowerment, these findings both illustrate the relation among these variables and illuminate the need to more clearly understand the mechanisms underlying them.

The negative appraisal of caregiving is negatively associated with empowerment. Hence it can be interpreted that the meaning SSPs make of the caregiving process redefines their ability to successfully face caregiving challenges and solve problems when necessary. Approaching any stressful event as a challenge and a learning opportunity can lead to positive outcomes such as
personal and psychological growth and a higher sense of efficacy and empowerment. On the other hand, a negative appraisal of caregiving such as higher perceived levels of caregiving burden and dissatisfaction can result in low perceived control and a reduced sense of caregiving efficacy and empowerment (Park, 1998).

Thus, the current findings also confirm that perceived social support and positive meaning making (positive appraisal of caregiving) are vital in developing a sense of empowerment. As Lord and Hutchinson (1993, p.13) suggested, social support can act as a “catalyst” fostering control and therefore mentoring opportunities, resources, informational, and moral support from others can assist the support providers in “recapturing their dreams” and navigate through the demands of caregiving.

**Demand, employment duration, appraisal of caregiving, and depression.** In some sense it was encouraging to note that weekly caregiving duration, employment of SSPs and functional level of B/S with IDDs did not significantly impact SSPs appraisal of caregiving, which is inconsistent with several studies on mothers of children with IDDs and family support providers of elderly (Gerstein, Crnic, Blacher, & Baker (2009; National Alliance for Caregiving and AARP, 2009). In terms of intensity and duration, prior research has found that family members who provided 20+ caregiving hours/week (reflecting higher demands) reported higher negative appraisals of caregiving in terms of dissatisfaction, feelings of isolation, and caregiving burden (National Alliance for Caregiving, 2009). Similarly, Gerstein, Crnic, Blacher, and Baker (2009) found that mothers of children with IDDs reported higher levels of isolation, resentment, bitterness, and frustration with caregiving and depression. Raver, Michalek, and Gillespie, (2011) speculated that among SSPs, greater time spent on caregiving tasks can mean fewer hours to relax or exercise and the inability to keep health maintenance appointments for
continued preventive medical care. This may further contribute to feeling burdened and to depressive symptoms. Similarly, lower functional level of individuals with IDDs or mental illnesses and higher levels of support needs have been found to complicate caregiving. Higher functional limitations of the individuals with IDDs over a period of time can become excessive and lead to higher perceptions of demands and can contribute to feelings of isolation and helplessness and greater caregiving demands (Talley & Crews, 2012).

Inconsistent with study hypotheses, SSP employment duration was not associated with appraisal of caregiving. Researchers have often noted both positive and negative impacts of caregiver’s employment on their appraisal of and adjustment to caregiving. Higher duration of employment resulting in negative appraisal of caregiving can be explained by the competing demands hypothesis. This suggests that the competing roles can produce an overload for the support provider and therefore they become less efficient and effective in either role (Dunham & Dietz, 2003). On the contrary, many researchers have reported the positive effects of employment on caregiving and suggested role enhancement hypothesis. According to role enhancement hypothesis part-time employment may provide opportunities of respite from caregiving and contribute toward personal growth, and greater financial resources (Coughlin, 2010). One interpretation of this finding is that family members are resilient in the face of stress, or at least that the effects of providing support are not ubiquitously negative, as is commonly assumed. This suggests that there are unseen variables operating to determine appraisal of caregiving. Based on the findings of the current study, it can be concluded that caregiving is not necessarily detrimental to the support provider’s career goals, the appraisal of caregiving, or mental health.
Limitations of the Study

The current study has several limitations, among them is cross sectional nature of the study, the coverage bias and, disregard for other forms of caregiving such as providing financial support. Therefore, the SSPs who were part of the study may not be reflective of the epidemiology of intellectual and developmental disabilities. In addition, due to convergence issues the full conceptual model could not be tested. Integrating the study of this population into some bigger national population based studies can help to test the full model.

