CHRONIC SORROW AND THE IMPACT ON PARENTS OF CHILDREN WITH DISABILITIES

Rhianna Mayra Nordlund
California State University - San Bernardino

Follow this and additional works at: https://scholarworks.lib.csusb.edu/etd

Part of the Disability Studies Commons, and the Social Work Commons

Recommended Citation

This Thesis is brought to you for free and open access by the Office of Graduate Studies at CSUSB ScholarWorks. It has been accepted for inclusion in Electronic Theses, Projects, and Dissertations by an authorized administrator of CSUSB ScholarWorks. For more information, please contact scholarworks@csusb.edu.
CHRONIC SORROW AND THE IMPACT ON PARENTS OF CHILDREN WITH DISABILITIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Rhianna Nordlund
May 2023
CHRONIC SORROW AND THE IMPACT ON PARENTS OF CHILDREN WITH DISABILITIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

by
Rhianna Nordlund

May 2023
Approved by:

Dr. Carolyn McAllister, Faculty Supervisor, Social Work

Dr. Yawen Li, M.S.W. Research Coordinator
ABSTRACT

Purpose: Chronic sorrow was assumed to be a common feeling experienced by parents of children with disabilities, and if not supported properly it would impede a parent’s ability to support their child through the treatment of a disability and other life stressors that come with a lifetime diagnosis. This research looked to see how family type, the child’s diagnosis, feelings of support expressed by the parent, societal stigma about disability, and coping abilities impacted the parents’ experiences of chronic sorrow and who was most at risk of chronic sorrow.

Methods: Through a positivist research design, the researcher addressed the rate of occurrence of the experience of chronic sorrow by parents with children with disabilities. The researcher used the quantitative method of surveying parents to see the effects of family structures on the ways that parents cope with their experience of chronic sorrow. Sampling methods utilized a bivariate correlation of multiple interval ratio variables. The only significant correlation found was between ratings of chronic sorrow and distress of comparing the disabled child to their other non-disabled children.

Implications: This study addressed a variety of factors (both protective and risk factors) that social workers should be observant of in assessing parents of children with disabilities and their experiences with feelings of chronic sorrow. With this knowledge, social workers would then be better prepared to choose
interventions that fit the family’s needs while considering the stress levels of those parents.
ACKNOWLEDGEMENTS

I would like to thank my family in supporting me emotionally, mentally, and physicially throughout my education to obtain my Masters in Social Work. Thank you to my parents who drove me to and from classes every week throughout my Bachelor of Arts in Social Work. Thank you to my two oldest younger brothers for sharing my mother on those nights when she had to sit and wait for me to get out of class instead of making them dinner or helping them with homework. Thank you to my grandparents who cheered me on and told me I could accomplish anything I put my mind to. I would also like to give extra thanks to my maternal grandmother who was a part of the reason I chose social work and for having our many knowledgeable discussions over the years. Thank you to all my teachers and professors over my 23 years of education who inspired my love for learning and my instructional assistants who made it possible for me to attend mainstream classes. Thank you to any social service or medical staff who was instrumental in getting me resources and services to be as independent as I could be. You too were a motivating factor for me to want to be a social worker and help other people with disabilities.
DEDICATION

I would like to dedicate this research study to all the parents who are raising children with disabilities. You are an important part of them achieving their highest potentials and experiencing fulfilling lives. Please keep advocating for your children and believing in their value to society. With your help, we may be able to create a more inclusive society.
# TABLE OF CONTENTS

ABSTRACT .......................................................................................................................... iii

ACKNOWLEDGEMENTS .................................................................................................. v

LIST OF TABLES ................................................................................................................ ix

LIST OF FIGURES .............................................................................................................. x

CHAPTER ONE: ASSESSMENT ......................................................................................... 1
  Introduction ......................................................................................................................... 1
  Research Focus .................................................................................................................... 1
  Rationale for a Positivist Paradigm ..................................................................................... 3
  Literature Review ................................................................................................................ 4
    What is Chronic Sorrow .................................................................................................... 4
    Prevalence ......................................................................................................................... 6
    Consequences of Chronic Sorrow ..................................................................................... 7
    Batchelor’s Adaption of Kendall’s Chronic Sorrow Instrument ....................................... 9
    Interventions ..................................................................................................................... 10
  Theoretical Orientation ..................................................................................................... 11
  Potential Contribution of the Study to Micro and Macro Social Work Practice .......... 13
  Summary ............................................................................................................................. 14

CHAPTER TWO: ENGAGEMENT .................................................................................... 15
  Introduction ......................................................................................................................... 15
  Study Site ............................................................................................................................ 15
  Gatekeepers at the Research Site ....................................................................................... 16
  Engagement Strategies ...................................................................................................... 17
LIST OF TABLES

Table 1: Demographics ................................................................. 35
Table 2: Frequency of Care Demands................................................. 40
Table 3: Definitions of Disability ...................................................... 44
Table 4: Feeling Words ................................................................. 44
Table 5: Word Associations (Sheets et al., 2012).................................. 46
Table 6: Wickler (1981) Graph Responses .......................................... 48
Table 7: Common Stigmatizing Statements Reported by Parents ............ 50
Table 8: The Chronic Sorrow Scale (Batchelor, 2019) .......................... 52
Table 9: Correlating Factors- Mean and Standard Deviation ................. 54
Table 10: Additional Topics Expressed by Parents .............................. 65
LIST OF FIGURES

Figure 1: Wickler (1981) Graph Results for Mothers and Fathers Chart .......... 49

Figure 2: Stigma Categories Chart ................................................................ 51

Figure 3: The Chronic Sorrow Chart ................................................................ 52
CHAPTER ONE:
ASSESSMENT

Introduction
This study looked at Olshansky’s (1962) definition of chronic sorrow. The research focused on chronic sorrow and its impacts on a variety of family structures of children with disabilities. A positivist paradigm for researching chronic sorrow was used to look at this topic. The literature review included topics on Olshansky’s (1962) chronic sorrow, the prevalence of chronic sorrow, Batchelor’s (2019) instrument to measure chronic sorrow factors, themes of this topic, interventions, and the demographic makeup of families of children with disabilities. Westberg’s (1962) model of grief, an extension of Kübler-Ross’ (1969) model, was the theoretical orientation employed for this research because of its application to ambiguous loss. Lastly, the potential contributions this research has for how social workers interact with parents of children with disabilities, within the micro and macro levels, will be the closing section of this chapter.

Research Focus
The focus of this research was to look at how chronic sorrow impacted how parents reacted to their child’s disability. Do differing familial structures and the gender of parents impact whether they felt more or less chronic? Chronic sorrow, in this subject, is a model of grief experienced by parents who expected
an average child and gave birth to a child with a disability. It can vary with the level of support needed by the child, with severe disability possibly leading to worse cases of chronic sorrow.

The definition of family is changing. A family can consist of the nuclear, single-parent, divorced, same-sex, adoptive, stepfamilies, cohabitating, and non-cohabitating individuals. These differing familial structures could respond to chronic sorrow differently, leading to a parent who is more or less adept at supporting a child with a disability throughout their life and coping with their own stress from their chronic sorrow experiences.

The topic of chronic sorrow experienced by parents of children with disabilities is important in that the parents are the main caregivers and supporters of the child. Without the parent’s ability to cope with the stress of their child having a disability, the parent will be less capable to take the necessary steps in reaching out for treatment resources. In the early years of a child’s life, the parents take control of all medical decisions. Social workers may overlook the stress that a child’s diagnosis may put on the parents because they may be focused on the child having a successful treatment plan rather than the role that the parents play in the child’s care. Therefore, the additional goal of this research is to look at the environmental factors surrounding disability and its impact on the parents so they can focus on caring for their child, rather than worried about the “what if’s” of their child’s diagnosis and its impact on the child’s life.

Environmental factors would be the stigma of disability and the impact of gender
roles on parenting. The ability to be supportive of the child and the parent’s ability to cope with the stress of chronic sorrow may be affected by environmental factors. At what age the child was diagnosed is yet another factor leading to more or less chronic sorrow. This research project also seeks to know how the different family forms operate as protective or risk factors when experiencing chronic sorrow.

Rationale for a Positivist Paradigm

A positivist paradigm of research was used within this study due to its usage of a quantitative method of gathering data (Morris, 2013). The positivist assumes that the subject is “objective” and has “regulatory mechanisms” that control why and how things happen (Morris, 2013, p. 10). It also believes that the observer must stay an outsider in research (Morris, 2013).

Quantitative data allows ordinal results on a sliding scale from “strongly disagree” to “strongly agree” for the experiences of symptoms of chronic sorrow and the extent of the impact of the child’s diagnoses (Morris, 2013). This will allow the research to show the varying degrees of experience of chronic sorrow amongst the family structures. Quantitative data can also be collected nominally for whether families are made up of divorce, cohabitation, non-cohabitation, same-sex parents, stepfamilies, single-parent families, and adoptive families (Morris, 2013). Nominal data on race and/or ethnicity can also be collected for comparative and demographic reasons (Morris, 2013). This data shows the variety of experiences of families. Quantitative data, the application of numerical
data, collected on the population being focused allows for generalizability across each factor studied in the research (Morris, 2013).

**Literature Review**

The literature review looked at what chronic sorrow was and how it came to be a term used for the experiences of parents with children with disabilities. Depression, guilt, and shame are pervasive throughout experiences of chronic sorrow. Prevalence of the experience of chronic sorrow depended on the level of care and severity of the child’s diagnosis. This literature review attempted to look at the demographics of family types and the types of children with diverse levels of severities of disability. There are eight common themes identified in research on chronic sorrow. The consequences of chronic sorrow are isolation and decreased family income, which could put stress on the family and lead to divorce. Within the study of chronic sorrow, Batchelor (2019) created an instrument that measured whether someone was or was not experiencing chronic sorrow. Lastly, interventions utilized were providing knowledge to parents about treatments and diagnoses, validation of the parents’ experience, counseling, respite care, and coping humor.

**What is Chronic Sorrow**

Chronic sorrow (CS), a term first introduced by Olshansky (1962, p. 190), was a term originally used to describe the “pervasive psychological reaction” of parents of children with mental delays. Boss (2002) related chronic sorrow further to feelings of ambiguous loss. Now, chronic sorrow has been broadened to
parents’ feelings towards children with a variety of diagnoses (Coughlin & Sethares, 2017; Fernández-Alcántara et al., 2015; Nikfarid et al., 2015; Smith et al., 2015).

Before Olshanky created the term chronic sorrow, this feeling of guilt, shame, and anger were portrayed by clinicians as a negative experience that parents had to set aside rather than the natural feeling of an unfortunate occurrence; acceptance was pushed over adaptation and a new meaning of life with the child with a disability had to be reintegrated into their daily lives (Olshansky, 1962). Medical personnel seeing some parents’ positive coping and lack of despair over time as maladaptive permeated throughout the literature (Coughlin & Sethares, 2017; Gordon, 2009; Olshansky, 1962). The themes found throughout the literature were: an array of emotions, a motivation to advocate to the fullest extent for their child, caregiver burnout, the stigma of disability on the entire family, aligning parenting expectations to the child’s diagnosis, normalizing ambivalence of parenting and the family, restructuring of the parent’s identity, and finding hope in the new family structure (Parrish, 2010; Patrick-Ott, 2011).

It was expressed that clinicians should give factual information about the child’s diagnoses and allow the parent to talk about how their child’s diagnoses made them feel, as a helpful process towards healing and reintegration of life (Olshansky, 1962) as well as mention common treatment and procedures during the initial engagement phase of interacting with these families (Coughlin & Sethares, 2017). Chronic sorrow is a cyclical process where a triggering event
occurs and the feelings of chronic sorrow reappear, therefore counseling would have to reoccur as feelings of chronic sorrow re-surfaced (Coughlin & Sethares, 2017; Eakes et al., 1998; Olshansky, 1962; Parrish, 2010; Wickler, 1981). 

Prevalence

According to the 2000 Census, 20.9 million families had at least one family member with a disability (Wang, 2005). 0.7% had a child with a sensory or physical disability, 1.2% had both a sensory and a physical disability, 2.8% had a child with a mental disability, 0.6% had a child who needed assistance with self-care or going outside of the home, and 3.9% of the children had a combination of all of these disabilities (Wang, 2005). 87.1% of families had one child with a disability, 10.9% reported having two children with a disability, and 2% reported having three or more children with a disability (Wang, 2005). The literature also dealt a lot with individuals diagnosed with Down Syndrome (DS) and Autism Spectrum Disorder (ASD) as specific disabilities that chronic sorrow has been studied (Lopez et al., 2018; Olshansky, 1962; Ratto et al., 2016; Rueda et al., 2005; Sheets et al., 2012).

