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## The Social Inclusion of Young Adults with Intellectual Disabilities: A Phenomenology of Their Experiences

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THE SOCIAL INCLUSION OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES:  
A PHENOMENOLOGY OF THEIR EXPERIENCES

by

Sarah A. Hall

A DISSERTATION

Presented to the Faculty of

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For the Degree of Doctor of Philosophy

Major: Educational Studies

(Educational Leadership and Higher Education)

Under the Supervision of Professor Marilyn L. Grady

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# THE SOCIAL INCLUSION OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES: A PHENOMENOLOGY OF THEIR EXPERIENCES

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University of Nebraska, 2010

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Social inclusion enhances the quality of life of young adults with intellectual disabilities (ID). Young adults with ID continue to face prejudice and discrimination that limit their social inclusion. They experience limited social inclusion because there are not enough appropriate activities available and they have limited opportunities to develop friendships. The social inclusion that people with disabilities experience within their local community varies greatly.

There is a deficiency in the literature concerning the social inclusion of young adults with ID. Previous considerations of disability have focused primarily on physical access and reflect the local contexts in which the participants live. There is a need to understand the social inclusion of young adults with ID and to advocate for change.

The purpose of the present study was to describe the social inclusion of young adults with intellectual disabilities and to identify contexts that limit or enhance their social inclusion. Social inclusion was defined as being involved in activities, developing and maintaining relationships, and having a sense of belonging. Participants included fourteen adults from 22 to 35 years of age with a mild or moderate intellectual disability who were able to verbally communicate their thoughts and experiences.

I used the phenomenological qualitative research design to explore the lived experiences of social inclusion for young adults with ID. I collected data through semi-structured interviews. During the interviews, I asked the participants open-ended questions about their experiences of social inclusion and the context of their experiences. The length of each interview session and number of sessions were flexible to accommodate the needs of the participants.

The findings consisted of themes that described their experiences of social inclusion and the contexts of their experiences. Their social inclusion consisted of involvement in work, volunteer, social, recreational, and leisure activities; reciprocal relationships; and the sense of belonging derived from accepting environments and self-determination. Their social inclusion was influenced by the contexts of their experiences including living accommodations,

transportation options, personal abilities and skills, financial resources, assistance from family members, and assistance from service providers.

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## CHAPTER 1

### INTRODUCTION

Through my experiences as a sibling of a young adult with multiple disabilities, co-director of a Bible study for adults with intellectual disabilities, and special education teacher, disability has become a normal part of my everyday life. I was a high school special education teacher for three years and had the chance to teach students with learning disabilities, behavior disorders, and intellectual disabilities. As a teacher, I observed that most of the students with intellectual disabilities did not participate in as many organized activities and did not spend as much time with their friends as other high school students. There was a need in the community for activities appropriate for youth and adults with intellectual disabilities. To create more opportunities in the community, I assisted in setting up a Bible study for adults with intellectual disabilities and became a co-director. This turned out to be a meaningful opportunity for the participants to interact and socialize with other adults with and without disabilities.

A great amount of my knowledge and understanding of disability comes from growing up with an older brother who has multiple disabilities such as autism, Downs syndrome, epilepsy, and severe intellectual disabilities. My brother went to a separate school during his elementary years and was in separate classrooms throughout high school. He participated in activities with other people with disabilities such as the Boy Scouts and Special Olympics. There was no place for him at the church my family attended once he was old enough for Sunday School, so we switched to a different church where my mom taught him one-on-one in their resource room. Through the transition program at his high school, my brother practiced work skills and received a job cleaning at a church with the assistance of a job coach. A short time after he graduated, he lost his job and has not had the opportunity to work or volunteer for many years.

When we went out as a family, people would stare at my brother. Some people would look and make comments to each other or avoid us, but most of the people we were familiar with were kind. It seemed that most people did not know how to interact with him. He had teachers with high expectations who prepared him for his adult life and others who taught him little because they could not see his potential. When he became an adult, appropriate services were not available for my brother. My parents had to fight for the residential services my brother needed through a long, stressful, and emotional process. They met with a group of professionals including service providers, the mayor of the city, and legal representatives to determine a solution to the problem. Months later, one service provider established their first group home in the city where my brother would live.

My brother attends a day activities program. The staff members are friendly and provide him with leisure activities, but he does not socialize often and has very few interactions with people in the community. He practices socially appropriate communication with staff and receives physical therapy. He would benefit from having more learning opportunities to increase his vocational, daily living, and socialization skills. Our family would like to see him participate in more meaningful and productive activities, but more than anything, we want him to be happy.

Throughout my life, I have known people with intellectual disabilities who have a variety of abilities, interests, personalities, and opportunities for social inclusion. People with intellectual disabilities need opportunities to participate in more meaningful and productive activities and to socialize with people with and without disabilities. They need to be encouraged to pursue their interests and to reach their potential. Social inclusion is an important aspect of a person's quality of life. We need to reach out as a community to reduce the barriers that people with intellectual disabilities face and find ways to enhance their social inclusion.

### *Background*

The experience of social inclusion for people with disabilities is reflected in the opportunities, services, and attitudes present in society. Their level of social inclusion has been impacted by their living situations such as living independently in the community, with parents, in a group home, or in a large institution. The opportunities people with disabilities have in education, employment, church, recreational activities, and leisure activities also make a great impact on their social inclusion. The living situations and opportunities available to people with disabilities are significantly influenced by the attitudes of society. As society's attitudes have changed throughout the years, so have the support services, relationships, and social inclusion of people with disabilities.

#### *From Idiots, Imbeciles, and Morons to People with Intellectual Disabilities*

The evolution of the terminology and definitions associated with intellectual disabilities (ID) has reflected the knowledge and attitudes of society at the time. The original terminology of idiot, imbecile, feeble-minded, and moron was used to describe people with ID in the late 1800s (Linneman, 2001). The diagnostic approach to disability emerged and became predominate in the early 1900s. This approach was based on medical explanations and defined disability as a "long-term physical, behavioral, psychological, cognitive, or sensory impediment" (Gilson & DePoy, 2002, p. 154).

At the beginning of the 1950s, people were still being referred to as idiots, imbeciles, and morons. They were judged on their social competence, which was defined as "the functional ability of the human organism for exercising personal independence and social responsibility" (Doll, 1953, p. 10). By the end of the decade, the term mental retardation was introduced, referring to "subaverage general intellectual functioning which originates in the developmental

period and is associated with impairment in adaptive behavior” (Linneman, 2001). Mental retardation became the common label for the rest of the 20<sup>th</sup> century as people worked to develop and refine measurements to assess intellectual and adaptive skills.

In the 1970s, the social model of disability developed and gained support. The social model rejects the medical assumptions and views disability as a social form of oppression (McClimens, 2003). The disability rights movement began to advocate for the right to be known as people first (McClimens). Through people first language, they emphasized the humanity of people with disabilities by saying “the people with disabilities” instead of “the disabled.” By 1990, the Americans with Disabilities Act defined an individual with a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities” (Ainsworth & Baker, 2004, p. 182). This definition follows the ideas of earlier definitions but also reflects the views of the social model of disability.

In February of 2008, the American Association on Intellectual and Developmental Disabilities replaced the term mental retardation with intellectual disabilities. Intellectual disabilities (ID) is defined as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” which originates before the age of 18 (AAIDD, 2008). According to the Nebraska Department of Education, Rule 51 (2006), people with ID may be verified as having mild, moderate, or severe/profound intellectual disabilities depending on their intelligence quotient score and adaptive skills.

### *Experiences of People with Intellectual Disabilities throughout the Years*

Individuals with ID have had a variety of experiences throughout the years determined by the attitudes of society, services available, opportunities present, and support from advocates.

During the late 1800s, people with ID were perceived as a potential asset or value to society if provided with appropriate education (DeKraai, 2002). Schools and institutions were established to educate people with ID. Though the institutions were envisioned as schools, they soon began serving the role of teaching the ‘teachable’ and providing custodial care for the ‘unteachable.’ As more emphasis was placed on custodial care, residents of the institutions were taught to function within the institutional setting, where they would most likely remain for life. According to DeKraai, “the motivation behind this custodial philosophy derived from a desire to protect the person from society, rather than to protect society from the individual” (p. 115). The segregated institutions, where people with disabilities supported themselves through manual labor, became the institutional model for several decades (Crane, 2002).

In the early 1900s, the view of people with disabilities changed. Society began to view people with ID as threats and therefore efforts were made to segregate and confine them (DeKraai, 2002). Institutions were expected to keep people with disabilities from creating trouble in the community. They were also expected to prevent them from reproducing because people believed that mental retardation was hereditary (Crane, 2002). In an effort to eliminate mental retardation, tens of thousands of people in institutions were involuntarily sterilized (DeKraai; Crane).

Throughout the early 1900s, there were no schools, programs, or residential facilities set up specifically for people with ID (Crane, 2002). They were grouped in institutions with people who had mental illness and only taught skills that they could use in the institution. During the 1950s, families who had children with ID began joining together for support and collaborated to form local associations and to establish schools (Ferdinand & Marcus, 2002). Parents used their

own financial resources, became teachers, and fought for services they could not provide themselves. During this time, the families were the most persuasive force for change (Crane).

The American civil rights movement of the 1960s inspired the movement toward reform for people with disabilities both philosophically and strategically (Middleton, Rolling, & Harley, 1999). In 1962, Ed Roberts won an appeal to enroll in the University of California-Berkley, where he was initially denied admission because he relied on a wheelchair, an iron lung, and a personal caregiver. According to McCarthy (2003), “This is perceived by many as the beginning of the disability rights movement in the United States” (p. 209). From the movement, people with disabilities became more aware that they were being treated as second-class citizens and of the injustice of their exclusion. People with disabilities and their advocates demanded rights to the mainstream of society, certain income and medical benefits, education, and other entitlements (Middleton, Rollins, & Harley). The leaders of the disability rights movement organized self-advocacy groups and engaged in civil disobedience (McCarthy).

The 1960s also established a new ideology based on “the principle of normalization, the developmental model, emphasis on programs rather than buildings, use of generic community services, and providing services in small, dispersed, and integrated community settings” (Evans, Stork, & Phillips-Stork, 2002, p. 152). As a result of the developmental model, people with ID were again perceived as capable of growth, development, and learning. By using generic community services, people with ID would be able to interact with community members on a daily basis. The principle of normalization “asserts the right of all people to a lifestyle that includes the privileges and opportunities typically afforded in the culture” (Crane, 2002, p. 5). This principle allows all people to have the chance to enhance their social image and acceptability in society.

There was strong support for deinstitutionalization and the substitution of community services by the end of the 1960s (Crane, 2002; Evans, Stork, & Phillips-Stork, 2002). In 1967, Burton Blatt advocated for networks of small community-centered residential facilities linked to a total community program (Herr, 1995). The community alternatives developed had better conditions and services than the institution services (Evans, Schere, & Rasmussen, 2002). Ed Roberts founded the first Center for Independent Living (McCarthy, 2003). The independent living movement, defined as having control over one's life (Middleton, Rollins, & Harley, 1999), emerged and grew strong throughout the 1970s.

Federal and state legislatures appropriated money specifically for deinstitutionalization. People with ID became eligible to receive Supplemental Security Income benefits and State Supplemental Assistance, which became the most important source of payment for group homes (Evans, Schere, & Rasmussen, 2002). Between 1970 and 1979, the number of people living in state institutions decreased by more than 50,000 (Crane, 2002). Not everyone who moved out of a state institution had appropriate options for inclusive living. Though some people had more control over their lives, others were placed in congregate settings that were inappropriate or marginal (Kavanaugh, 2002).

The social model of disability emerged in the 1970s. It acknowledged the disabling effects of society for people with disabilities such as the absence of human rights, poor physical access, lack of personal assistance, and discrimination across all life areas (Bigby, Fyffe, & Ozanne, 2007). To eliminate some of the discrimination faced by people with disabilities, various laws and procedures were established. The Architectural Barriers Act of 1968 required all federal buildings and facilities to be physically accessible, including "all building structures, paths of travel, parking space allocation, ramps, counter heights, restroom facilities and related

public spaces” (Ainsworth & Baker, 2004, p. 175). The Rehabilitation Act of 1973 was established to prohibit discrimination on the basis of disability in federal programs and employment (Ainsworth & Baker). This Act changed public policy by giving people with disabilities equal access to educational, employment, health, and other opportunities (Middleton, Rollins, & Harley, 1999). In 1975, the Education for All Handicapped Children Act (EAHCA) asserted “full, free, and appropriate rights for all children with disabilities” (Ainsworth & Baker, p. 178). This was a huge accomplishment that switched the responsibility to educate children with disabilities from their parents to the government.

Changes continued to be made in the 1980s to reflect the philosophy of normalization and to increase the quality of life for people with disabilities (Kavanaugh, 2002). The federal government worked to create home and community services for them. The Client Assistance Program was established to provide legal support for people with disabilities and their families (Ainsworth & Baker, 2004). The federal waiver was also implemented, which allows people with disabilities to select the service providers of their choice when using federal funds. Because of these changes, “people requesting services were again being offered reasonable choices in determining the most appropriate services to meet their needs” (Kaanaugh, p. 190).

After the foundation had been set, there was a surge in the rethinking and redrafting of policy related to disability in the 1990s. The policies comprised of “antidiscrimination legislation and service priorities that emphasized greater access to services and full involvement of individuals with disabilities” (Merrill, 2002, p. 205). The Americans with Disabilities Act (ADA) of 1990 set the tone by prohibiting discrimination in employment, government, public accommodations, transportation, and telecommunications on the basis of disability (Ainsworth & Baker, 2004). According to the ADA, the states are required to provide these services and



programs in the most integrated settings appropriate for each individual. If services or programs do not comply, they will receive significant monetary penalties (Middleton, Rollins, & Harley, 1999). Because of the ADA, many changes have been made to increase and enhance the opportunities for people with disabilities and further include them in society overall.

The Individuals with Disabilities Education Act of 1990 (formerly the EAHCA) was established to ensure that students in public schools receive free and appropriate special education services in the least restrictive environment. The next year, services from the state vocational rehabilitation agencies became available to assist people with disabilities in job attainment (Ainsworth & Baker, 2004). Additional antidiscrimination legislation was redrafted in the 2000 reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. This Act prohibits discrimination on the basis of disability in employment, housing, education, and access to public services, and requires reasonable accommodations to be made to ensure equal opportunities for people with disabilities (Ainsworth & Baker). From the support of advocates and legislation, many improvements have been made since the segregation and discrimination practices that were common in the past.

### *Current Experiences of Social Inclusion for People with Intellectual Disabilities*

People with disabilities have received more rights, services, and respect they need to become a greater part of their communities. According to McCarthy (2003), the achievements of the disability community include more physical access, more access to education and jobs, accessible busses, preservation of the ADA, easier access to disability services and information, enforcement of housing codes, community integration, and a consciousness of inclusion. Because of these achievements and the change in attitudes of society, people with disabilities are able to experience a greater degree of social inclusion.

Though people with disabilities experience more social inclusion overall, the social inclusion they experience within their local community varies markedly (McConkey, Walsh-Gallagher, & Sinclair, 2005). Some people with ID enjoy the friendships they develop in group living situations and have regular opportunities to socialize with other group home residents within the agency (Jahoda & Markova, 2004; Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). Others have become socially isolated because they have little to no contact with their family or friends (McConkey, 2007). As observed by Partington (2005), many still suffer direct discrimination because of the attitudes of others.

In the workplace, Vander Hart (2000) found that many adults with ID do not have the opportunities to socialize with their coworkers in natural settings. Wistow and Schneider (2003) observed both examples of close friendships and socializing outside of work and alienation from the rest of the workforce. The varying experiences of social inclusion they observed support the view that physical integration does not necessarily mean social integration.

The experience of social inclusion for people with ID is also variable concerning their interactions and relationships with people in the community overall. According to Blessing (2004), people with ID were concerned with their lack of meaningful activities and lack of social connections or friendships. Most of their time at work and in the community was spent with other individuals with disabilities (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). They did not often socialize or participate in activities with adults who do not have disabilities. Hall (2005) discovered: “within places of seeming exclusion- care homes and non-paid work- can be found spaces of inclusion, and within apparent contexts of inclusion- independent living and paid employment- exclusion is commonly experienced” (p. 113). As determined from these multiple variables, the experiences of social inclusion is different for each person with ID.

### *Social Inclusion Definitions and Descriptions*

Social inclusion for people with ID is having full access to activities, social roles, and relationships (Partington, 2005) as well as having valued presence and participation in society (Lemay, 2006). As described by Jaeger and Bowman (2005), social inclusion is equal access to physical places and equal opportunity to access and understand intellectual content. It is also a sense of belonging that stems from friendships (Crane, 2002). Having positive interactions as well as developing and maintaining a network of friendships is an important aspect of social inclusion (Crane; Lemay). Social inclusion is also viewed as having meaningful social roles that may take place in the family, workplace, at activities, and in the community (Lemay). According to Crane, the social roles of people with ID help them feel like they belong and become accepted as legitimate parts of their community.

Social inclusion for people with ID consists of three elements: being involved in the community, maintaining reciprocal relationships, and having a sense of belonging. Involvement in the community includes the use of community amenities and participation in structured recreation, leisure, church, and volunteer activities. Developing and maintaining reciprocal relationships with family, friends, coworkers, and acquaintances in the community is important for people with ID. A sense of belonging is developed when a person is accepted by others, seen as an individual, has positive interactions with others, and is not excluded through marginalization, teasing, or bullying. People with ID experience social inclusion in a variety of contexts. They experience social inclusion at work, school, day programs, living accommodations, in community settings, in their family, and at their structured activities. In these various contexts, they experience social inclusion at the infrastructural, interpersonal, and personal levels.

There is a variety of factors that act as facilitators or constraints to social inclusion, depending on if they are present or absent. Factors present in the community include the opportunities available, attitudes and awareness of others, work environment, advocates and volunteers, quality of service providers, and access to information, services, activities, and education. Additional factors that facilitate or constrain social inclusion for people with ID include personal abilities and skills, self-advocacy, transportation, and natural supports they receive from others.

### *The Research Problem*

Young adults with intellectual disabilities (ID) continue to face prejudice and discrimination that limit their social inclusion. As found by McCarthy (2003), “the struggle against overt and covert discrimination continues” (p. 221). People with ID have been segregated from the mainstream of society and will remain segregated as long as they are subjected to prejudice and intolerance (Crane, 2002). Even the participation restrictions imposed by society limit the achievement of typical social roles for young adults with ID (Bigby, Fyffe, & Ozanne, 2007). As found by McCarthy, many people with disabilities argue that discrimination against them is so ingrained in our taken-for-granted assumptions and norms that “its invisibility ranges from mindless personal slights to systemic exclusions” (p. 210).

Though friendships are an important part of social inclusion, young adults with ID generally have limited opportunities to develop and sustain friendships. Though they have a desire for friends, supports are absent and they may not have adequate social skills (Bigby, Fyffe, & Ozanne, 2007). It is difficult for young adults with ID to develop friendships with those without disabilities because people with ID are usually segregated and are often limited to roles that engage them primarily with other people with ID (Lemay, 2006). In a study by Pedlar,

Haworth, Hutchison, Taylor, and Dunn (1999), the participants with disabilities were involved in segregated leisure activities and had few encounters with the world beyond the service system. Participants expressed that they were not happy with a social network that included only people with disabilities.

Young adults with ID are segregated from the rest of society through various activities that are designed specifically for them. Many of them work in sheltered workshops or work activity programs where they are isolated from people without disabilities in jobs that may not even be considered true work (Ainsworth & Baker, 2004). Because of transportation barriers, young adults with ID have also attended segregated camps (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). As found by Keogh, Bernheimer, and Guthrie (2004), many of the recreational and social interactions of young adults with ID have been limited to their families.

Young adults with ID experience limited social inclusion because there are not enough appropriate activities available. Research conducted by Ainsworth and Baker (2004) shows that they have fewer choices of activities. Gaylord and Hayden (1998) found that individuals with ID have limited access to postsecondary education and community involvement. Many young adults with ID are unable to participate in the social and recreational events of a community because they lack supporting friendships, transportation, adequate personal funds, personal assistance, or the knowledge of how to find and navigate recreational activities.

Social integration is an important aspect of life for young adults with ID. They should be able to live like others in the community and fulfill typical social roles (Bigby, Fyffe, & Ozanne, 2007). According to Keith (2002), when people with ID are simply seen as neighbors and coworker, “individuals will experience true integration and be able genuinely to live in community with the broader culture” (p. 234). Parents have been concerned by their young

adult's lack of friends, social isolation, and limited number of appropriate programs and services (Keogh, Bernheimer, & Guthrie, 2004). Lemay (2006) determined that segregation, congregated settings, and social isolation are the main problems that need to be addressed with social inclusion. Despite the increase in the physical presence of people with disabilities, it is evident that real social inclusion is not occurring.

There is a deficiency in the literature concerning the social inclusion of young adults with ID. The findings of the few research studies about their social inclusion are limited to the local contexts in which the participants live. Abbott and McConkey (2006) acknowledged that their findings reflect the local context, which may be different from other regions and countries. Additional studies were also relatively small and thus cannot generalize to a wider population (Chadsey-Rusch, Linneman, & Rylance, 1997; McConkey, Walsh-Gallagher, & Sinclair, 2005; Wistow & Schneider, 2003).

Additional research is needed to understand the social inclusion of young adults with ID and to advocate for change. In spite of the progress that has been made, "the ongoing integration and inclusion of persons with disabilities still has a long way to go" (Jaeger & Bowman, 2005, p. 121). Leaders in the disability community consider access and integration related to all domains of life to be the most evident area of future accomplishment (McCarthy, 2003). It is important to include the social aspects of inclusion in research because previous considerations of disability have focused primarily on physical access (Jaeger & Bowman, 2005). There is also a need to hear the voices of young adults with ID themselves to really understand their current experiences and what can be done to enhance their social inclusion.