Cross sectional design. Being a cross-sectional study, the purpose of the study is to provide a snapshot of variables associated with depression and empowerment among sibling support providers as potentially mediated by caregiving appraisals. Since the study is being carried out at one time point, it provides no indication of the sequence of events, and causality cannot be inferred. Nevertheless, cross-sectional studies indicate strength of the associations that may exist and are therefore useful in generating hypotheses for future research (Babbie, 2008).

Coverage Bias. The most important drawback to electronic survey approach is the large number of U.S. households—about 30% in 2009—that are not yet connected to the Internet (U.S. Census Bureau, 2011, p. 724). Households without Internet access differ systematically from those with access, tending to be older, poorer, and more likely to be in rural areas than those that are connected (Tourangeau, 2004, pp. 792–793). Hence, the findings may have some coverage bias.

Implications of the Study

The current study has several implications for future research, practice, and family policy. In this section we will discuss implications for research, family support and policy, and challenges it presents to the notion of pathologizing siblings of individuals with IDDs.
Research Implications

Long-term caregiving by family members as a public health issue started receiving attention in the 1980s. Since then discussions have ensued regarding its implications for public and family policy, long-term support providers, and research (Talley & Crews, 2007). Family caregivers such as siblings not only provide caregiving, but also facilitate communication between formal providers, are advocates for their brothers or sisters, and are an alternative to institutional accommodation of the individual with IDDs (Sibling Leadership Network, 2013). Until now, researchers have tended to focus on parents of individuals with IDDs or on siblings who are willing to undertake future caregiving roles. How sibling caregiving is maintained throughout life, and how it may be experienced as a natural aspect of family life rather than a burden, is understudied. In the current study, the application of a conceptual model of support provision enables a framework to examine SSPs deeper and unexplored issues such as appraisal of caregiving, perceptions of social support, emotional consequences of caregiving, and the sense of empowerment. Nevertheless, the need for more and rigorous research is obvious as there are still many unanswered questions. Questions that can be explored by future researchers are a) What are their motivations to assume future caregiving roles, their challenges and barriers in providing caregiving, b) what are the processes of division of caregiving when there is more than one sibling and c) How do SSPs view their own life goals such as marriage, maintaining their own family and social life and career while caregiving for their brothers/sisters with IDDs, d) what are the racial and ethnic variations in sibling caregiving of individuals with IDDs, and e) what are the financial challenges faced by SSPs of individuals with IDDs.
Implications for Support Programs and Family Policy

In the current study, higher perceived social support was associated with lower depressive symptoms, better appraisals of caregiving, and a greater sense of empowerment. These findings provide evidence for strengthening support programs and family policy. Most SSPs feel unprepared and anxious about the caregiving responsibilities (Heller et al., 2008; Heller & Kramer, 2009) and need assistance with transportation, medical care, managing finances, providing daily care and in gaining/maintaining employment for the B/S with IDDs (Easter Seals, 2012). Affiliation with support groups can serve to increase positive appraisal of caregiving and lower depressive symptoms. Experts argue that first, such groups might enable family members to gain insight into their brother/sister’s disability and more effectively cope with demands of caregiving (Lukens, Thoring, & Lohrer, 2002). Siblings need up-to-date information to improve their understanding of the problem and develop effective coping strategies. Third, similar to any other family caregivers who have a significantly higher prevalence of mental health issues (Cochrane Goering, & Rogers, 1997), siblings of individuals with IDDs also require mental health support to facilitate caregiving processes and outcomes. The average rating of SSPs on CES-D scale was 20.5 (scores over 16 can be indicative of significant levels of depressive) further affirms that siblings need support and more support programs should be created as these support programs have a potential to lower stress (Kyzar, Turnbull, & Summers, 2012). Kane and Penrod (1993) argued that supporting families of caregivers is both “pragmatic and humanitarian” (p. 274). The authors elaborated on three kinds of family support services that must be integrated in social and family policy for caregivers. These services are (a) direct services that include educational, informational, and referral programs and mental health services (b) subsidized short-term and extended respite services that
offer caregivers’ relief from caregiving on a regular basis and (c) financial incentives ranging from direct payment to the caregivers to income tax benefits.