86% of parents of a child with a disability have had depressive episodes alongside their chronic sorrow (Hobdell, 2004). The literature stated that mothers have the most involvement in caring for their children with disabilities than fathers, and this level of responsibility adds that mothers deal with more emotional consequences of stress involved in chronic sorrow (Coughlin & Sethares, 2017; Olshansky, 1962). Fraley (1986) stated that 50% of mothers felt
depressed by their child’s diagnosis. Fathers who did report struggling with their child’s diagnosis reported feelings of confusion, concern for the future, and stigma associated with their child’s diagnosis (Coughlin & Sethares, 2017). Literature on the diversity of family structures and how they cope with having a child with a disability were very limited. Wang (2005) only talked about three categories of families: married couples, female heads of household, and male heads of household.

**Consequences of Chronic Sorrow**

Chronic sorrow leads to feelings of guilt, shame, anger, and depression (Olshansky, 1962). Furthermore, parents may distance themselves from friends and loved ones who do not understand the stress of caring for a child with a disability (Batchelor, 2019; Sheets et al., 2012). Parents who are the main caretakers may have to quit their job because finding appropriate child care that meets the child’s extra needs may be too difficult (Batchelor, 2019), decreasing the available family income to one earner if the parent is a two-earner household or no earners if the family is a single-parent household. Also, Moor & de Graaf (2016) talked about how parents who lose a child had less happiness than parents who hadn’t, ten years later. Chronic sorrow is a type of ambiguous loss that could impact happiness. Lopes et. al. (2014) stated that the more depressive episodes a person has, the more likely their depression will continue to reoccur. Shame and guilt in fathers, which is a common theme of rumination, affected the child’s rumination habits more than the mother’s rumination (Psychogiou et al.,
2017). All of these consequences put a strain on a marriage and could possibly lead to divorce.

As for the stigma of disability, Ali et. al. (2012) stated that those with intellectual disabilities faced the most stigma (6.1%). “Stigma is a process by which certain groups, such as those with mental illness or intellectual disability, are marginalized and devalued by society because their values, characteristics or practices differ from the dominant cultural group” (Ali et al., 2012). It occurs through stereotyping, prejudice, and discrimination (Rüsch et al., 2005) and because of power differentials due to social, economic, and political differences (Link & Phelan, 2001). This same stigma can also be felt by the parents of a child with an intellectual disability.

Manago et. al. (2017) stated that parents deflect and challenge the stigma experienced from having a child with a disability through the utilization of medical and social models of disability. “Deflections refer to strategies that minimize the negative psychological effects of stigmatization while maintaining the social order. In contrast, challenges refer to strategies that push back against stigmatizing structures through political mobilization and/or interpersonal confrontation” (Manago et al., 2017, p. 169).

The medical model of disability, which has historically predominated in the public imagination, depicts disability as a deficit from the norm, a malady to be fixed through physical therapy, technological devices, and personal
willpower. In contrast, the social model of disability resists the medicalized ‘personal tragedy’ orientation, and advocates instead for an orientation of social oppression (Manago et al., 2017, p. 170; Oliver, 1990, 2013, 2018; Oliver & Barnes, 2012).

The social model suggests “deploy[ing] a social framework in efforts to dismantle stigma (i.e., challenging), while enacting a medical narrative to navigate—but not disrupt—stigmatizing landscapes (i.e., deflecting)” (Manago et al., 2017, pp. 169–170). Other ways parents manage stigma is through “invoke[ing], ignor[ing], and reject[ing] medical labels, medical authorities, social-structural arrangements, and institutional infrastructures” (Manago et al., 2017, p. 170).

**Batchelor’s Adaption of Kendall’s Chronic Sorrow Instrument**

Kendall created a 57-question instrument with “reliability with a Cronbach’s alpha of 0.80” to measure chronic sorrow, which Batchelor (2017, p. 12) adapted to 18 questions. It asked about “triggers, disparity, sadness, lack of voice, isolation, feelings of unfairness, and renormalization” (Batchelor, 2017, p. 12; Kendall, 2005). This instrument was adapted by the researcher of this paper to be incorporated into the current survey in Appendix B for this study since it has already developed “reliability with a Cronbach’s alpha of .91” for chronic sorrow (Batchelor, 2017, p. 12). Instead of asking about “loss,” this researcher wanted to change it to “chronic sorrow.” “The range score for this tool was 0-124: 0-38 no
CS present, 39-82 likely CS present, and scores greater than 83 CS present” (Batchelor, 2017, p. 12).

**Interventions**

Interventions can be very important for the multitude of stressors caused by having a child with a disability, especially for those with severe disabilities that demand more parental support. For parents of children with Autism Spectrum Disorder (ASD), especially, 20.1% went to counseling and 11.8% attended support groups (Bordonada, 2017). Respite care was a very important intervention for parents experiencing chronic sorrow because it reduces the stress of caring for the child by giving the parent a brief amount of time to fully focus on self-care (Coughlin & Sethares, 2017).

“Coping humor is defined as a use of humor in which individuals seek to manage the effects of one or more life stressors” (Rieger & McGrail, 2013, p. 89). Being able to laugh during stressful situations is a good indicator of cohesion and adaptability within families (Rieger & McGrail, 2013). Families of children with disabilities who can face their struggles with a humorous attitude did not face the same level of chronic sorrow as families who did not utilize humor (Rieger & McGrail, 2013). Interventions as remedies to the stress caused by chronic sorrow allow the parent to be consciously supportive of that child’s needs.

Chronic sorrow is a very complicated experience full of adaptation and redefinition of the family and self for parents. It is an ambiguous type of grief
process that affects parents who were expecting an average child and had a child with a disability. It only affects a small portion of families but can have a large effect on parental mental well-being. Academic knowledge about how chronic sorrow affects varying family structures is very limited. Common themes were found amongst parents who have dealt with the experience of chronic sorrow. There was evidence that parents of children with disabilities feel isolated and have decreased family incomes, which could lead to divorce, but there was no evidence that compared families of children with varying severities of disabilities. Knowledge about treatments and diagnoses, validation of the crisis, counseling, respite care, and coping humor are very important intervention methods clinicians should use. This research sought to expand the knowledge base in the literature review on the parental experience of chronic sorrow to look at how it impacts the parental relationships within varying family structures. It also seeks to find who is most at risk of experiencing chronic sorrow. Most of the literature focused on Down Syndrome and Autism, but this research will look at other disabilities. This leads to a deeper look at whether parents questioning divorce would have stayed together if they had more support when dealing with their feelings of chronic sorrow for their child, and whether not getting divorced led to less chronic sorrow.

Theoretical Orientation

Greif is a process that goes through many stages. Chronic sorrow in and of itself does not include its own stages of grief, but grief is part of the process.
Grief occurs after there has been a severe loss in a person’s life. Kübler-Ross (1969) created the five stages of grief: denial, rage and anger, bargaining, depression, and acceptance that explain a process after a literal death of a loved one. Westberg’s (1962) model of grief expanded Kübler-Ross’ stages to include: shock and denial, emotional eruption, anger, illness, panic, guilt, depression and loneliness, reentry difficulties, hope, and affirming reality; expanding the conversation of grief to include ambiguous loss explained by Boss (2002). Westberg’s (1962) model is a continuum of the experience of grief and a person can move along that continuum—back and forth—as they are coping with the loss they feel. Kübler-Ross (1969) and Westberg (1962) both noted that some people may never reach “healed/new strength.”

These two models of grief are important to the research because they set the pathway for normal grief progression. Since chronic sorrow includes feelings of grief for the loss of the able-bodied child, parents of children with disabilities are assumed to progress through these stages of grief and readjustment during critical moments in their child’s life. It is important to know this reality when studying chronic sorrow so you can understand the difference between a parent who is coping well with their child’s diagnosis and a parent who may be experiencing more suffering due to chronic sorrow. Westberg’s (1962) model is the mechanism for the experience of chronic sorrow, due to its well-defined stages and applicability to all experiences of loss; not just explicitly for the experiences of death. Parents of children with disabilities are not always
experiencing a literal death of a child, but the idea of losing the average child they thought they would have. In this research, much attention was placed on where parents fall on the continuum and whether their placement was causing stress which leads to disruptions in the marriage or partnership. The research also looked at the placement of the parents on the continuum for those who adopted a child since they chose the child to join their families despite their child’s diagnosis.

**Protentional Contribution of the Study to Micro and Macro Social Work Practice**

Within the micro-level of the family as the client, learning the limitations of current services for parents of children with disabilities assists micro practice social workers in making better recommendations and allows macro social workers to focus their advocacy on the obstacles mentioned by those directly affected. Learning the levels of chronic sorrow and potential predictors of chronic sorrow allows a micro practice social worker to offer more tailored interventions. It also provides information for the macro social worker to advocate for better services and supports to address this issue. Lastly, hearing from parents about the stressors they experience raising children with disabilities also allows the micro practice social worker to better identify appropriate resources and interventions and allows the macro practice social worker to advocate for changes in our systems of care and environments to reduce these stressors for all families of children with disabilities. The more cohesive the disability
community is, the more aware stakeholders will be in including individuals with disabilities into greater society and destigmatizing disability.

Summary
This chapter looked at the experience of chronic sorrow of parents with children with disabilities. Chronic sorrow affects many different forms of families based on the composition of the family. The research took a positivist paradigm to look at chronic sorrow quantitatively to seek who is most at risk for chronic sorrow. The literature review looked at Olshansky’s (1962) chronic sorrow, factors and themes of this topic, took a look at the instrument previously adapted by Batchelor (2019) to define chronic sorrow, interventions, assessment tools, and the demographic makeup of families of children with disabilities. The theoretical orientation was Westberg’s (1962) model of grief that utilized an application of ambiguous loss (Boss, 2002) and the expansion of Kübler-Ross’ (1969) stages of grief. Lastly, social workers should learn directly from parents about the obstacles and stressors in their lives with a child with a disability that the social worker can ultimately use for advocacy work for the disability community.
CHAPTER TWO
ENGAGEMENT

Introduction

This chapter focuses on the engagement skills needed when conducting positivist research. The researcher chose to partner with a special education department located at a Southern California school district, but parents and staff soon spread the word about the research through a snowball sampling method to individuals around the United States. Engagement is very important because the researcher and partner will collaborate within the data collection stage to meet a mutual goal. This chapter talks about sampling, surveying, diversity issues, ethical concerns, the effects of politics on this research, and technology concerns unique to the research plan. The researcher also considered the knowledge about the population being studied that will be needed to create a competent research project. Only general information was given about the location of respondents and the partnership to maintain confidentiality.

Study Site

The special education department that the researcher originally partnered with was in charge of serving to accommodate all children with disabilities for a school district located in Southern California. This department works in collaboration with parents, students, colleagues, outside agencies, and advocates within the community to provide quality services determined by an
Individualized Education Program Team. Clients make up all individuals from preschool to early adulthood who have a confirmed diagnosis and their parents. Workers at this special education department ranged from teachers, aides, support staff, school psychologists/social workers, data technicians, and administrative staff. Services offered through this school district were school psychologists, speech-language pathologists, health services, and community referral services. Participants in the study, along with employees from the school district, quickly spread the word about the research and gained individuals outside this location and across the country to participate in the research study, a positive quality of sharing information found within the community of those with disabilities and the people supporting them.

Gatekeepers at the Research Site

Two gatekeepers that would be very useful in connecting with for the purpose of this research project were the director of special education and the program manager of this school district in Southern California, since both of these individuals held authoritative positions in this district. These two individuals were also important because they had the power to decide whether the researcher could utilize their agency or not for this research project. The behavior specialist and other staff from this school district were additional assets to this project because they had direct access to students with disabilities and their ability to put the researcher in direct contact with other staff that had direct access to students with disabilities. They also disbursed the research study to a
bigger population outside of the immediate regional location and around the country for more respondents to participate.

Engagement Strategies

The researcher approached all interactions with gatekeepers in a respectful and approachable manner to make sure that gatekeepers felt that the researcher was open to discussion and would work harmoniously with the organization. The researcher also assured the gatekeepers felt that the research aligned with their mission and values by educating them on the research focus.

