8-2015

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Recommended Citation

Jenkins, Benjamin C., "The perceived impacts of disability on family by individuals with disabilities in VR services: A multivariate analysis" (2015). *Theses and Dissertations - UTB/UTPA*. 214.
https://scholarworks.utrgv.edu/leg_etd/214

THE PERCEIVED IMPACTS OF DISABILITY ON FAMILY BY INDIVIDUALS WITH DISABILITIES IN VR SERVICES: A MULTIVARIATE ANALYSIS

A Dissertation

by

BENJAMIN C. JENKINS

Submitted to the Graduate School of
The University of Texas-Pan American
In partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

August 2015

Major Subject: Rehabilitation Counseling

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August 2015

ABSTRACT

Jenkins, Benjamin C., The Perceived Impacts of Disability on Family by Individuals with Disabilities in VR Services: A Multivariate Analysis. Doctor of Philosophy (PhD), August, 2015, 209 pp., 16 tables, references, 97 titles.

The purpose of this study was to explore the perceptions of individuals with disabilities regarding the impact of disability on family as encountered in the literature. Despite an abundance of research and literature documenting the experience of disability in the family the individual with the disability has largely been excluded from this research. This study investigated perceptions of individuals with disabilities regarding the impacts their disabilities have on their family that have been documented in the literature. Specific demographic variables were examined to determine any differences in perceptions based on these variables. Lastly, the underlying concepts of the perceptions of individuals with disabilities on their family experiences were explored and compared to literary and theoretical conjectures on the topic.

The dependent variables observed in this study were the claims made in the literature regarding the physical, psychological, social, financial, and spiritual impacts of disability on family compiled into the Individual Perception of Family and Disability-Revised (IPFD-R) survey. The IPFD-R consisted of two likert-type scales of agreement and frequency. The independent variables consisted of select demographic variables. The study participants included 410 state VR clients predominantly from Oklahoma, District of Columbia, and Florida.

Descriptive and inferential statistical methods including Pearson's product moment correlation coefficient were employed to analyze data and respond to the stated research questions.

The overall results reveal that individuals with disabilities disagree or perceive that their disability never or rarely affects their family as documented in the literature. Analyses of participant perceptions point to significant social and financial/economic concerns for individuals with disabilities and their family. Based on the findings, implications will be offered for educators, practitioners, employers, and policy makers. Limitations of the study, future research and suggestions are also discussed.

DEDICATION

Yea, I know that I am nothing; as to my strength I am weak; therefore I will not boast of myself, but I will boast of my God, for in his strength I can do all things; (Alma 26:12).

Second only to God I dedicate this to my best friend and eternal companion Chayla Mae Jenkins. Words cannot express my affections sufficiently. No one could ever understand the sacrifices you made, or the compassion, support, understanding, and patience you gave to me during this journey. We did this! Also to my children Elena, Clayton, and Charlie: you've known seemingly little else of daddy but him sitting in front of a computer to this point in your young lives. Your hugs and kissies brought so much light to me during some very dark times.

A special dedication goes to my parents Jim and Kristine Jenkins who taught me in the ways of the Lord and encouraged me to "seek learning by study and by faith." Also, to my "twin-sister" who expressed an unconditional support and concern for my family and me during this daunting pursuit.

Lastly I dedicate this work to the memory of my dear friends Dr. Mark F. Kailing, and Dr. David E. Harrison whose philosophical mentorship were crucial to my embarking on this most rewarding journey.

ACKNOWLEDGEMENTS

"Nothing in the world can take the place of persistence. Talent will not; nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education will not; the world is full of educated derelicts. Persistence and determination alone are omnipotent. The slogan 'Press On!' has solved and always will solve the problems of the human race." –Calvin Coolidge

I would like to first thank Dr. Noreen Graf for her guidance, support, and patience. She made space for me at a time when it seemed that no one else would. She also challenged me to be a better professional. A special thanks also goes to my other committee members Dr. Paul Sale and Dr. Shawn Saladin for their encouragement, guidance, mentorship, and most of all friendship.

I want to thank the entire "Pan Am" rehabilitation department especially the staff. I am also grateful to Dr. Bruce Reed for his mentorship, Dr. Roy Chen being kind and for looking out for me, Dr. Eva Miller for believing in me, Dr. Charlene Blankenship for keeping an eye on me, and last but not least Dr. Irmo Marini for giving me a hard time. Special thanks to Dr. Ralph Carlson and Dr. Mike Millington ("The Professor") for teaching me and inspiring me in so many ways.

Lastly, I want to acknowledge my classmates who were down in the trenches with me. I owe a special shout out to Alicia Brown Becton who was constantly "fussing" at me to do my best and be on time.

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CHAPTER I

INTRODUCTION

Background of the Problem

There are approximately 56.7 million people living with some form of disability in the United States (Brault, 2012). The National Council on Disability (NCD, 2010) has reported there are roughly 35.1 million households with one or more members with a disability. This data coupled with the current 2.64 average member household size in America (U.S. Census Bureau, 2011) yields an estimated 92.6 million family members impacted by disability every day.

Disability is experienced most comprehensively within the space of the family system (Cottone, Handelsman, & Walters, 1986). At all stages of life, the onset of disability "creates challenges for the family, sometimes even to basic care obligations, depending on the resources available to, and the unique characteristics of, the members" (Glover-Graf, 2012, p. 169).

The predominant discourse families living with disability indicates that disability impacts families in many ways and across multiple domains. As an example, The National Alliance for Caregiving and The National Multiple Sclerosis Society (2012) reports that family members may experience: physical exhaustion and injury, depression and anxiety, social exclusion and isolation, job loss and financial disparity in connection to the disability of a loved one.

Despite the impacts of disability on the family reported in the literature, the response paid to family issues in rehabilitation counseling practice is generally lacking (Institute on Rehabilitation Issues, 2000). The field of rehabilitation counseling has evolved gradually over its approximate 60 year existence (Leahy, Rak, & Zanskas 2009), yet similar to the field of psychology, has often addressed family or significant other concerns as peripheral issues (Millington, 2012).

When attention is given to family issues related to disability, much of the research, policy, and practice regarding family and disability are often conceived exclusively within the framework of the traditional family (e.g., married mother and father with children; Glover-Graf, 2012). However, according to the 2010 U.S. Census, the traditional family has been steadily on the decline, and now represents only 20% of the US population (Lofquist, Lugaila. O'Connell, & Feliz, 2012).

Consequently, individuals and families with disabilities are frequently excluded from full community inclusion because they do not fit within the established socio-political norm that is the "traditional family" (Arriagada, 2002). As Millington (2012) stated: "Family is a complex living system of relationships beyond biological relatives to include anyone who lives with, has a substantial interest in, or influence over, [the person with a disability]" (p. 401). Therefore the definition of family in research and practice should be subject to the determination of each individual and the significance of the relationship within his or her system.

Statement of the Problem

Over time, literature on families with disabilities has focused on: a) the impact of disability on family functioning and b) the impact family functioning has on the disability

(Biegel, Singer, & Conway, 2012; Marini, 2012b; Rolland, 1994). However, the prevailing research fueling this discourse has relied on accounts given by family members (i.e. parents, siblings, and spouses) and by and large excluded the perceptions of the individual member of the family with a disability (Glover-Graf, 2012; Marini, 2012b; Rosenthal, Kosciulek, Lee, Frain, & Ditchman, 2009). Wright (1988) explained that the problem with rehabilitation and disability related research is that inferences and conclusions are based on outsider perceptions. In these cases, Wright explains that "the context is sparse or simplified, and the negativity of the problem dominates the train of thought" (p. 10). Olkin (1999) stated: "Certainly disability is a family affair, but the almost exclusive focus on the effect of the person with the disability on the family, and not the reverse, is emblematic of a pervasive perspective, that of the nondisabled looking at the disabled (pp. 47-48). Therefore, the specific problem addressed in the present study is the lack of inclusion of individual or insider perspectives regarding how their disability affects their family present in the literature.

Statement of Purpose

Family functioning and support have become recurrent topics in rehabilitation counseling practice and research over the years (Millington, Jenkins, & Cottone, 2015). Despite a plethora of research and literature documenting the experience of disability in the family (Glover-Graf, 2012) the individual with the disability has largely been excluded from this research. Therefore, the purpose of this study was to explore the impact of disability on the family from the perspective of the person with the disability and compare finding to the relevant literature in order to determine if differences exist in these two perspectives (family members and the member with the disability). To fulfill the purpose of the study, data was collected from VR participants in Oklahoma, District of Columbia, and Florida. The research variables of interest in the study are the perspectives family members with disabilities as measured by level of agreement or frequency to statements made about the impact of disability on family in the literature.

Research Questions

The purposes of research questions are to specify the goals of a study and to connect them to the research design, "communicate the purposes of the analyses, and facilitate replication of the results" (Rumell, 1988, p. 183). In response to the stated objectives the researcher sought to answer the following research questions regarding the perceptions of persons with disabilities (PWDs) toward the impact of disability on their family.

R_1 - How do PWDs perceive the impacts of disability on family?

a. What are the perceptions of individuals with disabilities regarding the physical impact of their disability on the family?

b. What are the perceptions of individuals with disabilities regarding the psychological impact of their disability on the family?

c. What are the perceptions of individuals with disabilities regarding the social impact of their disability on the family?

d. What are the perceptions of individuals with disabilities regarding the financial impact of their disability on the family?

e. What are the perceptions of individuals with disabilities regarding the spiritual impact of their disability on the family?

R_2 - Are there differences in PWDs perceptions of the impacts of their disability on the family based on demographic variables?

a. Is there a difference in perception of impact of disability on family based on gender?

b. Is there a difference in perception of impact of disability on family based on race/ethnicity?

c. Is there a difference in perception of impact of disability on family based on relationship status?

d. Is there a difference in perception of impact of disability on family based on employment?

e. Is there a difference in perception of impact of disability on family groups based on education?

f. Is there a difference in perception of impact of disability on family based on income?

g. Is there a difference in perception of impact of disability on family based on income source?

h. Is there a difference in perception of impact of disability on family based on disability?

R_3 - Are the perceptions of PWDs regarding health and quality of life related to their perception of the impact of disability on their family?

a. Is there a relationship in how PWDs perceive the impact of disability on their family based on their perception of their overall health?
b. Is there a relationship in how PWDs perceive the impact of disability on their family based on their perception of their quality of life?
c. Is there a relationship in how PWDs perceive of impact of disability on their family based on their perception of their families' quality of life?

Nature of the Study

A quantitative research design using survey research was used to explore the research questions stated above. Sample survey research is perhaps the most common research method employed in the social sciences today (Marsden & Wright, 2010). In fact, survey research is found to be the most utilized quantitative research design in empirical-based journals in rehabilitation counseling (Bellini & Rumrill, Jr., 2009). Surveys provide a numeric (quantitative) description of the trends, attitudes, or opinions within a given population (Fowler, 2014).

A review of the literature was conducted to search for instruments that examine the impact of disability on family from the perspective of the family member with a disability. A number of studies were encountered that document the impact of disability on families; however, these were targeted to solicit the perception of spouses who are caregivers of a loved one with a disability (Zarit, 2006), siblings of a loved one with a disability (Hodapp, Urbano, & Burke, 2010), or parents of children with disabilities (Blacher & Baker, 2007; Park, et al., 2003; Stein & Jessop, 2003; Stein & Riessman, 1980).

In absence of an instrument that met the objectives of this study, a survey, which was developed by this author for a previous pilot study, was chosen because it is based upon relevant literature regarding the impact of disabilities on families. This survey was distributed among adults with disabilities who were participants in public VR programs throughout the United States. In this way, participants were asked to indicate their perception of the impacts of disability on families that were identified in the literature.

Definition of Terms

Wilkinson (1991) noted, “scientists have sharply defined terms with which to think clearly about their research and communicate their findings and ideas clearly” (p. 22). The following terms are defined operationally as they are used throughout the study:

Burden: A perceived heavy load, liability, or affliction that often describes the effect a disability has on someone who does not have a disability (Olkin, 1999).

Caregiver: An individual who provides care for someone else who may not be able to care for their own personal needs. This person can be a professional, family, or friend (Family Caregiver Alliance, 2012).

Caregiver Burden: The physical, mental, social, and or financial impact of caring for someone who is unable to care for himself or herself (Leong, 2008).

Community: A group of people living in the same place or having a particular characteristic in common. Also, the experience of fellowship with others, as a result of sharing common attitudes, interests, and goals (Community, n.d.; see also Cohen, 2013).

Disability: A physical, mental, sensory or communicative condition that in some way limits a person's movements, senses, or activities (Disability, n.d.; see also Bagenstos, 2015).

Endogenous: A trait or characteristic that has an internal origin or cause (Pfister, Kiesel, Thomaschke, & Janczyk, 2012).

Exogenous: A trait or characteristic that has an external origin or cause (Pfister, Kiesel, Thomaschke, & Janczyk, 2012).

Family: A group of individuals who consider themselves family regardless of blood, marriage, or formal union, who care for, support, and interact with one another frequently (Turnbull, et al., 2000).

Financial Impact: The influence or effect on an individual or entity relating to monetary or material well-being by some other force or being (Garner, 2014).

Fundamental Negative Bias: The attitude or predisposition of individuals or groups toward people with disabilities that is perceived as negative or bad (Wright, 1988).

Impact of Disability: The influence or effect on an individual or entity relating to or imposed upon by disability (see also *Caregiver Burden*).

Insider: A person within a group, experience, or community, especially someone privy to information unapparent to others (Insider, n.d.).

Mental Disorder: A chronic and pervasive condition affecting thought, emotion, and or behavior (American Psychiatric Association, 2013).

Outsider: An individual or entity without a group of interest whose experiences or information is of curiosity, concern, or importance (Outsider, n.d.).

Perception: The cognitive process of identification, interpretation, and organization of information in order to understand the environment (Schacter, Gilbert, & Wegner, 2011).

Physical Disorder: A chronic and pervasive condition of bodily function that results, in some way, in impaired activities of daily living (e.g. bathing, eating, walking, etc.; U.S. Department of Education, 2013; Wiener, Hanley, Clark, & Van Nostrand, 1990).

Physical Impact: The influence or effect on an individual or entity in terms of bodily function by some other force or being (Schulz & Sherwood, 2008).

Psychological Impact: The influence or effect on an individual or entity in terms of mental or emotional function by some other force or being (Schulz & Sherwood, 2008).

Reciprocal Transactions: An exchange or interaction between individuals or entities that is cyclical in nature (Bandura, 1978).

Rehabilitation Counselor: A professional who specializes in the experience of and adaptation to disability (Commission on Rehabilitation Counselor Certification, n.d.).

Rehabilitation Process: A method or pathway toward adaptation and achievement in the experience of disability (Rubin & Roessler, 2001).

Sensory/Communicative Disorder: A condition of bodily function that results, in some way, in impaired hearing, balance, smell, taste, voice, speech, and/or language (U.S. Department of Education, 2013).

Capital: Referring to wealth or possessed value of interest for the purpose of exchange within a community (Hobfull, 2001).

Social Impact: The influence or effect on an individual or entity in terms of community interactions or civic functioning by some other force or being (Lewin, 1946).

Spiritual Impact: The influence or effect on an individual or entity in terms of faith or religious belief by some other force or being (Kaylayjian, Kanazi, Aberson, & Feygin, 2002).

Vocational Rehabilitation: A public (government) entity charged with the resources and responsibility to assist individuals with disabilities to prepare for, enter into, engage in, and maintain gainful employment in an integrated environment (Spitznagel, 2013).

Assumptions

The following assumptions were considered fundamental in this study. Every reasonable measure was taken to ensure objectivity and representation of the field of study. Lunenburg and

Irby (2008) defined assumptions as “postulates, premises and propositions that are accepted as operational for the purposes of the research” (p. 135).

1. Individuals who participated in the research study were aware of the vocabulary used throughout the questionnaire.
2. Individuals who participated in the research study responded honestly and to the best of their ability.
3. The researcher was unbiased and the interpretation of the survey results accurately reflects the perspectives of individuals who participated.
4. The participants shared perspectives about the impact of disability on family, and survey responses revealed an area of knowledge to add to the body of literature.

Limitations and Delimitations

The responses in this study may not accurately reflect perceptions of all individuals with disabilities. The distribution of the survey questionnaire was limited to individuals with disabilities who are clients of participating state VR agencies. Results were limited to assessing the answers to the research questions as previously stated. The study was limited by the nature of participants receiving the electronic questionnaire from the administrative assistance at participating VR agencies.

This research study had the following delimitations:

1. The sample for this study was delimitated to clients of VR agencies that opted to participate in this research.
2. This study was delimitated to the use of an online survey instrument for data collection.
3. This study was delimitated to a period of data collection that took place from July 15, 2014 to October 31, 2014.

4. This study was delimitated to particular geographical regions: Oklahoma, Florida, and District of Columbia.
5. This study was delimitated to participant voluntary participation.

Summary

When family members are counted, an estimated 92.6 million people daily experience disability in the United States. According to the literature, experiences of disability within the family are laden with challenges that can affect every facet of family life (Glover-Graf, 2012). Family members reportedly experience physical exhaustion and injury, depression and anxiety, social exclusion and isolation, job loss and financial disparity in connection to the disability of a loved one (National Alliance for Caregiving & National Multiple Sclerosis Society, 2012). In light of these struggles, rehabilitation counseling policy and practice often exclude family participation in the process because it is perceived as too complex and a liability to successful outcomes (Millington, 2012). Similarly, research regarding the impact of disability on the family has excluded the perspectives of individuals with disabilities. A study of the impacts of disability on family as perceived by individuals with disabilities may serve well to influence research policy and practice that is more inclusive of individuals and family members with disabilities. This may, in turn, result in more productive rehabilitation outcomes for individuals, families, and professionals.

The following chapters will describe in detail the tenets, procedures, and outcomes of this study. Chapter two will document the literature reviewed and present the theoretical framework for this study. Chapter three will describe the methods used to test the research questions. Chapter four will report the results obtained from the study. Finally, chapter five will discuss the results as they relate to the questions proposed in this study.

CHAPTER II

REVIEW OF THE LITERATURE

The purpose of this study is to examine the impact of disability on the family from the perspective of the person with the disability. The following chapter is a review of the literature and theory as it pertains to individuals and families in the experience of disability. This chapter lays the groundwork for the study through a review of published literature by focusing on: (a) the experience and support of family in disability; (b) the impact of disability on family; and (c) theoretical framework to support the study.

Introduction

Every family in the world experiences disability at some point in life (Rolland, 2012). Its arrival is often unexpected and almost always a challenge to the family system (Vash & Crew, 2004). As it resonates through the family, disability becomes the arbitrator and object of family behavior (Millington, 2012). Experiences vary greatly depending on multiple factors such as who in the family has the disability and the nature of the relationship to that person, socioecomic status, education, community attitudes toward disability, etc. Accordingly, family roles are often challenged and family functioning and relationships can change with the nature or condition of the disability (Olkin, 1999) that can outpace the family's ability to adapt (Walsh, 2006).

These changes can also affect the relationship the family has with their community. Previous relationships with others outside the family circle may change and/or diminish and the family eventually associates with others in the experience of disability (Millington, 2012). Eventually the disability becomes a part of the family identity (Olkin, 1999).

In this experience, the family can be its own greatest source of support for both individual and collective well-being (Rolland, 2012). This sense of well-being or resilience largely depends on the family's ability to adapt or adjust to the disability (Walsh, 2006). Power and Dell Orto (2004) suggest that positive family adjustment to disability depends on the following seven factors:

1. *Risk factors* involves adequate external support systems, conflict within the family, blame and criticism, family composition (e.g. single parent or divorced spouse), and persistent external stress.
2. *Protective factors*, which consists of effective communication and problem solving skills, time for self-care and family recreation, and satisfying community and social connections.
3. *Belief systems* can involve the family's understanding of disability, comprehension of the process of change, cultural and religious connections, and spiritual beliefs and practices.
4. *Availability of coping resources* can include family personality strengths such as an optimistic attitude, previous life experiences, satisfying vocational pursuits, support from extended family members or fictive kin, anticipation of and involvement in community resources (e.g. self-help groups), and financial resources.
5. *Previous family history* takes into consideration the physical and mental health of other family members, and how the family has coped with crisis and loss in the past.

6. *Family communication styles and interactive relationships* should be nurturing, well structured, open to differences in ideas and opinions, willing to listen, and able to express feelings without concern for criticism.
7. *Who is ill or disabled in the family system* can determine the degree of adaptation charged on the family. The disability of the principal household earner or caretaker tends to have a greater impact than the disability of a child, sibling, or extended family member.

Historical Overview of The Literature

The literature on families with disabilities has historically focused on: a) the impact of disability on family functioning and b) the impact family functioning has on the disability (Biegel, Singer, & Conway, 2012; Marini, 2012b; Rolland, 1994). However, the prevailing research fueling this discourse has focused on the accounts given by family members (i.e. parents, siblings, and spouses) and excluded the perceptions of the individual member of the family with a disability (Freedman & Fesko, 1996; Rosenthal, Kosciulek, Lee, Frain, & Ditchman, 2009).

In a post hoc study of American's with disabilities Franklin (1977) described marital and familial relationships among individuals with disabilities as less stable and more likely to dissolve when compared to those without disabilities. She further noted that educational, vocational, and economic resources were more limited for family members of an individual with a disability than those families without a loved one with a disability. Lastly Franklin indicated that families with disabilities collectively were more likely to experience social isolation than those without disabilities.

In a longitudinal study among married couples in the U.S. (n = 819) Beach, Schultz, and Yee (2000) found that spouses of individuals with a disabilities reported higher levels of stress and steeper physical and mental health declines over time than couples without disabilities. Similarly, the National Alliance for Caregiving and The National Multiple Sclerosis Society (2012) conducted a study among family caregivers and found that a substantial proportion of respondents “suffer from depression” (p. 10), have sustained physical injuries, and lost a job resultant from caring for a loved one who has a disability.

Although the impacts of disability on family documented in the literature are numerous and severe family functioning and support have been documented as deterministic and beneficial factors in rehabilitation outcomes (Lindenberg, 1977; Kelly & Lambert, 1992; Millington, 2012; Pederson & Revenson, 2012). Studies dating as far back as the late 50’s and early 60’s document that active family support were conducive to employment outcomes among adults with disabilities (McPhee & Magelby, 1960; Neff, 1959). On the other hand, researchers also discovered that dysfunction within the family system could also impede rehabilitation progress including employment (Klausner 1969; Rosenstock & Kutner, 1967).

Burgess and colleagues (1987) found in their study among 180 adults hospitalized for cardiac complications that family well-being and support was negatively associated with length of hospitalization and medical intervention. Similarly, in their study among adults with type II diabetes (n = 61) Mayberry and Osborn (2012) concluded that informed family support was associated with treatment adherence and improved glycemic control. Of course researchers also found that non-compliance with treatment and glycemic dysfunction were associated with unsupportive family behaviors.

Amidst the abundance of accounts about the experience of disability within the family there exists a dearth of literature and research that includes the perception of the individual with the disability. Dembo, Leviton, and Wright (1975) observed the excess of research and literature on disability matters conducted from the perspective of people without disabilities or “outsiders”. Such an approach contributes to detrimental attitudes and beliefs that persons with disabilities are “handicapped”, “disabled”, and otherwise a burden on others (Olkin, 1999).

This imbalance of perspectives and the exclusion of the “insider” or persons with disabilities also perpetuates what Wright (1988) describes as the fundamental negative bias. Dembo (1964; 1977) has repeatedly called for a balance of perspectives in rehabilitation research that is inclusive of individuals with disabilities. In spite of this, Freedman and Fesko (1996) discovered in their review of literature regarding individuals and families with disabilities in pursuit of employment “there [persists] a scarcity of research in the vocational rehabilitation field based upon the perspectives of people with disabilities” (p. 49).

Impact of Disability on Family

The impact of disability on family describes the apparent outcomes experienced by family members individually and collectively (positive or negative) related directly or indirectly to the experience of disability (Summers, et al., 2005). While some researchers strive to accentuate the positive outcomes of disability within the family system, historically most studies have emphasized the negative consequences (Olkin, 1999; Wright B. , 1988) including (but not limited to) marital, financial, social, emotional, psychological, and physical problems.

The literature regarding the impacts of disability on family reviewed for this study is divided into five domains: (a) Physical; (b) Social; (c) Psychological; (d) Financial; and (e)

Spiritual (Glover-Graf, 2012; Marini, 2012a; 2012b; 2012c; Marini & Stebnicki, 2012; Millington, 2012; Rosenthal et al., 2009; Walsh, 2009). The studies examined document perception of spouses who are caregivers of a loved one with a disability (Zarit, 2006), siblings of a loved one with a disability, and parents of children with disabilities (Blacher & Baker, 2007; Stein & Jessop, 2003; Stein & Riessman, 1980).

Physical Impact

The physical impact of disability on the family refers to any benefit or detriment to the physical wellbeing of family members related to the disability of a loved one. Family members are reported to be at risk for generalized physical ailments (e.g., acid reflux, headaches, bodily injury; National Alliance for Caregiving & Evercare, 2006), diminished immune response (Kienecolt-Glaser, Dura, & Speicher, 1991), increased risk of heart disease (Lee, Colditz, Berkman, & Kawachi, 2003) and mortality (Schulz & Beach, 1999) associated with the disability of a loved one. The physical impact of disability on the family is most commonly documented in literature focused on parents of children with disabilities and family caregivers.

Physical impact of parents of children with disabilities. An estimated 8.5% of all children in the U.S. have a disability (Brault, 2012). Estimates of households with at least one child with a disability range from 13% to 20% (Bethell, Read, Blumberg, & Newacheck, 2008). In a qualitative study of health conditions among parents with children with disabilities (n = 40) Murphy, Christian, Caplin, and Young (2007) found that more than half of participants (n = 22) reported worsened physical health over the past year resultant from care of their child with a disability. Furthermore, almost all participants reported chronic fatigue and sleep deprivation and most attributed one or more chronic physical ailments (e.g. back and shoulder pain) to care of their child with a disability.

Physical impacts of family caregivers. A nationwide study of family caregivers indicates that 42.1 million caregivers age 18 or older provide an average of 18.4 hours of care per week to care recipients age 18 or older. (Feinberg, Reinhard, Houser, & Choula, 2011). The National Alliance for Caregiving and The National Multiple Sclerosis Society (2012) conducted a study on family caregivers and found that nearly a third of respondents reported a physical injury as result of caring for a loved one with a disability. Furthermore, almost half of participants reported being physically exhausted and approximately 20% reported getting sick more frequently as a result of providing care.

Other studies indicate that family caregivers struggle to have time to care for their own physical well-being due to the demands of caring for a loved one with a disability. Buchanan, Radin, Charkravorty, and Tyry (2009) found that 51.5% of family caregivers struggled to find time for themselves and over 45% struggled to manage their physical and emotional stress resultant from caregiving. In their national survey among family caregivers (n = 528) Evercare and The National Alliance for Caregiving (2006) reported that 51% of participants said they are unable to see a doctor as often as they should because of the time required in the care of a loved one with a disability.

Psychological Impact

The literature regarding the psychological impacts of disability on family describes emotional and cognitive challenges of family members in response to the disability of a loved one (Vash & Crew, 2004). In a longitudinal study conducted on family response to acquired disability, Brooks, Campsi, Symington, Beattie, and McKinlay (1986) reported that family members experienced steadily increasing levels of psychological strain and distress over time. Evercare and the National Alliance on Caregiving (2006) reported in their study that 91% of participants experience depression resultant from care of a loved one with a disability. Furthermore, 81% say caregiving makes their depression worse. Lastly, results from this study indicate that time spent giving care increases the likelihood and severity of depression.

A longitudinal study on siblings of individuals with disabilities indicated that individuals who have an adult brother or sister with a disability are more likely to experience a major depressive episode in their lifetime when compared to those who do not have a sibling with a disability. As well, the experimental group reported an overall lower psychological well-being than those in the control group (Taylor, Greenberg, Seltzer, & Floyd, 2008).

Hartley, et al. (2010) studied divorce rates among families with disabilities. They found that divorce rates among families with disabilities was higher than families without disabilities (23.5% vs. 13.8%). Kersh, Hedvat, Hauser-Cram, and Warfield (2006) concluded that couples with children with disabilities in their study experience lower marital quality than the general population. Conversely, Norlin and Broberg (2013) found that there was no difference in marital quality among parents with disabilities in their study (n = 104) versus the control group (n = 319).

Aunos, Feldman, and Goupil (2008) noted mothers of children with disabilities had clinically significant levels of stress and overall poorer mental health compared to population norms. Feldman and Walton-Allen (1997) observed in a small sample study that children of mothers with disabilities showed reports of lower academic achievement and increased behavioral problems. Mazur (2008) interviewed 19 families where one parent has a disability and at least one adolescent child. Using a list of disability-related events (e.g. My parent with a disability asked me to retrieve something for him/her) adolescent children were asked to rate their experience as positive, negative, or neutral. Overall adolescents regarded experiences with their parent's disability as positive three times more than negative. However, correlation analyses revealed that negative appraisal of parent disability correlated significantly with self-reported depression and lower self-esteem.

Social Impact

The social experience of disability resonates through the family system (Marini, Glover Graf, & Millington, 2012). For family members, prevailing negative attitudes and beliefs about disability continue to result in missed opportunities, isolation, guilt, and public shame (Lefley, 1989; Olkin, 1999; Rolland, 1994).

A study by Kozloff (1987) on the social support of individuals and families with disabilities revealed that families tend to lose "social standing" (p. 14) and become increasingly isolated over time following the onset of disability. More recently Green, Davis, Karshmer, Marsh, and Straight (2005) conducted a qualitative study on the experience of stigma among families with disabilities. Participants in the study reported similar experiences of discrimination, blame, stigma, and isolation. For example a mother with a child with a disability would receive a comment like, "For God's sake aren't you spoiling that child. She's too big to be carried" (p. 206). The authors concluded such attitudes lead to feelings of depression and social isolation.

In a study on husbands of breast cancer patients Bigatti and colleagues (2011) found that the majority of participants felt isolated leading to depression in many cases. In a large recent study on family caregivers, researchers found that a majority of respondents reported that they experienced social isolation because they did not have time to socialize with anyone outside of service providers (Anderson, Larson, & Wuorio, 2011).

Though the majority of the literature documents the negative social impacts of disability on the family, some positive aspects have been documented in the form of family cohesion and closeness. For example, Mazer (2006) found overall high levels of family cohesion due to increasing emotional bonds attributable to the disability of a loved one. Similarly in a nation-wide online study (N = 421) for family caregivers of a loved one with a disability, 59% of respondents reported that helping care for their loved one brought the family closer together (National Alliance for Caregiving & National Multiple Sclerosis Society, 2012).

Financial Impact

The financial experience of disability and family, as documented in the literature, generally tells of penury, disadvantage, and indigence (Kyzar, Turnbull, Summers, & Gomez, 2012; Park, Turnbull, & Turnbull, 2002). For example households in America with one or more persons living with a disability are 2.5 times more likely to report extremely low income compared to households without disabilities (National Council on Disability, 2010). Financial burden for families with disabilities is attributed to increased cost of care and to unemployment/reduced employment (Cottone, 2012; Hakim et al., 2000; Marini, 2012b; McMordie & Barker, 1988).

A recent report on family caregiving estimates the overall value of unpaid care for family members with a disability in the U.S. to be $450 billion (Feinberg, et al., 2011). In a national study on families of individuals with developmental disabilities (N = 5287) researchers found that 67% of respondents felt they could not pursue work/career goals due to caretaking responsibilities. Furthermore, 80% agreed that they did not have the resources to pay for care (Anderson, Larson, & Wuorio, 2011). Another study revealed that more than three in ten family caregivers had to get a second job or work more hours to cover caregiving costs (Evercare, & National Alliance for Caregiving, 2009)

The World Report on Disability (World Health Organization, 2011) revealed households with disabilities incur greater pecuniary expenses than those without disabilities. Yeo and Moore (2003) posited that conditions of disability leads to poverty and conditions of poverty lead to disability. They suggest that conditions of poverty translates globally to: (a) limited access to education and employment; (b) limited access to land and shelter; (c) poor sanitation; (d) excluded from political/legal process; (e) limited access to healthcare; and (f) insufficient or unhealthy food. These conditions ultimately lead to a higher risk of illness, accident, and impairment. Conversely they propose that global conditions of disability translate to: (a) fewer skills; (b) low self-esteem; (c); lack of ability to assert rights; and (d) poor health/physical impairment. These conditions lead to reduced income generating opportunities which ultimately leads to chronic poverty.

Spiritual Impact

Spirituality plays an important role in the lives of families with loved ones with a disability (Postin & Turnbull, 2004). Spirituality and religion are prevalent topics in social, health, and disability related studies. Spiritual beliefs and practices are determining factors in family resilience and well-being (Walsh, 2009).

Spirituality and religion. The discourse regarding the definition of spirituality and religion (S/R) yields mixed results. In many cases S/R are used interchangeably (Glover-Graf, Marini, Baker, & Buck, 2007; Selway & Ashman, 1998). However, a growing body of literature indicates that the two concepts seem to overlap in meaning and importance but are very different in belief and practice (Marini & Glover-Graf, 2010). Philips (2003) explained that spirituality refers to "intrinsic personal beliefs and practices that can be experienced within or without formal religion" (p. 249). Religion is described in the literature as a socio-behavioral practice of belief or spiritual orientation (Selway & Ashman, 1998).

Research on the health related benefits of S/R is ineed vast (Miller & Thoresen, 2003). For example Holt-Lunstad, Steffen, Sandberg, and Jensen (2011) found that S/R practices are directly linked to lower cardiovascular risk factors. In a longitudinal study Koenig and Valliant (2009) found S/R beliefs and practices led to lower stress and depression levels across the lifespan of participants.

Conversely, however, some research indicates that S/R beliefs and practices can have negative consequences on ones health or well-being. Exline, Yali, and Sanderson (2000) found that religious strain or spiritual struggle was associated with increased depression and suicidality. Similarly, in a sample of individuals with cardiovascular disorders, Park, Brooks, and Sussman (2009) found spiritual struggle at baseline to predict higher depression, and decreased levels of self-efficacy at 6 month follow up.

