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Parents Perceptions of Social Inclusion of Adults With Intellectual Disabilities

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Abstract

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MBA, University of Phoenix, 2006

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Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
Educational Psychology

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Abstract

Researchers have shown that the voices of parents of adults with intellectual disabilities can help build supports in the community. Research regarding the perceptions and lived experiences of these parents regarding social inclusion of adults with intellectual disabilities is limited. Guided by positive psychology, the purpose of this interpretive phenomenological study was to examine parents' lived experiences of social inclusion of adults with intellectual disabilities. Research questions were framed to understand and describe the meaning of how parents experience social inclusion with their adult children with intellectual disabilities. Data were elicited through 6 individual interviews with parents of adults with intellectual disabilities from Shelby County, Tennessee. Data was analyzed using a phenomenological and double hermeneutic approach that is consistent with the interpretative phenomenological analysis. The findings from this study were compared with existing literature indicating that parents must facilitate social inclusion for their adult children with intellectual disabilities. Another finding from the study was that parents believe that there is a need to build relationships in the community. Including the voices of parents of adults with intellectual disabilities with those of professionals could influence policy makers in designing supports for parents and families, which could have positive social change implications. Adults with intellectual disabilities may benefit from the study, in that their parents' voices are being heard and the study draws attention to the need for continual support from service providers, policy makers, and the community itself. This study also helps to fill a gap in research regarding parents' lived experiences and perceptions concerning social inclusion of their adult children with intellectual disabilities.

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Dedication

I would like to thank God, who is the head of my life and my keeper. This dissertation is dedicated to my husband, the late Dr. Jerry L. Green, and my daughter, Tykira J. Bullins. Both my husband and my daughter were the driving force in my push to complete my dissertation. My late husband took a lot of the pressure off of the day-to-day things that I needed to do as a wife and a mother so I could write. Since my husband passed away in 2016, my daughter has been a constant voice in my ear encouraging me to keep going. This dissertation is also dedicated to my parents and my 11 siblings. I am the first in my immediate family to make it this far educationally. I would also like to dedicate this dissertation to my brother-in-law, Terry Green, who risked his life trying to save the life of his identical twin, my late husband. This dissertation is also dedicated to the many parents of adults with intellectual disabilities who strive every day to help their adult children be socially included. Last, but certainly not least, this dissertation is dedicated to all individuals with developmental and intellectual disabilities.

Acknowledgments

I have to always put God first in everything I do because Philippians 4:13 tells me I can do all things through Christ who strengthens me. Glory to my God for the things he has done in my life and for giving me the strength to stand when I felt I couldn't make it. I would like to thank my committee members: Dr. Elizabeth Clark, my chair, and Dr. Reba Glidewell. A special thank you to Dr. Clark, who was compassionate during the loss of my husband. I am so appreciative of her understanding me and meeting me where I was at that time. I would like to say a special thanks to the best editor in the world, Dr. Mary Beth Haines. I would also like to thank Dr. Nancy Ray, who helped me process my thoughts when I started this process, and Dr. Larry Durbin for his support and encouragement throughout this process.

To all my family, friends, and church family, thank you for your continual support. I cannot thank you all enough for wrapping your arms around me when I was at my lowest point. You all were my strength. To you, Terry, no matter where this life takes me, I will never forget the act of love you showed my late husband, or how you have continued to encourage me. You have been a constant presence in my and my daughter’s life. My late husband, Dr. Jerry Green, would always tell people everywhere we went, "My wife is working on her doctorate." Now, Dr. Green, I know you are smiling down from heaven and saying to yourself, "My wife is a doctor." You are gone but you will never be forgotten.

Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Introduction

In the United States, very few research studies exploring parents' perception of social inclusion of adults with intellectual disabilities (AID) have been conducted. In Europe and Australia, extensive research studies have been done on attitudes and opinions concerning social inclusion of AID (Happell & Harrow, 2010). Awareness regarding social inclusion has been raised on a national and international level during the past decade because of an increased presence of AID in communities (Needham & Sands, 2010).

Researchers have studied social inclusion of AID since the first wave of research on such individuals leaving institutions (Amado, Stancliffe, McCarron, & McCallion, 2013). Social inclusion has been measured and described across different age groups, school environments, community living situations for AID, employment situations, faith communities, and community service organizations (Amado, Boice, & DeGrande, 2012). Social inclusion in this research study refers to how welcomed AID feel when they are in the community and how parents feel watching their adult children with intellectual disabilities interact in the community. The presence of people with intellectual disabilities (ID) in the community has increased in society (Barrett, Savva, Timonen, & Kenny, 2011). Novak, Stancliffe, McCarron, and McCallion (2013) suggested, however, that mere presence in the community is not sufficient to demonstrate social connectedness. More work is needed regarding AID, and greater consideration should be given to families in this research (McCarron et al., 2011). This study's findings add to the research on social inclusion by providing an understanding of parents' lived experiences and perceptions of social inclusion for their adult children with ID.

I provided services to AID between the years 2001 and 2015. These services included both working with them directly and managing the direct support professionals who provided care in the homes of AID. My responsibilities also included finding homes in the community with service providers for AID.

As a community transition coordinator employed with the State of Tennessee, I had the opportunity to work closely with different service providers, government agencies, and families in the community. In this job, I had to make quick decisions with the help of parents, families, and service providers for AID regarding living arrangements for these individuals. In some communities, people did not want AID living in their neighborhoods. If any people in a community experienced an outburst from an adult with ID, those in the community might ask that AID move out of their community. Many times, I had to move an adult with ID from one community to another community to keep him or her safe.

The relationships I built with parents and families as a coordinator opened my heart and eyes to experiences of social inclusion for AID that were not always positive. It was during this time that I learned that parents do not have a platform to voice their experiences of social inclusion. It is necessary to engage parents in a discussion about their social inclusion experiences involving AID to identify factors that can lead to successful social inclusion experiences in community, school, and employment settings.

In this chapter, I provide background information regarding social inclusion and AID. I present the problem of lack of social inclusion for AID and the purpose of this research study, describing why the research study is significant. The research question, theoretical foundation, nature of the study, definitions of terms, assumptions, scope and delimitations, and limitations applicable to my study are included. A detailed discussion of why this research study is significant, with a hint of the areas of literature to be covered in Chapter 2, concludes Chapter 1.

Background

Social inclusion of adults with intellectual disabilities (AID) became an issue as early as 1967, when many AID left institutions, primarily because the institutional setting had been filled with other individuals with various disabilities (Novak et al., 2013). Novak et al. (2013) reported that AID who left institutions wanted to pass as normal and focused on physical inclusion. *Physical inclusion* refers to the number of community resources available to AID; the proximity of community resources for AID, or how far they have to go from home to get to these resources; and the frequency of community activities for individuals with intellectual disabilities (Novak et al., 2013). Physical inclusion of AID in the community has not often offered these individuals a sense of belonging, and these adults tend to have few relationships with their nondisabled peers (Novak et al., 2013).

Parents play a vital role in the lives of individuals with intellectual disabilities

(Resch et al., 2010). Cobigo and Stuart (2010) reported that parents believe that once a disability is understood, the focus will shift to the capabilities of people with ID. Most people with intellectual disabilities are dependent on their parents for access to most social inclusion experiences, in that their parents control transportation and finances. This dependency makes it important to understand parents' lived experiences of social inclusion of their adult children with ID, to ensure the development of proper interventions, services, and support (Resch et al., 2010).

Several benefits of social inclusion have been documented in research. Heaney and Israel (2009) reported that social relationships provide informational, emotional, and instrumental support to AID. Social support for AID is primary for their wellbeing and takes place by developing and maintaining relationships with AID (Johnson, Douglas, Bigby & Iacona, 2012a). Age, degree of disability, environmental factors, and personal characteristics are all aspects of life that have been studied regarding social inclusion for AID. Little research that addresses parents' perceptions of social inclusion for AID is available (Novak et al., 2013). Mayer and Anderson (2014) reported finding research on the following topics: AID feeling part of the community, improvement in self-image when accepted, increasing physical fitness, increasing self-esteem, and decreasing negative stereotypes for AID.

Mansell (2010) ascertained that families face many challenges in caring for AID, such as battling public service systems and dealing with perceived indifference. Mansell further explained that parents caring for a family member with ID face a stressful and heavy responsibility. He advocated raising awareness concerning AID. In Mansell's review of services for AID, he indicated that families' common negative experiences include prejudice, discrimination, lack of services, and poor-quality care for individuals with intellectual disabilities. These negative experiences contribute to parents' low expectations of services and support for AID. Mansell asserted that parents should be recognized as family-centered experts because of their involvement in ensuring that AID receive needed services.

Self-determination, families, and health and wellness are critical factors in increased social inclusion. Social inclusion, health, and education are factors that affect quality of life for AID (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Although life for some AID has improved, AID continue to be marginalized in the areas of social inclusion, employment, and health and wellness (Anderson et al., 2013). As a result, it is important to understand research findings and then to use the research to inform practice and create systems to improve social inclusion for AID (Hewitt et al., 2013).

Problem Statement

Families are essential to the promotion of social inclusion for AID because families are the primary caregivers for adults with intellectual disabilities, both during their developmental years and through adulthood (Chadwick et al., 2013). Parents are the primary family members facing the challenge of helping AID achieve social inclusion (Hewitt et al., 2013). Despite the United States' national push to change service delivery systems for persons with ID, few studies are available on how to support families (Hewitt et al., 2013).

This research study was guided by the concern that research on parents' lived experiences of social inclusion for AID remains limited (Cobigo & Stuart, 2010). Parents' voices are important because parents' ideas can help build supports in the community for AID (Zuna, Brown, & Brown, 2014). Parents' ideas provide an understanding of lived experiences and perceptions of social inclusion for their adult children with ID. The findings of this study may help providers and organizations delivering services to AID to increase social inclusion and may shed light on areas that tend to be a problem for parents. This research study adds to the limited research that addresses the active role of parents who care for AID. This study brings out individual parents' voices about their perceptions and meaning-making processes in relation to social inclusion of AID.

Purpose of Study

My purpose for this qualitative research study was to use interpretative phenomenological analysis (IPA) to understand and describe the meaning of parents' lived experiences of social inclusion of AID in their charge. *Lived experiences* can be defined as understandings and representations of a researcher's or research participant's human experiences, options, and choices and how those factors influence the perception of knowledge (Given, 2008). I was interested in learning about how welcome parents of adult children with intellectual disabilities feel when they are in a community setting and how parents of AID feel watching their adult children in the community. Through this research study, I am adding to the few existing research studies by providing parents of AID a platform for their voices to be heard (Khan & Jahan, 2012). My research study's goal was to provide an understanding of the lived experiences and perceptions of social inclusion of AID from parents' point of view, using a positive psychology (Khan & Jahan, 2012) frame of reference.

Research Questions

My aim for this study was to present parents' experiences of social inclusion of AID from parents' perspective. Because limited research exists regarding parents' perception of social inclusion for their adult children with intellectual disabilities, my findings in this study provide knowledge of parents' experiences to broaden understanding of social inclusion for AID (Zuna et al., 2014). The guiding research questions for this research study were as follows:

1. What are parents' lived experiences of social inclusion of their adult children with intellectual disabilities in their charge?
2. How do parents describe their meanings of social inclusion experiences of their adult children with intellectual disabilities in their charge?

I addressed these research questions using an IPA design.

Theoretical Foundation

The theory foundational to this research study is positive psychology (Khan & Jahan, 2012). Researchers using positive psychology study human strengths and virtues. They seek to find what works, what is improving, and what is right (Khan & Jahan, 2012). Positive psychology focuses on fulfillment, happiness, and flourishing of the human condition. Using this lens afforded me the opportunity to concentrate on positive experiences without excluding negative experiences (Khan & Jahan, 2012). Using positive psychology as a foundation for my study offered parents a way to challenge negative self-talk and see negative experiences from another angle (Lyons, 2009).

Seligman and Csikszentmihalyi (2000) developed a “three-tier framework that included subjective positive experience, individual level experience, and group level experience” (p. 5). According to these authors, the subjective positive experience focuses on valued subjective experiences: “life satisfaction, contentment, well-being, optimism, hope, and happiness” (p. 5). The individual level experience focuses on positive personal traits, such as “courage, interpersonal skills, and capacity for love, forgiveness, perseverance, originality, spirituality, wisdom, and talent” (p. 5). Lastly, the group level experience focuses on virtues and institutions that guide individuals to better citizenship, which include “tolerance, work ethics, responsibility, altruism, nurturance, civility, and moderation” (p. 5).

Using a positive psychology lens, I was interested in learning how the parents of AID make meaning of experiences of social inclusion of their adult children with intellectual disabilities. This positive psychology lens helped me focus on the well-being and the functioning of AID as they relate to social inclusion, as viewed through the meaning-making processes of the parents of these adults. This was a dual lens, involving the framework of positive psychology plus the experiences of parents concerning social inclusion of AID. Positive psychology researchers are interested in what leads to human flourishing (Lyons, 2009). In data analysis, I was open to the possibility that elements of the three-tier framework developed by Seligman and Csikszentmihalyi (2000) could show up in the parents' descriptions and the meanings they made.

Social inclusion was an integral focus for this study. Social inclusion is a goal of legislation, policies, supports, and services for persons with intellectual disabilities (Officer & Groce, 2009). Cobigo and Stuart (2010) found evidence suggesting that social inclusion and participation of AID are still limited. Social interaction is imperative to achieve social inclusion (Watson & Nolan, 2011). AID may have little or no communication skill; they find social interaction and building relationships challenging (Johnson, Douglas, Bigby, & Iacono, 2012a). Johnson et al. (2012a) stated that the social interaction of AID and the diversity of people with whom they interact remain unexplored. A vital part of relationships is having fun. In their research findings, Johnson et al. (2012b) contended that fun should be articulated as an avenue to positive interaction and developing relationships with AID. Having fun consists of laughter and enjoyment (Johnson et al., 2012a). Positive psychology researchers explore factors such as happiness and positive emotions (Lyon, 2009).

Nature of the Study

The nature of this research study was qualitative. IPA was used to understand meaning-making processes and parents' perceptions of social inclusion of adult children with intellectual disabilities. Smith (2011) reported that the IPA approach aims to offer an understanding of a phenomenon being studied as experienced by several individuals.

According to Biggerstaff (2008), qualitative research approaches have much to offer when exploring participants' feelings and when asking participants to reflect on their experiences. IPA as a discipline within the qualitative paradigm also helped me gain an understanding of what those experiences meant to participants within their social realities, and what the participants thought and felt about those experiences. Qualitative research is a tradition in which researchers uncover aspects of participants' lives that have not yet been explored.

According to Larkin et al. (2008), the IPA method is a qualitative approach to understanding participants' lived experiences related to a phenomenon being studied. Using IPA, the researcher develops an interpretive analysis of participants' descriptions and makes sense of participants' lived experiences as they relate to social, theoretical, and cultural contexts (Larkin et al., 2008). The IPA qualitative method is rigorous and flexible enough to fit a variety of studies (Biggerstaff, 2008).

I asked open-ended questions (see Appendix D) to collect data from participants. Qualitative researchers use open-ended, informal interview techniques rather than fixed-response questionnaires or surveys. Researchers use interviews to gather information in the participants' own words, from which insights into their experience can be obtained (Merriam, 2009). The process of conducting face-to-face interviews tends to be longer than the process of reviewing written descriptions from participants. According to Englander (2012), face-to-face interviews are richer than written descriptions in terms of depth.

I expected that the largest portion of the interviews would consist of exploring relevant topics through clarifying and follow-up questions that might be discovered during the course of the interview process. Participants were encouraged to talk about feelings, beliefs, and experiences during the interview process (Merriam, 2009). All interviews were digitally recorded and sent to a professional transcriber so that data could be transcribed verbatim afterward, to protect against bias and to provide documentation of what had been said (Merriam, 2009). This was done after the professional transcriber signed a confidentiality agreement (see Appendix C).

Participants were six biological parents of AID who lived in the Shelby County area of Tennessee. Participants were parents of AID who were actively attending outings at least two times per month with AID. According to Marshall, Cardon, Poddar, and Fontenot (2013), an IPA study sample size should range from six to 10. I was interested in recruiting six to 10 participants so that I could explore each case with the necessary time, energy, and rigor required for an IPA research study (Callary, Rathwell, & Young, 2015). At six to 10 participants, I expected to reach data saturation, a situation in which no new information comes by adding more data. I was able to achieve data saturation with six participants.

If six participants had not provided enough data to reach data saturation, I would have used a snowball sampling technique to add up to four more participants, for a total of up to 10. Snowball sampling begins with interviewing an initial set of research participants who serve as informants about not only the research topic, but also other potential participants. In some cases, the process of snowballing that follows the initial interviews is indirect in the sense that these original sources mostly supply information about how to locate others like themselves and where the researcher is likely to find other participants (Given, 2008). The process of gaining participants is explained further in Chapter 3.

Smith (2011) reported that when researchers use IPA, they aim to determine what an experience means for participants who have had the experience, which they depict through thick descriptions. I developed interview questions (see Appendix D) focused on garnering detailed descriptions of the parents' experiences and what those experiences meant to the participants. Each participant's transcript was a description of the experience with a variety of different aspects related to that participant. IPA research involves the researcher deeply understanding the phenomenon using reflective analysis and comparisons of participants' accounts.

Definitions

The following terms have been used in this study:

Charge: A charge limits the right to make decisions for an adult with intellectual disabilities, in that someone else has permission to make decisions about his or her life (Disability Rights Ohio, 2013).

Intellectual disabilities (ID): This disability involves impairments of mental abilities that impact adaptive functioning in the conceptual, social, and practical domains

(American Psychiatric Association, 2013).