The researcher did this by introducing themselves and the project they planned to complete. Next, the researcher set up a meeting with the gatekeepers to discuss what the purpose of this research was and how it could affect the future practice of social workers—especially locally in their area. Another important topic that was discussed was how this research could impact how the special education department employees, and social workers within their district, interact with families of children with disabilities in the future to be sensitive to and observant of parents’ experiences with feelings of chronic sorrow. The researcher also discussed with the gatekeepers how data would be collected and stored while the research was ongoing, and how the final report would be disseminated to interested parties of the research. Lastly, the researcher had to have an agreement with those gatekeepers to disburse the survey flyer to parents of children with disabilities.
Self-Preparation

The survey was sensitive to the difficult emotions that come with having a child with a disability—validating the feelings of guilt, depression, and anxiety that coincide with chronic sorrow—and negative opinions about this validation. The researcher had to be sensitive to the nature of talking about divorce and other societally taboo, non-traditional family structures because these types of families may face stigma in the general society; as well as being sensitive to any parent who has a disability and reports they experienced no chronic sorrow. This stigma could have created a reluctance to answer the survey and required the researcher to have an extra layer of understanding and compassion—aspects of engagement—for the respondents.

Handling information on minors’ diagnoses, another topic that has a stigma, also was included in the considerations that the researcher took precaution of to have an ethical research project. Because of this sensitivity, there was an informed consent form attached to the beginning of the survey for the parent to agree to before continuing the survey.

When preparing for data collection, the researcher considered how large of a sample they were going to need and what the demographic breakdown should have looked like for that area. This research sample included individuals who are parents to children with disabilities across all races and addressed family types and dynamics that may have been difficult for individuals to address. The researcher did their research beforehand on what the demographic
breakdown of this school district in Southern California looked like, as well as a
general breakdown of the United States demographics.

Diversity Issues

In diversity issues, the researcher addressed the following when creating
the questions for the survey: “appearance, assumptions and norms; norms about
appropriate behavior; perspectives, language and vocabulary; history;
[and]…intersectionality” that were deemed important by Morris (2013, pp. 84–85
and 87) of race, ethnicity, sexuality, family structure, and diagnosis.

For this particular research, the diversity issues surrounded family
structures and dynamics, the sexuality of the parents and how gender roles are
distributed for the care of the child with a disability, adoption status, and the
children's diagnoses. The area that the partnered special education department
served was a very racially diverse area of Southern California. The breakdown of
this special education department student body was “White (51%), Hispanic
(34%), Black (.09%) out of a total of 9,187 students” (Southern California Special
Education Department Director, personal communication, August 30, 2021). This
special education department also does not collect data on the parents’ sexuality
or the adoption status of the child (Southern California Special Education
Department Director, personal communication, August 30, 2021). 75.8% of the
U.S. was White alone while 59.3% were White (not Hispanic or Latino) (U.S.
Census Bureau, 2020). 13.6% were African American, 1.3% were American
Indian or Alaska Native, 6.1% were Asian American, 0.3% were Native Hawaiian
or Pacific Islander, 18.9% were Hispanic or Latino, and 2.9% were two or more races (U.S. Census Bureau, 2020).

Ethical Issues

Ethical values of research encapsulate the following three types of values: moral, competency, and terminal values (Morris, 2013). Moral values lead us to do the “right” thing, while competency values lead us to the “most effective way [of doing] something” (Morris, 2013, p. 74). Terminal values can be broken down into: personal (“what a person hopes to achieve”) and societal (“how a person wishes society to operate”) values (Morris, 2013, pp. 74–75).

Ethical issues involved in this research were: issues of confidentiality, questions centering around the causes of the child’s disability, and bringing up negative feelings about the parents’ experience of chronic sorrow that they may have repressed as a way of coping. This research addressed these ethical issues by giving the respondents space to speak their truths without judgment or influence from the researcher. The researcher only reported what the data explicitly showed even if it went against the original hypothesis. When the researcher asked questions that could signal a cause of disability, the researcher formed the questions in a less accusatory way and more informational matter to not blame the parent for the child’s disability. The researcher also shared a list of counseling services that the parents can seek out if they are experiencing negative side effects of talking about the feelings brought up by the topic of chronic sorrow, which was included at the end of the survey.
The approval of an Institutional Review Board (IRB) was the final motive to make sure the research was done ethically. Proof of this approval is included in Appendix B. Confidentiality concerns were of the utmost importance, and this was addressed by creating a password-protected file on the main computer that was utilized for the research with all documents that pertain to surveys and data compilation. The researcher explained the purpose of the research to respondents within the informed consent document that was required to be signed before continuing the survey.

Political Issues

When addressing political issues, the following four questions are important considerations for a positivist research design: “(1) Who decides appropriate arenas and topics for research? (2) How are such choices made?... (4) What data is available and how was it collected and organized?...[and] (6) Who will know about the research findings?” (Morris, 2013, pp. 80–81). For this project, the researcher decided on the topics of the study with consideration for topics that the partnering gatekeepers mentioned when planning for this project and their partnership. This consideration was made since the gatekeepers were the ones introducing the researcher to the respondents. The researcher looked at data that the gatekeepers already possessed, but the researcher identified what, if any, political perspective was behind the data shared and determined whether it aligned with the research purpose. Finally,
after the publication of this paper, the research results were shared with anyone who participated in this research study if they were interested.

The Role of Technology in Engagement

Technology was the center of this research design using Qualtrics to disburse the survey. The gatekeepers were brought into the partnership and informed of the research progress through phone or email as data was collected and this final report was written. Confidentiality for the research design was maintained through a password-protected Qualtrics account and a password-protected file on the researcher’s computer. When all data was collected, it was then inputted into the IBM SPSS system to run the statistical mathematics.

Summary

The researcher chose the location in Southern California because of the ease of data collection, but data soon came in from around the country due to respondents sharing the flyer. Collaboration, compromise, respect, and teamwork were great engagement skills when completing this project alongside the gatekeepers. The researcher had to keep in mind their own goals of the research, while also considering the goals of the gatekeepers. When doing research, it was important that the sample best resemble the general society being studied, and that surveys were sensitive to the diverse factors addressed in working with a variety of families of children with diverse disabilities. Confidentiality and allowing space for free speech about the topic were major
ethical concerns. The researcher made themselves aware of political opinions both personally and through the partnered organization that could influence the research and planned for how to minimize its effects. Lastly, because of the great usage of technology that occurred during this research, steps were taken to protect the virtuosity of this project.
CHAPTER THREE

IMPLEMENTATION

Introduction

The implementation phase of this research looked at the characteristics of the respondents, how the researcher planned on collecting and analyzing data, and the process of terminating the researcher/respondent relationship. In this study, the researcher looked at parents who were and/or were not experiencing chronic sorrow. The researcher utilized pieces of instruments by Sheets et. al. (2012) and an adapted version (replacing “loss” with “chronic sorrow) of the instrument by Batchelor (2019) that had already been used to address aspects of chronic sorrow to address a more diverse population of parents of children with disabilities. Finally, the researcher created a dissemination plan that will guide gatekeepers and participants to where they can find the final report and any recommendations for the future practice of social work with this population.

Study Participants

Participants sought out consisted of parents of children with disabilities from all family structures. Family structures consisted of nuclear, single-parent, divorced, same-sex, adoptive, stepfamilies, cohabitating, or non-cohabitating individuals. The participants also consisted of all gender identities of parents who claim to be experiencing distress for their child’s diagnosis, as well as those parents who appear to be coping well with their child’s diagnosis. This was
employed to show the positive and risk factors associated with chronic sorrow. Because of the nature of responsibility and prolonged care for a child with a more severe diagnosis, the participants could be of any age from adolescence (the onset of puberty and reproductivity) and further ages. Some participants could have had their children living in the home with them, and others’ children could have lived in group homes. Participants were sought out that varied in sexuality and gender identity.

Selection of Participants

The researcher’s sample size was 72 collected surveys. The researcher used convenience and snowball sampling techniques to gather participants for this project. The element will be individuals who are raising a child with a disability and have/have not gone through a divorce related to caring for the child with a disability. The population was parents of children with disabilities, for which the study sample was 72 individuals. Variables were the family type, primary caregiver status, child’s diagnosis, the number of services that child receives, how prepared the parent felt at birth compared to how they felt as the child grew older, the level of stress the parent felt, the independence/dependence level of the child, environmental factors that exasperated the parent’s stress, whether one parent feels supported by the other parent or other important people, societal stigma’s about disability, the reaction to that stigma, whether chronic sorrow was experienced by the respondent, and the parent’s ability to cope and adapt to life with a child with a disability.
Data Collection

Batchelor (2019) created an instrument that was made to address whether a person was experiencing chronic sorrow. The researcher utilized this instrument—replacing the word “loss” with the words “chronic sorrow”—to address who experienced chronic sorrow.

The graphs from the Overall Pattern of Adjustment (Wickler, 1981) and questions pulled from the Guided Interview: Latina Mothers of Children with Down Syndrome and Breaking Difficult News (English Version) (Sheets et al., 2012) will be adapted to survey other disabilities other than Down Syndrome and other races other than Latinos; and they address a level of distress parents feel over a period of time. Wickler’s (1981) graphs measure whether a parent is experiencing chronic sorrow gradually that get better over time or the parent has ups and downs of emotions that relate to the difficulties their child faces throughout life.

Sheets et al.’s (2012) instrument lays a foundation for measuring the level of distress for Latino mothers of children with Down Syndrome, that with a change in wording can be addressed by all people with any ethnic identity. This assessment also could be used to look at—when adapted to varying disabilities—how the mother reacted to receiving their child’s diagnosis, and whether the individual who gave them the diagnosis and how they did it impacted the mother’s reaction (Sheets et al., 2012). Thirdly, Sheets et. al.’s (2012) assessment could be used to look at the meaning the mother gave to the child’s
diagnosis when adapted to varying disabilities through her word choice. Lastly, they looked at the mother’s sources of support (Sheets et al., 2012), which the researcher included in their survey.

**Procedure for Gathering Data**

A survey was created by the researcher to address the demographic breakdown of this population and the occurrence of chronic sorrow per varying family types. A copy of the survey can be found in *Appendix B* of this paper. The procedure for gathering data was broken down into the following five steps: “(1) decide what information is required, (2) draft some questions to elicit the information, (3) put them into meaningful order or format, (4) pretest the result, [and] (5) go back to step 1 *(if needed)*” (Morris, 2013, p. 168). The researcher brainstormed the types of questions they want to ask about the family structures, primary caregiver status, child’s diagnosis, the number of services that child receives, how prepared the parent felt at birth compared to how they felt as the child grew older, the level of stress the parent felt, the independence/dependence level of the child, environmental factors that exasperated the parent’s stress, whether one parent feels supported by the other parent or other important people, societal stigma’s about disability, the reaction to that stigma, whether chronic sorrow was experienced by the respondent, and the parent’s ability to cope and adapt to life with a child with a disability. The researcher looked over the questions to make sure that they were not too intrusive and held a neutral stance throughout. Then the researcher decided, of
these thirteen categories, what should the order of importance be? The researcher tested their survey on individuals first to see if the survey was reporting what they want it to report for this research topic. Upon determination of a substantial survey, it was then emailed to the Southern California school district’s special education department leaders to disburse to parents who were interested in participating in the research. The staff of this school district and the parents disbursed the survey flyer out to other groups, which led to data collection from around the country. These leaders, and those staff under them, were told the types of participants to look for and were provided a flyer with a QR code that took the participants directly to the online survey for completion.

Procedure for Recording and Managing Data

The procedures for recording and managing data were that all surveys were completed in Qualtrics. When the sample size was met, the researcher downloaded the data into the IBM SPSS program for analysis. The data file was saved within a password-protected file on the researcher's computer during the research process. At the conclusion of the research process, the researcher handed over all data via email to California State University, San Bernardino to delete all records from participants. The researcher will also diligently observe that all data is removed from their personal computer.

Data Analysis

Survey data was inputted into an IBM SPSS file for analysis. The type of quantitative analysis the researcher conducted was multiple bivariate correlations
to determine the impact parent’s age, the child’s age, how many daily life activities the child can complete on their own or need help with daily, the parent’s report of the child’s independence level, which parent does the most care, how many times the parent has to call in sick per month due to the child’s special needs, and feelings of preparedness over time have on the intensity of the experience of chronic sorrow. The researcher utilizes the multiple bivariate correlations because the independent variables (parent’s age, the child’s age, how many daily life activities the child can complete on their own or need help with daily, the parent’s report of the child’s independence level, which parent does the most care, how many times the parent has to call in sick per month due to the child’s special needs, and feelings of preparedness over time) are thought to act upon the dependent variable (the intensity of the experience of chronic sorrow).