Family spirituality. Spirituality is believed to be as impacting and relevant within the family as it is for the individual (Walsh, 2009). Tanyi (2006) noted that family spirituality is described in the literature as "the search for meaning and purpose in life, meaningful relationships, individual family member spirituality, family values, beliefs, and practices, which may or may not be religiously based, and the ability to be transcendent" (p. 287). She further explained that "family spirituality can be much broader than individual spirituality, as it encompasses individuals' distinct spirituality and that of the family unit" (p.287).

Research reveals that spiritual belief and practice in the family is conducive to overall family resilience, functioning, and well-being across the life-span (Postin & Turnbull, 2004; Walsh, 2009). For example, multiple recent studies have found a positive association in shared spiritual beliefs/practices and marital satisfaction (Ellision, Burdette, & Wilcox, 2010; Fincham & Beach, 2010; Mahoney, 2010; Wolfinger & Wilcox, 2008).

In addition to influencing couples relationships, spirituality is known to have an impact on parent-child relationships and health (Walsh, 2009). Marks (2006) found that spiritual beliefs and religious practices tend to improve parent-child communication and overall relational satisfaction. In a longitudinal study Carothers, Borkowski, Lefever, and Whitman (2005) found that children of young mothers with high levels of S/R involvement reported lower levels of depression and higher levels of developmental adjustment.

Spirituality and disability. A growing body of research has emerged in the past 10 to 15 years documenting the experience of S/R for individuals with disabilities. The overall discourse on the subject is that spiritual beliefs and practices among individuals with disabilities is conducive to effective coping and adaptation to disability (Doherty, 2009; Marini I. , 2012c). Glover-Graf, Marini, Baker, and Buck (2007) reported that the majority of individuals with chronic pain agree that their spiritual beliefs contributed to coping with pain as well as an increase in happieness overall. Similarly, in their study of spirituality among persons with spinal cord injury, Marini and Glover-Graf (2011) found that 72% of participants reported that their spritual beliefs/practices gave them a greater sense of purpose. Furthermore, 62% agreed that their injuries were part of a higher purpose in life.

Despite the multiple reports of postitive effects of S/R in the experience of disability, not everyone has positive experiences with S/R . Both Glover-Graf et al. (2007) and Marini and Glover-Graf (2011) found that a minority of participants believed that their disability was a punishment from God and were angry or resentful with God for having a disability.

Family spirituality and disability. The experience of spirituality for families with disabilities is much broader than experiences of individuals with disabilities as it encompases the encounters of all proximally involved (Tanyi, 2006; Walsh, 2009). Families tend to rely on spiritual traditions and beliefs to interpret disability, especially where other information may not be available (Zhang & Bennett, 2001).

In a qualitative study on family well-being among families with disabilities Poston and Turnbull (2004) found multiple themes of S/R emerge in the experience of disability such as: (a) having faith; (b) finding meaning; and (c) religious participation. Most participants in the study indicated that they relied on God to help them understand and cope with their disability related experiences. Many suggested that having a child with a disability was a gift from God. Some viewed this gift as a blessing and others as a test of their faith. Many indicated that religious participation was a strong source of community inclusion. However, some families remarked that their loved one with a disability was not fully accepted within their religious community and this constituted a barrier to the families' participation.

While S/R impacts families with disabilities, the family can have an important effect on the spiritual experiences of individuals with disabilities (Walsh, 2009). In their study of the spiritual experiences of individuals with spinal cord injuries Marini and Glover-Graf (2011) found that participants who lived with family expressed greater agreement that they considered themselves a spiritual person than those living alone or with non relatives. Also, those living with family seemed to agree more that God helped them find meaning or purpose in their lives than those living alone or single. Married participants tended to value their relationship with God or a spiritual power more than single people. Likewise, married persons agreed more strongly that God was a source of happiness than did single participants.

Although most studies indicate an overall positive impact of spirituality on families with disabilities, the discourse on culturally diverse families with disabilities seems to accentuate negative S/R perceptions of disability (Millington, 2012b). For example, many have stated that hispanic/latino families perceive disability as a curse or a punishment from God (Lynch & Hanson, 2011; Smart & Smart, Acceptance of disability and the Mexican-American Culture, 1991). However, Glover and Blankenship (2007), discovered in their study of Mexican and Mexican American beliefs about God in relation to disability that a majority of participants believe that disability is not a curse or a punishment from God. Furthermore, overall, participants indicated that God is a beneficient, and helpful entity toward individuals and families with disabilities.

Theoretical Foundations

The experience of disability is a complex phenomenon with a multiplicity of conditions and factors. Historically, disability has been conceptualized as an individual experience with physical or psychological debilitations (Smart & Smart, 2006). Rehabilitation counseling, however, has fostered an integrated concept of disability as a product of individual, social, and environmental factors since its inception (Dembo, Leviton, & Wright, 1975; Marini, 2012b; Millington, 2012).

While rehabilitation counseling has successfully conceptualized disability within an integrated framework, understanding family in the experience of disability has proven a more perplexive matter (Millington, et al., 2015). Accordingly, this section will present multiple theories pertinent to the experience of disability within the family; upon which this study is grounded. Theories considered in this study are: (a) Lewin's (1935; 1946; 1951) theories of social psychology; (b) McCubin and Patterson's (1983) model of family stress, coping, and adaptation; (c) Bowen's (1965; 1966: 1976) family systems theory; and (d) Cottone's (2012) family systems model in rehabilitation counseling.

Social Psychology

Kurt Lewin is known for profoundly changing the landscape of psychology by turning the focus of human function/dysfunction away from individual and biological traits to social and environmental factors that ultimately contribute to social change (Burns, 2004). Lewin's theories have also been credited as the foundation and catalyst for contemporary rehabilitation counseling values, practices, and theories (Dembo, 1964; Dembo, Leviton, & Wright, 1975; Marini, 2012b; Millington, et al., 2015; Wright B. A., 1983). Lewin is best known for his field theory (Lewin, 1935), which posits that individual behavior (B) is a function of the person (P) interacting within their environment (E) [$B=f(PxE)$]. However, field theory only explains a singular aspect of Lewin's overarching theory of social change that can only be understood in the aggregate of his works, which include: (a) field theory; (b) group dynamics; and (c) action research (Burns, 2004).

Field theory. Lewin intuited that individual adaptation was neither a matter of nature nor of nurture but rather dependent on an interaction between the person and his environment. That is to say that self-concept is derived of both endogenous and exogenous factors. This phenomenon was expressed by Lewin's (1936) formula, individual behavior (B) is a function of the person (P) interacting within the environment (E), or $B=f(PxE)$. This theory demonstrated that an individual's behavior or adaptation to the world did not occur in isolation or in a linear pattern, but rather is contingent upon the reciprocal interaction of an individual and factors in his or her environment. Wright (1983) applied Lewin's field theory to rehabilitation counseling explaining that both individual and family adaptation to disability is a function of individual and environmental factors in a very systematic or reciprocal manner.

Group dynamics. Merriam-Webster's dictionary (n.d.) defines the term dynamic as "of or relating to energy, motion, or physical force" (para. 1). Lewin (1939) stated that "…it is not the similarity or dissimilarity of individuals that constitutes a group, but interdependence of fate" (p. 165). As a pioneer of systems thinking Lewin (1939) perceived change in terms of group behavior. He argued that change at the individual level is unproductive, as individuals exist as part of an interconnected network or group not in a vacuum. Therefore change occurs in the form of reciprocal transactions negotiated between individuals and groups. Millington, Jenkins, and Cottone (2015) explain that in accordance with Lewin's theory individuals with disabilities negotiate change, function, and participation within the context of family and community.

Action research. Aware of the reciprocal nature of groups and the tendency to resist change, Lewin (1946) formulated a method called action research whereby members of a group or community might engage in and develop means for change that is meaningful to them. Action research was conceptualized in an effort to empower minority groups to effectuate change under majority social pressure. Under such pressure, Lewin (1946) identified that oppressed groups experience ambiguity with regards to: (1) the present problem; (2) evaluation of risks of change or stagnation; and (3) how to change and move forward; thus inhibiting progress.

Weary of society's natural draw toward homeostasis despite efforts of change or progress, Lewin (1947) devised a three-step model of change that represents the culmination of his theories. The first step involves "unfreezing" or destabilizing present beliefs and behaviors. The second step is "moving" or changing unproductive beliefs or actions toward more constructive means. Lastly, a process of "refreezing" must ensue so as to stabilize new beliefs and behaviors that are congruent with the change and reduce regression toward the problem.

Individual and familial perceptions of disability are subject to the prevailing scripts written by larger society, which tends to govern change (Goffman, 2009). The modern disability movement implements a "Lewinian" approach that includes individuals and families and disability in change in terms of research, policy, and practice (Dembo T. , 1982; Dunn, Uswatte, Elliott, Lastres, & Beard, 2013).

Family Stress Model

The family stress model is commonly encountered in the literature to explain the family experience of disability (Boss, 2001; Conger, et al., 2002; Glover-Graf N. , 2011; Hastings & Taunt, 2002; Lustig, 2002; Patterson & Garwick, 1994; Rosenthal, Kosciulek, Lee, Frain, &

Ditchman, 2009). Also known as the ABCX model (Hill, 1949; 1958) and later the Double ABCX model (McCubbin & Patterson, 1983) the family stress models purport predictable stages of family response to crisis.

ABCX model. Acknowledged as the father of family stress theory (Boss, 2001), Reuben Hill (1949; 1958) introduced the ABCX model to describe "the crisis-proneness and freedom from crisis among families" (Hill, 1958, p. 143). The ABCX formula explains family variables as they contribute to crisis in a linear fashion. The *A* refers to the stressor or the precursive event that Hill (1958) described as "a situation for which the family has had little or no prior preparation and must therefore be viewed as problematic" (p. 139). This leads to *B*, which considers the family's available resources in managing the activating stressor. These resources are generally considered emotional but can also be material such as finances. The availability of these resources can determine whether or not a state of crisis ensues. The final consideration in determining the eminence of crisis is the family's perception of the event represented as *C*. According to Hill (1958) if the family's resources are heavily taxed then their perception of the precipitous event will likely be one of calamity; triggering the final stage (*X*), being crisis. Hill (1958) explained that this stage of crisis often results in challenged family roles and chaotic interaction patterns that can have adverse and potentially permanent impacts on family relationships.

Hill's concept of family stress and crisis was criticized as being laconic, linear, and deterministic; examining only inauspicious variables (Boss, 2001). In response, McCubin and Patterson (1983) expanded Hill's model by integrating post-crisis variables and examining conditions of recovery as opposed to focusing on crisis. This expansion resulted in the formation of the Double ABCX model.

Double ABCX. McCubin and Patterson's (1983) model mirrored Hill's ABCX model variables. Following Hill's crisis variable (*X*) McCubin and Patterson's model continued on with *aA*, which represents a pileup of stressors as fallout from the preceding crisis. McCubin and Patterson explained that following the pileup families in crisis have a tendency to take inventory of existing resources (*b*) and then begin to identify new resources (*B*) that help the family prevail beyond the crisis. This process leads to a cognitive reconciliation of the culmination of previous events (*cC*) resulting in the attribution of meaning in the present. If the process of *cC* yields a positive impression of the present then balanced family interactions are observed or *bonadaption* in terms of *xX*. If this reckoning produces a negative perception of previous events and current situation then *maladaptation* occurs resulting in continued imbalance in familial transactions.

Family Systems Theory

Bowen (1966; 1976) posited that disability is experienced inseparably within the context of the family. Bowen's family systems theory was nascent of his experiences working with individuals and families with schizophrenia. In his theory he explains the experience of disability as a counterpoise of individualism and community within a network of relationships that constitutes the family (Nichols & Schwartz, The essentials of family therapy, 2005). Six interconnecting constructs form the basic framework of the theory: (1) family emotional process; (2) triangles; (3) multigenerational transmission process; (4) emotional cutoff; (5) societal emotional process; and (6) differentiation of self.

Family emotional process. The family emotional process refers to Bowen's (1966) belief that family members interact in systemic predictable ways in an effort to establish homeostasis or emotional stability. In this pursuit, he described the development of what he called the “undifferentiated family ego mass” (p.66) or an emotional fusion among family members that results in emotional reactivity, especially in response to change. Families who experience disability have a tendency to become emotionally enmeshed or undifferentiated in response to the disability (Glover-Graf, 2011). This can result in physical or psychological dysfunction in one or more family members or exacerbation of the disabling condition, as well as relationship conflict, and ultimately emotional distancing or cutoff (Nichols & Schwartz, The essentials of family therapy, 2005).

Triangles. Bowen (1966; 1976) exemplified stress within a family between two people or a dyad (e.g. husband and wife). He explained that stressful interactions would polarize the dyad causing one or both parties to seek comfort in a third party resulting in an emotional triangle and freezing up the conflict between the dyad of origin. In the experience of disability this process often results in the projection of stress onto the individual with a disability causing this individual to internalize the conflict as his or her fault. This ultimately results in maladaptation to the disability for the whole family system and poor overall functioning (Bowen, 1965).

Multigenerational transmission process. The multigenerational process refers to the attitudes and beliefs regarding family function that is passed down from generation to generation. Bowen (1976) posited that children who were most triangulated were most likely to continue the family dysfunction into the next generation. Therefore a child with a disability will more than likely transmit maladaptive attitudes about his disability onto his children especially if they are born with a disability.

Emotional cutoff. This maladaptive multigenerational transmission of emotional reactivity often results in distancing or disengagement from the family of origin (Bowen, 1976). This emotional cutoff is most often exemplified in adult children who move away from family and are resistant to return or contact. While many might view children moving out on their own as an act of maturity, this can result in continued maladaptation all the same into subsequent generations. Nichols (1986) explains this phenomenon stating: “Only one thing robs Superman of his extraordinary power: kryptonite, a piece of his home planet. A surprising number of adult men and women are similarly rendered helpless by even a brief visit to or from their parents” (p. 190).

Social emotional process. In his later iterations of the family systems theory, Bowen (1976) identified the social influence on the family functioning. Akin to the family emotional process the attitudes, and beliefs of society are also projected onto the family. This is particularly relevant to families with disabilities as social insecurities are projected onto families causing a sense of self-blame (as described in Bowen, 1965) for the individual and family for problems caused by the disability resulting in maladaptation to the disability and perpetuated stigma of disability in society.

Differentiation of self. Despite the natural and social forces forecasting dysfunction, Bowen (1965; 1966; 1977) believed that individuals and families are capable of adapting and achieving what he called differentiation of self. The differentiation of self is the ability to think and behave independently of stressors or emotional pressures without becoming disengaged from the family process. Individuals with disabilities and their family members are considered differentiated when they are able to positively function, psychologically and socially, free of personal and social stigma related to the disability while maintaining their identity within the family.

Families and Systems in Rehabilitation Counseling

Cottone (1987) intuited one of the first family and systems theories within the rehabilitation counseling framework. At the time Cottone and Cottone (1986) found that VR system functioned more in interest of preserving its own organizational homeostasis by "screening social deviance" than its stated purpose of perpetuating well-being of individuals with disabilities through employment. This included the exclusion of services to family members and family involvement in the rehabilitation process.

In response, Cottone (1987) proposed that successful rehabilitation outcomes are based more on the interaction between the rehabilitation service and the family than the embraced philosophy of "person x environment fit" (Millington, et al. 2015, p. 11). Furthermore, he intuited a rehabilitation paradigm wherein individuals with disabilities are assisted in more fully participating in family, community, and culture rather than being compelled toward a "successful case closure." In fact Cottone, Grelle, and Wilson (1988) found that familial and social relationships more readily predicted employment outcomes than psychological indicators such as individual self-determination. Cottone (2012) advocates a family systems-based rehabilitation counseling framework wherein counselors act merely as facilitators of adjustment to disability within the family and rehabilitation system rather than authorities and gatekeepers.

Summary

This chapter provided a review of literature pertinent to the impact of disability on the family. The existing literature establishes that disability impacts family members in mostly a negative way. Based on the review of literature, there is a paucity of data inclusive of individuals with disabilities in the experience of family and disability. Since there is a deficiency of literature pertaining to individual perspectives of disability and family, this study will sample adult individuals with disabilities who are participants in public rehabilitation programs throughout the United States. Chapter 3 presents the methodology used to investigate the problem and describe the procedures used to accomplish the purpose.

CHAPTER III

METHODOLOGY

The following chapter presents the methodology used in the current research, the research design, research setting and participants, instrumentation, validity and reliability, data collection, and data analysis. This study was approved by the University of Texas-Pan American Institutional Review Board, which reviews all research that meets the definition of human subjects research (UTPA IRB # 2014-047-04). A copy of the approval is contained within Appendix A.

Research Design

The research design is the blue print of the study and defines the research type, the research questions, and defines the variables in question (Placeholder2). This descriptive survey research was designed to explore and describe the perceptions of adult individuals with disabilities regarding disability impacts on the family. The purpose or objective of this study was to compare findings to the relevant literature in order to determine if differences exist in these two perspectives (family members and the member with the disability). The methodology employed in this study were guided by the following research questions:

R_1 - How do adults with disabilities perceive the impacts of disability on family?

f. What are the perceptions of individuals with disabilities regarding the physical impact of their disability on the family?
g. What are the perceptions of individuals with disabilities regarding the psychological impact of their disability on the family?
h. What are the perceptions of individuals with disabilities regarding the social impact of their disability on the family?
i. What are the perceptions of individuals with disabilities regarding the financial impact of their disability on the family?
j. What are the perceptions of individuals with disabilities regarding the spiritual impact of their disability on the family?

R_2 - Are there differences in PWD's perceptions of the impacts of their disability on the family based on demographic variables?

k. Is there a difference in perception of impact of disability on family based on gender?
l. Is there a difference perception of impact of disability on family based on race/ethnicity?
m. Is there a difference perception of impact of disability on family based on relationship status?

n. Is there a difference perception of impact of disability on family based on employment?

o. Is there a perception of impact of disability on family groups based on education?

p. Is there a difference perception of impact of disability on family based on income?

q. Is there a difference perception of impact of disability on family based on income source?

r. Is there a difference perception of impact of disability on family based on disability?

R_3 - Are the perceptions of PWDs regarding health and quality of life related to their perception of the impact of disability on their family?

d. Is there a relationship in how PWDs perceive the impact of disability on their family based on their perception of their overall health?

e. Is there a relationship in how PWDs perceive the impact of disability on their family based on their perception of their quality of life?

f. Is there a relationship in how PWDs perceive of impact of disability on their family based on their perception of their families' quality of life?

Instrumentation

Development of the IPFD

The development of the instrument used for this study was initiated in an earlier study and refined based upon the results of that study. A search was conducted for existing scales related to the topic of impact of disability on family. Although a number of scales were encountered that measured the impact of disability on families, these were targeted to solicit the perception of parents of children with disabilities (Blacher & Baker, 2007; Stein & Jessop, 2003; Stein & Riessman, 1980), spouses who are caregivers of a loved one with a disability (Zarit, 2006), or siblings of loved ones with a disability (Hodapp, Urbano, & Burke, 2010). Studies that focused specifically on family impact of disability as experienced by the individual with the disability were unapparent in the literature. Therefore an instrument was developed to test the validity of assumptions regarding the impact of disability on the family as pertaining to the family member with the disability.

Following a comprehensive review of the literature, five dimensions emerged related to impact of disability on family: physical (Buchanan, Radin, Chakravorty, & Tyry, 2009; Schulz & Sherwood, 2008), psychological (Brooks, Campsi, Symington, Beattie, & McKinlay, 1986; Vash & Crew, 2004), social (Anderson, Larson, & Wuorio, 2011), familial (Mazur E. , 2006; Moore, Feist-Price, & Alston, 2002), and financial (Kyzar, Turnbull, Summers, & Gomez, 2012; Park, Turnbull, & Turnbull, 2002). These dimensions became the conceptual basis for the instrument developed. Individual items were constructed around these dimensions and in accordance with findings expressed in the literature. Once the instrument was constructed it was pilot tested using a group consisting of seven PhD students in a research course to assess readability and length of time to complete the survey. With feedback from the pilot group, the instrument was revised by removing items that were less relevant to the purpose of the study and correcting for grammatical errors. The survey was then submitted for review to five university professors who are experts in the areas of psychosocial aspects of disability, rehabilitation, research methods, and family systems. Their recommendations included framing some of the questions in a positive direction to avoid leading the respondent, rewording questions that were perceived as ambiguous or misleading, and excluding the neutral response on the Likert scale to promote more definitive responses.

The Individual Perception of Family and Disability (IPFD) survey was developed by Jenkins, et al (2015) to assess the impact of disability on families from the viewpoint of individuals with disabilities. The IPFD contained a 12-item demographic section; 6 items to assess the physical impacts of disability; 8 items to assess the psychological impact of disability; 11 items to assess the social impact of disability; 7 items assessing the familial impact of disability; and 11 items to assess the financial impact of disability on family. The 43 items pertaining to the five dimensions of the impact of disability on family used a 6-point Likert-type scale to indicate the degree of agreement or disagreement with the statements provided (strongly disagree=1, disagree=2, slightly disagree=3, slightly agree=4, agree=5, strongly agree=6).

The original IPFD survey was disseminated among rehabilitation consumers in a mountain-west state vocational rehabilitation (VR) agency and yielded over 300 useable surveys. Internal consistency reliability, which refers to the “measure of the stability of scores across the items that compose a test” (Bellini & Rumrill Jr, 2009, p. 68), was estimated using Cronbach’s alpha and resulted in an overall internal consistency estimate of .92. A copy of the original IPFD is contained in Appendix G.

Development of IPFD-R

Based upon the results of this earlier study the IPFD was refined and expanded by the present author in order to more comprehensively address the current research questions. A post-hoc exploratory factor analysis was conducted to determine how well the items in the survey aligned with the intended phenomenon. This resulted in the elimination of the familial category of the original IPFD survey as the items originally placed under the this construct were either removed because (a) they did not load on a single factor at a 0.4 or greater; (b) cross-loaded with another factor in the model; or (c) they were repositioned into other categories where they better fit the model being examined. Lastly, an additional review of the literature elucidated the notion of spirituality as a significant domain of adjustment to disability and family life (Glover-Graf, Marini, Baker, & Buck, 2007; Postin & Turnbull, 2004; Walsh, 2008). Accordingly, a spiritual category was added to examine how spiritual beliefs and the experience of disability might impact the family of the person with the disability.

Validity

In order to establish the content validity of the Individual Perception of Family and Disability-Revised (IPFD-R) instrument a more extensive review of the literature was conducted to attend to the present research questions. This review is documented in detail in the previous chapter.

In addition, a new panel of experts was asked for feedback about the items created and the instrument in general. Five university professors were selected as experts who specialize and have published empirical literature in the following content areas specific to this study: (1) rehabilitation counseling; (2) psychosocial aspects of disability; (3) family systems; (4)

psychometrics; and (5) research methods. These experts provided a rigorous review of the instrument. Their suggestions included allowing participants to indicate their disability in an open form rather than selecting from a preformulated list of disabilities or disability categories. The researcher would then code the disability entries into defined categories. Other suggestions included changing some of the Likert scales to measure frequency of certain items (i.e. Never, Sometimes…All of the time) instead of agreement (i.e. Strongly Disagree…Strongly Agree). The rational given for this was an agreement scale might incorrectly assume a given condition occurs whereas a frequency measure gives the respondent an opportunity to indicate if and how frequent the given phenomenon occurs. These suggestions were implemented to formulate the current instrument.

Lastly the revised IPFD-R survey was subjected to a Flesch-Kincaid readability test. The instrument tested at a grade 8.5 with the omission of the word “disability”; that reading level appears appropriate for this sample, which had a mean education level of “some college” (M = 3.4, SD = 1.1).

The IPFD-R was then input into an online survey program called Qualtrics (www.qualtrics.com). The online IPFD-R was disseminated to associates of the researcher with disabilities for pilot testing. Among the 10 pilot study participants, five identified as Hispanic/Latino, two as White/non-Hispanic, two as Asian, and one as African American. Seven participants were female and three male. Four of the pilot study participants indicated deaf or hard of hearing as their primary disability, two noted ADHD, two indicated chronic anxiety, and two filled in spinal cord injury. These 10 pilot study participants provided feedback regarding: (a) accessibility of the study; (b) understanding of the purpose of the study; (c) level of personal comfort taking the survey; (d) clarity of wording of items; and (e) length of survey. This feedback resulted in the purpose of the study being stated more concisely at the beginning of the survey. Additionally, headings were added to each section of the survey to explain the purpose of that section as well as encouraging comments between survey pages to motivated participants to complete the survey. A copy of the IPFD-Revised is found in Appendix N.

Final Instrument

The Individual Perception of Family and Disability-Revised (IPFD-R) survey is an online survey that consists of 10 items regarding participant demographics, 3 items questioning participant and family health and quality of life, and 50 items addressing physical, social, psychological, financial, and spiritual domains of life that represent impacts of disability present in the literature. A more detailed discussion of the survey content follows.

The demographic section gathers information regarding participant: (a) ethnicity; (b) gender; (c) relationship status; (d) parent status; (e) living status; (f) employment; (g) education, (h) income; (i) income source; and (j) disability.

Three questions inquire participant health status, personal quality of life, and family quality of life. These items are measured on a 5-point Likert scale (1 = Poor, 2 = Fair, 3 = Good, 4 = Very Good, 5 = Excellent).

The physical domain of family impacts of disability consists of nine items that address issues of: (1) family health; (2) physical injury; (3) tiredness; (4) time for self-care; (5) daily routines; (6) sibling responsibility for disability care; and (8) nutrition. These items are measured using a 5-point Likert-type scale to indicate the frequency of occurrence (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = all of the time).

The psychological domain consists of 12 items that assess the psychological impact of disability including experiences of: (1) happiness; (2) sadness; (3) guilt; (4) loneliness; (5) distress; (6) anger; (7) frustration; (8) jealousy; and (9) worry. These items are also measured on a 5-point Likert-type scale to indicate the frequency of the experience (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = all of the time).

The social scale consists of 11 items that query family socialization in terms of: (1) family outings; (2) family friends; (3) treatment from others; (4) community contact; and (5) intimate relationships. These items are measured on a 4-point Likert-type scale to indicate the degree of agreement or disagreement with the statements provided (strongly disagree = 1, disagree = 2, agree = 3, strongly agree = 4).

Ten items are used to assess the financial impact of disability on family. These include items related to: (1) disability income; (2) medical expenses; (3) financial sufficiency and sacrifice; (4) financial planning for the future; and (5) financial burden. These items are measured on a 5-point Likert-type scale to indicate the frequency of the experience (never = 1, rarely = 2, sometimes = 3, often =4, all of the time = 5).

Eight items represent the spiritual/religious experiences of disability in the family including feelings of: (1) proximity to God; (2) blaming God for disability; (3) penance from God; (4) reliance on God; (5) increased spirituality; (6) reduced spirituality; and (7) belief that God can improve disability. These items are measured on a 4-point Likert-type scale to indicate the degree of agreement or disagreement with the statements provided (strongly disagree = 1, disagree = 2, agree = 3, strongly agree = 4). A copy of the IPDF-R is found in appendix F.

Reliability

Analysis of the reliability of the IPFD-R provided an estimate of internal consistency. The reliability of each of the scales was analyzed using Chronbach's coefficient alpha (Cronbach, 1951). Chronbach's alpha is the index most often used to quantify reliability (Bellini & Rumrill Jr., 2009; Creswell, 2013; Norušis, 2005). "Cronbach alpha statistics estimate the lower bound of the true reliability of the scale-the proportion of observed score variability that is due to true score variability" (Norušis, 2005, p. 436). The overall reliability of the instrument was also investigated by calculating the internal consistency for all of the constructs and yielded a Cronbach's alpha of $r = .92$; which, is a strong indicator of internal consistency (Drost, 2011). Reliability coefficients on the individual IPFD-R scales are discussed in the next chapter on results.

Sampling, Procedures, and Participation

Bellini & Rumrill (Placeholder2) explain that the most common sampling method in rehabilitation counseling research is convenience sampling. In addition to ease, timeliness, and cost-effectiveness, this approach allows researchers to target specific populations and minimize risks associated with broader sampling techniques (Dattalo, 2010). The research questions posed in this study required the response of adults with disabilities who represent a specific and potentially vulnerable population. For this purpose a non-probability convenience sample was utilized for this study. Participants were recruited from state VR agencies throughout the United States that provides employment assistance to adults with disabilities. VR agencies provide rehabilitation services (such as vocational evaluation, guidance and counseling, job development, and placement) to an estimated 19 million adults with disabilities throughout the United States and its territories (Council of State Administrators of Vocational Rehabilitation, 2015).

Following IRB approval, endorsement for recruitment assistance was sought from the Council of State Administrators of Vocational Rehabilitation (CSAVR) which is composed of the chief administrators of the public rehabilitation agencies serving individuals with physical and mental disabilities in the 50 states, District of Columbia, and territories of the United States. CSAVR presented the study to the chief administrators of the 80 VR agencies via email and requested they contact the researcher directly with intent to participate. Of these 80 only three state VR agencies opted to participate. Participating agencies were provided a letter detailing the study and inviting VR consumer participation. An administrator of each participating agency then sent out the letter to VR consumers via email. The letter included a link to the survey hosted by Qualtrics (www.qualtrics.com). This resulted in a total of 558 persons who logged into the survey.

Sample Size

In addition, the researcher conducted a power analysis a priori in order to "achieve a sensitive statistical test given the estimated size of the variable effects under consideration" (Placeholder2p. 143). The analysis was conducted using software developed by Soper (2015) to identify the ideal sample size needed to determine statistically significant differences in this study given the probability level ($\alpha = .05$), the anticipated effect size (*d*= .50), and the desired statistical power level ($\pi = 0.8$). This resulted in N = 102; meaning a minimum sample size of 102 will yield statistically significant differences (alpha = 0.05, one-tail) with approximately 80% power to reject the null hypothesis of zero correlation in this study.

Ethical Concerns

According to Bellini and Rumrill Jr. (Placeholder2; Placeholder2; Placeholder2; Placeholder2) rehabilitation researchers have an obligation to research participants, collaborating researchers, employers, supporting agencies, research results consumers, and the profession to conduct research in a legal and ethically sound manner. For this purpose and in accordance with the National Research Act of 1974 the proposal and execution of study was subject scrutiny by the Institutional Review Board (IRB) at the University of Texas- Pan American to ensure ethical practice and human subject protection. Accordingly, an informed consent protocol was devised to inform participants of the purpose of the study, benefits and risks of participation, and measures to ensure anonymity and confidentially. There were no benefits to the participants identified in the study nor were any incentives for participation provided. It was suggested that the participant may experience emotional or psychological discomfort in the course of the study due to the nature of the questions posed regarding the impact their disability may have on family members or loved ones. This risk was mitigated by encouraging the participant to visit with their rehabilitation counselor if discomfort occurs. Participants were also informed of the risks to confidentiality inherent in online surveys but that the researcher had disabled the IP address tracking function in the online survey system. It was also explained that withdrawal from the study was possible at any time. The informed consent statement was provided in writing on the first page of the online study along with contact information for the researcher and IRB (see appendix B). The participant was then prompted to indicate whether or not they agree to participate in the study by clicking a button on the online survey prior to proceeding to the rest of the survey. Lastly, the researcher worked with developers of the online survey program to ensure that the informed consent as well as other functions of the online survey were accessible for screen reader software on mobile and desktop computers.

Summary

This chapter provided an outline of the methodology that was used for the exploration of the impact of disability on families as perceived by individuals with disabilities that are VR consumers. A survey research design defined and framed the concepts of the overall study. Data was collected through a survey questionnaire. The sampling procedures were reviewed, along with methodologies for power analysis for minimum sample size. The chapter concluded with discussion on ethical concerns and standards that apply to this study. Chapter four will detail data analysis procedures and present findings of the research study.

CHAPTER IV

RESULTS

The purpose of this study was to explore the impact of disability on the family from the perspective of the person with the disability among participants of State Vocational Rehabilitation (VR) programs. This chapter provides results collected through the Individual Perspective of Family and Disability-Revised (IPFD-R) survey.

Data Analysis

The first research question, regarded the perception of individuals with disabilities toward the impact of their disability on their family. Descriptive statistics including frequencies, percentages, means, and standard deviations were used to examine the demographic, physical, psychological, social, financial, and spiritual variables for the sample as presented in the IPFD-R. A one-way multivariate analysis of variance (MANOVA) was used to test the second research question examining the differences in individual perceptions of impact of disability on family based on select demographic variables contained in the IPFD-R. A Pearsons's product-moment correlation was run to test the third research question assessing the perceptions of health and quality of life and their relationship to the perceptions of the impact of disability on family. All analyses for this study were conducted using SPSS version 22 and will be reported in this chapter.

Data Refinement

Following a process of listwise deletion for incomplete surveys (Howell, 2012) a total of 410 out of 558 surveys were retained for data analysis. In order to increase comprehensibility and reduce variance, select demographic variables were recoded to collapse cells that represented less than 10% of the sample population (Funnell, Bryer, Grimbeek, & Davies, 2004). The state of residence variable was collapsed to include the state of Oklahoma (67.6%), District of Columbia (14.1%), Florida (11.2%), and Elsewhere (4.1%). Race/Ethnicity categories were collapsed to "Black/African American" (19.5%), "White/Non-Hispanic" (67.8%), and "Other" (10.2%). Education categories were reduced to "High School or Less" (18.5%), "Some College" (39.5%), "College Degree" (31.7%), and "Masters or Higher" (10.2%). The relationship status variable was collapsed to "Married/Committed Relationship" (41.7%), "Single, never married" (29.5%), and "Divorced, widowed, or separated" (27.3%). Responses to annual income were collapsed to "Less than $20,000" (69.8%), $20,000 to $39,999 (18.5%), and "More than $40,000" (10.2%).

Regarding disability data: participants were asked to indicate their primary disability in a single (short) text field. In a subsequent question participants were asked to list any secondary conditions or disabilities in a larger text field. The researcher then reviewed each entry in the primary disability field and manually coded each into one of three disability categories: (1) "Sensory/Communicative" (31%); (2) "Physical" (41.5%); (3) "Mental" (25.9%). The disability categories chosen for this study are those used in the RSA 911 database (U.S. Department of Education, 2013). Results of participant demographics are presented in greater detail in the next section.

