2018

Well-Being Among Parents of Young Adults With Intellectual Disabilities When Transitioning From High School

Teshawnia Thompson
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Teshawnia Thompson

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Rhonda Bohs, Committee Chairperson, Psychology Faculty
Dr. Sandra Street, Committee Member, Psychology Faculty
Dr. Andrea Goldstein, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2018

Abstract

Well-Being Among Parents of Young Adults With Intellectual Disabilities When Transitioning From High School

by

Teshawnia Thompson

MS, Florida A&M University, 1998

BS, Florida A&M University, 1995

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
General Psychology – Educational Psychology

Walden University
May 2018

Abstract

Transition out of high school for young adults with intellectual disabilities (IDs) has been described as a stressful time for individuals and their families, with increased demands for caregiving and parental support. A lack of research is associated specifically with those individuals with moderate IDs and their parents' experiences of well-being during the transition process. The purpose of this phenomenological study was to understand how parents of young adult-aged children with moderate IDs experience well-being as their child transitions from high school to adulthood. Ryff's model of psychological well-being was used as the conceptual framework to better understand and explore the psychological well-being of parents as they navigate through the transition process. Eight parents from an urban Georgia school district were recruited through criterion sampling and participated in individual semistructured face-to-face interviews. Constant comparison analysis was used to analyze the data. There were 8 major themes that emerged from describing the lived experience of parents: (a) expectations and preparation, (b) experience with school, (c) accessing and coordinating services, (d) social support systems, (e) daily activities and planning, (f) life as an adjustment, (g) personal growth, and (h) looking toward the future. School districts and adult service providers may gain insight from parent perspectives to help alleviate rather than exacerbate the challenges parents face during the transition process, which would contribute to the parents' psychological well-being.

Well-Being Among Parents of Young Adults With Intellectual Disabilities When Transitioning From High School

by

Teshawnia L. Thompson

MS, Florida A&M University, 1998

BS, Florida A&M University, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

General Psychology- Educational Psychology

Walden University

May 2018

Dedication

I would like to dedicate this work to my parents, Joseph and Jessie Mae Thompson, for being such inspirational figures in my life, as well as to my daughter Khai. They represent both my past and my future. I admire my parents so much for their love, perseverance, and commitment to our family and their legacy. My parents started off with very little material possessions, but they at their core valued God, relationships, and a strong work ethic. They went on to raise 16 amazing children who in turn internalized those same values. They always wanted us to have a better life and become productive members of the community. I thank God for placing me in this family and giving me the wisdom and strength to pursue this passion and destiny I was created for. I know that my parents are looking down on me and are proud of what I've accomplished. To Khai, I encourage you to never stop learning, make a positive impact on your community, and to never forget who you are. God has given you so many gifts and talents to use to help make this world a better place and most of to contribute to positive social change. I love you more than you will ever know!

Acknowledgments

I want to take this time to say thank you to Carlton Dickey, my husband, who has encouraged, inspired, loved, and tolerated me throughout this journey. He was the one who continued to push me to pursue my dream, even when I didn’t think I could do it. Without his love and support, I could not have made it through this process. I want to acknowledge my daughters Khai and Candice. They were there with me every step of the way. They cheered me on and celebrated my victories, but also motivated me to keep moving forward when times got rough. I would also like to thank my sisters and nieces who are always there to offer their love and support, they truly are my rock. Alice, Amelia, and Becky, my sister friends, you just don’t know how valuable your friendship has been. To Brandon Cockrell who challenged me to dream big and chase lions, thank you for your words of encouragement and prayers.

Additionally, I would like to thank Dr. Rhonda Bohs, Dr. Sandra Street, and Dr. Andrea Goldstein for serving on my committee and your commitment to the work I’ve done. Dr. Bohs, as my committee chair, you have been so supportive and always provided me with timely and relevant perspectives that challenged me to dig a little deeper.

My deepest and most sincere appreciation to all of the participants who volunteered and gave of their time in order to assist me with this study. Their willingness to invite me into their lives and share their personal experiences goes far beyond what I expected. I appreciate and value all that you added to my work because without you, it would not have been possible.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

The definition of *intellectual disability* (*ID*) has evolved to reflect the legal and social gains made by individuals with such a disability and their families. The changes reflect the movement from institutionalization to inclusive practices, self-advocacy, and self-determination (ASHA). A point of interest in this evolving definition is not only the effects on the individual with ID, but also to their families. In addition to the stigmatizing effects placed on the individual and their families, ID involves the consumption of large public health resources (Maulik, Mascarenthas, Mathers, Dua, & Saxena, 2011).

The cost of ID to the society in the form of additional resources to provide adequate services is significant. Estimates from the United States suggests that the lifetime cost of ID for persons born in the year 2000 will be 51.2 billion (Honeycutt, Dunlap, Chen, al Homsi, & Schendel, 2004). Much of the cost associated to providing care to an individual with ID transitioning from free school-based services to adult services falls on the parent. However, it is paramount to realize that much of the expenses associated with being a caregiver cannot be represented in a dollar amount. For a child with an ID, the burden of care generally falls on the parents to serve as an informal caregiver, a job for which they are not afforded any compensation. Physical effort, combined with lack of support, sleep, and limited to no medical knowledge can often place the health of the caregiver at risk and significantly affect their psychological well-being. The health of caregivers was identified by the U.S. government as an objective in the Healthy People 2020 initiative (U.S. Department of Health and Human Services, 2010). This further supports the notion that the well-being of caregivers is in fact a social problem warranting further investigating.

For parents of children with ID, their dedication to care for their child can often result in unique challenges extending beyond those strictly related to finances and extend to their social, emotional, physical, and psychological well-being. The period in a child's development when they transition from adolescence to adulthood can prove to be a test of their parent's dedication and commitment to their child. In a study conducted by Faw and Leustek (2015), parents raising a child with a disability identified transition to adulthood as one of the seven major challenges they faced. The parents further reported that it was difficult to make plans and structure their life when they were so uncertain about their child's future as well as their capacity to manage it. All adolescents with IDs as well as those without disabilities will inevitably experience the transition to adulthood. For both groups, this period has been depicted as a time of critical development and change, which includes lots of uncertainty and challenges (Blacher, 2001). There are several hallmarks of this transition to adulthood, which begin with graduation from high school and put into motion the decision-making process to determine what's next in life: will they will attend college or any type of postsecondary education or enter into the workforce? This is a time that can be exciting for the young person and their families as they experience this milestone in their lives. However, for the individual with an ID and their families this period represents an even more critical and monumental stage in their lives. They are faced with more obstacles and fewer choices. They are at a point where they will undergo a shift that will alter school-based services and support they have had provided to them and guaranteed to a system of adult services where eligibility and availability are not certain. The Individuals with Disabilities Education Act of 2004 (IDEA) mandated that all individuals with disabilities are entitled to a free appropriate public education up until the age of 21 years that will meet their unique needs and prepare them for further education, employment, and independent living. The problem arises, however, once these young adults exit the school system and are no longer provided with the entitlements that are guaranteed within the confines of the school setting and are faced with securing adult services that are based on eligibility and availability.

The transition to adulthood for typical adolescents is often characterized by evolving expectations of their future roles in the areas of educational preferences, work choices, living experiences, relationships, and ideas pertaining to marriage and family (Hogan & Astone, 1986). However, given the limited cognitive aptitude of individuals with moderate ID, they may not have the capacity to develop realistic expectations for their future. This task then falls back on the parent. The data regarding future postsecondary choices for individuals with ID point out that these young adults are less likely than youth with other disabilities to be engaged in school, work, or preparation for work during the early post school years (Newman et al., 2009).

Caregiving inevitably challenges the health of caregivers in a significant and holistic way; it affects their everyday living, it compromises their ability to make choices, it constrains their ability to gain satisfaction from living, and it ultimately affects their psychological well-being. There are also positive benefits to providing care for an adult aged child with an ID. The caregiving experience is one that is life changing and consuming. The parent's ability to identify and negotiate postsecondary adult and community services, advocate for their child, and their level of participation in the transition process greatly influence whether the child will have access to the services they need once they exit high school. This is why parents' voices must be heard. They know their child and their child's needs better than any other member serving on the transition committee and are committed to providing lifelong support and care for their child.

As a result of this study, I hope that caregivers or parents will gain a more in-depth awareness of both the positive and negative benefits and outcomes experienced by other parents during the transition process, which has been regarded as a period filled with growing responsibility and increased levels of stress provoking experiences. By exposing the perspectives of the parents, school personnel, policy makers, and community support service providers stand to gain relevant insight that may assist them in facilitating a smoother transition for parents while navigating through this crucial period of their child's development and growth. In addition, things that can be done in preparation of this transitional time to help make it a more positive experience.

In this chapter, I will include background information on ID, including the problem statement and the purpose of the study. The research questions will also be provided as well as an overview of the conceptual framework, definitions, assumptions, scope and delimitations. Finally, the significance of the study and its potential implication for social change will be discussed.

Background

A long history exists of the support parents that have played in the lives of their children with IDs. Parents have been called upon to act in the role of primary caregiver for their children with ID as they transition into a period referred to as adulthood that, for these individuals, spans beyond what is typically considered as reaching the legal chronological age of majority. The transition from school-based (children's) services to adult services has been identified as a time that is multifaceted and full of challenges for both the parent and the child (Plinick, Clegg, Murphy, & Almack, 2011). For parents of children without disabilities, the transition from high school to adulthood is suggestive of a period where they are able to take a less hands-on approach and have more free time that is less centered on acting in the caregiving role for their young adult child. However, parents of children with ID may experience the opposite. Parental control and involvement is expected to diminish during this period, when in fact for the parents of young adults with ID, there tends to be a shift toward an increased dependence on resources provided by parents. Dyke, Bourke, Llewellyn, and Leonard (2013) described the transition to adulthood as crucial because of the shift from being thought of as a child with reinforced security and protection to the independent and autonomous life of an adult. U.S. society emphasizes successful adult roles as those related to employment, postsecondary education, independent living, relationships, and a sense of independence.

For individuals with ID, federal legislation provided through the Individuals with Disabilities Education Act (IDEA) mandates certain parameters be put into place to provide individuals with disabilities the same opportunities to realize those same adult roles with support. According to IDEA 2004, based on the child's needs, a coordinated set of activities and transition services should be put into place no later than the age of 16 years that will facilitate the movement from school to postsecondary education, employment, adult services, independent living, or community participation (IDEA, 2004) It affords the young adult with the opportunity to remain in school until they reach the age of 21 years to increase the likelihood that they exit high school with the skills necessary to make a successful transition.

Even with this extended amount of time provided for the young adult with ID to receive school based services and support, many individuals with moderate ID are not prepared to live independently. They continue to live at home well into adulthood and require a substantial amount of support from their parents (Braddock et al., 2013; Williamson & Perkins, 2014). Based on the results of the National Longitudinal Transition Study – 2 (NLTS$_2$), 97% of individual with moderate/severe ID were living dependently at home after transitioning from high school. This is important because once the child leaves school, they are also leaving behind the certainty of full-time caring that was available during school hours, leading to an increased responsibility and potentially decreased freedom for parents of young people who may need constant supervision. Parents in a study conducted by Raperno, Bartu, and Lee (2008) reported that they at times felt resentment toward parents of children without disabilities because of the loss of freedom and independence they felt during their own child's transition to adulthood. They recounted experiencing a greater amount of emotional and mental energy than they were used to in the past on trying to identify and acquire services and trying to promote positive experiences for their young adult. This transition to adulthood for young adults with ID is characterized with termination of access to guaranteed school services at one end of the spectrum whereas on the other end, eligibility criteria for adult services are based on availability, funding, and limited resources.

An extensive amount of literature highlights both the challenges and positive benefits associated with parental caregiving for young adults with ID. In a qualitative study conducted by Chadwick et.al. (2012), they examined what it is like for families who have a member with an ID. From their research, they identified four prevailing themes that parents identified as significant: family well-being, support and advocacy, communication and accessing information, and attitudes and governance. With regard to family well-being, parents in this study reported that the inconsistency in their lives and the challenges they faced during transition presented as the central theme that yielded the greatest concern. They also mentioned feelings of happiness, joy, pride, and inspiration they gained from their family member with ID. Another qualitative study conducted by Dyke et, al. (2001) of mothers of young adults with ID transitioning from secondary school to adult life. The key themes that emerged were similar and included: anxiety of leaving the school environment, the timing of the transition with the loss of other informal supports, and concerns related to potential consequence on the mother's ability to continue to work. The parents also reported on the positive influence and life satisfaction they had experienced.

Gallagher, Phillips, Oliver, and Carroll (2008) explored predictors of psychological morbidity in parents of children with ID. Caregiver burden presented as the strongest predictor of psychological morbidity, which led to substantial symptoms of depression and anxiety for parents caring for children with ID versus those of typical developing children. They posited caregiver burden is a broad concept; however they identified three essential components: negative social and personal consequences, psychological burden, and guilt. Feelings of guilt was identified as the most consistent and strongest predictor of caregiver burden. Bhatia, Bhatia, Gautam, Saha, and Kaur (2015) conducted a similar study and concluded with similar findings which suggests that caregivers of people with IDs perceived a significant burden and suffered psychiatric morbidities in the form of depressive symptoms and anxiety disorders with burden of care being the most important factor responsible. In a more current study, Gray et, al. (2014) reported that 25% of the parent participants caring for their young adult child with ID in the home reported fair to poor physical health, and elevated mental problems, including anxiety and depressive symptomatology, and feelings of social isolation, which is consistent with the study conducted by Gallagher et al. 2008. They concluded that the development of anxiety and depression in parents was a related to possible parental concerns of what the future holds for their child. Although the parents identified the aforementioned factors as problematic, they did not identify caring for their child as a burden.

In contrast, Seltzer, Floyd, Song, Greenberg, and Hong (2011) conducted a study examining the implication of lifelong parenting an adult with intellectual and developmental disabilities. They found that in terms of attainment, social participation, psychological functioning and health there was no difference in midlife parents of a child with ID than their peers without a child with ID. However, parents living with their adult child with ID for a long term displayed lower levels of psychological functioning only after the parents reached the early years of old age. The parents experienced elevated rates of depressive symptoms, poorer physical health, and functional impairments in comparison with their peers who did not have a child with ID. This suggests that as parents get older they may begin to struggle with who will provide care for their child given limitations set forth by their age and diminishing health status, which may open them up to become more vulnerable to feelings of depression that were not problematic in midlife. This is significant because as people with IDs are living longer, their family members continue to act in the capacity as the principle care providers (Factor, Heller, & Janicki, 2012; Williamson & Perkins, 2014). Although this does not pertain specifically to the period of transition from school to adulthood, it does shed light on the lasting consequences of decisions that are made and services that are put into place at the time of the transition that serve to prepare the young adult for postsecondary options and the support that is rendered to the parent to assist with providing care to their loved one.

Rapanaro, Bartu, and Lee (2008) and Willigham-Storr (2014), stressed the importance of not only providing support for the individual with an ID, but to the parent as well. Although the authors did identify that parents experience negative aspects of burden, they highlighted the implications for positive outcomes over those which focused solely on negative effects. They indicated the need for support and services for the parent caregiver as well as their young adult aged child. The authors found that parents in their study who serve as care giver for their child with an ID reported they experienced strain in other areas, which lead to conflicts in the family, feelings of being exhausted, stressed, overwhelmed, and fearful about the future. On the other hand, the same parents indicated that given the role of caregiver they have been able to feel a sense of empowerment and fulfillment. The effect on the family, their ability to cope, access to supports and service networks, and the transition process were identified by the parents as dynamics that provoked the greatest amount of stress when reflecting back on raising a child with an ID. These parents identified varying levels of limitations and strengths as factors that influenced the family's response to and ability to cope with their family member with an ID. These four areas are similar to those that I examined in the current study.

According to Williamson and Perkins (2014), the complexity of the U.S. disability service system makes measuring family caregiver outcomes on a national level a complicated endeavor. The health and well-being of family caregivers is critical in supporting the existing system of care in the United States and will only become more critical with the aging of the population in the years to come (Talley & Crews, 2007). In this study, I addressed a gap in the literature by focusing specifically on parents of individuals with a moderate ID versus referring to the global category of ID during the specific developmental period of transition into adulthood as they exit high school.

Understanding and responding to the needs of family caregivers is a public health issue, and therefore it has been strongly advocated that additional funding should go to support caregiver resources (Collins & Swartz, 2011; Talley and Crews, 2007). Understanding the experiences of parents, including what factors influence their well-being, is essential for the development of meaningful and effective intervention, services, and supports. The well-being of the child can be linked to the parent's well-being, which gives more justification of the importance of gaining the parent's perspective of their experiences.

Problem Statement

According to the 2015 Caregiving in the U.S. study, caregivers provide support for their spouses or aging family member who experience prolonged illness for an average of 4 years. In contrast, parents of a child with an ID are tasked with a permanent responsibility of caregiving that has the likelihood to become a lifelong occupation (Haley & Perkins, 2004; Kim, Greenberg, Seltzer, & Krauss, 2003). Because of the increased life expectancy of individuals with IDs, caregivers are confronted with more challenges and responsibilities extending throughout the course of the lifespan which may affect their well-being. In previous research, it was found that mothers of children with IDs were at a higher risk of poor well-being than other parents (Kim et al., 2003; Norlin & Broberg, 2013; Olsson & Hwang, 2001). Of considerable interest of this study is the period in which an individual with an ID transitions into adulthood.

Purpose of the Study

The purpose of this phenomenological study was to understand how parents of young adult aged children with moderate IDs experience well-being as their child transitions from high school to adulthood. It is essential to explore the lived experiences of parents of young adult aged children with moderate ID as their child transitions from high school to adulthood, because it can offer pertinent information that is needed about how parents view themselves given the benefits and challenges associated with this period, how their lives have been adjusted due to the transition, and how those lived experiences may or may not have shaped their attitudes and beliefs about their life's purpose and attainment of that purpose.

Research Questions

The central research question (RQ) I explored for this study was:

RQ1: What is the lived experience of well-being in parents of adult aged children with moderate IDs as their child transitions from high school to adulthood?

Secondary research questions (SRQs) were as follows:

SRQ2: How do parents describe their purpose in life and attainment of that purpose given the responsibility for the caregiving of their adult aged child with an ID after the transition from high school?

SRQ3: How has the experience of transition contributed to the participants' views about themselves in light of the challenges and benefits faced during the transition period?

Conceptual Framework

I used Ryff's (1989) model of psychological well-being as the basis of this research study. Ryff's model of psychological well-being affirms that well-being is a concept that involves perceived thriving in the face of existing challenges of life. According to Ryff (2014), the concept of well-being must incorporate meaning-making, self-realizing, and the striving aspect of being human. Acting as caregiver for an adult age child with an ID has been depicted in the literature as a being a stressful and challenging period for parents as well as the child. Parents are faced with balancing both burden and benefits of caring for their child. Caregivers describe their experiences as multi-faceted, ranging from joyful and rewarding to sorrowful and challenging. Positive aspects to caregiving have been reported such as feelings of fulfilment, satisfaction, and knowing their loved ones are happier at home. Sometimes the enormity of the task maybe overshadowed by the day-to-day tasks that weigh heavily on their physical, emotional, spiritual, social, economic, and psychological well-being. How parents perceive this transition given the challenges and benefits associated with this stage of their life can contribute to how they internalize their true potential and establish the direction of and make meaning of their lives. When parents come to embrace the notion that we are all adults actively engaged in negotiating the challenges of life to maintain or regain well-being in the face of adversity, it may serve to reduce or alleviate the stress that comes from parenting an adult child with a moderate ID transitioning from school to adult services.

Ryff's model of psychological well-being is appropriate for capturing the core lived experiences of these parents because they summarized the study's purpose, meaning, and significance. I will discuss Ryff's model of psychological well-being fully in Chapter 2.

Nature of the Study

I used qualitative inquiry for this study, specifically an interpretive phenomenological approach as a means to capture the lived experience of well-being in parents with an adult aged child with ID transitioning from high school to adulthood.

Interpretive phenomenology was an appropriate method of inquiry because it sought to embody the essence of a particular experience by examining the meanings that the individuals assigned to it. According to Smith, Flowers, and Larkin (2009), IPA is committed to examining the way people interpret major life experiences by gaining their personal perspectives, specifically, what happens when the daily routines become an experience that's regarded as important as the individual reflects on its significance while trying to make sense of it. Transition from high school to adulthood could be viewed as a naturally occurring event that is considered somewhat as a rites of passage that every parent will eventually face. However, I was concerned with how this process takes on a particular meaning for parents with adult age children with ID as they experience this period of transition.

I conducted in-depth interviews with the parent caregiver participants. An interview guide served as an agenda to confirm that all participants receive the same general lines of inquiry. I asked all participants the same questions in the individual face-to-face interviews. I also used member checking by conducting follow-up interviews. This allowed me an opportunity to confirm whether the data provided accurately reflected the views that were expressed by participants.

I analyzed the data by first providing a qualitative summary by transcribing any field notes and audio recordings. Next, I employed the method of constant comparison. Constant comparison includes a cycle of coding, comparing, analyzing, and reflecting. I initially cycled through the data to first identify initial patterns or key word and then moved on to phrases. According to Sandelowski (2000) given qualitative research, the process of data collection is considered interactive and reflexive given the fact that researchers are constantly adjusting the way they view data to integrate additional data and new understandings about those data. A more in-depth description of methodology is in Chapter 3.

Definitions

For this study, the following definitions were used.

Informal Caregiver: Any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care. For this study, caregiver refers to the parent of a child with a moderate ID.

Moderate ID: Intellectual functioning ranging from an upper limit of approximately 55 to a lower limit of approximately 40; and deficits in adaptive behavior that significantly limit a child's effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility, and especially school performance that is expected of the individual's age-level and cultural group as determined by clinical judgement (Georgia Department of Education, nd).

Transition Services: The term "transition services" means a coordinated set of activities for a child with a disability that: is designed to be within a results oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities including postsecondary education, vocational education, integrated employment (including supported employment); continuing adult service, independent living, or community participation, is based on the individual child's need, taking into account the child's strengths, preferences, and interests: and includes instruction, related services, community experiences, the development of employment and other post-school adult living and functional vocational evaluation (US Department of Education, nd.).

Assumptions

Several assumptions were made going into this study. It was assumed that each research participant will provide honest and accurate responses to the questions posed to them based on their individual experiences. Additional assumptions made for this study included: the parent accurately reported their child's eligibility of moderate intellectual disability (MOID), the parent participating in the study was the primary caregiver for their child, and that the child lives in the home with the parent.