**Assessment Tools**

There was no one single assessment tool used to address chronic sorrow. Throughout the literature, there were three types of assessment tools that stood out that test for aspects of the experience of chronic sorrow. They were Wickler’s (1981) *Overall Pattern of Adjustment*, Sheets et al.’s (2012) Guided Interview: Latina Mothers of Children with Down Syndrome and Breaking Difficult News (English Version), and Batchelor’s (2019) instrument.

Wickler’s (1981) graphs were adapted to determine whether it was common for parents to have a sudden decrease in happiness at their child’s
diagnosis and then a gradual increase in attitude as time went on (graph 1) or if chronic sorrow was a matter of ups and downs in attitude (graph 2); then they are asked to identify which experience they felt resembled their experiences (Wickler, 1981). Fathers’ experiences followed a steady increase in attitude about their child’s condition over time (83%), while mothers often experience peaks and valleys (68%) in their experiences of chronic sorrow over the child’s lifetime (Damroch & Perry, 1989, p. 25; utilizing an adaption of Wickler, 1981, Overall Pattern of Adjustment exercise). There was a correlation between having a child with a disability and marital distress, but by very little and may be due to “problematic adaptions” by the couple themselves (Risdal & Singer, 2004, p. 102).

The Guided Interview: Latina Mothers of Children with Down Syndrome and Breaking Difficult News (English Version) in Appendix A was also adapted to assess parents’ distress levels with their child being diagnosed with varying disabilities (Sheets et al., 2012). Sheets et. al.’s (2012) assessment also looked at how the news of the child’s diagnosis was expressed to the parents and how that affected their experience of chronic sorrow.

The Plan for Termination and Follow-Up

The plan to disseminate the findings was that the gatekeepers and participants identified in Chapter 2 of this paper were notified of the finalization of the research. The researcher also reminded the gatekeepers and participants of the finalizing of the report when it comes to terminating the relationship, and they
were directed to the findings within the California State University, San
Bernardino’s library after publication. The researcher created a PowerPoint
presentation with all the main findings in laymen’s terms that was showcased at
the research symposium at California State University, San Bernardino. This
PowerPoint presentation could also be requested by the partnering organization
and participants. The researcher made sure to include a section of the flyer that
devotes attention to the applicability and importance and practicality of this
research to social work with children and their families who may experience
chronic sorrow related to disability.

Summary
In summary, the link between research-informed practice and this
research occurred throughout the implementation phase. Participants were
chosen for their applicable characteristics and the sample size was made to
replicate the general population being studied. The instruments utilized in this
research combined past instruments on Down Syndrome and Autism and the
experience of chronic sorrow and broadened it to multiple disabilities. IBM SPSS
and the synthesis of data were the centers of data collection and management.
Bivariate correlations were used to look at the relationships between the multiple
interval ratio variables and chronic sorrow ratings. Password protection of data
ensured that participants’ identities and responses were protected. A final report
and PowerPoint presentation were made available to all people involved in this
research so they could understand the findings and how it impacts social work.
CHAPTER FOUR

EVALUATION

Introduction

This next chapter evaluates the data from the research project. It covers the demographic makeup of the population surveyed, the demands placed on parents of children with disabilities, word associations with disability, responses to the Wickler (1981) graphs, common stigmatizing statements heard by parents, and the scores on the Chronic Sorrow Scale (Batchelor, 2019). A lot of the focus will be within a section that looks at the correlation of the Chronic Sorrow Scores and the parent’s age, the child’s age, how many daily life activities the child can complete on their own or need help with daily, the parent’s report of the child’s independence level, feelings of distress about comparing disabled children to non-disabled children, which parent does the most care, how many times the parent has to call in sick per month due to the child’s special needs, and feelings of preparedness over time. Stigmatizing misconceptions about disabilities, the parents’ abilities to cope with their child’s diagnosis, feelings towards their child’s diagnosis, demands for advocacy on behalf of the child, changes in parenting, and family adaption were reported through common themes in parents’ words and statements. Lastly, the researcher asked for input from respondents on areas of focus for future chronic sorrow research. This is included in the final discussion section that looks at the finding alongside models of disability, the
effects of ableism, strengths and limitations of this study, and the implications and recommendations for social work practice, policy, and future research.

Demographics

The study surveyed 72 parents of children with disabilities (see Table 1). Of these individuals 18.1% (n=13) were male, 75% (n=54) were female, 1.4% (n=1) identified as non-binary/third gender, and 5.6% (n=4) preferred not to state their gender; while 45.8% (n=33) of their children were male, 50% (n=36) were female, and 4.2% (n=3) of parents declined to state their child’s gender. 4.2% (n=3 per category) of respondents were African American, Latino American, or Asian American, 12.5% (n=9) were Hispanic, 68.1% (n=49) were non-Hispanic White, and 1.4% (n=1 per category) were Native American / Indigenous Origin or identified with multiple ethnicities. 2.8% (n=2) of parents were the adoptive mother, 1.4% (n=1 per category) were the adoptive parent, stepmother, or an uncle, 5.6% (n=4) were the father, 76.4% (n=55) were the mother, and 9.7% (n=7) stated they were just the parent. 8.3% (n=6 per category) of parents were in their 20’s and their 60’s, 38.9% (n=28) were in their 30’s, 27.8% (n=20) were in their 40’s, 13.9% (n=10) were in their 50’s, and 2.8% (n=2) were in their 70’s. 26.4% (n=19) of the children were either infants or toddlers, 29.2% (n=21) were school-aged, 23.6% (n=17) were teens, 15.3% (n=11) were in their 20’s, 1.4% (n=1) were in their 30’s, and 4.2% (n=3) were in their 40’s (age categories associated with Zastrow et. al. (2018)).
68.1% (n=49) of families were biologically related to the child, 9.7% (n=7) were adoptive, 8.3% (n=6) were stepfamilies, and 4.2% (n=3 per category) were made up of parents that lived together but were not married, not living together and not married but raising the child together, or selected more than one of the previous categories. 80.6% (n=58) of families consisted of one man and one woman as the head of the family, 5.6% (n=4) had two women, 4.2% (n=3) were single-parent one man and one woman households, 1.4% (n=1 per category) were either single-parent non-gender specific, multigenerational, or separated two women households, and 2.8% (n=1 per category) were separated one man and one woman households or preferred not to state. This data expended upon Wang’s (2005) study that only looked at married couples, female heads of household without a husband, or male heads of household without a wife.

88.9% (n=64) of respondents were the primary caregiver. 1.4% (n=1 per category) of their children had deafness, blindness, and Bipolar Disorder, 8.3% (n=6) had intellectual disabilities, 23.6% (n=17) had mobility impairments that required a wheelchair or other mobility equipment, 9.7% (n=7) had Autism, 2.8% (n=2) had Cerebral Palsy, 5.6% (n=4) had a neurodevelopmental disorder, and 45.8% (n=33) had multiple co-occurring disorders.
Table 1: Demographics

<table>
<thead>
<tr>
<th>Categories</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender of Parent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>18.1%</td>
</tr>
<tr>
<td>Female</td>
<td>54</td>
<td>75.0%</td>
</tr>
<tr>
<td>Non-Binary/Third Gender</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Prefer Not to State</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td><strong>Gender of Child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>33</td>
<td>45.8%</td>
</tr>
<tr>
<td>Female</td>
<td>36</td>
<td>50.0%</td>
</tr>
<tr>
<td>Prefer Not to State</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>9</td>
<td>12.5%</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>49</td>
<td>68.1%</td>
</tr>
<tr>
<td>Latino American</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>Asian American</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>Native American / Indigenous Origin</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Multiple Ethnicities</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td><strong>Relation to the Child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adoptive Mother</td>
<td>2</td>
<td>2.8%</td>
</tr>
<tr>
<td>Role</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>-----------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Adoptive Parent</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Father</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Mother</td>
<td>55</td>
<td>76.4%</td>
</tr>
<tr>
<td>Parent</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>Stepmother</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Uncle</td>
<td>1</td>
<td>1.4%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of Parent</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>20's</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>30's</td>
<td>28</td>
<td>38.9%</td>
</tr>
<tr>
<td>40's</td>
<td>20</td>
<td>27.8%</td>
</tr>
<tr>
<td>50's</td>
<td>10</td>
<td>13.9%</td>
</tr>
<tr>
<td>60's</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>70's</td>
<td>2</td>
<td>2.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of Child</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infants and Toddlers</td>
<td>19</td>
<td>26.4%</td>
</tr>
<tr>
<td>School Age Children</td>
<td>21</td>
<td>29.2%</td>
</tr>
<tr>
<td>Teens</td>
<td>17</td>
<td>23.6%</td>
</tr>
<tr>
<td>20's</td>
<td>11</td>
<td>15.3%</td>
</tr>
<tr>
<td>30's</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>40's</td>
<td>3</td>
<td>4.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Structure</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological</td>
<td>49</td>
<td>68.1%</td>
</tr>
<tr>
<td>Family Form</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>--------</td>
<td>------</td>
</tr>
<tr>
<td>Adoptive</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>Stepfamily</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Living Together But Not Married</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>Not Living Together and Not Married, But Raising Children Together</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>More Than 1 Category</td>
<td>3</td>
<td>4.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Form</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Man, 1 Woman</td>
<td>58</td>
<td>80.6%</td>
</tr>
<tr>
<td>2 Women</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Single-Parent (1 Man, 1 Woman)</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>Single-Parent (Non-Gender Specific)</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Multi-Generational (Includes Aunts, Uncles, and Grandparents Living with the Parent and Child)</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Separated (1 Man, 1 Woman)</td>
<td>2</td>
<td>2.8%</td>
</tr>
<tr>
<td>Separated (2 Women)</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Prefer Not to State</td>
<td>2</td>
<td>2.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Caregiver Status</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>64</td>
<td>88.9%</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>11.1%</td>
</tr>
</tbody>
</table>
Disability Categories

<table>
<thead>
<tr>
<th>Disability Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deafness</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Blindness</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Mobility Impairments that May Require the Use of a Wheelchair or Other Mobility Equipment</td>
<td>17</td>
<td>23.6%</td>
</tr>
<tr>
<td>Autism</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>2</td>
<td>2.8%</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Neurodevelopmental Disorders</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Multiple Co-Occurring Disorders</td>
<td>33</td>
<td>45.8%</td>
</tr>
</tbody>
</table>

Care Demands

When asked how often they take their children to doctor’s appointments: 39.8% (n=28) said monthly, 26.4% (n=19) said every three months, 11.1% (n=8 per category) said every six months or that their child hadn’t visited a doctor in a while, and 12.5% (n=9) said yearly. When asked how often their child attends physical therapy or counseling; 52.8% (n=38) said weekly, 11.1% (n=8) said monthly, 1.4% (n=1 per category) said every three months or yearly, 2.8% (n=2) said every six months, and 25% (n=18) said that their child hasn’t attended these services in a while. 62.5% (n=45) said their child requires additional
appointments for other needs, of which: 16.7% (n=12 per category) had 1 or 2 additional appointments, 9.7% (n=7) had 3 additional appointments, 8.3% (n=6) had 4 additional appointments, 4.2% (n=3) had 5 additional appointments, and 1.4% (n=1) had 6 or 12 additional appointments. Of these additional appointments: 1.4% (n=1) were daily, 23.6% (n=17) were weekly, 18.1% (n=13) were monthly, 9.7% (n=7) were every three months, 5.6% (n=4) were every six months, and 4.2% (n=3) were yearly.