Despite strong evidence of the merits of family and social support, the average annual rate of total IDD spending has steadily declined from 7% in 1970’s to 2.5% in 2000’s (Braddock, 2011). In 2011, only 7% (out of $ 52.6 billion) was allocated to support individuals with IDDs living with their family (Braddock et al., 2013). A lack of funds for support and the need for participation in a caregiving role brings forth concerns about SSPs’ long-term risks and the need to examine the presence of resilience. If caregiving stress extends beyond what is considered reasonable by SSPs, negative outcomes may follow and pull SSPs away from caregiving or can create a pile-up of stressors on SSPs affecting their entire family’s psychological, financial, and emotional well-being (Raver et al., 2011).

The study also provided ample evidence to support the idea that the term “family” in social policy and law for families of individuals with IDDs must explicitly include siblings. Without explicit inclusion, siblings might not get opportunities to participate in the planning and collective discussion on the rights and supports of individuals with IDDs or become beneficiaries of Lifespan Respite Care Act, the Family Medical Leave Inclusion Act and the Community Choice Act and caregiver tax credits (Heller et al., 2008; Perkins, 2011). Policies such as respite care provide a break from continual caregiving responsibilities and allow the caregivers to rest and focus on other family relationships and their own needs. Hence, with adequate respite, the risk of “role overload” and “burnout” can be reduced (Perkins, 2011). In addition to social policy, state incentives such as subsidized housing and financial assistance can encourage and facilitate siblings to take care of their B/S with IDDs for a longer period (Heller et al., 2008).
**Challenges the Ideology of Pathologizing Siblings of Individuals with IDDs**

Investigation of siblings developmental outcomes started with Grossman’s (1972) landmark exploratory study of siblings of individuals with intellectual disabilities. Until the early 1980s, most researchers paid little attention to siblings of individuals with IDDs. Studies of mothers dominated the research agenda, to the almost total exclusion of fathers, extended families, and siblings (Emerson et al., 2001). Since the 1990s, there has been an increasing focus on the experiences of the siblings and they are considered an important part of the family (Kresak et al., 2009). Despite emphasis, much of the early research pathologized the experiences of having a brother/sister with IDDs (Hodapp & Ly, 2005; Rossiter & Sharpe 2001). Almost all studies were negatively tinged with respect to the research question—how are siblings adversely affected, in which ways, and by how much. Researchers continue to ask the same questions even today (e.g. Neece, Blacher, Baker & Bruce, 2010; Williams et al., 2010). The negative research question is reflective of an assumption that siblings experience predominantly if not exclusively negative effects as a result of having or supporting a brother/sister with IDDs (Cuskelly, 1992).

Positive findings (such as non-significant findings between demand, duration of employment, appraisal of caregiving and depression) suggested the need to investigate salutary effects and life affirming aspects of caregiving or at least the idea that SSPs might consider providing care to be normative and a developmental expectation.

**Conclusion**

The current study provides evidence for the associations between social support, appraisal of caregiving, depression, and empowerment among SSPs of individuals with IDDs. Non-significant findings between demand, duration of employment, appraisal of caregiving, and depression assures that caring for a brother/sister with IDDs might not necessarily be detrimental.
for their mental health or career goals. However, it is also necessary to understand that SSPs have an extremely valuable role to play in the lives of individuals with IDDs and therefore we need to ensure that they are well-supported in these roles.
References


Cochrane, J.J. Goering, P.N., & Rogers, J.M. (1997). The mental health informal caregivers


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<tr>
<td></td>
<td></td>
<td>26-35</td>
<td>29.8</td>
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<tr>
<td></td>
<td></td>
<td>36-45</td>
<td>9.9</td>
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<td>46-55</td>
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<td>55 and above</td>
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<td>Female</td>
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<tr>
<td></td>
<td></td>
<td>African American</td>
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<td></td>
<td>Hispanic/Latino</td>
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<tr>
<td></td>
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<td></td>
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<td></td>
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<td></td>
<td>Some college or 2-year degree</td>
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<td></td>
<td></td>
<td>4-year college graduate</td>
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<td></td>
<td></td>
<td>$25,000-$49,999</td>
<td>23.8</td>
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<td></td>
<td></td>
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<td></td>
<td>$150,000-$174,999</td>
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<td></td>
<td></td>
<td>$175,000-$199,999</td>
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<td></td>
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<td>$200,000 and up</td>
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<td>5.5</td>
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<td>Yes, 11-20 hours/week</td>
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<td></td>
<td>Yes, 21-30 hours/week</td>
<td>8.5</td>
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<td></td>
<td></td>
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<td>------------------------------------------------</td>
<td>------</td>
</tr>
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<td>Marital Status</td>
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<td>Never Married</td>
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<td>Dating and/or cohabiting</td>
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<td>11-49 miles</td>
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<td>50-149 miles</td>
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<td>150-249 miles</td>
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<td>Residential proximity from the B/S with IDDs</td>
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<td>Beyond 250 miles</td>
<td>17.7</td>
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Table 2