Scope and Delimitations

The focus of the study included a purposive sample of eight parents of a child with a moderate ID as their primary disability who has transitioned from a Georgia high school to adulthood within the past 3 years. Transition from high school to adult services can present as a very difficult challenge for an individual with limited intellectual capacity. Opportunities for educational, social, community involvement, and work experience were provided by the schools system, however no longer are available once the student exits the educational system. Therefore, much of the responsibility for providing caregiving and post-secondary services and supports rests with the parent. Parents were chosen because how they perceive the transition period and experience psychological well-being can provide information on the challenges and benefits that are associated with this transitional period of life for an adult aged child with a moderate ID as they navigate through this next stage of life.

Interviews were utilized to gain deep and rich descriptions of the participants lived experiences relating to psychological well-being while navigating through the transition process through the use of semi-structured face-to-face interviews. The interviews were audio recorded with the participants' permission. This was followed by data analysis and coding. One of the delimitations of this study includes the use of a small population.

Limitations

A limitation to this phenomenological study was the use of a small sample that was purposefully selected from within the same region. The methodology research justifies the appropriateness of the use of criterion sampling as the sampling strategy. However, the fact that the all participants are from the same geographical region, the range and availability of transition opportunities and adult service options for individuals with moderate ID and their parents may be specific to that area. Therefore, the results may be less informative to parents outside of this region given the range of service options that are accessible based on what is offered in their specific location because the range can vary greatly between states and even from school district to school district. Variations in services and supports may limit the individual and contextual factors that may influence the parent's perspective and contribute to their personal experience of well-being during the transition period.

An additional limitation included the potential for researcher bias. In phenomenological research, the researcher is the primary instrument. In this research study I was tasked with the exclusive responsibility for collecting and analyzing the data. According to McCaslin and Scott (2003), because we are human, there are innate biases and assumptions that may negatively affect our ability as a researcher to detect data even though it exists. I have served as a professional working with students with IDs in the process of evaluating and formulating Individual Education Plans. Therefore, this increased the potential for researcher bias. To reduce this bias, I kept a self-reflective journal. Reflexivity provides an opportunity for the researcher to understand how his or her own experiences and understandings of the world affect the research process. (Morrow, 2005). Furthermore, Moustakas (1994) suggested that the researcher must set aside prejudgments which then frees them to be present and receptive so they may engage in an unbiased research. By acknowledging and bracketing my biases, using a reflective journal, member checks, and providing in-depth rich descriptions, this helped to ensure that my past experiences did not interfere with data collection and analysis and assisted with reducing possible researcher bias.

The final limitation was that the participants were asked to accurately recall information that occurred one to three years ago. This suggests that taking into account the processes of time and memory the information reported may be somewhat distorted or incomplete. The potential for recall bias could play a role in how they report the information. Recall bias is often more related to case-control or cross sectional studies, however given the time lapse, the participants' accuracy of recall regarding their prior experiences may be a factor in how they respond to the questions they are being presented to them. In an effort to reduce recall bias, I provided the participants with an adequate amount of time to think through and reflect back on their experiences before answering the questions that were presented to them (E. Hassan, 2005).

Significance

The experiences and opinions of families providing care for their caring offspring with IDs is an area that has been previously studied. There is extensive literature that addresses this concept. Nevertheless, there have not been in-depth studies documenting the opinions and experiences of those families providing care for their young adult aged child with moderate IDs as they make the shift from high school and transition into adulthood. Due to the fact that longer life expectancies have been reported for persons with IDs, families are placed in a position where they are tasked with continuing to serve as the primary care giver for these individuals even after they exit high school and transition into young adulthood. This gives greater credence to the importance of soliciting the parent’s perspectives because they will most likely have a major influence on what decisions are going to be made regarding the transition process. According to Braddock et al., (2013), 71% of individuals identified as having an ID, as of 2011, resided with a family member who provided care for them. Additionally, the NLS-2, provided data that further supported that individuals with IDs had a greater chance of relying solely on their families, without taking on normative adult roles. The study was significant because the results of this study provided an additional understanding of how parents of young adult children with IDs continue to care for and provide support to their child even after the extinguishing of those guaranteed services implemented in the public school setting have been exhausted. The need for subsequent quantitative research was implicated based on the patterns and themes that were brought to the forefront by parent caregivers in this study. These potential patterns and themes may also serve to enlighten policy makers, school personnel, and community service providers who develop and implement services on specific areas of need that might be beneficial to and serve to support family careers. Although primary careers and families alike possess varying levels of coping styles, strength, and limit, a large number continue to report they do not believe they are adequately equipped with suitable options for resources and support to meet their child's needs (Willingham-Storr, 2014). By better understanding and appreciating how parents cope with providing continued care for their children with a moderate ID will contribute to the body of existing knowledge and can be directed towards practical implications as well.

Summary

This chapter provided the reader with an introduction to the major issues involved in parenting an adult aged child with a moderate ID as they transition from high school to adulthood and the lack of research on how parents experience well-being during this critical transition period for both the parent and the child. The purpose of this phenomenological study was to understand the lived experiences of parents during their child with a moderate disability transition from high school to adulthood. The central research questions identified for this study to assist with better understanding the lived experiences of the parents included: What is the lived experience of well-being in parents of adult aged children with moderate IDs as their child transitions form high school to adulthood?, How do parents describe their purples in life and attainment of that purpose given the responsibility for the caregiving of their child with an ID after their transition from high school, and finally, How has the experience of transition contributed to the participants' views about themselves in the light of the challenges and benefits faced during the transition period? The significance of this study was to better understand how parents cope with continued care for their children with IDs and the practical implications it could possibly add to the field of educational psychology.

Chapter 2 examines the literature that is relevant to caregiving, provides a historical overview of the transition process, and defines characteristics of moderate ID and how these factors pertain to parental psychological well-being. Furthermore, perceived benefits and burden as provided in the literature is explored.

Chapter 2: Literature Review

Introduction

The purpose of this phenomenological study was to understand how parents of young adult aged children with moderate IDs experience well-being as their child transitions from high school to adulthood. My focus was on the identification of specific challenges and positive factors parents attribute as beneficial in assisting them to strive when navigating through this transitional stage of their child's life and how they contribute to well-being.

In this chapter, I present a review of the literature that contributes to the understanding of the phenomena of psychological well-being. In addition, I review the definition and characteristics of ID and a historical overview of the transition process including the role of the parent, and existing research that provides pertinent data related to the research questions that supports the need for further exploration of the phenomena of well-being during the transition process. The National Alliance of Caregiving and AARP (1997) reported that caregivers provide support for their spouses or aging family member who experience prolonged illness for an average of 4.5 years. In contrast, parents of a child with an ID are tasked with a permanent responsibility of caregiving that has the likelihood to become a lifelong occupation (Haley & Perkins, 2004; Kim et al., 2003). Because of the increased life expectancy of individuals with IDs, caregivers are confronted with more challenges and responsibilities extending throughout the course of the lifespan which may affect their well-being. In previous research, it was found that mothers of children with IDs were at a higher risk of poor well-being than other parents

(Kim et al., 2003; Norlin & Broberg, 2013; Olsson & Hwang, 2001). Of considerable interest of this study is the period in which an individual with an ID transitions into adulthood. Transition from high school to adulthood is a long-standing social issue. First addressed at the federal level through the reauthorization of the Individuals with Disabilities Education Act (IDEA) of 1990. This legislation mandated that school systems begin to prepare students with disabilities for transition to adulthood starting no later than the age of 16 years.

Henniger and Taylor (2014) pointed out that the perspectives of families of individuals with IDs will play a significant role in establishing a true definition of what the transition into young adulthood means and will play a germane role in guiding future practice and research in the field. Additionally, Pilnick, Clegg, Murphy, and Almack (2011) posited that families as well as the individual with IDs have to sustain the separation from the school setting where they were once provided with consistent social networks and outlets as well as predictable and mandated care to adulthood, where there are no assurances for the quality or quantity of services that will be offered. This transition process can be characterized by the amplification of burden and a sense of diminished freedom for parents who have become dependent on the supervision provided within the constraints of the public school system, which they will no longer have access to due to the inevitable transition process. Dyke et al. (2013) reiterated that as a result of the complete change that may occur within the family dynamics during this crucial time of transition when the formal and informal services delivered by the school system cease, and how caregivers adjust, warrants further study. It is essential that the stories of caregivers pertaining to the adjustments and flexibility required during the transition to postsecondary opportunities be shared because they are the ones who serve diligently to ensure that their child obtain the most optimal outcomes (Dyke et al., 2013). It was further reported by Bayen et al., (2015) that the multifaceted burden process and the accompanying needs of informal caregivers must be placed on high priority if there are hopes of gaining a better understanding of their experiences that will essentially assist with supporting their continued dedication to their sons and daughters and offering them adequate intervention programs.

A lack of literature exists on the experience of well-being in the lives of parents who provide long-term care for their adult children with disabilities. Many studies stress challenges and negative outcomes; however, well-being is an area that is underrepresented in the literature and deserves greater attention in future research (Blacher, Neece, & Paczkowski, 2005; Resch et al., 2010). Furthermore, Neece, Kraemer, and Blacher (2009) suggested that there is limited empirical research on families during the transition period and additional work must continue to examine the implications of young adult transition outcomes for family well-being.

Gaining a better understanding of the experiences of parents, including what experiences influence their well-being and how they strive in the presence of these challenges may prove beneficial in identifying aids and interventions to alleviate burden and identify benefits which may contribute to the overall well-being experienced by parents.

Literature Search Strategy

According to Randolph (2009) electronic searches result in the identification of approximately ten percent of scholarly articles that encompass an exhaustive review and recommends that by examining the references of the selected articles, the researcher is then able to identify any additional research that may be applicable. The following databases were used to locate a varied array of literature on the transition of individuals with moderate IDs from high school to adult services and their parent's experiences of psychological well-being: PsycARTICLES, PsychINFO, PsychBOOKS, PSycEXTRA, Google Scholar, ERIC-Educational Resource Information Centre, ProQuest, SAGE, and Therou. Terms that I used in this search included *intellectual disability, parenting, transitions, psychological well-being, special education, adult, adolescent, adult services, post-secondary, caregivers of adults with disabilities, and transition to adulthood.* These keywords were used independently and grouped together using 'AND' as the Boolean operator. Although the term mental retardation is no longer deemed appropriate, it was included in the search using ID and the Boolean operator 'OR' mental retardation. The search was extended using the Cumulative Index of Nursing and Allied Health Literature (CINAHL) because several of the results for caregiving resulted in articles related to nursing and gerontology. The search was further narrowed by using the publication dates of 2010 to 2016 as an inclusion criteria.

Results of the search yielded limited information pertaining specifically to moderate IDs and parental perspectives of the transition process. Most of the literature examined ID as an exhaustive category. It was even suggested that taking into consideration the severity level of the ID would serve to better understand some of the complexities and differences in the experiences of those transitioning to adult services. It was also noted that much of the research related to parenting, IDs, and transition was based on qualitative studies conducted outside of the US. Given these gaps and deficiencies in the literature, the need for additional research concerning the lived experience of well-being in parents of adult aged youth with an ID transitioning from school based to adult services is warranted.

Conceptual Framework

There is a wealth of literature on psychological well-being, however the problem lies in the fact that there is not much consistency in the way that it has been defined. Well-being is a multifaceted concept. In my literature review I found that in some cases well-being is measured in terms of an individual's perception of levels of stress or negative influence (Crnic, Friedrich, & Greenberg, 1983), depression (Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997: Kobe & Hammer, 1994), and caregiver burden (Gallagher et al., 2008). For the purpose of this study Ryff's model of psychological well-being was utilized. The notion of psychological well-being as defined by Ryff's (1989) model is depicted as the perceived notion of thriving while being faced with challenges that arise in life. There are six characteristics that she attributed to this model, which are as follows: evaluating one's self and one's past in a positive light (self-acceptance), a desire for personal development and continual personal growth (environmental mastery), believing that your life has meaning and a purpose (purpose in life), establishing meaningful relations with others (positive relations with others), effectively managing your life and the world surrounding you (personal growth), and a sense of self-determination (autonomy). This model of well-being is grounded in the eudaimonic perspective, which asserts the fact that human potential, self-determination, and personal growth are the cornerstones to well-being versus a hedonic approach which is more concerned with being happy, life satisfaction and the balance of positive and negative emotions (Huppert, Abbott, Ploubidis, Richards, & Kuh, 2010).

Psychological well-being has been related to various family roles, transitions, and unforeseen (non-traditional) family events (Ryff, 2013). Greenfield and Marks (2006) found that parent's well-being was linked with how their child fared in life. It was found that well-being was compromised in the parents of children who experienced more challenges. Parents of young adults with moderate ID transitioning from high school to adulthood do indeed face many challenges. Issues that may arise as a result of termination of services in the public school system could be viewed as problematic if the parent is faced with difficulty acquiring adult services. The task at hand then becomes trying to balance the benefits in addition to the burdens that are associated with providing care for their child. As a result of this challenge, careers can find themselves in a situation where they begin to not only question themselves, but also their capacity to parent. Ryff's model of psychological well-being was used to frame how parents perceive and adjust to the benefits and burdens of caregiving during a specific period (transition) that is depicted as being stressful and challenging in the literature. Is it then possible for caregivers to experience psychological well-being, while at the same time dealing with challenges that are associated with transition? Ryff's model of well-being goes beyond a feeling of happiness in the moment and seeks to explore psychological well-being as a construct that is evolving despite the perceived burden caregivers might identify. Thus, the focus is more on how these challenges may be used to augment well-being and contribute to caregiver satisfaction which could ultimately lead to an enhanced sense of fulfilment and accomplishment.

Ryff and Singer (2006) went on further to point out two distinct features of psychological well-being. The first suggests that well-being, interpreted as growth and self-actualization, is strongly shaped by the environmental circumstances that are experienced in individual's lives. This implies that the chances for self-realization are not dispersed equally. The second feature is that eudaimonic well-being may have significance for health in that it promotes operative regulation of multiple biological systems. These two distinct features are important to note, because although the participants comprised in this research study are homogeneous in the sense that they are all parents of adult age children with ID transitioning from high school to adulthood, their individual circumstances, environments, resources, and perceptions may widely vary. This further supports the need and importance of hearing the parent's individual stories of their unique experience during this period of transition. The negative affect on health has been widely reported as one of the consequences of providing care for adults with disabilities. If it is possible to identify patterns that lead to an increase in psychological well-being based on the reported lived experiences of the parents in the study, consequently, there may also be an opportunity to influence the overall health of these caregivers.

In a comparative study of parental and family well-being in children with Down Syndrome, Van Riper, Ryff, and Pridham (1992) explored each of the six characteristics of psychological well-being. This is not to say that the results of this study will be generalizable to parents of children with ID, but there may be some similarities. They initially predicted that the parents would experience lower functioning on measures of autonomy, environmental mastery, personal growth and self-acceptance and higher functioning on the measures of positive relations with others and purpose in life than comparison parents. Additionally there would be an effect on environmental mastery due to the fact that they are faced with additional challenges (unusual educational needs, health problems, financial demands). Purpose in life would be affected due to parents need to advocate for their child and the rights of others with disabilities. Self-acceptance because parents may have negative feelings about themselves and believe their life has changed due to having a child with a disability. Personal growth may be influenced due to the parent's responsibility to meet additional demands placed on them regarding the care of their child. Decreased autonomy may be experienced because the parent may experience feelings of inadequacy and higher levels of depression leading to lower levels of autonomy. Positive aspects include positive relations with others and purpose in life.

Informal Caregiving

An informal caregiver is defined as a nonprofessional person providing a significant amount of care for and assisting a disabled person in activities of daily living. A large number of individuals with ID reside at home and continue to live with their parents well into adulthood (Braddock et al., 2013). Assuming the caregiving role for an individual with ID has been associated with increased levels of stress, psychological, social, economic, and health costs for the family caregiver (Haley & Perkins, 2004). For this study, the parent of an adult aged child with an ID was considered as an informal caregiver. An estimated 43.5 million adults in the United States have provided unpaid care to an adult or a child in the past 12 months. The majority of caregivers are female (60%) and two in five are male (40%). Additionally, 85% take care of a relative. On average, caregivers spend 24.4 hours per week providing care. About one in four provide care for 41 hours or more each week (23%) and three in 10 provide between nine and 40 hours of care (31%). An average of 4% report caring for a family member with a developmental or intellectual disorder. A total of 38% of caregivers considered their caregiving situation to be highly stressful, 25% reported moderate stress, while 36% indicated little to no stress. Sixty percent assist with activities of daily living. Seventy two percent of caregivers feel that providing care has not affected their own health. Sixty percent of caregivers were employed at some point in the past year while also caregiving. Eighteen percent reported experiencing financial stress as a result of providing care (National Alliance for Caregiving, in collaboration with AARP, 2015). Those individuals providing care for a person with ID can experience a high level of stress which could lead to substantial financial, psychological, social, and medical expenses (Haley & Perkins, 2004).

As individuals with ID are living longer lives, the need for caregiving has increased as well as the time span required to provide the care which can lead to the experience of caregiver burden. Reportedly, from the 1930’s until the 1990’s, there was a considerable rise in the mean age of death for an individual with ID from 18.5 years to 66.2 years of age (Haley & Perkins, 2004). Unlike providing care to a spouse or family member with a chronic illness, caring for a child with ID has the potential to span across 60 years or more, which leads to a lifelong responsibility.

Reportedly, within the context of caregiver burden, guilt was identified as the major contributor to anxiety and depression. In the literature, there are two competing explanations of patterns that are experienced over time that influence caregiving. One suggests that the longer the duration of care, the poorer the caregiver well-being (burden). The other suggests that over time, some caregivers develop new coping skills and derive a new purpose in life from the caregiving role (benefits).

Burden

Caregiver burden can be associated with two dimensions. The first is objective burden, which refers to the individual's care needs associated with observable caregiving tasks. The second is subjective burden, which refers to feelings aroused in caregivers as they fulfill their caregiving responsibilities (Bayen et al., 2015). Stress, depression, and insomnia are cited as the most frequent, significant negative influences on caregiver health (Science of Caregiving, 2015). More specifically, caregivers of cognitively impaired individuals are at a greater risk of psychiatric and physical morbidity compared to population norms and control groups (Bédard, Koivuranta, & Stuckey, 2004).

Gallagher et al., (2008) found that parents of children with ID registered high with depression and anxiety scores, and the majority met the criteria for possible clinical depression and/or anxiety. The strongest predictor of psychological morbidity was caregiver burden (Bhatia et al., 2015; Okewole, Dada, Ogun, Bello-Mojeed, & Usoh, 2011). In a study conducted by Murphy, Christian, Caplin, and Young (2007) of informal caregivers of children with developmental disabilities, five themes emerged from caregiver experiences: 1.) caregiver stress – not being able to control daily events/limited time to completing day-to-day responsibilities/decreased time for other family member/advocating for their child, 2.) unsatisfactory caregiver health – chronic fatigue and lack of sleep/physical health problems/ injuries caused by child' behavior/ limited time for self-care of caregiver/respite care, 3.) social support – identifying people who are trustworthy to watch after the child/time to prepare for alternate caretaker, 4.) concern about the future – what will happen to the child when they're gone/how to pay medical expenses, and 5.) caregiver coping strategies – (things found to contribute to positive feelings) included: short breaks, small naps, identifying supportive family members and friends. Rapanaro et al., (2008) identified similar themes: negative feelings/emotions, loss of freedom and independence, burnout, and extra demands/pressure on resources.

Olson and Hwang (2001) completed a quantitative study of depression of mothers and fathers of children with ID. Despite the fact they concluded that the outcome and consequences a stressful situation has on an individual is determined by how that individual attaches meaning to the situation, they found that the experience of parenting a child with ID is likely to provoke feelings of loss (i.e. of the perfect or dreamed of child, and of one's personal freedom), helplessness (i.e. experiencing high stress, not being able to change the situation and not being able to get the help one need) and failure (i.e. having a child with difficult behavior and not being able to pursue one's personal goals in life), which are all negative factors that would contribute to the conceptualization of burden. These results were consistent with previous studies which concluded that mothers of children with disabilities area at a markedly increased risk of suffering from psychological distress and depression. Additionally, fathers of children with depression showed normal depression scores

The cumulative implications associated with caregiving may not be manifested for decades. Seltzer et al., (2011) conducted a study where they compared three groups regarding parental patterns of social attainment, social participation, psychological functioning, and health in midlife and early old age. The groups consisted of parents of adult children with ID who co-reside with their parents, those who lived outside of the parent's home, and those whose children did not have a disability. They concluded that midlife parents of individuals with IDs were similar in general to their counterparts who did not have a child with a disability, with similar patterns of attainment, psychological well-being, and health. In contrast to those in their mid-60's who displayed lower levels of social participation, more health problems, and elevations in depressive symptoms. When we consider these findings it almost suggests that as the caregiver of an adult child with an ID grows older, they then experience a lesser sense of well-being. This is not necessarily the case. Ryff (1995) posited that as age increases certain aspects of well-being such as personal growth and purpose in life decrease. Could it be that as these parents age they start to realize their limitations and thus begin to focus on their inadequacies which leads them to contemplate about their child's future including planning for long-term care, which may leave them more susceptible to developing physical and mental problems that were not apparent during earlier stages of their life?

Benefits

Not all caregiving is associated with a negative outcome, nor should it be viewed as a pathological issue. Several rewards or benefits have been associated with caring for an adult with ID. Benefits that are reported by caregivers include a sense of contentment in knowing that their relative is receiving excellent care, personal growth, and gaining meaning and purpose in one’s life (Haley & Perking, 2004). Additionally, terms such as fulfilment, growth, and happiness have also been used to describe the payoff associated with caring for an adult age child with ID. The perceived positive aspects of caring have been referenced in several ways which include benefits, positive perceptions, positive appraisals, positive meaning, gains, satisfaction, and rewards. Contradictory emotions of grief and joy, hope and fear have been reported by parents. Rapanaro et al., (2008) conducted a study focused on exploring the positive outcomes associated with the challenges encountered by parents during the transition of their child with ID to adulthood. They adopted the term “benefit finding” from McCausland & Pakenham (2003) which is used to refer to the belief or conclusion that an adverse event or circumstance has the ability to evoke positive outcomes in an individual’s life. A sense of fulfilment and/or pride, personal growth, enhanced social networks, and absence of certain care demands were identified as positive outcomes associated with the chronic demands of caregiving. In their qualitative study of primary parental caregivers of adults with IDs in transition to adulthood, Rapanaro et al., (2008) identified three categories of positive outcomes reported by parents. Enhanced personal resources/personal growth of parent, improvement in social support/relationships, and enhanced personal resources/personal growth of son or daughter. This particular study focused on the parent's perspective of perceived benefits during the time of transition to adulthood. Although the parents did also report burden associated with this transitional period, they were also able to see and report on the positive aspects confirming that regardless of the chronic demands that area associated with this period, parents are able to identify and affirm positive emotions.

