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Phenomenological Investigation of Parents' Decisions Regarding Group-Home Placement of Adult Children with Intellectual Disabilities

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Walden University
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Abstract

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MA, Norfolk State University, 2009

BA, Norfolk State University, 2007

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
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Abstract

Parents of individuals with intellectual disabilities are confronted with challenging decisions regarding whether to place their adult child in a group-home. The research question for this study was to ascertain the lived experiences of parents confronted with this life altering decision. Limited research exists on parents who face this difficult life choice. The purpose of this study was to explore the lived experiences of parents of individuals with intellectual disabilities when contemplating residential placements. Ten participants from the north Atlantic coastline in the U.S. were recruited and shared their lived experiences during semi structured interviews. Utilizing qualitative methodology to undergird Heidegger's phenomenology framework, data was collected and analyzed using the hermeneutic circle. The thematic outcomes included best option, physical aggression, death/absence of a spouse, caregiver medical conditions, mental health-behavioral disorder, community integration, hospital/emergency, verbal aggression, and financial burden. The results can inform counselors regarding the struggles the parents of adult children with intellectual disabilities confront and how they influence decisions regarding alternative living arrangements. The findings inform parents enduring emotional and physical stressors, caregiver burden, and relationship strain. Positive social change can be realized through disseminating the results of this study to parents, counselor educators and supervisors. Coursework could introduce students and practitioners to the parental decision-making process to help understand family dynamics and alternative living arrangements for individuals with intellectual disabilities.

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Chapter 1: Introduction

Caring for an adult child with intellectual disabilities is a responsibility many parents experience (Bigby, Knox, Beadle-Brown, & Clement, 2015; Baumbusch et al., 2015; Crettenden et al., 2014; Luijkx et al., 2013). Parents designate other family members to take on this obligation in the event of death or significant loss. However, they often become unable to attend to the adult child's daily needs as they grow older and become physically or mentally incapacitated. Parents meet extensive medical needs, such as lifting their son or daughter in and out of a wheelchair or having adaptive equipment installed in their home to ensure the safety of their adult child (De Laat, Freriksen, & Vervloed, 2013). Ultimately, they must often find alternative living arrangements for their children as they can no longer be their primary caregivers.

Group home placements are an option for parents and guardians to care for their adult child with an intellectual disability (Bigby et al., 2015; Norlin & Broberg, 2013). An alternative living environment can support the adult child's ability to learn new skills and become more independent. The staff members at group homes establish daily structured routines including program-based activities, social skill development, and age-appropriate peer relationships (Bigby et al., 2015). Knowing their adult child is in a safe, secure, caring facility often opens the door for parents to have peace of mind about the future (Bigby et al., 2015).

Placing their adult child in a group home facility reduces daily responsibilities that can restrain them from having outside employment or the freedom to shop, visit friends, or participate in other enjoyable activities. However, parents may receive severe criticism from their immediate family and community members when they become unable to care for their adult child in their home (Bigby et al., 2015; Norlin & Broberg, 2013). Outsiders may label them as detached, neglectful, and inconsiderate when they decide to place their adult child with an intellectual disability in a group home (Norlin & Broberg, 2013). Researchers found that community members often judge parents harshly without understanding the underlying circumstances behind their placement decisions (Bigby et al., 2015; Norlin & Broberg, 2013). Finally, parents with intellectually disabled adult children often suffer from their own emotions such as guilt, shame, and feelings of loss when they place their adult children in a group home (Bigby et al. 2015; Norlin & Broberg, 2013).

Background

Parents who face difficult life choices around group home placement for their adult child with intellectual disabilities often need counseling services and other interventions (Gibbons, Owen, & Heller, 2016; Grossman & Webb, 2016; Heller, Gibbons, & Fisher, 2015). Parents often seek counseling to address problems they may experience around group home placement such as anger, shame, anxiety, stress, and guilt; however, counselors are not as well informed about the hardships that parents and individuals with intellectual disabilities face. Therefore, they are not effectively able to connect them to resources that will increase their coping mechanisms (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015). Documenting the lived experiences of parents who face complex decisions regarding placement options can assist counselors in helping parents meet their personal emotional, physical, and financial obligations while living a fulfilled life (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015). In this chapter, I introduce the foundations of the study including the background, problem, and purpose of the investigation. In addition, I present the research questions and theoretical framework guiding the study. After documenting the assumptions, limitations, delimitations, and scope, I conclude by suggesting the significance of the study and offering a brief summary.

Problem Statement

Parents who care for their adult children with intellectual disabilities in their homes often experience anxiety, depression, tension, and sleep deprivation. They often experience several other stressors, which include health and financial problems, single parenting, widowhood, unfamiliarity with community resources, and worrying about the future care of their adult child (Hauser, Olson, & Drogin, 2014). Parents struggle to care for their family members in their homes to avoid placing them in residential facilities. However, situations arise where these parents cannot continue to provide care for their adult children (Bigby et al., 2015; Luijkx, Brug, & Vlaskamp, 2016). For example, adult children with intellectual disabilities who remain at home can present a danger to themselves, as well as their parents and other family members (Hauser, Olson, & Drogin, 2014).

Parents confront additional problems such as property destruction, elopement, and medical concerns when an adult child with intellectual disabilities lives with them. Luijkx et al. (2016) and Hauser et al. (2014) indicated both the parents' and their adult children's quality of life increased following placement in a group home setting, despite feelings of loss. The parents experienced high stress, shame, anxiety, and feelings of guilt after making the decision to place their adult child with an intellectual disability in a group-home setting (Bazzano et al., 2015; Cmic et al., 2017).

Parents resist seeking supportive services because they feel counselors are not aware of the problems they face with their adult child being in a group home setting (Williamson & Perkins, 2014). They might have concerns that counselors do not receive a significant amount of training to address issues with adults with intellectual disabilities, which prevents them from providing effective resources, intervention strategies, and the appropriate techniques to meet the individual with intellectual disabilities and family member’s needs (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015). Counselors face challenges when attempting to help parents because many are unfamiliar with the intellectually disabled population and the hardships this population may cause their parents (Rowbotham et al., 2011).

Because counselors are not well-informed about this topic, they are not able to effectively provide services to parents of adults with intellectual disabilities. I was unable to locate salient literature regarding how parents in this situation resolved to move in a particular direction for continued care for their children, nor was I able to locate previous studies targeted at exploring their lived experiences as they journeyed through the process.

Through this research, counselors can also become aware of the challenges parents who place their adult children in these facilities experience, and thereby develop a better understanding of how to engage and assist them. By providing contextual information directly from the parents, counselors will have additional information, which can increase their abilities to advocate for parents of adult children with intellectual disabilities.

Counselors can develop innovative strategies to overcome obstacles and access resources for parents dealing with guilt and shame about their decisions (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015). Qualitative methods like phenomenological studies illuminate the voices of parents and individuals with intellectual disabilities. Phenomenological researchers support bringing the lived experiences of parents challenged with a life changing decision affecting their adult child with intellectual disabilities to the forefront of research (Beail & Williams, 2014). The phenomenological approach plays a vital role in enlightening researchers about their lived experiences, thereby filling the gap in empirical literature (Beail & Williams, 2014).

There are still methodological issues that require future exploration to increase participation of parents and individuals with intellectual disabilities in facets of qualitative research (Beail & Williams, 2014). Novice researchers avoid engaging vulnerable populations because of the additional protections required to assure they do not inflict harm on groups such as intellectually disabled adults (Shivayogi, 2013). I intentionally focused my research on this group because of the lack of attention they receive in academic studies.

Purpose of the Study

The purpose of this phenomenological study was to examine the lived experiences of parents who choose group home placement for their adult child with intellectual disabilities. I explored the decisions of parents who do not place their adult child with intellectual disabilities in other types of placements such as sponsored residential facilities, institutions, or nursing homes. Counselors working with this population are often ill-equipped to help these parents because they do not have the proper information or resources to support them as they cope with feelings of grief, loss, and rejection (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015; Krauss et al., 2005). Research on this topic could inform not only parents but counselors, counselor educators, and supervisors about the advantages and disadvantages of placing their loved one in an alternative living situation, such as a group home. Using the outcomes of the research, I provide information allowing the counseling profession to improve upon various strategies to address symptoms faced by parents who have placed their son or daughter in a group home such as sadness, fear, worry, and uncertainty (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015).

Research Questions

To assure I gathered data in an organized method, responsive to the stated problem, I posed the following research question:

RQ1. What are the lived experiences of parents involved in the decision-making process who choose to place their adult children with intellectual disabilities in group home settings?

I also queried my participants using the following sub questions:

SQ1. What experiences led parents to decide upon placing their adult children with intellectual disabilities in group home placement?

SQ2. What experiences contributed to parents placing their children in group home placements as opposed to other residential care facilities?

Conceptual Framework

Using phenomenological approaches, I collected data related to the lived experiences of parents who choose group home placement for their adult child with intellectual disabilities. To frame this study, I utilized interpretative phenomenology as presented by Heidegger, which is also known as hermeneutic phenomenology. Hermeneutic phenomenology focuses on the subjective experience of individuals and groups (Heidegger, 1962; Kafle, 2011). Heidegger's philosophical stance was that human beings are part of the world in which they exist and are inseparable from that world (Heidegger, 1927).

I sought to explore the parents' lived experience based on key concepts including average everydayness, *Dasein*, which literally means being there, being in the world, being-with, encounters with entities, temporality, and the participants' care structures (Heidegger, 1927). Heidegger used truth to understand experiences and develop an account of the interrelated structural features of human existence underlying and giving coherence to the ways people relate to things (Wrathall, 2011).

The hermeneutic circle, a key element in my data analysis, described how interpretation emerges. When one seeks to understand an experience, there is a constant moving back and forth between the parts and the whole statement (May, 2009). In understanding the meaning and importance of individual texts, the researcher depends on the understanding of the whole body of text, which builds upon the understanding of individual words (May, 2009). I offer additional concise information in Chapter 2, demonstrating how researchers use hermeneutic phenomenology to help unveil the world as experienced by the participants through their life stories (Kafle, 2011). Kafle (2011) reported a good phenomenological description constituted the construed essence of an experience revealed to us in such a fashion, which enables us to grasp the nature and significance of this experience in an unobtrusive way. I will present a more detailed description of the use of Heidegger's hermeneutic philosophy and how I used it to frame my research questions in Chapter 2.

Nature of the Study

I used qualitative, interpretive, hermeneutic phenomenology methodology to undergird the data collection and analysis processes. Information pertaining to phenomenology came from Heidegger, a philosopher who practiced interpretive phenomenology, also known as hermeneutic phenomenology (Connelly, 2010; Converse, 2012; Flood, 2010). Heidegger believed in revealing preconceived notions and beliefs, so others could decide whether researcher bias existed within the studies produced from a phenomenological investigation (Flood, 2010). The theorist indicated it was completely impossible to remove or bracket oneself from situations and life experiences (Converse, 2012). As Moran (2000) stated, "Phenomenology is seeking after meaning, which is perhaps hidden by the entity's mode of appearing. How things appear or are covered up must be explicitly studied" (p. 516). Tuohy, Cooney, Dowling, Murphy, and Sixsmith (2013) thought of hermeneutics as the interpretation of text or language by an observer and used it as a methodology. In phenomenological inquiry, a researcher focuses on peoples' perceptions of the world or the perception of the things in their experiences, which I describe specific aspects of in Chapter 2 (Tuohy et al., 2013).

I followed a set of tasks required to collect data, analyze the data, and report on findings around the decision-making process leading up to the parents' choice of a group home placement. The findings of this type of study are a collection of descriptions of meanings for individuals of their lived experiences, and their experiences of concepts or phenomena (Constantine, 2013; Sloan & Bowie, 2014). I employed an interview data collection method, which allowed flexibility to conduct interviews using multiple methods of communication (Memnun, Aydın, Özbilen, & Erdoğan, 2017).

Parents who have adult children with intellectual disabilities living in a group home setting responded to open-ended interview questions, which aligned with and responded to my research questions. Along with recording the interviews and noting observations using field notes during the face-to-face interviews, the semistructured interview approach allowed me to ask in-depth and probing questions to gain more information from the participants. I used a transcribing service to document the recorded data. The transcribing agency agreed to maintain HIPAA compliance and protect the confidentiality of each participant by controlling the format of the records and the way they access records. To protect the identity and confidentiality of all research participants, the transcriptionist signed a confidentiality agreement, and used the unidentifiable number attached to each parent. After receipt of the transcribed interviews, I read the transcripts, coding the identified patterns and themes in each parental decision around group home placement. Using codes, I identified the common themes and patterns, based on repeated words, phrases, and sentences generated from the participant's responses in the interview. I present this process in greater detail in Chapter 2.

Definitions

Adult Child: The adult child in this study is the son or daughter of parents making the decision to choose group home placement (Archard, 2012).

Decision-making: A person-centered thought process used by parents to make decisions around group home placement for the well-being of their son or daughter (Jones & Lowe, 2008).

Group home placement: A residential facility licensed by the state for individuals with intellectual disabilities. A group home placement includes 24-hour support for people with intellectual disabilities, and the number of individuals that can occupy the group home depends on the size of the home and the dimensions of the room (Department of Behavioral Health & Developmental Services (DBHDS), 2014).

Hermeneutic phenomenology: Hermeneutic phenomenology focuses on the subjective experience of individuals and groups. It is an attempt to unveil the world as experienced by the subject through their life world stories. Researchers using this school of philosophy asserted that interpretations are all we have and description itself is an interpretative process (Kafle, 2011).

Intellectual Disability: An individual that has an IQ score below 70, as well as deficits and impairments in the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (American Psychiatric Association (APA), 2013).

Parent: The parent in this study refers to the biological mother or father in the household that made the decision to choose group home placement for their adult child with an intellectual disability. These parent genes have contributed to the existence of the adult child with an intellectual disability (Archard, 2012).

Residential Care Facilities. Residential care facilities can be permanent or temporary housing for adults with intellectual disabilities, not limited to the following: group homes, sponsored residential homes, nursing homes, state training centers, and intermediate care facilities (DBHDS, 2014).

Assumptions

I assumed the parents in my study would continue to care for their adult children until they could no longer function, either physically or emotionally. The family dynamics of marriage, divorce, separation, widowhood, remarriage, and death may complicate the decision-making process related to group home placement (Vogan, 2015; Vogan et al., 2014). I also assumed the family structure, such as the number of parents and siblings in the home, age, family differences, and the connection between family members might obscure the decision-making process related to group-home placement. Lastly, the family's socioeconomic status could influence the decision-making process related to group-home placement (Cantwell, Muldoon, & Gallagher, 2015). The research questions reflect the intention to highlight their lived experiences to undergird an understanding of the complexities involved in determining the best outcome for everyone involved.

Scope and Delimitations

The scope of this study included the experiences of biological parents who decided to place their adult children between the ages of 18 to 60 in a group home setting. I did not include adult children potentially requiring alternative housing based on mental illness or physical disabilities. I inquired about the nature of the adult child's disability but only used the information to establish whether they met the study criteria. A region on the northeast coastline of the Atlantic Ocean was the target area. I selected the area because of its proximity to where I live and the need to minimize the cost of traveling long distances.

I exclusively interviewed parents who have an adult child diagnosed with an intellectual disability. My target population included those living outside of the geographical boundaries in my recruitment efforts. By restricting my populations to only including the biological, not adoptive, mothers or fathers directly involved in the decision-making process, I was able to narrow the study to 10 strong participants. The extended family members could have contrary opinions but do not always have the authority to make placement decisions because they are not an active participant in their family member's daily living. I also excluded parents who had their adult child removed from their home against their will by a legal authority because I considered their situation to be a traumatic event. People who experienced traumas fall under the category of vulnerable populations. Finally, I did not include parents who have an intellectual disability or mental health diagnosis. Also considered a vulnerable population, they might have been unable to withstand the interviewing process.

Limitations

There are inherent limitations to the outcomes of this study. The small sample size and restricted geographical boundaries may limit the generalizability and transferability of the outcomes to other populations (Houghton, Casey, Shaw, & Murphy, 2013; Pearson, Parkin, & Coomber, 2011; Suri, 2011). The narrow focus of intellectually disabled adult children, as opposed to including other categories of incapacitating conditions, also limits the use of the outcomes of my research. The results apply to parents of an adult child with intellectual disabilities and are therefore not necessarily generalizable or transferable to other populations such as adults with physical disabilities or mental illnesses (Houghton et al., 2013; Pearson et al., 2011; Suri, 2011). The outcomes of the study are dependable and credible, based on my use of member checking and reflective journaling. I limited the geographic region of participants volunteering for inclusion (Suri, 2011). A broader search area would elevate the reliability and transferability of the study.

Significance

Understanding the lived experiences of parents who have made the decision of group home placement for their adult child with intellectual disabilities can assist parents who may be struggling with this difficult choice. Parents making decisions concerning the living arrangements of their adult child need to be aware of the difficulties they may face caring for their adult child in the home, which include verbal and physical aggression, elopement, psychotic episodes, and self-injurious behaviors. In addition, there may be a need to provide extensive medical care (Jackson & Roper, 2014; Williamson & Perkins, 2014).

I used my findings to postulate a need for acknowledgment and awareness of the experiences faced by each parent before and after their final decision to choose group home placement. Using the outcomes of my study can enhance the existing literature regarding the experiences of parents choosing group home placement for their adult child, and increase the awareness in the counseling profession, which will help guide parents in coping with stress, anxiety, anger, fear, worry, and feelings of loss (Bazzano et al., 2015; Cmic et al., 2017; Wark, Hussain, & Edwards, 2014).

By illuminating this population's insights, I contribute to social change by providing beneficial research for counselors to guide their practices when working with struggling parents. This includes parents enduring emotional and physical stressors, caregiver burden, role, and relationship strain, along with navigating the difficulties and benefits of group-home placements. There are groups such as the National Association of Mentally Ill (NAMI) who represent parents and caretakers of mentally ill adult children who can also benefit from knowing the experiences parents face when considering alternatives for their adult children, even if the population has varying demands (Mercado et al., 2016).

Summary

Multiple factors contribute to the parental decision-making process regarding residential care for adult children with an intellectual disability (Bigby et al., 2015). The determination to reside in a group home is often the personal choice of the individual with an intellectual disability if he or she can make an informed decision. However, many parents are the legal guardians and authorized representatives for their sons or daughters, which makes them responsible for making residential decisions (DBHDS, 2014). Parents who lack this legal status still have a substantial influence on placement decisions (DBHDS, 2014). Many people are not aware of the daily adjustments and sacrifices parents make for their adult child (Bigby et al., 2011). Researchers addressed the needs and wants of the individual with an intellectual disability, without always acknowledging the remarkable role the parents play as part of their support system (Bigby et al., 2011).

Chapter 2: Literature Review

In preparing to conduct my study exploring the lived experiences of parents who made a choice to place their adult child with ID in a group home setting, I performed a search of salient literature on related topics. The literature I reviewed included historical and relevant peer-reviewed articles focused on the decision-making process parents undergo when considering what options offer their adult child the most appropriate care setting. The choices ranged from keeping them in their homes to placement in a confined facility. Other possibilities included placement in group homes and self-care residential facilities.

The purpose of conducting this literature review was to describe some of the key factors influencing parents' decision to choose group-home placement rather than other community or residential options. Along with providing information on decision-making factors leading to making a choice, I present information regarding out-of-home placement kinship options.

There is a scarcity of studies conducted on the individual's choice for community or out-of-home placement. I was unable to find research targeting the parents' decision-making processes and overall satisfaction with the placement of their adult child with an ID. My intention was to examine the biological parent's decision-making processes around group-home placement for their adult child with an ID using qualitative phenomenological methodology. In this chapter, I present the findings of my literature review. Beginning with the framework I used, I reviewed literature focused on the main topics enfolded the in decision-making process parents of intellectually disabled adult children. I then offer insight into hermeneutic phenomenology and conclude with a summary of the chapter.

Literature Search Strategy

I acquired the literature for this study using the Walden University library's databases. The Walden Library has several research databases that I used, which included PsycArticles, PsycINFO, SocINDEX, Eric, Academic Search, Sage Online, CINAHL, MEDLINE, along with Google Scholar. In addition, I obtained information from the Department of Behavioral Health and Developmental Services (DBHDS) and the American Association on Intellectual and Developmental Disabilities (AIDD) online websites. I reviewed over 150 peer-reviewed journal articles, using the keywords: *parents, family, caregiver, decision-making, group homes, developmental disabilities, intellectual disabilities, mental retardation, parental satisfaction, parental dissatisfaction, community placement, residential placement, son, daughter,* and *adult child*.