Demographic Data

Demographic data presented in this section are tabulated using the frequencies function in SPSS (v. 22). The percentages are representative of the total sample (N = 410) instead of the number that responded to each question. Specific demographic profiles used in this study are contained in Table 1. Overall, among the 410 participants, most were female (67.6%) and 67.8% identified as Caucasian. The majority of participants claimed Oklahoma as their state of residence (n = 277, 67.6%). Participants reported a full range of disabilities with the preponderance (41.5%) reporting a physical disorder/illness (e.g., spinal cord injury, arthritis, HIV/AIDS, cancer, etc.). The largest percentage of participants (47.8%) reported being unemployed, earning less than $20,000 per year (69.8%), and having completed some college (39.5%). Over 41% of respondents reported their primary source of financial support was from public support (SSI/SSDI etc.) and over 30% personal income. More than one-third of participants indicated being married or in a committed relationship. Lastly, over half reported that they are parents of one or more children and over 96% of participants report sharing residence with other people (Table 1 indicates frequencies for participant demographics).

Table 1

Participant Demographics

	n	*Percentage*
Gender		
Male	128	29.5%
Female	277	67.6%
State		

Oklahoma	277	67.6%
District of Columbia	58	14.1%
Florida	46	11.2%
Elsewhere	17	4.1%
Race/Ethnicity		
Black/African American	80	19.5%
White/Non-Hispanic	278	67.8%
Other	42	10.2%
Education		
High School or Less	76	18.5%
Some College	162	39.5%
College Degree	130	31.7%
Masters Degree or Higher	42	10.2%
Employment Status		
Full Time	74	18.0%
Part Time	65	15.9%
Unemployed	196	47.8%
Income		
Below $20,000	286	69.8%
$20,000-$39,999	76	18.5%
$40,000 or More	42	10.2%
Primary (largest) Source of Income		

Personal Income	125	30.5%
Spouse/Family/Friend	81	19.8%
Public Support (i.e. SSDI, SSI, TANF, etc.)	169	41.2%
Other Sources such as insurance or charities.	30	7.3%
Relationship Status		
Married/In a Committed Relationship	171	41.7%
Single/Never Married	121	29.5%
Divorced, Widowed, or Separated	112	27.3%
Parent of at least one child?		
Yes	208	50.7%
No	164	40.0%
Number of Persons who Share Residence		
1-4	343	86.6%
5-8	43	10.8%
10+	5	1.2%
Disability Category		
Sensory/Communicative	127	31.0%
Physical	170	41.5%
Mental	106	25.9

Research Question 1: Individual Perceptions of Family and Disability

Descriptive analyses were used to respond to the first research question: “What are the perceptions of adult individuals with disabilities regarding the impact of disability on their family.” The descriptive results of this study revealed that overall participants feel that their disability does not frequently impact their family as presented in the IPDF-R. The data presented in this section utilize frequencies, means, and standard deviations to describe and report the physical, psychological, social, financial, and spiritual impacts of disability as experienced by the participants in this study. Lastly, Chronbach’s alpha is utilized to represent the internal consistency or reliability (Cronbach, 1951) of the items within each of the impact categories.

Physical Impacts of Disability

Nine items assessed the physical impacts of disability on family that consisted of: (1) family health; (2) physical injury; (3) tiredness; (4) time for self-care; (5) daily routines; (6) sibling responsibility for disability care; and (8) nutrition. These items were measured using a 5 point Likert-type scale to indicate the frequency of occurrence (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = all of the time). Overall mean scores indicated that participants never or rarely perceive a physical impact of their disability on individuals in their family. A substantial majority of participants (*n* = 305, 74.4%) indicated that their disability is never caused a family member to turn to substance use (*M* = 1.4, *SD* = 0.9). As well, participants indicated family members never or rarely experience: (a) being physically injured (*M* = 1.4, *SD* = 0.8); (b) being physically tired (*M* = 2.0, *SD* = 1.2); (c) requiring sibling care (*M* = 1.7, *SD* = 1.1); (d) being healthier (*M* = 1.7, *SD* = 1.1); or (e) in worse health (*M* = 2.2, *SD* = 1.2) because of their disability.

Conversely, over half of participants indicated that their family members sometimes to always have time to care for themselves (*M* = 2.9, *SD* = 1.5) and prioritize eating healthy (*M* = 2.8, *SD* = 1.4) because of their disability. However, 52.5% of participants also indicated that that their disability sometimes to always affects their family member's daily routine activities (*M* = 2.6, *SD* = 1.4).

Internal consistency for this scale was computed using Cronbach's alpha and resulted in a reliability coefficient of .71; which is a moderate indicator that the items in this category are measuring the same underlying dimension (Drost, 2011). Table 2 indicates means and frequencies for participants answering these questions.

Table 2
Individual Perception, Family, Disability-Revised--
Physical Impact

					Never	Rarely	Sometimes	Often	Always
#	Item	*n*	*M*	*SD*	%	%	%	%	%
1	Because of my disability, a loved one physically hurt themselves while taking care of me.	388	1.4	0.8	69.8	12.2	9.0	2.9	0.7
2	My family members seem physically tired because of the effort required to care for me.	391	2.0	1.2	46.6	16.6	19.0	9.5	3.7
3	Because of my disability my family members have time to do things to care for themselves physically (like exercise).	371	2.9	1.5	25.9	11.5	18.3	17.3	17.6

4	My disability causes worse health (back pain, headaches, sick more often, etc.) for someone in my family.	387	2.2	1.2	40.2	16.3	22.4	10.5	4.9
5	My disability causes better health for someone in my family.	387	1.7	1.1	60.5	12.9	14.4	3.9	2.7
6	I think my disability affects my family's daily routine activities.	397	2.6	1.4	30.5	13.4	26.3	14.1	12.4
7	Because of my disability my siblings will have to care for me as I get older.	374	1.7	1.1	55.1	17.1	12.0	3.7	3.4
8	Someone in my family turns to substances (alcohol, drugs, etc.) because of my disability.	384	1.4	0.9	74.4	8.5	5.1	3.4	2.2
9	Eating healthy is important to my family because of my disability.	371	2.8	1.4	26.8	13.2	19.8	17.3	13.4

Psychological Impacts of Disability

Twelve items assessed the psychological impact of disability including: (1) happiness; (2) sadness; (3) guilt; (4) loneliness; (5) distress; (6) anger; (7) frustration; (8) jealousy; and (9) worry. These items were also measured on a 5-point Likert-type scale to indicate the frequency of the experience (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = all of the time). Participants indicated that their family members are sometimes happy to help with disability (*M* = 3.0, *SD* = 1.2) and sometimes prefer to help with the disability rather than have a non-family member help (*M* = 3.0, *SD* = 1.6) with greater frequency than any other items (see table 4). However, over half of participants indicated that someone in their family sometimes to always feels depressed (*M* = 2.5, *SD* = 1.2) and frustrated (*M* = 2.7, *SD* = 1.3) because of their disability.

According to mean scores, participants perceive that their disability never or rarely cause family members to feel: (a) guilty (*M* = 1.9, *SD* = 1.1); (b) lonely (*M* = 1.8, *SD* = 1.1); (c) stressed (*M* = 2.8, *SD* = 1.2); (d) angry (*M* = 2.3, *SD* = 1.2); (e) worried (*M* = 2.7, *SD* = 1.4); or (f) jealous (*M* = 1.5, *SD* = 1.0). Regarding their parent's relationship, the majority of participants indicated that their disability never caused the relationship to be better or worse.

Cronbach's alpha indicated internal reliability for this scale was .83; which is a good indicator that the items in this category are measuring the same underlying dimension (Drost, 2011). Table 3 provides means, standard deviations, and frequencies for these items.

Table 3
Individual Perception, Family, Disability-Revised
Psychological Impact

#	Item	*n*	*M*	*SD*	Never %	Rarely %	Sometimes %	Often %	Always %
10	Someone in my family feels happy when they can help with my disability.	381	3.0	1.2	15.4	12.4	31.7	21.7	11.7
11	Someone in my family is sad or depressed because of my disability.	392	2.5	1.2	26.8	14.6	37.1	11.2	5.9
12	Someone in my family feels guilty because of my disability.	383	1.9	1.1	46.6	18.0	19.0	6.8	2.9
13	Someone in my family feels lonely because of my	380	1.8	1.1	54.6	12.0	17.0	6.3	2.7

	disability.								
14	Someone in my family feels stressed because of my disability.	390	2.8	1.2	21.2	12.9	34.1	17.6	9.3
15	Someone in my family feels angry because of my disability.	383	2.3	1.2	33.7	16.1	28.8	8.5	6.3
16	Someone in my family feels frustrated because of my disability.	388	2.7	1.3	23.4	12.2	34.6	15.4	9.0
17	My siblings are jealous of the attention I get (or got) because of my disability.	365	1.5	1.0	64.9	9.8	7.8	4.1	2.4
18	My parents worry a lot because I have a disability.	361	2.7	1.4	28.5	11.0	21.7	14.1	12.7
19	My parent's relationship is (or was) better or more loving because of my disability.	342	1.8	1.3	52.4	9.8	9.0	6.3	5.9
20	Because I have a disability my parents argue (present or past).	348	1.7	1.1	58.5	9.0	9.5	3.9	3.9
21	My family would rather care for my disability needs than have a non-family member do it.	355	3.0	1.6	25.6	8.0	15.6	14.9	22.4

Social Impacts of Disability

The social scale consisted of 11 items that queried family socialization in terms of: (1) family outings; (2) family friends; (3) treatment from others; (4) community contact; and (5) intimate relationships. These items were measured on a 4 point Likert-type scale to indicate the degree of agreement or disagreement with the statements provided (strongly disagree = 1, disagree = 2, agree = 3, strongly agree = 4). Overall, mean scores indicate disagreement with items categorized as social impacts.

Participants disagreed that their disability caused their family: (a) to have fewer friends (*M* = 1.8, *SD* = 0.9); (b) to engage in fewer social activities (*M* = 1.8, *SD* = 0.9); (c) to be treated disrespectfully by others (*M* = 1.8, *SD* = 0.9); (d) to make new friends (*M* = 2.0, *SD* = 0.9); to socialize with other families with disabilities (*M* = 1.9, *SD* = 0.9); or (e) increased community contact (*M* = 1.8, *SD* = 0.8). The least amount of disagreement was found relative to the participant initiating and maintaining a relationship with a significant other (*M* = 2.4 and 2.5 respectively). Cronbach's alpha reliability estimate was .81 for this scale; which is a good indicator that the items in this category are measuring the same underlying dimension (Drost, 2011). Table 4 provides means, standard deviations, and frequencies for items in this scale.

Table 4
Individual Perception, Family, Disability-Revised
Social Impact

#	Item	*n*	M	SD	Strongly Disagree %	Disagree %	Agree %	Strongly Agree %
22	Family outings are difficult because of my disability.	386	2.3	1.0	26.6	24.4	29.5	13.7
23	My family members are social with fewer friends because of my disability.	373	1.8	0.9	44.4	23.2	18.8	4.6
24	My family members have made new friends because of my	370	2.0	0.9	33.9	27.3	24.4	4.6

	disability.							
25	My family socializes with other families with disabilities.	364	1.9	0.9	36.1	27.1	20.2	5.4
26	My family spends more time together because of my disability.	369	1.9	0.9	35.4	31.0	20.0	3.7
27	Some people treat my family with disrespect because I have a disability.	375	1.8	0.9	44.6	25.6	17.8	3.4
28	My family members take part in fewer social activities because of the time required to care for my disability.	368	1.8	0.9	48.5	19.8	16.1	5.4
29	Because of my disability I need family members to help me be social with others outside my household.	371	2.0	1.0	37.1	24.4	20.7	8.3
30	My family has more community contact because of my disability.	364	1.8	0.8	37.3	32.7	15.9	2.9
31	Maintaining a loving relationship with a significant other is difficult because of my disability.	369	2.4	1.2	26.8	17.8	23.4	22.0
32	Finding a boyfriend or girlfriend is or has been difficult because of my disability.	342	2.5	1.2	25.9	14.1	18.5	24.9

Financial Impacts of Disability

Ten items assessed the financial impact of disability on family. These included items related to: (1) disability income; (2) medical expenses; (3) financial sufficiency and sacrifice; (4) financial planning for the future; and (5) financial burden. These items were measured on a 5 point Likert-type scale to indicate the frequency of the experience (never = 1, rarely = 2, sometimes = 3, often =4, all of the time = 5).

Overall mean scores for the items categorized as financial impacts of disability show that participants' income as well as the income they obtain from work is seldom sufficient to care for their family (*M* = 1.7, *SD* = 1.1). Most participants (58%) indicated that their families never or rarely have sufficient funds to care for their disability related needs (*M* = 2.1, *SD* = 1.3). However, participants also indicated that family members rarely had to go without the things they need (*M* = 2.2, *SD* = 1.3) or want (*M* = 2.5, *SD* = 1.4) or had to have multiple jobs (*M* = 1.8, *SD*= 1.3) because of their disability. Cronbach's alpha indicated internal consistency for this scale was .73; which is a moderate indicator that the items in this category are measuring the same underlying dimension (Drost, 2011). Table 5 provides means, standard deviations, and frequencies for these items.

Table 5
Individual Perception, Family, Disability-Revised
Financial Impact

					Never	Rarely	Sometimes	Often	Always
#	Item	*n*	*M*	*SD*	%	%	%	%	%
33	My disability income (i.e. SSI/ SSDI etc.) is sufficient to care for my family.	320	1.7	1.1	49.8	12.2	9.0	4.1	3.8
34	Because I have a disability the money I make from work is	307	1.7	1.1	45.4	13.9	8.0	4.6	2.9

	enough to care for my family.								
35	My family has enough finances to care for my disability needs	353	2.1	1.3	40.2	17.8	13.4	8.5	6.1
36	My family has to pay more for medical costs because of my disability.	348	2.6	1.5	30.5	11.7	15.9	12.2	14.6
37	My family members go without the things they NEED because of my disability care costs.	356	2.2	1.3	39.0	13.9	18.3	7.3	8.3
38	My family members go without the things they WANT because of my disability care expenses.	356	2.5	1.4	33.4	11.7	19.0	12.2	10.5
39	Because of my disability, my family members need to keep more than one job to provide for me.	337	1.8	1.3	48.0	13.4	9.3	5.6	5.9
40	Because of my disability, my family members find it difficult to plan financially for the future.	355	2.6	1.5	33.7	9.5	14.9	13.7	14.9
41	Because of my disability my family members have a hard time preparing for unexpected financial crisis.	351	2.7	1.6	32.7	10.2	13.7	11.2	17.8
42	My family helps me to get jobs and work.	344	2.1	1.3	42.9	13.2	13.7	7.3	6.8

Spiritual Impacts of Disability

Eight items represented the spiritual/religious experiences of disability in the family including feelings of: (1) proximity to God; (2) blaming God for disability; (3) penance from God; (4) reliance on God; (5) increased spirituality; (6) reduced spirituality; and (7) belief that God can improve disability. These items were measured on a 4 point Likert-type scale to indicate the degree of agreement or disagreement with the statements provided (strongly disagree = 1, disagree = 2, agree = 3, strongly agree = 4).

Overall mean scores for items categorized as spiritual impacts demonstrate that participants disagree that their disability has an impact on their family's spiritual wellbeing. Greatest disagreement came to the items that stated, "*My family blames God for my disability"* (*M* = 1.4, *SD* = 0.6) and "*My family feels that my disability is a punishment from God"* (*M* = 1.6 *SD* = 0.7). Disagreement was likewise demonstrated for items related to disability contributing to: (a) decreased spirituality (*M* = 1.5, *SD* = 0.7); (b) feeling proximity to God (*M* = 2.3, *SD* = 1.1); (c) increased spirituality (*M* = 2.3, *SD* = 1.0); and (d) belief that God can cure the disability (*M* = 2.4, *SD* = 1.1).

Mean scores approximated agreement on items related to the family belief that God can improve the disability (*M* = 2.6, *SD* = 1.1) and the family relying on God to help with difficult times because of the disability (*M* = 2.5, *SD* = 1.1). Cronbach's alpha indicated internal consistency for this scale was .77; which is a moderate indicator that the items in this category are measuring the same underlying dimension (Drost, 2011). Table 6 provides means, standard deviations, and frequencies for these items.

Table 6
Individual Perception, Family, Disability-Revised
Spiritual Impact

#	Item	*n*	*M*	*SD*	Strongly Disagree %	Disagree %	Agree %	Strongly Agree %
43	My family feels closer to God because of my disability.	352	2.3	1.1	22.7	25.4	24.6	13.2
44	My family blames God for my disability.	349	1.4	0.6	56.8	23.7	3.4	1.2
45	My family feels that my disability is a punishment from God.	350	1.6	0.7	59.8	18.8	4.9	2.2
46	My family relies more on God to help us through hard times because of my disability.	353	2.5	1.1	22.9	15.9	27.6	19.8
47	My disability has helped my family become more spiritual.	352	2.3	1.0	23.7	24.9	24.6	12.7
48	My disability has made my family become less spiritual.	351	1.5	0.7	50.0	27.3	5.6	2.7
49	My family believes God can make my disability better.	352	2.6	1.1	20.2	16.8	27.6	21.2
50	My family believes that God can cure my disability.	350	2.4	1.1	27.3	18.8	20.7	18.5

Research Question 2: Group Differences in Perceptions of Family and Disability

A one-way multivariate analysis of variance was used to examine the second research question: “Are there differences between participant’s perceptions of the impact of disability on family and demographic variables?” These variables were: (a) gender; (b) race/ethnicity; (c) relationship status; (d) education; (e) income; (f) primary income source; (g) employment status; and (f) disability.

All 50 of the scale items from the IPFD-R were run as dependent variables and the eight identified demographic variables, as described in this chapter, were run as fixed factors or independent variables using the Multivariate function in SPSS (22). This resulted in significant differences among four out of the eight groups examined. Tukey univariate post hoc analyses (Tukey, 1949) were performed to examine specific differences among statistically significant findings. Results are presented in this section as *F*-statistic (hypothesis df, error df), statistical significance (expressed as "*p"*); Pillai's Trace; and partial eta-squared (expressed as "partial η2"). The partial eta-squared is commonly reported in SPSS in analyses of variance as a measure of effect size. A partial eta-squared is considered an acceptable measure of effect size on one-way analyses of variance or multivariate analyses of variance (Levine & Hullett, 2002).

Gender

Gender comparisons were examined among Male (n = 70) and Female (n = 129) participants. There were no statistically significant gender differences in participants' perceptions of the impact of disability on family, *F* (50,148) = .948, *p* = .576; Pillai's Trace = .243; partial η2 = .243.

Race/Ethnicity

Race/Ethnicity comparisons were examined among: (1) "White/Non Hispanic" (n = 125); (2) "Black/African American" (n = 44); and (3) "Other" (n = 26) categories. There were no statistically significant differences in participants' perceptions of the impact of disability on family by race/ethnicity groupings, *F* (100, 288) = 1.085, *p* = .299; Pillai's Trace = .547; partial η2 = .274.

Relationship Status

Relationship comparisons were examined among: (1) "Married/In a Committed Relationship"(n = 85); (2) "Single, never married"(n = 60); and (3) "Divorced, Widowed, or Separated" (n= 55) groupings. There was a statistically significant difference in participants' perceptions of the impact of disability and family by relationship status, *F* (100, 298) = 2.258, *p* < .0005; Pillai's Trace = .862; partial η2 = .431.

Between subjects tests revealed 10 statistically significant differences between participants by relationship groupings: *(1) Eating healthy is important to my family because of my disability F* (2, 197) = 4.361, *p* = .014; partial η2 = .042*; (2) Family outings are difficult because of my disability F* (2, 197) = 3.512, *p* = .032; partial η2 = .034*; (3) Maintaining a loving relationship with a significant other is difficult because of my disability F* (2, 197) = 3.905, *p* = .022; partial η2 = .038*; (4) Finding a boyfriend or girlfriend is or has been difficult because of my disability F* (2, 197) = 21.450, *p* < .0005; partial η2 = .179*; (5) My family has enough finances to care for my disability needs F* (2, 197) = 12.947, *p* < .0005; partial η2 = .116*; (6) My family members go without the things they NEED because of my disability care costs F* (2, 197) = 3.765, *p* = .025; partial η2 = .037*; (7) My family members go without the things they WANT because of my disability care expenses F* (2, 197) = 3.704, *p* = .026; partial η2 = .036*; (8) Because of my disability, my family members find it difficult to plan financially for the future F* (2, 197) = 7.073, *p* = .001; partial η2 = .067*; (9) Because of my disability my family members have a hard time preparing for unexpected financial crisis F* (2, 197) = 6.259, *p* = .002; partial

$\eta 2 = .060$*; and (10) My family helps me to get jobs and work F* (2, 197) = 7.488, *p* = .001; partial $\eta 2 = .071$.

Table 7 presents means, standard deviations, and cell size of each relationship group found to be statistically significant. Table 8 presents post hoc analyses for the mean score differences found to be significant.

Tukey post hoc analyses of the first item regarding healthy eating revealed significant mean differences were between those who are married or in a committed relationship (*M* = 3.1, *SD =* 1.4) and single, never married (*M =* 2.5, *SD* = 1.4). The mean score difference between these groups was .66 (95% CI, .10 to 1.2, *p* = .017) indicating that the true mean differences in the population presented here lies between the lower and upper bound scores (Salkind, 2010).

The second item regarding family outings revealed similar post hoc results in that significant differences were encountered between married/committed relationship (*M* = 2.4, *SD =* 1.0) and single, never married (*M* = 1.9, *SD* = 0.9) groups. The mean score difference between these groups was .45 (95% CI, .03 to .86, *p* = .031).

Post hoc analyses on the third item regarding relationship maintenance with a significant other revealed mean score differences between divorced, separated, or widowed (*M* = 2.7, *SD* = 1.2) and married/in a committed relationship (*M* = 2.1, *SD* = 1.0) groups. The difference between these groups

Post hoc analyses of the fourth item regarding intimate relationship development revealed mean score differences between those who reported married/in a committed relationship (*M* = 1.8, *SD* = 0.9) and single, never married (*M* = 2.9*, SD =* 1.1) as well as divorced, separated, or widowed (*M* = 2.8, *SD* = 1.2) groups. The mean score difference between "married/in a committed relationship” and “single, never married” was 1.06 (95% CI, -1.5 to -0.6, *p* < .0001). The mean score difference between “married/in a committed relationship” and “divorced, separated, or widowed” was 1.0 (95% CI, -1.4 to -0.5, *p* < .0001).

Post hoc analyses of the fifth item regarding family finances revealed mean score differences between those who reported divorced, separated, or widowed (*M* = 1.4, *SD* = 0.6) and married/in a committed relationship (*M* = 2.1, *SD* = 1.2) and single, never married (*M* = 2.5, *SD* = 1.4) groups. The mean score difference between “divorced, separated, or widowed” and “married/in a committed relationship” was .72 (95% CI, -1.2 to -0.2, *p* = .002). The mean score difference between “divorced, separated, or widowed” and “single, never married” was 1.1 (95% CI, -1.6 to -0.6, *p* < .0001).

Post hoc analyses of the sixth item regarding family members going without the things they need revealed mean score differences between single, never married (*M* = 1.8, *SD* = 1.0) and divorced, widowed, separated (*M* = 2.4, *SD* = 1.4) groups. The mean score difference between “divorced, separated, or widowed” and “single, never married” was .64 (95% CI, -1.2 to -0.7, *p* = .023).

Post hoc analyses of the seventh item regarding family members going without the things they want revealed mean score differences between participants who are married/in a committed relationship (*M* = 2.6, *SD* = 1.3) and those who are single, never married (*M* = 2.0, *SD* = 1.1). The mean score between these groups was .59 (95% CI, .05 to 1.1, *p* = .030).

Similarly, post hoc analyses on the eighth item regarding financial planning revealed mean score differences between participants who are married/in a committed relationship (*M* =

2.8, *SD* = 1.5) and those who are single, never married (*M* = 1.9, *SD* = 1.2). The mean score between these groups was .92 (95% CI, .34 to 1.5, *p* = .001).

Post hoc analyses on the ninth item regarding family financial crisis revealed mean score differences between participants who are married/in a committed relationship (*M* = 2.9, *SD* = 1.6) and those who are single, never married (*M* = 2.0, *SD* = 1.2). The mean score between these groups was .91 (95% CI, .30 to 1.5, *p* = .001).

Lastly, post hoc analyses revealed mean score differences on the tenth item regarding job acquisition between participants who are single, never married (*M* = 2.6, *SD* = 1.5) and those married/in a committed relationship (*M* = 1.8, *SD* = 1.1). The mean score between these groups was .86 (95% CI, .33 to 1.4, *p* < .0001).

Table 7
Relationship Status Comparisons: Means, Standard Deviations, and Group Size

	Item	Relationship	Mean	Std. Dev.	N
1	9-Eating healthy is important to my family because of my disability.	Married/In a Committed Relationship	3.1	1.4	85
		Single/Never Married	2.5	1.4	60
		Divorced, Widowed, Separated	2.6	1.4	55
2	22-Family outings are difficult because of my disability.	Married/In a Committed Relationship	2.4	1.0	85
		Single/Never Married	3.0	1.0	60
		Divorced, Widowed, Separated	2.4	1.1	55
3	31-Maintaining a loving relationship with a significant other is difficult because of my disability.	Married/In a Committed Relationship	2.2	1.1	85
		Single/Never Married	2.5	1.2	60
		Divorced, Widowed, Separated	2.7	1.2	55

4	32-Finding a boyfriend or girlfriend is or has been difficult because of my disability.	Married/In a Committed Relationship	1.8	1.0	85
		Single/Never Married	2.9	1.2	60
		Divorced, Widowed, Separated	2.8	1.2	55
5	35-My family has enough finances to care for my disability needs	Married/In a Committed Relationship	2.1	1.3	85
		Single/Never Married	2.5	1.4	60
		Divorced, Widowed, Separated	1.4	0.7	55
6	37-My family members go without the things they NEED because of my disability care costs.	Married/In a Committed Relationship	2.3	1.3	85
		Single/Never Married	1.9	1.1	60
		Divorced, Widowed, Separated	2.5	1.5	55
7	38-My family members go without the things they WANT because of my disability care expenses.	Married/In a Committed Relationship	2.6	1.4	85
		Single/Never Married	2.0	1.2	60
		Divorced, Widowed, Separated	2.6	1.5	55
8	40-Because of my disability, my family members find it difficult to plan financially for the future.	Married/In a Committed Relationship	2.9	1.5	85
		Single/Never Married	2.0	1.2	60
		Divorced, Widowed, Separated	2.6	1.5	55
9	41-Because of my disability my family members have a hard time preparing for unexpected financial crisis.	Married/In a Committed Relationship	3.0	1.6	85
		Single/Never Married	2.1	1.3	60
		Divorced, Widowed, Separated	2.6	1.6	55
10	42-My family helps me to get jobs and work.	Married/In a Committed Relationship	1.8	1.2	85
		Single/Never Married	2.7	1.5	60
		Divorced, Widowed, Separated	2.1	1.3	55

Table 8

Relationship Status Comparisons: Tukey Post Hoc Analyses

							95% Confidence Interval	
	Dependent Variable	I	J	Mean Diff. (I-J)	Std. Error	Sig.	Lower Bound	Upper Bound
1	9-Eating healthy is important to my family because of my disability.	1-Married/In a Committed Relationship	2.00	.66*	.240	.017	.10	1.23
			3.00	.51	.246	.098	-.07	1.09
		2-Single/Never Married	1.00	-.66*	.240	.017	-1.23	-.10
			3.00	-.15	.266	.836	-.78	.48
		3-Divorced, Widowed, Separated	1.00	-.51	.246	.098	-1.09	.07
			2.00	.15	.266	.836	-.48	.78
2	22-Family outings are difficult because of my disability.	1-Married/In a Committed Relationship	2.00	.45*	.174	.031	.03	.86
			3.00	.07	.179	.927	-.36	.49
		2-Single/Never Married	1.00	-.45*	.174	.031	-.86	-.03
			3.00	-.38	.193	.125	-.83	.08
		3-Divorced, Widowed, Separated	1.00	-.07	.179	.927	-.49	.36
			2.00	.38	.193	.125	-.08	.83
3	31-Maintaining a loving relationship with a significant other is difficult because of my disability.	1-Married/In a Committed Relationship	2.00	-.31	.195	.260	-.77	.15
			3.00	-.55*	.200	.018	-1.02	-.08
		2-Single/Never Married	1.00	.31	.195	.260	-.15	.77
			3.00	-.24	.216	.498	-.75	.27
		3-Divorced, Widowed, Separated	1.00	.55*	.200	.018	.08	1.02
			2.00	.24	.216	.498	-.27	.75

4	32-Finding a boyfriend or girlfriend is or has been difficult because of my disability.	1-Married/In a Committed Relationship	2.00	-1.06*	.186	.000	-1.50	-.62
			3.00	-1.00*	.191	.000	-1.45	-.55
		2-Single/Never Married	1.00	1.06*	.186	.000	.62	1.50
			3.00	.06	.206	.949	-.42	.55
		3-Divorced, Widowed, Separated	1.00	1.00*	.191	.000	.55	1.45
			2.00	-.06	.206	.949	-.55	.42
5	35-My family has enough finances to care for my disability needs	1-Married/In a Committed Relationship	2.00	-.40	.201	.118	-.87	.07
			3.00	.72*	.206	.002	.23	1.20
		2-Single/Never Married	1.00	.40	.201	.118	-.07	.87
			3.00	1.12*	.222	.000	.59	1.64
		3-Divorced, Widowed, Separated	1.00	-.72*	.206	.002	-1.20	-.23
			2.00	-1.12*	.222	.000	-1.64	-.59
6	37-My family members go without the things they NEED because of my disability care costs.	1-Married/In a Committed Relationship	2.00	.43	.218	.119	-.08	.95
			3.00	-.21	.224	.620	-.74	.32
		2-Single/Never Married	1.00	-.43	.218	.119	-.95	.08
			3.00	-.64*	.241	.023	-1.21	-.07
		3-Divorced, Widowed, Separated	1.00	.21	.224	.620	-.32	.74
			2.00	.64*	.241	.023	.07	1.21
7	38-My family members go without the things they WANT because of my disability care expenses.	1-Married/In a Committed Relationship	2.00	.59*	.231	.030	.05	1.14
			3.00	.04	.237	.983	-.52	.60
		2-Single/Never Married	1.00	-.59*	.231	.030	-1.14	-.05
			3.00	-.55	.256	.083	-1.15	.06
		3-Divorced, Widowed, Separated	1.00	-.04	.237	.983	-.60	.52
			2.00	.55	.256	.083	-.06	1.15

8	40-Because of my disability, my family members find it difficult to plan financially for the future.	1-Married/In a Committed Relationship	2.00	.92*	.244	.001	.34	1.49
			3.00	.30	.251	.456	-.29	.89
		2-Single/Never Married	1.00	-.92*	.244	.001	-1.49	-.34
			3.00	-.62	.271	.062	-1.25	.02
		3-Divorced, Widowed, Separated	1.00	-.30	.251	.456	-.89	.29
			2.00	.62	.271	.062	-.02	1.25
9	41-Because of my disability my family members have a hard time preparing for unexpected financial crisis.	1-Married/In a Committed Relationship	2.00	.91*	.259	.001	.30	1.53
			3.00	.38	.265	.321	-.24	1.01
		2-Single/Never Married	1.00	-.91*	.259	.001	-1.53	-.30
			3.00	-.53	.286	.154	-1.21	.14
		3-Divorced, Widowed, Separated	1.00	-.38	.265	.321	-1.01	.24
			2.00	.53	.286	.154	-.14	1.21
10	42-My family helps me to get jobs and work.	1-Married/In a Committed Relationship	2.00	-.86*	.223	.000	-1.39	-.33
			3.00	-.30	.228	.381	-.84	.24
		2-Single/Never Married	1.00	.86*	.223	.000	.33	1.39
			3.00	.56	.246	.065	-.03	1.14
		3-Divorced, Widowed, Separated	1.00	.30	.228	.381	-.24	.84
			2.00	-.56	.246	.065	-1.14	.03

*. The mean difference is significant at the .05 level.

Employment Status

Employment comparisons were examined among: (1) Full time (n = 31); (2) Part-time (n = 29); (3) Unemployed (n = 99); and (4) Other groupings (n = 41). There were no statistically significant differences in participants' perceptions of the impact of disability on family by employment groupings, *F* (150, 437) = 1.140, *p* = .156; Pillai's Trace = .830; partial η2 = .277.

Education

Education comparisons were examined among: (1) "High School or Less" (n = 33); (2) "Some College" (n = 91); (3) "College Degree" (n = 60); and (4) "Masters Degree or Higher" (n = 18) categories. There were no statistically significant differences in participants' perceptions of the impact of disability on family by education groupings, *F* (150, 453) = .770, *p* = .971; Pillai's Trace = .609; partial η2 = .203.

Income

Comparisons were examined by Annual Income among: (1) "Less than $20,000" (n = 153); (2) "$20,000-$39,999" (n = 31); and (3) "Greater than $40,000" (n = 16) groupings. There was a statistically significant difference in participants' perceptions of the impact of disability and family by income groupings, *F* (100, 298) = 2.258, *p* = .001; Pillai's Trace = .705; partial η2 = .353.

Between subjects tests revealed four statistically significant differences between participants by income groupings: *(1) Because I have a disability the money I make from work is enough to care for my family, F* (2, 197) = 23.730, *p* < .0005; partial η2 = .194; *(2) My family has enough finances to care for my disability needs, F* (2, 197) = 7.860, *p* = .001; partial η2 =

.074; *(3) My family members go without the things they WANT because of my disability care expenses, F* (2, 197) = 3.166, *p* = .044; partial η2 = .031; *and (4) My family helps me to get jobs and work F* (2, 197) = 4.410, *p* = .013; partial η2 = .043.

Table 9 presents means, standard deviations, and cell size of each income group found to be statistically significant. Table 10 presents post hoc analyses for the mean score differences found to be significant.