Perception: The process by which people organize or interpret their sensory impressions to give meaning to their environment (American Association on Intellectual and Developmental Disabilities [AAIDD], 2011).

Service provider: Provides services and supports that are intended to strengthen, identify, expand, and increase formal and informal support for AID so that they may exercise self-determination in the direction they would like for their lives to go (U.S. Department of Health and Social Sciences and Florida Developmental Disabilities Council, 2008).

Social inclusion: Social inclusion is defined as a view of how society values, respects, and meets the needs of ID adults, as well as how society embraces full participation of every citizen in that community (Westfall, 2010).

Assumptions

According to Smith (2011), IPA researchers aim to determine what an experience is for persons who have had that experience and who can provide a comprehensive description of the experience. Because of their relationships with AID, participants were assumed to have knowledge of experiences of social inclusion for AID. Another assumption was that the participants would answer the interview questions openly and honestly. A basic premise on which this study was based was that the experiences, voices, and perceptions of parents of AID would add information to the research literature regarding parents' lived experiences of social inclusion of AID.

Scope and Delimitations

The study includes semi structured interviews with six parents of AID. In order to participate in this study, an individual needed to be the biological mother or father of an adult with ID and needed to have attended at least two outings in the community per month with the adult with intellectual disabilities in Shelby County, Tennessee, for at least the previous 6 months. I used IPA to explore parents' experiences and perceptions of social inclusion of AID. IPA was used to understand and describe the meaning of parents' lived experiences of social inclusion for AID. The information in this IPA study relied on the descriptive information provided by the participants (Smith, 2011).

The study was restricted to interviews with parents of AID. This was a delimitation because I interviewed only biological parents, which meant that I was only interested in learning about how the moms or dads of AID made meaning of their experiences. I was not interested in the experiences of caretakers, adoptive parents, or legal guardians for this study.

Readers of qualitative research should be able to make connections between aspects of a study and their own personal experience (Barnes et al., 2012). I accomplished transferability through the use of purposive sampling. Purposive sampling may provide more in-depth findings than any other sampling method (Cohen, Manion, & Morrison, 2011). This study included rich descriptive data about the participants so that they could decide if the results conveyed their experiences. If the results of my study have meaning for individuals who are not involved in my study and readers can associate the results with their own experiences, then it meets the transferability criterion (Cope, 2014).

Limitations

This qualitative IPA study was limited to participants who were parents of AID who currently lived in their own individual housing where the study organization provided staffing 24 hours a day to AID. The geographic location of the study was restricted to Shelby County, Tennessee. It is possible that the study could have yielded additional findings if a larger geographic location had been explored. All data were gathered from the sample of parents of AID.

In an IPA study, it is important for the researcher to set aside personal experiences and biases so that a fresh perspective can be taken (Callary et al., 2015). Because of my experiences with AID, I had biases that could have impacted my analysis of data. Bracketing my experience allowed me to showcase potential biases that could shape the interpretation of the data, and it may have enriched the understanding of the experiences that participants shared (Callary et al., 2015).

My bracketing began with identifying any biases and preconceived notions regarding the phenomenon of social inclusion of AID. My mindset going into the data-gathering phase of the research was that of a person who has knowledge of the phenomenon being studied. Allen-Collinson (2009) suggested that it is impossible to bracket biases completely, but I looked forward to this subjective process of identifying and setting aside preconceptions in order to embrace a self-critical and reflective approach (p. 286). Focusing on the experience of participants while I suspended assumptions kept me in line with the aim of IPA, which is to get at the meanings of the participants' experiences as expressed in their descriptions of the experiences (Smith, Flowers, & Larkin, 2009). Finlay (2008) recommended that phenomenological researchers have a phenomenological attitude, which means being open to new information and seeing things as if they are fresh.

Significance

Policymakers currently strive to include AID in community opportunities, though public attitudes and perceptions can be a barrier to achieving social inclusion (Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010). The Olmstead Decision of 1999 brought about a significant change for AID (Milne, 2012). The Olmstead decision mandated that states operate their Medicaid programs in compliance with the Americans With Disabilities Act of 1990. This decision promotes the idea that AID should be granted choices to live independently in their communities, and it advocates the removal of barriers for AID (Milne, 2012). Two goals of the Olmstead Decision are to create more person-centered systems and to create ways to promote social inclusion (Milne, 2012). The Olmstead Decision involved policymakers and service providers. Because parents' voices were not involved in the Olmstead Decision, this study may improve the understanding of how current systems work and ways to support families of AID.

AID are among the most marginalized groups, consistently encountering social inequalities (Cobigo & Stuart, 2010). My goal for the research study was to describe the parents' lived experiences of social inclusion of AID, along with the meanings they made of those experiences. The findings from this study could increase service providers' and state representatives' knowledge of parents' experiences. These findings could even play a vital role in creating systems of interventions, services, and supports to improve social inclusion of AID.

In this study, I hoped to promote positive social change by increasing knowledge and understanding by giving parents the opportunity for their voices to be heard concerning perceptions and meaning-making processes of social inclusion for their adult children with intellectual disabilities. My choice to use positive psychology (Seligman & Csikszentmihalyi, 2000) as a foundation for this study meant that I used that lens as a way to understand the experiences participants shared of social inclusion with their adult children with ID and the meanings they made of those experiences. By studying parents' lived experiences of social inclusion of AID, I sought to add to the literature on the experiences of families, especially parents, and perhaps also add to the literature on social inclusion experiences of AID themselves.

This research study was significant to parents of AID because it provided them a stage so that their voices could be heard. Information is still needed to identify practices that support the needs of AID and their families. Further research is also needed to address the practical use of public resources to ensure that parents receive the necessary guidance (Hewitt et al., 2013). This research study built on existing research by adding the voices of parents.

Summary

As the researcher for this study, I explored parents’ experiences and perceptions of social inclusion of adults of intellectual disabilities. Understanding the parents’ perceptions of social inclusion of AID required an understanding of the parents’ lived experiences of social inclusion. My goal for this study was to gain an understanding of how parents made meaning of their lived experiences of social inclusion of their adult children with intellectual disabilities.

Having provided an overview of the study along with its significance, background, and other general issues, I move in the next chapter to an examination of the literature regarding parents’ experiences and perceptions of social inclusion of AID. This examination includes the literature search strategy, details on the theoretical foundation for the study, and what has already been explored by previous researchers about experiences of social inclusion for AID and their parents. The literature reviewed both lays the groundwork for the study and demonstrates the need for an exploration of this phenomenon using an IPA method with a foundation of positive psychology.

Chapter 2: Literature Review

Introduction

As stated in Chapter 1, the problem I addressed in this study is the issue of parents' lived experiences of social inclusion of AID from the parents' perspective. Algood, Harris, and Hong (2013) and Speraw (2006) completed studies that addressed the experiences of adults with disabilities and the experiences of their parents. What made this project different from other research studies regarding social inclusion was that it focused exclusively on the voices of the parents of AID and their experiences of social inclusion of their adult children with ID. Unlike research conducted using focus groups or online surveys, this study brought out individual parents' voices about their perceptions and meaning-making processes regarding social inclusion of AID.

The parents participating in this study lived in Shelby County, Tennessee. Since large numbers of AID left institutions, social inclusion has been studied, and a vision of persons with ID having valued social roles and a sense of belonging to the community has emerged (Novak et al., 2013). The number of research studies available regarding parents' perceptions of social inclusion is limited. The scarcity of scholarly literature, particularly in the United States, on parents' lived experiences of social inclusion of their adult children with ID was discovered by using the terms *social inclusion* and *parents' lived experiences* in a literature search. In my search for literature, I found only three studies related to parents' perception of social inclusion (Henninger & Lounds, 2014; Resch et al., 2010; Schleien, Miller, Walton, & Pruett, 2014). Expanding the search to include families' experiences of social inclusion for AID added two other studies on the subject: Bedia, Cilleros, Primo, and Fernandez (2009) and Martin and Couto (2014). The literature on social inclusion of persons with ID was broader.

Social inclusion of AID is an important policy objective for state legislators, parents, and families (Cobigo & Stuart, 2010). To a large extent, people's understanding of disabilities drives the approaches used to promote social inclusion for persons with ID. Parents have reported that once the nature of the disability is understood, it is important to focus on the capabilities of persons with ID, acknowledge the obstacles that hinder the social inclusion process, and address barriers that cause persons with ID not to feel socially included (Cobigo & Stuart, 2010). Walton, Schleien, Brake, Trovato, and Oakes (2012) suggested that there is a need for continual conversation regarding social inclusion of AID.

The literature review below begins with background information regarding social inclusion. Connected to the literature on social inclusion, I review the limited research on parents' experiences and perception of social inclusion. Subsequent to the sections on parents' experiences and parents' perceptions of social inclusion is a review addressing support for parents of AID. Following these topics, I review information relating to community relationships with AID.

In the final section of the literature review, I discuss the future of social inclusion for AID. Literature on the future of social inclusion for AID describes the importance of using people-first language to decrease negative stereotypes in society, conducting more research on the needs of parents and families of AID, and providing services and supports for parents of AID. In the summary and conclusions section at the end of this chapter, I emphasize AID' need for inclusion, parents' desire for inclusion of their adult children, and the conclusion that, based on research, there is still much work to be done regarding AID and social inclusion.

Literature Search Strategy

To conduct this literature review, I performed an advanced search for peer-reviewed articles using the Walden Library research databases, including ProQuest Central, EBSCOhost, and Academic Search. Additionally, I conducted a Google search on social inclusion for AID. Key words included *social inclusion, adults, intellectual disabilities, parents,* and *community.* Although multiple studies have been completed regarding social inclusion of AID, particularly outside the United States, my search turned up few studies regarding parents' lived experiences of social inclusion.

Theoretical Foundation

The theoretical foundation for this research study was positive psychology (Seligman & Csikszentmihalyi, 2000). Positive psychology is a field of psychology that cannot be defined as belonging to any of mainstream psychology's various sub disciplines (Joseph, 2015). Since the 2000s, positive psychologists have pursued an applied and academic agenda, analyzing structures and processes accounting for growth and individual development at a social level (Joseph, 2015). Currently, researchers who use positive psychology focus on how to enable all individuals to function at a more optimally effective level to enhance their growth intellectually, morally, and socially (Joseph, 2015). According to Khan and Jahan (2012), positive psychology provides a hopeful framework for developing fully functional human beings (p. 210).

Linley and Joseph (2003) said that the well-being that is held to be a desired outcome of positive psychology is best conceptualized as a psychological well-being eudemonia, or human flourishing, a well-being that accords with the civic and personal values of broader community, society, and ecology as much as it does with the individual. Ault (2010) wrote that personal development, emotional well-being, self-determination, interpersonal relationships, physical well-being, and social inclusion are all factors associated with quality of life for AID. These items are critical to an exploration of parents' perspectives on social inclusion for AID. In conducting an IPA study of parents' perspectives, I sought to present a view of the flourishing these parents wished to see for their adult children with ID in the community. This study involved both a view of the individual experience and a broader look at the community in which participants found themselves in Shelby County, Tennessee.

A positive psychology framework involves positive subjective experiences, positive relationships, positive individual traits, and positive groups (Seligman, 2011). Positive psychology is a holistic outlook on the human experience (Joseph, 2015). Seligman and Csikszentmihalyi (2000) recommended that psychology acknowledge strengths and abilities of people in order to "make normal people stronger and more productive and make high human potential actual" (p. 8). Such an effort includes recognizing the capacity of individuals with intellectual disabilities to be active participants in their lives, as well as building upon such individuals' positive qualities to promote health and a good life. It also inherently includes exploring the experiences of parents involving social inclusion of their adult children with ID as part of a search for buffers against mental illness, which Seligman and Csikszentmihalyi (2000) stated is the purpose of positive psychology.

Hart and Sasso (2011) wrote that the diversity of research suggests that positive psychology focuses on more than "the study of enjoyable feelings" and "happy thinking in fortunate people who are privileged to live in pleasant circumstances" (p. 91). It also has an increasing focus on "morphing of the experience of suffering, and . . . [transforming] the conditions that give rise to this suffering" to create a "subjective sense of meaning and a purpose and a style of virtuous living marked by a quest for authenticity" (p. 91). An example of the latter is a study by Mankiewicz, Gresswell, and Turner (2013) that focused on positive psychology research on social inclusion of individuals with mental illness. The study highlighted that individuals with mental illness, similar to AID, are in need of multidisciplinary support to enhance their well-being.

If a parent of an adult with ID is regularly participating with that adult with ID in social activities, which are an aspect of social inclusion, then the parent is a person who has strength and purpose in the face of difficult life experiences. In exploring these parents' experiences of social inclusion with their adult children with ID, this study is squarely aligned with the focus of the positive psychology field. Its aim was not just to ascertain what can support parents and families of AID or to add parents' voices to the literature on social inclusion for AID, but also to add to the positive psychology literature on courage, optimism, hope, perseverance, and insight (Seligman & Csikszentmihalyi, 2000). These are qualities that parents of AID could express and that can be understood by exploring their experiences and the meanings they make of them.

Social Inclusion

The definition of social inclusion for this study is as follows: Social inclusion is how society values, respects, and meets the needs of AID, as well as how society embraces full participation of every citizen in the community (Westfall, 2010). This definition makes it clear that social inclusion combines social interaction, belonging, and community (Simplican, Leader, Kosciulek, & Leahy, 2015). Power (2013) suggested that social inclusion is not just a sense of belonging, but involves how people fit in a specific environment. Martin and Cobigo (2011) reported that in order to ensure that social inclusion is meaningful to AID, one must consider the frequency of access to the community that AID exhibit, the number of personal relationships they have, and the number of activities they engage in, both inside and outside the home. Hall (2010) stressed that society needs to think beyond these areas of inclusion to other ways of conceptualizing paths to improve the lives and acceptance of people with ID, with an emphasis on space, belonging, and well-being. Situations that promote social inclusion include gaining employment and living independently with limited help while being an active participant in normal social activities in local communities (Hall, 2010).

Hall (2010) completed a study in the United Kingdom on social inclusion of people with ID. This study provided a critique of social inclusion and social exclusion. Situations and experiences of people with ID were examined alongside those of other groups, based on the assumption that their experiences are both serious and unacceptable products of social processes beyond their control. This study characterized persons with ID as one of the most socially excluded groups in the United Kingdom. Some causes of social exclusion for this group include lack of education, lack of employment opportunities, lack of housing, and prejudice toward people with ID (Hall, 2010, p. 50).

AID benefit from social inclusion through friendships and community environments. Social inclusion improves lives for all people with and without ID (Mahar, Cobigo, & Stuart, 2013). AID deserve to be respected and included in activities and typical places (Schleien et al., 2014). McKnight and Block (2010) reported that AID who are deprived of social inclusion generally have smaller social networks, have limited skill sets, and make fewer choices (McKnight & Block, 2010). When AID are included socially, the entire community can acquire benefits such as increased knowledge, positive attitudes, empathy, and increased opportunities for friendships (Schleien et al., 2014). Social inclusion of AID relieves stress and lifts some responsibility from parents who shoulder much of the burden of advocating for, building skills with, and attempting to provide social networks for their adult children with ID.

Although benefits are important to people with ID, they are unlikely to change societal discrimination and exclusion (Mahar, Cobigo & Stuart, 2013). Emira and Thompson (2011) reported that societal lack of understanding, awareness, and training are environmental barriers to social inclusion. Families recognize that social and behavioral skill deficits in AID can also be barriers to social inclusion (Emira & Thompson, 2011).

Power (2013) suggested that social inclusion enables people with ID to overcome social exclusion and contribute to society, as well as combat unemployment, poverty, and poor access to healthcare. Power also stated that social inclusion protects people with ID against abuse and enhances community safety (Power, 2013). Abbot and McConkey (2006) discussed individual and group benefits of social inclusion that require changes in societal behaviors and attitudes in relation to interacting with AID. These benefits could bring about an increased level of social inclusion, increased positive attitude, and decreased negative attitudes. Social inclusion can be achieved when families and service providers support inclusion opportunities in which everyone is positively involved (Schelein et al., 2014).

Parents' Experiences of Social Inclusion

Family members of an individual with an intellectual disability have a life commitment to AID. Martin and Couto (2014) conducted a research study to understand parents' experiences of social inclusion. The authors examined the fears and difficulties felt by parents and discussed health and social supports for families of AID. They reported that having that a family member with a disability can cause frustration, anxiety, and apprehension regarding the present and future for the adult with ID. Parents' feelings of frustration, anxiety, and apprehension are increased by finding very few resources and little support in society (Martin & Couto, 2014). Families with a disabled family member have to adapt to situations, find resources, and seek support from society when confronted with challenges each day (Bedia, Cilleros, Primo, & Fernandez, 2009). It is important for parents of AID to be allowed an opportunity to release energy and frustrations in socially appropriate ways, which are important to these parents' quality of life and the quality of life of their adult children with ID (Schleien et al., 2014).

In order to review all sides of issues related to parents' perception of social inclusion of AID, researchers' attention must be turned to parents' social inclusion experiences. Parents' knowledge and perspectives are an essential component of social inclusion of AID (Schleien et al., 2014). Martin and Couto (2014) reported that family plays an essential role in enabling AID to have a satisfying quality of life. The authors further explained that AID require their parents to make an additional effort to facilitate social inclusion because society still does not consider leisure activities a right of AID (2014). The families in Martin and Couto's (2014) study expressed the need for social support. The overall conclusion of the authors in this research study was that support for parents of AID is scarce.