Hubert (2011) found that parents of children with severe IDs and challenging behaviors living at home regarded their relationship with their child to be one of the most important and rewarding relationships in their lives despite the demanding tasks. The mothers in this ethnographic study indicated that the perspectives of the mothers was overwhelmingly one of strength and enjoyment. The main source of dissatisfaction was the lack insufficiency of assistance and support that was available to them.

Based on the aforementioned information, it has been shown that providing care for an adult age child with ID during the transition to adulthood can have positive consequences on the mental health of the caregiver, especially in terms of feeling as though one's life has importance, direction, and purpose. Some parents take comfort in spirituality, which helps them to view their child as a blessing or as a test of their faith, rather than a as a burden. To further affirm themselves and their quality of life, participation in recreation, church activities, and family functions which provide social outlets that are more accepting of the child’s disability were identified as sources of positive support.

Defining Intellectual Disability

As of October 5, 2010, legislation was signed by President Obama requiring the federal government to substitute the term “mental retardation” with “intellectual disability” and “the mentally retarded” with “individuals with intellectual disabilities”. This legislation is known as Rosa’s Law. It mandates that the terms “mental retardation” and “mentally retarded” be removed from federal health, education, and labor policies. ID is the most common developmental disability. Approximately 6.5 million people in the United States have an ID. More than 540,000 children (ages 6-21) have some level of ID and receive special education services in public schools under the category of ID as it is defined by the Individuals with Disabilities Education ACT, the nation’s special education law (NICHCY, 2011). In fact, 1 in every 10 children who need special education have some form of ID. In 2014, individuals with intellectual disabilities accounted for 15.2% of the population of children 3 to 21 years old served under IDEA in the United States (USDOE, 2016). An intellectual disability should not be confused with a disease or a mental illness. It is a lifelong disorder for which there is no cure.

The Georgia Department of Education special education regulations defines an intellectual disability as:

> Significantly subaverage general intellectual functioning which exists concurrently with deficits in adaptive behavior that adversely affects education performance and originates before age 18. Significant subaverage intellectual

> functioning is defined as an approximately 70 IQ or lower in combination with deficits in adaptive behavior which encompasses limitations in the child's effectiveness to meet standards of maturation, learning, personal independence, or social responsibility that is expected of the individual's age-level and cultural group. Mild intellectual functioning is the range of scores from approximately 70 to 55, Moderate ranges from approximately 55 to 40, Severe approximately 40 to 25, and Profound is below approximately 25 (GDOE, nd.).

The population of interest for this study is those young adults who fall within the moderate range. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), levels of severity is assessed based on the intensity of supports needed. Those individuals Moderate (MOID) disabilities require additional support to navigate everyday situations (limited support).

Some parents find out in the first months of life that their child is going to be disabled, however, the extent of the disability is not fully realized and tends to become more apparent over time. This often depends on the severity of the disability. The way parents respond to the birth of a child with a disability may look different depending on the family. Shock, sadness, fear, frustration, anger, depression, or an amalgamation of these feelings may become evident. When parents do find soon after the birth of their child, this allows them to begin the process of acclimating to their child's disability relatively early in their child' life. In contrast, some parents don't become aware that their child is disabled until they begin to recognize delays in developmental rates and sequences.

To meet the diagnostic criteria for ID, deficits in cognitive and adaptive behavior functioning must be identified or have an onset prior to the age of 18. For some parents, they are not made aware of the fact that their child has a disability until the child is school aged and enters school for the first time. Once the child enters school it may become more apparent that their child is lagging behind in comparison to the progress being made by their age typical peers. This could include deficits in the acquisition of language, communication, socialization skills, academics, and adaptive behavior functioning which is then brought to the parent's attention by the teacher. This is also a period where it is common for the school system to conduct an evaluation to further investigate areas of concern. Intellectual disability is diagnosed based on the results of standardized tests assessing both intelligence (IQ) and adaptive behavior functioning. If the child meets the eligibility criteria set forth by our nation's education law, IDEA, a categorical label of ID along with a recommendation for special education services may be suggested. This can be a devastating experience for the parent, in that they are faced with coping with the fact that their child has a disability. Some parents my experience a sense of loss and thus are faced with progressing through the stages of grief. First denial and isolation, followed by anger, then bargaining, and finally acceptance. Not everyone who has an ID experiences the exact same characteristics, so it may look different based on the child and the level of severity. Thus the effect of having an ID varies significantly among families. The good news is that at once there is an awareness that ID is present, the next step is to make a conscious effort to personalize support for each individual based on their needs in the form of strategies and services that will be provided and maintained over a sustained period of time.

Transition Process

Transition to adulthood is considered to be a stressful time for families of typically developing youth and even more so for families of individuals with ID. It is considered a pivotal time period that is accompanied by an increased level of stress for parents of young adults with ID (Green, 2004). This transition represents a momentous period of development in our modern American culture and is characterized by an increased sense of autonomy and a focus on making more life decisions than was experienced in earlier stages of development for our newfound young adults. In the United States, the age of 18 denotes the age where children are legally emancipated from their parents. At this time, countless children leave home after high school by venturing out on their own to pursue post-secondary education, vocational training, independent living, or full-time employment. For typically developing youth, the period from 18 to 25 years of age represents a time when children in American families experience independence and contemplate their future life pathways as adults (Fulignis & Pederson, 2002). This is not the case for individuals with moderate intellectual disabilities because of additional challenges they face due to cognitive deficits as well as deficits in daily living and adaptive behavior skills. Newman et al., (2011) in his researched found that young adults with ID are less likely than their typically developing peers to be employed, to enroll in postsecondary education, and to live independently after high school.

According to IDEA

> The term “transition services” means a coordinated set of activities for a child with a disability that: is designed to be within a results oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities including postsecondary education, vocational education, integrated employment (including supported employment); continuing adult service, independent living, or community participation, is based on the individual child’s need, taking into account the child’s strengths, preferences, and interests: and includes instruction, related services, community experiences, the development of employment and other post-school adult living and functional vocational evaluation (US Department of Education, nd.).

The Georgia Department of Education defines transition as “the movement from school to post school environments. It should include the skills necessary for the student to be successful in education, employment, and independent living after completion of high school”. Their transition requirements align with those set forth by IDEA. Specifically it mandates that transition services must be addressed in the Individual Education Plan (IEP) implemented when the students enters ninth grade or turns 16. The IEP must contain postsecondary goals that are deemed appropriate given the individual’s age and are measurable in the areas pertaining to training, education, employment, and if needed, independent living skills. Transition services must be addressed that will assist the individual in meeting the identified goals. Student involvement and participation is required. In the case where a student is not able to attend, the school system is tasked with providing documentation that shows that the student’s preferences and interest are taken into account prior to developing the transition portion of the IEP (GDOE, nd)

Transition is the point in the development-cycle when young adults with ID leave the school based services provided in special education and shift to support services provided through adult service agencies. High schools are compelled with the obligation to prepare students with ID for adult life by providing them with social interactions with typically developing same-age peers, as well as with training to prepare them with access to educational, job training, and recreational options that are available in the community. This cannot be easily achieved without the support and involvement of parents. Federal, local, and state guidelines have been established to help aid in the process of transition from high school to adulthood that highlight and encourage parent participation. If parents are actively involved and specific guidelines are being followed, shouldn’t these procedures lead to a successful transition experience for families? This is not necessarily the case. DeStefano, Heck, Hasazi, and Furney (1999) alluded to the fact that even when transition practices are being followed, barriers to effective interagency collaboration and a lack of appropriate services and community networks for youth and adults with disabilities remain to be a factor. Test (2008) recommended that parents remain vigilant in advocating for their child with disabilities because this could possibly make a drastic impression on policy makers to push legislation promoting more stringent guidelines to reduce the lapse in resources that numerous students encounter when transitioning. This may effectively aide in guaranteeing that long-term support services are in place at the point of exiting from high school based on eligibility versus available or limited resources.

Historically, in the USA, students with moderate/severe ID have received a functional life skills curriculum in school across grades. However, when changes were made in the Individuals with Disabilities Education Improvement Act (2004, IDEA) mandating that all students need access to and make progress in the general curriculum and academic standards there was a shift in the thinking. A functional curriculum, also referred to as a life skills curriculum is one where the concentration is placed on instructing students on essential skills they need to possess to function as an adult. Concepts such as grocery shopping, self-care skills, communication, and basic safety concepts are presented. Along with seeking to prepare students for post-secondary experiences, a functional curriculum generally includes components that touch on functional academic skills, vocational education, community access, daily living skills, financial skills, independent living skills, transportation, social/relationship skills and self-determination. The ultimate outcome of transition planning process is to maximize the chances that an individual will deal successfully with the multifaceted demands of adulthood, thus leading to higher degrees of personal fulfilment. Such transition planning must consider the student’s current needs as well as long-term needs. To function successfully in adulthood, one must have the knowledge and skills to handle the various situations that arise and/or be able to access supports and services when needed. A student acquires these competencies or connects with the appropriate services through school-based, family-driven, or self-initiated activities. No one is completely prepared for the realities of adulthood, but some students are more ready for the “big show” than others. For many students with special needs, significant gaps exist. Comprehensive transition planning, if conducted properly, attempts to even the playing field by providing a process of identifying, planning for, and acting on the needs students have in deal with the complexities of life.

In their qualitative study of parents of young adults with ID, McIntyre, Kraemer, Blatcher, and Simmerman (2004) concluded that there seems to be a misalignment between the current special education guidelines and procedures in the United States, and the aspirations of families of young adults with intellectual disabilities in that work or vocational opportunities were not the primary concerns expressed by the caregivers. The focus was placed more on the young adult’s ability to establish a meaningful, individualized quality of life.

Adult Services

Students with ID are afforded the opportunity to remain in public high schools through the year they turn 21. When they exit high school, there are numerous adult services that are available to provide them support during this time of transition. Often times many families don’t know how to contact or access agencies who are equipped to provide a linkage between school based and adult services. A major piece of the mandated transition procedures set forth by the federal government require that schools provide referrals to adult service programs, such as the state-federal vocational rehabilitation system. These referrals are essential in assuring that young adults with ID exiting the public school setting are afforded the opportunity to access, obtain, and maintain adult services in their communities. There are a wide variety of options for employment and other daily activities which include competitive or supported employment, sheltered work, day programs, group homes, supported living, or volunteer work. When considering transition models, there are basically two camps. One that stresses community adjustment and one that focus more on transition as a lifelong process rather than the obtaining of an outcome. Regardless of the model you choose to support, the commonality is that virtually all the models for individuals with ID involve a linkage between high school and adult service programs. Without this linkage there would not be a transition. Although helpful and certainly necessary, the life skills, employment skills, community use and socialization skills that are taught in the high schools as part of transition preparedness, may never be put into practice to the fullest degree possible without the needed supports that are offered under the auspices of adult services.

Easterseals of West Georgia offers a comprehensive therapeutic care program for adults with disabilities (over 18 years of age) offers full adult day services and after school care for adults still attending school. The focus of the adult program is to incorporate adaptive living skills and socialization into the participant’s life. It strives to improve the participant’s physical well-being, cognitive skills, social skills and level of independence. Community opportunities such as learning about money, joining community civic groups or clubs, and/or volunteering. They also offer a support employment program which emphasizes helping the participants to obtain competitive employment, work evaluations, job coaching and pre-vocational services. Additionally, participants are taught how to navigate their community with the assistance of a 1 to 1 peer support staff (Easterseals West Georgia, nd).

Vocational Rehabilitation provides services to help eligible persons with disabilities prepare for, start, and maintain competitive employment, thus becoming productive and independent citizens in their communities. Their vision statement is "Every Georgian with a disability can work and live independently" (GVRA, nd). Vocational Rehabilitation has more than 35 offices throughout the state of Georgia. VR provides services to individuals with disabilities that foster collaborative partnerships with federal and state agencies, community rehabilitation facilities, workforce investment boards and postsecondary schools. They also develop referral sources for the purposes of reaching eligible individuals with disabilities who can, will and want to work. Postsecondary support, supported employment, work readiness training, on-the-job training, work adjustment training.

Easter Seals and Vocational Rehabilitation are programs two of the most utilized adult services programs in Georgia. If these known services are available, then the local school system should have a working relationship with these agencies which allows the young adult with ID to move smoothly into these adult services. In the years between 2004-2005 and 2012-2013 it was found that Georgia experienced a -15.7 percentage change in the number of referrals made by high schools to VR referrals received by VR to (Cimera, Gonda, & Vaschak, 2015).

It In a study of vocational outcomes for young adults with dual diagnoses, Cimera, Fledman-Sparber, and Avallone (2015) pointed out a slight, yet continuous downtrend in the proportions of individuals who were referred to VR programs by their high school. The data further revealed that barely more than half of young adults with only ID who applied for VR were referred by their schools. Cimera et al. (2015) extended this study to include the examination of the source of referrals for VR services for 286,663 transition-age adults (17 to 25 years old) with a diagnosis of ID who applied for VR services throughout the United States over a ten year period (2004 to 2013). The results of their study were consistent with those reported in the prior study of individuals with dual diagnoses. They found that 62.3% of applicants with ID in 2004 were referred by their high school and by 2013, a decrease resulted in only 50% were referred.

Access and participation in adult services has been found to be useful in allowing individuals with disabilities to earn income, work in their communities, create lasting friendships, increase self-esteem and self-worth and contribute to increased physical and mental health. This in turn takes some of the pressure and stress off the caregiver as well as provides an opportunity for day care services, which may ultimately contribute to the well-being of the caregiver. Although employment has not been found to be the major concern of parents for their young adult with a moderate intellectual disability once exiting high school, it is one that is largely used to determine transition success of individuals with disabilities leaving high school. Carter, Austin, Trainor (2011) noted a strong correlation with post-school employment and individuals who were provided an opportunity to participate in hands-on work experience and who had parents with high expectations. This again asserts the importance of parent participation and support during the transition from high school to adult services, which so many parents have identified as one of their caregiving roles and a major concern which contributes to distress during the transition process.

Summary and Conclusions

An in-depth description of the characteristics of ID, the transition process, informal caregiving, and an operational definition of psychological well-being was presented. Each category was presented to provide the reader with a deeper understanding of this neurodevelopmental disorder and the components related to transition and caregiving.

Based on the review of the literature for this study, a number of major themes and some gaps and deficiencies were found. One of the major themes found in the literature review was that, although a plethora of data has been collected on issues related to psychological well-being, informal caregiving, intellectual disabilities, and the transition process, there is little research documenting the lived experience of parental perspectives of well-being during the specific period of transition from high to adult services for their adult age child with a moderate intellectual disability. Therefore, this study provided a definite rationale or justification for conducting this qualitative study.

The review of the literature also found a similar study (Neece et al., 2009) which explored transition satisfaction and family well-being among parents of young adults with severe intellectual disabilities. This study for one, looked at individuals with severe intellectual disability. This population differs from the one in the current study in the level of severity of the intellectual disability. Those individuals in the severe range experience a lower level of cognitive and adaptive behavior functioning, and sometimes physical limitations and more significant behavioral challenges which may further influence the transition to adult services. It was noted in this study, as well as in several research studies, that quantitative measures were used to measure well-being, which was not consistent. Quality of life (Boehm, Carter, & Taylor, 2015; McIntyre, et al., 2004), burden and reward (Heru, 2000, Raperno et al., 2007; Gallagher et al., 2008; Bhatia et al., 2015) stress, and depression, were identified as indicators of well-being, versus a clearly defined definition of well-being.

A review of literature regarding the concept of caregiving found that it has been extensively studied in patients with dementia and Alzheimer's and has slowly been integrated into other areas. Specifically into the care of aging people with ID. This is significant given that the life expectancy for individuals with ID has risen over the past few decades (Seltzer et al., 2011). This adds another factor to the role of caring for an adult age child with ID making it even more important that post schooling options are more clearly defined. Thus the transition from high school to adult services and parental involvement in the process become even more germane. Many Qualitative studies with parents of individuals with ID were reviewed (Chadwick et al., 2013; Resch et al., 2010, Dyke et al., 2013; and Raghavan, Pawson, & Small, 2013). It was ultimately found that caregivers are faced with ongoing issues of fears, challenges, and positive and negative experiences connected with different aspects and periods of transition in their child's life (Neece et al., 2009; Hubert, 2011; Strnadová & Evans, 2013). Because psychological well-being seeks to transcend beyond the idea of mere happiness and being free from distress. It is within Ryff's theory of psychological well-being (Ryff, 1989) that both the benefits and burdens that have been associated with caring for an adult aged child during the process of transition from high school to adult services can be viewed as a progression of growth where one seeks to gain meaning as they strive and actively negotiate through the challenges of life.

Chapter 3 includes a presentation of the methodology and design used in this research project. The research design and rationale are presented first, focusing on the research questions that drive the study. The role of the researcher is highlighted along with the process used for participant selection. Specific information regarding data collection and data analysis is reviewed. Issues of trustworthiness focusing on ethical concerns which stressed confidentiality and researcher impartiality are also discussed. Finally, a summary including the main points of the chapter is presented.

Chapter 3: Research Method

Introduction

My purpose in this phenomenological study was to understand how parents of young adult aged children with moderate IDs experience well-being as their child transitions from high school to adulthood. The focus of the current study was on the identification of specific challenges and positive factors parents attribute as beneficial in assisting them to strive when navigating through this transitional stage of their child's life.

This chapter includes a presentation of the methodology and design used in this research project. I present the research design and rationale, focusing on the research questions that drove the study. I highlight the role of the researcher along with the process used for participant selection. Next, I review specific information regarding data collection and data analysis. Then, I discuss issues of trustworthiness focusing on ethical concerns which stress confidentiality and researcher impartiality. Finally, I present a summary including the main points of the chapter.

Research Design and Rationale

The central RQ for this study was:

> RQ1: What is the lived experience of well-being in parents of adult aged children with moderate IDs as their child transitions from high school to adulthood?

SRQs were as follows:

SRQ2: How do parents describe their purpose in life and attainment of that purpose given the responsibility for the caregiving of their adult aged child with an ID after the transition from high school?

SRQ3: How has the experience of transition contributed to the participants' views -about themselves in light of the challenges and benefits faced during the transition period?

I used a qualitative research methodology as a means of gaining a better understanding of the lived experiences of parents of children with moderate IDs transitioning from high school to adult services.

In keeping with the focus of qualitative research, I applied all three questions to acquire an understanding of how study participants make sense of their experiences. Qualitative research seeks to discover how humans participate in the meaning making process, which leads to gaining a better understanding of how they make sense of their world (Hatch, 2006; Patton, 2015). Qualitative research relies heavily on comprehensive inquiry of a small target audience, which in this case was parents of adult-age children with a moderate ID, to interpret and make meaning of the participants' responses.

An advantage of qualitative inquiry is that it affords the researcher the opportunity to gain a better understanding of not only the individual, but also of the systems and context that contribute to their subjective experience (Crowe, Inder, & Porter, 2015). By using this approach, I was able to share insight on the human perspective of the experience of well-being in parents providing care for an adult-aged child with a moderate ID as they transition from high school to adult services.

For this study, I used an interpretive phenomenological approach (IPA) as a means of extracting in-depth and rich information from the parents. In general, IPA studies include a rigorous and comprehensive analysis of the information reported by a relatively small group of participants (Larkin, Watts, & Clifton, 2006). More specifically, interpretive phenomenological research is concerned with the detailed examination of the human lived experience. It is an interpretive process that draws on examining the participants' personal perspectives before moving to more general claims of the lived experience.

Role of the Researcher

The role the qualitative researcher adopts is unlike that of a quantitative researcher. The qualitative researcher is considered as a key instrument used to collect data versus relying on instruments, which is more specific to quantitative methods (Creswell, 2013). The qualitative researcher seeks more to understand, highlight, and surmise on to other comparable conditions rather than to seek generalizations of findings or make predictions, which is more characteristic of the quantitative researcher (Hoepfl, 1997). My objective was to gain an understanding of how parents of children with IDs attribute meaning to the phenomenon of well-being they have encountered while their child was transitioning from high school to adult services from the participants' perspective. I sought to gain an in-depth understanding of the phenomenon by collecting and reporting on the rich descriptions and narratives provided by the participants.

The interpretive phenomenological researcher is a critical part of the world they are recounting. This is not a position that should be taken lightly. According to Larkin et al., (2006) there are three relevant factors the researcher should keep in mind when choosing how to approach perspective participants to retrieve meaningful information that is going to prove valuable to the research study. First, the researcher must acknowledge that their decisions have real life repercussions. Second, the researcher must reflect on possible consequences and implications that may result due to what they presume to already know about the subject-matter. Last, the researcher must be cautious with material that is revealed by approaching each participants' contributions with sensitivity and responsiveness, hence allowing the maximal opportunity for the research to adequately reflect the subject being studied.

I had no previous relationship with any of the participants regarding professional, personal, or social concerns. However, I have served as a professional working with students with IDs in the process of evaluating and formulating Individual Education Plans. Conversely, I have not been directly involved in the transition process, nor with the potential individuals who will participate in this research study. I attempted to draw knowledge regarding parents of children with IDs and their experiences by utilizing semi-structured interviews. By probing the participants for explicit descriptions, I was able to obtain a significant amount of essential information needed to present their experiences as primary caregiver to children with IDs who have transitioned from school-based to adult services.

All researchers maintain a variable level of bias when engaging in a research project, which contributes to their influence on and in the research process (Hunt, 2010). To reduce bias, I employed the strategy of reflexivity. By using reflexivity, I was able to actively engage in critical self-reflection about any biases they may potentially possess by becoming more self-aware by engaging in self-reflection and monitoring. This seeks to assist with addressing any potential biases and predispositions shaped by experience and expertise that may affect the research process and conclusions (Johnson, 1997).