The primary criteria for my literature search was each peer reviewed article be published within the last 5 years or substantiated as the most recent. I focused on literature related to parents placing their adult child in a group home, those targeting parental concerns regarding adult children with ID remaining in the home with their parents, addressing parental satisfaction and dissatisfaction with group-home placement, and reporting on the various types of residential placements for adults with ID. The exclusion criteria for the review included; a) articles or studies addressing children with intellectual and developmental disabilities, b) studies focusing on other family member's caregiving for adults with intellectual disabilities, and c) articles discussing group home care for adults diagnosed with disabilities other than intellectual (Boedicker, 2013; Deveau & McGill, 2016; Ghosh, Greenberg, & Seltzer, 2012). I ensured that all articles focused on filling the gap in literature related to my study and no redundant or prior work existed in the publications I searched. For example, I searched older literature to see if there was research that applied but fell outside of the recent timeframe. I also searched in related fields to see if others had similar results. I often had to alternate between the terms mental retardation, disabilities, and intellectual disabilities to find more literature. The changing in terms obfuscated what could have been a fluent process (Griffith, Totsika, & Hastings, 2015). I also had to search for research on children to find the appropriate age group to apply to my study, as I only wanted information on adult children.

Conceptual Framework

Hermeneutic Phenomenology

I employed a hermeneutic phenomenological approach as the qualitative research methodology to explore the parents' lived experiences of placing their adult children in group-home placements. Researchers use qualitative research to gain a better understanding of how individuals and groups attribute societal problems (Chan, Fung, & Chien, 2013). Qualitative researchers collect data in the participants' setting where they analyze, interpret, and examine their information to provide rich textured descriptions of lived experiences (Converse, 2012; Marshall & Rossman, 2014; Peredaryenko & Krauss, 2013). A qualitative phenomenological researcher collects data by completing in-depth, open-ended interviews (Brinkmann, 2014; Converse, 2012; Peredaryenko & Krauss, 2013).

Phenomenology focuses on people's perceptions of the world and what those perceptions mean to them (Converse, 2012; Peredaryenko & Krauss, 2013;). The methodology originated from Husserl's (1859-1838) work. Husserl's student, Heidegger

(1889-1976), created a hermeneutic or interpretative approach of phenomenology (Converse, 2012; Peredaryenko & Krauss, 2013).

Hermeneutic phenomenologists examine how people make sense of their major life experiences, and their research focuses on understanding the lived experiences of participants through engagement and learning the meaning participants place on patterns and relationships (Tuohy et al., 2013; Valandra, 2012). The purpose of hermeneutic phenomenology is to describe and interpret the experiences of others. Hermeneutic phenomenologists describe the lived experiences of others and how social, cultural, and political exposures influence their worldviews (Flood, 2010; Tuohy et al., 2013; Valandra, 2012).

Heidegger's philosophical stance was based on his belief that human beings are part of the world in which they exist and are inseparable from that world (Heidegger, 1927). The philosopher's understanding of experience was based on key concepts including lived experiences, everyday ordinariness, *Dasein,* being in the world, encounters with entities, temporality, and the participants' care structure (Heidegger, 1927). Heidegger used truth to understand experiences and develop an account of the interrelated structural features of human existence that underlie and give coherence to the ways people relate to things (Wrathall, 2011). The scholar defined the term unconcealment as the uncovering of entities unless they had a stable position within social practices (Wrathall, 2011). Emotions, attitudes, and abilities can uncover entities when individuals or participants respond and disclose their experiences to the world (Wrathall, 2011). Heidegger indicated that language is not a totality of words and concepts, but it is the gathering of entities, activities, and relationships into a world that makes speech possible (Wrathall, 2011). The main goal was to expose the meaning of everyday ordinary human existence through experiences (Heidegger, 1927). Hermeneutic phenomenologists place emphasis on exploring the stories people tell of their experiences and reflecting deeply on what their transcripts reveal (Heidegger, 1962). The research method entails locating participants and then using data collection techniques and explication strategies, along with validating truthfulness (Converse, 2012; Groenwald, 2004).

Hermeneutic phenomenology focuses on the experiences of individuals and groups (Kafle, 2013; Sloan & Bowe, 2014). The process exposes the experiences of individuals and groups through their shared stories. Hermeneutic phenomenologists believe the meaning of the words people use, describes their lived experiences and the descriptions emerge from a interpretative process (Kafle, 2013; Sloan & Bowe, 2014). Using hermeneutic phenomenology allows the researcher to adapt to the phenomenon of interest while admitting to and understanding their own presumptions and prejudices (Kafle, 2013; Sloan & Bowe, 2014). Investigators use hermeneutic phenomenology to encourage the researcher to focus on what the text is saying (Kafle, 2013; Sloan & Bowe, 2014). The hermeneutic researcher explores and goes into a deep conversation with the text, which invites the reader to enter the world that the words disclose (Kafle, 2013; Sloan & Bowe, 2014).

Dasein

Heidegger used the term *Dasein*, which literally means “being there,” being in the world, or embedded in a world of meaning (Heidegger, 2014; Sturgess, 2016; Stroh, 2015; Tuohy et al., 2013; Valandra, 2012). Dasein is a state of being and is significant in the hermeneutic circle because it indicates a person cannot separate oneself from the world nor can the researcher, which makes bracketing impossible. (Heidegger, 2014; Stroh, 2015; Sturgess, 2016).

Researchers use the term *forestructure* to identify what is known or understood prior to interpretation and based on past experiences (Standing, 2009; Tuohy et al., 2013). It is imperative for researchers to recognize their former understandings, so readers of their research are aware of information, which may have an influence on the study (Tuohy et al., 2013; Valandra, 2012). Husserl used the term bracketing to encourage researchers to set aside their thoughts, beliefs, and influences to describe a particular phenomenon. However, bracketing does not align with hermeneutic phenomenology, which encourages researchers to bring their conscious and unconscious thoughts to the forefront, acknowledging them as influences or biases (Converse, 2012; Tuohy et al., 2013; Valandra, 2012;).

Hermeneutic Circle

The hermeneutic circle is a process by which scientific understanding can occur through the correction of prejudices or pre-understandings as analysis of the text occurs (Boell & Cecez-Kecmanovic, 2014; Stenner, Mitchell, & Palmer, 2016;). Researchers use the hermeneutic circle to discuss how to acknowledge prejudgments or assumptions by hearing the words used in the text (Boell & Cecez-Kecmanovic, 2014; Stenner et al., 2016). Through this circular process, prejudgments and pre-understandings transform into new understandings (Boell & Cecez-Kecmanovic, 2014; Stenner et al., 2016). Interpretation and understanding move along the globular process with a continuous re-examination of propositions taking place, complete the hermeneutic circle (Boell & Cecez-Kecmanovic, 2014; Tuohy et al., 2013).

This revision of understanding works best when there is back-and-forth questioning of the central topic that eventually causes the circle to expand, leading to innovative ideas (Stenner et al., 2016; Tuohy et al., 2013). I used the hermeneutic circle to understand the lived experiences of 10 parent participants who decided to place their sons or daughters in group-home settings. To accomplish this, I made my prejudices and assumptions known and pondered whether the data I collected altered my initial patterns of thinking. Using the hermeneutic circle, I can demonstrate how I contemplated the meaning of the words on varying levels and the intersectionality of the stages.

Heidegger's (1962) hermeneutical circle connects the interpreter's inner world to the unique meaning of each text to create a new picture or understanding based on the consciousness of the interpreter (Dunca, 2016). In analyzing text using the hermeneutical circle, four stages occur. The first stage begins the process with first choosing and reading the text. The second stage is laying out the social, historical, and cultural contexts leading to closing the hermeneutic circle by understanding the relationship between the text in stage one and the context in stage two. The third stage consists of a movement between the parts and the whole, allowing understanding of the meaning and totality of the surrounding text. In the fourth stage, the researcher forms a conceptual bridge to critical understanding, which provides a rich explanation of the text and context within a theoretical framework (Rytterstrom, Arman, & Unosson, 2013).

In using the hermeneutic circle, I made my biases or preunderstandings explicit by putting them in front of the participants and myself, and during the analysis of the data. I understood my biases might change, and previous meanings may become new meanings. Remaining open, I let the data convince me of the possible inaccuracy of my biases. Although I have worked with the parents of individuals with intellectual disabilities for many years, I continued to reflect on my biases and was open to learning additional information from the data I collected.

In using a hermeneutic phenomenology to examine the parents' decision-making processes to place their sons or daughters in group-home settings, I was better able to orientate to the lived experience of others and question the way others experience the world and have an in-depth data collection process that is rigorous (Lewis, 2015; Sloan & Bowe, 2014). The process required me to spend a significant amount of time categorizing information (Lewis, 2015; Sloan & Bowe, 2014).

Heidegger (2002) pursued the relationship between hermeneutics and the question of human understanding in arguing self-understanding and world understanding are undividable (Heidegger, 2002). Heidegger's main goal was to expose the meaning of everyday ordinary human existence through experiences (Heidegger, 1927). The researcher's understanding of experience is based on key concepts including lived experiences, everyday ordinariness, Dasein, being in the world, being with, encounters with entities, temporality, and the participants' care structure (Heidegger, 1927). Heidegger used truth to understand experiences and develop an account of the interrelated structural features of human existence underling and giving coherence to the ways people relate to things

(Wrathall, 2011). Researchers define phenomena as the lived experiences of parent who made choice to place their intellectual disabled adult child into a group home setting, which is the least restrictive environment given their disabilities.

Heidegger (1927) indicated every form of human awareness is interpretive, and used expressive works to interpret truth, language, thinking, dwelling, and being. The basic tenet of hermeneutic phenomenology is that our most fundamental and basic experience of the world is already full of meaning (Jared, de Oliveira, & Payne, 2016; Tuohy et al., 2013). The methodology allows us to understand our world, lived experiences, and meanings through other people, history, culture, and events (Tuohy et al., 2013; Van Manen, 2014). Researchers must first acknowledge there are pre-understandings prior to interpreting the meanings of the data collected (Spence, 2016). They should have the ability to recognize some of their prejudices may have a negative impact on the study; however, these same prejudices could leave a positive impression to the meaning of the hermeneutic phenomenon (Spence, 2016).

Hermeneutic phenomenology uses methods of the hermeneutic circle to capture shared experiences (Rennie, 2012). Hermeneutic phenomenology encourages researchers to create interpretative understandings around their chosen phenomena (Rennie, 2012). It differs from Husserl’s transcendental phenomenology because researchers use interpretive methods (Valandra, 2012).

Transcendental and hermeneutic phenomenology each require the researcher to have an open attitude, which allows unexpected meanings to emerge from the collected data (Giorgi, 2011). In transcendental phenomenology, Husserl used the term “bracketing” to describe a person setting aside his or her own beliefs about the phenomena or what he or she already perceives to be true or false (Husserl, 1929/1960). Heidegger did not believe in the concept of bracketing. He instead stated researchers could not ignore biases because they are always in the world with others and in the circumstances of existence (Heidegger, 1927/1962). Therefore, researchers should put their biases in front of them and use an interpretative perspective called the hermeneutic circle (Chan et al., 2013).

In the hermeneutic circle, researchers explain how the meaning of a whole text informs the meaning of its parts, and the meanings of the parts enlighten the meaning of the whole (Rennie, 2012). In research analysis, the understanding of the meaning and importance of individual texts depends on the understanding of the whole body of relevant literature, which in turn grows through the understanding of individual texts (Boell & Cecez-Kecmanovic, 2010; Rennie, 2012). There is a constant movement back and forth between the parts and the whole in the process of understanding (besay, Nåden, & Slettebo, 2008; Boell & Cecez-Kecmanovic, 2010; Rennie, 2012).

Using hermeneutic phenomenology revises the researcher's preconceptions about the study, which then allows the researcher to develop new conceptualizations of meaning based on the data collected (Gadamer, 1975/2004). When using the hermeneutic circle, I move in a cyclical direction from understanding the subject to my personal and professional comprehensions of the way they describe the phenomena (Heidegger, 1971/2005). I chose Heideggerian hermeneutic phenomenology because it supports understand the meaning people place behind the words they use to describe an experience in their lives. Using this approach provided a deeper conceptualization process for comprehending parents of individuals with intellectual disabilities lived experiences of the specific phenomena regarding group-home placement decisions. The use of this phenomenology as a conceptual framework required engrossing myself into the data to discern the language, concepts, and emerging themes. Throughout the study I placed emphasis on the lived experiences of parents making decisions concerning whether to place their with adult children with intellectual disabilities into a group-home.

Literature Review Related to Key Variables and/or Concepts

I reviewed and evaluated relevant literature based upon the most substantial content in the parents' decision-making process. The outcomes deemed the following factors significant in terms of the parents' decision-making process: (a) parental caretaking role; (b) caregiver burden; (c) role and relationship strain; (d) available community placements; and (e) barrier and benefits of group home placement. The abovementioned factors supported the research questions and aligned with the intent of the study. The themes in the literature review supported using a phenomenological approach to ensure readers gained an insightful awareness of the research participants' lived experiences.

To explore parent's lived experiences regarding their decision to place their intellectually disabled adult child in a group home setting, I began by reviewing the literature relevant to the history of disability services, to ground myself in knowledge of the origin of the problem. Afterwards, I moved forward to frame the influence of various laws, such as the Americans with Disabilities Act (ADA). After presenting the multiple roles parent caretakers play in the lives of their disabled adult children, I reviewed literature related the burden and strain of carrying out the daily responsibilities required to maintain their adult child in their home. I examined the alternatives to group home placement and finish the literature view by looking at the advantages and disadvantages of selecting group homes as opposed to the other available options. After compiling this data, I organized and scripted the information to contribute to my review of salient literature. I then explored literature related to hermeneutic phenomenology, prior to summarizing the review. The following documentation presents a concise articulation of the information I gathered and condensed.

History of Disability Services

Beginning in the 1850s and throughout the Industrial Revolution, institutions provided ongoing care for adults with ID (Walker, Rinck, Horn, & McVeigh, 2007). These facilities referred to as asylums included mental hospitals or settings with over ten residents receiving residential support from medical staff (Lucena & Bezerra, 2012; Rippon, 2013; Walker et al., 2007). This type of treatment discouraged parents from placing their adult children in institutions because of the stigma society attached to having a disability. Concerns regarding long term care facilities or asylums increased the need to advocate for deinstitutionalization of individuals with ID (Hudson, 2016; Lucena & Bezerra, 2012; Walker et al., 2007). An influx of professionals specializing in providing services to adults with ID emerged following World War II (Walker et al., 2007). Labeled as people with medical problems, they suffered from illnesses that doctors could cure using a medical model of care in an institutional setting (Feigelman & Alvarez, 2006; Walker et al., 2007).

The medical model of care focused on treating the deficits of individuals with ID (Grue, 2011; Yankauer, 1961). During the 1850’s, society considered individuals with ID as dangerous and disgraceful (World Health Organization, 2011). Based on the medical model, individuals with ID received treatment based on their deficits, societal views, and the biological cause of their disability (Hudson, 2016; McKenzie, 2013). Administrators managed institutions using a systems approach that neglected the choices, needs, and wants of the individual (Buntinx & Schalock, 2010; Lucena, & Bezerra, 2012). The systems approach placed emphasis on service delivery as opposed to the individual in need of services (McKenzie, 2013).

The goal of institutions was to diminish the intellectual impairment and increase adaptive and compensatory skills for adults with ID (Jackson, 2011). The important goal of institutions was to ensure individuals with ID would be able to function at least to a minimal standard in the community (Brown & Radford, 2015; Jackson, 2011). The number of individuals diagnosed with an intellectual disability residing in institutions began to drop in the late 1960's due to the implementation of new policies related to deinstitutionalization (Brown & Radford, 2015; Chowdhury & Benson, 2011; Turnpenny, 2012). The number of individuals living in institutions in the United States has drastically declined over the course of 30 years from 207,356 individuals in institutions in 1977 to 62,496 individuals in 2007 (Alba, Prouty, Scott, & Lakin 2008). Similarly, the numbers of individuals with intellectual disabilities living in group-home settings have increased from 40,000 individuals in 1977 to 437,707 in 2007 (Alba et al., 2008). Nota, Ferrari, Soresi, and Wehmeyer (2007) outlined the significance of community-based living for individuals with intellectual disabilities including, a) enhanced community integration and community living, b) the ability to have autonomy, self- determination, a purpose, and more control over living environment and c) an improved quality of life.

Disability Rights

Disability activists and their allies spent years struggling to gain rights for individuals with disabilities (Concannon, 2012; Foley, 2013). Individuals with ID lacked opportunities related to employment, state and local government activities, public transportation, public accommodations, telecommunications, housing, voting, institutions, educational, and rehabilitative, and mental health services (Americans with Disabilities Act (ADA), 2009; Groves, 2015). Similarly, individuals with intellectual disabilities experienced some of the same forms of discrimination and segregation as African-Americans and women (Concannon, 2012; Meyer, 2014). President Kennedy established the Civil Rights Act of 1964 on June 11, 1963 (National Archives, 2014). The Civil Rights Act of 1964 eliminated inadequate voting requirements and segregation in schools, public facilities, government agencies, and the workplace for African Americans, women, and individuals with disabilities (Hill & Goldstein, 2015; National Archives, 2014). The act required all people receive equal treatment regardless of their individual disability.

After numerous years of effort, President G. H. Bush signed ADA on July 26, 1990 (Concannon, 2012; Meyer, 2014). It took 17 years to get the ADA into law after the passing of the Rehabilitation Act of 1973 (Concannon, 2012; Leuchovius & Parker, 2014). The Rehabilitation Act of 1973 prohibited discrimination against individuals on the basis of their intellectual, developmental, and physical disabilities receiving federal funds (Concannon, 2012; Gostin, 2015). Section 504 of the Rehabilitation Act of 1973 undergirded the Civil

Rights Act of 1964, which forbids discrimination based on race, color, sex, religion, and national origin (Concannon, 2012; Riley, 2011).

The ADA was significant because it declared any exclusion, segregation, and mistreatment of individuals with ID acts of discrimination opposed to a consequence associated with the symptoms of their disability (Concannon, 2012; Kelly & Su, 2015). The ADA is relevant to this study because it identified factors influencing the parent's decision-making process. The ones who placed their adult child in a group-home setting were unaware of their son or daughter's rights in the following areas, voting, working, traveling, education, public transportation, social services, and healthcare (ADA, 2009; Baroff & Olley, 2014). Parents placed their adult child in group-home settings to enhance their overall quality of life. However, any acts of exclusion, segregation, or mistreatment could affect the parent's decision-making process (ADA, 2009; Kanter, 2015).

The Olmstead Law, established as part of the ADA Title II, occurred after the institutionalization of two women for several years and denial of the opportunity to live in the community (MacIntyre, 2015; Olmstead, 2014). On June 22, 1999, the Supreme Court found violations of female's disability rights under the Title II of the ADA, which required state and public organizations to ensure individuals with intellectual disabilities the ability to reside in the most caring integrated setting (Hatch, Crane, & Martinis, 2016; Olmstead, 2014). The Supreme Court found the individuals experienced discrimination and unwarranted segregation from the Georgia Regional Hospital (Olmstead, 2014).

The Olmstead Law is pertinent to this study because it outlines the significance of community-based residential services for adults with ID (Perlin, 2000). The courts assured adults with disabilities had the right to receive community-based services, if appropriate. Ccommunity service providers could receive additional incentives, as well as resources to ensure successful placement (Olmstead, 2014). According to the Supreme Court, institutional placement of persons who could handle and benefit from community settings perpetrated unwarranted assumptions that persons so isolated were incapable of or unworthy of participating in community life (Olmstead, 2014). Confinement in an institution severely diminished the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment (Olmstead, 2014; Thompson & Morris, 2016). The Olmstead law might impact a parent's decision regarding group-home placement as their adult child with an intellectual disability needed additional advocacy to ensure appropriate access to integrated community-based residential living and employment opportunities for people with disabilities (Hatch et al., 2016). On the other hand, this law protected the adult child with an intellectual disability and allowed them to make their own decisions pertaining to where they want to live or work. This Olmstead Law protected individuals with intellectual disabilities from parents who sought guardianship to make life decisions for their adult child who could benefit from less restrictive alternatives (Jameson et al., 2016; Rosenbaum, 2016). The Olmstead Law required individuals with intellectual disabilities received several options on where they want to live and work and required the individuals to choose a home and job which met their needs and wants (Hatch et al., 2016; Rosenbaum, 2016).

Intellectually Disabled Adult Children

The DSM-IV-TR defined an adult child with mental retardation as an individual with general intellectual functioning, meaning their IQ was 70 or below (APA, 2000). Individuals with mental retardation have significant limitations in adaptive functioning in at least two of the following areas: “communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety” (p.41). The onset of the adult child mental retardation diagnosis must occur prior to age 18 years (APA, 2000). Mental retardation has four degrees of severity, which identifies the adult child level of intellectual impairment including: Mild (IQ 50-55 to 70), Moderate (IQ 35-40 to 50-55), Severe (IQ 20-25 to 35-40), and Profound (IQ less than 20-25) (APA, 2000; Morrison, 1995).