When asked about how many tasks their child could complete on their own versus how many they needed help with: 8.3% (n=6) could complete one task on their own while 5.6% (n=4) needed help with at least one task, 13.9% (n=10) could complete two tasks on their own while 11.1% (n=8) needed help with at least two tasks, 19.4% (n=14) could complete three tasks on their own while 16.7% (n=12) needed help with at least three tasks, 9.7% (n=7) could complete four tasks on their own while 4.2% (n=3) needed help with at least four tasks, 2.8% (n=2) could complete five tasks on their own while 8.3% (n=6) needed help with at least five tasks, 8.3% (n=6) could complete six tasks on their own while 6.9% (n=5) needed help with at least six tasks, 6.9% (n=5) could complete seven tasks on their own while 5.6% (n=4) needed help with at least seven tasks, 4.2% (n=3) could complete eight or ten tasks on their own while 6.9% (n=5) needed help with at least eight or ten tasks, and 4.2% (n=3) could complete nine tasks on their own while 8.3% (n=6) needed help with at least nine tasks.
Table 2: Frequency of Care Demands

<table>
<thead>
<tr>
<th>Categories</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How often do you take your child to Drs. appointments?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monthly</td>
<td>28</td>
<td>39.8%</td>
</tr>
<tr>
<td>Every 3 Months</td>
<td>19</td>
<td>26.4%</td>
</tr>
<tr>
<td>Every 6 Months</td>
<td>8</td>
<td>11.1%</td>
</tr>
<tr>
<td>Yearly</td>
<td>9</td>
<td>12.5%</td>
</tr>
<tr>
<td>They haven’t needed to visit a doctor in a while</td>
<td>8</td>
<td>11.1%</td>
</tr>
<tr>
<td><strong>How often does your child attend physical/occupational therapy or counseling?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly</td>
<td>38</td>
<td>52.8%</td>
</tr>
<tr>
<td>Monthly</td>
<td>8</td>
<td>11.1%</td>
</tr>
<tr>
<td>Every 3 Months</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Every 6 Months</td>
<td>2</td>
<td>2.8%</td>
</tr>
<tr>
<td>Yearly</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>They haven’t attended physical/occupational therapy or counseling in a while</td>
<td>18</td>
<td>25.0%</td>
</tr>
<tr>
<td><strong>Does your child require any additional appointments for any other need?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>45</td>
<td>62.5%</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>37.5%</td>
</tr>
<tr>
<td>How many additional types of services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>0</td>
<td>10</td>
<td>13.9%</td>
</tr>
<tr>
<td>1</td>
<td>12</td>
<td>16.7%</td>
</tr>
<tr>
<td>2</td>
<td>12</td>
<td>16.7%</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>1.4%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If yes, how often?</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Weekly</td>
<td>17</td>
<td>23.6%</td>
</tr>
<tr>
<td>Monthly</td>
<td>13</td>
<td>18.1%</td>
</tr>
<tr>
<td>Every 3 Months</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>Every 6 Months</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Yearly</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>How many daily life activities can your child complete on their own?</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>------------------------------------------------------------------</td>
<td>---</td>
<td>-----</td>
</tr>
<tr>
<td>1</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>13.9%</td>
</tr>
<tr>
<td>3</td>
<td>14</td>
<td>19.4%</td>
</tr>
<tr>
<td>4</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>2.8%</td>
</tr>
<tr>
<td>6</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>7</td>
<td>5</td>
<td>6.9%</td>
</tr>
<tr>
<td>8</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>9</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>10</td>
<td>3</td>
<td>4.2%</td>
</tr>
</tbody>
</table>

Definitions of Disability

Parents were then asked to define disability in their own words. 22.2% (n=16) said it was a person who had additional needs or supports, 1.4% (n=1 per category) defined it as being “abnormal” or having “uniqueness,” 29.2% (n=21) said it was a condition that impacts daily life, 9.7% (n=7) defined it as being
outside of societal norms of ability, 5.6% (n=4 per category) defined it as having medical/mental factors or as a difference, and 2.8% (n=2) said it was something that must be overcome (Table 3). The words used by parents to describe how they felt about their child’s disability were “challenge/anger/frustration” (6.9%; n=7), “thankful” (1.4%; n=1), “sadness” (8.3%; n=6), “proud” (8.3%; n=6), “accepting/acceptance” (9.7%; n=7), “care,” “amazed,” “grave,” “love/incredible,” “randomness,” “isolated,” and “worry” (all 1.4%; n=1 per category), “hopeful/blessed” and “disbelief/numb” (both 4.2%; n=3 per category), “determined” (1.4%; n=1), they used a disability-related term (2.8%; n=2), and they used a neutral term (1.4%; n=1) (Table 4). 22.2% (n=16) used a positive word, 20.8% (n=15) used a negative word, 8.3% (n=6) used a neutral word, and 2.8% (n=2) used a word that would need to be used in a context to determine its category (Table 4).

To seek out a correlation between the choice of words given to describe their feelings towards their child’s diagnosis and the parent’s Chronic Sorrow Score, the researcher compressed the categories into positive, negative, or neutral words. There was no real significant correlation between these two factors.
<table>
<thead>
<tr>
<th>Themes</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional Needs/Support</td>
<td>16</td>
<td>22.2%</td>
</tr>
<tr>
<td>Abnormal</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>A Condition that Impacts Daily Life</td>
<td>21</td>
<td>29.2%</td>
</tr>
<tr>
<td>Outside of Societal Norms</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>Medical/Mental Factors</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Uniqueness</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Difference</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Something that Must Be Overcome</td>
<td>2</td>
<td>2.8%</td>
</tr>
</tbody>
</table>

Table 4: Feeling Words

<table>
<thead>
<tr>
<th>Common Words Given by the Respondent</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenge/Anger/Frustration</td>
<td>5</td>
<td>6.9%</td>
</tr>
<tr>
<td>Thankful</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Sadness</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Proud</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Accepting/Acceptance</td>
<td>7</td>
<td>9.7%</td>
</tr>
<tr>
<td>Care</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Amazed</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Grave</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Love/Incredible</td>
<td>1</td>
<td>1.4%</td>
</tr>
</tbody>
</table>
Parents were also given three groups of words, in the first two groups they were asked to identify the word that they felt the most comfortable with, and in the last group they were asked to pick the word that brought them the least discomfort. From the first group: 29.2% (n=21) chose “condition,” 5.6% (n=4) chose “syndrome,” 2.8% (n=2) chose “health problem,” and 51.4% (n=37) chose “disability.” From the second group: 66.7% (n=48) chose “genetic,” 5.6% (n=4) chose “heritable condition,” and 16.7% (n=12) chose “family health problem.” From the last group: 8.3% (n=6) chose “bad,” 16.7% (n=12) chose “difficult,”
15.3% (n=11) chose “unfortunate,” 13.9% (n=10) chose “unpredicted,” and 34.7% (n=25) chose “unexpected.”

Table 5: Word Associations (Sheets et al., 2012)

<table>
<thead>
<tr>
<th>Word Groups</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Which word are you the most comfortable with?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Group 1)</td>
<td>21</td>
<td>29.2%</td>
</tr>
<tr>
<td>Condition</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Syndrome</td>
<td>2</td>
<td>2.8%</td>
</tr>
<tr>
<td>Health Problem</td>
<td>37</td>
<td>51.4%</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Which word are you the most comfortable with?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Group 2)</td>
<td>48</td>
<td>66.7%</td>
</tr>
<tr>
<td>Genetic</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Heritable Condition</td>
<td>12</td>
<td>16.7%</td>
</tr>
<tr>
<td>Family Health Problem</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Which descriptive word brings you the least discomfort?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>discomfort?</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Bad</td>
<td>12</td>
<td>16.7%</td>
</tr>
<tr>
<td>Difficult</td>
<td>11</td>
<td>15.3%</td>
</tr>
<tr>
<td>Unfortunate</td>
<td>10</td>
<td>13.9%</td>
</tr>
</tbody>
</table>
Responses to Wickler

Parents were then given two graphs pulled from Wickler’s (1981) report (adaptions found in Figure 1 or the descriptions found in Table 5). 26.4% (n=19) said they identified with graph 1, which reported a gradual improvement over time. 56.9% (n=41) said they identified with graph 2, which reported ups and downs throughout the child’s life. Lastly, 2.8% (n=2) of parents said that not much time had passed since receiving a diagnosis for their child and they could not identify with either graph. When Damroch & Perry (1989)—who also utilized Wickler’s (1981) graphs—reported that out of their sample of 25 people, 83% of fathers identified with graph 1 and 68% of mothers identified with graph 2. Within this research, both mothers and fathers identified with the graph depicting the chaotic ups and downs; although the report by fathers was limited to n=3 responses on this question (Table 6).
Table 6: Wickler (1981) Graph Responses

<table>
<thead>
<tr>
<th>Graphs</th>
<th>N</th>
<th>%</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>I felt really great in the beginning, then I had difficulty adjusting</td>
<td>19</td>
<td>26.4%</td>
<td>34.79</td>
<td>47.50</td>
</tr>
<tr>
<td>to my child’s diagnosis, but then things started to improve again and</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>have gradually improved over time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life has been a series of ups and downs since my child was diagnosed.</td>
<td>41</td>
<td>56.9%</td>
<td>20.22</td>
<td>39.30</td>
</tr>
<tr>
<td>Not much time has passed since receiving a diagnosis for my child.</td>
<td>2</td>
<td>2.8%</td>
<td>82.67</td>
<td>38.15</td>
</tr>
</tbody>
</table>

Wickler (1981) Graphs: Mother/Father Comparison

| I felt really great in the beginning, then I had difficulty adjusting to my child’s diagnosis, but then things started to improve again and have gradually improved over time. | N |
| Life has been a series of ups and downs since my child was diagnosed. | |
| Not much time has passed since receiving a diagnosis for my child. | |
Figure 1: Wickler (1981) Graph Results for Mothers and Fathers Chart
Stigma’s Effects

Parents who reported having heard stigmatizing statements about their child’s disability reported that the “mother’s poor health during pregnancy was the reason for the disability” (1.4%; n=1), “institutionalization would have been a better placement for the child” (1.4%; n=1), “the parent does a poor job of disciplining the child” (1.4%; n=1), “the parent should have pushed the child to be more physically/mentally ‘normal’” (4.2%; n=3), “the child won’t be a successful citizen” (1.4%; n=1), “the child will always fall behind others their age” (2.8%; n=2), “God doesn’t give you more than you can handle” (1.4%), “others don’t believe the child is disabled” (2.8%; n=2), and parents were asked what was “wrong” with the child (1.4%; n=1). 29.2% (n=21) reported experiencing 2-4 stigmatizing statements, 12.5% (n=9) reported experiencing 5-8 stigmatizing statements, and 11.1% (n=8) reported experiencing 9 or more stigmatizing statements.

Table 7: Common Stigmatizing Statements Reported by Parents

<table>
<thead>
<tr>
<th>Stigmas</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Stigmatizing Statement Experienced</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>2-4 Stigmas</td>
<td>21</td>
<td>29.2%</td>
</tr>
<tr>
<td>5-8 Stigmas</td>
<td>9</td>
<td>12.5%</td>
</tr>
</tbody>
</table>
The Chronic Sorrow Scale

The Chronic Sorrow Scale was created by Batchelor (2019) to measure whether someone had experienced chronic sorrow or not. The researcher of this paper hopes to use this scale and other information to identify who is more at risk for chronic sorrow. 23.6% (n=17) of respondents experience no chronic sorrow present, 34.7% (n=25) likely experience chronic sorrow, and 5.6% (n=4) definitely experienced chronic sorrow. Interestingly, 36.1% (n=26) of the respondents chose not to answer this section of the survey. Factors thought to relate to this missing information will be further explained under the ableism section.
Table 8: The Chronic Sorrow Scale (Batchelor, 2019)

<table>
<thead>
<tr>
<th>Batchelor Scoring Criteria</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-38- No Chronic Sorrow Present</td>
<td>17</td>
<td>23.6%</td>
</tr>
<tr>
<td>39-82- Likely Chronic Sorrow Present</td>
<td>25</td>
<td>34.7%</td>
</tr>
<tr>
<td>83+ - Chronic Sorrow Present</td>
<td>4</td>
<td>5.6%</td>
</tr>
<tr>
<td>Missing Data</td>
<td>26</td>
<td>36.1%</td>
</tr>
</tbody>
</table>

Figure 3: The Chronic Sorrow Chart

Correlating Factors

The relationship between the Chronic Sorrow Scale and the level of distress a participant reported feeling—because of parents comparing their disabled children to their other non-disabled children—is significant \[ r(46) = .436, \]
Participants report higher distress levels when they report higher Chronic Sorrow levels. The mean for feelings of distress (n=61) was 6.02—where 1 meant “no distress” and 10 meant “a great deal of distress”—and the standard deviation was 2.61.

Other correlating factors (such as the parent’s age, the child’s age, how many daily life activities the child can complete on their own or need help with daily, the parent’s report of the child’s independence level, which parent does the most care, how many times the parent has to call in sick per month due to the child’s special needs, and feelings of preparedness over time) did not have much correlating significance to parents’ scores on the Chronic Sorrow Scale. The mean for the age of the parent (n=72) was 43—ages ranging from 23-71 years—and the standard deviation was 2.61. The mean for the age of the child (n=672) was 13—ages ranging from 1-48 years—and the standard deviation was 11.64. 

