

EXPLORING THE EVERYDAY LIFE INFORMATION
NEEDS, PRACTICES, AND CHALLENGES
OF EMERGING ADULTS WITH INTELLECTUAL DISABILITIES

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ABSTRACT

DANA HANSON-BALDAUF: Exploring the Everyday Life Information Needs, Practices, and Challenges of Emerging Adults with Intellectual Disabilities
(Under the direction of Dr. Sandra Hughes-Hassell)

This dissertation research addresses a gap in the library and information science literature on everyday life information (ELI) needs and experiences of emerging adults with intellectual disabilities (I/DD). Emerging adulthood refers to the period between the late teen years and mid-twenties. Although this is a period of significant change for all young people, for individuals with I/DD this life stage is recognized as one of the most stressful times of life. The challenges experienced by these individuals suggest considerable areas of information need. This case study research explored the ELI needs, practices, and challenges of four emerging adults with I/DD. Employing a participatory research approach, participants played a central role in the inquiry process by offering time, input, and invitations into their daily lives for observation and study. Data collection methods included semi-structured interviews, participant/non-participant observations, artwork, photography, and document review of IEP and PCP reports. Analyses revealed four rich and multifaceted lives led by individuals exhibiting a wide range of both formidable and whimsical ELI needs. Twenty-nine categories of ELI need were identified, including multiple subcategories. All four participants displayed high motivation and great initiative in their ELI practice as information seekers, consumers, producers, managers, and providers. They also employed a wide range of tools, resources, and strategies to their advantage, despite considerable challenges - inherent and imposed. Barriers inhibiting information access were identified under the

following categories: intrapersonal, physical, economic, social, and institutional. Results from this study parallel findings from other youth-ELI studies. The need for cognitively accessible information and proactive LIS service was underscored in each case study as a necessary mean toward supporting the developmental processes of emerging adults with I/DD and the development of knowledge, skills, and dispositions for self-actualization and enhanced adult life outcomes. A person-centered, outcomes-oriented model for LIS research and practice is proposed with emphasis on a strengths-based approach that capitalizes on individual capabilities, interests, and life priorities in recognition of the whole person. Five target areas are identified for LIS attention: individual capacity building, social capital, developmental processes, quality of life, and enabling environments.

In loving memory of my dad, David Allen Hanson.

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Chapter 1 Introduction

Each man's life means everything,
Or it means nothing.
He is the only man,
Or no man exists.
Each life and each death
Is a profound event,
Or no life - not a single life ever -
Was of any consequence.
Everything matters or nothing has mattered.

Burton Blatt, *Man through a Turned Lens*

Recent research on adult life outcomes for individuals with intellectual and developmental disabilities (I/DD) portray a dismal and unwelcoming future for our youth with I/DD. High unemployment, poor health outcomes, increased rates of victimization, community exclusion, weak social networks, and increased mental health difficulties - particularly depression - are some of the most troubling issues experienced by many adults with I/DD. These challenges suggest innumerable unaddressed everyday life information needs. Although individuals with I/DD have long been acknowledged as both an underserved and underrepresented population in the library and science (LIS) research literature, minimal effort has been made by the LIS community to address and rectify this neglect (Casey, 1971; Mendel 1995; Jaeger, Bertot, and Franklin 2010).

Targeting the life stage of emerging adulthood, this dissertation study explores the everyday life information (ELI) needs, practices, and challenges of four young people with I/DD: Jack, Marie, Ben, and Bella. This chapter provides the problem statement, outlines the study aim, and presents three questions guiding this inquiry. A glossary of frequently

used terms and acronyms applied in the reporting of this study can be found at the end of the chapter.

1.1 Problem Statement

Francis Bacon's (1597) adage, *knowledge itself is power*, speaks directly to the influence of information in our daily lives and the great advantage of one's ability to access, understand, and use information to construct meaningful outcomes. Gains may include satisfied curiosities, an expanse of interests, greater depth of knowledge, increased self-awareness, deeper spirituality, a healthier lifestyle, social acclimation, the development of new skills, employment and increased wealth, opportunities for fun and adventure, and other new life possibilities. For individuals with I/DD, however, these gains are often unrealized. The scarcity of cognitively accessible information has become a recurrent theme in I/DD literature and identified as a detrimental factor in life quality (Stewart, Freeman, Law, Healy, Burke-Gaffney, Forhan, Young, & Guenther, 2009; Yalon-Chamovitz, 2009; Karreman, Van der Geest, Buursik, 2007; Salmi 2007; Tarleton & Ward, 2005; Britz 2004; Edyburn, 2002).

This dissertation research focused specifically on the ELI needs, practices, and challenges of individuals with I/DD during the life stage of emerging adulthood. Emerging adulthood refers to the time period between late teen years and mid-twenties. Although a time of significant change for all young people, for individuals with I/DD this age period is recognized as one of the most stressful and uncertain times of life. While many young people with I/DD experience a less than ideal school experience, the school day still offers a place to go, daily structure, a social outlet, and fairly dependable supports and services. With the transition to post-school life, their lives change drastically. Parents of young people with I/DD commonly struggle to find ways to fill the void of school with few options. While

post-secondary education opportunities for young people with I/DD are expanding, these programs are often cost-restrictive. For individuals hoping to move into employment after graduation, prospects for employment in the general workforce are minimal and for many, sheltered employment workshops intended to help individuals with disabilities to develop viable work skills offer less than desirable options with mundane work tasks, segregated environments, and meager pay. Individuals with I/DD also often have difficulty connecting with others and experience reduced social opportunities once away from the school setting, as most are highly dependent upon others for transportation. All of these challenges negatively influence emotional and physical health and have significant implications for future life outcomes and overall quality of life.

Understandably, much of the I/DD research literature on young people during this stage of life has focused on their transition-related needs and efforts to promote positive adult life outcomes. However, less attention has been given to the developmental process of emerging adulthood for this population, with little reported about their needs as teens and young adults. Conversely, LIS researchers have made great gains in understanding and addressing the developmental-related information needs of neurotypical teens and young adults. Teens and young adults with I/DD are largely absent from this research, however. Moreover, little is known about the everyday life information needs, practices, and challenges of this population in general.

Norlin (1995) speculated on the lack of research related to individuals with I/DD and suggested that some researchers may hold research-inhibiting assumptions about this population.

The absence of appropriate studies may be accounted for by one or more of several

assumptions. Adults with mental retardation are (1) assumed to have no information needs; (2) perceived as being unable to use any information provided; (3) believed to have the same information needs as the general public; or (4) assumed to have information needs too costly to assess and meet. (p. 182).

Matysiak (2001) noted that researchers may have difficulty gaining access to potential research participants with I/DD without a personal connection. She also cited perceived difficulties gaining informed consent and potential ethical issues as possible reasons researchers have not engaged individuals with I/DD in research initiatives. Others have also suggested that researchers may hold general perceptions that individuals with I/DD are unable to adequately reflect on and articulate their experiences and therefore cannot contribute to the research process in meaningful ways (Turner, 1980; Norlin, 1995; Matysiak, 2001).

Historically, researchers conducting studies relating to individuals with I/DD have relied upon what Becker (1967) referred to as a “hierarchy of credibility”, consulting the highest ranked members involved with the studied population rather than the individuals themselves. This included administrators of residential institutions, doctors and other medical staff. Viewpoints by individuals with I/DD were (and continue to be) largely unsolicited or ignored and their representation in research has been informed by a medical model of I/DD that has perpetuated societal notions that they are deficient, in need of “fixing”, worthy of pity, and unable to care for themselves. In recent years, disability rights advocates have called for a more authentic representation of individuals with I/DD in research. Participatory research has been promoted as a means toward this goal, asserting individuals with I/DD as the primary experts on their own lives, capable informers, and

essential contributors to the research process.

1.2 Aim of Study

The purpose of this exploratory study was to examine the ELI needs, practices, and challenges of four young people with I/DD. A participatory research approach was employed, purposely designed and implemented to engage participants in the inquiry process in effort to best capture their individual voices, perspectives, and lived experiences. Given the historic underrepresentation of individuals with I/DD in research and prevalent societal misperceptions of I/DD, three principles grounded the inquiry process:

1. The individual is an expert on his/her own life. As such, his/her voice has value and must be an integral part of the research process (Matysiak, 2001; Lloyd et al., 2006).
2. Disability, as a conceptual understanding, refers to the impairment itself and the functional challenges inherent as a result of impairment, as well as the obstacles encountered as a result of society's response to the impairment (Brandt & Pope, 1997; Verbrugge & Jette, 1994; Pope & Tarlov, 1991).
3. People are unique. Unique in their histories, lived experiences, strengths and weaknesses, preferences and distastes. The construct of disability offers only a limited scope of commonality with regard to individuals, life experiences, and needs (Smith, 1987; Rogers, 1980).

1.3 Research Questions

1. What are the everyday life information needs of emerging adults with intellectual disabilities?
2. What are the everyday life information practices of emerging adults with

intellectual disabilities? What tools/resources/strategies do they commonly use to address their everyday life information needs?

3. What are the everyday life information challenges of emerging adults with intellectual disabilities?

1.4 Glossary of Key Terms

Adaptive behavior: Significant limitation in two or more everyday life skill areas (self-care, social skills, health and safety, academics, leisure activity, employment, etc) (American Association on Intellectual and Developmental Disabilities, 2010, pp. 43-55).

Adaptive physical education: A federally mandated program enacted under IDEA 1990 and defined by the National Consortium for Physical Education and Recreation for Individuals with Disabilities as “physical education which has been adapted or modified, so that it is as appropriate for the person with a disability as it is for a person without a disability” (Adapted Physical Education Standards, 2008).

Autism: A neurobehavioral disorder, typically identified by the age of three, influencing language development and communication skills, social interactions, cognitive processing, and behavioral traits (Autism Society, 2013).

Developmental delay: A medical diagnosis given in early childhood, typically before the age of eight, when a child is slow to reach typical developmental milestones in one or more of five skill areas, including gross and fine motor skills, language skills, social skills, and cognitive skills (National Dissemination Center for Children with Disabilities, 2012).

Developmental disability (DD): A term to describe impairment or irregularity in one or more body parts and systems, manifested before the age of twenty-two (National Institutes of Health, 2013).

Everyday life information: Various informational (both cognitive and expressive) elements which people employ to orient themselves in daily life and solve problems not directly associated with the performance of occupational tasks (Savolainen, 1995, p. 266-267).

Inclusion: The opportunity to participate in school activities and experiences afforded to

others in the general student population ((National Dissemination Center for Children with Disabilities, 2013).

Individual Education Plan (IEP): A federally mandated document of performance statements, procedures and measurable goals for a student with a disability related to academic growth and the identification of academic needs, supports and accommodations. Mandated under IDEA, goals are to be reviewed and updated yearly for continued relevancy (National Dissemination Center for Children with Disabilities, 2013).

Intellectual disability (ID): Significant limitations in both cognitive functioning and adaptive behavior origination before the age of eighteen (National Institutes of Health, 2013).

Person-Centered Plan (PCP): A life planning model constructed around the individual, his/her interests, strengths, and needs. Goals toward achievement are developed and implemented collaboratively by the individual, his/her family, friends, and other primary support providers (Employment and Disability Institute, 2013).

Quality of Life (QoL): A conceptual construct and assessment tool for identifying an individual's overall well-being (Schalock, Keith, Verdugo, & Gomez, 2011).

Transition Plan: A documented set of procedures and goals for students with disabilities in preparation for life after high school education relating to such topics as post-secondary education, employment, housing, supports and services, and so on. Mandated under IDEA 2004, public schools are required to begin transition planning for all students with a disability and an active IEP by the age of fourteen. Plan implementation toward identified goals is required by the age of sixteen, with goals reviewed yearly for continued relevancy (National Dissemination Center for Children with Disabilities, 2010).

Chapter 2 Intellectual/Developmental Disabilities

The purpose of this chapter is to provide a functional and conceptual framework of I/DD that includes definitions of intellectual and developmental disabilities and brief overviews of assessment and identification measures, prevalence, and etiological origins. The chapter concludes with a discussion of the meaning of disability in society.

