2019

Parental Needs Regarding the Future of Their Adult Intellectually Disabled Child

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The Office of the Provost

Walden University
2019

Abstract

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by

Jeannie Brown

MS, Kaplan University, 2014

BA, John Jay College of Criminal Justice, 2008

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Criminal Justice

Walden University

October 2019

Abstract

The problem examined in this study was the lack of policy in New York State regarding the provision of prioritized residential services for intellectually disabled individuals who are being cared for by an aging caregiver. The purpose of this qualitative phenomenological study was to explore and document the needs experienced by aging parents regarding securing the future of their intellectually disabled adult child. The theoretical framework for this study was based on Sabatier's advocacy coalition framework. The research questions examined the lived experiences of aging parents caring for an adult child with an intellectual disability what parents perceive their needs are in order to secure their adult intellectually disabled child's future. Data were retrieved from 5 parents who resided in New York State. The findings from this study confirmed existing literature indicating that aging parents will need to secure residential placement or alternative living arrangements before they can no longer care for their adult intellectually disabled child. Another finding from this study was that the pertinent service delivery program does not provide direct assistance to these families. Therefore, advocacy was a necessary action in order to obtain services. The voices of the parents could influence policy makers to make aging parents with an adult intellectually disabled child a higher priority when seeking residential placement, provide direct representation from OPWDD, and provide residential placement that fits the ID adult's needs. These programmatic changes may result in positive social change for this population.

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Dedication

I would like to dedicate this body of work to my son RJ who has an intellectual disability. Although his disability has hindered him in a lot of ways, he was able to navigate the world as if he was born without a disability. Thank you for teaching me to be patient and understanding; but most importantly teaching me how you see and understand the world. Because of you I was able to give back and share my love and advocate for people who are just like you.

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Chapter 1: Introduction to the Study

Introduction

The New York State Office for People with Developmental Disabilities (OPWDD) was established in 1978 as the Office of Mental Retardation (OPWDD, n.d., p. 1). The agency was an "independent cabinet-level state agency, largely because of the need for an autonomous entity to implement the Willowbrook consent decree and the resulting closure and downsizing of New York institutions (OPWDD, n.d., p. 1).

The Willowbrook decree established that residents of Willowbrook had a constitutional right to be protected from harm and required NY state to take immediate steps to improve the lives of those who lived there and to ready each resident…for life in the community at large and called for the placement of Willowbrook residents in the least restrictive and most normal living conditions possible (OPWDD.n.d.).The New York OPWDD grew over several decades which allowed this agency to support approximately 280,000 individuals in New York State (OPWDD.n.d.). The OPWDD provides important services including residential placement services for disabled adults (OPWDD.n.d.). Residential services are funded through the New York State Medicaid program which allows qualified disabled individuals to live in residential settings in the community (OPWDD.n.d.). Medicaid also funds family support services which assist families who care for a disabled family member residing at home (OPWDD, n.d.).

According to Federal Law P.L. 109-171, states have the option of creating home and community-based services and supports within the state Medicaid plan (OPWDD, n.d.). (States must establish a more stringent eligibility standard for placement of individuals in institutions than for services in a home and community-based setting. This act allows states to impose caps on services and to establish waiting lists for new home and community-based optional services (OPWDD, n.d.). According to New York State Regulation 1001.10 Residential Services; “The operator shall be responsible for the provision or arrangement of resident services, which shall include, at a minimum, housing, and 24-hour on-site monitoring (p.1)”.

Residential programs are licensed through OPWDD to provide different levels of supportive housing that are operated by OPWDD or not-for-profit agencies (OPWDD, n.d.).Residential services include “adaptive skill development; assistance with activities of daily living; community inclusion and relationship building; training and support for independence in travel; adult educational supports; and development of social, leisure, self-advocacy, informed choice and appropriate behavioral skills” (OPWDD, n.d., p. 1). Residential categories assist OPWDD to make decisions for residential placement for individuals and families seeking residential services. Residential support categories describe different circumstances based on the individual’s needs which are broken up into three categories. These consist of emergency need, substantial need or current need (OPWDD, n.d.). Although OPWDD uses category levels, intellectually disabled adults being cared for by an aging parent are not a priority (OPWDD, n.d.). As a result, they are not placed on the emergency needs list which gives an adult child less of a chance of being placed before their aging parent can no longer care for them (OPWDD, n.d.). .

The literature reviewed for this study revealed that other researchers have investigated aging parent’s stressors caring for adult children with intellectual disabilities, poor planning for an adult child, and lack of support from the government with placement services (see Band-Winterstein & Tova-Avilia , 2017; Breidenbach ,2016; Hartford Courant, 2014; Kirby-McLemore, 2017; Pryce, Tweed, Hilton, & Priest, 2017). There is a gap in the literature examining the lack of policies providing prioritized residential services for adult children with an intellectual disability living with an aging parent. This study will contribute to the literature by providing data for policymakers to consider when creating new state policies related to prioritizing residential placement and assisting parents with securing their adult child's future.

Background

Hartford Courant (2014) addressed the concerns of aging parents for their adult children with disabilities. The article contended that aging parents need support from the government with securing a residential placement (Courant, 2014). Pryce et al. (2017) examined aging parents who care for their adult children with intellectual disabilities. Pryce et al. employed semi structured interviews with 10 families and explored aging parents and their perceptions of the future (Pryce et al, 2017). The research contended that most aging parents are obligated to care for their special needs adult child (Pryce et al, 2017). Band-Winterstein and Tova-Avilia (2017) identified ways aging parents understood and conformed to their parental roles by taking care of their adult children with special needs. These parents' entire life revolved around their intellectually disabled children whose care caused stress and was a burden (Band-Winterstein and Tova-Avilia, 2017). The research findings provided an enriched understanding of how aging parents handle aging and caring for their adult child with special needs. Kirby-McLemore (2017) suggested that parents who have children with special needs often face many challenges. A challenge they face is determining who is going to care for their child after they are gone (Kirby-McLemore, 2017). The article concluded that creating and reviewing future care plans yearly is important in establishing a consistent and stable life for adult children with special needs (Kirby-McLemore, 2017). Breidenbach (2015) examined the number of adult children with special needs living with aging parents and their uncertainty for their children's future. The article stressed that aging parents need to plan for their adult child's future and the need for residential placement assistance (Kirby-McLemore, 2017). In summary, the literature found suggested that aging parents will eventually need a plan for their intellectually disabled adult child. The literature further suggested that caring for an adult child with an intellectual disability (ID) can be very stressful challenging and create burden.

Problem

Adult children with an intellectual disability face a lifetime of uncertainty when their primary caregiver is their aging parent. Currently, the OPWDD provides residential placement assistance for over 130,000 people with an intellectual disability (OPWDD, n.d.). The residential request list has three categories which consist of emergency, substantial, and current need for individuals who are seeking residential placement; however, according to OPWDD, a caregiver's age does not always indicate urgency need (OPWDD, 2016). Because of this, intellectually disabled individuals still face a life of uncertainty because there is no policy in New York State that provides prioritized residential services for intellectually disabled individuals being cared for by an aging caregiver. This problem will impact these adult children because their aging parent will eventually not be able to provide care for their adult ID child. The state is not prioritizing these individuals which can result in the state having to find residential placement that may not fit that adult child's needs or unfavorable placement such as nursing homes, psychiatric hospitals, or face homelessness.

McKiernan, Shaffert, and Murray (2015) indicated that families living with adult children with an intellectual disability are their primary caretakers; this causes the caregiver to experience stress, exhaustion, and worry about who will care for their adult child after they are gone (McKiernan et al, 2015). For all these reasons, this research will fill in the gap regarding the need of having a policy that addresses the need for prioritized residential services in New York State for an adult child with an intellectual disability living with an aging parent. The findings from this research could provide much-needed insight to leaders and policymakers into what support aging parents need from the government to secure their adult child’s future. The implication for social change includes informing the state of the importance of a policy that provides prioritized residential services for an adult child with an intellectual disability living with an aging parent. Having this policy will allow intellectually disabled adults to live richer lives after their parent are not able to care for them.

Purpose

The purpose of this qualitative phenomenological study was to explore and document the needs of aging parents regarding what they believe would help them plan for their intellectual disabled child’s future. This study used a qualitative methodology to gather data related to the lived experiences of aging parents caring for intellectually disabled adult.

Research Questions

The focus of this study was to examine aging parents' perceptions of what they need to secure their ID child's future in New York State. The following question was the foundation of this study.

1. What are the lived experiences of aging parents caring for an adult child with an intellectual disability?
2. What do aging parents of an adult child with an intellectual disability perceive their needs are in order to secure their adult child's future?

Theoretical Framework

The theoretical framework for this study was based on Sabatier's (1993) advocacy coalition framework (ACF).

> According to Sabatier and Weible (n.d.) the ACF assumes that policymaking in modern societies is so complex, both substantively and legally, that participants must specialize if they are to have any hope of being influential. This specialization occurs within policy subsystems composed of participants who regularly seek to influence policy. (p. 192)

Because this theory addresses policy change and difficulty of changing policies without substantial influence, ACF is an approach that can provide aging parents and adult children the ability to advocate for their needs to the government in order to create a policy that will benefit all aging caregivers and adult children with intellectual developmental disabilities.

Users of the ACF assume that participants who are involved in policy have strong beliefs and are interested in transcribing those beliefs into real policies. "Because the ACF assumes that scientific and technical information plays an important role in modifying the beliefs of policy participants, it correspondingly assumes that researchers are among the central players in a policy process (Sabatier & Weible, n.d, p.192)".

A main focus of ACF is to update policies that are more than a decade old (Sabatier & Weible, n.d)". The Americans with Disability Act was established in the 1990s and needs to be updated to reflect specific disabilities and what governmental agency should be required to provide services based on the needs of this population (Sabatier & Weible, n.d)". ACF proponents further believe that policymakers do not like to change older policies so policy change is difficult (Sabatier & Weible, n.d,)". Therefore, the act separates the mature policies or laws, such as the 1990 Americans Disability Act, from newly created polices or laws such as the Improving Long-Term Care under Medicaid of 2006 the Deficit Reduction Act.

Mature policy subsystems are characterized by a set of participants who regard themselves as a semi-autonomous community who share an expertise in a policy domain and who have sought to influence public policy in the domain of interest groups and research institutions that have had subunits specializing in that topic for an extended period (Sabatier and Weible, n.d, p. 196)." In this situation, the experts will be the parents and families who can inform the government of their struggles and what they need for their adult disabled child to live a full and healthy life. ACF assumes policy participants' goals are to transcribe pieces of their beliefs in real policies before people who do not agree do the same (Sabatier and Weible, n.d.). To be successful, policy participants must find other policy participants who share the same views, resources, and who can come up with the same strategies (Sabatier & Weible, n.d.).

There is no policy in New York State that provides prioritized residential placement for intellectually disabled adults who reside with an aging parent. Therefore, using ACF as the basis for this study was to provide an understanding of lived experiences and the perceptions of aging parents caring for intellectually disabled adults seeking residential placement.

Nature of the Study

The nature of this study was a qualitative method with a phenomenological approach. The participants consisted of five aging parents from the ages of 50-70 who lived with their adult child who was intellectually disabled. Keely et al. (2016) reported that qualitative research could facilitate understanding and point out specific outcomes that are important to participants. I used semi structured interviews and my sampling method was purposeful sampling. To analyze data, content analysis was used. By using content analysis, codes were created as well as themes to identify potential gaps in the data.

