

## Lived Experiences in Decision Making Among Parents with Intellectually Disabled Adults

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### Abstract

Parents may face difficult decisions as their children with intellectual disabilities reach adulthood. Counselors are not always well-informed about this topic due in large part to limited existing literature. Based on a study by Kay (2017), this hermeneutic qualitative analysis examined the lived experiences of 10 parents who made the difficult decision of placing their adult children with intellectual disabilities in group home settings. Results of a thematic analysis produced variables of best option, physical aggression, death, caregiver medical conditions, and more. Results, outcome themes, and recommendations for future research are discussed that inform counselors of the struggles parents experience when confronting challenges of placing their grown children into alternative living arrangements.

*Keywords:* intellectual disability, intellectual disabilities, alternative living, group homes, positive social change, quality of life

## **Lived Experiences in Decision Making Among Parents with Intellectually Disabled Adults**

Intellectual disabilities (ID), also known as general learning disabilities, can be characterized as limitations to a person's ability to learn at an expected level and function at daily life (CDC, 2020). Challenges to reasoning, problem solving, judgment, and the ability to learn through experience may be at risk. Children with ID may find it difficult to express their wants and needs, as well as functioning at activities of daily living. As children with ID age, basic needs may change for the children as well as for parents or legal guardians. Based on changing events and needs, parents or caregivers may face difficult decisions and stress as their children with ID reach adulthood (Lin et al., 2014), including the need for placing the child into a group home, if finding ways to care for their child at home cannot be found.

When parents are no longer able to care for the child as the child ages, an alternate living environment may be an option (Rowbotham et al., 2011). Parents of adult children with ID confront additional problems such as property destruction, elopement, and medical concerns when adult children with ID live with parents and may benefit from effective counseling. Outsiders may label parents as detached, neglectful, and inconsiderate when deciding to place the child with an ID in a group home (Norlin & Broberg, 2013).

Parents may seek assistance from clinicians in an effort to address problems commonly experienced in relation to group home placement. Issues may include feelings of anger, shame, anxiety, stress, and guilt (Grossman & Webb, 2016). When making decisions about caring for a child or adult with ID, parents or guardians may benefit from counseling services and other forms of intervention when considering difficult decisions, such as those around placement. Clinicians, including counselors, psychotherapists, social workers, and other helping professionals, may face challenges when attempting to help parents or guardians of those diagnosed with ID (Grossman & Webb, 2016) due to a lack of understanding the concerns. In addition, clinicians may not be fully prepared to help parents or guardians because they might not have the proper information or resources to support them as they cope with feelings of grief, loss, and rejection (Gibbons, Owen, & Heller, 2016; Rowbotham et al., 2011).

Understanding the lived experiences of parents who face complex decisions regarding placement options can assist in helping parents meet their personal, emotional, physical, and financial obligations, which can affect quality of life (Gibbons et al., 2016). Due to a limited literature, this study explored the lived experiences of parents or guardians of individuals diagnosed with ID when considering the complexity of issues faced when contemplating placing their grown child in an adult home. As a result, this qualitative study intended to examine the lived experiences of parents who have been in the position of having to make decisions of placing their adult children with disabilities into group home settings.

### **Historical Perspective**

Beginning in the mid-1850s and throughout the Industrial Revolution, institutions provided care for adults with intellectual disabilities (ID). The medical model of care focused on treating individuals with ID (Grue, 2011). During the mid-1800s, individuals with ID were considered to be dangerous and a disgrace to society (World Health Organization, 2011). Institutions were managed using an approach that neglected choices, needs, and wants of individuals. The focus placed emphasis on service delivery as opposed to individual needs. The goal of institutions was to diminish the intellectual impairment (take the disability out of the individual) and increase adaptive and compensatory skills for adults with ID (Jackson & Roper, 2014). Professionals better trained to work with individuals with ID became more accessible following World War II.

Individuals diagnosed with intellectual disabilities residing in institutions began to drop in number in the late 1960s due in large part to the implementation of deinstitutionalization policies (Chowdhury & Benson, 2011). Individuals living in institutions in the United States declined over the last 30 years or so, from 207,356 individuals in institutions in 1977 to 62,496 in 2007; while the numbers of individuals with ID living in group home settings rose from 40,000 in 1977 to 437,707 in 2007 (Alba, Prouty, Scott, & Lakin 2008). This is due in large part to the positive influence of community-based living for persons with disabilities, which consists of integration into the community with support to increase autonomy, self-determination, purpose, and improved quality of life. Nota, Ferrari, Soresi, and Wehmeyer (2007) identified the significance of community-based living for individuals with ID to include: (a) enhanced community integration and community living, (b) the ability to have autonomy, self-

determination, a purpose, and more control over living environment, and (c) and improved quality of life.

