WHAT ARE THE LIVED EXPERIENCES OF CAREGIVERS TO ADULTS WITH
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES?

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DEDICATION

For my parents, Bill and Sandy, my husband, Robert, and my daughters, Helen and Emily, thank

you for your patience and support during this experience.

ABSTRACT

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The purpose of this qualitative phenomenology design was to describe the experiences of caregivers to adults with I/DD in the State of Texas. The theory guiding this study was the social constructivism framework, which focused on how language and culture frame how individuals communicate, experience, and understand reality. In this study, the social constructivism framework assisted in understanding the challenges, and coping strategies employed by caregivers as they navigate the demands of caregiving. This study was guided by one research question: What are the lived experiences of caregivers of adults with I/DD that contribute to their perceived quality of life? An individual, semi-structured interview was completed with each of the four participants. The participants were asked three general questions: (a) What have you experienced in providing care to an adult with I/DD; (b) What are the highlights of your experience; and (c) What would you change. Through the narratives and experiences of the participants, several themes emerged such as familial bonds, challenges, coping mechanisms, and the need for support. The theme of family bonds underscores the connections that fuel caregiving journeys, while the challenges and coping strategies unveil the resilience of caregivers in navigating multifaceted responsibilities. The study's implications provide evidence for policy changes and societal shifts that can empower caregivers, enhance their support systems, and amplify the quality of life for both caregivers and those they care for.

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CHAPTER I

INTRODUCTION

Informal help-givers, such as family members, play a significant role in the care of adults with disabilities. Informal help-givers who provide care for adults with disabilities are often referred to as informal caregivers or family caregivers (Gérain & Zech, 2019). These individuals are usually family members, friends, or relatives who take on the responsibility of caring for a person with disabilities without formal training or compensation (Lindt et al., 2020). Informal caregivers play a crucial role in supporting and assisting adults with disabilities in various aspects of their daily lives. They may provide personal care, assistance with mobility, medication management, emotional support, household tasks, transportation, and advocacy, among other forms of care and support (Dixe et al., 2019). It is important to recognize and appreciate the invaluable contributions of informal caregivers in enhancing the well-being and quality of life for adults with disabilities.

Adults with intellectual and developmental disabilities (I/DD) are individuals who have limitations in intellectual functioning and adaptive behavior (Krahn, 2019). These disabilities typically originate before the age of 18 and persist throughout the person's life (Schalock et al., 2019). Intellectual disability refers to significantly below-average intellectual functioning, which is typically measured by intelligence quotient (IQ) tests (Barney et al., 2020). Developmental disabilities, on the other hand, encompass a broader range of conditions that affect a person's physical, cognitive, social, and emotional development (Scherer et al., 2019).

Adults with I/DD may have varying degrees of impairment, which can impact their ability to learn, communicate, reason, and carry out daily activities independently. They may require support and assistance in areas such as personal care, education, employment, healthcare,

housing, and social inclusion (Schalock et al., 2021). Individuals that have I/DD are unique and has a unique set of needs in which their abilities and support needs can vary. Caregivers frequently encounter the challenges of managing services, family finances, and their own well-being, often without adequate support. This situation can result in heightened stress levels compared to non-caregivers (Bridges et al., 2020). The objective of this study is to examine the experiences of caregivers who provide care for adults with I/DD in four key areas: (a) accessing and understanding state and local support systems, (b) managing the financial aspects of caregiving, (c) maintaining their own physical health, and (d) preserving their own emotional well-being. Conducting a study on the lived experiences of caregivers to adults with I/DD has the potential to positively impact the lives of both caregivers and care recipients by informing policies, improving support systems, and enhancing the overall quality of care provided.

Studying the lived experiences of caregivers to adults with I/DD has significant social implications. This research has the potential to challenge and reduce the stigma and misconceptions surrounding individuals with I/DD and their caregivers. By shedding light on the challenges, sacrifices, and resilience of caregivers, the study can foster a more inclusive and understanding society that recognizes and values the vital role these caregivers play. This chapter will provide the foundational elements of the study. It will start by addressing the statement of the problem and the purpose of conducting this research. The research questions that guided the study and the theoretical framework that informed the analysis will be discussed. Additionally, the nature of the study will be explained, providing a rationale for the chosen research method. This chapter will document clear definitions for the terms used in the study. It will also outline the scope of the research and identify any delimitations that may exist. The significance of conducting this study will be emphasized, highlighting the potential impact it can have on policy,

support systems, and societal attitudes towards caregivers and individuals with I/DD. Finally, the chapter will conclude by summarizing the key points that have been addressed, setting the stage for the subsequent chapters of the study.

Background

Crabb et al. (2020) researched national estimates of numbers of caregivers of older adults with disabilities in the United States using disability surveys and caregiver self-identified surveys. Approximately 43.5 million adults in the United States provide care for individuals who have a disability. Crabb et al. (2020) also concluded that about 85% of the number of individuals who provide care for an individual with a disability care for more than one family member. The estimated number of family caregivers of adults with disabilities aged 65 and older was, on average, 4.8 million in disability surveys and 24.4 million in caregiver self-identification surveys. Additional data also indicate a high prevalence of caregivers choosing home care over more expensive institutional care (Herbert & Molinsky, 2019).

Nevill and Havercamp (2019) found significant amounts of change occur within families regarding who is assigned primary responsibility to provide care. There is often a high rate of replacement in caregivers every couple of years to avoid burnout. While caregiving is a team effort, there is often a hierarchy with a primary caregiver who oversees and schedules the caregiving team. Siblings may take on the role of caregiver at a parent's direct or indirect request or by choice. In a United States survey of 79 adult siblings, 51 (65%) indicated they were in a caregiver role (Hall & Rossetti, 2017). The siblings reported taking on a variety of roles both formally, such as legal guardian, or informally in the role of friend. Additionally, in a study of 171 siblings of an adult with I/DD, 98 (57%) reported being the caregiver (Rossetti et al., 2018).

Many of the siblings reported starting in informal roles and transitioned to more formal and legal roles.

Statement of the Problem

The Individuals with Disabilities Education Act (2004) Part B makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to children ages 3 to 21. If a student has completed all the required coursework for a high school diploma but is needing additional time to complete the steps necessary to make progress toward their postsecondary goal, such as college or vocational training, the student can stay until age 21. In Texas, students can complete the school year if they are age 21 before September 1st (Texas Education Agency, 2021).

The rights of parents are transferred to their children when they turn 18. When a student with I/DD ages out of this federal program and is moving to post-secondary activities, the student will become the sole responsibility of their guardians or caregivers. As a result, these caregivers are asked to coordinate all the government supports that were previously provided by public schools. Legal guardianship is a timely and costly process that families can take on, or they can partner with their adult student to complete a supported decision-making agreement that allows them to be involved in educational and financial decisions.

Caregivers are often faced with navigating the services, family finances, and their own physical and emotional well-being with little support. This phenomenon may cause caregivers to experience more stress than others. State Medicaid waiver lists can take months or years of waiting and could lead to uncertainty while caregivers attempt to plan for the long-term success of adults with I/DD. This study looked at the experiences of caregivers of adults with I/DD in

four areas: (a) navigation of state and local supports, (b) financial ability to provide care, (c) maintaining own physical health, and (d) maintaining own emotional health.

Purpose of the Study

The purpose of this qualitative phenomenology design was to describe the experiences of caregivers to adults with I/DD in the State of Texas. The theory guiding this study was the social constructivism framework which focused on how language and culture frame how individuals communicate, experience, and understand reality (Akpan et al., 2020). In this study, the social constructivism framework assisted in understanding the challenges, and coping strategies employed by caregivers as they navigate the demands of caregiving.

Research Question

This study was guided by one research question:

RQ: What are the lived experiences of caregivers of adults with I/DD that contribute to their perceived quality of life?

Theoretical Framework

The theoretical framework that was used to guide this study is a social constructivism framework. Social constructivism is a theory that was developed by Lev Vygotsky in 1968 (Akpan et al., 2020). Social constructivism states that reality is constructed through communication as a process for survival where multiple realities are possible (Eads, 2023). The stress and coping theory was also be used in this study to understand the lived experiences of caregivers of adults with I/DD. The stress and coping theory, which was originally developed by Lazarus and Folkman, focuses on how individuals perceive and respond to stressful situations (Biggs et al., 2017). In the context of caregivers to adults with disabilities, this theory can provide insights into the experiences, challenges, and coping strategies employed by caregivers

as they navigate the demands of caregiving. The theory posits that caregiving can be a source of chronic stress, as caregivers often face multiple physical, emotional, and financial challenges in their caregiving role (Lazarus & Folkman, 1986). There are several key concepts of stress and coping theory. The first concept is stressors. These are the demands or challenges that caregivers encounter, such as managing complex care needs, financial strain, lack of support, or emotional burden (Lazarus & Folkman, 1986). These stressors can vary among caregivers and can impact their well-being and coping strategies. Another concept of the stress and coping theory is appraisal. This refers to the cognitive evaluation and interpretation of the stressor (Lazarus & Folkman, 1986). Caregivers may assess the demands of their caregiving role as either positive or negative. The appraisal process influences the emotional and behavioral responses to stressors (Biggs et al., 2017). Coping in the theory refers to the efforts made by individuals to manage and adapt to stressful situations (Biggs et al., 2017). Caregivers may employ various coping strategies, such as seeking social support, utilizing problem-solving skills, engaging in self-care activities, or utilizing spiritual or emotional resources. These coping strategies can influence the caregiver's well-being and their ability to provide care effectively.

The stress and coping theory posits that the individual's well-being and adjustment are influenced by their appraisal and coping strategies (Lazarus & Folkman, 1986). Positive coping strategies can lead to better psychological well-being, improved caregiver self-efficacy, and enhanced quality of care provided to adults with disabilities. By using the stress and coping theory as a framework, the researcher was able to explore how caregivers perceive and respond to the challenges of caregiving, examine their appraisal of stressors, identify coping strategies employed, and investigate the outcomes of caregiving on their well-being. This theoretical approach provides a comprehensive understanding of the experiences of caregivers to adults with

I/DD and informs the development of interventions and support services to enhance their coping abilities and overall quality of life.

Nature of the Study

This study utilized a qualitative phenomenology design to address the research question. Qualitative research is an approach to inquiry that aims to understand and interpret social phenomena through a deep exploration of people's perspectives, experiences, and meanings (Bloomfield & Fisher, 2019). Unlike quantitative research, which focuses on numerical data and statistical analysis, qualitative research seeks to capture the complexity and richness of human experiences (Busetto et al., 2020). Qualitative research involves gathering in-depth, non-numerical data through methods such as interviews, observations, and document analysis (Ahmadin, 2022). Researchers delve into the subjective interpretations and contextual factors that shape individuals' beliefs, behaviors, and interactions. Qualitative research is characterized by its open-ended and exploratory nature, small and purposeful sampling, reliance on qualitative data collection methods, and inductive analysis of the collected data (Bloomfield & Fisher, 2019). By examining the intricacies of human experiences, qualitative research provides valuable insights, generates hypotheses, and contributes to our understanding of the social world across various disciplines, including sociology, anthropology, psychology, education, and healthcare (Busetto et al., 2020).

Phenomenology is a philosophical approach that focuses on the study of subjective experiences and the conscious awareness of phenomena (Husserl, 1999). Phenomenology seeks to understand the structures of human consciousness and how individuals perceive, interpret, and make sense of the world. The term "phenomenology" was first used by the German philosopher Edmund Husserl in the early 20th century. Husserl aimed to establish a rigorous science of

consciousness, free from assumptions and preconceptions, by directing attention to the phenomena themselves and suspending judgments about their objective existence (Husserl, 1999). Husserl also emphasized the importance of bracketing which involves setting aside questions about the external world and focusing solely on the immediate experiences as they are given (Husserl, 1999). Phenomenology involves careful and detailed descriptions of subjective experiences, exploring the structures and patterns that underlie them. Phenomenology emphasizes the first-person perspective and recognizes that an individual's experiences are always embedded in a specific context and influenced by personal background, culture, and beliefs (Husserl, 1999). The goal of phenomenology is to uncover the fundamental structures of consciousness, such as intentionality (the directedness of consciousness toward objects) and temporality (the experience of time).

The phenomenon being investigated is the lived experiences of caregivers to adults with disabilities. The experiences of caregivers to adults with disabilities are complex and multifaceted. Using a qualitative phenomenological approach provided the researcher with a research method with the ability to explore these experiences in-depth, without being constrained by predetermined categories or theoretical frameworks (Husserl, 1999). This flexibility allowed for a comprehensive understanding of the unique challenges, emotions, and coping strategies that caregivers encounter. Phenomenology encourages an inductive approach to data analysis, allowing themes and patterns to emerge directly from the data (Bloomfield & Fisher, 2019). This approach is particularly useful when studying the lived experiences of caregivers, as it can uncover unexpected findings, generate new insights, and provide a deeper understanding of the factors that shape caregivers' experiences. The approach also allows researchers to capture the complexity and nuances of caregiving, providing a more holistic view.

The data collection for this study involved conducting semi-structured interviews with local families who served as the primary caregivers for adults over the age of 22 with I/DD. Semi-structured interviews provided a balance between allowing participants to share their experiences in their own words while also providing a framework to explore specific topics related to caregiving and the lived experiences of caregivers. During the interviews, caregivers had the opportunity to share their perspectives, challenges, and successes in providing care to adults with I/DD. The interviews were conducted in a sensitive and supportive manner, allowing caregivers to express their thoughts, emotions, and experiences openly. The goal was to gather rich and detailed accounts that reflect the complexity of their caregiving journey. Once the interviews were completed, the data was transcribed verbatim. Transcription ensures that the content of the interviews is accurately captured and ready for analysis. The transcribed data was subjected to thematic analysis using Braun and Clarke's (2021) 6-step approach. Braun and Clarke's thematic analysis provides a systematic and rigorous method for identifying, analyzing, and interpreting patterns, themes, and meanings within the interview data. The six steps involved in this approach include familiarizing oneself with the data, generating initial codes, searching for themes, reviewing and refining themes, defining and naming themes, and producing a final analysis report.

Scope and Delimitations

In a research study, the terms scope and delimitations refer to the boundaries and limitations of the study. The scope and delimitations help to define the extent and focus of the research, outlining what will be included and excluded from the study (Simon & Goes, 2013). The scope of a study refers to the breadth and coverage of the research. The scope defines the specific aspects, variables, populations, or geographical areas that will be examined (Akanle et

al., 2020). The scope sets the boundaries within which the research will be conducted, helping to establish the range of topics and the level of depth that will be explored. The scope clarifies the parameters of the study and provides a clear understanding of what will be addressed and investigated (Akanle et al., 2020). The scope of this study included using a sample of only primary caregivers for adults over the age of 22 with I/DD. The study only explored the caregivers' experiences related to the physical, emotional, and financial aspects of caregiving. The study was also conducted within the state of Texas.

Delimitations outline the limitations or restrictions of the study. Delimitations define the factors or elements that will not be included or considered within the study (Theofanidis & Fountouki, 2018). Delimitations may arise due to practical constraints, resource limitations, ethical considerations, or the specific research focus. By identifying delimitations, researchers acknowledge the aspects that are beyond the scope of their investigation, ensuring transparency and managing expectations. This study had several delimitations. One delimitation of this study was the sample did not include caregivers who were not the primary caregivers or who provided care to children with disabilities. The study also sought to explore the experiences of professional caregivers or healthcare providers.