*Characteristics of Individuals with IDDs who Received Care from their Adult Siblings.*

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<th>n</th>
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<th>Valid percent</th>
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<td></td>
<td></td>
<td>Female</td>
<td>34.7</td>
</tr>
<tr>
<td>Additional/Co-occurring disabilities</td>
<td></td>
<td>No other condition</td>
<td>5.9</td>
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<tr>
<td></td>
<td></td>
<td>Sensory impairment</td>
<td>18.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Language and communication disorders</td>
<td>38.5</td>
</tr>
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<td></td>
<td></td>
<td>Physical motor</td>
<td>27.3</td>
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<td></td>
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<td>Behavioral</td>
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<td></td>
<td></td>
<td>Learning</td>
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<tr>
<td></td>
<td></td>
<td>Emotional problems</td>
<td>17.7</td>
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<td></td>
<td></td>
<td>Mental illnesses</td>
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<td></td>
<td></td>
<td>Other conditions</td>
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<td>Daily Activities</td>
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<td>Works in a paid job within the community independently</td>
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<td></td>
<td>Works in a paid job with assistance</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>In school or training for future job</td>
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<td></td>
<td></td>
<td>Volunteer activities</td>
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<td></td>
<td></td>
<td>Does not work</td>
<td>16.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
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<td>40 hours or more</td>
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<tr>
<td>employment</td>
<td>20-39 hours</td>
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<td></td>
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<tr>
<td>------------</td>
<td>------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10- 19 hours</td>
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<td></td>
<td>5-9 hours</td>
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<td></td>
<td>1-4 hours</td>
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<tr>
<td></td>
<td>Does not work</td>
<td>15.1</td>
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<table>
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<th>Level of independence on selected tasks</th>
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</tr>
<tr>
<td>Read</td>
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<tr>
<td>Take medications</td>
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<td>Medical appointments</td>
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<td>Preparing meals</td>
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<td>Grooming and personal hygiene</td>
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<td>Household tasks</td>
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<td>Public transport</td>
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Table 3

*Unstandarized Loadings of the Pathways, their Significance Level of the Final Model (n=322)*

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<th>Outcome</th>
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<th>SE B</th>
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<td>.043</td>
<td>***</td>
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<td>Appraisal of caregiving</td>
<td>Depression</td>
<td>.161</td>
<td>.042</td>
<td>***</td>
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<td>Appraisal of caregiving</td>
<td>-.410</td>
<td>.066</td>
<td>***</td>
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<td>Employment Duration</td>
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<td>.630</td>
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<td>Empowerment</td>
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<td>.079</td>
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<td>.083</td>
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<tr>
<td>Demand</td>
<td>Depression</td>
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<td>.044</td>
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Table 4

Model Fit Summary (n=322)

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<th>df</th>
<th>P</th>
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<td>.968</td>
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***= p<.001
Figure 1

The Caregiver Empowerment Model (Jones, Winslow, Lee, Burns, & Zhang, 2012)
Figure 2
Functional Level of Individuals with IDDs who Received Care from their Adult Siblings.
Figure 3.
*Percentage of SSPs Involved in Selected Caregiving Tasks*
Figure 4. Conceptual Model