Mental and physical disorders influence the ability of individuals with intellectual disabilities to work (Stigmar, Grahn, & Ekdahl, 2010). According to Watson and Nolan (2011), people with ID who are interested in working are interested in jobs that are flexible and accommodate their disabilities. Bridging relationships, which brings people from various populations into contact with people who are different, improves employment outcomes for AID (Simplican, Leader, Kosciulek, & Leahy 2014).

Speraw (2006) focused on congregational experiences for parents of children with ID and reported that barriers exist. It is important to recognize the desire of parents of AID to participate in religious activities. Organizations such as churches offer one type of community environment in which both AID and their parents can experience benefits. Religious support has been found to buffer negative outcomes associated with caring for AID (Algood, Harris, & Hong, 2013). Ault, Collins, and Carter (2013) reported that spirituality may be associated with quality of life for AID, though they found that AID do not participate in religious activities as often as people without ID.

Resch et al. (2010) examined challenges identified by families of AID when interacting with unreceptive environments. The authors asserted that understanding the experience of families is important to ensure the development of proper interventions, services, and supports. Parents provide an important service to AID. Resch et al. (2010) identified four major areas in which families with AID experience gaps: family support, school, community inclusion, and financial support. Their overall findings suggested that positive interaction is developed by creating a social environment for families and parents (Resch et al., 2010).

Parents' Perception of Social Inclusion

Parents' perspectives of AID challenge AID's perspectives of adulthood living, social relationships, and independence at work (Schelein et al., 2014). Henninger and Lounds (2014) completed a research study that focused on independent living, employment, and friendships for AID. This study encompassed the person with ID and his or her environment. The participants in this study were parents of AID. The parents answered an online survey concerning adulthood and the environment for AID. My study builds on Henninger and Lounds' (2014) study because I did face-to-face semi-structured interviews. Face-to-face interviews afforded me the opportunity to probe for more information; in an online survey the researcher can only use the data gathered from that survey. Information that came up in interviews added facial expressions, gestures, voice tones, and the possibility of more expansive responses than an online survey is designed to gather, which adds to the information parents can provide about their perceptions and meaning-making processes of social inclusion of AID. I also explored the lived experience of these parents, and the meanings they made of their experiences of social inclusion of AID, which expands the scope of the information Henninger and Lounds (2014) gathered.

Henninger and Lounds (2014) reported that the families were more concerned with success in adulthood for the AID, with an emphasis on how they fit in their environment. Other research regarding parents of AID focused on challenges surrounding specific caregivers' tasks (Resch et al., 2010). While these factors can cause distress for the parents, the entire parent perspective was not captured in this study. The well-being of parents of AID is not only affected by parenting tasks, but also affected by the person-environment interaction (Resch et al., 2010). AID are influenced by socialization, community participation, employment, and other issues that affect their overall quality of life (Schleien, Miller, Walton, & Pruett, 2014).

A study conducted by Schleien et al. (2014) examined parental perspectives regarding social inclusion, community participation, and community access. Schleien and colleagues (2014) used focus groups to gather data. Schleien et al. (2014) used focus groups aimed to explore how parents think and feel about social inclusion. For their study, participants were recruited from the intellectual disability population. The focus groups consisted of 35 parents of AID. These parents voiced valuing social inclusion and participation in the community. Being a part of the community created a better quality of life for AID. The parents also shared that a hindrance to inclusion and participation in the community is limited access to community programs.

The research I conducted builds on these studies. Using a method focused on individuals, rather than groups, I had the opportunity to add to the above studies from a different perspective, perhaps adding depth. Interpretative phenomenological analysis (IPA) as a method offered the opportunity to delve more deeply into parents' experiences, as well as into the meanings they made of these experiences of social inclusion for AID.

Support for Parents of AID

Parents do not always receive the support they need from friends, family members, and professionals. Zuna et al. (2014) reported parents lack formal and informal sources of support to meet their needs, which supports the approach of this study to recognize individual strengths, family strengths, and whole family needs as parents care for AID. Personal relationships are essential to increasing a sense of social inclusion, both for parents and for their adult children with ID. Social support the development of personal relationships (Johnson, Douglas, Bigby, & Iacono, 2012a). Community support requires relationships both with AID and with their parents (Meissner, 2011). These relationships are based on a committed group of people working together to ensure AID can enjoy flourishing lives. Parents build flexibility and security by organizing and extending their personal networks, taking control of system resources, and maintaining dialogue that allows adjustments with people they rely on for support and assistance (Meissner, 2011). According to Meissner (2011), integrative supports for AID focus on their desire to live “a real life” (p. 386). A real life for AID is defined as having a place to call home (Meissner, 2011). Community supports could be designed to assist AID to hold wider aspirations, such as supporting them to take up valued and contributing social roles in a greater variety of settings (Meissner, 2011).

Factor, Heller, and Janicki (2012) reported parents of AID continue to be the primary providers of care. As AID experience longer life expectancy, it is essential parents receive support services that are effective and accessible (Williamson & Perkins, 2014). The Funding for Home and Community-Based Services (HCBS) waiver program is funded through Medicaid for long-term services and support for AID and their families (Braddock et al., 2013). Several federal initiatives in recent years acknowledged the role of the family caregivers (Williamson & Perkins, 2014). The Affordable Care Act released 25 million dollars to expand the Aging and Disability Resource Center (ADRC) into every state to provide more home- and community-based supports to older adults and AID. The ADRC is designed to provide parents with support and counseling services in one place (U. S. Department of Health and Human Services, 2012). A better understanding of parents' needs is being accomplished through supports, resources, and caregiver assessments that consider diverse challenges (Williamson & Perkins, 2014). When comprehensive assessments of families' supports and needs are made accessible and available, providers can help prioritize services and resources more effectively (Williamson & Perkins, 2014).

Community Relationships With AID

Swango-Wilson (2010) pointed out that socialization, education, and health for AID are heightened when the community is functioning properly. She went on to say the basic structure of the social system is the community. Interventions for current problems are needed at every level, such as parents, families, legal guardians, individuals, groups, communities, organizations, and society itself to meet the needs of AID. Swango-Wilson (2010) continued by stating that every level working to understand and acknowledge needs of AID is critical.

Swango-Wilson (2010) noted that AID are separated from the majority population and are further restricted by being denied access to the larger social systems of the general public. She also reported AID are marked as less capable, are denied control over their lives, and are in need of constant management. Similarly, McKnight and

Block (2010) reported that when AID are deprived of social inclusion, they have smaller networks, and they make fewer choices. Swango-Wilson (2010) acknowledged AID may require a larger amount of support to function adequately. This should not be a reason to assume they cannot be productive citizens in their communities. Determination of what can be achieved is in a large part created by societal values and expectations. While AID may require additional effort, with the parents' support this can be accomplished.

AID should be supported in every area of their lives, if needed, particularly in decision-making. This will enable them to establish relationships in their communities (Swango-Wilson, 2010). According to Swango-Wilson (2010), community involvement for AID often means placement in group homes or sheltered workshops. This situation limits full involvement of being socially included for AID and it denies them the experiences shared by the mainstream population, which adds to a sense of isolation and loneliness for AID.

Community conditions encompass culture, community attitudes, and geography. A community association or a work setting is a reflection of successful movement toward social inclusion. According to Stancliffe et al. (2012), relationships that spread beyond work and community have not been studied. Researchers know some relationships expand beyond work and community (Amado et al., 2013). According to Rossetti (2011), few research studies exist examining community members' attitudes toward what works to support social inclusion.

Jackson (2011) reported that even when AID have their own homes in the community, they still are not satisfied with the accommodations and sense of social belonging. The ability to choose friends and develop social relationships is limited for this population (Jackson, 2011) because social activities with nondisabled friends are infrequent, and in some cases nonexistent, in small and scattered accommodations for AID (Bertelli et al., 2013). Participating in a number of community activities or functions in a week does not necessarily mean AID experience a sense of belonging and membership (Amado et al., 2013).

Future of Inclusion for AID

The home page for the President's Committee for People with Intellectual Disabilities (PCPID) on the government website for the Administration for Community Living begins with the following paragraph:

> It is estimated that between 7 and 8 million Americans of all ages, or three percent of the general population, experience intellectual disabilities. Nearly 30 million, or one in ten families in the United States, are directly affected by a person with intellectual disabilities at some point in their lifetime. (ACL.gov, 2016)

These statistics support the idea of the importance of working to include AID in society. Society perceives its members through language. Offensive labels and using outdated language abet negative perceptions of AID. Using people-first language rather than using negative labels provides AID dignity and respect ("The Future of Equity and Inclusion" ASHE, 2013). Americans have made many strides in changing the perception of disability through science, medicine, technology, and education. Although disability education has evolved there is still work to be done.

People with disabilities continue to be a mystery to people without disabilities. An article in the *ASHE Higher Education Report* ("Future of Equity," 2013) reported that discrimination occurs due to negative attitudes toward AID, lack of awareness, antiquated policies, lack of allies, and practices. The article also indicated that despite years of legislation and activism, AID still have not experienced equality. AID are uncomfortable when interacting with individuals without intellectual disabilities and have voiced continuing concerns about appropriate communication and inclusive practice. Inclusion, equity, awareness, and access are challenges AID are experiencing. Meaningful change can happen in the future if one looks at how AID have been viewed in the past, how AID are understood today, and where intellectual disability education is headed in the future. Further research should focus on the needs of the parents and families of AID, the perspective of the parents, services, barriers, and supports (Resch et al., 2010). By doing this, policies and services will shift to a more person-centered approach of AID (Resch et al., 2010).

An accommodating community recognizes the contributions of many perspectives and people (Walton, Schleien, Brake, Trovato, & Oakes, 2012). Continual conversation and collective thought will lead to broader access, inclusion, and participation for those AID. So far, families have not been invited into discussions and their voices have seldom been heard. Due to the barrier of omission, many AID are overlooked, and are not extended the same courtesies as individuals with other disabilities. This interferes with the ability of AID to become involved in the community and keeps them dependent on families and advocacy agencies for their needs (Walton et al., 2012).

AID should be afforded the same opportunities as nondisabled groups. They should be afforded the opportunity to make choices concerning their community activities and opportunities they wish to pursue. AID will make an impact in the community once their voices are heard (Walton et al., 2012). Researchers, service providers, and advocates should continue to listen to parents' concerns regarding the needs, dreams, and preferences of AID. If we continue to build on the strengths of AID and cultivate the development of community groups that are open to this population, AID will achieve social inclusion (Walton et al., 2012). Research related to inclusion for AID remains limited ("Future of Equity," 2013).

Summary and Conclusions

As reflected in this chapter, despite the various discussions surrounding social inclusion, there is still limited research about parents' perceptions of social inclusion for AID. As noted in this literature review, AID express the need for inclusion, acceptance, and recognition regardless of their disability (Hall, 2009). Because they are the ones who know these adults the best, it is important to hear parents' perceptions of how AID experience social inclusion. This research study offers an understanding of parents' perception and experiences. With this understanding, organizations and providers can begin to work with parents to establish community connections and work with them on ideas of how to promote social inclusion. Although AID are in the community, they experience little sense of belonging and have few relationships with their nondisabled peers (Novak et al., 2013).

Overall, the literature presented in this chapter reported that parents and AID desire to be included socially in every aspect of their lives. The literature noted AID rely on family members to speak about their hopes, desires, and their needs in the community (Walton et al., 2012). Researchers have shown the needs for AID are significantly different from those of the general population (Molinari et al., 2011). In conclusion, the literature presented in this chapter demonstrated there is still much work to be done to assist and support families of AID to gain social inclusion. The findings from this study add to the current research regarding parents' experiences of social inclusion.

In Chapter 3, I include a comprehensive narrative of the study, the research questions, and the qualitative methods in regard to the theoretical framework. The research design and analysis of this study, my role as the researcher, how I plan to gain access to research participants, issues of trustworthiness, and ethical procedures are also discussed in Chapter 3.

Chapter 3: Research Method

Introduction

As stated in Chapter 1, my purpose for this qualitative research study was to use IPA to understand and describe the meaning of parents' lived experiences of social inclusion of AID in their charge. My goal for this research study was to provide an understanding of the lived experiences and perceptions of social inclusion of AID from the parents' point of view by using a positive psychology (Khan & Jahan, 2012) frame of reference.

In this chapter, I include details about the research method I used to study parents' perceptions of social inclusion of AID. I describe the procedures I used to conduct the study, addressing participant selection logic, instrumentation, data collection, and data analysis. I also describe steps taken to ensure a quality research study involving issues of trustworthiness and ethical procedures.

Research Design and Rationale

The research questions used to guide this dissertation were as follows:

1. What are parents' lived experiences of social inclusion for adults with intellectual disabilities who are in their charge?
2. How do parents describe the meaning of social inclusion for adults with intellectual disabilities who are in their charge?

I used a qualitative approach to explore parents' perception of social inclusion of AID. Qualitative researchers are concerned with the social aspects of the world and seek to answer questions about why people behave the way they do and how people are affected by the events that go on around them (Marshall et al., 2013). Qualitative research methods focus on data that cannot be expressed numerically, and researchers using such methods often observe groups of people who may have different ways of looking at reality (Marshall et al., 2013). According to Pathak, Jena, and Kalra (2013), qualitative research is used to understand people's experiences, attitudes, beliefs, interactions, and behaviors. In qualitative research, the researcher concerns him- or herself with giving participants an opportunity to have an active role in the study.

According to Pietkiewicz and Smith (2012), IPA is one popular methodological framework used in qualitative research. IPA studies are focused on how individuals make meaning of their life experiences, as well as on the experiences themselves. An IPA research study involves a dynamic process in which the researcher tries to understand an experience from the participants' perspective (Pietkiewicz & Smith, 2012). An IPA study tends to use a small sample size, as in the six participants in this study, in order to "explore in detail the similarities and the differences between each case. It is possible to move to more general claims with IPA but this should only be after the potential of the case has been realized" (Smith et al., 2009).

Phenomenology, ideography, and hermeneutics are all constructs that inform IPA (Smith et al., 2009). Phenomenological researchers describe the essence of an experience and describe the "what" and "how" of participants' experience. Researchers who use IPA add to the "what" and "how" of an experience a double hermeneutic, because the researcher must be aware of his or her own interpretation of the participant's interpretation of the experience (Pietkiewicz & Smith, 2012). Part of the double hermeneutic is combining an empathic hermeneutic with a questioning hermeneutic. This means that the researcher aims to understand the participant's experience and meanings from the participant's perspective while also being open to noticing what might be coming across in the descriptions that the participant himself or herself might not be so aware of (Smith & Osborn, 2008).

Callary et al. (2015) described four key characteristics of IPA: "inductive, idiographic, interrogative, and interpretive methods" (p. 64). IPA is inductive because research questions are constructed in such a way that themes can emerge. IPA is idiographic because each case is analyzed in detail before moving to the next. IPA is interrogative because the researcher's results from the data are discussed with participants to make sure that the experiences and their meanings are accurately described. The researcher must develop themes when interpreting data through his or her own lens. The researcher must be open to adjusting ideas based on the participants' responses (Larkin, Watts, & Clifton, 2008).

I chose IPA for this study because I wanted to give parents of AID the opportunity to provide personal experiences and perceptions of social inclusion of AID. I wanted to know in detail how these parents made meaning of social inclusion for their AID. IPA was best suited for this research study because it is a process with which the researcher can explore what an experience means to participants and how the participants make sense of their experiences (Pietkiewicz & Smith, 2012). This level of detail provided me, as the researcher, the information necessary to understand and interpret stories from these parents as they reflected on their experiences of social inclusion of AID.

Role of the Researcher

As the researcher in this qualitative study, I was the main instrument of data collection, interpretation, and analysis. Because I was the sole researcher, I gathered and recorded data, read data, interpreted data, and reported findings concerning each participant's experience without passing judgment. Using the IPA design, I adopted the role of both learner and observer. In trying to thoroughly understand the world of a parent's experience of social inclusion of AID, I listened carefully to make sense of each participant's description of experiences of social inclusion of the adult child with ID (Smith et al., 2009). This was a double hermeneutic (Pietkiewicz & Smith, 2012), in that it involved my observation of the meanings each participant made in describing the experience and the meanings I made of those descriptions as I attempted to deeply understand what participants shared.

In my previous employment, I worked for 15 years with AID in Shelby County, Tennessee. During my tenure working with AID, my position was one of managing staff who worked with AID in residential situations. My job was to make sure that AID had everything they needed, were well cared for, and had meaningful days, according to state standards. Occasionally, this position also required that I find places to move AID out of a community immediately in order to keep these adults safe. These duties put me in contact with parents of AID, who were ultimately responsible for them in cooperation with direct contact residential staff. My experiences in this position offered me perspectives that were both similar to and different from those of the parents of AID with whom I interacted. Because I had no personal or professional relationships with the participants in this study, I had no power over them. My intent in this study was to treat all participants fairly, show the parents respect, and keep all of their information confidential.

In an IPA study, the researcher's assumptions and any implications must be clear and explicit when the researcher is interpreting data (Callary et al., 2015). Further, as Larkin et al. (2008) stated, the researcher must be ready to adjust ideas and be responsive to interpretations based on participants' responses. This aligns with the interpretative tradition, in which researchers are interested in what happens when the everyday flow of lived experiences takes on a particular significance for the participant (Smith et al., 2009). Allen-Collinson (2009) reported that IPA includes an interpretative element; thus, I did not want to suspend my biases. Instead, I suspended my assumptions and adopted a more critical and reflective approach to research (Allen-Collinson, 2009, p. 286). My interview questions (see Appendix D) concentrated on the participants' descriptions of their lived experience of social inclusion and what meanings they made of experiences. I found myself making meanings as well, as participants shared their experiences of social inclusion of their adult children with ID (Pietkiewicz & Smith, 2012).