Limitations

Limitations in qualitative research refers to the boundaries or constraints that impact the study's design, implementation, findings, and generalizability (Theofanidis & Fountouki, 2018). These limitations arise from various factors that can influence the quality, scope, and applicability of the research. The study faced challenges in recruiting an adequate number of participants due to the specific population under investigation. The availability of caregivers who were willing to participate and meet the inclusion criteria was limited, affecting the diversity and

representativeness of the sample. Due to the qualitative nature of the study and the specific focus on a particular group of caregivers, the findings may not be generalizable to all caregivers of adults with I/DD. The unique characteristics of the sample and the context may limit the transferability of the findings to other populations or settings. Exploring the lived experiences of caregivers to adults with I/DD can involve discussing sensitive and emotionally charged topics. Participants may have experienced difficulty recalling or expressing their experiences due to the emotional toll of caregiving. This may have impacted the richness and depth of the data collected.

Significance

This study was significant to conduct in several ways. The study can raise awareness about the unique social and economic issues faced by caregivers. The study can also draw attention to the significant demands placed on caregivers, including navigating complex service systems, managing finances, and maintaining their own well-being. By shedding light on these challenges, the study can advocate for policy changes and increased support to alleviate the burden on caregivers, leading to improved outcomes for both caregivers and care recipients. The study can also help build social networks and support communities for caregivers. By sharing their experiences and insights, caregivers can connect with one another, exchange practical advice, and find emotional support. This sense of community can empower caregivers and reduce feelings of isolation, ultimately contributing to their overall well-being.

Understanding the experiences of caregivers can inform the development of inclusive and person-centered services. The study can provide valuable insights into the specific needs and preferences of caregivers and individuals with I/DD. This information can guide the design and delivery of support programs that promote independence, inclusion, and quality of life for

individuals with I/DD, while also addressing the unique needs of their caregivers. By highlighting the experiences of caregivers, the study can foster a more equitable and just society. The study can draw attention to the disparities in access to resources, services, and support experienced by caregivers and individuals with I/DD. This knowledge can drive advocacy efforts and policy changes to ensure that all individuals, regardless of their abilities, have equal opportunities for a fulfilling life and receive the support they need. A study on the lived experiences of caregivers to adults with I/DD can have significant social implications, including combating stigma, advocating for policy changes, building supportive communities, informing inclusive services, and promoting social equity. Ultimately, it has the potential to contribute to a more inclusive, empathetic, and supportive society for individuals with I/DD and their caregivers.

Definitions

Adults with Disabilities: Adults with disabilities are considered to be any adult who has a physical or mental impairment that limits their daily activities (U.S. Department of Justice Civil Rights Division, n.d.).

Burnout: Burnout is considered to occur when an individual reaches a physical and emotional state of exhaustion due to occupational or personal stressors (Schaufeli, 2021).

Developmental Disability: Developmental disabilities encompass a broader range of conditions that affect a person's physical, cognitive, social, and emotional development (Scherer et al., 2019).

Informal Help-Givers: Informal help-givers are individuals who provide care for adults with disabilities (Gérain & Zech, 2019). These individuals are usually family members, friends, or

relatives who take on the responsibility of caring for a person with disabilities without formal training or compensation (Lindt et al., 2020).

Intellectual Disability: Intellectual disability refers to significantly below-average intellectual functioning, which is typically measured by IQ tests (Barney et al., 2020).

Summary

This chapter provided foundational information regarding the study about the lived experiences of caregivers to adults with I/DD. This study was significant to conduct because it provided valuable insights to the challenges that caregivers of adults with I/DD experience and provided information that prompt additional supportive services for this group of individuals. The problem that has been identified that this study addressed is that caregivers of adults with I/DD are often faced with navigating the services, family finances, and their own physical and emotional well-being with little support. The purpose of this study was to explore the experiences of caregivers of adults with I/DD in four areas: (a) navigation of state and local supports, (b) financial ability to provide care, (c) maintaining own physical health, and (d) maintaining own emotional health. The study was guided by one research question, and a social constructivist framework and the stress and coping theory served as the foundation. The study utilized a qualitative phenomenology design to collect and analyze data for the data. This chapter also provided information about the scope, delimitations, and limitations that have been identified in this study. Chapter 2 of this study will provide a review of the literature related to the topic of this study.

CHAPTER II

LITERATURE REVIEW

Caregivers are often faced with navigating the services, family finances, and their own physical and emotional well-being with little support. This phenomenon may cause caregivers to experience more stress than others. State Medicaid waiver lists can take months or years of waiting and could lead to uncertainty while caregivers attempt to plan for the long-term success of adults with I/DD. This study looked at the experiences of caregivers of adults with I/DD in four areas: (a) navigation of state and local supports, (b) financial ability to provide care, (c) maintaining own physical health, and (d) maintaining own emotional health. The purpose of this qualitative phenomenological design was to describe the experiences of caregivers to adults with I/DD in the State of Texas. The theory guiding this study was the theory of stress and coping, which focuses on how individuals perceive and respond to stressful situations. The framework that was used in this study was a social constructivist framework. In this study, the theory of stress and coping and a social constructivist framework assisted in understanding the challenges, and coping strategies employed by caregivers as they navigate the demands of caregiving.

According to the National Institute of Child Health and Human Development (NICHD, 2016) an I/DD is a disorder that affects a person's physical, intellectual, and or/emotional development. Intellectual functioning and adaptive behavior skills are significantly below average. Developmental disabilities is a broader category that can include both intellectual and physical disabilities. An adult with I/DD may have been afforded services under the Individuals with Disabilities Education Act while enrolled in public school.

Adults with I/DD are living longer and may be reliant on family members to get their wants and needs met (Lauer & McCallion, 2015). When a family takes on the caregiver role,

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there may be additional challenges to be faced (i.e., financial, physical, and emotional; Bucci & Vanheule, 2018). Additionally, families of adults with I/DD may perceive a lower quality of life due to the stress of being a caregiver (Hole et al., 2015); as a result, there is a need to explore the shared experiences of caregivers in order to support families of adults with I/DD.

According to the 2018 American Community Survey, approximately 4% (663,261 adults) of Texans aged 18-64 years old have a cognitive disability compared to 9.6% (388,678 adults) of adults 65 years and older (U.S. Department of Commerce, 2018). About 69% of the population aged 85 and over had at least one type of disability, compared with 9% of the population under the age of 65. In Tarrant County, Texas, 36.1% of adults over the age of 65 had a disability as reported by the 2013-2017 American Community Survey 5-Year Estimates. As this population ages, so do their caregivers. Census data from 2015 indicates that, among the 3.6 million people with I/DD living with a family caregiver, 24% had caregivers who were age 60 and over (U.S. Department of Health and Human Services, 2018).

The remainder of this chapter will discuss several topics that are relevant to this study. The section immediately following this one will discuss the theoretical framework that will be used to guide this study. After the section discussing the theoretical framework, literature that relates to the topic under investigation will be discussed. The chapter will conclude with a summary and a transition to Chapter 3.

Theoretical Framework

The theory of stress and coping, developed by Richard Lazarus and Susan Folkman, provides a framework for understanding how individuals perceive and respond to stressful situations. According to this theory, stress is not solely determined by external events but is a result of the appraisal and interpretation of those events by the individual (Lazarus & Folkman,

1984). The theory proposes two key components: primary appraisal and secondary appraisal. Primary appraisal involves assessing the significance and meaning of a particular situation (Lazarus & Folkman, 1984). This component includes evaluating whether the situation is perceived as irrelevant, benign-positive, or stressful. If a situation is appraised as stressful, it is further evaluated in terms of its potential harm, threat, or challenge. Secondary appraisal involves once a situation is appraised as stressful, individuals engage in secondary appraisal, which involves assessing their own resources and capabilities to cope with the stressor (Lazarus & Folkman, 1984). This evaluation includes considering one's coping skills, social support, and available resources to manage the situation effectively. Based on these appraisals, individuals employ different coping strategies to manage the stress they experience.

Coping strategies can also be categorized into two broad types. Problem-focused coping aims to directly address the source of stress (Lazarus & Folkman, 1984). It involves taking practical actions to modify the stressful situation, seeking information or assistance, and problem-solving to alleviate the stressor's impact. Emotion-focused coping happens in cases where individuals perceive limited control over the stressor, emotion-focused coping strategies are employed (Lazarus & Folkman, 1984). These strategies focus on regulating and managing emotional responses to the stressor. Examples include seeking emotional support, engaging in relaxation techniques, or engaging in activities that provide a distraction from the stressor.

The theory of stress and coping highlights that individuals' appraisals and coping strategies are dynamic and influenced by various personal and situational factors (Lazarus & Folkman, 1984). Factors such as personality traits, past experiences, social support networks, cultural backgrounds, and available resources can shape an individual's appraisal and coping responses. The theory of stress and coping provides a valuable framework for understanding the

cognitive and behavioral processes involved in individuals' responses to stress. It emphasizes the subjective nature of stress and underscores the importance of individual perceptions and coping strategies in managing and adapting to stressful circumstances.

The theory of stress and coping is highly relevant to a study focusing on the lived experiences of caregivers who care for adults with I/DD. Such caregivers often face unique challenges and stressors in their caregiving roles, and understanding their perceptions and coping strategies is crucial for providing support and improving their well-being. Applying the theory of stress and coping to this study involved examining how caregivers appraise the stressors they encounter in their caregiving experiences and the coping strategies they employ to manage these stressors. According to the primary appraisal component caregivers engage in appraisal to evaluate the significance and meaning of their caregiving responsibilities. This could involve assessing the demands, challenges, and impact of caring for an adult with I/DD on their own lives. They may consider the situation stressful due to the emotional, physical, and financial demands, as well as potential challenges in accessing support and services. After primary appraisal, caregivers may engage in secondary appraisal to evaluate their own resources and coping abilities. This primary appraisal may include assessing their emotional resilience, social support networks, access to respite care, and available community resources. Caregivers may consider whether they have the necessary support and coping strategies to effectively manage the stressors associated with caregiving.

The theory of stress and coping recognizes that individuals employ different coping strategies to manage stress (Lazarus & Folkman, 1984). In the context of caregivers for adults with I/DD, coping strategies can vary. Problem-focused coping may involve seeking information about available services, advocating for the needs of the individual with I/DD, or engaging in

self-care activities to enhance resilience (Lazarus & Folkman, 1984). Emotion-focused coping may involve seeking emotional support from friends, family, or support groups, engaging in relaxation techniques, or practicing self-reflection to manage the emotional impact of caregiving (Lazarus & Folkman, 1984). By using the theory of stress and coping in a study on the lived experiences of caregivers, researchers can gain insights into the appraisal processes caregivers undergo, the stressors they face, and the coping strategies they utilize. This information can contribute to the development of targeted interventions, support programs, and policies aimed at improving the well-being of caregivers and enhancing the quality of care provided to adults with I/DD.

Several studies have been conducted that explored the experiences of caregivers using the theory of stress and coping. Goswami Vernal (2021) explored the coping strategies employed by caregivers of individuals with autism during the COVID-19 pandemic. The study aimed to shed light on the self-care practices and mental health challenges experienced by these caregivers during the unprecedented circumstances of the pandemic. The researcher utilized an exploratory study design to gather insights from caregivers regarding their coping strategies and the impact of the pandemic on their well-being. The sample for the study comprised caregivers residing in Hyderabad, India, who cared for individuals with autism. Data collection involved semi-structured interviews to delve into the experiences, challenges, and coping mechanisms employed by the caregivers. Goswami Vernal (2021) utilized the theory of stress and coping to understand the coping efforts of the caregivers. The study addressed the mental health challenges faced by the caregivers during the COVID-19 crisis, such as increased anxiety, stress, and emotional exhaustion. The study also emphasized the need for adequate support systems,

access to mental health resources, and tailored interventions to address the unique needs of caregivers of individuals with autism in the context of a pandemic.

Another study conducted by McKibben et al. (2021) explored the informational needs of family caregivers who provide palliative care to individuals with intellectual disabilities. Using a qualitative research approach, McKibben et al. (2021) investigated the perspectives and experiences of family caregivers in understanding the specific informational needs they encountered while caring for individuals with intellectual disabilities who require palliative care. The research focused on understanding the challenges faced by caregivers in accessing relevant and appropriate information to support their caregiving role and was underpinned by the transactional model of stress and coping. The participants in the study consisted of family caregivers of individuals with intellectual disabilities receiving palliative care. Data collection was carried out through in-depth interviews, allowing the researchers to gather rich and detailed insights into the caregivers' experiences and information requirements. Through thematic analysis of the interview data, the study identified several key themes related to the informational needs of family caregivers. These themes included the caregivers' need for information regarding symptom management, medication administration, care planning, communication strategies, and available support services. The study emphasized the importance of tailored and accessible information that addressed the specific needs and challenges faced by caregivers in the context of intellectual disability and palliative care. The findings of the study by McKibben et al. (2021) highlighted the critical role of healthcare professionals and service providers in recognizing and addressing the informational needs of family caregivers. The findings also emphasized the need for comprehensive and personalized information that is communicated effectively to caregivers

in a way that respects their level of understanding and enhances their ability to provide appropriate care.

Review of the Literature

Intellectual Disabilities

Intellectual disabilities, also known as intellectual developmental disorders, refer to a group of conditions characterized by significant limitations in intellectual functioning and adaptive behavior (Patel et al., 2020). Individuals with intellectual disabilities typically experience difficulties in areas such as learning, problem-solving, reasoning, and social skills. Intellectual disabilities are neurodevelopmental conditions that manifest during childhood or adolescence and are characterized by limitations in intellectual functioning and adaptive behavior (Schalock et al., 2021). The limitations affect an individual's everyday functioning and can vary in severity. Individuals with intellectual disabilities also have limited intellectual functioning. Intellectual functioning refers to an individual's cognitive abilities, including their capacity for reasoning, problem-solving, abstract thinking, and learning (Thurm et al., 2019). Individuals with intellectual disabilities typically have IQ scores below 70-75 (Thurm et al., 2019). Difficulties in adaptive behavior are a core feature of intellectual disabilities. Adaptive behavior encompasses the skills needed for independent functioning and daily living and includes areas such as communication, self-care, social skills, and functional academics (Lee et al., 2019).

Intellectual disabilities are typically diagnosed in childhood or adolescence, as the condition becomes apparent during developmental stages. The diagnosis involves comprehensive assessments of intellectual functioning and adaptive behavior, considering standardized tests, clinical observations, and interviews with individuals and their families (Kishore et al., 2019).

Intellectual disabilities are classified into different severity levels based on the individual's IQ scores and their level of adaptive functioning. The severity levels include mild, moderate, severe, and profound intellectual disabilities (Jansen et al., 2023). Intellectual disabilities can have various causes, including genetic factors such as Down syndrome or fragile X syndrome, prenatal factors such as exposure to toxins or infections during pregnancy, perinatal factors such as birth complications, and postnatal factors such as brain injury or environmental deprivation (Ilyas et al., 2020).