Methodology

Participant Selection Logic

Research participants and the context of their lives should be thoroughly depicted by the researcher to provide the reader with an in-depth description that can used to assist in developing a true representation of the span of individuals and conditions to which the findings might be relevant (Elliot, Fischer, & Rennie, 1999). The parents that were considered for participation in the study must have a.) a child with a moderate ID as their primary categorical area of eligibility according to the State of Georgia special education eligibility criteria, b.) their child must have exited a Georgia high school within the past three years, and c.) their child must reside within their home. In addition, only one parent (caregiver) per family was eligible for participation in the study. In instances where both parents or multiple caregivers expressed an interest in participating, the individual who assumes the most responsibility and is most effected by the role of providing care will be deemed most appropriate for participation. There was only one representative per family who could be considered for inclusion in the research study. The study participants was proposed of an approximate range between eight to 12 parents (married or single) who fit the participation guidelines. This sample size of eight to 12 was applied to this study because it is believed to be an appropriate size to capture the common beliefs, views, or behaviors that are shared by this reasonably homogenous group. A range was provided because it is understood that the sample could either increase or decrease depending on the point where saturation is reached. Mason (2010) suggested that the number of participants should be large enough to embrace the experiences of the group, but at the same time, not so large that the information becomes repetitive, which leads to data saturation. Boyd (2001) regarded a range of two to 10 participants sufficient to achieve saturation and Creswell (1998) suggested that in-depth interviews with up to 10 individuals as sufficient for a phenomenological study. Data saturation occurs when no new information is provided by the participants. Bowen (2008) went on further to advise that saturation occurs when both depth and breadth of information has been collected, which takes the focus from the number so much and places it on the quality of the insights and in-depth understanding that is relevant to the research study. It was found that participants were difficult to identify, subsequently the sampling strategy of snowballing was utilized to identify new potential participants. The snowball sampling relies on using the current participants to identify others whom they are familiar with who may have direct knowledge relevant to the research study. Only individuals who "have had experiences relating to the phenomena of a transition of a child with ID from high school to adulthood" were eligible for participation.

I recruited participants under the auspices of a local school system in and urban Georgia county. IRB approval from the school district along with permission from the director of the Program for Exceptional Students was requested to assist with disseminating invitations for participation in the research study to parents of young adults with a moderate ID who have exited the school district in the past one to three years. The school district was asked to mail out invitations for participation, which included the researcher's contact information, so that parents' rights for confidentiality of personal information was not violated. This served as the means of establishing a sample frame. Individuals who contacted the researcher using the contact information provided in the invitation for participation and show an interest in participating in the study were provided with a screening questionnaire, participant criteria, nature of the study, researcher contact information, and a copy of informed consent. A self-addressed stamped envelope was provided for participants to return documents. The informed consent form included information highlighting that participation was voluntary and participants had the option to drop out at any time without any penalty. Additionally, risks and benefits were included. No involvement of the young adult with ID was required. A purposeful sample was utilized because the focus was on having the researcher control the selection process to maximize the opportunity for working with individuals who have directly experienced the phenomenon of transition of a child with a moderate ID from high school to adulthood. This sampling strategy is one that seeks to intentionally sample a group of individuals who can best enlighten the researcher concerning the research problem that is being investigated. Specifically, criterion sampling is a type of purposeful sampling on preconceived criteria (Sandelowski, 2000). This method was used because it contributes to quality assurance. Snowballing was utilized as an alternate sampling strategy because were not enough participants identified during the initial recruitment phase. Fossey, Harvey, McDermott, & Davidson, (2002), recommended this strategy for use when the individuals being studied are difficult to access or approach.

Pre-interview screening, participant criteria, nature of the study, contact information was included in an information packet that will be disseminated by the researcher via mail. The pre-interview screening was designed to confirm potential participants meet eligibility criteria by providing them with a checklist of eligibility criteria. Self-disclosure from the parent was deemed as a sufficient source of documentation to confirm the child had a moderate ID and was living in the home with the parent. By recruiting potential study participants through the local school district, it helped to contribute to internal validity and generalizability versus recruiting participants through community services systems, which could possibly contribute to the cohort effect due to the similarity of their experiences. Furthermore, Willingham-Storr (2014), advised that the researcher keep in mind that the recruitment of parents and/or caregivers exclusively from formal groups or services could lead to the exclusion of other potential participants who do not utilize these supports and maintain different views to those receiving support. The appropriateness of the individuals for participation in the research study was determined after I received a copy of a completed and signed consent and screening form from the potential participant. If many individuals showed interest in participation in the study by returning the screening questionnaires, preliminary data would have been reviewed to assure that potential participants met inclusion criteria for participation. However, this was not the case. Demographic information was obtained using a questionnaire (see Appendix A). This data was used for descriptive purposes to provide a distinct representation of each participant to the reader. An interview guide consisting of predetermined structured open-ended questions was presented to the participants. The same questions were asked of each participant in an individual face-to-face interviews. I reviewed a summary of the interview with the participants to help determine the accuracy of their responses using the process of member checking. In addition, I conducted follow-up interviews with three of the participants to provide them with an opportunity to submit any feedback pertaining to the whether or not the data provided an accurate reflection of their views. Participants were asked to provide a tentative date for a follow-up interview. Follow-up interviews occurred no later than two weeks after the initial interview and were scheduled based on the participants' availability. Follow-up interviews lasted approximately 15 minutes.

Per Guest, Bunce, and Johnson (2006), the more similar the participants in a sample are in their experiences with respect to the research domain, the sooner one would expect to see saturation. Data saturation is the process by which the researcher combs through the responses of the interviews to identify themes. Once there comes a point in the collection and analysis when new information produces little or no change to the codebook, saturation is said to have occurred. Initially, eight interviews were conducted. The stop criteria was, after eight interviews, when four more interviews had been conducted with no additional information or new themes emerging, it was determined that data saturation has occurred. Morse et al. (2002) warned that one of the most common mistakes made by new researchers is when participants are saturated versus the saturation of the data. Saturating participants entails continual interviewing of the same participants until no further information emerges. Whereas, saturating the data focuses more on adding additional participants until the data set is comprehensive and the data repeats.

Instrumentation

In qualitative research the researcher is the primary instrument for data collection and data analysis (Merriam, 2002). The researcher as the primary instruments has definitive advantages as well as disadvantages. Since the goal of qualitative research is understanding how the participants experience a particular phenomenon, the researcher is available to immediately inquire and explore the participants' accounts. The researcher and the interviewee are both viewed as active participants in the research process. During this open dialogue, I was afforded the opportunity to increase my understanding by: engaging in the exchange of both verbal and non-verbal communication, clarifying and summarizing data instantaneously, probing unclear responses, and by verifying the accuracy of their interpretation of the participants' responses face to face. A major disadvantage that is worth mentioning is that the researcher as an instrument comes with his or her own set of biases that may ultimately have an effect on the research. This does not suggest that the research should attempt to eradicate these biases, but should bring them to the forefront by identifying them as well as monitoring them during the duration of the study.

An in-depth interview is crucial to IPA research as a means of ensuring the data is rich enough to be analyzed. According to Englander (2012), phenomenological interviewing has become the main data collection procedure utilized by qualitative researchers that is intrinsically related to the research process. Phenomenological interviewing aims to stimulate an individual representation by the participant of a lived experience that can be depict the phenomenon in a way which captures the essence of the lived-through moments (Patton, 2015). I developed an interview guide (see Appendix B) as a framework to help guide the semi-structured interview. The questions included in the interview guide allowed the participants to describe their experience of well-being including challenges and benefits as they related to their young adult child's transition from school based services to adulthood. The questions centered on the key elements contained in the research questions, in particular the parent's perception and experience of well-being, challenges and benefits associated with this time period, and personal growth outcomes or limitations that occurred as a result of the transition. Prompt questions related to the parent's purpose in life, attainment of the purpose, and personal views of themselves, were interjected when deemed appropriate. Smith et al., (2009) suggests that by preparing an interview guide, the researcher prepares an environment which maximizes the chances for a comfortable interaction with the participant which will permit them to provide a rich detailed first person account of their experiences. The interview guide can be used as an agenda throughout the interview to assure that all pre-determined topics are addressed. It also provides somewhat of a guide the interviewer can refer to as a way to confirm that the same general lines of inquiry are investigated with all interview participants. According to Patton (2015), the advantage of the interview guide is that it prompts the interviewer to explore in advance how to best make use of the limited time available in an interview situation and it assists with assuring that the process of interviewing multiple participants flows in a manner that is more efficient and organized by defining in advance the topics to be covered.

I aligned the interview questions with the research questions and associated with the theoretical framework and review of the research literature pertaining to this study. I placed an emphasis on the lived experiences, particularly those of well-being, of the parents while navigating through the transition of their child from high school to adult services. The initial interview began with introductory questions which will allowed the interviewee to become familiar with the interview process. Background information including descriptions of their experience with the transition process and their account of well-being was then elicited. I followed this set of questioning with descriptive questions which moved the interview from general questions to a more specific and structured line of questioning to ensure that areas relevant to the research question were addressed.

Interview questions were presented to the dissertation committee and Walden Institutional Review Board (IRB) for approval. Upon approved, I conducted a field test with one parent who met eligibility criteria for participation in the study. The parent was asked to take part in an interview to help determine if the interview questions elicited the type of responses for which they were developed to address the research questions. The responses were found to support their intended use. This process assisted in establishing content validity.

Procedures for Recruitment, Participation, and Data Collection

I received approval from the Walden University's IRB prior to the data collection process commencing. The potential research participants were evaluated based on the aforementioned eligibility criteria. I served as the main data collector by acting in the capacity of the interviewer.

In-depth inquiry in the form of semi-structured interview questions was used as a means of gaining an understanding of the lived experiences of the parents. Wagstaff and Williams (2014) suggested engagement prior to the interview is a vital dynamic in the recruitment and of participants which can influence the quality of information the participant is willing to disclose. I made it a priority to establish rapport and to create a safe and non-threatening relationship with the participants to promote an environment where trust was conveyed. This assisted with enhancing the participants' willingness to share their private experiences. The interviews consisted of open-ended questions, which will also allowed for additional probing of the participants. I presented the questions in a manner that sought to elicit responses from the participants that describe their lived experiences and captured their perspective of what it meant to care for an adult-aged child with an ID transitioning from school based to adult services. Smith and Osborn (2003) suggested that semi-structures interviews are an exemplary method for IPA. Interviews were conducted at a location that was convenient for the participants. Each interview lasted from an approximate time span of 25 to 65 minutes. With the permission of the participant, I audio recorded and then transcribed each interview. During the interview, I also took field notes and recorded any observations that are deemed relevant.

Information obtained from the participants during the interviews will be kept confidential. I organized all audio data and transcripts of the interviews in specific files. Password protection was assigned to all instruments used to store the data. Raw data collected will be discarded after five years.

After the interviews were completed, the process of member checking was employed. I felt there was a need for clarification with three of the participants. They were contacted by phone for me to verify if they agreed that the data reported was consistent with what they intended (Shento, 2004).

Data Analysis Plan

According to Larkin et al., (2006) an interpretive phenomenology researcher must approach their data with two aims in mind geared to understand their participants' world, and to describe "what it is like" by focusing on the participants experiences of a specific event, process, or relationship. Secondly, IPA aims to develop a more overtly interpretive analysis which positions the initial description in relation to a wider social, cultural, and perhaps even theoretical context by trying to provide a critical and conceptual commentary upon the participants' personal sense-making activities (Larkin et al., 2006).

I used a qualitative summary of the participants' responses and constant comparison to analyze the data. I transcribed audio recordings and referenced my filed notes to assist in summarizing the data. Then I cycled through the data to identify initial patterns or keywords. Boeiji (2002) suggested that through constant comparing, the researcher is presented with the opportunity to categorize, code, delineate categories, and connect them. This strategy involves a cycle of comparing and reflecting. The initial level of coding included combing through each interview transcript to see if there were any initial key words or phrases that were prominent in the text. The role of coding in data analyses is to organize and make of sense of the information that has been collected. It also allows the researcher an opportunity to immerse themselves in and become more familiar with the data to facilitate the understanding of the phenomena as it perceived by the participants (Basit, 2003). Next, I conducted a line by line search of each interview. During this phase, specific words, phrases, sentences, and portions of text were highlighted. I initially used a word frequency approach, but it was obvious that this was not the most efficient method since, given the nature of the questions, there were several words that would naturally be presented with a high frequency. I created a system where I used highlighting, color coding, and journaling in the margins to assist with this recursive process as a way to manage, organize, simplify, and streamline the data. The final step included reflection, where I took the time to reflect, segment, and compare the data, first in individual interviews and then I moved on to comparing the data between interviews. Similar topics were then broken down into more comprehensive themes. Diverse quotes and relevant evidence were removed and arranged into categories to support the formulation of general descriptions.

Issues of Trustworthiness

Establishing trustworthiness is a paramount task in qualitative research. Within the realms of qualitative inquiry, trustworthiness is encompassed in four key aspects which includes credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). According to Golafshani (2003) reliability and validity are viewed as separate entities in quantitative studies, however in qualitative inquiry these terms are not considered as separate. Instead the terminology that is used such as credibility, transferability, and trustworthiness is inclusive and incorporates both.

Ensuring credibility is one of the most important factors in establishing trustworthiness (Lincoln & Guba, 1985). According to Golafshani (2003) research credibility in qualitative research depends on the ability and effort of the researcher. Credibility is concerned with establishing confidence in the fact that the focus of the research is maintained through robust data collection and analysis which accurately addresses the intended focus of the research (Polit & Hungler, 1999). Triangulation, member checks, use of thick, rich descriptions, and reflective commentary were among the several suggestions for validity strategies provided in the literature that could be used to assist in establishing credibility (Creswell, 2009; Shenton, 2004). I was able to accomplish triangulation by using multiple participants to increase the likelihood of credibility. Shenton (2004) suggested by using multiple informants who contribute differing points of view and experiences can provide a richer picture of the attitudes, needs, or behaviors of the participants and phenomena being studied. Member checking was used in conjunction with triangulation. Member checking affords the researcher the opportunity to check for accuracy by providing the participants with the findings, interpretations, or themes to review, which can in turn increase the rigor and trustworthiness of the findings (Leech & Onwuegbuzie, 2007). For three of the eight interviews, there were inconsistencies that required me to follow-up with the parent for clarification. This was done by phone. Each of the parents contacted explained the meaning they were trying to convey and agreed with the summary of their responses. This was crucial in allowing me to provide a rich, thick, and detailed description of the participants' experiences to add to the validity of the findings.

A second aspect of ensuring trustworthiness is transferability. Transferability refers to the extent to which the findings can be transferred to other settings or groups (Polit and Hungler, 1999). To facilitate transferability, I included a clear and in-depth description of the participants' reports of their lived experience and the context they used to help make meaning of the experience. Adequate data reflecting the participant descriptions, research setting, procedures, and researcher-participant interactions allows for the reader to make a decision on how the information will transfer outside the boundary of the study (Morrow, 2005).

The third aspect of trustworthiness is dependability, which assures the way in which the study is conducted should be consistent across time, researchers, and analysis techniques. Information maintained in the audit trail may include detailed information such as, interview transcripts, research activities, theme development, and data collection processes (Morrow, 2005). I maintained an audit trail as a way to document the process by which data was collected and analyzed. I included the audio recordings and transcribed documents of the interviews, the reflective journal, field observations, and data analysis procedures.

The final and fourth aspect of trustworthiness is confirmability. Confirmability refers to actions taken to assist in ensuring that the data reported are based on the experiences and ideas provided by the participants rather than being subjected to the influence and interpretation of the researcher from their point of view (Shenton, 2004). Reflexivity provides an opportunity for the researcher to understand how his or her own experiences and understandings of the world affect the research process. (Morrow, 2005). Rennie (2004) defined reflexivity as “self-awareness and agency within that self-awareness” (p. 183). Morrow (2005) suggested that reflexivity, or self-reflection, can be implemented in a variety of different ways. Keeping a self-reflective journal from the on-set to the completion of the research study was reported as one of the most valuable ways. The journal, would provide an accurate account of the researcher’s experiences, responses, and developing awareness of any assumptions or biases that may surface. This may also serve to assist the researcher in maintaining high standards so that they are less likely to overstate the findings from the study and extend the conclusions beyond what the data supports (Grossoehme, 2014).

Ethical Procedures

I gained approval from the Institutional Review Board (10-10-17-0480489) prior to conducting any interviews. Once approval was received, I provided the school system with the information packets along with pre-stamped envelopes to disburse to potential research participants, which included my contact information. Participant who showed an interest in participating in the research study by contacting me were informed of the purpose of the research study along with the procedures and protocol that were to be followed. Potential participants were provided with both a written and verbal explanation of what the research will entail. Additionally, they were informed that if they chose to participate in the study they could withdraw at any time without any negative consequences or backlash from the researcher and that there would be no incentives provided for choosing to participate in the research. The participants were encouraged to ask any specific questions they had pertaining to the nature of the study. For those individuals who agreed to participate, a consent form was provided. At that time I also discussed limits of confidentiality.

Although there did not appear to be any known risks or harm related to participation in this research, McIlfatrick, Sullivan, and McKenna (2006) suggested that a crucial concern attached to qualitative research is that interviews can possibly arouse reflection, judgement, catharsis, and considerable self-disclosure for the participants. Therefore, researchers should be mindful and resources available if the participants' well-being becomes a factor. If any participant discloses any information suggesting potential harm to themselves or their child, an immediate report will be made.

I assured the participants that any possible identifying information would be altered to ensure that confidentiality would be maintained throughout the entire process. Parents' names, as well as their child's name were changed and issued a code name. Participants were also made aware of the fact that I will be the only individual who will access the data they provide. I stored all data in a secured file cabinet as well as on a password protected external hard drive. All data will be discarded after a five year period in accordance with university and established research guidelines. This is to include field notes, audiotapes, and interview transcripts.

Summary

The purpose of this study was to understand the lived experiences of well-being in parents with adult aged children with an ID transitioning from school based to adult services. Chapter three focused on methodology, the identified research design, and its utility for this particular study. Phenomenology was chosen as a way of depicting the detailed meaning of each individual parents' perception of their experiences with their child during this transition period. The rationale for the selection of the participants and the role of the researcher, highlighting the researcher participant relationship including acknowledgement of plausible bias by the researcher was explored. Steps disclosing how data collection, data analysis, along with a review of ethical issues was addressed. Emphasis pertaining to the issues of trustworthiness were reported and how they contribute to the validity of the study.

In chapter four, I will include a review of the findings of the research study. The setting, demographics, and specific details describing the results of the study will be discussed.

Chapter 4

Introduction

My purpose in this qualitative phenomenological study was to describe the lived experience of psychological well-being in parents of adult aged children with moderate IDs as they transition from high school to adult services. The study involved eight parents from an urban school district in Georgia, who indicated they had experienced transition within the past 1 to 3 years. I posed three research questions:

1. What is the lived experience of well-being in parents of adult aged children with moderate IDs as their child transitions from high school to adulthood?
2. How do parents describe their purpose in life and attainment of that purpose given the responsibility for the caregiving of their adult aged child with an ID after the transition from high school?
3. How has the experience of transition contributed to the participants' views about themselves in light of the challenges and benefits faced during the transition period?

In this chapter, I discuss participant demographics and characteristics, describe data collection procedures, provide an in-depth description of the data analysis method, present evidence of trustworthiness, and summarize the results of the study. The lived experiences of the participants become prominent in the context of this particular study because these experiences provide an understanding of how the experience of the transition of an adult age child with a moderate ID influence psychological well-being in their parents.

Interview Setting

I interviewed participants at a mutually agreed-on location: each participant chose a time and location that was convenient for them. Three participants were interviewed in their homes, two at the public library, and the remaining four were interviewed at a public location of their choice. There were no external factors that were believed to negatively influence the quality of the interviews. Prior to beginning the interview, I was able to establish rapport with each participant to enhance their willingness to share their private experiences and to ensure that the setting was conducive to a positive interview exchange and environment. Each participant appeared to be comfortable and at ease during the interview sessions.

Demographics

The participants interviewed were all females and were the biological parent of the child. Five of the participants were White and three were Black. Table 1 provides further demographic information for each of the parents. The demographic information contains relationship to the child, race, marital status, other children in the home, as well as the parent’s level of education.

Table 1

Demographic characteristics of parent of young adult with intellectual disability

	Characteristic	Relationship to Child:	Race:	Marital Status:	Other Children in home	Level of Education:
P1		Mother	Black	Single	2	4 year degree
P2		Mother	Black	Married	2	2 years college
P3		Mother	White	Married	1	GED
P4		Mother	White	Single	0	Some high school
P5		Mother	Black	Single	0	College Degree
P6		Mother	White	Married	1	College degree
P7		Mother	White	Married	0	High School
P8		Mother	White	Married	2	College degree

The participants are referred to using pseudonyms throughout the study. The format is “P” followed by the participant number. Participant 1, for example is referred to as P1. Table 2 provides information pertaining to the characteristics of the young adult child. This information includes the child’s race, age, number of years since transition, gender, and any other diagnosis the child may have acquired.

Table 2

Young Adult Characteristics

Participant	Race of child	Age of child (y)	Years out of high school	Gender of child	Other conditions	Services outside of home
P1	Black	24	3	Male	Hearing impaired	No
P2	Black	21	2	Female	None	Yes
P3	Mixed race	22	2	Female	Down syndrome	Yes
P4	White	23	2	Female	Bipolar/depression	Yes
P5	Black	23	2	Male	Autism	Yes
P6	White	23	2	Male	None	Yes
P7	White	22	1	Male	Seizure disorder	Yes
P8	White	24	3	Male	Down syndrome	Yes

Data Collection

Prior to beginning data collection procedures, I submitted a letter to the executive director of the Program for Exceptional Students in a local urban Georgia school district requesting their assistance with disseminating informational packets to parents. The packet included an invitation flyer, which stated participant criteria, the nature of the study, demographic information form, informed consent, and my contact information. After permission to conduct research was approved by the local school system's institutional review board on September 19, 2017, and permission to conduct research was granted by Walden's institutional review board on October 10, 2017, (approval #10-10-17-0480489), the school board mailed out the informational packets. The school district did not take responsibility for any cost associated with postage. I was required to provide both envelopes and stamps. I provided the local school system with 80 self-stamped envelopes which included the informational packets. The school district then mailed out the packets to parents of individuals with a moderate ID who exited the school district within the past 3 years. The individuals were provided with my contact information and instructed to call me if they were interested in participating in the research study.