A qualitative approach was a general way of thinking about conducting qualitative research. It describes, either explicitly or implicitly, the purpose of the qualitative research, the role of the researcher(s), the stages of research, and the method of data analysis (Social research methods, 2016). Phenomenology focuses on people's personal lived experiences and their understanding of the world (Social Research Methods, 2016). The phenomenological approach allows the researcher to obtain an understanding of the experiences of the participants and what their perceptions are based on their reality and expertise (Social Research Methods, 2016). .

Qualitative researchers use open-ended, semi structured or in-depth interviews (Jamshed, 2014). As the researcher of this study, I used open-ended questions to extract data from the participants selected. Face to face interviews is the most used format of data collection in qualitative research (Jamshed, 2014). According to Oakley (1998), qualitative interviews should not only be recorded but also be objected and strengthened. The biggest portion of the interview process was extracting the data and finding common themes and asking follow-up questions to ensure clarity and the participant's perceptions are interpreted. Participants were asked to talk about their perceptions and experiences during the interview, which were audio recorded. I then transcribed the interviews to ensure data accuracy, prevent bias and to provide a record of the interview.

Participants were five biological parents who resided with an adult intellectually disabled child who lived in New York State. Participants included parents whose adult children were on the nonemergency residential placement waiting list, considered residentially placed, or who might need residential placement in the future. According to Gonzalez (2009), when conducting phenomenological research, the sample size is selected to capture all the important facts within this approach; Gonzalez further suggested to achieve that goal a small sample size of less than 20 is common. I was interested in recruiting five participants to get a greater understanding on the needs of aging parents to secure their child's future and their experiences caring for and adult ID child. Data saturation was anticipated based on the already known concerns from the literature regarding a parent's struggles with securing residential placement. According to Guest et al. (2006), data saturation can be established with 12 interviews; more than 12 interviews are less likely to emerge a new phenomenon (Guest et al., 2006). If five participants were not able to provide enough data to obtain data saturation, a snowball sampling was considered to increase the sample to seven. Snowball sampling is a technique researcher's use by asking participants to help the researcher recruit other potential participants (Guest et al., 2006).

The procedure of obtaining participants is explained in Chapter 3. Interview questions were formulated by gathering detail descriptions of aging parents' perceptions and what those experiences reveal. Each participant's transcript was a detailed picture of his or her perceptions and experiences with a variation based on different experiences associated with each participant.

Definitions

The following terms have been used in this study:

Intellectual disability (ID): Intellectual disability "is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (American Association on Intellectual and Developmental Disabilities [AAIDD], n,d).

Residential Placement: Residential placement refers to “Residential programs are licensed by OPWDD to provide varying levels of housing and related services and are operated by OPWDD or nonprofit agencies” (OPWDD, n.d.).

Assumptions

I made the following assumptions during my study. Because aging parents know about raising their adult child with an intellectual disability and what they need to secure their child’s future, it was assumed that the sample would know the obstacles of trying to obtain residential placement. A second assumption was that the participants would answer the interview questions truthfully and openly. The purpose of this research was to understand the experiences and perceptions of aging parents with an intellectually disabled adult and what their needs are to secure their future.

Scope and Delimitations

The study included semi structured interviews with 5 parents who resided with an intellectually disabled adult child. To participate in this study, an individual needed to be the biological mother or father, between the ages of 50-70, who had an adult child with an intellectual disability. The adult child needed to be either on the substantial or current needs placement list, parent considered residential services, or would need residential placement in the future. The information in this phenomenological study was based on detail information gathered by the participants. The study was limited to interviews with parents because the focus of this study was to learn about the perceptions of the lived experience of aging parents caring for their adult ID child and what they needed to secure their adult child’s future. The perceptions of family members, stepparents, adoptive parents, siblings, or legal guardians for this study were not considered.

Transferability was obtained with the use of purposeful sampling; purposeful sampling is substantially used in qualitative research for the connection and selection of information-rich cases connected to the phenomenon of interest (see Lawrence et al., 2013). Because this study provided information-rich data regarding the participants, this allowed the participants to determine if the results related to their perceptions and experiences. Transferability is established when the researcher can provide the readers with proof that the research's findings could be applied to other “contexts, situations, times, and populations (Complete Dissertation, n.d.)

Limitations

This qualitative phenomenological study was restricted to participants who are aging parents between the ages of 50-70 with an intellectually disabled adult child who resided at home. All the data were retrieved from that sample of parents. The geographic location of the study was restricted to New York State.

In a phenomenological study, it is important for the researcher not to be biased or include their personal experience so a fresh outlook can be provided (citation). Because I have job-related experience connected to my research, it was natural to have biases that could affect my data analysis; therefore my goal was to conduct this research as if I have no knowledge of the topic. Bracketing was used to help mitigate my biases. My bracketing began by identifying any biases and preconceived notions regarding residential placement or OPWDD. To prevent biases, researchers should be able to write their research without any preconceived notions to obtain respect, trustworthiness, and prevent alienating your readers (Walden University, n.d.). Furthermore, the researcher should not form an opinion about the research being studied and write as if they were solving a mystery (Walden University, n.d.). To prevent my own biases during data collection, I approached the process as if I had no knowledge of the topic. Although it was impossible to completely bracket biases, removing all knowledge and preconceived notions to write an objective research and focus only on the perceptions and experiences of the participants is important. Again, phenomenological research should allow the researcher to be open-minded to new ideas and information to see things from a new perspective.

Summary

A manual and electronic literature review was conducted to explore the current literature related to aging parents' perceptions of what their needs are to secure their child's future. I continued this research by interviewing aging parents about the experiences they encountered working with OPWDD. Understanding aging parents' experiences dealing with OPWDD and their perceptions of what they need for their intellectual disabled adult child before they could no longer care for them was required to understand what areas OPWDD are not providing adequate assistance.

My goal for this study was to gain an understanding of what aging parents needs were to secure their child's future. Having provided a synopsis of the study along with its significance, background, and other pertinent issues, the next chapter examines the literature regarding aging parents' need of residential placement for their adult child, stressors for aging parents caring for an adult child with an intellectual disability and the lack of residential supportive services. This overview further includes literature research method, information on the theoretical framework, what researchers already identified about an aging parent with intellectually disabled children needing residential services. The literature I examined sets a foundation for the study which shows the need for further research of this phenomenon using a phenomenological method and advocacy coalition framework. Chapter 2 presented the literature review regarding this research.

Chapter 2: Literature Review

Introduction

Currently there is no policy in New York State that provides prioritized residential services for intellectually disabled individuals who are being cared for by an aging caregiver. I explored the perceptions of the lived experiences of aging parents caring for an adult child with ID and what the parents need secure their child's future. There is literature on this topic about parents seeking residential placement for their adult ID child. However, there was no research found that exclusively addressed what aging parents need to secure their adult ID child's future. There was one study completed in 2017 addressing older families' perceptions of the future of their adult children with an intellectual disability (Pryce et al., 2017). What made that study unique was the researcher explored the perceptions of older parents and adults with an intellectual disability regarding their future (Pryce et al., 2017).

The parents who participated in my study resided in New York State. In 2015, there were approximately 3,500 people with intellectual disabilities living with their aging parents (Mckiernan et al., 2015). Although this subject has been researched and studied in other aspects, there was no research found from the perception of aging parents and what they need to secure their adult child's future in New York State. However, using keywords such as *residential placement, parents, ID*, and *intellectually disabled* in the literature search, I found three studies directly related to the research topic.

In search for literature, one study relating to parents' experiences with residential placement for their adult child with ID (see Grey, Griffith, Totsika, V., & Hastings, 2015) was found. Expanding the search to include parents' perceptions of residential placement for their adult child with ID did not result in any additional research. Expanding the research parameters a third time using keyword *residential placement* resulted in a significant amount of research related to child/juvenile and elderly residential placement and a few literature searches focusing on residential placement for the ID population. Although literature was located, there was a limited amount of relevant literature that was completed in the last 5 years.

Residential placement is crucial for aging parents; however, they find their adult ID child on the waiting list over 10 years (Breidenbach, 2015. According to Breidenbach 2015, when parents register their adult ID child for residential placement, they are asked what their current needs are for residential placement (Breidenbach, 2015). The problem with this is, their current need may not be their future need, and an aging caregiver does not qualify for a high priority.

According to Fifield (2016), there are approximately 860,000 individuals with ID living with their families nationwide who have been waiting for residential placement for years. Because parents cannot afford to place their ID adult child in private care homes, they rely on state or nonprofit operated homes to become available to care for their adult ID child (Fifield, 2016). Subsequently, the number of older caregivers continues to grow, and their need for help becomes more prevalent. There have been a few states that have passed laws to make sure that older parents are given a chance to determine where and how their adult child with ID will live. For example, Tennessee passed a law in 2015 that addressed that anyone with an intellectual disability being cared for by a caregiver over the age of 80 will get the services they need for their ID child and Connecticut followed suit with a similar law but with caregivers over 70 (Fifield, 2016).

The literature examined below starts with background information regarding (a) causes of intellectual disabilities, (b) residential programs, (c) why aging parents seek residential placement, (d) Support for aging parents and (e) Future for ID adults. The literature review section will be summed up with a summary and conclusion.

Literature Search Strategy

To conduct this literature review, advanced searches for peer-reviewed articles using the Walden Library research databases, including ProQuest Central, EBSCOhost, and Academic Search and Google Scholar were used. The key words consisted of *residential placement, adults, intellectual disabilities, aging parents,* and *OPWDD*. There have been several studies completed regarding aging parents caring for their adult disabled child. However, my search did not show any studies regarding aging parent's perceptions of what they need to secure their ID child’s future in New York State.

Theoretical Framework

The theoretical framework for this research study was based on Sabatier’s (1993) ACF. “ACF is a framework of the policy process developed by Sabatier and Jenkins-Smith to deal with ‘wicked’ problems involving substantial goal conflicts, important technical disputes and multiple actors from several levels of government policy (Sabatier & Weible, n.d., p. 189)”. ACF posed a question which asked what issues justify the possibility of policy change taking place (Jenkins-Smith et al., 2014). Many research studies found using ACF was related to public health, gun laws, and foreign policies, which suggested that this framework was only geared to certain types of research (Jenkins-Smith et al., 2014). The ACF theory failed to address if forming a coalition will help change polices when going up against others who share different beliefs.

There does not seem to be any use of this theoretical framework in my research area. Therefore, the above ACF question as it relates to my research question in regard to what aging parents perceive their needs are to secure their adult ID child's future.

The ACF addresses various analyses of policy emphases on encouraging comparability, replicability, and falsification, which were established to comprehend the policy process in North America (Sabatier & Jenkins-Smith, 1993). It reflects public policy as an interpretation of challenging beliefs, specifically concerning disputed issues (Sabatier & Jenkins Smith, 1999). Because of this, a needs assessment needs to be conducted of the needs expressed by aging parents to secure their adult ID child's future. No matter how many times aging parents voiced their concerns regarding this issue, there still has not been any change.