Individuals with intellectual disabilities may experience associated features such as speech and language delays, motor skill difficulties, attention-deficit/hyperactivity disorder (ADHD), sensory processing issues, and mental health conditions such as anxiety or depression (Patel et al., 2020). Individuals with intellectual disabilities benefit from individualized support and interventions that target their specific needs (Schalock et al., 2021). These may include educational accommodations, specialized instruction, occupational and speech therapy, behavioral interventions, social skills training, and assistance with adaptive functioning. The focus of supporting individuals with intellectual disabilities has shifted towards promoting inclusion, independence, and self-determination (Schalock et al., 2021). Efforts are made to provide inclusive educational settings, employment opportunities, and community integration. Advocacy organizations work to protect the rights and improve the quality of life for individuals with intellectual disabilities.

It is also essential to recognize that individuals with intellectual disabilities possess unique strengths, talents, and capabilities. With appropriate support and opportunities, they can make meaningful contributions to society and lead fulfilling lives. Understanding intellectual disabilities helps foster empathy, promote inclusive environments, and provide appropriate

support for individuals with these conditions. By recognizing the diverse strengths and challenges associated with intellectual disabilities, society can work towards creating a more inclusive and supportive environment for all individuals.

Developmental Disabilities

Developmental disabilities refer to a group of chronic conditions that emerge during the developmental period and result in substantial impairments in physical, cognitive, communication, and social-emotional functioning (Tassé & Grover, 2021). These disabilities can have a lifelong impact on individuals, affecting their ability to participate fully in daily activities, learn new skills, and engage in social interactions. Developmental disabilities encompass a wide range of conditions, including intellectual disabilities, autism spectrum disorders, cerebral palsy, and specific learning disabilities (Centers for Disease Control and Prevention, 2020). The causes of developmental disabilities are diverse, including genetic factors, prenatal exposure to infections or toxins, birth complications, and environmental factors (Tassé & Grover, 2021). Early identification and intervention are crucial for supporting individuals with developmental disabilities and promoting optimal development. Multidisciplinary approaches, such as speech and occupational therapy, special education programs, and behavior interventions, play a vital role in enhancing functional abilities and maximizing independence for individuals with developmental disabilities (Hyman, 2020). Additionally, inclusive educational settings, community support services, and advocacy efforts are essential to ensure the inclusion and well-being of individuals with developmental disabilities in society (Hyman, 2020). By providing comprehensive support, understanding, and accommodations, society can create an environment that promotes the dignity and rights of individuals with developmental disabilities, enabling them to thrive and reach their full potential.

Various studies have been conducted on developmental disabilities in adults that have encompassed various topics. The state of employment for individuals with developmental disabilities is one area of research that has been conducted recently. Two such studies focused on the various aspects of employment for this population. Khayatzadeh-Mahani et al. (2020) conducted a study that focused on identifying the barriers and solutions to improve employment opportunities for individuals with developmental disabilities. The study by Khayatzadeh-Mahani et al. (2020) included persons with developmental disabilities, included a broad range of disabilities, and utilized a systematic review methodology to identify and prioritize barriers and solutions related to employment for individuals with developmental disabilities. The findings of the study revealed various barriers to employment, such as stigma, lack of support, limited job opportunities, and inadequate vocational training. Khayatzadeh-Mahani et al. (2020) also presented solutions such as workplace accommodations, inclusive policies, employer education, and vocational rehabilitation services. The study provided insights into the barriers and solutions related to employment for individuals with developmental disabilities, offering guidance for policymakers, service providers, and advocates to improve employment outcomes. Dreaver et al. (2020) examined the success factors enabling employment for adults on the autism spectrum from the perspective of employers. The study used a qualitative approach and gathered data through semi-structured interviews with employers who had experience hiring and working with adults on the autism spectrum. The findings revealed key success factors from the employers' perspective, including clear job descriptions, tailored interview processes, ongoing support and training, workplace accommodations, and fostering an inclusive and accepting work environment. The study highlighted the importance of employer perspectives and identified strategies that can enhance employment opportunities for adults on the autism spectrum.

While both studies addressed employment issues for individuals with developmental disabilities, Khayatzadeh-Mahani et al. (2020) focused on identifying barriers and solutions from a broader perspective, while Dreaver et al. (2020) specifically examined success factors for adults on the autism spectrum from the employers' viewpoint. The methodologies and findings of the two studies offer valuable insights into improving employment outcomes and promoting inclusivity in the workplace for individuals with developmental disabilities.

Adults With Intellectual and Developmental Disabilities

Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behaviors, such as communication, self-care, social skills, and problem-solving (Hodges et al., 2020). Developmental disabilities encompass a broader category that includes conditions such as autism spectrum disorders, cerebral palsy, and specific learning disabilities (Centers for Disease Control and Prevention, 2020). The severity and impact of I/DD can vary widely among individuals, ranging from mild to profound impairments in cognitive and functional abilities. Adults with I/DD often face health disparities and are at increased risk for various physical and mental health conditions. They may experience higher rates of chronic health conditions, such as obesity, diabetes, epilepsy, and cardiovascular diseases (Havercamp et al., 2019). Mental health concerns, including anxiety, depression, and behavioral disorders, are also prevalent among this population (Bakken, 2021). Access to quality healthcare and specialized services that address the unique needs of individuals with I/DD is crucial for promoting their health and well-being.

Ensuring community inclusion and participation is a vital aspect of supporting adults with I/DD. Inclusive educational opportunities, vocational training, and employment programs can enhance their independence, self-esteem, and social integration (Sabatello et al., 2020).

Additionally, community-based support services, such as residential programs, day programs, and respite care, can provide ongoing assistance and promote the inclusion of individuals with I/DD in various aspects of community life (Sabatello et al., 2020). Families and caregivers play a significant role in the lives of adults with I/DD. They provide emotional support, coordinate services, and assist with daily activities and decision-making (Baker et al., 2019). Caregiving can be demanding, and caregivers may experience elevated levels of stress, fatigue, and social isolation (Corréa et al., 2019). Access to respite care, support groups, and caregiver training can help alleviate these challenges and enhance the well-being of both individuals with I/DD and their caregivers. Adults with I/DD require comprehensive support to address their unique needs. Health and well-being, community inclusion, and caregiver support are critical areas to consider in providing effective services. By promoting inclusivity, addressing health disparities, and recognizing the importance of family and caregiver support, society can create a more inclusive and supportive environment for individuals with I/DD.

Quality of Life of Individuals With Intellectual and Developmental Disabilities

Two studies by Boehm and Carter (2019) and Nieuwenhuijse et al. (2019) both focused on aspects related to the quality of life of individuals with intellectual disabilities and their families, but they differed in terms of their specific populations and research methodologies. Boehm and Carter (2019) examined family quality of life (FQOL) and its correlates among parents of children and adults with intellectual disabilities. The purpose of the study was to understand the factors that contributed to the well-being and satisfaction of families in the context of caregiving for individuals with intellectual disabilities. The study used quantitative methods and utilized survey data collected from a larger sample of parents. The study explored various domains of FQOL, including emotional well-being, parenting satisfaction, and family

interaction, and identified factors such as social support, coping strategies, and child characteristics that are associated with FQOL. On the other hand, Nieuwenhuijse et al. (2019) conduct a narrative literature review to explore the concept of quality of life (QOL) specifically for individuals with profound intellectual and multiple disabilities (PIMD). The focus was on understanding how QOL is conceptualized, assessed, and evaluated for this specific population. The study utilized a qualitative approach, analyzing existing literature to gain insights into the different perspectives, instruments, and assessment methods used to measure QOL in individuals with PIMD. The review highlighted the importance of involving multiple perspectives, such as caregivers and professionals, in assessing QOL for individuals with PIMD.

In terms of similarities, both studies emphasized the importance of considering the subjective experiences and perspectives of individuals with intellectual disabilities and their families when assessing their quality of life. Both studies acknowledged the multidimensional nature of QOL and recognized that factors such as social support, family dynamics, and individual characteristics play significant roles in shaping the well-being and satisfaction of families and individuals with intellectual disabilities. However, the studies differed in terms of their populations of interest. Boehm and Carter (2019) focused on parents of children and adults with intellectual disabilities, exploring FQOL in a broader age range. In contrast, Nieuwenhuijse et al. (2019) specifically concentrated on individuals with PIMD, addressing the unique challenges and considerations associated with this severe level of disability. While both studies investigated aspects related to the QOL of individuals with intellectual disabilities and their families, Boehm and Carter (2019) emphasized FQOL among parents of children and adults with intellectual disabilities, while Nieuwenhuijse et al. (2019) provided a narrative literature review on QOL specifically for individuals with PIMD. The differences in the studies lie in their

research populations and methodologies, with Boehm and Carter (2019) utilizing quantitative methods and Nieuwenhuijse et al. (2019) using a qualitative review approach.

QOL encompasses various aspects of an individual's well-being, including their physical and mental health, financial situation, emotional state, work or vocational pursuits, social interactions, recreational activities, interpersonal relationships, personal values, and potential for growth and fulfillment (Boehm & Carter, 2019). While research on QOL is abundant, much of it has been conducted outside of the United States. International studies have consistently highlighted the crucial role played by informal caregivers, often family members, in supporting and caring for adults with disabilities. Collins and Kishita (2019) conducted a comprehensive review of literature to examine the prevalence of depression and burden experienced by these informal caregivers. Their findings emphasized the pressing need for effective interventions that can alleviate the burden and depressive symptoms experienced by caregivers.

The study conducted by Collins and Kishita (2019) underscored the significant challenges faced by informal caregivers, shedding light on the potential negative impact on their mental well-being. The prevalence of depression among caregivers was a concerning issue, indicating the strain and emotional toll associated with their caregiving responsibilities. The burden experienced by caregivers, resulting from the demands of caring for individuals with disabilities, was also a prominent aspect highlighted in the study. Given these findings, it becomes evident that interventions and support systems are essential to assist informal caregivers in managing their responsibilities effectively. Developing interventions that target the reduction of burden and alleviation of depressive symptoms among caregivers would be invaluable in enhancing their well-being and overall QOL. The prevalence of depression and burden among these caregivers highlights the need for interventions that can effectively alleviate their

emotional strain and enhance their overall well-being. By addressing the challenges faced by caregivers, it is possible to improve their quality of life and create a more supportive caregiving environment.

Beach Center Family Quality of Life Scale

The Beach Center FQOL Scale is a comprehensive assessment tool that aims to evaluate families' perceptions of their overall satisfaction with various aspects of their quality of life (Alnahdi, 2022). Initially developed with a specific focus on families raising children with disabilities from birth through the age of 21, the FQOL Scale offers valuable insights into the unique challenges and experiences faced by these families (Alnahdi, 2022).

The Beach Center FQOL Scale was meticulously developed through a comprehensive process involving extensive research and collaboration with various stakeholders (Beach Center on Disability, 2015). This process encompassed literature reviews, focus groups, and individual interviews conducted with family members of children with disabilities, individuals with disabilities, service providers, and administrators of service agencies (Beach Center on Disability, 2015). The stakeholders were invited to share their perspectives on the essential elements that contribute to a fulfilling family life. Their valuable insights were collected and analyzed to identify common themes and categories.

As a result of this thorough exploration, the research team identified 10 domains that collectively encapsulated the concept of FQOL (Beach Center on Disability, 2015). These domains include Family Interaction, Parenting, Daily Life, Financial Well-Being, Emotional Well-Being, Social Well-Being, Health, Physical Environment, Advocacy, and Productivity. Each domain represents a vital aspect of family life and contributes to the overall well-being and satisfaction experienced by families raising children with disabilities. To further refine and

validate the FQOL Scale, a pilot version consisting of 112 items was created and administered to a sample group comprising 1,197 individuals from 459 families. Through an exploratory factor analysis, the data generated by the pilot study revealed a five-factor solution. These factors were identified as Family Interaction, Parenting, General Resources, Health and Safety, and Support for Persons with Disabilities. This analysis helped to identify the underlying dimensions and structure of the FQOL Scale (Beach Center on Disability, 2015).

The factor structure of the FQOL Scale was subjected to further scrutiny and validation through two subsequent rounds of study involving a total of 488 families (Beach Center on Disability, 2015). These additional validation efforts aimed to confirm the factor structure identified in the pilot study and refine the scale. Through confirmatory factor analyses, the research team refined the FQOL Scale, resulting in a final version consisting of 25 items. These 25 items effectively assess the five domains of Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related Support. By following a rigorous and iterative development process, the FQOL Scale ensures that it captures the most significant dimensions of FQOL as perceived by the stakeholders involved. The scale's final version provides a concise and robust tool that can be utilized in research, interventions, and program evaluations to assess and improve the well-being and satisfaction of families raising children with disabilities (Beach Center on Disability, 2015).

Comprising five distinct subscales, the FQOL Scale delves into different dimensions of family life. The first subscale, Family Interaction, explores the dynamics and quality of relationships within the family unit. It takes into account factors such as communication, cohesion, and mutual support among family members. The second subscale, parenting, examines the parental experience and assesses the extent to which parents feel supported, competent, and

fulfilled in their caregiving role. This subscale acknowledges the demands and rewards associated with raising a child with disabilities, offering valuable insights into the specific needs and concerns of these parents. Emotional well-being is the third subscale of the FQOL Scale, focusing on the psychological and emotional aspects of family life. It gauges the overall level of satisfaction and contentment within the family unit, taking into consideration factors such as stress levels, resilience, and the presence of emotional support systems. The fourth subscale, physical/material well-being, evaluates families' satisfaction with their financial and material resources, as well as the physical environment in which they live. This subscale recognizes the potential impact of financial constraints and environmental factors on the overall quality of life for families raising children with disabilities. The final subscale, disability-related support, explores families' perceptions of the support they receive from various sources, such as healthcare professionals, educational institutions, and community organizations. It assesses the adequacy and effectiveness of the available support systems in meeting the unique needs of families and their children with disabilities (Alnahdi, 2022).

The FQOL Scale serves as a valuable research tool, allowing researchers and professionals to gather empirical data on family quality of life. Its versatility enables its application in various contexts, such as evaluating the effectiveness of interventions designed to support families or measuring the outcomes of programs and services aimed at enhancing the well-being of families raising children with disabilities (Beach Center on Disability, 2015). By providing a comprehensive and multidimensional assessment, the FQOL Scale contributes to a deeper understanding of the experiences, challenges, and strengths of these families. The scale also facilitates the identification of areas where additional support may be needed, as well as the

evaluation of interventions and programs that seek to enhance the overall quality of life for families in this context.

Caregivers of Adults With Disabilities

Caregivers of adults with disabilities play a vital role in providing support and care to individuals with diverse needs. These caregivers face unique challenges and responsibilities as they navigate the complexities of caregiving. In many cases, caregivers are family members, such as parents, spouses, or siblings, who assume the primary caregiving role (Zhong et al., 2020). The demands of caregiving can have a significant impact on the physical, emotional, and social well-being of caregivers. Caregivers of adults with disabilities often encounter various challenges in their caregiving journey. These challenges can include managing the individual's medical needs, aiding with activities of daily living, coordinating appointments and services, advocating for their loved one's rights and access to resources, and dealing with financial and legal matters (Lee et al., 2019). Caregivers may also experience emotional distress, including feelings of stress, anxiety, depression, and isolation, due to the demands of caregiving and the uncertainty of their loved one's future (Gallagher & Wetherell, 2020).