- Perceived Social Support
- Depression
- Weekly Duration of Caregiving
- Appraisal of Caregiving
- Functional Level
- Employment Status
- Demands
- Empowerment
Figure 5. Final Model

\[ \text{Perceived Social Support} \rightarrow -0.216 (***) \rightarrow \text{Depression} \]

\[ \text{Employment Duration} \rightarrow -0.410 (***) \rightarrow \text{Appraisal of Caregiving} \]

\[ \text{Appraisal of Caregiving} \rightarrow -0.348 (p=0.581) \rightarrow \text{Depression} \]

\[ \text{Demands} \rightarrow -0.032 (p=0.673) \rightarrow \text{Appraisal of Caregiving} \]

\[ \text{Appraisal of Caregiving} \rightarrow 0.066 (p=0.118) \rightarrow \text{Empowerment} \]

\[ \text{Appraisal of Caregiving} \rightarrow -0.34 (*** \text{ means } >.01) \rightarrow \text{Empowerment} \]

\[ \text{Depression} \rightarrow 0.161 (***) \rightarrow \text{Empowerment} \]
Appendix A

Consent Form for Participation in a Research Study

University of Connecticut

Principal Investigator: Mamta Saxena

Study Title: Depression and Empowerment among Sibling Support Providers of Individuals with Intellectual and Developmental Disabilities

Introduction

Hi and a warm welcome to the survey!

You are invited to participate in a research study that examines the lives of siblings who are currently providing any form of care and support to their brothers or sisters with intellectual and developmental disabilities on a daily or intermittent basis.

The purpose of this research study is to understand the type and duration of care you provide. In addition, you will be asked to report on the level of support available to you from friends and family, your feelings about caregiving, depressive symptoms, and your overall evaluation of yourself as a caregiver.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will be asked to complete the online survey. The survey questions are divided into six parts. Sections A and B ask information about yourself and your brother or sister with disabilities. Section C asks about joint activities and involvement between you and your brother and sister and your brother/sister's support needs. The items in section D are about ways you have been feeling lately and section E and F collects information on your feelings about caregiving and your evaluation of yourself as a caregiver.

To be eligible to participate in the survey, you need to be

1) 18 years old or more
2) Have a brother or sister’s with intellectual disabilities such as Down syndrome, fragile x, autism spectrum disorders that may co-occur with physical, sensory or language disabilities.
3) A support provider of your brother or sister with developmental disabilities
4) An English speaker and residing in the US

What are the risks or inconveniences of the study?

I believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the survey.
What are the benefits of the study?

You may not directly benefit from this research; however, I hope that your participation in the study will provide a foundation for future studies in this area, add to the body of empirical evidence on sibling caregiving, and add towards making evidence-based recommendations for the support needs of sibling support providers.

Will I receive payment for participation? Are there costs to participate?

There are no costs to you. You will not receive any payment for participation. Following participation in the study, however, you will be invited to participate in a drawing. If so, you will be asked to provide your email address. Four participants will be chosen at random to receive $25 gift cards from Sears. Participation in the drawing is voluntary and all email addresses will remain confidential and then destroyed/deleted.

How will my personal information be protected?

I will do my best to protect the confidentiality of the information we gather from you but I cannot guarantee 100% confidentiality. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties. You should also know that the UConn Institutional Review Board (IRB) and the Office of Research Compliance may inspect study records as part of its auditing program, but these reviews will only focus on the researcher and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. In the survey, you do not have to answer any question that you do not want to answer.

Whom do I contact if I have questions about the study?

Take as long as you like before you make a decision. I will be happy to answer any question you have about this study. If you have further questions about this study or if you have a research-related problem, you may contact the principal investigator, Mamta Saxena at mamta.saxena@uconn.edu. If you have any questions concerning your rights as a research participant, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible risks and inconveniences have
been explained to my satisfaction. I understand that I can withdraw at any time. My X indicates that I have received a copy of this consent form.
Appendix B

Online Survey

A. Here are some general questions about you. Please check any one that applies unless specified

1. Do you have a brother or sister with intellectual and developmental disabilities?
   a. Yes
   b. No

2. How old are you?
   a. 18-25
   b. 26-35
   c. 36-45
   d. 46-55
   e. above 55 years old

3. Gender
   a. Male
   b. Female
   c. Other


5. Please select one or more than one ethnic category/categories that best describe you.
   a. White
   b. African-American
   c. Hispanic/Latino/s
   d. Native American
   e. Asian or Pacific Islander
   f. Other: - __________________