In order to conduct a needs assessment, (1) I collected existing data regarding the problem. Then, determine what the coalition would like to do with the problem to solve it in the future and then provide the collation the information that is needed to decide if their goal or problem was solved or achieved. (2) conduct interviews or surveys on the problem, (3) conduct a public policy review of the current existing laws and regulations, (4) researching what has already been done to solve this problem, (5) possibly conducting a focus group and (6) possibly sponsoring an event for participants to express their views (NHSA, 2001). "Conducting a comprehensive needs assessment and developing a needs-based strategic plan is the only way a coalition/organization can truly be effective in reaching their goal". Furthermore, applying different ideas or strategies without knowing if they will be effective would not be beneficial. Researching the problem and then developing a resolution that will address the problem is the most logical way to achieve a goal (NHSA, 2001).

The stages of public policy which will stem from a needs assessment are the following:

- Problem recognition
- Agenda Setting
- Policy Formulation
- Policy adoption
- Budgeting
- Policy implementation
- Policy evaluations

The ACF (Sabatier, 1998; Sabatier & Jenkins-Smith, 1993, 1999 ;) explained that the policy process is a fight between the *coalitions of actors* who support their beliefs about policy issues and resolutions. The fight occurs within *policy subsystems* which are explained as a set of actors who are consistently worried about an issue and constantly looks to change a public policy related to a problem (Sabatier & Jenkins-Smith 1999. "Following works in cognitive and social psychology, the ACF argues that actors perceive the world and process information according to a variety of cognitive biases which provide heuristic guidance in complex situations (Sabatier & Jenkins-Smith 1999, p. 142)".

In relation to public policy, such influence is supported by belief systems regarding how a certain problem is outlined and how it should be handled. Within these belief systems ACF explains three categories: A deep core of fundamental normative and ontological axioms that define a vision of the individual, society and the world, a policy core of causal perceptions, basic strategies and policy positions for achieving deep core beliefs in a given policy subsystem, and a set of secondary aspects comprising instrumental considerations on how to implement the policy core. It is assumed that these structural categories of belief systems show decreasing resistance to change, with the deep core displaying the most, and the secondary aspects the least, resistance. (p.142)

ACF argued to determine the actor's beliefs; the advocacy coalition tries to influence government institutions to adapt by what they perceive the policy should look like (Sabatier & Jenkins-Smith 1999, p. 142). To get the attention of the government, coalition actors use governmental structures to rally and protest their needs (Sabatier & Jenkins-Smith 1999, p. 142). Although advocacy coalition framework focuses on core beliefs of policies, advocacy coalition members must coordinate with other members that are geared towards manipulating the policy development. Research describing and explaining advocacy coalitions may identify coalitions, beliefs, collaboration, stability, and defections (Sabatier & Jenkins-Smith, 1999). This theoretical framework of policy change is well aligned using the belief systems. A significant policy change relates to adjustment in essential and insignificant policy changes related to differences in secondary beliefs, which aligns with the perceptions of aging parents.

The two variables of the ACF theory are (1) stable systems of parameters (constitutional and societal structure and natural resources which change slowly) and (2) external events (public and economic dislocation, which often change over a decade and which are hypothesized to be necessary but not sufficient conditions for major policy (Sabatier, 2007, p. 205). The ACF support empirical research into policy processes within and across countries. While the framework provides a set of general questions about the policy process, each area of theoretical emphasis lays out a number of testable hypotheses. The level of attention devoted to these hypotheses varies and some have attracted more attention than others (Sabatier & Jenkins-Smith 1993; 1999).

The elements of ACF that can apply to understanding the problem that is being addressed in this research include the following factors.

- Actors making choices: Policymaking includes a significant amount of people. To make policy simpler, policy theories often identify key actors. Actors can be individuals in interest groups or governments bodies (Weible, 2014). In this research would be the parents advocating for their needs of their adult ID child.
- Networks or subsystems: “These are the relationships between actors responsible for policy decisions and the ‘pressure participants’ such as interest groups with which they consult and negotiate. Senior policymakers delegate responsibility for policymaking to bureaucrats, who seek information and advice from groups” (Weible, 2014, p. 2).

Exploring parents' perceptions about what their needs are to secure their adult ID child's future is squarely aligned with the focus of the ACF. This study is not geared only to ascertain what supports parents with an ID adult child need, but to provide parents with a voice to advocate for their needs. This study can hopefully get a policy enacted or get American with Disability Act updated to reflect specific disabilities and what state government agencies should be required to provide based on the needs of ID adults and their parents or caregivers.

Causes of an Intellectual Disability

According to The Arc (n.d.) intellectual disabilities are the result of any condition that negatively affects brain development before birth, during birth, or during childhood. Although research as discovered several hundred causes of intellectual disability, the cause remains unknown for close to one-third of people affected (The Arc, n.d.). Down syndrome, fetal alcohol spectrum disorder, and Fragile X syndrome are three major known causes of intellectual disability (The Arc, n.d.). The causes of intellectual disabilities in more details are categorized as genetic conditions that can come from genes inherited from parents, complications during pregnancy, and problems before birth such as alcohol use by the mother, problems at birth which can include prematurity and temporary loss of oxygen, and problems after birth that stem from childhood diseases. An intellectually disabled individual could function within a mild, moderate, severe, or profound range of an intellectual disability (The Arc, n.d.). A mild intellectual disabled person may need minor assistance with money management, food shopping, and other general daily living skills; a moderate individual needs assistance with personal care, feeding, and showering on an ongoing basis; a severe individual needs assistance with all daily living skills; and a profound individual needs total assistance with all aspects of their life (OPWDD, n.d.).

Residential Programs

According to Federal Law P.L. 109-171 this act gives states the option of creating home and community-based services and supports within the state Medicaid plan, without obtaining a waiver. States are permitted to allow individuals to choose to self-direct services. States must establish a more stringent eligibility standard for placement of individuals in institutions than for services in a home and community-based setting. Unfortunately, provisions added to the act before passage allows states to impose caps on services, and to establish waiting lists for the new home and community-based optional services. (p. 1).

> According to New York State Regulation 1001.10 residential services:(a) The operator shall be responsible for the provision or arrangement of resident services, which shall include, at a minimum, housing, 24-hour on-site monitoring, daily food service, case management services, development of an individualized service plan, personal care and/or home care services. (p. 1).

The OPWDD is a New York State agency who licenses residential programs that provide different levels of housing and related services which are managed by OPWDD or not for profit agencies. Residential programs entail "adaptive skill development; assistance with activities of daily living; community inclusion and relationship building; training and support for independence in travel; adult educational supports; and development of social, leisure, self-advocacy, informed choice and appropriate behavioral skills” (OPWDD, n.d.,p.1). This description provides a clear understanding what residential programs consist of and who manages these programs.

Residential Support Categories allows control for deciding admission to OPWDD residential programs. Residential support categories define an individual’s situation or the situation of the individual’s family or caretaker to determine what category that individual will fall under. The three categories are emergency, substantial and current needs are described verbatim.

(a) Emergency Need

Note: Residential Support Categories, OPWDD, n.d.

“Homelessness or Immediate Risk to Safety”
“Individual has no permanent place to live or is at imminent risk of having no permanent place to live. The individual is at imminent risk to health and safety”.
“Individuals Living with Family/Caregivers."
“Individual whose family/caregiver has an emergency where the primary caregiver is incapacitated for example due to long-term illness and permanent injury, and there is no other available caregiver."
“Individuals Living in Other Settings”
“Individual is ready for discharge from a hospital or psychiatric facility; ready for release from incarceration; in a temporary setting such as a shelter, hotel, or hospital emergency department."

(b) Substantial Need

“Individuals Living With Family/Caregivers"
“Individual has an increasing risk of having no permanent place to live. This includes an individual whose family or other caregivers are becoming increasingly unable to continue to provide care to manage the individual's needs, including behavioral needs”.
“Individual is at increasing risk to their health and safety, or presents an increasing risk to the safety of self or others."
“Individuals Living In Other Settings”
“Individual otherwise presents a substantial need for residential placement because they are: transitioning from a residential school or Children’s Residential Program (CRP); residing in a developmental center and ready to move to the community; or residing in a

skilled nursing facility and ready to move to the community."

(c) Current Need

"Individual needs residential placement has requested and is ready to seek a residential opportunity actively; the need is neither an emergency nor substantial as defined above."

These categories are decided when a referral is made by a person of interest which is then reviewed by the placement team at one of the respective OPWDD regional offices. However, according to the residential support categories a caregiver's age does not always "indicate urgency need." Once an individual is placed in one of these categories, a list is generated for each category. However, the emergency needs list is the only list disseminated to the licensed agencies, and the other categories are only provided upon request. Therefore an aging parent who is still able to care for their adult ID child who is seeking residential placement may not find placement before they can no longer care for their adult ID child.

Laporte et al. (2017) conducted a study in Canada on a long-term care waitlist placement. Three contributing factors identified to long waiting list were (1) care recipient, (2) informal caregiver, and (3) formal system (Laporte et al., 2017).

Laporte et al. (2017) asked who requires residential placement and who does not, and the answer to that question was everyone does, but that does not make anyone needs more important than the other. The research further noted that the needs of caregivers are the main reason for residential placement. As caregivers get older and are no longer able to care for their adult ID child the need for residential placement arises. "However, as international comparative analysis suggests, needs alone do not account for variation in rates of residential care across the industrialized nations, especially age (Laporte et al., p.286, 2017)”.

The researchers surveyed 2,469 community-based ID adults receiving services in the home in the NW region, 367 were on the wait list for residential placements. What was identified is, as long as an ID adult has a caregiver, they would remain on the waiting list and most likely never find placement.

The study concluded that the characteristics for residential placement in North West Ontario were “age, cognition, as well as capacity to perform ADLs were all associated with the likelihood that a caregiver would be waitlisted. However, caregivers needs turned out to be only one, although important, part of the story; as hypothesized, supply-side factors related to the formal system and informal caregiver capacity also played a significant role (Laporte et al., p.286, 2017)”.

Types of Residential Placements

According to OPWDD (n.d), there are currently five different types of certified homes that support people with ID which is determined based on their needs. These residences are Intermediate Care Facilities (ICF's), Individualized Residential Alternative's (IRA's), Community Residence, Supportive Apartments, and Supervised Apartments. ICF's provides 24-hour staffing for individuals who have several medical and mental health issues, however; these certified homes are being phased out and converted into IRA's. IRA's provides 24-hour staffing, and this setting can be in a home or an apartment for individuals with various levels of ID. Supervised apartments provide 24-hour staffing with high functioning ID adults, Supportive Apartments are for ID individuals who need minimum assistance as this certified home does not provide 24-hour staffing, and CR's provides 24-hour staffing in homes or apartments for individuals with various levels of functioning (OPWDD, n.d.).

Benefits of Residential Placements

Residential placements are extremely beneficial and important for parents and adult children with ID. Residential homes operate 24 hours with staffing who provides supervision and care for ID adults who reside there. These homes enhance the quality of life for these ID adults and try to normalize their daily life especially for those individuals who have lived at home for the majority of their lives (Bigby et al., 2016).

Parents who have found a residential placement for their ID child reported the benefits of them being in a residential setting. Some of the things that these individuals benefit from are learning how to become independent, learning new skills, having a better social life, structured environment and peers who they can relate too. Aging parents further noted that they are less stressed, able to have a life, work, and most important their adult child’s future is secured (Bigby et al., 2016).

