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EXPLORATORY STUDY OF THE PERSPECTIVES OF MIDLIFE ADULTS WITH
INTELLECTUAL DISABILITY, THEIR PARENTS, AND CASE MANAGERS
REGARDING QUALITY OF LIFE AND NEEDED
SUPPORTS AND SERVICES

Jane L. Lurquin

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Given that all people are living longer, increased opportunities are needed for services and supports to enhance one's quality of life both at midlife and in later years. The purpose of this exploratory study was to examine the quality of life perspectives of individuals with intellectual disability in midlife, their parents or guardians, and their day program case managers. Using an interview process, the study participants provided quality of life descriptors for participating individuals with intellectual disability, as well as perspectives regarding needed current and future supports and services.

The study included three triads, each consisting of an individual with intellectual disability who is in midlife, his or her parent or guardian, and a case manager who worked with the individual with intellectual disability for at least three years. Analysis involved coding of participant interviews to identify themes, subsequently allowing comparisons to be made within and across triads. Although participants within triads knew the individual with intellectual disability in their respective triad, participant-identified descriptors related to quality of life and needed supports and services varied

across triads. Participant descriptors were also compared to Schalock's eight core quality of life domains (Schalock, 2004).

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SUPPORTS AND SERVICES

JANE L. LURQUIN

A Dissertation Submitted in Partial
Fulfillment of the Requirements
for the Degree of

DOCTOR OF EDUCATION

Department of Special Education

ILLINOIS STATE UNIVERSITY

2014

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EXPLORATORY STUDY OF THE PERSPECTIVES OF MIDLIFE ADULTS WITH
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I wish to thank all my family and friends who supported me and believed that I could do anything to which I set my mind. The mutual encouragement from my fellow cohort members, which meant so much as we have all worked diligently to successfully complete our doctoral programs of study. Thanks to my very best friend, Steve, for being there and never giving up on me or letting me give up on myself. I also thank Debbie, the person who helped me find my courage and the strength within me to acknowledge and own my feelings and to hope for the best for myself, because I am definitely worth it.

This dissertation is dedicated to my very special little sister, Jan. It is because of her that this project was initiated. As her guardian, I often wondered whether she had what she needed for a good quality of life. Throughout the process of writing this dissertation, while concurrently observing and talking to my sister, I came to the realization that she enhances my quality of life much more so than what I bring to her life. Finally, I thank my parents who left Jan and me 10 years ago, thereby giving me the honor

to experience life with my sister.

J.L.L.

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CHAPTER 1

THE PROBLEM AND ITS BACKGROUND

In January of 1970, my siblings and I were anxiously awaiting the arrival of our sister, Jan, the 13th child of the family. The news of Jan's birth thrilled us, and we could hardly wait to have her come home-another new baby to hold, play with, and love. From the very start, however, it was apparent that something was wrong. After raising 12 children, it should have been easy to bring home another baby. However, Mom and Dad displayed sadness and deep concern about Jan, sentiments my parents never demonstrated when they brought the other babies home. Mom finally told us Jan was different. She told us Jan would not grow up and do the same things that other kids did. She would not learn the same or even go to the same school as the rest of us. The reason for all these differences was that Jan was born with Down syndrome. I was in the sixth grade and did not really understand.

My mom continued to worry and seemed so profoundly sad in those first weeks of Jan's life. It was as if she did not really know what to do or what to expect for her little baby girl. After 12 other children, my mother was in uncharted territory. A turning point came one day when one of my mother's friends came to visit, a friend who had a sister with Down syndrome. She told my mom how much Jan reminded her of her sister and assured my mother Jan would be able to do far more than was thought possible. Her friend's support helped Mom realize that Jan would have a happy, full life and that there

was nothing to worry about just because Jan had Down syndrome. Her friend's advice was to just love her and treat her like any of the other kids. She also explained that children are individuals, and that they all do things in their own way. She said Jan would grow a little more slowly than the other children would, but she would bring us joy and love her whole life just as her sister did for her.

As Jan got older, she did not eat independently, so we all took turns feeding her. At age two, she could barely sit up on her own, and she did not walk until after she turned four years old. Being so young myself, I still did not think there was anything that was too different about her; she was our sister, and we were all different in some way. To me, she was just being herself.

When Jan started school at age three, Mom carried her to the "special bus" because she still could not walk. It was at this time that I finally realized that there was something different about Jan. I had always assumed she would follow in all of our footsteps, although a little more slowly. The fact that she was unable to attend the neighborhood school made me realize there truly was a difference. The school district administration told us Jan needed special care and different services than the neighborhood school could offer, that Jan could not learn like everyone else, and her needs required her being kept separate from the rest of the children, so Jan was placed in a separate school only for students with disabilities.

As Jan was growing up, my exposure to children and adults with various types of disabilities increased. I began realizing that people from the regular public schools thought differently about individuals with disabilities and did not want them there. I still could not understand why they could not be at the regular school and just learn what they

could with everyone else. At home, we included Jan in everything we did as a family. There was no question about not taking Jan with us or excluding her from games and activities so she could play with us and the other children in the neighborhood. This is when I decided to become a special education teacher and give all students with disabilities a chance to learn and participate like anyone else.

Jan started school before least restrictive environment, inclusion, or person-centered planning became considerations in student placement. Special education was foreign to my parents; therefore, on behalf of my sister, I assisted my parents through the process of special education, individual education plans, and the transition from high school to adult services. Jan began in a separate school at age three and continued there until high school. She went to the public high school where her classes were located in the basement. She ended her formal schooling without a plan for transition, and few choices for adult services were available to her. With my assistance, my parents had to decide whether she would be best suited for a sheltered workshop or a day training program. The choice we made then is a decision Jan has lived with for over 20 years. She is now part of the group of people with intellectual disability who are all approaching midlife. At age 44, Jan is still doing the same contract work that she was doing when she first entered the sheltered workshop at age 22. My sister is one reason I have such an interest in adult services. Her needs, skills, and abilities are changing, but there are no plans in place for adjusting her supports and services to meet the challenges from these changes.

Importance of the Problem

The life expectancy of the general population has increased, as has the number of people living in the United States who are aging or elderly. This increase in life expectancy is also occurring for people with intellectual disability. Most literature uses the chronological definition of *old age* for people with intellectual disabilities. There is no consensus on when old age begins; it could be anywhere from 40 to 75 years (Janicki, 1991).

According to the American Association on Intellectual and Developmental Disabilities (AAIDD) Ad Hoc Committee on Terminology and Classification (2010) intellectual disability originates before age 18 and is “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” (p. 1). The culture and typical age peers and environment must be taken into consideration when discussing limitations and valid assessments should include individual factors of communication, sensory, motor, and behavior. Describing the limitations will lead to possible supports needed to improve the life functioning of the person with intellectual disability.

At one time, many older people with intellectual disability had spent time living in public institutions or segregated settings, and reaching old age was uncommon or not an immediate concern (Bigby, 2000). Deinstitutionalization of people with intellectual disabilities involved having them leave primarily public institutions and transition into community or family settings (Janicki, 1991; LePore & Janicki, 1991). The *normalization* principal (Wolfensberger, 1983) emphasizes that people with disabilities should be allowed to live a life as close as possible to that of the normal population.

Wolfensberger stated that Bank-Mikkelsen and Greenwald first developed the normalization principle and Nirje elaborated on the principle in the 1960s.

Wolfensberger further developed the normalization principle in the 1970s. Marchetti and Matson (1988) stated that the principle of normalization “essentially provided a means to enhance the developmental capabilities of developmentally disabled individuals” (p. 15). They continued to explain the normalization principle and developmental capabilities that occur as transitions, which can include (a) an increase of community integration, (b) increase of family involvement, (c) mainstream in one’s own culture, and (d) establish personal behavior characteristics.

One effect of such transitions into community settings is that people with intellectual disabilities have more opportunities for medical and health services now that they are more visible. Beange (2002) describes a concern with this increased visibility of people with intellectual disabilities in noting,

These people are no longer the responsibility of institutional staff, but are the responsibility of general health care providers, this has made their illnesses more visible and more of a worry: we do not know whether they are sicker or whether their ill-health was previously taken for granted. (p. 1)

Overall, however, additional medical services and advances in scientific technology have extended the life span of people with intellectual disability (Beange, 2002; Bigby, 2004; Boyd, 1997).

As students with intellectual disability graduate from high school, they transition to some varying adult services, e.g., post-secondary education, supported employment, job or vocational training, non-vocational day programs, or other service systems. When

my sister left high school, there was little choice afforded her, and most individuals with mild, moderate, severe, and profound intellectual disability went to sheltered workshops or adult day training centers (Sandys, 2007). The purpose of adult programming is to enhance and maintain the physical, social, and emotional well-being of the aging population with intellectual disability (Heller, 1999). As the person with intellectual disability continues to age, his or her abilities and needs change. However, the adult programming and supports available do not change as quickly as the person who needs them (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). According to Schalock (2000), appropriate programs, supports, and services for persons with intellectual disability will enhance their quality of life over their life spans.

Statement of Purpose

In this study, I explored the perspectives of individuals with intellectual disability, their parents or guardians, and their case managers regarding the definition of quality of life. I investigated the types of supports and services that participants considered necessary to enhance the quality of life for persons with intellectual disability as they reach and surpass midlife. I also compared the perspectives across the three groups of participants (individuals with intellectual disability, parents or guardians, and the case managers) to identify similarities and differences between the groups.

In order to enhance the quality of life for aging adults with intellectual disability, supports and services need to change to meet the physical, psychological, and social changes that are occurring (Bigby, 2004). I found limited information or research on supports and services to meet the needs of persons with disabilities who are growing

older. Most of the research was conducted in other countries, including England, Australia, China, and Canada; very little was conducted in the United States.

Research suggests that people in the general population, as well as those with intellectual disability, experience an increase of complex needs and a decrease in functioning level with advancing age (e.g., Bigby, 2004; Bigby, 2007b; Cooper, 1999; Tor & Chiu, 2002). Such changes may lead the person to be more dependent on others, which may decrease his or her quality of life (Petry, Maes, & Vlaskamp, 2005). Petry et al. (2005) explored the quality of life characteristics that are associated with people with intellectual disability. Their study involved interviewing parents and direct care staff of adults with intellectual disability; however, the researchers did not interview individuals with intellectual disability. Petry et al. used proxies, parents, and direct care staff who were to respond as the person with the disability.

In this study, the focus was on individuals with intellectual disability and their perspectives as compared to those of their parents or guardians and case managers. Views of quality of life may vary; self-reports of people with intellectual disability and reports from their proxies may not match (Heal & Sigelman, 1990). The parent or guardian and the case manager need to understand the supports, needs, and wishes of the person with the disability in order to enhance his or her quality of life. In this study, interviews were conducted with the person with the intellectual disability and their parent or guardian and case manager to obtain their perspectives of quality of life and the supports and services necessary for enhancing the quality of life of the person with intellectual disability.

Need For the Study

Few studies were found that explained the family's perspective of how adult services and supports can enhance quality of life as the adult child with intellectual disability ages. Even fewer studies were found that explored the perspectives of case managers. There is a rich literature base related to accessing services during the transition from high school to adult life and limited literature related to accessing end of life services. The least amount of literature and research was found for people with intellectual disability in the midlife age group of 35 to 55 years. Researchers have often neglected the perspectives of this group of older adults with intellectual and developmental disabilities (Brotherson, Berdine, & Sartini, 1993; Certo, Luecking, Murphy, Brown, Courey, & Belanger, 2008; Chadsey-Rusch, Rusch, & O'Reilly, 1991; Migliore, Mank, Grossi, & Rogan, 2007; Timmons, Whitney-Thomas, McIntyre, & Butterworth, 2004). A person with intellectual disability may reach midlife about the same time his or her parents are getting older and are less able to care for their adult child with disabilities (Bigby, 2004). This is the time during the aging process when a person's needs change; it may be necessary to obtain, maintain, or change services and supports (Seltzer & Kraus, 1987).

Examination of the literature revealed two overarching topics. The first topic focuses on the family's wishes and needs for their adult relative with intellectual disability. The second topic explores the case manager's responsibilities to the individual and his or her family with regard to adult services. The literature revealed a lack of perspectives from individuals with intellectual disability about their own lives, their wishes, their dreams, and their need for supports and services.

Research Questions

This qualitative study was designed to address the following research questions:

1. How do midlife people with intellectual disability and their caregivers (parents or guardians and case managers) define and describe the quality of life for people with intellectual disability?
2. What services and supports does each study participant believe are necessary to enhance the quality of life of the specific individual with intellectual disability as he or she reaches and surpasses midlife?
3. When comparing the perspectives, what are the similarities and differences between each group of participants?

Overview and Format of the Study

The purpose of this qualitative study was to explore the perspectives of midlife individuals with intellectual disability, their parents or guardians, and their case managers on the definition of quality of life. By comparing the perspectives across the three triads of participants, an effort was made to identify similarities and differences of the supports and services to enhance the quality of life of people with intellectual disability. In Chapter 2, an examination of the literature on the aging process and life expectancy of people with intellectual disability is provided. This chapter also described the development of the quality of life definition and various ways to enhance quality of life including making choices, adult services, and supports. Finally, in Chapter 2, quality of life literature was reviewed to examine the perspectives of parents or guardians, case managers, and the individual with disability.

In Chapter 3, an explanation of the research methodology used in the qualitative study is provided. Details are presented regarding the research strategy and its justification for this study coupled with detailed descriptions of the research site and participants. This study utilized various data collection techniques such as semi-structured interviews and field notes. Trustworthiness of the study and the approach to data analysis were also reviewed and discussed in this chapter.

CHAPTER II

REVIEW OF RELATED LITERATURE

The purpose of this study is to explore the perspectives of individuals with intellectual disability, their parents or guardians, and their case managers on their definitions of quality of life and the types of supports and services they think may enhance the quality of life for midlife adults with intellectual disability. Throughout life, supports and services may need to change as the person goes through the aging process, especially as he or she reaches midlife.

Literature Search

In this chapter, the researcher examined research on the characteristics of the aging process, quality of life, adult services, and informal and formal supports. The researcher discussed the results from research on the aging process, quality of life, and supports and services as they relate specifically to individuals with intellectual disability. This chapter will include an explanation of how this information will assist in the enhancement of quality of life for the person with intellectual disability.

The use of the database EBCSO Discovery Services and the search of publications from 1980 to 2012, there were 1,840,386 entries for *quality of life* and 32,248 entries for *people with intellectual disabilities and quality of life*; the researcher found only 23 related to *intellectual disabilities, quality of life, aging, or elderly*. The use of the terms *quality of life, adult, and developmental disabilities*, and the expanded period

from 1863 to 2012, there were 114,967 entries found, and only 442 were listed for *people with disabilities* who are *middle-aged*. Although this was not an exhaustive search, it did show the limited research that has been completed on middle-aged adults with intellectual disabilities and their quality of life. The search was continued using various terms such as *intellectual disabilities*, *developmental disabilities*, *cognitive disabilities*, and *mental retardation* with an expanded assortment of databases including ERIC, ProQuest, Social Service Abstracts, and Social Work Abstracts.

Limited research was found specifically related to adults with intellectual disability between the ages of 35 and 55 (midlife). The amount of research completed in the United States on midlife adults with intellectual disabilities and their quality of life was minimal; however, there have been studies conducted with a focus on early childhood, school age, transition from high school to adult services, and/or the end of life for people with intellectual disability.

Aging and Life Expectancy

The number of people with significant intellectual disability in the United States has increased over the last four decades and continues to grow (Heller, 2010). Heller (2010) estimated that the population of adults with intellectual disabilities over the age of 60 would increase from 641,860 in the year 2000 to a projected 1.2 million in 2030. According to the 2010 United States Census, there is approximately 18.7% of the United States population that has some type of disability with 12.6% having a severe disability. There was a 2.2 million increase of people with disabilities between 2005 and 2010; and there was a 12.3 million (4.4%) increase of severe disability. The 2010 census shows

roughly 1.2 million (0.5%) people with intellectual disability and another 944,000 (0.4%) people with other developmental disabilities (Brault, 2012).

An accurate count of individuals with intellectual disability is difficult to determine. There were at least 13,500 people found to be ineligible to complete the census (Brault, 2012). Many censuses of individuals with intellectual disability are from data created through formal disability services. The estimated number of adults with intellectual disability could be somewhat low because approximately 25% of this group does not receive any income or are unknown to any formal service system (Bigby, 2002).

Life Expectancy

The population of older people with intellectual disability is increasing at a similar rate as that of the general population. Both groups are living longer due to better medical care and lifestyle choices. Increased longevity of people with disabilities is a direct result of advancement in medical and social practices and improved living conditions that also extend the longevity of the general population (Campbell & Herge, 2000; Heller, 2010; Heller & Factor, 2004; Janicki, 2001; Kennedy, 2006). Although controversial, some researchers believe that people with intellectual disability begin the aging process at an earlier age than the general population (Heller, 2010; Sedlezky, 2010). Bigby (2004) stated that as a group, people with intellectual disability age at a similar rate as the general population, but may have a slightly reduced life span as compared to the general population. The exception to this are adults with Down syndrome and those with severe and multiple disabilities whose life expectancy is much shorter than that of the general population and of adults with other disabilities (Bigby, 2004, 2007b; Heller, 2010). Bigby (2004) explained, “Although many people with a

lifelong disability age in a similar manner to the general community as a group, they begin to age from a disadvantageous position, have high risk of poor health and experience multi-faceted obstacles to attaining effective healthcare” (p. 86).

Several researchers have argued that many people with intellectual disability can expect to live the same length of time as the people in the general population (Heller & Factor, 2004; Hogg, Lucchino, Wang, & Janicki, 2001). Kennedy (2006) disagreed and stated that they are still not living as long as people are in the general population. The life expectancy for people with intellectual disability has grown over the past few decades, with the age at death ranging from the mid-50s to early 70s (Heller, 2010). Women without disabilities have a life expectancy of approximately 79 years; excluding women with Down syndrome, the life expectancy of women with an intellectual disability is approximately 67 years. Men without disabilities have a life expectancy of approximately 73 years; men with intellectual disability, excluding men with Down syndrome, have a life expectancy of approximately 63 years (Janicki, 2001). The life expectancy of people with Down syndrome and more severe intellectual disability tends to be shorter than the general population and people with other intellectual disability (Bigby, 2004; Heller, 2010). As people with disabilities age, they have similar goals as the general population, including functioning as independently as possible by maintaining their physical and mental health, contributing to society through meaningful activities, participating in community life, and actively engaging in life through friendships (Heller, 2010).

Aging Process

The aging process across individuals varies greatly. Bigby (2007b) explained, “Aging is a process rather than an event that occurs at a fixed point in time, yet ‘old age’ is generally defined by the attainment of particular chronological age” (p. 607). Among other things, health, informal and formal supports, and genetics greatly influence the aging process (Bigby, 2004). The process consists of the biological, psychological, and social perspectives. Bigby (2004, 2007b) summarized the various aging perspectives: (a) biological aging emphasizes the physical changes that come with aging; (b) psychological aging emphasizes mental functioning such as memory, learning, personality, and emotional coping; and (c) social aging emphasizes the roles and relationships with family and friends as well as community, social, and work organizations.

Herr and Weber (1999) suggested that it is difficult to understand the aging process of persons with intellectual disability without first understanding their entire life span. Knowing their past will make it easier for others to assist them in old age. Experiences will define each person’s needs, challenges, and use of coping skills. All components of their lives may result in successful aging, which includes developing the capacity for personal independence, role transition, and adaptation to changes in family structure and other social networks (Herr & Weber, 1999).

Biological aging. Before 1970, many people with intellectual disability spent their lives in public institutions and reaching old age was not common or an immediate concern (Bigby, 2000; LePore & Janicki, 1991). The normalization movement resulted in many people with intellectual disability leaving institutions to live in communities.

Heller (2010) stated that over 75% of people with intellectual disability live at home with family members. Additional medical and scientific technology as well as increased availability of health services influenced the increase in the life expectancy for people with intellectual disability (LePore & Janicki, 1991). Boyd (1997) noted the heightened awareness of the needs of people with intellectual disability given the advances of medical technology, the increase of community participation due to deinstitutionalization, and the change of focus from children with intellectual disability to people with intellectual disability of all ages.

Definition of old age. According to Janicki (1991), the chronological definition of old age for people with intellectual disability is used in most literature, but there is no consensus among researchers as to when old age begins. Janicki suggested it could be anywhere between 40 and 75 years. Bigby (2004) stated there are beliefs that people with intellectual disability experience premature aging and therefore need a definition of old age that correlates to the pace at which their bodies' age. She stated, "Early research on ageing people with intellectual disability used ages as young as 40 years to define entry into old age, although more generally the age of 55 years has been used" (p.41).

There is a misconception that all people with intellectual disability age prematurely and enter into old age earlier than people in the general public (Bigby, 2007b). Although adults with Down syndrome have a shorter life span and begin to show characteristics of aging sooner than others, researchers have grouped together all adults with intellectual disability into the category of having shorter life spans (Bigby, 2004, 2007b; Heller, 2010; Heller, Miller, & Hsieh, 1990). Adults with intellectual disability who are in their 40s or 50s and receiving formal services are considered *older* persons.

This definition suggests that people with intellectual disability go from being young adults to older people, thereby skipping midlife (Bigby, 2007b).

Health conditions. As a group, people with intellectual disability have a comparable or higher rate of age-related health conditions than the general population has but receive less treatment for them (Bigby, 2004; Cooper, 1999). As compared to people in the general populations, people with intellectual disability are more likely to develop chronic health issues at an earlier age, depending on the syndromes or biological factors of their disability (Bigby, 2004; Heller, 2010). These age-related chronic health concerns include sensory loss, reduced mobility, increased falls and accidents, arthritis, hypertension, osteoporosis, hip fractures, cerebral vascular accidents, and cardiac anomalies. They may also be more prone to certain conditions due to their primary disability (Campbell & Herge, 2000). For example, people with Down syndrome are more prone to thyroid disorders, nonischemic heart disorders, and visual impairments than are people with other disabilities. People with profound intellectual disability are more likely to die from respiratory disease than people at any other level of disability. People who have severe motor disabilities or who require tube feeding may also die at an earlier age than other people do, with or without disabilities (Campbell & Herge, 2000).

Various researchers have stated that there appears to be a lack of medical treatment for people with intellectual disability (Cooper, 1999; Riddick & Keller, 1991). Campbell and Herge (2000) stated that there is available medical treatment but there are barriers to accessing the services. When people with intellectual disability were living in institutions, medical services were available through medical and therapeutic staff (Campbell & Herge, 2000). Currently there are more adults with intellectual disability in

community programs and at home making their needs more visible but the coordination of services is difficult (Campbell & Herge, 2000). In addition, there is an increase in advocacy for appropriate medical care. The problem is not always the availability of medical services but the cost and location, as well as the knowledge and training of the medical professionals who provide the services (Bigby, 2004, 2007b; Campbell & Herge, 2000). Physicians and other health providers have limited training and experiences concerning the health issues of people with intellectual disability and therefore may avoid providing services to this population (Gill & Brown, 2000).

Psychological aging. The rate of psychiatric problems is higher for older people with intellectual disability than it is for the general elderly population (Bigby, 2004; Tor & Chiu, 2002). Tor and Chiu (2002) stated that the rate of psychiatric problems in aging adults with intellectual disability is two to four times that of people in the general population. The high incidence of dementia, especially Alzheimer's disease, which may account for approximately one-fifth of all conditions in older people with intellectual disability, is one reason for this increased rate (Cooper, 1999).

Dementia, particularly associated with Alzheimer's disease, is more prevalent in people with significant intellectual disability than in the general population; in particular, people with Down syndrome have a higher prevalence of dementia associated with Alzheimer's disease (Bigby, 2004; Campbell & Herge, 2000; Cooper, 1999; Thorpe, Davidson, & Janicki, 2001). Adults with Down syndrome over the age of 40 have a 22% chance of having Alzheimer's disease, while only 0.1% of people in the general population will have Alzheimer's disease between the ages of 30 and 59. People with Down syndrome aged 60 years and above have a 56% likelihood of having Alzheimer's

disease (Janicki & Dalton, 2000). Not all people with Down syndrome develop symptoms, but more than half of those that live past the age of 60 will have Alzheimer's disease (Bigby, 2007b). In the general population, approximately 1.4% will have Alzheimer's disease between the ages of 65 to 69, and 13% will have it when they are over the age of eighty. The progression of Alzheimer's disease in people with intellectual disability is one to nine years, while in the general population it is three to 20 years (Janicki & Dalton, 2000). The high occurrence of Alzheimer's disease in people with Down syndrome increases the psychological need rate for people with intellectual disability as a group.

Psychological aging emphasizes mental functioning, including memory, learning, personality, and emotional coping. Behavioral disorders are more common in people with significant intellectual disability at all stages of life when compared with the general population (Thorpe et al., 2001). Thorpe et al. (2001) also stated that people with intellectual disability who are nonverbal or have difficulties communicating their wants and needs might present behaviors that are unacceptable to the general population.

The prevalence of mental disorders occurring in elderly people with intellectual disability is high (Cooper, 1999; Thorpe et al., 2001). The more common mental health disorders are emotional disorders, anxiety, phobias, and depression. Cooper's (1999) research demonstrated a relationship between physical disorders and dementia; a person with intellectual disability and a high number of physical disorders has a greater likelihood of having dementia. Cooper also stated there is no evidence that there is a relationship between the number of physical disorders and the presence of psychiatric disorders in elderly adults with intellectual disability.

Mental illnesses in people with intellectual disability can be undiagnosed for many reasons. Thorpe et al. (2001) described reasons for this, including (a) limited communication skills, (b) belief it is part of the disability, and (c) professionals' lack of familiarity with the characteristics of disability, aging, and mental illness. Early treatment or prevention of a mental illness is often difficult. The individual with the intellectual disability may not be able to explain their feelings due to not having the necessary communication skills to describe their feelings or symptoms to others, so diagnosis may rely on someone else's perceptions and reports (Cooper, 1999; Thorpe et al., 2001).

Another reason for the difficulty in diagnosing mental illness is that psychiatric medical professionals may not be familiar with intellectual disability; very few professionals are experts in both fields of disabilities and geriatrics (Thorpe et al., 2001). The professionals see the reported or observed symptoms as part of the disability or the natural aging process and therefore do not diagnose mental illness. Although this now may be changing, Thorpe et al. (2001) stated, "Formal services that specifically provide mental health care to older people with intellectual disabilities are minimal to non-existent throughout the world" (p. 224). Thorpe et al. added that there are limited mental health services for the general population, and people with intellectual disability are often the last to receive these services.

Lifestyle and social aging. Lifestyle is different for everyone, dependent on an individual's unique characteristics and behaviors (Brown, Buell, Birkan, & Percy, 2007). Brown et al. (2007) explained that lifestyle consists of the following components: (a) how people spend their day and night, (b) where they live, (c) where they work, (d) what

supports they need to complete daily activities, (e) how they interact with friends and family, and (f) how they participate in their communities.

When compared to the general population, people with intellectual disability are at a disadvantage when it comes to social support and social inclusion (Boyd, 1997). Chappell (1994) pointed out that social relationships are important to a person's quality of life. She also stated that loneliness, exclusion, and a sense of social failure could occur without relationship involvement. Social support includes having people involved in your life, sharing your interests and experiences, feeling respected and accepted by others, and having people with whom to share close bonds (Brown et al., 2007). Many researchers identified parents, family members, paid staff, and other people with intellectual disability as sources of social support for people with intellectual disabilities (Bigby, 2007a; Boyd, 1997; Brown et al., 2007; Greenbaum, 2007).

As a person ages, their social roles and relationships change. The environment and the life changes of others in their social network influence these changes (Bigby, 2007b). The changes may include the death of family members or friends, relocation of their residential setting, or family and friends leaving the area. These changes may lead to isolation and a loss of friendships. People with intellectual disability may have a harder time dealing with these changes due to having poor self-esteem and poor perception of their own competence due to limited life experiences and poor social support (Thorpe et al., 2001). Restricted social roles and lack of exposure to rituals such as funerals limit people with intellectual disability, and they are often shielded from unpleasant events throughout their lives (Thorpe et al., 2001).

Chappell (1994) explained the influence of normalization on friendships of people with and without intellectual disability. She states, “The influence of normalisation [*sic*] has created a clear assumption that relationships with non-disabled people are preferable to those between disabled people” (p. 431). Not having friends with similar interests and experiences may harm the self-esteem of a person with intellectual disability (Chappell, 1994). Older adults with intellectual disabilities who left institutions have deficits in social skills, social networks, verbal abilities, literacy, and community experiences that set them apart from the general population (Sutton, 1997). According to Greenbaum (2007), adults with intellectual disability rarely socialize with others outside their family; this can be a cause of loneliness. While they were attending school, they met with their friends daily; as adults, they have limited opportunities to socialize naturally with friends.

As a group, people with intellectual disability have fewer opportunities for leisure activities and decreased access to services and programs available to the nondisabled population (Bigby, 2004). People with disabilities require opportunities for leisure and social activities. Tedrick (1997) stated, “An element of quality of life particularly relevant to those who are aging is the degree to which leisure experiences can provide meaning, time, structure, and satisfaction to daily living” (p. 1). People with intellectual disability have fewer choices and opportunities for meaningful activities.

Boyd (1997) listed various reasons that leisure activities are important to adults with intellectual disability that include: (a) increased opportunities for socialization and feelings of self-worth, (b) improvement in fitness levels and physical skills, (c) relationship to high life satisfaction, and (d) conduciveness to inclusion in the community. Involvement in recreation and leisure activities is an integral part of the

quality of life for adults with intellectual disability (Hoge & Wilhite, 1997). They also noted that being involved in recreation and leisure activities empowers adults with intellectual disability as they learn to choose activities of interest for themselves. Activity involvement is a direct link to better health and functional status in adults with intellectual disability (Hawkins, 1997).

Summary of the Aging Process and Life Expectancy

Given that the population of aging adults is increasing, life spans are increasing at similar rates for people with and without intellectual disability (Heller, 2010). Some researchers still compare typical life spans with that projected for people with Down syndrome (Bigby, 2004, 2007b; Heller, 2010). However, such comparisons are problematic since persons with Down syndrome age more rapidly than the general population (Bigby, 2004, 2007b; Heller, 2010; Heller, Miller, & Hsieh, 1990). Researchers are still having difficulty defining old age and pinpointing an accurate age range when death occurs for people with intellectual disability; the suggested range of years when death occurs is from 50 to 70 years (Heller, 2010).

The aging process is unique to everyone, but all people will experience changes related to the biological, psychological, and social aspects of aging (Bigby, 2004). People with intellectual disability are prone to some of the same health conditions as people without disabilities. They are also at a high risk for other health concerns due to their primary disability (Campbell & Herge, 2000). These health conditions may go untreated in people with intellectual disability because they may be considered part of their disability and therefore are not treated in a timely fashion (Bigby, 2004). This is

also true of psychological aging among these individuals, e.g., mental illnesses in people with intellectual disability can go undiagnosed and untreated (Thorpe et al., 2001).

The rate of psychiatric problems is also higher for people with intellectual disability than among the general elderly population (Bigby, 2004; Tor & Chiu, 2002). This could be due to the high incidence of Alzheimer's disease, especially in people with Down syndrome (Cooper, 1999). The more common mental health disorders are emotional disorders, behavioral disorders, anxiety, phobias, and depression. Social roles and relationships change as a person grows older and people with intellectual disability are at a disadvantage due to their limited life experiences and poor social support (Bigby, 2007b; Thorpe et al., 2001).

Quality of Life

Quality of life is highly individualized, multi-dimensional, and includes life domains, indicators, and descriptors (Ilic, Millic, & Arandelovic, 2010; Schalock, 2000; Schalock, Gardner, & Bradley, 2007). Quality of life is a continuum across the life span and changes as one grows older or life situations change (Schalock, 2000). The belief now among many researchers is “that quality of life is a realistic and obtainable goal for *all* persons, including those with intellectual disabilities” (Schalock, 2004, p. 203).

Definitions

There are over one hundred definitions of *quality of life*. Similar themes seen across definitions include that quality of life is highly individualized and subjective in nature (Fresher-Samways, Roush, Choi, Desrosiers, & Steel, 2003; Luckasson, 1997; Neely-Barnes, Marcenko, & Weber, 2006; Schalock, 2000; Schalock et al., 2007).

Butterworth, Steere, and Whitney-Thomas (1997) described quality of life as “a uniquely

personal construct that is difficult to measure because the standards and criteria vary so widely from person to person. In fact, it has been suggested that quality of life must be understood as a unique personal experience” (p. 5).

There is no consensus among researchers regarding the definition of quality of life (Brown, 1997). “Quality of life is a vague and difficult concept to define, widely used, but with little consistency” (Ilic et al., 2010, p. 53). Ghylin et al. (2008) explained that the phrase “quality of life” is used inconsistently; some older definitions are based on medical criteria, while definitions that are more recent include psychological and social well-being factors. Ghylin et al. stated that people think “harmony in life” closely relates to quality of life. Other concepts or terms often used interchangeably with quality of life, but not necessarily correctly, include (a) life satisfaction, (b) well-being, (c) health status, (d) living conditions, and (e) pursuit of happiness (Ghylin et al., 2008; Ilic et al., 2010; Luckasson, 1997).

One of the simplest meanings of quality of life is *happiness*. The presence of quality of life in a person with intellectual disabilities is simply to be in the pursuit of happiness (Luckasson, 1997). Defining and measuring the terms “pursuit of happiness” and “quality of life,” understanding who can achieve them, and the role individuals and society play in determining them are difficult (Luckasson, 1997).