The caregiving role can take a toll on the physical and mental health of caregivers. The chronic stress and physical demands associated with caregiving can lead to health issues such as sleep disturbances, fatigue, compromised immune function, and increased risk of chronic conditions (Schulz et al., 2020). Caregivers may also experience mental health challenges, including elevated levels of distress, depression, and anxiety (Lee et al., 2019). It is crucial to recognize and address the health and well-being of caregivers to ensure their continued ability to provide care effectively. Caregivers of adults with disabilities require support and interventions to address their needs effectively. This support can include respite care, which offers temporary

relief to caregivers by providing opportunities for rest and self-care (Flynn et al., 2020). Access to information, resources, and training on caregiving techniques, self-care strategies, and available support services can empower caregivers and enhance their ability to meet the needs of their loved ones (Flynn et al., 2020). Psychosocial interventions, such as counseling, support groups, and peer support networks, can provide emotional support and a sense of community for caregivers (Bom et al., 2019).

The role of caregivers of adults with disabilities has garnered increased attention from policymakers and researchers. Recognizing the importance of caregiving, policies are being developed to provide financial support, flexible work arrangements, and respite care options for caregivers (Whiting et al., 2021). Society as a whole can contribute by promoting inclusivity, reducing stigma, and creating supportive environments that facilitate the participation and well-being of individuals with disabilities and their caregivers. Caregivers of adults with disabilities face numerous challenges that can impact their physical and mental health. They require various forms of support, including respite care, access to information and resources, and psychosocial interventions. Policies and societal efforts aimed at recognizing and addressing the needs of caregivers are essential in promoting their well-being and ensuring quality care for individuals with disabilities.

The financial needs associated with caring for an adult with I/DD can impose a significant burden on caregivers. The responsibilities of caregiving can hinder employment opportunities for caregivers, leading to lower rates of employment and reduced working hours (Diminic et al., 2019). This financial strain adds to the existing challenges faced by caregivers and further exacerbates the complexity of their role. The caregiving journey for families of individuals with I/DD often involves making sensitive decisions and navigating through

tremendous pressure. Caregivers find themselves obligated to support and care for their family member with a disability, which can have profound emotional and financial implications (Williamson et al., 2018). One significant challenge faced by families is coordinating their child's access to government support and services. The process of obtaining necessary assistance and communicating with managed care entities can be daunting and overwhelming (Williamson et al., 2018). The complex administrative procedures and the need to advocate for their loved one's rights and entitlements add additional layers of stress and frustration for caregivers.

Parents, in particular, often grapple with the transition from the role of a primary caregiver to embracing the idea that their adult child with I/DD should strive for a more independent life. This shift can be emotionally challenging as parents may have invested significant time, energy, and resources in providing care and support throughout their child's life (Bucci & Vanheule, 2018). Letting go of the caregiver role and fostering independence requires parents to confront their own fears, uncertainties, and concerns about the well-being and future of their loved one with I/DD (Bucci & Vanheule, 2018). This process can be emotionally complex and may necessitate support and guidance to navigate this transition successfully. The financial needs associated with caring for adults with I/DD can create a substantial burden on caregivers, impacting their employment opportunities. Caregivers face sensitive decisions and significant pressure as they strive to secure government support and navigate complex systems of care. Additionally, parents may struggle with transitioning from the caregiver role to promoting independence for their adult child. Recognizing the challenges faced by caregivers and providing appropriate support, resources, and guidance can help alleviate the financial, emotional, and psychological burdens associated with caregiving for adults with I/DD.

Contrary to the negative aspects often associated with caregiving, research suggests that caregivers of individuals with I/DD also experience positive emotions and feelings of satisfaction, alongside the more challenging aspects of their role. Olin and Duner (2018) highlight that caregivers often report a mix of emotions, including feelings of confinement, stress, and worry, but also feelings of satisfaction and fulfillment. This suggests that the caregiving experience is multifaceted, encompassing both positive and negative elements. One important aspect to consider is that caregivers tend to prioritize the QOL of their family member with I/DD rather than their own quality of life. Cuskelly et al. (2021) emphasized that caregivers often focus on the well-being and happiness of their loved one, sometimes neglecting their own needs and personal well-being in the process. This selflessness may stem from the deep sense of responsibility and commitment caregivers have towards ensuring the best possible outcomes for their family member with I/DD.

The caregiver's own QOL can fluctuate based on various factors, which, in turn, can impact their level of satisfaction. For instance, Boehm and Carter (2019) highlighted that caregivers may experience increased satisfaction when the frequency of challenging behaviors, such as aggression or self-injury, is reduced. This improvement in behavior can alleviate stress and enhance the overall well-being of both the caregiver and the individual with I/DD. Conversely, caregiver satisfaction may decrease if they perceive an imbalance in the caregiving relationship, feeling that they are giving more (emotionally and tangibly) than they are receiving. Sheehan et al. (2021) emphasized the importance of reciprocity in the caregiver-care recipient relationship. When caregivers feel that their efforts are not adequately acknowledged or reciprocated, it can lead to decreased satisfaction and potential strain on their well-being.

Caregiving for individuals with I/DD is a complex experience that encompasses both positive and negative aspects. While caregivers may face challenges, such as confinement, stress, and worry, they also report feelings of satisfaction and fulfillment. Caregivers often prioritize the quality of life of their family members with I/DD, potentially neglecting their own well-being in the process. Factors such as the reduction of challenging behaviors and the presence of reciprocity in the caregiving relationship can influence caregiver satisfaction. Recognizing the multifaceted nature of caregiving experiences and addressing the needs and well-being of caregivers are crucial in supporting them in their important role.

Caregiver Burnout

Caregiver burnout, also known as caregiver stress syndrome or caregiver fatigue, is a common phenomenon experienced by individuals providing care to loved ones with chronic illnesses, disabilities, or aging-related conditions. It refers to physical, emotional, and mental exhaustion resulting from the prolonged and demanding nature of caregiving responsibilities (Riffin et al., 2019). Caregiver burnout can have significant negative consequences for both the caregiver and the person receiving care. Caregiver burnout is characterized by a range of symptoms that can manifest in different areas of the caregiver's life. These symptoms may include chronic fatigue, sleep disturbances, irritability, feelings of helplessness or hopelessness, social withdrawal, and increased susceptibility to illness (Connors et al., 2020). The emotional toll of caregiver burnout can lead to increased levels of stress, anxiety, and depression (Armstrong & Alliance, 2019). Burnout can also impact the caregiver's physical health, leading to higher rates of chronic conditions and compromised immune function (Young et al., 2020).

Several factors contribute to caregiver burnout. The demanding nature of caregiving, including aiding with daily activities, managing complex medical needs, and navigating

healthcare systems, can be overwhelming and exhausting (Gérain & Zech, 2019). Lack of support, both practical and emotional, can also contribute to burnout (Montgomery et al., 2020). Caregivers who lack access to respite care, social support networks, and information resources may be at a higher risk of burnout. Additionally, caregivers who perceive their role as highly demanding, experience role strain, or have limited coping strategies may be more susceptible to burnout (Cohen et al., 2020).

Caregiver burnout not only affects the well-being of the caregiver but also has implications for the care recipient. When caregivers are overwhelmed and experiencing burnout, their ability to provide high-quality care may be compromised. This can lead to increased stress and poorer outcomes for the person receiving care (Broxson & Feliciano, 2020). Caregiver burnout can also strain the caregiver-care recipient relationship and contribute to feelings of guilt or resentment (Lauritzen et al., 2022). Preventing and managing caregiver burnout is essential for maintaining the well-being of both caregivers and care recipients. Support services, such as respite care, which provides temporary relief to caregivers, can help alleviate the burden and provide opportunities for rest and self-care (Zarit et al., 2019). Building a strong support network of family, friends, and support groups can offer emotional support and practical assistance (Boisvert et al., 2022). Caregivers should also prioritize self-care by engaging in activities that promote relaxation, exercise, and social connections (Sacco et al., 2022). Seeking professional help, such as counseling or therapy, can be beneficial for managing stress and burnout symptoms.

Caregiver burnout is a significant challenge faced by individuals providing care to loved ones. It can have profound negative effects on the caregiver's physical, emotional, and mental well-being, as well as impact the quality of care provided. Recognizing the symptoms and risk

factors of burnout, implementing preventive strategies, and accessing support services are crucial for managing caregiver burnout and ensuring the well-being of both caregivers and care recipients.

Summary

The literature review conducted in this chapter has shed light on various aspects related to adults with I/DD and their caregivers. Individuals with intellectual disabilities often encounter difficulties in areas such as learning, problem-solving, reasoning, and social skills. These disabilities are neurodevelopmental in nature and typically emerge during childhood or adolescence. They are characterized by limitations in intellectual functioning and adaptive behavior, as outlined by Schalock et al. (2021). On the other hand, developmental disabilities encompass a range of chronic conditions that arise during the developmental period, leading to significant impairments in physical, cognitive, communication, and social-emotional functioning. Tassé and Grover (2021) defined developmental disabilities as a group of conditions that have long-lasting effects on an individual's overall functioning and abilities.

Caregivers of adults with disabilities play a crucial role in providing support and care to individuals with diverse needs. These caregivers face unique challenges and responsibilities as they navigate the complexities of caregiving. The well-being of individuals with disabilities is closely intertwined with the support and care provided by their caregivers. Therefore, understanding the experiences and needs of these caregivers is essential for developing effective support systems and interventions. One common phenomenon experienced by caregivers is caregiver burnout, also known as caregiver stress syndrome or caregiver fatigue. This occurs when caregivers experience physical, emotional, and mental exhaustion due to the demands of providing care to loved ones with chronic illnesses, disabilities, or aging-related conditions.

Caregiver burnout can have a detrimental impact on the well-being of both the caregiver and the individual receiving care. Recognizing the signs of burnout and implementing strategies to mitigate its effects are crucial aspects of supporting caregivers in their caregiving role.

Chapter 3 will delve into the methodology that was used to conduct the study. The methodology will outline the approach, design, data collection methods, and analysis techniques that were utilized to gather and analyze information about the experiences of caregivers of adults with disabilities. By employing a rigorous methodology, the study aims to provide valuable insights into the challenges, needs, and support systems required to enhance the well-being of both caregivers and individuals with disabilities.

CHAPTER III

METHODOLOGY

The purpose of this qualitative phenomenological design was to describe the experiences of caregivers to adults with I/DD in the state of Texas. A social constructivism framework was used to understand how caregivers describe their experiences and perceive their quality of life in the form of open-ended questions using semi-structured interviews. In social constructivism, individuals seek understanding of the world in which they live and will develop subjective meanings of their experiences (Creswell & Poth, 2018). This framework was chosen to allow the researcher to look for the complexity of views in a caregiver's situation, not an explanation or analysis (Moustakas, 1994). The theory of stress and coping was also used in this study and provided a valuable framework for understanding the cognitive and behavioral processes involved in individuals' responses to stress. The theory emphasizes the subjective nature of stress and underscores the importance of individual perceptions and coping strategies in managing and adapting to stressful circumstances. The study was guided by one research question:

RQ: What are the lived experiences of caregivers of adults with I/DD that contribute to their perceived quality of life?

Chapter 3 of this research study will outline the methodology employed to conduct the investigation. The chapter will be divided into several sections, each addressing crucial elements of the methodology. The first section will provide a detailed discussion on the research design chosen for the study. It will discuss the specific research methodology employed and provide a justification for selecting that particular approach. The rationale behind utilizing qualitative methods to explore the lived experiences of caregivers to adults with I/DD will be presented, emphasizing the suitability of this approach in capturing the rich and detailed experiences of the

sample. The chapter will delve into the target population and sample utilized in the study. The specific characteristics and demographics of the caregivers of adults with I/DD included in the research will be outlined. The criteria used for sample selection will be provided, highlighting their relevance to the research objectives. The chapter will address the methods used for participant recruitment. The chapter will shed light on the steps taken to ensure a diverse and representative sample of caregivers, considering factors such as gender, age, cultural backgrounds, and caregiving arrangements. The subsequent section will outline the data collection processes and procedures implemented throughout the study. The methodology used to collect data will be described in detail.

Ethical considerations inherent to the study will also be thoroughly documented. The chapter will address the measures taken to protect the rights, privacy, and confidentiality of the participants. The chapter will conclude with a concise summary of the key points discussed throughout the methodology section. It will reiterate the research design, sample selection, data collection and analysis methods, participant recruitment strategies, and ethical considerations. By offering a comprehensive overview of the methodology, the chapter will ensure transparency of the study.

Research Design

For this study, a qualitative phenomenological design was used to address the research question. Qualitative research is an inquiry approach that seeks to comprehensively understand and interpret social phenomena by delving into the perspectives, experiences, and meanings attributed by individuals (Bloomfield & Fisher, 2019). Unlike quantitative research, which focuses on numerical data and statistical analysis, qualitative research aims to capture the intricate and multifaceted nature of human experiences (Busetto et al., 2020). Qualitative

research involves gathering detailed, non-numerical data through methods such as interviews, observations, and document analysis (Ahmadin, 2022). Researchers strive to explore the subjective interpretations and contextual factors that shape individuals' beliefs, behaviors, and interactions. The research process is characterized by openness, allowing for unexpected insights and discoveries to emerge. Small and purposeful sampling techniques are used to select participants who can provide rich and diverse perspectives related to the research topic. The data collection methods utilized in qualitative research emphasize depth and richness, enabling researchers to capture the experiences of the participants.

Qualitative research plays a significant role in providing valuable insights into the social world, shedding light on human experiences, and uncovering the complexities of phenomena. The research method goes beyond surface-level understanding, allowing researchers to explore the subjective, lived realities of individuals and the social contexts that shape their lives. Through its exploratory and interpretive nature, qualitative research generates hypotheses, informs practice, and contributes to theoretical advancements (Bloomfield & Fisher, 2019). There are several other qualitative research methods that researchers can utilize. One qualitative research method is grounded theory which is an iterative and inductive approach where researchers continuously collect, analyze, and develop theories from the data (Chun Tie et al., 2019). Researchers will use a grounded theory method when very little is known about the topic under investigation and the goal of the study is to produce or construct a theory to explain the phenomenon. This research method was not appropriate for this study because the researcher was not attempting to formulate a new theory but rather explore the experiences of caregivers of adults with I/DD. Ethnography is another research method that researchers use. In ethnography studies, the researcher will immerse themselves in a particular culture, community, or social

setting for an extended period (Rashid et al., 2019). Researchers engage in participant observation, interviews, and document analysis to gain a holistic understanding of the cultural practices, values, and social dynamics within the studied context. Ethnography was not an appropriate method for this study because the purpose of this study was not to understand a specific culture or social dynamic. Using a qualitative phenomenological research method in this study allowed the researcher to explore these experiences in-depth, without being constrained by predetermined categories or theoretical frameworks (Kahlke, 2014). This flexibility allowed for a comprehensive understanding of the unique challenges, emotions, and coping strategies that caregivers encounter.

Target Population and Sample

The target population of this study consisted of caregivers to adults with I/DD. The sample population were caregivers to adults with I/DD in the State of Texas. The targeted sample size was 10 local families. To participate in this study, participants had to meet specific eligibility criteria. Eligibility criteria established included local families who were primary caretakers of adults (over age 22) who have I/DD. This convenience sample can include parents, siblings, or extended family. The final sample consisted of four participants that met the eligibility criteria.