Carminati et al. (2017) wrote that many studies had revealed the significance of residential placement for adults with developmental disabilities and how they can improve this population's quality of life. Research conducted on the quality of life of people with ID shown that people with ID do better in a structured atmosphere than being at home with their aging parents (Carminati et al., 2017).

Parents Experience Seeking Residential Placement

Grey et al. (2015) completed a study in the United Kingdom on experiences of parents seeking residential placement for their adult child with ID. This study was completed to explore the process of nine families seeking residential placement for their adult child with ID. The two themes that were recognized were: "(1) reasons for seeking housing and (2) experiences of seeking housing (Grey et al., p.47)". The study further revealed if aging parents were able to currently support and care for their adult child with ID then they were not a priority or an emergency need, but hoped to resolve their residential placement need before it became an emergency.

Grey et al. (2015) noted that the nine families described their experiences of trying to find a residential placement for their adult ID child being more difficult than they expected. When starting the process of seeking residential services five parents reported that the staff members from the ID agencies made them believe that seeking residential placement would not be a difficult or lengthy process. The parents further found the agencies had poor follow-up and appeared to be attentive in supportive meetings (Grey et al., 2015). According to Grey et al. (2015), the most significant barrier was the lack of available residential placements which led to inappropriate housing offers for ID adults. When an inappropriate housing offer was made, and a family declined, then they were no longer a priority. This continuous cycle of inappropriate offers kept these ID adults on the waiting list; this made the families feel they entered into a system where the progression was slow and a lot of work. These families felt unsupported, and no progress was being made and was ultimately left to care for their ID child who was becoming more challenging to care for (Grey et al., 2015).

Grey et al. (2015) further reported that the parents "experienced a mismatch between rights and reality despite global policy recognizing the rights of people with ID to exercise personal agency and become autonomous members of their communities." These parents felt because they were capable of caring for their adult ID child and they were not in "crisis" they were a low priority on the residential placement waiting list (Grey et al., 2015).

Why Aging Parents Seek Residential Placement

The decision aging parents make to seek residential placement depends on their perceptions of what is most important to their adult child (Garcia et al., 2016; Grey et al., 2015; Hewitt et al., 2016). Aging parents prefer their adult ID child to live in a supportive resident where they can receive the quality of care that they cannot receive at home from their aging parent (Hewitt et al., 2016; Koenig, 2015).

According to Abramson (2015), seventy- six percent of people with developmental disabilities are cared for by their aging parents who are over 60 years old. Aging parents often consider seeking residential placement when they start having concerns about their age, their health, or suffering from being overwhelmed. Abramson further noted that aging caregivers caring for adult children with ID have a hard time navigating services for residential placement (Abramson, 2015).

Prager (2015) conducted a study in Long Island New York to investigate the phenomenon of how parents decided to place their adult ID child in a residential placement. The four themes that emerged from this study was “normalcy, burden, mortality, and support system” (Prager, 2015, p.1). The study further suggested when parents realized they were not able to care for their adult ID child because of the physical and emotional demands they were ready to place their adult ID child in a residential setting (Pager 2015).

According to Prager (2015) parents being ready to place their child in a residential setting was a "basic social problem" that was experienced by the parents. To resolve their problem, they had to recognize they could not be caregivers forever. The parents in this research identified that residential placement was a tough decision but a reality they had to face however it was a process that they had to be prepared for. The study further revealed that parents recognized that they would die someday and as they get older they realize their physical limitation to provide care. This along with other factors has prompted these parents to plan for their adult ID child's future (Prager, 2015).

According to Lauderdale-Littin & Blacher (2016) parents with adult ID children experience many stressors related to caring for their adult ID child in their homes (Lauderdale-Littin & Blacher, 2016). Continually caring for an adult child with ID can cause caregivers to be depressed, have anxiety, stress and sleep deprivation from caring for their adult ID child from birth (Bhatia et al., 2015). Lin et al. (2014) explained that ID adults have many physical ailments which can include hearing and vison lost, incontinence, less or no mobility and can suffer from chronic illness over time which leads caregiver stress (Lin et al., 2014). Additional stressors parents with ID children face are health and financial issues, caring for their adult ID child alone, unaware of resources for their adult ID child and most importantly the future care for their ID adult child (McMaughan, 2015).

According to McMaughan (2016) and Prakash et al. (2016) parents are obligated to support their adult ID child with their assisted daily living (ADL) because of their adult child is not self-sufficient. Many adult ID children have mobility limitations which influence a parent to decide to choose placement services for their adult ID child (McMaughan, 2015; Prakash et al., 2016). An adult ID child who has mobility issues will require adaptive equipment such as wheelchairs, walkers or canes which will not allow them to navigate the home if there are stairs, therefore they will need a barrier-free residential home. Most parents cannot afford to convert their homes for their adult ID child's needs (Geere et al., 2013; Prakash et al., 2016). As a result of these issues, parents have to decide against seeking residential placement (Geere et al., 2013).

Mobility issues that affect adult children with ID are Down syndrome, cerebral palsy, seizures disorders and vision impairments (Difazio et al., 2015). Because of these severe conditions parents have to make heartbreaking decisions to try and place their adult ID child in supportive homes (Geere et al., 2013; Prakash et al., 2016).

Prakash et al. (2016) further suggested that parents with ID children experience burden and a hard time dealing with their adult ID child physical and hygiene care. Aging parents taking care of their adult ID child's personal hygiene needs becomes extremely difficult because they are not children anymore. Aging parents often see their adult ID children needing more care then they can provide in the home, therefore, they search for respite relief so they can take care of their own needs (Prakash et al., 2016).

Lunsky et al. (2017) conducted a study of parents who had become lifetime compound caregivers. Lunsky et al. defined compound caregivers as parents having multiple caregiver roles. Caregiver roles consist of caring for their adult ID child along with other family members Data revealed that compound caregivers are overwhelmed with the multiple roles that they feel inclined to place their adult ID child in a residential placement setting (Lunsky et al., 2017). Compound caregivers reported that they need more time for themselves, assistance from other family members and resources to help with coping and support with their adult ID child. Because compound caregivers become overwhelmed these parents decide to place their adult ID child in residential settings (Lunsky et al., 2017).

According to Sullins (2016), aging parents seek residential placement for their adult ID child because it places a stain on their caregiver role and relationships (Sullins, 2016). A strain is related to a parent's emotional and physical health and the amount of support their adult ID child needs and limited resource (Sullins, 2016). Parents with ID adult children expressed how much love they have for their adult ID child but also expressed the severe strain caregiving has placed on them but also wished they could care for them forever (Crettenden, Wright, & Beilby, 2014; Griffith & Hastings, 2014). Being caretakers for an ID adult child has limited caregiver's ability to care for themselves and also limit the amount of time they can spend outside of the home because of the constant care and supervision is required (Woodman, 2014).

Several parents explained that caring for their adult ID child consumes all their time and is a burden when one parent does most of the caregiving. When one parent assumes the caregiver role more than the other, it can lead to marital problems, lack of a social life, confrontations with other adult children who does not have ID and relationship issues between the caregiver and the adult ID child because they feel they are the problem (McConnel & Savage, 2015).

Support for Aging Parents

According to Grey et al. (2015) parents who decide to place their adult ID child in residential placements is often not knowledgeable of various placement options (Grey et al., 2015). Pager (2015) explained it is imperative that placement information is provided to seeking parents by the appropriate entity to ensure the parents have a complete understanding what residential placement would look like for their adult ID child. This research also suggested that it was necessary for parents to speak to other parents and form a support system which can help them get an idea of what the future may look like for them and their adult ID child.

Burke et al. (2018) suggest that individuals with intellectual disabilities are living longer than their parents; therefore, future planning is needed to prevent unfavorable placements such as nursing homes or psychiatric facilities (Burke et al., 2018). Lunsky et al. (2017) reported that being a parent for an adult child with ID has significant challenges because parents are expected to sort through the adult service system to secure their adult child's future which could be difficult (Lunskey et al., 2017).

According to Williamson and Perkins (2014), an assessment needs to be conducted with caregivers to ensure their needs, and their adult's child's needs would be met when seeking residential services. Providing caregivers with the necessary tools and resources will be most effective when seeking residential placement services. Coyle et al. (2014) suggested that there is continue needs to acquire long term-services and supports along with educational resources to support aging parents and possible sibling caregivers as they age with their adult ID child (Coyle et al., 2014).

An article titled People with Intellectual Disabilities (n.d.) suggested that parents who have provided care for their ID child since birth will want to assume that role indefinitely and will often refuse to place their adult ID child in a residential setting. These aging parents will start having their physical, mental and health issues that will prevent them from caring for their adult ID child which will prevent these individuals from a good quality of life. These aging parents will start to depend on their ID adult child for companionship which is not beneficial for them (People with Intellectual Disabilities n.d.).

People with Intellectual Disabilities (n.d.) further suggested that parents might not be aware of residential placement options. For these parents to adequately plan for their adult ID child's future, certain information needs to be obtained such as if these parents chose to care for their child by choice or if they feel that alternative placement is unsuitable. Parents who can successfully transition their adult ID child need to be continually supported and involved in their adult child’s daily living. Aging parents also fear that their knowledge about their adult ID children will not be taking into consideration and they will lose their caregiving roles (People with Intellectual Disabilities n.d.).

A needs assessment needs to be conducted in order to determine the “discrepancy or gap between “what is” and “what should be (Comprehensive needs assessment, 1995) as it relates to aging parent securing their adult ID child’s future.

Future of ID Adults

According to Goldberg (2015), there is a lack of residential placements which is a rising nationwide problem. Vacancies are rear in residential facilities because individuals with ID live longer lives because of better medical care and the ability to understand the diseases that impair the cognitive ability. In addition to the lack of residential placements aging parents will not be able to care for their ID child forever leaving these ID adults possibly without a caregiver or residential placement (Goldberg, 2015).

Walker and Hutchinson (2018) conducted a theoretical perspective of hermeneutic phenomenology to understand lived experiences of aging parents planning of their adult offspring with intellectual disability future. The research found that aging parents are providing care for their adult ID child well in there '70s and some of the parents interviewed have started to think about residential placement but are uncertain what the future holds. The parents in this study have realized that they may never find the residential placement for their adult ID child before they can no longer care for them (Walker and Hutchinson, 2018).

An article written by Coyle et al. (2014) noted that many ID adults who reside in the United States living at home with their families or in a group home setting, however, the majority of them reside with their family. Coyle further noted that there are approximately 75% of adults with ID residing at home with their families and 25% of the caretakers are over 60 years old. It is undeniable that ID adults will continue to rely on their parents or caretakers for the rest of their lives, and unfortunately if other provisions are not made for these adult ID individuals, one of the possibilities is that their siblings will be left to care for them who will in turn age eventually (Coyle et al., 2014).

Goldberg (2014) interviewed a parent whose name was Joan K. who was 81 years old, her husband was 88, and they both had severe health problems. Their son was 57 years old who was diagnosed with a cognitive delay and suffered from seizures. Joan explained there was an opening in a group home close to their home; however, her son Mickey was priority two on the OPWDD waiting list. Joan begged OPWDD to make him a priority 1. However, she was told they could not, and there was nothing they could do about it, and there are many families in her same situation.