2.1 Intellectual Disability: Definition

The American Association on Intellectual and Developmental Disabilities (2010) defines intellectual disability as “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 age 18” (p.1). Intellectual functioning encompasses comprehension, rate of comprehension, attention, memory, abstract thinking, transferability of knowledge and skills, understanding complex ideas, problem solving, planning, and reasoning (pp. 31-42). Adaptive behavior refers to skills necessary to function and adapt in everyday life. These include:

conceptual skills: language and literacy, money, time, and numbers;

social skills: interpersonal skills, social responsibility, self-esteem, social problem solving, following rules and obeying laws, personal safety; and

practical skills: self-care, health, community mobility, occupational skills, self-direction, use of money use of the telephone, schedules. (pp. 43-55)

2.2 Developmental Disability: Definition

The term *developmental disability* (DD) is regularly applied in conjunction

and interchangeably with the term *intellectual disability* (ID). As a classification, DD serves as an umbrella term to describe impairment or irregularity in one or more body parts and systems, manifested before the age of two (National Institutes of Health, 2013). Beyond cognitive processing, examples of affected systems may include the nervous system (spina bifida, autism, Down syndrome), sensory system (deafness, blindness), metabolic systems (phenylketonuria aka PKU). DD also encompasses degenerative disorders that negatively affect organ and tissue health (Rhett Syndrome). While ID may occur comorbid with other developmental disabilities (for instance Fragile X, Down syndrome, cerebral palsy, and autism) it cannot be assumed in all cases.

One important distinction relates to the term developmental delay, often confused with the term developmental disability. A developmental delay is a medical diagnosis given in early childhood (typically before the age of eight) when a child is slow to reach typical developmental milestones in one or more of five skill areas, including gross and fine motor skills, language skills, social skills, and cognitive skills. Over time and with intervention the child may show marked improvement and the diagnosis is rescinded. For children exhibiting slower gains, the diagnosis of a developmental delay often changes to a developmental disability, a life-long diagnosis. It is not uncommon for some children with developmental disabilities to receive an initial diagnosis of developmental delay (National Dissemination Center for Children with Disabilities, 2012).

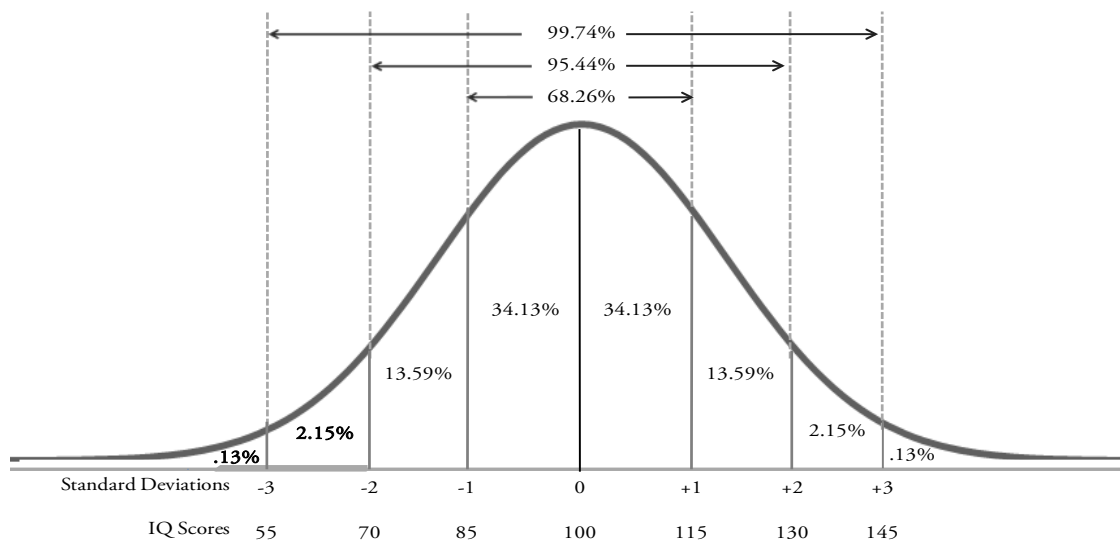
2.3 Assessment and Identification

The primary purpose of assessment is to identify individuals exhibiting exceptional need for the provision of support, services, education, advocacy, funding, and research. Intelligence tests and evaluations of adaptive behavior are two types of formal assessments

used in the diagnosis of I/DD.

2.3.1 Intelligence assessments. Tests for measurement of intelligence include the Stanford-Binet 5, Wechsler Test (WISC-III), and Woodcock-Johnson III (W-J III). Each test is a norm-referenced measure, meaning an individual's performance (score) is compared against the performance (scores) of others the same age. One of the criteria for a diagnosis of intellectual disability is a score falling approximately two standard deviations below the population mean score, taking into account a standard error of measurement (SEM) (AAIDD, 2010, p. 36).

Figure 1. *Normal Distribution of IQ Scores*



2.3.2 Adaptive behavior assessments. Measurement tools for adaptive behavior include the Adaptive Behavior Assessment System II (ABAS-II), the Scales of Independent Behavior, Revised (SIB-R), and the Vineland Adaptive Behavior Scales II (VAB-II). As with assessments of intelligence, individual scores are held against a normative sampling of

scores from the general population. A score of two standard deviations below the mean on assessments in either one or more of the three adaptive skill areas (conceptual, social, and/or practical) or an overall score on a standardized measure of conceptual, social, and practical skills (AAIDD, 2010, p. 47-48).

2.3.3 Assumptions. Five assumptions accompany the identification of I/DD:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within any individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with I/DD generally will improve. (AAIDD, 2010, p. 1)

2.4 Prevalence and Etiological Origins

The President's Committee for People with Intellectual Disabilities (2005) reports that approximately seven to eight million Americans of all ages (three percent of the population) have an intellectual disability. Intellectual disability can result from genetic, physical, or non-physical origins;¹ approximately forty to fifty percent of individuals identified with an intellectual disability have no known point of origin (AAIDD 2002 System Implementation Committee, 2007, p. 6). Table 1 presents the etiology of the most common causes of intellectual disabilities.

¹ Examples of genetic-related I/DD include Fragile X, Down syndrome, phenylketonuria (PKU), and Prader-Willi syndrome. I/DD can also result from fetal alcohol syndrome and drug exposure, environmental toxins, traumatic brain injury, severe poverty and malnutrition, under-stimulation and neglect.

Table 1. *Causes of Intellectual Disabilities*

Origin	Examples
Brain Injury	Prenatal and postnatal Examples: cerebral hemorrhage, hypoxia, severe head injury
Infectious	Congenital and post natal Examples: rubella, meningitis, encephalitis, congenital cytomegalovirus, congenital toxoplasmosis, HIV
Chromosomal abnormalities	Examples: irregularity in numbers of chromosomes or placement of genes on chromosomes, other defects in chromosomes
Gene abnormalities and inherited metabolic disorders	Examples: galactosemia, Tay-Sachs disease, phenylketonuria, Lesch-Nyhan syndrome, Rett syndrome, tuberous sclerosis
Metabolic	Examples: Reye's syndrome, congenital hypothyroidism, hypoglycemia
Toxic	Examples: intrauterine exposure to alcohol, cocaine, amphetamines, other drugs, methylmercury, lead
Nutritional	Example: Malnutrition
Environmental	Example: poverty, low socioeconomic status ²
Unknown	N/A

Note. Reprinted from *Understanding Mental Retardation*, (p. 3), by P. Ainsworth. & P. Baker, 2004, Jackson: University Press of Mississippi.

2.5 The Construct of “Disability”

The discussion would be incomplete without acknowledgement that while individuals with I/DD may or may not experience similar traits and challenges, he/she is unique in personality, interests, needs, and history. The coupling of person and label - while useful for the communication of needs for the provision of support, services, and funding – is a practice

²Ainsworth (2004) notes that prevalence estimates tend to be higher in impoverished groups though isolation of any direct impact of poverty is difficult. She additionally states, “it is important to remember that the vast majority of individuals living in poverty display normal intellectual function” (p. 3).

imposed upon an individual without want or say³ and can be debilitating in ways that have little to do with their challenges, but rather, society's identification and response to their challenges.

Historically, the construct of "disability" has been largely understood from a medical frame of reference – a reference placing focus on individual deficiency and curative initiatives and asserting the onus on individuals to overcome or adapt. Over the last quarter of a century, this assumption has been challenged by many who argue that disability is an artificial and exclusionary product of social design by a normalizing society founded on rigid ideas, structures, and systems in promotion of conformity (Oliver, 1990; Hasler, 1993; Olkin, 1999). Subscribers to this ideology - the social model theory - assert that one is disabled not by his or her impairment, but rather by a society unwilling to accommodate for the wide diversity of humanity. As a result, individuals on the fringes - those who do not or cannot conform – inevitably are subjected to discrimination and oppression. In an examination of intellectual disability throughout history, Scheerenberger (1983) concluded similarly, stating,

Mental retardation⁴ is primarily a sociocultural phenomenon that undoubtedly has been apparent since the dawn of man. Any given society, including the earliest tribes, unquestionably contained members who were more capable and less capable than average. The impact of debility has, however, varied with the needs of the society, its expectancies and social consciousness. (p. 3)

The social model theory served as an emancipatory force for many, prompting

³ Finally, Lyons, and Taylor (2005) highlight multiple studies showing the rejection of labels by persons with various disabilities. Among the reasons cited include denial of disability, protection of self-esteem, associated stigma, uncertainty of label meaning, and irrelevance (pp. 120-134).

⁴ At the time of Scheerenberger's publication, *mental retardation* was a common term in the disability-field lexicon to describe what is now referred to as an intellectual disability. An explanation of change can be found in Schalock, et al. (2007) article "The Renaming of Mental Retardation: Understanding the Change to the Term Intellectual Disability."

individuals to begin asserting their rights for the removal of disabling obstacles and liberating many individuals from confines of charity reliance (Barnartt & Altman, 1991). Despite great gains, this shift in the conceptualization of disability has not been without critics who have expressed concerns that the model too heavily sidesteps the reality of physical and cognitive impairments and the challenges inherent (Shakespeare & Watson, 2001). In recent years, many have advocated for a more ecologically-grounded conceptualization of disability - recognizing both the organic and social origins of disablement (Schalock, Luckasson, & Shogren, 2007). The power of this discourse is reflected in new research initiatives, shifts in terminology and definitions, improvements in supports and services, and evolving societal perceptions of what it means to be disabled.

While this discussion has offered three distinct conceptualizations of disability – disability as individual deficiency, disability as social construct, and most recently, disability as a human phenomenon of both organic and social origins, Wolfensberger (1988) and Smith (2009) offer an alternative construct – disability as a positive attribute. Wolfensberger (1988) is credited as one of the first to draw public attention to the admirable qualities often displayed by individuals who share the I/DD label. These qualities include authenticity, honesty, generosity, forgiveness, positive spontaneity, trust, and the unique ability to bring out gentleness, patience, and tolerance in others. Similarly, J. David Smith (2009) wrote of the “powerful humanizing influence” individuals with I/DD have on others and the benefit to society by virtue of their inclusion. He stated,

When I reflect on the importance of these children and adults and their qualities, I find I must say something that I have often lacked the courage to say directly and publicly: A disability can be a valuable human attribute. (p. 4)

Chapter 3 Intellectual Disability in Society

I long for the time when all human history is taught as one history. I am stronger because you are stronger. I am weaker if you are weaker.

Dr. Maya Angelou

Chapter three begins with a brief historical perspective on I/DD, followed by a review of significant I/DD-related legislation. The chapter concludes with a discussion on current quality of life issues commonly experienced by individuals with I/DD.

3.1 A Historical Perspective

Understanding the lives of individuals with I/DD has been a challenging task for historians. A historian's commitment to authenticity relies heavily on the use of primary source evidence. Prior to the 19th century, very little was documented with regard to the lives, status, and treatment of individuals with disabilities in society. Further, reports available to scholars were derived primarily from an authoritarian medical viewpoint rather than from the perspective of individuals with intellectual disabilities and their families, themselves. This gap in knowledge has imposed historians to rely predominantly on skills of interpretation and the use of secondary sources as a means to tell the story (Braddock & Parish, 2001).

Scheerenberger (1983), Braddock and Parish (2001), and Nielsen (2012) all highlight a painfully unjust history for persons with I/DD - a history marked by centuries of marginalization, neglect, and gross mistreatment from societies largely informed by their religions, superstitions, and fear. Scholars of classic antiquity report that infants born with

abnormalities were commonly perceived as possessed by evil spirits or representations of God's wrath on families for sins and misdeeds (Braddock & Parish, 2001, p.15). Although prevalence has been debated, infanticide was a known practice in Ancient Greek and Roman civilizations (Albrecht, Seelman, & Bury, 2001, p. 15). Plato's Republic stated, "The offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be." Similarly, Aristotle (384-322 B.C.) wrote, "as to the exposure and rearing of children, let there be a law that no deformed child shall live" (Scheerenberger, 1983, p. 11). In the city of Sparta, an infant was subject to the judgment of both the father and the city-state as to whether he/she would live or die. If deemed unsuitable, the child was thrown from the cliff of Mat Taygetus (Scheerenberger, 1983, p.12). For children who escaped early death, it was not uncommon for them to be sold into slavery, exploited for purposes of entertainment and amusement, or sent to beg on the streets. To increase their value, some were mutilated for the appearance of greater desperation to evoke increased pity from people passing by (Scheerenberger, 1983, p. 17).