Tukey post hoc analyses of the first item regarding personal income revealed that the significant mean score differences were between income groups “Less than $20,000” (*M* = 1.5, *SD* = 0.9) and “$20,000-$39,999” (*M* = 2.3, *SD* = 1.4) and “$40,000 and higher” (*M* = 2.7, *SD* = 1.5). The mean score difference between “Less than $20,000” and “$20,000-$39,999” was .91(95% CI, -1.4 to -0.5, *p* = .0005). The mean score difference between “Less than $20,000” and “$40,000 and higher” was 1.4 (95% CI, -2.0 to -0.8, *p* = .0005).

Post hoc analyses of the second item regarding family finances revealed that the significant mean score differences were between income groups “Less than $20,000” (*M* = 1.9, *SD* = 1.1) and “$40,000 and higher” (*M* = 3.1, *SD* = 1.7). The mean score difference between “Less than $20,000” and “$40,000 and higher” was 1.2 (95% CI, -1.9 to -0.4, *p* = .001).

Post hoc analyses of the third item regarding family members going without the things they want revealed that the significant mean score differences were between income groups “Less than $20,000” (*M* = 2.5, *SD* = 1.4) and “$40,000 and higher” (*M* = 1.6, *SD* = 1.1). The mean score difference between “Less than $20,000” and “$40,000 and higher” was 0.9 (95% CI, .05 to 1.8, *p* = .034).

Post hoc analyses of the fourth item regarding family employment assistance revealed that the significant mean score differences were between income groups “Less than $20,000” (*M* = 2.3, *SD* = 1.4) and “$40,000 and higher” (*M* = 1.4, *SD* = 0.9). The mean score difference between “Less than $20,000” and “$40,000 and higher” was 0.9 (95% CI, .04to 1.7, *p* = .036).

Table 9

Income Comparisons: Means Standard Deviations, and Category Size

	Item	Income Category	Mean	Std. Dev.	N
1	34-Because I have a disability the money I make from work is enough to care for my family.	<$20,000	1.4	0.8	153
		$20,000 - $39,999	2.3	1.3	31
		>$40,000	2.8	1.7	16
2	35-My family has enough finances to care for my disability needs	<$20,000	1.9	1.1	153
		$20,000 - $39,999	2.3	1.4	31
		>$40,000	3.1	1.7	16
3	38-My family members go without the things they WANT because of my disability care expenses.	<$20,000	2.5	1.4	153
		$20,000 - $39,999	2.4	1.3	31
		>$40,000	1.6	1.1	16
4	42-My family helps me to get jobs and work.	<$20,000	2.3	1.4	153
		$20,000 - $39,999	1.8	1.3	31
		>$40,000	1.4	0.9	16

Table 10
Income Comparisons: Tukey Post Hoc Analyses

	Dependent Variable	(I) Income Category	(J) Income Category	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
							Lower Bound	Upper Bound
1	34-Because I have a disability the money I make from work is enough to care for my family.	<$20,000	$20,000 - $39,999	-.91*	.188	.000	-1.36	-.47
			>$40,000	-1.37*	.251	.000	-1.96	-.78
		$20,000 - $39,999	<$20,000	.91*	.188	.000	.47	1.36
			>$40,000	-.46	.294	.263	-1.15	.23
		>$40,000	<$20,000	1.37*	.251	.000	.78	1.96
			$20,000 - $39,999	.46	.294	.263	-.23	1.15
2	35-My family has enough finances to care for my disability needs	<$20,000	$20,000 - $39,999	-.45	.240	.153	-1.01	.12
			>$40,000	-1.19*	.320	.001	-1.94	-.43
		$20,000 - $39,999	<$20,000	.45	.240	.153	-.12	1.01
			>$40,000	-.74	.375	.122	-1.63	.15
		>$40,000	<$20,000	1.19*	.320	.001	.43	1.94
			$20,000 - $39,999	.74	.375	.122	-.15	1.63
3	38-My family members go without the things they WANT because of my disability care expenses.	<$20,000	$20,000 - $39,999	.14	.270	.859	-.50	.78
			>$40,000	.90*	.361	.034	.05	1.76
		$20,000 - $39,999	<$20,000	-.14	.270	.859	-.78	.50
			>$40,000	.76	.423	.171	-.24	1.76

		>$40,000	<$20,000	-.90*	.361	.034	-1.76	-.05
			$20,000 - $39,999	-.76	.423	.171	-1.76	.24
4	42-My family helps me to get jobs and work.	<$20,000	$20,000 - $39,999	.51	.264	.135	-.12	1.13
			>$40,000	.88*	.352	.036	.04	1.71
		$20,000 - $39,999	<$20,000	-.51	.264	.135	-1.13	.12
			>$40,000	.37	.412	.644	-.61	1.34
		>$40,000	<$20,000	-.88*	.352	.036	-1.71	-.04
			$20,000 - $39,999	-.37	.412	.644	-1.34	.61

*. The mean difference is significant at the .05 level.

Primary Income Source

Comparisons were examined by Primary source of support or income among: (1) “Your personal income (earnings, interest, dividends, rent, etc); (2) “Your spouse’s income or support from family and friends”; (3) Public support such as SSDI, SSI, TANF, etc.”; and (4) “Other sources such as insurance or charities” categories. There was a statistically significant difference in participants’ perceptions of the impact of disability and family by primary income source, *F* (150, 450) = 1.5, *p* = .001; Pillai’s Trace = .999; partial η2 = .333.

Between subjects tests revealed 12 statistically significant differences between participants by primary income source: *(1) My family members seem physically tired because of the effort required to care for me F* (3, 197) = 2.867, *p* = .038; partial η2 = .042; *(2) My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family F* (3, 197) = 4.949, *p* = .002; partial η2 = .070; *(3) Because of my disability my siblings will have to care for me as I get older F* (3, 197) = 3.827, *p* = .011; partial η2 = .055; *(4) Someone in my family feels lonely because of my disability F* (3, 197) = 3.654, *p* = .014; partial η2 = .053; *(5) Someone in my family feels stressed because of my disability F* (3, 197) = 4.239, *p* = .006; partial η2 = .053; *(6) Family outings are difficult because of my disability F* (3, 197) = 3.070, *p* = .029; partial η2 = .045; *(7) Finding a boyfriend or girlfriend is or has been difficult because of my disability F* (3, 197) = 7.522, *p* < 0005; partial η2 = .103; *(8) Because I have a disability the money I make from work is enough to care for my family F* (3, 197) = 7.217, *p* < 0005; partial η2 = .099; *(9) My family has enough finances to care for my disability needs F* (3, 197) = 3.541, *p* = .016; partial η2 = .051; *(10) Because of my disability, my family members find it difficult to plan financially for the future F* (3, 197) = 3.388, *p* = .019; partial η2 = .049; *(11) Because of my disability my family members have a hard time preparing for unexpected financial crisis F* (3,

197) = 2.940, *p* = .034; partial η2 = .043; *(12) My family believes that God can cure my disability* *F* (3, 197) = 5.116, *p* = .002; partial η2 = .072.

Table 11 presents means, standard deviations, and cell size of each income group found to be statistically significant. Table 14 presents post hoc analyses for the mean score differences found to be significant.

Tukey post hoc analyses of the first item regarding physical fatigue of family members revealed that the significant mean score differences were between primary income source groups "Your personal income" (*M* = 1.7, *SD* = 1.1) and "Public Support (SSDI, SSI, TANF, etc)" (*M* = 2.2, *SD* = 1.2). The mean score difference between "Your personal income" and "Your spouse's income, or support from family and friends" was 0.5 (95% CI, -1.1 to -0.1, *p* = .041).

Post hoc analyses of the second item (*My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family*) revealed that the significant mean score differences were between primary income source groups "Other sources such as insurance or charities" (*M* = 3.4, *SD* = 1.1), "personal income" (*M* = 2.0, *SD* = 1.2), "spouse's income, or support from family and friends" (*M* = 2.3, *SD* = 1.3), and "Public support such as SSDI, SSI, TANF, etc." (*M* = 2.2, *SD* = 1.3). The mean score difference between "Other sources such as insurance or charities" and "personal income" was 1.3 (95% CI, 0.4 to 2.2, *p* = .001). Mean score difference between "Other sources such as insurance or charities" and "spouse's income, or support from family and friends" was 1.1 (95% CI, .15 to 2.0, *p* = .016). Finally, the mean score difference between "Other sources such as insurance or charities" and "Public support such as SSDI, SSI, TANF, etc." was 1.1 (95% CI, .25 to 2.0, *p* = .005).

Post hoc analyses of the third item regarding sibling care of the individual with a disability revealed that the significant mean score differences were between primary income source groups “Your personal income” (*M* = 1.7, *SD* = 1.1) and “Public Support (SSDI, SSI, TANF, etc)” (*M* = 2.2, *SD* = 1.2). The mean score difference was 0.6 (95% CI, -1.0 to -.06, *p* = .021).

Post hoc analyses of the fourth item regarding feelings of loneliness for a family member revealed that the significant mean score differences were between primary income source groups “Your personal income” (*M* = 1.5, *SD* = 0.9) and “spouse’s income, or support from family and friends” (*M* = 2.1, *SD* = 1.2). The mean score difference was 0.6 (95% CI, -1.1 to -.01, *p* = .046).

Post hoc analyses of the fifth item regarding feelings of distress for a family member revealed that the significant mean score differences were between primary income source groups “Your personal income” (*M* = 2.3, *SD* = 1.1) and “spouse’s income, or support from family and friends” (*M* = 3.2, *SD* = 1.1). The mean score difference was 0.8 (95% CI, -1.5 to -.19, *p* = .005).

Analyses of the sixth item regarding family outings revealed no significant post hoc mean score differences. Mean scores on this item were: (a) “Personal income” (*M* = 1.9, *SD* = 1.0); (b) “spouse’s income, or support from family and friends” (*M* = 2.4, *SD* = 1.0); (c) “Public support such as SSDI, SSI, TANF, etc.” (*M* = 2.3, *SD* = 1.0); and (d) “Other sources such as insurance or charities” (*M* = 2.6, *SD* = 1.0).

Post hoc analyses of the seventh item regarding intimate relationship development revealed that the significant mean score differences were between primary income source groups: (a) “spouse’s income, or support from family and friends” (*M* = 1.8, *SD* = 1.0); (b) “Public support such as SSDI, SSI, TANF, etc.” (*M* = 2.8, *SD* = 1.2); and (c) “Other sources such as insurance or charities" (*M* = 2.9, *SD* = 0.9). The mean score difference between "spouse's income, or support from family and friends" and "Public support such as SSDI, SSI, TANF, etc." was 0.9 (95% CI, -1.5 to -0.4, $p < .0005$). The mean score difference between "spouse's income, or support from family and friends" and "Other sources such as insurance or charities" was 1.1 (95% CI, -1.9 to -0.2, $p = .008$).

Post hoc analyses of the eighth item personal earned income revealed that the significant mean score differences were between primary income source groups: (a) "Personal income" (*M* = 2.2, *SD* = 1.4); (b) "spouse's income, or support from family and friends" (*M* = 1.4, *SD* = 0.9); (c) "Public support such as SSDI, SSI, TANF, etc." (*M* = 1.4, *SD* = 0.8); and (d) "Other sources such as insurance or charities" (*M* = 1.4, *SD* = 0.8). The mean score difference between "Personal income" and "spouse's income, or support from family and friends" was .71 (95% CI, .18 to 1.3, $p = .004$). Mean score difference between "Personal income" and "Public support such as SSDI, SSI, TANF, etc." was .74 (95% CI, .29 to 1.2, $p < .0005$). Finally, the mean score difference between "Personal income" and "Other sources such as insurance or charities" was .74 (95% CI, .02 to 1.5, $p = .042$).

Post hoc analyses of the ninth item regarding family finance revealed that the significant mean score differences were between primary income source groups "Your personal income" (*M* = 2.5, *SD* = 1.5) and "Public Support (SSDI, SSI, TANF, etc)" (*M* = 1.8, *SD* = 1.0). The mean score difference was 0.6 (95% CI, .09 to 1.2, $p = .014$).

Post hoc analyses of the tenth item regarding family financial planning revealed that the significant mean score differences were between primary income source groups "Your personal income” (*M* = 2.0, *SD* = 1.3) and “spouse’s income, or support from family and friends” (*M* = 2.9, *SD* = 1.5). The mean score difference was 0.9 (95% CI, -1.6 to -0.1, *p* = .020).

Analyses of the eleventh item regarding family financial crisis revealed no significant post hoc mean score differences. Mean scores on this item were: (a) “Personal income” (*M* = 2.1, *SD* = 1.3); (b) “spouse’s income, or support from family and friends” (*M* = 2.9, *SD* = 1.5); (c) “Public support such as SSDI, SSI, TANF, etc.” (*M* = 2.7, *SD* = 1.6); and (d) “Other sources such as insurance or charities” (*M* = 2.8, *SD* = 1.8).

Lastly, post hoc analyses of the twelfth item regarding the family belief that God can cure disability revealed that the significant mean score differences were between primary income source groups “Your personal income” (*M* = 1.9, *SD* = 1.1) and “Other sources such as insurance or charities (*M* = 3.1, *SD* = 0.9). The mean score difference was 1.3 (95% CI, -1.9 to -0.3, *p* = .002).

Table 11

Primary Source of Income Comparisons: Means, Standard Deviations, and Category Size

		Primary Income	Mean	Std. Deviation	N
1	2-My family members seem physically tired because of the effort required to care for me.	Your personal income (earnings, interest, dividends, rent)	1.7	1.1	59
		Your spouse's income, or support from family and friends	2.2	1.3	41
		Public support such as SSDI, SSI, TANF, etc.	2.2	1.2	84
		Other sources such as insurance or charities	2.2	1.2	17

2	4-My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family .	Your personal income (earnings, interest, dividends, rent)	2.0	1.2	59
		Your spouse's income, or support from family and friends	2.3	1.3	41
		Public support such as SSDI, SSI, TANF, etc.	2.2	1.3	84
		Other sources such as insurance or charities	3.4	1.1	17
3	7-Because of my disability my siblings will have to care for me as I get older.	Your personal income (earnings, interest, dividends, rent)	1.5	0.9	59
		Your spouse's income, or support from family and friends	1.5	0.8	41
		Public support such as SSDI, SSI, TANF, etc.	2.0	1.3	84
		Other sources such as insurance or charities	1.9	1.4	17
4	13-Someone in my family feels lonely because of my disability.	Your personal income (earnings, interest, dividends, rent)	1.5	0.9	59
		Your spouse's income, or support from family and friends	2.1	1.2	41
		Public support such as SSDI, SSI, TANF, etc.	1.7	1.1	84
		Other sources such as insurance or charities	2.2	1.1	17
5	14-Someone in my family feels stressed because of my disability.	Your personal income (earnings, interest, dividends, rent)	2.3	1.1	59
		Your spouse's income, or support from family and friends	3.2	1.1	41
		Public support such as SSDI, SSI, TANF, etc.	2.8	1.3	84
		Other sources such as insurance or charities	3.1	1.1	17
6	22-Family outings are difficult because of my disability.	Your personal income (earnings, interest, dividends, rent)	1.9	1.0	59

		Your spouse's income, or support from family and friends	2.4	1.0	41
		Public support such as SSDI, SSI, TANF, etc.	2.4	1.0	84
		Other sources such as insurance or charities	2.6	1.1	17
7	32-Finding a boyfriend or girlfriend is or has been difficult because of my disability.	Your personal income (earnings, interest, dividends, rent)	2.3	1.2	59
		Your spouse's income, or support from family and friends	1.8	1.1	41
		Public support such as SSDI, SSI, TANF, etc.	2.8	1.2	84
		Other sources such as insurance or charities	2.9	1.0	17
8	34-Because I have a disability the money I make from work is enough to care for my family.	Your personal income (earnings, interest, dividends, rent)	2.2	1.4	59
		Your spouse's income, or support from family and friends	1.4	0.9	41
		Public support such as SSDI, SSI, TANF, etc.	1.4	0.8	84
		Other sources such as insurance or charities	1.4	0.8	17
9	35-My family has enough finances to care for my disability needs	Your personal income (earnings, interest, dividends, rent)	2.5	1.5	59
		Your spouse's income, or support from family and friends	2.1	1.2	41
		Public support such as SSDI, SSI, TANF, etc.	1.8	1.0	84
		Other sources such as insurance or charities	1.7	1.0	17
10	40-Because of my disability, my family members find it difficult to plan financially for the future.	Your personal income (earnings, interest, dividends, rent)	2.0	1.3	59
		Your spouse's income, or support from family and friends	2.9	1.5	41
		Public support such as SSDI, SSI, TANF, etc.	2.6	1.6	84
		Other sources such as insurance	2.7	1.5	17

		or charities			
11	41-Because of my disability my family members have a hard time preparing for unexpected financial crisis.	Your personal income (earnings, interest, dividends, rent)	2.1	1.4	59
		Your spouse's income, or support from family and friends	2.9	1.5	41
		Public support such as SSDI, SSI, TANF, etc.	2.7	1.6	84
		Other sources such as insurance or charities	2.9	1.8	17
12	50-My family believes that God can cure my disability.	Your personal income (earnings, interest, dividends, rent)	2.0	1.1	59
		Your spouse's income, or support from family and friends	2.5	1.1	41
		Public support such as SSDI, SSI, TANF, etc.	2.4	1.1	84
		Other sources such as insurance or charities	3.1	0.9	17

Table 12

Primary Source of Income Comparisons: Tukey Post Hoc Analyses

	Dependent Variable	(I) Primary Income	(J)	Mean Diff. (I-J)	Std. Error	Sig.	95% Confidence Interval	
							Lower Bound	Upper Bound
1	2-My family members seem physically tired because of the effort required to care for me.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.56	.243	.103	-1.19	.07
			3.00	-.54*	.203	.041	-1.07	-.01
			4.00	-.52	.330	.401	-1.37	.34
		2-Your spouse's income, or support from family and friends	1.00	.56	.243	.103	-.07	1.19
			3.00	.02	.228	1.000	-.57	.61
			4.00	.04	.345	.999	-.85	.94
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.54*	.203	.041	.01	1.07
			2.00	-.02	.228	1.000	-.61	.57
			4.00	.03	.318	1.000	-.80	.85
		4-Other sources such as insurance or charities	1.00	.52	.330	.401	-.34	1.37
			2.00	-.04	.345	.999	-.94	.85
			3.00	-.03	.318	1.000	-.85	.80
2	4-My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family .	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.23	.255	.794	-.89	.43
			3.00	-.20	.213	.772	-.76	.35
			4.00	-1.32*	.345	.001	-2.21	-.43
		2-Your spouse's income, or support from family and friends	1.00	.23	.255	.794	-.43	.89
			3.00	.03	.239	.999	-.59	.65
			4.00	-1.08*	.361	.016	-2.02	-.15

		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.20	.213	.772	-.35	.76
			2.00	-.03	.239	.999	-.65	.59
			4.00	-1.11*	.333	.005	-1.98	-.25
		4-Other sources such as insurance or charities	1.00	1.32*	.345	.001	.43	2.21
			2.00	1.08*	.361	.016	.15	2.02
			3.00	1.11*	.333	.005	.25	1.98
3	7-Because of my disability my siblings will have to care for me as I get older.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.01	.226	1.000	-.60	.57
			3.00	-.55*	.189	.021	-1.04	-.06
			4.00	-.47	.306	.425	-1.26	.33
		2-Your spouse's income, or support from family and friends	1.00	.01	.226	1.000	-.57	.60
			3.00	-.54	.212	.059	-1.09	.01
			4.00	-.45	.321	.493	-1.28	.38
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.55*	.189	.021	.06	1.04
			2.00	.54	.212	.059	-.01	1.09
			4.00	.08	.296	.992	-.68	.85
		4-Other sources such as insurance or charities	1.00	.47	.306	.425	-.33	1.26
			2.00	.45	.321	.493	-.38	1.28
			3.00	-.08	.296	.992	-.85	.68
4	13-Someone in my family feels lonely because of my disability.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.56*	.215	.046	-1.12	-.01
			3.00	-.16	.180	.816	-.62	.31
			4.00	-.73	.292	.064	-1.48	.03
		2-Your spouse's income, or support from family and friends	1.00	.56*	.215	.046	.01	1.12
			3.00	.41	.202	.187	-.12	.93
			4.00	-.16	.306	.952	-.95	.63
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.16	.180	.816	-.31	.62
			2.00	-.41	.202	.187	-.93	.12
			4.00	-.57	.282	.185	-1.30	.16
		4-Other sources such as	1.00	.73	.292	.064	-.03	1.48
			2.00	.16	.306	.952	-.63	.95

		insurance or charities	3.00	.57	.282	.185	-.16	1.30
5	14-Someone in my family feels stressed because of my disability.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.83*	.248	.005	-1.47	-.19
			3.00	-.43	.207	.157	-.97	.10
			4.00	-.72	.336	.143	-1.59	.15
		2-Your spouse's income, or support from family and friends	1.00	.83*	.248	.005	.19	1.47
			3.00	.40	.232	.322	-.20	1.00
			4.00	.11	.352	.989	-.80	1.02
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.43	.207	.157	-.10	.97
			2.00	-.40	.232	.322	-1.00	.20
			4.00	-.29	.324	.816	-1.12	.55
		4-Other sources such as insurance or charities	1.00	.72	.336	.143	-.15	1.59
			2.00	-.11	.352	.989	-1.02	.80
			3.00	.29	.324	.816	-.55	1.12
6	22-Family outings are difficult because of my disability.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.48	.209	.100	-1.02	.06
			3.00	-.41	.175	.088	-.87	.04
			4.00	-.66	.283	.098	-1.39	.08
		2-Your spouse's income, or support from family and friends	1.00	.48	.209	.100	-.06	1.02
			3.00	.07	.196	.985	-.44	.58
			4.00	-.17	.297	.937	-.94	.60
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.41	.175	.088	-.04	.87
			2.00	-.07	.196	.985	-.58	.44
			4.00	-.24	.274	.811	-.95	.47
		4-Other sources such as insurance or charities	1.00	.66	.283	.098	-.08	1.39
			2.00	.17	.297	.937	-.60	.94
			3.00	.24	.274	.811	-.47	.95
7	32-Finding a boyfriend or girlfriend is	1-Your personal income	2.00	.45	.234	.223	-.16	1.06

	or has been difficult because of my disability.	(earnings, interest, dividends, rent)	3.00	-.50	.196	.058	-1.00	.01
			4.00	-.63	.317	.198	-1.45	.19
		2-Your spouse's income, or support from family and friends	1.00	-.45	.234	.223	-1.06	.16
			3.00	-.95*	.219	.000	-1.51	-.38
			4.00	-1.08*	.332	.008	-1.94	-.22
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.50	.196	.058	-.01	1.00
			2.00	.95*	.219	.000	.38	1.51
			4.00	-.13	.306	.973	-.93	.66
		4-Other sources such as insurance or charities	1.00	.63	.317	.198	-.19	1.45
			2.00	1.08*	.332	.008	.22	1.94
			3.00	.13	.306	.973	-.66	.93
8	34-Because I have a disability the money I make from work is enough to care for my family.	1-Your personal income (earnings, interest, dividends, rent)	2.00	.71*	.206	.004	.18	1.25
			3.00	.74*	.172	.000	.29	1.18
			4.00	.74*	.279	.042	.02	1.46
		2-Your spouse's income, or support from family and friends	1.00	-.71*	.206	.004	-1.25	-.18
			3.00	.02	.193	.999	-.48	.52
			4.00	.03	.292	1.000	-.73	.78
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	-.74*	.172	.000	-1.18	-.29
			2.00	-.02	.193	.999	-.52	.48
			4.00	.00	.269	1.000	-.69	.70
		4-Other sources such as insurance or charities	1.00	-.74*	.279	.042	-1.46	-.02
			2.00	-.03	.292	1.000	-.78	.73
			3.00	.00	.269	1.000	-.70	.69
9	35-My family has enough finances to care for my disability needs	1-Your personal income (earnings, interest, dividends, rent)	2.00	.41	.251	.365	-.24	1.06
			3.00	.64*	.210	.014	.09	1.18
			4.00	.75	.340	.124	-.13	1.63
		2-Your spouse's income, or	1.00	-.41	.251	.365	-1.06	.24
			3.00	.23	.235	.769	-.38	.84

		support from family and friends	4.00	.34	.356	.771	-.58	1.27
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	-.64*	.210	.014	-1.18	-.09
			2.00	-.23	.235	.769	-.84	.38
			4.00	.12	.328	.985	-.74	.97
		4-Other sources such as insurance or charities	1.00	-.75	.340	.124	-1.63	.13
			2.00	-.34	.356	.771	-1.27	.58
			3.00	-.12	.328	.985	-.97	.74
10	40-Because of my disability, my family members find it difficult to plan financially for the future.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.87*	.298	.020	-1.64	-.10
			3.00	-.61	.249	.072	-1.25	.04
			4.00	-.67	.403	.344	-1.72	.37
		2-Your spouse's income, or support from family and friends	1.00	.87*	.298	.020	.10	1.64
			3.00	.26	.279	.788	-.46	.98
			4.00	.20	.422	.967	-.90	1.29
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.61	.249	.072	-.04	1.25
			2.00	-.26	.279	.788	-.98	.46
			4.00	-.06	.389	.998	-1.07	.95
		4-Other sources such as insurance or charities	1.00	.67	.403	.344	-.37	1.72
			2.00	-.20	.422	.967	-1.29	.90
			3.00	.06	.389	.998	-.95	1.07
11	41-Because of my disability my family members have a hard time preparing for unexpected financial crisis.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.80	.316	.058	-1.62	.02
			3.00	-.64	.264	.079	-1.32	.05
			4.00	-.78	.428	.266	-1.89	.33
		2-Your spouse's income, or support from family and friends	1.00	.80	.316	.058	-.02	1.62
			3.00	.16	.296	.945	-.60	.93
			4.00	.02	.449	1.000	-1.14	1.18

		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.64	.264	.079	-.05	1.32
			2.00	-.16	.296	.945	-.93	.60
			4.00	-.14	.414	.985	-1.22	.93
		4-Other sources such as insurance or charities	1.00	.78	.428	.266	-.33	1.89
			2.00	-.02	.449	1.000	-1.18	1.14
			3.00	.14	.414	.985	-.93	1.22
12	50-My family believes that God can cure my disability.	1-Your personal income (earnings, interest, dividends, rent)	2.00	-.48	.226	.149	-1.07	.11
			3.00	-.45	.189	.089	-.93	.04
			4.00	-1.13*	.306	.002	-1.93	-.34
		2-Your spouse's income, or support from family and friends	1.00	.48	.226	.149	-.11	1.07
			3.00	.03	.212	.998	-.51	.58
			4.00	-.65	.321	.177	-1.49	.18
		3-Public support such as SSDI, SSI, TANF, etc.	1.00	.45	.189	.089	-.04	.93
			2.00	-.03	.212	.998	-.58	.51
			4.00	-.69	.296	.095	-1.46	.08
		4-Other sources such as insurance or charities	1.00	1.13*	.306	.002	.34	1.93
			2.00	.65	.321	.177	-.18	1.49
			3.00	.69	.296	.095	-.08	1.46

Disability Category

Comparisons were examined by Disability among: (1) "Sensory/Communicative" (n = 55); (2) "Physical" (n = 87); and (3) "Mental" (n = 59) categories. There was a statistically significant difference in participants' perceptions of the impact of disability and family by disability category, *F* (100, 300) = 1.815, $p < .0005$; Pillai's Trace = .754; partial η2 = .377.

Between subjects tests revealed 19 statistically significant differences between participants by disability category: *(1) Because of my disability, a loved one physically hurt themselves while taking care of me, F* (2, 198) = 3.108, $p = .047$; partial η2 = .030; *(2) My family members seem physically tired because of the effort required to care for me, F* (2, 198) = 6.141, $p = .003$; partial η2 = .058; *(3) My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family, F* (2, 198) = 16.765, $p < .0005$; partial η2 = .145; *(4) Because of my disability my siblings will have to care for me as I get older, F* (2, 198) = 4.516, $p = .012$; partial η2 = .044; *(5) Someone in my family turns to substances (alcohol, drugs, etc.) because of my disability, F* (2, 198) = 8.702, $p < .0005$; partial η2 = .081; *(6) Eating healthy is important to my family because of my disability, F* (2, 198) = 3.065, $p = .049$; partial η2 = .030; *(7) Someone in my family is sad or depressed because of my disability, F* (2, 198) = 3.268, $p = .040$; partial η2 = .032; *(8) Someone in my family feels guilty because of my disability, F* (2, 198) = 3.110, $p = .047$; partial η2 = .030; *(9) Someone in my family feels lonely because of my disability, F* (2, 198) = 3.482, $p = .033$; partial η2 = .034; *(10) Because I have a disability my parents argue (present or past), F* (2, 198) = 5.231, $p = .006$; partial η2 = .050; *(11) My family members are social with fewer friends because of my disability, F* (2, 198) = 3.865, $p = .027$; partial η2 = .036; *(12) My family spends more time together because of my disability, F* (2, 198) = 3.175, $p = .044$; partial η2 = .031; *(13) Maintaining a loving relationship with a significant* *other is difficult because of my disability, F* (2, 198) = 4.312, *p* = .015; partial η2 = .042; *(14) My family has enough finances to care for my disability needs, F* (2, 198) = 6.441, *p* = .002; partial η2 = .061; *(15) My family has to pay more for medical costs because of my disability, F* (2, 198) = 3.553, *p* = .031; partial η2 = .034; *(16) My family members go without the things they WANT because of my disability care expenses, F* (2, 198) = 3.737, *p* = .026; partial η2 = .036; *(17) Because of my disability, my family members find it difficult to plan financially for the future, F* (2, 198) = 6.191, *p* = .002; partial η2 = .059; *(18) Because of my disability my family members have a hard time preparing for unexpected financial crisis, F* (2, 198) = 5.161, *p* = .007; partial η2 = .050; *(19) My family believes that God can cure my disability, F* (2, 198) = 3.589, *p* = .023; partial η2 = .038.

Table 13 presents means, standard deviations, and cell size of each disability category for each significant item. Table 14 presents the post hoc analyses for the mean score differences found to be significant. Post hoc analyses for items related to healthy eating, family members being sad or depressed, and family spending more time together because of the disability revealed no significant differences. Hsu (1996) explained that a statistically significant one-way MANOVA and no corresponding pairwise post hoc comparison is likely due to fundamental differences in the distributions used the analyses.

Tukey post hoc analyses of the first item regarding the physical injury of family members revealed that the significant mean score differences were between sensory/communicative (*M* = 1.2, *SD* = 0.5) and Physical (*M* = 1.6, *SD* = 0.9) disability categories. The mean score difference between these categories was 0.4 (95% CI, -0.7 to -0.02, *p* = .036).

Analyses of the second item regarding fatigue of family members revealed significant post hoc mean score differences between sensory/communicative (*M =* 1.6, *SD* = 0.9), physical (*M* = 2.1, *SD* = 1.3), and mental (*M* = 2.3, *SD* = 1.3) disability categories. The mean score difference between sensory/communicative and physical categories was 0.6 (95% CI, -1.1 to -0.09, *p =* .015). The difference between sensory/communicative and mental disability categories was 0.7 (95% CI, -1.3 to -.21, *p =* .003).

Post hoc analyses of the third item regarding worsening health for a family member revealed significant mean score differences between sensory/communicative (*M =* 1.5, *SD* = 0.8), physical (*M* = 2.7, *SD* = 1.4), and mental (*M* = 2.3, *SD* = 1.3) disability categories. The mean score difference between sensory/communicative and physical categories was 1.2 (95% CI, -1.7 to -0.7, *p* < .0001). The difference between sensory/communicative and mental disability categories was 0.83 (95% CI, -1.4 to -0.3, *p =* .001).

Post hoc analyses of the fourth item "Because of my disability my siblings will have to care for me, as I get older" revealed significant mean score differences between sensory/communicative (*M =* 1.4, *SD* = 0.7), physical (*M* = 1.9, *SD* = 1.3), and mental (*M* = 1.9, *SD* = 1.2) disability categories. The mean score difference between sensory/communicative and physical categories was 0.5 (95% CI, -.95 to -0.04, *p* = .028). The difference between sensory/communicative and mental disability categories was 0.57 (95% CI, -1.1 to -0.07, *p =* .020).

Post hoc analyses of the fifth item "Someone in my family turns to substances (alcohol, drugs, etc.) because of my disability" revealed significant mean score differences between mental (*M =* 1.9, *SD* = 1.3), sensory/communicative (*M* = 1.2, *SD* = 0.5), and physical (*M* = 1.3, *SD* = 0.7) disability categories. The mean score difference between mental and sensory/communicative disability categories was 0.68 (95% CI, 0.27 to 1.09, *p* < .0001). The difference between mental and physical categories was 0.51 (95% CI, 0.14 to 0.88, *p* = .003).

Post hoc analyses of the item regarding family feelings of guilt about the disability revealed significant mean score differences between sensory/communicative (*M* = 1.7, *SD* = 0.9) and mental (*M* = 2.2, *SD* = 1.2) disability categories. The mean score difference between these categories was 0.51 (95% CI, -1.0 to -0.02, *p* = .039).

Analyses of the item regarding family feelings of loneliness about the disability revealed significant post hoc mean score differences between sensory/communicative (*M* = 1.5, *SD* = 0.9) and mental (*M* = 2.0, *SD* = 1.2) disability categories. The mean score difference between these categories was 0.53 (95% CI, -1.0 to -0.05, *p* = .025).

Post hoc analyses of the item "Because I have a disability my parents argue" revealed significant mean score differences between mental (*M* = 2.0, *SD* = 1.4), sensory/communicative (*M* = 1.4, *SD* = 0.8), and physical (*M* = 1.5, *SD* = 0.9) disability categories. The mean score difference between mental and sensory/communicative disability categories was 0.58 (95% CI, 0.1 to 1.06, *p* = .012). The difference between mental and physical categories was 0.5 (95% CI, 0.07 to 0.93, *p* = .017).

Post hoc analyses of the item regarding family having fewer friends because of disability revealed significant mean score differences between sensory/communicative (*M* = 1.5, *SD* = 0.8) and mental (*M* = 1.9, *SD* = 0.9) disability categories. The mean score difference between these categories was 0.44 (95% CI, -0.8 to -0.04, *p* = .026).

Analyses of the item regarding relationship maintenance revealed significant post hoc mean score differences between sensory/communicative (*M* = 2.1, *SD* = 1.2) and mental (*M* = 2.8, *SD* = 1.2) disability categories. The mean score difference between these categories was 0.64 (95% CI, -1.2 to -0.1, *p* = .010).