The mean for how prepared a parent felt at the time of the child’s initial diagnosis (n=56) was 4.70—1 being “unprepared” and 10 being “well prepared”—and the standard deviation is 2.80. The mean for how prepared a parent felt currently about the child’s diagnosis (n=65) was 7.74—1 being “unprepared” and 10 being “well prepared”—and the standard deviation is 2.10. The mean for how many daily life activities out of ten the child could complete on their own (n=56) was 4.37 and the standard deviation was 2.63. The mean for how many daily life activities out of ten the child needed help to complete (n=58) was 5.17 and the standard deviation was 2.88. The mean for the parent’s level of stress about their
child’s level of need for assistance of daily life activities (n=58) was 5.97—where 1 equals “none at all” and 10 equals “a great deal”—and the standard deviation was 2.97. The mean for how many months out the last twelve months has someone in the household had to call out sick, for one or weeks in a month, due to the child’s needs (n=22) was 4.41 and the standard deviation was 4.10. Lastly, the mean for who does the most care—where 1 signals the respondent and 3 signals the other parent—(n=50) was 2.14 and the standard deviation was 0.99.

Table 9: Correlating Factors- Mean and Standard Deviation

<table>
<thead>
<tr>
<th>Factor</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much distress does this give you?—On a scale of 1-10</td>
<td>61</td>
<td>6.02</td>
<td>2.61</td>
</tr>
<tr>
<td>How old are you?</td>
<td>72</td>
<td>43</td>
<td>11.64</td>
</tr>
<tr>
<td>How old is your child?</td>
<td>72</td>
<td>13</td>
<td>10.05</td>
</tr>
<tr>
<td>Please rate the following on a 1-10 scale.</td>
<td>56</td>
<td>4.70</td>
<td>2.80</td>
</tr>
<tr>
<td>- How prepared did you feel you were to deal with your child's new diagnosis?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Rating</td>
<td>Mean</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------</td>
<td>------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Please rate the following on a 1-10 scale.</td>
<td>65</td>
<td>7.74</td>
<td>2.10</td>
</tr>
<tr>
<td>- How prepared do you feel you are now with your child's diagnosis?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please rate the following on a 1-10 scale.</td>
<td>56</td>
<td>4.37</td>
<td>2.63</td>
</tr>
<tr>
<td>- On a scale of 1-10, how many daily life activities can your child complete on their own?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please rate the following on a 1-10 scale.</td>
<td>58</td>
<td>5.17</td>
<td>2.88</td>
</tr>
<tr>
<td>- On a scale of 1-10, how many daily life activities does your child need help with?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you experience stress associated with your child’s diagnosis, how much do you think that your stress is related to the child's level of independence? - On a scale of 1-10</td>
<td>58</td>
<td>5.97</td>
<td>2.57</td>
</tr>
<tr>
<td>In the last year, how many months have you or somebody else in the household had to call out sick from work for 1 or more weeks because of your child's needs specific to their diagnosis? - Choose 1-12 months</td>
<td>22</td>
<td>4.41</td>
<td>4.10</td>
</tr>
</tbody>
</table>
Who does the most care for the child? | 50 | 2.14 | 0.99
---|---|---|---
On a scale of 1-5

Discussion

The results of this study showed that social workers cannot determine a parent’s level of risk for developing chronic sorrow based on the qualities of the parent, except for when parents report feelings of distress when comparing their child with a disability to their child/children without disabilities. 34.7% of parents could only be identified as likely being prone to feelings of chronic sorrow for their child with a disability.

Wang (2005) reported that 8% of respondents had “one or more members with blindness, deafness, or a severe vision or hearing impairment”; 16.6% reported “one or more members with one or more members with a condition that substantially limited one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying”; 10.2% with “one or more members who had difficulty in learning, remembering, or concentrating”; 5.7% with “one or more members who had difficulty with dressing, bathing, or getting around inside the home”; 13.3% with “one or more members who had difficulty going outside the home alone to shop or visit a doctor’s office”; and 17% with “one or more members who had difficulty working at a job or business.” In comparison to this study, more respondents now have either a mobility impairment that required the
use of a wheelchair or other mobility equipment (23.6%) or multiple co-occurring disorders (45.8%).

The researcher’s asking for respondents to create a personal definition of disability (found in tables 3 & 4) and Sheets et. al.’s (2012) three groups of “word choices” had a similar intention. Both wanted to identify positive and negative word associations. Sheets et. al (2012) exposed respondents to predetermined words that may carry some bias, while the researcher of this project left the definition open-ended so that respondents could express their unconscious thoughts and biases freely.

For Wickler’s (1981) study, utilizing the two graphs, the mean was 1.33 and the standard deviation was 0.58 for graph 1 and the mean was 2.38 and the standard deviation was 0.65 for graph 2. For this study, the mean was 34.79 and the standard deviation was 47.50 for graph 1, the mean was 20.22 and the standard deviation was 39.30 for graph 2, and the mean was 82.67 and the standard deviation was 39.30 for the third choice. Also, Coughlin & Sethares (2017) said that chronic sorrow is a cyclical process where a triggering event occurs and the feelings of chronic sorrow reappear. More than half of respondents (56.9%) identified with the tumultuous graph of highs and lows throughout the child’s life. 91.4% of those respondents who chose graph 2 were mothers. These families would then experience times of higher chronic sorrow, utilize coping mechanisms, experience lower chronic sorrow, experience a triggering event, and then rotate through the cycle again.
Yeager & Roberts (2015, p. 4) place “having a baby with a disability” under the crisis category of “transitional or developmental stressors and events” and explains how this event can cause “intense fear of what might occur next and how it will impact one’s loved ones.” Yeager & Roberts (Yeager & Roberts, 2015, p. 6) state that “Two key factors in determining whether or not a person who experiences multiple stressors escalates into a crisis state are the individual’s perception of the situation or event and the individual’s ability to utilize traditional coping skills.” They also talk about how “overwhelming feelings of anxiety, despair, and hopelessness, guilt, intense fears, grief over sudden losses, confusion, difficulty concentrating, powerlessness, irritability, intrusive imagery, flashbacks, extreme suspiciousness of others, shame, disorientation, loss of appetite, binge drinking, sleep disturbances, helplessness, terror, exhaustion, losses or lapses of religious beliefs, and/or shattered assumptions about personal safety” can be common symptoms or reactions to traumatic or crisis events (Yeager & Roberts, 2015, p. 9).

Parrish (2010) and Patrick-Ott (2011) described eight themes of parents caring for a child with a disability: an array of emotions, a motivation to advocate to the fullest extent for their child, caregiver burnout, the stigma of disability on the entire family, aligning parenting expectations to the child’s diagnosis, normalizing ambivalence of parenting and the family, restructuring of the parent’s identity, and finding hope in the new family structure. Looking at the results of this study in the open-ended responses in table 4, 20.8% of respondents gave a
negative word for disability while 22.2% gave a positive word. This just goes to show the array of feelings, the potential for caregiver burnout, and the stigma of disability. This array also normalizes the ambivalence of parents. Other responses brought up themes of motivation, hope, and changing parent expectations. Finally, 16.7% of respondents said they did adapt their parenting methods to the child’s abilities and 1.4% said they discontinued parenting methods taught by previous generations.

The Medical and Social Models of Disability

Manago et. al. (2017) explained the difference between the medical and social models of disability. The medical model of disability sees disabilities as something abnormal that needs to be fixed (Manago et al., 2017). The social model of disability defines disability as something socially constructed by society that prevents individuals with impairments from integrating fully with others (Manago et al., 2017).

Mackelprang & Salsgiver (1996) had dueling ideology such as the independent living and the minority models. In the 1970s the independent living concept was developed which focused on “societal responses and discrimination as the primary barriers to civil rights” (Mackelprang & Salsgiver, 1996, p. 10). In this model, social workers’ jobs are to link people with disabilities and personal attendants but it is the role of the person with a disability to hire and train the attendant (Mackelprang & Salsgiver, 1996). This model gives those with disabilities and their families more say over their own lives. “The minority model
asserts that discrimination against people with disabilities is rooted in the beliefs and values of the culture. The most fundamental belief is that people with disabilities cannot and should not work or otherwise be productive” (Mackelprang & Salsgiver, 1996, p. 10). This idea follows along with the ideas of the social model and that through society's opinions about people with disability, their bodies are devalued.

**Ableism**

When gathering data, the researcher encountered a group of parents with disabilities who were raising children with disabilities. This subsection of the larger population expressed disapproval of the research topic. 1.4% (n=1) of the total respondents did not like the terms “loss” or “chronic sorrow” (Table 9). They expressed feelings of judgment by the topic and assumptions that the researcher was coming from a biased perspective on disability. They also expressed believing that no parent of a child with a disability feels chronic sorrow for their child, or that this was something negative if they do. The data showed that 40.3% (n=29; a combination of the two categories) of the total parents were likely or more than likely to feel chronic sorrow for their child (Table 8), which is to be expected when you consider the effects of ableism and stigma on the disability community by society or the stress on parents to provide the best care for their child.

These two competing ideas can cause ableist ideologies to perpetuate throughout society. Even the most innocent interactions, without the cultural
humility for the disability community, can lead to families of individuals with disabilities feeling the pressure of their loved one not being thought of as a valuable member of society. The medical, social, and minority models are prevalent throughout society, while some parents with and without disabilities may try to challenge this by holding the independent living model within their personal lives and interactions. All four models have their pros and cons. When looking at the respondents’ opinions in the open-ended questions, and how they fit into Manago et. al.’s (2017) medical and social models and Mackelprang & Salsgiver’s (1996) independent living and minority models, you see that a lot of the respondents held opinions that society is very ingrained in thinking through the medical, social, and minority model ideas; and that these same individuals favor a more independent living model where they are in control of their own lives and valued for their strengths that they can contribute to society. Although they do not disagree with the ideas behind the social model, they feel that this model preserves ableism, and that to fight ableism we must fight the acceptance of the social model.

9.7% (n=7) of respondents mentions ableism in the additional comments section, where 1.4% (n=1) were comments of internal ableism and 8.3% (n=6) were comments of external ableism (Table 9). Some quotes pulled from the surveys are:

Anger that ableism is so pervasive, that our disabled lives are consistently deemed less worthy, less satisfying, and maybe not even worth living. I
am angry at the assumption that parents grieve long term over their child's diagnosis, rather than accepting their child for who they are and helping them have a life full of self-love and connection. Disabled people of all kinds deserve to be loved unconditionally and listened to. We deserve to have our needs fought for, and our differences respected and valued. Long term grief as a diagnosis undermines the ability to do any of these things, because the grief is about only seeing losses, without seeing that the child is ‘able to live a fulfilling, happy life’ and has unique gifts to give.”

“Disability is not a bad word…I’m deeply concerned about the framing of disability as chronic sorrow. That is not reflective of my experience as a parent of a disabled kid, at all.

I find that within our disability community, a common theme of those with the same disability as my daughter is ‘my family didn’t treat me any differently.’ I feel like this is incredibly ableist…However, we do treat her differently in areas where she has different needs that need different approaches and different solutions, as we do with each individual in our household. Another thing I see in our community is that there is a ‘push them’ mentality aimed at children with disability. I feel like this inordinately ‘others’ them as a disabled person, and is driven a lot by parental worries and fears and/or internalized ableism. I find this harmful.
Others questioned why “disability inclusion” is not taught in schools or why parents don’t teach their children “unconditional love” for people with different abilities.

Strengths and Limitations

The strength of this study is that it emphasizes that social workers need to be cognizant of how they react and perceive people with disabilities. If social workers hold those medical and minority models in their personal beliefs and do not advocate against the social model of disability, they cannot serve the disability community professionally in an appropriate manner. Social workers should emphasize peoples’ strengths and utilize the independent living model to engage the client in self-determinative decision-making processes. This too can empower parents of and people with disabilities to advocate for themselves to change the acceptance of the medical, social, and minority models that are prevalent in society.

The limitations are that it did not find significant risk factors in identifying who is most at risk for feeling chronic sorrow for their children with disabilities. This study showed that there was no identifiable character flaw that would trigger the social worker to implement treatments and interventions to help these families cope with the disability. In fact, it did emphasize flaws in society and those serving the communities due to unconscious biases and strong ableist beliefs.
Implications And Recommendations for Social Work Practice, Policy, and Future Research

Social workers need to use self-reflection to observe whether they are continuing ableist ideas with their clients. Social workers should also be educated on the history of disabilities in the world and the United States’ past to learn how demonized people with disabilities have been, and how this has led to us still holding oppressive and discriminatory opinions about these individuals. Thirdly, social workers should learn about considering methods of inclusion in advocacy movements for the disabled and ways all people with disabilities can have a voice in their human rights.

Policy reforms that include employers looking at how they can utilize people’s strengths rather than whether a person fits the qualifications of the job description and the general public appreciating the diversity of peoples’ abilities should be advocated in the legislative branch. There may need to be future amendments to the Americans with Disabilities Act (ADA) to push society further into a more inclusive era in U.S. history.