Historians note the emergence of foundling homes during the Middle Ages indicating possible shifts in societal perceptions of individuals with disabilities (Ainsworth, 2004, p. 50). The Renaissance Period was a time of great change for persons with I/DD, attributed to the rise of the scientific method leading to a more sophisticated understanding of mental impairment. A classification system developed during this period, distinguishing the difference between those with I/DD ("natural fools") and individuals with mental illness ("non compos mentis" or "lunatics") -- laying out parameters for normalcy. Braddock and Parish (2001) state,

This process of categorizing persons with disabilities into the minutiae of their

impairments resulted in the development of specialized treatments and residential and educational services, but also established and reinforced notions of the boundaries between normalcy and aberrance in Western society. (p.13)

The centuries that followed saw a significant increase in care facilities, almshouses, asylums, and prisons, promoted to shelter away individuals with abnormal appearances and behavior for the betterment of society and for the “good” of the individual. Infants and young children were relinquished to foundling homes and hospitals. The survival rate inside these facilities was extraordinarily low with only a small percentage of young children ever reaching adulthood (Ryan, 1834, p. 490-495). Life quality of older individuals with I/DD was equally dismal. Many were frightened away from their home communities with threats of beatings and it is believed that some individuals were simply boarded onto ships and sent out to sea – thus the origin of the phrase “ship of fools” (Foucault, 1965, p. 46). Individuals with I/DD were also loaded on carts and transported to the nearest institution where they were placed with persons with mental illness – men and women together, in small quarters, chained in restraints, underfed and mistreated. Philippe Pinel, a French physician and advocate for mental health reform, highlighted specifically on the plight of individuals with I/DD inside these facilities stating, “Their passive obedience and degradation expose them to inattention, and frequently to cruel treatment on the part of the keepers and servants” (Pinel, 1977, p. 202).

Individuals with mental illness and I/DD fared similarly in the United States during the first half of the 19th century. In a two year investigation of institutions and prisons, Dorothea Dix, documented and formally reported to the Massachusetts legislature in 1843 on the deplorable conditions she observed inside state-funded facilities. A sampling of her

findings included:

Medford: One idiotic chained, and one in a close stall for 17 years

Bridgewater: Three idiots; never removed from one room

Cohasset: One idiot, one insane; most miserable conditions

Plympton: One insane, three idiots; conditions wretched.

Ipswich (jail): Immediately adjacent to this stall was one occupied by a simple girl, who was “put there to be out of harm’s way.” (Dix, 2006, p. 623)

Dix’s advocacy for reform prompted the construction of more than thirty U.S. facilities to treat and care for individuals with mental illness and intellectual disabilities. These facilities were to practice more human therapeutic methods instituted by Phillip Pinel and William Tuke, both pivotal figures in the history of modern psychiatry. While Dix’s initial efforts showed promise, these facilities soon became overcrowded and the therapeutic care of residents turned to custodial care. Around this same time, studies emerged linking intellectual disability with immorality and criminal behavior, and thus legitimizing a growing trend of eugenics as a solution (Mackelprang and Salsgiver, 1996, p. 9). New laws prohibited individuals with intellectual disabilities to marry or procreate and forced sterilization and hysterectomies became common practice (Braddock & Parish, 2001, p. 40).

Other common practices that continued into the latter half of the 20th century included the administration of shock treatment, lobotomies, and pharmaceutical drugging to subdue and control institutionalized residents. Despite Dix’s earlier attempts for reform, institutions simply served as human warehouses, overcrowded and neglectfully understaffed. Residents lived in deplorable conditions and were regularly deprived of adequate clothing and food. Physical and sexual assaults were rampant, residents against other residents and

staff against residents. All the while, the medical profession continued to advise parents of children born with significant disabilities that institutionalization was the best option for appropriate care. Once a loved one was admitted, their families were discouraged to visit and kept oblivious to the horrific circumstances experienced inside. In the 1966 book titled *Christmas in Purgatory*, Burton Blatt and Fred Kaplan helped to bring attention to atrocities occurring inside these institutions. Their introduction starts, “There is a hell on earth, and in America there is a special inferno. We were visitors there during Christmas, 1965” (p. v). When revealed, the public responded with outrage. This anger fueled a disabilities rights movement and led to large scale deinstitutionalization, an overhaul of systems and services, and the creation of U.S. public policies and legislation in support for and protection of the rights of individuals with I/DD.

3.2 Quality of Life and Adult Life Outcomes

Referred to as “the degree to which a person enjoys the important possibilities of his or her life” (Renwick, Brown, & Raphael 1994, p. 201), the concept of quality of life (QoL) has evolved over the past few decades as an important field of study for understanding, measuring, and influencing the overall well-being of individuals with I/DD. From this work, eight core domains and key indicators emerged as principal factors influencing life quality for all individuals, with and without I/DD (Table 2).

Table 2. *Quality of Life Framework: Core Domains and Key Indicators*

Emotional well-being:	Contentment, self-concept, lack of stress
Interpersonal relations:	Interactions, relationships, supports
Material well-being:	Financial status, employment, housing
Personal development:	Education, personal competence, performance
Physical well-being:	Health and health care, activities of daily living, leisure
Self-determination:	Autonomy/personal control, goals and personal values, choices
Social inclusion:	Community integration and participation, community roles, social supports
Rights:	Human (respect, dignity, equality) and legal (citizenship, access, due process)

Note. Reprinted from “Quality of Life Model Development and Use in the Field of Intellectual Disability,” (p. 19) by R. L. Schalock, K. D. Keith, M. A. Verdugo, & L. E. Gomez, 2011, in R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disabilities [Electronic Resource]: From Theory to Practice*. Dordrecht: Springer Science+Business Media B.V.

In 2008, the United Nations General Assembly convened issuing the Convention on the Rights of Persons with Disabilities in support of the promotion, protection, and assurance of human rights and fundamental freedoms of individuals with disabilities. They outlined the essential socio-political conditions necessary for life quality, including:

- access to the physical environment, transportation, information and communication technologies and systems, and to all public facilities and services;
- freedom of expression and opinion, and access to information;
- inclusive education;
- access to quality and affordable health care;
- freedom from exploitation, violence and abuse;
- equal recognition before the law and equal access to justice;
- the right to live independently and with privacy;
- non-discrimination against persons in all matters relating to marriage, family, parenthood and relationships;
- non-discrimination in the work place and employment practices;

- adequate standard of living and social protection;
- community participation and personal mobility;
- participation in political and public life; and
- participation in cultural life, recreation, leisure and sport.

While this decree presented an impressive global show of support for all individuals with disabilities, the conditions asserted have yet to be realized by many. In September 2011, the Assembly reconvened with Deputy Secretary-General Asha-Rose Migiro (United Nations, 2011) providing the opening address,

Even today, almost five years after the adoption of the Convention, too many persons with disabilities do not even know this historic instrument exists. Far too many are denied the rights it is supposed to guarantee. As long as they are denied those rights, we cannot rest....You and I and millions of others know, that when we respect the inherent dignity of persons with disabilities, we enrich our human family.

Undeniably, the interplay between society and disability is complicated. While one cannot deny the inherent challenges individuals face as a result of their cognitive and physical differences, history also demonstrates the disabling impact of society. Despite a shift toward a more compassionate and ecological understanding of I/DD, remnants of the past remain. Individuals with I/DD continue to be denied the most basic human rights, regularly encounter blatant and veiled forms of discrimination, and experience significant exclusion within their own communities – including school environments, the general work setting, places of worship, and in their own neighborhoods. These and other challenges were highlighted in the most recent AAIDD manual, *Intellectual Disabilities: Definition, Classification, and Systems of Supports*, 11th edition (AAIDD, 2010, p. 151-169). The

following sections outline the recent research on adult life outcomes of individuals with I/DD.

3.2.1 Employment. Over 70 percent of adults with I/DD are unemployed (AAIDD 2010, p.157). Although Title I of the American's Disability Act prohibits employment discrimination, individuals with I/DD have an exceedingly difficult time obtaining employment in the general workforce. Of those employed, most are relegated to the most undesirable positions, earn minimum wage, receive few benefits, and have minimal opportunities for advanced skill development or promotion (Butterworth, Hall, Smith, Migliore, & Winsor, 2011). Multiple studies have found that most individuals with I/DD possess a strong desire to be competitively employed in the general work force and when given the opportunity and support, can contribute in diverse and meaningful ways (Certo, Luecking, Murphy, Brown, Courey, & Velanger, 2008; Migliore, Mank, Grossi, & Rogan, 2007; Brown, Shiraga, and Kessler, 2006). Unfortunately, these opportunities are rarely afforded and the large majority of individuals with I/DD, instead, spend their days in federally funded segregated sheltered workshops. Although promoted as a transitional path to cultivate work skills for future competitive employment, a recent study by the National Disabilities Rights Network (2011) found individuals engaged in menial and repetitive tasks in isolating environments. The report states,

Most are paid only a fraction of the minimum wage while many company owners make six-figure salaries. Many people profit off of their labor. All, except the worker. For many people with disabilities, their dream of leaving their "job training program" will never come true. (p. 3)

Comparison studies of participants and non-participants of sheltered workshop

programs found that individuals transitioning from workshops into the general workforce are generally less skilled, require more support, work fewer hours, and earn lower wages than those who have not participated in sheltered workshop programs (Cimera, 2011; Cimera, Wehman, West, Burgess, 2011).

3.2.2 Socio-economic status. Not surprisingly, adults with I/DD generally live 20 percent below the poverty threshold, typically earning only one-third the median household income (Stancliffe & Lakin, 2007, p. 429). Though eligible for governmental support, individuals encounter a bureaucracy that is both confusing and intimidating and their supplemental income makes little impact in raising income level over the poverty line (Certo et al., 2008, p. 93). Determined by income and need, these programs can draw individuals into an inescapable cycle of poverty by creating disincentives to work. Migliore et al. (2007), surveyed individuals with I/DD and most expressed a strong desire to work (p. 14), however often feel forced to reject opportunities for increased pay out of fear they will be penalized with a reduction or loss of government support (Certo et al., 2008, p. 93). Given the great difficulty many experience obtaining and keeping employment, the stability and assurance of a monthly government check is often a much safer bet when forced to choose. In recognition of this dilemma, the US Social Security Administration has made efforts to eliminate these disincentives to work, yet they are not well articulated to those who would benefit most (Certo et al., 2008, p. 93).

3.2.3 Housing options. In 1999, the Supreme Court ruled that individuals with disabilities have the right to live in “the most integrating settings appropriate” and that the unnecessary placement of individuals with disabilities in institutional type settings “perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating

in community life” (United States Department of Justice, 2013). Given the level of need and available options, living situations vary. Many individuals with I/DD live in group home settings with three to four roommates and full or part-time staff. Others live in apartments, independently or with a roommate and receive daily or weekly support. Often times, individuals continue to live at home with their aging parents. The waiting lists for supported living placements can be lengthy and the quality of services and staff vary widely among providers. For individuals able and wanting to live more independently, affordable housing is nearly impossible to find. A recent report by the Technical Assistance Collaborative, Inc., and the Consortium for Citizens with Disabilities Housing Task Force noted, “there is not one state or community in the nation where a person with a disability receiving SSI payments can afford to rent a modest-not luxurious-one-bedroom or efficiency housing unit” (Cooper, O’Hara, & Zovistoski, 2009, p. 1). Although the Department of Housing and Urban Development offers financial subsidies under Section Eight voucher programs, the application process and system are overly complex and waiting lists are long (AAIDD, 2010, p. 158).

3.2.4 Physical health. On average, adults with I/DD tend to have poorer physical health than those without I/DD, experiencing higher rates of obesity, poorer vision, increased rates of epilepsy and other complex health conditions, late stage cancer diagnosis, and more frequent and longer hospital stays (Krahn, Fox, Campell, Ramon, Jesien, 2010). They often have difficulty communicating their healthcare concerns to medical professionals and following through with prescribed treatment. Incomplete or absent medical histories are not uncommon among this population and attention from the medical profession tends to be more reactionary. Minimal attention is focused on health education and disease prevention,

particularly as it concerns reproduction, safe sex practices, and the sexual health of individuals with I/DD (Spitalnik & White-Scott, 2001, pp. 203-220).

3.2.5 Sex and sexual health. The social stigma attached to sex and misperceptions of persons with I/DD as child-like, even asexual, makes it difficult for individuals with I/DD to get information they need to make healthy decisions, learn appropriate socio-sexual behaviors, and be proactive in their sexual health. Further, this denial of information greatly increases this population's vulnerability to abuse and exploitation, contributes to unintended pregnancies, and sexually transmitted diseases (Gougeon, 2009, p. 283).