The relationships between caregiver and adult with I/DD included two fathers, one brother, and a cousin. Adam was a 30-year-old male who was a primary caregiver to his 35-year-old male cousin with intellectual disability. Brian was a 56-year-old caregiver to his 57-year-old brother with autism. Chris was the 60-year-old father to two 22-year-old twin daughters with cerebral palsy. David was the 60-year-old father to his 24-year-old son with autism. Participant demographic information is listed in Table 1.

Table 1

Participant Demographic Information

Participant	Sex	Age	Relationship	Family member area of disability	Family member Age
Adam	Male	30	Cousin	Autism	35
Brian	Male	56	Brother	Autism, Intellectual Disability	57
Chris	Male	61	Father	Cerebral Palsy, Intellectual Disability	22
David	Male	60	Father	Autism	24

Subject Recruitment

An invitation to participate in the study in the form of a flyer was sent to local parenting special needs organizations and day-habilitation facilities in Texas. Social media, community referrals, or other methods of recruitment were considered if the interested responses create a small sample. Before the interviews were conducted, Institutional Review Board (IRB) approval was obtained from Texas Woman's University. Each participant was provided with an informed consent to sign and send back before the interviews were conducted. The informed consent contained additional detailed information about the study, who the participants could contact if they had any additional questions, what was required of them by participating in the study, and what steps they would need to take to withdraw from the study. Informed consent was obtained from all four participants. The FQOL Scale was emailed to participants after the interview. Participants were asked pre-interview questions to establish their relationship to the adult with I/DD and a typical daily or weekly schedule.

Instruments

The Beach Center FQOL Scale was used to assess caregiver perceptions of their satisfaction with different aspects of family quality of life (Hoffman et al., 2006). The FQOLS contains five subscales: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related Support. Satisfaction is the primary response format and the items are rated on a 5-point scale. Participants completed the FQOL Scale on a Google Form. Cronbach's alpha for the FQOL Scale has an importance rating of 0.94 and a satisfaction rating of 0.88. The test-retest reliability in both the importance and satisfaction responses were significant at 0.01. The item-level overall had an acceptable fit (Beach Center on Disability, 2015).

Data Collection

Before data collection began on this study, IRB approval was obtained from Texas Woman's University. A series of interviews to initiate conversations with the caregivers were developed based on the research questions and as a guide for discussion. An open-ended question format enabled the participant to answer in their own words. This study used one-on-one teleconference and unstructured interviews as the primary method of data collection. The individual interviews with each caregiver were scheduled to last approximately 20 minutes. The interviews were conducted using a video telephone application, such as FaceTime or Zoom which was also audio recorded. The Beach Center FQOL Scale was used to assess caregiver perceptions of their satisfaction with different aspects of family quality of life (Hoffman et al., 2006).

An individual, semi-structured interview was completed with each participant. The participants were asked three general questions: (a) What have you experienced in providing care

to an adult with I/DD; (b) What are the highlights of your experience; and (c) What would you change. Additional open-ended questions were asked to probe or clarify responses: You mentioned (phenomenon) tell me what that was like for you; you mentioned (phenomenon) describe that in more detail. To ensure the validity of the transcribed interviews, member checks were conducted, and each participant had the opportunity to review the transcribed interviews.

Data Analysis

The data analysis process involved several steps and techniques to identify common themes and gain insights into the participants' experiences and perspectives. During the interviews, field notes were taken by the researcher. These notes served as a record of observations, non-verbal cues, and contextual details that provided valuable context to the interview data. The field notes were completed both during and after each interview, ensuring that no important information was missed. To facilitate the transcription process, Rev.com was utilized to convert the audio recordings into text format. This automated transcription method helped save time and ensured accuracy in capturing the participants' responses. Following the transcription, the data analysis process began. Burnard's (1991) method of analyzing interview transcripts was used to guide the analysis. The first step involved thoroughly reading the transcribed interview data. This close reading allowed the researcher to immerse themselves in the content, gaining a comprehensive understanding of the participants' narratives. The next step involved dividing the transcribed files into meaningful units. These units represented distinct ideas or related experiences within the interview data. By breaking down the data into these meaningful units, the researcher could identify specific aspects to explore further and analyze in relation to the research question.

The meaningful units were then grouped together based on similarities or commonalities to create themes. Themes were overarching patterns or concepts that emerged from the analysis of the meaningful units. The themes provided a way to organize and make sense of the data, allowing the researcher to identify significant trends, perspectives, or experiences shared by the participants. In addition to the analysis of the interview data, the researcher compared the identified themes with the FQOL Scale data. This comparison allowed for triangulation of the findings, examining the consistency or divergence between the participants' self-reported experiences and the quantitative data gathered through the survey.

Validity

The validity of the interview transcripts was checked for accuracy by a doctoral student at Texas Woman's University. Transcripts were sent to doctoral students to verify a) the caregiver identified their experience in providing care to an adult with ID/D b) the caregiver identified the highlights of their experience in providing care to an adult with ID/D c) The caregiver identified changes they would make d) the doctoral student agreed with the themes identified by the researcher.

Member checking with all participants was completed to ensure that the transcripts are accurate and reflect their perspectives regarding the phenomenon. Each participant was emailed and asked to review the attached transcript and let the researcher know if there were any discrepancies in the transcription. Each participant responded the transcription was correct based on their recollection of the interview.

Ethical Considerations

Due to the sensitive nature of the research topic, it was crucial to address ethical considerations in order to ensure the confidentiality and anonymity of the research participants

and the data they provided. To protect the participants' identities, informed consent procedures were implemented, and all individuals involved in the study were required to provide their voluntary and informed consent. The participants were fully informed about the purpose of the study, the interview process, any potential risks involved, and their rights to withdraw from the study at any time without facing any negative consequences. To safeguard the confidentiality and anonymity of the participants, several measures were taken. All audio recordings and transcribed files were labeled with pseudonyms, ensuring that the researcher could easily identify which transcribed file belonged to which participant. By using pseudonyms, the participants' real identities were shielded, and their privacy was protected.

Strict data security protocols were implemented to ensure the privacy and integrity of the participants' data. All data pertinent to the study, including the informed consent forms, recorded files, and transcribed files, were securely stored. The researcher took great care to store the data on a personal computer that was password protected, with restricted access limited solely to the researcher. By taking these precautions, the risk of unauthorized access to the data was minimized, thereby enhancing the participants' confidentiality. In addition to protecting the participants' data, it is important to ensure the emotional and psychological well-being of the participants throughout the research process. The researcher established a supportive and respectful environment during the interviews, ensuring that the participants felt comfortable and safe while discussing sensitive topics. The researcher remained mindful of their own biases and values throughout the research process. Reflexivity was used, involving critical self-reflection on the researcher's role and potential impact on the research. By acknowledging and addressing the researchers own biases, the researcher aimed to maintain objectivity and minimize any potential influence on the participants' responses.

Summary

In this chapter, the methodology used in the study was outlined, providing essential information about the research approach. The rationale behind selecting the qualitative phenomenological method was explained, along with an explanation of why other qualitative research methods were not deemed suitable for the study. The target population and sample were clearly documented, and the recruitment process for participants was described. The chapter discussed the instrument used in the study, specifically highlighting the FQOL Scale and provided a comprehensive overview of its details. The methods utilized for data collection and analysis were thoroughly detailed, ensuring transparency in the research process. Ethical considerations that were significant to the study were also addressed, acknowledging the measures taken to safeguard the well-being and rights of the participants. These ethical considerations are essential to ensure the study's adherence to ethical standards and protect the confidentiality and privacy of the participants. Chapter 4 will present the findings from the data collection and analysis.

CHAPTER IV

RESULTS

The current study aimed to document the experiences of caregivers to adults with I/DD. A social constructivism framework was used to understand how caregivers describe their experiences and perceive their QOL through open-ended questions. In social constructivism, individuals seek an understanding of the world in which they live and will develop subjective meanings of their experiences. This framework allowed the researcher to look for the complexity of views in a caregiver's situation, not an explanation or analysis. The theory of stress and coping was also used in this study and provided a valuable framework for understanding the cognitive and behavioral processes involved in individuals' responses to stress. The theory emphasizes the subjective nature of stress and underscores the importance of individual perceptions and coping strategies in managing and adapting to stressful circumstances.

To identify the main themes that characterize the caregiver's relationship with and attitude toward an adult with I/DD, a qualitative phenomenological design was utilized. A phenomenological study can be used to describe commonalities among individuals who have shared experiences. Moustakas's transcendental approach was chosen to enable the focus to be on the description of the experiences of caregivers.

The following research question of this study was: What are the lived experiences of caregivers of adults with I/DD that contribute to their perceived quality of life? The results presented in this chapter are a culmination of the interviews of four caregivers to adults with I/DD who met the inclusion criteria for the study.

All participants were interviewed over the phone. The time it took for the interviews varied from 5 minutes to 26 minutes. Each participant was asked three questions that consisted of

a) what you have experienced in providing care to an adult with ID/D; (b) what are the highlights of your experience; and (c) what would you change. The participants were emailed the Beach Center FQOL Scale after the interview. The scale was presented as a Google Form, and the responses were completed by participants within 48 hours of receiving the email. The interviews were transcribed and analyzed to determine themes between all participants. The results of the FQOL Scale were entered into a spreadsheet to determine the mean scores for each subscale. The following sections are descriptions of the participants and their answers to the interview questions.

Adam and Issac

Adam is a 30-year-old male, living in Georgia. He recently has been charged with and takes care of his cousin, Isaac, who is 35 years old. Isaac receives disability benefits but Adam does not receive community or agency support to assist in Isaac's care. Previously, the cousin lived with his parents. Adam reports that Isaac sometimes goes out in the community, but spends most of the time at their home.

> When asked about the experience and highlights of taking care of Isaac, Adam reports:
> For me that would be sharing memories together. You have more time together so, …
> coming together maybe sometimes when we have some people come … together during
> that time so, that's some part of the good that I know that we're together.

Adam reports that their living arrangement is comfortable, and he and Isaac take care of each other. Adam believes that he has enough support with the services Isaac currently receives.

Brian and Jack

Brian lives with his older brother whom he has taken care of since 1999. Brian was unemployed at the time of the interview, and Jack goes to a day program. The day program is

designed to help Jack work on functional living skills. Brian serves as unofficial guardian for Jack. He reports that the last 20 years have been extremely challenging with the level of care Jack has needed. When asked about the overall experience, Brian reports that it has been a pleasure to have his brother with him:

> I know personally that nobody will give him the level of care that I would, the level of attention that I would, that he expects from me as well, because we're tight like that. Overall, it's been great. Lately has been more challenging because, of course, my circumstances have changed as well. I don't have the levels of support that I had before with the kids or the ex and whatnot, so now it's all on my own.

Brian shared, in detail, some highlights in this experience:

> The highlights? Well, I guess... I don't want to get stuck in just because... "Jack" has been with me since 1999, so that's 20 plus years. Since he's been with me I can say that overall he has benefited tremendously because he reached some levels of maturity that I think back home people weren't looking at him as he doesn't have so much potential and yada yada, so you can keep him home. And over here he seems to just show nothing but signs of growth. Learning to pick up on another language. He had been introduced to English. Gosh, of course, when we were babies, he was exposed to it. And I'm sure you've heard it tons of times. I think maybe it helps to explain why he seems to understand some things and other things, of course, they're pretty obviously over his head. Overall, it's been a pleasure to have him because I know personally that nobody will give him the level of care that I would, the level of attention that I would, that he expects from me as well, because we're tight like that. Overall, it's been great.

However, Brian also reports there are some challenges, including adjusting to the role of a caregiver who is male when he has been raised around females who take care of children and household responsibilities:

> It is extremely challenging because of a lot of factors. It depends on the level of disability. It depends if there's language barriers. It depends on how warm the people are. Because I noticed with my bro... And I don't know, maybe there's something internal, but we're sensitive people so we like to be talk nice. I can tell with him, even with me, if I seem to have to need to get a little serious with him, or if I do inadvertently at times he gives me some attitude, so it's like, okay, God just help me through it. So basically learning to adjust to that role... I'll put it to you like this. As a man doing it, I have a whole new level of respect for women that are taking care of all their babies and doing everything else in the house and everything else.

Additional highlights include watching his brother's growth, especially in learning a second language after moving from Puerto Rico. Brian believes that when his brother was still with his parents, Jack was not able to mature as the family perception was that Jack did not have potential and should stay at home.

> And over here he seems to just show nothing but signs of growth. Learning to pick up on another language. He had been introduced to English. Gosh, of course, when we were babies, he was exposed to it. And I'm sure you've heard it tons of times. I think maybe it helps to explain why he seems to understand some things and other things, of course, they're pretty obviously over his head.

Brian did offer suggestions of what he would change for his brother. One thing Brian would change would be to encourage his brother to be even more independent by teaching him to take

care of himself. He related his experience with what he observed working as a special education para professional:

> If I could do it all over again for as long as I have, I think... I always ended up playing mama role. Maybe he could have been more independent in some areas. It wasn't until, for example, I'm working with (a student), and I'm working with other kids, and then I'm seeing my own kids and how they're responding to this. I'm realizing that, wow, mom doesn't... I felt really horrible with it. Not horrible, but I had this experience with this Mexican mom and she had little sweet little kiddo that she had, and we were trying to get her off of the diaper because she's in fourth grade right now. She's like, "Brian," I'm well used to it by now." And I'm like, oh damn, she reminded me of me because I'd be doing this shit for "Jack." If I didn't know that there was maybe a better way.

Brian regrets not pursuing guardianship to be able to make medical decisions during his brother's recent health battles:

> I don't have legal guardianship of him, because back in the day when I had him, when he first came to live with us we didn't have a whole lot of means. So somebody in the family said, "Hey, maybe you guys can do like foster care." Blah, blah, blah. "Get paid and just say we'll help you and whatnot." So we just kept that. That in a way I feel like it impacted us a little bit when it comes to having the doctors, for example, feel that I am indeed his voice, because I have been by the state assigned as his foster care companion and whatever. But the question that, "Do you have legal guardianship?" I'm like, "Well, no, I don't have that legal guardianship." Blah, blah, blah.

Chris, Kate, Kelly

Chris raised his twin daughters with his wife. Both daughters have cerebral palsy and have different needs. The daughters are currently 24 years old. Kate lives independently with support from the state. Kelly now lives in a facility due to her need for medical attention. Kelly requires 24-hour care and Kate requires less physical support. Chris was the primary caregiver to his daughter with the more severe needs, Kelly, while his wife took care of Kate. In the interview, Chris describes their care as overwhelming and a sacrifice as he put his daughters' needs before his own. Chris reports that he got to go to work and viewed that as an escape, and that his job of taking care of his daughters began when he got home.

> Cause at least I got to go to work during the day. So my job started when I got home from work. And so I guess I got a little bit of an escape from it, but she was the one, of course, that coordinated all the resources that came involved in it and stuff like that.

The highlight from Chris's experience was a sense of satisfaction of doing the right thing. Specifically,

> You do have a satisfaction amongst the heartaches, so you get kind of a mix, you get a squall of emotions, you get frustrated because sometimes you want to just get out, take off and run and hide, but you know, you can't hide. yeah. And just, I guess that's the end of the day through your struggles, you do get that margin of satisfaction. You know that, Hey, I didn't tuck my tail and run, I stayed in there and did what I needed to do.