6. What is the highest grade of schooling you completed?
a. GED  
b. HS  
c. AA  
d. BA  
e. GRAD DEGREE  
f. Other ________

7. What is your total household income?  
   a. Less than $10,000  
   b. $10,000 to $19,999  
   c. $20,000 to $39,999  
   d. $40,000 to $59,999  
   e. $60,000 to $79,999  
   f. $80,000 to $100,000  
   g. 100,000 or more

8. Are you currently employed?  
   a. No  
   b. Yes, 1-10 hours/week  
   c. Yes, 11-20 hours/week  
   d. Yes, 21-30 hours/week  
   e. Yes, more than 30 hours/week

9. What do you do for a living? ______________________

10. What is your current marital status?  
    a. Never Married  
    b. Dating and/or cohabiting  
    c. Married  
    d. Separated  
    e. Divorced  
    f. Remarried  
    g. Widowed
B. The following questions are about your brother or sister with disabilities. If you have more than one brother/sister with disabilities, please complete the questionnaire as it concerns that sibling who is closest to you in age. Please check any one that may apply unless specified.

11. Age of your brother/sister with disabilities in years ______________

12. Gender of your brother/sister with disabilities
   a. Male
   b. Female
   c. Other

13. Which of the following disability conditions does your brother/sister have in addition to intellectual disabilities? Please check all that apply
   a. No other Condition
   b. Sensory Impairment (Hearing, vision)
   c. Cerebral palsy
   d. Williams syndrome
   e. Language and communications disorder
   f. Physical motor problems
   g. Behavioral problems
   h. Learning disabilities
   i. Emotional disorders
   j. Mental illness(es)
   k. Other Condition(s) : _____________________________________

14. Which of the following best describes your brother or sister with disabilities' daily work or activities? Please check all that apply
   a. Works in a paid job within the community independently
b. Works in a paid job with some assistance, supervision, and/or modifications and accommodations  
c. In school or training for future job, day program, sheltered workshop  
d. Volunteer activities  
e. Does not work or has no activity setting.  
f. Other, please specify ______________________

15. All together, how many hours per week do you spend on these work/activity settings?  
a. 40 hours/week or more  
b. 20-39 hours/week  
c. 10-19 hours/week  
d. 5-9 hours/week  
e. 1-4 hours/week  

C. On a scale of 1-5, with 1 being “completely dependent i.e. cannot do at all on its own” to 5 being “completely independent i.e. can do completely on its own”, to what extent does your brother/sister with disabilities perform these activities?

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Completely dependent</td>
<td>Mostly dependent</td>
<td>Somewhat dependent</td>
<td>Mostly independent</td>
<td>Completely independent</td>
</tr>
<tr>
<td>16. Walk</td>
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<td>17. Speak</td>
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<td>18. Reading</td>
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<tr>
<td>19. Taking medications</td>
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<tr>
<td>20. Maintaining medical appointments</td>
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</tbody>
</table>
21. Preparing meals
22. Grooming/personal hygiene
23. Performing household tasks such as cleaning the house
24. Performing financial tasks such as paying bills
25. Take public transport to commute
26. Others -___________

The following are the questions on tasks that you do/supervise for/with your brother or sister with disabilities? On an average, how much time per week, do you estimate to spend on these activities?

<table>
<thead>
<tr>
<th>Item #</th>
<th>Task</th>
<th>Not all</th>
<th>1 - 2 hours</th>
<th>3 - 4 hours</th>
<th>5 - 9 hours</th>
<th>10+ hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>29.</td>
<td>Walk</td>
<td></td>
<td></td>
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<tr>
<td>30.</td>
<td>Speak</td>
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<tr>
<td>31.</td>
<td>Read</td>
<td></td>
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</tr>
</tbody>
</table>
32. Giving Medications
33. Maintain medical appointments
34. Prepare meals
35. Groom/personal hygiene
36. Perform household task such as cleaning the house
37. Perform financial tasks such as paying bills
38. Commute with them in a public transport or drive
39. Others --__________________