3.2.6 Victimization. Individuals with I/DD are at an elevated risk of becoming victims of crime, particularly sexually based crimes (Sobsey & Doe, 1991).⁵ Perpetrators specifically target this population with assumptions that they are easily manipulated, will not or cannot escape, and that assaults will go unnoticed and unreported. Usually, assailants are known to their victims. Repeat and ongoing victimization is not uncommon (National Sheriff's Association, 2008, p. 14). The high invisibility and isolation experienced by individuals with I/DD increases their vulnerability. Some individuals may not even recognize their abuse and mistreatment as abnormal. The legal system, including police, lawyers, judges, and courts, have been overwhelmingly ineffective in supporting, gathering evidence, and prosecuting perpetrators. Additionally, cognitively accessible legal resources are rarely available. Commonly, cases are dropped because victims with I/DD are perceived as unreliable informers (Sorenson, 2003).

3.2.7 Social-emotional health. In general, individuals with I/DD tend to have small support networks and few stable friendships. Instead, many rely on family members and care

⁵ Sobsey and Doe (1991) estimated that approximately 90 percent of individuals with ID will experience some form of sexual abuse in the course of their lives.

providers for social engagement and emotional support. Higher levels of social isolation, depression, and stress are reported by individuals with I/DD than those without (McGillivray & McCabe, 2007; Smiley, 2005). Further, issues related to transportation access and difficulties obtaining employment minimize opportunities for social engagement that are commonly afforded to others through work, their spiritual communities, and community gatherings (Verdonschot et al., 2009; Vogel, Polloway, Smith, & Taylor, 2006; Cummins & Lau, 2003). Although efforts toward community integration are increasing, studies show that one's physical presence in an environment does not always guarantee social acceptance, increased feelings of inclusion, or reduced stigma (Lippold & Burns, 2009).

Online social networks have been a positive outlet for increased connection among many isolated individuals, however those with I/DD are less likely to benefit from these systems as many individuals lack the literacy skills necessary to meaningfully engage. The cost of technology is another prohibitive factor. Compared to persons without I/DD, individuals with I/DD are less likely to own a basic cell phone. Additionally, the highly monitored lives many with I/DD experience can contribute to a perception of less need for a phone by care providers, encouraging an individual's increased dependency (Bryen, Carey, Friedman, & Taylor, 2007, p. 5).

3.2.8 Community mobility. Individuals with I/DD often have few opportunities for independence in their communities and are dependent on others for their transportation needs. However, a study by Bryen, et al. (2007) found that with appropriate instruction, practice, and cell phone access, many individuals - even with more severe degrees of I/DD - can be independently mobile in their communities. Unfortunately, way-finding studies highlight the inaccessibility of common navigational constructs, including public signage,

maps, schedules, labels, and landmarks due to a high reliance on print to convey meaning (Martinez, Mattson, Hough, & Abeson, 2010; Fischer & Sullivan, 2002). Although much attention has been paid to the mobility needs of individuals with physical and sensory disabilities (cut curbs, ramps, Braille signage, audio crosswalk signals), the mobility needs of individuals with cognitive disabilities have been largely ignored.

These barriers to mobility exacerbate many of the other challenges, making it difficult to find and keep a job, obtain medical care and legal support, engage in civic events and responsibilities, participate in spiritual communities, and socialize with friends and families (Verdonschot et al., 2009; Conely and Taylor, 2003). Moreover, these challenges contribute to the invisibility of individuals with I/DD in their communities, increasing their vulnerability and leaving many of their life circumstances unknown and needs dangerously unmet.

Chapter 4 Intellectual Disability and the Teen Years

This chapter draws attention to the lives and experiences of young people with I/DD. Areas posed for discussion include typical adolescent development, the school experience, peer relations, sense of self, issues of autonomy and self-determination, and transitions into post-school life.

4.1 Adolescent Development

The teen years are a time of profound change. Normatively, this is a period classically characterized by identity construction. Inwardly, teens are contemplating questions of “Who am I?” and “Where do I belong?” Outwardly, young people are often experimenting in look, behavior, and relations. Curiosities and interest in intimacy, sexuality, and sex increase during this time as peer relations become more intense and family dependency wanes. Experimentation, testing rules and limits, and questioning of authority are common teen behaviors. Although frustrating to parents, these behaviors contribute to the positive development of self and feelings of self-efficacy. Despite tendencies to prioritize present concerns over future considerations, teens are consciously and unconsciously making definitive movements toward adulthood. Havighurst (1948) described this transition as the developmental tasks of adolescence and identified eleven tasks:

1. adjusting to a new physical sense of self
2. adjusting to new intellectual abilities
3. adjusting to increased cognitive demands at school
4. expanding verbal skills

5. developing a personal sense of identity
6. establishing adult vocational goals
7. establishing emotional and psychological independence from his or her parents
8. developing stable and productive peer relationships
9. learning to manage his or her sexuality
10. adopting a personal value system
11. developing increased impulse control and behavioral maturity

Few studies have examined the developmental trajectories of teens with I/DD, though little evidence is available to suggest wide dissimilarity from teens without I/DD (Hauser-Cram, Krauss, & Kersh, 2009, p. 589). That said, notable points of departure from the normal adolescent experiences do exist and it would be remiss to diminish the impact an I/DD has on making sense of developmental changes and in negotiating the complexities of adolescent life.

4.2 The School Experience

Students with I/DD experience high segregation in the school setting, particularly by the time they reach high school. As general curriculum demands heighten, instructional emphasis turns pointedly toward the strengthening of independent living and work skills for post-school life. A shortage of special education teachers (U. S. Department of Education, 2011) and high turnover rates (Boe & Cook, 2006, p. 443) have major implications on the continuity and quality of instruction for students with I/DD. Student absenteeism rates tend to increase during secondary schooling (Newman, Wagner, Cameto, & Knokey, 2009) and approximately 29 percent of teens with I/DD drop out before graduation (Polloway, Lubin,

Smith, & Patton, 2010, p. 62).⁶ Commonly cited reasons for dropping out include poor relations with teachers and peers, overall dislike for school, stigmatization from segregation, and irrelevant education and transition goals and vocational experiences (Snell, 2010; Wagner, Newman, Cameto, Levine, & Garza, 2006, p. 7).

4.3 Peer Relations

Peer relations are an influential part of the teen years and contribute to the strengthening of appropriate social behaviors necessary for adult life. Friendships, in particular, help to develop competencies in areas of reciprocity, conflict resolution, trust, and loyalty, and create a sense of belonging and acceptance during a time of heightened insecurities and social stratification (Bukowski, 2001). However, many teens with I/DD have difficulty recognizing complex social cues and negotiating many of the subtle nuances involved in developing and maintaining friendships. They typically have fewer friends than their peers without I/DD (Hauser-Cram, et al., 2009). Additionally, teens with I/DD typically experience a high degree of social stigma and alienation related to their perceived differences by others and their segregated special education status in school. Rates of harassment and bullying are high for teens with I/DD, particularly for those with more visible differences.

In an effort to fit in, teens with I/DD (particularly those who have higher IQs)⁷ will sometimes attempt to mask their challenges by exaggerating their abilities or rejecting critical supports if they perceive these supports may draw negative attention to them (Snell & Luckasson, 2009, p. 225). These actions can backfire in detrimental and devastating ways. Their often displayed desires to please and naivety can make them easy targets for

⁶ The most recent U.S. national dropout rate of teens is approximately eight percent.

⁷ This categorization constitutes approximately 80 to 90 percent of all individuals with ID, with IQ's ranging roughly between 70-75.

exploitation and cruel attention.

4.4 Sense of Self and Place

Psychological well-being incorporates a sense of belonging, feelings of competence, personal fulfillment, and the belief that one's life has value and purpose. Studies on children and youth with disabilities show a strong correlation between psychological well-being and one's perceived level of social inclusion. Meaningful and positive interactions with peers contribute to an enhanced self-esteem and personal agency (Arvidsson, Granlund, & Thyberg, 2008; Wehmeyer & Gamer, 2003). Further, the ways young people with disabilities perceive themselves and their lived experience have a direct impact on learning and life outcomes (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001; Skinner & Belmont, 1993).

Teens with I/DD report higher degrees of depression, worry, and anxiety than their peers without I/DD (Forte, Jahoda, & Dagnan, 2011). On self-assessments of self-worth, teens with I/DD who have higher IQs tend to score themselves lower than their peers without I/DD and lower than teens with more severe degrees of I/DD. It has been suggested that these lower ratings are due to a heightened awareness of their peer hierarchy system and their perceived place in it (Cooney, Jahoda, Gumley, & Knott, 2006). However it would be wrong to assume that those with lower IQs are oblivious to their social circumstances. Numerous studies have shown that individuals with both mild and moderate degrees of I/DD are acutely aware of their devaluation and lack of acceptance in society (Jahoda, Wilson, Stalker, & Cairney, 2010; Cooney et al., 2006; Beart, Hardy, & Buchan, 2005).

4.5 Self-determination

Many young people with I/DD have few opportunities for personal control and tend

to exhibit a diminished sense of self-determination (Stancliffe & Lakin, 2007, pp. 429-448; Wehmeyer, Martin, & James, 2009, p.103). Self-determined behavior is defined as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, Abery, Mihaug, & Stancliffe, 2003, p. 177). It encompasses feelings of self-worth and personal agency and skill sets of decision-making, problem-solving, goal-setting, risk taking, safety, self-instruction, self-advocacy, and self-awareness (Wehmeyer, Martin, & James, 2009, p.102). The development of self-determined behavior hinges on meaningful opportunities for choice and personal control, more so than IQ score (Wehmeyer et al., 2003). Studies on post-school outcomes of youth with I/DD found that teens with higher self-determination assessments were more likely to be employed, earn higher wages with benefits, and live outside the family home than teens with lower self-determination scores (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997).

4.6 Transition

Issues of transition from secondary schooling to post-school life have received considerable attention in recent years in effort to address poor post-school outcomes for many with I/DD. The following barriers have been identified as major obstacles impeding successful transitions into adulthood:

- inadequate transition planning – too little and too late (Griffin, McMillan, & Hodapp, 2010)
- limited options for post-secondary education and employment (Conley & Taylor, 2003)
- lack of accessible information related to post-secondary options, services, and

supports (Griffin, McMillan, & Hodapp, 2010; Stewart et al., 2008; Stancliffe & Lakin, 2007)

- overly complex public support systems, fragmented supports and services, and long waiting lists (Martinez, 2009; Beresford, 2004)
- governmental disincentives to work (Martinez, 2009; Certo et al., 2008, Conley & Taylor, 2003)
- lack of public awareness/understanding about individuals with I/DD (Kersh, 2011)

IDEA (2004) mandates that public schools begin transition planning for all students with disabilities by the age of 14, with transition program implementation by the age of 16. Although intended to be a person-centered process tied to the strengths, preferences, and interests of the student, one study found that many young people with I/DD play a minimal role in their post-school planning and are often prescribed goals unrelated to their personal preference or interests (Powers, Gil-Kashiwabara, Geenen, Balandran, & Palmer, 2005, p. 53). A National Longitudinal Transition Survey 2 (NLTS-2) of over 11,000 students with disabilities revealed that students with I/DD are typically steered toward sheltered workshop programs over other post-school options (Grigal, Hart, & Migliore, 2011, p. 11). The same study also found that that workshop related transition goals are the primary predictor of future unemployment (p. 13).

With passage of the Higher Education Opportunity Act of 2008, opportunities are expanding for students with I/DD to continue their education beyond secondary schooling. Think College, an initiative of the Institute for Community Inclusion at the University of Massachusetts provides a growing database of available programs located on trade schools

and community colleges, four year colleges, and universities across the United States. Migliore and Butterworth (2009) found that students who completed post-secondary education programs were more likely to secure competitive employment and earned over seventy percent more than those who did not continue their education (p. 1). Unfortunately, parents and transition-aged students are unaware that these programs may be an option. In a 2010 study by Griffin, McMillan, and Hodapp, seventy-three percent of parents surveyed indicated that they did not receive information nor were provided adequate guidance in pursuing these programs (p. 342).

Chapter 5 Everyday Life Information

The seemingly empty space around us is seething with potential information.

B. C. Brookes

The study of everyday life information (ELI) practice is a messy and uncertain endeavor. Given its seemingly familiar and mundane nature, for some the notion of everyday life information may seem self-evident and require little explanation. However, in working toward a comprehensive definition, scholars of library and information science (LIS) continually struggle to characterize such concepts as everyday life, information, information behavior, and information need. The following chapter addresses these challenges and efforts toward increased understanding.

5.1 Everyday Life

Nothing (clearly) happens but something (obscurely) is and has been afoot.