Researchers agree that there is no consensus on a single definition for quality of life. Summarized in Table 1 are several definitions of quality of life. These definitions each draw on previous definitions and have similarities in at least three different areas. They (a) are individualized, (b) are multi-dimensional, and (c) have quality of life domains. All researchers agree that the perceptions of an individual are the basis of

quality of life for that person; in other words, what comprises quality of life differs among individuals. For example, Taylor and Bogdan (1996) explained that quality of life comes from the person's view and their feeling of satisfaction about their own situations. Cummins (1997) perceived well-being based on individual satisfaction and importance. Schalock (2000) and Schalock et al.(2007) suggested that quality of life comes from the individual's perspective of his or her desired living conditions.

Table 1

Quality of Life Definitions

Researcher	Definition
Quality of Life Research Unit (n.d.)	Quality of life is multidimensional and holistic in nature. It considers both the health and well-being of an individual. It emphasizes the dimensions of being, belonging, and becoming.
Felce & Perry(1995)	Quality of life integrates objective and subjective indicators, life domains, and individual values. It is a concept that can approach from the generalities of society and community well-being to specific situations of individuals or groups. Quality of life is multidimensional and categorized by five domains: physical well-being, material well-being, social well-being, emotional well-being, and development and activity.
Taylor & Bogdan (1996)	Quality of life is a subjective experience that has no meaning apart from the feelings and experiences of the person. It is how people view and feel about their own situations and their own lives. Quality of life refers to satisfaction with your life and a feeling of contentment or fulfillment with your experiences in the world.
Cummins (1997)	Both objective and subjective axes of human existence are the basis of quality of life. The use of seven domains supports the quality of life: material well-being, health, productivity, intimacy and emotional well-being, safety, and community. The objective axis incorporates culturally relevant measures of well-being, while the subjective axis incorporates measures of perceived well-being based on individual satisfaction and importance.

Table 1

Quality of Life Definitions (continued)

Researcher	Definition
Schalock(2000)	The concept of quality of life shows the person's desired living conditions as they relate to eight core domains in life: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. The value of the domains will change as the person ages, and enhanced quality of life is present when a person's basic needs are met and when they have the same opportunities as everyone else to pursue and achieve goals in the major life areas of home, work, and community.
Petry et al. (2007)	Quality of life is a multi-element structure based on various domains (These researchers use the five domains from Felce and Perry, 1995). Their research involved people with profound intellectual disabilities. They concluded that the quality of life for this group included domains that may have been similar but the indicators were very different. The quality of life for people with profound intellectual disabilities included the structure and internal organization of the environment, and the support staff available for meeting the needs of the individual. They also concluded that the utilization of quality of life domains depends on the age of the person and type of support setting they are receiving.
Schalock et al. (2007)	Quality of life is a multidimensional concept using eight life domains reflecting positive values and life experiences. Domains are sensitive to cultural and life span perspectives and relate to personal well-being. The eight life domains are interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and rights. Quality of life is a sensitizing notion that comes from the individual's perspective using the core domains. It is also a conceptual framework for assessing outcomes, a social construct for performance enhancement strategies, and a criterion for assessing the effectiveness of those strategies.

Table 1

Quality of Life Definitions (continued)

Researcher	Definition
Ilic et al. (2010)	Quality of life is a vague term and difficult to define. It has developed as an outcome of service delivery in the area of special education, health care, and social services. These authors come from the medical field, and after comparing many different viewpoints on quality of life have described quality of life in its “essential approach respects patient as a complete person and does not allow the separation of the patient’s body from his personality” (p. 52). There is no definite number of core domains, but they are derived from the subjective and objective aspects of quality of life.

Researchers have discussed the quality of life as a multi-dimensional concept that consists of two aspects. *Objective* aspects are external influences such as those found in society and the community as well as the culturally relevant measures of well-being (Cummins, 1997; Felce & Perry, 1995; Verdugo, Schalock, Keith, & Stancliffe, 2005). Objective aspects of quality of life can be measured and verified (Cummins, 2000). *Subjective* aspects include well-being based on individual satisfaction and personal well-being from the individual’s perspective (Cummins, 1997; Felce & Perry, 1995; Schalock et al., 2007). Cummins (2000) stated that subjective aspects of quality of life cannot be verified and will be different for every person. Schalock (2000) and Petry et al. (2007) agreed that quality of life will change as the person ages and supports undergo change in settings where they are provided to the individual.

Researchers have agreed that identifying core or life domains is necessary to define quality of life, although there is little agreement on the number of domains. Earlier definitions included five or seven domains; Schalock (2000) identified eight

domains that have changing values as a person ages. Ilic et al. (2010) stated there is no definite number of domains; however, all domains lead to the well-being of the individual.

Several differences and similarities among the various definitions for quality of life are extant. While others' definitions emphasized the quality of life of individual people with intellectual disabilities, Schalock et al. (2007) expanded the definition of quality of life to also be utilized as an agent for social change. They did this by the use of “(a) a conceptual framework for assessing personal outcomes, (b) a social construct that guides quality improvement strategies, and (c) a criterion for assessing the effectiveness of those strategies” (p. xi). Petry et al. (2007) also considered external factors in their definition such as the organization and support staff available to meet the needs of the person. The Schalock et al. (2007) definition brings forward the cultural aspects first described by Cummings (1997). Although all definitions are holistic in nature, the definition from the Quality of Life Research Unit (n.d.) is different from others because it emphasizes only the domains of being, belonging, and becoming.

Applying Quality of Life Definitions to People with Intellectual Disability

Not all researchers agree in the application of the concept of quality of life with regard to individuals with intellectual disability. Edgerton (1990) stated that there is a “currently popular enterprise of raising quality of life to the status of a master concept in our human service industry” (p. 149). The laws, regulations, and rules that societies created define what qualities people should enjoy. An historic characteristic of Western societies is to specify the rights of the citizens and the quality of life they were entitled to enjoy (Edgerton, 1990). Throughout history, there have been standards listed that

everyone should possess to have a good quality of life; people in the United States tend to believe that middle-class, Anglo-American culture is the standard for all people's quality of life (Edgerton, 1990).

Luckasson (1990) stated that the basis of quality of life derives from criteria developed by a powerful person or institution over a person without power, such as people with intellectual disability. Taylor and Bogdan (1990) noted that the general population would not accept applying standards to determine their quality of life, but there are standards used to determine the quality of life for people with disabilities. They also observed that an equation to determine the quality of life for people with disabilities might lead to the determination of treatment and "justification for euthanasia" (p. 28). Taylor and Bogdan offered several reasons for and against the use of standards to determine quality of life for people with intellectual disability. They stated that assigning standards to the quality of life will direct attention to the needs of people with disabilities but would also single them out as being different from other people, since they are one group that is consistently studied for quality of life.

Criteria for defining one's quality of life are unspecified, often distinctive to a single person, and not always shared by others. Luckasson (1990) opposed the use of the term "quality of life" in evaluating the lives of people with intellectual disability and suggested that the risk of using this term outweighs the benefits. She also stated that the use of the phrase "quality of life" could also cause undo harm, discrimination, and stereotypes. Luckasson recognized that the use of the term "quality of life" might lead to its use as justification for denial of rights to people with intellectual disability. Luckasson explained that the researchers are using their best efforts to find a definition

for quality of life, but any definition cannot change the risk of the term being “dangerous and places the lives and futures of people with disabilities in peril” (p. 211). Luckasson also stated that any definition of quality of life for people with intellectual disability might encourage the return of the practice of discriminatory treatment. She explained this with an example using medical treatment, such as organ transplants, that may be withheld from people with intellectual disability because they “lack the capacity to appreciate life” (p. 212).

Several researchers agreed that quality of life is rooted in the perceptions and values of the individual (Janssen & Stolk, 2005; Schalock, Braddock, & Verdugo, 2002; Verdugo & Schalock, 2009). Quality of life is important for all people and consideration of such should be the same for all people (Schalock et al., 2002). People with intellectual disability have the right to enjoy the same high quality of life as other individuals.

Requiring that all people apply the same standards to determine their own quality of life can cause frustration and expectations beyond reach (Edgerton, 1990). Professionals, service systems, parents, and others impose their beliefs about appropriate life styles on people with intellectual disability (Edgerton, 1990). Other people often decide what constitutes the quality of life for those with intellectual disability even though the person with intellectual disability is the expert on his or her own quality of life (Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2006). Adults with disabilities can state their wishes, only to have them rejected by staff or someone else in authority for more restrictive or less risky options (Edgerton, 1990).

Taylor and Bogdan (1990) discussed quality of life as a matter of subjective experiences. They stated, “Quality of life refers to one’s satisfaction with one’s lot in

life, an inner sense of contentment or fulfillment with one's experience in the world" (p. 34). The perspectives of the individual with disability are necessary to define and study their quality of life (Taylor & Bogdan, 1990). They also explained that there is no meaning apart from what a person feels and experiences or how a person views and feels about their life situations and not what others think (Taylor & Bogdan, 1990). Cummins (2002) stated that when people without disabilities view the life situation of people with disabilities they might consider that there is a lack of quality to their lives. All people should view their own quality of life; it is difficult to "assess the aversiveness of an environment by any means other than through first-hand experience" (Cummins, p. 266). External factors will influence the quality of life of all people, but only the person can determine his or her own quality of life. All people experience quality of life in different ways; people may experience the same circumstances but each person will view those circumstances from varying perspectives (Taylor & Bogdan, 1990).

Edgerton (1990) completed a longitudinal study to explore the relationship between objective criteria of quality of life and the subjective experience of well-being. Edgerton explained that quality of life is measured by objective criteria and experienced subjectively. Edgerton concluded that there is a need for various techniques to obtain the perspectives of people with intellectual disability on their quality of life and sense of well-being. He also found that improving quality of life may or may not increase the sense of well-being. Edgerton concluded that if a generally happy and satisfied person has major negative life changes (e.g., bad health, loss of loved one, or loss of a job), it would affect his or her life satisfaction; however, after some period of time the individual will return to his or her previous state of happiness and well-being. The converse

experience may also occur; if a person who is dissatisfied with his or her life experiences has positive changes (e.g., marriage, new employment, or a new home), his or her life satisfaction will increase for a short period of time and then return to the same dissatisfaction experienced in a previous state. In summary, Edgerton argued that people who are happy and hopeful would remain so, and people who are sad and negative would remain so, no matter what happens. According to Edgerton, people's dispositions are a better predictor of life satisfaction than environmental factors.

Quality of life is a continuum across the life span and includes all life stages: early and late childhood, adolescence, adulthood, and late adulthood (Schalock, 2000). Each stage reflects a continuum of the person's experience and varies with the level of support required. Reilly and Conliffe (2002) stated, "A high quality of life is something for which we all strive" and "cannot be taken for granted for it requires a concerted effort to ensure that appropriate supports are there when and where they are needed" (p. 108). Reilly and Conliffe also noted that the appropriate intensity and individualized supports and services for optimal functioning can encourage and promote participation in society and is crucial to a person's well-being. Lifestyles, as well as the services and supports provided to the individual, affect the quality of life (Thorpe et al., 2001).

Service systems should ensure that there are options for a better quality of life available for people with disabilities. Participating in appropriate services and programs can enhance a person's quality of life (Schalock et al., 2007). Quality services are a result of matching a person's wants and needs leading to fulfillment, as well as a match between the person and their environment (Schalock, 2000). Individual choice is essential for any improvement in the quality of a person's life (Brown, 1997; Brown

&Brown, 2009; Edgerton, 1990). The person with disabilities should be able to choose what he or she wants, not what others want for the person (Edgerton, 1990).

Domains and Indicators

Brown and Brown (2003) explained that life consists of many parts that are interwoven to make a whole. They also stated that it is easier and more practical to define the parts separately and then put them together to make a whole. The parts are the domains of quality of life (Brown & Brown, 2003). Domains are a set of factors that make up personal well-being (Schalock, 2004; Schalock & Verdugo, 2002). Various researchers have identified domains of quality life that allow comparisons to those developed by Schalock (2004) (see Table 2). Verdugo et al. (2005) and Schalock et al. (2007) are the only researchers to name self-determination as a core domain. Although there are various models of quality of life, many researchers now accept Schalock's domains as a preferred approach to measure and define quality of life (Wang, Schalock, Verdugo, & Jenaro, 2010).

The number of domains varies across quality of life definitions, although researchers have stated that the number of domains is not as important as how each domain varies among individuals and across the lifespan (Schalock et al., 2007). Renwick, Brown, and Raphael (2000) describe nine domains connected to three main categories: being, belonging, and becoming. Their model is also the only one that includes spiritual being, community belonging, and growth becoming. Only two models (Cummins, 1997; Felce, 1997) include domains that refer to work and production. There is considerable overlap among the models,

Table 2

Studies Including Quality of Life Core Domains Identified by Schallock et al. (2007)

Study	Domains							
	Emotional Well-Being	Personal Development	Self-Determination	Interpersonal Relations	Social Inclusion	Rights	Material Well-Being	Physical Well-Being
Felce & Perry (1996)	X			X			X	X
Cummins (1997)	X			X	X		X	
Felce (1997)	X				X	X	X	X
Renwick et al. (2000)	X				X			X
Schallock (2000)	X	X	X	X	X	X	X	X
Verdugo et al. (2005)	X	X	X	X	X	X	X	X
Schallock et al. (2007)	X	X	X	X	X	X	X	X

but all include domains in the area of emotional or psychological well-being. Only one (Cummins, 1997) does not have a domain that is similar to others in the area of health or physical well-being.

Schalock et al. (2007) described the concept of quality of life as one “that includes a number of domains that reflect positive values and life experiences” (p. 3). Each domain influences “the overall quality of the person’s life experiences” (Reilly & Conliffe, 2002, p. 108). Schalock (2004) stated that the “quality of life domains should be thought of as the set of elements to which a variable is limited, or the range over which the concept of quality of life extends” (p. 205). Ilic et al. (2010) explained that all domains should add up to the complete concept of quality of life. A standardized set of domains would not allow changes for culture, individualization, or life span (Schalock et al., 2007). Other issues that can influence the relative importance of domains for an individual include genetics, age, maturity, developmental history, and social, economic, and political variables (Felce & Perry, 1995).

The core domains are important across the life span and vary for each individual. The assessed value of each domain will change at different stages of life according to the needs and supports required at each age (Schalock, 2000). Schalock (2000) listed the core domains most important for each age group. He suggested that the core domains for children and youth are personal development, self-determination, interpersonal relationships, and social inclusion. The core domains most important for an adult include physical well-being, material well-being, rights, social inclusion, and interpersonal relations. Schalock identified the core domains of physical well-being, interpersonal relationships, and emotional well-being as the most important for the elderly. Success in

these areas during each stage of life is pertinent to the quality of life outcomes (Schalock, 2000).

Indicators and Descriptors

Quality indicators have been developed to measure quality of life in and across domains and often reflect personal outcomes (Schalock et al., 2007). Indicators are specific to a domain and describe the perception, behaviors, and conditions that define a person's well-being (Schalock, 2004). Schalock (2004) stated that measurement with indicators is (a) valid, (b) reliable, (c) sensitive to change, (d) specific to situational changes, (e) affordable, (f) timely, (g) person-referenced, (h) evaluated longitudinally, and (i) culturally sensitive. According to Brown and Brown (2003), indicators directly describe the degree of quality for each domain. Every indicator has specific descriptors related to quality of life (Brown & Brown, 2003). Each domain has its own set of indicators and descriptors, and there is no repetition of indicators or descriptors across domains (Schalock, 2000; Schalock, 2004; Schalock, Braddock, & Verdugo, 2002). The core quality of life domains, indicators, and descriptors are presented in Table 3 (Schalock, 2000, 2004; Schalock, Braddock, & Verdugo, 2002; Schalock et al., 2007).

Table 3

Eight Core Domains, Indicators, and Descriptors

Domains	Indicators	Descriptors
Emotional Well-Being	Contentment	Satisfaction, moods, enjoyment
	Self-concept	Identify, self-worth, self-esteem
	Lack of stress	Predictability, control

Table 3

Eight Core Domains, Indicators, and Descriptors (continued)

Domains	Indicators	Descriptors
Personal Development	Education	Achievement, status
	Personal competence	Cognitive, social, practical
	Performance	Success, achievement, productivity
Self-Determination	Autonomy/personal control	Independence
	Goals and personal values	Desires, expectations
	Choices	Opportunities, options, preferences
Interpersonal Relations	Interactions	Social networks, social contacts
	Relationships	Family, friends, peers
	Supports	Emotional, physical, financial, feedback
Social Inclusion	Community integration and participation	Contributor, volunteer
	Community roles	Support networks, services
	Social supports	
Rights	Human	Respect, dignity, equality
	Legal	Citizenship, access, due process
Material Well-Being	Financial status	Income, benefits
	Employment	Work status, work environment
	Housing	Type of residence, ownership
Physical Well-Being	Health	Functioning, symptoms, fitness, nutrition
	Activities of daily living	Self-care skills, mobility
	Leisure	Recreation, hobbies

Measuring Quality of Life

Measuring quality of life leads to understanding the extent to which people experience a good life. Schalock (2000) stated that people desire quality in their lives and “to enhance one’s quality of life became our goal” (p. 117). Quality of life is unique to every person, making it difficult to measure since the standards or criteria vary from person to person (Butterworth et al., 1997). In order to enhance the quality of life of people with intellectual disability, they must be given opportunities to express their goals and preferences (Edgerton, 1990; Schalock, 1990). Person-centered planning is one opportunity people with intellectual disability have to express themselves and increase their sense of empowerment (Butterworth et al., 1997). Butterworth et al. (1997) also identified empowerment as a critical element of quality of life.

Heal and Sigelman (1990) described four major methodologies to measure quality of life: measures are (a) subjective or objective, (b) absolute or relative, (c) reported by the subjects or someone else, and (d) authored or generated by someone else. When measuring quality of life, the *objective* measure focuses on verifiable circumstances of a person’s life such as income or housing. The *subjective* measure focuses on attitudinal phenomena, satisfaction with life, or non-verifiable specific circumstances such as perceptions of whether a person likes or dislikes their work environment. The *absolute* measure directly indicates a person’s quality of life, and *relative* measures are compared to an ideal standard to what they want, experience, or what other people experience. Another methodology from Heal and Sigelman include reporting the measures of quality of life by self-report of the individual’s perceptions or report by a proxy. The last

methodology to measure quality of life concerns who will generate or author the report, the researcher, or the study participants (Heal & Sigelman, 1990).

Enhancing Quality of Life

Choices. When describing self-determination, personal control, and quality of life, professionals in the field of intellectual disability frequently use the term *choice* (Brown & Brown, 2009). Stafford (2005) stated that many people take for granted their ability to make choices. She explained, “Being able to make choices, as well as taking advantage of opportunities to make choices, is an integral part of what makes humans able to function independently within the community” (p. 12). Brown and Brown (2009) stated choice is important to an individual to act upon or potentially to act upon.

Choice is a fundamental aspect of quality of life (Brown & Brown, 2009). People use various methods to make their choices known, “merely looking at, touching, or interacting with an item, activity, or person can represent a choice” (Stafford, 2005, p. 12). Brown and Brown (2009) clarified choice as a sign of an individual’s control to express personal wishes and the life direction he or she wishes to pursue. People with intellectual disability who express their choices find such expressions are helpful in achieving supports, interventions, and overall quality of life (Brown and Brown, 2009).

Brown and Brown (2009) stated, “The basic requirement for choice by people with intellectual disabilities appears to be the individual’s right and entitlement to make a choice” (p. 11). The right to make a choice refers to people with intellectual disability who should be making their own choices that affect their lives. The entitlement of choice resides with the public or service agency’s policy, which then extends opportunities and support to people with intellectual disability to make their own choices (Brown & Brown,

2009). Agencies that provide services to adults with intellectual disability and the staff of these agencies are critical in providing opportunities for choice making (Heller et al., 2011). Heller et al. (2011) stated that making choices gives control to the person with intellectual disability and can promote a positive self-image.

Brown and Brown (2009) also described the ethical dilemmas of the professionals who work with people with intellectual disability when making choices. One such dilemma is how to support the person with intellectual disability who makes choices not in his or her best interests. Professionals who repeatedly communicate that the individual has made bad choices can result in increased dissatisfaction by the person with intellectual disability. If the professional influences the person with intellectual disability to change his or her choice, it could lead to neglecting the person's real need (Brown & Brown, 2009).

When people with intellectual disability believed it was important to make choices they were taught and given opportunities to make choices (Agran, Storey, & Krupp, 2010). Agran et al. (2010) stated, their "study reinforces the finding that choice-making skills not only need to be taught but that supports are necessary for the individual to realize their choices and organizational supports within agencies for these individual choices are necessary" (p. 84)

Agran et al. (2010) also found that individuals that required less supports could be taught to make choices more often than those who needed more supports. Heller et al. (2011) stated that ongoing training to adults with intellectual disability and supports could be beneficial in choice making. The Agran et al. study concluded that the participants who required less supports were taught how to make choices more than those

who use or required more supports. Agran, et al stated that this was the opposite of what was expected, that those who needed more support would get more teaching and opportunities to make choices.

Brown (1997) stated his belief that personal choice should be part of the quality of life model, but the primary issue is the nature and role of personal choice. He also stated that a challenge to working with persons having intellectual disability is that they typically have little knowledge of the range of potential choices available. Brown stated, “Personal choice should be recognized and that variations in choices, attitudes, and interventions lead to individualized service options” (p. 4). Neely Barnes et al. (2008) disagrees and stated, the “presence of choice per se is not an indicator of improved quality of life and other positively oriented concepts” (p. 12). Brown and Brown (2009) stated that choice is a right and entitlement, which does not necessarily enhance or improve quality of life, happiness, or may not lead to the best course of action.

The concept of choice is a two-step process, having opportunities available and making decisions from available opportunities (Brown & Brown, 2009). Brown and Brown (2009) defined choice making as identifying a preference and making a selection from the available options. To effectively help people enhance their quality of life there needs to be a wide range of opportunities or options of choices within the range of their preferences and support and assistance to make choices (Gurland, Gurland, Mitty, & Toner, 2009). To ensure appropriate choice making by the person with intellectual disability, the environment needs to be structured. Stafford (2005) explained, “Individuals must actively seek items in their environments to make a choice” (p. 12).

There needs to be some control and support provided to the person with intellectual disability since making a choice involves some element of risk and exploration (Brown, 1997). Agran et al. (2010) indicated that the process of making choices might be new to a person and therefore the person with intellectual disability may not fully comprehend what is being asked of him or her. The person with intellectual disability may be hesitant to make choices due to experiences when others did not accept his or her choice (Agran et al., 2010; Brown, 1997). Caregivers should realize that individuals with intellectual disability are unable to make choices just because (a) they may change their mind, (b) the choice cannot be accepted due to the agency, (c) the caregiver views the choice as inappropriate for the individual, or (d) the lack of opportunities (Agran et al., 2010; Brown, 1997).

Stafford (2005) stated that learning to make choices “will benefit not only the individual with a severe disability but also his or her family and other caregivers because it results in improved participation in daily life, improved behavior, and less dependence on others” (p. 17). It is not enough to provide choices but staff must have the skills to assist, and the organization must have a culture of assisting people with intellectual disability to make choices (Brown & Brown, 2009; Heller et al., 2011). Heller et al., (2011) stated that it might be necessary and beneficial for both staff and the people with intellectual disabilities with whom they work to receive training on the topic of choice making.

People with intellectual disability demonstrate varying levels of skills in their ability to make choices because of the individual’s personal and environment characteristics (Brown & Brown, 2009). Providing and making their own choices can

increase satisfaction in making decisions and become more self-determined (Brown & Brown, 2009; Nota, Ferrari, Soresi, & Wehmeyer, 2007). Brown and Brown (2009) stated that there must be allowances made for differences between people with intellectual disability and their preferences and the number of choices they can manage. It is critical to assess the person's skills in a variety of life areas to ensure his or her ability to make choices. Choices should begin at the developmental level of the person involved, and, as skills and environmental supports are in place, move toward more complex choices (Brown & Brown, 2009).

Summary of Quality of Life

Quality of life has many definitions. Some researchers stated that what comprises quality of life differs among individuals. All researchers agree that the basis of quality of life comes from perceptions of individuals. Quality of life is multidimensional and consists of objective aspects that are external influences, and subjective aspects that are based on individual satisfaction and well-being (Cummins, 1997; Felce & Perry, 1995; Verdugo et al., 2005). Not all researchers agree that quality of life should be applied to people with intellectual disability since it is believed that the criteria for quality of life is developed by a powerful person over a person without power (Edgerton, 1990; Luckasson, 1990; Taylor & Bogdan, 1990). The criteria might lead to discrimination especially in the area of medical treatment (Luckasson, 1990).

Service systems should ensure that options to enhance quality of life are available for people who are older with intellectual disability (Schalock et al., 2007). The assessment of domains for each person leads to creation of programs, services, and supports necessary to enhance quality of life. Services and supports should be a result of

matching the individual's wants and needs as well as matching the individual and his or her environment (Schalock, 2000). Considered a fundamental aspect of quality of life, choice is essential for any improvement of a person's quality of life (Brown & Brown, 2009). People with intellectual disability have the right to make choices to enhance their quality of life by obtaining the supports and interventions that will meet their needs and wishes. Some researchers stated there is limited information on the relationship of choices and quality of life; therefore, choice should not be a component of quality of life (Brown & Brown, 2009; Neely Barnes et al., 2008).

Quality of life domains are factors that make up personal well-being. Most researchers had their own list of domains but nearly all now accept Schalock's eight domains to measure and define quality of life. The assessed value of domains changes at different stages of life depending on the needs and supports required. Indicators specific to each domain describe the degree of quality for each domain. Descriptors assigned to each indicator assist in the measurement of quality of life.

Adult Services

Major changes take place in the family unit as well as for the individual members during the transition of young adults with intellectual disability from high school to adult services (McIntyre, Kraemer, Blacher, & Simmerman, 2004; Timmons, Whitney-Thomas, McIntyre, & Butterworth, 2004). For example, at some point most parents will realize that they are getting older and that their adult children with intellectual disability will need lifelong care. Thus, they maybe unsure how to proceed to plan for the future of their children (Blacher, 2001). The involvement of families in the life of a young adult with disabilities is critical to successful transitional outcomes and a positive future life

(Beresford, 2004; Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Chambers, Hughes, & Carter, 2004; Neely-Barnes et al., 2008; Swenson, 2005; Timmons et al., 2004).

Research has suggested that information on adult services is available to parents on a limited basis during their children's transition from high school to adult services (Chambers et al., 2004; Timmons et al., 2004). Using focus groups to understand family needs and practices, Timmons et al. (2004) found that (a) parents were unaware of existing resources, (b) staff members did not easily volunteer information, and (c) there was a lack of advertising of adult agencies and services. The lack of information available to families may continue as the person with the disabilities continued to age (McCallion & Nickle, 2008). McCallion and Nickle (2008) continued to state that parents are still unfamiliar with the available services and supports for their adult children who are now midlife, and the parents no longer have as much energy to seek or fight for appropriate services.

Murray (2007) conducted in-depth interviews with parents whose children with severe or profound disabilities were transitioning from school to adult programs. Murray explored the parents' perceptions of the concept of transition and the arrangements that were made for their children after leaving school. The results showed that there was less attention paid to the parents, particularly the mothers, who are the primary caregivers for their children with severe or profound disabilities. Murray explained that these young adults are less likely to live independently, receive payment for work, and control their own finances or social lives like their nondisabled peers during the transition from

childhood to adulthood. Planning for life transitions for adults with intellectual disability is important because they continue to require high levels of care (Murray, 2007).

The bureaucratic transition from school to adult services is a complex process that involves negotiating service delivery while continuing the required day-to-day activities (Blacher, 2001). When working to obtain services, parents realize that they are the central people in their child's life. The development of family routines often depends on the availability of the supports including respite and transportation (Schneider et al., 2006). Their children's futures are uncertain due to the unpredictability and instability of the resources for adults with disabilities (Timmons et al., 2004). Schneider et al. (2006) stated that several families found that formal services are not dependable, do not meet the families' needs, and may rely on funding that is uncertain from year to year. As the individual with intellectual disability continues to age, and the need for adult services and supports increases and changes, additional strategies based on new experiences will need to occur (Schneider et al., 2006)

Adult Day Services and Programs

Menolascino (as cited in Matson & Marchetti, 1988) conceived a term to describe the adult with intellectual disability who continues to be treated like a child as *the eternal child*. This limits opportunities for individuals with intellectual disability because the belief is that even as adults they cannot progress beyond childhood. Menolascino continued to explain that treating people with intellectual disability as children their entire lives prevents independence associated with adulthood. The recognition of the changes throughout their lives affects the type of services and supports provided to adults with intellectual disability

Development of programs. The development of day programs for aging adults with intellectual disability began with a grassroots movement to meet the needs of the changing population as identified by program administrators, family members, and advocacy organizations (Seltzer & Krauss, 1987). Seltzer and Krauss (1987) explained that most of these programs were the result of modifying and restructuring existing programs (evolved) or starting new programs for the sole purpose to serve older people with intellectual disability (created). Development of community day programs for older adults with intellectual disability peaked in 1984. More than half of the programs evolved by modifying and restructuring the internal structure of respective program agencies to begin serving a group of clients that had aged over time in the same service setting(Seltzer & Krauss, 1987).

Services and programs are essential to people with intellectual disability to maintain independent living. The general areas of services provided are where to live, where to work, and where to play and/or socialize (McIntyre et al., 2004). Day services are limited and accessibility is not easy for aging people with intellectual disability (Beresford, 2004; Murray, 2007). Murray (2007) explained that once high school was completed, the young adults with intellectual disability moved to supported employment, sheltered workshops, or day training centers if there was room. Certo and Luecking (2011) noted that schools emphasized pre-academic and academic skills, leaving out the skills needed to be successful in the community and have a productive adult life. With regard to school curriculum, Certo and Luecking stated, “For students who were close to 18 years old and were about to age out of public schools, this was a totally bankrupt strategy, and it guaranteed an adult life of isolation or segregation at best” (p. 157).

Rusch and Braddock (2004) stated that prior to 1980, participating in sheltered workshops or staying at home were the primary employment or activity options for adults with intellectual disability. Buys and Rushworth (1997) indicated that without day services, people with intellectual disability are at a high risk for institutionalization or needing supportive care facilities. Segregated programs were predetermined and became the best option most of the young adults could hope for upon leaving school (Certo & Luecking, 2011). There were also high numbers of adults with disabilities needing services in day care programs, but due to funding, services were frequently unavailable, resulting in waiting lists for receipt of services (Murray, 2007; Swenson, 2005).

There is limited funding for day programs, inconsistent staffing patterns, and a lack of consideration for individual needs (Beresford, 2004; Blacher, 2001). Day programs often employ staff with limited training and lower expectations of aging individuals with disabilities (Bigby, 1997). Additionally, staff members may have considered adults with intellectual disabilities to be less independent, less motivated, and less capable of societal and individual achievement (Beresford, 2004; Bigby, 1997). The National Disabilities Rights Network [NDRN] (2012) explained that staff members have a strong influence on the employment of adults with intellectual disabilities. Their opinions and attitudes may often lead to an expectation that the adult with intellectual disabilities needs to remain in a segregated setting, which may reflect the tendency for staff to maintain the solvency of their own jobs (NDRN, 2012). Society may marginalize the adults with intellectual disability, exclude them, isolate them, and ignore their needs (Blackman, 2007). Bigby stated that people with intellectual disability might be old but are still healthy, productive, able to learn new things, and able to pursue new roles and

experiences. This can be a time of their lives to “broaden horizons and personal growth” (p. 105).

Buys and Rushworth (1997) observed that day services promote maintenance of skills and enable the persons with intellectual disability to remain in the community. Rusch and Braddock (2004) stated that in addition to sheltered workshops and non-vocational day programs, supported employment now should be a viable option for adults with intellectual disability. Flores, Jenaro, Orgaz, and Martin (2011) noted that employment is a factor for an enhanced quality of life.

Supported employment and segregated day programs are not the only options for adults with intellectual disability. Kleinert et al. (2012) commented that, from a historical perspective, post-secondary education was unfeasible for people with intellectual disability. These investigators also observed that few educational staff members, family members, or community members ever considered that people with intellectual disability could ever continue education past high school.

Types of day programs. The four main types of community day programs for adults with intellectual disability include (a) public or private school, (b) vocational or work training programs, (c) day activity programs, and (d) home-based training (Seltzer & Krauss, 1987). Janicki and MacEachron (1984) observed that the number of people with intellectual disability who did not participate in any day program or received services at home was increasing with age; those participating in sheltered workshops and day training programs decreased as their age increased. Lagomarcino, Trach, Rusch, and McNair (1988) stated that the adult vocational system has not changed in the past three decades and seldom allows adults to move through the system. Created more than a half

century ago, policies for adult services including employment for adults with intellectual disability have not changed to meet present needs (NDRN, 2012).

For more than two decades, the field of disabilities has advocated for community services such as supported employment, residence within the family home or home ownership, and integrated community activities. In January 2001, the U.S. Rehabilitation Services Administration removed facility-based or sheltered workshops from their listing of ideal placements for this population (Hasnain & Balcazar, 2009). However, in comparison to integrated services, sheltered workshops receive four times more financial resources and continuation of funding; as a result, the majority of adults with intellectual disability still participate in sheltered workshops (Hasnain & Balcazar, 2009; Rusch & Braddock, 2004).

Prior to 1980, options available to people with intellectual disability included sheltered workshops or staying at home (Rusch & Braddock, 2004). Supported employment has made significant gains since 1984, but segregated services continue to outpace supported employment. Today, supported employment and post-secondary education are viable options. Few educators, family members, or community members believed that adults with intellectual disability could participate in postsecondary education (Kleinert et al., 2012). With the passage of Public Law 108-446, the Individuals with Disabilities Education Improvement Act of 2004, all students with intellectual disability should be given the “opportunity to learn age-appropriate academic content and engage in activities alongside their peers without disabilities” (Kleinert et al., 2012, p. 26).