Professionals such as service providers and teachers would benefit from knowing the current experiences of young adults with ID and the contexts that limit or enhance their social

inclusion. Young adults with ID as well as family members and friends who advocate for them would also benefit from the information. Advocates may use the information to identify barriers and develop strategies to enhance the social inclusion of individuals or groups of people with ID. They may also use the information to educate community members and influence policies, procedures, and education of individuals with ID.

### *Purpose and Research Questions*

The purpose of the present phenomenological study was to describe the experiences of social inclusion for young adults with intellectual disabilities and to identify factors that limit or enhance their social inclusion. For this study, social inclusion is defined as being involved in activities, developing and maintaining reciprocal relationships, and having a sense of belonging.

### *Central Research Question*

How do young adults with intellectual disabilities (ID) describe their social inclusion?

### *Sub-Questions*

1. What are participants' experiences of social inclusion?
2. What are the contexts in which participants experience social inclusion?
  - A. What factors limit participants' social inclusion?
  - B. What factors enhance participants' social inclusion?

### *Definition of Terms*

*Intellectual disabilities* (ID) "is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18" (AAIDD, 2008). *Adaptive behavior skills* are conceptual, social, and practical skills that people use to function in their everyday lives (AAIDD, 2008).

*Mild intellectual disabilities* are verified if a person has an intelligence quotient test score of 56 to 70 (two to three standard deviations below the mean) and has deficits in adaptive behavior (Nebraska Department of Education, Rule 51, 2006).

*Moderate intellectual disabilities* are verified if a person has an intelligence quotient test score of 41 to 55 (three to four standard deviations below the mean) and has deficits in adaptive behavior (Nebraska Department of Education, Rule 51, 2006).

*Disability* “refers to the personal limitations that are of substantial disadvantage to the individual when attempting to function in society” (AAIDD, 2008).

*Americans with Disabilities Act (ADA)* is a law that prohibits discrimination on the basis of disability in employment, government, public accommodations, transportation, commercial facilities, and telecommunications (Ainsworth & Baker, 2004).

*Individuals with Disabilities Education Act (IDEA)* is a law that asserts full, free, and appropriate rights to educational services for all people with disabilities from birth to age 21 (Ainsworth & Baker, 2004).

*Deinstitutionalization* refers to the reduction in the population of state institutions by moving people with disabilities to alternative placements (Kavanaugh, 2002).

*American Association on Intellectual and Developmental Disabilities (AAIDD)* is a professional organization that “promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities” (AAIDD, 2007).

*People first language* emphasizes the humanity of a person by recognizing the person first and the disability afterwards, such as saying a man *with* intellectual disabilities (McClimens, 2003).



*Social inclusion* for people with disabilities consists of three elements: being involved in the community, maintaining reciprocal relationships, and having a sense of belonging.

Involvement in the community includes the use of community amenities and participation in structured recreation, leisure, church, and volunteer activities. Developing and maintaining reciprocal relationships with family, friends, coworkers, and acquaintances in the community is important for people with disabilities. A sense of belonging is developed when a person is accepted by others, seen as an individual, has positive interactions with others, and is not excluded through marginalization, teasing, or bullying.

*Contexts of social inclusion* refer to where social inclusion is experienced, including work, school, day programs, living accommodations, community settings, family, and structured activities. It also refers to the infrastructural, interpersonal, and personal levels in which social inclusion is experienced.

*Facilitators or constraints to social inclusion* include the opportunities available, the attitudes and awareness of others, the work environment, advocates and volunteers, quality of service providers, and access to information, services, activities, and education. Additional factors include personal abilities and skills, self-advocacy, transportation, and the natural supports they receive from others.

## CHAPTER 2

### REVIEW OF THE LITERATURE

There has been little research focused on the social inclusion of young adults with intellectual disabilities (ID). The majority of the research on social inclusion has concentrated on the physical integration of people with disabilities into school, work, home, and community settings. Of these studies, most describe the experiences of students with various disabilities in their primary and secondary school settings. The research concerning adults with disabilities has been focused on their integration into more inclusive employment settings and residential accommodations. The literature has started to shift from the basic idea of physical integration to a more comprehensive scheme of social inclusion. There are few studies that describe the elements of social inclusion. Most of the current research on the social inclusion of young adults with ID describes their experiences in specific settings and contexts of their experiences. The research describes the contexts that act as barriers as well as contexts that enhance the social inclusion of young adults with ID.

#### *Elements of Social Inclusion*

The elements of social inclusion for young adults with ID identified throughout the literature include their involvement in the community, relationships with others, and sense of belonging. How they experience social inclusion is determined by the contexts in which they live. In different social spaces, young adults with ID have a variety of experiences of inclusion and exclusion: “from avoidance, verbal taunts and physical abuse through to indifference, acceptance and incorporation” (Hall, 2005, p. 108).

*Community involvement.* One element of social inclusion is involvement in the community, consisting of involvement in activities and the use of community amenities.

According to Abbott and McConkey (2006), involvement in the community means having opportunities and using community resources such as having access to facilities, venues, and mainstream services such as doctors and dentists. The availability and cost of transportation is important for adults with ID in accessing community amenities, especially for those whose living accommodations are in more isolated locations.

The type of living accommodation provided for young adults with ID influences their involvement in the community (McConkey, Walsh-Gallagher, & Sinclair, 2005). The move from supported accommodation in the community to living independently in rented or owner-occupied housing was found by Hall (2005) as a key marker of social inclusion. Though having physical integration in the community is an important step, an aim of community involvement of people with ID has been “to become ‘of the community’ rather than to merely reside within it” (Blessing, 2004, p. 190). Wistow and Schneider (2003) also found that physical presence in the community does not necessarily mean social integration.

Social inclusion of young adults with ID includes their involvement in employment opportunities. Factors such as transportation, housing, and education of people with ID influence their employment opportunities and hence their potential for social inclusion (Wistow & Schneider, 2003). Vander Hart (1998) stated that inclusion with non-disabled coworkers in integrated work settings is essential for the social inclusion of adults with ID. Riches and Green (2003) defined social integration “in terms of social participation and involvement with co-workers at the completion of work, at shift changes and through involvement in social activities” (p. 138).

*Developing and sustaining relationships.* Developing and sustaining reciprocal relationships is another element of social inclusion for young adults with ID. Participants with

ID identified meeting and talking to people in the community as an important component of social inclusion (Abbott & McConkey, 2006). They feel like part of the community when they know people to say hello to and when others talk to them. Blessing (2004) emphasized the value of maintaining relationships within the broader community and providing supports for people with ID to increase their community participation. McConkey, Walsh-Gallagher, and Sinclair (2005) identified one aspect of social integration as the person's involvement with their natural families. They found that the involvement with one's family is an important determinate of involvement with the wider community.

Social inclusion also involves developing relationships and having a reciprocal rapport between people with ID and their coworkers (Carrier, 2007; Wistow & Schneider, 2003). Social interaction may include participating in a joking exchange or going out to lunch with others (Butterworth, Hagner, Helm, & Whelley, 2000). According to Vander Hart (1998), appropriate social skills that are accepted at a typical work culture are essential for developing relationships with coworkers. Supported employees with better social skills do not hesitate to greet, ask, or receive work-related assistance from non-disabled coworkers.

*Sense of belonging.* Having a sense of belonging is another element of social inclusion for young adults with ID. In a study by Mactavish, Mahon, and Lutfiyya (2000), the participants with ID viewed social integration as "the sense of belonging that emanated from the sharing of time, activities, and experiences with families and friends--independent of whether these individuals had a disability or not" (§ 47). They also found that the opportunity to enact valued social roles, such as being a paid employee or family member, added to some of the adults' feelings of belonging. The participants in their study identified six themes that contributed to their perceptions of belonging: school/work, structured recreation, friendship, family, valued

social roles, and day program/living situation. Depending on their presence or absence, these themes acted as either facilitators or constraints to their social inclusion.

Young adults with ID develop a sense of belonging when they are accepted by others (Abbott & McConkey, 2006). In a study by Jahoda and Markova (2004), one participant shared that he would like to be accepted more by boys his own age and to participate in activities with people who do not have disabilities. Another participant shared that she did not want to be seen as being ‘stupid’ by others, so she refused to use a ‘disabled’ bus pass. Adults with ID feel like they do not belong when they are neglected, left out of activities, or left out of positive peer interactions (Blessing, 2004). For the participants in Abbott and McConkey’s study, social inclusion meant, “meeting other people in ordinary settings and being treated similarly” (p. 281).

#### *Experiences of Social Inclusion for Young Adults with Intellectual Disabilities*

The social inclusion of young adults with ID is experienced within a wide range of contexts. These contexts include their school, work, day program/living situation, structured recreation, and family (Mactavish, Mahon, & Lutfiyya, 2000). Abbott and McConkey (2006) found that participants with ID had both positive and negative experiences in a variety of contexts. They suggest that social inclusion “is a reality for some but not for all persons, or that it occurred in some settings but not others” (p. 281). The following describes how young adults with ID have experienced social inclusion through their involvement in the community, relationships with others, and sense of belonging as described in the literature.

*Experiences of community involvement.* Many studies have documented the community involvement of young adults with ID, including involvement in activities and use of community amenities. Blessing (2004) discovered that a lack of meaningful activities were among the major concerns of participants with a cognitive disability. In the study, Blessing found that 38% were

involved in educational classes, 37% in employment, and 25% in volunteer activities. Eliason (1998) determined that the participants in institutional and community settings experienced about 4.79 outside events per week and were involved in productive activities for about 110.28 hours per month. McConkey (2007) found that more than three-quarters of the participants in the study accessed pubs, shops, and hairdressers at least monthly.

The social inclusion of people with ID within their local community was found to vary markedly (McConkey, Walsh-Gallagher, & Sinclair, 2005). As described by Hall (2005), some places in the community are known as sites of intimidation and rejection from both customers and staff, and others are known as welcoming to those with ID. Some places have well-developed networks of safe spaces and support for people with ID while there are limited number of resources and weak social networks in other places. The safe spaces and networks are used by people with disabilities to cope with everyday exclusionary experiences and to assert their own needs and identities.

The types of living accommodations available to people with ID influences the extent of their social inclusion as measured by contacts with other persons and use of community amenities (McConkey, 2007). In McConkey's study, people in any form of supported living tended to have greater levels of social inclusion than those in group or residential homes. Also, those living in the community were more likely to use community amenities. Eliason (1998) found that people with ID living in a community setting experienced three and one-half times as many social activities and engaged in more productive activities related to work and school compared to those in institutions. For some people with ID, living independently has been a positive experience though it has been a difficult and exclusionary experience for others (Hall, 2005).

A variety of social inclusion experiences have been described for young adults with ID in the workplace. Riches and Green (2003) described a situation where workers with ID worked along side or nearby other non-disabled workers and used common areas such as lunchrooms and facilities with other employees. They also participated in social activities such as birthdays, special events, and lunches occasionally. Butterworth, Hagner, Helm, and Whelley (2000) documented instances of participation in workplace customs for some participants, but not others. Though Riches and Green (2003) observed a high physical presence of employees with disabilities, many were not participating equally in the workplace.

*Experiences with relationships.* There have been a variety of experiences described in the literature about the relationships of young adults with ID with their friends, family, co-workers, and community members. Abbott and McConkey (2006) found that some people in the community were positive towards people with ID and others did not respond or talk to them. In another study, their lack of social connections or friendships was among the major concerns of people with ID (Blessing, 2004).

Friendships can be relatively superficial at the workplace as observed by Wistow and Schneider (2003). In their study, 40% of the participants with ID did not have a close friend at work. They observed examples of close friendships and socializing, but there were also examples of alienation from their co-workers. Butterworth, Hagner, Helm, and Whelley (2000) observed a variety of experiences from frequent social interactions to no interactions with coworkers. One participant had reciprocal relationships that extended beyond the workplace while another did not have any social or supportive interactions and did not participate in workplace customs. The participants in Riches and Green's study (2003) joked and socialized with other workers on a regular or occasional basis. In another study, 56% had regular contact

with peers throughout the day, 64% rarely interacted with peers outside of work, 34.6% frequently joked with peers, and 43.2% interacted with peers at lunch or on break (Blessing, 2004). Vander Hart (1998) reported that supported employees with mild disabilities had more interactions than those with moderate or severe disabilities. Vander Hart also discovered that many people with ID did not have the opportunities to socialize with their coworkers in natural settings because they were part-time workers and thus did not have lunch or take breaks at work.

Relationships of young adults with ID also depend on their living accommodation. People living in community settings were found to have better social networks and more contact with their family (McConkey, Walsh-Gallagher, & Sinclair, 2005). McConkey (2007) found that participants in clustered schemes had at least one friend outside of the accommodation who they saw regularly, had more contact with their families, and had visitors to their home for coffee or a meal. More participants living in campus settings had family visits and stayed away from home in the past month than those in clustered schemes. McConkey also found that almost 50% of the participants with ID had no friends from outside their home, two-thirds had no visitors to their home in the last month, and two-thirds did not know their neighbors. Some participants were socially isolated, meaning they had no contact with family or friends and were not known by their neighbors. Many participants in Jahoda and Markova's study (2004) wanted the camaraderie of peers with disabilities, but also wanted to "escape from prejudice and discrimination by distancing themselves from their peers" (p. 728).

The relationships of many young adults with ID were confined to the settings in which they were initiated. Because of lack of transportation and other constraints, they seldom had friendships across different situations (Mactavish, Mahon, & Lutfiyya, 2000). The social stigma of disability also prevented people from developing relationships across contexts. For example,



a young adult had a friend from work who would not socialize with him outside of the workplace (Mactavish, Mahon, & Lutfiyya).

*Experiences of belonging.* The literature also describes the sense of belonging experienced by young adults with ID associated with social inclusion. Adults with ID feel like they belong when people talk to them, their coworkers ask them to go out, and they are made to feel important and part of a team at work (Wistow & Schneider, 2003). Participation in workplace customs such as attending outings, being recognized for work accomplishments, and eating with other coworkers also help them feel like they belong (Butterworth, Hagner, Helm, & Whelley, 2000). Young adults with ID do not feel like they belong when they are left out, always on their own, do not feel respected, and have co-workers who are not very friendly (Wistow & Schneider, 2003). The sense of belonging felt by a young adult with ID is affected by the actions and responses of the people around them. According to Yazbeck, McVilly, and Parmenter (2004), “younger people, people with higher educational attainment, and individuals with prior knowledge of people with intellectual disabilities” (p. 106) have the most positive attitudes towards people with ID.

### *Barriers to Social Inclusion*

Young adults with ID have faced many barriers to social inclusion. These barriers are the specific contexts of their experiences and affect their involvement in the community, relationships, and sense of belonging. The following illustrates the barriers to social inclusion for young adults with ID identified in the literature that may occur in any area of their lives. The barriers that relate to the specific elements of social inclusion found in the literature are subsequently presented.

Adults with ID shared that their lack of personal abilities and skills are barriers to their social inclusion (Abbott & McConkey, 2006). These skills may include their lack of self-motivation, lack of knowledge about healthy living, poor literacy and numeracy skills, and poor knowledge of their area. McConkey, Walsh-Gallagher, and Sinclair (2005) determined that people with ID who are more dependent in their self-care are not as involved with their families and community.

The local community has also presented many barriers for young adults with ID. Abbott and McConkey (2006) heard from participants that the location of their home, the lack of accessible and affordable transportation, and having few community activities available were barriers they faced to social inclusion. In the community, they experienced negative attitudes from others, they did not have access to work places, and there were not enough advocacy and volunteer groups. In another study, choices such as job placements were also limited (Wistow & Schneider, 2003).

Young adults with ID experience prejudice and discrimination in the community (Jahoda & Markova, 2004). Some people with ID have been taken advantage of by others (Abbott & McConkey, 2006). The participants in Hall's study (2005) shared that they felt unwelcome in some places. They receive looks, body language, and verbal comments that are intimidating and hurtful. The participants also shared how one of their friends was attacked while walking down the street. According to Hall, physical abuse may be the ultimate form of exclusion.

*Barriers to community involvement.* Young adults with ID have experienced many barriers in their involvement in activities and use of community amenities. McConkey, Walsh-Gallagher, and Sinclair (2005) discovered that participants who were more dependent had a lack of involvement in the community. Abbott and McConkey (2006) found that adults with ID

needed more accessible transportation, more voluntary work opportunities, and more social venues close to home. Wistow and Schneider (2003) learned that all the jobs for adults with ID in their study consisted of low wages, low skill levels, and little job security. Hall (2005) also observed verbal and non-verbal intimidation and lack of career development in the workplace. The supposedly inclusive space of employment had become a place of discriminatory attitudes and processes for some participants.

Service providers have also acted as barriers to community involvement. Adults with ID in Abbott and McConkey's (2006) study shared that they are not treated as an adult, are not allowed to go out alone, are short staffed, and do not have enough one-to-one staff time. Support staff also may have lacked the expertise and experience in teaching others to acquire new skills. Chadsey-Rusch, Linneman, and Rylance (1997) found that not having enough resources such as time, money, and staff was a major barrier of social inclusion.

*Barriers to relationships.* Young adults with ID face many barriers to developing relationships and having positive social interactions. At the workplace, Butterworth, Hagner, Helm, and Whelley (2000) observed that one participant had limited proximity to coworkers and supportive interactions from the manager. Another participant had limited social interactions because of the duties of the job. In a few cases, Carrier (2007) observed coworkers who avoided a person with ID because she had difficulty speaking as well as coworkers who were just intolerant of people with ID. McConkey (2007) discovered that more able people living in dispersed community settings were more socially isolated. This may be related to lack of contact with peers as well as their personal challenges with social skills.

*Barriers to belonging.* Additional barriers limit the sense of belonging for young adults with ID. People will make fun of them, ignore them, single them out due to their disability, and

talk to staff instead of talking to them (Abbott & McConkey, 2006). People with ID know that they are seen as out of place in some situations (Hall, 2005). Jahoda and Markova (2004) discovered that the participants were concerned with their lack of social acceptance. They had to cope with the social stigma of having a disability in their everyday lives.

### *Enhancing Social Inclusion*

Research studies have identified contexts that enhance the social inclusion of young adults with ID. The contexts they describe are from their observations, suggestions from the adults themselves, and ideas derived from the research findings. The contexts that enhance the social inclusion of young adults with ID in any area of their lives are provided below followed by the contexts that specifically enhance their involvement in the community, relationships, and sense of belonging.

The opportunities for social inclusion are related to the quality of support for young adults with ID (Blessing, 2004). Families are important providers of opportunities for social inclusion for some individuals with ID (Mactavish, Mahon, & Lutfiyya, 2000). Coworkers may assist them by establishing reciprocal rapport, emphasizing their positive aspects, and providing continued adjustments to support them (Carrier, 2007). Service providers also need to embrace a support rather than a caring role and become aware of training opportunities for young adults with ID to further their education or prepare them for additional opportunities (Abbott & McConkey, 2006). Young adults with ID reported that they need to be listened to by staff and managers, to have more staff available, to have current information on community opportunities, and to be enabled to live independently (Abbott & McConkey).

To enhance their social inclusion, young adults with ID need to continually improve their personal abilities and skills. To accomplish this, they need access to appropriate skills training,

information on healthy living, and encouragement from staff to socialize (Abbott & McConkey, 2006). Riches and Green (2003) determined that having appropriate social behaviors were also considered critical for successful integration in the workplace. These behaviors include dressing appropriately, behaving in a manner appropriate to the workplace, and participating in conversation. Hall (2005) identified that having opportunities to self-advocate and to advocate for others also enhances the social inclusion of young adults with ID.

*Enhancing community involvement.* To enhance the social inclusion of young adults with ID, researchers have identified ways to increase their involvement in activities and use of community amenities. Abbott and McConkey (2006) discovered that moving to less restrictive living accommodations, such as supported living schemes, has increased the opportunities of social inclusion for many people with ID. Participants reported that they are given a lot of freedom and assistance through supported living and are also close to the places they want to go. In a study by Hall (2005), young adults with ID living in a group home benefitted from the nurturing community of friends they live with and the additional support given to them from staff. Blessing (2004) indicated that service providers need to have a range of options available to meet the individual needs of each client.

To enhance the use of community amenities, adults with ID identified that they need information provided on activities and events in an accessible format, more volunteers to accompany individuals, education of the community, and increased use of existing facilities and activities (Abbott & McConkey, 2006). Social inclusion can also be enhanced by teaching and allowing them to use public transportation and have free/affordable/accessible transportation options (Abbott & McConkey). It is also important to provide both community and facility-based options for the productive activities of people with ID in order to meet their individual

needs (Blessing, 2004). Having living accommodations in the community appears to be a necessary condition for social inclusion to occur, though merely locating people in ordinary housing is not sufficient to ensure their social inclusion (Eliason, 1998; McConkey, Walsh-Gallagher, & Sinclair, 2005).

At the workplace, planned and informal training as well as supportive interactions have increased the social inclusion of young adults with ID (Butterworth, Hagner, Helm, & Whelley, 2000). Supportive interactions included reminders of appropriate behavior and coaching on social skills. Worksites with high levels of inclusion had multiple context relationships, specific social opportunities, interdependent job designs, and a personal and team-building management style. Wistow and Schneider (2003) found that people with ID need greater opportunities to work, greater choice in the type of work, opportunities for training and career progression, continued support at work when required, and an increased understanding on the part of employers and their coworkers to enhance their social inclusion. Butterworth, Hagner, Helm, and Whelley (2000) determined that an employment consultant could enhance the social inclusion of young adults with ID. The consultant can support social relationships, ensure access to social opportunities, and provide instruction and coaching on the social norms of the workplace. A job coach or the person's coworkers can also provide similar support to enhance their social inclusion by making accommodations or improving their social relationships (Carrier, 2007).

The young adults with ID who are most likely to use community amenities are those with higher social competence (McConkey, 2007). People with ID have identified their need to acquire the knowledge and competence needed to become an active participant in the community (Abbott & McConkey, 2006). Those who have the knowledge and skills to advocate for

themselves and others are more able to achieve greater social inclusion (Hall, 2005).