Seigworth & Gardiner, 2004

Unquestionably, the task of inquiry into everyday life begins with the recognition that the everyday we live in is complicated. It is a man-made construct influenced and often masked by the seemingly ordinary and unremarkable (our habits, routines, and daily relations) and the unexpected - the business and chaos of being human. In an effort to establish and maintain a semblance of order, civilized societies have held fast to the construction and maintenance of boundaries. Formal or simply understood, these boundaries have historically defined marriage and the family, dictated gender roles, restrained our behavior, segmented our communities, structured our education, economic, and political

systems, and so on. Manifested through our laws and traditions, these boundaries have long provided structure and served to characterize our society, creating the illusion of a common reality and shared experience of everyday life. Suffice to say, we find comfort within these boundaries, even when we know they may be unjust or that there may be a more ideal alternative. Much has been written about the need for such structure (Giddens, 1984; Saunders, 1984; Silverstone, 1993). Silverstone (1993) writes,

Everyday life, it is argued, cannot be sustained without order - an order manifested in our various traditions, rituals, routines, and taken for granted activities - in which we paradoxically invest so much energy, effort and so many cognitive and emotional resources. In the ordering of daily life we avoid panic, we construct and maintain our identities, we manage our social relationships in time and space, sharing meanings, fulfilling our responsibilities, experiencing pleasure and pain, with greater or lesser degrees of satisfaction and control, but avoiding for the most part the blank and numbing horror of the threat of chaos. (p. 573)

The order that we have created has not been without cost, perhaps best brought forward in Dorothy Smith's (1987) pivotal work in the area of institutional ethnography and women's experiences in everyday life. Employing this methodological lens for inquiry, Smith drew attention to the sometimes ungraspable and often unintended influences our bounded constructs and systems have on everyday life.

One example of bounded constructs is the operative use of labels within systems. Related to this study, for instance, educational systems have long employed the use of labels to communicate information about students' cognitive abilities, behavioral challenges, and attention issues. Examples of terms used have included: gifted, learning disabled, special

needs, other-health impaired, at-risk, emotionally disturbed, and exceptional. Smith (1987) argued that such labels often negate the wide variety of individual circumstance and are insufficient communication tools. Moreover, their use commonly leads to the marginalization of individual students and groups of students and minimizes the scope of discourse related to the actual lived experiences of the individual. Other impacts may include the perpetuation of stereotypes, segregation of students from their same-aged peers, student frustration and self-esteem issues, and ultimately, the failure of the system to accomplish its central goal of education.

An additional argument presented by Smith (1987) in her research related to everyday life challenges academia's dogged tendency (particularly traditional sociology) for reliance on established theory or other conceptual apparatus as a jumping off point for inquiry of the everyday lives of others. Smith argues that both the earlier mentioned prescribed terminology and the utilization of theory based inquiry directly contributes to an objectification of the individuals studied and their related everyday life-situatedness, at the marked exclusion of subject voice and first-hand account of actual lived experiences. Smith (1990) states,

Sociology creates a construct of society that is specifically discontinuous with the world known, lived, experienced and acted in. The practice of sociology in which we were trained as graduate students was one that insisted that the sociologies should never go out without a concept; that to encounter the raw world was to encounter a world of irremediable disorder and confusion; to even begin to speak sociologically of that world required a concept, or concepts, to order, select, assemble, a sociological version of the world on paper. (p. 2)

Sandywell (2004) concurs highlighting a systematic denigration of understanding the ordinary as a result of the theorization of everyday life, and promotes relinquishing such efforts in order to reveal the authenticity and diversity of everyday life. Morgan (2004) contributes to the discussion, pointing out what may be characteristic of everyday life to many may not account for the experiences of others.

Indeed, it may be suggested that different understandings as to what is every day or normal (although the terms are not exactly the synonyms) are not only a fact of global life but play a major part in maintaining global divisions. A strong routine sense of what is every day or normal further marginalizes the experiences of those already at the margins. (p. 37)

Taking the above into consideration, Morgan (2004) identifies three interconnected universal understandings of everyday life:

1. Everyday life involves a sense of reference to those events or experiences that might be expected to happen to most people in the course of their lives...such as events linked to birth, to sexuality, to death, and to sickness...the 'talk-about-ables', in view of the role they occupy in everyday conversations.
2. Everyday life may refer to the regular, the repeated, the routine, the familiar, the quotidian, the banal, even the boring...frequently not seen as being worth talking about.
3. The idea of the everyday sometimes shades over into the more normative idea of the normal. The everyday or normal here is attached to people like us, normal people. It is frequently linked to local, class or national identities. (pp. 37-38)

Modern society, as a whole, has experienced a recent metamorphosis. Boundaries are

dissolving and with technological advancements, time and space are being renegotiated. Beck, Wolfgang, and Lau (2003), attributed this transformation to a growing culture of reflexive modernization characterized by increasing globalization, individualization, and an exponential degree of choice - expounded by new technologies and capabilities, market expansion, and legal universalism. Reflexive modernization has been defined as the modernization of modern society resulting in the production of "a new kind of capitalism, a new kind of labour, a new kind of global order, a new kind of society, a new kind of nature, a new kind of subjectivity, a new kind of everyday life..." (p. 3). The researchers cite a need more research and consideration in order to "produce a reasonable picture of this new world that people and institutions can use to orient themselves" (p. 3).

5.2 Information

Of information, Martin (1995) states, "definitions proliferate and interpretations multiply, but the answer to the question [What is information?] continues to elude the best minds in information science" (p. 17). Wilson (1981) notes that all too often in information and library research, researchers use the term *information* broadly leaving the reader to make assumptions as to the author's intention of its meaning, "even then it is sometimes unclear which of the senses the researcher had in mind when setting the research objectives" (p. 659). Dervin (1983) notes the discrepancy between the researcher's intended definition of information (observer construct) and the reader's understanding (user construct) of its meaning as well, stating "systems and researchers have been looking at something they call information rather than something users call information" (p. 158).

Dervin (1983) also discounts early research initiatives which worked from the assumption of absolute and contained knowledge....information is; its value, obvious. Using

this frame of reference, Dervin draws the analogy of information as a brick and the user, an empty bucket, to which the information can be thrown. Studies evidenced that practical application of these assumptions resulted in the development of information and systems that were minimally used, and prompted a turning point with increased attention toward the user's construct of information and related practices. From the standpoint of the user construct, information is not compared to a brick, but rather clay that can be molded, shaped by the individual according to his/her perceptual understandings.

Wilson (1981) proposes that perhaps a more useful endeavor would be to explore how information is put to use, rather than exerting efforts to impose criteria as to what qualifies or does not qualify as information. Buckland (1991) offers a typology of three distinct characteristics related to use: information-as-process (implies action, such as sharing or communicating), information-as-knowledge (that which is perceived or shared), and information-as-thing (objectified, such as data, documents, texts, etc.). Buckland (1991) also suggests that scholars might gain more insight from exploration into how one comes to be informed. Though, conflict comes in the recognition that the ways in which we become informed are innumerable and instances of revelation are sometimes not easily explained, as evident in Brookes (1979) rephrasing of Shakespeare, stating "scientists and others find 'sermons in stones and books in the running brooks.'" Buckland addresses this complexity concluding "if anything is, or might be, informative, then everything is, or might well be, information. In which case, calling something 'information' does little or nothing to define it" (p. 356).

5.3 Information Needs

One of the greatest challenges faced by information and library professionals is the

appropriate allocation of scarce funds to ensure the widest range of information needs can be easily addressed and met. While information need assessments are common tools toward this effort, many have highlighted the inherent challenge this task presents in consideration of the highly contextualized nature of “need.” Maurice Line (1974) stated, "strictly, a need is a necessity, something a person cannot do without. But who is to say what is 'necessary', for himself or others?" (p. 87). Likewise, Wilson (1997) stated, “need is a subjective experience that occurs only in the mind of the person in need and, consequently, is not directly accessible to an observer” (p. 552). That said, Wilson promoted the usefulness of understanding general need type by assessing the motive, or activating mechanism, prompting an information need. Incorporating the work of Morgan and King (1971) and McQuail (1972), Wilson (1997) identified six motives prompting information need:

Physiological: Hunger, thirst, pain

Unlearned: Curiosity, sensory stimulation

Social: Desire to belong, seeking approval, gaining status, aggression

Diversion: Escapism, emotional release

Personal relationships: Companionship, social utility

Personal identity: Comparison with life, reality exploration, value reinforcement (p. 553)

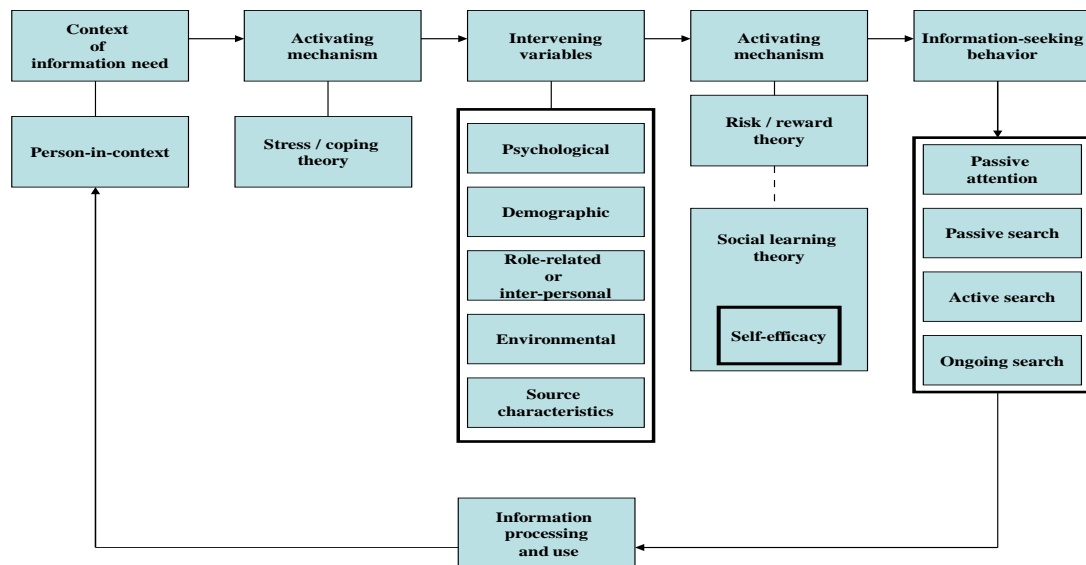
5.4 Information Behavior

Use of the terms "information behavior", or the more recently proposed "information practice" (Savolainen, 2008) for purposes of study, intends to encapsulate the active and inactive ways we interact with information in our daily lives. Savolainen (2008) defines information practice as “a set of socially and culturally established ways to identify, seek,

use, and share the information available in various sources such as television, newspapers, and the Internet. These practices are often habitual and can be identified both in job-related and non-work contexts” (pp. 2-3). Related terms of interaction include "information seeking"; "information use", "information sharing", and "information processing" are commonly recognized and generally understood within the field of library and information science. As with the earlier discussion of the concepts *everyday* and *information*, these terms have endured rigorous linguistic scrutiny (Wilson, 1997), as well. Similarly, definitions continue to remain obtuse and often dependent upon the user, intention, and situated context.

Wilson (1997) provides the following general model of information behavior incorporating situational context, information need, factors that prompt and influence one’s search for information, and strategies or behaviors related information interaction.

Figure 2. *Wilson's General Model of Information Behavior*



Note. Reprinted from “Information behavior: An interdisciplinary perspective,” by T. D. Wilson, 1997, *Information Processing and Management*, 33(4), p. 569.

Four types of information seeking behavior are identified in Wilson’s model: passive search, active search, ongoing search, and passive attention. Passive search refers to a search

for one type of information that yields unexpected useful information related to another aspect of interest. Active search refers to the active and intentional search process with end goal in mind. Ongoing search refers to expanding on known information through occasional searches. Lastly, passive attention refers to the acquisition of information through no active intention. For instance, while watching television, listening to the radio, overhearing a conversation, or while engaged in another experience. On these occasions, information may prompt immediate attention or possibly absorbed with little regard or reflection, recalled only later when a need arises. Savolainen (2008) notes,

it is characteristic of everyday information practices that people seldom think of collecting, processing, or using information as something separate from the task or problem at hand. Information practices are embedded in everyday contexts; in addition, their self-evident nature makes these practices "invisible" and difficult to see in greater detail. (p. 3)

Williamson (1998) highlighted the importance of study into the incidental acquisition of information in order understand the efficacy of information systems for providing information to those who may not be aware that they need information (p. 37).

Wilson's (1997) model also draws attention to activating mechanisms, or triggers, that prompt an individual's search for information. He proposed three motive-related theories of information seeking: stress/coping, risk reward, and social learning. Stress/coping theory posits that stress initiates information seeking as a way to cope. Coping strategies may be of a cognitive nature in which found information may enable an individual to solve a problem or coping strategies may be of an affective nature in which found information eases one's emotional stress (p. 554). Risk reward theory suggests that the degree in which one

expends or risks money, time, or energy/effort into his/her search for information is directly related to the expected return. The higher the risk, the higher the expected payoff or reward from information (p. 562). Social learning theory relates to one's concept of self-efficacy. One's feelings of ability or self-efficacy to impact change in their lives is related to whether or not they actively seek information to impact that change. Increased levels of self-efficacy result in increased and active search processes (p. 563).