Kleinert et al. (2012) stated that today's students and families are expecting that more service options, including post-secondary education, be available after persons with intellectual disability leave high school. Many of these students may have already succeeded in inclusive general education settings with individualized supports, and the belief is that the next step is transition into higher education (Kleinert et al., 2012). Students with intellectual disability who did attend postsecondary education settings showed improved employment outcomes and increased community participation (Kleinert et al., 2012).

For the purpose of this study, the focus was on individuals with intellectual disability in sheltered workshops or non-vocational activity day centers. The study focused on the population of adults with intellectual disability that are midlife and were likely placed in segregated settings upon leaving the school program; therefore, the following sections will focus on these services.

Sheltered workshops. The primary service setting for many individuals with intellectual disability is the sheltered workshop. These settings provide work activities that typically include contracted work (e.g., packaging, assembly, collating, or stuffing envelopes) with limited compensation being provided to workers. The creation of sheltered workshops occurred as a means to provide opportunities for adults with intellectual disability with activities to foster productivity during the day (NDRN, 2012). The NDRN (2012) also stated that the first sheltered workshop was created in 1840: "This concept was cutting-edge 170 years ago" (p. 39). One goal of the sheltered workshop was to train people with intellectual disability in the skills needed for community work (NDRN, 2012; Sandys, 2007). A second goal described by Sandys

(2007) was to provide long-term work activities in a protected environment for people with intellectual disability who were not yet prepared for community employment. While sheltered workshops were developed for the training of adults with intellectual disability, very few adults actually reached this goal or moved out of the workshop (Chadsey-Rusch & Gonzalez, 1988; NDRN, 2012). These programs often only prepared them for long-term sheltered employment. The NDRN stated that the “purpose and practice part ways as the reality for most individuals working in a sheltered workshop is [that it is] not a transition point but rather a dead end” (p. 47). Staff in sheltered workshops may be overprotective of adults with intellectual disability served in these settings; therefore, these staff members often provide a reduced number of opportunities for making choices, problem solving, and community activities (Flores et al., 2011).

Funds for sheltered workshops come from state social or rehabilitation services. Agencies operate and sponsor the sheltered workshops which Sandys (2007) considers “the most common type of work-related program for people with developmental disabilities” (p. 531). Chadsey-Rusch and Gonzalez (1988) observed that the participants at sheltered workshops seldom include adults with severe or profound intellectual disability, but rather those with mild and moderate intellectual disability. Sandys explained that for many adults with intellectual disability, sheltered workshops were the only places they had ever worked or will ever work. It was important to the participants to have opportunities to interact with others and to engage in some kind of work-related activities. Sandys further noted that families feel their adult children are safe, cared for, and kept busy at the workshops. She clarified that sheltered workshops are “not

considered ‘real’ places of work; workshop participants do not have the legal status of ‘employee’ and not covered by minimum wage legislation” (p. 532).

Non-vocational activity day centers. Another important service setting for individuals with intellectual disability is the non-vocational activity day center. Sandys (2007) noted the rationale for such programs, “Some people’s disabilities are perceived to be too severe for them to be able to engage in work in a meaningful way, so other activities are developed for these individuals” (p. 539). As a result, non-vocational day programs are segregated programs where adults with intellectual disability spend their day in meaningful activities such as leisure and social activities and independent living skills. Activity day programs are an alternative to work and receive funding through the social or rehabilitation services. These programs offer few work-related activities and, if they do, the pay is very low (Lagomarcino et al., 1988; Vlaskamp, Hiemstra, Wiersma, & Zijlstra, 2007). Chadsey-Rausch and Gonzalez (1988) stated people served in the activity day center are “performing activities that bear little if any relation to employment” (p. 239).

The activities offered are usually group activities in which 90% of the activities include some form of sensory stimulation such as tactile boards and music (Vlaskamp et al., 2007). Vlaskamp et al. (2007) described, “The activities offered tended to be passive in nature with a strong tendency to let persons with PIMD [primary intellectual multi disabilities] ‘just’ enjoy the atmosphere” (p. 157). They explained that only a small part of the day is spent on activities, while most of the day is custodial care. Vlaskamp et al. stated that there is a lack of individualization with 28.9% of the activities created for group participation, 13.0% is individual activities, and the rest of the time is not

structured. Vlaskamp et al. found that it is unknown if activities in the day program are purposeful for any given individual who participates.

Supports for the Aging Population

Staying in one's own home as long as possible is known as *aging in place* (Bookman, 2008; Kennedy, 2010; Mahmood, Yamamoto, Lee, & Stegull, 2008). Koch (2010) stated that, in general, older people want to remain independent as long as possible, maintain control over their own lives, and maintain a feeling of independence. People prefer to stay in their own homes after retirement (Kennedy, 2010; Mahmood et al., 2008). Researchers have determined that when people stay in their own homes, their quality of life and social connections to friends and family can be improved (Bookman, 2008; Gonzales & Morrow-Howell, 2009; Kennedy, 2010; Koch, 2010; Mahmood et al., 2008). People who are elderly and able to live safely in their own homes have fewer health care complaints (Mahmood et al., 2008). Kennedy (2010) explained that a person must consider how his or her living environment and community will provide the economic and social sustainability to live a good life and determine what, if any, supports will be needed to age in place and have a good quality of life.

According to the Encarta English Dictionary (2007), supports are “a means of holding something upright or in place.” Supports should also provide appropriate and sufficient conditions or facilities to enable people to function in their environment. This could include someone to provide assistance, encouragement, or comfort (Encarta, 2007). To support successful aging of people who are elderly or individuals who are elderly with intellectual disability, an array of supports in activities of daily living may need to be provided. Supports that are particularly important include opportunities for active

participation in community activities, mobility and transportation, interactions with people and environmental settings, and access to available support services (Kennedy, 2010).

Buntinx and Schalock (2010) explained that supports are necessary to promote a good quality of life for all people. The assessed needs of the individual determine the necessary supports, which may lead to improved human functioning and personal outcomes (Buntinx & Schalock, 2010). They advocated that supports (a) are to address what a person cannot do in different settings, as well as the changes needed so the person can participate; and (b) should enhance personal outcomes and improve human functioning.

Before providing the supports, Kennedy (2010) stated that there must be a plan to determine the availability of supports that are required to live in the community. Both Kennedy and Mahmood et al. (2008) agreed that supports must fit the personality and personal characteristics of the person who will utilize that support. When identifying supports, important considerations include (a) perceived need for services, (b) the functional status of the person, (c) the socio-spatial and cultural context where services will be provided, and (d) characteristics of the support, e.g., ease of use and fit to the person and their environment (Kennedy, 2010; Mahmood et al., 2008).

In the United States, our physical and social environments are typically designed with a *mobile* population in mind. People work in the day and go home in the evening using cars, trains, and buses (Bookman, 2008). Independent living and caring for oneself involves the ability to be effectively mobile in one's surroundings (Bookman, 2008).

Mobility is usually the first area where people who are elderly with or without intellectual disability may lose human ability and subsequently require supports (Bookman, 2008).

Engaging elderly people in community activities may take place by providing supports in their own homes and in places where they naturally gather. Supports may be required for the elderly population to participate actively in community activities in order to enhance their quality of life (Sassen, Selod, & Bavaro, 2011). Sassen et al. (2011) also observed that needed community supports to assist people who are elderly include neighbors and friends who provide (a) transportation; (b) grocery shopping; (c) home repairs; and (d) adaptive home alterations (e.g., ramps and grab bars).

Technology is another form of support for people who are elderly, both with or without intellectual disability. Mahmood et al. (2008) observed that 33% of people over 50 years of age already use some type of assistive technology or special equipment. *Gerotechnology* (i.e., technology specifically designed to support independent living by the elderly person), can be crucial “to reduce caregiver burden, extend healthy aging in place, and minimize demands on the health system” (Mahmood et al., 2008, p. 104). Examples of these supports include monitoring devices that allow the tracking of a person’s activities and notification of emergencies, cell phones, email, telephone help lines, and an array of assistive technology devices (Center for Technology and Aging, 2009).

Developing and maintaining social relationships is another life activity area in which people who are elderly with or without intellectual disability may need assistance to live independently. Bookman (2008) explained that social ties and community involvement are often overlooked when exploring the lives of people who are elderly.

These social relationships could have an impact on the quality of life of people who are elderly. Social support is especially important when the older person begins to show changes or face challenges in the areas of occupation, economic stability, functional skills, and health (Merz & Consedine, 2009). Lee, Lan, and Yen (2011) found that social support is important to the safety of the elderly person. They noted that the more people listen to and talk to the elderly, the lower the risk of maltreatment that may occur among the elderly.

Successful aging in place (i.e., staying in ones' own home and remaining as independent for as long as possible) for older adults includes the ability to function and remain active (Bookman, 2008; Kennedy, 2010; Mahmood et al., 2008). Of particular importance is their continued enjoyment of a "desired level of support from and interaction with other people" (Kochera & Bright, 2005-2006, p. 35). Social networks typically shrink as one ages, and support and care provided to the elderly person shifts to the family (Merz & Consedine, 2009). Merz and Consedine (2009) stated that important characteristics of family relationships are the receiving and giving of support. Although Merz and Consedine found that receiving emotional support from family members leads to greater well-being for older adults, elderly adults feel more social support with their friends than with their neighbors or families (Lee et al., 2011). Kim and McKenry (1998) stated that all relationships maintained with others "are one of the most important features of life" (p. 313).

To function in a typical environment people with intellectual disability need ongoing supports. Without a variety of supports, they would not be able to function successfully and survive in the world. People with intellectual disability may need

different types of supports than the general population requires (Thompson et al., 2009). Thus, the planning of supports for use by these individuals across skill area, events, and environments is essential. The underpinning of such planning derives from the preferences of the person who will be using them.

Planning of Supports

Planning and implementing the use of supports require a balance and alignment of personal priorities and areas of need (Schalock, 2004). The plan for supports must ensure that there is a fit between the person and his or her environment. The supports need to equal the person's individual capacity and the environment where the skills need to take place (Schalock, 2004).

Several researchers have agreed that there is a process for determining supports. This process begins with determining how the person with intellectual disability identifies his or her life experiences, interests, and goals, followed by identifying where and when changes are necessary to meet those goals (Thompson, Hughes, et al., 2002; Thompson, McGrew, & Bruininks, 2002; Thompson, Wehmeyer, & Hughes, 2010). Once the need for supports is determined, the next step is the identification of available and potential supports and the implementation of such supports. Monitoring and evaluating the supports are necessary to determine the need for changes in or replacement of supports to provide appropriate supports to meet the current needs of people with intellectual disability. Some supports may increase basic functioning skills, but do not enhance the person's outcomes because the supports are not the preference or priority of the person. In contrast, a person may receive all the supports they wish for but may still

lack positive outcomes due to gaps between the skills of the person and the environmental demands (Schalock, 2004; Thompson et al., 2009).

Barriers to Providing Supports

There are barriers to providing supports to adults who are elderly with intellectual disability. Some of these barriers include (a) unavailability; (b) insufficient access; (c) inadequate funding; (d) inadequate staffing; and (e) lack of required assets (e.g., expertise, knowledge, time, transportation, energy, and resources) (Brown, & Percy, 2007; MacDonald & Tyson, 1988). Brown and Percy (2007) observed that a primary barrier is that little information exists regarding the number of adults with intellectual disability who (a) require supports, (b) do not want or need supports, (c) have not been identified as needing supports, or (d) have not applied for supports. Such lack of information influences the ability to plan for supports for people with intellectual disability.

Another barrier to providing supports to adults with intellectual disability is the attitude of people in society (MacDonald & Tyson, 1998). Some people in the United States believe that people who are elderly and people with intellectual disability are disadvantaged and devalued, though this should be of little public concern (MacDonald & Tyson, 1988). MacDonald and Tyson (1998) also stated that society might portray both people who are elderly and people with intellectual disability as declining, stagnating, and withdrawing from social life. Staff members often have limited expectations of older persons with intellectual disability and characterize them as dependent, more frail, less motivated, or incapable of societal or individual achievement

(Bigby, 1997). Such negative attitudes limit the planning and implementation of supports for all elderly adults with or without intellectual disability.

Summary of Adult Services

The involvement of parents and guardians is important for the successful transition of their children from high school to adult services (Blacher, 2001). This comes at a critical time for both the parents and their children with intellectual disability. Parents and guardians historically received limited information regarding adult services during this transition period and later as their children entered midlife (Chambers et al., 2004; Timmons et al., 2004). Frequently parents or guardians must independently seek out appropriate services for their children.

Leaders within the field of disabilities advocate for community services such as supported employment. Although there is limited funding, inconsistent staffing patterns, and a lack of consideration for individual needs, the majority of adults with intellectual disabilities still participate in sheltered workshops (Beresford, 2004; Blacher, 2001). There are also non-vocational (or activity) programs used as an alternative to work programs for adults with intellectual disability who are perceived to have a disability too severe for participation in a work setting (Sandys, 2007).

In general, people who are older with or without disabilities prefer to stay independent in their own homes. Staying in their homes can improve their quality of life (Koch, 2010). Supports in many areas of independent living may be needed for adults to stay in their own homes and communities, and are critical for a good quality of life.

Barriers to providing supports to people who are older with or without intellectual disability include availability, access, funding, training, knowledge, and resources

(Brown & Percy, 2007; MacDonald & Tyson, 1988). The attitude of society is also a major barrier to the provision of supports to people with intellectual disabilities, which includes a lack of concern for people who are older with or without intellectual disability (MacDonald & Tyson, 1998). These attitudes limit the provision of appropriate supports to improve the quality of their lives.

Parents, Professionals, and the Individual with Intellectual Disability

Few studies have examined families' perspectives on obtaining services for older adults with intellectual disability, and a smaller number of studies have explored the perspectives of case managers. Fewer still have explored the perspectives of people with intellectual disability. There is a substantive literature base related to accessing adult services during transition from secondary school to adult life (Beresford, 2004; Bianco et al., 2009; O'Brien & O'Brien, 2001). Less research has been conducted pertaining to family access to end of life services (Bigby, 2007b; Schroeder, 1988). Similarly, a paucity of research is available that examines midlife services for adults with intellectual disability (Brotherson et al., 1993; Certo et al., 2008; Chadsey-Rausch et al., 1991; Migliore, Mank, Grossi, & Rogan., 2007; Timmons et al., 2004). Research often excludes the perspectives of older adults with significant intellectual and developmental disabilities when it comes to their life stories, services and supports, and quality of life (Certo et al., 2008).

The increasing life expectancy of people with intellectual disability presents new challenges to their families, service providers, and service systems. More and more adults with intellectual disabilities are living with their parents or family members. These family members are usually the ones who provide the necessary assistance to people with

intellectual disabilities (Kennedy, 2006). Caregivers and family members are not prepared for the intensity and complexity of their involvement in addressing the needs of older adults with intellectual disability (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009; McCallion & Nickle, 2008). As with the general population, when people with intellectual disability reach midlife, their needs change. Changes in health and functioning occur in all members of the family; parents are getting too old to care for their adult children with disabilities and may face challenges in obtaining, maintaining, and changing adult services (Blacher, 2001; Schneider et al., 2006).

Families or parents receive little or no information about adult services both at the time of high school transition and throughout the adult life span (Bianco et al., 2009; Blacher, 2001; Brotherson et al., 1993; Chambers et al., 2004; Grant & Rancharan, 2007; Murray, 2007; Neely-Barnes et al., 2008; Timmons et al., 2004). Parents are fearful that supports will not be available in a timely manner, if at all, since there are limited program options available (Schneider et al., 2006).

There are researchers that list several possible reasons for the lack of planning for the futures of people with intellectual disabilities (Brotherson et al., 1993; Grant & Rancharan, 2007; Murray, 2007; Schneider et al., 2006; Timmons et al., 2004). First, the parents are unfamiliar with formal services or believe they do not need them to care for their children with intellectual disability. Second, the parents have a lack of trust and confidence in service providers, which may be due to previous unsatisfactory experiences. Third, parents may fear the intrusion by formal service systems. Finally, parents may not want any change that may lead to more challenges.

Parents or guardians should be critical participants in the decision-making process to determine services and supports for adults with intellectual disabilities (Neely-Barnes et al., 2008). Except for the individuals themselves, the parents or guardians typically know their children best. Brotherson et al. (1993) stated that parents “can impact their child through their own values and expectations” and as parents, they “can be the single most effective advocates for their child” (p. 44). Adult service providers need to understand the family roles in planning. Service providers and families need to build a trusting relationship for problem-solving and positive changes for the person with intellectual disabilities (Brotherson et al., 1993).

Parents and Family Members

The quality of life of the individual with intellectual disability often relates to the level of functioning of the student and the involvement of his or her family (McIntyre et al., 2004). McIntyre et al. (2004) conducted a study with mothers of students with intellectual disabilities to obtain their views of quality of life as their children transitioned out of high school to adult services. The mothers identified five components of quality of life: recreation, basic needs, friendships, happiness, and family. It was important to mothers that their children were engaged in meaningful activities. Mothers who had children living in community residential facilities were more interested in ensuring that their children were getting their basic needs met. They wanted to make sure that their children were comfortable and safe. Agencies emphasize the importance of vocational opportunities more than the family members who put more emphasis on daily independent living skills (McIntyre et al., 2004).

Bianco et al. (2009) studied the perspectives of mothers of young adults with intellectual disability with regard to adult services. The results included the (a) lack of information about adult services upon graduation from high school; (b) increased feelings of stress, anxiety, and fear over the roles that they now have to perform; (c) intensity and complexity of their new roles; and (d) lack of knowledge they have in navigating adult service systems. These mothers saw themselves taking on new roles and responsibilities to ensure their young adult children entered the adult service system. These roles included being collaborators, decision-makers, evaluators, role models, trainers, mentors, instructors, and system change agents for the service staff. Implementing these roles with staff members was required to ensure the provision of appropriate supports to their adult children with intellectual disability (Bianco et al., 2009).

Service Providers

Many authors believe adults with significant intellectual and developmental disabilities need help from others due to the number, types, and intensity of their impairments (Bigby, 2007a; Mansell, 2007; McCallion & Nickle, 2008; Seltzer, 1992). In the field of adult services, the assistance needed to obtain opportunities in life usually comes from case management (Xie, Hughes, Challis, Stewart, & Cambridge, 2008).

Case managers play a major role in coordinating services for people with intellectual disabilities. Their role includes identifying the wants and needs of the person with disabilities; they are additionally responsible for the development and prioritization of goals that meet these wants and needs (Mansell, 2007; Seltzer, 1992; Shaw, Sumsion, McWilliam, & MacKinnon, 2004; Xie et al., 2008). Resources, services, and supports to meet these needs may come from a variety of sources including the community, parents,

family, and state agencies (Mansell, 2007). The case manager also takes on the role of the coordinator to ensure access to and the provision of services for individuals with intellectual disabilities (Seltzer, 1992). However, Seltzer (1992) stated case managers may not be prepared to address the ever-changing needs of these individuals as they move into mid life.

Adults with disabilities may have unique needs as they reach and go beyond 30 to 40 years of age. Case managers need “knowledge of the physiological, social, and psychological aspects of aging, both generally and for people with intellectual disabilities” (Bigby, 2007a, p. 223). Most service providers for people with intellectual disabilities have knowledge of disabilities but lack knowledge of the aging process (Seltzer, 1992). In addition, Seltzer (1992) stated that case managers need knowledge of services available to people with disabilities who are aging and how to access the appropriate services. The case manager needs to understand the aging and the developmental disabilities service systems since individuals with disabilities may require services from both service sectors (Seltzer, 1992). Thus, case managers’ knowledge of services should include multiple systems: disability care, aged care, healthcare, and Social Security (Bigby, 2007a; Seltzer, 1992).

With the increased life expectancy of adults with intellectual disability comes an increase in the number of older caregivers who are mostly parents (Bigby, Ozanne, & Gordon, 2002). The unique challenges of older caregivers include the ongoing support necessary to continue caring for their children and the need for assistance to plan and prepare for the futures of their children with intellectual disability. Older caregivers are more likely to be sole caregivers, live in smaller households, have smaller informal

support networks, be less likely to use formal supports, have a distrust of formal systems, and want to continue caring for their adult children for as long as possible (Bigby et al., 2002). Case managers play important roles in the balancing of services to people with intellectual disability and their families; therefore, case managers must consider the characteristics of the older caregivers (Bigby et al., 2002).

Bigby et al. (2002) conducted a study to determine services necessary to (a) enable adults with intellectual disability to continue living at home with aging parents, (b) assist families in planning for the future of their children with intellectual disability, and (c) develop and increase skills necessary for their adult children with intellectual disability to live independently. The researchers interviewed parents about their future plans for their adult children with intellectual disability. Results included the top five issues of the parents as provided by the case manager: (a) planning and preparing of the future, (b) increased trust in formal services, (c) maintenance of existing care situations, (d) support to implement transition plans to move away from home, and (e) increased knowledge of services and supports (Bigby et al., 2002). The parents reported that the most important changes they needed would be having a break from caregiver responsibilities, worrying less about their children when they are not together, accessing resources, and having emotional support and security from the case manager. The results also included the top five issues for the adult with intellectual disability as provided by the case managers: (a) increased access to out-of-home activities, (b) development of skills, (c) lifestyle changes, (d) increased choice and autonomy, and (e) attention to neglected health issues. Bigby et al. did not examine the perspectives of the individuals with intellectual disability.

Bigby et al. (2002) also focused on the perspectives of the case managers on the intensive case management procedures. The case managers reported that time for building trust with the parents was most important to obtaining positive outcomes for both the individuals with intellectual disability and their parents or guardians. Spending time with the family to discuss major and sensitive issues was also identified as important. One case manager stated, “Knowledge, experience and understanding of both sets [caregivers and the people with intellectual disabilities] of needs is required” (p. 39). Case managers agreed that the difficulty of increasing services for caregivers and the adults with disabilities could not happen without the additional support provided by focused support workers.

These studies clearly indicated that case managers often confront many challenges. There is a high turnover of case managers, who have large caseloads and “shrinking service budgets” (Seltzer, 1992, p. 2). Case managers are under pressure to meet the needs of not only individuals with disabilities but also of the service agency, the system, and the families (Shaw et al., 2004). Blue-Banning et al. (2004) explained that case managers need to focus on the importance of services to the individuals, as well as to their family members. Case managers need to work with the whole family to meet all the needs of the family member with intellectual disability.

Case managers should be able to identify the needs and expectations of the family and the individual and have some ability to address these needs (Brotherson et al., 1993; Mansell, 2007). Parents and other family members often have limited knowledge of what adult services are available for their children who are aging, and even less knowledge of how to obtain these services (McIntyre et al., 2004). Case managers need to be able to

assist parents, families, and individuals to plan for the future of the individual with intellectual disability in all areas of life, especially community living, employment, socialization, and independence (Brotherson et al., 1993).

Case managers need to understand families to be able to assist their adult children with disabilities. Comprehensive understanding of families will lead to a better alignment of services for individuals with intellectual disability (Chambers et al., 2004; Schneider et al., 2006). Case managers must be able to work with families while keeping in mind the best interests of their adult children with disabilities. Working with families begins with gaining trust, which may lead to achieving change and building acceptance of supports and services for people with significant disabilities (Bigby, 2007b; Bigby et al., 2002).

Knowledge of generational issues and parents' specific generations lead many case managers to a better understanding of families (Bigby, 2007b). Family histories as well as disability service histories shape the opportunities in life for people with intellectual disability (O'Brien & Lyle-O'Brien, 2001). For example, a person with intellectual disability born during a past era of institutionalization would not have had as many choices as those born when implementation of the least restrictive environment (LRE) was occurring in schools. Individuals with intellectual disability over the age of 45 years did not have the same educational or employment opportunities as those that are available now (O'Brien & Lyle-O'Brien, 2001; Posey & Myers, 2005). Blaming the parents or judging them for decisions made or for their parenting styles may alienate families and lead them to withdraw from services received by their adult children with disabilities (O'Brien & Lyle-O'Brien, 2001). Case managers must work toward building

trust with families to achieve life changes and the acceptance of services for individuals with disabilities (Bigby, 2007a).

Individuals with Intellectual Disability

The development of disability studies has led to the more frequent inclusion of individuals with intellectual disability in the research process (Ware, 2004). Ware stated there is “a more general shift towards taking account of the perspective of those who would not previously have been seen as able to form a valid view” (p. 175). The problem with such a shift toward gaining and understanding the perspectives of adults with intellectual disability was succinctly noted by Ware, who posited, “whether it is possible to obtain their views but also, a much more basic question about whether they can be said to have views about complex conceptual issues at all” (p. 176).

In responding to this question raised by Ware (2004), Barelds, Van de Goor, Van Heck, and Schols (2009) stated, “There is an urgent need to enable people with intellectual disabilities and their parents/relatives to report the quality aspects they want to use in judging the quality of their individual care and service” (p. 165). It is important for people with intellectual disability to be able to share their perspectives on the types of services and supports they require for enhancing their quality of life and independent living skills (Barelds et al., 2009). Barelds et al. continued to state that the service providers consider and choose the types of services and supports that would *best fit* the needs of people with intellectual disability more often than these individuals would. The expectations, values, and judgment of services often differ between the provider and the person receiving the services (Barelds et al., 2009). Ward (1990) interviewed people with intellectual disability with regard to their services and supports. He found that the

participants were dissatisfied with supports and services provided to them when they did not participate in making the decisions.

Van der Waal Mae, Lako, and Casparie (as cited in Barelds et al., 2009) found that the perceived quality of care and service provision important to individuals with intellectual disability is considerably different from the perceptions of their parents or relatives. Van der Waal Mae et al. stated that individuals with intellectual disability commented on the *current* supports and services they are receiving while their parents or relatives would comment on *broader* information and organizational issues.

There are varying perspectives of quality of life; the individual with intellectual disability may judge his or her quality of life quite differently than that of caregivers (Janssen & Stolk, 2005). Janssen and Stolk (2005) explored these similarities and differences between people with intellectual disability and their professional caregivers. The results indicated a low to moderate agreement between perspectives. There were cases where the person with intellectual disability saw a situation as satisfactory and the staff saw it as dissatisfactory and vice versa. Staff members and individuals with intellectual disability both agreed that flexibility, autonomy, and privacy are insufficient; however, individuals with intellectual disability placed more importance on freedom and autonomy, a perception of which staff members were unaware (Janssen & Stolk, 2005). Individuals with intellectual disability who had lower-level skills (i.e., unable to complete daily living skills, require supports, less independent) were more likely to report a higher quality of life than those with higher-level skills (i.e., completes daily living skills, requires less supports, has more independent skills). This is the exact opposite of what the caregivers stated. Janssen and Stolk concluded that this might be due to the

caregivers' perspectives, which centered more on factual care concerns than did those of the individuals with disabilities. This study illustrated that “caregivers may have blind spots for some of the quality of life issues that are important to clients” (p. 67).

Summary of Parents, Professionals, and Individuals

Parents often neglect to plan for the future of their children with intellectual disabilities due to their unfamiliarity with services, lack of trust in service providers, fear of the intrusion by service systems, and not wanting changes that cause more challenges (Brotherson et al., 1993; Grant & Ramcharan, 2007; Murray, 2007; Schneider et al., 2006; Timmons et al., 2004). Mothers identified the components of quality of life as recreation, basic needs, friendships, happiness, and family. Mothers also want to be ensured that their children are comfortable and safe, while social service agencies emphasized vocational opportunities (McIntyre et al., 2004).

Case managers play a role in coordinating services for people who are older with intellectual disability. Adults with intellectual disability have unique needs as they reach and exceed midlife; case managers need to expand their knowledge of the various services available for older adults and to understand the aging process (Seltzer, 1992). Since adults with intellectual disability are living longer, and their parents are getting older, case managers need to take into consideration the needs of the parents and family members to provide appropriate services and supports to older adults with intellectual disability (Bigby et al., 2002).

Parents or guardians and case managers fear that adequate services to meet the needs of older individuals with intellectual and developmental disabilities will not be available (Posey & Myers, 2005). The availability of adult day program services for

individuals with intellectual disability is limited due to: (a) lack of programming continuity between school programs and adult day programs, (b) unavailability of services in the adult day program, or (c) underutilization of adult day program supports and services (Beresford, 2004). Adult services are limited, but the process to obtain them can be frustrating to parents or guardians and case managers. The services may be available but not dependable and do not always meet the needs of the adult with disabilities (Murray, 2007; Schneider et al., 2006).

There is a belief that the perspectives of adults with intellectual disability should be included in research. The debate among researchers concerns whether or not adults with intellectual disability can share their perspectives or whether they must have a proxy to answer questions for them (Barelds et al., 2009). Barelds et al. (2009) found that the perspectives of adults with intellectual disability are different from their parents or guardians and case managers. Adults and their case managers also differ regarding perceived levels of quality of life, and adults with lower-level skills sometimes state they had a higher quality of life than those with higher-level skills (Janssen & Stolk, 2005). Case managers often believe the opposite (Janssen & Stolk, 2005), which may suggest that these professionals are concerned about showing that their job skills could be questioned.

Significance of the Study

The life expectancy of the general population has increased, as has the number of people living in the United States who are aging or elderly. This increase of life expectancy is also true of people with intellectual disability. There is a paucity of the literature and research for people with intellectual disability in the midlife age group of

35 to 55 years. Research has often neglected the perspectives of this group of older adults with intellectual disability (Brotherson et al., 1993; Certo et al., 2008; Chadsey-Rausch et al., 1991; Migliore et al., 2007; Timmons et al., 2004).

People with intellectual disability reach midlife about the same time that their parents are getting older and realizing that they are not able to care for their adult children with disabilities (Bigby, 2004). Bigby (2004) stated that this is the time during the aging process when the needs of adults with intellectual disability change. This may make it necessary for obtaining, maintaining, or changing services and supports. Beresford (2004) identified a lack of information and availability of future service options and opportunities for adults with intellectual disability. At times, parents or guardians and individuals are not included in decision-making or the planning processes to access supports. Petry et al. (2005) explored the quality of life characteristics that are associated with people with intellectual disability. Their study involved interviewing parents and direct care staff of adults with intellectual disability; however, they did not interview individuals with intellectual disability. There has been a trend to deemphasize professional determination of individual needs and emphasize the importance of choice and empowerment for people with intellectual disability (Ward & Stewart, 2008).

Many people who are midlife with intellectual disability maybe limited in their perspectives of supports they may need due to the lack of opportunities for choice making and new experiences. People with intellectual disability that have reached or surpassed midlife have not had the same opportunities as those that are just beginning adulthood, those that are 15 to 25 years of age.

Quality of life is unique to every person and only has meaning if the individual expresses his or her experiences and perspectives. The quality of life core domains are important across the life span and their importance changes according to the needs of the individual. Brown and Brown (2009) stated that choice is one way for a person to enhance his or her quality of life. Ward and Stewart (2008) emphasized that professionals need to provide opportunities for adults with intellectual disability to make choices about the supports and services needed. This need for choices has also been stressed:

Although people with an intellectual disability may temporarily or even permanently lack the necessary conditions to independently act in service of their goals they are still capable of experiencing wants, and have fundamental interests that if not met are likely to result in serious harm and if met, lead to significant well-being. In view of the fact that people with an intellectual disability have their own unique goals (desires, preferences, interests, etc.), and that action in pursuit of these goals will give them a sense of dignity, it follows that inability to act to achieve these goals will result in a lack of dignity and (feeling of) diminishment as a human being. (Ward & Stewart, p. 306)

American society has paid little attention to the call for needed adult services, and state systems are poorly equipped to serve the needs of aging adults with disabilities (Hodapp, 2007). During the mid-life years, there is little or no change in services. Supports and services need to change to meet the physical, psychological, and social changes of aging. The services and supports that a person with intellectual disability receives will enhance his or her quality of life (Schalock, 2000).

This study explored the perspectives of individuals with intellectual disability, their parents or guardians, and their case managers on the definition of quality of life and the supports and services necessary to enhance quality of life for people with intellectual disability as they reach and pass midlife. The comparison of the perspectives among all participants allowed for the examination of the similarities and differences of quality of life and the supports and services needed to enhance it. The significance of this study was to obtain information to increase the knowledge of parents, guardians, and case managers about the variety of supports and services to enhance the quality of life of people with intellectual disability. This information will assist in planning and developing appropriate goals for and by individuals with disability.

CHAPTER III

RESEARCH METHODOLOGY

This chapter describes the general characteristics of qualitative research methodology utilized in this study, including its application to individuals with intellectual disability. The focus of the study was to examine the perspectives of individuals with intellectual disability, their parents or guardians, and their case managers regarding the services and supports needed to enhance the quality of life for individuals with intellectual disability as they reach midlife and continue to age. This chapter explains the techniques used for data collection and data analysis utilized in the study, including various methods for collection of data from people with intellectual disability.

Purpose of the Study

The purpose of this study was threefold. First, it explored the perspectives of individuals with intellectual disability, their parents or guardians, and their case managers on the definition of quality of life for the individual with disability. Second, it examined services and supports necessary to enhance the quality of life of people with intellectual disability as they reach and pass midlife. Third, a comparison was made of perspectives of each person to describe the similarities of and differences between perspectives of the participants.

Selection of Qualitative Research

One focus of qualitative research is to find the meaning of a person's life using their stories in natural settings, and this focus provides a way to collect and analyze information based on the experiences, actions, feelings, reactions, and thoughts of the individuals (Hartley & Muhit, 2003; Kelly, 2007; Merriam, 1998). Hartley and Muhit (2003) stated, "Qualitative research embraces the view that as far as people's perceptions are concerned, there is no one single truth. In other words, different people in different places, at different times, interpret things differently" (p. 103). Qualitative research supports the idea that there are different ways of making sense of a given situation (Hartley & Muhit, 2003; McIntyre et al., 2004; Merriam, 1998; Niesz, Koch, & Rumrill, 2008). With the foregoing considerations in mind, qualitative research was chosen for the methodology of this study. The study focused on the perspectives of persons with intellectual disability, their parents or guardians, and their day program case managers.