Chris also reported that he would not do anything differently, as he believes the family did everything they could to take care of his daughters as they were growing up.

> I don't know that there's anything I would have done differently. Because in my experience. We pretty much did everything we could possibly do.

He reports that he and his daughter's mother exhausted every avenue that was available to them and utilized every network within their resources. Chris's situation is unique in that he had two children with significant disabilities.

David and Luke

David is the father of a college student with autism. He describes his experience as a caregiver fondly and describes still having to work with his son, Luke, on a daily basis. David helps his son to coordinate with a driving service and continues to work on money management.

> We're still working on money management, that will continue to be one of our challenges. But he understands now, as a young adult, how he needs to have better judgment for things. And he finally understands that he needs to ask for money to be deposited in his account.

The highlights in his experience include his son getting into college and watching his son advocate for himself. Specifically, David identified a "big highlight is watching him advocate for himself, for the classes that he wants to take."

One thing David would do differently is try to get his son into more inclusion settings during high school. Another thing David would have done differently would be to expose his son to more traveling, as opposed to just trips to visit family on school vacations.

> I think when we could have done another exploration of road trips, instead of just to Grandma's, we could have spread out more and gone different places just to discover what's there. It'd just open more opportunity for him.

Family Quality of Life Survey

The Beach Center FQOL Scale was used to assess caregiver perceptions of their satisfaction with different aspects of family quality of life (Hoffman et al., 2006). The FQOL

Scale contains five subscales: Family Interaction, Parenting, Emotional Well-being,

Physical/Material Well-being, and Disability-Related Support. Satisfaction is the primary

response format and the items are rated on a 5-point scale, where 1 = *very dissatisfied*, 3 =

neither satisfied nor dissatisfied, and 5 = *very satisfied*. Participants completed the FQOL Scale

on a Google Form. Their individual responses to each item are listed in Table 2.

Table 2

Results From the Beach Center Family Quality of Life Scale

FQOL Scale Item	Adam	Brian	Chris	David
Subscale 1: Disability-Related Support				
My family member with a disability has support to accomplish goals at school or at workplace.	5	4	4	5
My family member with a disability has support to accomplish goals at home.	5	4	4	5
My family member with a disability has support to make friends.	4	4	3	4
My family has good relationships with the service providers who provide services and support to our family member with a disability.	5	4	5	5
Subscale 2: Emotional Well-being				
My family has the support we need to relieve stress.	5	3	3	4
My family members have friends or others who provide support.	5	2	3	5
My family members have some time to pursue our own interests.	5	3	3	4
My family has outside help available to us to take care of special needs of all family members.	5	3	4	4
Subscale 3: Family Interaction				
My family enjoys spending time together.	5	4	4	4
My family members talk openly with each other.	4	2	3	4
Our family solves problems together.	5	5	3	4
My family members support each other to accomplish goals.	5	4	4	4
My family members show that they love and care for each other.	5	4	4	5
My family is able to handle life's ups and downs.	5	4	3	4
Subscale 4: Parenting				

FQOL Scale Item	Adam	Brian	Chris	David
My family members help the children learn to be independent.	5	4	4	5
My family members help the children with schoolwork and activities.	5	4	3	5
My family members teach the children how to get along with others.	4	4	4	5
Adults in our family teach the children to make good decisions.	4	4	4	4
Adults in my family know other people in the children's lives (friends, teachers, etc.).	5	4	5	5
Adults in my family have time to take care of the individual needs of every child.	4	4	4	4
Subscale 5: Physical / Material Well-being				
My family members have transportation to get to the places they need to be.	5	4	4	5
My family gets medical care when needed.	5	4	4	5
My family has a way to take care of our expenses.	4	4	4	5
My family gets dental care when needed.	5	4	5	5
My family feels safe at home, work, school, and in our neighborhood.	5	5	5	4

All participants completed this 25-item survey within 24 hours of receiving it in an email. The following chapter will interpret the results of the data collected from the interviews and the surveys in relation to the literature that was reviewed and the theoretical framework.

With Adam, I was not able to get as much information, and he did not elaborate even with prompting. The two participants who talked about having the most difficulty in providing care to their family member with I/DD also had the lowest average ratings on the FQOL Scale. Brian spoke emotionally about the challenges of taking care of his brother, yet reported more about how much growth Jack has shown over the years. Chris also spoke about making sacrifices and being overwhelmed but has a sense of satisfaction that he did the right thing with his daughters. David spoke much about Luke's continuing growth as an adult and opportunities Luke may have after college.

CHAPTER V

RECOMMENDATIONS AND CONCLUSIONS

This qualitative phenomenology design aimed to describe caregivers' experiences with adults with I/DD in the State of Texas. The theory guiding this study was the social constructivism framework, which focused on how language and culture frame how individuals communicate, experience, and understand reality (Akpan et al., 2020). This study was guided by one research question, What are the lived experiences of caregivers of adults with I/DD that contribute to their perceived quality of life? A qualitative phenomenological design was utilized to identify the main themes that characterize the caregiver's relationship with and attitude toward an adult with I/DD. The findings of the interviews revealed three main themes. The themes included the importance of family bonds, challenges caring for individuals with I/DD, and support systems. The following section will discuss the findings in more detail according to the themes and how the findings relate to the literature that was reviewed and the theory of stress and coping.

Importance of Family Bonds

An evident thread that emerged from the gathered data underscored the significance of family bonds. This theme is exemplified through Adam's emphasis on the constructive facets of spending time with his cousin, Isaac, which encompassed the profound opportunity to craft and exchange cherished memories. The spotlight on these affirmative aspects strongly underscored the indispensable nature of their familial connection and the shared moments they treasure. Similarly, Brian's unwavering dedication to providing care and unwavering attention to his brother, Jack, reinforced the centrality of family bonds in caregiving dynamics. Brian's account

underscored the distinctive quality of care and attention he extends, stemming from the profound bond they share.

The caregivers of adults with disabilities occupy an essential role in the intricate landscape of supporting and tending to individuals with diverse and intricate needs. This demanding role entails navigating multifaceted challenges and responsibilities that are inherent to the realm of caregiving. Often, these caregivers are close family members—be it parents, spouses, or siblings—who shoulder the primary caregiving mantle, mirroring the context of this study (Zhong et al., 2020). The observations in this study echo findings by Olin and Duner (2018), validating the experiences of the participants. These experiences often encompass a complex array of emotions—ranging from a sense of confinement, stress, and apprehension, to equally resonant feelings of satisfaction and contentment. This duality of emotions underscores the intricate tapestry of the caregiving experience, encapsulating both uplifting and challenging aspects. Furthermore, Brian's articulation of the positive repercussions of caregiving on Jack's personal growth and development amplifies the notion that caregiving is a multifaceted journey. The transformative impact of caregiving is evidenced by Jack's acquisition of a second language and enhanced independence. This facet hints at the nuanced and intricate nature of caregiving, which encompasses a spectrum of outcomes, where positivity and adversity coexist.

Challenges Caring for an Individual With I/DD

Another theme that emerged both from the survey responses and the in-depth interviews was the pervasive challenge inherent in caring for individuals with I/DD. Brian's acknowledgment of the inherent difficulties of caregiving, particularly when dealing with a family member who has disabilities, underscores the complexity of this role. Moreover, Brian's account also brings to light the intricate struggles he faces in juggling his responsibilities and

adapting to his caregiving role as a male figure in a context traditionally associated with females. A significant aspect is the inherent tendency of caregivers to place the paramount importance on enhancing the quality of life of their family members with I/DD, often at the expense of their own well-being. This overarching theme echoed in the narratives of the participants in this study. Chris's poignant portrayal of the overwhelming nature of tending to his twin daughters, both afflicted with cerebral palsy but manifesting distinct needs, encapsulates this sentiment. Chris's testimony further underscores the sacrifices he has unreservedly made to ensure their needs are met and their care is prioritized.

The narratives of Chris and Brian aligned with the observations in the academic sphere. Notably, the study conducted by Cuskelly et al. (2021) echoed Chris's experience. This research underscores the importance of caregivers to channel their energies towards the contentment and happiness of their loved ones with disabilities, oftentimes overlooking their own needs and personal well-being in the process. Thus, the findings of this study not only corroborate the challenges narrated by participants like Brian and Chris but also resonate with the wider body of research that substantiates the selfless dedication and prioritization of individuals with I/DD within caregiving contexts.

Support Systems

The overarching theme of support systems resonated across some of the participants, offering a foundational pillar in their caregiving journeys. Adam's perception of having a reliable safety net in the form of the current services that Isaac receives reflects the vital role that support systems play in caregiving contexts. Similarly, the commitment displayed by Chris and his wife, who explored every possible avenue and resource to ensure optimal care for their daughters, underscores the pivotal dedication that characterizes such caregiving endeavors. The narratives

of these participants echo a widely acknowledged truth: caregivers of adults with disabilities require comprehensive support and targeted interventions to effectively address the multifaceted needs of their loved ones. This inherent requirement for support aligns with the experiences conveyed by the participants in this study. Inclusive support systems encompass a spectrum of services designed to alleviate the challenges inherent in caregiving roles.

One key facet of this support landscape is respite care, a mechanism that offers caregivers a momentary reprieve by providing opportunities for rest and self-care (Flynn et al., 2020). Access to information, resources, and training regarding caregiving techniques, self-care strategies, and available support services emerges as a catalyst for empowering caregivers. This empowerment equips them with the necessary tools to capably address their loved ones' needs (Flynn et al., 2020). A holistic support framework extends beyond the tangible and encompasses psychosocial interventions as well. These include counseling, participation in support groups, and engaging in peer support networks, all of which provide invaluable emotional support and foster a sense of community among caregivers (Bom et al., 2019). This facet of support becomes a vital source of strength, bolstering caregivers' emotional resilience as they navigate the challenges and rewards inherent in caring for adults with disabilities. In essence, the identified theme of support systems resonates with the participants' experiences and aligns seamlessly with existing research. It reaffirms the pivotal role that structured and multifaceted support mechanisms play in shaping the caregiving landscape for individuals with disabilities and their devoted caregivers.

Findings in Relation to the Theory of Stress and Coping

The findings from these interviews can be related to the theory of stress and coping, which proposes that individuals experience stressors (such as caregiving responsibilities) and

employ coping strategies to manage and adapt to these stressors (Lazarus & Folkman, 1984). Adam's report of having enough support and Brian's mention of the levels of support decreasing highlight the importance of external resources in coping with caregiving stress. Adequate support can alleviate the burden of caregiving, while the lack of support can lead to increased stress and challenges in coping. Adam and Brian emphasized strong family bonds and positive relationships with their care recipients. These bonds can serve as emotional resources that help individuals cope with the challenges of caregiving. Close relationships and shared memories may provide emotional support that helps them manage stress. Brian's discussion of the challenges he faces, especially being a male caregiver in a role typically associated with females, aligns with the stress and coping theory (Lazarus & Folkman, 1984). His struggles with communication and attitude from his care recipient indicate potential stressors in the caregiving role.

Brian's adaptation to his role as a caregiver and his acknowledgment of the importance of "learning to adjust" demonstrates the coping strategies he has employed to manage the challenges. His learning to communicate effectively and handle his brother's attitude are examples of coping mechanisms he's developed. Chris's mention of "satisfaction amongst the heartaches" reflects a positive coping mechanism. Finding satisfaction in caregiving amidst the challenges can act as a psychological resource, helping caregivers maintain a positive outlook and manage stress. David's reflections on what he would do differently align with the coping theory. Caregivers often look back and consider alternative approaches or missed opportunities, which is a natural aspect of the coping process. The growth and development mentioned by Brian, such as his brother learning a new language and becoming more independent, demonstrated how individuals and caregivers can adapt and find positive outcomes despite the stressors they face.

The theory of stress and coping provides a framework for understanding how individuals in caregiving roles experience stressors, employ coping strategies, and adapt to their situations. The themes identified in the interviews align well with the concepts within this theory, providing insights into how caregivers navigate the challenges and rewards of their roles. The theory of stress and coping posits that stress is a transactional process between the individual and the environment (Lazarus & Folkman, 1984). In other words, stress is not simply a product of the environment, but rather it is the result of how the individual appraises and responds to environmental stressors. Caregiving is a complex and demanding role that can place significant stressors on individuals. Caregivers may experience physical stressors, such as the demands of providing physical care to a dependent person. They may also experience emotional stressors, such as the worry and anxiety that comes with caring for a loved one with a chronic illness or disability. The theory of stress and coping suggests that individuals use a variety of coping strategies to manage stressors (Lazarus & Folkman, 1984). Coping strategies can be either problem-focused or emotion-focused. Problem-focused coping strategies are aimed at changing the situation that is causing the stress. Emotion-focused coping strategies are aimed at managing the emotional response to the stress.

The themes identified in the interviews with caregivers align well with the concepts within the theory of stress and coping. For example, many caregivers reported using problem-focused coping strategies, such as seeking out information about their loved one's condition or learning new skills to provide care. Caregivers also reported using emotion-focused coping strategies, such as talking to friends or family members about their feelings or taking time for themselves to relax and de-stress. The theory of stress and coping provides a useful framework for understanding the challenges and rewards of caregiving. By understanding the stressors that

caregivers face, and the coping strategies that they use, we can develop interventions to help caregivers manage their stress and improve their quality of life.

Limitations

The study faced challenges in recruiting an adequate number of participants due to the specific population under investigation. The availability of caregivers who were willing to participate and meet the inclusion criteria was limited, affecting the diversity and representativeness of the sample. The study investigated the lived experiences of caregivers to adults with I/DD. This is a population that is often marginalized and difficult to reach. Caregivers of adults with I/DD may face unique challenges, such as the physical and emotional demands of caregiving, the financial burden of caregiving, and the lack of social support. These challenges may make it difficult for caregivers to find the time and energy to participate in research studies. In addition, the inclusion criteria for the study may have limited the diversity of the sample. The study required participants to be caregivers of adults with I/DD who were fluent in English and able to travel to the research site for interviews. This may have excluded caregivers who are non-native English speakers, caregivers who live in rural areas, and caregivers who have limited mobility. As a result of these challenges, the sample for the study was relatively small and not representative of all caregivers of adults with I/DD. This limits the generalizability of the findings to the broader population of caregivers.

Implications

The insights gleaned from the study have profound policy and social change implications that can shape and enhance the support systems for caregivers of individuals with disabilities. Policies should prioritize the availability and accessibility of respite care services. These services offer caregivers temporary relief, allowing them to rejuvenate and tend to their own well-being.

Implementing initiatives that provide caregivers with comprehensive information, resources, and training in caregiving techniques, self-care strategies, and available support services is an additional policy implication. This empowerment can equip caregivers with the necessary tools to navigate their roles more effectively. The findings of this study could also promote the availability of psychosocial interventions such as counseling, support groups, and peer support networks. These initiatives foster a sense of community, offer emotional support, and address the psychological toll of caregiving.

The study's findings highlight the need for a comprehensive, multifaceted approach to supporting caregivers of individuals with disabilities. This approach should address the physical, emotional, and practical needs of caregivers, and it should be collaborative in nature, involving policymakers, organizations, and communities. Policymakers, organizations, and communities must collaborate to create an environment that empowers caregivers, acknowledges their sacrifices, and ensures the holistic well-being of both caregivers and the individuals they support.