Additional topics not yet mentioned, that could be the focus of future research, were the stress on parents to advocate for their child without any resolution (1.4%; n=1), future research into this topic should include voices from disabled parents (4.2%; n=3), to consider the humanity of people with disabilities (1.4%; n=1), 4.2% (n=3) of parents appreciated the topic asking about their feelings, 1.4% (n=1) thought that the timing of diagnosis was also important to
this topic, 2.8% (n=2) felt abandoned by family, and 2.8% (n=2) mentioned more than 1 of these topics in their responses.

Table 10: Additional Topics Expressed by Parents

<table>
<thead>
<tr>
<th>Topics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree with the Term “Loss”/“Chronic Sorrow”</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>The Stress of Advocating without a Resolution</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Should Include Disabled Voices</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>The Humanity of Those with Disabilities</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Internal Ableism</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>External Ableism</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Parents’ Feelings Should Be Included in the Discussion of Children’s Disabilities</td>
<td>3</td>
<td>4.2%</td>
</tr>
<tr>
<td>Timing of Diagnosis is Important to this Topic</td>
<td>1</td>
<td>1.4%</td>
</tr>
</tbody>
</table>
Abandonment By Family  2  2.8%
(Felt by the Primary Caregiver and/or the Child)

More Than 1 of the Previous Topics  2  2.8%

Summary

This chapter looked at the results of the research and its implications for social work. Data from this study were compared with the data found in the literature review to give a more comprehensive idea of how chronic sorrow occurs within the disability community. It identified the demographics of the sample population, the care demands of children with disabilities on their parents, how parents define disability, identification by parents of Wickler’s graphs, stigmatizing statements commonly heard by parents, the Chronic Sorrow Scale, and other correlating factors. The study brought up ableism and its impacts on chronic sorrow and societal opinions about disability. Disability should be a cultural group that is taught to social workers so they can adequately engage and advocate with people with disabilities.
CHAPTER FIVE
TERMINATION AND FOLLOW-UP

Introduction
This chapter describes the termination process and how the research findings will be disseminated to the public. Most of the termination process occurred when respondents completed the survey and will cease when the final report is provided to the original agency and online locations where respondents discovered the project. The chapter also describes the process of publishing the study and showcasing it at a research symposium.

Termination
There was not an official termination process for this research study. Once respondents completed the survey, that ended the relationship between the respondent and the researcher. The relationship between the partnering agency and the researcher will conclude once the final copy of the report has been provided to them for their education and interests.

How the Findings were Disseminated
The final copy of this paper was published within California State University of San Bernardino’s ScholarWorks. The process for publication included a review process to check grammar and for plagiarism, a sign-off by the research supervisor and the M.S.W Research Coordinator, and then finally
another review process with the department of research studies. The researcher then provided the final paper to be found at in-person and online locations that respondents found the survey through.

The researcher also prepared a brief, two-slide PowerPoint presentation that was shown to other researchers at this institution, was included in a California State University of San Bernardino research symposium. The PowerPoint presentation summarized the main findings of the research and its implications within social work.

Summary

This chapter discussed the termination process and the dissemination plan for the study. The termination plan was very simple and was completed once data was completed the final report was published in California State University of San Bernardino’s ScholarWorks. The dissemination plan included publishing the study and presenting it at California State University of San Bernardino’s research symposium.
Chronic Sorrow and the Impact on Parents of Children with Disabilities

The study in which you are being asked to participate is designed to look at the effects of differing family forms on reports of chronic sorrow (grief that continues throughout the life of a child with a disability) and their ability to cope with the child’s disability. This study is being conducted by Rhianna Nordlund under the supervision of Carolyn McAllister: Director of California State University, San Bernardino, Social Work Program. This study has been approved by the Institutional Review Board, California State University, San Bernardino.

PURPOSE:
The purpose of this research is to look at the effects of differing family forms, perception of stigma, and the severity of the child’s disability on reports of chronic sorrow (grief that continues throughout the life of a child with a disability) and their ability to cope with the child’s disability. This could allow human service workers who work with these families to be able to better support parents struggling with caring for a child with a disability.

DESCRIPTION:
This research will involve you filling out an online survey. (Hardcopies of the survey will be available upon request only through your child’s school.) The survey will be available by typing in the website address or by scanning a unique QR code that will take you to the beginning of the survey.

PARTICIPATION:
Your participation is completely voluntary, and you do not have to answer any questions you do not wish to answer. You may skip or not answer any questions and can freely withdraw from participation at any time with no consequences.
CONFIDENTIAL:
All participants will be identified by a random number, and names of participants will not be collected. Data will be maintained on a password protected computer. All hardcopy surveys will be inputted into the computer and then immediately destroyed. The researcher will group data together in the final report, as to not allow identifying information from unique families to be detected. After 3 years upon the conclusion of the research process, the researcher will delete all study information.

DURATION:
The survey should take about 10-15 minutes to complete. It will consist of a variety of multiple choice and short answer questions.

RISKS:
Risks could involve discomfort in talking about sensitive topics. Lastly, families who have unique qualities may be at more risk for being identified than other families participating in this research study.

BENEFITS:
There is no individual benefit from participating in this research.

CONTACT:
If participants have any questions about this research, their rights, or concerns related to a research-related injury, they can contact Carolyn McAllister at cmcallis@csusb.edu or (909) 537-5559. Respondents also may contact the researcher at: Rhianna Nordlund at nordlundr@coyote.csusb.edu.

RESULTS:
Aggregate findings will be available to the research partner and participants in the California State University, San Bernardino library, and in a flyer that can be easily understood by any interested person.

CONFIRMATION STATEMENT:
☐ I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document and agree to participate in your study.
OR
☐ I have read and understand the consent document and DO NOT agree to participate in your study.
The Survey

Q1
Chronic Sorrow and the Impact on Parents of Children with Disabilities
The study in which you are being asked to participate is designed to look at the effects of differing family forms on reports of chronic sorrow (grief that continues throughout the life of a child with a disability) and their ability to cope with the child’s disability. This study is being conducted by Rhianna Nordlund under the supervision of Carolyn McAllister: Director of California State University, San Bernardino, Social Work Program. This study has been approved by the Institutional Review Board, California State University, San Bernardino.

PURPOSE: The purpose of this research is to look at the effects of differing family forms, perception of stigma, and the severity of the child’s disability on reports of chronic sorrow (grief that continues throughout the life of a child with a disability) and their ability to cope with the child’s disability. This could allow human service workers who work with these families to be able to better support parents struggling with caring for a child with a disability.

DESCRIPTION: This research will involve you filling out an online survey. (Hardcopies of the survey will be available upon request only through your child’s school.) The survey will be available by typing in the website address or by scanning a unique QR code that will take you to the beginning of the survey.

PARTICIPATION: Your participation is completely voluntary, and you do not have to answer any questions you do not wish to answer. You may skip or not answer any questions and can freely withdraw from participation at any time with no consequences.

CONFIDENTIAL: All participants will be identified by a random number, and names of participants will not be collected. Data will be maintained on a password protected computer. All hardcopy surveys will be inputted into the computer and then immediately destroyed. The researcher will group data together in the final report, as to not allow identifying information from unique families to be detected. After 3 years upon the conclusion of the research process, the researcher will delete all study information.

DURATION: The survey should take about 10-15 minutes to complete. It will consist of a variety of multiple choice and short answer questions.
RISKS: Risks could involve discomfort in talking about sensitive topics. Lastly, families who have unique qualities may be at more risk for being identified than other families participating in this research study.

BENEFITS: There is no individual benefit from participating in this research.

CONTACT: If participants have any questions about this research, their rights, or concerns related to a research-related injury, they can contact Carolyn McAllister at cmcallis@csusb.edu or (909) 537-5559. Respondents also may contact the researcher at: Rhianna Nordlund at nordlundr@coyote.csusb.edu.

RESULTS: Aggregate finding will be available to the research partner and participants in the California State University, San Bernardino library, and in a flyer that can be easily understood by any interested person. This flyer will be given to Morongo Unified School District to be shared amongst all the schools where parents participated.

Q2 CONFIRMATION STATEMENT:

☐ I understand that I must be 18 years of age or older to participate in your study, have read and understood the consent document, and agree to participate in your study. (1)

☐ I have read and understood the consent document, I’m not 18 years or older, and/or DO NOT agree to participate in your study. (2)

Skip To: End of Survey If CONFIRMATION STATEMENT: = I have read and understood the consent document, I'm not 18 years or older, and/or DO NOT agree to participate in your study.

Q113 Do you have a child with a disability?

☐ Yes (1)

☐ No (2)

Skip To: End of Survey If Do you have a child with a disability? = No
Q114 If you have more than 1 child with a disability, please choose 1 of them to respond to the following questions.

Q5 What is your identified gender?

- [ ] Male (1)
- [ ] Female (2)
- [ ] Non-binary / third gender (3)
- [ ] Prefer not to say (4)

Q104 What is your ethnicity?

- [ ] African American (2)
- [ ] Hispanic (5)
- [ ] Non-Hispanic White (8)
- [ ] Latino American (7)
- [ ] Asian American (3)
- [ ] Pacific Islander (9)
- [ ] Alaskan Native (6)
- [ ] Native American/Indigenous Origin (4)
- [ ] Not listed (10)

Q6 Does your family fit into the following categories? (Choose all that apply.)
Q7 Which of these categories does your family most fit into:
☐ Biological (1)
☐ Adoptive (2)
☐ Stepfamily (3)
☐ Living together but not married (4)
☐ Not living together and not married but raising children together (5)

Q8 How are you related to the child?

☐ 1 man, 1 woman (1)
☐ 2 women (2)
☐ 2 men (3)
☐ Non-gender specific couple (4)
☐ Single-parent (1 man, 1 woman) (5)
☐ Single-parent (2 women) (6)
☐ Single-parent (2 men) (7)
☐ Single-parent (Non-gender Specific) (8)
☐ Divorced (1 man, 1 woman) (10)
☐ Divorced (2 women) (11)

☐ Divorced (2 men) (12)

☐ Divorced (Non-gender Specific) (13)

☐ Separated (1 man, 1 woman) (18)

☐ Separated (2 women) (19)

☐ Separated (2 men) (20)

☐ Separated (Non-Gender Specific) (21)

☐ Other Relative (16)

☐ Multi-Generational (includes aunts, uncles, grandparents living with parents and child) (17)

☐ Prefer Not to State (15)

Q10 Are you the primary caregiver?

☐ Yes (1)

☐ No (2)

Q12 What category of disability does your child have, defined by the Americans with Disabilities Act (ADA)? (Choose all that apply.)

☐ Deafness (1)

☐ Blindness (2)

☐ Diabetes (3)

☐ Cancer (4)
☐ Epilepsy (5)
☐ Intellectual Disabilities (6)
☐ Partial or completely missing limbs (7)
☐ Mobility impairments that may require the use of a wheelchair or other mobility equipment (8)
☐ Autism (9)
☐ Cerebral Palsy (10)
☐ HIV infection (11)
☐ Multiple Sclerosis (12)
☐ Muscular Dystrophy (13)
☐ Major Depressive Disorder (14)
☐ Bipolar Disorder (15)
☐ Post-Traumatic Stress Disorder (16)
☐ Obsessive-Compulsive Disorder (17)
☐ Schizophrenia (18)
☐ Not listed here: (19)

Q123 What is the identified gender of your child?

☐ Male (1)
Female (2)
Non-binary / third gender (3)
Prefer not to say (4)

Q58 How often do you have to take your child to doctor’s appointments?
Monthly (1)
Every 3 months (2)
Every 6 months (3)
Yearly (4)
They haven’t needed to visit a doctor in a while (5)

Q59 How often does your child attend physical/occupational therapy or counseling?
Weekly (1)
Monthly (2)
Every 3 months (3)
Every 6 months (4)
Yearly (5)
They haven’t attended physical/occupational therapy or counseling in a while (6)
Never (7)

Q60 Does your child require any other additional appointments for any other needs?
Yes (1)
Q61 How many additional types of services do they receive?
________________________________________________________________
Q62 If yes, how often?
○ Daily (1)
○ Weekly (2)
○ Monthly (3)
○ Every 3 months (4)
○ Every 6 months (5)
○ Yearly (6)

Q88 In your own words, how do you define a disability?
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Q119 The next 3 questions are adapted from Guided Interview: Latina Mothers of Children with Down Syndrome and Breaking Difficult News (English Version) (Sheets et al., 2012)

Q90 Which word are you the most comfortable with?
○ Condition (1)
○ Syndrome (2)
○ Health Problem (3)
○ Disability (4)
Q92 Which word are you the most comfortable with?