Post hoc analyses of the item regarding family having sufficient finances revealed significant mean score differences between sensory/communicative (*M* = 2.5, *SD* = 1.3) and physical (*M* = 1.7, *SD* = 1.0) disability categories. The mean score difference between these categories was 0.75 (95% CI, 0.25 to 1.25, *p* = .001).

Post hoc analyses of the item regarding family medical costs revealed significant mean score differences between physical (*M* = 2.9, *SD* = 1.4) and mental (*M* = 2.3, *SD* = 1.6) disability categories. The mean score difference between these categories was 0.6 (95% CI, 0.02 to 1.2, *p* = .041).

Post hoc analyses of the item regarding family going in want because of the disability revealed significant mean score differences between sensory/communicative (*M* = 2.0, *SD* = 1.2) and physical (*M* = 2.6, *SD* = 1.4) disability categories. The mean score difference between these categories was 0.62 (95% CI, -1.2 to -0.1, *p* = .024).

Post hoc analyses of the item regarding family financial planning revealed significant mean score differences between sensory/communicative (*M* = 1.9, *SD* = 1.3), physical (*M* = 2.8, *SD* = 1.4), and mental (*M* = 2.6, *SD* = 1.6) disability categories. The mean score difference between sensory/communicative and physical categories was 0.9 (95% CI, -1.5 to -0.3, *p* = .002). The difference between sensory/communicative and mental disability categories was 0.66 (95% CI, -1.3 to -0.02, *p* = .042).

Analyses of the item regarding family financial crisis revealed significant post hoc mean score differences between sensory/communicative (*M* = 2.0, *SD* = 1.4), physical (*M* = 2.8, *SD* = 1.5), and mental (*M* = 2.7, *SD* = 1.7) disability categories. The mean score difference between sensory/communicative and physical categories was 0.82 (95% CI, -1.5 to -0.2, *p* = .007). The difference between sensory/communicative and mental disability categories was 0.73 (95% CI, -1.4 to -0.04, *p* = .035).

Finally, analyses of the item regarding relationship maintenance revealed significant post hoc mean score differences between sensory/communicative (*M* = 2.0, *SD* = 1.1) and mental (*M* = 2.6, *SD* = 1.1) disability categories. The mean score difference between these categories was 0.56 (95% CI, -1.1 to -0.06, *p* = .024).

Table 13
Disability Comparisons: Means, Standard Deviations, and Category Size

	Item	Disability Category	Mean	Std. Deviation	N
1	Because of my disability, a loved one physically hurt themselves while taking care of me.	Sensory/Communicative	1.2	0.6	55
		Physical	1.6	1.0	87
		Mental	1.5	1.0	59
2	My family members seem physically tired because of the effort required to care for me.	Sensory/Communicative	1.6	0.9	55
		Physical	2.2	1.3	87
		Mental	2.3	1.3	59
4	My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family.	Sensory/Communicative	1.5	0.8	55
		Physical	2.7	1.4	87
		Mental	2.3	1.3	59
7	Because of my disability my siblings will have to care for me, as I get older.	Sensory/Communicative	1.4	0.7	55
		Physical	1.9	1.3	87
		Mental	1.9	1.2	59
8	Someone in my family turns to substances (alcohol, drugs, etc.)	Sensory/Communicative	1.2	0.5	55
		Physical	1.3	0.8	87
		Mental	1.9	1.3	59

	because of my disability.				
9	Eating healthy is important to my family because of my disability.	Sensory/Communicative	2.5	1.4	55
		Physical	3.1	1.4	87
		Mental	2.6	1.5	59
11	Someone in my family is sad or depressed because of my disability.	Sensory/Communicative	2.1	1.0	55
		Physical	2.5	1.1	87
		Mental	2.5	1.2	59
12	Someone in my family feels guilty because of my disability.	Sensory/Communicative	1.7	1.0	55
		Physical	2.0	1.1	87
		Mental	2.2	1.2	59
13	Someone in my family feels lonely because of my disability.	Sensory/Communicative	1.5	1.0	55
		Physical	1.7	1.0	87
		Mental	2.0	1.2	59
20	Because I have a disability my parents argue (present or past).	Sensory/Communicative	1.4	0.8	55
		Physical	1.5	0.9	87
		Mental	2.0	1.4	59
23	My family members are social with fewer friends because of my disability.	Sensory/Communicative	1.5	0.8	55
		Physical	1.8	0.9	87
		Mental	2.0	1.0	59
26	My family spends more time together because of my disability.	Sensory/Communicative	1.8	0.9	55
		Physical	2.1	1.0	87
		Mental	1.8	0.8	59
31	Maintaining a loving relationship with a significant other is difficult because of my disability.	Sensory/Communicative	2.1	1.2	55
		Physical	2.4	1.1	87
		Mental	2.8	1.2	59
35	My family has enough finances to care for my disability needs	Sensory/Communicative	2.5	1.4	55
		Physical	1.7	1.0	87
		Mental	2.1	1.4	59
36	My family has to pay more for medical costs because of my disability.	Sensory/Communicative	2.5	1.4	55
		Physical	2.9	1.4	87
		Mental	2.3	1.6	59
38	My family members go without the things they WANT because of my disability care expenses.	Sensory/Communicative	2.0	1.2	55
		Physical	2.6	1.4	87
		Mental	2.5	1.5	59
40	Because of my disability, my family members find it difficult	Sensory/Communicative	2.0	1.3	55
		Physical	2.8	1.4	87
		Mental	2.6	1.7	59

	to plan financially for the future.				
41	Because of my disability my family members have a hard time preparing for unexpected financial crisis.	Sensory/Communicative	2.0	1.4	55
		Physical	2.8	1.5	87
		Mental	2.8	1.7	59
50	My family believes that God can cure my disability.	Sensory/Communicative	2.0	1.1	55
		Physical	2.4	1.1	87
		Mental	2.6	1.1	59

Table 14

Disability Comparisons: Tukey Post Hoc Analyses

Dependent Variable	(I) Disability Category	(J) Disability Category	Mean Difference (I-J)	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1-Because of my disability, a loved one physically hurt him/herself while taking care of me.	Sensory/ Communicative	Physical	-0.37*	.036	-0.73	-0.02
2-My family members seem physically tired because of the effort required to care for me.	Sensory/ Communicative	Physical	-0.58*	.015	-1.06	-0.09
		Mental	-0.74*	.003	-1.27	-0.21
4-My disability causes worse health (back pain, headaches, sick more often, etc.) for someone in my family.	Sensory/ Communicative	Physical	-1.19*	.000	-1.68	-0.7
		Mental	-0.83*	.001	-1.36	-0.3
7-Because of my disability my siblings will have to care for me, as I get older.	Sensory/	Physical	-0.5*	.028	-0.95	-0.04

	Communicative					
		Mental	-0.57*	.020	-1.06	-0.07
8-Someone in my family turns to substances (alcohol, drugs, etc.) because of my disability.	Mental	Sensory/ Communicative	0.68*	.000	0.27	1.09
		Physical	0.51*	.003	0.14	0.88
12-Someone in my family feels guilty because of my disability.	Sensory/ Communicative	Mental	-0.51*	.039	-1.01	-0.02
13-Someone in my family feels lonely because of my disability.	Sensory/Communicative	Mental	-0.53*	.025	-1	-0.05
20-Because I have a disability my parents argue (present or past).	Mental	Sensory/Communicative	0.58*	.012	0.11	1.06
		Physical	0.5*	.017	0.07	0.93
23-My family members are social with fewer friends because of my disability.	Sensory/ Communicative	Mental	-0.44*	.026	-0.84	-0.04

31-Maintaining a loving relationship with a significant other is difficult because of my disability.	Sensory/ Communicative	Mental	-0.64*	.010	-1.15	-0.12
35-My family has enough finances to care for my disability needs	Sensory/Communicative	Physical	0.75*	.001	0.25	1.25
36-My family has to pay more for medical costs because of my disability.	Physical	Mental	0.6*	.041	0.02	1.19
38-My family members go without the things they WANT because of my disability care expenses.	Sensory/ Communicative	Physical	-0.62*	.024	-1.17	-0.07
40-Because of my disability, my family members find it difficult to plan financially for the future.	Sensory/ Communicative	Physical	-0.87*	.002	-1.46	-0.28
		Mental	-0.66*	.042	-1.31	-0.02
41-Because of my disability my family members have a hard time preparing for unexpected financial crisis.	Sensory/ Communicative	Physical	-0.82*	.007	-1.45	-0.19

		Mental	-0.73*	.035	-1.41	-0.04
50-My family believes that God can cure my disability.	Sensory/ Communicative	Mental	-0.56*	.024	-1.06	-0.06

Research Question 3: Relationships between Perceptions of Health and Quality of Life and Perceptions of Impact of Disability on Family

A Pearson's product-moment correlation was run to examine the third research question: “Are the perceptions of PWDs regarding health and quality of life related to their perception of the impact of disability on their family?” The predictor variables used to answer this question were: (1) Individual perception of overall health; (2) Individual perception of quality of life; and (3) Perception of family quality of life. Response options for these items were originally on a 5-point Likert Scale ranging from “Poor” to “Excellent.” On all three items the “Very Good” and “Excellent” categories were collapsed into “Very Good” in order to increase comprehensibility and reduce variance resulting in a 4-point Likert scale (1 = Poor, 2 = Fair, 3 = Good, 4 = Very Good). Frequencies, means, and standard deviations for these items can be found in Table 15.

Table 15
Perception of Health and Quality of Life

Item	*n*	*M*	*SD*	Poor %	Fair %	Good %	Very Good %
How would you rate your overall health?	407	2.8	0.9	6.6	33.7	38.3	20.9
How do you feel about your overall quality of life?	406	2.7	1.1	11.5	35.4	29.8	22.7
How do you feel about your family’s overall quality of life?	407	2.9	1.0	7.8	24.6	40.0	27.0

All 50 of the scale items from the IPFD-R were run as criterion variables using the bivariate correlation function in SPSS (22). This resulted in multiple statistically significant correlations between participant perceptions of health and quality of life and perceptions of impact of disability on their family ranging from small (0.1 < | *r* | < 0.3) to medium/moderate (0.3 < | *r* | <0.5) correlations (Cohen, 1988). Results presented in this section are medium/moderate correlations. Table 16 shows the correlation coefficients between perceptions of health, quality of life, and family quality of life and perceptions of impact of disability on the family as represented in the IPFD-R.

Perception of Personal Overall Health

Of the 50 IPFD-R items three reflected medium/moderate correlations with how participants rated their overall health. All others were smaller or insignificant. These correlations were related to family outings, financial sufficiency, and financial crises. There was a medium negative correlation (r = -.309, n = 384, *p* < .0005) between how participants rated their overall health and how they responded to the item "Family outings are difficult because of my disability." There was a moderate positive correlation (*r* = .345, n = 352, *p* < .0005) between how participants rated their overall health and how they responded to the item "My family has enough finances to care for my disability needs." Lastly, there was a medium negative correlation between how participants rated their overall health and how they responded to the item "Because of my disability my family members have a hard time preparing for unexpected financial crisis" (r = -.371, n = 349, *p* < .0005).

Individual Perception of Quality of Life

Nine medium/moderate correlations were found between individual perception of quality of life and perceptions of impact of disability on the family. Negative correlations were found among eight of the following items: (1) *Someone in my family is sad or depressed because of my disability* (*r* = -.321, n = 388, *p* <.0005); (2) *Someone in my family feels stressed because of my* *disability* (r = -.350, n = 387, $p < .0005$); (3) *Someone in my family feels angry because of my disability* (r = -.352, n = 380, $p < .0005$); (4) *Someone in my family feels frustrated because of my disability* (r = -.319, n = 385, $p < .0005$); (5) *Family outings are difficult because of my disability* (-.373, n = 382, $p < .0005$); (6) *My family members go without the things they NEED because of my disability care costs* (-.302, n = 353, $p < .0005$); (7) *Because of my disability, my family members find it difficult to plan financially for the future* (-.348, n = 352, $p < .0005$); and (8) *Because of my disability my family members have a hard time preparing for unexpected financial crisis* (-.375, n = 348, $p < .0005$). Lastly, a positive moderate correlation (.417, n = 349, $p < .0005$) occurred between participant rating of quality of life and the item "My family has enough finances to care for my disability needs."

Perception of Family Quality of Life

Three out of the 50 IPFD-R items were found to be medium/moderately correlated with participant ratings of their family's quality of life. These items were related to family members experiencing depression and anger in response to the disability as well as financial sufficiency. Participant ratings of their family's quality of life were negatively correlated with the items: "Someone in my family is sad or depressed because of my disability" (-.315, n = 389, $p < .0005$), and "Someone in my family feels angry because of my disability" (-.316, n = 380, $p < .0005$). Finally, there was a positive correlation with the item "My family has enough finances to care for my disability needs" (.351, n = 351, $p < .0005$).

Table 16

Correlation Coefficients: Perceptions of Health, Quality of Life, and Family

Criterion Variable	Overall Health	Quality of Life	Family QOL
1-Because of my disability, a loved one physically hurt themselves while taking care of me.	-.092	-.103*	-.124*
2-My family members seem physically tired because of the effort required to care for me.	-.195**	-.266**	-.165**
3-Because of my disability my family members have time to do things to care for themselves physically (like exercise).	.043	.094	.116*
4-My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family.	-.284**	-.252**	-.267**
5-My disability causes better health for someone in my family.	.107*	.134**	.097
6-I think my disability affects my family's daily routine activities.	-.299**	-.293**	-.229**
7-Because of my disability my siblings will have to care for me as I get older.	-.195**	-.203**	-.183**
8-Someone in my family turns to substances (alcohol, drugs, etc.) because of my disability.	-.083	-.170**	-.275**
9-Eating healthy is important to my family	-.153**	-.071	-.070

because of my disability.			
10-Someone in my family feels happy when they can help with my disability.	.082	.256**	.255**
11-Someone in my family is sad or depressed because of my disability.	-.237**	-.321**	-.315**
12-Someone in my family feels guilty because of my disability.	-.111*	-.197**	-.206**
13-Someone in my family feels lonely because of my disability.	-.188**	-.219**	-.296**
14-Someone in my family feels stressed because of my disability.	-.217**	-.350**	-.282**
15-Someone in my family feels angry because of my disability.	-.212**	-.352**	-.316**
16-Someone in my family feels frustrated because of my disability.	-.210**	-.319**	-.267**
17-My siblings are jealous of the attention I get (or got) because of my disability.	.057	-.027	-.050
18-My parents worry a lot because I have a disability.	-.087	-.168**	-.079
19-My parent's relationship is (or was) better or more loving because of my disability.	.031	.061	.063

20-Because I have a disability my parents argue (present or past).	-.055	-.194**	-.247**
21-My family would rather care for my disability needs than have a non-family member do it.	-.049	.017	.139**
22-Family outings are difficult because of my disability.	-.309**	-.373**	-.256**
23-My family members are social with fewer friends because of my disability.	-.202**	-.232**	-.256**
24-My family members have made new friends because of my disability.	.043	.097	.126*
25-My family socializes with other families with disabilities.	.045	.105*	.038
26-My family spends more time together because of my disability.	-.042	.028	.055
27-Some people treat my family with disrespect because I have a disability.	-.123*	-.152**	-.222**
28-My family members take part in fewer social activities because of the time required to care for my disability.	-.201**	-.242**	-.199**
29-Because of my disability I need family members to help me be social with others outside my household.	-.117*	-.185**	-.104*

30-My family has more community contact because of my disability.	.050	.077	-.023
31-Maintaining a loving relationship with a significant other is difficult because of my disability.	-.229**	-.279**	-.157**
32-Finding a boyfriend or girlfriend is or has been difficult because of my disability.	-.033	-.176**	-.111*
33-My disability income (i.e. SSI/ SSDI etc.) is sufficient to care for my family.	.150**	.142*	.094
34-Because I have a disability the money I make from work is enough to care for my family.	.221**	.249**	.165**
35-My family has enough finances to care for my disability needs	.345**	.417**	.351**
36-My family has to pay more for medical costs because of my disability.	-.160**	-.128*	-.057
37-My family members go without the things they NEED because of my disability care costs.	-.274**	-.302**	-.197**
38-My family members go without the things they WANT because of my disability care expenses.	-.203**	-.256**	-.183**
39-Because of my disability, my family	-.241**	-.274**	-.165**

members need to keep more than one job to provide for me.			
40-Because of my disability, my family members find it difficult to plan financially for the future.	-.298**	-.348**	-.270**
41-Because of my disability my family members have a hard time preparing for unexpected financial crisis.	-.371**	-.375**	-.268**
42-My family helps me to get jobs and work.	.032	-.003	.129*
43-My family feels closer to God because of my disability.	.048	.159**	.159**
44-My family blames God for my disability.	-.100	-.137*	-.169**
45-My family feels that my disability is a punishment from God.	-.119*	-.211**	-.248**
46-My family relies more on God to help us through hard times because of my disability.	-.029	-.014	.041
47-My disability has helped my family become more spiritual.	.059	.113*	.097
48-My disability has made my family become less spiritual.	-.132*	-.225**	-.203**

49-My family believes God can make my disability better.	-.002	.046	.029
50-My family believes that God can cure my disability.	-.047	.008	-.039

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Summary of Results

The statistical analyses for this research were conducted using descriptive statistics (percentages, means & standard deviations), Cronbach's alpha, one-way MANOVA, Tukey post hoc analyses, and Pearson's product-moment correlation. Quantitative results were tested at a significance level $p < .05$.

Research question one asked what are the perceptions of adults with disabilities regarding the impact of their disability on their family. This question was analyzed using descriptive statistics including percentages, means, and standard deviations.

The second research question asked what are the differences between participants' perceptions of the impact of disability on family based on demographic variables such as: (a) gender; (b) education; (c) race/ethnicity; (d) income; (e) primary income source; (f) relationship status; (g) employment status; and (h) disability. This inquiry was explored using a one-way MANOVA with Tukey post hoc analyses.

Lastly, the third research question asked if there is a relationship between the perceptions of PWDs regarding health and quality of life and their perception of the impact of disability on their family. This question was analyzed by running a Pearson's product-moment correlation.

This chapter has presented results of the data analyses conducted for this study. Results for quantitative data were reviewed. In Chapter five, these results will be interpreted with respect to previous research. Chapter five also explains the limitations of the current study and discusses implications for practice and future research.

CHAPTER V

DISCUSSION

The family in the experience of disability has been an important topic in rehabilitation counseling literature over the years (Millington, Jenkins, & Cottone, Finding family in rehabilitation counseling, 2015). Literature on families with disabilities has focused on: a) the impact of disability on family functioning and b) the impact family functioning has on the disability (Biegel, Singer, & Conway, 2012; Marini I. , Implications of social support and caregiving for loved ones with a disability, 2012b; Rolland, Families, illness, and disability, 1994). However, the prevailing research fueling this discourse has focused on the accounts given by family members (i.e. parents, siblings, and spouses) and excluded the perceptions of the individual member of the family with a disability (Glover-Graf, 2012; Marini, 2012b; Rosenthal, Kosciulek, Lee, Frain, & Ditchman, 2009).

Therefore, the purpose of this study was to explore the impact of disability on the family from the perspective of the person with the disability and compare findings to the relevant literature in order to determine if differences exist in these two perspectives (family members and the member with the disability). The following discussion will address the extent to which the Individual Perception of Family and Disability-Revised (IPFD-R) survey results and subsequent analyses were able to answer the research questions expressed in this study. It will be followed by a report of limitations, implications, recommendations, and conclusion.

Research Questions

The research questions addressed in this study were as follows:

R_1 - How do PWDs perceive the impacts of disability on family?

s. What are the perceptions of individuals with disabilities regarding the physical impact of their disability on the family?

t. What are the perceptions of individuals with disabilities regarding the psychological impact of their disability on the family?

u. What are the perceptions of individuals with disabilities regarding the social impact of their disability on the family?

v. What are the perceptions of individuals with disabilities regarding the financial impact of their disability on the family?

w. What are the perceptions of individuals with disabilities regarding the spiritual impact of their disability on the family?

R_2 - Are there differences in PWDs perceptions of the impacts of their disability on the family based on demographic variables?

i. Is there a difference in perception of impact of disability on family based on gender?

j. Is there a difference in perception of impact of disability on family based on race/ethnicity?

k. Is there a difference in perception of impact of disability on family based on relationship status?

l. Is there a difference in perception of impact of disability on family based on employment?

m. Is there a difference in perception of impact of disability on family groups based on education?

n. Is there a difference in perception of impact of disability on family based on income?

o. Is there a difference in perception of impact of disability on family based on income source?

p. Is there a difference in perception of impact of disability on family based on disability?

R_3 - Are the perceptions of PWDs regarding health and quality of life related to their perception of the impact of disability on their family?

g. Is there a relationship in how PWDs perceive the impact of disability on their family based on their perception of their overall health?
h. Is there a relationship in how PWDs perceive the impact of disability on their family based on their perception of their quality of life?
i. Is there a relationship in how PWDs perceive of impact of disability on their family based on their perception of their families' quality of life?

Research Question 1

The first research question asks how adults with disabilities perceive the impacts of disability on family. This question was answered by analyzing descriptive data (frequencies, percentages, means, and standard deviations) derived from participant responses to the IPFD-R survey. The survey was organized into five dimensions, pursuant to the literature, which describe the impacts of disabilities on families. Overall, mean scores reveal that most adults with disabilities disagree or perceive that their family is never or rarely impacted by their disability as presented in the IPFD-R survey. However, upon examination of the subscales constructed in the IPFD-R some agreement was found with the literature and participant responses. The narrative below will describe some of the literary discussions regarding the physical, psychological, social, financial, and spiritual impacts of disability on the family, as defined in this study, and corresponding participant responses.

Physical Impacts

The physical impacts of disability on family examined in this study were defined as any benefit or detriment to the physical wellbeing of family members related to the disability of a loved one. The literature reviewed in this study document various physical health experiences of family members as a result of disability. Such experiences include physical injury (National Alliance for Caregiving & The National Multiple Sclerosis Society, 2012), increased risk of heart disease (Lee, Colditz, Berkman, & Kawachi, 2003), loss of time for self-care (Evercare & National Alliance for Caregiving, 2006), and addiction (Gutierrez-Rojas, Jurado, & Gurpegui, 2011).

Overall, mean scores derived from this study revealed that participants perceive their disability never (1) or rarely (2) has an impact on the physical wellbeing of their family members. For example, a majority (69.8%) of participants indicated that a loved one has never become physically injured because of their disability (*M* = 1.4, *SD* = 0.8). A majority of participants (60.5%) also indicated that their disability has never contributed to better health for a family member (*M* = 1.7, *SD* = 1.1). A substantial majority (74.4%) of participants marked that a family member has never turned to substances in response to their disability.

To the contrary, most participants (52.8%) indicated that their disability sometimes, often, or always affects their family's daily routine activities. Over half indicated that their disability sometimes, often, or always contributes to family members having time to care for themselves physically by exercising. And, just over half indicated that their disability sometimes, often, or always contributes the family eating healthy.

While a majority of participants indicated that their disability never or rarely affects their family members, attention should not be diverted from the substantial minority of participants who perceive their disability impacts their family. Combining figures on select items reveals that nearly 20 to 40 percent of participants indicated that their disability affects someone in their family physically in a negative way. For example, nearly 40% indicated that their disability sometimes, often, or always causes worse health for someone in their family. Also, nearly a third of participants marked that someone in their family seems physically tired because of the effort required to care for them.

Therefore, overall mean scores indicated discrepancy in the findings with what is stated in the literature regarding physical impacts of disability on family when compared to perceptions of persons with disabilities. However, serious consideration should be given to the substantial minority of PWDs who may experience these impacts in their family on a regular basis.

Psychological Impacts

The psychological impacts of disability on family studied in this investigation were defined as family members' emotional and cognitive responses to the disability of a loved one. The literature regarding the psychological impacts of disability on family describes various negative reactions by family members such as mounting distress, anger, resentment, depression, marital discord, divorce, etc. (Glover-Graf N. , 2012; Vash & Crew, 2004). Though much less common in the literature, some studies also show that disability can have a positive impact on family members (Hastings, Beck, & Hill, 2005). Some studies suggest that family members experience increased happiness, a more positive sense of self, and preference of care for a loved one with a disability over a professional (Schulz & Sherwood, 2008).

Similar to findings regarding the physical impacts perceived by participants, mean scores indicate overall disagreement with the literature on most items in the psychological subscale. However, combining frequencies on items where participants indicated sometimes, often, or always suggests accord with claims in the literature on half of the items in this subscale.

For example, results from this study show that most adults with disabilities perceive that their disability never or rarely affects their family in terms of guilt (64.6%), loneliness (66.6%), or jealousy (74.7%). However, half of participants indicate that someone in their family sometimes (34.6%) or often (15.4%) feels frustrated because of their disability. Likewise, half indicate that someone in their family feels sad or depressed because of their disability. More than half (60%) indicated that their disability sometimes, often, or always contributes to distress within the family. Regarding family inter-relationships, participants indicated that their disability never or rarely had any impact on their parents' or siblings' relationships.

On the other hand, a majority (65%) of participants indicated that their family members sometimes, often, or always feel happy when they can help care for disability related needs. Similarly, almost 53% indicate perceive that their family members prefer to help with the disability rather than have a non-family member help (*M* = 3.0, *SD* = 1.6).

While encouraging that most PWDs find family happy about caretaking, it is also evident a substantial amount perceive their families do not wish to be caregivers. Indeed nearly 30% indicated family members are never or rarely happy to help with disability related needs and more than a third indicated their family would rather not care for their disability.

Social Impacts

The social impacts of disability observed in this study were defined as interactions and experiences of family members with others and together because of the disability. Much of the discourse on the social impacts of disability on families talk of negative social attitudes and beliefs about disability that result in missed opportunities, isolation, guilt, and public shame by propinquity (Blacher & McIntyre, Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultrual differences in family impact, 2006; Livneh, On the origins of negative attitudes toward people with disabilities, 2012; Olkin R. , 1999; Rolland, Families, illness, and disability, 1994).

Participants in this study disagreed, overall, with statements that indicated that their disability had an impact on their families' social experience. For example, a substantial majority of participants disagreed or strongly disagreed that their disability caused their family to have fewer friends (67.6%), be treated disrespectfully (70.2%), or to engage in fewer social activities (68.3%; *M* = 1.8, *SD* = 0.9). However, mean scores approached agreement for items related to difficulty initiating or maintaining a relationship with a significant other because of the disability (*M* = 2.5 *SD =* 1.2; *M* = 2.4 *SD =* 1.2 respectively).

It is important to note here that participants in this study expressed disagreement that *their disability* contributed to their families' experience with social stigma toward disability; however, it remains plausible that participant family members experience effects of social stigma toward disability as suggested in the literature (Green, Davis, Karshmer, Marsh, & Straight, 2005). Green (2007) explained that research on families with loved ones with disabilities overemphasizes "Subjective Burden" or the perceived impact that disability would have on the social attitudes toward the family. Instead, research should observe the "Objective Burden" or the impact social attitudes have on individuals with disabilities and their family.

Financial Impacts

The financial impacts of disability studied here were defined as pecuniary benefits or detriments experienced by family members because of disability. The financial experience of disability and family in the literature, generally tells of penury, disadvantage, and indigence (Kyzar, Turnbull, Summers, & Gomez, 2012; Park, Turnbull, & Turnbull, 2002). For example, households in America with one or more persons living with a disability are 2.5 times more likely to report extremely low income compared to households without disabilities (National Council on Disability, 2010). Financial burden for families with disabilities is attributed to increased cost of care and to unemployment/reduced employment (Cottone, 2012; Hakim et al., 2000; Marini, 2012b; McMordie & Barker, 1988).

Participant responses in this study were more aligned with the literature on this subject than perhaps any other. For example, a majority of participants indicated that their disability income (62%) or income earned from employment (59.3%) is never or rarely sufficient to care for their family (*M* = 1.7, *SD* = 1.1). Nearly 60% of participants indicated that their family never or rarely has enough money to care for their disability needs. In fact, only 6% reported their families always have enough to care for the disability needs. Furthermore, just over half marked that their family never or rarely go without the things they need because of their disability indicating nearly half may be struggling even for basic necessities.

A majority indicated that family members never or rarely had to keep more than one job because of their disability (61.4%). However, over 20% indicated that someone in their family did have to work more than one job. Like other items in this study, a substantial minority of participants seem perceive that their disability has a negative impact on their families financial well-being. The financial impacts of disability on family and correlation to the literature will be explored in greater detail upon examination of participant group differences in research question two.

Spiritual Impacts

The spiritual aspects of family and disability studied in this project were defined as the spiritual/religious beliefs, attitudes, and experiences regarding disability found in the literature. Poston and Turnbull (2004) found that spiritual/ religious beliefs and experiences were important to family members of a loved one with a disability. In their study, family members reported that they were able to accept and adapt to disability through spiritual or religious beliefs/practices.

While most studies indicate an overall positive impact of spirituality on families with disabilities, some of the discourse on culturally diverse families with disabilities tends to emphasize negative spiritual or religious aspects of disability (Millington, 2012b). For example, some have stated that families in certain cultures perceive disability as a curse or a punishment from God (Jacobson, 2005; Lynch & Hanson, 2011; Salas-Provance, Erickson, & Reed, 2002; Smart & Smart, Acceptance of disability and the Mexican-American Culture, 1991).

Participants in this study disagreed overall that their disability affected the spiritual/religious experience of their family members. Similar to the study conducted by Glover-Graf and Blankenship (2007) on Mexican and Mexican American beliefs about God in relation to disability where the majority of participants expressed that disability is not a curse or a punishment from God, a considerable majority (78.6%) of participants in this study disagreed or strongly disagreed that their family believes that their disability is a punishment from God. Over 80% of participants disagreed or strongly disagreed that their family blames God for their disability and 77.3% disagreed or strongly disagreed that their disability has caused their family to become less spiritual.

Slight agreement was found among items that related to more positive aspects of spirituality and disability. For example, nearly half (48.8%) report their families believe God can make the disability better and a substantial minority believe that God can cure the disability. This begs the questions: are families waiting on God and how does this impact the family? Exline, Park, Smyth, and Carey (2011) studied sentiments toward God among family members of a loved one with a chronic illness. They found the duration and severity of the illness of a loved one tended to predict feelings of anger toward God.

Research Question 2

The second research question investigated differences in individual perceptions of the impacts of disability on family based on: (a) gender; (b) race/ethnicity; (c) relationship status; (d) employment status; (e) education; (f) income; (g) income status; and (h) disability. This question was answered by comparing how participants responded to the IPFD-R survey according to the aforementioned demographic groups. Comparisons were examined using multivariate analyses of variance and post hoc analyses. Scores of statistical significance, and effect sizes were observed. The discussion below will describe the statistically significant differences and discuss the relevant literature.

There were no statistically significant differences in how participants in this study perceive their disability impacts their family based on gender, race/ethnicity, employment, and education groupings. However, significant differences were found among relationship, income, income source, and disability groups. These will be discussed in detail below.

Relationship Status

Combined data derived from the 2009-2013 American Community Survey (ACS) reveal that: 38.7% of individuals with disabilities in the U.S. are married; 2.5% are separated; 13.8% are divorced; 23.8% are widowed; and 21.2% are single, never married (Ruggles, et al., 2010). In comparison, 41.7% participants in this study reported being married; 27.3% divorced, widowed, or separated; and 29.5% reported single, never married.

The discourse on relationships and disabilities documents a multiplicity of negative impacts on intimate relationships; emphasis in these studies are placed on the impact of the individual with the disability on the partner without a disability (Glover-Graf N. , 2012; Olkin R.

, 1999). Analyses in this study revealed 10 significant differences in relationship status regarding eating healthy, family outings, relationships with significant others, and financial/employment matters.

Participants who are married or in a committed relationship indicated that their disability contributed to healthy eating more than the other groups. In a general sense, the literature documents that married people report overall better self-related health (Liu & Umberson, 2008); indicating that in some aspects participants in this study may experience similar benefits of marriage as individuals without disabilities.

Research also shows that married people (likely without disabilities) experience higher income levels and ostensibly fewer financial stressors (Liu & Zhang, 2013). This, unfortunately, is not consistent with the findings of this study. Married participants indicated that their disability makes family outings, financial planning, and preparing for a financial crisis are more difficult than other groups indicated.

Similarly, analyses in this study revealed that participants who identify as widowed, divorced, or separated indicated that their family never has enough money to care for their disability needs. Furthermore, maintaining a relationship with a significant other was found more difficult for divorced, widowed, or separated participants than those who are married or single. Researchers have found varying statistics on divorce among couples with disabilities and many have attributed cause to the disability (Glover-Graf N. , 2012; Olkin R. , 1999). However, Singleton (2012) conducted a probability model of divorce among couples with disabilities and found economic conditions, common among PWDs, to be a more likely suspect than the disability itself.

Participants who are single, never married indicated that finding a boyfriend or girlfriend is more difficult than the other groups. While it may seem self-evident that single participants will express difficulty finding themselves in an intimate relationship than those who are married or otherwise, individuals with disabilities find themselves rejected from opportunities to date due to prevailing negative attitudes toward them (Olkin R. , 1999). Miller, Chen, Glover-Graf, and Kranz (2009) examined attitudes of college students toward dating persons with disabilities and found that participants were disinclined to engage in a significant relationship with an individual with a disability, particularly those with cognitive or psychiatric disabilities.

Income

Tabulations from the 2012 ACS reveal that the median annual income among households with an adult with a disability was $37, 300 (90% MOE ± 360); which is nearly half the income among households without a disability (Erickson, Lee, & von Schrader, 2014). Nearly 70% of participants in this study reported annual income levels below $20,000. Household poverty thresholds in the U.S. range from $10,890 for one person to $37,630 for a household of eight (U.S. Department of Health and Human Services, 2011).