The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) changed the term *mental retardation,* to *intellectual disability* or *intellectual developmental disorder* (APA, 2014; Regier, Kuhl, & Kupfer, 2013). The term mental retardation replaced demeaning terms like idiocy, mental sub normality, and feeblemindedness. Researchers eliminated the term mental retardation for the same reason (Harris, 2013; Reigier et al., 2013). The DSM-5 diagnostic criteria for intellectual disability (ID) included a change to the definition of adaptive impairment (APA, 2014; Papazoglou, 2014). The criteria in the DSM-5 only requires impairment in one adaptive domain rather than two or more skill areas (Papazoglou, 2014). The DSM-5 is similar to the DSM-IV-TR because individuals with intellectual disabilities must still meet the age of onset criteria, and have a deficit in intellectual and adaptive functioning (APA, 2014; Papazoglou, 2014). The categories mirror those in the prior version, mild (IQ 50-55 to 70), moderate (IQ 35-40 to 50-55), severe (IQ 20-25 to 35-40), and profound (IQ less than 20-25) (APA, 2014).

Medicaid Funding for Adults with ID

Congress authorized home and community-based waiver programs 1981 to prevent institutionalization of individuals with ID and other at-risk populations (Gettings, 2012). The advocacy for deinstitutionalization highlighted the need for more home and community-based programs (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). The ID waiver supported each state's decision to relinquish the historical requirement for individuals with ID to live in institutional settings to obtain Medicaid funding (DBHDS, 2014; Williamson & Perkins, 2014). The ID waiver enabled Medicaid funding to be available for certain community alternatives to institutional care that included placements such as group homes (DBHDS, 2014). Medicaid regulations provided individuals with ID the option to choose between waiver services or living in an institutional setting (Friedman, Lulinski, & Rizzolo, 2015; Rizzolo et al., 2013). For example, in the state of Virginia, the Intellectual Disabilities Waiver (ID Waiver) the Department of Behavioral Health and Developmental Services (DBHDS), Office of Developmental Services (ODS), and the Department of Medical Assistance Services (DMAS) manages the services of adults with intellectual disabilities (DBHDS, 2014). In 1990, Virginia applied for the first ID waiver to ensure individuals with ID received home and community-based residential services. At least 130 individuals with ID received waiver services in 1991, and DBHDS added services in 1994. Presently, the ID waiver covers the following services, assistive technology, companion services, crisis stabilization services, day support services, environmental modifications, personal assistance services, personal emergency response systems, prevocational services, residential support services, respite services, services facilitation, skilled nursing services, supported employment, therapeutic consultation, and transition services (DBHDS, 2014).

In order for individuals to qualify for waiver services, they had to meet the following eligibility requirements of diagnostic, functional, and financial eligibility (DBHDS, 2014). Adults with ID must have a psychological evaluation indicating a formal diagnosis of their disability (DBHDS, 2014). A licensed individual must complete a psychological evaluation, which includes the individual's level of functioning (DBHDS, 2014). Individuals with ID also take the level of functioning survey and meet at least two or more of the following categories: health status, communication, task learning skills, personal/self-care, mobility, behavior, and community living skills (DBHDS, 2014). The individuals must also qualify for Medicaid through the local Department of Social Services. Upon receiving eligibility status, they are added to the statewide waiting list. The waiting list includes the names of individuals who meet the urgent and non-urgent criteria for an ID Waiver slot. Those on the urgent criteria lists are more likely to get a waiver slot because they present as a significant risk and require services within the following 30 days. Examples of criteria for the urgent waiting list include primary caregiver(s) that are over the age of 55 and can no longer financially afford to care for the individual or have a chronic physical or psychiatric condition preventing them from caring for their loved one. The standards also provided for individuals whose behavior and physical needs pose a significant risk to the health and safety of the primary caregiver(s) (DBHDS, 2014). If they met the eligibility criteria for ID waiver, requiring services within 30 days, but do not meet the formerly mentioned urgent categories, the result was placement on the non-urgent waiting list (DBHDS, 2014). When a slot becomes available, the individuals with ID receive support with selecting their new providers, coordinators, or case managers. Their support professionals begin to develop a person-centered individual support plan (PC ISP) (DBHDS, 2014). The process to obtain an ID waiver slot can take a very long time. The adult child with an intellectual disability on the ID waiver waiting list may not receive a waiver slot to live in a group-home placement for several years (Peterson et al., 2014). The long wait for a waiver slot deters many parents from seeking this resource for their adult child, and thereby prevent group-home placement for individuals with ID who require this level of care.

Implications for the Counseling Field

Parents who choose to place their adult child with intellectual disabilities in a group home often have a difficult time accessing counseling services because they feel counselors are not familiar with the problems they face thereby limiting their ability to help them (Williamson & Perkins, 2014). Since many counselors do not receive a significant amount of training to address issues with adults with intellectual disabilities, they cannot provide effective resources, intervention strategies, and the appropriate techniques to meet the needs of parents struggling with placement decisions and accessing counseling services (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015). They are often unfamiliar with the intellectually disabled population and the hardships this population may cause parents (Rowbotham et al., 2011). Therefore, the counselors face significant challenges when attempting to help parents cope with the difficult decision of group-home placement

(Rowbotham et al., 2011). Along with other parents in similar situations, counseling professions would benefit from understanding the lived experiences of parents that have made the decision of group-home placement by learning strategies to appropriately address the emotional stressors and symptoms they face around receiving counseling (Crettenden et al., 2014; Jackson & Roper, 2014). It is critical for counseling professionals to obtain information about community resources and referral options for parents and their adult child with disabilities to assist in reducing parent’s negative feelings and emotions including grief, loss, and uncertainty about counseling (Healey,2015; Kripke, 2015).

Counselors often lack the knowledge of how to connect parents and adult children with intellectual disabilities to resources, make referrals to agencies, and use appropriate strategies for parents who tend to experience higher levels of stress (Gibbons et al., 2016; Grossman & Webb, 2016; Healey, 2015; Heller et al., 2015). This study can help guide counselors to identify referrals and resources based on the knowledge of the lived experiences of participants in this study. The participants obtained various resources and referral sources from the group-home setting, and information previously mentioned in earlier chapters. Counselor awareness and continued education around the lived experiences of parents with adult children with intellectual disabilities supports their ability to intercede with other parents struggling with accessing counseling services, social stigma, guilt, isolation, and feelings of inadequacy concerning their decision to place their ID adult child in group home facilities (Healey, 2015: Kripke, 2015).Helping professionals, including counselors can confirm or develop their insight into why parents continue to struggle with this difficult decision. They could consider the influence of culture and collective family beliefs regarding seeking outsiders assistance with caretaking for their adult child. (Healey, 2015: Kripke, 2015). Groups from collective orientated communities tend to insist on maintaining disabled family members and reject placing them with who they would consider strangers. (Healey, 2015: Kripke, 2015).

Parental Caretaking Role

Several researchers identified that caring for an adult child with disabilities has a significant impact on parents and their quality of life (Lauderdale-Littin & Blacher, 2016). The parental caretaking role is very intense, and to ensure parents have an increase in their overall quality of life, it is imperative that the adult child has less challenging behaviors, lower support needs, and the parents have a higher level of commitment to their spiritual lives (Williamson & Perkins, 2014). Long et al. (2015) conducted a study, which examined the associations among socioeconomic, cultural, and child factors with maternal distress among families of children with intellectual disabilities. They determined mothers of children with ID had higher levels of child behavior problems and adult child behavior problems (Long et al., 2015). Single-parent marital status, higher family support, and cultural factors contributed to elevated distress among mothers of children with ID (Bazzano et al., 2015; Lauderdale-Littin & Blacher, 2016). Similarly, stress among parents and other primary caregivers of children with developmental disabilities is pervasive and linked to lower quality of life, unhealthy family functioning, and negative psychological consequences (Bazzano et al., 2015; Lauderdale-Littin & Blacher, 2016). Researchers suggested community-based mindfulness stress reduction programs could be effective interventions in reducing stress and improving psychological well-being for parents and caregivers of children with intellectual disabilities (Bazzano et al., 2015; Cmic et al., 2017). Similar interventions could support counselors by developing new stress reduction strategies to reduce stressors associated with supporting parents of adult children with ID's quality of life, family functioning, and psychological concerns (Bazzano et al., 2015; Cmic et al., 2017). Adult children with ID demand intense parent caregiving accommodations from birth onwards (Wilder & Granlund, 2015). Professionals deem parental care-taking role successful when the adult child and parents have a daily routine, paternal involvement, couple connectedness, and emotional support (Wilder & Granlund, 2015). The parent care-taking role involves the adult child being in good health, which requires freedom from pain, diseases, and maladaptive symptoms. The parent caregiver also ensures their adult child adheres to current treatment and discontinues unnecessary interventions. Positive caretaking includes encouraging an adult child with an intellectual disability to participate in physical self-care, mental or spiritual self-care; and perform leisure and recreational activities they may want to do (Gibbons et al.,2016). While Bazzano et al. (2015), Long et al. (2015) and Cmic et al. (2017) stated of the various stressors parents experience when being a caretaker for their adult child with ID, previous researchers did not explore how these factors contributed to their decision to place their son or daughter in a group home setting. As I add to the body of literature regarding adults with ID's caretakers, using the outcomes of this study can also support how we inform parents who are currently or will in the future face these trials based on how other parents experienced their decision-making process. Understanding how people in similar situations overcame their obstacles might help other caregivers decrease their levels of stress.

Caregiver Burden

Parents of adults with an intellectual disability experience several stressors and worries associated with caring for their adult child with an intellectual disability in their home (Lauderdale-Littin & Blacher, 2016). The burden of caring for an adult child with an intellectual disability can lead to depression, anxiety, stress, and sleep deprivation after caring for an adult child in the home for an extended period of time (Bhatia et al., 2015).Adult children with intellectual disabilities have physical conditions associated with aging that include hearing and vision decline, incontinence, bone degeneration, tooth loss, physical strength decline, sense of taste and smell decline, and accompanied chronic illnesses, which all lead to caregiver burden (Lin et al., 2014). Parents in caregiving roles are often burdened by mental conditions associated with aging such as memory loss, language ability deterioration, poor sleep quality, and the onset of depression and sadness (Lauderdale-Littin & Blacher, 2016; Lin et al., 2014).

The adult child's level of intellectual disability severity, behaviors, medical concerns, and age determine the burden parents performing caregiving services may face (Vogan et al., 2014). Also, they associated the parent's inability to pay for services for their adult child with caregiving burden (Vogan et al., 2014). Parents worried their adult child was unable to handle financial and legal matters independently. Parents who did not have the financial means to support their adult child experienced more stress than parents who were financially secure (McMaughan, 2015; Ouyang et al., 2014; Vogan et al., 2014). Environmental characteristics such as socioeconomic status, age, lack of social support, and self-esteem also contributed to parental stress (Cantwell et al., 2015). Mothers who had more social support and marital satisfaction experienced less parental stress (Kwok, Leung, & Wong, 2014). Stressors faced by parents include health and financial problems, single parenting, widowhood, unfamiliarity with community resources, and worrying about the future care of their adult child (McMaughan, 2015; Vogan et al., 2014). Parents often spend more time supporting their adult child with their activities of daily living due to their lack of independence (Prakash et al., 2016). Mobility limitations impacted the parents' decision to choose out-of-home placement for their adult child (McMaughan, 2015; Prakash et al., 2016). The term mobility limitations refer to the immobility status of individuals with intellectual disabilities who are incapable of completing certain mobility-related activities (Geere et al., 2013; Prakash et al., 2016). Individuals with intellectual disabilities and mobility limitations require assistive technology devices such as scooters, wheelchairs, canes, or crutches (Geere et al., 2013; Prakash et al., 2016). The homes for many of the parents were not wheelchair accessible, and it was too costly to make the appropriate repairs to the home. The cost of the assistive technology devices and home improvement repairs deterred parents from allowing their son or daughter to remain in the home (Geere et al., 2013). Some of the factors associated with individuals with intellectual disabilities and mobility limitations include down syndrome, cerebral palsy, seizure disorder, visual impairment, impaired expressive communication, and behavioral problems (Difazio et al., 2015). Parents may have to make the decision to place their adult child in high support settings like nursing homes, institutions, or a group home due to their mobility status (Geere et al., 2013; Prakash et al., 2016). Parents continue to experience burden and have difficulties coping with their adult child's physical and personal care needs (Prakash et al., 2016). Personal care becomes difficult for older parents as their son or daughter grew in size. Caregivers witness ongoing pain and discomfort of their adult child in the home and spend countless hours negotiating the care and treatment of their adult child while still attempting to maintain their own activities of daily living. While Lin et al. (2014), McMaughan (2015) and Prakash et al. (2016) expressed the multiple stressors parents experience when attempting to care for their adult child with ID, none of the previous researchers investigated how these factors contributed to their decision to place them in group home care. As I add the body of literature regarding adults with ID's caretakers, using the outcomes of this study can also assist me in informing parents who are currently or will in the future face these challenges, how other parents experienced their decision-making process. Understanding how people in similar situations faired, might normalize the stress, sorrow or fear they anticipate enduring.

Role and Relationship Strain

Caregiver role and relationship strain relate to the challenges and difficulties parents confront when providing support for the disabled individuals (Rowbotham et al., 2011; Sullins, 2016). The parents can face strain related to the caregiver's emotional and physical health and demands exceeding their available resources or capabilities (Griffith & Hastings, 2014; Rowbotham et al., 2011; Sullins, 2016). Parents of adult children with intellectual disabilities expressed the love they have for their children and acknowledged the chronic strain the demands of caregiving placed upon them (Crettenden, Wright, & Beilby, 2014; Griffith & Hastings, 2014). The life-long commitment of caring for an adult child has constrained some parents to their homes (Rowbotham et al., 2011: Woodman, 2014). Many parents experience role strain and feel burdened because one parent spends more time caring for the son or daughter with an intellectual disability than the other parent (Rowbotham et al., 2011). Many parents reported the following role and relationship strains when caring for their adult child: marital stress, psychological well-being, social life, work, tension with other children without disabilities, and relationship stress between the parent and their adult child with an intellectual disability (McConnel & Savage, 2015; Rowbotham et al., 2011). Parents who experience family-to-work conflict were more likely to have a decrease in their quality of life and increases in depression, but only when they did not receive support from their supervisor (Li, Shaffer, & Bagger, 2015). Role and relationship strain correlated with father's involvement, marital connection, and emotional support (Rowbotham et al., 2011; Wilder & Granlund, 2015). Shared roles by the mother and father in the household appeared to relieve parental stress and decrease the dysfunctional behavior between the adult child and parental burden (Wilder & Granlund, 2015). Behavioral problems were more likely to occur from the adult child when the father was less involved in the household labor and more involved with the labor division outside of the home (McConnell & Savage, 2015; Wilder & Granlund, 2015). Mothers experience less relationship and role strain when the father participates in taking care of the adult child with intellectual disabilities and household work (McConnell & Savage, 2015; Wilder & Granlund, 2015; Woodman, 2014). The parents in one study conveyed the desire to have their adult child remain living in the home opposed to receiving care from a stranger (Crettenden et al., 2014). In the study, parents discussed their resistance to out-of-home placement despite challenging situations and their inability to cope with their son or daughter with an intellectual disability (Crettenden et al., 2014). The life-long commitment of caring for an adult child has constrained parents to their homes (Rowbotham et al., 2011; Woodman, 2014). Many parents experience role strain and feel burdened because one parent spends more time caring for the son or daughter with an intellectual disability than the other parent (McConnell & Savage, 2015; Wilder & Granlund, 2015; Woodman, 2014).

Parents conveyed feeling defenseless to coping with their adult child behaviors in the home (Benninger & Witwer, 2017). The parents in the study discussed the damaging effect their adult child's behavior had on the other children in the home and as well as the entire extended family (Benninger & Witwer, 2017; Coyle et al., 2014). Other children in the home were not able to have friends and family over due to their sibling's behavior, and parents experienced isolation from their social supports (Benninger & Witwer, 2017; Coyle et al., 2014). As parent and their adult children age together, the role of primary caregiver transitions from the parent to a sibling, as aging parents die or become unable to provide continued care for their son or daughter (Coyle et al., 2014) There continues to be a need to develop long-term services and supports as well as educational resources that accommodate parent and sibling caregivers as they age together with the adult child with intellectual disabilities (Coyle et al., 2014). While Rowbotham et al. (2011), Crettenden (2014) and Coyle (2014) reported the strain parents experience when attempting to care for their adult child with ID, none of the previous researchers investigated how these factors contributed to their decision to place them in a group home environment. As I add the body of literature regarding adults with ID's parents, using the outcomes of this study can also assist counselors in informing parents who face obstacles related to role and relationship strain.

Putting these obstacles in the forefront may help other parents experience some form of relief in their decision-making process around group-home placement.

Available Community Placements

Parents who make the decision to make of out of home placement for their adult child with an intellectual disability are often unaware of the various community placement options (Grey et al., 2015). The literature below describes different types of residential placements available in the community and why parents may choose group-home placement instead of the alternative options. Many parents are unable to provide the most appropriate care and quality of life for their adult child; therefore, they may seek several options for placement prior to making their final decision (Grey et al., 2015). The studies below provide information about a variety of community placements that parents may choose from to place their son or daughter.

The population of adult children with intellectual disabilities suffers from co-occurring mental health conditions such as psychiatric and genetic disorders, behavior problems, physical disabilities, and seizure disorders (Turygin, Matson, & Adams, 2014). Many of these individuals reside in residential treatment facilities due to their severe conditions, where they may obtain specialized treatment and management of their challenging behavior, which parents cannot handle in the home (Turygin et al., 2014). Individuals with intellectual disabilities had an increase in their quality of life when they moved from their parent’s home and institutions. (McConkey et al., 2016) For example, adult children with intellectual disabilities who moved into their own rented accommodation with person-centered support were more likely to have fewer support needs than those in group homes (McConkey et al., 2016). Rental accommodations and supportive living allowed the adult child with disabilities to have greater control and choice in their lives, more community engagement and increased personal relationships (Hewitt et al., 2016; McConkey et al., 2016) The researchers indicated individuals who lived independently had greater household participation; however, individuals in staffed housing had greater household participation and community integration than those adult children living in their parents' home (Hewitt et al., 2016). The researchers concluded adult children living in their parents' home have limited activity opportunities compared to other staffed community placements. They concluded parents chose alternative community placements to enhance their son or daughter's quality of life in the following areas: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, independence, self-determination, and social inclusion (Grey et al., 2015; Hewitt et al., 2016).

Additional community placement options for adult children with intellectual disabilities include group homes, family model homes, independent homes, or apartments, and in the family home (Koenig, 2015). The residential supports displayed in the available community placements had a significant impact on the parent's decision for out-of-home placement for their adult child. Group homes and family model homes did not support the domains of choice and control due to the amount of support given by support staff, parents, and family members (Garcia et al., 2016). The decision around residential or community placement depended on the parents' perceptions of what was most important to their adult child (Garcia et al., 2016; Grey et al., 2015; Hewitt et al., 2016). Parents preferred their son or daughter to live in group homes and family model homes because they met their needs in information and planning; access to and delivery of supports; community connections; satisfaction; and overall perception of outcomes because they deemed them more important than their choice and control (Hewitt et al., 2016; Koenig, 2015).

Lunsky et al. (2017) conducted a study of parents who had become lifetime, compound caregivers. The compound caregivers are parents who take on multiple caregiving roles, which may include caring for a son or daughter with an intellectual disability and caring for an additional family member (Lunsky et al., 2017). Over 37% of the parent caregivers reported caring for their mother, father, or spouse, along with caring for an adult child with an intellectual disability (Lunsky et al., 2017; Perkins & Haley, 2010). Other researchers reported caregivers spent an average of 39 hours a week caring for their adult child, 12 hours caring for the other family member, and this process had been ongoing for at least three years (Perkins & Haley, 2010). The compound caregiving role caused several problems with the participants in terms of their mental health and life satisfaction (Lunsky et al., 2017; Piazza et al., 2014). Data revealed the compound caregivers had an increased desire to place their son or daughter in residential care or an institutional setting compared to the non-compound parents or caregivers (Piazza et al., 2014). Compound caregivers reported the need for more personal time, self-care, and support from other family members, and accessibility of community resources (Piazza et al., 2014). In conclusion, the compound caregiving role led parents to make future plans to place their son or daughter in alternative residential care like group homes or institutions. Grey et al. (2015), Garcia et al. (2016) and Hewitt et al. (2016) conveyed the various forms of community placements available to adults with intellectual disabilities, they did not investigate how these placements significantly influenced the parent's decision to place them in group home care. Expanding the body of literature regarding community placement for adults with intellectual disabilities can support informing parents who require resources pertaining to community placement for their son or daughter with intellectual disabilities.