5.5 Information Challenges

One's access to information can be inhibited by an array of challenges. Brenda Dervin identified five information barrier types derived from a study by Warner, Murray, and Palmour (1973) on the information needs of urban residents. These included:

Societal barriers are those that impede the availability of resources necessary to satisfy needs with the social system.

Institutional barriers may be viewed as the incapacity and/or unwillingness of an institutional provider to deliver needed information to a certain type of seeker.

Psychological barriers arise when the individual is unable to perceive his or her needs as informational in nature, obtain needed information from appropriate providers, or accept the possibility that the information problems can be solved for psychological reasons.

Physical barriers impose themselves when the individual is unable to make contact with the appropriate information providers due to some physical consideration, such as the absence of library stairs for a handicapped individual.

Intellectual barriers are present when the individual lacks necessary training and expertise to acquire information. (as cited in Chen & Hernon, 1982, p. 19)

Harris and Dewdney (1994) cited some of these same barrier types in their investigation on the information needs and experiences of battered women – particularly psychological and intellectual barriers. The researchers found that many of their participants displayed an unawareness of their own need for certain types of information and when the need became apparent, some of the participants expressed uncertainty as to where to obtain needed information. The lack of self-confidence and poor communication skills were also identified challenges limiting their access to information (p. 3).

Wilson (1997) conducted a literature review outside the field of information science, applying his general model of information seeking (Figure 2) as a lens for the review. Using “intervening variables” as an overarching term, he highlighted four barrier-type categories that may negatively influence one’s access to information:

Personal characteristics may include differing levels of cognitive need experienced by individuals, biased information-seeking or the avoidance of certain types of information, personal motivation, hearing and language challenges, psychological factors (for instance, anxiety), knowledge base, education level and other demographic variables including age, gender,

Economic barriers refer to both the actual financial cost involved in addressing an information need as well as the time one might expend in the process of seeking information.

Social/Interpersonal barriers relate to information sources that are only accessible through interpersonal interaction. Specific examples that may inhibit someone from seeking information from a human information source might include attitude or demeanor of individual with access to the information or the intrusive presence of

others limiting opportunity or creating an uncomfortable atmosphere from which to ask questions.

Environmental/Situational barriers may be related to lack of time, unfamiliar language, and stress of a situation. Geography presents another barrier if the information source is geographically inaccessible. Cultural differences also may inhibit information access. (pp. 556-561)

In consideration of the ELI experiences of individuals with I/DD, the barrier types presented by Dervin (1973), Harris and Dewdney (1994), and Wilson (1997) are exceedingly evident, even without scholarly attention. They may include *personal barriers* relating to a lack of cognitively accessible information or diminished feelings of self-efficacy that inhibit personal action toward information acquisition; *societal barriers* of discrimination, prejudice or uninformed perceptions of an individual's ability and need; *physical barriers* relating to inadequate transportation systems or the lack of assistive supports including ramps into a physical spaces or assistive technology; *economic barriers* that may prohibit access to informative programs or the Internet; and, *institutional barriers* of imposed segregation and information systems that do not account for diverse populations.

5.6 Everyday Life Information and Related Research

The term *everyday life information* emerged from the work of Reijo Savolainen (1995) and is defined as:

the various informational (both cognitive and expressive) elements which people employ to orient themselves in daily life and solve problems not directly associated with the performance of occupational tasks. (p. 266-267)

Early studies of ELI needs and behaviors were situated within the parameters of an undefined

non-work environment. Over the past decade, ELI study topics have become more nuanced and defined with the increase of mobile technologies - changing how, when, and where individuals work and leisure. The following section provides a general overview of the ELI research spanning the last fifty years.

5.6.1 Parker and Paisley (1966). Parker and Paisley (1966) initiated one of the earliest studies on what is now referred to as everyday life information seeking (ELIS) in attempt to answer the question “What kinds of people seek what kinds of information through what channels?” Funded by the Office of Education, U.S. Department of Health, Education, and Welfare, the researchers conducted one thousand eight hundred and sixty-nine semi-structured interviews of Fresno and San Mateo residents. Interview questions focused on information needs and preferred information sources related to occupation, health, international affairs, education, citizenship, religion, homemaking, and leisure activities. Additional areas explored included achievement, motivation, need for affiliation, and ego involvement. Participant responses were cross-tabulated by participant age, gender, education, occupation, income, and length of residence in the community. An examination of relationships established a link between level of education and preferred information source. The higher level of education obtained by an individual proved to be a significant predictor of printed information source use. Printed information sources included reference books, magazines, newspapers, and non-fiction books. Individuals having less education exhibited a reliance on television and radio to address information needs.

5.6.2 Rieger and Anderson (1968). Rieger and Anderson's (1968) surveyed approximately four hundred household from five counties in the Grand Traverse Bay region of Michigan in attempt to answer two questions:

1. What are the types of information sources used by local people in connection with certain topics of concern in everyday life?
2. What are the topics about which local people feel the need for useful and reliable information but find it difficult to get?

Responses were cross tabulated by age, education, residence, and sex and a typology of information need was generated. Areas of information need included finance, occupations, public and consumer affairs, and education. Findings revealed that individuals with more education tended to use a wider variety of information sources and were more likely to express dissatisfaction with the quality, applicability, and relevance of information retrieved. Additionally, researchers found that younger respondents exhibited a higher level of expressed information need and a higher use of diverse information sources than older respondents. Younger respondents also displayed a higher reliance on friends and relatives as primary information sources than older respondents.

5.6.3 Zweizig (1973). Zweizig's (1973) dissertation study of public library use surveyed five hundred individuals over the age of twenty-one years in Onondaga County, New Jersey, chosen as a survey site for its diverse mixture of urban, suburban, and rural areas. Surveys were conducted as phone interviews and overall aim of the study was to answer three questions:

1. Predicting statistical variation in amount of library use from predictor variables which measure various aspects of the user's life;
2. Identifying the "best" predictors of library use;
3. Developing statistical typologies of different kinds of users and non-users and comparing these typologies to each other. (p. 32-33)

Zweizig concluded that the following demographic identifiers related to higher library use: education (advanced degrees), gender (females), and age (younger patrons). Non-demographic indicators of high library use included individuals who were ardent book readers, involved in their community, displayed “open mindedness”, had a familiarity with the library and a history of accessing library resources, and perceived the library as having credible resources.

5.6.4 Warner, Murray, and Palmour (1973). Warner, Murray, and Palmour (1973) conducted household telephone surveys of two thousand six hundred urban residents in Baltimore, Maryland and found that income, age, and education were indicative of one's awareness of information need, awareness and use of information sources, and ability to express the nature of the information need. Specifically, younger, more educated, and wealthier participants were more likely to identify problems and seek information than less educated, poorer, and older participants. They were also more likely to access a wider variety of information sources to address their needs. Personal contacts were cited as the most relied on source of information. Warner et al. note that although the subgroups (less educated, older, and poor) appeared less likely to articulate information needs and seek help, it should not be concluded that they have fewer information needs than any other group.

5.6.5 Chen and Hernon (1982). Chen and Hernon (1982) surveyed two thousand nine hundred and two individuals by phone from six New England states during a two and a half month period. Their study looked at work and non-work information needs of individuals to establish "baseline data depicting the dimensions of who gets what information, from where, and why" (p. 6). Similar to studies by Reiger and Anderson (1968) and Warner et al. (1973), Chen and Hernon (1982) found interpersonal relationships to be a highly valued information

source for participants with approachability, quality of feedback, convenience and comfort cited as contributing factors.

5.6.6 Chatman (1990). Chatman (1990) examined the information seeking behavior of working class individuals, specifically janitors. Employing gratification theory as a methodological lens, Chatman sought to understand why individuals reject available information sources when experiencing an information need. Collecting data over a two year period using participant observation and interviews, Chatman interviewed janitors, their supervisors, and other individuals in their workplace and found that although study participants identified information needs, they often chose not to access resources outside of their familiar environments. Instead, Chatman found participants generally exhibited an orientation toward immediate gratification and often displayed a sense of fatalism in their efforts toward information access. Information seeking attempts were typically brief, with minimal effort, time, or money expended out of the belief that efforts would end in failure.

5.6.7 Julien and Michels (2002). Julien and Michels (2002) conducted a case study of one individual for the purpose of exploring information behaviors within the daily life routine. Data collection included diaries and interviews. Their study participant was a male in his twenties who was employed in the technical field and had an active non-work life that involved many hobbies and interests. Findings revealed that the participant relied on a limited number of information systems to address his everyday information needs, with preference toward personal contacts as information sources. Time and motivation were identified as two factors that influenced information seeking behavior. For instance, constraints on time resulted in satisficing behavior and internal motivation appeared to motivate the participant to employ a wider variety of information sources.

5.6.8 Harris et al. (2001). Harris, Stickney, Grasley, Hutchinson, Greaves, and Boyd (2001) investigated the use of formal information help services by abused women.

Researchers conducted one hundred and five face-to-face interviews of women who had experienced abuse. Participants ranged in age from twenty to seventy years old. Findings highlighted the importance of personal empathy displayed by service providers.

Additionally, location of support and the bridging to other systems of support were also noted as contributing factors that motivating participants to use information help services.

5.7 Everyday Life Information and Youth⁸

Prior to the 1970s, minimal consideration was given to the information needs of children and teens with exception to the realm of the school environment. As with studies on adult ELI needs and behavior, interest has increased over the last two decades and targeted toward populations of youth who share common life experiences and similar circumstances for information need. The following review highlights youth-related ELI research initiatives spanning the last four decades.

5.7.1 Walton (1971). Walton (1971) conducted one of the earliest studies on youth library service. Surveying New Jersey public librarians, Walton questioned librarians on the types of serviced offered to their young adult patrons in comparison to services offered to children and adults. “Young adults” were generally identified as individuals in grades seven through twelve. In the United States, this grade distinction correlates to adolescents between the ages of twelve and eighteen. With exception to homework assistance, Walton noted a lack of

⁸ Although a number of studies fit within the context of everyday life information practices, many were considered and excluded in this review if the research focus addressed a specific type of information need. Sample of excluded research: Sexual health and reproductive information (Pierce, 2007); homosexuality and “coming out” information (Mehra and Braquet, 2007); and adolescent girls and heroin information (Todd, 1999).

programming and resources in support of non-school related information needs and stated,

This seems unfortunate in a social institution like the library, since the teenage years are the prime years of exploration through interaction with the peer group - an experience excellently offered by discussion and backed up with the written and other recorded materials held by libraries. (p. 12)

5.7.2 Farrell (1974) and Minudri (1974). In 1972, a National Commission on Libraries and Information Science delegated two committees to examine the quality of youth library service and found both school and public libraries negligent of the non-academic information needs of children and teens. Diane Farrell and Regina Minudri, representatives from each committee, were first to publically address findings. Farrell (1974) reported on library services for children,

Both institutions [school libraries and public libraries] have tended to define their programs of service in terms of the perceived function of the institution, for example, “to support the school curriculum” or “to acquaint children with the literature of the world” rather than in terms of children's actual needs, which we are only beginning to discover and define. (p. 147)

Similarly, Minudri (1974) who chaired the committee on teen library service stated,

In many instances, service to young adults and students varies considerably from what they really want and need. Many libraries state that they serve this age group without taking the time to investigate and determine that the group called “young adult” has radically changed in the past few years. (p. 155)

Table 3 and Table 4 outline major findings highlighted in the final report.

Table 3. *Major Areas of Information Needs of Young Children*

Type of information	Purpose to User	Response Mode	Priority
General: • Self • Environment • Other people	Physical Emotional Social Cognitive: ▪ growth ▪ development	Variety of forms of media according to needs: print, non-print, visual, audio, manipulative – books, pictures, films, filmstrips, slides, records, tape cassettes, TV, videotape, toys, dolls, games, puzzles, animals, plants, puppets, clay, paper, crayons, paste, paint, cardboard cartons, realia, etc. Emphasis on manipulative materials. Storytelling, drama, conversation, creative play. In appropriate environments: Physical space, opportunity for activity, noise. By persons who can mediate (provide guidance in selection, use of materials/ through librarians or other adults (parents, teachers, child-care professionals, paraprofess.). In resources centers, homes, neighborhoods, schools.	Access to appropriate materials and services. Interaction with informed adults who can provide guidance in the selection and use of materials, help to interpret materials and experiences. Access to an environment that lends itself to exploration and use of materials.
Life Needs: • Health • Nutrition • Safety • Emotional security • Intellectual stimulation			

Note. Adapted from “Library and Information Needs of Young Children,” (p. 153) by D. G. Farrell, 1974, in C. A. Cuadra & M. J. Bates (Eds.), *Library and information service needs of the nation: Proceedings of a conference on the needs of occupational, ethnic and other groups in the United States*. Washington, D.C.: U.S. Government Printing Office.