Income categories considered in this comparison was “Less than $20,000”, “$20,000 - $39,000”, and “Greater than $40,000” per year. The items that resulted in statistically significant differences pertained to financial sufficiency, and employment assistance from family. Major differences were found between income groups less than $20,000 and greater than $40,000. Participants whose annual income is less than $20,000 indicated that the income they earn from work is never or rarely sufficient to care for their family (M = 1.5, SD = 0.9) and that their family never or rarely has enough money to care for their disability needs (M = 1.9, SD = 1.1) while those whose income is greater than $40,000 a year indicated that their and their family's income (*M* = 3.1, *SD* = 1.7) is sometimes or often sufficient. Lastly, those with lower income levels indicated seem to get more assistance with employment from family than those with higher incomes. This may be due to limited opportunities for training or education often cited among individuals and families with low income (Simkiss, Blackburn, Mukoro, Read, & Spencer, 2011).

It has been said that the economic wellbeing of individuals and families with disabilities is the most understudied topics in the field of labor economics (Burkhauser, Moffit, & Scholz, 2010). Perhaps one of the most evident ways that society devalues and debases individuals with disabilities and their families is in terms of economics (Marini I. , 2012). This constant economic oppression can result in decreased physical and mental health for both PWDs and their families (Marini, Glover-Graf, & Millington, 2012).

Primary Income Source

Figures from RSA 911 data reveal that only 22.7 percent of State VR program participants in the U.S. report personal earnings as their primary source of income at intake (U.S. Department of Education, 2013). Therefore, nearly 80% of these adults with disabilities require financial assistance from others.

Primary income source groups compared in this study were: (a) personal income (30.5%); (b) spouse or family (19.8%); (c) public funds (SSI, SSDI, etc; 41.2%); and (d) other sources such as insurance or charities (7.3%). The analyses resulted statistically significant differences among 12 items that related to fatigue and poor health, sibling care, stress and loneliness, family outings and intimate relationships, financial issues, and spiritual beliefs.

Differences occurred largely between participants whose principal source of income was from their own means and those who are primarily dependent on others (i.e. spouse, family, public funds, etc.). The mean score differences on these items indicate that participants whose principal source of income is from their own means perceive that their disability impacts their family less than those who are dependent on others for financial or material support.

Source of income represents an individual's ability to provide for themselves and others. Benight and Bandura (2004) found the ability to provide for oneself and family to be a determining factor in adult self-efficacy. Their findings indicate loss of income or resources predicted increase in distress and decrease in sense of self-efficacy. Relatedly, in a study on quality of life of individuals with traumatic brain injuries researchers found that gainful employment increased overall sense of self-determination and quality of life post injury (Tsaousides, et al., 2009).

Disability

In examining the experience and adjustment to disability researchers have found the nature of disability to be a significant factor (Li & Moore, 1998; Marini, et al., 2012). Among adults with disabilities in the U.S. an estimated 17.6% have a sensory/communicative disability, 60.5% have a physical disability, and 21.9% have a mental disability (Brault M. W., 2012). Among participants in this study 31% reported having a sensory/communicative disability, 41.5% have a physical disability, and 25.9% have a mental disability.

Disability group comparisons in this study revealed statistically significant differences among 19 items related to physical injury and fatigue, poor health, healthy diet, emotional health, parents' relationship, siblings, friends, family time, substance use, financial issues, and spiritual beliefs. The overall mean score differences on these items are suggestive that participants with a sensory or communicative disorder largely perceive their disability less impactful on their family than those with a physical or mental disability.

Joiner, Lovett, and Goodwin (1989) found that among disability categories, participants who identified as deaf or blind were significantly more accepting of disability and more assertive than any other disability group in the study. Dutta, Gervey, Chan, Chou, and Ditchman (2008) found that among VR participants across the U.S. individuals with sensory/communicative disorder had the highest successful employment rate (75%) among disability categories.

Regarding significant findings among the other disability groups, mean score differences suggest that participants with a physical disability perceive their disability impacts their families most among disability groups. Participants with physical disabilities perceived that their family experiences worse health more often than those with other disabilities (*M* = 2.7, *SD* = 1.4). Relatedly, in a national online study of family caregivers of a loved one with multiple sclerosis (n = 421) nearly half (49%) of participants indicated that they get physically exhausted from providing care and approximately 20% reported getting sick more frequently as a result of providing care (National Alliance for Caregiving & National Multiple Sclerosis Society, 2012).

Mean score differences in this study also indicate that individuals with physical disabilities struggle to maintain intimate relationships and perceive that their disability impacts their family financially more than the other disability groups. Sadly, the literature is replete with evidence of the financial impacts on physical disability and family. For example, tabulations of the 2012 ACS revealed that nearly one out of three adults with an ambulatory disability (30.5%, MOE ± 0.41) or self-care disability (32.5%, MOE ± 0.70) live below poverty standards compared to only 12.4% (MOE ± 0.07) of able-bodied individuals (Erickson, Lee, & von Schrader, 2014). Contributing to this, the National Spinal Cord Injury Statistical Center (2014) reports that only 12% of adults with SCI are employed at year 1 post-injury.

Conditions of poverty and unemployment contribute to chronic stress and places strains on relationships (Charles & Stephens, 2004). Glover-Graf (2012) explains that the spouse or partner of an individual with disability may have to take on additional financial responsibilities following the onset of disability further challenging the relationship. Furthermore, Li and Moore (1998) found income to be significantly correlated with acceptance of disability among individuals with physical disabilities. Olkin (1999) postulated that a couple might only achieve the level of acceptance of disability held by the partner with the disability. Therefore, low income contributes low levels of acceptance by an individual with a disability and his or her partner. For example, a person with a spinal cord injury may not be able to work as before and cannot generate income once earned. This would put a strain on his or her level of acceptance of the disability as well as the relationship with a significant other.

Findings in this study concerning mental health disabilities revealed significant differences regarding substance use of a family member in response to disability, as well as emotional and spiritual responses of family members to disability. Mental health disorders are found to be the most common cause of long-term disability among all other disability types (Mathers & Loncar, 2006).

Mean score differences in this study suggest that participants with mental health disabilities perceive that family members experience depression (M = 2.5, SD = 1.1), guilt (M = 2.2, SD = 1.2), and loneliness (M = 2.0, SD = 1.2) in response to their disability more frequently than the other disabilities examined. These emotional impacts are common among family members in adjustment to the often-changing conditions of a mental health disorder (Panayiotopoulos, Pavlakis, & Apostolou, 2013). However, researchers have also found similar responses among family members of a loved one with a mental health disability due to social stigma and discrimination (Karnieli-Miller, Perlick, Nelson, Mattias, Corrigan, & Roe, 2013; Larson & Corrigan, 2008; Stein, Aguirre, & G, 2013).

While adjustment to any disability is challenging, responding to stigma can be worse due to the external nature of stigma and its far-reaching impacts such as unemployment, negative social attitudes, and policies (Goffman, Stigma: Notes on the management of spoiled identity, 2009). It is thereby reasonable to assume that among these impacts would be substance use in response to the stigma of the mental health disability. Mean score differences in this study also indicated that participants with a mental health disability perceive that someone in their family experiences substance use as means of coping with their disability more than participants in the other disability categories ($M = 1.8$, $SD = 1.3$). While no empirical evidence was found in this study to support the notion that the disability of one person would cause another person to use substances, Gorka, Shankman, Seely, and Lewinsohn (2013) found many studies have indicated that depression in one does increase the risk of substance use.

Research Question 3

The third and final research question investigated the relationship between PWD's perceptions of health and quality of life and their perceptions of the impact of disability on their family? This question was answered by running a Pearson's product-moment correlation analysis on the perceptions of participant: (a) personal overall health; (b) personal quality of life; and (c) family quality of life with responses to the 50 IPFD-R items. Scores of statistical significance and correlation coefficients were observed. The following discussion will describe the findings and expound upon the relevant literature.

Multiple statistically significant correlations were found among participant perceptions of personal health, quality of life, and family quality of life regarding the impact of disability on their family. Out of the 50 IPFD-R items 15 were observed to have a medium/moderate correlation ($0.3 < | r | <0.5$) all other findings yielded a small or insignificant correlation (Cohen, 1988).

Personal Overall Health

According to the 2001-2005 National Health Interview Study (Altman & Bernstein, 2008) over 50% of adults with severe disabilities in the United States reported their overall health as fair or poor compared to only 3.4% of adults with no disability. Furthermore, nearly two-thirds of adults with cognitive difficulties (64%) or self-care limitations (65%) reported fair or poor health. More than half of individuals with emotional difficulties and only 31% with sight or hearing difficulties reported fair or poor health. In the present study just over 40% of participants self-reported their health as fair or poor. Conversely, nearly 60% reported good or very good.

Research on self-rated or subjective health has revealed that how one perceives their health is correlated with objective health, disability, and social functioning. For example, Howell, Kern, and Lyubomirsky (2007) found that subjective health is positively associated with short and long-term health outcomes as well as symptom control. Similarly, Wu, et al. (2013) conducted a study to test the correlation between subjective health measures and objective health measures in China (N = 16,091). Participants responded to a questionnaire regarding their health and health related behaviors. They were then given a medical examination including blood tests and body mass index (BMI) calculations. These researchers found that subjective health measures corresponded with objective measures. Furthermore, they found positive correlations between self-rated health and work satisfaction, spirituality, and quality of interpersonal relationships.

Amstadter, et al. (2010) found in their study among adults in the US that poor self-rated health was associated with marital dissolution, low social support, emotional problems, unemployment, low income, and needing help in activities of daily living.

Correlation analyses revealed a moderate relationship between PWDs perception of health and the impact their disability has on their family in terms of family outings and financial or economic issues. There was a negative correlation between self-rated health and the item stated: *Family outings are difficult because of my disability* ($r = -.309$, $p < .0005$). This finding suggests that PWDs who rate their health as good or very good may disagree that their disability impacts their family's ability to engage in outings or leisure activities. Relatedly, Eriksson, Undén, and Elofsson (2001) found in their population study that positive self-rated health correlated strongly with leisure and family satisfaction.

Subsequent analyses in this study revealed moderate correlations regarding the families' financial well-being. A positive correlation with the item stating "My family has enough finances to care for my disability needs" suggests that a poor or fair self-assessment of health is associated with a perception that one's family never or rarely has enough money to care for their disability needs. Correspondingly, a negative correlation with the item stating "Because of my disability my family members have a hard time preparing for unexpected financial crisis" indicates that a poor or fair self-assessment of health is related to the perception that one's disability often or frequently impacts their family's ability to cope with financial crisis. In relation, multiple studies have indicated that financial insecurity is associated with poor self-rated health (Amstdter, Begle, Cisler, Hernandez, Muzzy, & Acierno, 2010; Cundiff, Smith, Uchino, & Berg, 2013; Kawachi, Kennedy, & Glass, 1999). Kondo and colleagues (2009) explained that financial instability has an adverse effect on one's overall health.

Quality of Life

Participants in this study were asked how they perceive their overall quality of life (QOL). Over 46% perceived their QOL as either poor or fair and over half (52.5%) as good or very good. Correlation analyses in this study revealed that there is a relationship in how PWDs perceive their quality of life and the impact their disability has on their family. Medium/moderate correlations were found among nine of the 50 IPFD-R items. These correlations were related to emotional reactions of family members to the disability, family outings, and financial issues.

According to these findings poor perceptions of one's QOL are associated with negative perceptions of the impact of disability on the family; the opposite is also true. For example, a poor or fair concept of one's QOL was associated with the perception that someone in their family often or frequently experiences negative emotions, such as depression, stress, or frustration, because of their disability.

In a comprehensive review of the literature Livneh and Antonak (2005) found that the individuals with disabilities often experience loss and grief, challenges to body image and self-concept, stigma, uncertainty and unpredictability, and changes in quality of life in the process of adjustment to disability. Falvo (2009) explained that PWDs perceptions of quality of life are based on “the degree to which they feel they have control over their life circumstances or destiny” (p. 26).

Nancy Crewe (1980) asserted that the ultimate goal of rehabilitation counseling is to promote improved quality of life among PWDs. Wright (1983) explained that some might see that the quality of life for individuals and families with disabilities is a tragedy. However many, perhaps most, experience a process of cognitive restructuring wherein values and attitudes regarding are adjusted to resolve the dissonance that may exist between level of actual function and desired function. This results in steady improvement of overall quality of life. Rehabilitation counselors are uniquely qualified to assist in this process of cognitive restructuring in the experience of disability. The results of this study support the notion that improvement in the subjective quality of life for the PWD may improve the quality of life for families as well.

Family Quality of Life

Participants in this study were asked to rate their family’s overall quality of life. Nearly a third of PWDs in this study regarded their family’s QOL as fair or poor. On the other hand, 67% replied as good or very good in response to the question. Correlational analyses revealed a medium correlation between how PWD’s perceive their family’s quality of life and the impact their disability has on their family among three out of the 50 IPFD-R items. These correlations were related to the emotional reactions of family members to the disability and family financial sufficiency.

Moderate negative correlations were found among the items that stated: *Someone in my family is sad or depressed because of my disability*; and *someone in my family feels angry because of my disability*. As well, there was a positive correlation with the item stating: *My family has enough finances to care for my disability needs*. Similar to correlations among self-rated health and quality of life, there is an association between poor or fair concept of family quality of life and negative perceptions of the impact of disability on family. Naturally, there is also a relationship between good or very good ratings of family quality of life and more positive perceptions of the impact of disability on the family.

Looking at the percentages of responses for self-rated health, quality of life, and family quality of life it is easy to see that a majority of PWDs in this study have a positive concept of health and quality of life and therefore may perceive that their disability does not impact their family as has been presented in the literature. However, in each case there is also a substantial minority who perceive that their health is poor, that their quality of life is poor, and their families' quality of life is poor. Consequently, results from this study demonstrate that these PWDs may well perceive a number of unpleasant consequences for their family because of their disability.

For this purpose rehabilitation counseling was born. Rehabilitation counselors specialize in the minority and disenfranchised (Marini I. , 2012). From the results found in research question three, rehabilitation counselors should be mindful of the perceptions of PWDs and how those perceptions and experience their clients and family members. Specific concerns encountered in this portion of the study of importance to both individuals with disabilities and their families are the emotional reactions to the disability, the limited access to recreation or leisure (aka family outings), and financial concerns.

Limitations

A number of limitations were evident in this study. One is the data was collected through a web based survey. Participants who were invited to participate needed to access the survey online. While measures were taken to ensure accessibility for screen readers, the survey may not have been accessible for all disability needs. Additionally, the web based questionnaire was designed to read at a 9th grade reading level but the researcher was unable to determine if respondents would comprehend all of the survey questions. It is possible that not all disability groups were adequately represented in the sample. Furthermore, it was impossible to know the nature of the respondents' motivation, and capability of completing the survey. Most importantly, there was no way to identify if respondents would answer in a socially desirable manner.

Several limitations presented themselves in the instrumentation itself. The IPFD-R was devised pursuant to a comprehensive review of relevant literature; however, it is possible that aspects of the literature were not encountered, and therefore not included within the framework of this study. Also, the use of different likert scales across items presented challenges in the data analysis affecting validity and making comparisons between scales.

The sampling methodology also presented some challenging limitations. It was determined to recruit individuals enrolled state vocational rehabilitation programs throughout the U.S. as they represented a large cross-section of adults with disabilities. However, by nature of eligibility for VR services, one must be presumed able to work or gain employment with substantial assistance. This would likely exclude individuals with severe disabilities who cannot work from participation in the study. Furthermore, only three states opted to participate in the study due to restraints in time and interest, which greatly limits generalizability to other populations. Also, the states that participated were not able to provide the number of participants that were solicited for participation therefore response rate was not ascertained. Lastly, this research was not an experimental design study, and therefore precision is limited by inability to control extraneous variables.

To reduce limitations in future studies the population could be expanded to VR programs throughout the entire U.S. Other disability populations should also be sought out namely, those with intellectual and developmental disorders, persons who are hospitalized or otherwise institutionalized, and perhaps military personnel with disabilities. Lastly, the pragmatic, empirical, and theoretical basis of the IPFD-R should be continually challenged to improve the way it represents the statements in the literature regarding the impacts of disability on the family.

Ethical Dimensions

Although answers to the questionnaire items were not associated with identifying information by the participant (e.g., name), and the Qualtrics security feature protected privacy, many participants may have experienced frustration or anxiety related to the confidentiality of the study. Various participants did not complete the survey. Some participants stopped completing the questionnaire because they may have been concerned that the internet was not a safe place to answer specific types of questions, especially items they considered private information. Some participants skipped certain questions possibly due to discomfort or the question triggers unhappy thoughts. No other ethical issues were noticeable in conducting the study.

Implications for Future Research

This research demonstrated that much of the literature regarding the impact of disabilities on families is absent of an essential element: the perspective of the individual with a disability. Olkin (1999) highlighted several factors that have limited research on disability; this study calls attention to two of them: (1) “underrepresentation of people with disabilities”; and (2) “an almost exclusive focus on the effects of persons with disabilities on others” (pp. 319-320). The results of this study revealed that individuals with disabilities perceive the experience of disability within their family differently than what is presented in the literature.

Overall the participants in this study indicated that their disability does not inherently affect their family adversely as it has often been portrayed in the literature. This is likely because studies regarding family experiences with disability continue to embrace an outsider approach that utilizes medical model of disability (Millington, et al., 2015). This approach pathologizes disability and those in proximity of its experience. In turn, this perpetuates social stigma and social injustice for individuals and families with disabilities (Marini I. , 2012); which is a contradiction to rehabilitation counseling core values (Miller & Millington, 2002).

Wright (1988) recommended several strategies for research conceptualization that minimizes the fundamental negative bias perpetuated by outsider-based research approaches; a few of which can be applied here. First, when exploring impacts of and attitudes toward people with disabilities, at very least, an equitable amount of positive aspects of disability should be present as are negative to give a better representation of the phenomenon. Second, researchers should be aware of their own perception of what is being observed. There is a natural pull on researchers attention toward what is viewed as different, “unsightly or bizarre” (p. 21), which leads to false (negatively laden) conclusions. An awareness of the negative and exclusive nature of impact studies regarding disability will lead to more accurate and productive research, practice, and policy outcomes (Olkin, 1999; Wright, 1988).

Future Research

Perhaps the most valuable recommendation for future research considering the results of this study would be in support of Yuker's (1994) call for a moratorium on research that exploits the perceived impacts of individuals with disabilities on others (see also Olkin, 1999). Future research should turn its focus instead to the impact of social perceptions and injustice on individuals and families with disabilities.

The most salient theme that emerged from this study was the economic impacts on individuals and families with disabilities. Results depicted here indicated that individuals with disabilities are frequently unable to generate enough capital to support their family and their family is not able to generate enough capital to support their disability. Participant responses were in more agreement with the economic aspects of disability found in the literature than any other aspects presented in this study. However, like the other aspects of disability presented in this study, much of the literature falsely attributes the economic struggles of individuals and family to the disability rather than social injustice and exclusion (Marini I. , 2012). Therefore, future research should also focus on the development and testing of models that increase access to social and economic capital for individuals and families with disabilities (Lukersmith, Scarf, & Millington, 2015).

Recommendations for Rehabilitation Counselors

Advocating for full community inclusion of individuals with disabilities has been at the core of rehabilitation counseling since the beginning (Wright, 1983). However, similar to the field of psychology, the field of rehabilitation counseling has often addressed family or significant other concerns as peripheral or cursory issues. Millington (2012) asserts, “In the absence of a best practice, or much in the way of its pursuit, the family remains relegated to the periphery of rehabilitation. Families are a counseling afterthought and an addendum to service, despite calls to the contrary” (p. 399).

This research builds on the growing evidence that family is an integral part of the rehabilitation process (Millington & Marini, 2015). Specifically, this research supports the empowerment of individuals in rehabilitation counseling as gatekeepers for family inclusion in the process. Rehabilitation counselors should attend to such issues with an open mind, not assuming consumer views of family are either consistent with the literature or with their own family member’s views. Counselors should acknowledge the family as an “essential component of efficient and effective service in the present and sustaining inclusion into the future” (Millington, et al., 2015, p. 40). Lastly, counselors should be overt in allowing the client to “define what the family is in the collective sense, who its constituents are, and the role family will play in the development, execution, and evaluation of rehabilitation counseling plans and services” (p.40).

Regarding the economic considerations presented in this study, we have an ethical obligation to assist individuals and families with disabilities in overcoming this most insidious form of social injustice and deprivation perhaps more than any other responsibility (Miller &

Millington, 2002). Rehabilitation counselors are more equipped and qualified to assist individuals and families with disabilities to engage productively in the marketplace than any other professional. Furthermore, individuals and families as well as rehabilitation counselors stand to gain from this pursuit. Lukersmith and colleagues (2015) explain this transaction succinctly:

> Families turn to rehabilitation counseling for resources, not direct care. These resources are the stuff of rehabilitation counselor's trade and trade requires reciprocation from the family. The rehabilitation counselor wants access to the family social capital as well. They share a goal, the family and counselor but for different outcomes. The family seeks improvement in its standing in the community and more resilient well-being. The counselor seeks the most efficient and effective path to successful case closure (p. 70).

As we turn to the family as a resource instead of a liability in the rehabilitation process we will achieve our goals in empowering individuals with disabilities to access their community in a manner that promotes independence and overall well-being. For this truly is "what is required of us" (Miller & Millington, 2002, p. 298).

Conclusions

The purpose of this study was to explore the how individuals with disabilities perceive the impact of disability on family that is discussed in much of the literature. A review of the literature framed the impact of disability on families in terms of physical, psychological, social, financial, and spiritual domains. Participants in this study were recruited from state VR agencies. In this study participants expressed divergent views regarding the impact of their disability on their family from what was discovered in the literature with the exception of financial or economic issues. Multiple significant differences were found among relationship, income, income source, and disability groups. These findings revealed a fundamental issue with the literature regarding family and disability in that much of it emphasizes the negative aspects of disability as criticized by Wright (1988).

This study contributes to the growing body of evidence supportive of family inclusion in the rehabilitation process according the dictates of client informed choice. Individuals with disabilities should be progressively empowered in the rehabilitation process, which should fundamentally include their families. Results of this study should be used by rehabilitation professionals as evidence toward more insider-based research, practice, and policy.

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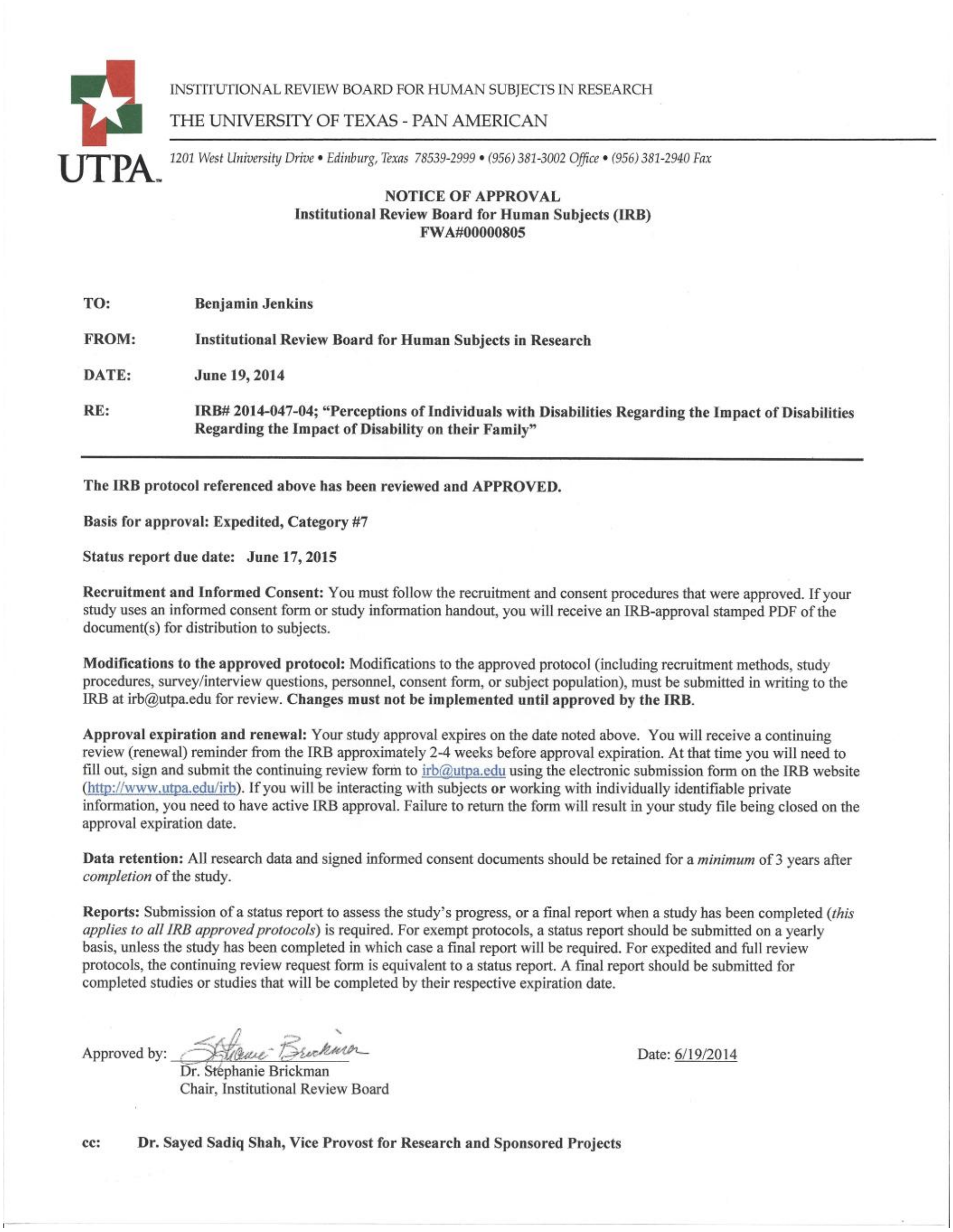
APPENDIX A

APPENDIX A

IRB APPROVAL TO CONDUCT STUDY



UTPA

INSTITUTIONAL REVIEW BOARD FOR HUMAN SUBJECTS IN RESEARCH
THE UNIVERSITY OF TEXAS - PAN AMERICAN
1201 West University Drive • Edinburg, Texas 78539-2999 • (956) 381-3002 Office • (956) 381-2940 Fax

NOTICE OF APPROVAL
Institutional Review Board for Human Subjects (IRB)
FWA#00000805

TO: **Benjamin Jenkins**

FROM: **Institutional Review Board for Human Subjects in Research**

DATE: **June 19, 2014**

RE: **IRB# 2014-047-04; "Perceptions of Individuals with Disabilities Regarding the Impact of Disabilities Regarding the Impact of Disability on their Family"**

The IRB protocol referenced above has been reviewed and APPROVED.

Basis for approval: Expedited, Category #7

Status report due date: June 17, 2015

Recruitment and Informed Consent: You must follow the recruitment and consent procedures that were approved. If your study uses an informed consent form or study information handout, you will receive an IRB-approval stamped PDF of the document(s) for distribution to subjects.

Modifications to the approved protocol: Modifications to the approved protocol (including recruitment methods, study procedures, survey/interview questions, personnel, consent form, or subject population), must be submitted in writing to the IRB at irb@utpa.edu for review. **Changes must not be implemented until approved by the IRB.**

Approval expiration and renewal: Your study approval expires on the date noted above. You will receive a continuing review (renewal) reminder from the IRB approximately 2-4 weeks before approval expiration. At that time you will need to fill out, sign and submit the continuing review form to irb@utpa.edu using the electronic submission form on the IRB website (http://www.utpa.edu/irb). If you will be interacting with subjects **or** working with individually identifiable private information, you need to have active IRB approval. Failure to return the form will result in your study file being closed on the approval expiration date.

Data retention: All research data and signed informed consent documents should be retained for a *minimum* of 3 years after *completion* of the study.

Reports: Submission of a status report to assess the study's progress, or a final report when a study has been completed (*this applies to all IRB approved protocols*) is required. For exempt protocols, a status report should be submitted on a yearly basis, unless the study has been completed in which case a final report will be required. For expedited and full review protocols, the continuing review request form is equivalent to a status report. A final report should be submitted for completed studies or studies that will be completed by their respective expiration date.

Approved by: Stephanie Brickman
Dr. Stephanie Brickman
Chair, Institutional Review Board

Date: 6/19/2014

cc: **Dr. Sayed Sadiq Shah, Vice Provost for Research and Sponsored Projects**

APPENDIX B

APPENDIX B

RECRUITMENT LETTER

Date: July 15, 2014

Dear Consumer

I would like to invite you to participate in a study about the opinions of adult individuals with disabilities, *specifically what you think about the experience of disability within your family*. Your local vocational rehabilitation office is sending, on my behalf, this invitation to be a part of this new study.

Your participation in this study is voluntary; you may quit at any time without penalty and all your responses are anonymous. Please note you must be 18 years or older to participate. This survey should take about **20 minutes** to complete.

To complete the survey, simply click on the link below or copy and paste the link into your browser.

https://utpa.qualtrics.com/SE/?SID=SV_cuuZLzoaviMmYD3

If you have any questions please feel free to contact me using the email listed below.

Thank your time.

Regards,

Benjamin C. Jenkins, MRC, CRC
Doctoral Candidate
The University of Texas-Pan American (UTPA)
Email: jenkinsbc@utpa.edu

APPENDIX C

APPENDIX C

INFORMED CONSENT FORM

NFORMED CONSENT DOCUMENT

Study title: Individual Perception of Family and Disability

This research is being conducted by Benjamin C. Jenkins from the University of Texas – Pan American. The research study aims to investigate how individuals with disabilities perceive the impact of *their* disability on *their* family. *The survey should take about **20 minutes** to complete*.

If you would prefer not to participate in this study, simply close out of the browser page. Your responses are anonymous; you should not include any identifying information on this survey. We ask that you try to answer all questions. However, if there are any questions that you would prefer to skip, simply leave the answer blank. You must be at least 18 years old to participate. *If you are not 18 or older, please do not complete the survey.*

If you experience any discomfort or concern while participating or about your responses to this study please contact your rehabilitation counselor. If you have any questions or concerns about this study please contact the researcher directly.

Researcher contact information:

Name: Benjamin C. Jenkins
Title: Doctoral Candidate
Dept: Rehabilitation Services
The University of Texas-Pan American
Phone: 956-665-7344
Email: jenkinsbc@utpa.edu

All survey responses that we receive will be treated confidentially and stored on a secure server. However, given that the surveys can be completed from any computer (e.g., personal, work, school), we are unable to guarantee the security of the computer on which you choose to enter your responses. As a participant in our study, we want you to be aware that certain technologies exist that can be used to monitor or record data that you enter and/or websites that you visit.

This research has been reviewed by the Institutional Review Board for the Protection of Human Subjects (IRB). If you have any questions about your rights as a participant, or if you feel that your rights have been violated, please contact the IRB at 956-665-2889 or irb@utpa.edu. You may also submit anonymous comments to the IRB at www.utpa.edu/IRBfeedback

By clicking "agree" you are confirming that you have read and understand the consent statement above, that you are eligible to participate, and voluntarily consent to continue on to the survey.

Feel free to print this page for your reference.

APPENDIX D

APPENDIX D

INDIVIDUAL PERCEPTIONS OF FAMILY AND DISABILITY-REVISED SURVEY

Impact of Disability on Family

Q1 In what state do you currently reside?

Alabama (1)
Arizona (2)
Arkansas (3)
California (4)
Colorado (5)
Connecticut (6)
Delaware (7)
District of Columbia (8)
Florida (9)
Georgia (10)
Idaho (11)
Illinois (12)
Indiana (13)
Iowa (14)
Kansas (15)
Kentucky (16)
Louisiana (17)
Maine (18)
Maryland (19)
Massachusetts (20)
Michigan (21)
Minnesota (22)
Mississippi (23)
Missouri (24)
Montana (25)
Nebraska (26)
Nevada (27)
New Hampshire (28)
New Jersey (29)
New Mexico (30)
New York (31)

North Carolina (32)
North Dakota (33)
Ohio (34)
Oklahoma (35)
Oregon (36)
Pennsylvania (37)
Rhode Island (38)
South Carolina (39)
South Dakota (40)
Tennessee (41)
Texas (42)
Utah (43)
Vermont (44)
Virginia (45)
Washington (46)
West Virginia (47)
Wisconsin (48)
Wyoming (49)
Puerto Rico (50)
Alaska (51)
Hawaii (52)
I do not reside in the United States (53)

Q2 With which ethnicity do you most identify?

○ Asian/Pacific Islander (1)
○ Black/African American (2)
○ Hispanic/Latino (3)
○ White/Non-hispanic (4)
○ Native American or Alaskan Native (5)
○ Other (7)

Q3 What is your gender?

○ Male (1)
○ Female (2)
○ Other (3) ____________________

Q4 Which of the following best describes your current relationship status?

○ Single, never married (1)
○ Single, in a committed relationship (2)
○ Single, divorced (3)
○ Single, widowed (4)
○ Married (5)
○ Married, separated (6)
○ Other (7) ____________________

Q6 Which of the following best describes your current living arrangement?(Select ALL that apply)

☐ Living Alone/Private Residence (1)
☐ With Partner/ Spouse (2)
☐ With Family Members (3)
☐ With Friends (4)
☐ With attendant or paid caretaker (6)
☐ In a group home, hospital or other treatment facility (7)
☐ Other (5) ____________________

Q5 Do you have any children?

○ Yes (1)
○ No (2)

Q7 How many persons usually live in your household including yourself?

Q8 Which of the following best describes your current employment or work status?

○ Full time (1)
○ Part-time (2)
○ Unemployed (3)
○ Other (4) ____________________

Q9 What is the highest level of education you have completed?

- ○ Less than High School (1)
- ○ High School / GED (2)
- ○ Some College (3)
- ○ College Degree (4)
- ○ Masters Degree or Higher (6)

Q10 About how much money do you make each year?

- ○ Below $20,000 (1)
- ○ $20,000 - $39,999 (2)
- ○ $40,000 - $59,999 (3)
- ○ $40,000 - $49,999 (4)
- ○ $60,000 - $89,999 (5)
- ○ $80,000 or more (8)

Q11 What is your primary (largest) source of income? Check one of the following:

- ○ Your personal income (earnings, interest, dividends, rent) (1)
- ○ Your spouse's income, or support from family and friends (2)
- ○ Public support such as SSDI, SSI, TANF, etc. (3)
- ○ Other sources such as insurance or charities (4) ____________________

Q12 What is your primary disability? (Please write only one)

Q13 Do you have other disabilities?Please list or describe below.