*Enhancing relationships.* Developing and maintaining reciprocal relationships enhances the social inclusion of young adults with ID. McConkey (2007) determined that social competence was a significant predictor of friendships. Riches and Green (2003) suggest that staff and management encourage and facilitate informal interactions on an ongoing basis. They believe that acceptance will only be gained when people with ID blend into their workplace in terms of dress and behavior. The location and types of activities should be taken into account to provide more opportunities for people with ID to develop stronger relationships (Eliason, 1998). The type of living accommodation may also influence the development of relationships. McConkey (2007) discovered that those who lived in supported living accommodations around others with disabilities were likely to have more visitors to their home compared to those living in campus settings.

Relationships developed at work are important for young adults with ID. Butterworth, Hagner, Helm, and Whelley (2000) found that people with ID developed relationships that crossed over life areas or contexts at worksites with high levels of interaction and support. Relationships were also supported by managers who implemented strategies to build teamwork and who worked side by side with employees. Additional informal social interaction skills need to be encouraged to enable those with disabilities to socialize appropriately at the workplace (Riches & Green, 2003). Vander Hart (1998) discovered that more personal interactions occurred between adults with ID and their coworkers the longer they were employed and the better their social skills were.

*Enhancing a sense of belonging.* Social inclusion for young adults with ID is enhanced by their sense of belonging. To develop a sense of belonging, a change in attitudes is needed

from people in the community to counter the bullying that some people experience and to create a welcoming community (Abbott & McConkey, 2006). Awareness raising is needed in communities where people with ID live and yet still feel separated (Hall, 2005). Some people with ID believe that they would have to break away from their stigmatized past of living in an institution or working in a sheltered workshop to achieve acceptance in the wider community (Jahoda & Markova, 2004). When community members have personal contact with someone who has ID, Yazbeck, McVilly, and Paramenter (2004) discovered that they tend to have lower misconceptions and more positive attitudes about other people with ID. They determined that policies and strategies are needed to bring people with and without disabilities together and to promote an appreciation of the competence of people with ID.

#### *Outcomes of Social Inclusion*

An increase of social inclusion for young adults with ID affects their lives as well as the community in which they live. Having a greater public presence can be seen as an assertion of a positive identity as well as a community that is opening up to its diversity. It could also be seen as a temporary movement in a community where people with ID continue to live separately (Hall, 2005). Riches and Green (2003) observed that direct experience with employees with ID had a positive effect on the attitudes of supervisors and coworkers. They also found that “while attitudes have progressed, practical applications are still wanting” (p. 139). When people with ID are accepted into the workplace, Wistow and Schneider (2003) determined that high levels of reward and satisfaction are expected. Eliason (1998) also discovered that young adults with ID tend to experience increased satisfaction when they are involved in activities that facilitate social inclusion in the community. The satisfaction they receive is an important component of their overall quality of life.



### *Advocating for Change*

Research has determined that change is needed to increase the social inclusion of young adults with ID. For these young adults, “the desire to do more or different activities continues” (Blessing, 2004, p. 191). According to Hall (2005), the focus of social inclusion should switch to “a broader restructuring of how work and housing are socially and spatially organized” as well as institutional reform and equality law. Strategies for facilitating the inclusion of supported employees into work settings are needed (Vander Hart, 1998). Ongoing work is also needed for people with ID to realize full participation in activities and social integration (Blessing).

People who advocate for and work with young adults with ID view social inclusion outcomes in different ways, which could interfere with their achievement of social inclusion. Chadsey-Rusch, Linneman, and Rylance (1997) believe that the individuals with disabilities should make the final decision on the desired outcomes. Abbott and McConkey (2006) emphasize the contribution these individuals could make to planning local services. Their study “demonstrated that individuals with intellectual disabilities were able to identify the barriers they had experienced to social inclusion and they could articulate ways of reducing or removing them” (p. 283).

### *Summary*

Social inclusion for young adults with ID consists of being involved in the community, developing relationships, and having a sense of belonging. The literature describes the experiences of social inclusion for participants with ID as well as factors that limit and enhance their social inclusion. Factors that limit or enhance their social inclusion include their own abilities and skills, transportation, opportunities available, the quality of supports, accessible information, and the attitudes of others. When young adults with ID experienced greater social

inclusion, they also experienced greater satisfaction and quality of life. Young adults with ID have a desire to be more involved in activities, have more friends, and feel like they belong. It is important for people to hear their voices, understand their experiences, and advocate for change to increase the social inclusion of young adults with ID.

There are gaps in the literature concerning the social inclusion of young adults with ID as revealed in this literature review. There are few studies that focus on the social inclusion experiences of individuals with ID who are young adults. Most of the studies reflect the local contexts in which the participants live and cannot be generalized due to the small number of participants. There is also a lack of research conducted directly with young adults with ID in order to obtain their perspectives. The present research study adds to the literature by expanding on the experiences of young adults with ID in the Midwest and providing them with a voice. Therefore, the purpose of my research is to describe the experiences of social inclusion for young adults with ID and to identify factors that limit and enhance their social inclusion.

## CHAPTER 3

### RESEARCH METHODS

I used the qualitative research design to explore the lived experiences of social inclusion for young adults with intellectual disabilities (ID). Pugach (2001) explained that qualitative research has the strength to advocate for and address disability-related issues by giving a voice to those who have been marginalized. Creswell (2007) determined that the qualitative design is emergent to allow the researcher to make changes to better address the research. The design includes “the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action” (Creswell, p 37). Hatch (2002) described the objects of study in qualitative research as “the lived experiences of real people in real settings” (p. 6). The participants are seen as the experts and their perspectives are central to understand the phenomenon. The stories of the participants are anchored in real, local meaning and experience (Pugach). McCarthy (2003) reported the change in attitudes concerning people with disabilities will occur mainly through exposure to the voices and visions of individuals.

#### *Phenomenology*

Phenomenology is the best qualitative research design to understand the experience of social inclusion for young adults with ID. A phenomenology describes the meaning of several individuals’ lived experiences of a phenomenon (Creswell, 2007). It seeks to reveal more fully the essences and meanings of human experience (Moustakas, 1994). Long interviews are the most common form of data collection in a phenomenological study (Moustakas). The researcher and participant work together to construct the meaning of the participant’s experiences. Phenomenological data analysis consists of bracketing one’s own thoughts and experiences,

selecting significant statements from the data, developing meaning units and themes, and writing textual descriptions, structural descriptions, and the essence (Moustakas, 1994; Creswell, 2007).

The researcher reports how the participants experience the phenomenon differently through detailed descriptions in the themes and presents the common elements of their experience in the essence. The essence is presented to enrich and clarify our knowledge and experience of everyday situations, events, and relationships (Moustakas, 1994). The findings in a phenomenology also provide a voice for the participants.

### *Instrument Development*

To design the interview protocol for the present study, I used the findings of a qualitative meta-analysis research study by Hall (2009) about the social inclusion of people with disabilities. Hall's study found that social inclusion consisted of three elements: being involved in activities, maintaining reciprocal relationships, and having a sense of belonging. Involvement in activities included the use of community amenities as well as involvement in structured recreation, leisure, church, and volunteer opportunities. Developing and maintaining reciprocal relationships was important with family, friends, coworkers, and acquaintances in the community. A sense of belonging was experienced when the person was accepted by others, seen as an individual, had positive interactions with others, and was not excluded through marginalization, teasing, or bullying.

I used the elements of social inclusion that emerged in Hall's (2009) study to create the three main sections of the interview protocol (see Appendix A). The protocol began with the most concrete concepts and built to the more abstract concepts in order to allow the interview to flow more smoothly and provide participants with a reference to describe their experiences. Hall's meta-analysis also found that people with disabilities experienced social inclusion in a

variety of contexts such as work, school, day programs, living accommodations, in community settings, in their family, and at their structured activities. I created probing questions from the context of social inclusion to elicit more in-depth information.

Through pilot testing and expert review, I adapted the interview questions and procedures to accommodate young adults with mild or moderate ID. I interviewed a young woman about 20 years old and a young man about 18 years old who both had moderate ID. The young adults voluntarily agreed to do the interviews, and permission was granted by a parent and their summer school coordinator. I conducted the pilot interviews with each young adult separately in a quiet room at their school. The interviews lasted about 45 minutes each. We discussed each section of the protocol to check for the accuracy of the questions and reviewed the informed consent form to check for understanding. I also met with two professionals in the field of disability to discuss and obtain feedback about the interview protocol and procedures. Afterwards, I added additional probing questions to ask about the different types of activities in which the adults may be involved. To increase the accuracy of the findings, I rephrased the questions about what limits or enhances their involvement in activities and the section on their sense of belonging. I also determined that the data collection would consist of interview sessions with each participant on two consecutive days when needed to allow the participant to provide more in-depth information in shorter interview sessions.

### *Purposeful Sampling*

Purposeful sampling is used in qualitative research to select information-rich cases for in-depth study (Patton, 2002). Mactavish, Mahon, and Lutfiyya (2000) emphasized that when conducting research about the social inclusion of people with ID, the research must include the individuals with ID to fully understand their social inclusion. The participants are seen as

experts in their own right (Knox, Mok, & Parmenter, 2000) and their voices need to be heard. Criterion sampling was the purposeful sampling technique I used in the present study. Criterion sampling is used to study cases that meet a predetermined criterion of importance (Patton, 2002). For the purpose of the present study, the participants had to be from 21 to 35 years old and have an intellectual disability. They also needed to have verbal communication skills sufficient to provide in-depth information about their thoughts and experiences of social inclusion. As defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in 2008, an intellectual disability (ID) originates before the age of 18 and is characterized by significant limitations in intellectual functioning and in adaptive behavior. Adaptive behavior refers to the conceptual, social, and practical skills used in everyday life. To be verified as having a mild ID, a person must have an intelligence quotient test score of 56-70, or in the range of two to three standard deviations below the mean. To be verified as having a moderate ID, a person must have an intelligence quotient test score of 41-55, or in the range of three to four standard deviations below the mean (NDE Rule 51, 2006).

Fourteen young adults with mild or moderate ID participated in the present study (see Appendix B). The age of the participants ranged from 22 to 35 years. Four participants had a legal guardian and ten were their own legal guardian. The participants were clients of a cooperating service provider, which provided vocational, residential, and day services for people with developmental disabilities. Directors of the cooperating service provider identified potential participants who fit the criteria of the study. They talked to potential participants about the study to ensure they understood the study and that they were comfortable and willing to participate. I then called each participant to introduce myself, describe the study, ask if he/she would like to participate, and set a time to meet for the interview. The service provider

contacted the legal guardians of participants and determined if they were interested in allowing their young adult to participate in the present study.

### *Obtaining Permissions*

I obtained approval from the University of Nebraska-Lincoln Institutional Review Board to conduct this study. I gained access to participants and scheduled interviews through their cooperating service provider. I also received signed informed consent forms from the participants and legal guardians (see Appendices C and D). When I met with each participant, I shared the purpose of the study, his/her role as a participant, and how the data would be used. I considered each participant's informed consent as a process rather than an initial agreement (Knox, Mok, & Parmenter, 2000). Participants with emotional/behavior disabilities in Jones's (2007) study, for example, expressed unwillingness to participate by not responding to questions through passive-aggression or by shouting obscenities. During the interviews, I observed the participants to see if they were still willing participants.

Legal guardians must provide permission to allow their young adult to participate in research if the participant is not his/her own legal guardian. Legal guardians advocate for and make decisions on behalf of their young adults for all or a limited number of the persons' personal needs. I sent each interested legal guardian an invitation letter (see Appendix E) and an informed consent form to allow their young adult with ID to participate in the present study. I contacted the potential participants only after I had received the signed informed consent form from their legal guardian.

### *Data Collection*

I collected data through semi-structured interviews. During the interviews, I asked the participants open-ended questions about their experiences of social inclusion and the context of

their experiences. This approach provided structure and created a relaxed, conversational setting (Mactavish, Mahon, & Lutfiyya, 2000). The interviews were held at locations convenient and comfortable for each participant. I met with participants at various locations such as their house or apartment, a public library, a coffee shop, and their service provider. The length of each interview session was flexible to accommodate the needs of the participants and ranged from 30 minutes to 1 hour and 15 minutes. I completed ten of the interviews in one session and four of the interviews in two sessions. When I met with participants for the second interview session, I reviewed the content of the previous session to check for accuracy and gather more in-depth information. I made an effort to develop rapport with each participant throughout the interviews by showing interest in their stories and creating a relaxed conversational environment. Rapport is seen as establishing an atmosphere where the participant feels comfortable discussing issues of relevance to the interview (Knox, Mak, & Parmenter, 2000). Mactavish, Mahon, and Lutfiyya (2000) discovered that multiple contacts with participants with ID facilitate the building of rapport. I audio-recorded and transcribed the interviews. After I completed the transcriptions, I erased the voice recordings and stored the transcriptions in a secure file cabinet.

### *Ethical Considerations*

To protect the anonymity of the participants and the confidentiality of the data, I assigned pseudonyms to any names mentioned in the interviews and used general terms in place of the service provider and other specific organizations. I also used people-first language to show respect for individuals with disabilities. To maintain the necessary ethical standards, I provided participants with the full disclosure of the nature, purpose, and requirements of the research study (Moustakas, 1994). I also viewed informed consent as a process (Jones, 2007). The participants were willing and seemed eager to participate in the present study. When two of the



participants became tired during the interview and did not seem as interested in providing full descriptions to questions, I decided to conclude the first session and met with them the next day.

### *Field Issues*

The field issues in the present study related to the interviews. Creswell (2007) found: “Challenges in qualitative interviewing often focus on the mechanics of conducting the interview” (p 140). The quality of each interview depended on the ability of the participant to understand the questions, communicate clearly, and provide in-depth information. It also depended on my ability to state the questions in an understandable format and provide appropriate probing questions. Some participants provided more in-depth descriptions and shared examples to describe their experiences, but others had trouble describing examples of their experiences and gave short answers to my questions. A few of them would answer my questions using only a few words or one sentence. It was also difficult for some of the participants to identify what limited or enhanced their social inclusion. Though I did not have as many examples or stories from these participants, I was still able to get a good picture of their social inclusion through probing questions. I thought developing rapport with participants could be an issue, but the participants in the present study were open and willing to share their lives and experiences with me. Many of them also encouraged me to contact them if I had any further questions for them.

### *Data Analysis*

Qualitative data analysis is an inductive process that establishes patterns or themes that emerge from the data. It consists of organizing the data, reducing the data into themes through a process of coding, and representing the data in figures, tables, or a discussion (Creswell, 2007). It is an interpretative process that allows the researcher to make personal assessments (Creswell,

2008). I analyzed the data following the phenomenological method Moustakas (1994) described. I first bracketed my own perspectives to set aside my biases and become open to new ideas. I used the qualitative data analysis software MAXqda2 to assist in organizing the data. From the transcripts, I selected significant statements relevant to the experience of social inclusion. Next, I collapsed the significant statements into groups of meaning units and further into themes. From the themes and significant statements, I used textural and structural descriptions of the participants' experiences of social inclusion to construct a description of the essence of their experiences.

#### *Validation Procedures*

Validation in qualitative research is the process of assessing the accuracy of the findings (Creswell, 2007). To increase the accuracy of the findings, I used member checking. Member checking is used when the findings are brought back to at least one of the participants to check for the accuracy and credibility of the account (Creswell, 2007; Lincoln & Guba, 1985). I reviewed the content of the first interview session with four participants at the beginning of their second interview session to check for accuracy, ask questions, and allow the participants to provide additional information.

## CHAPTER 4

### PARTICIPANT VIGNETTES

James was 24 years old and shared a house with three roommates. The house had bigger doors to accommodate wheelchairs, which he used, but the kitchen was not accessible enough for him to use independently. He attended his service provider's day program where he worked on his website and practiced life skills. He took a leadership class that he planned to teach, and studied to become a minister. James and his new fiancé, who he still accidentally calls his girlfriend, were making preparations for his wedding. He was his own legal guardian who received assistance from his mother and service provider.

Darren was 32 years old, his own legal guardian, and lived in an apartment with one roommate and staff who came in the evenings and on weekends. He worked part-time at a grocery store and either walked or used the city bus for his main transportation. Darren enjoyed going to his social group for people with disabilities and playing sports with his friends.

Mark was a 35-year-old artist who enjoyed painting. His mother was his legal guardian, and he lived in an apartment with one roommate that was next to many apartments owned by his residential service provider. Mark had a visual impairment and listened to books on CD. He was expressive in his story-telling and enjoyed sharing his experiences. Since he could not drive, staff from his service provider picked him up twice a week to run errands and work out at the YMCA with his roommate.

Shannon was 32 years old and her own legal guardian. She lived with her mother and brother. She liked to be efficient, organized, and have her space. She was very clear in what she did and did not like and could be brutally honest. She valued her friendships with staff members who drove her to the day program, her job sites, and to places in the community on specific

evenings. At the day program, she completed office work, traveled to her job sites, and played games in the afternoon if she had time.

Daniel was 32 years old and lived in an apartment on his own. He had staff support two evenings a week and his parents were his legal guardians. He worked at a gas station and volunteered at a thrift store. Daniel was involved in an advocacy group for people who have disabilities. He also enjoyed bowling, attending the social group for people with disabilities, and even making latch hook rugs that he gave away at Christmas.

Kara was 22 years old and her own legal guardian. She lived with her parents and worked at a grocery store. Kara volunteers to bring people to chapel at a day program for older adults. Each week, she scheduled a van to take her to the library and to work. She enjoyed going to church and spending time with her boyfriend on the weekend.

Rachel was 28 years old and lived with her parents and sister who had severe disabilities. She used a wheelchair and was her own legal guardian. One day a week, she folded boxes for two hours at a pizza restaurant. She was also working on vocational and life skills with her job coach twice a week. It was difficult for her to meet people, participate in activities, and use community amenities because she did not drive and lived outside of town.

Joe was 23 years old and lived in a small town with his parents who were his legal guardians. He worked in a high school cafeteria, mainly cleaning dishes, and was taking a college class to reach towards his goal of becoming an elementary para-educator. His job coach helped him study for college and took him places to get out in the community. Every Friday, his friend, who used to be his personal staff, picks up him and his friends so they can hang out.

Stacy was 32 years old and her own legal guardian. She lived with a supporting family who acted like an extended family so she would have the support she needed until she was able

to move to her own apartment. She worked part-time at a sandwich restaurant, where she had been for nine years. She enjoyed seeing her friends at the social club, spending time with her boyfriend, bowling, and making crafts. She was also involved in an advocacy group for people with disabilities and was passionate about the rights of people with disabilities.

Jessie was 27 years old and lived with a supporting family who taught her daily living and problem-solving skills to prepare her to live on her own. She enjoyed spending time with them and playing video games. Jessie was taking general college classes and working on her basic skills so she can pursue a career in the health field. She was applying for jobs with the assistance of her job coach. She was involved in the Special Olympics and loved to keep physically active. Her parents are her legal guardians and she occasionally drove about an hour to visit them as well as her brother.

Barbara was 24 years old and her own legal guardian. She lived with her parents and had staff from her service provider work with her three evenings a week. They worked on laundry, cooking, and budgeting and also went to plays, the mall, and fairs. Her job coach was teaching her how to use the city bus for transportation. She worked part-time at a fast-food restaurant and volunteered once a week cleaning at a non-profit thrift store.

Dustin was 29 years old and his own legal guardian. He lived in an apartment on his own and had residential staff support in the evenings and on weekends. He considered his personal staff his friends. They supported him in his leisure activities and went with him on his vacations. Dustin went to a vocational workshop where his reception duties were cut and he just filled vending machines. He had fun talking and joking with people at the workshop. He met his girlfriend at the workshop and enjoyed taking her on their first date.

Alec was 22 years old and his own legal guardian. He lived with his parents in a small town and drove to a nearby town to work, go to church, and participate in Special Olympics. He worked part-time as a department store freight worker and provided respite services for a man with disabilities. He loved working with computers and became involved in running PowerPoints for his church's worship music. His main hobby is filmmaking.

Yesenia was 28 years old and her own legal guardian. She lived with her mom and step-dad and drove her own car. She was a public school bus para and provided respite services for people with disabilities. In the summer, she provided childcare and worked at a summer camp for children with disabilities. She enjoyed her dart league, Special Olympics, and spending time with her boyfriend on the weekends.

## CHAPTER 5

### FINDINGS

The findings of the study describe the experiences of social inclusion for young adults with intellectual disabilities (ID). Seven themes emerged from the data: work and volunteer; social, recreational, and leisure activities; reciprocal relationships; accepting environments; self-determination; living accommodations and transportation; and personal skills and resources (see Appendix F).

#### *Work and Volunteer*

The young adults with ID were employed in a variety of positions. Mark, Darren, and Kara worked at grocery stores and sacked groceries. Kara worked at the grocery store between three to four days a week. Her schedule was different each week and she worked on any day except Sunday. She explained: “I’m not going to work on Sundays. I go to church on Sundays.” When asked if she liked her work, she quickly replied: “Yeah, I love that.” Mark described his job: “The technical term was Courtesy Clerk. I was basically a sacker. I took people’s groceries out to their cars for them, you know, talked to them a little bit.” After a while, Mark needed to find another job that would accommodate his summer allergies and visual impairment: “my eyes just couldn’t take that any longer.” He also shared at his grocery store: “People are just whizzing through the stop signs right in front of the store,” and joked, “Why am I not getting hazard pay when I’m in serious danger of getting run over by a car?” Mark switched from sacking groceries to working with children: “I started working at daycare facilities around town.” He enjoyed his time with them: “They’re a lot of fun, especially when they haven’t quite learned tact...when they’re brutally honest.” He worked with the children and noticed when they were about to do something they should not: “I would just lean over towards them and say, ‘Don’t even bother.