### **Disability, Rights, and Services**

An adult child's level of intellectual disability, severity of behaviors, medical concerns, and age determine the burden parents performing caregiving services may face (Vogan et al., 2014). Adult children with ID face issues typically not faced by individuals without ID. Adult children with ID experience cognitive deficits, but they may also have comorbid physical conditions that can worsen with age. These can lead to ever-increasing caregiver burden (Lin et al., 2014). In addition, social independence, social skills, judgement, communication skills, math, writing and reading skills, ability to manage money, and other activities of daily living may be compromised. Individuals with ID have traditionally lacked opportunities related to employment, public transportation, public accommodations, telecommunications, housing, voting, educational, rehabilitative, and mental health services (Delman, Kovich, Burke, & Martone, 2017).

The Civil Rights Act of 1964 eliminated discriminatory voting requirements and segregation in schools, public facilities, government agencies, and the workplace for minorities, women, and individuals with disabilities (Hill & Goldstein, 2015), ensuring equal treatment regardless of disability. The Rehabilitation Act of 1973 was subsequently passed in an effort to prohibit discrimination against individuals on the basis of intellectual, developmental, and physical disability. Following years of effort, the Americans with Disabilities Act (ADA) was signed into law (Americans with Disabilities Act, 1990), for the purpose of eliminating a broad range of barriers that prevented individuals with disabilities from integrating into society (Meyer, 2015). The ADA was designed to provide equal access to work, transportation, education, and other areas of public life. It took 17 years following passage of the Rehabilitation Act of 1973 for the ADA law to go into effect. Section 504 of the Rehabilitation Act, along with the ADA, served to strengthen the Civil Rights Act of 1964 that outlawed discrimination based on race, color, sex, religion, and national origin (Concannon, 2012).

The ADA was significant for this study due to its declaration that exclusion, segregation, and mistreatment of individuals with ID are acts of discrimination (Kelly & Su, 2015). These factors likely influence parents' decision making for their children. Parents who placed grown children into group home settings may have been unaware of the child's right to vote, work, travel, earn an education, access public transportation, or access social services or healthcare (Baroff & Olley, 2012).

### **ADA, Medicaid Funding, and Financial Burden**

Medicaid, a jointly funded federal/state insurance program, funds services to millions of eligible Americans. Congress, in the early 1980s, authorized home and community-based waiver programs in an effort to offer alternatives to institutionalization of individuals with ID who could no longer live in parental or guardian home settings (Gettings, 2012). The ID waiver program gave individuals with ID the option of going into community homes that provided services. The ID waiver program offers a more positive alternative to conventional or standard institutionalization. To qualify for waiver services, persons eligible under Medicaid are required to meet certain diagnostic, functional, and financial eligibility according to the Department of Behavioral Health and Developmental Services (DBHDS, 2014).

### **Group Homes**

Group home placement may be an option for individuals with ID (Norlin & Broberg, 2013). Group homes often are staffed 24 hours a day and 7 days per week. The typical group home has at least four to six adults with intellectual disabilities. The goal of the group home staff is to increase the quality of life of individuals with ID by teaching socialization skills, communication skills, independent living skills, money management, and building relationships. Felce, Perry, and Kerr (2011) surveyed 721 adults with ID who were either living at home, independently, or in staffed group homes. Quality of life parents provided to their grown children who lived independently contributed to greater household participation. However, those in staff group homes had greater household participation and community integration than those still living at home with parents. Among the variables examined by Felce et al. (2011), parents who chose group home placement for their adult child with ID resulted in increased emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, independence, self-determination, social inclusion.