Barriers and Benefits of Group Home Placement

Bigby et al. (2014) described a group home as a staffed home, which usually houses four to six adults with intellectual disabilities. The facility operates 24-hours a day with support and supervision provided by paid staff. The employed personnel at group homes ensure normalization and enhance the quality of life for individuals who may have lived with their parents, family members, or in an institutional setting (Bigby et al., 2014). The parents identified the following positive aspects of their adult child living in a group-home setting: learning new skills, being more independent, structured life with better program-based activities, better social life, and age-appropriate lifestyle (Bigby et al., 2014; Luijkx, Brug, & Vlaskamp, 2013). The parent's perceived benefits of group home placement included having more freedom, less stress, ability to work, and peace of mind about the future (Bigby et al., 2014; Luijkx et al., 2013). Group-homes encouraged parents to be involved with their adult child. Staff encouraged the adult child to stay involved with parents and extended family members and enabled parents to feel comfortable and involved in the household. For example, parents reported calling the group-home to make important notifications, and the staff calling the parents when the adult child wanted to discuss their day (Baumbusch et al., 2015). Staff encouraged parents to visit the residence and participate in significant events like birthdays and holidays (Baumbusch et al., 2015; Bigby & Beadle-Brown, 2016). Adult children reported the following positive outcomes of group-home placement: increased levels of respect for themselves and others, improvement in independent living skills, and reductions in challenging behaviors (Crettenden et al., 2014). Parents approved of group-home placement because they experienced a reduction in their stress levels and caregiving load, as well as improved mental health and well-being for them and their other children (Crettenden et al., 2014; Luijkx et al., 2016). Parents appeared to be more satisfied with group-home placement when they could maintain involvement with the residential setting by trusting the residential staff to care for their adult child (Crettenden et al., 2014; Luijkx et al., 2016). Also, parents had to accept the reality that they are unable to care for their adult child and be open to accepting help from others. Parents can maintain healthy involvement by having balance in their lives, experiencing and coming to terms with healing from shame, and maintaining healthy involvement with their adult child in a group home setting by maintaining a reasonable number of scheduled visits at the group home, facilitating support from other professionals, and expressing appreciation for the care of their offspring (Baumbusch et al., 2015; Luijkx et al., 2016). Also, parents who are active participants in support groups, educational meetings, and community gathers were more likely to maintain healthy involvement with their adult child in the group home (Baumbusch et al., 2015; Luijkx et al., 2016). Lastly, parents maintain healthy involvement by supporting, listening, and learning from professionals who help their adult son or daughter with their activities of daily living (Baumbusch et al., 2015).

Many parents believed placing their adult child in a group-home setting induced their emotional stress and created the following symptoms: guilt, sadness, fear and worry, anger and frustration, and uncertainty (Crettenden et al., 2014; Jackson & Roper, 2014). Some of the negative outcomes parents experience around group-home placement were grief, loss and rejection, and continuous behavioral problems (Crettenden et al., 2014; Jackson & Roper, 2014). This research will influence the counseling field by bringing attention to the shared experiences and emotional stressors of parents who have made the difficult decision to place their adult child in a group-home setting (Harwick, Lindstrom, & Unruh, 2017). Counselors can gain more insight regarding the stressors parents face by placing their son or daughter in a group home. The lived experiences shared by these parents will effectively help counselors address negative outcomes around group-home placement, and increase their awareness of available community resources and appropriate referral options (Harwick et al., 2017). The undesirable aspects of living in a group-home placement included problems with the program staff such as: improperly trained, concerns about the quality of care and staff turnover, and lack of communication with staff (Laws, Kolomer, & Gallagher, 2014). Some of the negative concerns for the son or daughter with an intellectual disability and autism include safety concerns, personal appearance concerns, less integration withfamily, and feelings of loneliness (Laws et al., 2014). Lastly, the parent’s concerns with out-of-home placement included missing their adult child, feelings of worry and guilt, limitation on seeing son or daughter, loss of control and inability to know details, concerns about adult child health status, and ongoing caregiving and missing caring for their son or daughter (Crettenden et al., 2014; Jackson & Roper, 2014).

Adult children that live ingroup homes tend to experience the following problems requiring admission into the hospital, staff inattention to basic needs such as toileting and nutrition, poor communication between staff and patient, over sedation, medication errors, patient fear and anxiety, insufficient pain management, and poor discharge preparation (Tuffrey-Wijne et al., 2016). Most of the studies examining hospital experiences of people with intellectual disabilities reported ongoing involvement from the parent, and sometimes the parent is present 24 hours a day during the hospital stay (Iacono & Bigby, 2016). Parents have reported their presence at the hospital as necessary to ensure their son or daughter receives adequate care and safety, to minimize fear and anxiety, and to ensure a safe return to the group-home setting (Iacono & Bigby, 2016; Tuffrey-Wijneet al., 2016). The study indicated that younger persons with intellectual disabilities are more likely to have parents able to provide ongoing care during the hospital visit than older adults with intellectual disabilities (Iacono & Bigby, 2016). The results of this study indicated that parents remain satisfied with their adult child group-home placement when they can partner with the group-home staff at medical appointments, emergency room visits, and when their son or daughter requires hospitalization (Tuffrey-Wijneet al., 2016).

Many parents develop tunnel vision and are unable to meet their needs because they are excessively thinking about the needs of their son or daughter in a group-home placement (Hwang & Kearney, 2014). Over-involved parents tend to still think of their adult child as a child, and feel the need to be involved in every decision involving their child especially their group-home placement (Hwang & Kearney, 2014). Many parents make decisions based on their own needs; however, healthy parents appreciate mental health professionals, encourage their adult child to take risk, understand their son or daughters functional age and of the adult child's goals, along with acknowledging group-home providers make mistakes (Crettenden et al., 2014: Hwang & Kearney, 2014). The emotional over-involved parent does not trust their adult child's residential provider, have not dealt with their own grief regarding out-of-home placement, and tend to experience feelings of fear, anger, and frustration (Hwang & Kearney, 2014; Jackson & Roper, 2014). The emotionally healthy parent has their own balanced life, healthy relationships, and base their decisions pertaining to their son or daughter placement on facts rather than emotions (Asselt-Goverts, Embregts, & Hendriks, 2015; Duggan & Linehan, 2013). Lastly, the over- involved parent has poor relationships and communication skills, make demands without looking at the big picture and are very inconsistent in the continuity of care for their adult child (Duggan & Linehan, 2013; Hwang & Kearney, 2014). The healthy relational parent has the ability to form a strong relationship with their son or daughter group-home providers, demonstrate flexibility, and believe that good working alliances with the staff of their son or daughter's group-home are essential to a solid residential placement (Asselt-Goverts et al., 2015; Duggan & Linehan, 2013). Parents without a support system had a difficult time adapting to their son or daughter placement; however, parents with other children, extended family, and friends were able to get through the barriers of group-home placement a lot easier (Baumbusch et al., 2015; Piazza et al., 2014). The primary coping mechanisms parents use to decrease emotional stress around group-home includes the following: reassurance regarding the necessity of placement, involvement in their adult child's life, counseling, and the passage of time (Baumbusch et al., 2015; Jackson & Roper, 2014; Luijkx et al., 2016).

Bigby et al. (2014), Baumbusch et al. 2015 and Luijkx et al. (2016) expressed the barriers and benefits of adults with intellectual disabilities living in a group-home setting. They did not, however, investigated how these factors contributed to the parent's decision to place their son or daughter in a group home setting. The body of literature regarding the pros and cons of group-home placement can help parents make informed decisions around group-home placement for their adult child. Identifying what works in group-home settings can help parents be more selective in terms of what type of group-home they would want their son or daughter to reside.

Summary and Conclusions

Despite the rise in the number of group-home placements in the United States, limited research exists concerning parents' decision-making process as to where to place their adult child with an intellectual disability (Bigby et al., 2014). A majority of the studies conducted associated with the parent's decision-making process took place over ten years ago (Beail &Williams, 2014). This is partially the reason for the age of references outlined in the literature review. Researchers identified that parents are an essential component in their sons and daughters support system (Luijkx et al., 2013). Luijkx et al. (2013) indicated parents tend to have a major influence on their adult child's choice of community placement. As reflected in this chapter, the parents' decision to place their son or daughter in a group-home setting is very taxing, and this challenging process deserves more attention and recognition from counselors in the community.

Overall, the literature outlined in this chapter consistently identified the hardships faced by parents that led to needing to make a decision regarding group-home placement for their adult child. In fact, research has backed the level of parental satisfaction with group-home placement before and after placement of their son or daughter in the group-home. In conclusion, understanding parents' decision-making process is necessary to develop support for other overwhelmed parents coping with a similar decision. Additional information can increase the communities' support for more parental involvement in the decision-making process around group-home placement. Hearing the voices of the parents can lead to increasing the effectiveness of services, developing innovative services, and supports, to enhance the overall quality of life for adults with intellectual disability living in the community.

In Chapter 3, I provide an in-depth overview of the methodology I used to conduct the study. I include the design, participants, and procedures used for data collection and analysis. In describing the recruitment of participants, I also address ethical procedures to protect their confidentiality and verify the findings.

Chapter 3: Research Methods

In the previous chapters, I provided an overview of factors influencing the lived experiences of parents who have made the decision to place their adult child with intellectual disabilities in a group home facility. The issues associated with this decision include age, medical, behaviors, mental illness, and supporting the enhancement of the adult child's quality of life along with their quality of care (Woodman,Mailick, Anderson, & Esbensen, 2014). The decision-making around group-home placement can be a challenging and time-consuming process. Many parents attempt several different options prior to choosing out-of-home placement such as in-home supports, skilled nursing services, respite care, counseling, crisis intervention, and behavioral therapy (Jackson & Roper, 2014; Williamson & Perkins, 2014). Nevertheless, they make their decisions for group home placement after countless efforts to keep their adult child in the home.

In this chapter, I address the methodology I used to discover and explain each parent's lived experience around their decision of group-home placement for their adult child. In addition, I provide a description of the participants, data collection, and analysis, along with verification of the findings of this study. I conclude the chapter by documenting the ethical procedures used to assure the protection of the participants, followed by a summary.

The purpose of this qualitative, phenomenological study was to gather data describing each parent participant's lived experience around their decision to place their adult child with an intellectual disability in a group-home placement. My intent was to explore the lived experiences that influenced parents' choice of group-home placement as an option compared to other types of placements such as sponsored residential facilities, institutions, or nursing homes for individuals with intellectual disabilities. I reviewed group home placement from a parental perspective, as opposed to prior studies that focused on the disabled individual's choice. To identify common patterns and themes associated with their choice to place their adult child in a group-home setting, I collected and analyzed data reflecting the parents' lived experiences.

Research Design and Rationale

I designed the study to illuminate significant aspects of the phenomenon related to collecting the lived experiences of parents of adult children with intellectual disabilities. The intent of this research was to validate the lived experiences of phenomena by exploring how individuals experienced the phenomenon under investigation. Essential to preventing indirect methods of exploration, I focused on uncovering the descriptions of these lived experiences (Giorgi, 1985). Two tasks were significant in this phenomenological research design: (a) specifying results in a problem area where research is essential and (b) providing concreteness and specificity around the phenomenological methodology (Buchwald, Delmar, & Schantz-Laursen, 2012).

I considered using other qualitative strategies such as grounded theory research, ethnography, narrative research, and case study, but they would not have been as effective as phenomenology in describing the lived experiences of parents who decided to place their adult child in a group-home. Using grounded theory guides the researcher to focus on the development of a process or theory (Lawrence & Tar, 2013). This type of study assists a researcher with understanding the decision-making process of parents considering placement from a theoretical perspective. However, a researcher would need more participants and would also have to spend a significant amount of time with the parents to develop an effective decision-making theory or process (Lawrence & Tar, 2013).

Ethnography is a qualitative research tool used to study the interactions, behaviors, and perceptions of various groups of people (Constantine, 2013). The primary focus of ethnography is to offer thick descriptions and insights on the cultural aspects of a group's views and actions (Constantine, 2013). Ethnography could assist the researcher with documenting the culture and practices of parents of adult children with intellectual disabilities in group home settings. However, the goal of this study was to understand the parents lived experience of placing their adult child with an intellectual disability in a group-home (Constantine, 2013). Ethnography also requires the researcher to spend a significant amount of time collecting detailed observations and interviews (Constantine, 2013).

When using narrative research, the researcher studies the lives of their participants who provide detailed stories about their histories (Lewis, 2015; Garner & Scott, 2013). Narrative researchers document the parents' individual stories to create a collaborative narrative with their views and the experiences of the participants (Lewis, 2015; Garner & Scott, 2013). The goal of this study was to understand the parents' experiences regarding their decision around group-home placement without considering the personal stories of each parent's life.

Researchers use case studies to explore a common experience of one or more individuals (Hott, Limberg, Ohrt, & Schmit, 2015). Researchers employing a case study approach use various data collection procedures to complete a comprehensive study (Hott et al., 2015). I could have conducted a case study on one or two parents who made the decision to place their son or daughter in a group home; however, the goal of the study was to describe the shared experiences of the participants based on the common themes and patterns among several parents who encountered the stressful decision around group-home placement.

Role of the Researcher

In 2007, I accepted my first job out of college as direct support staff in a group home working with individuals with intellectual disabilities. Later, I served in several other positions that involved working with individuals with intellectual disabilities in various settings like case management, day support, sponsored residential services, and crisis intervention. I encountered several parents who were very involved with their adult child's daily needs but also witnessed some individuals who never had any parental support.

During my time working with this population, I often wondered how parents experienced choosing a group-home placement and why the parent would place their son or daughter in a group home if they are fully capable of caring for their adult child. After working with parents of individuals with intellectual disabilities for over 6 years, I discovered there were several factors associated with the decision to choose group-home placement. For example, some parents had their son or daughter at a late age and were no longer able to care for their family member because of their own medical needs. Some parents were not able to meet the medical needs of other family members in the home. I worked with parents who were physically capable of caring for their adult child, but could not handle the aggression and abusive behavior displayed by their son or daughter. For example, parents expressed fear of Adult Protective Services (APS) investigating them for abuse if they had to defend themselves physically.

Others could not provide care for their family member with an intellectual disability because the individual had severe mental health symptoms requiring around the clock support. Alternatively, parents chose group home placement for several positive reasons such as enhancing their adult child's overall quality of life, including increased financial resources, better living conditions, community integration, and the ability for their son or daughter to become a productive citizen in society.

I explored this topic to educate parents who are experiencing the same difficult decision and those having a difficult time coping with their decision. There is a need to educate community service providers who are unaware of the factors associated with parents not being able to care for their adult child with an intellectual disability, which leads to the ultimate decision of group-home placement. As a participant-observer, I was fully aware of my personal and professional experiences and acknowledge any preconceptions related to the parent's decision making around group-home placement. A power imbalance existed between the participants and myself, as they viewed me as the professional. However, the effect was minimal as they remained in control of their decisions to participate and ability to withdraw at any time with no recrimination (Harrison, 2013).

In hermeneutic reflection, I focused on the data and put my biases and pre-understandings in the forefront. The goal of hermeneutic phenomenology is to replace my current notions with more appropriate ones through reflection (Gadamer, 1975/2004).

Interpretation does not include the process of “bracketing” (Husserl, 1929/1960) because interpretation is a process used to revise personal biases, which invites opportunities for thought revision. Thought revision is the process of revising a pre-conception, which leads to a new projection of meaning (Gadamer, 1975/2004). My preconceptions were that parents made the decision for group-home placement because of their own medical needs or their adult child’s medical needs that they could not satisfy in the home. The new projection of meaning was that parents have other significant experiences that could lead to group-home placement such as aggression and abusive behavior displayed by their son or daughter or severe mental health symptoms requiring around the clock support.

I had to acknowledge a possible bias due to my experience working with parents and adults with intellectual disabilities in this geographic location for numerous years. I did not in any way attempt to deny the bias, but rather disclose it as a means of supporting the stories shared by each of the ten participants. I openly disclosed this bias because it requires consideration when reviewing this study. Interpretive researchers, including Gadamer and Heidegger, theorized that disclosing biases and researcher information related to the study supports the reader’s ability to decide the affect their experiences and beliefs skewed the analysis and thereby outcomes of the study (Converse, 2012; Tuohy et al., 2013).

Methodology

Participant Selection Logic

Research participants for the study were biological parents of individuals diagnosed with an intellectual disability. The focus of this study only included biological parents, and the participant’s adult child had to be currently living in a group home setting and between the ages of 18 to 60. I utilized a sample size of 10 participants. Stenfert et al. (2016) conducted a phenomenological study using 10 participants. Thackeray and Eatough (2016) conducted a phenomenological study with five father participants, and each father discussed the challenges and lived experiences of caring for their adult children with intellectual disabilities. Sullivan et al. (2016) conducted a phenomenological study using 10 participants to explore how people with intellectual disabilities perceive and experience close relationships.

Marshall (2013) stated that there is no set sample size in qualitative research; however, data saturation is a clear indicator the researcher has an adequate sample size. Achieving data saturation occurs when the researcher reaches a point when no new information emerges from the interviews with the participants (Marshall, 2013).

I found participants from a local agency. After leaving flyers in the agency and working with the program directors, I identified parent participants interested in sharing their lived experiences. The participants in this study agreed to volunteer in the interview process and provided detailed information about their decision-making process. I used purposive sampling when recruiting the participants. Purposive sampling allowed me to learn a great deal of information specific to the parents' decision-making process (Noordzij, Dekker, Zoccali, & Jager, 2011). I did not select the participants from a random group but chose them based on meeting the study criteria, their ability to complete the interview process and adhere to the rules and regulations outlined in the consent form (Noordzij et al., 2011). Hearing and documenting the participants' decision-making process enabled me to describe their lived experiences when contemplating and deciding to place their adult child with an intellectual disability in a group-home setting.

Instrumentation

The data collection instrument that I used was an interview protocol. I produced the interview protocol to answer the overarching research questions. Given the semistructured nature of the planned interviews, I felt I would be able to use one set of questions for every interview and then ask probing questions to individuals based on their responses, to elicit more information. I did not conduct a pilot to test the questions prior to the interview, but my committee and Walden University's Institutional Review Board (IRB) reviewed and approved my intended inquiry (#07-31-15-0247171).

I conducted all in-depth interviews face-to-face and used them to build rapport, collect demographic information, and to identify the decision-making around group-home placement. The parent participants answered questions related to their decision-making, which included personal demographic information. During our meetings, they offered their step-by-step process and factors leading to the decision to choose group-home placement, which I detail later in Chapter 4.

I designed all the interview questions to sufficiently answer all my research questions. In adding two sub questions, I sought to gain more finite information about the group-home decision-making process. I developed interview questions to focus primarily on the parent's experiences but inquiring about smaller portions by using incremental inquires. All questions centered on eliciting responses concerning the parent's experiences and steps they made toward the final decision to pursue group-home placement. I also formulated the interview questions to determine the affect placement had on the parents and adult child with intellectual disabilities, making sure I collected enough data to answer all research questions and subquestions. Although I did not conduct a pilot study, I used the semistructured nature of the interview to probe for additional information as indicated by their answer or body language Matsumoto & Hwang, 2014).

To establish content validity, I reviewed my interview tapes and transcripts three times (Başerer, Başerer, & Tüfekçi akcan, 2016). I compared the transcripts to the research question to establish whether I had collected material responsive to the intent of the investigation. Content validity reflects whether the data collected aligns with solving the stated problem (Başerer et al., 2016). I also used member checking by forwarding the participant's transcripts for their final review and approval (Houghton, Casey, Shaw, & Murphy, 2013). The participants all indicated satisfaction with the transcribed interviews, and they did not identify any discrepancies. Had mistakes or inconsistencies occurred, they would detract from the validating the content of the outcomes.

Procedures for Recruitment, Participation, and Data Collection

Prior to distributing fliers and recruiting participants for the data collection process, I obtained approval from Walden University's IRB. After the IRB had granted approval, I contacted the chief executive officer or executive directors of the group homes and agencies in the targeted area and provided detailed information about the intended study. I requested the assistance of the highest-ranking administrator to recruit biological parents as participants for this study. Upon obtaining agreement, I requested they execute a letter of cooperation from the chief executive officer or executive director stating that he or she would cooperate in the study (see Appendix D).

I recruited participants through local group homes licensed by the State's Department of Behavioral Health and Developmental Services. The parents resided in the target locations; however, there was no requirement for them to live in the same city as their adult child. To recruit participants, I placed flyers at group homes and agencies providing services to individuals with intellectual disabilities (see Appendix A). I sent letters to potential participants who answered the fliers and expressed interest in participating in the study (see Appendix C). The letter and informed consent form explained the purpose of the study, along with reassurance of confidentiality. The participants who agreed to volunteer read and signed the informed consent form, which included an agreement to terminate the interview and audio taping consent. To demonstrate my appreciation for their time and information, I offered the participants a $10.00 gift card to Wawa. Walden's IRB granted prior permission for me to offer the gift card.