Table 4. *Young Adult and Student User Needs*

Type of Information	Purpose of User	Delivery Mode	Priority
School and curriculum	Education information and data	A/V, computer, print, oral.	1
Recreational	Leisure activity	A/V, print, realia.	3
Personal development	Enrichment	Print, A/V, oral, realia.	4
Vocational career guidance	Economic data	Print, computer, A/V, oral	5
Accomplishment skills, and information	Practical, educational, leisure	A/V, print, oral, realia.	6
Audio Visual	Educational, leisure, enrichment, economic, practical, information and data.	A/V	2

Note. Adapted from “Library and Information Needs of Young Children,” (p. 161) by R. Minudri, 1974, in C. A. Cuadra & M. J. Bates (Eds.), *Library and information service needs of the nation: Proceedings of a conference on the needs of occupational, ethnic and other groups in the United States*. Washington, D.C.: U.S. Government Printing Office.

5.7.3 Gratch (1978). Gratch (1978) conducted a large scale multi-method study of the information needs and library use of young adults through the Pioneer Library System in Rochester, New York. The researcher collected data through interviews, questionnaires, census data and local demographic/socio-economic reports. Additionally, the research team gathered data from previous library and school surveys, teen crisis hotline logs, and county youth bureau assessments. Identified areas of information need included information about sexual health (particularly pregnancy and abortion information), drugs and alcohol, family conflict, the criminal justice system, peer problems, self-image and self-understanding, finding a job and job training, and exploring recreational activities and hobbies. Gratch also added,

General characteristics of adolescence that create problems and information need are: the struggle for identity; need to achieve economic and emotional independence from parents; the selection of and preparation for an occupation; the development of an appropriate sex role; and the development of conscience, morality, and a set of values. It is not difficult to infer from these aforementioned concerns that are universal to all young adults what kind of information is needed (p. A37).

5.7.4 Amey (1985). Amey (1985) also explored the nature and extent of media and library use by adolescents in support of their everyday lives. Surveying two hundred and ninety-two tenth grade students, Amey's questionnaire presented questions on student library use and reading, viewing, and listening habits. Study findings led Amey to classify study participants as *reading elites* and *neglected enthusiasts*. The *reading elite* were described as a select group of high achievers from upper income families who were "most involved with printed materials such as books and magazines" (p. 49). Amey referred to the larger majority of

young adults as *neglected enthusiasts*. Although this group relied less on formal print sources, they exhibited high use of informal print and non-print resources. Newspaper, radio, movies, audio tapes, and television were also popular media types accessed by this age group. Amey found that surveyed students demonstrated an eagerness for information, though libraries were less inclined to respond to their information needs. Amey also stated, “For too long, the pattern in young adult service has been one of inadequate staffing, training, and research” and advocated for libraries to tailor their collections in wider support of adolescents from diverse backgrounds and varying skill levels (p. 53).

5.7.5 Poston-Anderson and Edwards (1993). Poston-Anderson and Edwards (1993) interviewed twenty-eight girls between the ages of thirteen and fourteen to examine the ways girls express their personal information needs and their perception of school and public libraries as a source for resolving these needs. The interview process involved collecting both qualitative and quantitative data through closed and open questioning techniques. Reported life concerns fell within one of two categories, "relationships" and "education and work" and question types ranged from fact searching, interpretation (advice, judgment, opinion) and searching for understanding (i.e. cognitive or empathetic). Findings indicated that question types varied depending on information source. For instance, fact finding queries were often satisfied through interpersonal sources of information such as peers and family and less through "expert" information sources. Questions posed to "expert" information sources tended to be more interpretive or perspective searching, such as “What [university course] would I be best suited for, and enjoy, and be able to get into?” When asked about their perception of the availability of information related to life concerns, most participants felt their life concern information needs could not be adequately met through school and public

libraries.

5.7.6 Walter (1994). Walter (1994) investigated the information needs of children, gathering input from twenty-five ethnically diverse adults. Participants were employed in a variety child-centered positions including social worker, school nurse, child care provider and administrator, children's librarian, classroom teacher, school administrator, community organizer, 4-H administrator, Girl Scout leader, minister, police officers, probation workers, recreation center directors, and soccer coach. Walter supported the decision to survey adults rather than children using reasoning provided in Farrell's 1974 study:

1. Children are unable to adequately recognize and articulate their information needs.
2. Children's information needs are largely determined and provided for by adults.

Adjusting for social and cultural variables, Walter conducted her study in two southern California counties, one densely populated and ethnically diverse and the other less so. Using in-depth, open-ended interviews, Walter's questioned participants about their perceptions on the information needs, practices, barriers, and gaps of children they served. Aligned with Maslow's Hierarchy of Needs, Walter identified the following types of needs:

Self-actualization: Formal education or curriculum needs, leisure activities, ethics and values

Esteem: Multicultural awareness, emotional awareness, social system knowledge (legal, economic, etc.), sex education, ethics and values

Love and belonging: Multicultural awareness, emotional awareness, leisure activities, interpersonal skills, ethics and values, sex education

Safety: Crime avoidance, traffic rules, emergency procedures, basic literacy, sex

education

Physiological: Personal hygiene; nutrition; general health issues; AIDS prevention; drug, tobacco, and alcohol abuse; child abuse; sex education. (p. 120)

Walter also identified multiple barriers inhibiting information access, including lower placement of priorities on children's information needs, cultural and language barriers, complexities related to society, fragmented delivery systems, incompatible modes of delivery, and insufficient adult support.

5.7.7 Latrobe and Havener (1997). Latrobe and Havener's (1997) study of high school honor students explored their information needs, behaviors, perceived achievement of information task resolution, and information universe. The researchers surveyed and interviewed eighteen students about the strategies students used to resolve specific information needs. Latrobe and Havener created a pre-study typology of possible information related categories of need. Broadly, they included: course-related activities, general information, future plans, relationships, current lifestyles, and health. Findings revealed that students tended to gravitate to peers, parents, and teachers as sources to resolve information needs, citing influential factors including time, convenience, accessibility, and personal preference. On personal issues, for instance relationships, researchers found students less inclined to consult any information source. This was also true for health-related information needs. Latrobe and Havener speculate that participants perceived the available information sources to be of little value in addressing the more personal needs, providing the following quotes from participants,

You can go to someone else and try to ask questions. They can give you advice, but you generally have to work it out for yourself because everyone's situation is

different.” Another explained, “Nobody can tell you about relating to yourself.” A third observed, “I don’t think it’s right to impose my problems on another person (p. 194).

Personal characteristics, including flexibility, determination, curiosity, and self-confidence, were cited as influential factors of information seeking.

5.7.8 Shenton and Dixon (2003a). Shenton and Dixon (2003a) conducted individual and focus group interviews of one hundred and eighty-eight participants between the ages of four and eighteen. Participants were asked to reflect on a time when a decision needed to be made or a particular worry prompted an information need and to describe steps they took toward resolution. The researchers also reviewed data from national curriculum requirements and internal school documents. A typology of thirteen areas of information need developed from their study, including: advice, response to problems, personal information, affective support, empathic understanding, support for skill development, school-related subject information, interest-driven information, consumer information, self-development information, preparatory information, reinterpretations and supplementations of information, and verificational information (p. 39).

5.7.9 Agosto and Hughes-Hassell (2005). Agosto and Hughes-Hassell (2005) explored the ELI needs and practices of twenty-seven urban teens between the ages of fourteen and seventeen through written activity logs and semi-structured group interviews. Notably different from previous studies, participants played a primary role in constructing a typology of information need and preferred ELIS sources and media type. Study participants identified friends and family as preferred sources of information. Feelings of trust and closeness were cited as influential factors, though the specific type of information needed

also influenced who participants chose to approach. For instance, questions relating to sex were often directed to trusted friends rather than family members. While face-to-face interaction was ranked as the most preferred mode of information delivery, participants also identified cell phones as a preferred technology for information exchange. Convenience and the ability to engage more personally (i.e. hear laughter, voice intonations, etc.) were contributing factors related to cell phone preference. Overall, participants held negative perceptions of libraries and librarians and did not feel library collections were relevant to their ELI needs. Table 5 presents a combined typology of preferred ELI sources, media type, and topic developed by participants in the study.

Table 5. *ELI Combined Typology of Sources, Media Type, and Topics*

1. People	2. Media	3. Topics
1.1 Friends/family	2.1 Telephone	3.1 Schoolwork
1.2 School employees	2.2 Television	3.2 Time/date
1.3 Mentors	2.3 Computers	3.3 Social life/leisure activities
1.4 Customer service staff	2.4 Radio	3.4 Weather
1.5 Librarians	2.5 Newspapers	3.5 Daily life routine
1.6 Passers-by	2.6 Product packaging	3.6 Popular culture
	2.7 Personal communication systems	3.7 Current events
	2.8 Printed school materials	3.8 Transportation
	2.9 Product catalogs	3.9 Personal finances
	2.10 Printed ephemera	3.10 Consumer information
	2.11 Books	3.11 Personal improvement
	2.12 Magazines	3.12 Job information
	2.13 Phonebooks	

Note. Reprinted from “People, places, and questions: An investigation of the everyday life information-seeking behaviors of urban young adults” (p. 159), by D. Agosto & S. Hughes-Hassell, 2005, *Library and Information Science Research*, 27.

5.7.10 Meyers, Fisher, and Marcoux (2009). Meyers, Fisher, and Marcoux (2009)

conducted a study of the ELI needs and behaviors of thirty-four tweens - adolescents between the ages of nine and thirteen. Funded by the National Science Foundation, the study was one part of a larger study investigating interpersonal information seeking. Employing interviews

and focus groups for data collection, Meyers et al. reported that study participants perceived needing information on the following topics: schoolwork, social events, relationships, sports and hobbies, consumer information, fashion, pop culture, neighborhood information, bullies, dangerous strangers, drug and alcohol issues, and “stuff” (related to spontaneous needs). Trust and privacy were important to tweens in their information seeking. Study participants preferred consulting peers and family in addressing their information needs over other types of resources, ranking face-to-face interactions as most preferred. The telephone, instant messaging, and email were also identified as ways participants connected with others for information. Internet use varied depending on ease of access. Print sources (books and magazines) and mass media (television and radio) were less preferred over digital content and other individuals. Participants also identified the following barriers inhibiting their access to information: concerns for safety, reduced mobility, adult authority, oversight, monitoring, access to information technology, schedules and daily structure, social costs and perceptions. Meyers et al. presented the following five principles as a guiding framework for youth-centered library service:

1. Info seeking is a natural and necessary part of tweens' physical, social, and intellectual growth.
2. All aspects of information behavior have social and affective nuances.
3. Information literacy is developed and honed in informal settings as well as in tandem with formal scholastic venues.
4. Trust, as a blend of cognitive authority and multivariate cost, is a critical determinate of information seeking.
5. Informal social settings provide key opportunities for information exchange,

particularly about everyday-life situations. (pp. 332-334)

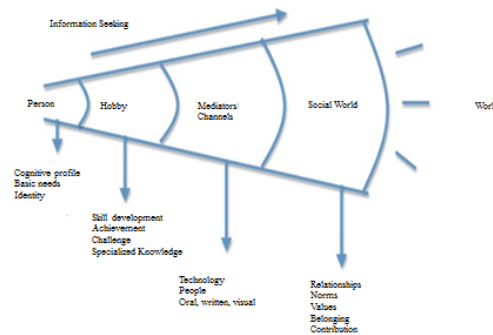
5.8 Everyday Life Information and Individuals with I/DD

Little is known about the ELI needs and behaviors of individuals with I/DD. The following review provides an overview of the information-related research conducted in and outside the LIS field.

5.8.1 Holmes (2008). Holmes conducted a face-to-face interview survey of ninety-eight adults with intellectual disabilities on their library usage, attitudes about libraries, and the types of resources they typically acquire from libraries. Of individuals surveyed, less than half (31%) stated that they did not use the library. Of those who used the library, most (78%) shared that they went to find books and fewer individuals (<12%) stated magazines, music, and movies. Library technology was accessed minimally (4%). Given findings, Holmes concluded that individuals with I/DD do not see the library as relevant to their needs and cited a dependency on others for transportation and the unawareness of library services and types of resources as inhibiting barriers.

5.8.2 O'Leary (2012). O'Leary's case study research examined the information seeking behaviors of young man with Asperger's syndrome related to his interest in hockey. She found that the young man's consumption of hockey-related information contributed to his sense of self and his ability to connect with others, satisfying cognitive, affective, and social needs. At the same time, his fixation on hockey also negatively affected other areas of his life, particularly his ability to develop and maintain independent life management skills (cooking, shopping, laundry, etc.) O'Leary proposed a model for LIS service in which librarians can serve as mediators of hobby-related information to increase an individual's sense of belonging, personal fulfillment, identity, and worldview.