Participant Selection

The participants in this study were six biological mothers of AID who were actively engaged in any community outings with their adult child with ID.   If both parents of an adult child with intellectual disabilities had chosen to participate in the interview, they would have been considered as a single participant. Participants needed to be at least 36 years old because they had to be parents of an adult child with ID, which meant that the child with ID needed to be at least 18 years old. They were chosen from one service provider, in Shelby County, TN. All six participants were selected based on the criteria that they were willing to talk in person about the phenomenon being studied, were parents of AID who lived with service providers in Shelby County, TN, and had been participating in community outings with AID at least two times per month for at least the previous 6 months. A minimum of 6 months of this level of activity with their adult children with ID in community outings was necessary to provide enough exposure and continuity for the parents to have a solid base of experiences of social inclusion with AID to share.

Only parents of AID who participated in community outings met the criteria for this study. Biological parents were chosen for this study because the literature that I examined showed me that parents of AID know them best (Hall, 2009), and they are the primary providers of care (Factor, Heller, & Janicki, 2012). I also found in the literature that AID rely on parents and family to speak on their behalf regarding their aspirations and needs (Walton et al., 2012).

Smith and Osborn (2008) suggested that researchers can use purposive sampling in order to find a closely defined group of potential participants to whom the research question will be significant. Participants for this study were selected through purposive sampling based on the participant criteria. Smith and Osborn (2008) reported that there is no single best recommendation for sample size in an IPA study, though many researchers recognize that using a small sample size when conducting an IPA study is more realistic. IPA involves detailed analysis of verbatim accounts of a small number of participants, typically not more than 10 (Callary et al., 2015). IPA researchers are interested in relatively small sample sizes so that they can explore each case with the necessary time, energy, and rigor for this type of analysis (Callary et al., 2015). Marshall et al. (2013) wrote that an IPA study's sample size should range from six to 10 participants.

Participants in an IPA study are those for whom the research question is significant, with boundaries suggested by the question itself, which can be narrowed by the researcher (Smith & Osborn, 2008). I chose purposive sampling and the snowball technique (Given, 2008) to gain access to the participants I invited to be in the study, who were biological parents of AID. Such individuals were the group for whom the research questions were significant. The concept of purposive sampling falls within the process of defining the population of potential data sources (Given, 2008).

Potential participants received a flyer (see Appendix B) through the director of the service provider. The director is the gatekeeper of AID activities and is responsible for ensuring that participating AID are an active part of their community. According to

Given (2008), gatekeepers are individuals who can be of help to a researcher as entry points to specific communities. Gatekeepers have inside information that can help a researcher in determining who the best participants are to access in a given community or organization. Gatekeepers can also help the researcher access the population being studied through introductions and establishing a related or appropriate environment for the research process (Given, 2008).

I set up a meeting with the director of the service provider to share information about this study, and I asked her to share an invitation to participate with all biological parents of AID who met the criteria for the study whose adult children with ID resided in homes run by the agency. I talked with her about the study and provided her with at least 20 flyers (see Appendix B) for her to distribute, which included information on what the study was about and what it would involve, as well as my name and contact information and all other necessary information.

I believe that the director of the service provider was willing to assist me with getting the participant pool (see Appendix A) needed for this study because the State of Tennessee is interested in ensuring that AID are included in their communities (Department of Intellectual and Developmental Disabilities, 2015). According to the State of Tennessee's Department of Intellectual and Developmental Disabilities (2015), community inclusion is so important that an entire team is dedicated to improving the system for the individuals it serves. The department has a project named People Talking to People (PTP). Since 2009, the staff assigned to this project have been completing random sampling of individuals receiving services through service providers. They conduct face-to-face interviews with questions regarding choice, control, respect, dignity, access to care, and community inclusion. Because of this activity by the State of Tennessee, I believed that the director of the study organization would be very interested in knowing more about parents' lived experiences of social inclusion of their adult children with ID. Six participants were chosen on a first-come basis.

Data saturation was reached when the new data did not add to the research on the phenomenon being studied (Mason, 2009). If I did not receive six interested participants by extending this invitation, or if I did not reach data saturation with six participants, I planned to employ the snowballing technique (Given, 2008). This technique involved asking the participants I gained from the invitation extended through the study organization to recommend other biological parents they knew who might be interested in the study so that I could share the invitation with those people. The snowball sampling technique is an informal means of reaching a target population by creating contacts using a respondent's circle of acquaintances (Heckathorn, 2011). The snowball sampling technique has been demonstrated to be especially useful in conducting research in marginalized social groups (Cohen & Arieli, 2011). Four of the six participants in this study were gained via snowball sampling.

According to Mason (2009), in a qualitative research study there is a diminishing return, which means more data do not necessarily lead to more information. The concept of data saturation was developed originally for studies using grounded theory. Since that time, data saturation has been found to be applicable to all qualitative studies. I employed interviews as the primary data source for this study. Data saturation happens when the gathering of new data does not add to the research on the phenomenon of interest (Mason, 2009).

Instrumentation

The researcher is the primary data collection instrument for a qualitative research study (Merriam, 2009). As the researcher in this IPA study, I asked participants semistructured questions (see Appendix D) designed to prompt detailed responses. In qualitative research, the interview process is used to elicit information from participants, rather than identifying issues from the researcher's perspective (Davison, 2014). IPA researchers conduct interviews because interviews are the best way for a researcher to engage in dialogue with participants in real time (Pietkiewicz & Smith, 2012).

My goal was to ask open-ended, nonleading questions that invited the participant to choose the depth and the direction of the answers. The questions in this IPA study were broad and open enough not to limit the participants' responses (Smith & Osborn, 2008). My research goal was to understand the lived experiences of social inclusion of parents of AID and the meaning they made of these experiences. This interview protocol (see Appendix D) was a guide to help me make sure that I was able to gather information from the participants about the research questions and stay focused on the purpose of the interview. My expectation was that I would not be following this protocol as a strict plan; I sought to use it more as a guideline, as suggested by Given (2008), as I encouraged parents of AID to share their experiences of social inclusion for AID.

As the primary data collection instrument, I had the opportunity to immediately adapt and respond to changes during the research process (Merriam, 2009). Merriam (2009) reported being the primary instrument is an advantage because I can expand my understanding through verbal and nonverbal communication, process data immediately, clarify and summarize material, check with participants for accuracy and interpretation, and explore unusual or unanticipated responses.

In each one-to-two-hour interview with participants, I began with a warm-up discussion, to relax the participant and to set the tone for the participant to discuss personal issues (Pietkiewicz & Smith, 2012). Interviews were recorded on a digital recorder so I could go back and listen to the original conversation, partly to ensure a verbatim transcript was produced by a professional transcriptionist I hired, who was required to sign a confidentiality agreement first. I also listened to the original conversations to help me with the analysis of the transcripts.

Recruitment, Participation, and Data Collection

The purpose of this research study was to gain an understanding of parents' meaning making processes and perceptions of their experiences of social inclusion of AID. The first criterion for participation in this study was parents of AID who were willing to be interviewed in person. The other criteria were that participants were biological mothers or fathers, that they be at least 36 years of age, and attend community outings with the adult with intellectual disabilities at least two times per month for at least the previous 6 months. I set 36 as the minimum age, because participants were to have adult children with ID, which meant the children were age 18 or older. Potential participants were recruited through the study organization in Shelby County, Tennessee. Because I was interested only in biological moms and dads of AID, legal guardians, adoptive parents, and caregivers were not interviewed. Participants in this study were selected purposively to ensure I was in line with the theoretical underpinnings of IPA (Pietkiewicz & Smith, 2012). IPA procedures require potential participants to be a fairly homogeneous group that represents the phenomenon being studied (Pietkiewicz & Smith, 2012). Data was collected from six parents of AID via face-to-face interviews.

Potential participants were recruited in Shelby County, Tennessee through the study organization I sent an email to the director requesting a meeting. In the meeting, I asked the director to distribute a flyer (see Appendix B) to participate in the study to at least 20 possible eligible parents who were connected to their program. The letter described the study and requested participation in the study. I included in the letter the nature of the study, criteria for potential participants, and my contact information. My hope was to acquire six to 10 participants. Because I was not successful in acquiring at least six participants, I used snowball sampling (Given, 2008) to try to get additional participants.

Snowball sampling was accomplished in this study by my asking the participants during the interview if they were aware of other potential participants who would like to participate in the research study. If they were aware of others, I asked them to share an invitation to participate with people they knew who fit the criteria, and request that these people contact me. Smith et al. (2009) noted a small sample size is acceptable because "IPA is an idiographic approach concerned with understanding particular phenomena in particular contexts" (p. 49). Marshall et al. (2013) recommended an IPA study sample size should range from six to 10 participants.

I asked each potential participant to review an informed consent form carefully. Participants were asked to sign and return consent forms to me prior to the interview. The participants were informed that even if they consented to the study, they could still opt out of the study at any time. The participants who were interested in the study received a phone call, so I could answer any questions or concerns regarding the study, and schedule a time and place for the interview, according to the participants' availability. The signed informed consent form from the participants served as participants' acknowledgement that they understood the purpose and procedures of the study. The signed consent form also showed that participation in the study was voluntary.

A face-to-face, semi-structured, in-depth interview was conducted at a neutral and quiet place at the local library. Location and times were previously agreed upon with each participant. Interviews were scheduled to last 60-120 minutes. Permission to use a digital recorder during the interview was obtained during the informed consent process with each participant before the interview.

At the beginning of the interview, I thanked each participant for agreeing to participate in the research study, and mentioned my experience working with AID and parents of AID. I shared that part of what motivated this research was my respect and appreciation of parents. From there, I moved on to the interview protocol. The questions asked in the interview were appropriate for an IPA study, with a theoretical foundation of positive psychology. My protocol began with broad questions to allow me to build rapport, and then I moved into more sensitive questions. Smith and Osborn (2008) reported "a good interview technique often involves a gentle nudge from the interviewer rather than being too explicit" (p. 61). The questions were asked in a manner that was not leading and in a way that was open to the participants' ideas (Callary, 2013). I made a point of including questions that focused on positive experiences as well as challenging ones, which connected the data more strongly to the theoretical foundation. To this rich data I added descriptions of the participants themselves, which I used to make notes after the interviews. The data collected in the first couple of interviews had the potential to bring out a need for questions of participants I had not thought of before, based on the information these first participants shared. This is part of the flexibility of asking open-ended questions.

Interviews were transcribed verbatim by a professional transcriptionist for use in the analysis. The transcriptionist was required to sign a confidentiality agreement (see Appendix C) and send me a copy before recordings were sent to the transcriptionist. All notes and electronic data were, and will be maintained on my personal computer that is password protected during the data gathering and analysis process and for five years following the study. All information will be deleted at the end of the five years. All files containing any information about participants and signed consents will be kept in a locked file drawer for five years, after which they will be destroyed. Each participant was emailed the transcript of her interview to verify my interpretation, as part of member checking. Member checking gave the participants an opportunity to approve my interpretation of data they provided (Doyle, 2007).

Data Analysis Plan

As noted above, the recorded interviews were transcribed by a professional transcriptionist. I analyzed the transcripts using a phenomenological and double hermeneutic approach that is consistent with the IPA approach. Gadamer's philosophy of hermeneutics and the understanding of the text is what IPA draws upon (Smith & Osborn, 2008). The IPA process can be described as a double hermeneutic, or a double interpretation process, because the researcher tries to make meaning of the participants' world and decode the meaning of the participants' experience (Smith & Osborn, 2008).

Cooper, Fleischer, and Cotton (2012) reported IPA analysis consists of the following characteristics:

> (a) psychological focus on personal meaning-making within a particular context, (b) movement from what is unique to what is shared among the participants, (c) commitment to understanding the participant point of view, and (d) description of the experience which moves to an interpretation of the experience. (p. 5)

Narrative analysis, descriptive analysis, and interpretive analysis are all possible analytical strategies that can be used in phenomenological research (Esin, 2011). For this research study, I used an interpretative analysis. According to Pietkiewicz and Smith (2012), the initial stage in analyzing data using IPA is to read the transcript a number of times and listen to the audio recordings a number of times. Each time through the transcript and each time listening to the recordings I thought about the setting of the interview, recalled the atmosphere of the interview, and immersed myself in the data. Each time the transcripts were read and the recordings were heard it was possible for new insights to emerge. During these reviews, I made descriptive notes on the transcripts about reflections and observations regarding the interview experience, which I dated, as well as making notes about thoughts and comments that showed up as significant in the interpretation (Pietkiewicz & Smith, 2012).

In the next stage, I looked for emerging themes. I attempted to formulate concise phrases involving a slightly higher level of abstraction. As the researcher, I was influenced by the annotated transcript and my experiences with the participants (Pietkiewicz & Smith, 2012).

Subsequent readings of the data revealed emerging themes, which I grouped according to their conceptual similarities, providing each cluster with a descriptive label. I compiled themes from the entire transcript before looking for clusters and connections. At this stage, some of the themes were dropped because they did not fit well with the emerging structure. The themes and the participants’ experiences were written in a narrative account that explained the participants’ experiences in their own words

(Pietkiewicz & Smith, 2012).

Issues of Trustworthiness

Credibility involves participants' views of whether the transcripts accurately demonstrate what they shared with the researcher in the interviews to make sure there are no misinterpretations of what I was told (Anney, 2014), and the researcher's interpretation and presentation of the data (Polit & Beck, 2012). "Peer briefing, member checks, reflexivity, and triangulation are all techniques that can be used to establish credibility" (Anney, 2014, p. 276). Member checking was the strategy for improving the quality of qualitative data that I used. This can involve the researcher sending data back to the participants for them to evaluate and make suggestions (Anney, 2014). Credibility involves designing a study, from the definition of the phenomenon being studied to the conclusion of the study. It includes an understood relationship with the community through interaction related to research findings (Collier-Reed, Ingerman, & Berglund, 2009).

In qualitative research, readers of the research should be able to make connections between aspects of the study and their own personal experience (Barnes et al., 2012). I accomplished transferability through the use of purposive sampling, described previously. Purposive sampling may provide greater in-depth findings than any other sampling method (Cohen, Manion, & Morrison, 2011). I provided thick descriptive data and extensive details in the study so that readers and other researchers can make a comparison of the context of this study to other contexts in their lives (Anney, 2014). If the results of my study have meaning to individuals who are not involved in my study, and the readers can associate the results with their own experiences, then it meets the transferability criterion (Cope, 2014).

According to Thomas and Magilvy (2011), dependability refers to the stability of data over time and under different conditions. For this study, it meant that I needed to be careful to state the principles and criteria used to select participants, and to make sure to detail the participants' main characteristics so that transferability of the results to other contexts can be assessed (Thomas & Magilvy, 2011).

Anney (2014) reported "triangulation, peer examination, an audit trail, stepwise replication, and a code-recode strategy" are other methods of making sure research is credible (p. 276). "Triangulation can help reduce researcher bias and cross-examine participants' responses" (Anney, 2014, p. 277). An audit trail, triangulation, and reflexive journal are all ways that confirmability can be achieved in qualitative research (Bowen, 2009). I used triangulation and reflexivity in order to ensure credibility and confirmability. Triangulation is a process where a variety of sources are used during the research process, such as notes, interviews, and journal record (Houghton, Casey, Shaw, & Murphy, 2013). As I moved through the data analysis process, I documented insights, awarenesses, thoughts, and responses I had to the data, as well as observations. That documentation is called a reflexive journal. A reflexive journal includes personal reflections, and notes in an attempt to bracket perceptions (Polit & Beck, 2012).

Confirmability in this research study happened through the audit trail and reflexive journal because I provided how data was collected, recorded, and analyzed and I kept a journal of my thoughts and events that took place during this research study. I made notes about the participants after each interview, to remind myself of details that could enrich the information they shared with me verbally. I kept a journal of my reflections and notes about the analysis process that helped me to bracket my experience, as well as add an additional source of data that might be used for creating themes. It was part of the double hermeneutic spiral of the process, documenting the experiences I had and the meanings I made of gathering and analyzing the data while I analyzed the experiences and meanings shared by the participants.

Ethical Procedures

Ethical research practices were adhered to throughout the research process. I obtained Institutional Review Board (IRB) approval prior to the beginning stage of the research process. I emailed the director of the service provider, which is the organization from which participants were chosen, and developed a flyer for potential participants. I gave the participants an opportunity to ask any questions they may have had about the study and what participation would involve via email or by phone prior to each interview. Each participant completed a confidentiality form and an informed consent form that will be kept in a locked file cabinet for which I will have the only key. There was no risk or harm involved in this study. Participants could withdraw from the study at any time. This was made clear in the informed consent form that parents signed before they were interviewed.

Participants' identity remained confidential throughout the research process. The confidentiality was maintained by use of assigned numbers for the participants and for their adult children mentioned in the interviews. All transcripts of interviews will be locked in the researcher's home office for five years. The researcher, participants, and the university committee have had access to the interview transcripts. I no longer worked with AID in Shelby County, Tennessee and had no relationship with any of the potential participants at the study organization in Shelby County. This meant that there was no power differential because I was not in a position to have an undue influence on any potential participants, and I did not know any of the clients at this agency or those referred by snowball sampling.

Summary

In Chapter 3 I explained the rationale for using an interpretative phenomenological approach and an explanation of how the IPA approach aligned with the research questions. I presented the procedures for data collection, recruitment and participation, and issues of trustworthiness. The issues of trustworthiness section included credibility, transferability, dependability, and confirmability, all of which described the efforts I made to minimize research biases and misinterpretations, as well as to engage in effective data collection and analysis. Ethical issues describing participants' protection was also presented in this chapter. In Chapter 4 I include details of the results from the data after they were collected and analyzed.