Future Research

The findings of this phenomenological study will provide useful insights into the lived experiences of caregivers who provide care to adults with I/DD. Local education agencies that provide special education services for school-aged individuals with I/DD can prepare caregivers for the transition to post-secondary services. Government and community agencies will be able to develop support programs to meet the needs of this population.

Additional areas that could be explored with this population includes their experience with the transition from high school to adulthood. Collecting information about how caregivers are able to connect with local and state agencies would be beneficial for local education agencies to target those resources during transition planning.

Conclusion

In conclusion, this study served as a significant exploration into the experience of caregiving for individuals with disabilities. Through the narratives and experiences of the participants, several themes emerged such as familial bonds, challenges, coping mechanisms, and the need for support. The theme of family bonds underscores the connections that fuel caregiving journeys, while the challenges and coping strategies unveil the resilience of caregivers in navigating multifaceted responsibilities. The study's implications provide evidence for policy changes and societal shifts that can empower caregivers, enhance their support systems, and amplify the quality of life for both caregivers and those they care for. Ultimately, this study not only enriched the understanding of caregiving dynamics but also underscores the urgent need for a holistic approach that transcends challenges and cultivates an environment of empathy, acknowledgment, and comprehensive assistance for caregivers in their noble and demanding roles.

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BEACH CENTER FAMILY QUALITY OF LIFE SCALE

BEACH CENTER FAMILY QUALITY OF LIFE SCALE

Thank you for agreeing to complete this survey. The survey is about how you feel about your life together as a family. We will use what we learn from families to inform policy makers and service providers for children and families.
Your "family" may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people:
-Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
-Who support and care for each other on a regular basis.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.
The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how Satisfied you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

-Checking the first circle means you are very dissatisfied.
-Checking the fifth circle means you are very satisfied.

Thank you so much for sharing your opinion with us!
There are 25 items

lmcdaniel4@twu.edu Switch account
Not shared

* Indicates required question

Name *

Your answer

My family enjoys spending time together. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members help the children learn to be independent. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family has the support we need to relieve stress. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members have friends or others who provide support. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members help the children with schoolwork and activities. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members have transportation to get to the places they need to be. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members talk openly with each other. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members teach the children how to get along with others. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members have some time to pursue our own interests. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

Our family solves problems together. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members support each other to accomplish goals. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family members show that they love and care for each other. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family has outside help available to us to take care of special needs of all family members. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

Adults in our family teach the children to make good decisions. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family gets medical care when needed. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family has a way to take care of our expenses. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

Adults in my family know other people in the children's lives (friends, teachers, etc.). *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family is able to handle life's ups and downs. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

Adults in my family have time to take care of the individual needs of every child. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family gets dental care when needed. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family feels safe at home, work, school, and in our neighborhood. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family member with a disability has support to accomplish goals at school or at workplace. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family member with a disability has support to accomplish goals at home. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family member with a disability has support to make friends. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

My family has good relationships with the service providers who provide services and support to our family member with a disability. *

	1	2	3	4	5	
Very Dissatisfied	○	○	○	○	○	Very Satisfied

What type of gift card would you prefer: *

○ Amazon

○ Wal-Mart

○ Kroger

○ Target

○ Other: _____

How would you like to receive the gift card? *

○ Email

○ Postal Mail

Email address or US Mail address: *

Your answer

Submit ▬▬▬▬▬▬ Page 1 of 1 Clear form

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ADAM INTERVIEW TRANSCRIPT

Lisa: And so you are the caregiver for your cousin? Is that correct? Hello... Hello, can you hear

me?

Adam: Hello.

Lisa: Hello, can you hear me?

Adam: Hello, yeah.

Lisa: Yes. Okay, so do you take care of your cousin?

Adam: Yeah.

Lisa: Yeah, okay. Does he or she go out to work or go to a Day Hab during the day? Or did they

stay with you all day?

Adam: Sometimes they'd leave, sometimes he has some time at home.

Lisa: Okay. So sometimes he goes out and sometimes he stays home all day.

Adam: Yeah.

Lisa: Okay. All right. So let me ask you. What have you experienced in your providing care...

What has been your experience of taking care of your cousin?

Adam: Yeah,

Lisa: I can barely hear you. I don't know if it's my phone. What are some of the highlights of

your experience? What are the good things that have happened in your experience?

Adam: (silence).

Lisa: Hello?

Adam: Hello.

Lisa: Hi. I'm sorry. Yeah, would you rather me email you these questions and you could spend some time writing your answers because I'm having a really hard time hearing you and it's very quiet on the phone.

Adam: Yeah. I can't [inaudible 00:03:17] continue [inaudible 00:03:20].

Lisa: Okay. What are some of the highlights and the good experiences of taking care of your cousin?

Adam: For me that would be sharing memories together. You have more time together so, [inaudible 00:03:36] coming together maybe sometimes when we have some people come [inaudible 00:03:48] together during that time so, that's some part of the good that I know that we're together.

Lisa: Okay. So share the memories and the good times. Okay. What is something that you would, I'm sorry? What is some things that you would change about your situation?

Adam: [inaudible 00:04:17] When I drink. I can just improve, not [inaudible 00:04:23] there he takes good care of me because [inaudible 00:04:30] time with him. [inaudible 00:04:32] comfortable situation.

Lisa: Okay. Do you feel like you're getting enough support from community services or state services?

Adam: Yeah, for me I think my supporting enough.

Lisa: Okay. All right. I'm going to email you the...

APPENDIX C

BRIAN INTERVIEW TRANSCRIPT

Lisa: Of course. Well, I really, really appreciate it. It'll be really quick. And then I'll send you an
   email with a survey, and then options for how to get the compensation gift card. So
   whatever works for you.

Brian: Okay. Okay.

Lisa: Are you ready?

Brian: Yeah, sure.

Lisa: Okay.

Brian: Shoot away. Let's do it.

Lisa: Okay. All right. Okay. So first of all, we just get some demographics, so your age and then
   some information. Well, first of all, how's he doing?

Brian: Well, he's medically fragile, right?

Lisa: Yes.

Brian: That's the best term I've learned to cope with. He suffered basically two strokes. The
   second time around, I learned that he has something called vertebrobasilar dolichoectasia,
   or something like that, which is basically... If you can picture his brain and all the wiring
   in there where, instead of some of these, I guess, arteries or vessels, instead of being a
   linear form, they're really all elongated and all out of shape and twisted all about.

Brian: A neurosurgeon tells me that that's what caused his stroke. I ended up coming with
   questions, but of course they didn't occur to me after the fact. So, it's been somewhat of a
   trying process because at the same time Jack is going through his transition of going

through his new assigned doctor from UNT. Because basically, he's under the care of a student doctor, but that's practicing under a licensed doctor of course with UNT.

Brian: Long story short, the one that was just about to become his current PCP, well, she wasn't going to be out of pocket by the time Jack was coming out of the rehab and I was trying to schedule something with the PCP, because that way I can try to hopefully have everybody on the same sheet of music. As it turns out, well, they're still waiting for medical records from areas and blah, blah, blah. I try to go and see if I can get it personally and deliver them quicker, but they told me, "Oh, sorry, the medical records department is closed because of the pandemic." And I'm like, oh shoot, because I didn't think to call and ask about that.

Brian: He is delicate. He's responding to therapy. I can tell they're painful on him. Anyway, you know what? I can sit here and sing the blues for you, but why don't we sit there and let's take care of your business?

Lisa: Okay. Okay. Well, again, I really appreciate it. And I'll be quick because I know you have a lot on your plate. Okay. So my first question is: What have you experienced in providing care to an adult with an intellectual developmental disability? So what's your overall experience in doing this, taking care of him?

Brian: That it's extremely challenging.

Lisa: Okay.

Brian: It is extremely challenging because of a lot of factors. It depends on the level of disability. It depends if there's language barriers. It depends on how warm the people are. Because I noticed with my bro... And I don't know, maybe there's something internal, but we're sensitive people so we like to be talk nice. I can tell with him, even with me, if I seem to

have to need to get a little serious with him, or if I do inadvertently at times he gives me some attitude, so it's like, okay, God just help me through it.

Brian: So basically learning to adjust to that role... I'll put it to you like this. As a man doing it, I have a whole new level of respect for women that are taking care of all their babies and doing everything else in the house and everything else.

Lisa: Right.

Brian: I've always been female friendly, but I say that because I mean it, because I lived it, because I seen it with my own parents. I see sometimes, I'm sure they regret it, my dad's face and whatever through pictures and whatnot. But at the same time you have to, as they say, pull yourself by your bootstraps and keep on trucking because the world moves whether you're ready or not.

Lisa: Right. Right. And Jack, he's your older brother, is that right?

Brian: Yes. Yes. He is 57 and I'm 56 to answer your earlier question.

Lisa: Okay. So then my next question is: What are the highlights of your experience?

Brian: The highlights? Well, I guess... I don't want to get stuck in just because... Jack has been with me since 1999, so that's 20 plus years. Since he's been with me I can say that overall he has benefited tremendously because he reached some levels of maturity that I think back home people weren't looking at him as he doesn't have so much potential and yada yada, so you can keep him home. And over here he seems to just show nothing but signs of growth. Learning to pick up on another language. He had been introduced to English. Gosh, of course, when we were babies, he was exposed to it. And I'm sure you've heard it tons of times. I think maybe it helps to explain why he seems to understand some things and other things, of course, they're pretty obviously over his head.

Brian: Overall, it's been a pleasure to have him because I know personally that nobody will give

    him the level of care that I would, the level of attention that I would, that he expects from

    me as well, because we're tight like that. Overall, it's been great. Lately has been more

    challenging because, of course, my circumstances have changed as well. I don't have the

    levels of support that I had before with the kids or the ex and whatnot, so now it's all on

    my own. And my son... I live on a second floor apartment right now, for example, and I

    can get him down on the wheelchair all by myself, no problem, if I have to get him to an

    appointment. But getting him up, I'm like, "Hey, (son), can you make yourself available

    because I need help?"

Brian: The residential people here are trying to work with me as far as finding a more suitable

    place for us to live. They call for moving to a sister property, but we're crossing that

    bridge very slowly. Right now we're just trying to work on the supports that he needs

    because life had really been great up until recently. First stroke, which happened two

    years ago, he recouped out of that like, wow. I was amazed. I remember when the

    therapists were coming, because he was able to walk really soon. And by the time the

    therapist came home to do their therapies, he's in the kitchen with them trying to show off

    how well he can [inaudible 00:09:07]. And I'm like, "Okay, Jack. Let's keep going. Show

    her what else you got."

Brian: So yeah, he's always been willing to cooperate and all that, but this time around it's a lot

    more challenging, I guess, as they tell me, "This stroke happens to hit a lot harder." I

    don't know. I have a funny vibe, meaning when he... I wasn't crazy about having to leave

    him in rehab as long as he was. By the time I got him he looked like Santa Claus. His

    nails were horrendous. His body looked okay. He didn't have any marks or anything,

even though they call me, "He managed to somehow fall off his chair." And I'm like, oh yeah, what else? That's exactly what I want to hear.

Brian: He came and he seemed to be really cool and be a lot more willingness. And then we had a issue there where I ended up having to call 911. I could tell that they dispatched us earlier than they should have. And I agreed to that because I had to sign, but I know that they were trying to say it's for COVID patients and whatever. It was a really awkward situation to come home, because since then, Wednesday, that was two Wednesdays ago, he's just shown regression and I'm like oh damn.

Brian: He's responding to therapies, but he's just showing to be so weak in other areas, almost uninterested on things that... I kind of make it a hype it up about, "Hey, Jack. How about looking good? I'll shave you up and put on your new baseball cap that cousin so-and-so sent you." He just looks at me and shakes his head no. He wants to be shaved, but don't worry about the cap. We're having to learn a new communication lately because he's not as expressive. I'm not able to... Even as they say, I'm able to recognize basically what he needed, and now that's also more challenging. It's just, I guess, matter of stages in life, right?

Lisa: Right.

Brian: Sorry I'm going about such a long way to-

Lisa: No, that's fine.

Brian: ... answer your question.

Brian: Yeah.And that's why I love showing him off on Facebook. I'm hoping that maybe the other people are inspired. And even though they have challenging cases, hey man, even if you just get a little bit out of him. They asked me... We had to sit down, redo his goals

and yada yada for the plan that he's on. "What are the goals, Mr. (Brian)?" I'm like, "You know what? I'd be happy if I can just get him to stand again and hold onto things and try to jam the symbol like he loved to do."

Brian: But I've also have noticed that since the first stroke, for example, before he could stay there for an hour and jam with me when I'm over here making noise with my other drums, and he's just having a time of his life. But now anymore I could tell that to get 10, 15 minutes out of him, that's a chore.

Lisa: Right. It's just his endurance. Yeah.

Brian: Yeah, his endurance has declined tremendously. The doctor basically just told me that to get home and give him the best quality of life. And I'm like, oh man. I didn't have the guts to ask him how much time it was he had left. It's a question I've always avoided. I have an auntie influencing me to ask that question. So I posed the question. We're working on trying to see if there's an answer. I don't even know, honestly, if I want to pursue that answer or not. Let it be what God says.

Lisa: Right. Okay. So you're pretty connected. Jack has people looking out for him and, I guess, case managers. Just your experience in being his caregiver, what would you change about this experience?

Brian: If I could do it all over again for as long as I have, I think... I always ended up playing mama role. Maybe he could have been more independent in some areas. It wasn't until, for example, I'm working with Julian, and I'm working with other kids, and then I'm seeing my own kids and how they're responding to this. I'm realizing that, wow, mom doesn't... I felt really horrible with it. Not horrible, but I had this experience with this Mexican mom and she had little sweet little kiddo that she had, and we were trying to get

her off of the diaper because she's in fourth grade right now. She's like, "Mr (Brian), I'm well used to it by now." And I'm like, oh damn, she reminded me of me because I'd be doing this shit for Jack. If I didn't know that there was maybe a better way.

Lisa: It was just easier for you to do it at the time.

Brian: Yeah. Nothing wrong with them learning to be independent. I've learned that he loves that. When he gets dressed, when he was able to... I'm like, "Jack. Okay. So here are the choices of the clothes." And he picks, and then after he's dressed he stands in front of his mirror and adjusting his shirt and his buttons. I'm like, "Hey man. Oh dude, you're looking like... I'm sorry for the ladies tonight." I know he loves to hear that. That's how we always kept it here. So yeah, it's sad to know that that's probably not going to happen anymore.

Lisa: I'm sorry to hear that. And I know that you probably been the best thing for him. I see your all's bond. I know you're doing all that you can, and it's hard being in this situation. Just a lot of responsibility, the choices you're having to make every day.

Brian: Yeah, I know. I don't have legal guardianship of him, because back in the day when I had him, when he first came to live with us we didn't have a whole lot of means. So somebody in the family said, "Hey, maybe you guys can do like foster care." Blah, blah, blah. "Get paid and just say we'll help you and whatnot." So we just kept that. That in a way I feel like it impacted us a little bit when it comes to having the doctors, for example, feel that I am indeed his voice, because I have been by the state assigned as his foster care companion and whatever. But the question that, "Do you have legal guardianship?" I'm like, "Well, no, I don't have that legal guardianship." Blah, blah, blah.