- Genetics  (1)
- Heritable Condition  (2)
- Family Health Problem  (3)

Q91 Which descriptive word brings you the least discomfort?

- Bad  (1)
- Difficult  (2)
- Unfortunate  (3)
- Unpredicted  (4)
- Unexpected  (5)

Q66 Of these two graphs, which one do you think best represents your feelings towards your child’s disability over time?

*Graphs from Overall Pattern of Adjustment (Wickler, 1981)*

- I felt really great in the beginning, then I had difficulty adjusting to my child’s diagnosis, but then things started to improve again and have gradually improved over time  (1)
- Life has been a series of ups and downs since my child was diagnosed  (2)
- Not much time has passed since receiving a diagnosis for my child  (3)

Q67 Please rate the following on a 1-10 scale.

<table>
<thead>
<tr>
<th>1 being unprepared</th>
<th>10 being well prepared</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

How prepared did you feel you were to deal with your child’s new diagnosis? ()
How prepared do you feel you are now with your child's diagnosis? ()

Q68 Do you ever compare your child with a disability to your other child(ren) without a disability—even if you only do it privately—based on things they can or cannot do?

○ Yes (1)
○ No (3)
○ Sometimes (2)

Q69 How much distress does this give you?

<table>
<thead>
<tr>
<th>None at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

On a scale of 1-10 ()

Q70 Please rate the following on a 1-10 scale.

<table>
<thead>
<tr>
<th>They need help 24/7</th>
<th>They can completely care for themselves</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

On a scale of 1-10, how many daily life activities can your child complete on their own? ()

On a scale of 1-10, how many daily life activities does your child need help with? ()

Q71 If you experience stress associated with your child's diagnosis, how much do you think that your stress is related to the child's level of independence?

<table>
<thead>
<tr>
<th>None at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
On a scale of 1-10 ()

Q72 In the last year, how many months have you or somebody else in the household had to call out sick from work for 1 or more weeks because of your child's needs specific to their diagnosis?

Not Applicable

Choose 1-12 months ()

Q82 Who does the most care for the child?

*Leave blank if you're unsure.*

I do  We equally share the responsibility  The other parent does

On a scale of 1-5 ()

Display This Question:

If Does your family fit into the following categories? (Choose all that apply.) = Divorced (1 man, 1 woman)

And Does your family fit into the following categories? (Choose all that apply.) = Divorced (2 women)

And Does your family fit into the following categories? (Choose all that apply.) = Divorced (2 men)

And Does your family fit into the following categories? (Choose all that apply.) = Divorced (Non-gender Specific)

Q87 Since you stated that you were divorced, were any of the above related to your decision to get divorced?

☐ Loss of income (1)

☐ Stress of caring for my child with a disability (2)

☐ Concern about my child's prognosis (3)
☐ Lack of support from the other parent (4)
☐ Lack of support from others (5)
☐ Stigma of having a child with a disability (6)
☐ Other reason (7)

Display This Question:
If Which of these categories does your family most fit into: = Living together but not married

Q109 Since you stated that you live with the other parent of your child, but are not married, has your child's diagnosis had an impact on this decision?

☐ Yes, please explain how: (1)

☐ No (2)

Display This Question:
If Which of these categories does your family most fit into: = Not living together and not married but raising children together

Q111 Since you stated that you are not living with the other parent of your child and you are not married, has your child's diagnosis had an impact on this decision?

☐ Yes, please explain how: (1)

☐ No (2)
Q78 Have you or your child ever experienced any stigma associated with their disability?

☐ Yes (1)
☐ No (2)

Q79 Have you ever been told by others or others around you believe (even if they may not be true):

☐ That your child's diagnosis is related to use of alcohol/other substances during pregnancy (1)
☐ You should have taken better care of your health while pregnant (2)
☐ It would have been more humane to have had an abortion (3)
☐ That you should have given your child up for adoption (4)
☐ That you should have put your child in an institution (5)
☐ Asked whether your child was in some terrible accident (6)
☐ That your child's behavior is related to your inability to discipline your child (7)
☐ That you should have pushed your child to be more "normal" (physically or mentally) (8)
☐ Your child's diagnosis is a punishment by "God" for something you've done wrong in your life (9)
☐ Your child's diagnosis is a punishment by "God" for something they've done wrong in a past life (10)
☐ Your child will never be a successful member of society (11)
☐ Your child will always fall behind others their age (12)
☐ Your child will never get married/have a family (13)
☐ Your child will never be able to hold a steady job (14)
☐ Other (15) ________________________________________________

Q81 How has stigma affected your feelings about your child's diagnosis?

_Leave blank if you're unsure._

Not at all | A little | A moderate amount | A lot | A great deal
-----|---------|------------------|------|----------
1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

On a scale of 1-10 ()

Q80 How many days has your child expressed that this stigma has affected their self-esteem? (If they are aware of it.)

Not Applicable

1 | 2 | 3 | 4 | 5 | 6 | 7

During a 7-day week ()

Q120 How has your child's reaction to stigma affected you?

Not at all | A little | A moderate amount | A lot | Great deal
-----|---------|------------------|------|----------
1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10

On a scale of 1-10 ()

Q134 Rate these from 0-6: Chronic sorrow involves the grief that continues throughout the life of a child with a disability.
An adapted scale from an adaption by Batchelor (2017) of Kendall's (2005) Chronic Sorrow Instrument- change "loss" to "chronic sorrow"

<table>
<thead>
<tr>
<th>Q95</th>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not Sure</th>
<th>Usually Not</th>
<th>Infrequently</th>
<th>Almost Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

I think about the loss as if it had just happened ()
I feel saddened when I think of the loss. ()
I feel just as sad when I think of the loss as I did when the loss first happened. ()

<table>
<thead>
<tr>
<th>Q129</th>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not Sure</th>
<th>Usually Not</th>
<th>Infrequently</th>
<th>Almost Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

I feel like crying when something reminds me of the loss. ()
I feel full of sorrow. ()
I feel sadness when I am reminded of the loss. ()

<table>
<thead>
<tr>
<th>Q130</th>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not Sure</th>
<th>Usually Not</th>
<th>Infrequently</th>
<th>Almost Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

I feel saddened by things that other people see as unimportant or minor. ()
I feel full of sorrow when I think about what might or could have been if the loss had not happened. ()
I feel that the sadness related to the loss comes and goes. ()
Q131

<table>
<thead>
<tr>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not Sure</th>
<th>Usually</th>
<th>Infrequently</th>
<th>Almost Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

I feel that I have to give up things in my life because of the loss. ()
I feel that I have control over my life situation. ()
I feel my life is not the same as I had hoped or dreamed it would be because of the loss. ()

Q132

<table>
<thead>
<tr>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not Sure</th>
<th>Usually</th>
<th>Infrequently</th>
<th>Almost Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

I think about what my life might have or could have been when I am reminded of the loss. ()
I feel alone during times that I feel sadness related to the loss. ()
I feel that I have enough energy to deal with my life. ()

Q133

<table>
<thead>
<tr>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not Sure</th>
<th>Usually</th>
<th>Infrequently</th>
<th>Almost Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
The changes in my life because of loss are unfair. ()
I believe that life is unfair. ()
I feel older than my age because of my loss. ()

An adaption by Batchelor (2017 of Kendall’s (2005) Chronic Sorrow Instrument

Q95 In what ways do you cope with your child’s diagnosis, if any?
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

Q96 Give 1 word for how you feel about your child’s diagnosis.
______________________________________________________________________

Q98 Have you ever had to advocate on behalf of your child due to their disability? Please explain how you advocated.
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

Q100 Has the way you’ve parented changed since your child’s diagnosis?

○ Yes (1)

○ No (2)

○ Maybe (3)

Q101 If so, please explain:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
Q103 How has your family adapted to your child’s diagnosis?

________________________________________________________________
________________________________________________________________
________________________________________________________________

Q93 Is there anything else you’d like to share?

________________________________________________________________

Q94 Is there anything that I didn’t ask that is important to you? Your family?

________________________________________________________________
________________________________________________________________
________________________________________________________________

Some questions adapted from Batchelor (2017), Wickler (1981), and Sheets et. al. (2012).

IRB Letter of Approval
CSUSB INSTITUTIONAL REVIEW BOARD
Administrative/Exempt Review Determination
Status: Determined Exempt
IRB-FY2022-117

Carolyn McAllister-Rhiana Nordlund
CSUSB - Social Work
California State University, San Bernardino
5000 University Parkway
San Bernardino, California 92407

Dear Carolyn McAllister-Rhiana Nordlund:

Your application to use human subjects, titled "Chronic Sorrow and the Impact on Parents of Children with Disabilities" has been reviewed and determined exempt by the Chair of the Institutional Review Board (IRB) of CSU, San Bernardino. An exempt determination means your study had met the federal requirements for exempt status under 45 CFR 46.104. The CSUSB IRB has weighted the risks and benefits of the study to ensure the protection of human participants.

This approval notice does not replace any departmental or additional campus approvals which may be required including access to CSUSB campus facilities and affiliate campuses. Investigators should consider the changing COVID-19 circumstances based on current CDC, California Department of Public Health, and campus guidance and submit appropriate protocol modifications to the IRB as needed. CSUSB campus and affiliate health screenings should be completed for all campus human research related activities. Human research activities conducted at off-campus sites should follow CDC, California Department of Public Health, and local guidance. See CSUSB’s COVID-19 Prevention Plan for more information regarding campus requirements.

You are required to notify the IRB of the following as mandated by the Office of Human Research Protections (OHRP) federal regulations 45 CFR 46 and CSUSB IRB policy. The forms (modification, renewal, unanticipated/adverse event, study closure) are located in the Cayuse IRB System with instructions provided on the IRB Applications, Forms, and Submission webpage. Failure to notify the IRB of the following requirements may result in disciplinary action. The Cayuse IRB system will notify you when your protocol is due for renewal. Ensure you file your protocol renewal and continuing review form through the Cayuse IRB system to keep your protocol current and active unless you have completed your study.

- Ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study.
- Submit a protocol modification (change) if any changes (no matter how minor) are proposed in your study for review and approval by the IRB before being implemented in your study.
- Notify the IRB within 5 days of any unanticipated or adverse events experienced by subjects during your research.
- Submit a study closure through the Cayuse IRB submission system once your study has ended.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at (909) 537-7068, by fax at (909) 537-7028, or by email at mglispey@csusb.edu. Please include your application approval number IRB-FY2022-117 in all correspondence. Any complaints you receive from participants and/or others related to your research may be directed to Mr. Gillespie.

Best of luck with your research.

Sincerely,

Nicole Dabbs
Ph.D., IRB Chair
CSUSB Institutional Review Board
REFERENCES


Batchelor, L. L. (2017). *The lived experiences of parents with chronic sorrow who are caring for children with a chronic medical condition* [Nursing Theses and Dissertation, University of Texas at Tyler].

http://hdl.handle.net/10950/626


Bordonada, T. M. (2017). Examining chronic sorrow among parents of a child with Autism Spectrum Disorder (ASD) [Ph.D., University of South Carolina]. In *ProQuest Dissertations and Theses*.

http://search.proquest.com/docview/1927880711/abstract/C654AEA9D1E44A6PQ/1


https://doi.org/10.1016/j.pedn.2017.06.011


https://doi.org/10.1016/j.dhjo.2014.06.003


https://doi.org/10.1146/annurev.soc.27.1.363

https://doi.org/10.1016/j.jad.2014.05.042


https://doi.org/10.1093/sw/41.1.7


https://books.google.com/books?hl=en&lr=&id=tkZdDwAAQBAJ&oi=fnd&page=PR9&ots=7Su8X6NUPH&sig=QbsQFpqxCrNNXAEwstS8oOq3XMw#v=onepage&q&f=false


https://doi.org/10.1177/104438946204300404

Parrish, R. N. (2010). Mothers’ experiences raising children who have multiple disabilities and their perceptions of the chronic sorrow phenomenon [Ph.D., The University of North Carolina at Greensboro].

http://search.proquest.com/docview/365970904/abstract/92DBA202D10B48BEPQ/1
Patrick-Ott, A. S. (2011). *The experience of chronic sorrow in parents who have a child diagnosed with a significant disability: Investigating chronic sorrow across parental life* [Ph.D., Texas Woman’s University].

http://search.proquest.com/docview/926213601/abstract/164C9641DF3941D8PQ/1


https://doi.org/10.1177/1088357615587501


https://doi.org/10.2511/rpsd.29.2.95

https://doi.org/10.1177/001440290507100402


Southern California Special Education Department Director. (2021, August 30). *The demographic breakdown of a southern California school district* [Personal communication].