### **Caregiver Burden, Barriers, and Benefits**

Parents who care for their adult children with ID in their parental homes often experience anxiety, depression, tension, and sleep deprivation. Parents of children with ID often experience several other stressors, which include health and financial problems, single parenting, widowhood, unfamiliarity with community resources, and worrying about the future care of their adult child (Hauser, Olson, & Drogin, 2014). Parents often continue to struggle to care for their family members in the parental homes to avoid placing grown children with ID in residential facilities. However, situations arise where parents cannot continue to provide care for their adult children in their home (Bigby & Beadle-Brown, 2018; Luijkx, Brug, & Vlaskamp, 2013). For example, adult children with ID who remain at home can present a danger to themselves as well as to their parents and other family members. Parents confront additional problems such as property destruction, elopement, and medical concerns when an adult child with an intellectual disability lives with them. Both the parent's and their adult child's quality of life increased following placement in a group home setting, despite feelings of loss (Bazzano et al., 2015; Crnic, Neece, McIntyre, Blacher, & Baker, 2017). The parents experienced high levels of stress, shame, anxiety, lowered quality of life, unhealthy family functioning, and negative psychological consequences, along with feelings of guilt after making the decision to place their adult child with an ID in a group home setting. Parents may resist seeking supportive services (Williamson & Perkins, 2014). Parents may have concerns about counselor training to address issues related to adults with intellectual disabilities; which may prevent them from providing effective resources, intervention strategies, and appropriate techniques to meet the individual with ID and family member's needs (Gibbons et al., 2016; Grossman & Webb, 2016).

In contrast to the preceding concerns, knowing the adult child is in a safe, secure, caring facility can open the door for parents to experience increased peace of mind (Bigby & Beadle-Brown, 2015). Placing the adult child in a group home setting may reduce daily responsibilities for parents around activities of daily living (ADLs). Caring fulltime for adult children can restrict parents from having outside employment, freedom to shop, visit friends, or participate in other social activities. However, parents may also receive criticism, sometimes severe, from immediate family, friends, and community members when they become unable to care for their adult

children in their homes (Bigby & Beadle-Brown, 2015). Outsiders may label parents as detached, uncaring, neglectful, and inconsiderate when they decide to place their adult child in a group home. Community members tend to judge parents harshly, without understanding the underlying circumstances behind their placement decisions, and as a result, parents of ID adult children can experience personal emotions such as guilt, shame, and feelings of loss when they place their adult children in a group home (Norlin & Broberg, 2013). Having to make the decision to place the adult child in a group home facility can be anxiety provoking. Once made, the process of moving the adult child into the new setting can also be challenging.

### **Problem Statement**

Parents and guardians often experience significant challenges when faced with the difficult decision of moving their adult children with ID from the home to an alternative living environment. As a result of limited current literature on the topic, a precursor to this article (Kay, 2017) was completed to further assess the lived experiences of parents who were thrust into the position of having to make the difficult choice of whether or not to place their adult child into a group home setting. This should also better inform clinicians to help them assist such families.

### **Rationale**

A dearth of literature and preconceived ideas about the experiences of parents and guardians surrounding their decision-making process on seeking group home placement of their adult children with ID led to the decision to use a phenomenological hermeneutic approach. The ultimate intention was to inform counselors on the emotional and practical issues faced by such parents surrounding what is often viewed as a drastic or last-ditch change. Once the choice has been made, the decision to move the child into a group home setting may offer some benefit to parents and their children, in spite of the difficulty in making the choice. Reducing daily responsibilities can serve to restrain parents or guardians from outside employment or the freedom to shop, visit friends, or participate in other enjoyable activities (Grossman & Webb, 2016). Anger, shame, anxiety, and guilt are common issues faced by parents who placed their adult children in group homes (Heller, Gibbons, & Fisher, 2015). Changing the known environment can be disenfranchising for the individual moving away from a known setting, particularly for an individual diagnosed with ID (Gibbons et al, 2016).

### **Method**

A hermeneutic phenomenology approach was used to focus on the subjective experiences of parents of children with ID. The question asked in this study was, what are the lived experiences of parents involved in the decision-making process who choose to place their adult children with ID in group home settings? In order to gain a better understanding of the issues faced by parents or guardians of individuals with ID and to provide avenues for social change, the study focused on a group of parents who had experienced the difficult decision of placing the child in an alternative group setting. Hermeneutic phenomenological is a qualitative methodology that grew out of phenomenological philosophy (Husserl, 1970). It is used to explain fundamental experiences of a world filled with meaning. Hermeneutic phenomenology focuses on the subjective experiences of individuals and groups (Heidegger, 1927: 1962; Kafle, 2011), providing an avenue for assessing the subject experiences of parents surveyed in this study.