I've tried it myself and trust me, it doesn't work.'” Looking back at his work in daycare, he shared: “In retrospect it was fun while it lasted. It just didn't seem to last very long. Either I was getting laid off or I didn't get along with my boss.” Finally, Mark became an artist who did commissions and art shows. While I talked with him, I saw many paintings in the back room of his apartment. Pointing to a group of finished paintings, he shared: “I do try to sell some of these whenever I get the chance.” He added: “I also do commissions. I've got a relatively large commission coming up.” Mark described an elaborate scene he was planning to paint in a little girl's bedroom with a meadow and castle. Though it was more like a hobby, he found something he really enjoyed.

Shannon worked at a pizza restaurant in the mornings: “I do my boxes and windows and napkin holders and that's pretty much it.” A staff member drove here to work and back to her day program each day. Shannon added: “I like getting out and going to my work.” Rachel also folded boxes at a pizza restaurant, but she worked for only two hours a week. She explained: “Because that's apparently all I can do. I would like more responsibility, but right now I don't think they need it.” She had asked for more responsibility at the restaurant, but they did not have additional jobs for her and as she stated: “Everybody's been getting laid off lately.” Stacy worked at a fast-food sandwich restaurant where she prepared ingredients, assembled sandwiches, unloaded the delivery trucks, and cleaned. She was willing to do extra tasks to assist her manager like getting the mail and preparing for the day: “Sometimes when I get in there before my shift starts, I talk to my manager and if she needs me to do something, like make coffee...I'll climb up to get a couple packets down and make coffee.” She has worked for her manager for many years: “Been there nine years. It doesn't feel like it's been that long, but it has.” Even though she was able to do everything but work the cash register, she only worked



four to five hours a day. Stacy shared: “Usually I’m there for so little a time that I don’t get a break and then work more. We just get everything done and then go, go, go.”

Alec was a freight worker at a department store and provided part-time respite care for a man with disabilities. At the department store, he shared: “I was technically hired as a freight worker so I basically unload trucks, put the cardboard in the cardboard recycler, and other things that need to be done...bring each box of merchandise in its correct zone palate...and we’ll go to the sales floor and get out as much merchandise as we can.” Alec described his work hours: “No one who does truck is full time, except the supervisors...We do have break times, but it depends on how many hours we’re working.” Alec had another part-time job working in respite care after his work at the department store was done: “it’s basically supervision, making sure the client is able to do things independently.” He supervised a man with disabilities five days a week for about two to two and a half hours a day: “I go to his house. Once in a while he will want to break away, and as long as he has money and gets everything he needs to get done first, we may head over to the mall or other places.” Yesenia provided respite care for people with disabilities as well. On days there was no school, she worked with an 11-year-old boy who lived in her neighborhood. For example, she shared: “I just had him for the whole week that we were out for spring break in March.” She also worked with Amy who was the same age as her: “She just can’t stay home all by herself, so she has to have somebody with her.” Yesenia shared: “She usually comes to the bar with us...she’s really fun to be with.” She also worked part-time as a school bus para-educator. She enjoyed working there for many years: “It will be nine years next month.” While she was participating in her high school’s transition program for students 18 to 21 years old in special education, she filled out an application for the job: “They actually hired me when I was still in school. I would get on the bus after school.” In the summer when she

was not working as a bus para-educator, Yesenia spent four weeks working at a camp for children with disabilities and provided additional childcare for people she knew. At the day camp, she described: “We take the kids swimming, on field trips, and do arts and crafts with them.” Joe worked at a school cafeteria: “I have to fill up the Power Aid machines and the silverware, but thank goodness we don’t have knives yet.” Joe did not want to wash dishes his whole life, so began taking college courses to become an elementary para-educator. He was taking an online college course and received tutoring assistance from his job coach. Jessie was also taking classes to work on her math and reading skills so she could qualify for college level coursework. None of the participants worked full-time, though many had two jobs or volunteered in addition to their paid employment.

Three of the participants attended a day program organized by their service provider. When they were at the day program, they worked on job skills, practiced independent living skills, played games, and went out in the community. Dustin attended a day program that focused on vocational work experiences. He used to do reception work when it was available such as “answering phones, shredding, filing stuff, sorting.” After a while, the number of responsibilities he had decreased though he was still supposed to stay there from nine to three o’clock each day. He explained: “Much of what I’m doing now is doing vending machines.” He was worried and shared: “I’m not going to be able to handle it as far as my finances.” Dustin talked with his personal staff about his situation: “He thinks I’m going to have to do something different and that’s what it looks like, so I don’t disagree with him...I might even have to look for somewhere else as far as not even work there anymore, which I hate to have to do.” James attended a different day program that focused on life enrichment, which included getting out in the community in groups, learning life skills through individualized programs, participating in

leisure activities, and possibly practicing minimal vocational skills. With his day program, he explained, “I sometimes go out in the community. Sometimes I just stay here and work.” The program’s site had offices, space to store personal belongings, and multipurpose rooms for working, eating, and participating in leisure activities alongside a number of other clients. James worked on programs individualized to his specific needs in order to become more independent, including his safety, calendar, and money programs. He worked on each program until he learned the skills and information well. James determined that he was about finished with the calendar program because, as he explained: “I pretty much know my days of the week and stuff like that.” James also worked on the computer to develop and update his website on the Internet: “I have a website and that website is basically my prayer site...I’m the host of it.” He had business cards to hand out with the website for his online prayer group and his contact information. Shannon went to a day program similar to the program James attended. Staff at her day program drove her to her work and volunteer sites in the mornings. At the day program she would “play games and in the afternoon, just do my own paperwork,” which was office work given to her by the staff. She became irritated when the other clients stared at her and were noisy: “I just don’t like being here, all that screaming and yelling.” Shannon added: “I don’t like to eat lunch with all the crowd in there...I don’t like people staring at me while I’m having lunch. That’s irritating. Kids will make scenes and stuff.” She preferred to eat by herself at a different time and work alone.

Volunteering was a part of life for many young adults with ID. Their volunteer activities included working at an animal shelter, painting a backdrop for a church play, cleaning for a non-profit, delivering mail at a hospital, and cleaning at a thrift store. Barbara volunteered for a non-profit warehouse and store: “I just clean bathrooms and sweep and dust.” Daniel volunteered at

a nursing home and provided assistance to his grandparents when he could. He described his work at the nursing home: “I help with people that are elderly, like take them on walks and playing bingo with them...I really enjoy it.” He also updated their medical charts by “marking people when they do their activities there.” On Wednesdays, Daniel volunteered at a thrift store that was established by his service provider to provide vocational opportunities for adults with disabilities. When I asked if he liked the work there, he replied: “I love it.” Kara also volunteered with elderly community members. She described that her main volunteer job was to “bring people to chapel and back to their rooms.” In the past, Jessie had volunteered at an animal shelter: “I played with the dogs, I walked them, I cleaned their bowls, cleaned their toys, just cleaned up after them.” To make sure the dogs were well cared for, she “put some blankets in with the puppies or some of the dogs to just make them a little more comfortable...They get them to be as comfortable as possible so they’re not so scared.” Yesenia supervised and played with kids who have disabilities at their social group on Tuesday nights. She also volunteered to assist individuals on a Special Olympics team with track, basketball, and volleyball.

Some participants held leadership positions in their volunteer activities. Barbara was on her residential service provider’s safety committee where she would “go to people’s houses to make sure they have all of their supplies or if they’re safe.” Stacy and Daniel served on a council for people with developmental disabilities, which worked on advocacy, awareness, and provided input about policies affecting people with disabilities. For example, Stacy shared: “If the legislature needs help on phrasing, like passing some bills, they’ll get our input on it.” Daniel participated in many of the activities of the council such as lunches, developmental disability awareness, and proclamation signing at the state capital. They wanted to increase advocacy efforts for people with disabilities and encourage their participation in leadership

activities to have their voice heard. Stacy explained: “We were teaching other people with disabilities that they have a right to get out there and sit on a board and have their voice heard because the people without disabilities don’t have to make up the person with disabilities’ mind.” It was important for her that “people without disabilities understand where people with disabilities are coming from and kind of get on their level.” Stacy was passionate about the work of the council: “That is one of the best things that I’ve helped to do.”

Many young adults with ID benefitted from the assistance of a job coach who taught vocational skills, assisted them in applying and interviewing for a job, and provided the necessary support so they are able to keep a job. Their services were broad enough to fit the individual needs of the person. Mark described the responsibilities of a job coach: “if someone is having difficulty learning the job, whatever that job may be, then they try to help out the person and eventually they try to get to the point where the person needs them less and less so they can just kind of fade away and eventually don’t need to be there for the person to do their job and do it well.” He added: “A job coach is also involved in helping locate a job so if you want the job coach there at the interview to make sure there’s no misunderstanding between you and your perspective boss.” Jessie met with her job coach to find and apply for jobs that were a good fit for her and shared: “They help me with job skills and help me find the right employment for me so I can be successful at the job.” More specifically, she added: “They kind of help me with applications, filling them out, answering the questions on the application properly.” Daniel also worked with his job coach Asha: “She’s helping me with finding jobs.” They practiced social skills so he would have “appropriate behavior out in the community,” which was important for him to keep a job. Barbara was working on bus training with her job coach in order to “learn how to do the city bus to get around.” With these skills, she would be able to

travel to her job and use community amenities independently. Joe's job coach helped him study for a future career as a para-educator and drove him to events and social activities to get him out in the community. He met with his job coach every Wednesday to study for his online college class. He explained: "The book's kind of hard and big pages and sometimes I get frustrated...so I started studying with Maria, my job coach." A few of the job coaches assisted young adults in learning daily living skills such as cooking and took them to special events and other leisure activities. Many of the young adults considered their job coach to be a friend.

The interactions young adults with ID had in the workplace influenced their social inclusion. Dustin enjoyed his work at the vocational day program he attended: "I talk to people all the time at work. I joke around with people all the time." He beamed when talking about the jokes he shared at work: "I don't know where I get it from. The other day I made a joke from somewhere...It was just unbelievable. Told my staff it and he just started cracking up." Alec also enjoyed talking to people at work. At the department store where he unloaded trucks, he was beginning to get to know one coworker: "The girl's been with the store since the beginning, but we've never really bumped into each other until now." He added: "We get into nice conversations. We had a nice one that just happened to be when she was about to go on break, so talked to her for like ten minutes before I had to get to work." Alec worked and talked with his coworker Bryan regularly: "We tend to get along fairly well." Though Alec "met and befriended a few of the workers there," he shared, "I've never really hung out with them outside of work yet." When Mark worked at the grocery store, he also had a friend he talked to during break times that he really enjoyed. He shared: "Everyone else was kind of just casual acquaintances." Mark explained that he "got along with everybody just fine," but he only seemed to click with his one friend because "everyone else was just too busy being mature."

When he worked at a day care provider, Mark sometimes had difficulty communicating with his supervisor. He shared: “My boss was only talking to me when I was doing something wrong...I didn’t know when I was doing something right.” The lack of communication made it difficult for him to be successful at his job.

A few of the young adults had closer relationships with their coworkers because of the time they spent with them during their shared breaks and work parties or activities outside of the workday. Joe’s coworkers at the school cafeteria were friendly and sometimes gave him rides to work. He explained: “Sometimes they pick me up when my parents are not home.” He was able to get to know his coworkers more because of their shared break times: “We eat in our break room during break time.” They talk about “what’s going on in the world.” He spent time with coworkers outside of work when his boss had get-togethers at the school such as their Christmas parties. Joe seemed to enjoy his coworkers at the school and stated: “I have friends there.” Darren also spent time with his coworkers at the grocery store during break: “If I see them on lunch break...we go down and visit.” His work had a softball team that he wanted to join though forgot to sign up. Darren was interested in participating in additional activities with his coworkers and shared: “I talked to them about doing bowling.” They also had work parties that he attended: “We had our store Christmas party in January and I won the grill.”

Many of the young adults did not have opportunities to interact with their coworkers often, so they did not know the names of most of their coworkers, talk to them, or develop friendships. At the grocery store where she worked, Kara saw a lot of people and said ‘hi’ to them, but had limited interactions with her coworkers. She explained: “I don’t know their names.” Shannon did not interact with people very often when she was cleaning tables at her part-time job. She explained: “I just know my boss...I just like being efficient and be done. I

don't mess around." Shannon talked to people besides her boss only if she had questions. She preferred to have privacy: "I don't like people in my space." Though she did not have many opportunities to interact with others, she also enjoyed being on her own: "I like to do whatever I want to do...People like to ask me what I'm doing. I really don't want to respond." Rachel also shared: "I'm not a very talkative person sometimes." Though she only worked for two hours a week folding boxes, she tried to interact with her coworkers more: "Lately I can say 'hi' and stuff like that and 'burr it's cold.'" Barbara did not interact with her coworkers at the fast food restaurant often. During break, she spent the time on her own: "I just talk on my phone. I just play games...like checkers and air hockey...I just play by myself." Language barriers also keep her from talking with her coworkers: "I can hardly understand some of my coworkers because they talk in a different language and I don't understand them." Young adults with ID had limited opportunities during breaks and outside of work to interact with coworkers. Many of the participants did not work enough hours to take breaks with their coworkers. Stacy shared: "Usually I'm there for so little a time that I don't get a break." She knew her manager and made small talk with people, but did not interact or develop friendships with her coworkers.

### *Social, Recreational, and Leisure Activities*

Six of the participants were involved in a social group specifically designed for adults with ID. These social groups met once a week and had sessions throughout the year. Some participants got rides from family or staff from their residential service provider. There were also the social group's staff members who drove vans to give participants rides and assisted them during the activities when needed, though many participants could do everything on their own. Darren described some of the activities he enjoyed: "We do some exercise, go to a park, play a game, some games, and go for a walk." Stacy enjoyed the activities at the social group when she



and her friends went to dances, made crafts, and watched movies and basketball games. Kara shared: “Mostly we hang out with friends...every week we do something.” With her group, Kara had gone bowling, went to the movies, and went to a fun center in her town. The social groups also held holiday parties and special events. Shannon looked forward to one of her group’s annual parties and invited her evening staff to go with her: “I’m going to the Holiday Ball Thursday...I’m taking Kelsey, so she’s going to take me home.” One disadvantage of her social group was the cost of activities: “They do a lot of fun things...most of them take a lot of money, which I don’t really like.” Dustin had participated in a social group for people with disabilities in the past: “I stopped going because I had no way to go and I needed to get my hours in with my staff...and it’s kind of just not appealing to me anymore anyway.” He didn’t get along with some of the other people who attended and was not interested in participating in many of the activities.

On Sunday mornings, half of the participants attended church. When they were at church, some young adults visited with people while others only knew the name of their pastor. Kara enjoyed going to church with her parents and affirmed: “I would never miss church.” Both Darren and Daniel attended a Sunday school with other adults their age. Daniel also enjoyed the men’s steak night at his church where they had guest speakers and other activities. Stacy went to church with her extended family: “I usually do church service and if my extended family home’s daughter goes to the daycare, we go to the early service and then I’ll help with the little kids for an hour.” She loved working with the children and the interactions she had with them. Dustin used to go to church when he was growing up with his mother, but shared: “I’m not really a morning person. I kind of like to sleep-in in the mornings on the weekends.” He added: “I was always raised that way as far as I was always going to church with my mom, so I want to kind of

start going again.” Alec became involved in church through a Bible study, volunteering for the Sunday services, and attending special events. He volunteered to run the PowerPoint slides on Sunday mornings for the praise and worship songs during the service. He explained how he initially became involved: “I think I’ve demonstrated myself as a computer guy, so I basically nominated myself for the position.” When he started, there was a rotation of three people who prepared and ran the slides, but that soon changed when two people quit: “For a year I was the only person doing it. I was there every Tuesday evening. I had to even miss out and not do basketball for Special Olympics...Don’t get me wrong, I enjoyed it.” After a year, he was finally able to train other volunteers to work behind the computer: “Now I’m up once every four to five weeks.” Alec was a part of his church’s college group Bible study and found a good support system with the members of his group. Kara was also involved in a Bible study group. She explained: “It’s a gospel, like a study for young adults with disabilities. We talk about Jesus and God.” She met with about ten people at a group member’s house once a month. James was involved in a different Christian group that met at his house: “We get together and hang out...play board games.” They talked about their faith but spent most of their time in Christian fellowship with peers their age.

Most of the young adults were involved in recreation activities. Yesenia was in a dart league with her friends and participated in Special Olympics: “I am an athlete, so I do bowling and I used to do volleyball but we decided not to do it...This summer I’m doing bocce.” Stacy enjoyed bowling on her summer league and used the time to relieve stress: “That also lets me get steam out if I’m pissed. I love throwing the ball and going ‘wheeyaa!’ because that’s what I did when I was growing up. Loved to throw the ball or watch my dad play.” When she was younger, her grandma showed her how to play pool and she revels in the skills she has learned:

“I’m a bowler slash pool player, so don’t mess with someone who knows how to do either or it will get uglier than ugly.” Six of the young adults were in Special Olympics and competed in sports, such as basketball, track and field, softball, soccer, volleyball, swimming, golf, bowling, bocce ball, the softball throw, and walking. Darren was on a bowling league and ran track in the Special Olympics. Mark participated in track and basketball in his free time: “If I’m not doing my artwork, I’m usually doing my Special Olympics.” Daniel kept busy with activities throughout the year: “I do bowling, swimming, bocce ball, and golf...I like doing it.” Outside of practice and competitions, Daniel does not spend time with his teammates except when they have team get-togethers: “Like picnics and that stuff, a lot of eating.” Jessie participated in a variety of sports with her Special Olympics team: “I do track and swimming, basketball, and bowling right now.” Her team even participated in a basketball clinic held by college athletes: “They helped us learn more skills and our exercises and stuff like that to improve our basketball.” In Special Olympics, individuals and teams compete in regional events to see who will go to state. Jessie explained the qualification path: “First place is obviously the best place, but fourth place is the last best place you can get to go to the state tournament.” At the state tournament, athletes stay in college dorms and participate in events such as the dance they have each year. Most of the Special Olympics teams included the same people for a variety of sports. Jessie explained her group’s dynamics: “The majority of the time it’s the same, but different amounts of people do different things...A lot of people just switch out and do something else. There’s a ton of events you can do in Special Olympics.” Jessie’s team holds fundraisers throughout the year to cover some of the expenses. She shared: “There’s different fundraisers that we do that are pretty fun...We have what’s called a polar plunge, like you’re going into freezing cold water and you’re trying to raise money...I think it’s going to be funny. It’s my

first year doing that.” Her team also held raffles and attended football and hockey games where they would pass buckets down the isles to raise money for the Special Olympics. Joe was also involved in fundraising for his team but he was not as excited about his activity: “If you do it, you have to sell raffle tickets...it’s okay.” He competes in the softball throw and a walking race. Joe’s former teacher, Mrs. Mandel, is the coach of his team and receives assistance from other parents and educators: “Some of the paras she works with and my dad helps to be a coach...She helps me to throw the softball, like even farther.” He was limited in the availability of sports he could do with his team, but when I asked Joe if there were any other sports he would like to try, he cleverly responded: “I don’t know, probably nothing like the javelin throw.” Alec played basketball with his Special Olympics team when he was not busy volunteering at church and was preparing for a track meet. He shared: “I’m a long distance runner, one of the few...There aren’t really a lot of distance runners in Special Olympics. A lot of them tend to go for the 100-meter dash. That’s the most popular event...So I kind of come up with this idea that Regionals is kind of the race before the race and State is the race.” He liked to identify himself with the long distance runners because it set him apart from the majority of runners. Kara, Barbara, Rachel, Shannon, and Dustin were not involved in any structured recreation. Dustin shared: “I used to do track a long time ago as far as years ago and then I started gaining weight. I’ve lost some since then...My back’s gotten a lot better, but still not near the point for me to be ready to start running track again. I mean, I was fast at one point.”

Many young adults with ID liked to do unstructured recreation activities on their own or with a few friends. Darren liked to ride his bike and played basketball and football for fun with his friends. When I talked to Daniel at his apartment, he shared: “When it’s nice outside, I go for walks...I also work out over here at our clubhouse...They have a swimming pool in here and in

the spring and summer I can go swimming. They also got a tennis court and basketball court together. I do not play...I have some health problems, a knee problem.” It was beneficial for him to live close to a walking path and have recreational facilities at his apartment complex because he could not drive a car and the proximity made it convenient for him. Rachel enjoyed bowling with her sister who had severe disabilities because there were metal ramps to aim the bowling ball and accommodate for their needs. She explained how convenient it was: “They have these little ramp things that you just push the ball.” It was difficult to find other recreational activities that accommodated her wheelchair and was accessible for her sister as well. Rachel and her personal staff had been looking for ways to get her more active: “Lately we’ve been going to the Y. First I looked around for a while and then I go to the gym. I throw around a basketball.” Mark and his roommate went to the YMCA twice a week when their residential staff drove them. Mark followed a set workout using the treadmill, stair-stepper, and stationary bike: “I try and do 25 minutes on each machine if I can. It just depends on what the schedule is for our staff.” Jessie also enjoyed going to the YMCA: “I go there and work out. I’m in the process of getting into their taekwondo there.” She really enjoyed physical activities because, as she explained: “I want to get further into shape. I like to stay pretty physically active, it kind of helps. It helps me stay more confident about myself.”