Joan died two months later of a heart attack, and Mickey spent one night in a respite home which provides temporary relief for families. Mickey couldn't cope and had a behavioral episode and was taken to the emergency room. The next day he was taken to a group home, the same group home his mother fought for when she was alive. Mickey again acted out and was taken to the emergency room. Two days later after he was taken the emergency room he had another behavioral episode and the police were called, he was handcuffed, and taken back the emergency room. His sister stated if he only transitioned when their mother was alive he would not have to go through all this pain (Goldberg, 2014). With this brief story, the goal of this research is to try and make the state understand the importance of making aging parents a priority 1 when seeking residential services.

Summary

Despite various research regarding ID adults residing with aging parents and the benefits of residential placement, there is no research found regarding parents perceptions of what they need to secure their child's future. As documented in this literature review, aging parents expressed how necessary it is for residential placement for their adult ID child before they can no longer care for them or before they die.

Overall the literature examined in this chapter reported that parents need residential placement for their ID adult child, the waiting list is substantial without any hope of finding residential placement and the need of support from the disability agencies. Previous researchers have shown that these parents need residential placement for their adult ID child and the burden and stress that they feel with knowing they cannot care for their adult ID child forever. Aging parents also reported how burden and stress could affect other household members while caring for adult ID child.

In conclusion, the literature revealed there is still much work to be done to support and assist these aging parents with securing their adult ID child's future. The findings from this research will contribute to the current research in regards to parent's perceptions of their experiences caring for an adult ID child and their need to secure their future. Chapter 3 will include a complete narrative of the study, research questions, and the qualitative method related to the theoretical framework. Chapter 3 will further include the research design and analysis, my role as the researcher, obtaining research participants, issues of trustworthiness, and ethical procedures.

Chapter 3: Research Method

Introduction

The purpose of this qualitative phenomenological study was to explore and document the needs of aging parents regarding what they believe would help them plan for their intellectual disabled child's future. My goal for this study was to provide an understanding the perceptions of the lived experiences of aging parents caring for an adult ID child and what their needs are to secure their child’s future by using ACF as the foundation for this research. This understanding served as a needs assessment. This chapter will include information about the research method used to gather data for the study. This chapter further described the methods proposed to conduct this study addressing participation selection, data collection, and data analysis. Lastly, issues involving trustworthiness and ethical procedures were presented.

Research Design and Rationale

This study was conducted to shed light on important aspects of the phenomenon related to collecting the lived experiences of parents of adult children with ID. The purpose of this research was to provide a needs assessment using a phenomenological approach**.** Other qualitative methods, such as grounded theory research, narrative research, and case study were considered. However, after further research phenomenology was chosen as the best choice to describe the lived experiences of aging parents caring for an adult ID child and what they need to secure their future. A grounded theory "identifies patterns, trends, and relationships among the data. Based on these, the researcher develops a theory based on the data (Crossman, 2017). Using a ground theory approach, the researcher would need more participants to develop a theory based on needs of aging parents.

Narrative research is best for capturing the "detailed stories or life experiences of a single life or the lives of a small number of individuals (Creswell, 2006)". This type of research would include the researcher to spend a substantial amount of time with the participants to retrieve data through observation and recorded field notes. Narrative research would also require the researcher to analyze the participants' stories, and then "restore" them into a framework that makes sense (Creswell, 2006). My research does not consist of any observations or the need to restore data into a framework that relates to aging parents needing residential placement for their ID child.

Case studies are used to seek common experiences with one or more participants and will require different types of data collection to complete a thorough case study (Creswell, 2006). A case study approach can be used; however, my goal was to describe the experiences of the participants based on shared experiences, themes and patterns that can emerge and enrich the needs assessment process.

Role of the Researcher

As the researcher in this qualitative study, I was the main source of data collection, interpretation, and analysis. Data was gathered via individual interviews, analyzed, interpreted to reflect each participant's perceptions and experiences regarding my research topic. Using the phenomenological approach my role was to get a deep understanding of the perceptions and experiences of aging adults caring for an adult child with ID and what their needs were to secure their adult child's future.

I have worked for 5 years in the human services field as an investigator for ID adults in New York State. In March of 2017, my role transitioned from an investigator to a director of residential services which oversaw eight residential programs. My role as a director was to ensure the overall well-being and safety of ID adults.

My role also allowed me to provide residential placement for ID adults in my program when a vacancy became available. Reaching out to families to extend an offer for residential placement who have been on the waiting list for many years was rewarding and challenging. Sometimes the families declined because the placement was not the right fit which left them on the waiting list longer. Interacting with different families in this capacity allowed me to get an understanding of some of the challenges they face when seeking residential placement. This topic was explored to get a greater understanding what obstacles they face and what these family's needs are secure their child's future. There is a need to continue to inform OPWDD and state policies makers who are aware of the struggle that aging parents face with securing their adult child's future with residential placement.

Because I had some relationship with families to whom I had extended offers and who used to reach out to me to vent and express their concerns of never finding residential placement, I had to remove myself from my program completely and speak to families with whom I had no personal connection to prevent bias in my research. Participants were selected from a day program in New York State where individuals from my residential program attended. My bracketing began with identifying any biases and preconceived notions regarding residential placement.

In hermeneutic reflection, the researcher will focus on the data and put any biases and experiences front and center (Khan and Jahan, 2012). The goal of hermeneutic phenomenology was to replace current preconceived notions with more objective ones through reflection (Khan and Jahan, 2012). My preconception was that aging parents needed prioritized residential placement. However, when participants were interviewed, other needs surfaced regarding their children's future.

The study interview questions concentrated on the participants' lived experiences caring for an adult ID child and what their needs were to secure their adult child's future. All study participants were treated fairly and with respect and all data remained confidential

Participant Selection

The participants were five biological parents of an adult ID child who currently resided at home. Boyd (2003) suggested that a phenomenological study recommends a sample size of 2-10participants. The adult child was either on the substantial or current need placement list, considered for placement, or their parents would require residential placement in the near future. The participants needed to be in the age range of 50-70 years old because they need be an older parent with an adult ID child. The participants were selected from one service provider in New York State. All five participants that were selected had to be willing to have a face to face interview about the phenomenon being studied.

Biological parents were chosen for this study because the literature revealed that biological parents are the ones who are struggling with finding a residential placement for their adult ID child. Palinkas et al. (2016) suggested that purposeful sampling is often used in qualitative research for the "identification and selection of information-rich cases" connected to the phenomenon being studied. The participants for this research were selected through purposeful sampling from a day program based on the criteria noted. According to Gonzalez (2009), when conducting phenomenological research, the sample size was selected to capture the important facts within this approach. Gonzalez further suggested achieving that goal a small sample size of less than 20 is common.

Potential participants received a flyer from the program director which had detailed information regarding the study. The program director was the person who managed the program that provided all daytime activities for ID adults. Most of these adults who attend this day program reside with their aging parents. I had a meeting with the program director of the day program and provided information about the study. I asked the program director was asked if she could provide the flyer to biological parents who met the criteria for this study. Twenty-five flyers were provided to her to distribute, which included pertinent information about the study and what would be involved. My contact information and all other necessary information were included. The program director of the day program assisted me with getting the participants needed for this research.

Five participants were obtained; however, only one participant was secured by the extension of the invitation. A snowball technique was implemented to secure four more participants. This technique involved asking the participants who agreed to participate to recommend other biological parents they knew who were interested in the study. I used interviews as the primary data source for this study.

Instrumentation

The data collection tool that was used was individual interviews. The interview protocol consisted of semi structured interview questions. The questions focused on the participants lived experiences, which connected the data to the theoretical foundation regarding what they need to secure their adult ID child's future.

Face to face interviews was conducted to build a rapport, collect personal information about the phenomenon being studied. The participants were audio recorded and I wrote in details what was discovered and reported it in chapter 4. To ensure validity, I listened and read my transcripts four times. The transcripts were reviewed to ensure the research questions were answered based on the purpose of this investigation to establish content validity. The participants were provided with a copy of their transcripts for their final review and confirmation that all the content is accurate.

Recruitment, Participation, and Data Collection

The first criterion for participation in this study was aging parents caring for an adult ID child in their home who was willing to be interviewed face to face. The second criteria was aging biological parents at least 50 years old with an adult child who will be seeking residential placement for their adult ID child in the future, considered residential placement or their adult ID child is on the substantial or current needs list. The potential participants were recruited from a day program in New York State. A phenomenological study was concerned with the lived experiences of the people related to the specific phenomenon (Groenewald, 2004). Data were retrieved from five parents who had an adult ID child via face-to-face interviews. Potential participants were recruited in New York State from a nonprofit agency. A meeting was requested with the program director and the researcher asked her to disseminate a flyer to a minimum of 25 participants who were connected to her program. The flyer described the study, the requested participants needed for this study and my contact information. My goal was to obtain five to seven participants. If I was unsuccessful in obtaining five participants, a snowball effect would be used by asking participants that were recruited if they knew anyone that would be interested in participating in the research study.

Each potential participant was asked to review the informed consent form thoroughly, sign and return the consent forms prior their face to face interview. The participant was informed that although they consented to this study they could opt out if they chose to.

The participants who were interested in the study received a phone call, and asked any questions or concerns they had regarding this study. During the call a scheduled time was requested. The signed consent forms acknowledged that the participants understood the purpose and procedures of the study and confirmed that participation in the study was voluntary.

The face-to-face semi structured and in-depth interviews were conducted in a neutral location. The location and times were decided and each participant would be informed that the interviews would last between 60-120 minutes. The participants were asked if a digital recorder could be used during the interview. At the start of the interview, an introduction was made which included informing the participants of the researcher’s job-related experiences with assisting families in securing a residential placement. The participants were also informed the reason why this researcher wanted to conduct this study. The questions were appropriate for a phenomenological study, with an ACF theoretical framework.

Interviews were initially transcribed by a transcription website for data analysis purposes; however the researcher transcribed the data due to the transcription website inaccuracies. If a real transcriber was used, then a confidentiality agreement would have be signed and provided to me. All notes and recorded data were stored on my laptop that was password protected during the data collection and analysis process. All information will be kept for 5 years and deleted at the end of the fifth year. Additionally, my data and the participants' information will be locked in a lock box for five years and destroyed after that. Each participant was emailed a copy of the transcript for verification and accuracy purposes.

Data Analysis Plan

As mentioned above, the recorded interviews were transcribed by the researcher. The data analysis process included the following steps:

Data Analysis Steps:

1. Read the transcripts to ensure they were transcribed verbatim.
2. Organize the data
3. Find common themes, words, and concepts: establish the coding scheme to organize the themes, etc.

4. Ensure validity and reliability
5. Find possible and plausible explanations for the findings
6. Formulate a description of what parents express are their need to secure their child's future.

Issues of Trustworthiness

Trustworthiness was extremely important to research because the researcher must ensure that the findings are credible, transferable, confirmable, and dependable, which are the four criteria's of trustworthiness (Statistic Solutions, 2018). When a researcher collects data through observations, transcription, or interviews**,** the four major themes of trustworthiness are important to ensure that the research is accurate, dependable, and without bias**.**

Confirmability

Qualitative research believes that researchers provide a different perspective to the field of study. Confirmability refers to if the results from the research could be determined to be true by others. There are different ways to ensure comfortability such as the researcher checking the data throughout the research study. Another researcher can review the data and try to contradict the finding, or the researcher can perform a "data audit" that reviews the data and analyze for possible bias (Social Research Methods, n.d.).