I received phone calls from seven individuals who indicated they had received the flyer. Two of the individuals did not meet the study criteria and were disqualified from participation. One of parents had a child who had been out of school for four years, thereby did not meet the criteria of graduating within the past one to three years. For the second parent, although her child graduated within the eligibility criteria window and did have an ID, she was classified within the mild range. Per the study requirement, the child must have a moderate ID. Two individuals indicated that at this time, they were not interested in participating. With the remaining three individuals, I reviewed the nature of the study via telephone and was able to schedule a date and time for the interviews. It took approximately one week to agree on a time and location for the interviews. One of the potential participants did not show up and could not be contacted after several attempts. Once I met with the two participants, as outlined in Chapter 3, I used snowballing as an alternate method of recruitment and asked if they knew any other parents of children with IDs who they thought would be interested in participating in the study. I was able to identify seven additional volunteers through this method. I contacted the individuals by telephone and provided them with an overview of the study along with the participation criteria. We were able to schedule a mutually agreed upon time and location to conduct the interviews. For these participants, the informed consent form and demographic questionnaire was provided and reviewed prior to beginning the interview. It took approximately two weeks to plan and finalize all interview times and locations.

I actually collected data for this study from eight parents who volunteered to be a part of the study. The mothers who agreed to participate met the study criteria outlined in the invitation flyer and informed consent. To obtain data for the study, each of the parents participated in a face-to-face interview that lasted over a time span of 25 and 65 minutes. I conducted the interviews over a period of six weeks due to the lack of initial response during the initial recruitment phase. I asked the parents were asked nine questions (see Appendix A). During the interviews, there were follow-up questions and prompts that allowed for the development of rich, in depth meanings from the information given by the mothers. All questions were centered on the key elements contained in the research questions highlighting the parents' perception and experience of well-being, challenges and benefits associated with the transition of their child, and personal growth outcomes and limitations that occurred as a result of the transition.

I digitally recorded and then transcribed each interview. Additionally, I kept field notes, a self-reflective journal, and recorded observations that were deemed relevant. During the data collection process and subsequent dissertation development process, I was the only person who had access to the data. All audio files, informed consents, and transcripts were kept in a locked cabinet in my home. I assigned password protection was assigned to all instruments used to store all data. After transcription, I transferred electronic forms of data to a password-protected USB and stored it in a locked cabinet in my home.

For three of the eight interviews, there were inconsistencies that required me to follow-up with the parent for clarification. This was done by phone. Each of the parents contacted explained the meaning they were trying to convey and agreed with the summary of their responses. This process is referred to as member checks (Leech & Onwuegbuzie, 2007). The data collection procedures were consistent with those that were presented in Chapter 3. I did not encounter any variations or unusual circumstances.

Data Analysis

This study relied on Constant comparison analysis. Constant comparison analysis was originally developed for grounded research to analyze data that was collected over a series of stages, however it has become versatile and is being used in numerous types of qualitative research (Onwuegbuzie, Leech, and Collins, 2012). The constant comparison analysis allowed me to look for relationships between concepts and categories through constantly comparing the concept or category until saturation occurred. Boeiji (2002) modified Glaser and Strauss constant comparative method (CCM). The five steps of Boeiji method of data analysis involve (a) comparison within a single interview, (b) comparison between interviews, (c) comparison of interviews from different groups, (d) comparison in pairs at the level of the couple, and (e) comparing couples. It is noted that the term group refers to persons who share the same experience, for purposes of this research study it refers to parents with adult aged children with a moderate ID who have transitioned from high school within the past 3 years. Although Boeiji offered five steps, she did indicate that the data that is available dictates the number of steps. Steps one and two are limited to people who share the same experience, which is what I followed.

Furthermore, Boeiji emphasized that more than anything the number of steps is not important, but the idea that the researcher goes into the interview with a clear and organized plan as to what steps are needed in the analysis is of greater importance. The first step included multiple reading and playing back of the audio recordings of each individual interview. I did this multiple times as an effort to immerse myself in the data and to ensure that I did not leave out any important concepts or ideas. I made notes in the margins and used highlighters to color code key words or phrases. In this process of open coding, I was able to comb through each line of the interview to identify initial key words and phrases that were prominent in the text. After the first review I went back through the interview to check for consistency within the individual interview. For example, a parent indicated that their interaction with the school was challenging, but indicated in a subsequent portion of the interview that it was a good experience. In this instance clarification was needed, which resulted in me determining that the meaning unit "experience with the school" could be broken down into two distinct categories based on the parent's perspective of their personal interaction with the school versus the school's interaction with their child. The next step involved comparison between interviews leading to delineating categories. I was able to take the meaning units I initially identified in each interview and compare them between interviews. I took sections from each interview that I categorized as dealing with the same theme and that I had given a similar code based on the characteristics of the responses (axial coding) and compiled them together to further define that concept. At this point I was able to identify patterns and to streamline and combine some themes. The final step was identifying relationships and connecting themes. I paired themes together that were similar or related. I then listed multiple quotes from each participant that directly pertained to and supported the theme. I read through the categories, the paired themes, and the participant quotes numerous times as a means to confirm that the essence of the participant's experience was truly depicted. Their own words were used to support themes and capture their experiences and reduce any biases that I might have by using my own words. At this point, based on the analysis, it was believed that data saturation had occurred. Data saturation is said to occur when the data set is comprehensive and the data begins to repeat. Table 3 provides information to support data saturation.

This process lead to the development of eight primary themes that were identified were (a) expectations and preparation, (b) experience with the school, (c) accessing and coordinating services, (d) social support systems, (e) daily coordination and planning, (f) life as an adjustment, (g) personal growth and (h) looking towards the future. One subtheme networking/parent support groups was also identified. These themes and subtheme are discussed in detail.

Table 3

Saturation Grid

Themes	P1	P2	P3	P4	P5	P6	P7	P8
Expectations and preparation	x	x	x	x	x	x	x	x
Experience with the school parent	x	x	x	x	x	x	x	x
Experience with the school child	x	x	x	x	x	x	x	x
Accessing and coordinating services	x	x	x	x	x	x	x	x
Social support systems	x	x	x	x	x	x	x	x
Networking/parent support groups	x	x	x	x	x	x	x	x
Daily coordinating and planning	x	x	x	x	x	x	x	x
Life as an adjustment parent	x	x	x	x	x	x	x	x
Life as an adjustment child	x	x	x	x	x	x	x	x
Personal growth	x	x	x	x	x	x	x	x
Looking toward the future	x	x	x	x	x	x	x	x

Theme 1: Expectations and Preparation

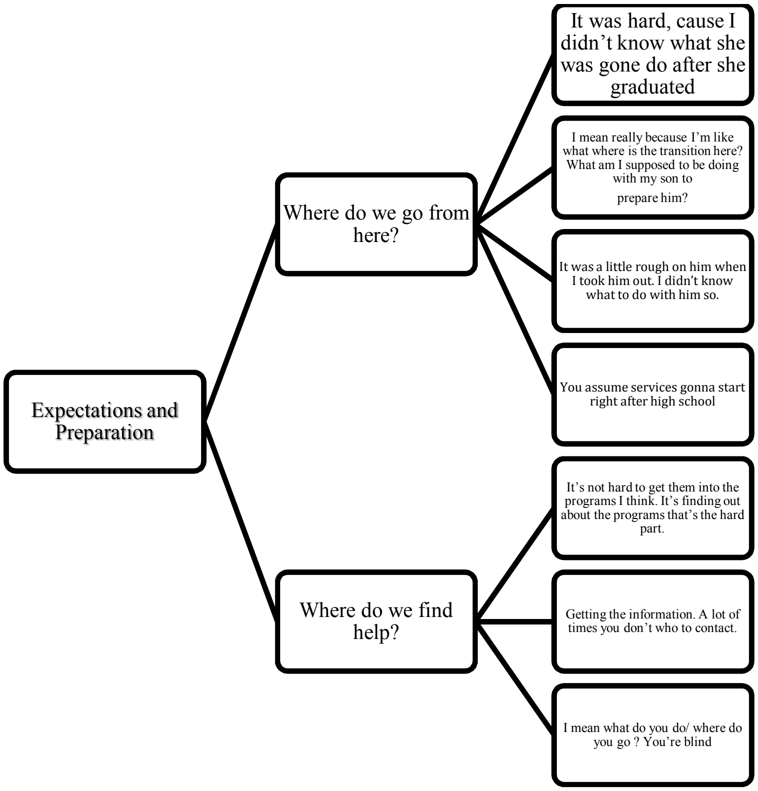

Figure 1. Thematic map: Expectations and preparation.

Federal, local and state guidelines have been established to help aid in the process of transition from high school to adulthood for students with disabilities that highlight and encourage parent participation. Each participant in this study identified concerns with their expectations and preparation with the transition process. All of them reported they did not know what to expect and therefore did not feel prepared for the transition once their child exited high school. They all reported a lack of adequate understanding of the transition process, which resulted in unclear expectations and minimal preparations being made to facilitate the process. This is depicted in Figure 1. P1 stated:

> As a parent of a child with a special need, you assume services gonna start right after high school which is not the case. I'm thinking services were gonna kick in like within the next month or two but they didn't. So then I had to send him back to school until he turned 21 just so he wouldn't sit home and be bored."

Furthermore, P2 stated:

> When she finished her four years she didn't want to go back to high school and I couldn't talk her into it. They suggested another program, but we didn't actually know what the other program was cause it was new. That's when we waited and waited.

P3 stated the following:

> Transition was hard, cause, I didn't know what she was gone do after she graduated. That's one thing cause you get comfortable with the teachers and you get comfortable with the people. So I didn't worry about it when she was in school.

P4 responded as follows:

> Well, it took a while. Her senior year was stress. I had trouble out of Autumn because she has, she has uh Bi-Polar and anti-depression. And uhm she has, she's slower, she's special ed. She wanted to go to college to a local college and she did, but uhm it didn't work out for her. You know she was uh, she was lost and she couldn't figure it out. It didn't seem like anyone could understand her or know what to do with her. So then we went into the depression again and then we was in the hospital a couple times.

P5 said:

> My son and our transition experience was horrible. Uhm first of all I don't think that he was done fairly through the school. I think he was housed the majority of the time he was in school. His senior year might've been his best year. Uhm, however, that wasn't as good as it should've been. The senior experience to me, the transition, which is supposed to be the transition, was awful. Mainly because parents or caregivers seem to get lost in the shuffle of graduation. When it comes to, uhm transition, maybe this was my experience maybe not everybody, but uhm not everybody. I felt left out.

P6 note that:

> It was a little rough on him when I took him out. I didn't know what to do with him so…. They talked to me about transition, I guess the last IEP meeting and whenever. I guess the last exit meeting so I guess, I don't know.

P7 said the following:

> Awe it was a little, a little hard. I think the hard part was trying to get him groups to as far where he can go uhm and the there’s not enough information given out in the school system for that, what they can do after school. They have a fair, but you don’t get very much information as far as the age groups, the qualifications that are needed or anything like that. I think that was the hardest part. It’s not hard to get them into the programs I think. It’s finding out about the programs that’s the hard part. Like if a month before the transition if we could have everything in line before then so when he got out then he could go in for his interviews, that would’ve been awesome, but it’s getting that part set up that’s the hardest because we didn’t know what we needed. I’m still doing research trying to find out things.

P8 responded as follows:

> Yes it was not as well as expected. I thought there was going to be some kind of thing to help us. Some kind of organization for us to get prepared for them to be out in the real world. I mean really because I’m like what where is the transition here. What am I supposed to be doing with my son to prepare him?

Theme 2: Experience With the School

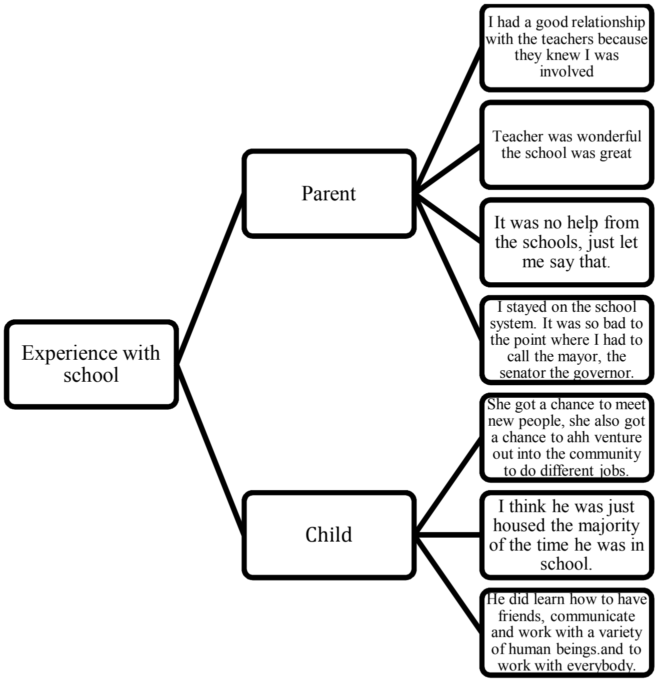

Figure 2. Thematic map: Experience with the school.

Another overarching theme that emerged from the data was the experiences the participants had with the school. The experience with the school varied from parent to parent. When creating this theme it became apparent that the school experience was reported in two separate categories that were not always similar in nature. The parents tended to report how they experienced a personal interaction with the school as well as how the school interacted with their child. Both interactions were found to be crucial when gaining an overall perspective of how this theme would contribute to the psychological well-being of the parent.

P2 “Teachers were wonderful and school was great.”

P3 “The teachers helped me. I used to worry a lot, but the teacher and I have taught her not to let people uhm, you know abuse, I’m not going to say abuse but run over her.”

In response to their perception of the child’s experience,

P2 stated:

> “She got a chance to meet new people, she also got a chance to venture out into the community to do different jobs. I mean she worked with Piggly Wiggly, she went to Good Will several times, uhm, she worked with several different uh organizations, and they did some volunteer work.”

P3 reported “The teachers helped prepare her. Before she could only do sign, they taught her how to use more words.”

P7, reported a difference in her experience with the school versus her son’s interactions with the school.

P7 said:

> They didn’t tell you information in detail on what the specific programs are. You have to do a lot of that research on your own. I think that that’s really rough for parents especially those who do have a full time job and who are trying to work it into other things. However, her recollection of her child’s experience with the school was, there were some downs and some ups, but overall positive.

P5 responded as follows:

> P5 did not report a positive experience with her or her child’s interaction with the school. I did that all on my own. The school didn’t help as far as the transition, there is nothing good about the transition. Not with the school involved. In

reference to her child’s experience, she exclaimed, I tell you the school just did not do anything. He was in a separate school for years.

Theme 3: Accessing and Coordinating Services

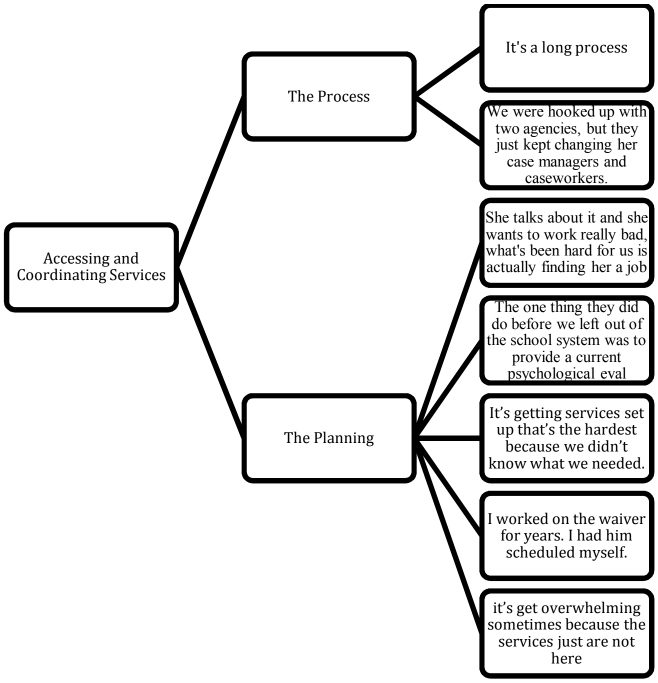

Figure 3. Thematic map: Accessing and coordination services.

Accessing and coordinating services developed as a key theme in describing the transition from school to adulthood for each of the parents. Given the fact that seven of the eight parents allowed their children to remain in school until the age of 21, the break from guaranteed school services to adult services that had to be sought out and secured by the parent was a noteworthy undertaking. The parents described their experiences as a process that was much different than what they were used to in the school setting. According to the parents, accessing services outside of the school environment was mainly parent directed. Whereas in the school environment, the school system took the lead in driving services and securing activities for their children. DeStefano (1999) suggested that even when transition practices are being followed, barriers to interagency collaboration and a lack of appropriate services and community networks for youth and adults with disabilities remain to be a factor.

P1: “It’s still a process. You have waiting lists cause like the state might not have funds at the time. They keep switching your case worker. It’s just always something.”

P2 said:

> She got into a program and we were all ready to go and after her last Dr. appointment, her doctor changed her medication and put her on iron because her blood was low and when we did that, they said they could no longer accept her because she started a news medication. That made me soo mad. I was so mad and upset because that was the final thing and it looked like were ready to go all ready to go like she was going to get in and everything and when they told her it was just like she was just on iron pills, iron pills. They said since she started a new medication she couldn’t come. So that was kind of discouraging to us very discouraging.

P3: “She went to Easter Seals when she was little. Now she has to go back cause I don’t know what else to do with her.”

Furthermore, P4 stated:

> Within a year. I think within a year, within a year I found this program (Parks & Rec). So the hospital told me, this is a program, Parks & Rec.) that keeps her busy, keeps her mind motivated, keeps her confidence going.

P5 noted that:

> The only thing good about the transition was that what he had was because of me. I had scheduled him, I had done everything I needed to do. He had the Medicaid waiver already I had been working on the waiver for years.

P6 said:

He's been out of high school for year and a half now. I put him over at the uhm Parks & Rec program. As far as services wise, I don't have him on any social security or anything at this point.

P7 said the following:

> I was already involved with Ms. C and Muscogee Sports. So that got me in the door for a lot of other things. If it hadn't been for M Sports I wouldn't have had information about half the stuff he's in now because she's the one who geared us into it.

P8 responded as follows:

> The Medicaid Waiver is like if you imagine a big umbrella and all the services fall under it. He gets uhm actually I have his paperwork right here. He gets a federal fund from the government and it allows him to have resources. One of them is like job. Someone comes here and works with him, uhm before he actually got his job. It's so worth it and this has been the best. You just, but the only thing is it's really hard to get while they're in school. Uhm it's more of a, I was on the waiting list for two years and uh it's kinda like an emergent thing happening.

Theme 4: Social Support Systems

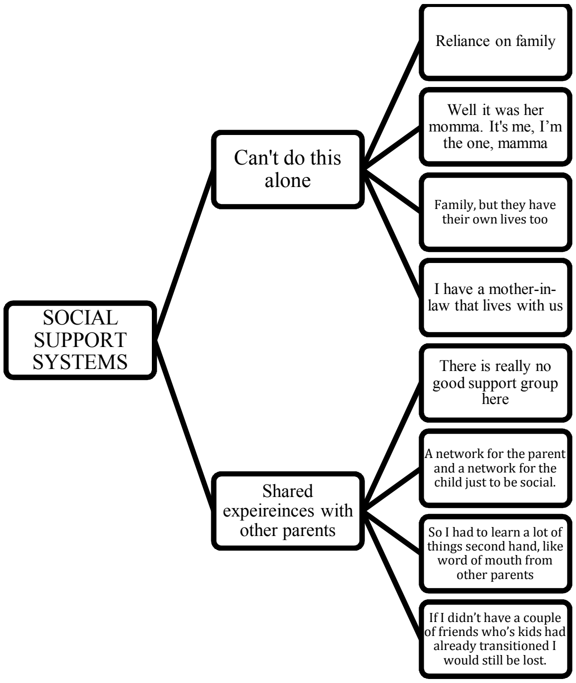

Figure 4. Thematic map: Social support systems.

Social support systems were found to be key in navigating through the transition process. The support from family was identified by all the participants as an important factor in managing their child. Although the parents identified themselves as the main caregiver, they also indicated that they relied heavily on the assistance and support from family and friends.

P1: “Family, like sometimes, a few times when I couldn’t go get him my mom went and got him.”

P2: “Family, family, mainly my family.”

P3:“Family, my mother lives with us.”

P4: - “Well it was her momma. I’m the one maam I’m the one maam, I ‘m the one that loves Autumn. I’m the one that stuck the gun cause she lives with me.”

P5 said the following:

> Uhm my tenacity, my motivational skills, my confidence levels. It was no help from the schools, just let me say that. I don't mean to step on any toes, but it's the truth. School offered as little help as possible.

P6 said" "It all fell on me cause I'm the main number one caregiver. My mom, she's did a lot for me, helping me and of course my daughter, but they have their own lives to, so." Furthermore, P7 stated:

> Family. I have a mother-in-law that lives with us. So he has his grandma she's legally disabled so she doesn't work. I'm lucky enough to have a stable family gathering, but if there was someone who didn't have that around them, I think it would be pretty hard.

P8 said:

> Family and friends. So poor M, was basically being shoved from here to there uhm you know just like who's house, who's going to pick him up from school today or who's who's gone be here when he gets off the bus? Sometimes nobody and that was scary. So you know we made it work and I don't know how, but we did it.

Subtheme: Networking /Parent Support Groups

The participants in the study described networking and parent support groups were essential for not just their child, but also for the parent. Being able to share your situation with someone who understood because of the commonality of the experience without being judged or having to explain over and over was comforting and deemed as a necessary part of developing as a parent and gaining more insight into the process of transition. It was also identified as way to gather and share information.

P5 stated the following:

> Uhm, there are parents that try to be helpful but they don't have time because they're too overwhelmed with their kids. If they have kids with disabilities so it's hard to get help so there is really no good support group here that has really helped out. There is really very little for people his age with disabilities in our city. Maybe one day it will be different, but that's it. Nobody alerted me to that. If I didn't have a couple of friends whose kids were already attending (Parks & Rec.), I would still be lost.

P7 said:

> Sports is very much a network for the parent and a network for the child just to be social. Not only that but it gives parents connections on hey how did you do that? This child is 5 years older and is out of school how did you do that?

P1: "Any other information I get, it's because I got it on my own by asking other people or researching it myself not from the school."

P2: "Someone told us about Parks and Recreation Therapeutic Program."

P3 responded the following:

> Other parents have told me about meetings and I need to start going to the meetings they have for parents in the community cause there's a lot of things she can do that I have not allowed her to do.

P4 said:

> Ah, April had been in three different hospitals and so the last one uh uh a nurse found the number for me and I got in here and I made it no, we made it happen. We need more programs like the Rec Center and we need more people like Ms. S, you know she saved her.

Furthermore, P5 stated:

> Uhm, there are parents that try to be helpful but they don't have time because they're too overwhelmed with their kids. If they have kids with disabilities so it's hard to get help so there is really no good support group here that has really helped out. There is really very little for people his age with disabilities in our city. Maybe one day it will be different, but that's it. Nobody alerted me to that. If I didn't have a couple of friends who's kids were already attending (Parks & Rec.), I would still be lost.