Acceptance of Qualitative Research in Special Education

The value of using qualitative research with people with disability is well documented in the professional literature. Although considerable research has been conducted on people with intellectual disability, there are limited studies that contain self-reports and perspectives of this group (Hartley & Muhit, 2003; Kelly, 2007; Kirkevold & Bergland, 2007; Niesz et al., 2008). A central reason for conducting qualitative research with people with intellectual disability is to *hear* and *listen* to their voices (Hartley & Muhit, 2003; Kelly, 2007; Niesz et al., 2008). Researchers may find it difficult to conduct research with people with intellectual disability due to systematic response biases, responsiveness of the participant, test-retest reliability, communication

skills, and limited cognitive functioning of the participant with intellectual disability (Barelds et al., 2009; Perkins, 2007; Schwartz & Rabinovitz, 2003; Sudman & Bradburn, 1982; Verdugo, 2005). Kelly (2007) stated that it is unacceptable to ignore people with intellectual disability in research just because it may provide challenges to the researcher. Hartley and Muhit (2003) explained that when target populations are vulnerable, qualitative research could provide opportunities to “listen and include the voices of the vulnerable population” (p. 109).

Method: Collective Case Study

The qualitative method chosen for this study was the collective case study. Merriam (1998) stated that the case study method is prevalent in education, and described a case as “a thing, a single entity, a unit around which there are boundaries” (p. 27). A case may be a person, group, or specific policy. The case study is used to “gain an in-depth understanding of the situation and meaning for those involved” (Merriam, 1998, p. 19). Merriam also explained that case studies could directly influence policy, practice, and future research (Merriam, 1998).

The collective case study involves the study of multiple cases to “investigate a phenomenon, population, or general condition” (Stake, 2006, p. 437). Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005) described collective case study as “a study that takes place in multiple sites or includes personalized stories of several similar (or distinctive) individuals” (p. 197). Miles and Huberman (1994) suggested that collective case studies “develop more sophisticated descriptions and more powerful explanations” (p. 172). Understanding an individual case will assist in forming general categories of the relationship between multiple cases (Miles & Huberman, 1994). This

study used the qualitative research methodology of a collective case study to gain adequate insight of the perspectives of the individual participants, as well as each triad, and the three distinct groups (parent/guardian, case manager, and individual with intellectual disability).

Participants

Criterion Sampling

The current study used criterion sampling to select the participants who met predetermined criteria. According to Lindstrom, Doren, Metheny, Johnson, and Zane (2007) this technique leads to quality assurance of the interpretation of data because of what the researcher already knows about the participants. The present study included three triads ($n = 9$ individuals) who provided their perceptions on the definition of quality of life and services to enhance the life quality of people with intellectual disability. Each of the three triads in this study consisted of an adult with intellectual disability, his or her parent or guardian, and a case manager that worked with the individual with intellectual disability in the day program.

Participants

Individuals with intellectual disability and their parents or guardians. The predetermined criteria for choosing the adults with intellectual disability included (a) age, (b) level of disability, (c) communication skills, (d) comprehension skills, (e) day program, and (f) residence. Presented in Table 4 are descriptions and a rationale for the selection criteria for participants with intellectual disabilities. This study focused on adults with intellectual disability who are currently in their midlife, between 35 and 55 years of age, and who were participants in High View, a sheltered workshop or non-

vocational day program located in a southwest suburb of Chicago, Illinois. The participants lived with their parents or guardians in the community. The individuals with intellectual disability had verbal communication, to express their opinions and perspectives.

Table 4

Selection Criteria for Adults with Intellectual Disabilities

Criteria	Description	Rationale	Supporting Studies
Age	Middle age 35-55	Researchers state that it is unclear when a person reaches middle age. Some researchers consider that people with intellectual disability age earlier than the general population, particularly people with Down syndrome who age at a faster rate than the general population and others with disabilities.	Bigby (2004) Heller (2010) Janicki (2001) Kennedy (2006) Sedlezky (2010)
Level of disability	Severe to moderate levels of disability	There is an increase of life expectancy in intellectual disability but limited research in this population. Research is now moving to incorporate people with severe to moderate intellectual disabilities so their perspectives are included.	Barelds et al. (2009) Bigby (2002) Heller (2010) Ware (2004)

Table 4

Selection Criteria for Adults with Intellectual Disabilities (continued)

Criteria	Description	Rationale	Supporting Studies
Communication skills	Ability to articulate and talk freely	Limited articulation will not limit the participation in the study as long as the participant can make his or her perspectives known to the interviewer. "Fluency is not the only way to tell a story" (Booth & Booth, p. 57).	Booth & Booth (1996)
Comprehension skills	Ability to understand a variety of different types of simple questions	Individuals with intellectual disability may be more susceptible to systematic response biases, but this should not eliminate them from participating in this study. Qualitative research allows the researcher to be flexible and creative with question structure to meet the needs of the participants.	Budd, Sigelman, & Sigelman (1981) Heal & Sigelman (1990, 1995) Kelly (2007) Niesz et al. (2008) Perkins (2007) Sigelman, Budd, Spanhel, & Schroenrock (1981)
Residence	Living at home with parent or guardian	Quality of life can be different for people in different settings, such as residential facilities, or their own apartments. People with intellectual disability or their parents often prefer to stay in their family homes as they grow older.	Bookman (2008) Chambers et al. (2004) Kennedy (2010) Mahmood, Yamamoto et al. (2008) McIntyre et al. (2004) Timmons et al. (2004)

Table 4

Selection Criteria for Adults with Intellectual Disabilities (continued)

Criteria	Description	Rationale	Supporting Studies
Day program	Sheltered workshop or non-vocational day program	Prior to 1980, one of the most common options for people with intellectual disability was the sheltered workshop. This group is now middle aged with changing needs and abilities. The purpose of the day program is to enhance and maintain physical, social, and emotional well-being. The person with intellectual disability continues to grow older and change faster than the supports and services they receive.	Hasnain & Balcazar (2009) Menolascino (1997) Sandys (2007) Rusch & Braddock (2004)

Case managers. The case manager was the person who worked with the individual with intellectual disability on a daily basis for at least six months and knew the abilities and needs of the individual. If there was more than one case manager who met the study criteria, the case manager who knew the individual the longest amount of time was chosen as the participant. There was a different case manager for each individual.

Procedures of the Study

Recruitment of participants took place through the High View day program, which is located in the southwest suburb of Chicago. High View began by a group parents and continues to be a family oriented agency with a parent board of directors. It has grown into a large agency with day programs that include supported employment,

sheltered workshop, day training center, high school transition program, and senior day program. It also has several residential settings including large and medium intermediate care facilities, several community integrated living arrangements, and group homes. The researcher contacted the director of the day programs and explained the study and criteria for participant selection. The director agreed to participate and sent a letter of intent (see Appendix A) to parents and guardians of the adults in the day program. The letter explained the study and criteria for participating and instructions for the potential parent and/or guardian to contact the researcher if interested. Once the parent or guardian made contact, study criteria enabled selection of four people with intellectual disability for participation in the study (see Table 4). The parents of all four individuals with intellectual disability selected were the guardians of their adult son or daughter. The researcher then contacted the case manager for the selected individuals with intellectual disability to complete the triad. The researcher ensured that there was a different case manager representing each individual. Although only three triads participated in the study, additional participants were available if others could not complete the study. During the explanation of the study, one individual with intellectual disability would not speak or answer simple questions. Thus, another individual was selected who met the communication ability criteria.

Before meeting with the participants with intellectual disability, the researcher obtained signed consent and permission forms from parents or guardians, thus allowing the researcher to speak to their sons or daughters. Verbal and picture-supported explanation of the study was provided to each person with intellectual disability (see Appendix B). To ensure that the individuals with intellectual disability understood the

study and were comfortable to choose to participate or not in the study, questions to ascertain understanding were asked throughout the explanation and questions were encouraged from the participants. A representative of High View witnessed each of the participants answering questions about the study before signing the letter of assent (see Appendix C) to minimize coercion and undue influence of participation. Each participant received his or her own copy of the written and picture-supported explanation of the study (see Appendix D) and the signed letter of assent. All letters of assent and consents of participation were written according to the guidelines of the Institutional Review Board (IRB). Scheduling the time and place for the interviews took place after all consents and letters of assents were signed for each member of the triad.

Ethics

Qualitative research presents various unique ethical issues due to the flexible design and the use of human subjects (Bloomberg & Volpe, 2008). Bloomberg and Volpe (2008) listed three main ethical areas for consideration when completing qualitative research: (a) informed consent, (b) potential harm to those involved, and (c) assurance of confidentiality and/or anonymity. An explanation of the study purpose and methods and related consent forms were submitted to the Institutional Review Board for review, and approval was obtained before any recruitment or research activity began.

Informed Consent

Informed consent began with the explanation to all participants of the purpose and the methods of the study. The explanation must be accurate and understandable (Patton, 2002). To enhance communication with and facilitate understanding by participants with intellectual disability, the researcher adapted and rephrased verbal explanations, which

were paired with picture supports. Any risks to the participants during the study were discussed verbally and picture-supported before obtaining informed consent. Participants were assured that participation was voluntary and they could stop at any time they wished, could skip questions, or take breaks during the interview with the researcher.

Confidentiality and Anonymity

Confidentiality of data and anonymity of participants was explained as part of the informed consent and letter of assent. Pseudonyms for all participants were assigned; names or identifying information were not used for any participant. An explanation of the study was discussed verbally with all participants, and a written explanation was provided in both the consent letter and the letter of assent. Participants were advised that all interviews would be audio taped and remain confidential. Additionally, it was stated that audio tapes would be deleted after they were transcribed. To ensure confidentiality, it was explained to all participants that all data and field notes (a) would be stored in a locked cabinet maintained by the researcher, and (b) would remain in the locked cabinet during the study and for at least seven years thereafter. The only people who would have access to the data would be the researcher and her dissertation chair.

Potential Harm or Risk

The potential harm and ethical issues were acknowledged and explained to the participants of the study. In accordance with recommendations by Bloomberg and Volpe (2008), potential risks were communicated to the participants along with an explanation of how potential risks would be avoided. Patton (2002) stated that not every risk could be anticipated in advance of research implementation. After the researcher carefully reviewed the study with the participants, few foreseeable participant risks were deemed

present that might occur during this study. The potential risks that were considered and reviewed included (a) emotional distress while audio taping the interviews, (b) sensitivity of topics discussed with participants, and (c) possibility of the loss of confidentiality. It was decided that should cases arise wherein there was difficulty in collecting data, interpretation of data, or other unanticipated risks, the dissertation chair would be contacted for advice on the procedure to correct the situation before the study proceeded.

Participating Triads

Since this qualitative research study sought to understand individuals and their perspectives pertaining to quality of life, it is important to present a profile of each of the participants. A description is provided of each individual with intellectual disability, parent/guardian, and case manager in the three study triads.

Triad 1: Tom Rose

Individual with intellectual disability. Tom, 49 years of age, lives at home with his mother. He is the only child and was adopted when he was four days old. Tom was able to understand the variety of questions presented in the interview and could orally communicate his views and tell his stories. Although some of his responses were one-word or short phrases, he was able to make his responses understandable and informative. Tom does have health issues, such as diabetes and seizure disorder, of which he is well aware, but from his responses during the interview, he has some difficulty understanding the ramification of his health.

Parent. Mrs. Rose is in her late 70s and is the legal guardian of Tom. She is a widow and lost her husband approximately 10 years ago. She has no other children and

devotes her time to caring for Tom. She has health issues of her own and stated that little assistance is provided to her for Tom's care.

Case manager. Mark is the case manager at High View that works with Tom on a daily basis. He has worked with Tom for over 12 years. One of his responsibilities is to review and prepare a yearly summary of Tom's strengths and weaknesses, and develop targeted service goals for Tom. Mark stated during the interview that he believes Tom has a lot of potential to learn so people need to "let him blossom and grow."

Triad 2: Beth Doris

Individual with intellectual disability. Beth, 50 years old, lives at home with her mother. She has a large family of which she is proud, and which includes seven siblings, 25 nieces and nephews, and one new grandchild. Her family members live in several different states and she visits them regularly. Beth has been attending High View School and workshop since she was five years old. Beth was able to understand all the questions of the interview and orally answer them with clarity. She did repeat herself several times, usually when speaking of her family or High View, though the researcher easily understood her stories and opinions.

Parent. Mrs. Doris, late 80s, is the mother of Beth and recently obtained guardianship due to the encouragement of the High View staff. Mrs. Doris is a widow; her husband died many years ago. She and Beth live together and care for each other. Mrs. Doris described it as a mutual need for caring. Mrs. Doris has health issues, including complications from a minor heart attack in the last year, and stated that, though she worries about Beth, she knows that Beth will be well cared for when she is unable to provide needed support as a parent.

Case manager. Sue has been Beth’s case manager for the last three years at High View. She is responsible for reporting Beth’s progress and develops service goals for her. She believes that Beth lives a “pretty swell life.”

Triad 3: Penny Gray

Individual with intellectual disability. Penny, 43 years old, lives at home with her parents and sister. She also has one brother and another sister that are both married. She has been attending High View for the past 19 years, and has prior work experience in a community job at a local McDonalds where her mother acted as her job coach. Penny now attends High View day program/work shop and has a community job at a local golf club one day per week. Penny was able to understand the questions of the interview; the researcher would repeat or rephrase questions when necessary. During the interview, Penny would limit her responses by injecting repeated statements that she “was happy.” She did articulate “yes” and “no” and used one word or short phrases to communicate her opinions and feelings in response to the interview questions.

Parents. Mr. and Mrs. Gray, both in their mid to late 70s, live with Penny and another daughter in a southwest suburb of Chicago. Although they were both concerned with Penny’s future, they felt no immediate need to plan for her future. During the interview, they answered questions together and often used a tag-team approach, wherein one parent would continue an answer after the other stopped commenting. This approach gave more detail to responses, but also allowed the parents to continue the discussion characterized by a back and forth response technique.

Case manager. Jean is Penny’s case manager. She has been working with Penny for over 12 years. Jean sees Penny on a daily basis and jointly discusses and develops

Penny's yearly goals in targeted areas of need. Jean is also developing enrichment programming so that all High View participants will have a full and diverse activity schedule. She ensures that Penny is receiving services and supports that she needs for her success. Jean believes that friendships are important to Penny, as she talked of Penny's friends, including special friends and her boyfriend.

Data Collection and Management

Use of a variety of techniques for data collection was deemed necessary to provide the participants opportunities to express their feelings and opinions and share their stories and experiences. The current study drew on the most common research method used with individuals with intellectual disabilities--the interview (DiCicco-Bloom & Crabtree, 2006; Nicholls, 2009). Detailed field notes of all research activities were maintained. During data collection, a researcher must remember that data collection methods are "always for the purpose of promoting your research goals" (Bogdan & Biklen, 1982, p. 93). Bogdan and Biklen (1982) also explained that the researcher should "internalize the research goal while collecting data" (p. 93) to ensure that he or she stays on topic.

Interviews

The semi-structured interview is the most utilized data source in qualitative research (DiCicco-Bloom & Crabtree, 2006; Nicholls, 2009). This interview style focuses on a pre-defined set of questions and themes but allows for additional questions and comments to permit the participant to shape the content and tell their story (Bogdan & Biklen, 2007). This method of interviewing allows the participants to discuss what they think is important, while enabling them to address issues relevant to the study. The

semi-structured “format also allows the researcher to respond to the situation at hand, to the emerging worldview of the respondent, and to new ideas on the topic” (Merriam, 1998, p. 74). The semi-structured interview is effective for clarifying or obtaining additional information from the participant throughout the interview (DiCicco-Bloom & Crabtree, 2006; Kelly, 2007; Nicholls, 2009).

This study used semi-structured interviews as the dominant strategy for collecting data. The emphasis of each interview was the perspectives of the individual with intellectual disability, his or her parent or guardian, and a respective case manager. The focus of the interview questions included the quality of life and the supports and services for midlife adults with intellectual disability. The interview questions were open-ended with additional probes for clarification that elicited the perspectives of the participants. At times, supplementary questions were necessary to obtain additional information on the topic or to redirect the participant back to the discussion. Attachment E presents the interview protocols.

To develop the interview questions, the researcher conducted an informal pilot test with individual with intellectual disability who met all the criteria of the study. The first question asked used the phrase “quality of life” (i.e., “Can you tell me about your quality of life?”). The individual did not understand and the question was rephrased to “What is good in your life?” She responded, “My house, my TV, and I go to work.” She could also describe what was not good in her life (i.e., “My sister bugs me.”) When asked additional interview questions she did answer with one or two words or short phrases but the researcher was able to understand the communicative intent. This process of asking these and other questions and examining the responses provided enabled the

researcher to develop an interview protocol that included “rephrasing for clarification” and “probe questions” as needed.

During the interviews, especially with the participants with intellectual disability, questions and interview techniques were adapted for each person depending on his or her communication style and endurance as well as individual needs. Bogdan and Biklen (2007) explained that the approach to interviewing differs for each participant. They believed the goal is for the participant to be relaxed and comfortable in order to talk and tell their story; therefore, the researcher needs to be flexible, respond to the immediate situation, and adapt the interview to the individual person. Rephrasing of questions for the person with intellectual disability may be necessary to ensure that he or she understands the question and has minimal distracters to meet the communication abilities of the individual. During the interviews in the current study, pictures were available for use, if necessary, to support communication responses by the individual with intellectual disability. This ensured that his or her opinions were understood.

The interviews took place in the participants’ homes or work settings, as they deemed appropriate and were comfortable for them to enhance the researcher’s opportunity to gather the needed information. It was important for the location to be free of distractions and to enable tape recording (Creswell, 2007; Merriam, 1998; Patton, 2002). The location should be one where the participant “is not hesitant to speak and share ideas” (Creswell, 2007, p. 133). The participants gave their consent and all interviews were audio taped. Within a week following each interview, the tapes were transcribed verbatim for the purpose of data analysis.

The interviews lasted approximately 45 to 60 minutes for each participant. Clarification of data collected from the first interviews from parents or guardians and case managers required additional interviews in telephone conversations. A short second interview was required for clarification from one parent and one case manager. Due to potential communication difficulties and the possible limited endurance and attention span of some individuals with disability, additional interviews were planned if necessary to complete the collection or clarification of information (Booth & Booth, 1996; Heal & Sigelman, 1995; Kelly, 2007). To ensure that participant answers were understood during these interviews, the researcher repeated responses and asked clarifying questions.

Field Notes

Field notes were critical to the data collection process and were maintained for the research activities of this study. Bogdan and Biklen (1982) described field notes as, “the written account of what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting on the data in a qualitative study” (p. 118). They continued to explain field notes as “a personal log that helps keep track of the development of the study” and assist the researcher “to remain aware of how he or she has been influenced by the data” (p. 119). Field notes required the researcher to *jot down notes* containing descriptions of what happened during the interview and the reactions of the participants, including nonverbal communication, while being interviewed (Merriam, 1998; Patton, 2002). While interviewing, the researcher took field notes that included a format that made it easy to retrieve information throughout the process of collecting and analyzing data (Merriam, 1998). The notes included detailed and accurate descriptions of not only the researchers’ observations and experiences, and the participants’ interactions, but also

the researchers' own personal reflections, feelings, judgments, insights, ideas, and inspirations (Patton, 2002).

Since field notes are necessary for successful research outcomes (Merriam, 1998), the researcher began classifying the information as the study developed and continued to note everything believed to be noteworthy to the study (Patton, 2002). Merriam (1998) stated, "The right way to analyze data in a qualitative study is to do it *simultaneously* with data collection" (p. 112). Utilizing the field notes assisted the researcher in reviewing the interviews as they were completed. The researcher wrote comments on the data, including participant reactions; tentative themes and researcher *hunches*, ideas, and things that are missing or require clarification (Merriam, 1998). This information from the field notes assisted the researcher in deciding whether to conduct the second telephone interview.

Data Analysis

Data analysis consists of systematically searching and arranging all data to develop findings (Bogdan & Biklen, 1982). Data analysis and data collection is done simultaneously (Huberman & Miles, 1983; Merriam, 1998). The research of the current study utilized the analysis processes described by Saldana (2009) and Miles and Huberman (1994). Saldana describes two cycles of coding: first is simple and direct, and second is advanced reorganizing, prioritizing, and integrating data.

Miles and Huberman (1994) described the cross-case analysis process. This study used these steps to analyze the data collected. During the process of analysis, the researcher along with the chairperson and one member of the dissertation committee

read, coded, and discussed sections of transcriptions. This increased the credibility of the data analysis. The following are the steps employed during data analysis.

Organization of Data

The organization of the data leads to sections that are more manageable for the researcher (Bogdan & Biklen, 1982). Huberman and Miles (1983) described organization of data, “analysis of a form which sharpens, sorts, focuses, throws away, organizes and clarifies data in such a way that final analysis can occur coherently” (p. 331).

Transcribing the interviews and typing the field notes led the researcher to become familiar and “immersed” in the data (Patton, 2002). Patton stated that immersion in the data is “an experience that usually generates emergent insights” (p. 441). This step for organization of data included reading and placing notations in the margins of transcripts pertaining to anything that the researcher felt was noteworthy.

Coding Part One

Saldana (2009) defined coding as “the transitional process between data collection and more extensive data analysis” (p. 4). Miles and Huberman (1994) explained data coding as the “part of analysis [that] involves how you differentiate and combine the data you have retrieved and the reflections you make about this information” (p. 56). The first cycle of coding includes line by line coding which continues the organization and separation of the data. The use of codes, words, or short phrases assisted in arranging the data in a systematic order and creating categories based on similar characteristics (Miles & Huberman, 1994; Saldana, 2009). The researcher reread the data several times and grouped sections of transcribed interviews into predetermined categories in relation to the research questions. The chairperson and another member of the dissertation committee

also read and completed a line by line coding of selected sections of the transcripts. After this joint coding, discussions occurred regarding development and agreement of codes and definitions. Table 5 presents the categories and definitions developed during the first round of coding and discussions among the three researchers.

Table 5

Coding of Categories

Code	Category	Definition
1	Descriptors of quality of life	Emotion/feeling activity leading to quality of life
2	Supports and services for enhancing quality of life	Contexts-High View, work, family, friends, community, medical
3	Non-informational	Reponses that do not fit other categories
4	Daily activities	Consistent life activities, what do you do?
5	Emotive response	Spontaneous responses, no relation to quality of life

Coding Part Two

The second cycle of coding is the advanced way of reorganizing and refining data with the goal “to develop a sense of categorical, thematic, conceptual, and/or theoretical organization from your array of First Cycle codes” (Saldana, 2009, p. 149). Prioritizing and integrating data took place during the second cycle and continued with the abstracting, conceptualization, and theory building (Saldana, 2009). During this cycle, the researcher refined and organized the classifications for easy retrieval and analysis for the final analysis of cross case analysis using the Schalock model of the eight quality of life domains and indicators.

Cross Case Analysis

The final step of analysis of data for this study was the use of cross-case analysis. Miles and Huberman (1994) described this as analyzing each individual case as a whole entity and then compare each analysis with all cases. Huberman and Miles (1983) stated that displays of data could assist the researcher “make sense of a large data set” and retrieve only the selective data needed as well as “facilitate cross-case analysis” (p. 286). Once each case was written, analyzed separately, and well understood by the researchers, they are “stacked” into a “meta-matrix” (Miles & Huberman, 1994, p. 176). This matrix, or table in this study, condenses case information to permit a more systematic comparison of all cases. Stacking leads to a better understanding of categories, patterns, and conditions that may be related (Miles & Huberman, 1994). The use of matrices or tables in the current study compared the data of (a) each participant in a triad, (b) triad to triad, and (c) each participant across triads. The study process compared the descriptors of all participants to the Schalock quality of life domains and found corresponding domains for the definitions for each individual with intellectual disabilities.

Trustworthiness/Credibility

Qualitative researchers must ensure that the data are credible and trustworthy through different strategies (Brantlinger et al., 2005). They also stated that researchers must implement practices to indicate to their audience that they can trust the data and conclusions of the study. Bloomberg and Volpe (2008) stated that credibility includes the “participants’ perception match up with the researcher’s portrayal of them” (p. 77). Bloomberg and Volpe also stated that the researcher must accurately represent “what the participants think, feel, and do” (p. 77). The strategies used in this study included (a)

collaborative work, (b) member checking, (c) thick detailed descriptions, and (c) the role of the researcher. The next sections include a description of each of these credibility strategies.

Collaborative Work

Faber (2006) stated, “A qualitative researcher is never entirely bias-free, the objectivity of any study can be enhanced by utilizing multiple individuals to code your data” (p. 10). Brantlinger et al. (2005) explained the use of collaborative work so that the “analyses and interpretations are not idiosyncratic and /or biased” (p. 201). The current study included the committee chairperson and another member of the dissertation committee, who also coded various sections of the written data of the study. The researchers participated in discussions to describe and define all codes which Farber stated, “increases the reliability of the labels you develop” (p. 10). This study utilized predetermined codes for the first coding, which did correspond with the research questions. As the coding continued additional codes and gradually categories were defined that were then utilized for the remainder of the data analysis. Comparing the interviews and field notes for patterns and consistency across participants verified and supported the major themes of the study.

Member Checking

Member checking, the sharing of coding and categories and findings with the participants, will check for accuracy of the data and add to the quality of the data analysis (Merriam, 1998; Saldana, 2009). Brantlinger et al. (2005) explained that member checking might happen at two levels: the first level includes the participants reviewing the transcripts of the interviews prior to analysis, and the second level is presenting the

analysis and interpretations to the participants for validation of the researcher's conclusions. The current study included member checking during the interview by asking each participant to clarify what he or she stated. This ensured that the researcher understood participant responses and let the participant clarify any mistakes or missing information. The second level of member checking included reviewing the analyzed data with the participants to ensure that what was transcribed was what the participants meant to say. These discussions took place by telephone or at a place convenient to the participant.

Thick, Detailed Description

Brantlinger et al. (2005) characterized thick, detailed descriptions as “sufficient quotes and field note descriptions to provide evidence for researchers' interpretations and conclusions” (p. 201). Merriam (1998) stated, “The end product of a case study is a rich, ‘thick’ description of the phenomenon under study” (p. 29). She further explained that thick description refers to the complete description of the setting, incident, or the entity being studied. Brantlinger et al. noted that, “Descriptive information from qualitative studies leads to an understanding of individuals with disabilities, their families, and those who work with them” (p. 198). The results of this study include detailed descriptions of each person with intellectual disability that includes their age, disability, communication skills, and interview characteristics. There are also descriptions of the parent or guardian and the case manager. The results of the study include descriptions of the conversations using quotes of the participants illustrating their perspectives.

Researcher Reflexivity

In qualitative research, the researcher is the primary instrument for data collection (Brantlinger et al., 2005; Merriam, 1998). Merriam (1998) states, “Because the primary instrument in qualitative research is human, all observations and analyses are filtered through that human being’s worldview, values, and perspective” (p. 22). The researcher in this study had many experiences that shaped her view of the disability world and the people in it. In all of her experiences, she worked with children and adults with moderate, severe, and profound intellectual disability, their parents, guardians, family members, and direct care staff to discuss and determine necessary supports and services for people with intellectual disability.

The researcher has been a case manager, teacher, and administrator in agencies and schools for individuals with moderate and severe intellectual disability of all ages. As a social worker, she worked at an infant-parent center and facilitated discussions with parents on the diagnosis of their young child with a severe disability and the provision of services. She also worked with foster parents and court personnel to advocate for children with intellectual disability. Working in schools, sheltered day programs, residential facilities, and nursing homes, she saw the skills and abilities of adults with intellectual disability decrease without appropriate supports or services available.

Given the researcher’s diverse experiences with people with intellectual disability, there can be a tendency on the part of the researcher to feel that she understands their challenges and the types of accommodations, adaptations, and services they may require. However, “The qualitative researcher’s role is that of an active learner who can tell the story from the participant’s point of view rather than as an expert who knows more about

the experience than those living it” (O’Day & Killeen, 2002, p. 10). O’Day and Killeen (2002) also stated that to obtain optimal information from people with intellectual disability, researchers require creativity to formulate open-ended questions, facilitate discussions in a non-directional manner, and to understand the participants’ needs and communication skills. The researcher’s knowledge and experiences with people with intellectual disability, as well as with people who have limited speaking abilities, assisted her with adapting the interview style to better suit the individual, still ensure consistency, and not skew the data in the process.

The researcher heard many concerns from parents and guardians about school systems and adult services. As guardian of her sister, she has many of her own challenges with adult services and agencies. In addition, she had experiences as a direct care staff person and as a supervisor of direct care staff that had provided her with perspectives that may cause her to think she understands what the staff member is referring to during the interview. Because of these experiences, she has preconceived ideas about what the parents or guardians and case managers may say during interviews, and she may strongly identify with them or disagree with them. However, it is because of all these past experiences, that the researcher was sensitive to her own personal biases, as well as how those biases may have influenced the collection and analysis of the data.

Summary

This chapter described the details of the qualitative research methods and procedures used in the study. The method of the collective case study is prevalent in the field of education; therefore, the researcher chose this method for use in the study of adults with intellectual disability. The data collection methods for this study included

interviews and field notes. The levels of analysis in the study included, (a) organization of data, (b) coding part one, (c) coding part two, and (d) cross-case analysis.

Organization of data included transcriptions and margin notes. The first coding of transcripts consisted of line-by-line coding utilizing the predetermined codes based on the research questions. Discussions between the researcher, dissertation committee chairperson, and one member included the first codes, defined and refined as necessary during the coding process (see Table 5). The second coding of transcripts involved additional reorganization and refinement of categories. The last step prior to cross-case analysis was to classify coded data according to the domains and indicators of quality of life (see Table 3). The last level of analysis utilized the cross-case analysis to organize data in a visual display of a matrix or tables to compare cases. Types of credibility and trustworthiness included member checking, collaborative work, and researcher reflexivity. The use of qualitative research methods generated a rich, thick, description of the participants' perceptions on the quality of life and services and supports to enhance the quality of life of the individuals with intellectual disability who are in midlife.

CHAPTER IV
ANALYSIS OF THE DATA

This study focused on the quality of life perspectives of middle-aged individuals with intellectual disability as compared to the quality of life perspectives of their parents and case managers. The researcher conducted interviews with each member of three triads: the individual with disability, their parent(s), and their case manager (see Table 6).

Table 6

Triad Members¹

Triad	1	2	3
Individual	Tom	Beth	Penny
Parent	Mrs. Rose	Mrs. Doris	M/M Gray
Case manager	Mark	Sue	Jean

¹ Pseudonyms are used for participants

The first set of responses to the interview questions presented to each triad member provided descriptors of how each person defined quality of life for the person with intellectual disability in his or her triad. For the second set of responses, each person described the types of supports and services he or she considered necessary to enhance quality of life for the individual with intellectual disability in his or her respective triad. The researcher compared the perspectives of all participants within and across the three triads to identify similarities and differences between the groups.

Schalock's (2004) quality of life domains (Table 3) were then compared to the participants' quality of life definitions.

Chapter 4 was organized according to the three research questions: (a) How do people with intellectual disability in midlife and their caregivers (parents and case managers) describe and define quality of life for people with intellectual disability? (b) What services and supports does each study participant believe are necessary to enhance the quality of life of the specific individual with intellectual disability as they reach and pass midlife? and (c) When comparing the participant's perspectives, what are the similarities and differences within and across triads? The last section of this chapter will include visual displays showing descriptors from the members of each triad in relation to the quality of life domains according to Schalock (2004). The interview questions investigated the perspectives of the participants and revealed both positive and negative aspects of quality of life for the individual with intellectual disability. The responses from the interview questions were organized within the same three categories under each research question: (a) descriptors of quality of life, (b) what enhances quality of life, and (c) what limits or hinders quality of life.

Quality of Life: Descriptions and Definitions

The definition of quality of life is individualized and can be different for every person (Fresher-Samways et al., 2003; Luckasson, 1997; Neely-Barnes et al., 2006; Schalock, 2000; Schalock et al., 2007). The interview questions were developed to obtain optimal information from all participants, although, while interviewing the individuals with intellectual disability, some leading questions were used (e.g., "What kind of classes do you have at work?" "That sounds like fun. What else would make you

happy?” “Is following the schedule important to you?”). Often, the individuals with intellectual disability directly responded to the questions with “I like,” “yes,” “no,” or other simple response. The researcher accepted a response from individuals with intellectual disability as a quality of life descriptor if the response was a direct answer provided with an accompanying emotion. Committee members checking reliability determined that this practice of accepting descriptors was allowable. For example, Penny was asked if she had a job at the community golf club. Her response was, “I like it.” Therefore, community job was subsequently included as a descriptor for Penny’s quality of life since she used the emotion of “like” when asked about her job.

Organization of Data Presentation

The following sections present summary analyses and supporting responses for each participant of the study who responded to questions pertaining to (a) quality of life, (b) supports and services for adults with intellectual disability who are midlife, and (c) quality of life domains. Presented in Appendix I is a compilation of *Identified Categories and Frequency of Responses to Interview Questions by Triad Study Participants*. This Appendix presents the total number of responses of each study participant within the two research question topics (a) descriptors for the quality of life definition for the individual with intellectual disability, and (b) supports and services to enhance the quality of life of the individual with intellectual disability. Each of these two main topics are separated into seven categories created by the researcher during analysis of the data, (a) work related responses, (b) family and friends, (c) community, (d) health and safety, (e) independence, (f) feelings, and (g) not applicable to the research question. The table will give the total number of responses and percentage for each of the seven response areas

for each participant. There will also be listed examples of responses or short phrases for each area.