Credibility

When addressing credibility whether it's through an interview process or observation, the researcher should ensure that a precise picture of the phenomenon is presented regardless of the data source. Credibility focuses on knowing that the findings from the research are valid and or accurate. To establish credibility there, triangulation can be used to show that the results are credible. Triangulation is a method that employs different sources which are used to check for validity in research (Social Research Methods, n.d.).

Transferability

Transferability refers to how well the results of the research can be connected to another setting. According to Statistic Solutions (2018), other settings can mean similar situations, similar populations, and related phenomena. Qualitative researchers can use thick description to show that the research study's findings can apply to other contexts, circumstances, and a situation which is a technique used to ensure that there is transferability present in the research. In other words, thick description is described by Lincoln and Guba as a way of achieving a type of valid externality (Amankwaa, 2016).

Dependability

Dependability focuses on whether the research can be duplicated by other researchers within the researcher's field of study. The researcher who duplicates the study should be able to produce similar findings however dependability my difficult to achieve. According to Shenton (2014) being able to meet dependability, criterion is hard in qualitative research although researches should attempt to allow a future researcher to duplicate the researcher. According to Statistic Solutions (2018), a qualitative researcher can use inquiry audit to create dependability, which requires an outside person to review and examine the research process and the data analysis to ensure that the findings are consistent and could be repeated.

Ethical Procedures

The parents who participated in this study will choose to volunteer and provide information related to their experiences caring for their adult ID child and their needs to secure their future. The participants were not pressured or coerced to provide any information. When the interviews were occurring, they were made aware that they can end the interview at any time. The participants was furthered informed that their participation in this research will not provide them with a residential placement, make their adult child a higher priority or jeopardize their current placement on the waiting list.

Informed consent was obtained from all the participants and any questions the participants had were answered. I ensured the participants that their confidentiality will be maintained, and explained how their identity will be protected. The data were coded to protect the identity of the participants and the adult ID child. The participants were informed that the data would be backed up on USB that was password protected and stored in a locked box. Additional precautions included keeping all recordings on a password protected laptop which the researcher would only have access to. The participants were notified that the only other people who would be privy to this study would be researcher’s committee members, a possible transcriber, and Walden University's IRB if requested.

Summary

A qualitative phenomenological approach was selected to conduct this study. This methodology described the perceptions of aging parents based on their lived experiences and their need to secure their adult ID child's future. The participants were biological parents of an adult child with an intellectual disability who resided at home with their parent who is either on the substantial or current needs list or will be seeking residential placement in the near future or considered residential placement. Semi-structured interviews was used and transcribed. The data were manually coded after they were transcribed. In chapter 4, the results of the interviews were documented and initial themes and patterns identified.

Chapter 4: Results

Introduction

The purpose of this study was to use a phenomenological approach to describe the lived experiences of parents caring for an adult ID child and explore and document their needs. This chapter referenced the procedures used for conducting interviews, demographic information on participants, and the results of the semi structured interview questions. The research questions for this study were the following:

RQ1: What are the lived experiences of aging parents caring for an adult with an intellectual disability?

RQ2: What do aging parents of an adult child with an intellectual disability perceive their needs are to secure their adult child's future?

This chapter will present data from interviews with five parents with an ID adult child. Information about the setting, data collection, and data analysis was reported. The remaining sections in this chapter would relate to evidence of trustworthiness and the results of the study.

Setting

I met with the program director at an organization in Rye Brook, NY, that oversaw a day habilitation program working with individuals with developmental disabilities. I asked her to read my proposal and to contact me when she finished. The program director contacted me and I asked her if she would be willing to distribute flyers to families once I received IRB approval, she agreed. After receiving IRB approval (approval number 06-10-19-0675491) I emailed her the flyer for distribution. I received a response from one interested family who met the criteria. I used snowball sampling by asking the participant who responded from the invitation if they knew anyone that might be interested in participating in this research. Four additional participants were gained through the snowball technique, which allowed me to interview five families.

Demographics

Participants in this research were five parents of an ID adult child, who resided in New York State (see Table 1). All participants signed the informed consent form prior to the interview, and all participants met the inclusion criteria: (a) at least 50 years of age, (b) biological parent(s) of an adult child with ID, and (c) their child was on the residential placement list, considered, or seeking residential placement in the near future. Three parents were White, one parent was African American, and one parent was Hispanic. Three out of the five families were on the residential list, and their category on the list was substantial need. The other two families considered residential placement, however, decided on alternative arrangements for their adult child.

Table 1

Participant Demographics

Participant	Gender of parent/ Gender of adult child	Race	Placement list
1	Female/ Female	Hispanic	Considered Placement
2	Male/Male	White	Substantial Need
3	Female/Male	White	Substantial Need
4	Female/Male	African American	Considered
5	Female/ Male	White	Substantial Need

Data Collection

I conducted five face-to-face interviews. All interviews were held in an office space located in New York State. Interviews were scheduled to last 60-120 minutes but the actual time ranged from 30-40 minutes. Each participant received a phone call before the interview to determine whether they had any questions regarding the research before the interview. The consent forms were sent to each participant via email and were signed and sent back before the interviews. There were no follow-up interviews, and a recorder was used to collect the data.

During the interview process, I informed each participant that I would be taken notes. I wrote down important facts about their perceptions of their lived experiences caring for their adult ID child and their needs to secure their adult ID child's future. During the interviews and the data analysis, I kept my biases and preconceived notions about this research to myself and did not provide my opinions or knowledge to the participants.

After the interviews, I used a transcription website but had to go back and transcribe the participants’ interviews myself because not all the data were captured. I sent each participant a copy via email. Each participant contacted me via email or text and confirmed that the transcripts were correctly documented; this was done to ensure accuracy. No unusual circumstances were presented during data collection.

Data Analysis

I analyzed the research data, listened to the recordings, and read all the transcripts three times each to ensure validity. I wrote notes on the transcripts to develop themes.

Some of the notes included common and different experiences that families shared. I used these notes and re-read the transcripts to ensure I was interpreting the data correctly.

For example, while I read the transcripts and listened to the recordings, I realized that each participant talked about stress caring for an adult child with ID and lack of services for them. All the participants agreed that they needed a plan to secure their adult's child future or already had a plan for their future. Further information will be examined later in this chapter. All the data were analyzed by hand and no software was used.

After reading the transcripts, I highlighted key themes and grouped them according to similarities and wrote a title for each theme. I placed quotes under each title for each theme that expressed their experiences and needs. A table was created to identify the emergent themes (see Table 2). The five major themes that surfaced from the data were (a) stress, (b) navigating the system, (c) placement/ plans for adult ID child's future. (d) needs of the family and (e) challenging OPWDD. A narrative was written for each of the major themes using verbatim statements made by the participants.

Table 2

Emergent Themes

Emergent themes	Descriptive Comments	Sample Statements	Participants
Stressful	Overwhelming Tiring No support	Major, major struggles Extremely overwhelming and doom and gloom Extremely stressful Stressful being a single mom and working	P1, P3, P4, P5

Table 2 Continued

Navigating the system	No knowledge of the OPWDD process	To this day, I do not know where any of their offices are located. I didn't even know that they existed. My sister asks me how the hell did you do all of this for her. I said sweetheart, you have to learn, you have to work and you have to reach out the right people. Because all of these agencies will have you sit down and wait. Have you ever dealt with OPWDD in any instances? No Does OPWDD make themselves available, saying this is who we are… these are the services we provide…. Not really	P1, P2, and P4
Placement/ Plans for adult ID child's future.	Reluctance, willing to place if necessary, waiting on placement, staying with family	The few things I have seen out there I am scared of what to do, don't see anything that I would like to put him in, or that he would be able to survive in. He has his way of living, and he is so used to living a certain way and being autistic like he is, is going to be like a completely different change for him. I don't know how he is going to be able to survive. Yes. I have considered it. Because of you never no, but knowing the way my family is, we are not doing	P1, P2, P3, P4, and P5

		that. When I am unable to care for her… we had discussed that, and her siblings did not want me to look for residential placement for her, because they say this is her house, and this is for her. We built this for her Is he still on the substantial needs list or did his priority change? Substantial, waiting on placement. My daughter is next in line, so we have all of that taken care of. It's in my will, and she will know what to do Yes, he has been on the priority list since he was 21, not a peep from OPWDD.	
Needs of the families		They do not only have to help the child; they need to help the parents. Better communication, training their people who represent them…better communication with the parents and see what the parent's needs are as well as the child I would like to see an opportunity to create a housing setting that is customized. I would like to take the same funds that are allocated for individuals	P2, P3, P4, and P5

		that are in group homes and build housing for my son with that budget if they can personalize and make it person-centered just for him. They need to go to these programs and have a town hall meeting for people who have special needs children and get them in there and do workshops. Justice and responsibility, they are not responsible	
Challenging OPWDD	Anger/ frustration	There was a very strong effort to do that last year because I had so many issues with him and I was very angry at the fact that they were not helping me at all and there weren't any options. It was escalated to a lot of head people at OPWDD because I made a point to copy everyone and to make sure they were being zeroed in on. I have gone head to head with these guys because being a part of an advocacy group and I went head to head with them. Oh were going to fix it, two years later oh were going to fix. Oh, he's on the list… no, he is not on the list… again he had been dropped.	P3 and P5

Stressful

Participants reported being stressed when caring for their adult ID child for various reasons. Most of the stress stemmed from either being a single parent, not knowing what's going too happened when they are not able to care for their child, and lack of services for their adult child. The participants confirmed that they were their adult child's primary caregiver and their main and often only focus was their child. All five participants expressed similar stress, but what all of them had in common was fear of someone else caring for their adult ID child other than themselves.

> P1: uh it's been a major, major struggle. It got more severe at age 21 because are no programs out there that are decent. So basically, he is homebound with me. He has no communication, and he needs 24-hour supervision. He cannot go out by himself; he is not verbal at all. But thank god his bathroom manners are fine; he takes a shower himself and dresses. He has a lot of pluses, but he needs 24 hours of supervision, and he is 34 years old. He only sleeps home; he does not sleep at his mother's home. I am like his survivor. Basically, I am everything to him.
>
> P2: That's why we are in the process of finding someone now that can spend a little time with her… I want to ease her into having someone other than the family around her in the house. I think that would help her understand… that there is a possibility that they will not take care of her as I do. I have to ease her to do all the work
>
> P3: Very, very difficult because he's a boy in a man's body and does not look physically impaired. So, there are a lot of expectations for him to communicate

> and he does not… life is difficult and has become more and more difficult. At this point, it is very doom and gloom, it his heart breaking to see someone that you love struggle with a long amount of time and do not fit in and have so many obstacles. The coping is one or two individuals that understand you and do not judge you, let you vent and do not judge you. You have to have some kind of support because it is overwhelming and gets worst with time.
>
> P4: Do you have a plan B just in case your daughter cannot take care of him for any reason. My cousin is next in line. I sat down and thought about all that stuff, I said let me do it now while I'm in my right frame of mind. Even to the plots, if anything happens, we got that covered. Have you ever considered putting him in a residential setting? Yes, but that's not an option because he would die. Was it stressful for you working and being a single mom, yes.