Young adults with ID participated in a wide range of free time activities at home and in the community. Many of them enjoyed playing video games, spending time on the computer, and hanging out with friends. Rachel rode horses when she was younger, but was not able to as an adult: “I don’t do that anymore. They say it’s too dangerous for people with disabilities.” She told a similar story about when she went to the State fair: “I used to go to the fair every year, but I don’t do that anymore.” It was difficult for her to get around in her wheelchair: “That’s

what is wrong with this society. They don't put enough handicapped things up." She felt that her activities were "somewhat limited." Her job coach talked to her about taking a cooking or craft class to build on her skills. She shared: "I'm mostly into baking and I used to do floral stuff." Stacy liked to make crafts: "I can do friendship bracelets, crochet, and embroidery." She also enjoyed ceramics: "You should see my ceramics, the stash that I have." She went to a store in a nearby town to purchase her materials and work on projects: "You can go there and pick your stuff out...they have a shredder that they shred paper in to put around...and fire it before you paint it, but the pots themselves, you have to glaze them first." Stacy beamed when she described her creations, but it was a difficult craft for her to pursue because it was expensive and she had to get a ride from her supporting family to get to the craft store. Barbara liked crafts as well: "I know how to make a non-sew blanket." Daniel also spent time making small latch-hook rugs. He shared: "I made at least 20 since last year...I love doing it." Most of the rugs he made ended up being Christmas gifts for his family and close friends. Alec's main hobby was filmmaking: "I make films for people, for myself, for friends. They tend to be around the realm of highlight film or documentary." He completed most of the work on his own, but involved others when needed: "Usually I'll have help, just because I need to do interviews. I'll also ask for pictures...I'll have a slideshow, that kind of thing, to show other things that I couldn't get on camera." He planned to create a video for the Special Olympics and stated: "I'm hoping to make a film for them in the future." Mark also pursued artistic hobbies. His passion to paint blurred the line between work and hobby. He confessed: "To be honest, the painting stuff, that's a hobby too," and added, "Most of the time this stuff is just for my own personal amusement, although I do try to sell some of these whenever I get the chance." He displayed his paintings at a couple local art shows. At the art shows, he described: "If anyone comes to my display and

looks at my stuff, I'll talk to them, you know, try and get them to take at least one of my brochures." When he was not painting, Mark spent time listening to books on CD: "I've got a bunch of books on audio. Being as my eyes don't work right, reading is technically not easy, so I just use books on audio."

Many of the young adults with ID spent their free time similar to other young adults their age. They spent time playing on the computer, watching television, hanging out with friends, and playing video games. Yesenia, Jessie, and Joe all really liked to play video games. Jessie shared: "I like to play video games. I play a lot of Guitar Hero games." She played on her own and with her supporting family when they were home. When I asked Alec what he did on the weekends, he confessed: "A lot of people my age would probably say, 'yeah, I hang out with my girlfriend,' but I don't have one." His time was spent mostly on the computer and by a radio: "I'm on the computer a lot. In an ideal scenario, I would be checking my email several times a day on a weekday...I am kind of a radio junkie. Every weekend there's at least some interesting sports event on the radio." Joe listened to music at home: "I have a CD player in my room. I listen to music when I make my bed." In his free time he surfed the Internet and played with his Legos: "I got a new Lego set. Sometimes I work on that if I have time." He also liked to be physically active and shared: "Sometimes I like to go outside and go out with the dogs if it's nice." Dustin shared many activities he enjoyed: "I like video games a lot...I like fishing too...I like to fly kites. I like puzzles." He played video games often, but only got to go fishing on his summer vacations. He also shared: "I have an occasional alcohol. I don't have it that often." Dustin enjoyed cooking and was excited to describe the cooking ideas he had for the future: "I would like to make lobster one of these days in a cream sauce." He looked forward to trying out new recipes and learning new skills.

Many of the young adults with ID spent most of their free time at home. Shannon spent most of her free time in the evenings and on weekends inside her house. She explained: “I’m just like a girly-girl. I stay inside.” At home with her mom in the evenings, Shannon shared: “I just do whatever I feel like, so long as I’m out of trouble. It’s not hard to get in trouble; it’s hard to get out of trouble.” She liked to read, watch movies, and play on the computer. She confessed: “I like to play computer a lot. I just look up anything. I can’t go to chat rooms or stuff like that...That’s one thing I like the most.” James was also at home a lot and said: “I pretty much just hang out at home and go shopping for groceries.” Rachel lived outside of town and was dependent on others to drive her places, so she spent most of her time throughout the day at home: “I can do things around the house like play on my computer, I can check my emails, I can skype somebody.” Kara also liked to play on the computer and watch television, but her parents wanted her to limit her time: “They say, ‘you watch too much TV.’ I do but my favorite show is on TV.” She also spent time with her boyfriend on the weekends when he called. Similar to many of the young adults, Barbara enjoyed watching movies, being on the computer, listening to music, and hanging out with her friends. She spent most of her time at her house and had friends over once in a while. The young adults in the present study enjoyed activities similar to other adults their age, but how they got there and with whom they spent their time were many times different. Many young adults with ID spent their free time in the community with staff and were not with friends as often.

Young adults with ID occasionally attended special events in the community and get-togethers with friends. Half of the participants had been to at least one concert. James, Jessie, Barbara, and Darren had gone to concerts at the State fair. Jessie went to many concerts at the county and State fair and saw bands such as Boys II Men and Toby Keith. She reflected: “Most



people don't think that those type of bands show up at state fairs." While she was at the fair, Jessie also went on the rides and explained: "I have to go on the big rides. It's just that adrenalin rush." Kara went to the Faith Hill and Tim McGraw concert in a nearby city. She had a great time and shared: "It was so much fun 'cause I got the front row seats. I wanted to touch him, but I did not want Faith Hill to get mad." This was her first concert experience, but she already knew what she liked: "I never go to small concerts. I like big concerts." A few participants had attended college or professional sports events. Jessie and a friend of hers went to wrestling events: "I'm a professional wrestling fan, so I go to a lot of events." Darren went to the college basketball and minor league baseball games in his town with his staff and sometimes his friends. Joe and his staff went to the local event center to see a boat and travel show as well as a home and garden show. There were few events that happened in Alec's small town except for their annual hay-days. Alec described the festival: "There's a pancake feed- it's definitely the highlight- a parade, cookout, garage sales...a volleyball tournament...and then a street dance at the end." To attend other events, Alec had to drive to the nearby city where there were more opportunities. The service provider for the young adults in the present study held more than one picnic and dance each year. Barbara attended the picnics: "We do the potluck thing where we bring food. I do that sometimes." She declined on the dances though: "I don't go to that. I'm not very good at dancing." Many of the young adults went to birthday parties for their family members. Dustin even went to a birthday party for his staff's son and shared: "He's so funny, his son is. He would try to grab the glasses off my face and tried to put them on his face and didn't know what to do with them." In that environment, he was shy at first but felt more comfortable after spending time and interacting with his staff's family. Jessie's Special Olympics team had a picnic, pool party, awards celebration, and Christmas party each year. She

described one of the picnics: “We did an open swim for the entire team after the summer picnic. That was fun because the whole entire pool was just to ourselves, just for our team.”

A few of the young adults with ID planned their own special events. Mark threw a Halloween and a Fourth of July party every year, and many of the people on his Special Olympics team who live near him attended. He had a great time hosting the Halloween parties: “We get the whole place creeped out. We put webbing everywhere...It’s also a costume party. If you don’t come with a costume, by gosh, you’re definitely going to leave with a mask because I’ll drag out my face paints...That’s always a lot of fun.” For the Fourth of July, Mark explained: “I kind of raise a little bit of a ruckus about everybody get some fireworks so we can light them off. I affectionately refer to it as the Great American Blast.” On New Year’s Eve, Mark, his roommate, and maybe a few of his neighbors will spend the evening together: “We’ll try to stay up as late as we can and toast the new year and I’ll get my hands on a bottle of Cold Duck...We get out the plastic Champaign glasses...I can’t afford crystal and I can’t drink alcohol, so it’s got to be the alternative.” For the Fourth of July, Joe stayed home with his parents and had a party. He confessed: “My dad’s a big Fourth of July fan. He’s addicted to having people over and clean up the house...We have the pool and hot tub open for people to use.” James made Christmas celebration plans with his girlfriend: “Christmas day or Christmas Eve I’m going to have dinner with my girlfriend’s family...and then they’re coming over to my place.” He was in charge of cooking specific dishes to preparing for the meals.

Most of the young adults spent Christmas, Thanksgiving, and other holidays with their family. Darren spent his holidays with his mom, brother, and cousin. They would meet at his place and watch television or play board games. Yesenia, Joe, Barbara, Daniel, and Alec usually spent the holidays with their immediate families. They generally had meals together, played

board games, watched television, and saw fireworks on the Fourth of July. Dustin usually spent holidays with his family as well, though sometimes they had friends from church join them too. Stacy spent Christmas and Thanksgiving with her supporting family and a few of their friends. Her plans would be different for the future because she was planning on moving to an apartment on her own. She shared: “Thanksgiving we had some people over and we played games, but this year will be different ‘cause I will be on my own and probably go somewhere for those holidays.” It was difficult for many young adults with ID to arrange their own get-togethers, and they usually had few opportunities to do so. Most participants spent their holidays, such as Thanksgiving and Christmas, with their immediate family.

The participants had various experiences in regards to vacations. Alec, Barbara, and Stacy had not been on a vacation in several years. When asked about vacations, Stacy replied: “I haven’t had my own vacation in years.” Her last vacation was a camping trip ten years ago. Alec’s reply was short as well: “Vacations? Used to. Nothing much anymore.” James could not remember the last time he went on vacation, but shared: “I go on some vacations, but I don’t go on a lot of vacations.” For participants who went on vacation, most of them went with their parents and possibly other family members to cities and amusement parks around the country. Kara took vacations with her parents: “I went to Kansas City and Chicago last summer to see a baseball game...parents are totally fans of the Red Sox.” They have also gone camping and traveled to Colorado and Disneyland. When Yesenia was a teenager, she went to Disney World in Florida with her mom and grandparents. She also went to Las Vegas with her mom and aunt and loved it. With a smile she added: “I’m going back next year for my 30<sup>th</sup> birthday.” Joe went to Colorado and Nevada with his parents for two of his vacations. In Las Vegas, he shared: “I gambled. We went on tours. We went to The Sahara, the casino with the pyramid, and we took

a tour of that.” Joe shared future plans as well: “We might go camping maybe this summer...If we take along the TV then maybe we will.” When Jessie went on vacation, it was always with her mom and grandma. They traveled to a few different amusement parks around the country. With wide eyes, she described one ride: “It was the most scariest ride ever there. It goes straight up and it goes straight back down and you kind of go back up again and you spin. It’s like ‘wow’! I like the thrill of those kind of rides.”

A few of the young adults with ID went on vacations with their personal staff and other friends. Daniel regularly took trips with an advocacy organization for people with disabilities. He explained: “It varies but sometimes they do cruises. I went to Alaska. That was a lot of fun...They do have one going to Africa for a safari, but I don’t think I’m going to go to that one.” Darren has taken a vacation every year. For his last vacation, he went to Kansas City with his friend to go to the casinos. Dustin went on fishing trips and other vacations with his friend and his friend’s dad. He also went on vacation with one of his staff members. He described his vacation in Toronto, Canada with his staff: “Five days I was there. At one point I went to what was the world’s tallest building...We went to one of the world’s largest zoos. To get through the whole entire thing, you would have to go through it in, like, four or five days...I went to this authentic Italian restaurant. It’s really awesome...Went to the Hard Rock Café in that area and that was cool too.” Dustin and his staff also went to Arkansas where they went fishing and explored: “For my celebration of catching my fish, I went to this Italian restaurant...Then we went to this outlet mall that was really nice and got me a nice bottle of cologne that I still have...Tried to figure out my way around and everything.”

Most of the young adults with ID did not talk about attending family reunions and many families did not have formal reunions. For Mark, it was his main vacation that he looked

forward to every three years. Mark enjoyed telling about his reunions: “I think it’s every three years we have a family reunion. Where, and I mean this literally, everybody gets together...Not everybody makes it, but everybody tries to come. So you know over half of the people. I have no clue how I’m related to them all...Usually we hold them at a national park...Officially it’s supposed to be for a week, but usually people come in from Oregon, California, Texas.” He described his favorite tradition at the reunion: “There’s this little group of us that we like to go horseback riding. So it’s almost a tradition that the very first day before anybody leaves...we go on a horseback ride...just to be able to say that we are upholding the tradition.”

### *Reciprocal Relationships*

The young adults with ID experienced social inclusion through the relationships and social interactions they had with others. They felt included when community members talked to them and knew their name. Jessie was a very social person: “When I’m on the bus, if somebody starts talking to me or I hear an interesting conversation and I have something interesting to say back, I’ll join in.” Kara went to church with her parents and knew her pastor: “because he’s been my pastor for a long time.” Though she did not talk to or know anyone else’s name, she talked to her pastor: “He talks to us a lot. He knows our names.” Stacy’s main mode of transportation was the bus system. She was comfortable riding the bus and knew the bus drivers on her routes. She shared: “I know most of the bus drivers anyways. They’ll be like, ‘what’s up with you? Haven’t seen you in a while.’”

When community members provided unsolicited assistance to the young adults, they felt either thankful or patronized at times. For example, Rachel was going uphill in her wheelchair and a stranger decided to push her: “Some of those parking lots are uphill where we were shopping...and I hate hills too. I was huffing and puffing. This one guy comes up and...he just

grabbed me, my chair. Mandy was right next to me, she would have screamed. When I realized he was helping me, I said ‘thanks’ of course.” Though she appreciated his assistance, she knew there was little need for it. Mark had a visual impairment and people have grabbed his shoulder to guide him though he did not need assistance. He thought to himself: “If you want to do your good deed for the day, that’s fine. Go earn your merit badge.”

Similar to other people in the community, young adults with ID have varied social experiences with their neighbors. Yesenia lived in a house with her parents. She described the dynamics with her neighbors: “They don’t even talk to us. Our neighbors are not like other neighbors. I mean, I do have a neighbor down the street that I’ll talk to. That’s because I do respite care for her son, so that’s the only reason why.” Kara, Dustin, and Barbara did not know their neighbors well, but would greet them and thought they were nice. Barbara explained: “We say ‘hi’ once in a while, like if they are out of the house.” Daniel lived in an apartment and got along with most of his neighbors except one: “He is a pain...pounding on my walls, pounding on my door, and that other stuff...Cussing and fighting is not what I like at all...and the smoking. I had a complaint that I did on them.” Joe lived with his parents in a small town and had neighborhood get-togethers. Joe described their activities: “We did have a bon fire,” and added, “We have like a block party.” When asked who came, he replied: “The whole neighborhood does...I only went to the first one. It was really silly...They play games and have food.” Alec also lived with his parents in a small town and knew his next-door neighbors well: “They’ve been pretty welcoming. We’ve basically become fast friends over the years.” He played basketball with the boy his age growing up and when the boy played basketball in school, Alec shared: “I was the high school student manager for basketball.”

Half of the young adults still lived with one or both of their parents. To support their adult children, the parents spent time running errands, setting schedules, assisting with chores and cooking, driving to activities, and doing leisure activities with the young adults. When Joe's parents were gone overnight, his brother stayed with him until they returned: "He stayed until... mom and dad [got] home to leave." Kara spent time with her parents. She described her time with them: "Go to church. I go to eat lunch and eat dinner here with my parents and walk the dogs with them," and during the week she added, "They don't see me very much because they work and I work. We never have time for each other." Shannon lived with her mother and shared: "I like my mom but she gets on my nerves. It's hard to explain. She gets on my nerves and then I get on her nerves." Her brother also lived at home and she complained: "I really don't like him. He takes over the TV...I don't like to share with my brother." It was difficult for Shannon to visit her extended family because of their family dynamics: "I can't go to my other grandma's house because my brother and my dad don't get along." Rachel also lived at home with her parents and sister who had severe disabilities. She kept in touch with her extended family through email and Skype and spent time occasionally with her niece. Most of Rachel's time throughout the week was spent with family: "Anything I don't do with them, I do with Sonya," her job coach. She also spent time with her parents' friends when they were invited over to play games. Alec lived with his parents but could drive, so he was able to be more independent. When he spent time at home, he did not necessarily spend much time with his parents. He explained: "Weekdays I live there, they live there. Unless of course my mom's cooking and then nagging me on taking my pills." Yesenia was in a similar situation where she was able to drive and did not spend much time with her mom and step-dad: "My mom has a work schedule...She goes from one job to the next. She's never home. I mean, I was really

close in October when my step-dad had surgery. Somebody had to be there for him. I mean, we hang out and when I'm home we play on the Wii."

Stacy and Jessie lived with supporting families and spent time with the members of the supporting family when they were home. Jessie explained: "It's like a second family." When they're together, she added: "Sometimes we go shopping, grocery shopping. Most of the time we're just hanging out at the house together...I'm playing with the three-year-old and all that." She also has a brother who lives an hour away and two half-brothers she sees on the holidays. She shared: "Me and my brother, we talk on the phone and sometimes he comes down here and also I go and hang out with him." Jessie spent time with her parents going to movies, sporting events, shopping, and out to eat. Stacy had limited contact with her parents and extended family, but spent time with her supporting family: "on the weekends and in the evenings." She added: "We eat supper together and we go to church on Sundays. Sometimes we watch TV, movies together."

Five of the young adults with ID lived apart from their parents in a house or apartment with various levels of support. Darren lived in an apartment and spent time with his brother a few days a week. They have gone shopping and played computer games. He also spent time with his mom talking on the phone, going for walks, and walking the dog. Mark lived in an apartment and explained that he spent time with his parents "on special occasions like on holidays or, my sister has two boys, so if it's one of their birthdays." He made it clear: "It's usually me going over to their place. 'Cause otherwise my mom gets here and has a conniption fit over the state of my room. You know how moms are. It's like, 'have you ever cleaned over here?' It's like, 'mom, it's not the point, why you came over.' So it's usually me going over there." Mark also described how he spent time with his family at reunions and interacted with a



great number of people there. He confessed: “I know this sounds kind of pathetic, but there are members of the family that I only see at reunions, so of course at each reunion I have to ask them for their name again.” When he was at the reunions with his family, they joked around, played volleyball, swam, rode horses, and shared stories. Dustin also valued the time he spent with family: “Wish I could hang out with my mom more often. I feel like I don’t get to hang out with my mom often enough.” He mostly saw his mom when he worked at his vocational day program: “I see her when I go over to that workshop and whenever she stops over and does stuff as far as my workshop...Every now and then she’ll help me out with stuff like get-togethers, family get-togethers.” He added: “I go to birthday parties when I remember them as far as family, just don’t always get the chance.” Time with family was important to Dustin: “Making it a priority because it’s always important to do that as far as spend time with family.”

Friends of the young adults with ID included their roommates, classmates, Special Olympic teammates, coworkers, and service provider staff. Dustin spent a lot of time with his personal staff in the evenings and on weekends: “I consider him staff and a friend at the same time.” He knew most of his friends from the day program where he worked: “Some other staff there, I really like them a lot too. I’ve known them since the beginning. And then I got my friend who’s deaf. I’ve known him since I started working there. And then a few other friends I talk to all the time.” James had friends from his church group in addition to his three roommates. As far as his relationship with these friends, he explained: “I wouldn’t say they’re close, really close. Some of the people I hang out with are.” Many young adults did not have very close relationships with their friends. Kara knew a friend from the grocery store where she worked, but she did not spend time or talk with her there. When asked if she spent time with her friend outside of work, she replied: “No, except I talked to her on her birthday.” Rachel did not have

anyone she considered a friend with whom to spend time outside of her family. She made a friend when she went to school, but has not seen her in years: “We used to talk a lot... We met at the mall once. She spent the night once too. That’s about it.” Mark met his best friend when he was in elementary school. He lost touch with her since then and thought: “I wonder what happened to her. Honestly, I haven’t seen her since she got married and moved to Louisiana. Then her folks moved several years later so I haven’t had any contact with her unfortunately.” He spent a lot of his time with his Special Olympics teammates: “Most of the people that are on the basketball team are on the track team, so I see them year-round.” He did not spend time with them outside of Special Olympics often, but thought: “If we knew each other’s phone number or address or something, then we would probably hang out.”

The young adults had relationships with significant others similar to other adults their age though much of the time they spent with each other, communication, and privacy were different. Stacy had a boyfriend who she used to date many years before they got back together: “When he came back in December, saw him and those sparks just went.” They attended a social group for people with disabilities together once a week: “Sometimes we go to movies, out to eat, bowling, to just flirt.” She talked about their free time together: “I talk to my boyfriend every night,” and added, “we just hang out and have lunch. That’s mainly it.” She lived with a supporting family and shared that the mother “usually lets me go out on the weekends with my boyfriend, and he’s pretty special.” Kara described a date she went on with her boyfriend: “One weekend we went bowling... His mom and dad [took us] and my parents picked us up... I like hanging out with him.” They talked on the phone once a week: “because he don’t have time to talk that much ‘cause he has a job too.” Similar to many young adults, Daniel felt down after he separated from his girlfriend: “I left her because she had some problem issues, so I’m not dating anyone at all.

I'm going to be single for the rest of my life." Yesenia spent time with her boyfriend at her dart league and in their free-time every other weekend. She explained: "He works every other weekend so we won't go out. So like next weekend we'll stay at his house and rent movies and chill at his house or he'll come out and play on the Wii." James spent time with his fiancé and was working on preparations for their wedding: "Trying to get my wedding on the way...Trying to get everything situated with that." Dustin gushed about his girlfriend of three months: "I love her a lot. She always calls me on the phone...I want her to be my last girlfriend. She appreciates me and loves me for who I am...I haven't had that in a relationship before. I feel special." He also confirmed: "I consider her my friend at the same time I consider her my girlfriend." Dustin enjoyed spending time with her: "We've already went out on one date before, which I don't get to hang out with her that much." They went to a nice restaurant and out for coffee afterwards. He concluded: "She liked it a lot. She said 'thank you', even a big ol' hug for it." Looking into the future, Dustin shared: "I told my girlfriend as far as if me and her are still here in January, possibly getting engaged."