Chapter 4: Results

Introduction

The purpose of this study was to use IPA to understand and describe parents' lived experiences of social inclusion of AID in their charge. In this chapter, I present the procedures I used for conducting interviews, demographic information on participants, and the results of the open-ended interview questions. The research questions for this study were the following:

RQ1: What are parents' lived experiences of social inclusion of their adult child with intellectual disabilities in their charge?

RQ2: How do parents describe their meanings of social inclusion experiences of their adult child with intellectual disabilities in their charge?

In this chapter, I present data from interviews with six parents of AID. Details about setting, data collection, and data analysis are also covered. Other sections in this chapter pertain to evidence of trustworthiness, such as transferability, dependability, and conformability, and results of the study.

Setting

I met with the director at an organization in Shelby County, TN that specializes in working with AID, on May 16, 2017, to explain the study in detail and to give her flyers after I received IRB approval (04-25-17-0147746). After waiting for 2 weeks with no phone calls, I called the director of the study organization and asked her if anyone had inquired about the research study. She informed me that no one had asked her anything about the study. I asked her whether it would be possible for her to place the flyers somewhere else in the office. She told me that she would place flyers in a spot where she places correspondence for parents to pick up from the agency, and she told me she would place one flyer on the door. Within two weeks of her moving the flyers to a different place, I received calls from two parents who met the criteria and were willing to participate in the research study.

I employed snowball sampling (Heckathorn, 2011) by asking the participants I gained from the invitation extended through service provider agency to recommend other biological parents who might be interested in participating in the study. I interviewed a total of six parents face to face. Two of the participants were gained through flyers at the study organization. The other four participants were gained through snowball sampling (Given, 2008).

Demographics

Participants in the study were six parents of AID in Shelby County, Tennessee. All participants signed the informed consent form prior to the interview, and all participants met the inclusion criteria: (a) at least 36 years old, (b) biological parent (mother or father) of an adult with ID, and (c) participated in at least two community outings a month with an adult child with ID in the previous 6 months. All participants were African American females. The average number of outings ranged from three to 10 outings per month.

Table 1

Participant Demographics

Participant	Gender of parent/ Gender of adult child	Ethnicity	Average number of outings per month
1	Female/Male	African American	3
2	Female/Male	African American	7
3	Female/Female	African American	10
4	Female/Female	African American	7
5	Female/Male	African American	3
6	Female/Female	African American	5

Data Collection

I conducted six face-to-face interviews. All interviews were held at a library located in Shelby County, Tennessee, during June and July 2017. Interviews were scheduled to last 60-120 minutes; the actual time ranged from 48-65 minutes. Each participant received a phone call prior to the interview to determine whether she had any questions regarding the study before the interview. No follow-up interviews took place.

Interview data were collected on a digital recorder. During the interview process, I informed each participant that I might take notes. I jotted down any change in body language and facial expressions as the participant and I talked about her perceptions and lived experiences of social inclusion. During the interviews and the data analysis, I kept a reflexive journal to record my own reactions, meanings, and experiences of gathering and analyzing data. This reflexive journal was also used as a way to bracket my experiences, so that I could focus on those of the participants.

After the interviews, a professional transcriptionist transcribed the interviews in a timely manner. The transcriptionist signed a confidentiality agreement (see Appendix C) prior to receiving the recordings. When the participant interviews were transcribed, each participant received a copy of the transcript through the U.S. Postal Service. Each participant contacted me via phone after she had received and read the copy of the transcript to inform me that the transcript correctly documented what she had shared. This was done as a means of member checking. Member checking is a technique used to validate participants' responses (Birt, Scott, Cavers, Campbell, & Walter, 2016).

The only variation from my original data collection plan was that one of the six participants did not have email access, which meant that I was not able to send a consent form to the participant prior to the interview. Although this was different from the original plan, it did not hinder the process, because the participant was able to review the consent form in detail by herself prior to my going over the form with her before conducting the interview. After the participant had gone over the consent form in detail and had time to ask questions, she signed the consent form, and I conducted the interview. This kept the process within the scope of what was approved by Walden's IRB (04-25-17-0147746). No unusual circumstances were present during data collection.

Data Analysis

I analyzed the research data using a double hermeneutic and phenomenological approach consistent with the IPA approach. A double hermeneutic analysis means that while the participants were trying to make sense of their experiences, I was trying to make sense of the participants' experiences (Smith et al., 2009). I listened to recordings and read all of the transcripts four times each. I wrote notes on the transcripts as I reflected on the interview experience. The kinds of notes I took included notes regarding how anxious the participants may or may not have been about answering interview questions and notes indicating repetition of information. As I looked through the notes, I looked specifically for what things were similar and different. I used these notes as I listened to the recordings and reread the transcripts for my process of a double hermeneutic, making sure that I understood the meaning each participant made while she was making sense of her own experiences as she talked with me (Smith & Osborn, 2008).

For example, while I listened to each discussion, I noticed that each participant talked about the feelings she had when out in the community with her adult child. I noted that and listed which feelings participants had while in the community. The participants' reported feelings when out in the community led to the subthemes of fear, sadness, and happiness, which are discussed later in this chapter.

All data were analyzed by hand; no computer software was used. I chose not to use computer software to analyze data because I wanted to make sure that I could immerse myself fully in the data, finding the themes without assistance. After listening to the recordings and reading the transcripts repeatedly, I highlighted the statements that were significant to each participant. Using the steps from Smith and Osborn (2008), I grouped themes according to similarities, and I provided a descriptive label for each theme. Under each descriptive label, I placed a quote from each participant's experiences that explained the theme in the participant's own words. A table was created for each transcript that worked to develop emergent themes (see Table 2).

The four major themes that emerged from the data were (a) feelings, (b) outings/destinations, (c) church, and (d) letting go. A narrative was written for each of the major themes using verbatim statements made by the parents of AID. *Emotional responses*, *knowledge and understanding*, *people can be themselves*, and *independence* were the four superordinate themes that emerged from the data, as noted in Table 3. There were no discrepant cases identified in this study.

Table 2

Emergent Themes

Emergent themes	Descriptive comments	Sample statements	Participants
Feelings when out in the community	Fear Sadness Happiness Proud	My son has no boundaries when it comes to strangers Son not always socially included He loves to be told “good job” I am proud when I see my child making friends and getting to know people	P3, P2, P4, P5, P6
Outing/ Destination	Shopping Movie Going out to eat Bowling	My daughter loves picking out her own clothes and jewelry when we go shopping He loves bowling and he’s good at it My son loves the movies where he can eat popcorn and get a drink My daughter loves to pay for her own food when we go out to eat	P4, P5, P1, P6
Church	Active Feel free Interact	My son is in a good mood and is comfortable He sits with other church members while I sing in the choir My daughter is always recognized when we go to church. She loves the recognition My son loves church functions that involve the neighborhood, so he can play games and interact with others My son makes a lot of noise but my church family loves and understands him My daughter loves going to church especially when she is on the program	P1, P2, P3, P4, P5, P6
Letting Go	Semi-independent Spoiled Excited	My daughter want to do things on her own but I can’t let her go too far My son is spoiled he won’t t act right without me being there I allow my daughter a little space to do things like order and pay for her own food I want my daughter to be as independent as possible just in case I am not around to help her	P3, P5, P6, P4

Table 3

Superordinate Themes

Emotional responses	Protective of child Turning negative into positive
Knowledge and understanding	Family support Encouragement is key Being attentive Lack of understanding in the community
People can be themselves at church	No worries Understanding Participation Interaction
Independence	Lack of control Adaptation Adulthood Acceptance

Feelings

Participants discussed their feelings about their experiences when they were out in the community with their adult children with intellectual disabilities. Every participant described moments when she felt fearfulness, sadness, and happiness when she spent time with her adult child with intellectual disabilities at the various places they attended. Participants talked about how they felt when their adult children with intellectual disabilities were not treated like people without disabilities when they were on outings in the community, which made the parents feel fearful, sad, and sometimes angry. Five of the six participants experienced similar fears. One participant was fearful that when her adult child heard anything that was negative, it would contradict what she had taught her to believe about herself, which was that she could do anything she put her mind to. Each participant also shared moments when she felt happiness while on an outing with her adult child with intellectual disabilities.

To capture every aspect of what parents of AID told me about their feelings during the interview process, I included what the parents of AID told me regarding fear and sadness. Even though the parents mentioned instances when they felt fear and sadness, there were many comments about the parents feeling positive during outings with their adult children with intellectual disabilities. This happiness was felt because their adult children seemed to enjoy being a part of the community. The participants chose to focus on the positive experiences.

Fear. All six participants told me about experiences when they felt fearful while on outings with their adult child with intellectual disabilities. Five of the six participants described feeling fear about their adult children with intellectual disabilities not knowing how to sense that they were or could be in any danger. The other participant expressed fear for a different reason. P4, as described below, was more fearful that her daughter might believe negative statements made by other people or receive negative treatment from other people.

The adult children with intellectual disabilities of five participants loved people, and each had particular ways of showing this. They might show their affection by speaking to people with whom they came in contact, for instance, or they might try to touch people when out in the community. One young man tried to give kisses to the women with whom he came in contact. Participant 3 offered an example of fears related to such interactions.

> P3: Because my daughter is so social, she don't meet a stranger, she talk to anybody. She still doesn't know strangers yet. That makes me really fearful for her because she will walk up and talk to anybody. For example, she has a bad habit of going up to people with babies, and she tries to pick up anybody babies. I have to constantly talk to her and tell her that she has to ask the parent if she can interact with their baby. Some parents have a problem with her messing with their child, and that make me fearful because I am scared someone that don't know her might do something to her.

As noted above, one participant expressed that she felt fearful for a reason different from that of the other five participants. Participant 4 expressed she was concerned that her adult child with intellectual disabilities would begin to doubt herself because of actions of others that were not always favorable. This participant worked hard to build her adult child's confidence, so she was hoping that the negative experiences that her daughter had gone through would be the motivation that she needed to strive to be the best she could be.

> P4: The biggest fear I have is that my daughter will start believing in the negative actions she experience from time to time. I am fearful that all the things I instilled in her would be tarnished because others are not treating her the way I tell her she should be treated.

Sadness. All participants expressed the sadness they felt when they were on an outing with their adult child with intellectual disabilities because of how people in the community tended to stare at their adult children. The participants also expressed feeling sad when their adult children tried to be nice to others and it was not accepted. Each described finding herself either trying to explain that person's actions to her adult child, or trying to explain her adult child's condition to whomever was staring. All the participants expressed how people in the community can be cruel. For example, Participant 2 explained:

> My son attended a back-to-school function where the local barbers and beauticians gave free haircuts and hair styles. This happened when he was a young adult. I took him to get a free haircut and some of the young men that are younger than my son were talking about my child. They wanted to know if my son was crazy. The barber that cut my son's hair got onto them and made them stop. Being a parent, I felt so much sadness because I can't go off on everybody that talks about my son. I felt so sad because I didn't know that people could be so mean. Years later my son and I talked about it.

Participant 5 shared how she often has to explain to people in the community that her son is not a threat. She added that she makes sure they know he is not alone, so that they will not feel threatened, or think that he will do anything to them. Participant 5 reported:

P5: I feel sad when people look at my son funny. They look at him as if he's

> going to do something to them. I immediately let them know he's ok and that he's not alone. I tell them that he won't hurt nobody. You know you have people staring and kids laughing. I have even had kids to ask me what's wrong with him.

Happiness. Participants shared stories about how happy they felt when they watched their adult children with intellectual disabilities have fun while out in the community. The positive experiences of the participants' adult children with intellectual disabilities made the participants feel there are still some good people in society who understand their adult children with intellectual disabilities. More than one parent voiced feeling proud of her adult child with ID.

Participant 3 talked about a lot of activities her daughter engages in. While she accompanied her daughter for most of these activities, she felt very gratified that her daughter was able to be some places by herself, because the people in those places knew her, and P3 knew they would treat her daughter respectfully. For example, Participant 3 stated:

> P3: I am very happy and proud of my daughter because she is so social. I drop her off at karate because the people there know her. I am very happy that she can do karate, swim, sing in church choir, and skate because when her dad and I was told about her disability, we were told about all the things she wouldn't be able to do, but she has excelled in everything she attempts to do.

Participant 5 shared a time when she allowed her son to go to a game without her. She felt so happy to see him interact with her neighbors. Participant 5 described her experience with allowing her son to go with her neighbors:

> P5: One of the happiest times I always talk about is when I allowed my neighbors to take my son to a football game. I was nervous about letting him go but the neighbors told me he did well. I was skeptical at first but I knew they would take care of him. When he came home, I asked them how did he do and they said he enjoyed himself, jumping up and down. For a brief moment, I got a chance to feel like my child experienced something normal without me.

Participant 6 discussed what happened when she and her daughter went on outings. She expressed feeling glad at how her daughter learns more each time. She seemed to feel good both about her daughter learning, and about the fact that she had been teaching her, and could see the results of what she taught her daughter. Participant 6 stated:

> P6: When me and my daughter go on outings, I get so happy because she knows how to interact and she's learning how to better interact as the days go by. She is able to pay for things and she's able to order her own food when we are out. Seeing that makes me feel so happy and proud that my daughter is learning what I am teaching her.

Outing/Destination

All six participants came from at least two different locations in the same county, yet each of them mentioned two similar common activities: going out to eat and going to church. The participants believed that the outings in the community that they shared with their adult children with intellectual disabilities had a great impact on their lives. The participants discussed in detail how much they enjoyed going on outings in the community with their adult children. For example, Participant 6 stated, "When we go on outings we like to go shopping, out to eat, and movies. We go to the movies that she sees on television that she thinks will be a good movie."

They identified the following places that their adult children with intellectual disabilities enjoyed going: church, movies, shopping, restaurants, roller skating, bowling, swimming, karate, and going to get their nails done. Two of the participants described a developmental center that their adult children attended sometimes during the week. The developmental center was a place that their adult children could go to help them develop more intellectually and meet peers who have various disabilities.

Participant 2 reported that her son attends a developmental center for AID, and she felt good about his being involved with it. She seemed to appreciate that he had something to do during the day several days per week, and saw it as part of a social inclusion issue.

> P2: My adult child attends a developmental center that has people that is just like him. When my adult child goes to Developmental Center he has fun because he have friends that have the same problems that he can be around. When the developmental center go on outings I go with them.

Participant 5's son also attended the developmental center, but her experience with his attendance was a bit different from Participant 2's. While she seemed glad to have her son attend the center, she also described that it could be a bit of a struggle getting him to go.

> P5: My adult child with intellectual disabilities attends a Developmental Center when I can get him to go. I have to ask him more than once sometimes. He likes to go but he be really happy when he comes home. I like him to go because I know the people at the Developmental Center understands him. The instructor that teaches him said he likes to help put up the tables and chairs after they eat lunch.

All of these places were places that the participants thought that their adult children were most comfortable. Some examples of going to church were in the following quotes from participants: P4: "We like going to church, shopping at the mall, and going out to eat. . . . We go to church every other Sunday." P5: "He likes going out to eat, bowling, and to church."

Church

Of all the places that the parents of AID went to for an outing with their adult children, church was where the parents felt the most comfortable and free. All six of the participants attended church. Four of the six participants were either a part of the church choir or they ushered. The participants discussed how their adult children with intellectual disabilities were free when they were at church, which afforded them an opportunity to serve as an usher or sing in the choir. Church, to the participants, was a major part of their lives and the lives of their adult children with intellectual disabilities.

Participant 1 expressed:

> P1: At church my son is comfortable with the pastor, a few church members, his god-mom, and there are a couple of other adults at church that he is comfortable with. When we at church he will go with them, he'll just walk over to them and I don't have to worry about him.

Participant 2 explained her experiences of what happened when her son goes to church. She expressed how excited her son gets when the pastor is preaching. Participant 2 stated:

> P2: He loves church because he marks the pastor. He got the pastor down. Preach, sing, whatever pastor is doing, or anybody doing, sometimes he mark them, but he know when the spirit hits him. . . . He got plenty of godparents; his granny and papa all attend the same church. Most of the time he sits up front with the ministers and when I get his attention from the choir stand and try to make him sit down anyone that notices me trying to say something to him tells me to leave him alone.

Participant 3 shared a different kind of experience when she and her adult child with intellectual disabilities attend church. They both participated in the church choir together. Participant 3 noted:

> P3: My daughter is very active at church. She is the only young adult in the choir at church; the rest of the choir is older adults. She loves singing and interacting with the church members.

Participant 4 shared that while they try to go to church regularly, they don't make it as often as some other people. She seemed a combination of a little bit defensive about attending less frequently than some, while still emphasizing that their attendance was regular.

> P4: We try to go to church every other Sunday. At church, she is always spotlighted. Not in a negative way, but to let people see that she's out, she's open, and she has special needs and she is still singing. We feel very comfortable at church.

Participant 5 remarked on the lack of concern that she has when her adult child with intellectual disabilities attends church:

> P5: My son likes going to church. He loves making a lot of noise. I have to tell him all the time that he has to be quiet at church. What is so amazing, he will be quiet during church and as soon as we leave church he's back to making all sorts of noises. Everybody knows him at church, so I don't have to ever worry about him being mistreated at church. Church is one place that I am the most at ease when he's out with me.

Participant 6 sounded happy when describing her experience at church with her adult daughter with ID. She made a point of sharing a story that combined some of the every-Sunday experiences with a special experience in the following quote:

> P6: Church is where we feel most comfort. At church, she is on program to do the welcome each Sunday. When they call her name, she is very happy that they

> called her name and they gave her a standing ovation. She is very proud of herself and everybody boosts her, and cheered for her, and it made her feel really good. She even clapped for her own self.