P6: "He's involved in Special Olympics which he's been involved in you know since he was younger so that helps a lot."

P7 said the following:

> M Sports. I was already involved with Ms. C and M Sports. So that got me in the door for a lot of other things. If it hadn't been for M Sports I wouldn't have had information about half the stuff he's in now because she's the one who geared us into it. Sports is very much a network for the parent and a network for the child just to be social. Not only that but it gives parents connections on hey how did you do that? This child is five years older and is out of school how did you do that?

P8 responded as follows:

> So I had to learn a lot of things second hand, like word of mouth. Someone would say hey I did this, I got this, you need to go here, you need to go here, this is out, this kinda program is here blah, blah, blah. So by word of mouth I ended up, it took me two years to get him what they call the Medicaid Waiver. So he's got that now. It took me two years of hard work. That's something I didn't even learn from the school.

Theme 5: Daily Coordination and Planning

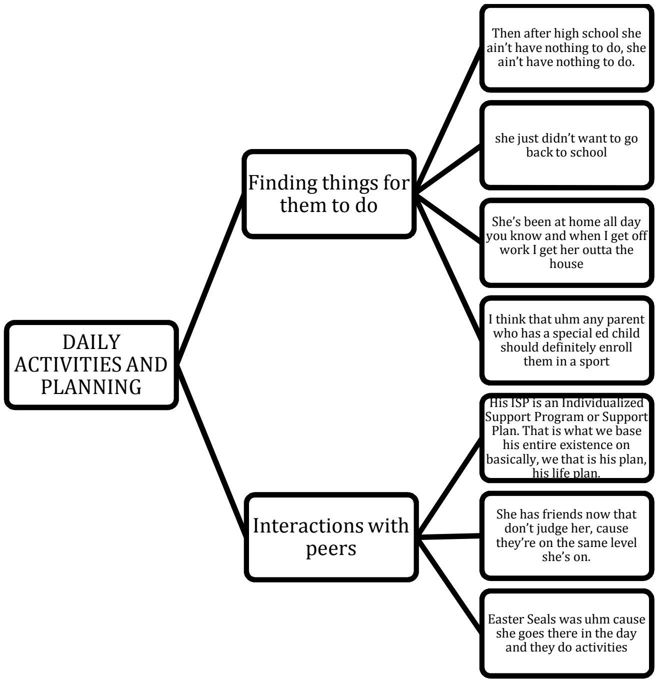

Figure 5. Thematic map: Daily coordination and planning.

This theme emerged out of the data because all of the participants described finding and coordinating daily activities for their child as a priority. Making sure their child was active, continued to interact with peers, and had access to community involvement was important. Newman et al., (2011) in his research found that young adults with ID are less likely than their typically developed peers to be employed, to enroll in postsecondary education, and to live independently after high school

P1: “He stay up all night and sleep all day long cause he don’t got nothing to do.”

P2 said:

> She goes to the Parks and Recreation Therapeutic Program. It is wonderful. She goes faithfully. She loves it. She bowls every Tuesday and it’s not just the field trips and doing things. They also have classwork that keeps her busy. I can even tell with her verbalizations that she is doing better. She is doing well at this program. My other daughter takes D in the morning and I pick her up in the afternoon after I get off from work.

P3: “She to Easter Seals in the day and they do activities with her and uhm they have goals that we set also.”

P4 said the following:

> She comes here off and she comes here off and on (Parks & Rec.), but when she comes here, she feels good when she leaves she gets to see her friends, she was treated with kindness and love and respect. When she’s at the Rec. Center, it’s good. It gets her mind, like I said it’s a different set of friends that it is here than it is in high school. High school bullies, they make fun of you, but here nobody makes fun of you. I mean if you fall they help you get up. Uhm this program saved my kids life. I will truly say that til the day you know.

Furthermore, P5 stated:

> Transportation and everything and planning his daily things. Like I said he still has the waiver so we have to just keep on his ISP trail. His ISP is an Individualized Support Program or Support Plan. That is what we base his entire existence on basically, we that is his plan, his life plan. Uh just like in school there is an IEP. They go by that plan to address school issues this is his plan to address his adult issues.

P6 said:

> We found Parks & Rec, we found the recreation center that's helped him. Brad does work or do anything. So, he's not on any type of work program or job just because of his disability at this point. He has some social skills problems so..

P7 responded as follows:

> He goes to Parks & Rec Monday through Thursday and uhm Friday's I can usually be home or he goes with his grandmother to volunteer at Hospice. So he doesn't sit at home. There's no sitting at home. Even when I'm home we're out and about doing something.

P8:" It took me two years of hard work to get him what they call the Medicaid Waiver. The Waiver is like a big umbrella and all the services fall under it. He gets"

Theme 6: Life as an Adjustment

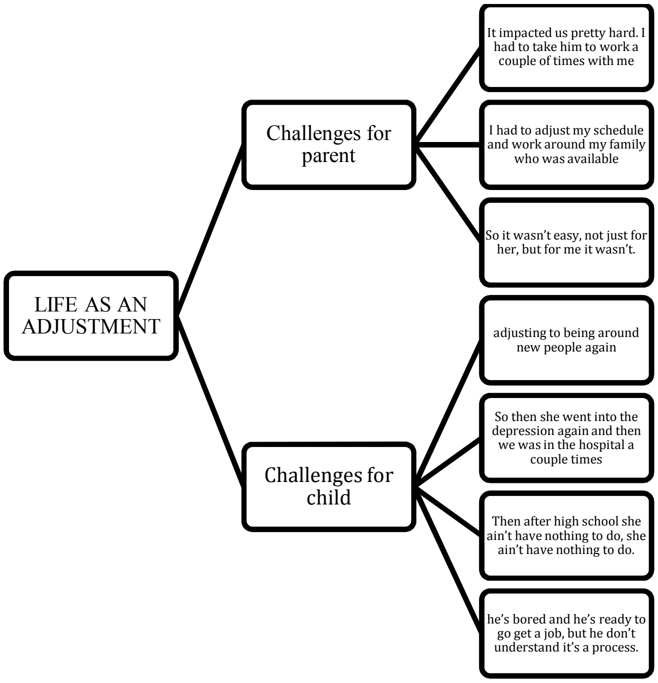

Figure 6. Thematic map: Life as an adjustment.

The participants described major changes in their lives as well as the lives of their child. The ultimate outcome of the transition planning process is to maximize the chances that an individual will deal successfully with the multifaceted demands of adulthood, thus leading to a higher degree of personal fulfilment. The parents in this study reported that factors ranging from altering family schedules, adapting to new environments other than school, relationship strain between mother and child, parent job consequences, to just their child being happy all played a major role in their shift from school to adulthood.

Parent Adjustments:

P1 responded as follows:

> I had to take off work you know to take him all the way back to the school. I would have to take the whole day off because it was 3.5 hours. When I couldn't get him my mom went and got him.

P2: “My other daughter was off in school, but she had to come home. Now she’s working around Denise’s schedule and school.”

P3: “I still go to work every day and all. Uhm and you know Easter Seals picks her up and brings her home so it didn’t really impact us.”

P4 said:

> I mean, uh I was having a big problem with Autumn. I was at an ending point and I called the center, and she kept talking to me and I said if I bring her up here (Parks and Rec.) and you met her and, and, and just see what you know, you think cause I promise you she would be good here if you just give her a chance.
>
> P5: Well I used to feel sorry and play a pity party and say I don’t have a life and I have a degree but I don’t use. I don’t say that anymore. I don’t feel sorry for myself a bit, because I do have a life. He want something to do every day. So, I stopped working. We have to incorporate that into his life. We take him on errands so he can learn this and learn that. We go pick medication so we say we’re going to pick up your medication Al, we’re going to Wal-Mart to get you snacks. We’re doing this, so that is how transition impacted me. Knowing that ok now he was in school but now he’s a grown man letting me know ok we’re preparing him for adulthood. He’s, he’ll be 24 in January so he is indeed an adult. It gets hard and scary sometimes, but you just have to keep going through and do it.

Furthermore, P6 stated:

> Oh the transition has been rough on me because I've had to take on a job that is flexible. I can't go and get a regular job, I can't do anything like that? There are times when he has to go to work with me, I mean he doesn't drive so I have to take him to work with me sometimes. It's basically like having a child in school still. If you want to do anything you still have to find care for him so he can't stay by himself so yeah he's with me 24/7. Yeah

P7 said the following:

> Uhm, I think he is hindered by us not knowing what jobs he's capable of doing. There wasn't enough job experience. He went through several programs with the high school and Goodwill and all they said is no he doesn't qualify for our program, but they didn't give us what programs he would qualify for, so that was a hindrance for finding something for him to transition to.

P8:"It impacted us pretty hard. I had to take him to work a couple of times with me. My work was like you can't do that. You can't bring your kid to work."

Child Adjustments:

P5 responded as follows:

> He's getting mad at me cause he said he's bored and he's ready to work, but he don't understand it's a process. Like I say, he has a learning disability so, he's like on a four year old level like an elementary school level, so you can't talk to him about one thing and he is way over in left field. The way his disability is, he don't understand it's not me.

P2 said:

> So uhm, that was another thing, trying to find her something to do. She want to get a job. She's been at home all day you know and when I get off work I get her outta the house and we do stuff on the weekend, but she was in the house all day.

P3 said the following:

> It was hard for her adjusting to being around new people again. She was used to the classroom being at school she was used to her peers. Now that she's older and going back to Easter Seals, she has to readjust to the people there. That wasn't it easy, not just for her, but for me is wasn't.

P4: "She didn't have nothing to do and she couldn't make college she just couldn't make it I mean I love her, she loves me, but I mean you know I couldn't do college either."

P5: "He would just be at home sedentary and they hate that being at home sedentary."

> P6: I put him over at the Therapeutic Program (Parks & Rec). It took him a good, I don't know probably a good six to seven months to, before he was able to get used to everything and not have issues every day. He's doing very well in that program now and they're working with him every day.

P7: It's his goal to be independent. He wants a job, he wants to get out and work, but with him having seizures, he is really limited.

P8 said the following:

> Because we had the Waiver I was able to hire someone to assist him. He has an individual access individual. Before I had the waiver, I spent my whole time

> running errands with him. So, poor Michael, he was just being shoved from here to there, like who's house today? With the Waiver, it's respite services, so when I need a break on the weekends, I can get it.

Theme 7: Personal Growth

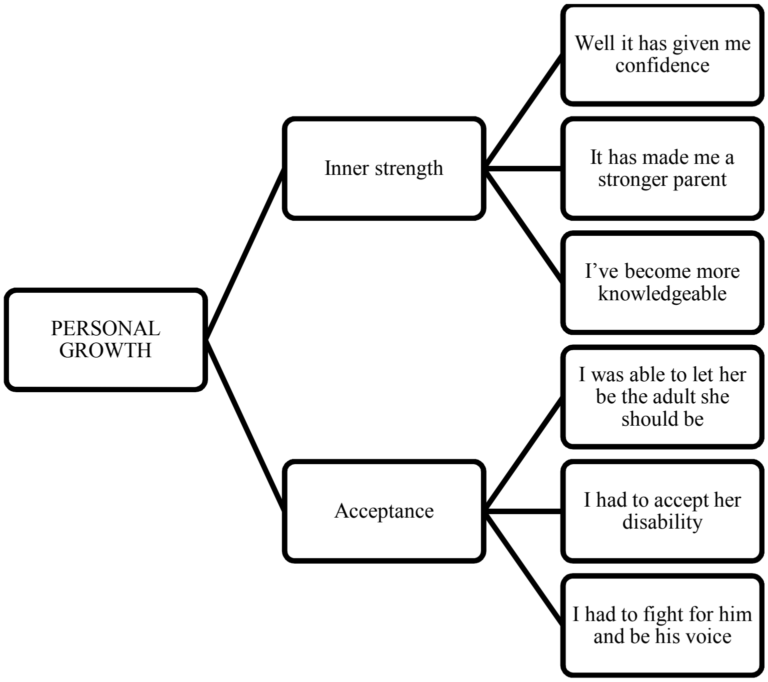

Figure 7. Thematic map: Personal growth.

In response to the question "How have you grown by having a child with a disability, most of the caregivers reported positive growth, despite the challenges? All the parents indicated that they had grown in some way. Descriptives such as stronger, more confident, more patient, more knowledgeable, and more compassionate towards others were used by the parents. McCausland & Pakenham (2003) coined a term "benefit finding" which referred to the belief or conclusion that an adverse event or circumstance has the ability to evoke positive outcomes in an individual's life. All eight participants made a point to identify how they had grown in response to having a child with an ID and through the transition experience.

P1: “I’m a stronger person. I like, I just had to fight for him and be his voice.”

P2: “Well it has given me confidence. The confidence I need to let her be the adult she should be. It has made me a stronger parent.”

P3: “It’s helped me to understand more about her disability and not be so protective.”

P4: “I have accepted Autumn’s disability. For a long time I said there’s nothing wrong with her, but there is. Now I know that.”

P5 said the following:

> I’ve grown in a lot of ways. I listen, I’m more patient because they’re a lot of people who know what they’re talking about just like I do, so I don’t shoot people down as quickly as I used to because we are experts and we don’t even realize it. We are experts as parents, we are really more than parents because we know our own child so well and any professional that will admit that to you is telling the truth. I’ve had professionals tell me you’re the expert and they’re right. I used to, I would say thank you so much, but now I’m like, yeah you’re right and you’re right I am. Yeah I appreciate it but I already knew that. I don’t have the big head about that it, it’s just a fact. I’m way more knowledgeable. I’m pretty much a professional uhh of everything about him. Anything about him, ask me and I can tell you and I can do it in laymans terms or I can do it in clinical terms.

P6 responded as follows:

> I do volunteer work now for the Challenger little league (special needs baseball team). I think that all people should introduce their children to some kind of special needs program. Like take them to a softball game or baseball game you know or to this bowling facility because you have a different outlook on life when you see that. Compassion.

P7 said:

> Patience, I have patience to where I did not know I had because until you have a kid or a relative or someone you deal with on a daily basis that has limitations even though they don't think they have limitations, you learn to be really patient. That is the one….

P8 responded as follows:

> Uhm yeah of course. I'm totally different from in general just having a child with a disability? Oh yeah! It's different. I'm not naïve to everything. The world is different and it's really not about you and there's more emphasis on the normal than …. I never thought in a million years that I would have to fight so much for 1 child. It's sad, it's sad to say, but you know it sure does make you a stronger person.

Theme 8: Looking Towards the Future

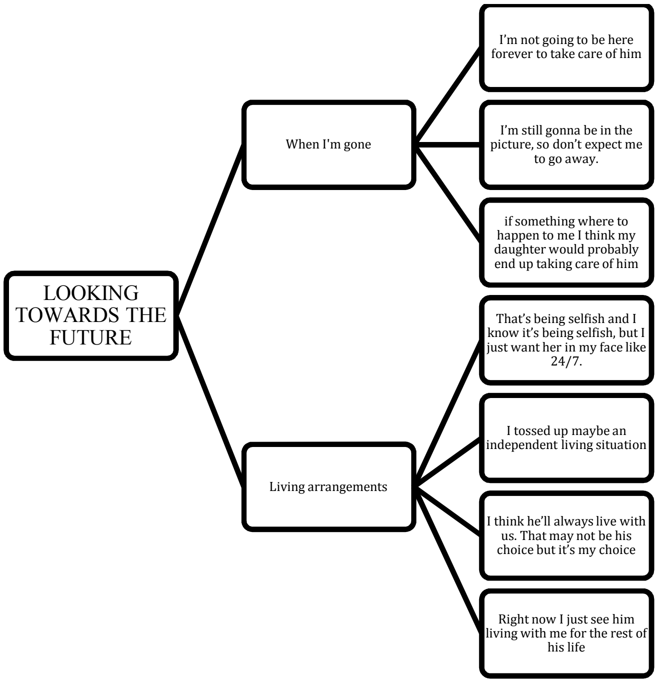

Figure 2. Thematic map: Looking towards the future.

All of the parents, regardless of their experience, reported having a positive outlook on their child's future. Concern for their child's future living arrangements, future goals, and making sure that they were taken care of in the future were the reoccurring patterns found in the interviews. No matter what the case, the parents were all committed to playing an active role in their child's life and foresaw them as living at home with them.

P1 stated the following:

> I'm not going to be here forever to take care of him, so that's why I was so hard on the teachers in the school system. In the future, I see him working and living independently but not by himself. No matter what, I'm going to keep advocating for him!

P2 responded as follows:

> I'm proud of her and the back of my mind I still want, I want her close to me. That's being selfish and I know it's being selfish, but I just want her in my face like 24/7. I know that's not going to get it, but I know that momma ain't gone always be there. I just want to know that Denise will be fine by herself. I know she will do just fine.

P3 said:

> I handicapped her in a lot of ways by not allowing her to do things because of how people are in society. She wants to have a boyfriend and other things and it's kinda like, I have not allowed her to do that because she has Down's, not to say that she couldn't, but she's not developed. You know she is developed but not mentally developed to have a baby cause she wants to get married, she wants to have kids. I don't see that. I think she'll just be here with us. I want to be more open-minded. I still want her to do more, but I'm kinda scared. But hopefully, I'm going to let her do more independent things in the future.

P4 noted that:

> Autumn is probably going to be with me for the rest of her life and that's good. She is she's gone have her up and down days. I see, I see, I see a brighter side. Because maybe someday she'll want to go back to school if she want to go to school she can go to school or maybe she, she wants to get a little job she can or she can volunteer. I see I see uh a big difference you know a brighter future instead of a darker days.

Furthermore, P5 stated:

> I mean the way life is I may not even be in his life all the time. I may go, I may pass before he even gets a certain age and if that's the case that's why I'm working so hard now. Because if I leave, for that reason if I die, he, somebody will say, she was working hard to do this and I will have it in my notes and I will have it on my computer, I would've told somebody about it. Hopefully, I will have worked with him through this and he will be able to live alone, maybe not alone because he would have around the clock staff. He could have it now, but he can't because I'm there and they know that I'm going to be by his side no matter what. But if I died or something and if his program were to continue I'm pretty sure he would have around the clock staff. It wears me out, it wears me down but my spirit is not shut cause that's my son and you gotta take care of him no matter what.

P6 said the following:

> Right now I just see him living with me or if something were to happen to me I think my daughter would probably end up taking care of him. I tossed up maybe an independent living situation, but I don't know what our city has to offer that… he, and for me to trust someone to take care of him….

P7 said:

> I think he'll always live with us. That may not be his choice but it's my choice only because he doesn't know how to cook for himself. Uhm, there's just little things that he can't do uhm that he just physically can't do. Yes, like showering, he can shower by himself, but he doesn't like it so if he lived by himself it would

> be three weeks before he took a shower. Little stuff like that that you don't think about normally, but little stuff like that is the stuff that keep them from being able to be independent is that little kind of stuff. They don't understand prioritizes. Yes you have a job but you need to pay bills it's not just living on your own. Everybody gets to do everything for you and you just get to be by yourself in your room. It doesn't work like that.

P8 said:

> I don't know if he will ever be able to live on his own or if he will ever show any interest in it. Uhm he's got it good here, you know what I mean? He really does. We do make him have chores. I've never treated him any differently than my other kids. I never have. If he wants to move out we can make it happen. I mean that's just one more struggle and fight to deal with.

There were no discrepant cases identified during the data analysis procedures. Each participants had something to contribute to each of the final themes that emerged from the data collection and analysis.

Evidence of Trustworthiness

To establish credibility, triangulation and member checking was used. I examined each participants' interview separately. This allowed me to use multiple informants who contributed differing points of view and experiences of the transition of their child as a means to establish the credibility of the data. Member checks were also utilized to verify and in some cases clarify my understanding of the parents' experience.

To establish transferability, I provided a clear and in-depth description of the parents' reports of their lived experience and the context they used to help make meaning of the experience. These detailed descriptions allow for the reader to make decisions regarding the transferability of findings.

I used an audit trail to assure dependability was maintained. I retained a record of the interview transcripts and a journal. In the journal, I recorded my thoughts and processes I followed as I moved through the data analysis. Detailed information pertaining to the identification of patterns and structuring of theme development that emerged from the data was included.

Reflexivity was used to ensure confirmability. I kept a self-reflective journal from the beginning of the study to record an accurate account of my experiences and responses. By doing this, I was able to maintain an ongoing awareness of any personal assumptions or biases that I might have brought to the study and to assure that they did not negatively influence the data analysis process.

Data Analysis Results

Interpretive phenomenological studies are concerned with the detailed examination of the human lived experience. It is an interpretive process that draws on examining the participants' personal perspectives before moving to more general claims of the lived experience. Eight themes and one subtheme emerged from the interviews which allowed me to gain a greater insight of the parents' experience of the transition process of their child from high school to adult services.

The themes and subtheme that were identified through the data analysis procedures address each research question and therefore create a foundation for the presentation of the key research findings presented in this study. In regards to Research Question 1, (What is the lived experience of well-being in parents of adult aged children with moderate IDs as their child transitions from high school to adulthood?), three findings were brought to light.

The first theme that emerged from the data is that all of the parents in the study viewed their experience with the transition process as one that was very stressful for both them and their child. They all agreed that the felt the school would have done more to prepare them for the transition and to equip them with options that were available after they made the shift from school-based to adult services. Feelings on anxiety, disappointment, and sadness were evident in their responses.

The second theme was that in general participants held two different views about their relationship and experience with the school. The views were reported in terms of the parent's personal experience with school and then based on their child's experience with the school. In regards to the parental experience, three of the parents reported positive experiences with the teachers. The remaining five parents indicated that they were frequently in a place where they felt they had to advocate for their child and felt unsupported by the school. They indicated that they did not believe the school provided them with the necessary information needed to ensure a smooth transition for their child. A lack of resources, limited direction given for securing post-graduation services, and feelings of frustration were some of the feelings that were reported. The parents did not place blame on the teachers directly, but eluded to the fact that it was a more systematic problem versus an individual teacher or school problem. In terms of the experience parents' reported as it pertained to their child, seven of the eight parents identified that they believed school was a positive experience for their child. In describing their child's experience with the school, most of the responses stressed social interaction, peer relationships, community based experience, and general feeling of preparedness for their child to move on to life outside of the school setting. Only one of the parents' provided input that addressed academic skills.