### **Recruitment**

No external or third-party funding was used for this study. There was no requirement for parents to live in the same city as their adult child. Following Institutional Review Board (IRB) approval, participants were recruited through local group homes licensed by the State's Department of Behavioral Health and Developmental Service in a southeast region of the United States. Assistance of the highest-ranking administrator to recruit biological parents as participants for this study was sought after identification of the above-mentioned state licensed group homes. To recruit participants, flyers were placed at group homes and agencies providing services to individuals with intellectual disabilities. Letters outlining the study were sent to potential participants who answered the fliers and expressed interest in participating in the study. A follow-up letter was sent to those who expressed a desire to participate in the study. This included an informed consent form explaining in detail the process and the purpose of the study, along with reassurance of confidentiality. Participants were selected primarily on a convenience sampling basis. The participants agreed to volunteer, read and sign the informed consent form, which included an agreement to terminate the interview and audio taping consent at any time a participant chose to do so. Ten participants were chosen for the study. All 10 participants were interviewed one time and the duration of interview time varied.

### **Demographics**

Research participants for the study were biological parents of individuals diagnosed with an intellectual disability. Age of parents ranged between 45 and 74 years old. The median age of parents was 56 years old. There were six African American parents and four European American parents who participated in this study. Socioeconomic status was self-reported and based upon their own personal identification of belonging to upper, middle, or lower socioeconomic classes. Of the parents in this study, eight considered themselves middle class and two self-reported as lower class. The marital status of the 10 parents varied. There was one widowed parent, two divorced parents, three married parents, and four single parents. The parents' highest level of education varied as well. One parent had a master's degree, one had a bachelor's degree, two parents had received associate's degrees, five had some college, and one parent had a high school education. The participant's adult child had to be currently living in a group home setting, and the children were aged between 18 to 60.

### **Guidelines for Collecting Data**

The methodology for data collection involved in-depth interviews (see below for further details), audio-recording of each interview, and verbatim transcribing. The transcriptions followed the Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliance rules and confidentiality of each participant was preserved throughout the process, ensuring data privacy. Data were secured throughout and following the study. Data were collected via personal interview, which allowed for flexibility to conduct interviews using multiple methods of communication (Memnun, Aydın, Özbilen, & Erdoğan, 2017).

Data collection utilized an interview guide, including several open-ended questions. A semi-structured interview approach allowed in-depth and probing questions to gain more information from the participants. The participants were provided with the option of conducting the interview in a comfortable, private location of their choice, such as a private room in a public

library. In the event the researcher or participants expressed any issues with safety or privacy, the interview would be rescheduled at a more appropriate setting in the community; however, this never became necessary.

### **Interview Questions**

Interview questions were designed to capture the full decision-making process around group home placement.

Participants were asked the following demographic questions:

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

After each participant answered the demographics question, three interview questions were asked:

1. What decision-making processes do parents use when deciding to place their adult child with an intellectual disability in a group home setting? Please identify the step-by-step process you engaged in to arrive at the decision of a group home placement for your adult child.
2. How did you come to the conclusion of group home placement for your adult child with an intellectual disability? Describe the initial experience that triggered a possible decision for group home placement. Describe the final experience that made group home placement a definitive decision?
3. What factors contribute to the decision to make group home placements as opposed to other residential care facilities?

### **Member Checking**

Member checking or respondent validation encourages participants to confirm the accuracy of their words (Houghton, Casey, Shaw, & Murphy, 2013). The process was conducted prior to coding in an effort to verify findings. Member checking was substantiated by forwarding participants' transcripts for their final review and approval. All participants indicated satisfaction with the transcribed interviews and did not identify any discrepancies.

## **Results**

Parents who have adult children with intellectual disabilities living in group home settings responded to open-ended interview questions designed to address the research questions. The recording of the semi-structured face-to-face interviews and making field notes of observations allowed for in-depth probing questions in order to gain more information from the participants. Trustworthiness of the findings is found through examining the conformability, credibility, and dependability of the outcomes (Houghton, Casey, Shaw, & Murphy, 2013).