P5: I live in a constant state of stress since he has been very little because of his health issues. What kills him is not the Down syndrome or the autism, is the rejection by this world and autoimmune is terrible for him. It makes him so sick he could hardly stand up. Another big problem of his that he knows that he is special needs and it is horrible for him… There is no one I trust with my kid.

Navigating the System

The participants talked about their ability to navigate the OPWDD system with and without assistance. Three participants stated they did not know that OPWDD existed or how to obtain services from OPWDD without the help of secondary source. Two out of the five participants stated they were able to navigate the OPWDD system on their own. The three participants that required assistance with services went through their doctors, caseworkers, or school programs to get the assistance they needed for their child.

> P1: “Do you know anything about the OPWDD process? No”
>
> P2: “To this day I do not know where any of their offices are located. I didn't even know that they existed. My sister asked me how the hell did you do all of this for your daughter. I said sweetheart, you have to learn, you have to work, and you have to reach out the right people. Because all of these agencies will have you sit down and wait”.

P4: “Does OPWDD make themselves available, saying this is who we are… these are the services we provide…. Not really, I found out about the disability expo myself... I was referred by his school for an advocate to help with services”.

Placement/ Plans for adult ID child’s future

The five participants reported their plans for their adult ID child's future when they are not able to care for them anymore. Three of the families are on the substantial needs list, and 2 out of 3 have been on the list for almost ten years with no placement offers. One of the participants indicated that she was 66 years old, and she should be a higher priority based on her age. Two participants stated that they considered placement; however decided on other means of care because their adult ID child would be best with family. All five participants agreed that they need for their ID adult child to be cared for when they cannot care for them anymore.

> P1: **“**The few things I have seen out there I am scared of what to do, don't see anything that I would like to put him in, or that he would be able to survive in. He

has his way of living, and he is so used to living a certain way and being autistic like he is, is going to be like a completely different change for him. I don't know how he is going to be able to survive. The coach… the social worker we have working with us… she gave us a couple of places, but they are far from here. I didn't want that. A few private homes that I saw out there have six people living in one private home, which would be great. This is important to me, especially if I am not here anymore."

P2: "Yes. I have considered it. When I am unable to care for her… we had discussed that, and her siblings did not want me to look for residential placement for her, because they say this is her house, and this is for her. We built this for her. Where would she go, would she remain at home? Yes, she would remain at home under the care of her older brother, basically her siblings. Plan B is that they will look for a placement for her… that would be the impossibility that no one could take her".

P3: "It's really difficult to make plans at this point because he does not have any siblings, and there are no family members that are willing to take him. Nor do I think it's appropriate to ask them to do such because he is so difficult. The best plan I can have is to be able to access some kind of… probably a live-in caregiver for him with support staff and respite. Basically, have 1or two people that have kids that are like Christian who might want to live together in that setting. I think it would have to be customized and specialized for him because he is resistant to do anything with individuals he does not know. Is he still on the waiting list?

Yes”.

P4: What is your plan when you are not able to care for him anymore?

My daughter is next in line… so we have all of that taken care of. It's in my will, and she will know what to do.

P5: He has been on the priority list since he was 21, not a peep.

Have you heard nothing? I have inquired; nothing is available. No homes are available. I said when I die you take over, and you will have this huge apartment, his brother would have a huge apartment, but you could see what the caregiver is doing. The brother will do that; the brother loves him

Needs of the Families

All five participants had different needs; P1 needed more residential options for his son and was not satisfied with the options that he saw. P2 needed OPWDD to support the parents, not only the child. P3 needed residential homes to be customized to fit the needs of her child. P4 need OPWDD to make themselves known to the parents, and P5 need OPWDD to take accountability for not protecting her son from abuse.

P1: “The few things I have seen out there I am scared of what to do, don’t see anything that I would like to put him in."

P2: “Better communication, training their people who represent them…better communication with the parents and see what the parent's needs are, as well as the child”.

P3: "I would like to see an opportunity to create a housing setting that is customized. I would like to take the same funds that are allocated for individuals that are in group homes and build housing for my son with that budget if they can personalize and make it person-centered just for him. If you are going to spend three dollars, what is the difference with using the same money to build something that is more person-centered were they could be happy".

P4: "OPWDD need to go to these programs and have a town hall meeting for people who have special needs children and get them in there and do workshops. Hey… there is an abundant of information out there get going. Also, find schools… just because they are leasing in cheap neighborhoods… but good programs so they could be independent. You have to go out of the city to have something nice".

P5: "What do you need from them? Justice and responsibility, they are not responsible. It not just me I see it everywhere; people who abuse kids are just transferred them need to be in jail. The heads of agencies just let them stay there even though they knew about; they should be in jail too. But I don't think any government, but New York State will do anything about it. The saw called Justice Center is a piece of shit, after my kid was abused in Boise; they asked if there were any witnesses that were willing to testify. I said no what about my kid; he said no, he could not …he was not a valid witness".

Challenging OPWDD

Two out of the five participants challenged OPWDD regarding their residential placement status. One of the two participants challenged OPWDD by going “head to head” with executives because she felt they were not doing enough to help her find residential placement for her adult ID child. Although she challenged them, residential placement still has not been found. P5 went to Albany to try and get answers regarding the lack of residential placement however, her concerns were ignored.

> P4. "There was a very strong effort to do that last year because I had so many issues with him and I was very angry at the fact that they were not helping me at all and there weren't any options. It was escalated to a lot of head people at OPWDD because I made in a point to copy everyone and to make sure they were being zeroed in on. Even with that, the efforts to have meetings to be incompliance with rules and regulations. As far as the end of the day problem solving and finding appropriate programing and or opportunities just does not happen".
>
> P5: "OPWDD knows me very well because I was an advocate. Have you ever challenged them? Are you kidding me, they have dropped him from the list more than once. Why? He was difficult to place with his food needs; they pretend they do not know; they cannot do anything right. I have gone head to head with these guys because being a part of an advocacy group and I went head to head with them. Oh were going to fix it, two years later oh were going to fix. Oh, he's on the list… no, he is not on the list… again he had been dropped. Have you gone up to Albany? Yes. What did you do there? They quack, but they don't talk to you, they quack at you. They have a canned speech, the person you need is never in they were called away at the last minute. Even if you make appointments, they were called away at the last second…. Because he is difficult to place… so they are not

going to place him. I had to remind them, and I had several people go up to Albany when I was in the hospital".

Evidence of Trustworthiness

Credibility, transferability, dependability, and conformability are all aspects of establishing trustworthiness in research. Credibility means to ensure the researcher depicts the data accurately (Social Research Methods, n.d.). I accomplished this by sending the transcribed interviews to the participants. I asked them to contact me if any changes needed to me made. All five participants received their transcripts, and one of them indicated the need for changes to their transcript based on clarity to the content provided.

I accomplished transferability by providing thick descriptions so other researchers or readers could apply my findings to other studies or circumstances. All five of the participants met the criteria to participate in this research, and I hit data saturation after my fifth interview. I obtained detailed information from the five participants', which was consistent with a phenomenological study.

Dependability was achieved by an inquiry audit through interview transcripts and member checking. Confirmability was achieved by me checking the data throughout my research. I read the transcripts and listened to the interview four times to ensure the data was accurate.

Results

The purpose of this phenomenological study was to understand the perceptions of the lived experiences of aging parents caring for an adult ID child and to explore and document needs of the families. The research questions guided this research to obtain the lived experiences and needs of the families.

The first research question was: What are the lived experiences of aging parents caring for an adult with an intellectual disability? From the data obtained, the families shared similar experiences describing how they cared for their ID child as an adult and as a child. The participants vented about the difficulty of raising an adult child with ID, the lack of services, and lack of residential placement available. The parent's descriptions of their experiences caring for their adult ID child varied.

Participant 1 stated, "Uh it was very difficult from day one because when he was born, he actually died three times in the emergency room, and ever since then things went downhill for him. He only sleeps home; he does not sleep at his mother's home. His mother would never take him" I am like his survivor. Basically, I am everything to him. Participant 2 stated, "My mom took care of her because I had to finish school, what was the hardest thing you had to deal with when taken care of her as a child, finding the right services for her." I was married for 20 years and poof he was gone".

Participant 3 indicated, "When he was younger he was easier to manage, and I did have the ability to leave him with his grandparents, and that helped tremendously. But as he became older, it became more and more difficult for people to manage him and understand him. Initially, he was an impinged and I could not leave him in anyone's care and could not trust a lot of people to understand his nuance and special needs. Because he had issues with his speech and I was the best person who understood him… OPWDD is not equipped to handle people who are outside of people who are standard or compliant, or consistent with what they have in place. I think more specialized individuals or have more comorbid behaviors problems than individuals who are more challenging they just don't have those type of placements".

Participant 4 indicated He was born with cerebral palsy… neurologist and I found out that he had issues on his left side… He had brain damage. I had my mom, and I did have an aid because the time work ends five o'clock, and his bus would come in at 3 pm. So I had to get aid from AHRC. That's who I used… They had a male aid, which lasted about a month then he started into the drugs. He got aggressive with my son. When my son called, and he was crying, I called the agency, and he got him fired, so ever since then no aids. So it's just been you? Was it stressful for you working and being a single mom, yes"? Participant 5 stated, "My adult child starting at four years old became autistic or had autism, and it decided to burst out of his little brain. He has Down syndrome, and he started suffering from and autoimmune condition after he had scarlet fever four times. My son and I are very, very alone. He is afraid of people for a good reason; he has no self-confidence for good reason and his family rejections him. That is tough to get it over…I love him dearly, and I fought to have him. I love him. But it has been hard he did not sleep more than two hours until he was 17 years old. Now he also has seizures… he faints a lot; I have to watch him every second and I live in a constant state of stress since he has been very little because of his health issues".

The data revealed stress, struggle, and worry for the parents of an adult ID child. The parents lived experiences provided insight into what parents go through as it relates to raising a child with ID. What all the parents had in common was caring for their child without a second parent and medically conditions that came along with their intellectual disability.

The second research question was: What do aging parents of an adult child with an intellectual disability perceive their needs are to secure their adult child's future? The parents described what their needs were to secure their adult child's future. Two parents opted not to place their adult child in a residential setting, although they considered residential placement. One of the parents who was on the substantial needs list did not want to place his child before he passed away but knew that he needed to transition with his son before he dies. The other two parents who's ID child are on the substantial needs list are content with the fact they will not find placement for their adult ID child and are making other arrangements to secure their adult ID child's future. Participant 1 stated, "Residential placement is important to me, especially if I am not here anymore, but not now I could never put him away with me being alive. That is not happening. I could never do that to him; he would never understand. He would probably say what did my father do to me, put me away. We are extremely close. I see other parents out there, but he and I are close…I could never hurt him". Participants 1 need was to care for his adult ID child until he died. Participant 2 indicated that "Yes. I have considered it. Because of you never no, but knowing the way my family is, we are not doing that. Plan B is that they will look for a placement for her… that would be the impossibility that no one could take her." Participant 2 need was to ensure her daughter remained with her family when she passed on.