The third theme is that all the parents agreed that accessing and coordinating services was a challenging undertaking for them. This theme is significant due to the fact that there was a clear distinction in the amount of time it took for the parents to get their child connected with an adult service based on whether or not the child was already linked with an agency outside of the school prior to the transition. All the parents reported that their connection with services for their child was due to their efforts and were not a result of any information provided by the school. Three of the parents reported that their access and child's participation in services was based on a prior relationship and referral they received from another agency that their child was already involved with. The other five parents identified factors such as waiting lists, availability of funding, inconsistency with agency personnel, and meeting eligibility criteria as barriers to accessing and coordinating services for their child.

For Research Question 2, (How do parents describe their purpose in life and attainment of that purpose given the responsibility for the caregiving of their adult aged child with an ID after the transition from high school?), three themes emerged. The fourth theme that emerged from the data is that the parents believed that without a strong support system that consisted of family and friends, they would not have been able to make it through the transition process. The parents took the responsibility of caring for a child with a disability very seriously and saw that as one of their main purposes in life. They did not believe that they could successfully fulfil this purpose without the reliance and support of others. One parent, P8 reported “So you know we made it work, and I don’t know how, but we did.” P7 added “I’m lucky enough to have a stable family gathering, but if there was someone who didn’t have that around them, I think it would be pretty hard.”

Daily coordinating and planning emerged as the fifth theme and played and essential part in the parents feeling like they were working towards meeting the needs of their child (purpose). In working towards ensuring their child remained active and continued to stay connected to peers and the community. Two of the parents reported that their child has access to the Medicaid Waiver which is very instrumental in assisting with daily planning and coordination of services based on an Individual Support Plan (ISP) which is very similar to the IEP, but it is a life plan versus an education plan. Five of the parents indicated that their child is involved with a community agency and the remaining parent reported that her child is at home still awaiting services to open up for him.

A sixth theme that emerged was dealing with life as a major adjustment. Given the fact that all the parents identified that taking care of their child gave their lives purpose, they all reported that they were committed to making sure their child was able to adjust to the realization that they were no longer attending school. The parents responses were broken down into the adjustments they had to undergo as well as those that were evident in their child. For the parents, altering family schedules, job consequences, and assuring their child was happy and supported were identified as some of their goals for maintaining a smooth transition. In terms of the parent adjusting, P5 indicated “Well I used to feel sorry and play a pity party and say I don’t have a life and I have a degree but I don’t use. I don’t say that anymore. I don’t feel sorry for myself a bit, because I do have a life. He want something to do every day, so I have to do it.” P6 reported having to make adjustments with employment, “Oh the transition has been rough on me because I’ve had to take on a job that is flexible. I can’t go and get a regular job, I can’t do anything like that.” Accepting the fact that school had ended, adjusting to a new environment, and meeting new people were some of the factors that were reported as part of the challenges experienced by the child. Several of the parents indicated that their child had a hard time understanding that the transition from school at adulthood was a process. According to P1, “He’s getting mad at me cause he said he’s bored and he’s ready to work, but he don’t understand it’s a process. Like I say, he has a learning disability so, he’s like on a four year old level like an elementary school level, so you can talk to him about one thing and he is way over in left field. The way his disability is, he don’t understand it’s not me.” P2 reported a similar experience “She want to get a job. She’s been at home all day you know and when I get off work I get her outta the house and we do stuff on the weekend, but she was in the house all day.”

Research Question 3 asked: How has the experience of transition contributed to the participant's views about themselves in light of the challenges and benefits faced during the transition period?

In relation to this research question, a seventh theme emerged from the data analysis, which was personal growth. All of the parents reported that they had grown in some way due to having a child with a disability and moving through the transition process. Even given the challenges that were associated with this period in their child's life, the parent were able to see the benefits rather than focusing on the challenges. Two of the parents reported that they've become more knowledgeable because they've had to come to a place where they were able to accept that their child has a disability and what that entails. Two other parents placed a strong emphasis on patience. In the words of P7, "Patience, I have patience to where I did not know I had because until you have a kid or a relative or someone you deal with on a daily basis that has limitations even though they don't think they have limitations, you learn to be really patient." and P5 added "I've grown in a lot of ways. I listen, I'm more patient because they're a lot of people who know what they're talking about just like I do, so I don't shoot people down as quickly as I used to because we are experts and we don't even realize it. We are experts as parents, we are really more than parents because we know our own child so well." Strength, courage, confidence, and compassion were some of the other reoccurring attributes that came to light as the parents presented their accounts of their personal journey and the growth they associated with it.

Lastly, an eighth theme emerged from the data analysis concerning the parents' recollection of their transition experience. The parents all held a positive outlook regarding their child's future. Similar patterns were noted in the way the parents thought about what was in store for them and their child in the future. Assuring that their child was provided for, issues pertaining to their living situation (at home/independent), acknowledging that as a parent they won't be around forever were some of the common threads shared in the interviews. The parents shared the following: P5, "I mean the way life is I may not even be in his life all the time. I may go, I may pass before he even gets a certain age and if that‘s the case that's why I'm working so hard now. It wears me down but my spirit is not shut cause that's my son and you gotta take care of him no matter "what." P6, "Right now I just see him living with me or if something were to happen to me I think my daughter would probably end up taking care of him. I tossed up maybe an independent living situation, but I don't know what our city has to offer that… he, and for me to trust someone to take care of him?" P7, "I think he'll always live with us. That may not be his choice but it's my choice." P1, "I'm not going to be here forever to take care of him, so that's why I was so hard on the teachers in the school system. In the future, I see him working and living independently but not by himself. I'm going to keep advocating for him."

Summary

In Chapter 4, I presented the findings of the research study. I explored the lived experience of 8 mothers of adult aged children with moderate IDs as they transitioned from high school to adulthood. The identified purpose of this study was to understand how parents of young adult aged children with a moderate ID experience well-being as their child transitions from high school to adulthood. Also I sought to address an identified gap in the literature regarding the lack of literature with the focus being on well-being versus stressing the negative effects and challenges of parents who provide long-term care for their disabled adult children, specifically, those with a moderate ID as they transition from high school.

I relied on the constant comparing process to analyze the data from each parent to identify the essence of their experience of psychological well-being through the process of the identification of the major themes that were derived from the interview questions of the research study. The major themes were expectations and preparation, experience with the school, accessing and coordinating services, social support systems, daily coordinating and planning, life as an adjustment, personal growth, and looking towards the future. Networking and support emerged as a subtheme under social support systems.

In Chapter 5, I will present information regarding the interpretation of the findings as they relate to Ryff's Model of Psychological Well-Being as the theoretical framework. Also, in Chapter 5, I will address limitations of the study, recommendations for further research, implications for positive social change, and the conclusion of this research study.

Chapter 5

Introduction

My purpose in this qualitative phenomenological study was to describe the lived experiences of psychological well-being in parents of adult aged children with moderate IDs as they transition from high school. The study participants included eight parents from an urban school district in Georgia, who indicated they had experienced transition within the past one to three years.

Significant findings of the study revealed eight central themes in the lived experiences of parents of adult aged children with a moderate ID and their transition from high school. The themes included: (a) expectations and preparation, (b) experience with school, (c) accessing and coordinating services, (d) social support systems, (e) daily activities and planning, (f) life as an adjustment, (g) personal growth, and (h) looking towards the future.

Interpretation of the Findings

I used nine open-ended questions as a means to capture the lived experience of the parents of adult aged children with a moderate ID and their transition from high school. Included is a review of the research literature because it compared to the study findings as well as an interpretation of themes that emerged throughout this study.

Expectations and preparation

All of the parents in this study indicated that they faced significant challenges while navigating through their child’s transition out of high school. This is consistent with the literature which portrays transition as a time of increased stress and challenges for parents (Davies & Beamish, 2009; Plinick et al., 2011; Raghaven, Pawson, & Small, 2013). The participants identified a lack of adequate understanding of the transition planning process. This resulted in them developing vaguely defined expectations and limited direction in making preparations for their child postgraduation. All of the parents described being given limited information regarding their options. This is consistent with the previous research where transition planning was depicted as a process where parents reported a lack of adequate understanding which contributed to a considerable levels of stress (Raghavan et al., 2013). According to Georgia's transition process, it is mandated that transition services must be addressed in the Individual Education Plan when the student enters ninth grade or turns 16 years old. None of the parents were able to recall any specific goals that were created or a plan for achieving the identified goals that would assist with the shift from school to the access to educational opportunities, job training, and/or recreational options that were available in the community, which were the highlights of the state of Georgia provisions. Although some of the parents recollected participating in an exit meeting, they were not able to recall a specific plan that was developed.

P6 reported "They talked to me about transition I guess at the last IEP meeting and I guess it was the last exit meeting so, but I don't know." P7 shared

> There's not enough information given out in the school system for what to do after school. They have a transition fair, but you don't get specific information as far as the age groups, the qualifications that are needed or anything like that. I think that's the hardest part.

P8 reported,

> I don’t recall much that was said about the meetings. There was a meeting, but I didn’t feel like I got anything out of it. They told me you need to try and find this and find that. Really because, I’m like where is the transition?

Neece et al. (2009) posited that when programs fail or do not live up to parents’ expectations, the family system is affected. Hence, parent’s dissatisfaction with the process can potentially affect psychological well-being.

Experience With School

The experience with the school was another theme that emerged and was discussed by all parents. In the recalling of their experience with the school, the parents tended to report their experience as a two-fold interaction. One was their personal experience and the other was their child’s experience. Seven of the eight parents (88%) reported a positive experience with their child’s interactions in the school setting. They reported that their child was provided with strong social networks, seemed to be happy, safe, and enjoyed coming to school. They were very complimentary about the interactions between their child and the school environment. The parents did not seem to be overly concerned with the traditional definitions of success as it pertained to transition. The parents in this study did not put emphasis on continued education, competitive employment, or independent living as a measure of success. This mirrored what Henniger and Taylor (2014) found in their study, which was that parents of young adults who had already transitioned out of high school were less likely to see goals such as postsecondary education and occupation as essential to adult success.

In terms of the parents' relationship with the school, the parents reported that for the most part they had developed great relationships with the teachers throughout their child's educational career. This was mainly due to the fact that they considered themselves as being very involved parents in their child's education. They reported that teachers made it very clear to them from the time their child was in elementary school that would be afforded the opportunity to remain in school throughout the year in which they turned 21. However, the parents did not feel as if the school provided them with a detailed plan of how the transition from school would unfold. The fact remained that the teachers did not seem knowledgeable about the continuum of services, resources, or options available for their child that were available post-graduation that were specific to their child's interest and ability level once they left school. Several parents indicated that they were presented with a list of general resources that could possibly be available. One of the parents even stated "It's not the teacher's responsibility, they are there to teach." They did not specifically blame the teacher for the lack of information. They felt it was more of a system-wide problem because the teachers had not been properly trained or were not knowledgeable on how to link what they were teaching in the classroom including the opportunities for employment and community inclusion with a plan of action on how that would translate into opportunities for the child after they left the school setting.

Accessing and coordinating services

The majority of the parents expressed the need for better communication and information about services. The need for information about adult service provision has been consistently reported in the literature. A few of the parents indicated that they had made connections due to the fact that their child was previously involved with or had access to particular services or organizations outside of the school environment prior to transition. Specific information that outlined how to access services and with choosing the most appropriate option for their child was identified as a key element that was missing. When positive post-secondary outcomes were achieved, the parents attributed this to the part they played versus an extension of the transition planning. Research indicates that one of the likely reasons for heightened stress during this period is that families have the added burden of finding, coordinating, and financing adult services (Henniger & Taylor, 2014). Despite the mandated transition support set forth in IDEA, it has been suggested that many schools fall short of meeting the needs of transitioning students with ID in the areas of engaging student and family participation, setting goals based on students' skills and interests and ensuring full participation in employment, post-secondary education and independent living opportunities (Henniger & Taylor 2014).

Social support systems

A sense of family solidity presented as a strong characteristic in the parents' accounts. The immediate family unit as well as the maternal grandmother were cited as central sources of support. Gallagher et al., (2008), studied the predictors of psychological morbidity in parents of children with IDs and reported that social support was one of the key factors that accounted for much of the distress in parents. He further reported that to minimize the effect of caregiving on parental distress that those with greater social support showed better psychological adjustment. This was consistent with what the parents in this study reported. All of the participants interviewed identified family support as a major factor in surviving transition. According to the literature, increased social support is known to reduce burden. Heru, (2000) in her study found that family support systems can act as the mediating environment to foster caregiving burden or reward. In this current study, the latter seemed to be the case. None of the participants identified family as a source of burden or added pressure.

Positive parent groups which served as an avenue for networking was identified as a subtheme to social support systems. Several of the parents reported that they found it beneficial to engage in relationships with other parents of children with disabilities as a means to sharing information and building relationships with others who shared similar experiences. Shilling et al (2013) identified four specific themes in their work on peer support for parents with a chronic disabling conditions that they found lead to supporting well-being. Social identity, learning from experiences of others, personal growth, and supporting others were all identified as factors that influenced the experiences parents encountered. Three of the participants even reported that they were committed to assisting other parents who were going through the same process in any way they could which included providing information, sharing resources, and sharing in daily care in some cases. By developing these positive connections and creating these networks of parents, this further added to the feeling of purpose and being given a higher calling in life.

Daily activities and planning

The parents expressed a need to want to feel confident that their child would be in a stimulating environment where they were safe, able to learn new skills that were consistent with their functioning level, and were surrounded by peers to continue with developing and maintaining friendships. The parents seemed to want services that were comparable to what their child was receiving while at school to promote continuity for their child. Dyke et al. (2013) identified concerns with adult roles assumed during the day as one of the five major themes that parents in their study reported concerns with after their child transitioned from high school. All of the parents indicated that finding community based programs and activities that were appropriate for the child was difficult. Four of the parents reported that their child was simultaneously involved in sports and other activities in the community while still in high school, which made it a little less difficult to access those services after transition. Although they continued to participate in those activities, it was limited and did not span across the same hours that the child was accustomed to spending in school. Transportation and balancing work schedules were identified as barriers, but not one of the parents reported that they considered this as a burden, but more of responsibility that came along with raising a child with a disability.

Life as an adjustment

This was another area that was reported on with a distinction made to the parent versus the child experience. All of the parents expressed the adjustment from the discontinuation of school services as one that significantly affected not only them, but by the child in major ways. In terms of parental adjustments, this was consistent with the literature which posits that the transition period is characterized by a series of events and decisions that parents are required to address simply because the fact remains that although their child might be adult age, their capacity to reason and make sound decisions is significantly impaired (Green 2004; Newman et al. 2011; Test 2008; Neece et al., 2009). Parents reported a myriad of factors that contributed to adjustment such as the change in the daily routine of going to school, meeting new people, a gap in services, identifying new services, changes to family routines, employment issues, and merely keeping their child engaged. Of course individual characteristics of the child (level of cognitive ability) and their level of appropriate social behavior were key factors. Parents reported that what their child envisioned for themselves was not necessarily realistic. Several of the children were anxious about securing jobs and living independently, which lead to conflict between the parent and child. This speaks to the importance of including the parents and the child in the decision making portion of establishing a transition plan. This would ensure that parental input into developing an appropriate plan where the specific interest of the child, their goals, and capacity to execute them are explored. That way no one is shocked when trying to find services or programs after transition.

Personal growth

Bhatia et al., 2015; Srivatava, Guatam, Saha, and Kaur, 2015; and Gallagher et al., (2008) found that caregivers of people with IDs perceived a significant burden and suffered psychiatric morbidities in the form of depressive and anxiety disorders. This would suggest that the significant effect and negative consequences of burden and stress on caregivers result in a reduction of their caregiving ability. Gallagher, et al 2008 also focused on caregiving burden and the implications for the presence of symptoms of depression and anxiety. They actually found that the strongest and most consistent predictor of psychological morbidity was caregiver burden. None of the parents in this study reported any physical or psychological symptoms or diagnosis. They actually offered the opposite in light of having a child with an ID. The parents did not deny that they faced challenges and difficulties, however they choose to focus on the positive attributes that they believed contributed to personal growth. Being more confident, knowledgeable, patient, and compassionate where some of the perceived benefits they were able to convey in their descriptions. This is consistent with MaCausland & Pakenham, (2003) term “benefit finding” which focuses on how positive outcomes are realized in the midst of an adverse circumstance or event. These parents made a conscious decision to view their contributions to their child’s outcomes in a positive light, which resulted in perceived benefits for both them and their child.

Looking towards the future

Willingham-Storr (2014), pointed out there was a range of feelings conveyed by parents of children with IDs with regard to transition, ranging from fear of the change to hope that their child would continue to grow and develop. Although the transition from school brought about new challenges for the parents in this study, reflecting on the transition as a learning experience and viewing the future as positive was a common theme expressed by all the parents. None of the parents in this study suggested plans for residential or assisted living facilities. Six of the parents reported that they believed their child would continue living with them throughout their lives. One parent shared “He’ll probably always live with us. That won't be his choice. There's just little things that he can't do uhm that he physically can't do." The remaining two parents indicated, that in the event that their child would move out, it would not be independent living. They would have to have a roommate.

Conceptual Framework and Findings Interpretation

Ryff's (1989) model of psychological well-being was the conceptual framework used for this study. This model affirms that well-being is a concept that involves perceived thriving in the face of existing challenges of life. Ryff's model of psychological well-being was applied to this study to explore how parents perceive and adjust to the benefits and burdens of caregiving during a specific period (transition) that is depicted as being stressful and challenging in the literature. Ryff's model of well-being goes beyond a feeling of happiness in the moment and seeks to explore psychological well-being as a construct that is evolving despite the perceived burden caregivers might identify. Thus, the focus is more on how these challenges may be used to augment well-being and contribute to caregiver satisfaction which could ultimately lead to an enhanced sense of fulfilment and accomplishment.

As presented in the literature review, Ryff's model of psychological well-being encompassed six specific characteristics: (a) self-acceptance, (b) environmental mastery, (c) purpose in life, (d) positive relations with others, (e) personal growth, and (f) self-determination. The responses provided the mothers and the themes that emerged aligned with these characteristics. All of the mothers reported that the transition of their child was difficult for both them and their child and did not go without challenges. However, given the nature of process they remained encouraged to support and advocate for their child in spite of the life adjustments that were presented. The transition process, like Ryff's model of well-being is multidimensional and can be viewed as a work in process rather than a single isolated event. In regards to self-acceptance, the mothers in this study all reported that their lives had changed due to having a child with a disability, which included some victories and some defeats, which did not compromise their well-being. Environmental mastery – the parents did not deny that the situations they were placed in were difficult. They were able to reflect back on their experiences during the transition stage and reaffirm their desire to obtain only the best outcomes for their child's future by placing them in environments that were conducive to further development of their child despite their limitations. Purpose in life – The parents in this study all reported that they had a clear and defined purpose in life which included advocating for their child. Positive relations with others – all the parents reported that they each had built a positive support system which consisted mainly of family. However, most participants reported a need to seek out and establish bonds and relationships with other parents. Several of the parents further reported that they were committed to assisting other parents who were going through the same process in any way they could which included providing information, sharing resources, and even sharing in daily care in some cases. Personal growth – based on the responses of the mothers, personal growth was the area where they seemed most proud to discuss. Given the obstacles and barriers that arose, they all indicated that they had grown in some way. Autonomy is the last area and based on the interview questions, was addressed. The mothers were all in agreement that autonomy was influenced as it would be given the task of parenting any child. This was the area where they seemed to struggle most. So much of what they reported about the transition process was based on what the school had to contribute. The parents did not feel as if they were knowledgeable enough about the process to make informed decisions that would guide them in making arrangements and setting the ground work for what would transpire in their child's life after they left the academic arena. Parents identified a sense of purpose in helping their son or daughter to gain independence and progress through this period of transition.

Limitations of the Study

During the execution of this study, several limitations arose. First, this study was limited by the size of the sample population, given that eight parents participated. I was able to minimize this limitation by making sure saturation had been reached. Since all the participants were from the same geographical region, the range and availability of transition opportunities and adult service options for individuals with moderate ID and their parents were specific to that area. Therefore, these results may be less informative to parents outside of this region given the range of service options that are accessible based on what is offered in their specific location because the range can vary greatly between states and even from school district to school district. An additional limitation that is directly related to the study participants was the fact that seven of the eight participants had an affiliation or participated with a particular organization or service. Willingham-Storr (2014) cautioned that by using participants who participated in groups or services, you stand a chance of missing the views of a hidden population who may hold views that are different from those who participated. Therefore, the study was limited by the characteristics of the sample.

An additional limitation that presented itself during the research study was the potential for researcher bias. In phenomenological research, this is due largely to the fact that the researcher is the primary instrument. To reduce potential researcher bias, I kept a self-reflective journal, which provided me with the opportunity to bracket any personal feelings, experiences, and judgements. I also relied on incorporating member checks, and providing in-depth rich descriptions to help ensure that my past experiences did not interfere with data collection and analysis.

Another limitation of the study was that the participants were asked to accurately recall information that occurred one to three years ago. The potential for recall bias could play a role in how they reported the information. Given the time lapse, the participants' accuracy of recall regarding their prior experiences could've possibly presented as a factor in how they responded to the questions that were presented to them. In an effort to minimize potential recall bias, I presented the interview questions in a standardized manner that was consistent between all participants. The questions were clearly articulated and clarified if needed using additional probing. I also provided the participants with an adequate amount of time to think through and reflect back on their experiences before answering the questions that were presented to them. (E. Hassan, 2005).

Recommendations

By conducting this phenomenological study, I sought to address the identified gap in the literature regarding the lived experiences of well-being in parents of adult aged children with a moderate ID as they transition from school-based to adult services. The 8 parents who participated in the study were all mothers from an urban city in Georgia who had experienced transition in the past one to three years. This is not uncommon since typically, mothers are the primary caregivers for children with disabilities. Further research would be improved if the sample included fathers or male caregivers.

Most of the participants reported that their child was involved with or in some way connected with an agency that provided support for their child. Thus, a potential area for future study would be accessing and identifying those parents who do not have any support systems for their child. These parents who volunteered for this study are involved and play a more active role in their child's life, so those parents with less resources may be able to provide a different perspective of the transition experience.

Implications

The implications of positive social change included a better understanding of the lived experiences of well-being as reported by the parents of adult children with moderate IDs as they transition out of high school. This study may also contribute to the understanding, awareness, and current evidence of this social problem to inform others of the implications.