Credibility requires ensuring the transcripts have accurately documented what research participants related to the researcher and this was done. It involved examining the appropriateness of the content in the interview questions and how they related to the overarching research question. Dependability strategies in the data analysis process underscored the accuracy of the findings (Kornbluh, 2015). Dependability was established by verifying and analyzing transcripts for mistakes, confirming codes, and definition consistency.

### **Coding and Thematic Analysis**

Immersion in the transcripts in the first-round coding resulted in 59 themes. The redundancy and number of themes was accomplished in several iterations. For example, physical aggression and property destruction mental were placed together. To ensure accuracy, each word or phrase was once again reviewed to determine if any needed moving or re-categorization. The second round of coding had 22 themes. Third round coding resulted in the following 9 themes. The top nine codes outlined why parents chose to place their sons or daughters in group home settings are shown in the table 1 below.

Table 1. Coding and Thematic Analysis

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

Data were analyzed using the following steps:

- The ten transcripts were read to the participants to ensure that they were consistent and verbatim to the recorded interviews.
- Generated Preliminary Meaning Units (based on words, phrases, sentences, captured in the participant's interviews).
- Generate Secondary Meaning Units.
- Generate Final Meaning Units for each interview questions.
- Synthesized situated narratives into general narratives integrating all major themes of participants.
- Generate descriptions of the parents' decisions around group home placement for their adult child with intellectual disabilities.

### **Findings**

Upon completion of data collection and transcription, analysis resulted in the nine themes shown in table 1, emerging from the information shared. The experiences leading to a decision for group home placement included best option, physical aggression, death/absence of a spouse, caregiver medical conditions, mental health behavioral disorders, hospital/emergency, community integration, verbal aggression, and financial burden. The following themes, identified



from the narratives told to the researcher by the participants, reflect the meaning they made of their experiences.

**Best Option.** Group homes increase community awareness by individuals with intellectual disabilities due to the significant amount of time spent in the community. Also, group homes can be effective in enhancing socialization and relationship building skills by individuals with intellectual disabilities because they spend a significant amount of time with peers. The staff also encourages individuals with disabilities to build natural support systems with individuals without disabilities, along with volunteers, family members, and others who take care of them without compensation.

Participant B noted when his son was 18, he wanted to be his own person, and live in his own place. So, he decided he wanted to go to a group home. He went there and said, “This is where I want to be, I want to be here.” And I said, “Are you sure?” and he says “Yeah, I’m sure.”

**Physical Aggression.** Some of the physical aggression parents face from their son or daughter with intellectual disabilities include biting, punching, slapping, kicking, and pushing. Adults with intellectual disabilities also engage in self-inflicted behaviors, such as head banging, cutting, and hitting themselves. Physical aggression displayed by adults with intellectual disabilities can lead to their caretakers deciding to place them in a group home.

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

**Death/Absence of Spouse.** Single parents found it hard to care for their adult child with intellectual disabilities while working, maintaining the home, and still providing care to their other children without disabilities. After parents experience the loss of their spouse, they found it hard to continue to care for their adult child with disabilities while grieving at the same time. Parents tend to provide better care for their adult child with disabilities when both parents are present and actively involved.

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

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

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

**Mental Health-Behavioral Disorder.** Adults with intellectual disabilities may experience mental health behavioral disorders, such as bipolar disorder, schizophrenia, mood disorder, anxiety, and intermittent explosive behavior disorder. Many adults with intellectual disabilities experienced abuse, neglect, and exploitation by parents, family members, peers, and others in the community. Such traumatic experiences increased their chances of receiving a mental illness diagnosis.

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

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

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

**Community Integration.** Due to their parent's ages, medical conditions, or transportation concerns, the amount of time adult children who live at home spend in the community may be limited. Ability to manage money, including learning budgeting skills when making purchases in the community, may be challenging.

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

**Verbal Aggression.** Some adults with intellectual disabilities require a significant amount of time and attention, and they often become jealous when their parents show love, attention, time, and affection to anyone else. Many of the participants indicated group home placement offered their adult child more community integration, which allowed them to participate in more activities in the community with peers. Participants found it difficult to handle the verbal aggression and use of profanity displayed by their adult child with a disability.

Participant D reported: “We were coming home one day. I took him out to the arcade. I really wanted to spend some guy time with him, some father time with him. He got upset because I said, ‘Hey it’s time to go to home.’ He was like, ‘I want to stay at the arcade.’ I said, ‘You can’t do that, we have to get back home.’”