Most of the young adults' friends had disabilities. They encountered these individuals in environments that included homes, social groups, recreation activities, and work. Kara and Daniel only had friends with disabilities. Barbara was not sure if her friends had disabilities or not, adding: "I like them just the way they are." Shannon had a few friends with disabilities from her day program, but it was difficult to be with them at times: "It's kind of hard for me about disabilities. It's hard to cope with that." She added: "I have friends with no disabilities." These friends included her personal staff in the evenings and staff at the day program she attended. For most of the young adults, it did not matter whether their friends had a disability or not. For example, it did not matter to Jessie whether her friends had a disability: "I'm not the type of

person that just really pays attention to that stuff. I'm just like, 'you're an interesting person.' Alright, I'll try to be friends with you." Alec saw himself as a bridge between those who have and those who do not have disabilities because he could relate to people from each group and treated them similarly. He explained: "This little piece of Autism I have gives me an advantage to the point that I can relate to people. I can relate to those who have no disabilities 'cause I'm mostly like them. Meanwhile, I can relate to those who have some major [impairments] like mental retardation or they're super-deaf or whatnot...I'm kind of a bridge." He described his interactions with his friends from Special Olympics: "I communicate with my Special Olympics teammates almost like a normal person. It's not like they're super different. They still function, they still compete, they still have a life."

Young adults with ID participated in a variety of activities with their friends similar to other adults their age. They talked on the telephone, hung out at home, went to movies, and played video games. Joe's previous staff worker, Andrew, drove him and a few of his friends each Friday so they could spend time together. They would either go out or spend time at Andrew's house: "He made us some popcorn and pizza and had a good time...We sit around and talk and sometimes watch TV." Daniel regularly met a friend of his at fast food places: "We go play cards someplace and have a drink or something." He also shared: "Sometimes on Sundays I have a friend of mine who takes me out to a movie and go out for dinner." Dustin regularly spent time with his best friend and his friend's dad: "We've been to different vacations, just fishing trips, out to dinner many times, had cigars together, beer tasting...playing video games, just a bunch of different stuff." Alec wanted to spend more time with friends and stated: "I'm hoping to connect with them more." He shared: "I just met with a friend of mine who's also looking into video just last week and showed me a website that was just awesome in terms of

tutorials and hookups to enhance after-effects, which I have almost nothing on.” Jessie had more freedom to meet and spend time with her friends because she could drive: “Sometimes we go to the mall, sometimes we go to movies, sometimes we just hang out downtown...and then sometimes we also hang around each other’s houses.” She enjoyed spending time with her teammates in Special Olympics. She was comfortable with the group: “Everybody gets along, everybody has fun, and nobody judges somebody because they can’t run as fast or something like that.”

It was difficult for some young adults with ID to spend time with their friends to develop close relationships. Shannon had friends at her social club, but admitted: “I just only talk to them and they talk to me and that’s it.” She had friends over at her house when she was younger but was not able to anymore: “We have my brother’s dog, so we can’t have friends at our house.” For James, it was difficult to spend time with his friends: “They’re usually busy or they don’t have time for me.” He did not have friends over and explained: “most of my friends do not know where I live.” James spent time with his roommates watching movies or playing board games at home. Stacy did not spend time with people from work: “I haven’t hung out with anybody from work in a while...Last time I hung out with somebody was four to five years ago.” Stacy had a close friend in the mother of her supporting family whom she felt understood her, cared about her, and talked to her about everything.

### *Accepting Environments*

The young adults with ID felt a sense of belonging when they were in accepting environments, including their home, work, Bible study, Special Olympics, and reunions. Mark felt like he belonged at his family reunions where he shared in a tradition with a group who went horseback riding and participated in other activities together. When he was younger, he went to

a residential school for people with disabilities. Mark described the atmosphere: “In a residential school, not only do you have the dorms but you got a nice commons area where you could hang out, play games, watch TV,” and he added, “That was like a second home for me for about six years.” Mark confirmed: “I go to class reunions and alumni weekends whenever I can up there.” He enjoyed going to his class reunions to “hang out with the gang again” and reminisce about old times. Alec felt a sense of belonging with his Special Olympics team: “A lot of teammates there I’ve been really close to for over a decade.” Rachel felt like she belonged at home when she was a part of activities, but sometimes felt that she was a burden: “I try not to get in anybody’s way.” Jessie felt like she belonged when she was around people who knew her: “You don’t have that fear of someone trying to judge you or somebody saying the wrong thing.”

Fitting in and being accepted helped the young adults with ID feel like they belonged. Some participants felt like they belonged in a group when they enjoyed the activities and could fully participate. Kara enjoyed her social group where she felt important and was treated the same as everyone else. She explained: “I like to do all the things that the people, that they pick us to do.” Mark felt like he fit in at places “where being different is really okay.” He lived in an apartment next to many other people with disabilities: “Obviously I’m not really questioned around here.” His advice for others: “Just be yourself and if you do make friends, you know it’s the real thing... You won’t have to worry about whether they will be there for you through thick and thin because the ones that accept you for who you are, they’ll be there for you.” Jessie also felt like she was accepted around her friends: “They don’t really judge me for what I do.” Her advice: “Don’t judge a book by the cover. You actually got to read it first.” Stacey felt like she fit in at her social group for people with disabilities, at bowling, at work, and around people she did and did not know. She stated: “I fit in everywhere. If they don’t like my attitude, they can

just hit the road.” She believed that people with disabilities need to ask others how to fit in and how to talk to people “because if people with disabilities don’t ask stuff, then they won’t fit in anywhere, not even in a public place.”

The young adults with ID felt a sense of belonging when people talked to them, they were treated similarly, and they had positive interactions with others. To help people feel like they belong, Barbara suggested: “Just talk to them to get to know them. See how their day went.” She felt like she was treated the same as others as an adult, though when she was in middle school, “people made fun of me ‘cause my clothes didn’t match or something.” Kara felt like she was a part of her group because “they treat people the same, don’t put people down.” Other times she felt she belonged were “when my mom give me a hug.” To make people feel happy and important, she suggested: “Maybe they could talk to them.” James, Joe, and Alec also expressed that they feel they belong more when people just talk to them. Daniel expressed that he did not talk very much around others and it would help him if others would talk to him: “When I can just listen and be quiet and speak when you’re supposed to and use nice language towards others.” Mark had similar thoughts: “It’s like, what am I supposed to say here? Once you get past ‘hi’, okay now what? If they strike up a conversation then I’m fine with that.” It was difficult for many young adults with disabilities to initiate conversations and get to know their peers. Dustin felt special because of the love his girlfriend shared with him: “She makes me feel special a lot and she’s so sweet to me.” When Stacy was out in the community, she felt like she belonged because: “They treat me with respect.” Mark felt like he was treated similar to other adults in the community though he has a visual impairment. He explained: “I’ll usually have my shades on, but that doesn’t really seem to bother people anyway because it’s daytime, and it’s not like I advertise that I’m visually impaired. ‘Cause then you get people grabbing your

shoulder, trying to guide you around everywhere.” Yesenia and two of her friends were switching teams for Special Olympics and the team invited her to go out to eat with them after a track meet: “I’m not even accepted in this team yet and we’re getting invited.” Alec could relate to people with and without disabilities: “A lot of people treat me as if I’m a normal person.” When he was taking college classes, he shared: “I had a real good support system with my classmates.” In his Special Olympics team, Alec felt like he belonged through “the friendships that we share just by being together, being teammates, and by that trusting each other to get a team job done.” At one point, Alec wanted to attend a retreat with his church, but did not have enough money. He talked to a church member about it and the man offered to pay for his whole trip: “That was the moment I really felt a sense of belonging that I don’t think I’ve ever felt before, ever.” He added: “It actually even felt so much that God wanted me there...Really adjusted my way of thinking for the better.”

Participants stated they did not belong when they were left out, ignored, and treated differently by others. They usually felt left out through the individual interactions they had with friends, family, and community members. Rachel felt left out “when everybody else does something that I can’t do.” There were some activities she did not participate in because she used a wheelchair: “This Thanksgiving they were going to do paintball. They were going to do this thing where I could stay on the deck and shoot people there...but they ended up doing it without me.” She was not able to play cards with her family most of the time because it was too complicated: “They like to play cards in the middle of the night and the only game I know is Pass the Trash, so they do that for me once in a while.” Daniel had friends who would make fun of him and call him names. He felt left out when his friends did not spend time with him. For example, he shared: “When people have parties, they don’t ever call me. When I had a party,



there was only two of us and the other people didn't even call me back.” Alec had begun to feel left out when his friends did not invite him to their weddings. He shared: “The only thing that I feel left out of is of late is weddings. No one invites me to weddings anymore. It's just a little awkward. Those kind of things you want to hug congratulations to both of them and it's kind of like, ‘oh, you did.’ Takes the excitement out of it.” In the community, people sometimes looked at Dustin like he was worthless. He responded: “I don't know why I get that, it just doesn't make sense. There's some days I don't get that at all. Some days where people just think I'm really cool.” He would get attitudes from others that were demeaning “as far as look or they'll just say something to me.” He also felt left out when his close friend or girlfriend made decisions or went places without telling him. He stated: “Sometimes someone will decide something...They'll just walk off and do something and not tell me anything.” Jessie also found: “There's some people that will just kind of look at you weird 'cause you did something a little bit different, like I have a habit of pacing back and forth while I'm waiting for the bus.” People have made fun of her “at the bus stop and sometimes places in the community, but I don't really pay attention to them. I just kind of blow them off.” Jessie also described how people were ignored because they could not communicate well: “Some people that...can't maybe speak totally 100% clear...sometimes the people in public and at stores, the people that work there, just ignore them. I just step in there and I'm like, ‘they're trying to talk to you’...I'm a straight up kind of person.” To help people feel like they belong, Barbara suggested: “Not making fun of them or something if they can't do something.” When Stacy was with her friends, people in the community made comments and indicated that there was something wrong with one or more of them. She shared: “They'll act like they don't know us or they don't want to know us.”

### *Self-Determination*

Young adults with ID felt included when they had skills in self-determination and were given opportunities to use those skills. To increase their self-determination, they took on responsibilities and became as independent as possible. The young adults took on personal responsibilities such as cleaning, cooking, running errands, handling money, and doing laundry. On the weekend, Shannon cleaned and organized: "I just get my things ready for the week. Get things cleaned up. I like to be organized." With assistance, Daniel takes responsibility for his money: "I go to the bank, but not with staff, they don't do that anymore...My mother takes me there." Rachel is also responsible for her own money: "I go shopping with my own money...I have my own bank account so I have a card and cash." Joe washed his bedding, took out the trash, and helped with the cooking at home. He explained his cooking preferences: "I don't like using the oven very much...I like microwave better 'cause I tried using one at the high school today and I didn't know how it worked...Sometimes I cook soup. I help my mom make pizza, the home-made pizza. I help her chop up ingredients." Stacy helped her supporting family shop for groceries and run errands. With her supporting family, Jessie explained: "We have assigned chores. I help with taking out the trash. We have a dog there, so I feed the dog and pick up around the house and clean my room, clean the bathroom, stuff like that." Alec also had assigned chores at his parents' house: "It depends on the day, but every week there's a set of chores for the family...Once in a while, I'll make the family dinner." He also folded clothes, vacuumed, cleaned the bathroom, washed dishes, and mowed the lawn. Kara shared: "I mostly walk the dogs 'cause they need the exercise." Her other responsibilities included: "laundry, dishwasher, wash dishes, clean up my room."

Young adults with ID became more independent when they were able to make their own plans and decisions. Daniel tried to lose weight and, because he lived on his own, shared: "It

will be all up to me to make the right choices.” He completed his menu planning on his own. James was able to be independent at his social club because he explained: “I can pretty much do it all.” Many of the young adults who lived on their own enjoyed more independence. James explained: “I don’t got to ask my mom permission for any visitors.” James also attended and shared his thoughts at his yearly planning meetings for his service provider. He planned to change one of the programs he worked on at his day program: “With the money program they have me recognizing the coins, the dollar bills. I pretty much have that down pat. I’m trying to get that out of my program.” With assistance from his staff, Mark decided to change jobs. He thought: “Why am I doing something I don’t really care about?” and realized, “It was basically just for the paycheck.” Mark believed: “If you are going to do something, do something you like.” He defended his stance: “Why tie yourself down to a job that you absolutely dread going to everyday?” Joe made the decision to take college classes so he can be a para-educator at an elementary school. He decided: “I kind of wanted not to be a dishwasher all my life. I kind of wanted to help little kids.” Dustin also made plans with guidance from his residential service provider coordinator. He acknowledged: “I have to keep my place clean, like if I want to get a house or something...It’s one of my goals, one of my coordinator’s goals...and he wants me to be set for life as far as having some place and, of course, if I want to get married down the road.” Stacy was an advocate for people with disabilities and suggested: “If people with disabilities want to change it up a little bit, they can ask and say: How do I change this? How do I change that? How do I go about keeping my friends?”

Some of the young adults with ID were leaders in the community and in their own lives. James and Stacy took a leadership class through their service provider and planned to help teach the class in the future. Stacey identified what she learned: “Since I did the leadership training

classes and I was teaching people, I can tell that people without disabilities can put themselves in people with disabilities shoes and be there for them if they need it.” James used his leadership skills in his ministry work as he sat on the board at his church and assisted his pastor: “I’m getting the word out.” Daniel participated in advocacy groups and events and identified himself as “a good leader and a good speaker.” Young adults with ID became leaders in their own lives when they made their own plans and voiced their thoughts and opinions. James worked on plans for his wedding and Dustin was making plans to move to a house and buy a car in the future. Stacy received more appropriate services to prepare her to live independently because her service providers listened to her and they understood that “she’s got a voice and she knows what she wants.” She found: “People with disabilities have a voice and they have a right to say what they want when they want it and the pros and cons of everything.” Stacy believed: “They have a right to get out there and sit on a board and have their voice heard because the people without disabilities don’t have to make up the person with disability’s mind.”

Young adults with ID expressed a need to be recognized for who they were as individuals. Mark referred to himself as a “starving artist” and enjoyed being an uncle. He admitted: “Yes, I’ve been the human jungle gym.” He has a teacher who told him that he was “a natural born story teller,” which Mark joked, “I think he meant it as a compliment.” Jessie valued honesty and respect. She saw herself as “a straight up kind of person” and lived by the motto, “you don’t have to like a person, but at least you can show them your respect.” Alec had an understanding of his disability and what it meant to him: “I’ll be honest; I have kind of a low form of Autism, kind of an Asperger’s Syndrome...I can’t exactly say I’m really, truly limited in what I can do. Now in terms of talents I am limited.” Shannon also communicated her own personality with honesty: “I like to be efficient...I really don’t have patience.” Some of the

young adults had been publically recognized. Daniel was on a committee for an advocacy group and received the Volunteer of the Year award. He had an article written in the newspaper about him including: “my apartment living and also my volunteer and now the job too.” Mark’s Special Olympics basketball team was interviewed on television: “That was really cool...My mom and dad recorded that and gave it to me.” This public recognition highlighted aspects of their lives and allowed people to see them for who they were as individuals.

### *Living Accommodations and Transportation*

Appropriate living accommodations enhanced the social inclusion of young adults with ID. Of the participants in the present study, seven lived with their parents, three lived in a house or an apartment with a roommate, two lived on their own in an apartment, and two lived with supporting families. James had physical adaptations made to his house, such as wider doors, to accommodate for his wheelchair, but still had difficulty using the kitchen thus he could not be totally independent. He shared that his mother is working on: “putting together a committee so we can build a new house that’s handicapped accessible.” Alec lived with his parents in a small town, which determined the activities available in close proximity to him. For example, he stated: “In the winter, it’s pretty quiet and there’s virtually nothing going on...The only things that are happening during the winter are grocery shopping, maybe an occasional eatery, and people filling their cars up with gas, and maybe an occasional bit antique shopping.” Stacy was placed with a supporting family through her service provider to help her become more independent as she worked towards living on her own. Stacy explained that they help her “learn how to go and shop for stuff, to get bargains, to balance money.”

Certain participants had support from their service provider staff so they could live in an apartment on their own or with roommates. Stacy had waited a long time to move out on her

own. She was excited about getting an apartment soon: “Before you know it, I’ll have a party of one.” Jessie also lived with a supporting family. She moved from a group home because her service provider thought that she had the social skills to move on, though she admitted: “I’m not quite ready to live on my own yet.” With her supporting family, she explained: “I basically get to do what I usually do everyday and I get to come and go as I please.” Mark lived next door to his Special Olympic teammates he saw all the time and wanted more privacy. He explained that to see his friends, “if I had to walk down the street or something...that’d be okay...That way it’d be a little more private.” He was also thinking about the next step in his life: “I’m kind of at that point in my life where I’m kind of starting to think about settling down.”

Other participants found that it was difficult to move to more independent living accommodations. Shannon lived with her mother and was not ready to move out unless she had support from staff. She identified her need for assistance: “[I am] vulnerable because I can’t make it on my own.” Living in close proximity to community amenities was important for many young adults with ID because they did not drive and were dependent on others for transportation. It was important for both Daniel and Mark to live close to a bus route, for example. Mark shared: “Wherever I would live, I would probably have to be on a bus route.” Dustin and Daniel enjoyed living close to places they go, such as grocery stores, hardware stores, restaurants, and department stores.

The young adults with ID used a variety of transportation options. Yesenia, Jessie, and Alec had a license and regularly drove. Many of the participants got rides from their parents or supporting family, and others used the public bus system to get around. Stacy had years of experience: “I’ve been taking the city bus for 23 years.” Barbara was “working on bus training” with her job coach. She believed this will help her because “if I don’t have a ride, I can ride the

city bus.” Darren also used the bus, but sometimes missed the last bus and had to walk home in the evening. Jessie shared: “I drive, but usually I take the bus a lot of places I go. But then since the bus only runs to six, if I want to do anything after that, like go to a friend’s house or just go out with friends, then I would be driving.” A few participants used a program through public transportation services, whereby people with disabilities could call ahead to schedule appointments to get rides in a van. Kara used this program regularly: “I call them each week.” In the evening, her parents drove her to activities because the van was only available during the day. For planned activities, James also used the program: “We have a van that we take, but we have to schedule it in advance.” The service allowed him to become more involved in the community, but he was still unable to go out if he needed to run errands or wanted to hang out with friends with short notice. To attend a social group for people with disabilities, Darren shared: “They got a van that comes for us every Thursday.” Dustin would like to get together with his family and spend time with his girlfriend more, but as he explained: “Mom doesn’t always have a way to get me there,” and with his staff, “The weekends are tricky as far as hours.” He planned to buy a car and learn how to drive so that “on the weekend, I could just pick up my girlfriend...instead of relying on staff to do that.”

Many of the participants received rides from their service provider staff to go to work, attend activities, and run errands. Daniel had staff drive him regularly to run errands: “She comes on Tuesdays and Thursdays.” Shannon got rides to her day program, job sites, and special events in the evenings from her service provider staff. Mark explained: “I’m visually impaired, so I can’t drive. John and I both have a lady from [our service provider] that comes in and basically is our chauffeur.” Without appropriate transportation options, it was difficult for young adults with ID to see friends and participate in activities. Shannon was not able to

volunteer on days her staff was sick because she did not have a ride. Rachel lived out of town and said it was difficult because of “access to a vehicle. Sometimes mom gets too busy to do stuff. I don’t know how to drive.” She shared: “Sometimes I don’t have a choice. I have to wait until mom goes shopping, and then I can go shopping.” Her job coach came to her house twice a week, which allowed her to do more activities out of the house. Sometimes they received rides from friends or their friends’ staff. Mark was on a Special Olympics team with his neighbor Joshua and shared: “Since I don’t have anybody to give me a ride to practice every week, it’s usually Joshua’s staff.”

### *Personal Skills and Resources*

A variety of personal skills and resources influenced the social inclusion of young adults with ID. These skills and resources included communication and planning, personal characteristics, accommodations, and assistance from others. Young adults with ID identified that communication and planning affected their social inclusion. Some participants would have spent more time with their friends if they had their contact information. Mark explained: “If we knew each other’s phone number or address or something, then we would probably hang out.” James also stated: “Most of my friends do not know where I live.” Some of the young adults had old friends they had not seen any more. Their friends might have lived in the same city or moved away, but they did not have their contact information. Rachel believed she had more freedom with her cell phone. She explained that, when she was shopping, “finally I could do certain things by myself, like if I get lost.” For example, she added: “Sometimes I like to look at stuff for a while and mom has to go shopping. It’s nice to have a cell phone to ask her which isle she’s in.” Alec entered many names in his cell phone and thought it would be useful “if I want to say ‘hey’ to a person or see if there’s a day that could work where we could just hang.” He



was hesitant to call his friends though because he did not want to be inconsiderate: “My own scary thing is I hate to call a person when they’re in the middle of something even though it’s not anyone’s fault.” For some young adults, having their own cell phone not only allowed them to communicate with friends but also gave them a sense of independence. Daniel proudly stated: “I have my own cell phone.” He was responsible for taking care of it and watching his minutes on his own. Shannon wanted a cell phone but stated: “That’s not going to happen because mom says ‘you don’t need a cell phone because you don’t call anybody.’ I would if I had it.”

Because of transportation issues and other conflicts, many young adults with ID needed more time to plan for activities. Kara could schedule time for dates because “my boyfriend calls me a week in advance.” James would have seen his friends more “if they called me ahead of time to let me know what they’re doing and if they want company. Then I know what going on and I can plan my schedule around that.” He received assistance from his mother and personal staff to plan his week: “I’m so busy that I got to work on my schedule.” Dustin missed opportunities to spend with his friends and family because he had difficulty keeping track of his schedule: “I always seem to forget stuff as far as birthday parties. I don’t write them down.” Mark was able to plan around his roommate John’s schedule easily: “John is a creature of habit. He’s totally set in his ways so you can pretty much bet that he’s going to do the same thing on Monday each week.” For other young adults, it was difficult to work around their friends’ schedules. Stacy explained: “Some days it’s hard to maneuver round their schedule and meeting up with them and just trying to make everything go.” Joe also had difficulty communicating with his friends and scheduling time together on days they did not have regular activities. He wanted to spend more time with them, but thought: “They might be busy on the other days.” Jessie found that some of her friends worked during the evening so they could not spend time

together, but others were still looking for jobs so they had more free time. A few of the young adults had many activities throughout the week and thus had difficulty scheduling additional activities. Stacy shared: “I’m kind of busy every weekend.”