Using semistructured, in-depth, face-to-face interviews, I collected data from participants consistent with phenomenological methods by asking open-ended questions, which led to the determination of essential themes in the parents' decision-making around group-home placement (Birkbeck, 2015; Pietkiewicz & Smith, 2014). I provided the participants with the option of conducting the interview in a comfortable, private location of their choice, such as a private office in a public library. In the event the researcher or participants expressed any issues with safety or privacy, I planned to reschedule at a more appropriate setting in the community; however, this never became necessary.

After ensuring all participants received a copy of the consent forms and interview questions prior to beginning the interview, I confirmed they still wanted to volunteer information. I also encouraged the participants to ask me any questions they had about the data collection process. As suggested by Rubin and Rubin (2005), to build rapport during the first part of the interview process I asked simple questions, including the parents' demographic and background information relevant to the study (see Appendix F). A semistructured interview approach allows the researcher to ask in-depth and probing questions to ascertain the participant's information. I developed the interview questions to capture the full decision-making process around group-home placement (see Appendix F). After inquiring about demographic information, I began to ask more personal question directly related to the parents' decision-making process. The interview questions related to the overarching research question. I posed follow-up questions relating to data they shared while recording their responses. All participants granted permission to tape record the interviews. I protected the identity and confidentiality of all research participants while tape-recording the interviews by making sure I closed the room door to avoid interruptions or anyone seeing or overhearing the conversation.

I conducted one interview with each of the ten participants. The length of the interviews averaged between 30 minutes to one hour. Some of the interviews were shorter because the parent was very vague when they responded to questions. When this occurred, I had to probe for more information to ensure addressing the research questions and sub questions. I did not use a follow-up plan for recruitment because I had enough participants to achieve data saturation. Data saturation assures I collect all pertinent information

(Hennink, Kaiser, & Marconi, 2017). When repetition of the richly textured responses from participants occurs, researchers determine they have achieved saturation, ending the need for further interviews (Hennink et al., 2017). When I realized I achieved saturation, I was also cognizant of checking and assuring myself I fully understood the possible responses to the research questions (Hennink et al., 2017). I also informed the participants their involvement in this study was strictly voluntary and they could withdraw at any time. If they initially decided to participate, they were still free to withdraw at any time later without any explanation for their decision to withdraw. Prior to exiting the interview, I observed each participant to determine their risk for distress when recalling their decision to place their adult child in a group-home setting. During the debriefing process, I identified free counselors, counseling hotline numbers, and community counseling agencies that were willing to provide free counseling to parent participants who became upset because of thinking about the decisions they made. I kept audiotapes, files, transcripts, research records, and all other confidential information related to the participant's identity under lock and key. Other than myself, the assigned transcriptionist had access to the records. I made the participants aware Walden's IRB or my committee members could request access to raw data. Additionally, I informed the participants that I would breach confidentially in the event they made a disclosure regarding anyone being a harm to self or others and reveal acts of child or elder abuse. Interviews were audio recorded for purposes of providing accurate data. I will destroy the recordings in five years, consistent with IRB requirements. Upon concluding the interviews and following the procedures outlined above, I sent the tapes to the transcription service, which was HIPPA compliant.

Data Analysis Plan

By using the methodology to conduct in-depth interviews, audio-recording, verbatim transcribing, and a detailed qualitative analysis, I categorized the most common responses from the interviews and hand coded the data while keeping the overarching research question, concerning the parents' experiences during the decision-making process around group-home placement, at the fore of my thinking (Birkbeck, 2015; Pietkiewicz & Smith, 2014).

The initial steps I took in the data analysis process included reading the ten transcribed interviews to ensure they coincided with the recorded interviews. I then generated codes based on words, phrases, sentences, and paragraphs captured in the participant's interviews. The research questions and codes/themes that appeared frequently directed me to the final codes for each interview. I then synthesized codes from the participant interviews into categories and subcategories to condense the codes related to the parents' decision-making process. The procedure generated a General Description of the parents' decision around group-home placement for their adult child with intellectual disabilities.

Data Analysis Steps

1. Read the ten transcripts to ensure it was verbatim to the recorded interviews.
2. Generated Preliminary Meaning Units (based on words, phrases, sentences, captured in the participant's interviews)
3. Generate Secondary Meaning Units.
4. Generate Final Meaning Units for each interview questions.

5. Synthesized situated narratives into general narratives integrating all major themes of participants.
6. Generate descriptions of the parents' decision around group-home placement for their adult child with intellectual disabilities.

Data Analysis Illustrated Steps

The first step in this phenomenological methodological study was reading each of the ten transcripts verbatim to gain a better understanding and full description of each parent's lived experience around group-home placement. After reading all ten transcripts, I broke down the initial codes, which focused on the each of the parents lived experience (Giorgi, 1985). Researchers use codes to identify or describe significant characteristics around the parents lived experiences or a particular phenomenon. The initial review generated 59 codes. Some examples of the initial codes included: *lack of community integration, lacked family support, refused medication, overeating, parent-substance abuse, school problems, seizures, self-injurious behaviors, and sexual behaviors.*

In my second step, I reviewed my codes again several times until similar words began to emerge. I started to see how certain words had the same or similar meaning. For example, I placed physical aggression and property destruction together. The secondary categorization reduced the number of codes to 22 codes/themes. Some examples of the secondary categories included: *mental health anxiety disorder, lacked family support, property destruction, medication, individual independence, anger, agitation, and community supports.*

The third step consisted of creating final themes, which emerged after a final analysis of the codes and categories. I coded data from words, phrases, sentences, and paragraphs captured in the participant's interview transcripts (Learning Domain, 2014). I used open coding to label words and phrases found in the participants' transcripts and axial coding to create themes and categories by grouping the codes together (Learning Domain, 2014). I used open and axial coding to assess the connection between the data and the overarching research question. To code the data, I identified repetitive patterns of action and consistencies in the parents' decision-making (Converse, 2012). I characterized patterns leading to codes by the following similarities, frequencies, sequences, and causations (Converse, 2012). I took some time away from the codes to reflect on the most popular of them, and why they appeared the most throughout the interviews. This step produced nine themes, which included: *best option, physical aggression, death/absence of spouse, caregiver medical conditions, mental health-behavioral disorder, hospital/emergency, community integration, verbal aggression, and financial burden.*

Within this step of creating nine themes, I developed categories and subcategories to condense the codes related to the parents' decision-making process they shared during the interviews (Converse, 2012). I separated themes associated with parent's decision-making into the following subcategories, age, mental health, medical, behaviors, and supporting their son or daughter's enhancement of life. I separated alternative options attempted prior to choosing group-home placement into the following subcategories, in-home supports, skilled nursing, respite care, counseling, crisis intervention, and behavioral therapy. I then recoded and re-categorized the subcategories from data collected, after completing a deeper reflection on the patterns and codes representing the meanings of the parent's lived experiences (Converse, 2012). I identified themes from the categories and subcategories by reviewing the codes from each of the parent's interviews. The codes mentioned several times in each of the parent's interviews I labeled as categories and then subcategories as I recoded the data. These themes emerged from the subcategories based on recurring patterns in each of the parent's statements regarding the decision-making process around group-home placement. Below is one example of a theme:

Best Option

According to the participants, group homes have a 1:1 ratio and other facilities have a 3:1 ratio, so they are not able to provide appropriate supervision, which indicated the care is not as good as being in a group-home. Group homes increase individuals with intellectual disabilities community awareness due to the significant amount of time spent in the community. Also, they are effective in enhancing individuals with intellectual disabilities socialization and relationship building skills because they spend a significant amount of time with peers. The staff also encourages them to build natural supports with individuals without disabilities along with those who take care of them without compensation.

Participant B stated that when he was eighteen, he wanted to be his own person, live in his own place. So, he decided he wanted to go to a group home. He went there and goes like 'this is where I want to be, I want to be here'. And I said, 'are you sure?" and he says 'Yeah, I'm sure'.

Participant J connected the initial experience that triggered group-home placement with her son needing ongoing treatment and behavior therapy in a group-home setting. It is *imperative not to interrupt services for individuals with intellectual disabilities inappropriately because this can cause a significant decline in the progression of their future goals.*

In the next step, I took the nine recurring themes from the interviews and created a general narrative. A general narrative is formed from the situated narratives where lived experiences of the participants were integrated into a general description of all the participant's experiences. The goal of this step was to jointly organize the data from the situated narratives, collectively emphasizing the meanings of all the participants' experiences. Below is an excerpt from the general narrative:

In the past, parents considered other options of residential placement; however, researchers determined all parents opted to place their adult child with intellectual disabilities in a group-home setting instead of any other residential facilities. Most parents elected to place their son or daughter with an intellectual disability in a group-home setting after experiencing several episodes of physical aggression. Some parents elected the placement option after experiencing the loss of their husband or wife.

In the final step, I created a general description, which was used to shift the typical perceptions of the participants. The focal point of the general description was to discuss the themes that were implied in the details of all or most of the participants' descriptions of their lived experiences ("Some" was used as needed to speak to a topic where participants differed in responses). The purpose was to connect the major phenomenological themes into a unified general description. Below is an excerpt from the general description:

During the parent's decision-making around group-home placement for their adult child with intellectual disabilities, they often seek to find the best placement to address their son or daughter's overall needs. They base their decisions on the quality of care provided and the quality of life the group-home providers offer to their adult child with intellectual disabilities. Many providers assess the individual's level of care and functioning prior to accepting them into the group-home.

Discrepant Cases

After examining the data, I will review any identified discrepant cases. Discrepant cases are those who offered information no found in other interviews (Coromina, Capó, Coenders, & Guia, 2011). Researchers review them to determine whether they offer information, which could contribute more to the study (Coromina et al., 2011).

Issues of Trustworthiness

In reviewing the study to assure trustworthiness, Schreier (2012) reported there is no clear division between the content analysis in qualitative and quantitative research. The researchers determined the acceptable use of similar terms such as reliability and validity (Schreier, 2012). Many researchers use qualitative criteria when evaluating validity in content analysis; nevertheless, in verifying trustworthiness, researchers use terms such as credibility, transferability, dependability, confirmability and reliability or authenticity (Elo et al., 2014; Kyngäs et al., 2011; Morse, 2015).

Credibility and Transferability

Researchers establish credibility by accurately identifying and describing the participants in the study (Morse, 2015). The selection of the appropriate data collection method is also important when establishing credibility in the data analysis (Elo et al., 2014; Polit & Beck, 2012). Concentrating directly on the research and focusing on how well the data addresses the purpose and goals of the study contributes to increased credibility (Morse, 2015; Polit & Beck, 2012). Using an appropriate sampling method and selecting the proper sample size is vital to confirming the credibility of the analytical process (Elo et al., 2014; Polit & Beck, 2012). There is no set sample size for qualitative research because the ideal sample size is based on the purpose of the study, research questions, richness of the data, and point of saturation (Elo et al., 2014; Morse, 2015; Polit & Beck, 2012). The ability to generalize the findings determines transferability to a different setting or group (Morse, 2015; Polit & Beck, 2012).

Dependability

Dependability in qualitative research refers to the stability of data over an extended period of time and in various conditions. I based dependability in this study by stating the principles and criteria used to select the parent participants and providing details about the characteristics and experiences of each parent (Elo et al., 2014; Moretti et al., 2012). The degree of dependability allows researchers to determine whether repeating or replicating the study results in with the same or similar results using participants within the same context (Lincoln & Guba, 1985; Polit & Beck, 2012). Thomas and Magilvy (2011) reported dependability of a study is higher when a different researcher can duplicate the study used by the initial researcher.

Conformability

Conformability in qualitative research refers to the neutrality between two or more people reviewing precision, significance, and meaning of the data (Elo et al., 2014; Moretti et al., 2012). Researchers use conformability to ensure the data truthfully represents the information the participants provided (Polit & Beck, 2012). The researcher's interpretation should not reflect their biases (Polit & Beck, 2012). Elo et al. (2014) and Schreier (2012) suggested conducting the data analysis with more than one person to increase the thoroughness and sound interpretation of the data. It is imperative that the findings reflect the participants' voice and eliminate the researcher's biases (Lincoln & Guba, 1985; Polit & Beck, 2012). I utilized member checking and reflexivity to assure confirmability.

Reliability

Lastly, the researcher's abilities determine authenticity in showing fairness and faithfulness to each of the participant's experiences (Lincoln & Guba, 1985; Polit & Beck, 2012). To achieve authenticity, the researcher provides a clear depiction of the culture, context, selection, and characteristics of participants (Elo et al., 2014; Morse, 2015; Polit & Beck, 2012). To establish dependability, I had several individuals observing the data analysis process to ensure the study was consistent and reproducible (Morse, 2015). I checked transcripts for mistakes and ensured the consistency of the codes and definitions to assure conformability (Polit & Beck, 2012).

I used member checking, documenting rich and thick descriptions, and stating researcher bias to establish credibility and authenticity (Elo et al., 2014; Morse, 2015; Polit & Beck, 2012). I presented the final themes to the participants and had each parent comment on their accuracy (Kornbluh, 2015). Member checking encourages participants to confirm the accuracy of their words, which I transcribed prior to coding, to further verify my findings (Kornbluh, 2015). In providing a rich and thick description of the process, I ensured the reader could create a realistic understanding of the participants' experience. Using the verbatim transcriptions also provided me with specific, detailed information. The transcripts verified themes, patterns, and quotes from each participant's statements, validating the data I used in my analysis. Lastly, I also used self-reflection to contemplate whether I accurately depicted my experiences with the parents of adults with intellectual disabilities, along with their descriptions of how their individual experiences influenced my interpretations.

Ethical Procedures

The biological parents participating in this study made a choice to volunteer and share information related to their decision-making process free of pressure or coercion, and with my assurance involvement did not present harm or risk. I continued to check the well-being of the parents during the interview process and informed each parent of their ability to end the interview process if exhibiting feels of discomfort or any other reason and provided them with contact information to local service providers. The providers included licensed professional counselors, clinical social workers, and clinical psychologists with experience in family counseling and trauma. The above-mentioned professionals agreed to participate in providing services to parents who experienced distress after participating in the study. The service providers read and signed a letter of cooperation, although no one required care during or following the interview (see Appendix E). Finally, I explained to the parents their son or daughter’s group-home placement and community resources would not be at risk based on their participation in the study.

I obtained informed consent from each parent after reading and answering any questions they had concerning their involvement. The informed consent form explained the purpose of the study, along with reassurances of confidentiality (see Appendix C). They affixed their signature to the document, which included an agreement to digital audio tape the interview along with acknowledging they had the right to terminate the meeting at any point, without fear of recrimination. In assuring I maintained their confidentiality, I explained how I would maintain and protect any identifying information. My actions would include coding the data to protect the parent’s and adult child’s identity, along with any other information connecting them to the study. Lewis (2015) indicated researchers should keep backup copies of the data they have collected to prevent data loss. Following this suggestion, I also explained how I would back-up any data entered into the computer at least every other day and save it onto a USB jumpdrive (Lewis, 2015). I assured them all jump drives had password protections and I stored them along with other study related material in a locked office for additional protection.

Other safeguards included keeping all electronic data on a password-protected computer, available only to me. I also explained the individuals who had access to study information included my approved chair, committee member, a transcriptionist, who would sign a confidentiality agreement, and Walden University’s IRB upon request (see Appendix H). A HIPAA compliance agency transcribed the data and protected all study related information in an electronic database that only they could access. I sent and received all emails from the transcriptionist in a secured email setup by the transcriptionist's agency. To access the participant's transcribed interviews, I created a unique username and password.

Summary

I selected qualitative interpretative phenomenology to conduct this study, as the methodology supports describing the lived experiences of parents who struggled with the decision to place their son or daughter with an intellectual disability in a group-home placement. The participants were biological parents of an adult child with an intellectual disability currently residing in a group home setting. Using semistructured interviews, I collected the data and later had them transcribed using professional services. I hand-coded the transcribed data. The first portion of the interview included demographic information related to the family structure, systems, and boundaries. During the second part of the interview, I collected information directly related to the participant's decision-making around group-home placement. Following coding and thematic identification, I analyzed the data to identify significant themes and patterns associated with the parents' decision to place their son or daughter in a group-home setting. In validating the outcomes, I used member checking, compiling rich and thick descriptions, along with recognizing any researcher bias through reflexivity. I present significant themes resulting from the analysis process, alignment with the research questions, and rationale behind any modifications to the methodology in Chapter 4.

Chapter 4: Results

The purpose of this qualitative phenomenological study was to explore the lived experience of parents who chose a group-home placement for their adult child with an intellectual disability. I provide excerpts of each parent's description of how they experienced making the decision concerning placing their child in a group home setting. Using the phenomenological methodology, I focused on identifying common experiences associated with each parent's personal experience around group-home placement. In this chapter, I also provide information related to the setting, demographics, data collection, data analysis, trustworthiness, and the results of this study. I offer my coding process along with the thematic identification. I placed them in context based on the participant's feedback. I explore the parents' lived experiences to reveal commonalities between their expressions.

Setting

I obtained all the participants from the same agency Just People Incorporated (JPI) located in Chesapeake, Virginia. The participants selected were diverse in respect to age, race, sex, and the geographic location. There were 10 participants due to the anticipation that their interviews would provide an abundance of rich data. The transcripts from the interviews of the participants culminated in 118 pages of typed text. I conducted all the interviews at a public location in a private room, a library, and office locations of the participant's choice. There were no personal or organizational conditions influencing the participants or their experience during the time of the interviews. The lack of personal or organizational conditions decreased the chances of influence and effect on the interpretation of the study results.

Demographics

A total of 10 participants participated in this study. There were nine biological mothers who participated in this study and only one biological father. The age range of parents was between 45 and74 years old. The median age of parents that cared for their adult child with an intellectual disability was 56 years old. There were six African American parents and four European American parents who participated in this study. The socioeconomic status was self-reported and based upon their own personal identification of belonging to upper, middle, and lower socioeconomic class. Of the parents in this study, 80% of the parents considered themselves middle class; the other 20% considered themselves to be lower class. The marital status of the 10 parents in this study varied. There was one widowed parent, two divorced parents, three married parents, and four single parents. The parents' highest level of education varied as well. For example, one parent had a master's degree, one had a bachelor's degree, two parents had received associate's degrees, five had some college, and one parent had a high school education. I reviewed the current employment history of each participant and found three parents received disability benefits, two were unemployed, three had jobs, one was self-employed, and one retired from their long- term jobs. The demographic interviews revealed four parents had at least one other child living in the home, and the other six parents did not have any other children living in the home. I asked if there were any other children in the home with an intellectual disability. Nine reported they had only one adult child with an intellectual disability and one parent had two children with intellectual disabilities. The demographic information presented provides future implications for additional research, which I discuss later in Chapter 5.

Data Collection

I interviewed a total of 10 participants regarding their decision-making process around group-home placement for their adult child with an intellectual disability. The data collection instrument that I used was an interview guide consisting of several opened-ended questions. I completed a comprehensive interview, which supported the development of each participant's decision-making process. In conducting the interviews, the participants selected public but private office settings in the community. I met with all 10 participants one time and the duration of each interview varied.

I documented the meetings using a digital recorder. After recording all 10 interviews, I used a professional transcription service to each document each interview verbatim. After the transcription of each interview, I reviewed them for accuracy. Using member checking to assure content validity, I forwarded all transcripts and interviews to each participant for their final review and approval. The participants all indicated satisfaction with the digitally recorded and transcribed interviews, and they did not identify any discrepancies from the recordings or transcripts. I made every effort to follow the data collection process and did not identify any variations in my intended process. Some of the counseling techniques I used to gain pertinent information about the decision-making process included asking open-ended questions, summarizing, paraphrasing, note taking, and reflecting feelings.

Data Analysis

By using the methodology to conduct in-depth interviews, audio recording, verbatim transcribing, and a detailed qualitative analysis, I categorized the most common responses from the interviews and hand coded the data while keeping the overarching research question concerning the parents' experiences during the decision-making process around group-home placement, at the fore of my thinking (Birkbeck, 2015; Pietkiewicz & Smith, 2014).

The initial steps I took in the data analysis process included reading the 10 transcribed interviews to ensure they coincided with the recorded interviews. I then generated codes based on words, phrases, sentences, and paragraphs captured in the participant's interviews. Frequently, I used the research questions and codes/themes that appeared to direct me to the final codes for each interview. I then synthesized codes from the participant interviews into categories and subcategories, and checked the condensed codes against my research questions regarding the parents' decision-making process. The procedure generated a general description of the parents' decision around group-home placement for their adult child with intellectual disabilities.

Discrepant Cases

Investigating discrepant information allows the researcher to consider whether there is sufficient evidence of information, not anticipated in the initial questioning (Coromina, Capó, Coenders, & Guia, 2011). The researcher can decide to pursue it further or disqualify it as unresponsive in answering the research questions posed in the study. (Coromina et al., 2011). In reviewing the data for the study, I did not identify any discrepant cases.