Quality of Life

As noted in Appendix I, the three individuals with intellectual disability emphasized certain words or phrases when describing or defining their quality of life: Penny continually stated that she was “happy,” Beth emphasized “My family very important to me,” and Tom talked of work both at High View and in the community. They also had common responses to questions for descriptors of the definition for quality of life. These included work at High View, friends, family and/or mother, and things to do, e.g., shopping. Beth and Penny included church and being happy as necessary for a good life; only Beth required travel as a descriptor of quality of life. She explained, “The time go to Michigan, my sister lives in Michigan. I’ve a brother; he’s from Minnesota, Saint Paul”. [interviewer-“so you like traveling?”] “Yes.”

Penny considered her community job important to her quality of life, “Sweeping for my job. At Stony Creek. I like it.” Penny also said making choices was important for a good quality of life. Tom was the only individual that answered the question what could make his life better or would enhance his quality of life. Tom explained, “I’m hoping to get a second chance at Saint Xavier’s” (his previous community job). He also equated quality of life with, “I’d like to get a job at Dunkin’ Doughnuts” and “get into a group home.”

When the researcher asked the participants about what was not so good in his or her life, the responses provided were considered as descriptors for the definition of quality of life. For example, Tom spoke of not being able to (a) eat what he wants, (b)

work at the jobs that he wants, or (c) go where he wants. His overall statement, “I can’t do what I want to” indicated that part of his description of quality of life would be to have some independence or decision-making.

In response to being asked what was not so good in her life, Beth spoke of being upset when there are changes in her routine or schedule. Beth described her laundry routine when her family visits:

Sometimes we don’t do the same thing, might be use to do. Sometimes like I went downstairs to do laundry, some people don’t like to do laundry, but I do laundry. I was helping my Mom out. When I do it I like to do it, done on time, but some people do it later. [So they don’t follow the schedule?] No, makes me, kind of a little upset a little. [Sounds like a schedule is important to you] Yes.

Beth indicated that she needed structure in her life to be happy which would be a descriptor and part of her definition of quality of life. Beth also thought that several factors hindered her quality of life: money received was different for various jobs, people making fun of others, lack of community access, lack of safety at the workshop, and the feeling of confusion.

Penny did not have any descriptors that limited her quality of life because as she stated, “I’m happy, I’m always happy. I like it here.”

Quality of Life Definition by Parents

The three parents had several descriptors in common that would define quality of life for their adult son or daughter with intellectual disabilities. High View workshop, staff, family, and friends were mentioned most often by all the parents as descriptors for

the definition of quality of life. Mrs. Doris (Beth's mother) stated, "High View is a Godsend." Mr. Gray (Penny's father) stated, "High View has so much for her," and Mrs. Rose (Tom's mother) stated about High View, "He's working [at High View] and if not, there's other things to do, they're not just sitting." Mrs. Rose and Mrs. Doris included people who care about their children and wanting their adult son or daughter to be happy as descriptors for the definition of quality of life. When Mrs. Doris was asked the question, "What would make life better for Beth?" she answered, "Naturally, what you want for your child is to be happy and normal, but that didn't work that way. And I think Beth is happy. I asked her if she's happy and she tells me yes."

Mrs. Rose was the only participant who included the need for her child to care about someone as a quality of life descriptor. She also stated that it was necessary for Tom to get what he needs and wants as part of his quality of life definition. Mrs. Doris added the descriptors of social ability, travel, and contentment for Beth to have a good quality of life. Mr. and Mrs. Gray included several descriptors for Penny's quality of life definition: a community job, a paycheck, the feeling of importance and purpose, good health, and helping others. When asked what makes for a good life, Mrs. Gray emphasized the importance of living at home as long as possible; however, she also commented on the possibility of a group home placement:

That she's still living at home, she's still here. But in the back of her mind, she sees a lot of her friends going into group homes and going into CILAs [Community Integrated Living Arrangement]. And I think she knows some day that may happen to her. And she's never talked about it, but she knows, she'll tell us that so and so went into a CILA and we talk about it. I said are you ready to go

into a CILA? And she says, not quite yet, not quite yet—those were her exact words. That said a lot.

All the parents discussed various programming that High View could develop to enhance the quality of life of their son or daughter and be included as descriptors for their definitions of quality of life. Mrs. Rose stated that Tom needed more reading, Mrs. Doris wanted Beth to have an exercise program, and Mr. and Mrs. Gray believed that a variety of work would be beneficial for Penny and her quality of life. Mrs. Rose also considered increased independence and community employment as desired descriptors necessary for the definition of Tom's quality of life. Mrs. Rose emphasized community employment for Tom:

He wants to go outside to work, wants a job outside. He wants a job outside of High View like some of the other kids have. So I'm hoping it can happen. So I'm hoping they'll consider him for another job if there is one for him.

Penny's parents considered community living arrangements for her future but also discussed factors of disability awareness for people in the community and respite care for parents who have children with disabilities, which, in turn, would increase quality of life for Penny and all individuals with intellectual disabilities. Mr. Gray began:

It's hard, I don't know how to educate the people. I don't know how you can make the entire village more aware to understand disabilities. Respite care, sometimes is needed. To give parents timeout, and they don't have anybody else to help, it would be helpful. Education, I don't know how to do that. Maybe something with the grade schools, almost have to do with the kids because the adults are too screwed up already.

Mrs. Gray added:

People are afraid of what they don't know. And they might be afraid of the handicapped because they think they are out of control. But you know when I see these kids they aren't from High View, these are other kids in the stores from different schools. When I see the handicapped kids, they are the most well behaved kids in the stores. I think you educate the people by getting the handicapped out among them and letting the people know they're nothing to be afraid of, because I think people are not accustomed to the handicapped. You fear what you don't know.

When the parents in this study noted something as limiting the quality of life for their adult son or daughter, those comments were added to the list of descriptors since such limiting factors would make an impact on their son or daughter's quality of life. Mrs. Rose, Tom's mother, indicated that Tom's quality of life is limited because of his lack of independence; therefore, independence is considered important and was added as a descriptor for a good quality of life for Tom. Mrs. Rose described Tom's lack of independence as:

The ability to think for himself. He's really held back, because he wants to drive a car; he wants to do this; and he just can't. I check on him. His meds, I have to check on him. He wants to go but he loses his sense of direction if he goes out. But the ability that he can't come and go like the normal boys-the men do. Kind of like he is stuck in the middle. If he goes anywhere I have to take him, someone has to supervise him. That's what hurts me the most, that he just can't say "hey Mom I'm going out I'll be back in a couple hours."

Mrs. Rose also gave medical, emotional, and lack of understanding as descriptors that would hinder or limit Tom's quality of life.

Mrs. Doris listed the descriptor of never being able to leave Beth alone. She acknowledged that there is a lack of independence and confusion when Beth is not with her mother. Mrs. Doris explained Beth's lack of independence:

Well, you know it's funny, socially she does so well, but her comprehension is another thing, she could never be on her own. When we go out, I hold her hand all the time. She got away from me. In fact, even at Disney. I mean that was a frantic time. Oh my gosh, you know they don't talk, any of the characters, they just motion and that. But they found her. She was with me one minute and gone the next. With all the millions of people there, but they found her. And at the store it's the same thing. Beth gets very confused. She could never be on her own, never, never. She does well when there is family support and friends. But to be left on her own, she gets confused and she gets lost. I can't leave her in the grocery store, she has to hold my hand. She gets upset and crying, she gets very, very upset. The more it happens, the more confused she became. So I realized one day that I had to hold her hand all the time, and I do. I never let her go I hold her hand all the time, no matter where we go.

Beth's mother, Mrs. Doris, stated a lack of community access as something that would hinder Beth's quality of life. Mr. and Mrs. Gray could not identify anything that hinders or limits Penny's quality of life. When asked what is not so good in Penny's life, Mr. Gray answered, "You'd have to ask her, she would be the only one to know." They

stated that Penny is always so happy that they could not think of anything that would hinder her good quality of life.

Case Managers Define Quality of Life

Two of the three case managers, Mark and Jean, have worked at High View for over 15 years; Sue has been at High View for three years. As noted in Appendix I, the quality of life descriptor “work” was most frequently cited by case managers. All three case managers emphasized High View as being important to the individual, therefore will be included in the definition of quality of life. Mark, Tom’s case manager, considered family/friends, community, and independence equally important as descriptors for quality of life. However, his descriptors for family and independence were that of Tom’s dependence on his mother, thereby hindering his quality of life.

He would not be solely dependent on one person for everything. It’s almost as if he’s trapped. I think Tom has always been close to family, that’s a given. But I think now he is so intertwined with mom, I’m just not sure how good that is for him. And how well he’ll be able to adjust if she wasn’t around. I think that if he was living in a CILA or some kind arrangement of that fashion. There are still yet a lot of things that Tom can learn how to do, let him blossom and grow. To give him more independence.

Sue, Beth’s case manager, had equally responded to family/friends, community, and independence for descriptors for Beth’s quality of life definition. She also considered these descriptors as hindering Beth’s quality of life. Sue stated that Beth is influenced by her mother.

Mark (Tom's case manager) and Jean (Penny's case manager) added to their list of descriptors that, when speaking of work, it is important to have a sense of purpose and self-importance for a good quality of life definition. Jean, Penny's case manager, included two important descriptors for the definition of quality of life for Penny: community employment, opportunities, and exposure to learn new things. Penny is the only participant who had a community job. Regarding Penny and her community volunteer job, Jean stated:

She volunteers out in the community, which I think that makes her feel really good. She volunteers at a golf course, her father use to work at this golf course and so I think she has this special feeling, "Well I'm working at the golf course just like you used to." She has the job at the golf course and that's very important to her.

When asked about enhancing the quality of life of the individual with intellectual disability, Jean explained that having Penny participate in additional individualized enrichment programming would be beneficial to her and enhance her quality of life.

One of the things we're looking at now is, kind of like starting another program, where it would be enrichment. Moving away from sheltered workshop. We feel some people that don't enjoy working or it's not important to them. A majority do like it, but some that don't care for it, so we're talking about a new program that would just be enrichment all day. She wouldn't necessarily fit into that group but we do keep trying to find ways to enhance people life's. Activities that are beyond life skills, some extra things like art appreciation, a travel club.

Mark included opportunities to learn new things as important to Tom as part of his quality of life definition:

Part of what a good life for Tom is being at High View. That he does participate in different activities. That he's willing to participate. Making the choices that he has with the opportunities to have friends, to learn different things.

Mark (case manager for Tom) and Jean (case manager for Penny) discussed all the descriptors positively or as enhancing the quality of life, while Sue (case manager for Beth) listed her descriptors as limitations of quality of life.

The descriptors that limit or hinder quality of life were different for each case manager. Sue gave no response to the question for enhancing Beth's quality of life but stated that community integration and community work are limiting factors on her quality of life:

Well in Beth's case, she does have a pretty swell life in my opinion. I think it might be slightly better if she was more exposed to the community. Like, I know here at High View, she's not really allowed to go get a job in the community. She was able to volunteer but her mom, now her guardian, decided to end that. Not 100% sure on the reasoning. But I know mom has influenced Beth to stay back at the workshop, when I thought she was enjoying her volunteering in the community.

When describing limiting factors, Sue also included lack of opportunities for decision and choice making in describing Beth's quality of life definition, i.e., "offering her the opportunity to make decisions for herself." Sue also included Beth's mother as a descriptor that hinders Beth's quality of life: "Why I just know that if Mom has an uneasy

feeling about the location of an activity, that if she sees it is unsuitable or unsafe for Beth, more than likely Beth will not be participating.”

Mark, the case manager for Tom, succinctly noted that health and dependency on his mother are limiting Tom’s quality of life. When asked what would a good life look like for Tom, his case manager answered, “He wouldn’t be on as much medication as he’s on. He would not be solely dependent on one person for everything.” Penny’s case manager, Jean, was asked, “what would be not so good about Penny’s life,” and noted,

Well, I think, well, her parents are older, and I don’t want to say much about their own personal life, but they have their own health issues. I don’t want to say too much about their life other than they have health issues, and there’s been a question of what will happen with Penny if something happens.

Jean explained that Penny’s’ aging parents and the question of what will happen to Penny when her parents are no longer available to care for her are certainly hindering Penny’s quality of life.

Summary of Definitions of Quality of Life

Definitions for quality of life were individualized and the descriptors identified across individuals varied. Through interviews, each participant told their stories and gave their perspectives of quality of life. Individuals with intellectual disability named specific concepts and ideas to develop their descriptors. Their parents and case managers developed descriptors that were more general in nature. The creation of the quality of life definition for the individual with intellectual disability came from the collection of descriptors of the triad members. As presented in Appendix I, all of the study participants included High View as a descriptor of quality of life definition.

Services and Supports to Enhance Quality of Life

Supports and services may enhance a person's quality of life. In this section of the study, the researcher explored the perspectives of the participants regarding the types of supports and services they believed necessary to enhance the quality of life of the individual with intellectual disability in the respective triads. During the interview, various questions were asked so the researcher could understand what each participant considered necessary to enhance the quality of life, what was desired, or what limited the quality of life for the individual with intellectual disability in his or her respective triad.

Tom, Beth, and Penny were all asked questions (or variations of these questions) about what would make their life better, what they needed to make life better, and/or things or people they needed to have a good life. Participants with intellectual disability responded with concrete answers when asked about supports and services. They all indicated they are provided with help at work from staff, case managers, or a job coach. All three individuals responded similarly in the area of work; sample responses included High View, community job, staff, and a variety of jobs.

The three individuals with intellectual disability agreed that their quality of life is better because of the services at High View and staff support. When asked how does High View make your life good, Tom stated, "Doing jobs here. I do the Christmas tree bags. I wish I could do the flashlights." He continued talking about the staff when he was asked who could help him when he felt sad, "Just Sharon [social worker]. She makes it better. Just talk to Sharon makes me happy."

The individuals also stated they received support from family--mostly their mothers--some siblings, and friends. When answering the interview question about

supports and services, Beth's responses referred to her family and friends who supported her and enhanced her quality of life. Beth explained, "My family very important to me." All of the individuals stated that they supported their families as well. Beth indicated that helping her mother, siblings, and extended family, and their help in return enhanced her quality of life. As Beth stated, "I have a Mom that takes care of me, like she always does. I have a lot of sisters and brothers. I always help them and treat them nice, brothers and sisters help each other."

According to Tom, family support consisted of his mother making decisions of where, when, and what he can do. Tom desired support from his mother, though he wanted to understand her decisions about why she takes his snacks away. When Tom was asked what his Mom could do to make his life better, he answered, "Talk to Mom, I can try to talk to mom, not to take away my snacks. She can talk about it."

Tom and Penny were the only individuals who named supports that they wanted to help them have a better life. Penny wanted to have help with the use of the telephone. Tom stated he wanted help from the social worker to control his anger and potentially get his community job back. Having a community job is very important to him and he stated that his life would be much better with it. Tom also declared his life would be better if he could at some point live in a group home and return to camp to go horseback riding. When asked the question, is there anything else in life that makes life really good? Tom explained, "Horseback riding. Yeah at camp, I want to go in 2014. I miss Red Robin, my horse. Yeah seeing my horse will make my life better." Tom also declared what made his life not so good was that he does not get what he wants and he does not

understand why. He wants someone to explain to him why he cannot do what he wants to do.

When Beth was asked about services and supports, she focused on her lack of participation in community activities or a community job. She stated, “My mom don’t want me in a job in the community.” Beth described the types of community activities she would like to participate in: “I like to go shopping because it’s fun. I like to go downtown to look at the lights, the Christmas lights.”

Supports and Services Described by Parents

The services of High View and the support of the staff were considered important by Tom, Beth, and Penny, but Mrs. Doris and Mr. and Mrs. Gray found five of the seven response areas equally as important in the supports and services category. The number of responses for Mr. and Mrs. Gray ($n=40$) and Mrs. Doris ($n=43$) were 12% to 14% in the response areas of family/friends, community, health/safety, independence, and work. Mrs. Doris gave more details when she spoke of supports to enhance the quality of life for Beth based on family responses:

It’s just teaching her, you know. I think that’s the most important thing, that you’re there as a family. She’s active all the time. She goes with me all over, we travel a lot. Beth is such a joy, we teach her. I’d talk to her, teach her everything I can. And so does her siblings. They spend time with her, they teach her, they teach her different things. Having so many sisters and brothers and nieces and nephews, they had a big impact on her.

Mrs. Rose and Mr. and Mrs. Gray considered health care providers, social club volunteers, and park district programs and staff to be important support and services for

Tom and Penny to have a good quality of life. Mrs. Rose considered Tom's health as needing supports and services for his quality of life. She stated:

Since he became diabetic, he's lost quite a bit of weight. He's starting to eat a little more cookies. He has roashea on his nose; I need to take him to the doctor for it. His meds, I have to check on his meds. He's under medication a lot. Out of 12 medications, nine of them are drowsiness and irritable. They wrote a letter to the psychiatrist, he doesn't want to take him off anything right now.

Although Mrs. Rose stated, "He doesn't really get involved in the community that much," she began to list all the services and supports that he does receive.

I signed him up today for zumba, it's a dance like yoga. I registered him for that and for bowling again. He bowls twice a week, for the park district and Wednesday for High View. I tried to get him into the social club on Fridays, he likes to get to do that. They start going on trips to Navy Pier, to the show, I'm not sure where they always go. He's going to try power lifting. He's involved with the Spread program at church. He also goes to the friendship club. That's at the Lutheran church, all the kids there are mostly Catholic.

Only Mrs. Doris considered the support of learning new things as necessary for a good life for her daughter, Beth; and Mr. and Mrs. Gray considered Penny's community job and job coach as important services and supports for a good quality of life. Penny is the only participant who had a community job.

Two parents, Mrs. Rose (Tom's mother) and Mrs. Doris (Beth's mother) listed supports that are limited or not in place that affect the quality of life for their children. They indicated that both Tom and Beth could not be left alone and needed to stay with

their mothers. According to Beth's mother, the supports and services that limit Beth's quality of life are due to losing opportunities to participate in the various community park district programs. Beth enjoyed the programs and activities in the community, her mother registered her, and then let Beth choose between the community program and a family outing. Mrs. Doris explained:

I'd sign her up for something and three quarters of the time she couldn't go because we had something else going on. And it was a choice, I'd leave it up to Beth, do you wanna go here or do you wanna go with the family? She always wanted to go with the family, so no sense for her being signed up for these programs.

Mrs. Doris also stated with regard to Beth and community activities, "She could never really be on her own. I hold her hand all the time. I never let her go. I hold her hand all the time, no matter where we go, church, or anything."

Tom's mother, Mrs. Rose, suggested that it is required that she support Tom to enhance his quality of life. She answered many interview questions beginning with "I take him," "I signed him up," "I get him to," "I go with him," and "I take care of him." She also indicated that staff at work enhanced his quality of life especially his male case manager. Mrs. Rose stated Tom was missing supports and services that might hinder his quality of life, which included health concerns, lack of emotional control, and his lack of understanding. She explained about his lack of understanding:

Sometimes he doesn't understand things. We always talk things out before we go to bed, we need to talk so it is all right. He doesn't understand things. Like

watching a game show, he'll ask why didn't that couple win? It's hard. He has a hard time.

Mr. and Mrs. Gray noted that quality of life for Penny is enhanced by services provided by High View, the community job, and her family and friends. They stated that Penny helping others is very important to her and enhances her quality of life. They also agreed that disability awareness for people in the community might enhance Penny's quality of life more than individual services alone. Mr. and Mrs. Gray suggested that the people in the community needed to be educated on disabilities so that people with intellectual disabilities can be accepted in the community, everyone would benefit, and everyone's quality of life enhanced.

Case Managers Describe Supports and Services

The case managers described the category of "work" most frequently across their total responses to interview questions regarding supports and services that enhance quality of life. Mark identified work in 9 of 29 responses, Sue in 7 of 23 responses, and Jean in 5 of 21 responses (see Appendix I). Mark (Tom's case manager), Sue (Beth's case manager), and Jean (Penny's case manager) named other common descriptors for this category: High View, staff, case managers, and community jobs. All case managers suggested the services and staff from community park district programs impact the quality of life for all individuals with intellectual disabilities.

Mark stated that he provides supports and services as Tom's case manager by not only reporting progress and yearly goals but, as he stated, "I serve as a conduit for Tom, in some sense, if he has problem with somebody he can come to me; if he has a question he can certainly come ask me." The supports that Mark indicated he gives Tom include

ways for him to control his anger and teach him socially appropriate skills, which will enhance Tom's quality of life. Mark stated:

Well I think Tom's main support that he needs is emotional and social more than anything else. Helping him control or curb his anger and outbursts, as well as trying to help him learn how to be socially appropriate as he interacts with his peers.

Mark listed limited opportunities that Tom currently has to make choices, to learn new things, explore different work activities, and living arrangements, as areas that decrease his quality of life. These were the same areas that Mark suggested as desired programming when asked what was needed to increase or enhance Tom's quality of life.

As Beth's case manager, Sue stated she supports Beth by creating goals for the year and interacting with her family as a liaison for High View. When asked what High View does that is good for Beth, Sue explained:

Since she's still maintaining what skills she had for as long as she had them. So if those skills were to decrease or become difficult for her, we can at least see that and try to intervene and let the family know this is what we're seeing. Continue on with what we've been doing, for as long as we have been doing. Beth seems pretty content and satisfied here.

According to Sue, Beth has great support from her family, who will go out of their way to help Beth, even the family members from out of state. She indicated that the family supports and community activities would enhance Beth's quality of life if given more opportunities to make her own decisions and choices. Accommodations for larger print

for reading and non-glare glass cover for the computer are the only other supports that Sue indicated that Beth utilizes at the workshop.

Jean's role as Penny's case manager is to work with Penny to set up goals in areas that she believes would provide needed supports. Jean stated that Penny requires someone to oversee her work, though she is self sufficient while in the work setting. When questioned about things that High View does that is good for Penny, Jean explained, "I think we provide her with a sense of purpose, and a sense of community. We give her opportunities to learn and be exposed to different things." Jean also stated that Penny receives supports at High View to enhance her quality of life in programs in which she participates and with the staff and her job placement at the community golf course. Jean suggested that this job is very important to Penny and enhances her quality of life. An important quality of life support for Penny, should something happen to her aging parents, was described by Jean: "One of the things she may need support with is I believe is the aging parents."

The three case managers listed no common desired supports or services that would enhance the quality of life for each adult with intellectual disabilities, but each had several ideas for descriptors that would influence the specific individual with whom he or she worked. Sue listed disability awareness for community people that would benefit Beth's quality of life: "I suppose if the community had a better awareness of Beth's disability as well as everybody else's disability, they be more open to a conversation." Jean described Penny's future and the support she will need due to her aging parents.

Mark had the longest list of supports and services that he thought would enhance the quality of life for Tom. He described them:

We need to take a look at the medication he's on and how it affects his life now. And can there be changes made. I would say more counseling. I think that if he was living in a CILA or some kind arrangement of that fashion. There are still yet a lot of things that Tom can learn how to do, to let him blossom and grow. To give him more independence. Interacting with others, building and maintaining friendships, and social things. Maybe some type of social group. I mean we try to work on social skills here but a group that attempts to work on social skills in the community and then tries to do it in the community, make a real world trial. He needs a different job in the community, potentially a job in the community, I should say.

Mark stated he believed that Tom has potential to grow and gain independence with the support of the staff and people who care about him, thus potentially enhancing his quality of life.

Limits to enhancing quality of life are minimal according to all case managers. Jean could not identify any limits since she stated that anything that she could think that may hinder Penny's quality of life could be turned around into a goal with a support or service. Jean stated, "Like I said, with her it's hard. I feel like she's pretty happy." Sue stated that community access was limiting to Beth as was just maintaining her skills. Mark listed medical issues, choice making, emotional issues, and social skills as limitations that would hinder Tom's quality of life but he also listed these as needing supports and services to enhance his quality of life.

Summary of Services and Supports

As a group, individuals with intellectual disability had the highest number of responses for services and supports in the areas of family/friends and community. Parents only had the highest number of responses in the area of health and safety, while case managers had the other three areas, work, independence, and feelings. However, individuals were very close in the number of response in the area of work (see Appendix I for complete counts). Individuals found that supports from family and friends and community services were important and necessary to enhance their quality of life. Work is also important for individuals; both Tom and Penny had the highest number of responses ($n = 27$). Penny also had the highest number of responses in the areas of family and community.

All of the parent participants emphasized supports in the community as enhancements to quality of life for their adult son or daughter with intellectual disability. Mr. and Mrs. Gray had the similar response frequency in the categories of supports and services of community, work, family and friends, and independence. Mrs. Doris had the highest number of responses ($n = 27$) in family but a low count in the area of work and independence. The lowest number of responses for parents was in the area of feelings, with Mrs. Rose having the lowest number.

When case managers described their job responsibilities, they emphasized the support they provide to individuals with intellectual disability quality of life. They described supports and services related to skills at work, including writing annual goals and overseeing the individual service plans. All case managers stated that supports at

work are necessary to enhance the quality of life for all individuals with intellectual disability. The response area of work was the highest in number for case managers.

Comparison of Quality of Life Within Triads

The third research question investigated the participants' perspectives within and across triads. Each triad was explored separately or within the triad, illustrated the similarities and differences of all the participants who have something in common with each other in the same triad. For example, in Triad 1, everyone has Tom in common; there is Tom, his mother, and his case manager. The researcher explored the perspectives of each member within the triad to gain an understanding of Tom's quality of life definition through the similarities and differences of the descriptors. Comparison within each triad will include the quality of life descriptors followed by the supports and services to enhance the quality of life.

Table 7 illustrates the various descriptors provided by the participants in Triad 1 to show descriptors that enhance and limit the quality of life. These are the more common descriptors that occurred as responses during interviews. Comparing the descriptors of quality of life from the participants of Triad 1 shows more differences than similarities. The only item that Tom, his mother, and his case manager agreed upon is that work is necessary for Tom to have a good quality of life.

Tom and Mark agree that friends and family are necessary, or as Tom stated "helping Mom" is necessary for his quality of life. Tom and his mother agree that there needs to be things for Tom to do, such as fishing, shopping, and music. His mother stated, "I keep him involved in everything I can." Tom's mother and case manager suggested that having people who care about Tom help define his quality of life, but it

was his mother who considered Tom caring about other people as an important descriptor for his quality of life.

Table 7

Quality of Life Descriptors by Participant in Triad 1: Tom

Descriptor	Triad Participant		
	Tom	Mrs. Rose (Parent)	Mark (Case Manager)
Descriptors for the definition of quality of life	Work	Work	Work
	Helping Mom	People that care about him	Family
	Friends		Friends
	Things to do (fishing, music, shopping, pull tabs)	Things to do (shopping, collections) Happy Get what he want/needs People to care about	People that care about him Contentment Sense of purpose
Descriptors that enhance the quality of life	Community job	Speak up for self	Independence
	Group home	Keep involved	
	More choices	Independence	
Descriptors that limit quality of life	Bad health	Can't think for self	Health/medication
	Not doing what he wants/lack decisions	Held back	Dependent on one person

All three members of Triad 1 used the word independence as a descriptor to both enhance and limit Tom's quality of life. Tom's mother and his case manager used the word independence as a descriptor but Tom portrayed his descriptor for independence with more details. For example, Tom described his independence as wanting to make more choices, to live in a group home, and to have a community job. Tom specified the job he wanted in the community, "I'm hoping to get a second chance at Saint Xavier's.

[Would that make your life better?] Yeah. [Is having a community job important to you?] Yeah.”

All three participants used the descriptor independence when speaking of limiting Tom’s quality of life, although they explained independence in their own unique way. Mark described Tom as dependent or “intertwined with Mom.” Tom’s mother stated, “That he does not have ability to think for himself.” Tom said, “I can’t do what I want to.” Tom and Mark added to these statements about independence that Tom’s health was also hindering the quality of Tom’s life. Tom described how his health condition of diabetes impedes his quality of life because he could not have the snacks or McDonalds foods he wants, does not understand why he cannot have them, and they are important to him. He stated, “There’s McDonalds. I can’t eat ‘em. I miss Big Macs.”

Table 8 shows the descriptors provided by the participant of Triad 1 to show the services and supports that are important the quality of life for Tom. Members of Triad 1 agreed that High View and work are important services for Tom’s quality of life (see Table 8). They also conveyed that the staff, friends, and his mother are important supports for Tom. However, to enhance the quality of life for Tom, all members of Triad 1 concurred that Tom would benefit from a community job. Tom named the job he wanted: “I’m hoping I get a second chance at Saint Xavier’s.” Tom also had a second choice for a community job: “I’d like to get a job at Dunkin Doughnuts.”

Tom and his mother spoke of church as a support important for Tom’s quality of life, although Tom’s description of church was different from his mothers. Tom’s explanation included his friends at church who are the supports that are important to him

Table 8

Participant Descriptors of Supports and Services Within Triad 1: Tom

Descriptor	Triad Participant		
	Tom	Mrs. Rose (Parent)	Mark (Case Manager)
Descriptors of supports and services for quality of life	Staff Work Mom Friends Church/friends	Staff High View programming Mom Friends Church Park district Social club Medical/doctors	Staff/case manager High View Mom Park district Friendship club
Desires of supports or services	Community job More support from social worker Group home Go to camp/horseback riding	Community job Ability to do things alone Reading program	Community job Social/emotional supports/counseling Living arrangement Increased opportunities Learn new things Increased friendships Change meds Medical evaluation
Supports/services limits quality of life	Doesn't get what he wants and doesn't understand why	Medical Emotional Lacks understanding Can't do things on own; Mom has to do everything with him	Medical Emotional Choice making Social skills

and not just the church as his mother stated. Tom described his activity and friends at church: “Yeah I go to church. I’m an altar server there with Father Larry. [Do you have other friends at church?] Sister Ann.”

Tom and his case manager suggested Tom’s quality of life could be enhanced by changing his living arrangements, increasing his social/emotional support, adding counseling, and social work services. Mark continued to explain that a medical evaluation and medication review and changes might enhance Tom’s quality of life since he now sleeps at work and has other medical issues that need attention from medical personnel. Tom’s mother also spoke of medical issues limiting Tom’s quality of life but not as in much detail as did Mark. Tom’s case manager explained his concerns with medical issues:

He wouldn’t be on as much medication as he’s on. We need to take a look at the medication he’s on and how it affects his life now. And can there be changes made. He complains a lot that he can’t sleep and he’s tired. Maybe there needs to be some changes that allows him to stay awake yet control the medical issues that he has.

Tom’s mother explained her concerns with Tom’s medical issues and stated,

Since he became diabetic he’s lost quite a bit of weight. He’s starting to eat little more cookies. He has roesasha on his nose; I need to take him to the doctor for it.

Out of 12 medications, nine of them are drowsiness and irritable.

Mrs. Rose listed other descriptors that limit the quality of life for Tom, such as his lack of understanding and inability to do things on his own. Tom explained he does not

understand why he cannot do what he wants and get what he wants. He suggested that his mother support him by talking to him and explaining these things to him.

Members of Triad 2 had several descriptors in common that suggested importance in defining the quality of life for Beth (see Table 9). These descriptors included family, friends, High View, and work. Beth explained, “My family is very important to me. I have a good life. I have a Mom that takes care of me like she always does. I have a lot of sisters and brothers.” Her mother explained family as:

They talk to her, and having so many sisters and brothers and nieces and nephews, they had a big impact on her. I’d talk to her, teach her everything I can. And so does her siblings. She has a family that will care for her and love her. Well, I think that’s the most important thing, that you’re there as a family.

Beth’s case manager also realizes that family is important to Beth: “Her family support, I’ve seen that she does keep in touch with plenty of her family members, even out of state family members.”

All Triad 2 members stated being happy, and Beth’s mother and case manager added being content as being valuable to Beth’s quality of life. Sue, her case manager when asked what would make life better for Beth, said, “Just happiness, just the feeling of being happy, regardless of what’s going on. Beth seems pretty content and satisfied.” Mrs. Doris explained happiness in the following way:

I’m content with my life, I have been for a long time. And I think Beth is happy. I asked her if she’s happy and she tells me yes. As I said I’m content with our life, my life. I know Beth is happy. She has a good life, she goes a lot of places,

she has people who love her, she has nieces and nephews who spend time with her, she's fortunate, she's very fortunate.

Beth and her mother agreed to other descriptors such as travel and things to do which included music, dancing, shopping, and helping others. Beth explained that schedules and keeping routines are very important to her and therefore necessary for her to have a good quality of life. As she discussed when completing laundry for her mother, Beth stated:

Sometimes like I went downstairs to do laundry, some people don't like to laundry but I do laundry. Yeah, I was helping my mom out. When I do it I like to do it done on time, but some people do it later. [They're not following the schedule?] No. [How does that make you feel?] Kind of a little upset a little. [Sounds like a schedule is important to you]. Yeah.

Beth had no suggestions for enhancing her own quality of life; however, her mother and her case manager had ideas that were very different from each other. Mrs. Doris stated that having Beth be treated as everyone else would enhance her quality of life. When asked what High View could do to enhance Beth's life, her case manager stated:

"I guess providing a variety of programming for her that would suit her interests. Trying to get that out of her, trying to provide programming that would make her happy. And like I said, offering her the opportunity to make decisions for herself.

Community access is one descriptor that all members of Triad 2 agreed limits Beth's quality of life, though for different reasons. Beth did have a community volunteer job and participated in various park district programs, which she stated that she enjoyed. Her

mother did take Beth out these programs and her community volunteer job. Beth's case manager stated for this was for unknown reasons. Mrs. Doris explained she let Beth choose to attend park district activities or family outings.