The personal abilities and skills of the young adults with ID influenced their social inclusion. Jessie was able to live with a supporting family because she had sufficient social skills. She worked on her problem-solving skills so she could live on her own in the future and become more independent. Shannon did not want to move away from her mother unless she had staff from her service provider to assist her. She explained: “I can’t make it on my own by myself.” Rachel was dependent on her family for transportation and explained: “I don’t think I’m the type to drive. I get confused easily. I can follow directions pretty well, but I’m slow at it, like I do it step-by-step.” This situation limited her ability to go places in the community and meet new people. She was also not able to play most of the card games her family played because they were too complicated, so she had to just watch when they played cards. Jessie had friends who had difficulty with their speech and thus were ignored or made fun of in public. She also shared that “my reading scores are kind of low” so she was taking a class to improve her reading so she could get into college. Daniel felt like he was limited in his activities by his “health and medical” issues. He had knee problems which kept him from participating in most sports and had medication that made him tired during the day.

Many young adults with ID were limited in the activities they did because of money. Stacy shared: “I haven’t done ceramics for months because of money situations.” Some young adults were not able to go to movies, concerts, social activities, visit family, or go on vacations due to money issues. Mark enjoyed going to concerts at the State fair when he could, but admitted: “it’s not always affordable.” Jessie was also limited in her activities and could not

attend many concerts and simply stated: “Don’t always have the money for it.” Shannon had mixed feelings about her social group for adults with disabilities: “They do a lot of fun things...most of them take a lot of money, which I don’t really like that.” Dustin enjoyed activities that required money such as eating out, going to coffee shops, having cigars, and purchasing cologne. He shared: “If I’m not making enough money, I get in a sour mood.” Stacy wanted to move to an apartment on her own, but had to wait until she saved enough money from her part-time job: “Trying to save up money for my apartment. Just chilling out, trying to get that money coming in.” For a few participants, money was not an issue and they were able to participate in activities and special events. Rachel explained: “The money’s not a problem. I get a paycheck every other Friday so that works fine.”

The availability of accommodations and the arrangement of public and private spaces influenced the social inclusion of participants who used wheelchairs, had a visual impairment, or needed assistance navigating new places. Rachel used a wheelchair and was able to enter some public places easily. She indicated: “Some of those places have ramps or the sidewalks with the slant so that people can get in and they have the mechanical doors.” It was difficult for her, though, when she visited her family’s friends and they had to carry her and her wheelchair up and down stairs: “This chair is pretty heavy and with me in it, it’s doubly. I don’t like being carried.” James lived in a house specially made with wider doors for people in wheelchairs. He could move around the house, but it was still difficult for him to use the kitchen: “I thought it was going to be handicapped accessible, but it’s not really handicapped accessible.” Mark had a visual impairment and kept up with his reading using books on CD. He shared: “I used to get them on tape, now I get them on CDs.” Yesenia was able to travel by plane to visit family members because the airline assigned an escort to help her find her connecting flight. She

explained: “They had me and the seven-year-old wait until everyone got off and then we had an escort,” and added, “I could have gotten lost.”

The young adults with ID benefitted from the assistance they received from family members and their service provider. Parents of the young adults who lived at home cooked, cleaned, did laundry, and provided transportation. They helped the young adults learn how to budget their money, use the bank, and save for the future. Barbara indicated that her parents assisted her with “budgeting my money and saving up for stuff like moving out on my own someday.” Service providers provided a wide range of assistance for young adults with ID. They provided assistance at their home with cooking, cleaning, finances, and planning. Dustin’s residential coordinator took care of his finances for him: “It was kind of getting messed up at one point...The only thing I really do is keep the bills in the ledger.” When James moved to his house, he had to find his own staff to assist him with cleaning and cooking. Mark also shared: “John and I have a lady that comes every two weeks to take care of the cleaning, kind of like a maid service, and she’s actually the reason the place looks like it does.” They also taught the young adults skills to become more independent. Stacy’s supporting family taught her “how to go and shop for stuff, to get bargains, to balance money.” Jessie’s supporting family helped her practice problem-solving skills. She explained: “If I run into a problem living on my own, I’ll be able to handle it and not get as frustrated.” Rachel explained that her job coach tried “to teach me some life skills, like we do cooking...It’s pretty much any life skill that I need if I ever decide to move out.” Barbara shared: “My staff is helping me with my laundry and cooking in case I move out...and how to budget my money.” They also provided transportation and support to allow the young adults to enjoy leisure activities at home, participate in social and recreation activities, and to be active in the community. Barbara’s staff took her out in the community for

leisure activities such as going to the mall, fairs, and community plays. Daniel's personal staff took him to the store, played games with him, and helped him plan a party.

## CHAPTER 6

### DISCUSSION

The experiences of social inclusion for fourteen young adults with intellectual disabilities (ID) were the focus of this study. The social inclusion of the young adults with ID consisted of meaningful involvement in work, volunteer, social, recreational, and leisure activities; development and maintenance of reciprocal relationships; and the sense of belonging derived from accepting environments and the practice of self-determination. The young adults with ID had various experiences of social inclusion and exclusion. Their social inclusion was influenced by the contexts of their experiences including living accommodations, transportation options, personal abilities and skills, financial resources, assistance from family members, and assistance from service providers (see Appendix G). The themes identified in the present study aligned with the elements, contexts, and factors of social inclusion identified in previous studies (Abbott & McConkey, 2006; Hall, 2009; Mactavish, Mahon, & Lutfiyya, 2000).

Young adults with ID have many experiences of social inclusion similar to others their age. They have experienced a greater social inclusion because of the achievements of the disability community, including more physical access, access to education and jobs, easier access to disability services and information, accessible busses, and a consciousness of inclusion (McCarthy, 2003). Many of the young adults in the study lived away from their parents and strove to live as independently as possible. They learned, practiced, and took on personal responsibilities to become more independent at home and in the community.

Bigby, Fyffe, and Ozanne (2007) declared that young adults with ID should be able to live like others in the community and fulfill typical social roles. Participants in the study had valued social roles of family members, employees, volunteers, teammates, self-advocates,

leaders, and adults. Yet, the views of others, who did not understand or appreciate their abilities and contributions, limited many of the social roles of participants. Other limitations were lack of knowledge, minimal assistance from others, and inadequate accommodations and opportunities. The participants who assumed more social roles had more natural supports from their family and friends.

In line with Abbott and McConkey's (2006) findings, the young adults with ID in the study developed a sense of belonging when others accepted them. Participants reported they belonged around people who accepted their differences and treated them the same as others in the community. The study findings confirm that people with ID feel like they belong when they know people and when others talk to them. They feel like a part of the community when they know people at church, at places they go to regularly, and at businesses where their friends work. They feel like they do not belong when they are left out, ignored, always on their own, not able to fully participate, and not respected. Many of the young adults in the study have been made fun of and looked at differently because of their disability. The participants with ID in Mactavish, Mahon, and Lutfiyya's (2000) study viewed social inclusion as "the sense of belonging that emanated from the sharing of time, activities, and experiences with family and friends" (¶ 47), as well as the opportunity to enact valued social roles. The study's participants reflected these findings. The study added to the meanings young adults with ID ascribe to social roles, such as having personal responsibilities, individualized identities, and a voice.

According to Mactavish, Mahon, and Lutfiyya (2000), families are important providers of opportunities for social inclusion. Young adults with ID are able to work, participate in activities, and develop friendships because of the support they receive from their families, friends, and service providers. The families in the study provided transportation, identified

activities and special events to attend, and provided assistance when needed. They also provided opportunities for vacations and holiday celebrations. Their families or service providers assisted them with household responsibilities, handling and budgeting money, and being active in the community. Parents and service providers taught young adults with ID life skills to become more independent and solve problems in their daily lives.

In the workplace, young adults with ID experience frequent to no social interactions with coworkers (Butterworth, Hagner, Helm, & Whelley, 2000). Some participants in the study talked to and joked with their coworkers, while others worked alone and only knew their boss. A few participants developed friendships from work, though many viewed their coworkers as just acquaintances.

In the workplace, young adults with ID have limited employment opportunities and interactions with coworkers. None of the participants in the study had full-time employment and most of the participants held jobs consisting of low skills and low wages. Consistent with Vander Hart's (1998) study, many did not have the opportunity to interact with their coworkers in natural settings at lunch or on break because of their part-time status. The minimal interactions most young adults have with their coworkers make it difficult for them to develop relationships that cross over life areas or contexts (Butterworth, Hagner, Helm, & Whelley, 2000). Most of the participants did not interact with coworkers outside of their work environment.

People with ID are usually segregated from the mainstream of society, which limit the achievement of typical social roles for people with ID (Bigby, Fyffe, & Ozanne, 2007; Crane, 2002; Lemay, 2006). Young adults with ID tend to participate in social and recreation activities designed specifically for people with disabilities. They limit their recreation and social



interactions to their families. In the study, participants attended social groups each week specifically designed for people with disabilities. They were involved in the Special Olympics and attended segregated day programs with their service providers. Because they spend most of their time in segregated activities or with their families, most young adults with ID have few friends without disabilities. It was difficult for many of the participants to have privacy with their friends at times because they need transportation or other assistance from their parents or personal staff.

## CHAPTER 7

### IMPLICATIONS

The present study offers recommendations for service and care providers of young adults with ID as well as educators and community members. In particular, young adults with ID need to receive appropriate assistance and accommodations, continually learn to become independent, develop valued social roles, and have their voice heard in order to enhance their social inclusion.

Young adults with ID need appropriate assistance and accommodations. They need appropriate transportation options available during the day, in the evening, and on weekends. The participants suggested that additional transportation options should become available in the evenings and on weekends when there is no public transportation available. Natural supports such as family members, friends, church members, and teammates could provide transportation. Young adults with ID benefit when service providers have a variety of living accommodations available for them that are individualized to their specific needs. As young adults become more independent, they should be able to live in an environment with less assistance. Service providers and parents may provide information on the least restrictive living accommodations, assist them in identifying locations near key community amenities, assist them in deciding what changes to make, and offer support as they transition to their new living arrangements.

Employers need to be open to hiring people with ID for full-time positions and allowing them to advance in their careers. None of the participants in the study had full-time employment and thus had less time and fewer breaks with coworkers. Young adults with ID also benefit when employers help facilitate positive interactions between coworkers. For example, workplaces might have a common area for coworkers to eat lunch and take breaks together, provide recognition, encourage positive interactions, and offer opportunities to socialize outside

of work. Young adults with ID could also benefit when service providers assist them with obtaining and maintaining employment. Service providers could assist them with their application, interview, and transition to work. They could also provide the young adults with continued support and facilitate communication with employers.

Young adults with ID need assistance in learning about and getting involved in a variety of activities. Service provider staff could play an important role in identifying new activities and supporting them as they begin to participate in the activities. Staff may discuss options with the young adults with ID that fit their interests and abilities and possibly include their family members who know them well. Staff also may have the role of communicating with people in the community to increase their awareness of what they could do to accommodate for the needs of young adults with ID. Young adults with ID may also benefit when staff provide assistance in scheduling times to spend with their friends. Staff may help them organize get-togethers and parties, provide transportation, and work with the young adult on appropriate social skills.

Young adults with ID need to continually learn to become as independent as possible. Participants in the present study who were more dependent on others for transportation, assistance in communication, identifying activities to attend, and knowing how to act in different situations were less involved in the community. Similar to young adults with ID in Abbott and McConkey's (2006) study, participants in the study identified that teaching could enhance their social inclusion. Young adults with ID would benefit from the assistance of staff who teach them to become as independent as possible, to use behaviors that are appropriate in various environments, and to communicate with others in the community.

It is important for young adults with ID to have valued social roles. Service providers, families, and friends could provide them with valuable support to develop and maintain these

roles. They could talk to the young adults with ID about upcoming holidays, birthdays, vacations, and other family traditions in order to make preparations and practice appropriate social behaviors. To develop and maintain friendships, they could assist the young adults with ID in planning events, contacting friends, transportation, social skills, and developing ideas for activities to do with friends.

Self-advocacy is an important aspect of social inclusion. Hall (2005) found that those who have the knowledge and skills to advocate for themselves are better able to achieve social inclusion. Participants in the study determined that if people with ID wanted change, they should ask for it themselves. It was important for them to have a voice, make decisions for themselves, and influence change in the community. Parents and service providers can give them opportunities to voice their own opinions and decisions, make plans, and provide input. They can teach the young adults about their rights as well as skills to become self-advocates. Service providers and parents can also provide them with options and information in an accessible format to inform their decisions. With the support of family, friends, service providers, and members of the community, young adults with ID will be able to become self-advocates and have their voice heard.

People with ID benefit when they are included and have meaningful participation in elementary and secondary school. When they are placed in the least restrictive environment, teachers could insure that they are actively participating in activities and encourage positive social interactions with other students. Teachers could emphasize their abilities and the similarities they have with their classmates. They may also assist youth with ID and their classmates in communicating with each other, reducing misconceptions, and forming positive

relationships. The experiences youth have in school will allow them to better understand people with ID, communicate with them, and develop positive relationships with them as adults.

Faculty in higher education may enhance the social inclusion of people with disabilities by enhancing programs and developing knowledgeable future educators and leaders in the fields of disability and educational leadership. They could include disability awareness and social inclusion in the instruction of educational leaders who plan to work in a school system or lead programs in the community. Faculty may present strategies for future leaders to communicate with generic community organizations and businesses to include people with ID through simple accommodations. Instruction on how to include students with ID in the general and special education classrooms in meaningful activities and social interactions may be included in special education methods courses as well as information and strategies to assist them socially as they transition to their adult lives. Future educators would also benefit from knowing how families and community members could enhance the social inclusion of students and young adults with ID. They could share this information with family members and use what they have learned to enhance the education and transition plans of students with ID.

Meaningful involvement in generic community programs and organizations increases the social inclusion of young adults with ID. Church groups and other organizations could extend their outreach to include them in their generic activities. Members of the church and other organizations may become more intentional in making connections, developing friendships, and inviting people with ID to their activities. They could accommodate for the needs of people with ID by using plain language in an accessible format. Churches could provide opportunities for them to attend Bible studies, social groups, and special events. To include people with ID, they may provide accommodations such as simplified descriptions of concepts, visual aids, repetition

of concepts, and the use of plain language. They could also have a church member volunteer to introduce a person with ID to other people in the group, show them around, explain how the group usually interacts, answer their questions, and be a friend.

Awareness-raising is needed for young adults with ID to become more involved in the community. Community members need to become aware of the abilities, similarities, and individual identities of young adults with ID. Newspapers, television programs, business newsletters, and other sources of communication should be open to the voice of young adults with ID. Service providers may have the resources to provide information for and communicate with individuals, businesses, and organizations in the community to make them aware of what they can do to include and accommodate the needs of young adults with ID. Service provider staff have the opportunity to emphasize the abilities of young adults with ID. They can redirect community members who talk to staff instead of talking directly to the young adults with ID.

The social inclusion of people with ID is enhanced by research completed with their assistance. It is not only important for researchers to study issues related to people with ID but also to include them directly in forming research questions, collecting data, and verifying the accuracy of qualitative findings. Service providers, teachers, and family members have valuable perspectives and can provide important information to understand issues related to intellectual disabilities, but it is the voice of individuals with ID themselves that is essential to understanding their thoughts and experiences. Researchers could include people with ID in focus groups (Abbott & McConkey, 2006), conduct one-on-one interviews, or use visual aids and manipulatives to assist in gathering information. In an interview setting, researchers may accommodate the diverse abilities and needs of participants by meeting at locations convenient for them, reading the informed consent form aloud and providing explanations, viewing consent

as a process (Knox, Mok, & Parmenter, 2000), allowing flexibility in the duration and number of sessions of the interview, rephrasing questions and providing multiple probing questions, connecting concepts to concrete examples, reading transcripts aloud and making corrections with the participants to check the accuracy of the findings (Jones, 2007). Researchers may also need to obtain permission to access clients of service providers and receive consent from legal guardians before contacting potential participants if they are not their own legal guardian. The additional procedures and accommodations allow people with ID to participate in research and contribute to our knowledge. It is through the voice of people with intellectual disabilities that we will understand their experiences and have the wisdom to advocate for meaningful change.

## CHAPTER 8

### LIMITATIONS AND FUTURE RESEARCH

The qualitative nature of the research posed limitations of the study. The findings cannot be generalized because of the small number of participants and the context of the local setting. Future studies can explore the social inclusion of young adults with intellectual disabilities (ID) in different areas of the country, including rural and urban settings. Also, the sample included only young adults who had a mild or moderate ID. Future studies can explore the social inclusion of youth and older adults with ID, as well as people with severe/profound disabilities. Social inclusion is a complex and broad concept with multiple elements, settings in which it occurs, and influential factors. To understand the social inclusion of young adults with ID with greater depth, additional research should explore each element of social inclusion individually and focus on the factors that limit and enhance that social inclusion.

Conducting research with people who have disabilities can be difficult. They are a vulnerable population and research methods should be designed to accommodate for their needs and abilities. It can be difficult to gain access to people with disabilities; agencies and organizations keep their information confidential and additional procedures and permissions need to be aligned. I received permission from the cooperating service provider's Program Ethics Committee to conduct the present study. The directors of the service provider approached the young adults first and asked if I could contact them. Certain potential participants were not their own legal guardians. The directors contacted their guardians to ask permission for their young adult with ID to participate. I made no contact with the potential participant until after I received the legal guardian's permission.



Data collection may also need to be modified to accommodate the needs and abilities of the participants with ID. My interview protocol began with questions that were more concrete and led to more abstract questions. I then added probing questions to solicit additional in-depth information. It was important to keep the length of each interview flexible. As in Jones' study (2007), I regarded informed consent as a process. Many participants were able to complete the entire interview in one session, but some needed to meet for a second session because they became tired or had a lot more to share. The second interview sessions also allowed me to review the questions, clarify responses, and receive more in-depth information. Each additional procedure and modification made to include the young adults with ID in the research was essential to obtain their own thoughts and experiences. The voice of people with ID is the most important to identify their experiences and advocate for change.

The present study confirms that awareness-raising and opportunities to self-advocate can enhance the social inclusion of people with ID (Hall, 2005). Awareness-raising reduces the misconceptions community members have about people with ID, teaches them how to make accommodations, and emphasizes their similarities. Consistent with Abbott and McConkey's (2006) study, adults with ID are able to identify barriers to their social inclusion, as well as ways of reducing or removing those barriers. The participants in the study were open about their experiences of social inclusion and seemed to enjoy talking about their lives. Research with individuals with ID gives voice to that unique perspective.

## References

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*, 275-287.
- Ainsworth, P., & Baker, P. (2004). *Understanding mental retardation*. Jackson, MS: University Press of Mississippi.
- American Association on Intellectual and Developmental Disabilities. (2010). American Association on Intellectual and Developmental Disabilities: FAQ on Intellectual Disability. Retrieved March 6, 2010, from [http://www.aaidd.org/content\\_100.cfm?navID=21](http://www.aaidd.org/content_100.cfm?navID=21).
- American Association on Intellectual and Developmental Disabilities. (2007, September). AAIDD's Mission Statement. Retrieved October 17, 2008, from [http://www.aaidd.org/About\\_AAIDD/mission\\_statement.shtml](http://www.aaidd.org/About_AAIDD/mission_statement.shtml)
- Bigby, C., Fyffe, C., & Ozanne, E. (Ed.). (2007). *Planning and support for people with intellectual disabilities: Issues for case managers and other professionals*. Philadelphia: Jessica Kingsley.
- Blessing, L. A. (2004). Social integration, support and sense of community: Exploring the productive activities of persons with a cognitive disability (Doctoral dissertation, Queen's University at Kingston, Canada, 2004). *Dissertation Abstracts International, 66*, 1161.
- Butterworth, J., Hagner, D., Helm, D. T., & Whelley, T. A. (2000). Workplace culture, social interactions, and supports for transition-age young adults. *Mental Retardation, 38*, 342-353.

- Carrier, S. (2007). Understanding social and professional integration as an adjustment process: Contribution to a theory of coadaptation. *Intellectual and Developmental Disabilities*, 45, 10-22.
- Chadsey-Rusch, J., Linneman, D., & Rylance, B. J. (1997). Beliefs about social integration from the perspectives of persons with mental retardation, job coaches, and employers. *American Journal on Mental Retardation*, 102, 1-12.
- Crane, L. (2002). *Mental retardation: A community integration approach*. Belmont, CA: Wadsworth/Thomson Learning.
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (3<sup>rd</sup> ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.
- Creswell, J. W., Hanson, W. E., Plano Clark, V. L., & Morales, M. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist*, 35, 236-264.
- Dattilo, J., Hoge, G., & Malley, S. M. (1996). Interviewing people with mental retardation: Validity and reliability strategies. *Therapeutic Recreation Journal*, 30(3), 163-178.
- DeKraai, M. (2002). In the beginning: The first hundred years (1850 to 1950). In R. L. Schalock & D. L. Braddock (Eds.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 101-122). Washington, DC: American Association on Mental Retardation.
- Doll, E. A. (1953). *Measurement of Social Competence: A manual for the Vineland Social Maturity Scale*. Circle Pines, MN: American Guidance Service.

- Eliason, S. L. (1998). Social integration and satisfaction among individuals with developmental disabilities: A sociological perspective. *Education and Training in Mental Retardation and Developmental Disabilities*, 33(2), 162-167.
- Evans, E., Schere, M., & Rasmussen, K. (2002). Making it happen: The 1970s. In R. L. Schalock & D. L. Braddock (Ed.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 155-173). Washington, DC: American Association on Mental Retardation.
- Evans, J. H., Stork, W., & Phillips-Stork, E. (2002). Setting the course: The 1960s. In R. L. Schalock & D. L. Braddock (Ed.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 135-153). Washington, DC: American Association on Mental Retardation.
- Ferdinand, R., & Marcus, J. (2002). Doing what we had to do in the 1950s: Parents build the foundation. In R. L. Schalock & D. L. Braddock (Ed.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 123-134). Washington, DC: American Association on Mental Retardation.
- Gaylord, V., & Hayden, M. (1998). A decade later: Employment, residential, and social changes in the lives of adults and young adults with moderate and severe disabilities. *Policy Research Brief*, 9, 1-12.
- Gilson, S. F., & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education*, 38, 153-165.
- Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place*, 11, 107-115.