Issues of Trustworthiness

I verified trustworthiness by examining the conformability, credibility, and dependability of the outcomes (Houghton et al., 2013). Qualitative researchers also use terms such as quality or rigor to describe trustworthiness (Simon, 2011). According to Houghton et al. (2013), Kornbluh (2015), and Simon (2011), trustworthiness referred to the rigor in testing the confirmability and credibility of the data, typically using member checking. I used member checking to confirm the information collected from the targeted group of parents. Each participant confirmed the accuracy of their words I transcribed prior to coding, which established the trustworthiness of my findings

Consistent with Houghton et al.'s (2015) suggestions, to ensure the reader could create a realistic understanding of the participant's experience, I provided a rich and thick description of the information they shared. Using the verbatim transcriptions, I documented the participant's replies to reflect the rich and detailed information they offered. The credibility rested on verifying themes, patterns, and quotes from each participant's description of their decision-making process (Houghton et al., 2015). I also incorporated self-reflection to describe my feelings related to experiences parents of adults with intellectual disabilities shared and how it influenced my interpretations of the findings. Also referred to as reflexivity, while I was coding I would take walks and think about the choices I made (Peredaryenko & Krauss, 2013). I would contemplate whether my personal biases interfered with my decisions and then return to begin the analysis again, with fresh eyes and thoughts

Creditability speaks to ensuring the transcripts accurately reflected what research participants related to me (Houghton et al., 2015; Kornbluh, 2015; Simon, 2011). The process included examining the appropriateness of the content in the interview questions and how they related to the overarching research question (Simon, 2011). Qualitative researchers use the term dependability as a replacement for reliability, which is used primarily in quantitative studies (Houghton et al., 2013; Simon, 2011). I established dependability by checking transcripts for mistakes, confirmed codes, and used definitions consistently (Houghton et al., 2013). Dependability strategies in the data analysis process underscored the accuracy of my findings (Houghton et al., 2015; Kornbluh, 2015).

Simon (2011) suggested qualitative researchers have no expectation of exact replication. Qualitative researchers use persistent observation to establish a match between the responses from the researcher and the data identified in the study (Cope, 2014; Simon, 2011). For example, I checked the parent participant's response to each interview question to confirm it was identical to the transcribed interviews before identifying codes within the study and described persistent observation as when the researcher provided sufficient observation enabling them to identify significant characteristics relevant to the problem and purpose (Simon, 2011). For instance, I had enough observation after completing nine lengthy interviews with participants. The interviews and detailed transcripts included the required information necessary to elucidate the experiences of parents making decisions concerning group-home placement.

In conclusion, I conducted an ongoing process of coding and categorizing during the data analysis process. I started by identifying initial codes, which became more elaborate categories. Following this, I grounded the categories into a formal data analysis process regarding the parent's decision-making process (Simon, 2011). It was evident I achieved saturation when no new codes or categories emerged (Hennink, Kaiser, & Marconi, 2017; Simon, 2011).

Results

After reviewing the data, I identified a total of 59 codes and a total of 593 identified quotations to support the 59 codes emerging from the 10 transcripts. After reviewing each transcript, I identified the codes appearing to be most significant to this study based on the number of times each code appeared in the transcripts. I linked all the most significant characteristics in the decision-making process to the research questions. The first round of coding reflected 59 codes (see Table 1).

Table 1

First Round coding

Codes	**Codes**
adult child medical conditions age	agitation
caregiver medical conditions cerebral palsy	anger
children residential facility	elopement
community supports	autism
death/absence of spouse	down syndrome
elderly grandparent support	fear-parents
group-home community integration	financial burden

hospital/emergency

jealous of others

lack of community integration.

lacked family support

mental health-behavioral disorder

mental health-bipolar

mental health-schizophrenia

parent-substance abuse

performing activities of daily living

refusing medication

removed from group-home

residential facility-nursing homes

rural area/lack of supports

school problems

self-injurious behaviors

sexual behaviors

sponsored residential placement

stealing

weight gain

wheelchair bound/use

independent living

in-home residential support

g-tube

IEP/special education

medication

individual independence

mental health-anxiety

overeating,

peer support,

physical aggression

mild ID

pica

returned home,

safety

seizures,

severe ID

sibling medical conditions

smearing feces

verbal aggression,

size

property destruction

To reduce the codes to themes, I reviewed my codes again several times until like words began to emerge. I started to see how certain words had the same or similar meaning. For example, I placed physical aggression and property destruction together. After putting them together, I reviewed each word or phrase once again to see if any needed moving or re-categorizing. I gave myself some time away from the codes and upon returning re-read them and decided on what represented themes and what codes I would list under them. The second round of coding reflected 22 themes (see Table 2).

Table 2

Second Round Coding

Code		**Code**	
Best option	112	Property Destruction Mental	15
Physical aggression	53	Medication	15
Death/absence of spouse	33	Individual Independence	14
Caregiver's medical condition	30	Anger	14
Mental health-behavioral disorder	27	Agitation	14
Hospital/Emergency	22	Seizure Disorder	14
Community integration	20	Parent Substance Abuse	13
Verbal aggression	20	Community Supports	13
Financial burden	18	Elderly Grandparent Support	12
Health Anxiety Disorder.	17	Mental Health Bipolar Disorder	12
Lack of family support,	16	Adult Child Medical Conditions	15

I used the top nine recurring themes from the interviews to identify the final thematic descriptions of the parents' decision around group-home placement and derived them from the abovementioned research questions and sub questions. The final themes in Table 3 included the parents decision-making process around group-home placement for their adult children with intellectual disabilities. I also used this table to outline the experiences leading to group-home placement, and identified why parents chose group-home placement over other residential care facilities. Those descriptions follow the list below.

Table 3

Final Themes

Code	**Theme**
Code 1	Best option (112)
Code 2	Physical Aggression (53)
Code 3	Death/Absence of Spouse (33)
Code 4	Caregiver Medical Conditions (30)
Code 5	Mental Health-behavioral disorder (27)
Code 6	Hospital/Emergency (22)
Code 7	Community Integration (20)
Code 8	Verbal Aggression (20)
Code 9	Financial Burden (18)

Theme Descriptions

Best Option. According to the participants, group homes have a 1:1 ratio and other facilities have a 3:1 ratio, so they are not able to provide appropriate supervision, which indicated the care is not as good as being in a group-home. Group homes increase individuals with intellectual disabilities community awareness due to the significant amount of time spent in the community. Also, they are effective in enhancing individuals with intellectual disabilities socialization and relationship building skills because they spend a significant amount of time with peers. The staff also encourages them to build natural supports with individuals without disabilities along with those who take care of them without compensation.

Participant B stated when his son was eighteen, he wanted to be his own person, and live in his own place. So, he decided he wanted to go to a group home. He went there and goes like “this is where I want to be, I want to be here”. And I said, “are you sure?” and he says “Yeah, I’m sure”.

Participant B reported his son indicated he wanted to be in a group home on his own will. The participant wanted their son to have a normal life like any other adult in today’s society. Participant B stated often parents and other individuals in their support system shelter individuals with disabilities and ignore that they have the same desires as everyone else, and they should be able to seek independence and develop meaningful relationships.

Participant J connected the initial experience that triggered group-home placement with her son needing ongoing treatment and behavior therapy in a group-home setting. It is imperative not to interrupt services for individuals with intellectual disabilities inappropriately because this can cause a significant decline in the progression of their future goals. Participant B shared, “He just loved it as soon as he went in there. When he toured the group-home his room was very small, but that’s what he wanted. I thought I would just go ahead and let him experience that”.

Participant B supported their adult child with wanting to be more independent, and this was the final factor leading to group-home placement. Adults with intellectual disabilities require the support of their parents, caregivers, and community members to be more independent and active citizens in the community. Participant F decided group-home placement was a definitive decision after touring a group-home setting, and learning they could still be active in their adult child life. Participant B reported, “I didn’t think there were any residential facilities. I took my son to the first group home. I thought that was our only option.” Participant C indicated:

> We all went out, and we visited different places and different types of placements. So, for me when we went out it wasn’t just me it was my son it was my husband. We all went as a family. His case worker went with us and showed us different places, but when he went into the group home he just sat in the chair, and he was looking around, and he was laughing, he was smiling, because I believe it was more so that he saw other people like himself versus being at home. When he was around other people, it seemed like his whole demeanor changed. You saw him smiling. He went up and tried to talk to different people, and some of them would talk to him and some of them wouldn’t. And he just sat there and when I asked him ‘you ready

> to go?' He said 'no'. He said 'I want to be here with my friends'. So, he didn't know them, but he found the friends that he kept talking about at home.

Participant D discussed:

> I went online and read about other different group homes. I got some good feedback. You have got to learn to trust the internet these days just a little bit. Sometimes I would go out there and analyze group homes just on my free time. I would do these little things.

Participant E reported:

> Well, I wanted her to be in like a family environment. I didn't want her to be in a facility that is so clinical. So, I wanted to make sure that she had friends in the same age group she's in or same like status. That was really the main thing when I thought about placements. We've toured several different ones, and I wanted to know whether or not she could mesh with the people that were there. I looked at in-home supports, and I looked at sponsor residential. Sometimes in sponsor residential, they think that they are there's. I wanted to make sure that my child was mine and I would have rights. Sometimes you go to sponsor residential places, and they start calling that person mom. 'You didn't give birth to her'! In-home supports do not offer 24-hour care, and there are times that she may need toileting or different things of that nature during the night or whatever I needed 24-hour support, so that was literally one of my major concerns. Group home placement allows me to see her every day, she knows who I am, they take her out in the community, and they have games. I still make sure if I'm sick I call her, those things are going well right now.

Participant F stated:

> You know it's like if you ever bought a home, it's like you know that home when you go in it. It's like, 'Dag, this is it; this is the one that I have been looking for'. That is kind of sort of how we felt in regards to this particular placement. You know you have to feel the people, and we felt comfortable with the people that we were going to leave our baby in care with. And on top of that again we were able to have that open-door policy where we could come and go. They didn't seem like they were going to turn us away or they were going to question us about a whole lot of different things. Again, we pick him up on the weekends, and we take him back. So, we just felt comfortable. He had his own staff and his own room. I didn't want him sharing a room with someone else, and it's around the clock. He had around the clock staff at all times and then he also had nursing on call. So, the nurses did their rounds, but then they also were on call. So, that helped me. Staff were trained to do the g-tube and trained with seizures and all that.

Participant F and Participant G both chose group-home placement due to the medical model around g-tube feeding. Participant H stated:

> He actually didn't initially go into a group home setting. We chose more so independent living, where he had his own apartment, and he had care to come in because his level of functioning where he was high functioning, but he did need the support in certain areas. The hygiene and things like that but he could still function day to day with minimum support. So, the apartment setting I felt was the best thing for him at the time to give him that independent feeling or you know so he could be

> able to gain the skills that he needed just with someone coming in providing him the support, but that was not a good choice. He became very aggressive to those who were in the apartment setting with him. He was going into their apartments breaking in; stealing food, beating them up, it was just one thing after another. So, which what I thought was a good choice it just felt like it was a nightmare because he needed more supervision. He actually lost his placement in that setting. From there we had to find another placement that was further away from home. Because nobody would accept him because of the level of aggression that he was it was hard to find a placement. This location did accept him, and when he first got there, he was definitely a handful. But I guess because it was more so in a city area he had more things, and it was a different feel to him. He had a lot of resources and the support. What you all call them? The support coordinators they did more frequent visits. He had more of a family feeling in that setting with more people in that house, in the group home setting. That turned out to be more successful than the apartments setting. I think due to him having the 24-hour staff, I think that made a big difference in the progress that he's now showing and the support of the staff and seeing the other individuals in the home setting functioning and not displaying those behaviors that he was displaying. So, I guess he had to say, 'Hey, well I got to fit in somewhere', so I think that kind of contributed to him making the progress that he did in the group home setting.

Participants A-J had tried other residential care facilities prior to a group-home and expressed dissatisfaction. Participants A-J appeared to be unhappy with residential care in the following settings, nursing homes, sponsored residential placement, independent living, and in-home residential support. Participant's A-J confirmed feeling pleased with group homes that could address the following medical and behavioral needs of their adult child: g-tube feeding, seizures, bipolar symptoms, schizophrenia symptoms, anger, agitation, stealing, physical aggression, and overeating. The summary disclosed the similarities and differences in Participants A-J decision-making process; however, the trends and patterns in the coding identified the parent's satisfaction with their decision-making process around group-home placement.

Physical Aggression. Some Individuals with intellectual disabilities are aggressive towards their parents when living in the home; therefore, the decision of group-home placement has become more relevant. Some of the physical aggression parents face from their son or daughter with intellectual disabilities include, biting, punching, slapping, kicking, and pushing. Adults with intellectual disabilities also engage in self-inflicted behaviors such as, head banging, cutting, and hitting themselves. Physical aggression displayed by adults with intellectual disabilities can lead to their caretakers deciding to place them in a group-home.

One participant stated, "My child would become physically aggressive by fighting, shoving, kicking, grabbing knives, head banging, and even throwing hot grease". Participant C offered:

> I was in the kitchen, and I was cooking dinner, and I was frying some chicken, and he said he didn't want any chicken. And I just turned around just for a moment from the stove, and he went and grabbed the pan with the grease in it and threw it. If it

> wasn't for the Lord and God just telling me to look quickly, I would have got burnt up with hot grease. You know, and so that was my point of no return.

Participant D stated:

> Well, there were too many altercations between me and my son. And if I would have like family, friends over, and he would always find a way to be a distraction. He threatened their lives, and I couldn't have that. I couldn't have that around my family and friends even though I love him dearly.

Participant J added:

> My son is twenty-seven, and he has autism and intellectual disability and a seizure disorder. He also has some sensory issues with his autism. So, he's on medication for a seizure disorder. He is on medication for mood stabilization, and he is on medication for anxiety. When his structure is interrupted, he will develop anxiety if his day gets changed and if something happens unexpectedly. And that can occur most of the time throughout the day. So, when he has anxiety, then his OCD manifested itself. So, if we can keep his anxiety to a reasonable level, then he seems to function better. When he started going through adolescence that's when his seizure disorder occurred. When the medication was added in to help control the seizures we started noticing more behavior problems such as, not cooperating, becoming more aggressive, which could also have been in addition to adolescence. More of the testosterone kicking in and that's hard enough when you're typically developing. So, as time went on then he started gaining a lot of weight from the seizure medication. We were having behavior problems other than locking cabinets

> and the refrigerator. It was very difficult to control his eating as he would become aggressive if he didn't get to eat. He would kick the wall. He would throw things. Whatever he could pick up and it would escalate, till you gave into him. I mean he would think nothing of he picked up a broom one day knocked a hole in the ceiling with it. Just starts throwing anything, and putting his hand and fist through the wall. He would shove you, and it would seem like once he escalated to a point, it was almost as if he had to finish it in order to get calmed down like he physically had to go through that process and kind of almost wear himself out to be able to calm down.

Participant B associated the initial experience that triggered group-home placement with the adult child wanting to seek independence. The parent reported the adult child experienced an increase in anger and agitation; nevertheless, what adult would not get agitated if someone instructed them what to do, where to go, what to wear, and with whom they can spend their time 24 hours a day. Participant C suggested, “I think it was more so when he swung and hit me”. Participant C connected the initial experience that triggered group-home placement with the adult child being physically aggressive. Physical aggression towards another person is completely unacceptable. Physical aggression puts the health and safety of anyone at risk; nevertheless, 50-year-old parents suffered from being physically abused by their 20-year-old adult child. Participant D stated:

> Well, I had a girlfriend and me, and her were dating for about two or three years. Somehow, he felt like my girlfriend was his girlfriend and he would get upset every time I would touch her. He would cuss me out and say, ‘She belongs to me’. I'm

> looking like, hold it, you don't take her out on dates, I do, so I had to let him know. This happened a whole lot. I needed my girlfriend to myself, and I couldn't have her to myself as long as he was around.

Participant H, I and C were comparable, as they all identified physical aggression as the initial trigger for placing their adult child in a group-home setting. Participant I stated:

> She started demonstrating the things and the actions of her dad. I mean fighting with me and not just fighting verbally. I mean she started putting her hands on me, she started throwing things in my house, breaking things and you know destroying things. And just out cursing me out and calling me everything but her mom. So, that's when I was just like 'you know I can't really do this. Like I'm not built for this, I'm not strong enough for this'. So, I just-- that was the final straw. It was just like I couldn't, I wasn't going to sit in my house and be abused by a child. I just couldn't. It's sad to be fearful of your daughter.

Death/Absence of Spouse. Participants offered closely related statements from those who were single parent participants, widow participants, and participants who experienced the loss of their significant other. Single parents found it hard to care for their adult child with intellectual disabilities while working, maintaining the home, and still providing care to their other children without disabilities. After parents experience the loss of their spouse they found it hard to continue to care for their adult child with disabilities while grieving at the same time. Parents tend to provide better care for their adult child with disabilities when both parents are present and actively involved.

Participant H lacked family support other than her parents. After the death of her father, it was evident that she could no longer care for her adult child and still maintain the other areas of her life. The death of her father was the final experience that led to group-home placement. Participant H stated:

> Well, it wasn't so much of his behavior that made it get to that point. Again, my mother and my father were taking care of him while I was in school. My father ended up passing away, and I knew that my mom couldn't manage it by herself. Because, again I was in school all the time, my schedule, trying to maintain, get a degree, so I could care for him. So, we discussed it amongst the family, and we just came to the conclusion that we thought that it was time. This would help him have as much as a normal social life as possible with us you know making this decision for him and not enabling him any longer.

Participant A contributed:

> Well, one thing, he has seizures. He's unable to do for his self. And then my husband passed, and on top of all of that I fell and hurt myself. I hurt my back and-I have you know arthritis in my back. Plus, I'm a diabetic.

This statement indicated this participant struggled to care for their adult child with significant medical concerns and had to cope with the unbearable death of their spouse. Later, this participant began to experience some significant health issues of her own making it almost impossible to care for her adult child with an intellectual disability. The loss of a spouse and considerable medical issues made it necessary to seek group-home placement as an alternative option for their adult child. Participant I shared:

> Well, definitely I would say the death of her father. Yes, the death of her father was very hard for her and me. So, I believe you know I couldn’t and I didn’t mourn very well. Like I kind of shut down. Had shut her out and everybody else out and having a child with ID you can’t really shut them out. Like they need all the care that you can give to them, and I just couldn’t do that at the time. Even though my husband he had his issues and he did his thing but I mean he was a part of that household, and he was the only reason why I was able to keep her, and you know sustain that care for her as I did was because of him. I knew you know I just knew that he was there and he was going to come back even if he went to jail I knew he was going to be back. You know that kind of thing. So, definitely the difficult time that I had when he passed. I mean I just couldn’t be the mother that she needed me to be. I wanted to give her that good quality of life again like I said, you know, and I just couldn’t deal with her crying you know for her father and the many nights of just asking the questions she just never understood where her dad went you know and it was just very hard.

Participant A highlighted the initial experience that caused them to consider group-home placement, “Well after my husband’s death and being placed on disability. My husband use to help me with them. But after he passed I found out that I needed other help. I can’t do what my husband was doing”. Participant A expressed how grief and loss was an extensive process, and attempting to be a caregiver and heal simultaneously can be very difficult. Participant B described, “He was becoming more agitated at home. He wanted what we couldn’t give him. He was getting angry. He wanted what everybody else had”.

Participant I was comparable to Participant A as they both identified that the death of their spouse was the initial cause for them to consider group-home placement.

Caregiver's Medical Condition. Many of the participants suffered from their own medical conditions, which included arthritis seizure disorders, diabetes, lupus, and myasthenia gravis. Parents with significant medical conditions were unable to manage their own health concerns and doctor appointments while still meeting the medical needs of their son or daughter. Parents with chronic medical conditions were often too fragile to provide care to their adult child with intellectual disabilities. The caregiver's medical conditions often limited the amount of support they could provide to their child and the adult child's overall quality of life decreased when they had a parent with significant medical conditions. Participant G regretfully acknowledged:

> Well, it's been a struggle with my health. I have lupus and just each day is different for me. I have flare ups and just some days I just can't do anything. That's unfair for my child. Also, my child has anxiety problems. When she gets to that point, she likes to throw things and pick at her vaginal area and rip up things.

This participant experienced a severe medical condition similar to Participants A, G, and E, which was a clear indication of their need to seek future group-home placement. The significant symptoms related to the disease lupus made it almost impossible to deal with medical concerns, mental health symptoms, and behaviors displayed by the participant adult child. This participant experienced a severe medical condition like Participants A and E, which was a clear indication of the need to seek group-home placement. The significant symptoms related to the disease lupus made it almost impossible to deal with medical concerns, mental health symptoms, and behaviors displayed by the participant adult child.