Brian: Decisions have been made where I know I hadn't been consulted. Communication could have been much better, put it that way. And I also realized how everybody covers for them and their team and their jobs. I was freaking going nuts after his first stroke and I'm driving home to get some rest and they call me, "Your brother fell off the bed." I'm like, "You have an alarm on that bed. How the heck did he fall off the bed?" By the time I got there they had a sorry, and I'm like, "No, we need to address this." And blah, blah, blah. I never ended up pursuing anything because it was damn near impossible to me to prove anything. God knows if that's what that damn aneurism came from, because that, first of all, hadn't been discussed first time around. And then the second time around, they tell me, "Oh yeah, he's got also an aneurism that has grown from eight millimeters to 18, or 11 to 18." I was like, oh.

Lisa: Oh, goodness. goodness.

Brian: Yeah. To tell you the truth, it's not been an idea situation in regards to medically how... I mean, you don't have to be grateful. Jack has had a number of things happen to him. He had to have his... Oh, God. Shoot, I forget now. It was something before we get removed. And he came out of that okay. Harris did a great job. His pulse works. Everything was going well. It wasn't until later when... What, in 2016, I guess, is when he had that first one. Or 2018, rather. Just learning and trying to learn and try not to let the pains and the aches distract you too much so that you don't end up just caving in. You know what I mean?

Lisa: Right. Well, I don't know what you mean, but I mean, I can hear what you're saying.

Brian: No, I think you do. You know what I mean.

Lisa: I know.

Brian: Just trying to stay mentally strong enough to continue to do the best that I can. I'm grateful. I've already come to accept that if our father up above says it's time, I'll be okay. It'll suck. Yeah, it'll suck for a good while at first, but he's had the best years that he's had.

Lisa: Oh, (Brian), he has. I mean, he's had the best experience. I mean, he's lived life. Your ride or die. And just has enjoyed life. And yes, and that's just the best that we can do is just make sure that he's living his life, and he has. He can recover and he can get his strength back. And with that strength, maybe his motivation and his interests and the things that he was interested in before will come back.

Brian: Well, I love to hear you there. I tend to be that helpful one as well. I don't want to be like... I don't know. I find myself a little bit twisted up because my go-to mechanism usually is like, no, I agree. My dad taught me, "(Brian), try to stay on the positive side of life. Don't let negativity impact you too much. It's there, but you can work with that." But lately, I don't know, I've just been maybe learning that, well, maybe there's just a reality that I have to... But at the same time, I would... You're right. I have a ton of people supporting him that love him. I know that they're praying for him. They got him in their thoughts. And that's wonderful.

Brian: In the meantime, what I see the therapist doing, I'm trying to reinforce so that his motivation... In other words, I'm great at hyping it up. When the physical therapist, for example, is challenging him in some areas, and then we notice that, wow, check that out. So I just, "Oh, Jack, great." And so of course, then he seems to wants to do it some more. Just trying to keep that state of mind that, you know what, it's tough now, but God knows he just got home practically. This pandemic has just been a bear also-

Lisa: Oh, gosh, I know.

Brian: ... in regards to, for example... I'm just trying to give you a real case. For example, I had to call and stop Jack's therapies when when we realized that we potentially got exposed to COVID through my son. The lady at Bridgeway was like, "We have a mobile system that can come over to your place to give him a test." And I'm like, "Oh, wow, really? Well, that'd be great because of our circumstances." They already know that we're on the second floor, yada, yada. She tells me, "Well, it probably won't be able until such and such date." And I'm like, "Okay, it's Saturday. Well, we're not going anywhere. That's fine."

Brian: And they didn't show up Saturday. They didn't show up Sunday. Saturday, a nurse came by I talked to her. I told her, "You guys are not supposed to be coming. I'm not expecting you to be coming." "Oh, no. We're not worried about it." She's got her N95 mask and all that. I'm thinking, okay, she's not a play, whatever.

Brian: So right now, because we haven't been visited by these folks, and I asked this lady, "Do you suppose I should call and bug them about this mobile unit?" She said, "No, not really." Okay. I'll give them the benefit of the doubt. She had already hinted that it most likely won't be until Monday. So now I have the therapist call me, "Hey, have you gotten our results yet?" And I'm like, "He hasn't even been tested. They never showed." I'm trying to work something out through Walgreens because the occupational therapist tells me, "Well, you know what? You can do it like this and I won't cost you." Yada yada. I checked into that and they cannot schedule him for the next few days because of the holidays. And within the next 100 miles there's nothing available.

Brian: I'm like, geez. I'm thinking to myself, should I be an asshole and call that lady and tell her, if you would have assured that a mobile unit would have gotten here, now your girls

would continue getting paid. But now they're not getting paid. And whose fault is that? In the meantime we're over here still not showing any symptoms, so I'm not really sweating it. You know what I mean? But these are those realities that I'm like, wow, man. Yeah, this shit's hard to get going.

Lisa: I know. I know.

Brian: But I'm glad that I got the strength. I had stuff at times want to sit there and cry like a baby sometimes, but ...

Lisa: Well, you got to take care of yourself.

Brian: Like a movie, I don't have time to bleed now.

Lisa: Right. Okay. Well, I really do appreciate your time. Check your email probably in about 30 minutes for the survey.

Brian: Okay.

CHRIS INTERVIEW TRANSCRIPT

Lisa: Okay. So I really, really appreciate your time. This won't take too long, I don't think. So I just have kind of three questions about your experience as a caregiver of someone with a disability. So reflecting on taking care of your girls. And so my first question is what has been your experience in providing care to someone with an intellectual and developmental disability?

Chris: What is my experience?

Lisa: Yeah. What was your experience like?

Chris: Well, it's overwhelming and it's pretty much sacrifice.

Lisa: Mm-hmm (affirmative).

Chris: You learn that you have to put their needs above your needs and wants, so you give up everything that you... What I could do, on most of it, because you don't, for one, you don't have the time and you have to make sure that you are providing everything, that's your patient, I might call it, needs.

Lisa: Right.

Chris: So you have to provide so that... you know, Sandy was really the person that was in the shoes. Cause at least I got to go to work during the day. So my job started when I got home from work. And so I guess I got a little bit of an escape from it, but she was the one, of course, that coordinated all the resources that came involved in it and stuff like that.

Lisa: The therapies and appointments.

Chris: Right. Tight. I don't know exactly how that got started. It started off with Stacy to Bevin. She had a profit coming. What do you call that profit three organization [crosstalk 00:02:46] non-profit and she did the therapy. So we brought the girls to the therapy all the time, well (Wife) did. And they start of in the house and stuff like that. So she took care of all the resources, all the help that we got, just to have avenues and all.

Lisa: So what were some of the highlights of that experience with your daughters?

Chris: Some of the highlights?

Lisa: Yep.

Chris: Well, you kind of get a satisfaction of maybe... I don't know how to explain it, that you did the right thing.

Lisa: Okay.

Chris: Does that make sense?

Lisa: Yes.

Chris: You do have a satisfaction amongst the heartaches, so you get kind of a mix, you get a squall of emotions, you get frustrated because sometimes you want to just get out, take off and run and hide, but you know, you can't hide. ,yeah. And just, I guess that's the end of the day through your struggles, you do get that margin of satisfaction. You know that, Hey, I didn't tuck my tail and run I stayed in there and did what I needed to do.

Lisa: Right. Okay.

Lisa: And so what would you change? What would you do differently going if you were to go back?

Chris: What would I do differently?

Lisa: Yep.

Chris: I don't know that there's anything I would have done differently. [crosstalk 00:05:21] Because in my experience. We pretty much did everything we could possibly do.

Lisa: Right.

Chris: So I don't.. I can't think of anything that was omitted. Now, if you could talk to her, you would probably get different answers.

Lisa: Yeah.

Chris: But like I said, because from my recollection, we pretty much exhausted every avenue that was available to us. And you kind of network in with your resources. Of course, she did all that. I don't know that there was anything that I would've changed. [crosstalk 00:06:26] That's what I was with as well. That just comes along with it.

Lisa: Right.

Lisa: That's just being a dad of daughters probably too.

Chris: Right, right. And you kind of... the rope is not, is not as tight when you have special needs involved.

Lisa: Yeah.

Chris: At least, not with me.

Lisa: I get it, I get it.

Chris: I'm kind of a softie.

Lisa: No, [crosstalk 00:06:59] I would not have picked up on that.

Chris: So yeah. There's a factor that plays into it, but no. I really can't think of anything that comes to mind. That's how I would have changed.

Lisa: Okay.

Chris: So, if you're looking... What you were looking for there. Exactly. But-

Lisa: No, I'm looking for your experience. And that's what I mean, that's exactly what I was looking for, for your experience, because this is so individualized and-

Chris: Right. Right. Everybody's got their own-

Lisa: Right.

Chris: -experience.

Lisa: Yes. So, okay. Well that was it. That was quick.

Chris: That's it?

Lisa: That's it. That's it.

Chris: I'm sorry. I mean, I feel like I'm not any help.

Lisa: No, if you were able to explain to me your experience of what the highlights were and you know, what you would change and you did all that, and there's no [crosstalk 00:08:01] wrong answer.

Chris: The highlight and the biggest thing that he has made with my whole experience with what happened to me in another life was just the sacrifice.

Lisa: Right.

Chris: That's a big word right there. Yeah. You, like Ben said, you have no life for you. Your life is to try to get well, in my case, my girls, along as far as they could get, and you're constantly worried, am I doing this right? Or is there something else that I could be doing? But like I said, we exhausted all of our avenues. And we hit doctors as far as Tulane Medical Center down in New Orleans to a children's hospital in New Orleans. So we went through it all, but outside of work it was, the big word that sticks out to me is sacrifice.

Lisa: Okay.

Chris: And there's no fishing trips. There's no nothing. Every now and then we were able to take a vacation, so yeah. It's mostly just sacrifice.

Lisa: Okay. All right. Well, thank you.

Chris: Okay.

Lisa: That really, really helped.

Chris: Well I hope so.

Lisa: It did. [crosstalk 00:09:54] No, it did. It did. So I'm going to probably in about 10 minutes or so, I'm going to email you a form to fill out online is this quality of life. And then at the end of that, it gives you the options of how to get compensated for your participation in this study. And I just really appreciate it-

Chris: No I don't really need to be compensated.

Lisa: No, you do. No you do. And that's just a part of the studies, you have compensation. And so there's some different options, but I just really appreciate your time. And [crosstalk 00:10:34] speaking with me.

APPENDIX E

DAVID INTERVIEW TRANSCRIPT

Lisa: What has been your experience in providing care to someone with an intellectual and
developmental disability?

David: I have to arrange a Lift driver, Uber, for him. If he hasn't already gotten on his driver's
list, we'll find something that's available.

Lisa: Okay.

David: We're still working on money management, that will continue to be one of our
challenges. But he understands now, as a young adult, how he needs to have better
judgment for things. And he finally understands that he needs to ask for money to be
deposited in his account.

Lisa: Right.

David: So he doesn't go overboard.

Lisa: Okay. So are you still having to be involved in managing his care and legal responsibilities
or any kind of guardianship with him?

David: It's, an unofficial guardianship. Everything still has to come through me. I take care of all
of his SSI services as far as his benefits. And then through our care agency rooting my
mom. Where's it. Come on. Oh, okay. I've been in three meetings so far-

David: Not direct care or self, like I take care of all of his coordination for service work.

Lisa: Okay.

Lisa: So what have been the highlights of your experience in working with Luke just as, as he's
gone out of high school and as he's going into adulthood, what are the highlights?

David: Oh, wow. Okay. Well of course, he is in college.

Lisa: Mm-hmm (affirmative).

David: He is that his dream college and just going through that process of the regular college application and then getting him through the interview process to be accepted to the school room. A big highlight is watching him advocate for himself, for the classes that he wants to take.

Lisa: Oh great.

David: He still wants to be an entertainer and huge highlight this semester, two of them, he was he's one of the singers in the blues fan class on cats.

Lisa: Oh, it's amazing. And he's Got talent. He's got talent.

David: Yes he does. He's trying to turn that talent into not just something fun to do, but he wants to do this through bed and try to get the program directors at school to find the right classes, four to eight classes for him to meet that job. This semester, he's taken an independent study clients, and this is all basically to develop his comedy routines. And his [inaudible 00:03:16].

Lisa: That's great.

David: Yeah. We gave him two minutes. And he remembers seeing important people, like (Friend), (Friend), not too many people from Oklahoma that whole time we were there...

Lisa: Yeah.

David: And his course, some of his teachers from here talked to people in town that have always been there to help him and encourage him. He still keeps what he calls the "Trust Its." When he was in high school, he would hand me a sheet of paper that had names on it. I don't know what it was at first, but I figured out these were people that he trusted. And it

always amazed me, like my band kids who was still on the list, or who he had removed from it or who he had added.

David: And yeah, over the years there were some that were consistent with it, and he still stays in touch with them.

Lisa: That's-

David: So that's really good.

Lisa: That's good, that's good.

Lisa: So the past couple years, what are some things or events that you would change or do different looking back?

David: Let me see.

David: I've taken his high school years. I would've ... Pushed our system through ... put in more inclusion-type classes.

Lisa: Mm-hmm (affirmative) oh, I agree.

David: Yeah, and I do inclusion at a junior high now. I came out of retirement to do that. So, I think there are things that we could have prepared him for that were not to just get him graduated from high school, but really to prepare him more for the next step. Now, moving closer to adulthood.

Lisa: Okay.

David: Another highlight or talent ... I think when we could have done another exploration of road trips, instead of just to Grandma's, we could have spread out more and gone different places just to discover what's there. It'd just open more opportunity for him.

Lisa: Okay, okay.

Lisa: And I think he would be a great travel buddy.

David: Oh yes, he is. Yes, yes. He usually takes care of the mapping, even before GPS, he would

do that. And that's still now ... like he wants to go to Jackson, Mississippi, at least he

wanted to go this weekend. But after he looked at the weather says, "Nah, we're not going

to do that." But he had already sent me the map saying, all right, this is how we're going

to get it. These are the things that we're going to do, trying to hotel meet the view. So he's

very, very astute with planning in advance and logistics that pertain to him.

Lisa: Right. Well, that'd Be good for when he goes on his world tour-

David: Of course, yes.

Lisa: And he'll be very involved in that planning.

David: Yes, yes. So he plans to somehow audition for America's Got Talent. And, he came up

with that because what I told him, "What we need to do is audition for Disney," to see if

there's an internship he can do there, particularly the Autism at Seas cruise program.

Lisa: Mm-hmm (affirmative).

David: Because I know they invite families to do that. It's low-sensory they give to young people

on the spectrum, but what we want to explore is, do they include any service workers on

the ship? Like stewards, tour guides, entertainment groups [inaudible 00:07:44] on the

stage for their shows? Do they put an emphasis on performers with disabilities?

Lisa: Right.

David: So that's our big goal right now.

Lisa: That would be amazing.

David: Yeah, I had to get them done. I think he fears ... because he is researching ... he says,

"Okay. Well, I'll have to take Dramamine so I don't get seasick, because that's not good."

He's thinking about it.

Lisa: Oh goodness. Okay.

Lisa: All right. Well that's it. Thank you so much.

David: Oh sure, yeah.