The experiences and opinions of families providing care for their caring offspring with IDs is an area that has been previously studied. There is extensive literature that addresses this concept. Nevertheless, there have not been in-depth studies documenting the opinions and experiences of those families providing care for their young adult aged child with moderate IDs as they make the shift from high school and transition into adulthood. Due to the fact that longer life expectancies have been reported for persons with IDs, families are placed in a position where they are tasked with continuing to serve as the primary care giver for these individuals even after they exit high school and transition into young adulthood. This gives greater credence to the importance of soliciting the parent's perspectives because they will most likely have a major influence on what decisions are going to be made regarding the transition process. According to Braddock et al., (2013), 71% of individuals identified as having an ID, as of 2011, resided with a family member who provided care for them. Additionally, the NLS-2, provided data that further supported that individuals with IDs had a greater chance of relying solely on their families, without taking on normative adult roles. The results of this study may assist with providing additional understanding of how parents of young adult children with IDs continue to care for and provide support to their child even after the extinguishing of those guaranteed services implemented in the public school setting have been exhausted. The need for subsequent quantitative research may be implicated based on the patterns and themes that are brought to the forefront by parent caregivers in this study. These potential patterns and themes may also serve to enlighten policy makers, school personnel, and community service providers who develop and implement services on specific areas of need that might be beneficial to and serve to support family careers. Although primary careers and families alike possess varying levels of coping styles, strength, and limit, a large number continue to report they do not believe they are adequately equipped with suitable options for resources and support to meet their child's needs (Willingham-Storr, 2014). By better understanding and appreciating how parents cope with providing continued care for their children with IDs will contribute to the body of existing knowledge and can be directed towards practical implications as well.

All of the parents who participated in this study, reported an unclear understanding of the transition process which lead them to faulty expectations and preparation. School districts are not only required by federal and state law to provide adequate transition opportunities to students and parents, but they play a crucial role in setting the foundation for a smooth transition. By listening to families, working and building better relationships with them, and meeting their needs, the challenges families face may be alleviated rather than exacerbated. Policy makers, service providers and the wider community should work more closely with families to help address the needs to enable people with IDs and their families to feel empowered, supported, and included.

Conclusion

The goal of this phenomenological study was to offer a meaningful understanding of the lived experience of well-being in parents of a young adult child with a moderate disability as they transition from high school. The eight mothers who participated in this study openly shared a detailed recollection of their individual experiences and perspective of their journey through the transition process. Common views about their experience were revealed as they presented both the positive and challenging situations they faced while navigating through the process.

All of the parents in this study described an unwavering commitment to their child's success beyond high school and a desire to be more involved in the transition process, which they believed would better equip them to as parents to deal with issues that arise as a result of their child's separation from the school system. They were able to identify positive aspects and benefits of their child's education that they believed helped prepare them for life beyond the halls of the school. The parents were very vocal in identifying many of the short-comings associated with their individual experience and offered insight to how things could be improved to lessen the burden experienced by parents.

Neece et al. (2009), found that parents who were more satisfied with their child's transition had higher well-being than parents who were dissatisfied with the transition. One of the most eye opening revelations in this study was that the parents tended to equate the transition process as a responsibility of the school. By doing so, there was little to no accountability or ownership prescribed to the parent's role. This was crucial because from the parent's point of view, they tended to identify the school as the main contributor in the transition process rather than the facilitator of the process. When we look at the eight themes that developed as a result of this study, they were all driven by or can be linked to the parent's perception of the school's involvement or lack of involvement in the process. The themes included: (a) expectations and preparation, (b) experience with school, (c) accessing and coordinating services, (d) social support systems, (e) daily activities and planning, (f) life as an adjustment, (g) personal growth, and (h) looking towards the future.

Due to the fact that the young adult child with a moderate ID experiences such significant deficits in cognitive and adaptive behavior functioning, much of how they understand and interpret the experience of transition is based on their parents' perspective and contributions to the process. The parents in this study indicated that they were provided with inadequate information and for the most part could not provide an in-depth description of what exactly the transition plan entailed and how it was to be implemented. They further reported that they didn't recall being included in the development of the plan, which was casually presented to them close to the time their child was scheduled to exit school. If roles and expectations were more clearly defined and presented, this would possibly provide a better initial platform for the parents to participate in the process which is designed to assist with making a smooth transition from school to the next phase of their child's life.

It was established in this research study that both transition and well-being are more than just merely a state of being or singe isolated experiences. They are both multifaceted processes that we seek to better understand to improve transition outcomes for young adult aged children with moderate IDs and their parents. As an effort to empower parents and contribute to their well-being during this specific period in their child's life, it will require a collaborative effort and commitment from the school, parents, and community organizations to result in a positive experience for the child and their family as they move from school services. If school systems are willing to step outside of the traditional box of thinking and adopt a model of transition that not only focuses on the mandates set forth by IDEA, but also incorporates what I refer to as parent consciousness, this will allow for both young adults and their parents to encounter a more positive transition experience. Parent consciousness refers to an increased awareness and concern for the responsibilities and challenges that parents incur due to transition of their young adult child out of high school with an emphasis on improving communication and building positive relationships.

To assure successful transition outcomes and contribute to parental psychological well-being, it will take coordinated planning, collaboration, and decision making among school, staff, families, and a network of community agencies. This phenomenological study accomplished its purpose, as it gave the parents an opportunity to provide insight into their description of the transition process and it also provided them with the platform to make their voices heard. This study confirms that much still needs to be done in this area through the collaborative efforts which include the student, parents, teachers, other school personnel, and community organizations, to smoothly shift from school to adult life.

References

Basit, T. (2003). Manual or electronic? The role of coding in qualitative data analysis. *Educational Research*, *45*(2), 143-154. http://dx/doi.org/10.1080/0013188032000133548

Bayen, E. Papeix, C., Pradat-Diehl, P., Lubetzki, C., & Joel, M. (2015). Patterns of objective and subjective burden of informal caregivers in multiple sclerosis. *Behavioral Neurology*, 2015. http://dxdoi.org/10.1155/2015/648415

Bédard, M., Koivuranta, A., & Stuckey, A. (2004). Health impact on caregivers of providing informal care to a cognitively impaired older adult: Rural versus urban settings. *Canadian Journal of Rural Medicine*, *9*(1), 15-23. https://pdfs.semanticscholar.org/c767/e3cf7702ecf84e1624430529ea3bb13f6e53

Bhatia, M. S., Bhatia, S., Gautam, P., Saha, R., & Kaur, J. (2015). Burden assessment, psychiatric morbidity, and their correlates in caregivers of patients with intellectual disability. *East Asian Archives of Psychiatry*, *25*(4), 159.

Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry*, *18*(5), 507-513. doi:10.1097/01.yco.00001794885.e8

Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latina mothers with and without children with retardation: Implications for caregiving. *Family Relations*, 46(4), 325-334.http://dx.doi.org/10.2307/585093

Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American journal on intellectual and developmental disabilities*, *120*(5), 395-411. doi:10.1352/1944-7558-120.5.395

Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity, 36*(4), 391-409. https://doi.org/10.1023/A:1020909529486

Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative research*, *8*(1), 137-152. http://dx.doi.org/10.1177/1468794107085301

Boyd, C. O. (2001). Phenomenology the method. In P. L. Munhall (Ed.), *Nursing research: A qualitative perspective* (3rd ed., pp. 93-122). Sudbury, MA: Jones and Bartlett.

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., Lulinski, A., & Wu, J. (2013). State of the states in developmental disabilities, 2013: The greatest recession and its aftermath. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Carter, E. W., Austin, D., & Trainor, A. A. (2011). Factors associated with the early work experiences of adolescents with severe disabilities. *Intellectual and Developmental Disabilities*, *49*(4), 233-247. http://dx.doi.org/10.1352.1934-9556-49.4.233

Chadwick, D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F.,& Harrington, G. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, *26*(2), 119-132.http://dx.doi.org/10.1111.jar.12003

Cimera, R., Gonda, J., & Vaschak, J. (2015). Are high schools referring transition-age youth with intellectual disabilities to vocational rehabilitation? A state-by-state analysis. *Journal of Vocational Rehabilitation*, *42*(3), 263-270. doi:10/3233/JVR-15-747

Creswell, J. W. (2013a). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Creswell, J. W. (2013b). *Research design: Qualitative, quantitative, and mixed method approaches*. Thousand Oaks, CA: Sage Publications, Inc.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, *39*(3), 124-130. Retrieved from http://www.psycnet.apa.org

Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency, 88(2), 125-138*.

Crowe, M., Inser, M., & Porter, R. (2015). Conducting qualitative research in mental health: Thematic and content analyses. *Australian and New Zealand Journal of Psychiatry, 49*(7), 616-623. doi:10.1177/0004867415582053

Davies, M. & Beamish, W. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on “life as an adjustment”. Journal of Intellectual & Developmental Disability, 34(3), 248-257. https://doi.org/10/1080/13668250903103676

Destefano, L., Heck, D., Hasazi, S., & Furney, K. (1999). Enhancing the implementation of the transition requirements of IDEA: A report on the policy forum on transition. *Career Development for Exceptional Individuals*, *22*(1), 85-100. journals.sagepub.com/doi/pdf/10.1177/088572889902200107

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with and intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual & Developmental Disability, 38*(2), 149-162. http://dx.doi.org/10.3109/13668250.2013.789099

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British journal of clinical psychology*, *38*(3), 215-229. http://dx.doi.org/10.1348/014466599162782

Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology*, *43*(1), 13-35. http://dx.doi.org/10.1163/156916212X632943

Factor, A. Heller, T, & Janicki, M. (2012). Briding the aging and developmental disabilities service networks: Challenges and best practices. Retrieved from http://www.rrtcadd.org/resources/Resources/Publications/Policy/Service/Briefs-&-Reports/Bridiging-Report.pdf

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand journal of psychiatry*, *36*(6), 717-732. https://doi.org/10.1046/j.1440-1614.2002.01100.x

Fuligni, A. J., & Pedersen, S. (2002). Family obligation and the transition to young adulthood. *Developmental psychology*, *38*(5), 856. http://dx.doi.org/10/1037/0012-1649.38.5.856

Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, *33*(10), 1129-1136. doi:10.1093/jpepsy/jsn040

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The qualitative report*, *8*(4), 597-606. http://www.nova.edu/ssss/QR/QR8-4/goalfshani.pdf

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*, *24*(2), 105-112. http://dx.doi.org/10.1016/j.nedt.2003.10.001

Gray, K., Piccinin, A., Keating, C., Parmenter, T., Hofer, S., & …Tonge, B. (2014). Outcomes in young adulthood: Are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*, 58(8), 734-745. https://doi.org/10.1111.jir.12069

Greenfield, E. A., & Marks, N. F. (2006). Linked lives: adult children’s problems and their parents’ psychological and relational well□being. *Journal of Marriage and Family*, *68*(2), 442-454. https://doi.org/10.1111/j.1741-3737.2006.00263.x

Grossoehme, D. (2014). Overview of qualitative research. Journal of Health Care Chaplaincy, 20(3). 109. Doi:10.1080/08854726.2014.925660

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, *18*(1), 59-82. https://doi.org/10.1177/1525822X05279903

Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *1*(1), 24-30. https://doi.org/10.1111.j.1741-1130.2004.04004.x

Hatch, J. A. (2006). *Doing qualitative research in educational settings*. Albany, NY: State University of New York.

Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Mental Retardation*, *52*(2), 98-111. doi:10.1352./1934-9556-52.2.98

Heru, A. (2000). Family functioning, burden, and reward in the caregiving for chronic mental illness. *Family Systems & Health*, 18:91-103. http://dx.doi.org/10.1037/h0091855

Hoepfl, M. C. (1997). Choosing qualitative research: A primer for technology education researchers. *Journal of Technology Education*, 9(1), 47-63. doi:10.21061/jte.v9i1.a.4

Honeycutt, Dunlap, Chen, al Homsi, & Grosse, 2004). Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment in United States. *Morbidity and Mortality Weekly Report*. 53 (3).

Hubert, J. (2011). ‘My heart is always where he is’. Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home. *British Journal of Learning Disabilities*, *39*(3), 216-224. https://doi.org/10.1111/j.1468-3156.2010.00658.x

Hunt, M (2010). “Active waiting”. Habits and the practice of conducting qualitative research. *International Journal of Qualitative Methods*, 9(1), 69-76. https://doi.org/10.1177/160940691000900107

Huppert, F. A., Abbott, R. A., Ploubidis, G. B., Richards, M., & Kuh, D. (2010). Parental practices predict psychological well-being in midlife: life-course associations among women in the 1946 British birth cohort. *Psychological medicine*, *40*(09), 1507-1518. doi:10.1017/S0033291709991978

Johnson, R. B. (1997). Examining the validity structure of qualitative research. *Education*, *118*(2), 282. Retrieved from https://www.researchgate.net/publication/246126534_Examining_the_Validity_Structure_of_Qualitative_Research

Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, *47*(4-5), 313-327. https://doi.org/10.1046/j.1365-2788.2003.00493.x

Kobe, F. H., & Hammer, D. (1994). Parenting stress and depression in children with mental retardation and developmental disabilities. *Research in Developmental Disabilities*, *15*(3), 209-221. http://dx.doi.org/10.1016/0891-4222(94)90012-4

Kvale S. (1996) *Interviews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: Sage Publications, Inc.

Larkin, M., Smith, J. A., & Flowers, P. (2009). *Interpretative phenomenological analysis: Theory, method and research.* Thousand Oaks, California: Sage Publications, Inc.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology*, *3*(2), 102-120. doi:10.1191/1478088706qp062oa

Leech, N. L., & Onwuegbuzie, A. J. (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. *School psychology quarterly*, *22*(4), 557. http://dx.doi.org/10.1037/1045-3830.33.4.557

Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications, Inc.

Mason, M. (2010). Sample size and saturation in Ph.D. studies using qualitative interviews. Forum: Qualitative Social Research, 11(3), 1-19. doi:10.1177.1468794112446106

McCaslin, Mark L., and Karen Wilson Scott. "The five-question method for framing a qualitative research study." *The Qualitative Report* 8.3 (2003): 447-461.

McCausland, J., & Pakenham, K. I. (2003). Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. *AIDS Care*, *15*(6), 853-869. http://dx.doi.org/10.1080/09540120310001618694

McIlfatrick, S., Sullivan, K., & McKenna, H. (2006). What about the careers?: Exploring the experience of caregivers in a chemotherapy day hospital setting. *European Journal of Oncology Nursing*, *10*(4), 294-303. https://doi.org/10/1016/j.ejon.2005.12.003

McIntyre, L., Kraemer, B., Blacher, J., & Simmerman, S. (2004). Quality of life for young adults with severe intellectual disability: Mothers' thoughts and reflections. *Journal of Intellectual and Developmental Disability, 29(2), 131-146.* https://doi.org/10.1080/13668250410001709485

Merriam, S. B. (2002). Introduction to qualitative research. *Qualitative research in practice: Examples for discussion and analysis*, *1*, 1-17.

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology*, *52*(2), 250. http://dx.doi.org/10.1037/0022-0167.52.2.250

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International journal of qualitative methods*, *1*(2), 13-22. http://dx.doi.org/10.1177/160940690200100202

Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, California: Sage Publications, Inc.

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: care,* *health and development*, *33*(2), 180-187. http://dx.doi.org/10.1111.j.1365-2214.2006.00644.x

National Alliance for Caregiving & AARP. (1997). Family caregiving in the U.S.:Findings from a national survey. Retrieved June 23, 2016, from http://www.caregiving.org/pdf/research/finalreport97.pdf

Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and developmental disabilities*, *47*(1), 31-43. http://dx.doi.org/10.1352/2009.47:31-43

Newman, L., Wagner, M., Cameto, R., & Knokey, A. M. (2009). The post-high school outcomes of youth with disabilities up to 4 years after high school: A report from the national longitudinal transition study-2 (NLTS2). NCSER 2009-3017. Menlo Park, CA: International

Norlin, D., & Broberg, M. (2013). Parents of children with and without intellectual disability: couple relationship and individual well□being. *Journal of Intellectual Disability Research*, *57*(6), 552-566. http://dx.doi.org/10.1111.j.1365-2788.2012.01564.x

Okewole, A., Ogun, O., Bello-Mojeed, M., Usoh, T., & Dada, M. U. (2011). Prevalence and correlates of psychiatric morbidity among caregivers of children and adolescents with neuropsychiatric disorders in Nigeria. *African Journal of psychiatry*, *14*(4), 306-309. http://dx.doi.org/10.4314/1jpsy.v14i4.8

Olsson M. B. & Hwang C. P. (2001) Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research,* 45(6), 535-543. http://dx.doi.org/10.1046/j.1365-2788.2001.00372.x

Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Thousand Oaks, CA: Sage Publications, Inc.

Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just being selfish for my own sake...': balancing the views of young adults with intellectual disabilities and their carers in transition planning. *The Sociological Review*, *59*(2), 303-323. http://dx.doi.org/10.1111/j.1467-954X.2011.02006.x

Polit, D.F., Hungler, B.P., 1999. *Nursing Research. Principles and Methods*, sixth ed. Philadelphia, New York, Baltimore: J.B. Lippincott Company.

Raghavan, R., Pawson, N., & Small, N. (2013). Family carers' perspectives on post□ school transition of young people with intellectual disabilities with special reference to ethnicity. *Journal of Intellectual Disability Research*, *57*(10), 936-946. doi:10.1111/j.1365-2788.2012.01588.x

Randolph, J. J. (2009). A guide to writing the dissertation literature review. *Practical Assessment, Research & Evaluation*, *14*(13), 1-13. Retrieved from http://pareonline.net/getvn.asp?v=14&n=13

Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities*, *21*(1), 34-47. http://dx.doi.org/10.1111/j.1468.2007.00367.x

Rennie, D. L. (2004). Reflexivity and person-centered counseling. *Journal of Humanistic Psychology*, 44, 182–203. https://doi.org/10.1177/0022167804263066

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation psychology*, *55*(2), 139. http://dx.doi.org/10.1037/a0019473

Robinson, OC & Smith, JA 2010a, Investigating the form and dynamics of crisis episodes in early adulthood: The application of a composite qualitative method, *Qualitative Research in Psychology*, 7(2), 170–91. http://dx.doi.org/10.1080/14780880802699084

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, *57(6),* 1069–1081. http://dx.doi.org/10.1037/0022-3514.57.6.1069

Ryff, C.D. (2013). Psychological Well-Being Revisted: Advances in the Science and Practice of Eudaimonia. *Psychotherapy & Psychosomatics, 83(1)*, 10-28. doi: 10.1159/000353263

Sandelowski, M. (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health*, *23*(4), 334-340. https://doi.org/10.1002/1098-240X(200008)23:4<334::NUR9>3.0CO;2-G

Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, *116*(6), 479-499. http://dx.doi.org/10.1352/1944-7558-116.6.479

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75.

Shuy, R. W. (2003). In-person versus telephone interviewing. In J. A. Holstein & J. F. Gubrium (Eds), Inside interviewing: New lenses, new concerns (pp. 175-193). Thousand Oaks: Sage Publications, Inc.

Singh, K., Kumar, R., Sharma, N., & Nehra, D. K. (2014). Study of burden in parents of children with mental retardation. *J Indian Health Psychol*, *8*, 13-20.

Smith, J. A., Flowers, P., & Larkin, M. (2009) *Interpretative phenomenological analysis: theory, method and research.* London: Sage Publications, Inc.

Smith (2008) *Qualitative psychology: A practical guide to research methods.* London: Sage Publications, Inc.

Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative health research*, *17*(10), 1372-1380.

Stirling, J.A. (2007). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, *1*(3), 385-405. doi: 10.1177/146879410100100307

Strnadová, I., & Evans, D. (2013). Schooling transitions within the lifespan of people with an intellectual disability: Perceptions and recommendations of ageing mothers. *Australasian Journal of Special Education*, *37*(01), 64-78. http://dx.doi.org/10.1017/jse.2013.7

Talley, R. C., & Crewa, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health*, 97(2), 224-228. http://dx.doi.org/10.2105/AJPH.2004.059337

Test, D. W. (2008). Seamless transition for all. *Research and Practice for Persons with Severe Disabilities*, *33*(3), 98-99. http://dx.doi.org/10.2511/rpsd.33.3.98

Van Riper, M., Ryff, C., & Pridham, K. (1992). Parental and family well□being in families of children with down syndrome: A comparative study. *Research in Nursing & Health*, *15*(3), 227-235. https://doi.org/10.1002/nur.4770150309

Wagstaff C., Williams, B. (2014) Specific design features of an interpretative phenomenological analysis study. *Nurse Researcher. 21(3)*, 8-12. http://dx.doi.org/10.7748/nr2014.01.21.3.8.e1226

Williamson, H. J., & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with US services and supports. *Mental Retardation, 52(2)* 147–159. http://dx.doi.org 10.1352/1934-9556-52.2.147

Willingham-Storr, G. (2014). Parental experiences of caring for a child with intellectual disabilities: A UK perspective. *Journal of Intellectual Disabilities, 18(2),* 146-158. http://dx.doi.org/10.1177/1744629514525132

Appendix A: Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE/CHECKLIST

Please provide information on your son/daughter who has transitioned from High School within the past three years.

1. Current age of your child: _________________________

2. Gender:
   ______ Male
   ______ Female

3. Ethnicity of son/daughter: (Check only <u>ONE</u>)
   _____ African American
   _____ Asian or Pacific Islander
   _____ Caucasian/White
   _____ Hispanic/Latino
   _____ Mixed Race/Ethnicity
   _____ Native American/American Indian
   _____ Other

4. Does your child currently live with you?
   _____ Yes
   _____ No

5. Does your child have an Intellectual Disability? If yes, check level, please only check one:
   _____ Mild
   _____ Moderate
   _____ Severe
   _____ Profound

6. Did your child exit a public Georgia High School? (Please list year of exit)
   _____ Yes
   _____ No
   Year ___________________________

7. Does your child participate in activities outside of the home? List
   _____ Yes

_____ No

____

____

8. Mother's Educational Background: (Highest degree earned) _____________

9. Father's Educational Background: (Highest Degree earned) ______________

10. Parent's marital Status:
    _____ Single
    _____ Married
    _____ Divorced
    _____ Widowed

11. What is your relationship to the child?

[ ] mother
[ ] father
[ ] stepmother
[ ] stepfather
[ ] guardian
[ ] other (describe) ________________

Appendix B: Interview Guide

INTERVIEW GUIDE

1. Can you tell me what the transition experience was like for you?
2. What were the good things about transitioning from high school?
3. What were the challenging experiences you experienced during the transition from high school?
4. How did the transition impact the family?
5. What supports did you rely on to help you make it through the transition?
6. What specific factors assisted or impeded your progress through this stage of your child's life?
7. Several caregivers have reported that they have grown in some way because of having a child with a disability. Is that true for you?
8. Do you have any regrets in how you handled navigating through the transition process?
9. What do you see in the future for yourself and your child?