Participant E connected the initial experience that started thoughts of group-home placement with her chronic medical condition. Parents coping with a severe illness are not able to properly care for their adult child with an intellectual disability for extended periods of time. It takes a selfless parent to recognize and admit they are unable to continue providing care for their adult child. Participant F shared:

> Well again, we were in the hospital, and we had to make that choice, 'Do we bring him back home and try to set up our house to have it to be more functioning for him. The financial aspect of that meant that we had to then convert our home totally. He's on a breathing machine, so we had to get the right equipment for him. And I'm not saying we probably couldn't have done it because we probably could have done it, but it would cause us to have to change our entire lifestyle. I know it may sound like-- For some parents-- You might hear them say, 'Well that's kind of selfish,' but it's like, and do you live and have a life while having a child?' "Does he consume your every aspect, or all of the aspects of who you are"?

Participant A stated the final experience that made group-home home placement a definitive decision:

> I became ill and the diabetes and the rheumatoid arthritis, which keep me from doing things I was doing. Such as cooking and washing and especially driving. I don't know what it was, but it made me nervous, and I had a seizure when I was driving,

> and I had to pull over and let my sister drive. I started shaking so I haven't driven since then. I don't want to cause anyone to be hurt or die. Participant G stated:

> I had lupus, and I was in the hospital, and it was kind of hard for me to find someone to take care of my daughter when I'm in the hospital because I had a flare up. So, that was my initial issue with how can I take care of my daughter, and I'm sick also.

Participant A's final experience that made group-home placement a definitive decision was experiencing symptoms related to their own medical conditions. Participant A was comparable to both Participants E and Participant G as they all experienced chronic medical conditions of their own which led to their decision of group-home placement. Participant E stated:

> Well, the one major thing is I went back in the hospital several times, and the doctors basically said that they couldn't really do anything and my condition was worsening. There's certain times that I can't speak and she maybe you know wanting certain things that I can't do for her or you know different things. I had to downsize my home and just get certain things in place because I was on social security disability so the funds weren't there as much as I would like to. And I couldn't pay for someone to come in the house and take care of her and me too. So, that was really the bottom line. The money wasn't there, my health wasn't there, and I had to do something.

Mental Health-Behavioral Disorder. Adults with intellectual disabilities also suffer from mental health behavioral disorders such as bipolar disorder, schizophrenia, mood disorder, anxiety, and intermittent explosive behavior disorder. The dual diagnosis required them to see a psychiatrist for counseling and medication management to cope with the symptoms based on their mental health diagnosis. It is common for individuals with intellectual disabilities to suffer from depression and anxiety based on traumas experienced in their past. Many adults with intellectual disablities experienced abuse, neglect, and exploitation by parents, family members, peers, and others in the community. The traumatic experiences increase their chances of receiving a mental illness diagnosis. Participant C stated:

> Well, first to start off with my son has Bipolar as well as schizophrenia. As my child got older, we began to see him act out more.He's mild ID and acted out more and more as he got older. We saw that he wants to be around other children rather other adults just like himself. He decided that he wanted to do whatever he wants to do. He doesn't realize that he has a disability. He wants to be just like everybody else.

Adults diagnosed with intellectual disabilities and mental health disorders often do not see the disability or disorder. They often deny their diagnosis with attempts of leading a productive life, and they do not normally seek additional support until dysfunction takes place. The dysfunction that takes place in adults with dual diagnosis includes agitation, depression, suicidal ideation, delusions, hallucinations, inappropriate medication management, and inability to complete their normal activities of daily living. Participant H shared:

> Well, my child diagnosis is Down syndrome. With the Down syndrome that came with explosive behavior disorder that was diagnosed early on. I would say probably high school. My child was a child that attended school, had an IEP and was in

> special education. The behaviors became unmanageable in the home. As a single parent, of course, raising him and I live in a rural area, so therefore resources were very limited. And not having a lot of knowledge or support with knowing what steps to take, it was very difficult, so again that was family support that was there, so it was my mother and my father who are you know elderly.

Single parents often have a tough time caring for their adult child with an intellectual disability. Many single-parents experience burnout while caring for their adult child because they never get a break. These parents are often responsible for attending doctor appointments, psychiatrist appointments, school conferences, and dealing with behavioral concerns alone. Single parents rely on grandparents for support, and if their family members are not available, they seek additional resources and support in the community not limited to group-home placement.

Participant J's adult child experienced mental health behavioral disorders similar to participants C and D. Also, participant J's adult child received a medical diagnosis like participants F and H's adult children. The participant's adult child's behavioral concern was food driven, which as a result led to excessive weight gain. Food appeared to be a trigger for this individual with an intellectual disability, and if the parent could not provide food, they would experience an increase in seizures and physical aggression not limited to kicking, shoving, throwing items, and property destruction.

Hospital/Emergency. It is common for adults with intellectual disabilities to experience one or more visits to the emergency room or the psychiatric hospital. Adults with intellectual disabilities go to the hospital due to chronic medical conditions and self-inflicted injuries. If the adult child with intellectual disabilities appears to be in danger of hurting themselves or others, parents take them to a psychiatric hospital for professional assessment. Often adults with intellectual disabilities require a higher level of care because parents cannot handle the concerns on their own. Participant J stated,

> I had to call 911 several times due to my son's behavior in the home. Later he went into a neurobehavioral unit, not just for the developmental behavior problem, but you have to have a health problem considered to be dangerous. Because of his seizure disorder, they had to reduce and then wean him off the seizure medication, which was too dangerous at home. He was also on a mood stabilizer that might not have been as effective for him. But, until we got him off it we were involved in positive assimilation for him. So, it was dangerous to do that at his level of escalation.

This participant experienced a significant medical diagnosis similar to Participant A, which made the decision-making process around group-home placement urgent. The participant had to make an immediate decision to ensure her adult child was in a safe and nurturing environment that would provide a better quality of life than she was receiving at home. It is normal for a parent to want more for their children, and to expect nothing but the best when it comes to the care they receive in a group-home setting. Participant F suggested:

> Okay, well my child he was brought into the world with multiple issues. I was involved in a car accident, and by virtue of a car accident, I had him at 29 weeks gestation, which meant I was almost 7 months pregnant. Well, he stayed in the

> hospital for approximately two months, and after that, we brought him home. He was in my care for up until he was about 10 years old. We did the best we could, my husband and I. We brought in people you know, we took advantage of the services that we had. However, it got to be a little tedious because he needed around the clock care. His health and his breathing were one of his major issues. So, with that and his seizures that he was having we couldn't just watch him around the clock.

Unfortunately, some individuals are born with an intellectual disability; however, other individuals experienced a tragedy that caused them to develop an intellectual disability later. This participant experienced a catastrophic car accident that changed not only their life but the life of their child forever. When these misfortunate events take place, many parents could not provide nursing services and 24/7 care for their adult child. As a result, parents seek additional community supports and group-home placement. Participant J reported:

> This is what I found, and it took a long time to emotional get there. When he was at home the last three months before he went into the hospital, he was either eating or screaming. I had a couple of people coming in helping but, it reached a point that I couldn't even leave. He got so upset, and he got to the hospital, and one day it was just like a light bulb went off. It was so hard when he was home, and I loved him, but I did not like being around him.

Participant F expressed:

> Well, you know like I said we were going around to the different locations and for a moment I said, 'Okay we are going just to figure out how we are going to do it the

> best way we could' and kind of go through increments on getting the house together, but this place that I was telling you about. Once we saw that place, I was able to meet the director you know. I was able to meet the line staff and seeing that it wasn't so many people in there that he would actually have that one on one care. My husband felt pretty good about it, and it's not too far from where we live at. We can always come in and go and still see him. We still come and get him and take him out on weekends and bring him back. He's still active in our lives.

Participant J added:

> I expected to bring him home and so at the hospital we worked with a social worker at the hospital who was part of his team. She gradually, I guess over time really educated us in terms of the fact that he still needed behavior therapy, and that after fifteen months all that work and effort that he needed to step down in a therapeutic group home to get to manage those behaviors.

Community Integration. Due to their parent's age, medical conditions, or transportation concerns, limits the amount of time adult children who live at home spend in the community. Laws mandate the staff at group-homes to ensure adults with intellectual disabilities go in the community at least two or three times a week. They also must keep a community activity calendar, which details where they decide to go and that they do not visit the same locations. Lastly, community integration increases adults with intellectual disabilities ability to manage money, including learning budgeting skills when making purchases in the community.

Participant I and J were both satisfied that group-home placement increased the community integration for their adult child. Participants A-J discussed the significant factors that contributed to their choice of group-home placement opposed to other residential care facilities. The significant factors related to group-home placement included community integration and peer support. Participant E stated:

> Well, the step by step process was more, so I had to look for a place that would be more like my home. I looked at the statistics of the places around and how many times people are moving, what the staffed looked like, and how much interaction they had with the community. I looked at whether or not I could afford it because that was very important to me. Whether they had something in place to help my child or whether it was just some placement where they're just going to sit and do nothing because some places are like that.

Participant G offered:

> I think it was when we were out in the community, and she had that anxiety, and she was just throwing a fit. I couldn't deal with it, and at the time I wasn't feeling good either. So, it was just like I have to do something; I need help. That's when I had to look it up and do some researching.

Participant A added:

> Well you know I didn't want him in a nursing home because I had worked in a nursing home. I saw how some of the residents were treated. They didn't show any love. They were there just to make money, do their job and go home. So, it wasn't like they cared. I saw how they treated the patients. They wouldn't wash them or

> give them a bath. They just let them keep on the same clothes that they had on the day before. The staff would not feed them most of the time. You know I saw this for myself, so I wanted my child to be in a kind of a home environment. Being in a group home, it was like a home. They would go out and take the young people out shopping and take them to the movie and take them to the church. My son really loves going to church. Participant I reported:

> They had one on one care. They had great management behind them. They had staff. They had counseling services. They had crisis interventions. They had medical medication and nurses onsite. It was very family oriented. There were other people like her. She had peers and friends. They had things that they do every day. They had an activity calendar where they did all kind of outings. They were part of Special Olympics where she can be involved in sports like basketball and soccer.

Participant J offered:

> He has a social life, which prevents him from isolating and eliminates his aggression. Group homes provide structure. They also provide him with the twenty-four seven supervision. He is exposed to different people from all different walks of life, which has caused his vocabulary to increase and he is actually learning from others around him. I feel like the staff is on top of him and nurturing.

Verbal Aggression. Some adults with intellectual disabilities require a significant amount of time and attention, and they often become jealous when their parents show love, attention, time, and affection to anyone else. The behavior results from to lack of social integration, and the verbal aggression displayed is conduct used to get the individual closer to what they want or away from something they do not want. Many of the participants indicated that group-home placement offered their adult child more community integration, which allowed them to participate in more activities in the community with peers. On the other hand, participants found it difficult to handle the verbal aggression and use of profanity displayed by their adult child with a disability. Participant I, J, and D were comparable because verbal aggression was the final experience that impacted their choice of group-home placement. Participant D reported:

> We were coming home one day. I took him out to the arcade. I really wanted to spend some guy time with him, some father time with him. He got upset because I said, ‘Hey it’s time to go tohome’. He was like, ‘I want to stay at the arcade’. I said, ‘You can’t do that, we have to get back home’. So, on the way to the house, I gave him the keys to get into the house, and he went in and locked me out the house. He said this was his house and he paid the bills. I said, ‘No more, you are not going to do this to me’. I had to call the police just to get the door open because he locked me out of my house. There was no way for me to get back in. He said, ‘This is my God-- house’. He started barking like a dog and growling. He told me, ‘if I come in he was going to bite me, he’s was going to shoot me’. He didn’t have a gun, but this is what he said he was going to do to me. I never had been locked out of my own house. He threatened my life; he even said he was going to kill me.

Financial Burden. Parents experience financial burdens when caring for their adult child in the home. Feeling drained can result from trying to cover the cost ofmedication, and medical equipment insurance companies do not reimburse. Many parents have limited or fixed incomes and live in income restricted homes. Some receive food stamps and survive using their social security or disability incomes. Caring for a child with an intellectual disability can be very expensive. However, group-homes receive additional funding to provide services to them.

Participant I, similar to Participant H experienced difficulties of being a single parent from time to time. Single parents often face financial hardships when there is only one income in the household, and required to care for monthly expenses and the expenses of your adult child with an intellectual disability. Dysfunctional factors in the family dynamics make it difficult to enhance the overall quality life of an individual with an intellectual disability. Dysfunction prevents parents from supporting their adult child with maximizing their full potential. The elimination of substance abuse, verbal abuse, physical abuse, and incarceration in the family dynamics can create a better living environment for parents and their adult child with an intellectual disability. One parent reported:

> I had to downsize my home and get certain things in place because I was on social security disability, so the funds just weren't there. I couldn't pay for someone to come in the house and take care of her and me too. So, that was really the bottom line. The money wasn't there, my health wasn't there, and I had to do something.

Participant I added:

> Okay, well what impacted my decision were personal issues dealing with my child's father. He was an alcoholic, so he was in and out of jail for DUI's for abuse, verbal abuse, and physical abuse. And he did it in front of her. I just felt like it was unsafe for my child to live in an environment where she was emotionally unstable. And I

> felt like I was emotionally unstable to take care of her. Or take care of a child for that matter with intellectual disabilities. The financial burden of him not being home and him losing jobs after jobs put a big burden on our life. So, she couldn't have the same-- she couldn't have things that normal kids her age would have. Such as just simple things for Christmas presents or even like three meals a day kind of thing. You know snacks if she wanted to have a snack if she wanted to. So, that was really the reason you know. I just didn't want her to lack the quality of life that she could have somewhere else where she was not getting with me.

Participant D adult child appeared to be afraid that he was losing his father to his new girlfriend, and his way of expressing himself and getting his father attention was to become verbally aggressive. Participant E stated:

> Well the main thing that caused me to think about placing her initially was more so because I have myasthenia gravis. Myasthenia gravis is an autoimmune disease that causes your muscles to weaken, and it causes you not to be able to talk, sometimes your muscles get weak, sometimes you can't swallow, sometimes you can't breathe. It causes a lot of your muscles that are voluntary to not work because you get tired or because they feel like they don't want to work. I went in the hospital, so I didn't have really anybody to care for her because my other child has lupus so she really couldn't take care of her.

Participant F connected the initial experience that triggered group-home placement with finances. Caring for a child with an intellectual disability can be very expensive. Some of the significant expenses related to caring for an adult child with an intellectual disability include medication, medical equipment, and making environmental modifications.

These nine codes appeared to be very significant to the parent’s decision-making process when considering group-home placement. There were 12 significant codes that scored slightly lower, and another 37 codes scored 10 and below, which indicated these codes were not as significant to the overall parent decision-making process around group-home placement. I did not identify any discrepant cases in this study. All cases were significant and interconnected. Each interview and transcript contributed to the data analysis process.

General Narrative

In the past, parents considered other options of residential placement; however, researchers determined all parents opted to place their adult child with intellectual disabilities in a group-home setting instead of any other residential facilities. Most parents elected to place their son or daughter with an intellectual disability in a group-home setting after experiencing several episodes of physical aggression. Some parents elected the placement option after experiencing the loss of their husband or wife. Many parents struggle with their own medical conditions and side effects; therefore, there is no other option for living arrangements other than group-home placement. A few parents admitted they could not cope with their adult child with intellectual disabilities mental health related behavioral disorders. Instead, they opted for group-home placement, which is a higher level of care that can effectively address concerns with depression, anxiety, and psychosis. Many adults with intellectual disabilities experience numerous psychiatric and hospital visits due to their aggression and mental health behavioral disorders; nevertheless, most parents reported they feel equipped to deal with excessive hospital visits. Some parents acknowledged the limitations of integrating their son or daughter with an intellectual disability into the community due to their busy schedules. However, group home staff can give them access to community activities several times a week. Verbal aggression, which is a form of abuse, is another issue many parents reported. The parents chose group-home placement to lessen the stress and embarrassment of coping with the aggressive language. Finally, some parents chose group-home placement to eliminate financial burden and hardships on their family unit.

General Description

During the parent's decision-making around group-home placement for their adult child with intellectual disabilities, they often seek to find the best placement to address their son or daughter's overall needs. They base their decisions on the quality of care provided and the quality of life the group-home providers offer to their adult child with intellectual disabilities. Many providers assess the individual's level of care and functioning prior to accepting them into the group-home. It is imperative for group-home providers to ensure the adult child with intellectual disabilities is a good fit for their program and the other individuals in the home.

Most parents know the needs and want of their adult child with intellectual disabilities better than anyone else. Group-home providers tend to work closely with the parents to assure the transition from their home to a group-home setting goes smoothly. They work with the parents and other healthcare providers to make sure they meet the needs of the individuals with intellectual disabilities. It is imperative to have ongoing communication between the adult child with intellectual disabilities, parents, group home supervisors, and all other medical providers.

Many parents feel a sense of loss once their child moves into a group-home. It is important for them to continue to receive updates on their adult child's progress and areas of opportunity for growth. The decision of group-home placement for parents is already difficult; therefore, assuring they remain connected through visits, phone calls, and letters are vital. During holidays, it is important group-home providers encourage and support vacations or home visits with their parents, siblings, and extended family members.

Most parents feel that group-home placement is the best placement for their son or daughter after leaving their home. It provides individuals with intellectual disabilities a sense of belonging because of the family atmosphere. Most parents agree that physical aggression clearly indicates the need for their adult child to go into a group-home placement. Parents grieving the loss of their significant other often seek group-home placement to alleviate stress while they attempt to heal. Many single-parents seek group-home placement because they do not have the family support or financial means to care for their son or daughter. Some parents have severe medical conditions causing them to seek group-home placement for their adult child because due to the demands of handling their own medical conditions along with the medical conditions of their son or daughter. Some parents have adult children with a dual diagnosis of mental health-behavioral disorders and intellectual disabilities. Adult children with mental illness and intellectual disabilities challenge parents when they do not have a mental health background and cannot identify the signs, symptoms, side effects, and coping mechanisms to support their son or daughter appropriately. Often parents seek group-home placement in addition to other services to manage their son or daughter mental health-behavioral disorders. Many times, physical aggression and mental health-behavioral disorders create circumstances where the adult child needs frequent emergency room visits or hospitalization. Most parents begin to seek group-home placement when they have children with intellectual disabilities in and out of different hospitals and emergency settings. All the parents want their son or daughter to remain active by integrating into the community and experiencing new life experiences. Group-home placement opens the door for community integration in various settings with travel accommodations. Some parents experience verbal aggression from their son or daughter no matter how much they attempt to meet their needs and give them what they want. After dealing with verbal aggression for an extended period of time, parents grow tired and give up fighting with their son or daughter. Turning to a group-home for placement offers them a sense of relief. Many report struggling financially to maintain a household for their adult child with intellectual disabilities along with other members of the family. Individuals with intellectual disabilities often have unexpected cost due to prescriptions, medical equipment, hospital/emergency visits, various modes of therapy, along with additional leisure and recreational activities. Most parents are eager to alleviate the financial burden of caring for their adult child; therefore, they seek group-homes because they have more resources from various funding sources. They feel the group staff can meet the overall needs of individuals with intellectual disabilities in the most effective manner.

Summary

Parents who related their lived experiences when making the decision of group-home placement for their adult child with intellectual disabilities discussed the significant factors driving their choices. The participants described the step-by-step process the experienced, leading to arriving at the decision of a group-home placement for their adult child with an intellectual disability. Upon completion of data collection and transcription, I completed my analysis. Nine themes emerged from the information they shared. The experiences causing a possible decision for group-home placement included physical aggression, death/absence of a spouse, caregiver medical conditions, mental health behavioral disorders, best option, hospital/emergency, community integration, verbal aggression, and financial burden.

Group-home placement relieves parents from the everyday stress of taking care of their adult child. Many families felt there were no other living options available for their adult child in the community. Placing their adult child saved parents from experiencing verbal and physical abuse and alleviated the financial burden of being a caregiver. Group-home settings provide a family-oriented and nurturing environment to both the parents and adult children who have experienced the loss of a loved one. The staff encourages parents to remain a part of their child's life. Lastly, group home staff encourage individuals with intellectual disabilities to socialize and communicate with peers and individuals in the community from diverse backgrounds, which increases their overall well-being. In the following chapter, I will present the limitations, interpretations and implications for social change on multiple levels of change.

Chapter 5: Discussion

The purpose of this qualitative phenomenological study was to explore the lived experiences of parents choosing a group-home placement for their adult child with an intellectual disability. I reviewed group home placement from a parent's perspective instead of focusing on the adult child's choice, which reseacher's explored in previous studies (Bigby et al., 2015). The parent's decision-making process evolved from their experiences with their adult child with intellectual disabilities. In analyzing the data, the parent's final decision of group-home placement for their adult child with intellectual disabilities, the following nine themes emerged: (a) best option, (b) physical aggression, (c) death/absence of spouse, (d) caregiver medical conditions, (e) mental health-behavioral disorder, (f) hospital/emergency, (g) community integration, (h) verbal aggression, and (i) final burden.