Letting Go

As parents, it is natural for the participants to provide unconditional love to their adult children with intellectual disabilities. The participants focused on the joys and well-being of their adult children. All of the participants want their adult children to feel a sense of accomplishment and build relationships (Seligman, 2011). In all the interviews conducted, I learned that the participants referred to their adult children with intellectual disabilities as the “child.” These parents did not see their adult children as adults who could take care of themselves or adults who could make decisions for themselves. Based on the interviews, it was evident to me that all the participants loved their adult children with intellectual disabilities unconditionally. All the participants wanted their adult children to flourish in their lives and they wanted to see their adult children happy. Each of the participants was open about her struggles of letting go. However, they were all about finding ways to discover and promote positive social inclusion experiences for their adult children (Seligman & Csikszentmihalyi, 2000).

Five of the six participants were still holding on to their adult children with intellectual disabilities and they were not willing to let them go or to allow them to do too many things without them. The sixth participant voiced feeling excited that her daughter was learning how to become independent. The following quotes were the clearest examples of those who had difficulty letting go.

Participant 3 expressed ambivalence about her daughter growing up. While she seemed to feel proud of her and felt good about her doing more adult-type things, her reluctance about encouraging independence showed up. She knows her daughter is not able to make adult decisions because of her intellectual ability; however, she supports her endeavors.

> P3: My daughter is an adult now, so I have to let her do some things. I have to allow her to wear some things and get her hair and nails done. I know I have to allow her to be herself, but I can't allow her to go too far because age-wise she is still like a little girl. Intellectually she is not her age.

Participant 5 explained why her adult child can't be without her or his father. She seemed to feel protective of her son, and at the same time a bit worried about how he might behave when she or her husband are not with him:

> P5: I think about letting my son go with others quite often, but he be acting differently without me being there. We got him spoiled to us so most times he's going to be with me and his father. When we go out anywhere he be on my heels. He won't let me go too far without him.

Participant 6 explained how much independence she is willing to give her adult child, focusing on helping her do things for herself in public, while staying close by. She seemed to think this was important, as demonstrated in this quote:

> P6: My daughter is an adult now, but she will always be my baby. I don't know

> if I will ever be able to completely let her be independent. I allow her to do some interacting as it relates to ordering and paying for food or functions that we may attend. I will sit behind her or stand beside her but that is the most freedom I can give her right now.

Emotional Responses

Responses to community experiences showed uniformity across participants. All six of the participants expressed that their adult children with intellectual disabilities need their support. Because of fear and sadness, the participants could be very protective of their adult children with intellectual disabilities. All participants understood that some people in the community do not know or understand their adult children with intellectual disabilities, so they have to be guides for their adult children with intellectual disabilities while in the community. All participants reported great experiences where they were able to change a negative situation into a positive situation. Two examples of this are from Participants 6 and 3:

> P6: When walking in the mall and I see people smirking at my daughter, I keep walking and talking with my daughter and I tell her that everybody is different and everybody do not see people the same way. So, I tell her not to worry about those people because those people are different from my daughter and everybody just do not understand people with intellectual disabilities. Anytime I see sadness in her face I tell her she is great and she perks up.
>
> P3: My daughter loves little children. She immediately runs to a little child and

> attempts to pick the child up when we are out in the community. I was fearful that someone would hurt her because they do not understand her. Initially, she did not understand when I tried to explain to her that this is wrong. She understands better now because when she see little children now she will walk up and ask the parent for permission to pick up the child. We have had great responses to her request.

Knowledge and Understanding

Each participant's account showed she was knowledgeable and had a clear understanding of where to take her adult child with intellectual disabilities to experience social inclusion. It appeared to me that the key to their success was to support and encourage the things that their adult children with intellectual disabilities did in the community, while being very attentive of their adult children's environment. Participant 4 offered the following example of this:

> P4: When we go shopping and out to eat my daughter picks out her own items and orders her own food. When we are in a restaurant, she is not able to read everything on the menu but the things she can read she will. She will tell me what she want and I will repeat back to her what she said. When the waitress takes our order, I tell her to tell the waitress what she wants.

People Can Be Themselves at Church

Church was the one place that every participant expressed a sense of freedom, not just for themselves but for their adult child as well. At church their adult child was free to participate in the service without the parent of the AID feeling worried. Their adult children interacted with others without a disability because their church congregation understood. Church was where their adult children could be themselves around their church family. Examples of every participant's experiences are listed under the emergent themes. To reiterate the importance of the participants' AID experience at church is the following example from Participant 5:

> Everybody knows him at church so I don't have worry about him being mistreated at church. Church is one place that I am most at ease when he is not with me.

Independence

All but one of the participants expressed the difficulty they have with their adult children becoming adults. The participants struggled with not having full control because of the growth they witnessed in their adult children with intellectual disabilities. Participant 4 was the one participant excited to see her daughter become more independent.

Participant 4 discussed her outlook of her adult child's independence. Although Participant 4 struggled to watch her adult child become more independent, she believed it was necessary. Participant 4 believed it was necessary in the event she is no longer able to care for her daughter. She expressed the importance of her adult child learning to do some things on her own. Participant 4 described this experience in this way:

P4: It's exciting to see my daughter growing into her independence. I want her to

> continue growing into her own independence, and learning how to handle herself. Because in the event something, you know, I may not be around for her all the time, or whatever, I want her to be able to handle herself. I can't lie, I am still struggling with allowing my daughter to be independent. I know no matter how independent she becomes she will always need me.

During each interview, every participant referred to her adult child with intellectual disabilities as her child. Each participant corrected herself, then said to me, "they gone always be my baby." Participant 2 stated it this way:

> P2: He not my baby no more. He's growing up on me. He doesn't like to spend much time with me anymore, he wants to be with his dad. I have to adjust to adulthood. I know he is getting older and wiser and I have to adapt to it.

Evidence of Trustworthiness

Credibility, transferability, dependability, and conformability are all aspects of establishing trustworthiness in research. Credibility means to ensure I interpreted what participants shared accurately (Anney, 2014). As noted above, I accomplished this through member checking. I sent transcribed interviews to participants and I asked that they read them and contact me if any of the information was a misrepresentation of what I was told. All six participants called me once they received and read transcripts to inform me that the transcripts were correct and there were no changes necessary.

I accomplished transferability by providing thick descriptive data and through purposive sampling, so readers and other researchers can make a comparison of this study to other contexts in their lives (Anney, 2014). All six of my participants met the criteria to participate in this study. I started to reach saturation by the fourth interview, but I continued to interview another two participants to see if anything different would emerge and it did not. Research studies are not universal, so there is no one size that fits all (Fusch & Ness, 2015). Data should be thought of as thick and rich, rather than thinking of the sample size (Burmeister & Aitken, 2012). When it comes to data saturation, researchers should think quality and not quantity (Fusch & Ness, 2015). I was able to achieve detailed information of participants' experiences with six participants. In order to be consistent with IPA, I read and reread the transcripts several hours a day for about a week, so I could become familiar with the data (Smith & Osborn, 2008). After the first week of reading the transcripts, I revisited the transcripts four times while analyzing the data. To address dependability, I provided a thick description and I engaged triangulation through interviews, a reflexive journal, and member checking.

I accomplished confirmability through the audit trail and a reflexive journal (Anney, 2014). I provided a detailed description of how data was collected, recorded, and analyzed. I kept a reflexive journal of my thoughts during the research study. The reflexive journal helped me to bracket my experiences. It also informed how I created themes.

Results

The purpose of this interpretative phenomenological analysis investigation was for me to gain an understanding of the lived experiences and perceptions of social inclusion from the point of the view of parents of AID. Descriptions of the lived experiences of six parents of AID were gathered and interpreted for the purposes of research. The descriptions of lived experiences provided me insight into the questions that guided this research. The first question of this research project was: *What are parents' lived experiences of social inclusion of their adult children with intellectual disabilities in their charge?* From the data gathered, parents have mixed experiences. While most of the parents participating in this study shared positive experiences, they also shared examples of making sure outings took place at times and in places where they and their adult children felt most comfortable. Participants talked about how people can be hurtful by not responding to an AID who greets them in some way, or by laughing at them or making hurtful comments.

The parents' descriptions of social inclusion while out in the community varied. Participant 1 stated, "When we go out, he speaks to everybody and people that is normal don't speak, I say they are not courteous. They'll see you and won't speak, but he speaks to everybody." Participant 2 said, "being sociable, making friends, getting to know people. You start to see where you fit and don't fit in." Participant 3 asserted,

> She's more able to advocate for herself. Like sometimes we go to a restaurant, and she wanna order. People come to me for me to place her order and I tell them talk to her. 'You can ask her what she wants, she'll tell you.'

Participant 4 commented,

> I'm very disappointed at how society treats people with special needs. You have

> some people that treat them very well, but then you have some people that just put a label on them. You know you look at a person in a wheelchair, or you look at a person that may not be all the way on your level, you just wanna push them aside.

The data revealed that feelings about past experiences were still relevant for some of the participants. It appeared that parents' lived experiences of social inclusion offered insight to the importance not only of building relationships but also of being able to distinguish where AID were more socially accepted when they were on outings with their adult children with intellectual disabilities.

The parents affirmed a commonality in the places that they felt comfortable going with their adult children with intellectual disabilities. Going out to eat, shopping, church, and movies were all places the participants had in common. The participants talked about their lived experiences while at the movies, shopping, eating, or attending church with their adult children with intellectual disabilities. For example, Participant 1 said, "He likes restaurants and he is comfortable at the movie theater and church. He doesn't like to go to basketball games, football games, graduation, or anywhere where there is a real large crowd." Participant 3 stated, "We like to go out to eat and church. We go to church every other Sunday." Participant 6 mentioned, "We like going out to eat and shopping."

All the participants in this study allowed their adult children with intellectual disabilities to attend church. The participants allowed their adult children with intellectual disabilities the freedom to be active and sociable with the other members in the church. Each participant described her adult child with intellectual disabilities with the members of the church. For example, Participant 2 said, “When we have a block party at church. . . . We play gospel music, and he runs with the kids and the adults. I know my son feels free around church members. He is happy and so am I. My heart feels so good to see my church members show my son love.”

Letting go was the last theme that emerged. All participants shared moments when their adult children with intellectual disabilities showed independence. However, no matter how much independence their child showed them, the parents still had a hard time letting go. For example, Participant 1 stated,

> When I had him, I didn’t understand. Listening to stories from others help me understand him better. As he grew older, I feel you don’t ever stop parenting because he is an adult. Some of them can function on their own and some can’t.

This was similar to what Participant 2 said: “He just don’t [sic] socialize with anybody when we shopping unless I’m standing there. He just stands there and let me talk.” Each participant was able to describe moments when her adult child with intellectual disabilities felt independent, even though the parent was right there with the adult with intellectual disabilities. The most passion expressed was when each parent described the adult with an intellectual disability having positive interactions while on outings. Their faces lit up with joy as they described these experiences.

The second research question was: How do parents describe their meanings of social inclusion experiences of their adult children with intellectual disabilities in their charge? Parents described social inclusion experiences as meaning that their adult children are accepted and included by others in the community. The most poignant example of this came from Participant 2 in the following story:

> One of the happiest moments in our life is when we took my daughter to college in another part of Tennessee. The people at the college, at the stores, and restaurants, they made my entire family feel welcome. They didn't look at my son like he was crazy or nothing. We were standing in line at a restaurant, my adult child was sitting there hitting himself in the chest, and he was singing and rocking his head. A pastor and a deacon walked up to us while my family was sitting at the table and gave my daughter a business card and invited her to church. Not only did they talk to her they talked to my adult child with intellectual disabilities and made him feel welcome. I was so happy because I knew that my daughter chose a great place to be and I was happy that the people in that town seem to be aware and educated about AID.

Summary

The purpose of this study was to understand and describe the meaning of parents' perceptions and lived experiences of social inclusion of AID. The perceptions and experiences as described by the six parents of AID were obtained from semi-structured interviews. The interviews generated significant statements regarding perceptions of social inclusion of parents of AID.

Chapter 4 provided an overview of the procedures I used to collect and analyze data. I collected data from six participants who were purposively selected. The participants described to me how they made meaning of their lived experiences of social inclusion. I presented results of the data analysis of the transcribed interviews. Four themes emerged from the data analysis: (a) feelings, (b) outing destination, (c) church, and (d) letting go.

In Chapter 5, I present an interpretation of findings, limitations of study, and recommendations. The chapter concludes with a section on implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this IPA study was for me to gain a deep understanding of the lived experiences of parents of AID through their perceptions of social inclusion. I investigated how parents of AID described and made meaning of their adult children's social inclusion experiences. I organized this study in a manner consistent with IPA. My goal was to provide an understanding of the lived experiences of social inclusion of parents of AID and to build on the existing literature on parents' experiences of social inclusion.

According to Smith (2011), the nature of an IPA approach is to offer an understanding of the phenomenon being studied as experienced in individuals' lives. My aim was to understand how parents of AID feel when they are out in the community with their adult children. The phenomenon studied was perceptions of social inclusion of parents of AID.

Previous research studies showed that AID have fewer social networks and their friendships are linked to others with intellectual disabilities and family relationships (Gilmore & Cuskelly, 2014). This was reported by the participants in this study as well. The six participants in this study reported both negative and positive experiences in the community. However, the majority of the community experiences of parents of AID with their adult children were positive. This finding echoed that of Schleien et al. (2014) that parents value social inclusion experiences and participating in the community with their adult children with ID.

Findings from the study revealed that participants did not believe that society fully embraces AID, thus supporting the findings of Emira and Thompson (2011) that there are societal barriers unfavorable to social inclusion. Participants felt that church was the one environment from which both parents and AID benefitted. This might be an expression of Martin and Couto's (2014) recommendation that families need social support, which all of the participants in the current study commented on experiencing at church, both for themselves and their adult children with ID. Overall, parents of AID appeared to be satisfied with social inclusion experiences and shared feeling happy when they were able to watch their adult children with intellectual disabilities participate in community activities.

Interpretation of the Findings

In my review of the literature, I found that few studies in the United States had focused on lived experiences of parents of AID regarding social inclusion. One study provided information on perceptions of parents of AID regarding social inclusion and family experiences of social inclusion of AID (Henninger, & Lounds, 2014). The information, descriptions of experiences, and interpretations presented in that study demonstrated that the voices of parents of AID are essential in ensuring that AID succeed in the community. Input from parents of AID provided an understanding of AID when out in the community. The findings from this study of parents of AID expanded the scope of Henninger and Lounds' (2014) study. The findings of this study not only gave the parents of AID a platform to discuss in detail their experiences of social inclusion, but also gave them an opportunity to discuss the limited places in the community that they believed that their adult children with intellectual disabilities fit in.

Corroborating existing research, participants in this study shared accounts of positive and negative experiences while in the community. Each of the participants described their feelings when out in the community, their outing destinations, church, and letting go. Mahar, Cobigo, and Stuart (2013) suggested that the lives of AID are improved when they are socially included. Hall (2010) also suggested that consideration be given to paths that can improve the lives of people with intellectual disabilities in relation to belonging, well-being, and space.

Findings from this study confirmed previous research on perceptions of parents of AID and their lived experiences of social inclusion. Findings derived from this study revealed that participants did not believe that society fully embraces AID; that church was the one place where these parents of AID were most comfortable; that these parents were the main support for AID; and that participants still saw their adult children with intellectual disabilities as children.

Speraw (2006) reported that the one community environment where parents and AID benefit is church. Each of the participants expressed how comfortable and at ease she felt when she took her adult child with ID to church. For the participants, church was the one place where their adult children with ID could be themselves, in that the people at church understood them without judging them. Findings from this study confirmed that church is the environment where parents of AID feel the most open and free, and where their adult children seem to be welcomed and accepted. Given the limited places that parents of AID have available to them, it would be helpful to find more places that would accept AID more fully.

The findings of this study confirmed those of previous researchers. Parents of AID have to facilitate social inclusion for their adult children because society does not accept AID fully (Martin & Couto, 2014). Even employees who work with AID do not always accept AID due to physical and mental limitations. For example, Participant 4 shared that

> My adult child got left out of many outings that the developmental center participated in because my daughter is in a wheelchair. When the agency takes the AID on an outing they take all the AID that can walk, and they leave the wheelchairs behind.

It was not until she addressed this issue that she began to see a little change. Even though this agency specialized in working with AID, not all AID were fully accepted there. Parents of AID continued to be the main supports and providers of care when in the community, as noted by Factor et al. (2012). The findings from this study revealed no changes from the findings of past researchers. Participants in this study expressed that they still saw their adult children with intellectual disabilities as children who were not able to make their own decisions.

Theoretical Framework

The components of positive psychology include positive relationships, positive groups, and positive individual traits (Seligman, 2011). Throughout the study, all participants reported how friendly their adult children with intellectual disabilities were when they were out enjoying themselves in the community. Every participant in this study reported how her adult child with intellectual disabilities loved people. While all participants experienced moments of sadness when their adult children were not socially accepted, all participants made a point to turn any negative experiences into positive experiences. They loved seeing their adult children happy. The experiences they shared of church highlighted how all participants' adult children with intellectual disabilities felt that they were part of a group and had developed positive relationships there.

The goal of positive psychology is to build on positive qualities of an individual to improve mental health and optimal functioning (Seligman & Csikszentmihalyi, 2000). All participants chose to focus on positive experiences, and they informed me of how they changed any negative experiences into positive experiences. Every participant appeared to have intuitively applied the positive psychology technique of focusing on the positive in their lives and the lives of their adult children with ID. The participants did not focus on any of the negative experiences because they were so interested in focusing on making their adult children's social inclusion experiences positive ones. The participants demonstrated the application of positive psychology.