Q14 How would you rate your overall health?

- ○ Poor (13)
- ○ Fair (14)
- ○ Good (15)
- ○ Very Good (16)
- ○ Excellent (17)

Q15 How do you feel about your overall quality of life?

- ○ Poor (13)
- ○ Fair (14)
- ○ Good (15)
- ○ Very Good (16)
- ○ Excellent (17)

Q16 How do you feel about your family's overall quality of life?

- ○ Poor (13)
- ○ Fair (14)
- ○ Good (15)
- ○ Very Good (16)
- ○ Excellent (17)

Q17 Thanks for the info! The rest of the questions are statements from books and articles about how disability affects families. Please continue on to answer how your disability might or might not affect your family.

Q18 Please answer the following about how your disability might physically affect your family.Note: If a question does not apply to you then leave it blank and move on to the next.

	Never (16)	Rarely (17)	Sometimes (18)	Often (19)	All of the Time (20)
My disability causes better health for someone in my family. (5)	○	○	○	○	○
My disability causes worse health (back pain, headaches, sick more often, etc) for someone in my family . (4)	○	○	○	○	○
Because of my disability, a loved one physically hurt themselves while taking care of me. (1)	○	○	○	○	○
My family members seem physically tired because of the effort required to care for me.	○	○	○	○	○

(2)					
Because of my disability my family members have time to do things to care for themselves physically (like exercise). (3)	○	○	○	○	○
I think my disability affects my family's daily routine activities. (6)	○	○	○	○	○
Because of my disability my siblings will have to care for me as I get older. (7)	○	○	○	○	○
Someone in my family turns to substances (alcohol, drugs, etc.) because of my disability. (8)	○	○	○	○	○
Eating	○	○	○	○	○

healthy is important to my family because of my disability. (9)					

Q19 That was great! Please keep going!

Q20 Please answer the following about how your disability emotionally affects your family. Note: If a question does not apply to you then leave it blank and move on to the next.

	Never (1)	Rarely (2)	Sometimes (3)	Most of the time (4)	All of the time (5)
Someone in my family feels happy when they can help with my disability. (1)	○	○	○	○	○
Someone in my family is sad or depressed because of my disability. (2)	○	○	○	○	○
Someone in my family feels guilty because of my disability. (3)	○	○	○	○	○
Someone in my family feels lonely because of my disability. (4)	○	○	○	○	○
Someone in my family feels stressed because of my disability.	○	○	○	○	○

(5)					
Someone in my family feels angry because of my disability. (6)	○	○	○	○	○
Someone in my family feels frustrated because of my disability. (7)	○	○	○	○	○
My siblings are jealous of the attention I get (or got) because of my disability. (8)	○	○	○	○	○
My parents worry a lot because I have a disability. (9)	○	○	○	○	○
My parent's relationship is (or was) better or more loving because of my disability. (10)	○	○	○	○	○
Because I	○	○	○	○	○

have a disability my parents argue (present or past). (11) My family would rather care for my disability needs than have a non-family member do it. (12)	○	○	○	○	○

Q22 Please answer the following about how your disability socially affects your family. Note: If a question does not apply to you then leave it blank and move on to the next.

	Strongly Disagree (56)	Disagree (57)	Agree (58)	Strongly Agree (59)
Family outings are difficult because of my disability. (1)	○	○	○	○
My family members are social with fewer friends because of my disability. (2)	○	○	○	○
My family members have made new friends because of my disability. (3)	○	○	○	○
My family socializes with other families with disabilities. (4)	○	○	○	○
My family spends more time together because of my disability. (5)	○	○	○	○
Some people treat my family with disrespect because I have a	○	○	○	○

disability. (6)				
My family members take part in fewer social activities because of the time required to care for my disability. (7)	○	○	○	○
Because of my disability I need family members to help me be social with others outside my household. (8)	○	○	○	○
My family has more community contact because of my disability. (9)	○	○	○	○
Maintaining a loving relationship with a significant other is difficult because of my disability. (10)	○	○	○	○
Finding a boyfriend or girlfriend is or has been difficult because of my disability. (11)	○	○	○	○

Q23 Almost Done! Just a little more to go!

Q24 Please answer the following about how your disability financially affects your family.
Note: If a question does not apply to you then leave it blank and move on to the next.

	Never (6)	Rarely (7)	Sometimes (8)	Often (9)	All of the Time (10)
My disability income (i.e. SSI/ SSDI etc.) is sufficient to care for my family. (1)	○	○	○	○	○
Because I have a disability the money I make from work is enough to care for my family. (3)	○	○	○	○	○
My family has enough finances to care for my disability needs (4)	○	○	○	○	○
My family has to pay more for medical costs because of my disability. (5)	○	○	○	○	○
My family members go without the	○	○	○	○	○

things they NEED because of my disability care costs. (6)					
My family members go without the things they WANT because of my disability care expenses. (7)	○	○	○	○	○
Because of my disability, my family members need to keep more than one job to provide for me. (8)	○	○	○	○	○
Because of my disability, my family members find it difficult to plan financially for the future. (9)	○	○	○	○	○
Because of my disability my family members	○	○	○	○	○

have a hard time preparing for unexpected financial crisis. (10)					
My family helps me to get jobs and work. (11)	○	○	○	○	○

Q25 Thanks for hanging in there! Last set of questions ahead!

Q26 Please rate the following statements about how your disability spiritually affects your family. Note: If a question does not apply to you then leave it blank and move on to the next.

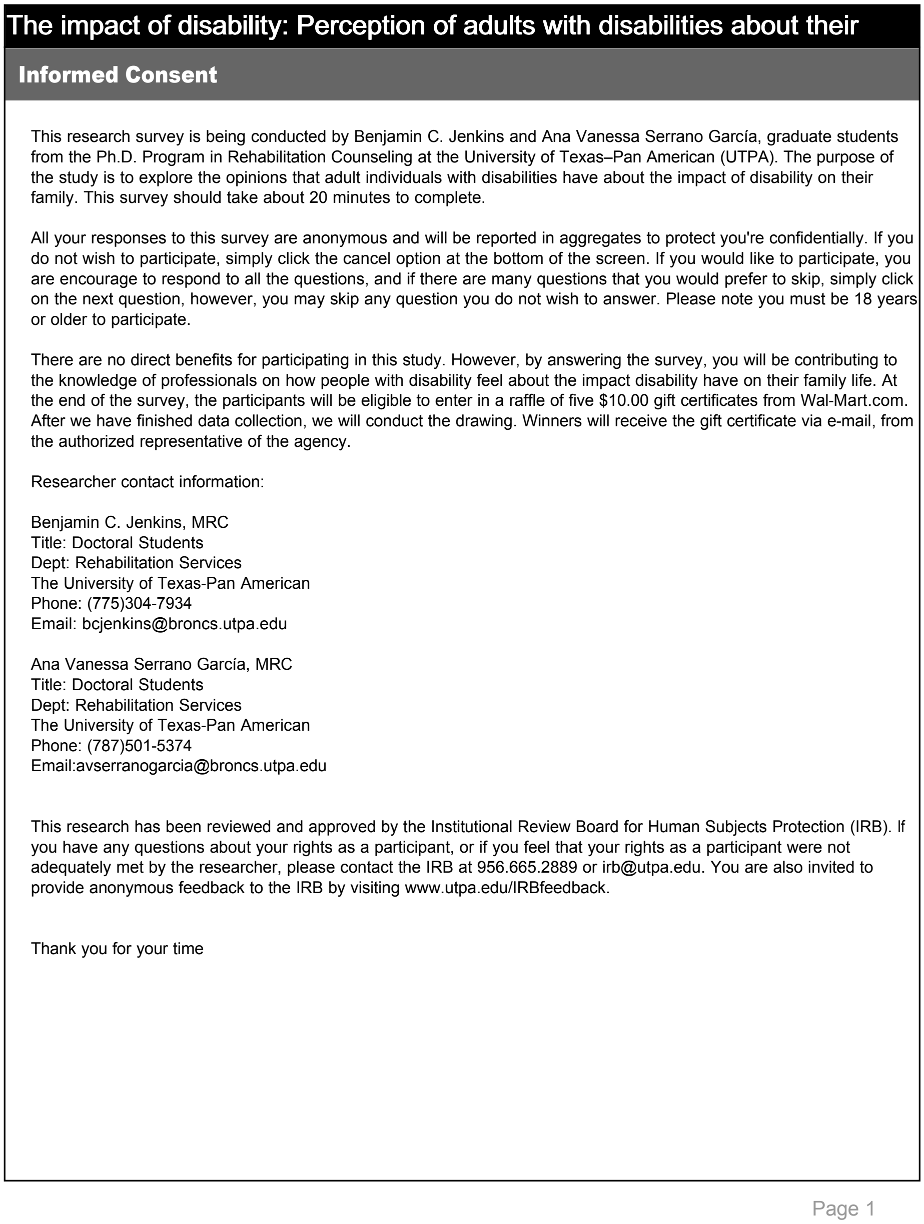
	Strongly Disagree (16)	Disagree (17)	Agree (18)	Strongly Agree (19)
My family feels closer to God because of my disability. (1)	○	○	○	○
My family blames God for my disability. (2)	○	○	○	○
My family feels that my disability is a punishment from God. (3)	○	○	○	○
My family relies more on God to help us through hard times because of my disability. (4)	○	○	○	○
My disability has helped my family become more spiritual. (5)	○	○	○	○
My disability has made my family become less spiritual. (6)	○	○	○	○
My family believes God can make my disability better.	○	○	○	○

(7) My family believes that God can cure my disability. (8)	○	○	○	○

APPENDIX E

APPENDIX E

INDIVIDUAL PERCEPTIONS OF FAMILY AND DISABILITY SURVEY (ORIGINAL)



The impact of disability: Perception of adults with disabilities about their

Informed Consent

This research survey is being conducted by Benjamin C. Jenkins and Ana Vanessa Serrano García, graduate students from the Ph.D. Program in Rehabilitation Counseling at the University of Texas–Pan American (UTPA). The purpose of the study is to explore the opinions that adult individuals with disabilities have about the impact of disability on their family. This survey should take about 20 minutes to complete.

All your responses to this survey are anonymous and will be reported in aggregates to protect you're confidentially. If you do not wish to participate, simply click the cancel option at the bottom of the screen. If you would like to participate, you are encourage to respond to all the questions, and if there are many questions that you would prefer to skip, simply click on the next question, however, you may skip any question you do not wish to answer. Please note you must be 18 years or older to participate.

There are no direct benefits for participating in this study. However, by answering the survey, you will be contributing to the knowledge of professionals on how people with disability feel about the impact disability have on their family life. At the end of the survey, the participants will be eligible to enter in a raffle of five $10.00 gift certificates from Wal-Mart.com. After we have finished data collection, we will conduct the drawing. Winners will receive the gift certificate via e-mail, from the authorized representative of the agency.

Researcher contact information:

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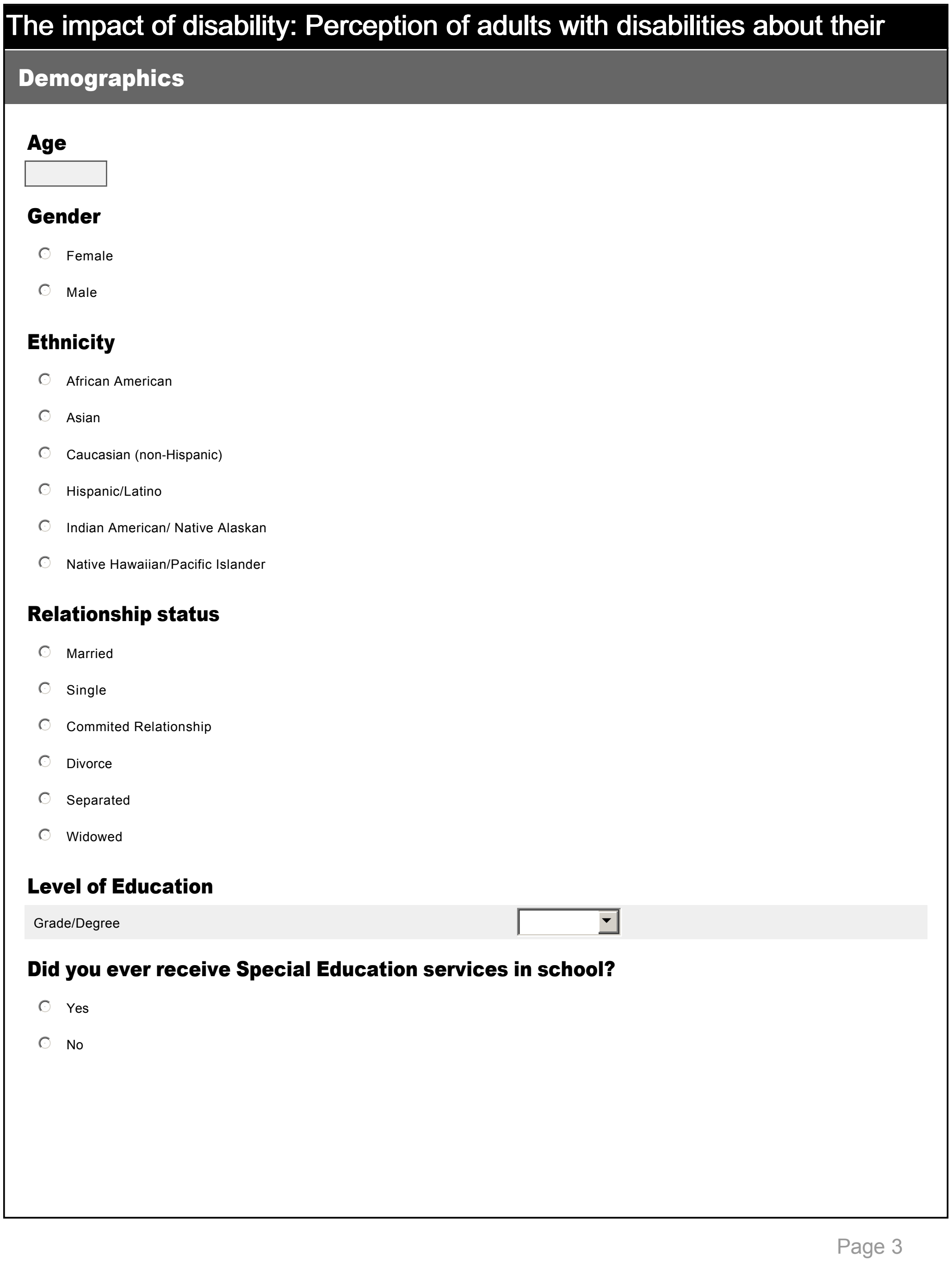
This research has been reviewed and approved by the Institutional Review Board for Human Subjects Protection (IRB). If you have any questions about your rights as a participant, or if you feel that your rights as a participant were not adequately met by the researcher, please contact the IRB at 956.665.2889 or irb@utpa.edu. You are also invited to provide anonymous feedback to the IRB by visiting www.utpa.edu/IRBfeedback.

Thank you for your time

Page 1



The impact of disability: Perception of adults with disabilities about their

Demographics

Age

Gender

○ Female

○ Male

Ethnicity

○ African American

○ Asian

○ Caucasian (non-Hispanic)

○ Hispanic/Latino

○ Indian American/ Native Alaskan

○ Native Hawaiian/Pacific Islander

Relationship status

○ Married

○ Single

○ Commited Relationship

○ Divorce

○ Separated

○ Widowed

Level of Education

Grade/Degree

Did you ever receive Special Education services in school?

○ Yes

○ No

Living Arrangement

☐ Living Alone, Private Residence
☐ With Partner/ Spouse
☐ With Family Members
☐ With Friends
☐ With Personal Attendant
☐ In Assisted Living Facility
☐ Rehabilitation facility
☐ Jail/Adult correctional facility
☐ Mental health facility
☐ Group Home

Other (please specify)

Work Status

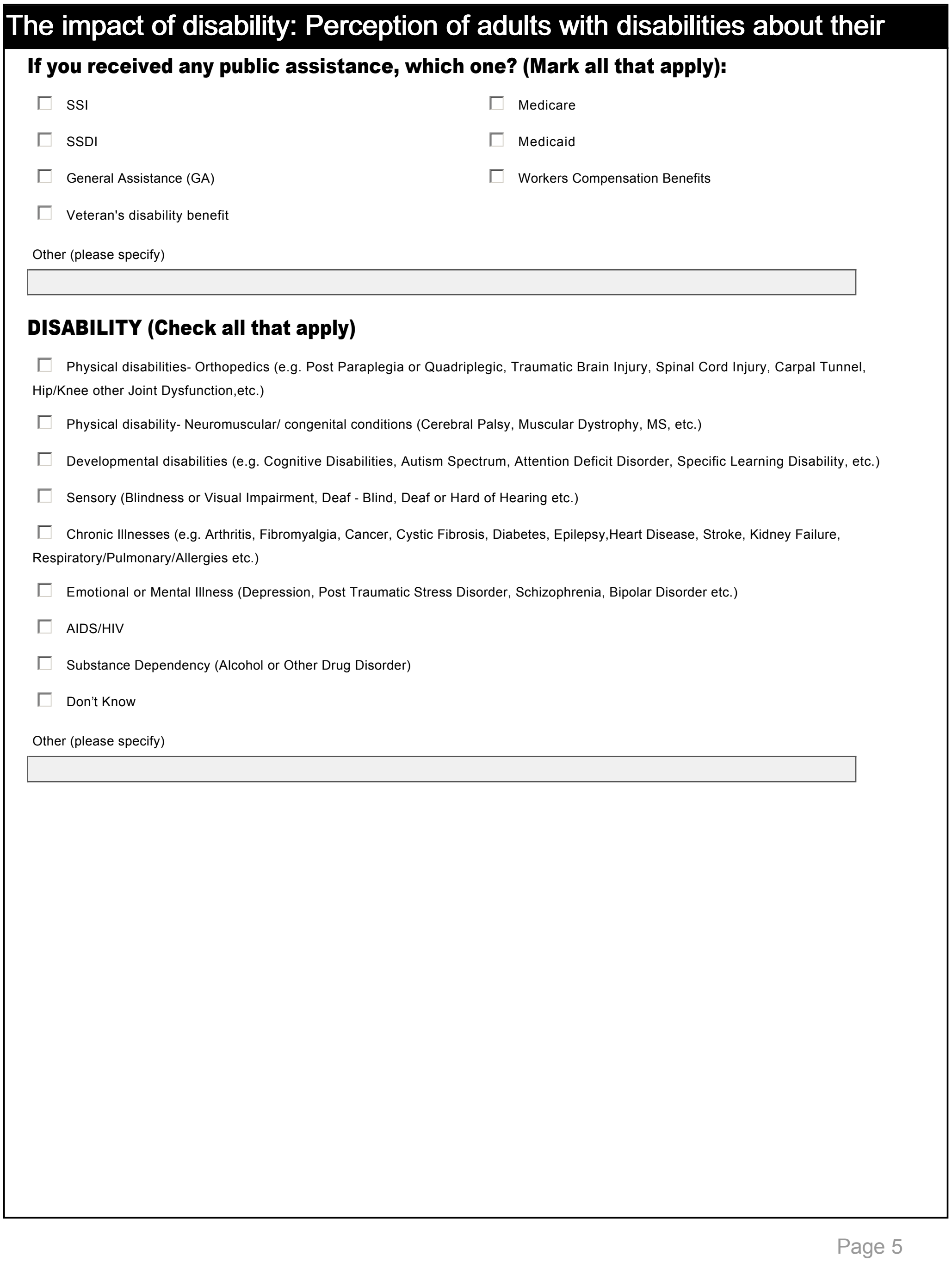
☐ Full time
☐ Part-time
☐ Unemployed
☐ Student
☐ Retired
☐ Home-maker

What is your income?

○ Less than $20,000
○ $21,000 to $34,000
○ $35,000 to $38,000
○ $39,000 to $52,000
○ Over $53,000

What is your primary (largest) source of support? Check on of the following:

○ Your personal income (earnings, interest, dividends, rent)
○ Your spouse's income, or support from family and friends
○ Public support such as SSDI, SSI, TANF, etc.
○ Other sources such as insurance or charities



The impact of disability: Perception of adults with disabilities about their

If you received any public assistance, which one? (Mark all that apply):

☐ SSI

☐ SSDI

☐ General Assistance (GA)

☐ Veteran's disability benefit

☐ Medicare

☐ Medicaid

☐ Workers Compensation Benefits

Other (please specify)

DISABILITY (Check all that apply)

☐ Physical disabilities- Orthopedics (e.g. Post Paraplegia or Quadriplegic, Traumatic Brain Injury, Spinal Cord Injury, Carpal Tunnel, Hip/Knee other Joint Dysfunction,etc.)

☐ Physical disability- Neuromuscular/ congenital conditions (Cerebral Palsy, Muscular Dystrophy, MS, etc.)

☐ Developmental disabilities (e.g. Cognitive Disabilities, Autism Spectrum, Attention Deficit Disorder, Specific Learning Disability, etc.)

☐ Sensory (Blindness or Visual Impairment, Deaf - Blind, Deaf or Hard of Hearing etc.)

☐ Chronic Illnesses (e.g. Arthritis, Fibromyalgia, Cancer, Cystic Fibrosis, Diabetes, Epilepsy,Heart Disease, Stroke, Kidney Failure, Respiratory/Pulmonary/Allergies etc.)

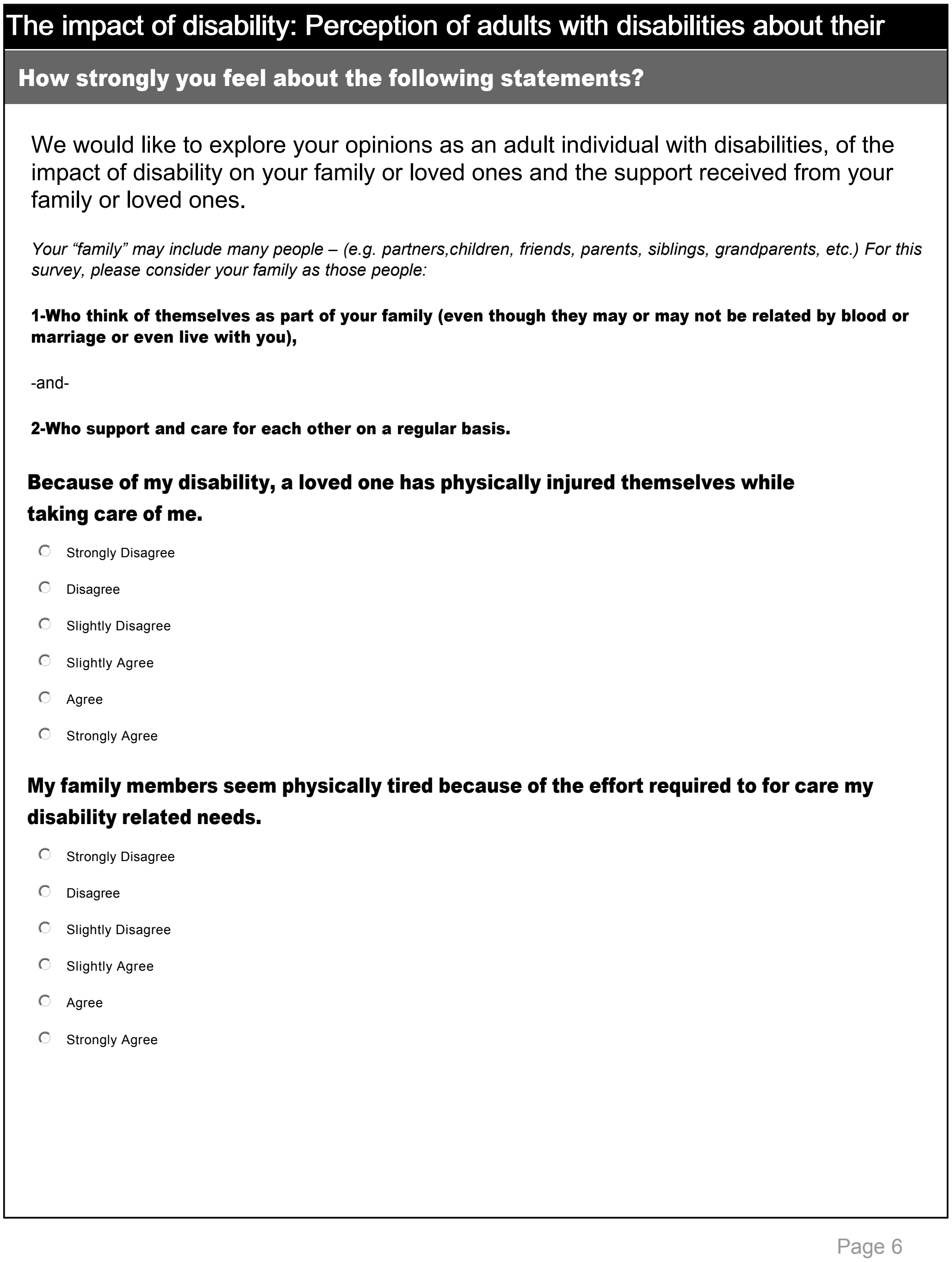
☐ Emotional or Mental Illness (Depression, Post Traumatic Stress Disorder, Schizophrenia, Bipolar Disorder etc.)

☐ AIDS/HIV

☐ Substance Dependency (Alcohol or Other Drug Disorder)

☐ Don't Know

Other (please specify)



The impact of disability: Perception of adults with disabilities about their

How strongly you feel about the following statements?

We would like to explore your opinions as an adult individual with disabilities, of the impact of disability on your family or loved ones and the support received from your family or loved ones.

Your “family” may include many people – (e.g. partners,children, friends, parents, siblings, grandparents, etc.) For this survey, please consider your family as those people:

1-Who think of themselves as part of your family (even though they may or may not be related by blood or marriage or even live with you),

-and-

2-Who support and care for each other on a regular basis.

Because of my disability, a loved one has physically injured themselves while taking care of me.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members seem physically tired because of the effort required to for care my disability related needs.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Page 6

My family members make time to take care of themselves physically (i.e. exercise etc.) because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members do Not have time to do things to care for themselves physically (i.e. exercise etc.) because they are caring for my disability.

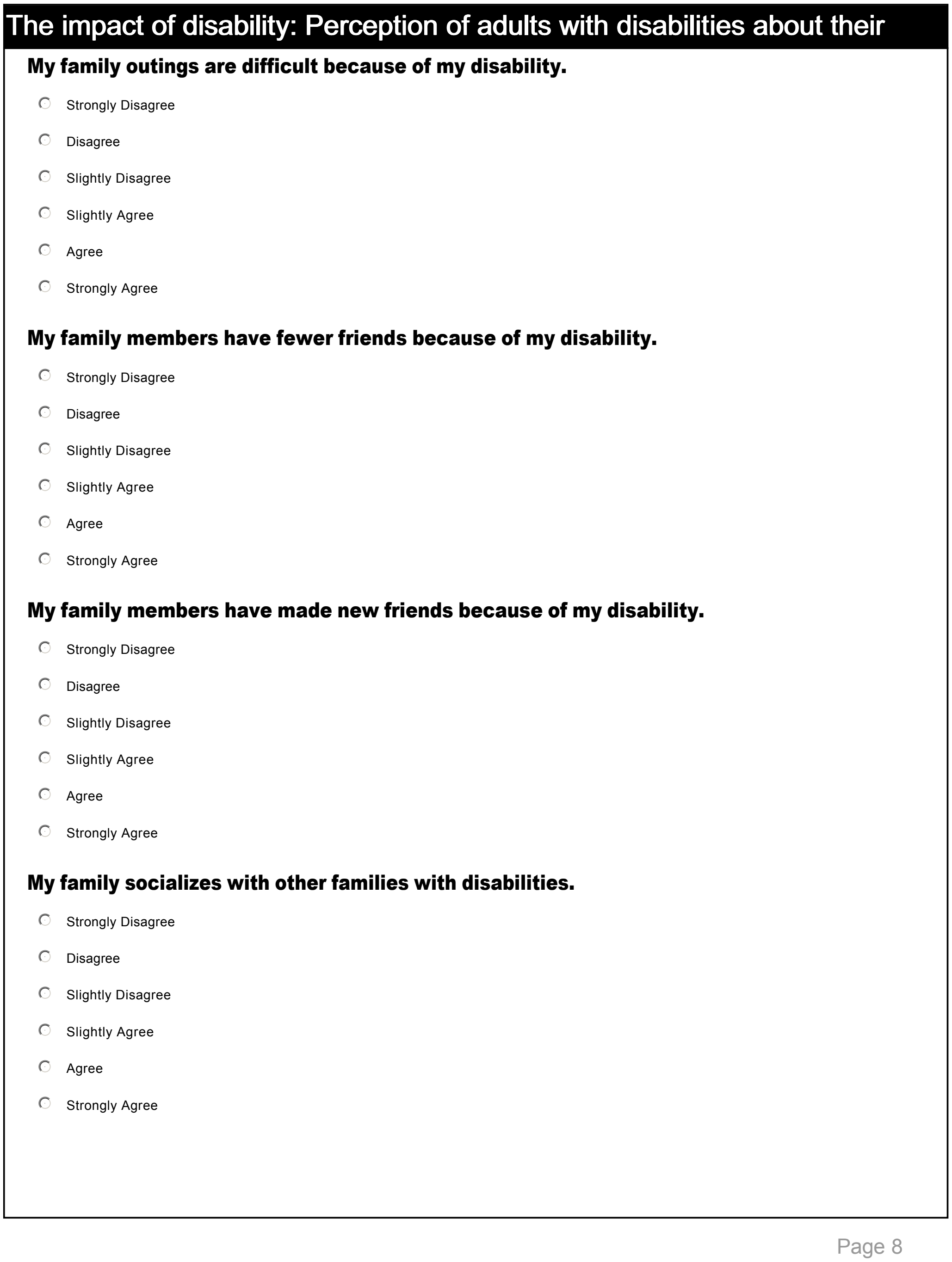
○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members are healthier because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Someone in my family has worsened health because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree



The impact of disability: Perception of adults with disabilities about their

My family outings are difficult because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members have fewer friends because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members have made new friends because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family socializes with other families with disabilities.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

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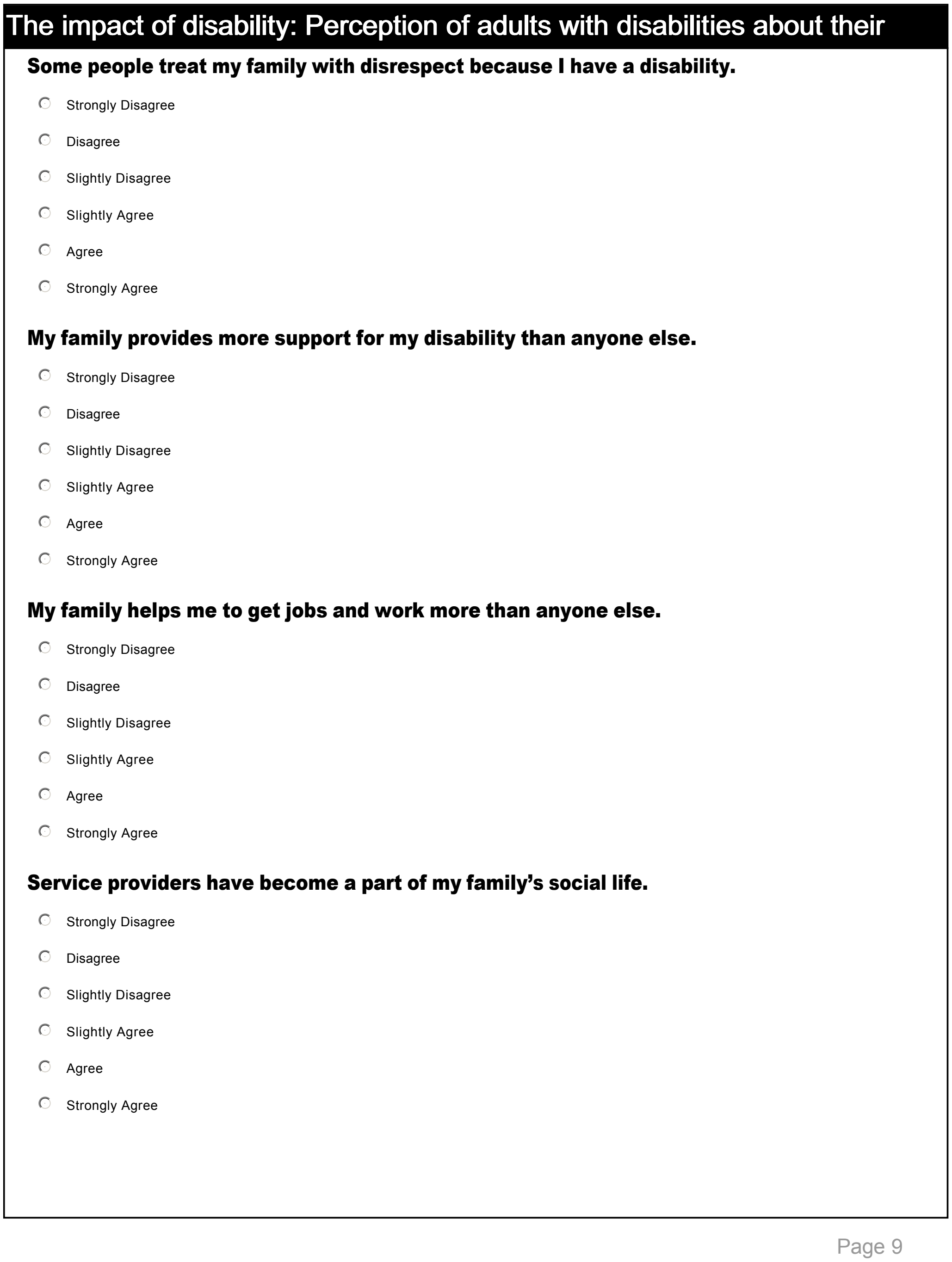

The impact of disability: Perception of adults with disabilities about their

Some people treat my family with disrespect because I have a disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family provides more support for my disability than anyone else.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family helps me to get jobs and work more than anyone else.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Service providers have become a part of my family's social life.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

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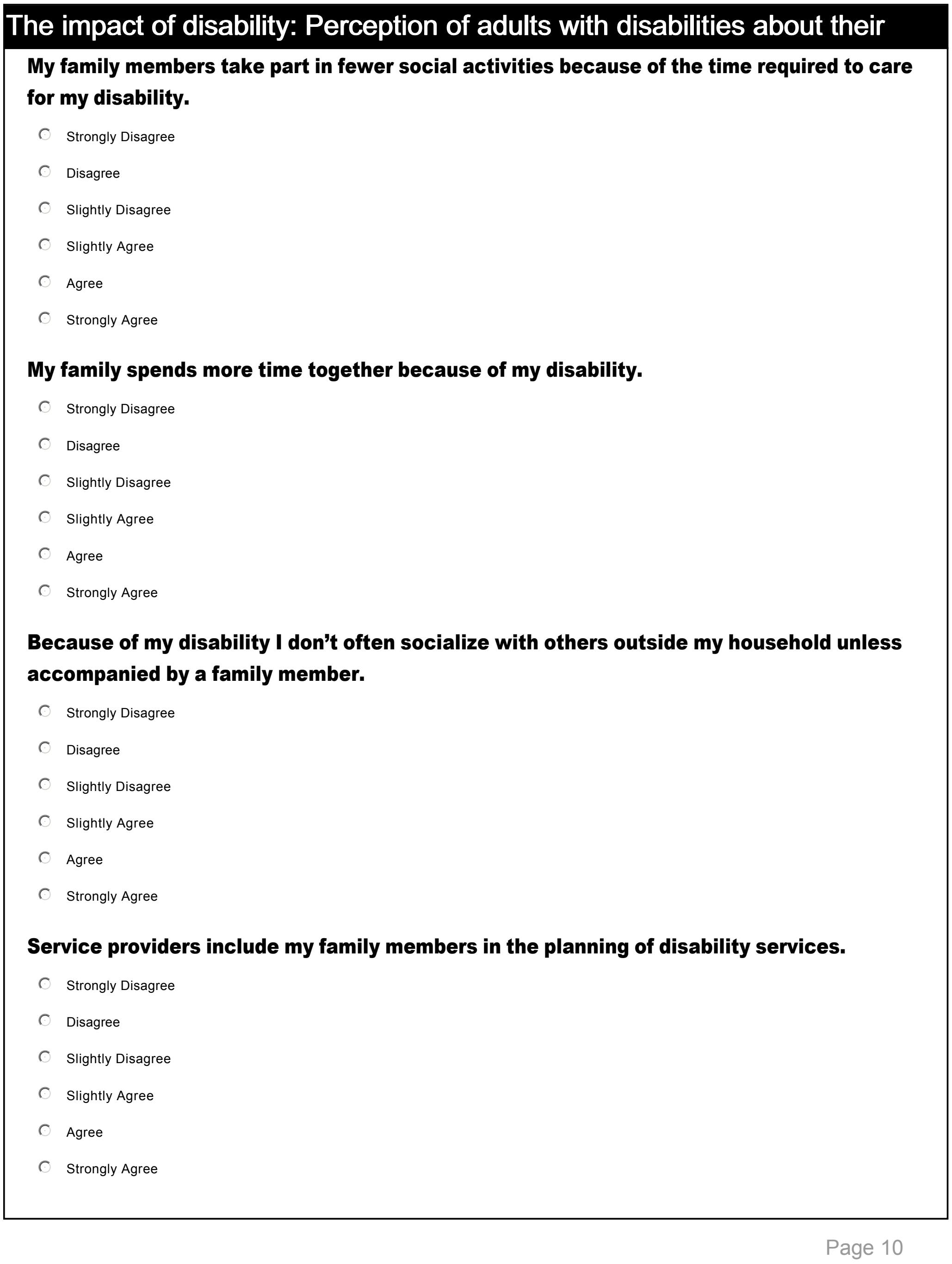


The impact of disability: Perception of adults with disabilities about their

My family members take part in fewer social activities because of the time required to care for my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family spends more time together because of my disability.