Table 9

Quality of Life Descriptors by Participant Within Triad 2: Beth

Descriptor	Triad Participant		
	Beth	Mrs. Doris (Parent)	Sue (Case Manager)
Descriptors for the definition of quality of life	Family	Family	Family
	Friends	Friends	Friends
	Work	High View	High View
	Happy	Content/happy	Work
	Travel	Travel	Happy
	Things to do (music, shopping, helping others)	Things to do (dancing, swimming, phone calls)	Content/satisfied
	Church		
	Routine/schedules	People who care	
Descriptors that enhance the quality of life	Nice to me	Social ability	
	--	Treat her like everyone else Indoor pools	Make own decisions Programs that suit her interests/make her happy
Descriptors that limit quality of life	No community job/access	Community access Choice making	Community integration
	confusion/changing things	Lack understanding	Community job/volunteering
	Talking bad	Comprehension	Lack of choice
	Money	Lack relationships	Lack of opportunities
	Lack of safety	Independence	

I'd sign her up for something but $\frac{3}{4}$ of the time she couldn't go because we had something else going on. And it was a choice, I'd leave it up to Beth, do you wanna go or do you wanna go with the family. She always wanted to go with the family, so no sense for her being signed up for these programs.

Beth would always choose family over the park district and her mother stopped enrolling her in any community programs.

Beth's mother and Sue agreed that the lack of choice making limits the quality of life for Beth. They both agreed that opportunities for choice making were limited. Sue commented several times that Beth is influenced when making choices: "But I know Mom has influenced Beth to stay back at the workshop, when I thought she was enjoying her volunteering in the community." When Beth was asked what she would like to do in the community, she responded, "That's a good question. My Mom don't want me in a job in the community." Sue also responded when asked what would enhance Beth's life, "It is the lack of opportunity that she has not been given to make her life better. I would just say give her the option to decide for herself without being influenced by anyone."

Beth, Mrs. Doris, and Sue have differences regarding the descriptors that limit Beth's quality of life. Sue stated that she believes the lack of opportunities for trying new activities is a major hindrance. Her mother stated Beth's lack of understanding and comprehension causes limitations. Mrs. Doris describes one example:

She has a few friends at High View, they call each other up, and that is good cause she needed that. What's nice is that they're females now. It use to years ago, the boys would call up. It became such a problem and that is difficult. When parents go through this because you can't explain to these kids, they don't

understand why can't I get married. Beth and I went through this many times.

One time at a party, she got three proposals. But you know they don't have the comprehension.

Beth does not like the fact that others ignore safety rules, especially at work. Beth continued to describe additional descriptors that hinder her quality of life, such as when she gets confused when people change things or the schedule, when she does not get enough money for a job, or when people say bad things or make fun of her. Beth explains the safety rules at work:

Different people are walking around on the floor. That's not good, that's bad.

People should not walk around. People go into the bathroom they should stay in their seats. When they go to the bathroom, they don't come back to their seat.

They need to come back for safety.

Beth also explained how people and what they say would hinder her quality of life.

When asked what is not so good in your life, she included examples:

I would say when people say bad things about you. When people make fun of you. Some people do, I'm not gonna say any names. When people say, ahh, like people are talking back to you. [So when other people are mean to you makes for a bad life?] Yes. Sometimes people say like, when people say some people, like something, like when people threaten you. Umm, I forgot the name of it when people say something about the other person. [When you're talking about other people] Yes.

Supports and services are important to a good quality of life (see Table 10). In Beth's case, all members of Triad 2 pointed out that the supports and services provided

by High View are necessary to enhance Beth's quality of life. All three triad members suggested the supports of staff and family are important to Beth's quality of life. Beth and her mother continued to list friends and church as supports for quality of life. Reciprocal support of Mrs. Doris helping Beth, and Beth helping her mother are important for a good quality of life according to both Beth and her mother. Beth explains that helping her mother is important: "Sometimes I help my mom. I wash the dishes with my mother, and put them away. I do a lot of things in my life, like help my mom, help myself, we always do things together."

Mrs. Doris also explains the reciprocal support between Beth and herself:

She's such a joy. I take care of her, and she takes care of me. We talk together, we do things together, I have her helping me. We make beds together, I put clothes into the machine, she takes them out. She folds them, she doesn't do a good job on them but she does it, she tries, she tries hard.

According to Mrs. Doris, having support for learning new things enhance Beth's quality of life. She also stated that the exposure to different people throughout Beth's life and the continued exposure explain the supports are very important for enhancing Beth's quality of life. Mrs. Doris explained the numerous people that support Beth:

Beth is one of eight children; she's the seventh child, the youngest girl. Her siblings are just fantastic with Beth. They treat her like one of them, she's never been any different, and I think that is one of the reasons why she has really advanced. Because everyone takes her all over, she's with people all the time where they talked to her. Our children and friends, they all know Beth. They enjoyed her, they all talk to her, and talk to her just as they would anyone. All say

how well she does. I think it's because she's so exposed to so many people all the time, they had a big impact on her.

The lack of community access was one support and/or service which all members of Triad 2 agreed was needed, limited, and hindered Beth's quality of life. Beth's mother stated that Beth cannot be alone and must have her hand held whenever she is out of the house. This limits any service that can be provided in the community, therefore hindering Beth's quality of life. When asked what the community could do to help Beth or make her life better, Mrs. Doris stated:

I think the community tried the best they could when we first started. They became aware in the sixties; Beth was born in 63, so it was towards the end of the sixties when we realized how many handicapped children there are. No one knew what to do with their kids; no one knew they used to close the doors and hide them. [What now a days could the community do to help Beth make her life better?] I really don't even know if I can really answer that. There's probably a lot of stuff the community could do. I haven't taken her anywhere in the community. I really don't know. I really don't know. I have no idea about the community. I can't really say, I don't really feel qualified to answer. She's not involved in any of that.

Beth named activities that she wanted to do in the community (outside of High View) and which she was not allowed to participate. She wanted to go into the community to go shopping, see Christmas lights downtown, and continue swimming. Not being able to do these things limits her quality of life.

Table 10

Participant Descriptors of Supports and Services Within Triad 2: Beth

Descriptor	Triad Participant		
	Beth	Mrs. Doris (Parent)	Sue (Case Manager)
Descriptors of supports and services for quality of life	High View	High View	High View
	Work	Staff/case manager	Family
	Staff/case manager	Family	Accommodations (reading/computers)
	Family	Friends	Create goals for Beth
	Friends	Church	
	Church	Mom helping Beth	
	Mom helps her	Learning new things	
	Helps Mom	Exposure to many people/siblings teach her things/activities	
Wallet/physical accommodation for identification			
Desires of supports or services	--	Exercise class	Disability awareness for other people
Supports/services limits quality of life	No community job/integration	Lack community integration	Community integration ("not allowed")
		Never alone/Mom holds hand	Just maintaining skills
		Taken out of friendship club that Beth liked	

The participants in Triad 3 (i.e., Penny, Mr. and Mrs. Gray, and Jean) listed many descriptors for defining quality of life for Penny (see Table 11). They all stated that Penny is consistently very happy. As Penny stated, "I'm happy, I'm always happy." The two common descriptors that are most important to Penny and her quality of life are

anything to do with High View and her community job at the golf course. When Penny was asked what made her happy, she responded:

Coming to workshop, High View and sweeping for my job at Stony Creek. [You have a job at the Stony Creek golf course?] Yes, I like it. [So that's important to you?] Yes. [What else is important in your life at work?] Terry, the staff. And Mary, the staff too. She helps us work.

Mr. and Mrs. Gray, Penny's parents, and Jean, Penny's case manager, took work one-step further and said that work gave Penny a sense of importance and purpose that she needed for a good quality of life. Mrs. Gray, when asked about Penny's experience at High View, explained:

She's very content with what she has and loves High View. The social environment is excellent. She loves her paycheck. She hands it to me and she says I'm taking you out to eat tonight. Yes, it's important. It makes her feel good about herself.

Mr. Gray agrees with Mrs. Gray but also adds his comments about Penny's community job at the golf course:

High View has done so much for her. I'm not sure what she likes the most, social or the paycheck. She really enjoys doing that, cashing the paycheck and then going out to eat. She's paying for it. To know that she's doing something with it. That's extremely important. She likes to go to Stony Creek. She goes to Stony Creek golf club once a week. She cleans the tables. What would I want them to do more of, it would be nice to have them have more work some days. Maybe a

variety of work, which is not easy to get. More like that, she's lucky to have what they do.

Table 11

Quality of Life Descriptors by Participant Within Triad 3: Penny

Descriptor	Triad Participant		
	Penny	M/M Gray (Parents)	Jean (Case Manager)
Descriptors of quality of life	Work	High View	Work
	Community job	Community job	High View
	Always happy	Work/pay check	Community job
	Family	Friends	Friends
	Family love and hugs	Choices	Happy
	Choices	Doing things (out to eat, shopping, shows)	Feeling of importance/purpose
	Doing things (out to eat, shopping, shows)	Feeling of importance/purpose	Satisfied
	Church	Health Live at home Helping others Choice of pretty, nice things	Opportunities to learn Exposure to new things
Descriptors that enhance the quality of life	--	Reasonable health Social opportunities Anything to do with High View	--
Descriptors that limit quality of life	--	Limited access to community	Aging parents Penny's future

People such as family, friends, and staff, are descriptors provided by all members of Triad 3 as necessary for a good quality of life for Penny. Jean, her case manager,

answered the question, “What do you think makes her life good?” She responded, “She has friends, she has her special friend, her boyfriend.” Mr. and Mrs. Gray and Penny gave various community and leisure activities that Penny likes such as; shopping, eating out, and movies that help describe the definition of her quality of life. Making her own choices is a descriptor that both Penny and her parents applied to her quality of life. Mr. and Mrs. Gray completed their list of descriptors of quality of life for Penny with good health, helping others, choice of pretty things, togetherness, and enough money to live on. Jean stated as a part of the quality of life definition, “We provide her with a sense of purpose, and a sense of community. We give her opportunities to learn and be exposed to different things.”

Mr. and Mrs. Gray were the only members of the triad to provide descriptors that would enhance the quality of life for Penny. These would include social opportunities and anything to do with High View. Penny’s’ parents and her case manager had labeled descriptors that might limit or hinder the quality of life for Penny. Mr. and Mrs. Gray stated that a lack of access to the community could decrease a good quality of life for Penny. Jean believed that aging parents could limit Penny’s quality of life only because of the question of what will happen to her when her parents are no longer able to provide care. When asked about what could hinder Penny’s quality of life Jean also stated, “That’s a hard question, I feel like she’s pretty happy. I guess it’s something I think about all the time, like are we doing all we can. We do keep trying to find ways to enhance people lives.” Penny had no limitations and only stated that she is “happy, I’m always happy.”

Many supports and services that enhance the quality of life for Penny are common by all members of Triad 3 (see Table 12). For example, all agreed that High View and work are the most important services that Penny receives that enhance her quality of life. All three members of the triad listed the supports provided by the staff including the job coach and case manager.

Jean, Penny's case manager, described High View services and supports with more detail than the others. She described the services as programming that is innovative and providing more enrichment to Penny, therefore enhancing her quality of life. Jean's explanation:

We provide her, you know, social outlets and opportunities for relationships.

We're developing enrichment activities. We're trying to fill up the schedule of things to do when we do not have work, kind of a set structure. Things that are beyond life skills, which we're including some extra things like art appreciation, a travel club. Right now, we're doing a half day of vocational training, half day of life skills and enrichment classes.

Supports and/or services from church, friends, and social activities benefit Penny and enhance her quality of life. Mr. and Mrs. Gray included the supports from Penny's health care providers as necessary components for a good life. They also noted the importance of Penny's independence and willingness to help and support others as important to her quality of life.

Penny and Jean spoke of wanting new programming, enrichment, and phone usage to support Penny and enhance her quality of life. Mr. and Mrs. Gray and Jean

thought the limited future planning and support for living arrangements for Penny when

Table 12

Participant Descriptors of Supports and Services Within Triad 3: Penny

Descriptor	Triad Participant		
	Penny	M/M Gray (Parents)	Jean (Case Manager)
Descriptors of supports and services for quality of life	Work	High View	High View
	Staff	Staff	Oversee work
	Community job	Community job	Community job
	Job coach	Job coach	Church
	Friends	Friends	Innovative programming
	Church	Church	Social club
	Family	Family	
	Reading program	Social club/volunteers Medical/doctors Penny helping others Her independence Park district/bowling	
Desires of supports or services	Phone usage program	Variety of work Living arrangements Disability awareness (for others) Respite (for others)	Enrichment programming Penny future support Aging parent support
Supports/services limits quality of life	--	--	--

her parents are no longer available may hinder her quality of life. When asked what makes Penny's life good, Mrs. Gray spoke of Penny moving into a Community

Integrated Living Arrangement (CILA):

That she's still living at home, she's still here. But in the back of her mind she sees a lot of her friends going into homes and going into CILAs. And I think she knows someday that may happen to her. And she's never talked about it, but she knows, well she'll tell that so and so went in a CILA and we talk about it, asking how's he's doing. She says he doing fine, he likes it. I said are you ready to go into a CILA? And she says not quite yet, not quite yet-those were her exact words. That said a lot.

Mr. and Mrs. Gray also discussed supports and services for community members, such as disability awareness and respite care that would enhance the quality of life for all individuals with intellectual disability.

Summary of Comparison Within Triads

The comparison within triads provided similarities and differences of participants who know the individual with intellectual disability. The researcher discovered that parents, case managers, and individuals with disabilities all have their own unique perspectives. Although there were some descriptors all participants listed, the individuals with intellectual disability provided consistent concrete details of their descriptors. For example, in Triad 1, Tom, his mother, and his case manager stated a community job would enhance Tom's quality of life. Tom expanded by providing details of what job he would like to have supplemented by comments of desired alternative placement: "I'm hoping I get a second chance at Saint Xavier's." With the alternative, "I'd like to get a

job at Dunkin doughnuts.” Later in the interview he stated, “I’d like working with animals.” Little else was similar between the participants in Triad 1.

In Triad 2, Beth and her mother had very little in common with the case manager but they had many similar responses to one another. Beth’s case manager, Sue, limited her responses to work, lack of community job and integration, and Beth making her own decisions. The responses between Beth and her mother were very similar and included work, family, friends, travel, things to do and taking care of each other.

Triad 3, represented by Penny, her parents, and her case manager, were the most compatible of all triads. Similar descriptors stated by triad members included, but were not limited to, work, High View, community job, family, being happy, and a feeling of importance. Jean and Mr. and Mrs. Gray had more in common though their responses were much more specific than those made by Penny.

Comparison of Quality of Life Across Triads

The comparison across triads gives an overview of all participants’ perspectives about the same two topics--independence and work. These topics were chosen because of their high rate of response from all nine participants in both categories, descriptors to define quality of life and the supports and services to enhance quality of life. The researcher considered the similarities and differences of the participants’ descriptions of independence and work, and then illustrated their importance in the quality of life for all individuals with intellectual disability.

“My Mom Don’t Want Me to Do That”

All parents spoke of wanting their children to have more independence to enhance their quality of life. Tom, Beth, and Penny also stated that they wanted independence to

enhance their quality of life. However, the data indicated contradictory messages between the parents and their children as well as between parents regarding the nature of independence. Only Mr. Gray showed that he provides opportunities for Penny to be independent. For example, when asked to describe quality of life for Penny, Mr. Gray replied, “You would have to ask her.” This gave the impression that it was her life and she would have to provide the answers to such philosophical questions. Mr. and Mrs. Gray also provided various activities to Penny to afford her opportunities to make choices, e.g., stores at which to shop, items to purchase, clothes to wear, and books to read. Mrs. Gray stated:

She buys her own clothes; she buys some things that she needs, another thing we do with her paycheck. We’ll go to Target and to Wal-Mart and get all the stuff that she needs. She knows what she likes. If we are going clothes shopping, she picks out what she likes, what color.

Mrs. Rose stated that she wanted Tom to be more independent, and described the pain she feels when she acknowledges his dependence on her and others. She stated:

The ability to think for himself. He’s really held back, because he wants to drive a car; he wants to do this; and he just can’t. I check on him. His meds, I have to check on him. He wants to go, but he loses his sense of direction if he goes out. But the ability that he can’t come and go like the normal boys-the men do. Kind of like he is stuck in the middle. If he goes anywhere I have to take him, someone has to supervise him. That’s what hurts me the most, that he just can’t say, “Hey mom I’m going out I’ll be back in a couple hours.”

Mrs. Doris stated she gave Beth independence to make her own choices, choices between going to a park district activity or to a family outing:

And it was her choice, I'd leave it up to Beth, do you wanna go here [park district programs] or do you wanna go with the family? She always wanted to go with the family, so no sense for her being signed up for these programs.

Another example of Mrs. Doris decreasing Beth's independence in the community was when she did not allow Beth continue her attendance at the Friendship Club. Beth received a personal volunteer to be with her during the program. Although Mrs. Doris stated Beth enjoyed this program, she stopped her from attending. This is how the mother explained her decision:

Beth went there for years, and it was wonderful. They take them apple picking, and women come and they make cookies, and they do crafts and she loved going. But then they had a conflict, had it the same night I go to High View meetings. So I take her, but I didn't like leaving her there alone all the time.

Another example of contradiction in the need for independence is reflected in comparing Mrs. Rose and Tom. She stated that she wants Tom to be able to go wherever he wants, to speak up for himself, and think for himself. These are all positive examples of independence. During the interview process, she stated how she signed him up for park district programs without his input. Mrs. Rose stated, "If he goes anywhere I have to take him, someone has to supervise him." When asked what would make Tom's life better, she commented that, "I don't know what else I can do to make his life more interesting or make him happier. I keep him going as much as I can." She described the responsibility of making his life independent but not teaching him the skills to be

independent. This also is evident when she begins several question responses as, “I want him to go,” “I try to keep him involved,” “I can get him to go,” “I signed him up,” and “I registered him.”

These statements about independence from parents were different from what the individuals with intellectual disability declared during their interviews. When asking Tom about what makes his life not so good, his response was “I can’t do what I want to.” He listed things that he would like to do and he feels would improve his quality of life; move into a group home, get his community job back, talk to the social worker, and talk to mom about why she takes his snacks away. These descriptors suggested that he is not in control of his life and lacks independence, subsequently influencing his quality of life. He repeated these descriptors during the interview and did not stray from his view of the independence that he desired.

Beth also partially speaks of independence through the activities in which she would like to participate, e.g., “going shopping because it’s fun” and “going downtown to look at the lights, the Christmas lights.” When asked about her participation in any park district activities she stated, “No I don’t do anything like that.” Asked what she would like to do in the community, Beth responded, “That’s a good question. My Mom don’t want me in a job in the community.” When asked what is good her life, Beth answered, “I do a lot of things in my life, like help my mom, help myself, we always do things together.” She always spoke about her mother and family members when making decisions, choices, or participating in leisure, work, or life activities. Sue, Beth’s case manager, referred to Beth being influenced by her mother when she was removed from

her community volunteer job. Sue also spoke of Beth's inability, or the lack of opportunity, for making her own choices.

I think it might be slightly better if she was more exposed to the community.

Like, I know here at High View, she's not really allowed to go to get a job in the community. She was able to volunteer but her mom, now her guardian, decided to end that. Not 100% sure on the reasoning. But I know mom has influenced Beth to stay back at the workshop, when I thought she was enjoying her volunteering in the community. To make her life better? I would just say giving her the option to decide for herself with being influenced by anyone. Allowing her to make her own decisions.

There is also some indication of dependency or a clear expectation of reciprocal care- giving between the parent and the individual in Triads 1 and 2. Both Tom and Mrs. Rose, and Beth and Mrs. Doris spoke of doing everything together. As stated by Mrs. Rose,

[Tom] is a very loving kid. He gets very upset and says why am I on this earth? I say God gave you to us because we needed someone to take care of us. Dad's gone, so Dad said take care of Mom, right? (Tom said "right") And God wanted us to take care of each other.

Tom's case manager also commented on the dependence between Tom and his mother. Mark described it as, "[Tom] is so intertwined with Mom, I'm just not sure how good that is for him."

Mrs. Doris also makes similar statements about Beth and herself, "I take care of her, and she takes care of me. We talk together, we do things together." For Beth it was

more of doing things together, as she explained when asked what's good in her life, "I do a lot things in my life, like help my Mom, help myself, we always do things together."

Sue, Beth's case manager, stated more of the lack of decision-making and influence that Mom has over Beth, "I know Mom has influenced Beth to stay back at the workshop, when I thought she was enjoying her volunteering in the community." When asked what can be done to make Beth's life better, Sue responded with maintaining her skills and "continue on with what we've been doing."

Although the parents spoke little of the future, the case managers did state that group homes or alternative housing might be better and offer more independence for the individual with intellectual disability. Mark suggested, "I think that if he [Tom] was living in a CILA [Community Integrated Living Arrangement] or some kind arrangement of that fashion. There is still a lot that Tom can learn to do, to let him blossom and grow; to give him more independence."

"No Mom, I have to Go to work."

All study participants agreed that the quality of life descriptor of "work" was important for a good quality of life for the individuals with intellectual disability. Work as a descriptor was a frequent response for eight of the nine participants. Table 13 illustrates the percentage of times each participant responded to an interview question with the descriptor "work."

Each group, individuals, parents, and case managers, varied the terminology for the definition when they spoke of work. The individuals with intellectual disability explained that it was the jobs that they were responsible for that made work important.

Table 13

Use of Work Descriptor Response Rate

Study Participant	<i>n</i> Interview Responses	% Work Responses
Mark	33	34
Penny	58	31
Jean	26	27
Beth	97	21
Tom	81	21
Sue	30	20
M/M Gray	50	18
Mrs. Rose	32	15
Mrs. Doris	55	11

The case managers named increasing independence, sense of purpose, and the sense of importance that made work important for the definition of quality of life. Even though Mrs. Doris did not put work in her first or second highest percentage of responses, the statements of all other parents were similar to those made by Mrs. Doris when she spoke about High View as being part of work: “High View workshop is Godsend. The best thing really, I wouldn’t want her sitting at home watching TV. That’s no life.”

Parents thought of work as a place for their children to be happy and safe during the day, where they have something to do, as Mrs. Rose stated when talking about Tom:

The main thing he just loves High View. He loves it there. They just don’t sit. If they have no work, there are classrooms, he’s learning Spanish, he’s learning sign language. He’s working and if not, there’s other things to do.

Mr. and Mrs. Gray also stated that High View has influenced Penny’s quality of life, not only the workshop but also her community job. Mrs. Gray stated:

She [Penny] loves going to workshop. It's her favorite thing. She really likes going. She likes being with the kids, and the staff. The staff is great. She likes the staff.

Mr. Gray concurred,

High View has done so much for her, I really do. I'm not sure what she likes the most. Social, her environment is excellent. Her paycheck is extremely important to her. She likes to go to Stony Creek. She goes to Stony Creek golf club once a week. She cleans the tables.

Another area that all participants identified as being important is the topic of community employment. Mr. and Mrs. Gray stated that Penny likes her job at Stony Creek golf club. Penny and her parents spoke of community jobs as a descriptor for her definition of positive quality of life. Participants of Triad 1--Tom, Mrs. Rose, and Mark--also responded regarding the importance of community jobs. Their responses reflected that Tom's quality of life would be enhanced if he were to get a community job. In responding to the question of what could enhance Tom's life Mrs. Rose noted:

He wants to go outside to work, wants a job outside. Wherever he goes, he asks for job applications, at every restaurant, every place he goes. He wants a job outside of High View, like some of the other kids have. So I'm hoping it can happen. I haven't had any bad reports about him. So I'm hoping they'll consider him for another job if there is one for him.

Participants in Triad 2 also spoke of community employment, but only after the question of what limited or hindered Beth's quality of life was presented. Beth did have a community volunteer job but her mother asked her to be placed back at the workshop.

Sue, her case manager, responded to this situation, by noting, “But I know mom has influenced Beth to stay back at the workshop, when I thought she was enjoying her volunteering in the community.” Sue explained that Beth’s quality of life is limited because of the lack of opportunities for community employment and she had been influenced to stay at the workshop.

Relationship of Definitions to the Quality of Life Domains

Domains are parts of a whole, the whole being quality of life (Brown & Brown, 2003). Schalock (2004) and Schalock and Verdugo (2002) explained that domains make up personal well-being and how one experiences a good life. Each domain has its own set of indicators and descriptors and there are no repetitions across domains (Schalock, 2004). For this study, domains were assigned to each participant according to their descriptors for the definition of quality of life for the individual with intellectual disability.

Based on the perspectives of the individuals, parents, and case managers of the study, they each provided descriptors to define quality of life and supports and services to enhance quality of life for individuals with intellectual disability. This data was organized according to the descriptors and indicators of the Eight Core Domains, Indicators, and Descriptors (Table 3) (Schalock, 2000; Schalock et al., 2007; Schalock et al., 2002). Presented in Tables 14, 15, and 16 are descriptors that each participant provided. Each of the descriptors was coded, sorted, and determined for placement within one of the eight core domains. Each table was developed across triads: Table 14 for individuals with intellectual disabilities, Table 15 for the parents, and Table 16 for the case managers.

The majority of the descriptors provided by the individuals with intellectual disabilities are categorized in the Material Well-Being quality of life domain (see Table 14). This domain represents employment, financial status, and housing. With one exception, the descriptors provided by these individuals are all related to employment. Tom shared the exception to employment; he said that living in a group home was very important to him and would enhance his quality of life. This descriptor is still a part of the Material Well-Being domain, and was placed in the category of housing.

Table 14

Core Domains and Response Descriptors for Individuals with Intellectual Disabilities

Domains	Response Descriptors		
	Triad 1: Tom	Triad 2: Beth	Triad 3: Penny
Emotional Well-Being	Social worker	Happy, routine,	Happy
Personal Development	--	confusion	Reading, phone use
Self Determination	Choices, independence	--	Choices
Interpersonal Relations	Friends, mom	Friends, family, Mom	Family, friends
Social Inclusion	Church, shopping	Travel, church, shopping, community access	Church, shopping
Rights	--	Nice to me	--
Material Well-Being	Work, staff, community job, Group home	Work, High View, staff, money/paycheck, community job,	Work, community job, staff, job coach
Physical Well-Being	Leisure activities, health	Leisure activities, safety, wallet/accommodation	Leisure activities

The least mentioned domain was Rights, which includes human and legal rights. Beth was the only person who offered a descriptor in the area of human rights when she spoke of people being nice to her. The domain of Personal Development also had a low number of descriptors (two) provided by the individuals. This domain included education, personal competence, and performance. Only Beth, who stated she gets confused at times, and Penny, who stated she wanted to learn to use the telephone, used this domain as part of their quality of life definition.

The quality of life domain with the highest response of descriptors presented by the parents is Material Well-Being (see Table 15). Parents provided descriptors that related to High View and work, and community jobs. Reference was also made to a future group home for Penny. The parents had a larger response to the domain of Personal Development than did the individuals with intellectual disabilities. They presented descriptors with regard to the lack of understanding and comprehension, and descriptions of their son or daughter not being able to complete a task or activity.

All three parents stated that they wanted independence for their son or daughter, which fall under the domain of Self Determination. Mrs. Doris indicated she does not let Beth go anywhere without holding her hand; and Mrs. Rose stated that she has to go everywhere with Tom.

The descriptors provided by the case managers in the domain of Material Well-Being had a high response count (see Table 16). All the groups, individuals with intellectual disability, their parents, and their case managers, spoke of work, staff, and community employment, which points toward work as extremely important to the quality of life of all individuals with intellectual disability.

Table 15

Parents' Descriptors and Quality of Life Domains

Domains	Descriptors		
	Triad 1: Tom Mrs. Rose	Triad 2: Beth Mrs. Doris	Triad 3: Penny Mr. & Mrs. Gray
Emotional Well-Being	Happy, held back, emotional control	Happy, contents	Feelings of importance, purpose
Personal Development	Can't think for self, lacks understanding, reading program	Comprehension, lack understanding, learning new things	--
Self Determination	Get for self, speak up for self, independence, dependent	Independence, choices, dependence	Choices, independence
Interpersonal Relations	People to care about and care about him, friends	Friends, family, Mom, social ability, relationships, people who care	Friends, family, helping others, social opportunities
Social Inclusion	Church, park district	Travel, community access	Limited community access, church, park district, clubs, volunteers
Rights	--	Treat like everyone else	--
Material Well-Being	Work, staff, High View, Community job	High View, staff	High View, staff, community job, job coach, work, pay check, live at home, future group home
Physical Well-Being	Leisure activities, health	Leisure activities, indoor pools, exercise class	Health, leisure activities

The case managers also provided a high response count to the quality of life domain of Self-Determination. This domain includes independence, goals, and choices. Although Jean, Penny's case manager, had nothing to say in this category, Mark and Sue

Table 16

Case Manager's Descriptors and Quality of Life Domains

Domains	Triad 1: Tom Mark	Triad 2: Beth Sue	Triad 3: Penny Jean
Emotional well-being	Contentment, social-emotional counseling	Happy, content, satisfied	Feeling of importance, has purpose, happy, satisfied
Personal development	Social skills	Maintaining skills	Innovative programming, opportunities to learn, exposure to new things
Self determination	Sense of purpose, independence, dependent, learn new skills, opportunities	Make own decisions, Choices, opportunities, dependent	--
Interpersonal relations	Family, Mom, friends, people that care	Friends, family,	Family
Social inclusion	Park district, Friendship club	Community integration	Church, social club
Rights	--	--	--
Material well-being	Work, High View, staff, community job, group home	High View, work, community job, staff	High View, community job, staff
Physical well-being	Health	Accommodations	--

offered descriptors of choices, independence, and opportunities. Sue presented her descriptors as limiting Beth's quality of life and decreasing her independence. For example, Sue responded to questions on how to make Beth's life better, "she's still

maintaining what skills she has for as long as she has them. Continue with what we've been doing. Beth seems pretty content and satisfied here.”

In summary, the high response of descriptors provided by the individuals, their parents, and their case managers were sorted and disseminated to the appropriate core quality of life domain. Each of the eight domains was represented by at least one descriptor. As illustrated in Tables 15, 16, and 17 the domain of Material Well-Being had the most descriptors from all participants. This domain includes employment, housing, and financial status. The second quality of life domain that participants of all triads provided descriptors for was Interpersonal Relations. This domain includes family, friends, peers, and other social contacts. Every participant responded with at least one if not more of the descriptors from the Interpersonal Relations domain as part of their definition of quality of life. The domain with the least responses from case managers was Physical Well-Being. This domain includes health, activities of daily living, and leisure. The quality of life domain responded to least was Rights, in fact only two people had a descriptor that fit in this domain, Beth and her mother.

Conclusions

In this chapter the perspectives of three triads consisting of middle-aged individuals with intellectual disability, their parents, and their case managers, were collected, sorted, and examined for similarities and differences. Descriptors were found to create quality of life definitions for the individuals with intellectual disability in each triad. When compared within triads, the descriptors looked similar in appearance, the words were the same, but upon further investigation, the meanings of the words were individualized to each participant. The individuals with intellectual disability named

descriptors with specific concepts while the responses of their parents and case managers were more general in terms.

Community supports and services was also a descriptor that everyone agreed was important to the quality of life for all individuals with intellectual disability in the study; however, different meanings across triads were noted. The individuals described community services as community jobs and community park district and leisure activities. Parents stated community supports and services as community access to park district activities but then some stated that they would not let their son or daughter attend without holding their hand or without the parent being there with them.

Descriptors to create the quality of life definitions were also used to determine the quality of life core domains, which are parts of the whole personal well-being (Schalock, 2004; Schalock, & Verdugo, 2002). The quality of life domain Material Well-Being had the highest number of responses from all three groups, individuals, their parents, and case manager. This domain includes employment, housing, and financial status. Study participants considered work important to the quality of life definition thereby falling into the Material Well-Being domain. The parents had the second highest domain as Personal Development, which includes descriptors of family, friends, and peers. The case managers' second highest domain was Self-Determination. This domain includes personal values, choices, personal control, and a descriptor of independence.

This study collected many perspectives from the participants, sorted, and distributed them according to the quality of life domains. Descriptors provided by individuals with intellectual disability to create their definition of quality of life were short and specific. The parents provided elaborate responses, life stories, and amazing

family histories. Case managers gave information when they could. Two of the three case managers stated they were nervous and unsure what they could say about the parents and clients. Therefore, their responses were somewhat short but informational.

However, a commonality among all the responses from all the participants was that all were thinking of what was best for the individual with intellectual disability, be it that they were happy, safe, or could make their own choices.

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This chapter discusses two main conclusions of the study: (a) while descriptors defining the quality of life for individuals with intellectual disability may be the same across triads, the meanings of those descriptors differ; and (b) parents and their children with intellectual disability differ in perceived supports and services needed to enhance the quality of life for individuals with intellectual disability. These conclusions are described and supported by related research. Finally, this chapter discusses the limitations of the study, implications for practice, and future implications for research.

Defining Quality of Life

Individuals with intellectual disability, their parents, and their case managers, provided their perspectives on the quality of life for the individual with intellectual disability. Participants assigned descriptors that were important to the individual with intellectual disability as part of the quality of life definition. By comparing the descriptors, the researcher found that the descriptors of the parents, case managers, and the individuals were similar by word but not by meaning. The word *independence* was considered important and labeled a descriptor by all participants. Upon further investigation, the researcher discovered that each person had a different meaning for the word independence. For example, the participants in Triad 1 considered independence as a descriptor for quality of life but each person used a different meaning. Tom considered

independence as doing what he wants, getting a community job, and living in a group home. His mother’s definition of independence for Tom was to be able to go wherever he wants, to speak up for himself, and think for himself. Mark, his case manager, described independence as limiting Tom’s quality of life when he described Tom as being “intertwined with Mom.” Additional examples of this finding are displayed in Table 17 for Triad 2

Table 17

Triad 2, Independence as a Descriptor

Participant	Descriptors Related to Meaning of Independence
Beth, individual with intellectual disabilities	Wants to go out, go shopping, see Christmas lights, enjoyed community volunteer job, wants to make her own choices, wants to have community job but “mom don’t want me to,” enjoyed park district programs
Mrs. Doris, parent	Will not allow Beth to go out without holding her hand, took her out of park district programs even though Beth was enjoying them, Beth would go out to eat “if I let her,” gave Beth choices between family and community activity
Sue, case manager	Should be out at community job, maintain current skills, make own decisions but could not because she was influenced by her mother

As noted in Table 17 all participants of Triad 2 stated that independence was a descriptor; however, Mrs. Doris and Sue did not have the same ideas as Beth. Beth wanted to go out into the community on her own, as reflected in her expressed need for a community job and shopping, but her mother would let her go only if Beth held her hand. Beth’s case manager thought independence was going to be achieved through maintenance of Beth’s current skills and limiting her opportunities to try new things. Mrs. Doris treated Beth as what Menolascino (as cited in Matson & Marchetti, 1988) referred to as *the eternal child*.