Limitations of the Study

The participants for this study met the criteria of being parents of AID who lived in Shelby County, Tennessee. The present study had a few limitations. First, the sample size was small because I used IPA, for which participant groups are usually small to enable the researcher to conduct an in-depth analysis of participants' experiences (Pietkiewicz & Smith, 2012). For this reason, the number of participants chosen for this study was limited to six. My experience of having worked with AID was another limitation of this study. Although I bracketed my biases and previous experiences to allow participants' lived experiences to evolve, I also consciously used my familiarity with this population to help parents recognize that I understood what they were telling me at times.

Another possible limitation was the fact that all participants in this study attended church. Therefore, this study provided no information about participants who did not attend church. Another study might include parents who do not go to church, which could alter the findings.

Recommendations

Findings from this study were significant. The findings from the study were that parents of AID believed that it is important to build relationships and there is a need to identify where AID are socially accepted. Future research should continue to explore the voices of parents of AID. Additionally, future research about parents' lived experiences of AID should be extended to the community itself. The participants expressed the need for people in the community to be more understanding. Their responses indicated that people in a variety of community settings are not accepting of AID, which can make AID feel uncomfortable.

I recommend that parents of AID be included when policies are being developed. This can ensure that the voices of parents of AID are being heard. Parents can provide policy makers examples of real-life social inclusion experiences. Parents of AID want and need support in the community. Finding ways to adequately provide this support could make a difference in the lives of both the parents of AID and AID themselves. Family involvement can improve the decision making regarding what services and supports for AID are most needed. Service providers should continue to encourage families to build upon existing community networks. Parents should be afforded more frequent opportunities to share and be heard in order to help them feel empowered.

Implications

There are several social change implications of my findings. From a policy and service provider standpoint, parents of AID could be part of the development of new policies that affect the system and supports that service providers offer. Changes to current policy could be in order. Policy makers could allow parents of AID to be the driving force in developing new policies because they are the primary supports for their adult children with intellectual disabilities when they are out in the community. The results of this study may inform state representatives, policy makers, and service providers. What these participants shared could also help in the development of systems, services, and supports to improve social inclusion of AID.

Other social change implications that could be drawn from this study are that attending more to the voices of parents of AID and recognizing their points of view could empower them to be even more effective in their work with their AID children and in their personal lives. If they could be heard more, parents of AID might be able to get more social and personal support that could be significant for them, altering their experience.

Parents who participated in this study were grateful for the opportunity to help others better understand AID. Participant 1 reported that she could not thank me enough for this study because it is well needed. She said that a lot of people need to be educated. Participant 5 stated, “I just want to say that I enjoyed the interview experience because I never heard of anybody doing research about social inclusion. It was a great experience for me.” Overall, these two participants were happy to be able to share their experiences of social inclusion of their adult children with intellectual disabilities.

Positive psychology was the practical framework that guided this study (Seligman & Csikszentmihalyi, 2000). Positive psychology was used to take a holistic look at the lived experience of parents of AID (Joseph, 2015). Positive psychology focuses not only on experiences of enjoyable feelings, but also on transforming experiences of suffering (Hart & Sasso, 2011). I explored positive psychology in relation to ways in which parents of AID were hopeful and optimistic about their lived experiences of social inclusion of their adult children. The research method provided a description of how parents of AID experienced social inclusion of AID.

The findings of this study were in line with positive psychology, because despite the experiences that participants shared that were not always pleasant, their adult children were flourishing because the participants made a point to transform every experience into a positive experience. My study adds to the literature on positive psychology because positive psychology supports individuals with intellectual disabilities by focusing on positive emotions and the role of healthy emotions in daily life (Seligman, Steen, Park, & Peterson, 2005). The literature on positive psychology, as described on the University of Pennsylvania's Positive Psychology Center website (2017), covers many areas, but not the area of positive psychology as used with AID or their families.

The most closely related literature listed on the aforementioned website is a dissertation on how teaching well-being increases academic performance (Adler, 2016). Where Adler (2016) taught specific well-being strategies in school classroom frameworks, the parents who participated in my study taught well-being strategies to their children with ID and voiced that they continued to do this as their children became adults and grew into adulthood. The stories of these AID experiencing positive activities with others and generally being friendly and loving people demonstrated the effects of the positive interpretations and mindset that these mothers taught their adult children with intellectual disabilities. This framework was appropriate and relevant for the present study in a way that I had not foreseen. Though I do not believe that they were aware of positive psychology, I noticed that the parents of AID with whom I spoke all seemed to apply positive psychology principles as they shared their experiences of social inclusion. Although they might not have been aware of it, their descriptions of their adult children with intellectual disabilities demonstrated the positive effects of focusing on positive emotions and mindset. The stories of their adult children with ID developing more confidence, being able to do more than originally expected, enjoying community activities, seeing others in a loving and friendly way, and having fun playing games or doing things with their families demonstrated what positive psychology is about, as stated by Gable and Hait (2005): the study of "understanding what is right with people" (p. 105).

Conclusion

The conclusion that I derived from this study based on my findings is that there is still much more work to be done with service providers, policymakers, and community partners concerning parents of AID and social inclusion. AID need to feel comfortable when they are participating in the community. Parents' voices need to be heard, not only to assist with building support for AID, but also to also provide a genuine understanding of the lived experiences of parents of AID regarding social inclusion.

Prior to this research study, little research had been conducted on perceptions and lived experiences of social inclusion of parents of AID. This study addressed a gap in research by investigating lived experiences of parents of AID and emphasizing the voices of these parents. Data analysis unveiled four major themes and four superordinate themes concerning the perceptions and lived experiences of social inclusion of parents of AID. Findings from this study supported findings of previous research on social inclusion of AID. Although more research is needed to provide parents a platform for their voices to be heard, this study adds to the limited research in this area and offers a beginning point for future researchers to address the lack of change in societal acceptance of AID and social inclusion. Perhaps it also points toward new directions for improving social inclusion experiences of AID and those of their parents and families.

Though the participant group for this study was a specific group within a specific location, my findings confirmed some of the previous research presented in Chapter 2. The study also provided individual perceptions of parents’ experiences of social inclusion of AID. The themes of letting go and church could be starting points for future researchers to investigate as scholars in this area seek to give parents of AID a way to be heard, advancing social change by increasing social inclusion.

References

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*(3), 275-287. doi:10.1177/1744629506067618

Adler, A. (2016). *Teaching well-being increases academic performance: Evidence from Bhutan, Mexico, and Peru* (Doctoral dissertation). Retrieved from http://repository.upenn.edu/cgi/viewcontent.cgi?article=3358&context=edissertations

Algood, C. L., Harris, C. E., & Hong, J. S. (2013). Parenting success and challenges for families of children with disabilities: An ecological systems analysis. *Journal of Human Behavior in the Social Environment, 23*(2), 126-136. doi:10.1080/10911359.2012.747408

Allen-Collinson, J. (2009). Sporting embodiment: Sports studies and the (continuing) promise of phenomenology. *Qualitative Research in Sport, Exercise and Health, 1*(3), 279-296. doi:10.1080/19398440903192340

Amado, A. N., DeGrande, M., Boice, C., & Hutcheson, S. (2011). *Impact of two national congregational programs on the social inclusion of individuals with intellectual/developmental disabilities*. Minneapolis: University of Minnesota, Institute on Community Integration.

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual disabilities.

Intellectual and Developmental Disabilities, 51(5), 360-375. doi:10.1352/1934-9556-51.5.360

American Association on Intellectual and Developmental Disabilities. (2011). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: Author. Retrieved from http://www.aaidd.org/content100cfm

American Psychiatric Association. (20013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.

Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. A. (2013). The state of science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 51*(5), 385-398. doi:10.1352/0047-6765-51.6.fmii

Anney, V. N. (2014). Ensuring quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies, 5(2),* 272-281.

Ault, M. J. (2010). Inclusion of religion and spirituality in the special education literature. *Journal of Special Education, 44*(3), 176-189. doi:10.1080/15228961003622195

Ault, M. J., Collins, B. C., & Carter, E. W. (2013). Congregational participation and supports for children and adults with intellectual disabilities: Parent perceptions. *Intellectual and Developmental Disabilities, 51(1),* 48-61. doi:https://doi.org/10.1352/1934-9556-51.01.048

Barnes, J., Conrad, K., Demont-Heinrich, C., Graziano, M., Kowalski, D., Neufeld, J., &

Palmquist, M. (1994-2012). Generalizability and transferability. Retrieved from https://writing.colostate.edu/guides/guide.cfm?guideid=65

Barrett, A., Savva, G., Timonen, V., & Kenny, R. (Eds.). (2011). *Fifty plus in Ireland: First results from the Irish Longitudinal Study on Ageing.* Dublin, Ireland: TILDA & Trinity College, Dublin.

Bedia, R., Cilleros, M. V. M., Prino, P. G., & Fernandez, Z. G. (2009). The quality of care processes to support adults with autism and their families. In M. Allonso (Ed.), *How to improve the quality of life of people com disabilities: Instruments and evolution strategies* (pp. 323-337). Salamanca, Spain: Amarú.

Bertelli, M., Salvador-Carulla, L., Lassi, S., Zappella, N., Ceccotto, R., Palterer, D., & Paoloa, R. P. (2013). Quality of life and living arrangements for people with intellectual disability. *Advances in Mental Health and Intellectual Disabilities, 7(4)*, 220-231. doi:https://doi.org/10.1108/AMHID-03-2013-0027

Biggerstaff, D. L., & Thompson, A. R. (2008). Interpretive phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology, 5,* 214-224.

Birt, L., Scott, S. E., Cavers, D., Campbell, C., & Walters, F. M. (2016). Member checking: A tool to enhance trustworthiness or merely a nod of validation? *Qualitative Health Research, 26*(13), 1802-1811. doi:10.1177/1049732316654870

Bowen, G. A. (2009). Supporting a grounded theory with an audit trail: An illustration.

International Journal of Social Research Methodology, 12(4), 305-316. doi:10.1080/13645570802156196.

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., Lulinski, A., & Wu, J. (2013). *The state of the states in developmental disabilities in 2013: The great recession and its aftermath.* (Prelim. Ed.). Boulder, CO: Department of Psychiatry and Chicago, IL: Coleman Development, University of Illinois at Chicago.

Burmeister, E., & Aitken, L. M. (2012). Sample size: How many is enough? *Australian Critical Care, 25,* 271-274. doi:10.1016/j.aucc.2012.07.002

Callary, B. (2013). Three ethical issues in narrative research of women coaches' lifelong learning. *The Qualitative Report, 18*(6), 1-14. Retrieved from http://www.nova.edu/ssss/QR/QR18/callary6.pdf

Callary, B., Rathwell, S., & Young, B. W. (2015). Insights on the process of using interpretative phenomenological analysis in a sports coaching research project. *The Qualitative Report, 20*(2), 63-65. Retrieved from http://www.nova.edu/SSS/QR/QR202/2/callary1.pdf

Chadwick, D. D., Mannan, H., Iriarte, E. G., McConkey, R., O'Brien, P., Finlay, A. L., Harrington, G. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research and Intellectual Disabilities, 26,* 119-132. doi:10.1111/jar.12003. Epub 2012 Dec 6.

Cobigo, V., & Stuart, H. (2010). Social Inclusion and Mental Health. *Current Opinion in Psychiatry*, *23*(5), 453-457. doi:10.1097/YCO.06013e32833e2929

Cohen, L. Manion, L. & Morrison, K. (2011). *Research methods in education* (7th ed.). New York, NY: Routledge.

Cohen, N., & Arieli, T. (2011). Field research in conflict environments: Methodological challenges and snowball sampling. *Journal of Peace Research, 48*(4), 423-435. doi:10.1177/0022343311405698

Collier-Reed, B., I., Ingerman, A., & Berglund, A. (2009). Reflections on trustworthiness in *phenomenographic* research: Recognising purpose, context and change in the process of research. *Education as Change, 13*(2), 339-355. doi:https://doi.org/10.1080/16823200903234901

Cooper, R., Fleischer, A., & Cotton, F. A. (2012). Building connections: An interpretative phenomenological analysis of qualitative research students' learning experiences. *The Qualitative Report, 17*(1), 1-6. Retrieved from http://www.nove.edu/ssss/QR/QR17/cooper.pdf

Cope, D.G. (2014). Method and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum, 41*(1), 89-91. doi:10.1188/14.ONF.89-91

Davison, T. (2014). Phenomenological research using a staged multi-design methodology. *International Journal of Business, Humanities, and Technology, 4*(2). Retrieved from www.ijbhtnet.com/journals/vol_4_No_2_March_2014/1,pdf

Department of Intellectual and Developmental Disabilities. (2015). People Talking to People. State of Tennessee. Retrieved from https://www.tn.gov/didd/section/people-talking-to-people

Dibley, L. (2011). Analyzing narrative data using McCormack's lenses. *Nurse Researcher, 18*(3), 13-19. doi:10.1177/1558689812437186

Disability Rights Ohio. (2013). Take charge of your life: Know about guardianship. Retrieved from http://disabilityrightsohio.org

Doyle, S. (2007). Member checking with older women: A framework for negotiating meanings. *Health Care for Women International, 8*(10), 888-908. Retrieved from http://www.nova.edu/ssss/QR/QR17-2/harper.pdf

Esin, C. (2011). Narrative analysis approaches. In N. Frost (Ed.). *Qualitative Research methods in psychology: Combining core approaches.* Maidenhead, Berkshire, UK: McGraw-Hill/Open University Press.

Emira, M., & Thompson, D. (2011). In the quest for their trust: The perceptions of families on accessing leisure services for disabled children. *Leisure Studies, 30(1),* 33-48. doi:10.1080/02614367.2010.506648

Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology, 43,* 13-35. doi:10.1163/156916212X632943.

Factor, A., Heller, T., & Janicki, N. (2012). Bridging the aging and developmental disabilities service networks: Challenging and best practices. Retrieved from http://www.rrtcadd.org/resources/resources/Publications/Policy/Service/Briefs-&-Repots/Bridging-Report.pdf

Finlay, L. (2008). A dance between the reduction and reflexivity: Explicating the phenomenological psychological attitude. *Journal of Phenomenological Psychology, 39*, 1-32. doi:10.1163/15916208X31160

Fusch, P. I., & Ness, I. R. (2015). Are we there yet: Data saturation in qualitative research. *The Qualitative Report, 20(*9). 1408-1416. Retrieved from http://www.nova.edu/ssss/QR/QR20/9/fusch1.pdf

The future of equity and inclusion: Creating meaningful change. (2013). *ASHE Higher Education Report*, *39*(5), 1-11. doi:10.1002/aehe.20011

Gable, S. L., & Hait, J. (2005). What (and why) is positive psychology? *Review of General Psychology, 9*(2), 103-110. doi:10.1037/1089-2680.9.2.103

Given, L. M. (2008). *The Sage Encyclopedia of Qualitative Research Methods.* Los Angeles, CA: Sage. doi:http:://dx.doi.org/10.4135/9781412963909

Hall, S. A. (2009). The social inclusion of people with disabilities: A qualitative meta-analysis. *Journal of Ethnography and Qualitative Research*, *3,162*-173. doi:10.5463/SRA.v1i1.10

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research, 54,* 38-57. doi:10.1111/j.1365-2788.2009.01237.x

Happell, B., & Harrow, A. (2010). Nurses' attitudes to the use of seclusions: A review of literature. *International Journal of Mental Health Nursing, 19*(3)*,* 162-168. doi:10.1111/j.1447-0349.2010,00669.x.

Hart, K. E., & Sasso, T. (2011). Mapping the contours of contemporary positive psychology. *Canadian Psychology, 52*(2), 82-92. doi:http://dx.doi.org/10.1037/a0023118

Heaney, C. A., & Israel, B. A. (2009). Social networks and social supports. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.) *Health and behavior education: Theory, research, and practice, 4*, 189-210. San Francisco, CA: Jossey-Bass.

Heckathorn, D. D. (2011). Comment: Snowball versus respondent-driven sampling. *Sociological Methodology, 41*(1), 355-366. doi:10.1111/j.1467-9531.2011.01244.x

Henninger, N. A. & Lounds, J. (2014). Family perspectives on a successful transition to adulthood for individuals with intellectual disabilities. *Intellectual and Developmental Disabilities, 52*(2), 98-111. doi:http://dx.doi.org/10.1352/1934-9556-52.2.98

Hewitt, A., Augusta, J., Heller, T., Williams, A.C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities, 51*(5), 349-59. doi:https://doi.org/10.1352/1934-9556-51.5.349

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher, 20*(4), 12-17.

Jackson, R. (2011). Challenges of residential and community care: The times are changing. *Journal of Intellectual Disability Research, 55*(9), 933-44. doi:10.1111/j.1365-2788.2011.01461,x.Epub 2011 Aug 4

Johnson, H., Douglas, J., Bigby, C., & Iacona, T. (2012a). Social interaction with adults with severe intellectual disability: Having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities, 25(4),* 329-341. doi:10.1111/j.1468-3148.2011.00669.x

Johnson, H., Douglas, J., Bigby, C., & Iacona, T. (2012b). A model of processes that underpin positive relationships for adults with severe intellectual disability. *Journal of Intellectual and Developmental Disability, 37*(4), 324-336. doi:10.3109/13668250.2012.732221

Joseph, S. L. (Ed.) (2015). *Positive psychology in practice: Promoting human flourishing in work, health, education, and everyday life. 2nd Ed*. doi:10.1002/9781118996874

Khan, S., & Jahan, M. (2012). Humanistic psychology a rise for positive psychology. *Indian Journal of Positive Psychology, 3*(2), 207-211. Retrieved from https://www,questia.com/library/journal/1P3-3561131091/humanistic-pschology-a-rise-for-positive-psychology

Larkin, M., Watts, S., & Clifton, E. (2008). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3,* 102-120. doi:10.1191/14780887-690620a

Linley, P. A., & Joseph, S. (2003). Putting it into practice [Special issue on Positive psychology]. *The Psychologist, 16*(3), 143. Retrieved from https://thepsychologist.bps.org.uk/volume-16/edition-3/positive-psychology-special-issue

Lyons, L. (2009, June 24). Positive psychology: Power of positive thinking is psychology's latest focus. *U. S. News & World Report*. Retrieved from http://health .usanews.com/health-news/family-health/brain-and-behavior/articles/2009/06/24

Mahar, A.L., Cobigo, V., & Stuart, H. (2013). Conceptualizing belonging. *Disability and Rehabilitation, 35*(12), 1026-1032. doi:10.3109/09638288.2012. 717584. Epub 2012 Oct 1.