D. Below is a list of the ways you might have felt or behaved in the last week. On a scale of 0-3 with 1 being “rarely” and 4 being “all the time”, check the column that may apply

<table>
<thead>
<tr>
<th>Item</th>
<th>Items</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Rarely or none</td>
<td>Some or little</td>
<td>Occasionally or</td>
<td>Mostly or all</td>
</tr>
<tr>
<td></td>
<td></td>
<td>of the time</td>
<td>of the time</td>
<td>moderately of the time</td>
<td>of the time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(less than 1 day)</td>
<td>(1-2 days)</td>
<td>(3-4 days)</td>
<td>(5-7 days)</td>
</tr>
</tbody>
</table>

41. I was bothered by things that usually
I did not feel like eating; my appetite was poor.

I felt that I could not shake off the blues even with help from my family or friends.

I felt I was just as good as other people.

I had trouble keeping my mind on what I was doing.

I felt depressed.

I felt that everything I did was an effort.

I felt hopeful about the future.

I thought my life had been a failure.

I felt fearful.

My sleep was restless.

I was happy.

I talked less than usual.
54. I felt lonely
55. People were unfriendly
56. I enjoyed life
57. I had crying spells
58. I felt sad
59. I felt that people dislike me
60. I could not “get going”

E. We are interested in how you feel about the following statements. Read each statement carefully and on a scale of 1-7 indicate if you very strongly disagree, strongly disagree, mildly disagree, are neutral, mildly agree, strongly agree, or if you very strongly agree with the statement.

<table>
<thead>
<tr>
<th>Item</th>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Very Strongly</td>
<td>Strongly</td>
<td>Mildly</td>
<td>Neutral</td>
<td>Mildly</td>
<td>Strongly</td>
<td>Very</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disagree</td>
<td>Disagree</td>
<td>Disagree</td>
<td>Agree</td>
<td>Agree</td>
<td>Strongly</td>
<td>Agree</td>
</tr>
</tbody>
</table>

61. There is a special person who is around me when I'm in need.

62. There is a special person with whom I
can share my joys and sorrows.

63. My family really tries to help me.

64. I get the emotional help and support I need from my family.

65. I have a special person who is the real source of comfort to me.

66. My friends really try to help me,

67. I can count on my friends when things go wrong.

68. I can talk about my problems with my family.

69. I have friends with whom I can share my joys and sorrows.

70. I have a special person in my life who cares about my feelings.

71. My family is willing to help me make
decisions.

72. I can talk about my problems with my friends.

E. Now we’re going to talk about some feelings you may be having in caring for your brother or sister. On a scale of 1-5, with 1 being “agree a lot” to 5 being “disagree a lot” please check the column that may apply to you.

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>No</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>Feelings either way</td>
<td></td>
<td></td>
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</table>

73. In general, I am able to handle most problems in the care of my brother or sister.

74. I can fit in most of the things I need to do in spite of the time taken by caring for my brother or sister.

75. Taking care of my brother or sister gives me a trapped feeling.
76. I get the sense of satisfaction from helping my brother or sister.

77. I am pretty good at figuring out what my brother or sister needs.

78. Helping my brother or sister has made me come closer to him or her.

79. My brother or sister is too demanding.

80. I feel reassured that as long as I'm helping my brother or sister, she is getting the proper care.

81. I feel that nothing I do seems to please my brother or sister.

82. I feel uncertain about what to do about my brother or sister.

83. I feel that I should be doing more for my brother or sister.

84. I feel that I can do a better job in caring for my brother or sister.

85. I really enjoy being with my brother or sister.

86. I feel that taking responsibility for my brother sister gives my self-esteem a boost.

87. I feel that my brother or sister’s pleasure over little things gives me pleasure.
88. My health has suffered because of the care I provide to my brother or sister.
89. I feel that I do not have enough time for myself because of the time I spend with my brother or sister.
90. I feel that my brother or sister shows real appreciation of what I do for him or her.
91. My social life has suffered because I have been caring for my brother or sister.
92. I'm very tired as a result of caring for my brother or sister.
93. I feel caring for my brother or sister gives more meaning to my life.
94. I feel that I will be unable to care for my brother or sister much longer.
95. I feel isolated and alone as a result of caring for my brother or sister.
96. I've lost control of my life because of caring for my brother or sister.
97. Caring for my brother or sister does not allow me as much privacy as I would like.
98. I feel uncomfortable about having friends over because of my brother or
sister.