- Hall, S. A. (2009). The social inclusion of people with disabilities: A qualitative meta-analysis. *Journal of Ethnographic and Qualitative Research*, 3, 162-173.
- Hatch, J. A. (2002). *Doing qualitative research in educational settings*. Albany, NY; State University of New York Press.
- Herr, S. S. (1995). A humanist's legacy: Burton Blatt and the origins of the disability rights movement. *Mental Retardation*, 33, 328-331.
- Jaeger, P. T., & Bowman, C. A. (2005). *Understanding disability: Inclusion, access, diversity, and civil rights*. Westport, CT: Praeger.
- Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48, 719-729.
- Jones, M. M. (2007). An ethnographic exploration of narrative methodologies to promote the voice of students with disabilities. *Journal of Ethnographic & Qualitative Research*, 2, 32-40.
- Kavanaugh, K. (2002). Focusing on quality and opportunities: The 1980s. In R. L. Schalock & D. L. Braddock (Ed.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 175-203). Washington, DC: American Association on Mental Retardation.
- Keith, K. (2002). Promises to keep. In R. L. Schalock & D. L. Braddock (Ed.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 229-234). Washington, DC: American Association on Mental Retardation.

- Keogh, B. K., Bernheimer, L. P., & Guthrie, D. (2004). Children with developmental delays twenty years later: Where are they? How are they? *American Journal on Mental Retardation, 109*, 219-230.
- Knox, M., Mok, M., & Parmenter, T. R. (2000). Working with the experts: Collaborative research with people with an intellectual disability. *Disability & Society, 15*, 49-61.
- Lemay, R. (2006). Social role valorization insights into the social integration conundrum. *Mental Retardation, 44*, 1-12.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage.
- Linneman, R. D. (2001). *Idiots: Stories about mindedness and mental retardation*. New York: Peter Lang.
- Lunsky, Y., & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research, 45*, 106-114.
- Mactavish, J. B., Mahon, M. J., & Lutfiyya, Z. M. (2000). "I can speak for myself:" Involving individuals with intellectual disabilities as research participants. *Mental Retardation, 38*(3), 216-227.
- McCarthy, H. (2003). The disability rights movement: Experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin, 46*, 209-223.
- McClimens, A. (2003). The organization of difference: People with intellectual disabilities and the social model of disability. *Mental Retardation, 41*, 35-46.
- McConkey, R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research, 51*, 207-217.

- McConkey, R., Walsh-Gallagher, D., & Sinclair, M. (2005). Social inclusion of people with intellectual disabilities: The impact of place of residence. *Irish Journal of Psychological Medicine*, 22, 10-14.
- Merrill, D. (2002). Adjusting to change: The 1990s. In R. L. Schalock & D. L. Braddock (Ed.). *Out of the darkness and into the light: Nebraska's experience with mental retardation* (pp. 205-218). Washington, DC: American Association on Mental Retardation.
- Middleton, R. A., Rollins, C. W., & Harley, D. A. (1999). The historical and political context of the civil rights of persons with disabilities: A multicultural perspective for counselors. *Journal of Multicultural Counseling & Development*, 27, 105-120.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Nebraska Department of Education. (2006). Regulations and standards for special education programs. Title 92, Nebraska Administrative Code, Chapter 51.
- Partington, K. (2005). What do we mean by our community? *Journal of Intellectual Disabilities*, 9, 241-251.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.
- Pedlar, A., Haworth, L., Hutchison, P., Taylor, A., & Dunn, P. (1999). *A textured life: Empowerment and adults with developmental disabilities*. Waterloo, Ontario, Canada: Wilfrid Laurier University Press.
- Pugach, M. C. (2001). The stories we choose to tell: Fulfilling the promise of qualitative research for special education. *Exceptional Children*, 67, 439-453.

- Riches, V. C., & Green, V. A. (2003). Social integration in the workplace for people with disabilities: An Australian perspective. *Journal of Vocational Rehabilitation, 19*, 127-142.
- Vander Hart, N. S. (1998). Social interactions between supported employees and their non-disabled co-workers in integrated work settings: Perceptions of supported employment professionals. (Doctoral dissertation, The University of Iowa, 1998). *Dissertation Abstracts International, 59*, 1795.
- Wistow, R., & Schneider, J. (2003). Users' views on supported employment and social inclusion: A qualitative study of 30 people in work. *British Journal of Learning Disabilities, 31*(4), 128-135.
- Yazbeck, M., McVilly, K., & Parmenter, T. R. (2004). Attitudes toward people with intellectual disabilities. *Journal of Disability Policy Studies, 15*, 97-111.



## Appendix A

## INTERVIEW PROTOCOL

## Social Inclusion of Young Adults with Intellectual Disabilities

Participant name \_\_\_\_\_

Location \_\_\_\_\_

Date &amp; time of interview \_\_\_\_\_

**Consent and Introduction**

I appreciate you taking the time to talk with me today. I am a student at UNL and am studying the social inclusion of young adults with intellectual disabilities. Social inclusion is being involved in activities, having relationships with others, and feeling like you belong.

Before we begin, I would like to read the informed consent form to you and answer any questions you have about the study. This form describes the study. If you agree to participate, you will sign your name at the bottom.

*Read the informed consent aloud. Briefly describe each section. Questions?*

*Signed consent form received?* \_\_\_\_\_

I will voice record the interview so I can have a record of your thoughts.

Do you agree to have the interview voice recorded? \_\_\_\_\_

To review:

Who will I tell your answers to? (Nobody.)

Will anyone be mad at you if you don't want to do this or if you stop? (No.)

If there is a question you do not want to answer, say, "I don't want to answer."

If you do not want to answer any more questions, say, "I am finished."

The interview may take about one hour today and one hour tomorrow to complete.

If you need a break at any time, say, "I need a break."

I am interested in hearing your thoughts and learning about your own experiences of social inclusion. I will ask you about the activities you do, your relationships with friends and family, and how you feel like you belong.

Do you have any questions before we begin?

Participant pseudonym \_\_\_\_\_

Disability verification \_\_\_\_\_

Age \_\_\_\_\_

### Background Questions

First, I would like to know a little about you.

1. What do you do during the day? Do you work, go to school, or go to a day program?

*Work: (volunteer) days/hours, where, jobs/responsibilities*

*School: full/part-time, assistance/accommodations, school name, objective*

*Day program: days/hours, activities, jobs, What do you do there?*

2. Tell me about where you live.

*House/apartment, with whom*

*What do you do at home? -Responsibilities, for fun, support from staff*

*Are you close to places you go? (Work, activities, restaurants, shopping)*

3. What do you like to do for fun? What things are you interested in?

### Involvement

A part of social inclusion is being involved in activities and going to events. Some people play sports, volunteer, play cards or other games, go to church groups or events, see concerts, shop, walk in a park, or go to fun events in the community.

4. What activities do you do in the evenings or on weekends?

What do you do when you go out (in the community)?

*Sports, social groups, church, volunteer, recreation centers*

*Parks, walk, shop, movies, eat out, coffee house, music concerts*

*Camps, vacations, holidays, fairs, festivals, community events*

*Groups- Art, craft, sing, bake, animal therapy*

*Visit family/friends, have friends over, spend time with roommates*

*How often? How do you get there? How do you know about them?*

*What do you do in each activity?*

*Who do you do these activities with? (People with/without disabilities?)*

5. What helps you become more involved (participate) in activities?

*Who helps you do things at your activities? What do they do?*

*What do you use to help you do things?*

*What helps you do as much as everyone else?*

6. What keeps you from participating (taking a part / being involved) in activities?

*Are there things you can't do at your activities?*

*What keeps you from doing more in your activities?*

*What keeps you from knowing about / signing up for activities, going places?*

7. What other activities would you like to do?

*Are there enough activities/opportunities for you?*

*What would help you do these activities?*

8. What would help you do more activities? What would help you become more involved in your activities?

*What could help you find out about more activities?*

*What could help you get to more activities?*

*How can (your service provider/family/friends) help you?*

### Relationships

The relationships we have with family, friends, and the people around us are also a part of social inclusion.

9. Who are your friends? What do you do with your friends?

*Where did you meet your friends?*

*Do you have close friends?*

10. How often do you see your family? What do you do with them?

11. Do you know your neighbors? Do you know other people in the community?

*Who? What do you say to each other? What do you do with them?*

*How do they treat you?*

12. What keeps you from spending (more) time with your friends and family?

13. What helps you make friends? What helps you spend time with them?

*What could help you meet new friends?*

*How can (your service provider/family/friends) help you?*

### Belonging

Feeling like you belong is also a part of social inclusion. When you feel like you belong, you feel like you are a part of the group, you fit in, you have a say, and you are important. People are nice to you, talk to you, ask you to do things, and help you.

14. Where do you feel like you fit in? Do you feel like you fit in at your (home, work, activities, community)?

*Where do you feel like you are important / have a part / have a say?*

*What makes you feel that you fit in?*

*What happens? Give me an example.*

15. Where do you feel like you do NOT fit in? (Home, work, activities, community)

*Where do you feel like you are NOT important / have a part / have a say?*

*What happens? Describe something that happened.*

*What keeps you from feeling like you fit in?*

16. How can people at your (home, work, activities, community) help you feel like you fit in?

*What can people do differently to help you feel like you fit in / are important / are a part of the group?*

*What other things should change to help you feel like you fit in?*

Thank you for your time. I appreciate hearing your thoughts and stories.

## Appendix B

## TABLE OF PARTICIPANT CHARACTERISTICS

## Participant Characteristics

Pseudonym	Age	Guardian	Living Arrangements	Work/Volunteer*
James	24	Own	House- 3 roommates Physical accommodations Staff- evenings	Day Program Teach class
Darren	32	Own	Apartment- 1 roommate Staff- evenings & weekends	Grocery store
Mark	35	Parent	Apartment- 1 roommate Service provider clients in surrounding apartments Staff- twice a week	Art- commissions & volunteering
Shannon	32	Own	Parent Staff- 2 evenings/week	Day program- office work Restaurant- napkins, tables, windows Deliver mail at hospital
Daniel	32	Parents	Apartment- on own Staff- 2 evenings/week	Gas station cleaning Thrift store volunteer
Kara	22	Own	Parents	Grocery store, bag groceries Chapel volunteer
Rachel	28	Own	Parents	Fold pizza boxes 1 day a week Working on vocational skills
Joe	23	Parents	Parents	College student, part-time School cafeteria
Stacy	32	Own	Supporting Family	Restaurant
Jessie	27	Parents	Supporting Family	College student, part-time Looking for a job
Barbara	24	Own	Parents Staff- 3 evenings/week	Fast food restaurant Volunteer- cleaning once a week
Dustin	29	Own	Apartment- on own Staff- evenings & weekends	Day program- minimal reception work Looking for a job
Alec	22	Own	Parents	Department store freight worker Respite services
Yesenia	28	Own	Parents	Respite services Public school transportation services Summer camp & childcare

\* All work and volunteer positions were part-time.

## Appendix C

### YOUNG ADULT INFORMED CONSENT FORM

#### **SOCIAL INCLUSION OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES**

You are invited to participate in this research study. The following information is provided in order to help you make an informed decision whether or not you would like to participate. If you have any questions please do not hesitate to ask.

The purpose of this study is to describe the experiences of social inclusion for young adults with intellectual disabilities. For this study, social inclusion will be defined as involvement in activities, developing and maintaining reciprocal relationships, and having a sense of belonging. I want to see how you and other people can be more involved in activities, make friends, and feel like you belong. You are eligible to participate in this study because you have an intellectual disability and are between 21 and 35 years old.

To do the study I will meet with you for about 45 minutes to an hour on each of two different days. I will ask you questions about what activities you do, your friends, and where you feel like you belong. We will meet at a place where you will be comfortable, such as a conference room at your work or day program. I will record what we say, so I can listen to it later. If you need to take a break or want to stop, we can do that at any time.

There are no known risks associated with this research.

The information obtained from this study may help us to better understand the experiences of social inclusion for young adults with intellectual disabilities. It may also help us understand the barriers they face and what changes can be made to increase their social inclusion.

Any information obtained during this study, which could identify you, will be kept strictly confidential. I will not share any of your personal information with anyone. I will not use your name or the names of your family or friends. The audio-recordings will be erased after the transcriptions have been typed. The transcriptions will be kept in a secure file in the investigator's residence for three years and then will be destroyed. The information obtained in this study may be published in scientific journals or presented at scientific meetings, but your identity will be kept strictly confidential.

Your rights as a research participant have been explained to you. If you have any questions about the study, please contact me, Sarah Hall, at (402) 613-2543. If you have any questions about your rights as a research participant that have not been answered by the investigator or to report any concerns about the study, you may contact the University of Nebraska-Lincoln Institutional Review Board (UNL IRB), telephone (402) 472-6965.

You do not have to be in this study if you do not want to. If you decide to participate in this study, you can withdraw at any time without adversely affecting your relationship with the

investigator, the University of Nebraska- Lincoln, or your service provider. Nobody will be upset if you do not want to participate.

If you have questions at any time, please ask me.

### **DOCUMENTATION OF INFORMED CONCENT**

**You are voluntarily making a decision whether or not to participate in the research study. If you sign this form it means that you have decided to participate and understand everything that is on this form. You will be given a copy of this form to keep.**

\_\_\_\_\_  
Signature of Young Adult

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

### **IDENTIFICATION OF INVESTIGATORS**

Primary Investigator

Sarah A. Hall (402) 613-2543

Secondary Investigator

Marilyn L. Grady, Ph.D. (402) 472-0974

## Appendix D

### LEGAL GUARDIAN INFORMED CONSENT FORM

#### **SOCIAL INCLUSION OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES**

You are invited to permit your young adult to participate in this research study. The following information is provided in order to help you make an informed decision whether or not to allow your young adult to participate. If you have any questions please do not hesitate to ask.

Your young adult is eligible to participate in this study because he/she has an intellectual disability and is between the ages of 21 and 35. Your young adult will also be asked if he/she is willing to participate.

The purpose of this study is to describe the experiences of social inclusion for young adults with intellectual disabilities. For this study, social inclusion will be defined as involvement in activities, developing and maintaining reciprocal relationships, and having a sense of belonging.

This study will take approximately 45 minutes to one hour of your young adult's time on each of two consecutive days. I will conduct two short interviews with your young adult about his/her experiences of social inclusion. The interviews will take place at a location that is convenient for your young adult, and may be a conference room located at his/her work or day program. The interview will be voice recorded.

There are no known risks associated with this research.

The information obtained from this study may help us to better understand the experiences of social inclusion for young adults with intellectual disabilities. It may also help us understand the barriers they face and what changes can be made to increase their social inclusion.

Any information obtained during this study, which could identify your young adult, will be kept strictly confidential. The audio-recordings will be erased after the transcriptions have been typed. The transcriptions will be kept in a secure file in the investigator's residence for three years and then will be destroyed. The information obtained in this study may be published in scientific journals or presented at scientific meetings, but your young adult's identity will be kept strictly confidential.

Your young adult's rights as a research participant have been explained to you. If you have any additional questions about the study, please contact me, Sarah Hall, at (402) 613-2543. If you have any questions about your young adult's rights as a research participant that have not been answered by the investigator or to report any concerns about the study, you may contact the



University of Nebraska-Lincoln Institutional Review Board (UNL IRB), telephone (402) 472-6965.

You are free to decide not to enroll your young adult in this study or to withdraw your young adult at any time without adversely affecting his/her or your relationship with the investigator or the University of Nebraska-Lincoln.

#### **DOCUMENTATION OF INFORMED CONCENT**

**You are voluntarily making a decision whether or not to allow your young adult to participate in the research study. Your signature certifies that you have decided to allow your young adult to participate having read and understood the information presented. You will be given a copy of this consent form to keep.**

\_\_\_\_\_  
Young Adult's Name

\_\_\_\_\_  
Signature of Legal Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

#### **IDENTIFICATION OF INVESTIGATORS**

Primary Investigator

Sarah A. Hall (402) 613-2543

Secondary Investigator

Marilyn L. Grady, Ph.D. (402) 472-0974

## Appendix E

## LEGAL GUARDIAN INVITATION LETTER

Name of legal guardian  
Address line 1  
City, State, Zip code

“Social Inclusion of Young Adults with Intellectual Disabilities”

(Date)

Dear (name of legal guardian),

I am a doctoral student at the University of Nebraska-Lincoln and am conducting a study to understand the social inclusion of young adults with intellectual disabilities. The following information is provided for you to decide whether you wish to allow your young adult to participate in the present study. You and your young adult are free to decide not to participate in this study or to withdraw at any time.

(Service Provider) has given permission to conduct this study. I will interview young adults with intellectual disabilities to better understand their experience of social inclusion and to identify factors that limit or enhance their social inclusion. Your young adult’s input and perspectives are important for this study.

I would like to meet with your young adult for an interview on two consecutive days for 45 minutes to one hour at a time. I will meet with your young adult in a conference room at (Service Provider) or at another location that is comfortable and convenient for him/her. The interview will be audio-recorded. Your young adult’s name will not be associated with the research findings in any way, and only the principal investigator will know his/her identity as a participant.

Do not hesitate to ask any questions about the study before allowing your young adult to participate or during the study. You may contact me at (402) 613-2543 if you have any questions or concerns about the study.

If you agree to allow your young adult to participate in this study, please sign and date the informed consent form and return it in the self-addressed, stamped envelope included in this mailing. Upon receiving your signed informed consent form, I will schedule the interview with your young adult.

Thank you for your consideration to allow your young adult to participate in this study.

Sincerely,

Sarah A. Hall  
Principal Investigator  
(402) 613-2543

## Appendix F

## TABLE OF THEMES AND MEANING UNITS

## Themes and Meaning Units

<b>Themes</b>	<b>Clustered Meaning Units</b>	<b>Meaning Units (Codes / Invariant Constituents)</b>
Work & Volunteer	Paid Employment  Alternative Opportunities  Job Coach Assistance Workplace Interactions	Work Future Goals Education & Experience Day Programs Volunteer Job Coach Interactions
Social, Recreational, & Leisure Activities	Social Groups Church Recreation  Free-Time Activities   Special Events  Holidays & Vacations  Becoming Involved	Social Groups Church & Bible Study Structured Recreation Unstructured Recreation Free-Time Free-Time at Home Free-Time Hobbies Free-Time in the Community Community Events Parties & Get-togethers Holidays Vacations Additional Interests Getting Involved
Reciprocal Relationships	Community Members  Family  Friends	Community Interactions Neighbor Interactions Family Family Interactions Time with Family Friends Making Friends Significant Others Friends with & without Disabilities Time with Friends Interactions with Friends
Accepting Environments	Contexts of Belonging  Negative Interactions  Positive Interactions	Places & Activities Knowing People Fitting in & Accepting Differences Left Out & Ignored Negative Situations People Talk to Them Treated Similarly Positive Interactions
Self-Determination	Personal Responsibilities	Responsibilities Independence

	Having a Voice  Individualized Identities	Leadership Making Own Plans Taking the Initiative Having a Voice Individuality Public Recognition
Living Accommodations & Transportation	Living Accommodations  Transportation	Living Accommodations Proximity to Living Accommodations Transportation Transportation Difficulties
Personal Skills & Resources	Personal Skills  Resources	Communication Planning Activities Personal Abilities & Skills Money Accommodations Family Assistance Service Provider Assistance

## Appendix G

## TABLE OF SOCIAL INCLUSION EXPERIENCES

**Young adults with ID experienced limited social inclusion when:**

- they could not drive thus depended on others for transportation.
- they could not take the city bus in the evenings or on weekends.
- their living accommodations did not have enough support or were too restrictive.
- physical accommodations were not available for people who used wheelchairs.
- they did not have enough money to participate in activities, take vacations, or live on their own.
- they worked part-time and did not spend time with coworkers.
- employers did not communicate with them clearly.
- their friends or family left them out of activities and conversations.
- they only spent time with people with disabilities at work, home, and recreation/leisure activities.
- they did not have privacy with friends and significant others or on their own.
- they only had superficial conversations with others and are not able to form friendships.
- they did not have skills or assistance to plan social events with their friends.
- they did not use appropriate social behaviors around people.
- they did not have contact information for their friends.
- they spent most of their free time with staff or parents.
- people made fun of them, called them names, and looked at them differently.
- community members avoided or ignored them.

**Young adults with ID experienced greater social inclusion when:**

- service providers were available to provide frequent transportation.
- they lived in accommodations that allowed them to be as independent as possible.
- services and accommodations were available such as escorts at airports, audio-books, and ramps.
- service providers helped them study for college, learn job skills, and find employment.
- high school transition programs helped them learn vocational skills and secure jobs.
- their job coach took them to events and activities in the community.
- family provided transportation, assistance with daily living tasks, and guidance when needed.
- they shared in family traditions.
- parents and service providers identified activities to attend.
- their service provider, parents, or friends took them on vacation.
- others organized and drove them to get-togethers with friends.
- they were able to be independent during recreation/leisure activities.
- they learned how to problem-solve, budget money, plan meals, and access transportation.
- they talked to friends and family on the phone or communicated through email.
- they knew and greeted people in the community they saw often such as bus drivers and pastors.
- community members and coworkers talked to them and treated them similar to others.
- they spent time with coworkers on break or outside of work.
- neighbors talked to them and included them in neighborhood parties.
- they were included in Bible studies and church activities.
- they took part in generic bowling and dart leagues.
- they were involved in sports and social groups for people with disabilities.
- they were on boards and held leadership positions.
- they were in advocacy groups and given opportunities to self-advocate.
- they were recognized as individuals with their own personality, skills, and interests.