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

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

These nine codes appeared to be significant to the parental decision-making process when considering group home placement for the grown child. Twelve significant codes scored slightly lower, and another 37 codes scored 10 and below. No discrepant cases were noted in this study. All cases were significant and interconnected. Each interview and transcript contributed to the data analysis process.

### **Limitations**

Parents participating in this study lived in a specific geographic region, the northeast shoreline of the United States and this may limit its generalizability. Data saturation was achieved, although a small sample size may have limited the study. In addition, due to the sensitive nature of the study, parents were interviewed once. The narrow focus on the lived experiences of parents of intellectually disabled adult children, as opposed to including adult children within other categories of incapacitating or disabling conditions, may also limit the usability of the results of this research. The results apply to parents of adult children with intellectual disabilities and are therefore not necessarily transferable. The outcomes of the study are dependable and credible, based on use of member checking. Although the interview questions were not piloted, the questions were instead sent to experts to determine appropriateness of the study and were deemed appropriate.

**Significance and Implications for Professional Practice.** Understanding the lived experiences of parents who have had to make the difficult decision or who may be making the difficult decision of placing adult children with ID into a group home setting may help to

explicate the multiple factors that influence the parental decision-making process for this challenging experience (Bigby & Beadle-Brown, 2015). The findings may also help to increase counselor or other helper awareness of the issues and challenges faced by these parents and their adult children with ID. Better preparation of practitioners in their programs of study and in ongoing continuing education would be an important consequence of using this study's findings. A greater appreciation for the social issues involved can help to increase the general public's understanding of what many parents face. Organizations such as the National Alliance on Mental Illness (NAMI) represent parents and caretakers of mentally ill adult children who can benefit by better understanding the types of experiences parents may face when considering alternatives for their adult children, even if the population has varying demands (Mercado, 2015). These changes of understanding may also lead to better services, funding for services, and changes to the law to continue and expand options for the families of individuals with ID and the individuals themselves.

### **Implications for Future Research**

Parents who opt to place their adult children with ID into group home settings may experience difficulty accessing efficacious counseling services due at least in part to an unfamiliarity with the problems they may face, a lack of familiarity to the hardships parents and offspring may face, lack of adequate training, or access to resources, thereby limiting their ability to help (Gibbons et al., 2016; Grossman & Webb, 2016; Williamson & Perkins, 2014). Counseling professionals could, therefore, benefit from better understanding the lived experiences of parents who have made decisions for group home placement by learning strategies to better address the emotional stressors and symptoms that may be faced.

An increased awareness and continued education on the part for counselors regarding the lived experiences of parents with adult children with ID supports their ability to intercede with other parents struggling with similar situations, including accessing counseling services, social stigma, guilt, isolation, and feelings of inadequacy concerning their decision to place their ID adult child into a group home facility. Helping professionals, including counselors, can work to develop insight into why parents continue to struggle with these difficult placement decisions. Counselors could consider the influence of culture and collective family beliefs regarding seeking outside assistance with caretaking for their adult children (Kripke, 2015). Groups from collective-oriented communities tend to insist on maintaining disabled family members and reject placing them with those who they consider strangers.

Future studies are needed to better understand the challenges faced by parents of children with ID who may consider placement into group home settings. Further understanding of aspects of counseling theory and technique would also help to better prepare counselors for productive interventions when helping those parents make better informed decisions. Replication of this study with other groups of parents in different parts of the country would increase generalizability. Quantitative analysis might add an element of reliability and validity following the results of the present study.

### **Conclusion**

In this study, 10 participants openly and willingly shared their decision-making processes surrounding moving their adult children with ID into a group home. What they shared was in some ways expected, and in other ways completely unexpected. Among the participants, parents in this study did not want to give up on their children. In addition, parents did not seem to seek group home options as a first choice and felt inadequate in their ability to care for their adult children. Yet, community resources can be of great value, leading to a more stable quality of life for the parents and their children, and increase the adult child's ability to remain successful in society. Parents who did make the decision for outside placement for their adult children with ID that resulted in the provision of high-level community integration, increased independence, and a nurturing family-like environment, seemed to fare best. As a result of the thematic analysis in this study, counselors aware of the issues may be better prepared to work with such parents and families, and help parents become more knowledgeable of options available, and in the development of coping mechanisms to assist them in working through this difficult decision-making process.

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