99. The caring for my brother or sister has interfered with the use of space in
my home.

Below is a list of your abilities. On a scale of 1-5 with 1 being “low ability” and 5 being “high ability”, check the column that may apply. The term family member refers to your brother or sister with intellectual disabilities.

<table>
<thead>
<tr>
<th>Item</th>
<th>Caregiver empowerment statement</th>
<th>Very Low ability (1)</th>
<th>Somewhat Low ability (2)</th>
<th>Moderate ability (3)</th>
<th>Somewhat high (4)</th>
<th>High ability (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>I have good coping skills.</td>
<td></td>
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<tr>
<td>101</td>
<td>I know what can be done and cannot be done for my brother or sister</td>
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<tr>
<td>102</td>
<td>I know the ongoing care needs of my brother or sister</td>
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<tr>
<td>103</td>
<td>I know when I am experiencing emotional difficulties (e.g., depression and anxiety).</td>
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<tr>
<td>104</td>
<td>I know how to express my feelings.</td>
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<tr>
<td>105</td>
<td>I am knowledgeable of rehabilitation services in the community (e.g., vocational rehabilitation, independent living, and respite care).</td>
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<tr>
<td>106</td>
<td>I have a good sense of the rehabilitation potential (i.e., work and independent living potential) of my brother or sister.</td>
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<tr>
<td>107</td>
<td>I know how to access community support and resources.</td>
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<tr>
<td>108</td>
<td>I can handle frustration related to negotiating services for my brother or sister</td>
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<tr>
<td>109</td>
<td>I know when to rest and regain energy.</td>
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<tr>
<td>110</td>
<td>I know how to deal with negative emotions.</td>
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<tr>
<td>111</td>
<td>I know how to apply for government benefits related to the support of my brother or sister.</td>
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<tr>
<td>112.</td>
<td>I know how to obtain training from professionals to better care for my brother or sister.</td>
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<tr>
<td>113.</td>
<td>I know how to motivate my brother or sister to participate in community integration activities (e.g., attend a social support group).</td>
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<tr>
<td>114.</td>
<td>I can deal with the financial hardships.</td>
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<tr>
<td>115.</td>
<td>I am fine with the personal sacrifices I have to make.</td>
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<tr>
<td>116.</td>
<td>I know how to think positively.</td>
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<tr>
<td>117.</td>
<td>I know how to motivate my brother or sister to participate in recreational activities.</td>
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<td>118.</td>
<td>I have spiritual beliefs.</td>
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<tr>
<td>119.</td>
<td>I know how to find times to attend to my personal needs.</td>
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<tr>
<td>120.</td>
<td>I know how to maintain a positive outlook about life.</td>
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<tr>
<td>121.</td>
<td>I can modify my expectations about the rehabilitation of my brother or sister</td>
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<tr>
<td>122.</td>
<td>I know how to change my life role to adapt to the need of my brother or sister</td>
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<tr>
<td>123.</td>
<td>I know how to express my feelings and frustration.</td>
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<tr>
<td>124.</td>
<td>I know how to reward myself for a job well done.</td>
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<tr>
<td>125.</td>
<td>I know how to establish a support network for myself.</td>
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<tr>
<td>126.</td>
<td>I know how to obtain legal help for my brother or sister.</td>
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<tr>
<td>127.</td>
<td>I participate in the socio-political process to effect changes for people with intellectual disabilities.</td>
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<tr>
<td>128.</td>
<td>I know how to influence the political system to advance service and research agenda for people with intellectual disabilities.</td>
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<tr>
<td>129.</td>
<td>I know how to select the appropriate healthcare and rehabilitation service providers for my brother or sister.</td>
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</tr>
</tbody>
</table>

Thank you and I truly appreciate your participation. If you have further questions about this study please contact the student investigator, Mamta Saxena at mamta.saxena@uconn.edu or the principal investigator Anne.Farrell@uconn.edu.