Interpretation of the Findings

Dillenburger and McKerr (2009) identified stressors faced by parents, which included health problems, financial problems, single parenting, widowhood, unfamiliar with community resources, and worrying about the future care of their adult child. The researchers identified the significance of early behavioral intervention for adult children with disabilities. They recommended early onset of future group-home placement would best prepare the child for long-term care.

I found parents experienced less stress after placing their son or daughter in a group-home setting. Parents reported staffed group-homes alleviated the pressure of attending countless medical appointments, and the staff reduced the stress related to medical bills due to Medicaid funding and other community resources available for adults with intellectual disabilities. Additionally, I discovered single parents and widows reported satisfaction with group-home placement because it created a sense of family and belonging for their son or daughter. The findings from my study indicated early onset of group-home placement decreased behaviors in adult children with intellectual disabilities and increased their communication and socialization skills, which was consistent with Dillenburger and McKerr's (2009) findings.

In another study found in the literature, researchers surveyed 721 adults with intellectual disabilities who were either living in their parent's home, independently, or in staffed group homes (Felce, Perry, & Kerr, 2011). The intent of the study was to identify the quality of life parents provided to their adult child living in the home compared to other residential placements in the community (Felce et al., 2011). The researchers indicated individuals who lived independently had greater household participation (Felce et al., 2011). However, individuals in staffed group-homes had greater household participation and community integration than those adult children living in their parent's home (Felce et al., 2011). They concluded adult children living in their parent's home have limited activity opportunities when compared to other staffed group homes (Felce et al., 2011).The researchers determined parents chose alternate residential placements in the community to enhance their son or daughter quality of life in the following areas: (a) emotional well-being, (b) interpersonal relations, (c) material well-being, (d) personal development, (e) physical well-being, (f) independence, (g) self-determination, (h) social inclusion, (i) occupation and rights (Felce et al., 2011).

Parents of adult children with intellectual disabilities in my study reported staffed group-homes as being the best option for their son or daughter living in the community. The results aligned with Felce et al. (2011) in that many parents chose group-home placement over other residential placements because group-homes supported their son or daughter being independent as possible. For example, group-home staff provided instruction to enhance their son's or daughter's independent living skills such as cooking, cleaning, shopping, and budgeting. I noted the parents reported group-home staff supporting their adult child with finding work or volunteer opportunities in the community; therefore, their adult child learned how to dress, manage their time, and ensure they intermingled with their peers, staff, and coworkers. Consistent with Felce et al. parents wanted their son or daughter to have a social life where they could make friends and access social activities in the community. Although the Felce et al. investigation was quantitative, the qualitative nature of the study I conducted confirmed many of their results based on parents' specific experiences.

The results of Felce et al.'s (2011) study reinforced the need for parents to be involved in the decision-making process around group-home placement for their adult child. It was evident parents are good advocates for their adult child and this alone supports the enhancement of their adult child's overall quality of life. Parents identified restrictions they had, which prevented them from caring for their adult child. These included having health problems, financial problems, single parenting, and widowhood. Lastly, the parents based their decision concerning group-home placement upon the group-homes ability to address the limitations and areas of concern they could not address or correct in their homes.

Limitations of the Study

The parents lived in a specific geographic region, the northeast shoreline of the Uniteds States with an adult child placed in a group-home in the local area. I considered the geographic region as a limitation because of the potential to decrease transferability. Regional differences and distinct cultural patterns within varying populations could have possibly affected the perspectives of those who experienced placing their children because of the anticipated social response based on where the family lived. All the participants in the study were female participants except for one male participant, which may limit the study outcomes to gender differences. Although I achieved data saturation, the sample size of 10 participants is a limitation. A larger pool of participants could have created additional themes that were more generalizable to the research population.

Internal and External Validity Threats

I conducted the study in an appropriate manner, to ensure internal validity, which ruled out irrelevant factors in the data collection process. Some of the internal threats to this qualitative research were (a) history, (b) maturation, (c) observer, (d) selection, (e) attrition or mortality, and (f) spurious conclusions (Yin, 2014). In this study, I was the data collection instrument due to the in-depth interviews of the 10 parent participants and observations of the parent participants in natural settings. The threats to internal validity are based on the researcher’s data collection characteristics and biases. To prevent internal validity threats, I asked all interview questions the same way, asked general questions that were easier to answer, conducted interviews in a neutral and comfortable setting in the community, and ensured the confidentiality of all participants (Yin, 2014).

The threats to external validity for this study were (a) selection, (b) setting, (c) history, and (d) construct (Yin, 2014). To reduce threats to external validity I fully described subjects and sites from this study, which enhanced the comparability to other studies. I ensured the setting for all 10 parent participants remained the same and historical experiences of groups or cultures and did not discuss the topics in the data collection process. Lastly, I examined current findings and prior research to ensure comparability.

To ensure content validity, I reviewed the interview questions and transcripts to assess whether they accurately measured what I wanted to know about the parent's decision-making process around group-home placement for their adult child with an intellectual disability (Simon, 2011). I employed content validity strategies of member checking, providing rich and thick descriptions, and stating researcher bias. I conducted member checking by having the participants confirm the accuracy of their words transcribed prior to coding (Kornbluh, 2015). To assured content validity by sending all transcripts and interviews to the contributing participants for their final approvals. The participants all indicated satisfaction with the recorded and transcribed interviews, and they did not identify any discrepancies from the recordings or transcripts.

In providing a rich and thick description of the setting, I assured the reader could create a realistic understanding of the participant's experience (Agrey, 2014). Using verbatim transcriptions resulted in the inclusion of detailed information throughout the analysis process. I identified and verified themes, patterns, and quotes from each participant's description of their decision-making process and their statements validated the data analysis.

Content validity refers to the appropriateness of the content in qualitative instruments such as the interview process (Simon, 2011). I used myself as a research tool by going over the data multiple times. After transcribing each interview, I reviewed all transcripts for accuracy. To establish dependability, I checked transcripts for mistakes and to assure the consistency of codes and definitions (Elo et al., 2014; Peredaryenko & Krauss, 2013). Re-checking data and emerging themes reduces researcher bias while increasing the validity of the outcomes (Peredaryenko & Krauss, 2013).

Recommendations

There are numerous ways in which future research could build upon this current study. One recommendation would be to include adoptive parents, foster parents, and siblings in the decision-making process since they are heavily involved with the adult child who has an intellectual disability in cases of death, severe illness, and or absence of the biological mother and father. The adoptive and foster parents could share their lived experience from a different perspective, leading to a possible comparison between how their decision of group-home placement was similar or differed from the biological parents. Also, siblings would have the opportunity to share their lived experience as a caregiver, and describe how they became responsible for their brother or sister. Their decisions would not be based on physical limitations resulting from age. Given different reasoning than the parents, who would be older, they could also explain what led them to choose group-home placement as the best option for their sibling.

Participants B, C, and J related that their final decision-making process centered on the adult child’s desire to be more independent. They felt their adult child wanted to experience life like other adults without an intellectual disability. Future researchers could review the outcomes of the parent's decision-making process to determine if the decision would vary if the adult child made their own choice, without support from their parents.

Limited research exists on adults with intellectual disabilities because they are a vulnerable population, making it challenging to use them as participants. In the future, if the researcher can assure the adult child with intellectual disabilities has the capacity to comprehend and withstand the entire research process without any negative side effects, researchers can pursue additional studies. For example, individuals with intellectual disabilities who have the capacity to complete the study could describe their lived experience and satisfaction with living in a group-home setting or explain how moving out of their parent's home affected their lives.

Quantitative research could provide an opportunity to use an online survey as the data collection instrument to contact participants from a larger pool of participants in an expanded geographic area. Administering surveys to a larger population of participants would increase the chances of having more male participants, younger participants, and other ethnic groups included in this study. The results would have greater reliability, transferability, and confirmability (Suri, 2011).

Recommendations for Professional Practice

Currently, there are few higher education courses addressing problems associated with adults with intellectual disabilities. The curriculum in higher education institutions fail to acknowledge difficulties faced by parents struggling with the decision to integrate their adult child into a residential group home setting. Furthermore, laws require higher education institutions to make accommodations for students with intellectual disabilities. However, they do not include how people acquire intellectual disabilities and the hardships faced by the individuals and parents in the program of study (ADA, 2009). Professional practice and coursework could introduce students and practitioners to the parental decision-making process concerning group-home placement. Increased knowledge of this specific population would help professionals understand family dynamics and alternative living arrangements for individuals with intellectual disabilities.

The human growth and development curriculum could address the causes of individuals with intellectual disabilities developmental delays. The course would address the IQ scores of individuals with intellectual disabilities and their adaptive and cognitive functioning (APA, 2014). Practicum and internship experiences can increase students' awareness by providing direct supports to individuals with intellectual disabilities and their parents. Direct services can take place in the form of advocacy, individual, family, and group counseling. The crisis management course could address crisis issues influencing the parent's decision-making process including (a) physical aggression, (b) lack of family support, (c) death/absence of a spouse, (e) caregiver medical conditions, (f) mental health behavioral disorders, (g) verbal aggression, (h) financial burden, (i) hospital/emergency, and (g) adult child medical conditions. The career development curriculum can address employment and advocacy opportunities for parents and adult children with intellectual disabilities in the community. This curriculum could also introduce job opportunities for future counselor educators and supervisors such as case management, crisis counseling, mental health counseling, vocational counseling, residential managers, day support managers, and entrepreneurs. The marriage and family therapy curriculum could introduce how the parent decision-making process around group-home placement affects the family dynamics or contributes to marital problems. The tailored curriculum could introduce family roles and relate them to the decision-making process.

Lastly, various types of intellectual disabilities/autism spectrum disorder, childhood disorders, eating disorders, and all other mental health disorders that affect individuals with intellectual disabilities and their families could be discussed in Mental Health-DSM-5 and epidemiology curriculums. Including subject matters around intellectual disabilities and the parent decision-making process around group-home placement in the school curriculum would inform students and family members about the history, biases, and family dynamics, which play a vital role in the lives of individuals with intellectual disabilities and their parents.

Implications

As an owner of an agency that provides services for individuals with intellectual disabilities, I have encountered several parents experiencing pressure regarding placing their adult child in a group-home setting. Earlier in my career, I learned adults with intellectual disabilities have rights, and should be able to make their own decisions whenever possible. Nevertheless, I learned parents have a vital role in the decision-making process because their adult child does not always comprehend matters affecting their health and safety.

Many parents are advocates for their adult children who do not have a voice due to their intellectual disability. As a supervisor, I sat in countless meetings with parents who struggled to maintain their adult child in the home due to physical aggression, verbal aggression, property destruction, and the need to attend to significant medical conditions. During these meetings I asked myself several times, “Why don’t they place them in a group-home”? Or, “What would it take for the parents to feel some sense of urgency around the decision for group-home placement”? I thought pursuing research on this topic would be effortless, and I could easily identify large amounts of literature on the topics related to the parent’s decision-making process and group-home placement. I had researched and completed various papers related to topics on individuals with intellectual disabilities and residential placements early in my graduate and doctoral program. Later, I developed a passion to learn more about the parents level of involvement in the decision-making process of their adult child group-home placement. I knew completing further research would increase my knowledge and awareness on this research topic, if I had the chance to interview and interact with the participants myself. This dissertation became the result of that endeavor. After completing my dissertation, I plan to publish a small booklet, which would allow me to disseminate information to parents struggling with a decision of group-home placement and community stake holders who are struggling to support and advocate for individuals with intellectual disabilities and their parents. The parental decision-making process regarding group-home placement for their adult child with an intellectual disability can create social change and educate counselor educators and supervisors all over the world. Illuminating this population’s insights benefits future researchers by contributing additional and expanded qualitative outcomes within this understudied population. Thematic outcomes can enlighten counselors about the struggles the parents of adult children with intellectual disabilities confront and how these challenges inform and influence decisions regarding alternative living arrangements. This includes parents enduring emotional and physical stressors, caregiver burden, role, and relationship strain, along with navigating the difficulties and benefits of group-home placements (Gibbons et al., 2016; Grossman & Webb, 2016; Heller et al., 2015). Each of these individual issues could become the focus of continued research to further enhance providing specialized supportive services within the broader population of adults with intellectual disabilities. Targeted approaches could emerge from understanding the specific obstacles parents experience leading them to consider other caretaking options (Williamson & Perkins, 2014). Additional literature and research on this topic could inform organizations seeking to expand or reduce services. Reasons for placement in various facilitates drive budgetary and service development decisions. Administrators and managers could consider the driving forces behind parent's decisions when developing future strategies for service delivery. An informed community of care can respond to the needs of both parents and adult children with intellectual disabilities, improving their quality of life and positive outcomes for the future of their all their family members.

Conclusion

The ten participants in this study opening shared their decision-making process. They appeared to be comfortable with the interview process, which was completely unexpected. I learned several things from interviewing each participant. For example, I learned parents do not want to give-up on their children, and they normally will not unless their adult child is at risk of hurting themselves or others. I learned parents considered several alternatives to group-home placement, such as independent living, supportive in-home residential services, and sponsored residential placement. Also, parents do not seek group-home placement as their first option because they do not want to feel like they failed or carry the label of an inadequate parent. Finally, parents have a fear of group-homes because they feel they will lose their connection with their adult child.

Parents diligently research group-homes to explore all the opportunities they offer their adult child with intellectual disabilities. These devoted parents conveyed in detail their triggers, hardships, and experiences around group-home placement decisions. They also expressed the highs and lows of caring for their adult child before and after the decision of group-home placement. These participants taught me the true meaning of selfless love, as each participant constantly put the needs of their adult child before their own. I learned it is imperative not to give up on your children. However, if you cannot personally help them, it is best to seek community resource providers who can provide a better or more stable quality of life. Parents should continue to be a voice for their adult child and teach their adult child self-advocacy sills. The parents involved in the decision-making process enhanced their adult child's quality of life and increased their chances of being successful in today's society. In this study, parents who selected group-home placement for their adult child with an intellectual disability because the homes provided the highest level of community integration, increased independence, and offered a nurturing family like environment.

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Appendix A: Flyer

Doctoral Study Opportunity

Offering $10 gift card for Participation

- **Do you have an adult offspring with an intellectual disability living in a group-home setting?**

- **Would you like to share your experience and decision-making process around group-home placement for your son or daughter?**

- **If you are the biological parent of an adult offspring with an intellectual disability who is currently living in a group-home setting, and would like to participate in a confidential doctoral dissertation study please contact:**

******LaShaunda Reese, Doctoral Student (757) 435-5297******
Dr. Jeffrey Edwards, Doctoral Chair (630) 890-7440

Appendix B: Letter to Group-home Directors

Date:

Name of (Group Home Chief Executive Officer/Executive Director)
Address

Dear (Name),

My name is LaShaunda Reese and I am a doctoral candidate at Walden University. I am conducting dissertation research on parent's decision-making process around group-home placement for their adult child with an intellectual disability. There are several studies that indicate the parents reasoning behind this decision; however, there is not a decision-making process to outline the steps that led to this difficult decision. It is my hope that counseling professionals, care givers, researchers, and community advocates may gain a better understanding of the family dynamics of parents that have made the decision to choose group-home placement based on a more in-depth study on the parent decision making process. It is my intent to develop a decision-making process that creates a social change, and has an impact on parents and other individuals in the human service field who provide services to this vulnerable population. The results of this study may also establish the need for additional resources for parents that have chosen a group-home placement for their son or daughter with an intellectual disability.

I would really appreciate your support in conducting research on this noteworthy topic. If willing, I need for you to identify individuals in your group-home that have a living biological mother or father that may be interested in participating in this study. It is imperative that the identified biological parents live within the Hampton Roads or Tidewater area. Once identified, I would like to meet with them to discuss the nature of this study. The participants of this study must be the biological mother and father, and their adult child must be currently living in a group-home setting. The participants are free to choose whether or not to participate and can discontinue participation at any time. Information provided by the participants will be kept strictly confidential.

I would welcome a telephone call from you to discuss any questions you may have concerning this study and your role in identifying research participants. I can be reached at [truncated] or emailed at [turncated] or if you have questions you may also contact [truncated] at [truncated]
Sincerely,

LaShaunda Reese, Doctoral Candidate

Walden University

Appendix C: Letter to Participants

Date:

Name of Participant
Address

Dear (Name),

My name is LaShaunda Reese and I am a doctoral candidate at Walden University. I am conducting dissertation research on the parent's decision-making process around group-home placement for their son or daughter with an intellectual disability. There are several studies that indicate the parents reasoning behind this decision; however, there is not a decision-making process to outline the steps that led to this difficult decision. It is my hope that counseling professionals, care givers, researchers, and community advocates may gain a better understanding of the family dynamics of parents that have made the decision to choose group-home placement based on a more in-depth study on the parent decision making process. It is my intent to develop a decision-making process that creates a social change, and has an impact on parents and other individuals in the human service field who provide services to this vulnerable population. The results of this study may also establish the need for additional resources for parents that have chosen a group-home placement for their son or daughter with an intellectual disability.

I really appreciate your time and consideration to participate in this study. In order to fully understand your family dynamics and decision-making process, we need to meet one time for approximately one hour. The meeting will be held in a public location such as a library meeting room or office. During the meeting you will not be required to do anything that makes you feel uncomfortable. The meeting will allow me to build a rapport with you, and learn more about your decision to place your adult child in a group-home setting. All information gathered during the meeting will remain confidential.

Please contact me at your earliest convenience to schedule a date and time that we can meet. My telephone number is [truncated]. You can also email me at [truncated]or if you have questions you may also contact [truncated] I look forward to hearing from you.

Sincerely,

LaShaunda Reese Doctoral Candidate
Walden University

Appendix D: Sample Letter of Cooperation from a Research Partner

Community Research Partner Name
Contact Information

Date

Dear Researcher Name,

Based on my review of your research proposal, I give permission for you to conduct the study entitled "The Parents Decision-Making Process Around Group-home Placement for their Adult Child with an Intellectual Disability" within the Insert Group-Home/ Name of Community Partner. As part of this study, I authorize you to interview, tape record, and transcribe data collected from biological parents that have made the decision to place their adult child with an intellectual disability in a group-home setting. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: Insert a description of all personnel, rooms, resources, and supervision that the partner will provide. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization’s policies.

I understand that the data collected will remain entirely confidential and may not be revealed to anyone outside of the student’s supervising faculty/staff without permission from the Walden University IRB.

Sincerely,

Authorization Official

Appendix E: Letter of Cooperation from a Service Provider/Counselor

Date:

Name of Service Provider

Address

Dear Walden University,

I give LaShaunda Reese permission to provide my contact information to research participants who feel distressed while participating in her research study, "Parent Decision-Making Process around Group-home Placement for Their Adult Child with an Intellectual Disability."

I agree to provide counseling services to the parent participants for free. This will ensure there is not an expense for the participants. Also, I will provide additional counseling resources such as free counseling hotline numbers and free community counseling agencies if the parent participants require additional supports or services outside the scope of my experience.

I will provide my contact information to parent's that may need my support after participating in this study. As part of this study, I agree to provide support to parents that are overwhelmed with their decision around group-home placement. I understand individuals' participation in counseling services will be voluntary and at their own discretion. Also, I understand the parents reserve the right to withdraw from the study and counseling at any time if their circumstances change. I agree to provide free counseling services to this population in the most appropriate setting, and that all information in the counseling session will remain entirely confidential. My name is (Service Provider/Counselor) and I can be reached at [truncated] if you have any additional questions or concerns.

Respectfully,

Service Provider/Counselor)

Appendix F: Interview Questions

Date: ____________________________Location: _________________________

Name of Interviewer: __________________Name of Interviewee:__________________

Demographic Interview Number One:

1. Please tell me if you are the biological mother or father?
2. What is your age?
3. What is your race?
4. What is your socioeconomic status (high, middle, low)?
5. What is your marital status?
6. What is your highest level of education?
7. What is your current occupation?
8. How many of your children are currently living in the home?
9. How many children do you have with an intellectual disability?

1.What decision-making processes do parents use when deciding to place their adult child with an intellectual disability in a group-home setting?

- Please identify the step-by-step process you engaged in to arrive at the decision of a group-home placement for your adult child.

2. How did you come to the conclusion of group-home placement for your adult child with an intellectual disability?

- Describe the initial experience that triggered a possible decision for group-home placement. Describe the final experience that that made group-home placement a definitive decision?

3. What factors contribute to the decision to make group-home placements as opposed to other residential care facilities?

- What significant factors contributed to your choice of group-home placement opposed to other residential care facilities?

During the course of my activity in transcribing data for this research: **"Parent Decision-Making Process around Group-home Placement for their Adult Child with an Intellectual Disability."** I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement, I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access, and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**