With regard to independence parents and case managers have different meanings that may further be explained by examining the findings of Beresford (2004) and Bigby (1997). They both suggested that day program staff have a strong influence on the movement of individuals with intellectual disability between workshop and community employment. There may be a lack of encouragement from staff to learn new skills so that individuals with intellectual disability will not leave the workshop and staff members will maintain their own jobs (NDRN, 2012).

Researchers have found that parents, especially mothers, are hesitant to plan for the future of their sons and daughters with intellectual disability due to: (a) a lack of confidence in service providers, (b) fear of intrusion by formal service systems, and (c) additional challenges that come with change (Bigby et al., 2002; Brotherson et al., 1993; Grant & Rancharan, 2007; Murray, 2007; Schneider et al., 2006; Timmons et al., 2004). These researchers have also noted that parents wanted their sons or daughters to live independently, though they had concerns about such independence. Safety of the individual with intellectual disability is a primary concern of many parents. Parents wanted to worry less when their children were away from them by (a) feeling confident that the staff would keep their children safe, and (b) trusting in the security of the formal service agencies where they placed their sons or daughters.

As in this study, parents spoke of wanting independence for their son or daughter but also were concerned for safety. Mrs. Rose noted, “[Tom] wants to go but he loses his sense of direction if he goes out.” Similarly, Sue commented about Beth’s mother and community outings: “If she thinks it’s unsuitable or unsafe for Beth, then likely Beth will not participate.” Mrs. Doris stated she was thinking of Beth’s safety:

Beth gets very confused. She could never be on her own, never, never. She does well when there is family support and friends. But to be left on her own, she gets confused and lost. So I realized one day that I had to hold her hand all the time, and I do. I never let her go, I hold her hand all the time, no matter where we go.

It is also true with individuals with intellectual disability having a separate meaning to the word “independence” when they labeled it as important to their quality of life. They declared they wanted to make more choices and their own decisions. Making choices is one way to develop a sense of control over their lives (Heller et al., 2011). The individual with intellectual disability needs to have the ability and opportunity to make choices. Stafford (2005) stated making choices “is an integral part of what makes humans able to function independently within the community” (p. 12). For example, Tom indicated that he had little control of his life due to a lack of decision making when he spoke of not being able to (a) eat what he wants, (b) work at the jobs that he wants, or (c) go where he wants. His overall statement, “I can’t do what I want to” indicated a lack of independence.

Another example of same descriptors but different concepts was reflected in the top three quality of life descriptors reported by the parents and case managers. McIntyre et al. (2004) discovered that mothers wanted their adult children with intellectual disabilities to have their basic needs met, be happy, have things to do, be comfortable, and be safe. The McIntyre et al. study also found that case managers were interested in vocational opportunities for the individuals with whom they were working. Once the descriptors in the current study were investigated and follow up meanings were explored, this study appears to parallel the findings of McIntyre et al. The top three quality of life

descriptors reported by the parents were High View, family, and friends. The top three descriptors of the case managers were work, High View, and community jobs. High View was among the top descriptors of both groups, though each group had different meanings affixed to this descriptor. The parents described High View as being a safe place for their son or daughter to be and have something to do while supported by caring staff. The case managers described High View as a work place that provides training to individuals with intellectual disability leading to potential placement in community job settings.

The responses regarding quality of life from individuals with intellectual disability reflected a mix of the descriptors used by both parents and case managers. The individuals' descriptors included work, friends, and family. They explained work as having jobs to do and having friends at the workshop, though they also included the descriptor of family as being important for quality of life.

The definition of quality of life is highly personal and individualized. Brotherson et al. (1993) stated that parents "can impact their child through their own values and expectations" (p. 44). Parents may think they know what their adult child would answer to questions such as those posed in this study and how they think about their life situation. However, without obtaining the perspectives of the individual, it would be unknown what they really desired or needed to have a good quality of life. Cummins (2002) explained that others might view the life situations of individuals with intellectual disability as having diminished quality. People experience the same circumstances differently and the circumstances will influence the quality of life of all people.

However, each person can determine his or her own quality of life (Taylor & Bogdan, 1990).

Supports and Services

Supports and services are necessary to meet the biological, psychological, and social changes of individuals with intellectual disability in order to enhance their quality of life (Bigby, 2004). The researcher explored the perspectives of each participant regarding the types of supports and services that were required or desired to enhance quality of life. The results indicated that individuals with intellectual disability and their parents choose different supports and services. Van der Waal Mae, Lako, and Casparie (as cited in Barelds et al., 2009) stated that parents will choose supports and services that are broader and organizational-focused, while individuals with intellectual disability tend to choose those that are current and more specific.

Upon initial examination of the supports and services identified by the participants with intellectual disabilities in this study, the findings contradict those reported in the Van der Mae et al. study. The top areas of supports and services identified by these individuals were High View, staff, and family. These are broad and general descriptors whereas Van der Mae et al. stated the individuals' supports and services would be specific and current. A more thorough review of the supports and services and corresponding concepts identified by participants aligns the study more with the findings of Van der Mae et al. For example, the top service listed for the individuals was High View, which they described as their current jobs at the workshop. The second support was family, which upon further review the individuals defined as helping mom; and the last support was staff, which the individuals described as their job coach, case

manager, or social worker. All the provided definitions of the supports and services are current, specific, and concrete to each of the individuals with intellectual disability and align to the Van der Mae et al. study.

The top areas presented by the parents included community services, family, and friends. Upon further review of the descriptors the parents named, there were no additional descriptions or points clarifying their choices. Van der Mae et al. stated that these supports and services would be broad and organizational-focused, and the parents' descriptors in this study paralleled the former findings. In this study, community services are organizational and family and friends are supports that are more general.

In summary, when describing quality of life, individuals with intellectual disability, their parents, and case managers provided common descriptors of independence and work. These descriptors are important to the definition of quality of life, though they have different meanings to each participant in the study. Quality of life is personalized and individualized; therefore, obtaining the perspectives from each participant is vital to defining of quality of life. Parents will choose descriptors that show they want to ensure their son or daughter will be safe, have something to do, and have someone to care for them. Case managers' choices were related to vocational skills and needs. Supports and services chosen by parents are different from those chosen by their adult sons or daughters with intellectual disability. Individuals with intellectual disability choose supports and services that are current, specific, and concrete in nature, while their parents choose supports and services that are organizational and broader in nature.

Limitations

This study provided insight into defining quality of life for midlife individuals with intellectual disability. The study had noteworthy limitations, which include (a) research sites and sample size, (b) communication level of individuals with intellectual disability, (c) interview questions/responses of adults with intellectual disability, and (d) the researcher. Each of these limitations is discussed in the following sections.

Research Sites and Sample Size

This study used one research site and three mid life individuals with intellectual disability. This small sample size did provide descriptors to create definitions for quality of life and determine the core domains for these individuals' quality of life. A larger number of participants would have included a more diverse sample providing greater variety in descriptors defining quality of life and determining the core quality of life domains.

Using only one research site restricted the variety of data collected due to the limited number of case managers. The case managers in this study were never employed at any other social service agency. High View is a family-oriented social service agency. The recruitment of several different day programs could have produced very different perspectives from case managers having different experiences in day programs of varying sizes and geographical locations. Additionally, case managers may have experiences with people from varying age groups and types of intellectual disabilities. Increasing the variety of research sites and range of case manager experiences in the study could have provided different results that would potentially be more generalizable.

Communication Level of Individuals with Intellectual Disability

Quality of life can only be defined and have meaning if the individual with intellectual disability can express his or her perspectives. Barelds et al. (2009) explained that without the individual sharing such perspectives, the service provider would consider and choose the type of supports and services perceived to best fit the individual with intellectual disability. In this study, the individuals were very willing to assist the researcher by answering the interview questions, though limitations were apparent in the communication levels of these participants. Examples of limitations reflected in interview responses included (a) use of one-word, two-word, and/or short phrases; (b) providing unclear and/or repetition of responses; (c) providing similar responses throughout the interview; and (d) presenting responses to please the researcher.

Some of the responses of the individuals limited their perspectives of both quality of life and supports and services to enhance quality of life. For example, Penny's short phrases (i.e., "I'm happy" and "I like it") are examples of limited perspectives and provision of the same answers to many of the same questions throughout the interview. Requesting an individual to repeat his or her response due to verbal clarity might have changed a prior answer to an interview question. For example, when Beth was asked to repeat an answer for clarity she would give a shorter answer, although it was unknown if it was changed from the prior answer. Tom and Penny were individuals who stated that they liked talking to the researcher and would like to do anything for her that might lead to enhancement of their own quality of life responses. Such examples reflect limitations in this study for obtaining complete and true perspectives from each individual with intellectual disability.

Interview Questions/Responses of Adults with Intellectual Disability

The third study limitation involved the interview questions that individuals with intellectual disability were asked regarding their perspective of quality of life and their responses. The questions may have been leading, as they were presented in such a way that made it easier for the individual to respond. If the individual had difficulty expanding or clarifying a response, a probe question was asked to make the interview situation more comfortable; however, this sometimes resulted in participants providing simple yes or no responses. If probe questions were not used the individual may have had problems with providing his or her perspectives on quality of life. This poses the question raised in the Barelds et al. (2009) study whether individuals with intellectual disability can provide their own perspectives, and emphasizing the potential need for a proxy to answer the interview questions.

Researcher

The final limitation of this study is the researcher. In qualitative research, the researcher is the primary instrument for data collection (Brantlinger et al., 2005; Merriam, 1998). The researcher needs to be flexible in adapting the interview to the individual with intellectual disability, and thus the interview approach may differ for each participant (Bogden & Biklen, 2007). The researcher in this study had extensive experience working with people with intellectual disability, including use of flexibility and creativity in adapting and accommodating instruction, implementation of training programs, and designing education curriculum to fit the needs of each individual person. During the interviews, adapting or changing the questions was flexibly employed;

rephrasing or changing wording occurred for the individuals as the researcher determined what was best for the individual to answer the questions. Interview questions were rephrased to ensure understanding, pictures were utilized as needed, and leading questions were asked to assist the individual answer the questions. The use of picture response sheets was in itself a limitation since they were not customized to the specific individual and were general in nature that may have affected usability and the responses provided during the interview.

Implication for Practice

The conclusions of this study have implications for practice that will affect the quality of life of midlife adults with intellectual disability. Three important areas in which professional practices are potentially affected include (a) professional development for case managers, (b) training for individuals with intellectual disability, and (c) increasing family involvement.

There are two main goals for professional development for case managers. First, professional development for case managers may increase their knowledge of services and support options to enhance the quality of life for individuals who are midlife. Second, professional development for case managers may increase their skills when providing assistance to parents and families of the individuals. To meet these two goals, professional development for case managers should include (a) multi-generational service coordination, (b) provision of supports and services based on the needs of midlife individuals, and (c) facilitation of choice making for individuals.

A case manager fulfills the role of service coordinator who has responsibility to ensure the provision of services and supports to individuals with intellectual disability.

These individuals and their caregivers are aging, requiring case managers to provide supports for families as they experience life-altering changes for themselves and their adult son or daughter with intellectual disability. Case managers need to support families, especially parents, while working on realistic goals for the individual with intellectual disability (Chambers et al., 2004; Schneider et al., 2006). To accomplish this goal, case managers need to learn skills enabling them to work with multi-generational family members and provide a variety of services for a range of age groups (including an aging population) (Brotherson et al., 1993; McIntyre et al., 2004; Mansell, 2007). They need to have the knowledge and skills pertaining to disability care, aged care, healthcare, social security, housing, and other social community services (Bigby, 2007a; Seltzer, 1992).

Professional development for case managers is also needed in the area of facilitating choice making for intellectual disability. Case managers, parents, and individuals in this study included choices or decision making as important descriptors for a good quality of life. The study participants listed making choices as limiting the quality of life for individuals with intellectual disability given their lack of opportunities for making choices. Based on results of their study, Agran et al. (2010) succinctly noted that choice making for people with intellectual disability could be improved when opportunities to make choices are provided. This suggests a need for targeted professional development designed to enable case managers to provide opportunities for individuals to make choices and support those individuals to make their own choices.

The second implication for practice is the design and delivery of training for individuals with intellectual disability in the area of choice making. Agran et al. (2010)

found in their study that choice making had to be taught to people with intellectual disability. Heller et al. (2011) observed that individuals with intellectual disability need to make choices in order to develop a sense of control over aspects of their lives and enhance their quality of life. The case managers and the parents in this study described choice making as a descriptor for the definition of quality of life. Therefore, training focused on making choices for individuals with intellectual disability holds potential to enhance their quality of life. Family members and day program staff would also benefit from attending such training opportunities so that there is consistency in providing choices across environments.

The third implication for practice is increasing family involvement in the life of the individual with intellectual disability. The increasing life expectancy changes the family structure and presents new challenges to the family members of individuals with intellectual disability. As the adults with intellectual disability age they are staying in the family home longer with parents and other family members taking on the roles and responsibilities of providing necessary supports and assistance (Kennedy, 2006). Blacher (2007) added that these parents and family members are unsure how to fulfill these new challenges and responsibilities that accompany the adult with intellectual disability.

There was limited information regarding supports and services when the individual with intellectual disability transitioned from high school to adult services (Chambers et al., 2004; Timmons et al., 2004) and there is still a lack of information as the adult with intellectual disability reaches and passes midlife (McCallion & Nickle, 2008).

As the person with intellectual disability reaches and passes midlife, the need for supports and services increases (Schneider et al., 2006), while the parents and family members continue to be unfamiliar with the available supports for their family member with intellectual disability (McCallion & Nickle, 2008). Except for the individuals themselves, parents typically know their son or daughter best. They are critical participants in the decision making process to determine services and supports for their son or daughter (Neely & Barnes et al., 2008; Brotherson et al., 1993). Brotherson et al (1993) suggested that parents and family members build a trusting relationship with the service providers (i.e. the case manager for their family member with intellectual disability). Case managers need to have a comprehensive understanding and work with families, which will lead to a better alignment of supports and services for the individual with intellectual disability (Bigby, 2007b; Bigby et al., 2002; Chambers et al., 2004; Schneider, et al., 2006). Collaboration between family and case managers for building trust is most effective for obtaining positive outcomes for all involved, the individual with intellectual disability, the family members, and the case manager (Bigby, et al., 2002).

Future Research Implications

This study demonstrates numerous areas for future research. Based on the findings of this study, this section will focus on three areas for future research: (a) the participation of individuals with intellectual disability, (b) exploration of quality of life with a variety of study samples, and (c) determination and implementation of supports and services.

First, future research needs to continue to increase opportunities for individuals with intellectual disability to tell their stories and provide their perspectives. Such opportunities to share perspectives in well-designed research studies is important for enhancing their quality of life and increasing appropriate supports and services for all individuals with intellectual disability.

Second, researchers must expand the study samples employed to increase the possibility of enhancing the quality of life for a diverse array of individuals with intellectual disability. Future research should not only explore quality of life of midlife individuals with intellectual disability who have a parent guardian, but include those who have a sibling as guardian or state guardian, or even are their own guardian. Guardianship could make a difference on the quality of life and the types of services and supports to enhance the quality of life for individuals with intellectual disability.

Additionally, individuals who live in various residential settings should be included in research investigations to examine the impact on their quality of life. In addition to living at home, common living environments for individuals with intellectual disability include residence in a community integrated living arrangements (CILA), an intermediate care facility (ICF), an apartment, or other living arrangements (e.g., own home, large facility). Future research may also include examination of work environments for individuals with intellectual disability. The workplace can influence the quality of life and the provision of services and supports for these individuals. Thus, an array of these settings may be targeted for research including supported employment, competitive employment, volunteer work, or unemployment.

Third, future research inquiries should investigate how supports and services to enhance quality of life are determined for midlife adults with intellectual disability. These individuals need to communicate their preferences during the planning processes where needed supports and services are identified. Listening to their stories and how their needs and preferences were both considered and valued in delivering subsequent supports and services could substantively contribute to our knowledge base. This future research should also investigate the perspectives of the individuals with intellectual disability regarding how the supports and services have enhanced their quality of life.

Conclusions

Throughout a person's life, there are variations in their biological, psychological, and social perspectives regarding quality of life. The eight core quality of life domains mean something different to any individual at various times in life. The definition of quality of life is both personal and individualized. The results of this study demonstrated that individuals with intellectual disability used similar descriptors (with different meanings) to those used by their parents and case managers when they defined quality of life. Individuals selected supports and services to enhance their quality of life that they already use at work or at home. Quality of life descriptors that the parents identified were to keep their sons or daughters happy, safe, and involved in targeted activities.

When listing quality of life descriptors, case managers were more work-related.. Parents and case managers need to listen to the perspectives of the individuals with intellectual disability, and consider the quality of life definitions expressed by these individuals when developing and implementing quality of life services and supports.

Providing the opportunity to both express their perspectives and tell their stories contributes to bringing meaning to quality of life for this population.

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APPENDIX A
LETTER OF INTENT AND PERMISSION
TO USE HIGH VIEW FOR RESEARCH SITE

Mr. Portada:

I am a doctoral candidate under the direction of Dr. Howard Parette in the College of Special Education at Illinois State University. I would like to do my research at High View Services (PLS) to explore the perspectives of three groups of people—adults with intellectual disability, their parents or guardians, and their case managers at the day program—on the quality of life for the adult with intellectual disability as they reach and pass mid age. The criteria for participation in this study for the person with intellectual disability includes: (a) being between the age of 35 and 55 years, (b) have verbal conversational abilities, (c) have the ability to understand a variety of simple questions, (d) attend day program at PLS, and (e) live at home with parents or guardian. Interview questions for each participant would include (a) what is good and not so good about their day program or High View, and (b) what could make it better. The results from these questions, as like the rest of the research, would be confidential and not shared with you or the day program staff.

I will be selecting three triads, each having an adult with intellectual disability, their parent or guardian, and their case manager.

What I would like from you includes:

1. The collection of names of the adults with intellectual disability that match the predetermined criteria. A computer generated list of names that meet the specified criteria will receive the prepared informational packets for participation. High View

Services in the past has generated such lists of names for activities and projects within the agency and other researchers in the field of special education. While working in several different social service agencies, my colleagues and I have frequently utilized this practice of completing generated lists as requested from various researchers and regulatory agencies.

2. Send the prepared packets to the parents of clients that fit the criteria. Packet A will go home with clients who are their own guardian and Packet B will go home with those clients who are not their own guardian. Each packet will contain the appropriate consents and permission for possible participation.
3. If necessary, allow me time and space to conduct the interviews at the day program. I will be flexible and as nonintrusive as possible. Although I gave the potential participants a choice to choose a convenient location, I did give them PLS office or conference room as an example of a possible location.

At this time, I am requesting to use High View as my research site. Please feel free to contact me if you have any questions or comments.

Jane L. Lurquin
Doctorate Candidate
Illinois State University
708-857-8189
jlurqu@ilstu.edu

I, Frank Portada, Director of High View Services agree that Jane L. Lurquin can use High View as the research site for her study as stated above.

Name

Date

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438-2529 or rec@ilstu.edu

After receiving the explanation of the research study, I, Frank Portada, Director of High View Services, give permission for Jane L. Lurquin to utilize High View Services to implement her research as part of her doctorate program. I agree that I will generate a list of names of potential participants that meet the predetermined criteria. I will also have the prepared packets distributed according to the instructions of the study presented by Ms. Lurquin. I give permission that the office area, conference room, or other areas may be used for interviews of High View clients and case managers if necessary. I understand that there are questions in the interviews that include what is good and not so good with the day program as it relates to the quality of life of the individual with intellectual disability. The individual results of these questions as well as the rest of the individual sections of the research will be kept strictly confidential. If requested, I may read the final copy of the study, which will not use any names, or identifying information of the participants.

I, Frank Portada, Director of High View Services give permission for Jane L. Lurquin, doctorate candidate from Illinois State University, to utilize High View Services to implement research for her dissertation entitled, Midlife Crisis: Services and Supports Necessary to Enhance Quality of Life for Middle-Aged Adults with Intellectual Disability.

Signature

Date

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438-2529 or rec@ilstu.edu

APPENDIX B

STUDY EXPLANATION:

INDIVIDUAL WITH INTELLECTUAL DISABILITY

Study Explanation

I am a student at Illinois State University and doing a research study to learn about people who are getting a little older, live at home, and work at High View. I want to hear about what you think is good about your life and what you think is not so good about your life. I want to hear if you think there is anything that could make your life better. If it is OK with you, I would like to ask what your parent and case manager have to say about what they think is good and not so good about your life. Do you know what an interview is? (wait for answer). That is when I ask you questions and you tell me what you think. I will interview all of you, your parent, and your case manager. I will ask questions about how everyone feels about the good and not so good things about your life. Then I will ask everyone what they think may be needed to make your life better.

Do you have any questions? Can you tell me what the study is about?

I will have one interview with you that will be tape-recorded. That way I can listen to it later and not forget anything that you say. I will not let anyone else hear what you say. I will write out everything you say from the tape and then erase it, that way I'll be sure no one will hear it. The interview will last about 45 minutes to one hour. If that is too long

for you, we can have breaks and make shorter sessions. You do not have to do the study, you can say no I do not want to do this; it is voluntary and do it only if you want to do it. You can stop the interview anytime you wish. You do not have to answer any question that you do not want to; or is too uncomfortable for you to answer; or if you do not know the answer just tell me and we can skip that question. We will schedule your interview when it is best for you at a place where we can talk and it is not too noisy. We can do it here at work, I have permission from the director and your case manager to take time away doing work for the interview, or we can set another place.

Do you have any questions?

After we complete your interview, I will interview your parent and case manager. After I talk to everyone, I may have to talk to you again, if that is OK with you. I may have to ask you a few more questions, you may have to tell me if I got everything that you said the last time correct; and then you can tell me anything else you need to tell me. After I talk to everyone, I will write a paper telling the stories and ideas that everyone told me. I will write what you think makes a good life and not so good life, what your parents think makes a good and not so good life, and what your case manager thinks makes for a good and not so good life. I will then write what everyone thinks is needed to make a better life for people who are getting older. I will not tell anyone your name, what you said, and will not use your name in my paper that I write because what you tell me is between you and me and no one else. Just like I will not tell you what your parent and case manager tells me; I cannot tell them what you say and I cannot tell you what they say.

Do you have any questions?

Now if you want to be part of my study you will have to answer some questions and then sign this agreement/paper so you can participate. First, let us ask one of the case managers to come in and have you tell them about the study. Questions to answer in front of witness:

1. What do I want to hear about in the study?
2. Who will I interview?
3. Do you have to do the study or can you say no?
4. Can you stop the interview whenever you want to?
5. Will I use your name in the paper?
6. Who will I tell what you say? Will I tell you what your parent says?

I will go over the agreement/paper with you. Then you will tell me if you want to be in the study. Then you can sign the agreement paper. You can take a copy of the papers home and talk to your parent or guardian about the study. I already talked to your parents or guardians so they know you are bringing the papers home. Remember that I can only have so many people in the study, so if I get too many people I will only pick some and others will not be able to participate. If you are picked, I will contact you and your parent or guardian to set up your interviews.

Do you have any questions?

STUDY EXPLANATION PICTURE SUPPORT

Process of Study

I am doing a study about you and I want to hear what you have to say about your life. I have pictures here to help you as I go through the steps of the study. Stop me whenever you have a question or do not understand.

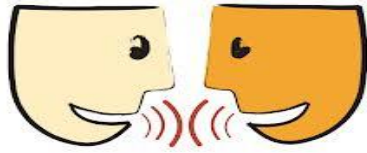
1. First lets go over the pictures so you understand what each one means before we start.

(review the words and pictures; can use picture cards of attachment L)

2. This is a study about you and your life.



3. I will interview you: talk between you and me.



a. Talk about what is good in your life

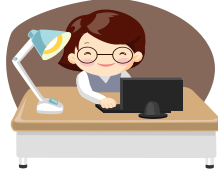


b. Talk about what is not so good

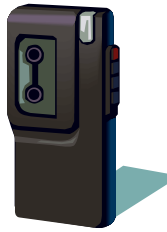


c. Talk about what you think might make it better

4. Will also interview your parent/guardian and case manager



5. I will use a tape recorder



6. You can say :

a. No

b. Stop



c. I need a break



d. Help



7. I will not tell anyone what you or anyone else says



8. I will not use your name.



9. Now we are going to bring in your case manager and tell her/him about the study (witness)



10. Now it is time to think and decide if you want to do the study.



APPENDIX C

LETTER OF ASSENT

Letter of Assent

Dear _____.

I am a student at Illinois State University. I am doing a research study to learn about people with intellectual disability who are getting older, live at home, and work at High View. I want to hear about your life and what you think is good and not so good about your life and if there is anything that would make it better.

1. There will be an Interview for you to tell me what you think is good and not so good about your life, and is there anything that may make your life better.
2. I will interview your parent or guardian and your case manager asking them what is good and not so good about your life and what they think may make it better.
3. You only have to do the study if you want to and can stop whenever you say.
4. There is no right or wrong answer; you just tell me whatever you wish.
5. You only have to answer the questions if you want to and tell me to stop anytime, you can skip any question you do not want to answer, and you can take a break, stop the interview, or come back later to finish the interview.
6. Our interview will be taped recorded so that I can go back, listen to it later, and not forget anything that you said.
7. I will not tell anyone your name or anything you say. I will not use your name in the paper that I write about anything you tell me.

Anytime during the study, if you have any questions, you can call me at 708-857-8189 or my professor at the university Dr. Parette at 309-438-8991. If you need any help making the phone call, you may ask a case manager or the social worker here at the day program for help. If you agree to everything here, and want to participate in the study, please sign your name below.

Jane L. Lurquin

IL State University

I will participate in the study.

Name

Date

Witness (relationship)

Date

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438-2529 or rec@ilstu.edu

APPENDIX D

LETTER OF ASSENT, PICTURE SUPPORT

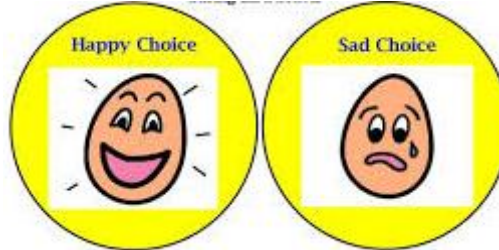
Letter of Assent with pictures



I listened to Jane tell me about the study.

If I want to do the study:

1. I will be interviewed about what is good and not so good in my life.



2. I can stop anytime I want to.



3. I can take a break anytime I want to.



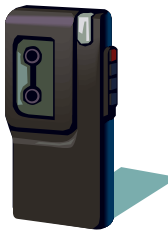
4. I can say no and not answer any question I do not want to.



5. No one will tell anyone what I say.



6. Jane will use a tape recorder, but no one will hear it but her. She will write it down and then erase the tape.



7. My name will not be in the study paper.



8. It will be my decision if I do the study.



I want to do the study.

Yes

No



Signature _____

Date: _____

Witness: _____

Date: _____

APPENDIX E
INTERVIEW PROTOCOLS

Interview with Person with Intellectual Disability

Name:

Age:

Day Program:

I. Introduction

Hi _____ (name). My name is Jane Lurquin. How are you today? I want to ask you some questions about your life. You can say anything you like. I will not use your name when talking about things that you say to me. Some questions may be hard and some easy. You only have to answer the questions you want to. If it gets too hard or you want to stop, tell me and we will stop. I am asking you questions about things you may want, but I cannot get these things for you. I do not work for High View and they cannot get them for you either. And I cannot tell your family to get them for you either.

II. Tell me something about yourself. Tell me about your day.

a. What kind of things do you do at home?

Probe question depending on the clarity of the response:

Are there other things that you do? (housework, living skills, leisure, recreation)

b. What kind of things do you do at work?

Probe question depending on the clarity of the response:

Are there other things that you do? (structured classes, different work activities, volunteer, recreation-bowling)

c. What are some of your favorite things (to do)?

Probe question depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me, what does that look like?

What does that mean?

Can you give me examples/describe/explain that?

III. About self

a. What is good in your life? (What do you like in your life?)

i. What do you like?

ii. What makes you happy?

iii. What do you need for a good life?

iv. Is there anything else that makes your life good?

Probe question depending on the clarity of any of the responses:

Can you tell me more about that?

Can you tell me what that looks like (give examples).

b. What is not so good in your life? (What do you not like in your life?)

i. Is there anything in your life that you do not like?

ii. What makes you sad?

iii. What makes a bad life?

iv. Can you think of anything else that is bad in your life?

Probe questions depending on the clarity of any of the responses:

Can you tell me more about that?

Can you give me examples/what does that look like?

c. What do you think would make your life better?

i. What do you think you need to make your life better?

ii. What would make your life easier?

iii. Is there anything that would make your life happier?

Probe question depending on the clarity of any of the responses:

Can you tell me more about that?

Can you give me examples/describe/explain that?

IV. High View:

a. What does High View do to make your life good?

i. What do you do at High View that makes you happy?

ii. What do you like about High View?

Probe question depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.
What does that mean?
Can you give me examples/describe/explain that?

- b. What does High View do to make your life not so good?
 - i. What at High View makes you sad?
 - ii. What do you not like at High View?
 - iii. What about work makes your life not so good?
 - iv. Is there anything else that you can think of about High View that makes your life not so good?

Probe question depending on the clarity of any of the responses:
That sounds interesting, can you tell me more about that.
Can you describe that to me, what does that look like?
What does that mean?
Can you give me examples/describe/explain that?

- c. Is there anything that High View can do to make your life better?
 - i. What can High View do to help you make your life better and easier to live?
 - ii. Are there things that you need at work that would make it better for you?

Probe question depending on the clarity of any of the responses:
That sounds interesting, can you tell me more about that.
Can you describe that to me, what does that look like?
What does that mean?
Can you give me examples/describe/explain that?

V. Family

- a. What does your family do to make your life good?
 - i. What do you do with your family?
 - ii. How does your family make you happy?
 - iii. How does your family make you feel good?
 - iv. Is there anything else that your family does that makes your life good?

Probe question depending on the clarity of any of the responses:
That sounds interesting, can you tell me more about that.

Can you describe that to me, what does that look like?
What does that mean?
Can you give me examples/describe/explain that?

- b. What does your family do that makes your life not so good?
 - i. What does your family do that makes you sad?
 - ii. Is there any other thing that your family does that makes your life not so good?

Probe question depending on the clarity of any of the responses:
That sounds interesting, can you tell me more about that.
Can you describe that to me, what does that look like?
What does that mean?
Can you give me examples/describe/explain that?

- c. Is there anything that your family can do to make your life better?
 - i. What could your family do make you happy?
 - ii. Are there things that you need from your family to make your life good?
 - iii. Are there things at home that you need more help with that would make your life better?

Probe question depending on the clarity of any of the responses:
That sounds interesting, can you tell me more about that.
Can you describe that to me, what does that look like?
What does that mean?
Can you give me examples/describe/explain that?

IV. Community

- a. What/how, does the community make your life good?
 - i. Describe what you do in the community.
 - ii. Do you participate in community activities such as park district programs, church, clubs, ...?
 - iii. Who decides where you go and what activities you attend?
 - iv. What do you like in the community?
 - v. Do you have friends in the community?
 - vi. Are there other things in the community that make your life good?

Probe question depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me, what does that look like?

What does that mean?

Can you give me examples/describe/explain that?

- b. What/how, does the community make your life not so good?
 - i. What makes it hard to be in the community?
 - ii. What do you not like about the community?
 - iii. Is there anything else about the community that makes your life not so good?

Probe question depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me, what does that look like?

What does that mean?

Can you give me examples/describe/explain that?

- c. Is there anything that the community can do to make your life better?
 - i. What can happen in the community that will make it easier for you to go out to different activities?
 - ii. What do you need to be comfortable while in the community?
 - iii. Is there anything else about the community you can tell me about that you would need to make your life better?

Probe question depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me, what does that look like?

What does that mean?

Can you give me examples/describe/explain that?

V. Conclusions

- a. Is there anything else you would like to tell me that would make your life better?
- b. Are there any questions you want to ask me?
- c. Is there anything I forgot to ask you?

Thank you for your time. You were very helpful. Remember I cannot get you any of those things you wanted. I do not work for High View and I cannot tell your family to get those things for you either. In about a month I may need to come back and ask you some more questions, would that be OK with you?

(Probe questions for adults with intellectual disabilities may need to be rephrased per individual's ability and understanding.

Interview for Parent or Guardian

I. Information/Introduction:

Name:

Name of son/daughter

Hi, and thank you for coming today. I just want to remind you that everything you say will be confidential and your name will not be used in any report or presentation of the research. If you want to stop at any time or the questions get uncomfortable, let me know and we can stop or you can withdraw from the study if you wish. Do you have any questions before we get started? I have some questions about your son/daughter's life. I will not use your name in any report or presentation where this research may be used in the future. I am looking forward to hearing about (son/daughter's name).