Participant 3 noted that “I do not think they are equipped to handle people who are outside of people who are standard or compliant, or consistent with what they have in place. I think more specialized individuals or have more comorbid behaviors problems than individuals who are more challenging they just don't have those types of placements…. I would like to see an opportunity to create a housing setting that is customized. I would like to take the same funds that are allocated for individuals that are in group homes and build housing for my son with that budget if they can personalize and make it person-centered just for him. If you are going to spend three dollars, what is the difference with using the same money to build something that is more person-centered were they could be happy". Participant 3 needs were for OPWDD to fund or to build a residential setting that was customized for her son. “Yes, Substantial need… He was high priority last year, and there was a lot of intervention, and he was presented at a pro-gathering last year. There were a few people who contacted me. He is a very odd individual, and he is very difficult to place… But again, ideally with a bunch of the moms that I know that has kids that he likes, could be a possibly good fit for them to live together. Ideally, I think that would be something wonderful and I am trying to pursue that now… Parents that are my age should be a number 1 priority".

Participant 4 stated “ my daughter is next in line… so we have all of that taken care of. It's in my will, and she will know what to do. Do you have a plan B just in case your daughter cannot take care of him for any reason? My cousin is next in line. I sat down and thought about all that stuff; I said let me do it now while I'm in my right frame of mind. Even to the plots, if anything happens, we got that covered. Have you ever considered putting him in a residential setting, yes, but because he is so used to this, being so independent, to revert something like that no? Participant 4 need was for her son to remain with the family and for OPWDD to make be more available. Participant 5 indicated that her son has been on the residential placement list since he was 21 years old, and he is currently 28. Participant noted that “Yes he has been on the priority list since he was 21, not a peep”.

Summary

The purpose of this study was to understand and describe the parents' perceptions of their lived experiences of raising an adult child with ID and exploring and documenting the needs of the families. This understanding could be the basis of policy related services to intellectually challenged children. The perceptions, experiences, and needs were described by the five parents by using semi-structured interviews. The interviews reflected significant statements regarding the families’ perceptions of their experience caring for their adult ID child.

Chapter 4 examined the procedures that were used to collect and analyze the data. The data was collected from five participants who selected through purposeful sampling. The participants described their lived experiences of caring for their adult ID child and their needs to secure their adult ID child's future. I presented the results of the data analysis of the transcribed interviews. Five themes emerged from the data analysis: (a) Stress, (b) Navigating the system, (c) Placement/ Plans for adult ID child's future (d) needs of the family and (e) challenging OPWDD. In Chapter 5, the findings will be interpreted, limitations of the study, and recommendations. The chapter will conclude with a section on implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this phenomenological study was to understand the lived experiences of parents raising an adult ID child and to investigate what the families needed to secure their adult ID child's future. My goal was to provide an understanding of the lived experiences of parents raising an adult ID child, determine their needs, and to build on the existing literature regarding this topic. The phenomenon studied was to understand what family perceived their needs were to secure their adult child's future. Previous research has shown that aging parents will not be able to care for their adult ID child forever, and a plan is required. All five participants reported that a plan was required to secure their adult child's future and described negative or nonexistent experiences with OPWDD. Findings from this study revealed that caring for an adult ID child is extremely difficult and stressful, and a plan is ultimately required to secure their ID child's future, whether it is in a residential setting or with family. Overall, the three families who are on the waiting list were not happy with the residential process and residential selections. They also felt that OPWDD was not sensitive to the needs of this population.

Interpretation of the Findings

In my review of the literature, I found that there was no research found from the perceptions of aging parents and what they needed to secure their adult child's future in New York State. There was one study found in related to parents experiences with residential placement for their adult child with ID (see Grey et al., 2015). The information from this study indicated that parents were not aware of various placement options and it was important for information to be provided. The findings from Grey et al.’s (2015) study not only gave the parents a platform to report their experiences of caring for an adult ID child and what they needed to secure their child's future but to voice their concerns about OPWDD and the residential process.

In connection with the existing research, the families in my study shared similar issues and concerns that the literature revealed. Each participant described their experience caring for their adult child and what their plans were for their future. Findings from this research agreed with previous research about parents needing residential services, support, and not being aware of the process for seeking services.

Findings from this study revealed that some of these ID adults have been on the waiting list for several years and they may never receive placement because there was no placement that fit their child's needs. Findings further revealed that the parents who have their adult ID child on the waiting list would have to make other arrangements to secure their child's future. Findings from this research also confirmed, based on previous research, the amount of stress parents are under and how overwhelmed these parents feel about caring for their adult ID child. Additional findings revealed that some of the parents interviewed did not want residential placement and opted that their adult ID child to remain with the family. The most important findings were that all the parents felt the need for OPWDD to be more present and supportive. Two of the families fought for higher priorities for their adult ID child by challenging OPWDD.

Theoretical Framework

ACF is described as people fighting for policy change or implementation of a policy based on their beliefs of a current policy issue (Sabatier, 1993). Research has shown that there was no policy that makes aging parents a priority when seeking residential placement for their adult ID child. Two parents in this research challenged the state (OPWDD) regarding their ability to provide residential services that fit their child needs and one participant noted that the parent's age should be considered as a priority guideline. Both parents addressed OPWDD not being equipped to provide residential placement for certain individuals who suffer from ID that have additional issues such as behaviors or health issues. One parent went to the state capital and fought for change but failed; she quit being a part of an advocacy group and decided she will find residential placement in Italy in the near future. Two of the participants were inadvertently aligned with the ACF, focusing on fighting for policy change or implementation of a policy based on their beliefs. The other three participants, although did not focus on policy change, were interested in OPWDD being more aware of the needs of the family and making themselves more present.

Limitations of the Study

The participants in this study met the criteria of being a parent with an adult ID child who resided in New York State. However there were some limitations in this study. First, the sample size was small, which was consistent with a phenomenological study however a larger sample size would have allowed the researcher to get more information regarding the parents lived experiences and needs. Second, not all of the participants shared the same experience of wanting the residential placement or having to challenge OPWDD. If another study was done with all the participants having the same concerns or issues, the findings might be different. Third, my experience working with families that sought residential placement was a limitation of this study. Although I bracketed by biases and previous experiences, I used my knowledge of this topic to show them that I understood what they were expressing to me during their interviews.

Recommendations

Future researchers should continue to study the concerns of aging parents who care for an adult ID child and extend it to policymakers as there is a need for them to fix the residential issues. The responses from the three family members indicated the residential selections are not conducive to the needs of their adult ID child. I recommend that aging parents with an adult child be included when policies are being created. This can ensure that their concerns are being heard and addressed to best suit their needs. Parents can provide policymakers real-life experiences regarding their struggles with securing an appropriate residential placement. Finding ways to support these parents can make a difference in the lives of the parents and the adult ID child. Parental involvement can improve the policy maker's decisions because the parents know what's best for their adult ID child. Lastly this study should be repeated with a larger population in order to see if new patterns or themes will emerge.

Implications

There are several social change implications related to my findings. From a policy and service provider standpoint, parents of a child with ID should be a part of the development of new policies because they can put in perspective what the residential placement process should look like. Parents can also assist with the implementation of supportive services. The result from this study can provide state representatives and policymakers insight to what families would like residential placement to look like to develop residential homes that can meet the needs of all ID individuals who are waiting for placement. An additional social implication that can emerge from this study are state representatives listening and hearing what these parents have to say and making a real change.

Conclusion

Based on the findings aging parents are not being supported by OPWDD and the needs of the families and adult ID children are not being addressed. Parents with adult ID children should be able to rely on the state agency that was created to provide adequate services for this population. The voices of these parents need to be heard so there could be a change in how residential placement is offered and outlined. The experiences of these families could explain their struggles, their needs, and what would best suit their adult ID child's needs. Before this research, there was minimal research related to this topic but there was no research found in relation to what parents perceived their needs were to secure their adult child's future in New York State. The study addressed the gap in the literature by examining the lack of policies providing prioritized residential services for adult children with an intellectual disability living with an aging parent. The data analysis presented five major themes related to this research. Findings from this study supported findings from previous research in connection with the research topic.

Although additional research will be required this is the starting point for future researchers to address the lack of support from policymakers and OPWDD regarding the needs of the families.

The theme of “challenging OPWDD” could be the starting point of future researchers to investigate. The researchers could investigate if the parent’s concerns can make any impact on OPWDD or the policymakers. This can advance social change by affording ID adults to live in residential settings that are conducive to their needs and for them to be able to transition into placement while their parents are still alive.

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Appendix A: Interview Protocol

Date: ___________________________
Location: ________________________
Name of Interviewer: ____
Name of Participant: ____
Assigned participant number: ____________________________

Script

Hi (use participant's name). Thank you for agreeing to be a participant in my study. As we discussed over the phone/email when you were invited to participate in my study, I am Jeannie Brown and I am attending Walden University as a doctoral student in the school of Behavioral Science. I am conducting research on the perceptions of aging parents and what their needs are in order to secure residential placement for their adult intellectual disabled child. I want to begin by thanking you for returning the signed consent form and now I will briefly review that before we start the interview. The interview is voluntary and at any time you can withdraw. You have the right to end the interview at any time or refuse to answer any question. Your identity and response will remain confidential and you will be assigned a participant number. All notes and recorded data will be stored on my laptop that is password protected during the data collection and analysis process. All information will be kept for five years and deleted at the end of the fifth year. Additionally, my data and the participants' information will be locked in a lock box for five years and destroyed after that.

Participation in this research involves this 1 to 2 hour interview and a follow up phone call if you or I need clarification after we leave here today. I will also be sending you a copy of your transcript to review so we are sure I recorded everything properly during the interview. I will include a self-addressed stamped envelope so you can send that transcript back to me. During this interview, I will be taking some notes and checking the recorder periodically to ensure its recording.

1. Tell me about your experience taking care of your ID child when he/she was younger.

2. Tell me about your experience taking care of your adult ID son or daughter.

3. Please explain what your future plan is for your adult ID child.

Is there anything else you would like to share with me about your experiences? And I would like to close with thanking you again for participating in this interview. If you should have any questions after this interview my contact information is on your copy of the signed consent form.

Appendix B: Participation Interview

Volunteers Needed for Research Study

The purpose of this study is to explore and document the needs of aging parents regarding what they believe would help them plan for intellectual disabled child's future.

This research will benefit the larger community by allowing parents to share their perceptions and experiences in regards to caring for an adult intellectual disabled child and what they need to secure their future.

Criteria:

Biological parents at least 50 years old with an adult child who resides at home and will be seeking residential placement for their adult ID child in the future, considered residential placement or their adult ID child is on the substantial or current needs list.

Involvement: 1 to 2 hour recorded interview in a private location (library or office space) to answer questions regarding lived experiences of aging parents caring for an adult child with an intellectual disability and what their needs are to secure residential placement for their adult child.

Disclaimer: This research is not affiliated with any service providers
Or local government organizations involved with providing services to adults with intellectual disabilities.

Appendix C: Letter of Cooperation

Date: March 18, 2019

Dear Jeannie Brown,

Based on my review of your research proposal, I give permission for you to conduct your research entitled "Parental Needs Regarding the Future of Their Adult Intellectually Disabled Child. I understand that participation in this study is voluntary and confidential. This site reserves the right to withdraw from the study at any time.

For the purposes of this study, you will not identify yourself as an employee of the site but as a graduate student of Walden University and you will complete all work related to your study outside of your normal work hours.

I understand that the site will not be named in any materials that are provided to the participants or in the final dissertation project.

I understand that the data collected will remain entirely confidential and may not be shared with anyone other than your supervising faculty.

Sincerely,

Associate Executive Director