Mankiewicz, P. D., Gresswell, D. M., & Turner, C. (2013). Happiness in severe mental illness: Exploring subjective wellbeing of individuals with psychosis and encouraging socially inclusive multidisciplinary practice. *Mental Health and Social Inclusion, 17*(1), 27-34. doi:10.1108/2042830/311305287

Mansell, J. (2010). Raising our sights: Services for adults with profound intellectual disabilities. *Tizard Learning Disability Review*, *15*(3). doi:http://dx.doi.org/10.5042/tidr.2010.0399

Marshall, B., Cardon, P., Poddar, A., & Fontenot, R. (2013). Does sample size really matter in qualitative research? A review of qualitative interviews in is research, *Journal of Computer Information Systems, 54*(1), 11-22. Retrieved from https://doi.org110.1080/08874417.2013.11645667

Martin, L., & Cobigo, V. (2011). Definitions matter in understanding social inclusion. *Journal of Policy and Practice in intellectual disabilities, 8(4),* 276-282. doi:10.11111j.1741-1130.2011.00316.x

Martin, M., & Couto, A. P. (2014). Everyday experiences of parents with disabled children. *Journal of Nursing Reference, 4(1),* 113-120. doi:10.12707/R1111266

Mason, M. (2009). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Research, 11*(3). doi:http://dx.doi.org/10.17169/fqs-11.3.1428

Mayer, W. E., & Anderson, L. S. (2014). Perceptions of people with disabilities and their families about segregated and inclusive recreation involvement. *Therapeutic Recreation Journal, 48*(2), 150-168. Retrieved from https://js.sagamorepub.com/trj/article/view/5192

McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Mcallions, P. (2011). *Growing older with an intellectual disability in Ireland 2011: First results from the intellectual disability supplement of the Irish longitudinal study on ageing.* Ireland: School of Nursing & Midwifery, Trinity College Dublin.

McKnight, J., & Block, P. (2010). *The abundant community: Awakening the power of families and neighborhoods*. San Francisco, CA: Berrett-Koehler.

Meissner, H. (2011). How the shift to individualize supports gets stuck and the first step out of gridlock. *Intellectual and Developmental Disabilities, 49*(5), 383-387. doi:https://doi.org/10.1352/1934-9556-49.5.383

Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation.* San Francisco, CA: Jossey-Bass.

Milne, D. (2012). Olmstead, new freedom and real choice system change grants: Bringing the disability movement to older adults. *Generations*, *36*(1), 44-51.

Molinari, A. L., Gill, C. E., Taylor, H. M., & Charles, P. D. (2011). Barriers to conducting research with community-dwelling adults who have intellectual disabilities. *Intellectual and Developmental Disabilities, 49*(5), 392-396. doi:https://doi.org/10.1352/1934-9556-49.5.392

Needham, H., & Sands, N. (2010). Post seclusion debriefing: A core nursing intervention. *Perspectives in Psychiatric Care, 46*(3), 221-233. doi:10.1111/j.1744-6163.2010.00256.x.

Novak, A. A., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual disabilities. *Intellectual and Developmental Disabilities, 51*(5), 360-375. doi:https://doi.org/10.1352/1934-9556-51.5.360

Officer, A., & Groce, N. E. (2009). Key concepts in disability. *The Lancet, 374*(9704), 1795-1796. doi:10.1016/S0140-6736(09)62043-2

Ouellette-Kuntz, H., Burge, P., Brown, H. K., & Arsenault, E. (2010). Public attitudes towards intellectual disabilities as measured by the concept of social distance. *Journal of Applied Research in Intellectual Disabilities, 23*(2), 132-142. doi:10.1111/j.468-3148.2009.00514.x

Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative Research. *Perspectives in Clinical Research, 4*(3), 192. doi:10.4103/2229-3485.115389

Pietkiewicz, I., & Smith, J. A. (2012). A practical guide to using interpretative phenomenological analysis in qualitative research. *Psychological Journal, 18*(2), 363-369. doi:10.14691/CPPJ.20.1.7

Polit, D. F., & Beck, C. T. (2012). *Nursing Research: Generating and assessing evidence for nursing practice.* Philadelphia, PA: Lippincott Williams and Wilkins.

Power, A. (2013). Making space for belonging: Critical reflections on the implementation of personalized adult social care under the veil of meaningful inclusion. *Social Science and Medicine, 88,* 68-75. doi:10.1016/j.socscimed.2013.04.008.Epub

President's Committee for People with Intellectual Disabilities. (2016). Home page describing the committee, last modified 05/27/2016. Retrieved from http://www.acl.gov/programs/aidd/Programs/PCPID/

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., Zhang, D. (2010). Giving parents a voice: A qualitative study of challenges experienced by parents of children with disabilities. *Rehabilitation Psychology, 55*(2), 139-150. doi:10.1037/90019473

Rossetti, Z. S. (2011). "That's how we do it": Friendship work between high school students with and without autism or developmental disability. *Research and Practice for Persons with Severe Disabilities, 36(*1-2), 23-33. doi:10.2511/rpsd.36.1-2.23

Schleien, S. J., Miller, K. D., Walton, G., & Pruett, S. (2014). Parent perspectives of barriers to child participation in recreational activities. *Therapeutic Recreation*

Journal, 48(1), 61-73. Retrieved from https://js.sagamorepub.com/trj/article/view/3656

Seligman M. E. P. (2011). Helping American soldiers in time of war: Reply to comments on the comprehensive soldier fitness special issue. *The American Psychologist, 66(7),* 646-647. doi:10.1037/a0025156

Seligman, M., Steen, T., Park, N., & Peterson, C. (2005). Positive psychology progress: Empirical validation of interventions. *American Psychologist, 60*(5), 410-421. doi:10.1037/0003-066X.60.5.410

Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*(1), 5-14. doi:http://dx.doi.org.fgul.idm.oclc.org/10.1037/0003-066X.55.1.5

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2014). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities, 38,*18-29. doi:http://dx.doi.org/10.1016/j.ridd.2014.10.008

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27. doi:10.1080/17437199.2010.510659

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research.* London, U.K.: Sage.

doi:http://dx.doi.org/10.1037/0003-066X.55.1.5

Smith, J. A., & Osborn, M. (2008). Interpretative Phenomenological Analysis. In J. A. Smith, (Ed.) *Qualitative psychology: A practical guide to research methods.* London, U.K.: Sage.

Speraw, S. (2006). Spiritual experiences of parents and caregivers who have children with disabilities or special needs. *Issues in Mental Health Nursing, 27*(2), 213-230. doi:10.1080/01612840500436974

Stancliffe, R., Bigby, C., Balandin, S., Wilson, N. J., & Craig, D. (2012). Transition to retirement and participation in inclusive community groups using active mentoring: an outcomes evaluation with a matched comparison group. Manuscript submitted for publication. *Journal of Intellectual Disabilities.* doi:10.1111/jir.12174. Epub 2014 Dec 11.

Stigmar, K., Grahn, B., & Ekdahl, Ch. (2010). Work ability-experiences and perceptions among physicians. *Disability and Rehabilitation, 32*(21), 1780-1789. doi:10.3109/09638281003678309

Swango-Wilson, A. (2010). Systems and the development of sexual identity for individuals with intellectual/developmental disabilities. *Sexuality and Disability, 28*(3), 157-164. doi:http://dx.doi.org/10.1007/s11195-010-9167-3

Thomas, E., & Magilvy, J. K. (2013). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing, 16*(2), 151-155. doi:10.1111/j.1744-6155.2011.00283.x

U.S. Department of Health and Human Services. (2012). Healthy People 2020 disability and health summary of objectives. Retrieved from http://www.bealtbypeople.gov/2020/topicsobjectives2020/objectivelist.aspx?topicld=9

U.S. Department of Health and Social Services and Florida Departmental Disabilities Council. (2008). Your life, your way: Self-directed supports and services for individuals with developmental disabilities and their families. Tallahassee, FL: Author.

Walton, G. Schleien, S. J., Brake, L. R., Trovato, C., & Oakes, T. (2012). Photovoice: A collaborative methodology giving voice to underserved populations seeking community inclusion. *Therapeutic Recreation Journal, 46*(3)*,* 168-178. Retrieved from https://js.sagamorepub.com/trj/article/view/2797

Watson, D., & Nolan, Brian (2011). *Social portrait of people with disabilities in Ireland*. Dublin: Department of Social Protection and the Economic and Social Research Institute.

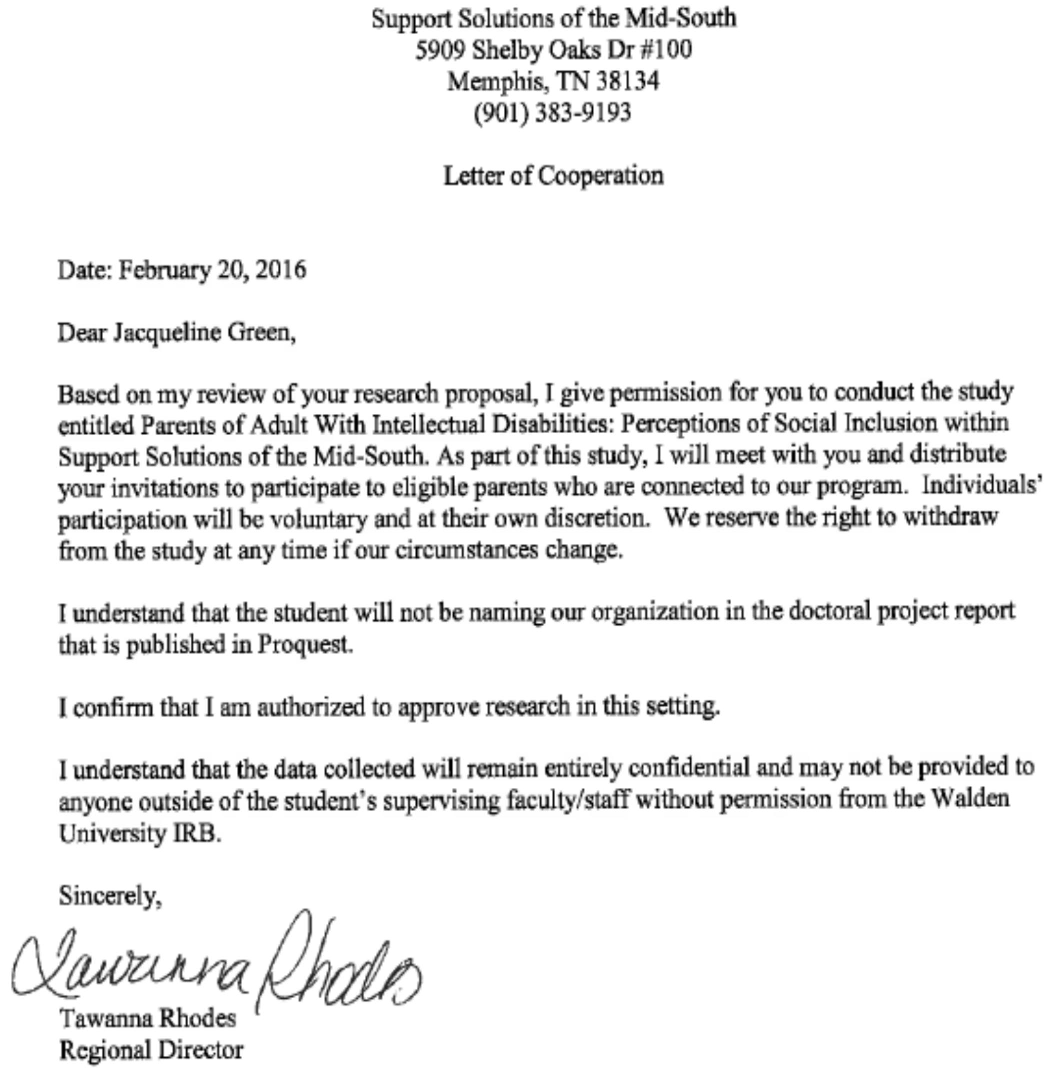
Westfall, R., (2010). Yukon Department of Health and Social Sciences. Bureau of Statistics 2010 (Microfiche). Whitehorse, Yukon, Canada: 2010: (Microlog 2011-03889).

Williamson, H. J. & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with U. S. services and supports. *Intellectual and Developmental Disabilities, 52*(2), 147-159.

doi:10.1352/1934-9556.52.2.147

Zuna, N. I., Brown, I., & Brown, R. I. (2014). Family quality of life in intellectual and developmental disabilities: A support-based framework. *International Public Health Journal, 6*(2), 161-184. Retrieved from http://search.proquest.com/docview/1625960329?accountid=14872

Appendix A: Letter of Cooperation, Signed



Support Solutions of the Mid-South
5909 Shelby Oaks Dr #100
Memphis, TN 38134
(901) 383-9193

Letter of Cooperation

Date: February 20, 2016

Dear Jacqueline Green,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Parents of Adult With Intellectual Disabilities: Perceptions of Social Inclusion within Support Solutions of the Mid-South. As part of this study, I will meet with you and distribute your invitations to participate to eligible parents who are connected to our program. Individuals' participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the student will not be naming our organization in the doctoral project report that is published in Proquest.

I confirm that I am authorized to approve research in this setting.

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

Sincerely,

Tawanna Rhodes

Tawanna Rhodes
Regional Director

Appendix B: Recruitment Flyer

Social Inclusion of Adults with Intellectual Disabilities

VOLUNTEERS NEEDED FOR RESEARCH STUDY

Walden University

Criteria:

Biological parents (mothers or fathers) of adults with intellectual disabilities at least 36 years old who are actively engaged in at least 2 community outings for the past six months with their adult child with intellectual disabilities

Adults with intellectual disabilities will be chosen from Support Solutions of the Mid-South in Shelby County, Tennessee.

Comfortable using the English language to do interview.

Involvement:

A single interview with me at an agreed upon neutral location (library or local community center-for 1 to 2 hours of your time).

Answer questions regarding your lived experiences of social inclusion of your adult child with intellectual disabilities.

The purpose of this study is to understand and describe the meaning of parents' lived experiences of social inclusion of adults with intellectual disabilities in their charge.

My aim for this study is to gain an understanding of how parents make meanings of their lived experiences of social inclusion of their adult child with intellectual disabilities.

As a participant, your participation will add to the few research studies by providing parents of adults with intellectual disabilities a platform for your voices to be heard. Participants will remain anonymous throughout the research process.

Biological Parents Mothers or Fathers of Adults with Intellectual Disabilities Needed

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

If you would like to participate I can be contacted at [phone number] or you can email me at [email address].
If you agree to participate in study you can withdraw at anytime.

Appendix C: Transcriptionist Confidentiality Agreement

Name of Signer: Mary Beth Haines

During the course of my activity in transcribing data for this research: “Parents of Adults with Intellectual Disabilities: Perceptions of Social Inclusion” I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

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

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

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

Signature: **Date:** 02/21/2017

Appendix D: Interview Protocol

Date: ___________________________

Location: ________________________

Name of Interviewer: ____

Name of Participant: ____

Assigned participant number: ____________________________

Script

Hi (use participants name). Thank you for agreeing to be a participant in my study. As we discussed via-email when you were invited to participate in my study, I am Jacqueline Green and I am attending Walden University as a doctoral student in the school of Educational Psychology. I am conducting research on what parents lived experiences of social inclusion mean to them and how they describe the meaning of social inclusion of adults with intellectual disabilities. 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 data collected will be locked in a file cabinet in my home office with me only having access for five years and then destroyed.

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 may be taking some notes and *checking the recorder periodically so everything you say is captured.*

1. How are you doing today?
2. I know you live in Shelby County, how long have you lived in Shelby County?
3. How many children do you have?
    a. Tell me more about them?
    b. Do you have boys or girls?
4. What do you and your adult child with intellectual disabilities like to do for fun?
    a. How do you feel when you and your adult child with intellectual disabilities are out having fun?
5. When you hear the term social inclusion, what does that mean to you?
6. What was the experience of social inclusion of your adult child?
    a. Tell me about some of the experiences of social inclusion that involved your adult child?
    b. How did that make you feel?
7. Please tell me about some positive social inclusion experiences of your adult child?
    a. Please give me some more examples of your positive experiences?
    b. How did that make you feel?
8. Please tell me about some challenges of your adult child with social inclusion?
    a. Please give me some more examples of your challenging experiences?
    b. How did that make you feel?

9. What changes have you seen in your relationship with your adult with intellectual disabilities since going on outings?
10. Please tell me about your best community experience of social inclusion of your adult child?
    a. How did that make you feel?
    b. Tell me what you were thinking?
11. Tell me about your worst community experience of social inclusion of your adult child with intellectual disabilities?
    a. How did that make you feel?
    b. Tell me, what you were thinking?

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.