1. Please tell me about your son/daughter (name).

Probe questions depending on the clarity and details of the response provided:

- a. What does his/her day consist of?
- b. How does (name) fit into the family?
- c. What are some of (name's) favorite things to do?
- d. What are some of his/her activities away from home?
- e. What type and amount of supports or assistance do you provide?

2. In general:

What do you believe makes for a good life?

- a. Overall, what do you think is necessary to have a satisfying life?
- b. What else, if anything, makes for a good life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

1. What do you believe takes away from having a good life?

- a. How would you describe what takes away from having a good life?
- b. What else, if anything, would take away from have a good life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

2. What do you believe would make a life better?

a. What do you need to make a life satisfying?

b. What else, if anything, would make a life better?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

3. About your son/daughter

What do you think is good about your son/daughter's life?

a. What makes his/her life satisfying?

b. What would his/her life look like as a good life?

c. What else, if anything, do you think makes his/her life good?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

4. What do you think is not so good about your son/daughter's life?

a. What could make (name) life sad, bad, or unsatisfying?

b. How would that make his/her life not so good? Could you give me a little more detail?

c. What else, if anything, would make his/her life not so good?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

5. What do you think would make their life better?
 - a. What would enhance their life?
 - b. What may make it easier or happier for them?
 - c. What else, if anything, would enhance (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

6. High View:

1. What do you think High View does that is good for your son/daughter's life?
 - a. What does High View add to (name's) life?
 - b. What does High View do to enhance his/her life?
 - c. Can you think of anything else that that High View does that is good for (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

7. What do you think High View does that is not so good for your son/daughter's life?
 - a. How does High View take away from (name's) life?
 - b. What do you mean when you say... Can you give me a little more detail?
 - c. What else, if anything, that High View does that is not so good for (names) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

8. What do you think High View can do to make your son/daughter's life better?
- Are there changes in what High View does that would enhance (name's) life?
 - Are there other activities or items from High View that would enhance (name's) life?
 - Are there supports or aides that could add satisfaction to his/her life?
 - What else, if anything, can High View do to make (name's) life better?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

9. Community

What do you think the community does that is good for your son/daughter's life?

- Are there activities or social events that son/daughter attends?
- What are some things that your son/daughter does in the community?
- Do you have any other comments on what the community does that is good for (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

10. What do think the community does that is not so good for your son/daughter's life?

- Are there things in the community that holds (name) back from participating in activities?
- Is there anything else that you may think the community does that is not so good for (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

11. What do think the community could do to make your son/daughter's life better?

- a. How would that make a better life for (name)?
- b. Are there items or services that are needed to make his/her life better?
- c. Are there people or groups that are needed to make his/her life better?
- d. What else, if anything, may the community do to make (name's) life better?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

VI. Conclusion

Are there any other comments or questions you would like to share?

Thank you for your time. I will be contacting you within the month about a second interview if needed to clarify any information that I received today or anything else that I may have missed.

Interview for Case Manager

Name: _____

Date: _____

I. Introduction

Hi, thank you for letting me interview. Everything you say will be kept confidential. Your name or any identifying information will not be used in any reports and no one except my professor and me will have access to the data. If for any reason you want to stop, let me know and we will. You can withdraw from the study or skip a question if it gets too uncomfortable for you. Do you have any questions before we get started? I have some questions about the person you work with and their life. I will not use your name in any report or presentation that this research may become in the future. I am looking forward to hearing about your work with (name of individual).

- a. Tell me about High View.
 - i. What type of agency is High View?
 - ii. What type of activities occur?
 - iii. What are the type of participants?

Probe questions depending on the clarity of any of the responses:

Can you expand on that?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- b. Tell me about your role at High View.
 - i. What is your role or interaction with (name)?
 - ii. How long have you worked with him/her?
 - iii. What does his/her day consist of?
 - iv. What kind of work does he/she do?
 - v. What type and amount of supports or assistance do you provide?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

II. In general:

- a. What do you believe makes for a good life?
 - i. Overall, what do you think is necessary to have a satisfying life?
 - ii. What else, if anything, makes for a good life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- b. What do you believe takes away from having a good life?
 - i. How would you describe what takes away from having a good life?
 - ii. What else, if anything, would take away from have a good life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- c. What do you believe would make a life better?
 - i. What makes a life satisfying?
 - ii. What else, if anything, would make a life better?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

III. About the person with intellectual disabilities:

- a. What do you think is good about the life of the person with whom you work?
 - i. What makes (name) satisfying?
 - ii. What would their life look like if it was a good life?
 - iii. What other reasons, if any, do you think makes his/her life good?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

b. What do you think is not so good about (name's) life?

i. How would that make his/her life not so good? Could you give me a little more detail?

ii. What could make their life sad, bad, or unsatisfying?

iii. What else, if anything, would make his/her life not so good?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

c. What do you think would make their life better?

i. What would enhance their life?

ii. What may make it easier or happier for them?

iii. What else, if anything, would enhance (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

IV. High View:

a. What do you think High View does that is good for (name's) life?

i. What does High View add to (name's) life?

ii. What does High View do to enhance his/her life?

iii. Can you think of anything else that that High View does that is good for (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- b. What do you think High View does that is not so good for (name's) life?
 - i. How does High View take away from (name's) life?
 - ii. What do you mean when you say..... Can you give me a little more detail?
 - iii. What else, if anything, that High View does that is not so good for (names) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- c. What do you think High View can do to make (name') life better?
 - i. Are there changes in what High View does that would enhance (name's)life?
 - ii. Are there other activities or items that would enhance (name) life?
 - iii. Are there supports or aides that could add satisfaction to his/her life?
 - iv. What else, if anything, can High View do to make (name's) life better?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

V. Community

- a. What do you think the community does that is good for (name's) life?
 - i. Are there activities or social events that he/she attends?
 - ii. Do you have any other comments on what the community does that is good for (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that?

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- b. What do think the community does that is not so good for (name's) life?
- i. Are there things in the community that holds (name) back from participating in activities?
 - ii. Is there anything else that you may think the community does that is not so good for (name's) life?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

- c. What do think the community could do to make (name's) life better?
- i. Are there items or services that are needed to make his/her life better
 - ii. Are there people or groups that are needed to make his/her life better
 - iii. How would that make a better life for (name)?
 - iv. What else, if anything, may the community do to make (name's) life better?

Probe questions depending on the clarity of any of the responses:

That sounds interesting, can you tell me more about that.

Can you describe that to me?

What does that mean? Can you give me more information on that?

Can you give me examples/describe/explain that?

VI. Conclusion

Are there any other comments or questions you would like to share?

Thank you for your time. You have been very interesting and helpful. I will be contacting you within the month for a second interview if necessary. That interview will help clarify any information that you gave today or any additional questions that I may have. Thank you very much for your cooperation.

Review of Picture Cards

1. Before we start the interview, I want to remind you what you can do if you get upset or the questions get too hard to answer.
2. (Review the picture cards). I will leave the picture cards where you and I can reach them. If at any time, you cannot think of the word you can pick a picture card.
3. If I see you having a hard time with the question, I will ask you a question and you can answer with a picture if you cannot think of the word.

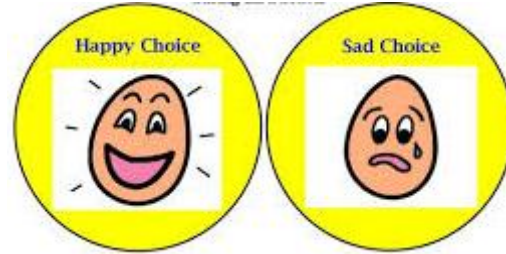
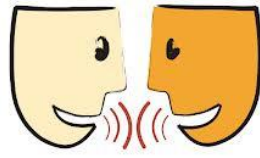




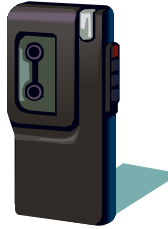
APPENDIX F
RELEASE FOR AUDIO TAPING
AND PICTURE SUPPORT

Release for Audio Taping

1. I will be interviewed about what is good and not so good in my life.



2. Jane will use a tape recorder, but no one will hear it but her. She will write it down and then erase the tape.



3. I can stop anytime I want to.

4. I can take a break anytime I want to.



5. I can say no and not answer any question I do not want to.



6. No one will tell anyone what I say.



7. My name will not be in the study paper.



8. If there are questions, I can telephone Jane at 708-857-8189. If I need help, I can ask my case manager or social worker.



I agree to let Jane use the tape recorder during my interview.



Signature



Date



APPENDIX G

Consents of Participation

Dear _____:

I am a doctoral candidate under the direction of Dr. Howard Parette in the College of Special Education at Illinois State University. I am conducting a research study to explore the perspectives of adults with intellectual disability, their parents or guardians, and their case managers, on quality of life for the person with the intellectual disability as they reach and pass midlife.

I will be selecting three triads, with each triad having an adult with an intellectual disability, his or her parent or guardian, and the case manager who works with the person with the intellectual disability. Criteria for participation in this study for the adult with an intellectual disability include (a) being between the ages of 35 and 55, (b) living at home with parent or guardian, and (c) attending day program at High View.

I am requesting your participation, which will involve one audio taped interview with me that will take place at a location and time convenient to you. I expect the interview to take approximately 45-60 minutes. The questions will relate to your definition of quality of life, the quality of life for the adult with intellectual disability, and the factors that would influence that quality of life. A second interview by telephone may be necessary if I need clarification or additional information.

Although limited, few foreseeable risks may occur to participants during this study. The risk of emotional distress may be due to audio taping interviews and /or the topics discussed. To reduce any risk of emotional distress it will be explained to all participants in the study that their participation in this study is voluntary. Therefore, if you choose not to participate or to withdraw from the study at any time, there will be no penalty of any kind. Additionally, if you feel the conversation is becoming uncomfortable or too emotional, you may choose to not answer specific questions, or stop the interview at any time. Any notice of emotional distress during the interview, I will stop and remind the participant that he or she has the option to stop, skip the question, or we could continue at another time.

There will be no coercion to be part of the study. All participation is voluntary. The director of High View Services will not know who agreed to participate or did not agree to participate. As a case manager, your decision to participate or not to participate in this study will not affect any work related benefits you receive from High View.

High View is not a part of this study and all your comments will be strictly confidential. The results of the research may be published, but your name or any identifying information will not be used. I will take all precautions to maintain your confidentiality (your name will not be used, and the transcript from our interview will not be shared with anyone). For example, the transcripts of the interviews, the final report, and any oral or written presentation from this research will contain pseudonyms and/or codes for all names which only the researcher will have access.

Although there may be no direct benefit to you, the possible benefit of your participation would be to learn what factors influence the quality of life for people with intellectual disability that are currently middle-aged and plan for their future and others approaching midlife.

If you have any questions concerning the research study, please contact me at 708-857-8189 or email at jlurqu@ilstu.edu or contact Dr. Parette at 309-438-8991.

Sincerely,

Jane L. Lurquin
Doctoral Student
Illinois State University

I consent to participate in the above study.

Signature

Date

Name of High View participant in the study:

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438-2529 or rec@ilstu.edu

Consent of Participation (Parent or Guardian)

Dear _____:

I am a doctoral candidate under the direction of Dr. Howard Parette in the College of Special Education at Illinois State University. I am conducting a research study to explore the perspectives of adults with intellectual disability, their parents or guardians, and their case managers, on quality of life for the person with the intellectual disability as they reach and pass midlife.

I will be selecting three triads, with each triad having an adult with an intellectual disability, his or her parent or guardian, and the case manager who works with the person with the intellectual disability. Criteria for participation in this study for the adult with an intellectual disability include (a) being between the ages of 35 and 55, (b) living at home with parent or guardian, and (c) attending day program at High View.

I am requesting your participation, which will involve one audiotaped interview with me that will take place at a location and time convenient to you. I expect the interview to take approximately 45-60 minutes. The questions will relate to your definition of quality of life, the quality of life for the adult with intellectual disability, and the factors that would influence that quality of life. A second interview by telephone may be necessary if I need clarification or additional information.

Although limited, few foreseeable risks may occur to participants during this study. The risk of emotional distress may be due to audio taping interviews and /or the topics discussed. To reduce any risk of emotional distress it will be explained to all participants in the study that their participation in this study is voluntary. Therefore, if you choose not to participate or to withdraw from the study at any time, there will be no penalty of any kind. Additionally, if you feel the conversation is becoming uncomfortable or too emotional, you may choose to not answer specific questions, or stop the interview at any time. Any notice of emotional distress during the interview, I will stop and remind the participant that he or she has the option to stop, skip the question, or we could continue at another time.

There will be no coercion to be part of the study. All participation is voluntary. The director of High View Services will not know who agreed to participate or did not agree to participate. As a parent or guardian, your decision to participate or not to participate will not affect the placement or services that your son or daughter now receives at High View.

High View is not a part of this study and all your comments will be strictly confidential. The results of the research may be published, but your name or any identifying information will not be used. I will take all precautions to maintain your confidentiality (your name will not be used, and the transcript from our interview will not be shared with

anyone). For example, the transcripts of the interviews, the final report, and any oral or written presentation from this research will contain pseudonyms and/or codes for all names and identifying information which only the researcher will have access.

Although there may be no direct benefit to you, the possible benefit of your participation would be to learn what factors influence the quality of life for people with intellectual disability that are currently mid-age and plan for their future and others approaching midlife.

If you have any questions concerning the research study, please contact me at 708-857-8189 or email at jlurqu@ilstu.edu or you may contact Dr. Parette at 309-438-8991.

Sincerely,

Jane L. Lurquin
Doctoral Student
Illinois State University

I consent to participate in the above study.

Signature

Date

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438-2529 or rec@ilstu.edu

APPENDIX I
CATEGORIES AND FREQUENCY OF RESPONSES TO
INTERVIEW QUESTIONS BY TRIADS

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars

Q: What would make for a good life for the individual with intellectual disability?		
Category: Quality of life		
<u>Participants (Triad 1)</u>		
<u>Tom</u> (n total responses = 81)	<u>Mrs. Rose</u> (n total responses = 32)	<u>Mark</u> (n total responses = 33)
Work related responses n = 17 (21%)	Work related responses n = 5 (15%)	Work related responses n = 11 (34%)
Exemplars <ul style="list-style-type: none"> • Getting community job High View • Doing jobs at High View • High View Players 	Exemplars <ul style="list-style-type: none"> • Loves High View • Staff is fantastic • He has to go to work • Likes his old case manager 	Exemplars <ul style="list-style-type: none"> • Being at High View • Opportunity to get paid for work • Sense of purpose • Community job
Family and Friends n = 18 (22%)	Family and Friends n = 6 (19%)	Family and Friends n = 4 (12%)
Exemplars <ul style="list-style-type: none"> • Helping Mom • Hang out with friends 	Exemplars <ul style="list-style-type: none"> • Gets along with his friends • He helps around the house • Caring about people 	Exemplars <ul style="list-style-type: none"> • Intertwined with Mom • Develop and maintain friendships

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What would make for a good life for the individual with intellectual disability?

Category: Quality of life

<u>Participants (Triad 1)</u>		
<u>Tom</u> (<i>n</i> total responses = 81)	<u>Mrs. Rose</u> (<i>n</i> total responses = 32)	<u>Mark</u> (<i>n</i> total responses = 33)
Community <i>n</i> = 16 (20%)	Community <i>n</i> = 3 (9%)	Community <i>n</i> = 4 (12%)
Exemplars <ul style="list-style-type: none"> • Shopping, fishing, bingo • Moving to group home • Horseback riding at camp • Church 	Exemplars <ul style="list-style-type: none"> • Loves to go shopping • Want him to go where ever he wants to 	Exemplars <ul style="list-style-type: none"> • Bowling • Park district • Friendship club
Health and Safety <i>n</i> = 6 (7%)	Health and Safety <i>n</i> = 6 (19%)	Health and Safety <i>n</i> = 2 (6%)
Exemplars <ul style="list-style-type: none"> • Being diabetic • Mom takes away my snacks • I miss McDonalds 	Exemplars <ul style="list-style-type: none"> • Epileptic • Psychiatrist • Medication 	Exemplar <ul style="list-style-type: none"> • Medication checked
Independence <i>n</i> = 3 (4%)	Independence <i>n</i> = 5 (15%)	Independence <i>n</i> = 4 (12%)
Exemplars <ul style="list-style-type: none"> • Don't make choices • Don't have opportunities 	Exemplars <ul style="list-style-type: none"> • Speak up for self • Come and go like normal boys/men 	Exemplars <ul style="list-style-type: none"> • Intertwined with Mom • Trapped, stationary

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What would make for a good life for the individual with intellectual disability?

Category: Quality of life

<u>Participants (Triad 1)</u>		
<u>Tom</u> (n total responses = 81)	<u>Mrs. Rose</u> (n total responses = 32)	<u>Mark</u> (n total responses = 33)
Feelings n = 8 (10%)	Feelings n = 4 (12%)	Feelings n = 3 (9%)
Exemplars <ul style="list-style-type: none"> • Good things • Wish not born • Violence • Anger control 	Exemplars <ul style="list-style-type: none"> • Being happy • Good life 	Exemplars <ul style="list-style-type: none"> • Caring • Anger
Not applicable n = 13 (16%)	Not applicable n = 3 (9%)	Not applicable n = 5 (15%)

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 97)	<u>Mrs. Doris</u> (n total responses = 55)	<u>Sue</u> (n total responses = 30)
Work related responses n = 20 (21%)	Work related responses n = 6 (11%)	Work related responses n = 6 (20%)
Exemplars <ul style="list-style-type: none"> • High View • A lot of stuff at High View • Mom don't let me have community job 	Exemplars <ul style="list-style-type: none"> • "High View is a Godsend" • Wonderful staff • Placed back at workshop 	Exemplars <ul style="list-style-type: none"> • No community job • High View • Staff/case manager

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What would make for a good life for the individual with intellectual disability?

Category: Quality of life

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 97)	<u>Mrs. Doris</u> (n total responses = 55)	<u>Sue</u> (n total responses = 30)
Family and Friends n = 33 (34%)	Family and Friends n = 16 (29%)	Family and Friends n = 5 (17%)
Exemplars <ul style="list-style-type: none"> • Help Mom • Spend time with my friends and my family 	Exemplars <ul style="list-style-type: none"> • Plays with nieces and nephews • “Miss social butterfly” • Exposure to many people 	Exemplars <ul style="list-style-type: none"> • Family • Influenced by Mom • Lifelong friends
Community n = 13 (13%)	Community n = 11 (20%)	Community n = 5 (17%)
Exemplars <ul style="list-style-type: none"> • Church • No park district 	Exemplars <ul style="list-style-type: none"> • Travel, own frequent flyer miles • Removed from park district programs • Church 	Exemplars <ul style="list-style-type: none"> • Need community exposure • Park district (past)
Health and Safety n = 2 (2%)	Health and Safety n = 6 (11%)	Health and Safety n = 0
Exemplars <ul style="list-style-type: none"> • Exercise • Safety at work 	Exemplars <ul style="list-style-type: none"> • Exercise • Comprehension • Hold hand whenever outside • Protected 	--

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What would make for a good life for the individual with intellectual disability?

Category: Quality of life

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 97)	<u>Mrs. Doris</u> (n total responses = 55)	<u>Sue</u> (n total responses = 30)
Independence n = 5 (5%)	Independence n = 5 (9%)	Independence n = 5 (17%)
Exemplars <ul style="list-style-type: none"> • No decision making • Make my own lunch • No community involvement 	Exemplars <ul style="list-style-type: none"> • Never left alone • “If I let her” • No community involvement • Family will protect her 	Exemplars <ul style="list-style-type: none"> • Lack decision making • Influenced by Mom
Feelings n= 4 (4%)	Feelings n= 6 (11%)	Feelings n= 3 (10%)
Exemplars <ul style="list-style-type: none"> • Everything makes me happy • Routines and schedules upset me, confusion • “I have a good life and I like my life.” 	Exemplars <ul style="list-style-type: none"> • “Beth is just a joy” • “She knows she’s loved” • She’s happy 	Exemplars <ul style="list-style-type: none"> • Enjoying her community job • “Pretty swell life”
Not applicable n = 20 (21%)	Not applicable n = 5 (9%)	Not applicable n = 6 (20%)

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What would make for a good life for the individual with intellectual disability?

Category: Quality of life

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 97)	<u>Mrs. Doris</u> (n total responses = 55)	<u>Sue</u> (n total responses = 30)
Work related responses n = 18 (31%)	Work related responses n = 9 (18%)	Work related responses n = 7 (27%)
Exemplars <ul style="list-style-type: none"> • Community job • High View jobs • Staff 	Exemplars <ul style="list-style-type: none"> • “Anything at High View enhances her life” • Community job at Stony Creek • Staff • Pay check 	Exemplars <ul style="list-style-type: none"> • High View • Community job • Staff/case manager • Oversee/Quality control
Family and Friends n = 15 (26%)	Family and Friends n = 5 (10%)	Family and Friends n = 2 (8%)
Exemplars <ul style="list-style-type: none"> • Hang out with friends • Parents take me out • Family dogs • Family visits • Family love and hugs 	Exemplars <ul style="list-style-type: none"> • Family • Social Club • Being together with friends and family 	Exemplars <ul style="list-style-type: none"> • Friends, special friend, boyfriend • Family, parents • Concern of aging parents
Community n = 10 (17%)	Community n = 10 (20%)	Community n = 2 (8%)
Exemplars <ul style="list-style-type: none"> • Shopping • Restaurants • Friendship Club • Church 	Exemplars <ul style="list-style-type: none"> • Going out to eat • Going shopping • Bowling • Social Club • Church 	Exemplars <ul style="list-style-type: none"> • Friendship club • Church • Park district (past)

Q: What would make for a good life for the individual with intellectual disability?

Category: Quality of life

<u>Participants (Triad 2)</u>		
<u>Beth</u> (<i>n</i> total responses = 97)	<u>Mrs. Doris</u> (<i>n</i> total responses = 55)	<u>Sue</u> (<i>n</i> total responses = 30)
Health and Safety <i>n</i> = 0	Health and Safety <i>n</i> = 6 (12%)	Health and Safety <i>n</i> = 3 (11%)
--	Exemplars <ul style="list-style-type: none"> • Cleaning bathroom is dangerous • Doctors proud of her health 	Exemplars <ul style="list-style-type: none"> • Parents health issues • What happens to Penny when parents can no longer care for her?
Independence <i>n</i> = 4 (7%)	Independence <i>n</i> = 4 (8%)	Independence <i>n</i> = 4 (15%)
Exemplars <ul style="list-style-type: none"> • Has community job • Buys own books 	Exemplars <ul style="list-style-type: none"> • Organizes closets • Community job • Independent living skills • Makes choices 	Exemplars <ul style="list-style-type: none"> • Community job • Opportunities to learn new things • Making choices
Feelings <i>n</i> = 4 (7%)	Feelings <i>n</i> = 5 (10%)	Feelings <i>n</i> = 5 (19%)
Exemplars <ul style="list-style-type: none"> • Always Happy • I love them • I'm good 	Exemplars <ul style="list-style-type: none"> • Everyone likes her • Sensitive to others • Feels good and important about pay check • Always happy 	Exemplars <ul style="list-style-type: none"> • “She’s pretty satisfied and happy with her life” • “Penny is so happy”
Not applicable <i>n</i> = 7 (12%)	Not applicable <i>n</i> = 11 (22%)	Not applicable <i>n</i> = 3 (11%)

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What supports and services enhance the quality of life for the individual with intellectual disability?

Category: Supports and Services

<u>Participants (Triad 1)</u>		
<u>Tom</u> (<i>n</i> total responses = 29)	<u>Mrs. Rose</u> (<i>n</i> total responses = 45)	<u>Mark</u> (<i>n</i> total responses = 29)
Work related responses <i>n</i> = 8 (27%)	Work related responses <i>n</i> = 7 (16%)	Work related responses <i>n</i> = 9 (31%)
Exemplars Support of social worker Support from staff/case manager Wanting community job back	Exemplars Staff at High View Need a reading class Male staff works better with Tom	Exemplars Case manager support to answer question, problem solve Social work services Community job
Family and Friends <i>n</i> = 8 (27%)	Family and Friends <i>n</i> = 12 (27%)	Family and Friends <i>n</i> = 5 (17%)
Exemplars <ul style="list-style-type: none"> • Support from Mom • Talk to Jan, his friend • Support from friends 	Exemplars <ul style="list-style-type: none"> • Mom shaves him • Mom keeps him involved • Mom goes with him everywhere/supervises him • Friends support him 	Exemplars <ul style="list-style-type: none"> • Opportunities to have friends • Learn to be socially appropriate when he interacts with his peers • How to adjust if mom wasn't around/intertwined

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What supports and services enhance the quality of life for the individual with intellectual disability?

Category: Supports and Services

<u>Participants (Triad 1)</u>		
<u>Tom</u> (n total responses = 29)	<u>Mrs. Rose</u> (n total responses = 45)	<u>Mark</u> (n total responses = 29)
Community n = 5 (17%)	Community n = 9 (20%)	Community n = 5 (17%)
Exemplars <ul style="list-style-type: none"> • Talk to Father Larry, friend at church • Park district services • Camp staff • Asking for community group home 	Exemplars <ul style="list-style-type: none"> • Park district services • Wants a community job • Wants to live in group home 	Exemplars <ul style="list-style-type: none"> • Park district services • Community job and group home • Social group, learn social skills • Counseling services
Health and Safety n = 2 (7%)	Health and Safety n = 7 (16%)	Health and Safety n = 1 (3%)
Exemplars <ul style="list-style-type: none"> • Support from Mom about his snacks 	Exemplars <ul style="list-style-type: none"> • Medical support from his doctors • Diabetic support 	Exemplars <ul style="list-style-type: none"> • Medication check and change if necessary
Independence n = 2 (7%)	Independence n = 4 (9%)	Independence n = 4 (14%)
Exemplars <ul style="list-style-type: none"> • Learn different ways to talk to people • Learn to make choices • Get my community job back 	Exemplars <ul style="list-style-type: none"> • Mom supports him • Tom supports mom • He has no sense of direction, cannot go on his own 	Exemplars <ul style="list-style-type: none"> • Support in making choices • Providing opportunities to learn new things

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: *What supports and services enhance the quality of life for the individual with intellectual disability?*

Category: Supports and Services

<u>Participants (Triad 1)</u>		
<u>Tom</u> (n total responses = 29)	<u>Mrs. Rose</u> (n total responses = 45)	<u>Mark</u> (n total responses = 29)
Feelings n = 3 (10%)	Feelings n = 2 (4%)	Feelings n = 3 (10%)
Exemplars <ul style="list-style-type: none"> Learn to control my anger Support from the social worker 	Exemplars <ul style="list-style-type: none"> Needs support to learn to stop talking at work/behaviors listed on quarterly reports Support needed for negative thoughts such as “He gets very upset and says why am I here on this earth?” 	Exemplars <ul style="list-style-type: none"> Helping him control/curb his anger and outbursts
Not applicable n = 1 (3%)	Not applicable n = 4 (9%)	Not applicable n = 2 (9%)

Q: *What supports and services enhance the quality of life for the individual with intellectual disability?*

Category: Supports and Services

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 70)	<u>Mrs. Doris</u> (n total responses = 43)	<u>Sue</u> (n total responses = 23)

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: What supports and services enhance the quality of life for the individual with intellectual disability?

Category: Supports and Services

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 70)	<u>Mrs. Doris</u> (n total responses = 43)	<u>Sue</u> (n total responses = 23)
Work related responses <i>n</i> = 17 (24%)	Work related responses <i>n</i> = 5 (12%)	Work related responses <i>n</i> = 7 (30%)
Exemplars <ul style="list-style-type: none"> • Support from staff and the case manager • All the help from High View 	Exemplars <ul style="list-style-type: none"> • High View services • Support from staff/supervisor 	Exemplars <ul style="list-style-type: none"> • High View services • Case manager some supervision • Not really allowed to get community job • Maintain current skills • Large print for reading • Anti-glare for computer
Family and Friends <i>n</i> = 18 (26%)	Family and Friends <i>n</i> = 6 (14%)	Family and Friends <i>n</i> = 4 (17%)
Exemplars <ul style="list-style-type: none"> • Help Mom and Mom helps me • Mom takes care of me • Brothers and sisters help each other • Friends help me out 	Exemplars <ul style="list-style-type: none"> • Mom holds her hand whenever outside • Family teaches her what they can • Family spends time with her 	Exemplars <ul style="list-style-type: none"> • Family support, go out of their way to support Beth • Influenced by Mom

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: *What supports and services enhance the quality of life for the individual with intellectual disability?*

Category: Supports and Services

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 70)	<u>Mrs. Doris</u> (n total responses = 43)	<u>Sue</u> (n total responses = 23)
Community n = 16 (23%)	Community n = 6 (14%)	Community n = 3 (18%)
Exemplars <ul style="list-style-type: none"> • No park district services • Church services • Always with family in community 	Exemplars <ul style="list-style-type: none"> • Travel with family • No park district services • No community job or group home • Mom holds hand • “I haven’t taken her anywhere in the community” 	Exemplars <ul style="list-style-type: none"> • Park district services (past) • Be exposed to more community services
Health and Safety n = 6 (9%)	Health and Safety n = 6 (14%)	Health and Safety n = 0
Exemplar <ul style="list-style-type: none"> • Mom helps with exercise 	Exemplars <ul style="list-style-type: none"> • Mom supports with exercise • Past support of Levenson foundation (when child) 	--
Independence n = 3 (4%)	Independence n = 5 (12%)	Independence n = 4 (17%)
Exemplars <ul style="list-style-type: none"> • Removed from community job (Mom) • Lack of choice making • Mom holds hand outdoors 	Exemplars <ul style="list-style-type: none"> • Increase community services • Opportunities for learning new things 	Exemplar <ul style="list-style-type: none"> • Increase opportunities for decision making

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: *What supports and services enhance the quality of life for the individual with intellectual disability?*

Category: Supports and Services

<u>Participants (Triad 2)</u>		
<u>Beth</u> (n total responses = 70)	<u>Mrs. Doris</u> (n total responses = 43)	<u>Sue</u> (n total responses = 23)
Feelings n = 3 (4%)	Feelings n = 4 (9%)	Feelings n = 2 (9%)
Exemplar <ul style="list-style-type: none"> • People say bad things, make fun of, threaten (support needed) 	Exemplars <ul style="list-style-type: none"> • Lack of understanding and comprehension • “Happy and normal” • “If I let her” 	Exemplar <ul style="list-style-type: none"> • Happier, “maybe she does miss it, but doesn’t say, or can’t tell it to us or won’t tell it to us, I’m not sure.” (enjoying past community job)
Not applicable n = 7 (10%)	Not applicable n = 11 (26%)	Not applicable n = 3 (13%)

<u>Participants (Triad 3)</u>		
<u>Penny</u> (n total responses = 62)	<u>Mr. and Mrs. Gray</u> (n total responses = 40)	<u>Jean</u> (n total responses = 21)
Work related responses n = 17 (27%)	Work related responses n = 5 (12%)	Work related responses n = 5 (23%)
Exemplars <ul style="list-style-type: none"> • Community job • High View • Staff, job coach • Case manager and my goals 	Exemplars <ul style="list-style-type: none"> • High View jobs • High View staff • Community job 	Exemplars <ul style="list-style-type: none"> • High View services • Opportunities to learn new and different things • Community job • Case manager and staff support

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: *What supports and services enhance the quality of life for the individual with intellectual disability?*

Category: Supports and Services

<u>Participants (Triad 3)</u>		
<u>Penny</u> (n total responses = 62)	<u>Mr. and Mrs. Gray</u> (n total responses = 40)	<u>Jean</u> (n total responses = 21)
Family and Friends n = 18 (29%)	Family and Friends n = 6 (15%)	Family and Friends n = 2 (10%)
Exemplars <ul style="list-style-type: none"> • Parents take me shopping • Friends help me • Family take me out to eat and buy books, I pick them out 	Exemplars <ul style="list-style-type: none"> • Mom washes her hair • Penny helps everyone • Friends help each other 	Exemplar <ul style="list-style-type: none"> • Family supports her
Community n = 16 (26%)	Community n = 5 (12%)	Community n = 3 (14%)
Exemplars <ul style="list-style-type: none"> • Park district services • Community job 	Exemplars <ul style="list-style-type: none"> • Friendship club program • Bowling program • Staff that help at the Community programs she attends • Community awareness of disabilities • Respite care 	Exemplars <ul style="list-style-type: none"> • Park district programs (past) • Friendship club
Health and Safety n = 0	Health and Safety n = 6 (15%)	Health and Safety n = 2 (10%)
--	Exemplar <ul style="list-style-type: none"> • Support from her doctors 	Exemplar <ul style="list-style-type: none"> • Support for Penny if something happens to her aging parents

Identified Categories and Frequency of Responses to Interview Question by Triad Study Participants and Exemplars (continued)

Q: *What supports and services enhance the quality of life for the individual with intellectual disability?*

Category: Supports and Services

<u>Participants (Triad 3)</u>		
<u>Penny</u> (n total responses = 62)	<u>Mr. and Mrs. Gray</u> (n total responses = 40)	<u>Jean</u> (n total responses = 21)
Independence n = 3 (5%)	Independence n = 5 (12%)	Independence n = 4 (19%)
Exemplar <ul style="list-style-type: none"> • Help using the phone 	Exemplar <ul style="list-style-type: none"> • “She’s very independent” 	Exemplars <ul style="list-style-type: none"> • Express what they really want. • Opportunities to learn new and different things
Feelings n= 1 (2%)	Feelings n= 2 (5%)	Feelings n= 2 (10%)
Exemplar <ul style="list-style-type: none"> • I’m always happy 	Exemplar <ul style="list-style-type: none"> • Always happy 	Exemplar <ul style="list-style-type: none"> • “I think she’s pretty satisfied and happy with her life”
Not applicable n = 7 (11%)	Not applicable n = 11 (3%)	Not applicable n = 3 (14%)