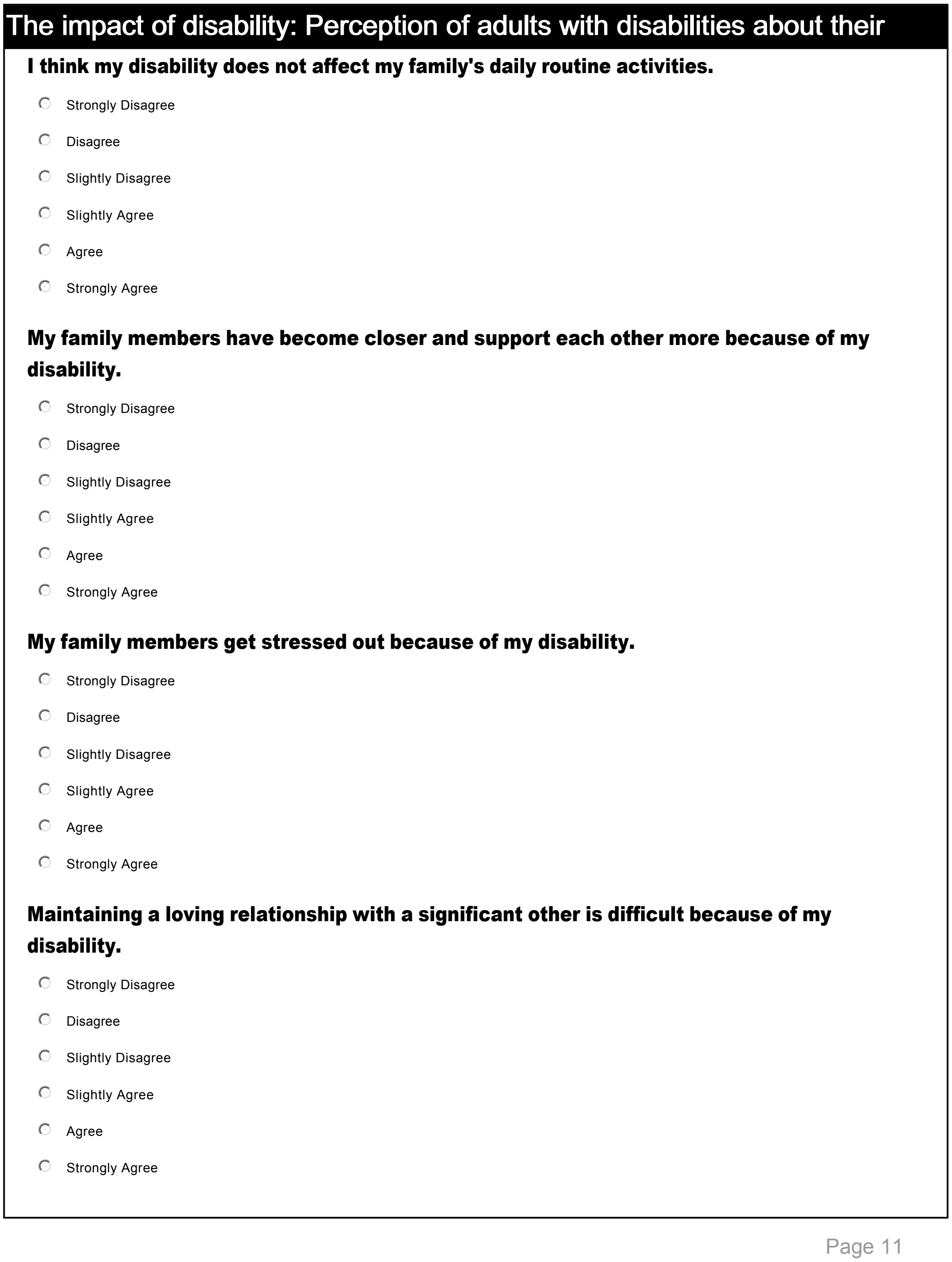
○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Because of my disability I don’t often socialize with others outside my household unless accompanied by a family member.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Service providers include my family members in the planning of disability services.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree



The impact of disability: Perception of adults with disabilities about their

I think my disability does not affect my family's daily routine activities.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members have become closer and support each other more because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members get stressed out because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Maintaining a loving relationship with a significant other is difficult because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

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My family members are happy when they can help with my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My parent’s relationship was affected by my disability.

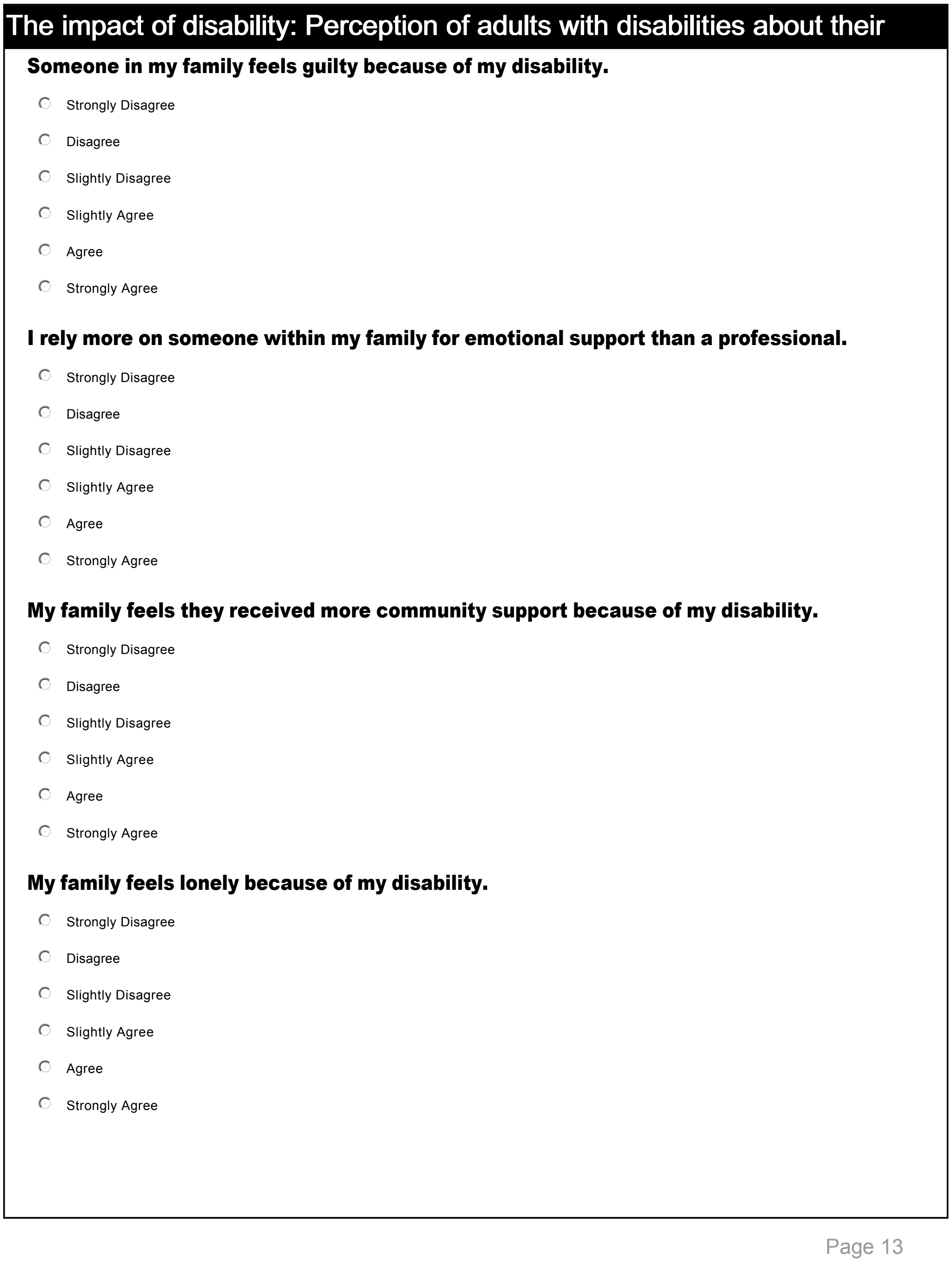
○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members get along better because I have a disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Someone in my family is sad or depressed because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree



The impact of disability: Perception of adults with disabilities about their

Someone in my family feels guilty because of my disability.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

I rely more on someone within my family for emotional support than a professional.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

My family feels they received more community support because of my disability.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

My family feels lonely because of my disability.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

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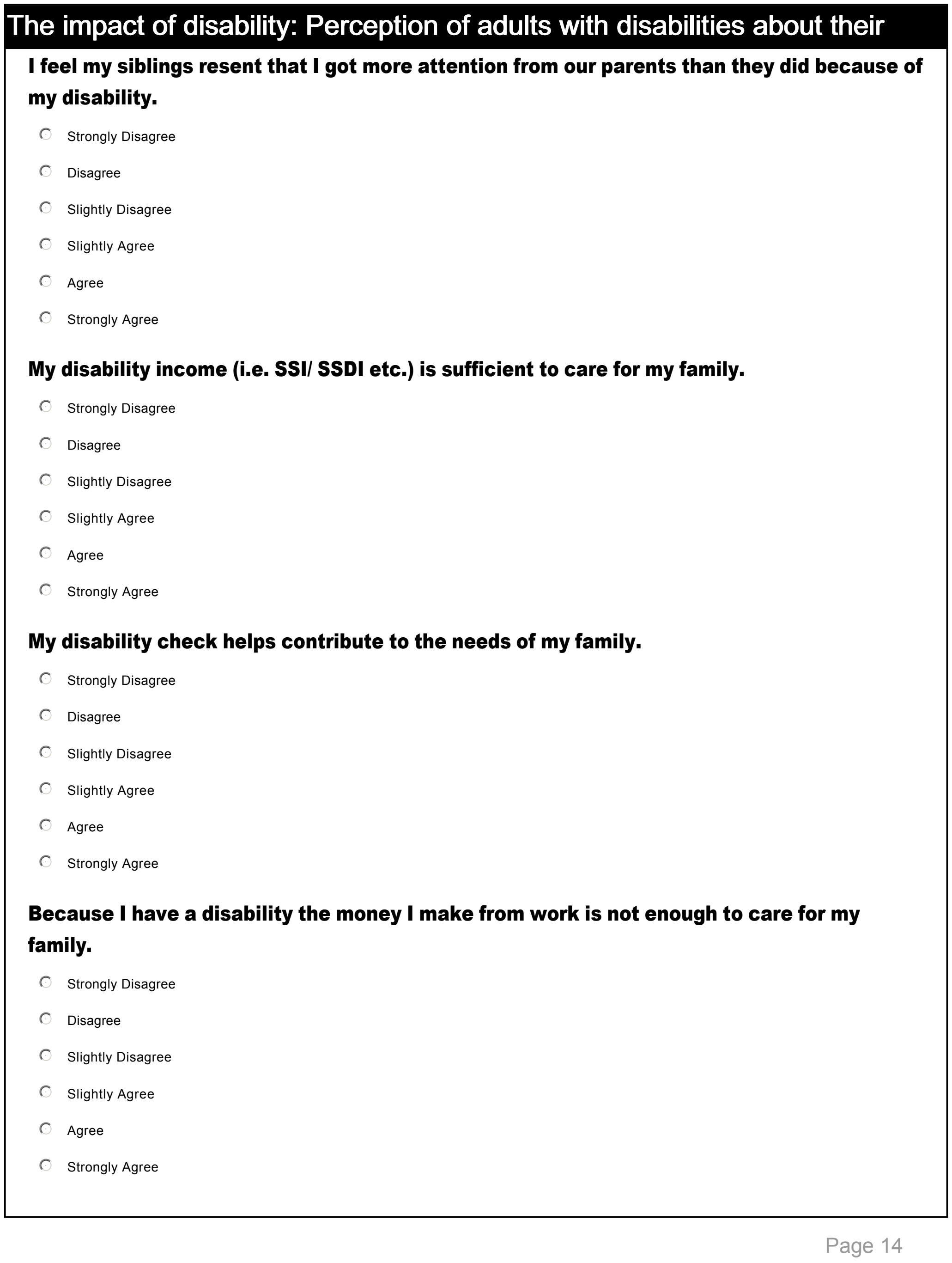

The impact of disability: Perception of adults with disabilities about their

I feel my siblings resent that I got more attention from our parents than they did because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My disability income (i.e. SSI/ SSDI etc.) is sufficient to care for my family.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My disability check helps contribute to the needs of my family.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Because I have a disability the money I make from work is not enough to care for my family.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

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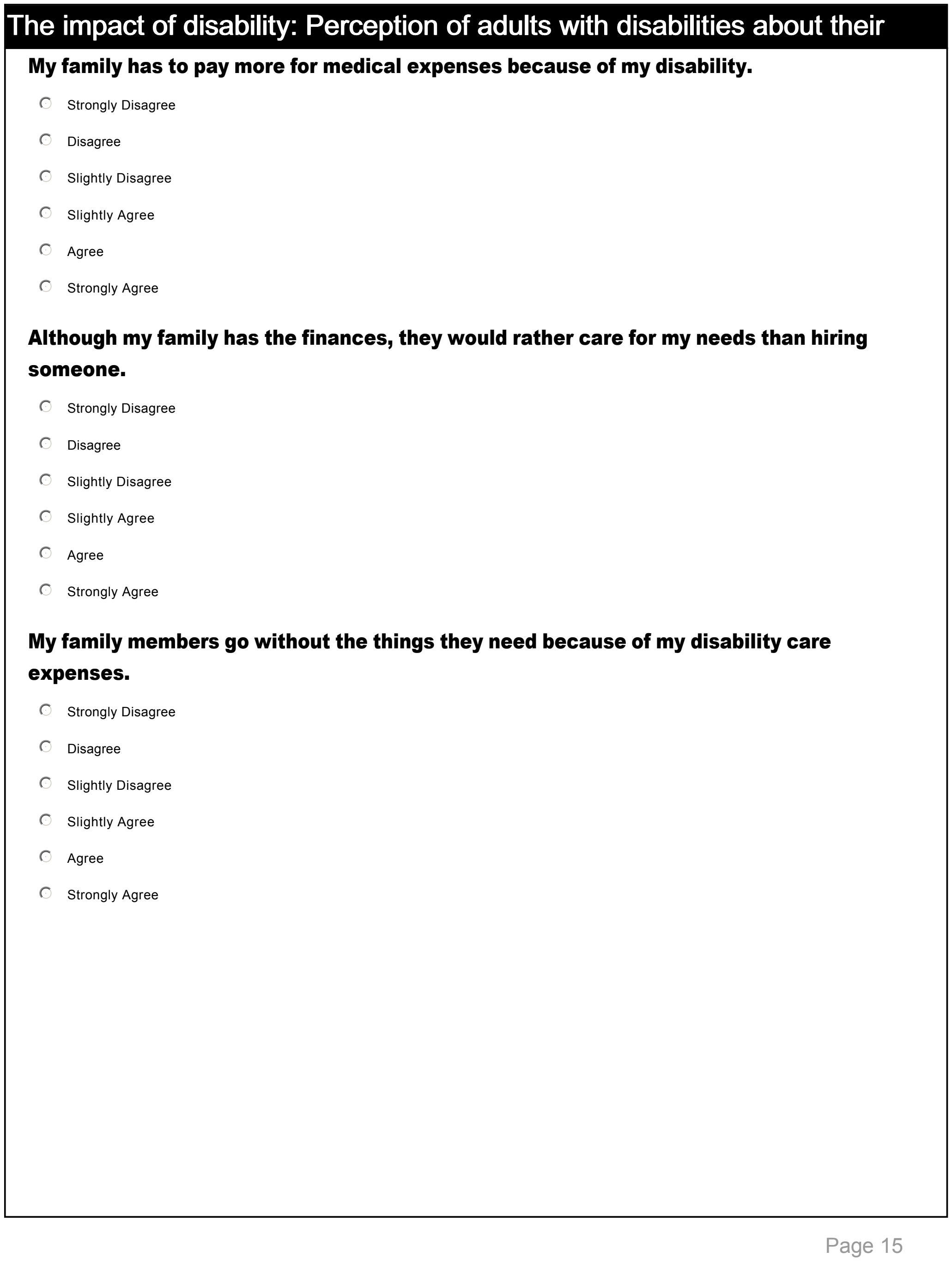

The impact of disability: Perception of adults with disabilities about their

My family has to pay more for medical expenses because of my disability.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

Although my family has the finances, they would rather care for my needs than hiring someone.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

My family members go without the things they need because of my disability care expenses.

○ Strongly Disagree
○ Disagree
○ Slightly Disagree
○ Slightly Agree
○ Agree
○ Strongly Agree

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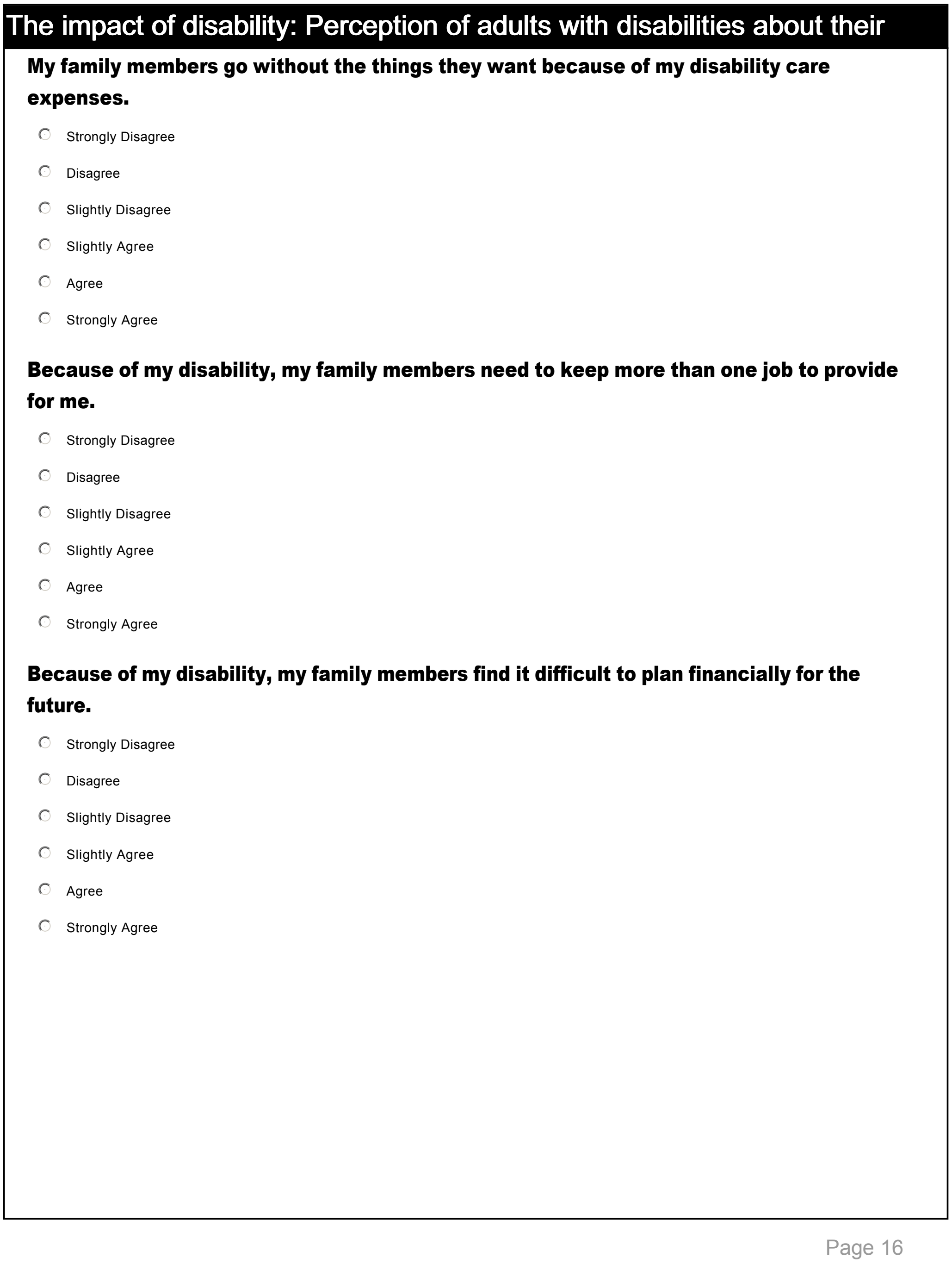


The impact of disability: Perception of adults with disabilities about their

My family members go without the things they want because of my disability care expenses.

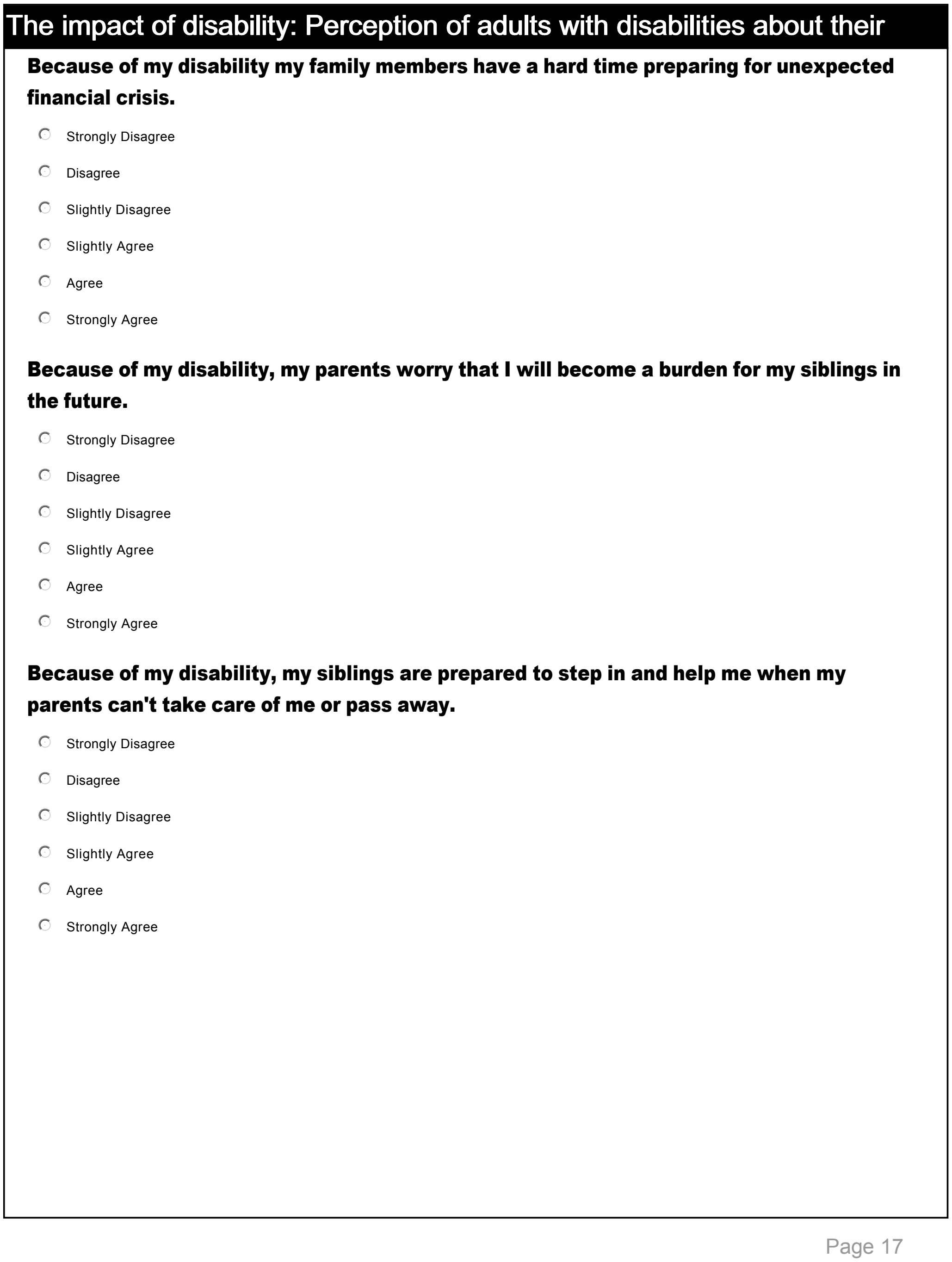
- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

Because of my disability, my family members need to keep more than one job to provide for me.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

Because of my disability, my family members find it difficult to plan financially for the future.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree



The impact of disability: Perception of adults with disabilities about their

Because of my disability my family members have a hard time preparing for unexpected financial crisis.

○ Strongly Disagree

○ Disagree

○ Slightly Disagree

○ Slightly Agree

○ Agree

○ Strongly Agree

Because of my disability, my parents worry that I will become a burden for my siblings in the future.

○ Strongly Disagree

○ Disagree

○ Slightly Disagree

○ Slightly Agree

○ Agree

○ Strongly Agree

Because of my disability, my siblings are prepared to step in and help me when my parents can't take care of me or pass away.

○ Strongly Disagree

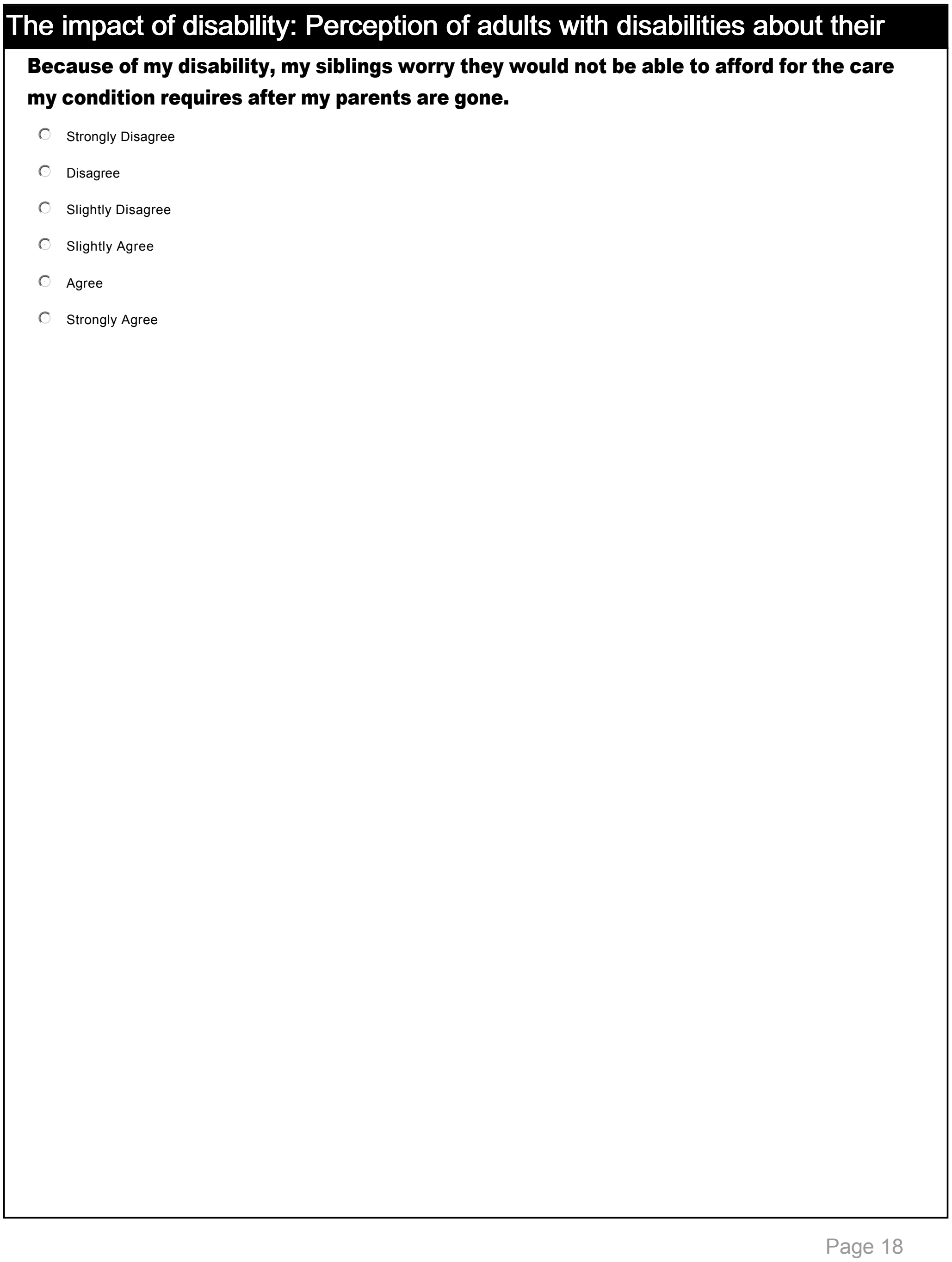
○ Disagree

○ Slightly Disagree

○ Slightly Agree

○ Agree

○ Strongly Agree



The impact of disability: Perception of adults with disabilities about their

Because of my disability, my siblings worry they would not be able to afford for the care my condition requires after my parents are gone.

- ○ Strongly Disagree
- ○ Disagree
- ○ Slightly Disagree
- ○ Slightly Agree
- ○ Agree
- ○ Strongly Agree

BIOGRAPHICAL SKETCH

Benjamin Clayton Charles Jenkins is a 7th generation native to Logan, Utah. He attended Utah State University receiving a Bachelor of Science in Family, Consumer, and Human Development in 2006. He continued at Utah State earning his Masters of Rehabilitation Counseling in 2008. Recently, Dr. Jenkins has satisfied all requirements and fulfillments to obtain a doctoral degree of philosophy in Rehabilitation Counseling at The University of Texas-Pan American (2011-2015).

Dr. Jenkins has practiced professional rehabilitation counseling in rural communities in Southeast Colorado and Northern Nevada where he served migrant farm-workers, Native Americans, and all disability groups in state vocational rehabilitation programs. Observing the fluctuating resources offered by state and federal government programs, Dr. Jenkins noted the strength and capacity of families to empower and engage their loved ones in community transactions. As result he has pursued study and research regarding the experience of individuals and families with disabilities in rehabilitation counseling. Recent publications titles include "Finding Family in Rehabilitation Counseling (2015)" and "Adults with Disabilities' Perceptions of The Impact of Disability on Family (In Preparation)." Dr. Jenkins also maintains a consulting business where he provides forensic/vocational evaluation and rehabilitation services. He can be reached at bcjenkinscrc@gmail.com.