Figure 3. *O'Leary's Model of Information Seeking in the Context of a Hobby*



Note. Information Seeking in the Context of a Hobby: A Case Study of a Young Adult with Asperger's Syndrome, by K. O'Leary, 2011, *Journal of Research on Young Adults and Libraries*.

5.8.3 Sherrod, Ozanne-Smith, & Staines (2004). Sherrod, Ozanne-Smith, & Staines

(2004) reviewed the literature on available injury prevention information for individuals with intellectual disabilities and found information lacking, with exception to basic safety skills, basic first aid, fire safety and fire evacuation. From the premise that there is a higher prevalence of injury among individuals with intellectual disabilities than other individuals, the results of this study are troubling. Sherrod, Ozanne-Smith, & Staines (2004) conclude that more research is necessary in this area to investigate the impact injury prevention information and intervention programs for individuals with intellectual disabilities has on reducing the number of injuries they experience.

5.8.4 Tuffrey-Wijne et al. (2005). Tuffrey-Wijne et al. (2005) investigated the

information needs of cancer patients with intellectual disabilities. Using observation and semi-structured interview with nine individuals, the researchers found that participants were not provided adequate information about their illness, greatly wanted this information, and seemed capable of comprehending it. One reason for this lack of information is that participant families shielded or "protected" individuals from the hard realities of cancer and spare them from the related stress. Researchers also suggested a possible disconnect between

the medical team and the families, with the medical team making assumptions that the family would explain the situation to the individual. Tuffrey-Wijne et al. (2005) identified key implications for practice and research including:

1. Increased awareness by the medical team to understand the cancer related information needs of individuals with intellectual disabilities is necessary, along with the understanding that lack of information can lead to distress for the individual.
2. The medical team needs to be properly trained and involved in providing sensitive support for the individual and should be given proper support themselves in dealing with these situations.
3. The rights of the individuals with intellectual disabilities for information concerning their well-being should always be a top priority and consideration of their ability to comprehend their circumstances should be carefully thought through.
4. Advice from individuals with intellectual disabilities who have been through similar situations should be sought and used to inform decision making.
5. More meaningful and accessible information for individuals with intellectual disabilities who have cancer is much needed.
6. Finally, more research that directly involves the voices and views of individuals with intellectual disabilities is essential to the research process and outcomes. (p. 115)

5.8.5 Tarelton (2004). A project by the Social Care Institute for Excellence explored the information needs of young adults with intellectual disabilities and their families and

supports as they relate to the period of transition from young adult to adulthood (Tarelton, 2004). The study took place from October 2003 to November 2004. Using four focus groups with twenty-six young adult participants between the ages of fourteen and twenty with varying degrees of intellectual disabilities and needed supports, researchers were interested in the following questions:

- What changes do you want to make as you grow up?
- What information do you want to help you with transition into adulthood?

In order to provide context to the focus group, researchers first initiated a discussion regarding the meaning of transition. Initially directly asking the question, ‘What is transition?’ researchers found they needed to change their approach to explain the term, using such phrases as ‘growing up’, ‘deciding what to do when you are older’, and ‘when you leave school.’

In response to the first question, ‘What changes do you want to make as you grow up?’ individuals represented their answers primarily through drawing, though a few individuals chose to write their responses. A member of the research team was present to ask questions and take notes during the process to ensure their understanding of what was drawn matched the participant’s intended meaning.

Drawings were rendered on Post-it notes and then placed on a chart with a large circle and two inner circles inside. Participants represented the importance of their identified wants for adulthood by positioning their drawing either inside the inner circle, indicating high importance, or further out indicating less importance. Eight categories were identified, including:

1. Having a job

2. College
3. Where to live
4. Social life
5. Interests and hobbies
6. Relationships
7. Emotional and physical changes
8. Don't know

The second question, 'What information do you want to help you with transition into adulthood?' was presented using a wide variety of pictures and symbols to assist participants to choose from. Researchers note this method was specifically helpful for participants who had language difficulties. Fourteen categories of information need were gleaned from this activity. They include:

- | | |
|--------------------------|---------------------------------|
| 1. Work | 8. Being in charge of your life |
| 2. College | 9. Living independently |
| 3. Where to live | 10. Healthy living |
| 4. Money | 11. Having fun |
| 5. Friends | 12. Music |
| 6. Sex and relationships | 13. Sport |
| 7. Safety | 14. Helping others |

Parents and supporters were also asked about their views of their child's wants for the future and the types of information their young adult might need. Set within the context of love and concern, parents expressed that their child's aspirations may not be realistic given their intellectual and functional abilities and that they fear their child may end up

disappointed. Parents also indicated they felt relevant and accessible information and supports were unavailable to their child to strive for their goals. Concerns of safety and protection as their child transitioned into adulthood were also expressed.

Supporters indicated hopes that young adults with intellectual disabilities may experience empowerment by access to meaningful information and in turn find their voice to impact change in their lives. Supporters' responses most paralleled the young adult participants in an expressed desire and need to be respected and have control in their lives.

Their desire to, and need for, information about work, housing, sex and relationships, living independently and 'being in charge of their life' all indicated their desire to live in the same way as their peers, to be respected as an adult and to hold the rights and responsibilities that come with being an adult. (p. 20)

Supporters also expressed concern for the lack of information available to their young adults.

The supporters felt that young people needed information to help them say 'this is my life' and 'this is what I want and how I want it'; information which assured them that they were allowed to make choices and be 'able to say no and change their mind.' (p. 21)

Chapter 6 Methodology

...we are active participants in making up the meaning of people.

Tanya Titchkosky, Reading and Writing Disability

The following study explored the everyday life information experiences of four young people with I/DD, Jack, Marie, Ben, and Bella, with the end goal of answering three questions:

1. What are their everyday life information needs?
2. What are their everyday life information practices? What tools, resources, and strategies do they use in support of their everyday life information needs?
3. What challenges do they encounter?

This chapter presents an overview of methodological considerations that informed this study and a description of the study design including the protocol followed, data collection methods employed and rationale for their use, the analysis process, and strategies used to strengthen the validity and reliability of findings.

6.1 Background.

Research related to individuals with disabilities has traditionally employed a narrow lens focused on increased etiological understanding, prevention or minimization of disabling conditions, and intervention to reduce the consequential impact of impairment. Largely quantitative in nature, this medical model of understanding has served to objectify individuals as sources of data rather than consider the value of their life stories as told from

their own perspective, in their own manner, time, place, and voice (Goodly, 1996; Booth & Booth, 1996, p. 56). Previously, narrative accounts have typically been from either the detached view of physicians or institution superintendents or from the perspective of teachers, parents, or care providers. Less often has research included the voice of the individual at the center of interest, those with intellectual disabilities (Lloyd, Gatherer, Kalsy, 2006, p. 1388; Becker, 1967). Why is this?

Becker (1967) spoke of a hierarchy of credibility that occurs in research related to individuals with disabilities, referring to a tendency by researchers to defer to the highest ranked members of any formal or informal dynamic as the most credible sources of information by virtue of the power and accountability their positions entail. This may include gathering viewpoints from other researchers, the medical profession, educators, and parents. Rarely, however, have the perspectives and voice of individuals, themselves, been invited. This exclusion can be largely attributed to the marginalization and imposed invisibility they experience as a result of centuries old societal perceptions of individuals with intellectual disabilities as lacking, different, in need of pity, and of segregation “for their own good” and “for the good of society.”

Matysiak (2001) offers additional explanations for the exclusion of individuals with intellectual disabilities in the participation of research, namely, issues surrounding the obtainment of informed participant consent and hesitancy among researchers who fear that individuals with intellectual disabilities may not fully understand what is being asked and the implications of their involvement in the research. Difficulties in gaining access and ethical issues involved in the research-related engagement of a historically vulnerable population may also contribute to researchers’ reluctance to pursue participation. Finally, exclusion may

be a result of researcher bias and the held notion that individuals with intellectual disabilities are unable to thoughtfully reflect, share, and articulate their experiences (Matysiak, 2001; Turner, 1980; Norlin, 1995; Paterson & Scott, 2002; Lloyd, et al., 2006). While it is true that some individuals with intellectual disabilities may have difficulty articulating and sharing their perspectives and experiences, many researchers have found effective ways to bring forth their stories despite such challenges. Assuming inability is not a valid excuse for omission of study (Lloyd et al., 2006, p. 1388; Matysiak, 2001; Biklen & Moseley, 1988).

6.2 Rationale for Participatory Research

Disability research advocates have begun to challenge the exclusion of individuals with intellectual disabilities in research by promoting successful participatory research initiatives encompassing a wide range of contexts and study topics including employment and education (Cinamon & Gifsh, 2004), relationships (Lofgren, 2004), parenting (Kroese, Hussein, Clifford, & Ahmed, 2002), and self-identity (Meadan & Halle, 2004). These inquiries have relied on qualitative data collection techniques to elicit meaningful input from participants throughout the research process. Tuffrey-Wijne, et al. (2006) advocated participatory research stating, "Research concerned with the experiences of people with intellectual disabilities will benefit from the advice of people with intellectual disabilities. If possible, a person with intellectual disabilities should be involved at all stages of the research process" (p. 115). Engaging historically vulnerable populations in the research process not only creates opportunities for individuals to begin asserting ownership of their life challenges, but also opportunities to become more empowered to enact positive change in their lives (Lloyd et al., 2006, p. 1388). Thus, research becomes an impetus for self-determination, enhanced life quality, and social change. As Matysiak (2001) contends, "in

order for people with intellectual disabilities to be fully included in the disability rights movement, research that involves and empowers them must become a priority" (p. 187). The mantra "nothing about us, without us" has emerged from such endeavors.

6.3 Rationale for Qualitative Research Design and Case Study Methodology

Wilson (1981) promoted the use of qualitative research for studies exploring ELI needs and practices of populations, arguing,

Qualitative research seems particularly appropriate to the study of the needs underlying information-seeking behaviour because:

- our concern is with uncovering the facts of everyday life of the people being investigated;
- by uncovering those facts we aim to understand the needs that exist which press the individual towards information-seeking behaviour;
- by better understanding of those needs we are able better to understand what meaning information has in the everyday life of people; and
- by all of the foregoing we should have a better understanding of the user and be able to design more effective information systems. (p. 666)

One type of qualitative research, in particular, has received positive attention and increasing acceptance by disability and library/information scholars alike – the case study method (Mazumdar and Geis, 2001; Benbasat, Goldstein, & Mead, 1987; Callison, 1997). Yin (2009) defines a case study as "an empirical inquiry which investigates a phenomenon within its real-life context when the boundaries between phenomenon and context are not clearly evident and in which multiple sources of evidence are used" (p. 18).

Benbasat et al. (1987) promoted the use of case study methodology as an effective

way to explore under-researched areas for the purpose of developing and improving information systems, highlighting the researcher's ability to explore social phenomena within real-life context, to gain "in-depth and first hand understanding" of subject matter, and the allowance for self-developing methodologies as appropriate throughout the research process (Benbasat et al, 1987, 371). For disability scholarship, Mazumdar and Geis (2001) outline several unique advantages in support of case study methodology:

1. A case study may depict society's treatment of, or responses to, a social group or a phenomenon and assist the reader in understanding how this affects some people.
2. Case studies can give a better sense of the effects of disabilities on the persons who face them.
3. Case studies can provide an excellent sense of the experiential uniqueness of the person with a particular disability.
4. A case study enables the researcher to offer to the reader an in-depth sense of the context, social and physical, of the life of a person with a particular disability or a known set of disabilities.
5. A case study enables the researcher to take up in as much detail as necessary how persons with specific disabilities manage their lives and the barriers the environment, social and physical, present.
6. Case study enables description of hopes and aspirations. Case studies possess the possibility of looking into the specific attempts by persons with disabilities to be accommodated and seen as equal.
7. Case studies can assist a researcher to learn which of the current approaches to

accommodate persons with disabilities works well and which does not.

8. The insight and understanding provided by case studies can enable change agents to take actions in that setting or to develop emancipatory policies that will enable all citizens to function as nearly as possible at their optimal capacity.
9. Case studies afford the depiction of the emotions of persons with disabilities. (pp. 266-269)

The employment of case studies as a methodological tool does not come without criticism. One of the most cited weaknesses of this approach is the inability to generalize findings. Though, as Stake (1995) counters, this not the ultimate intention of case study research. Rather, he argues,

The real business of a case study is particularization, not generalization. We take a particular case and come to know it well, not primarily as to how it is different from others but what it is, what it does. There is emphasis on uniqueness and that implies knowledge of others that the case is different from, but the first emphasis is on understanding the case itself. (p. 8)

Stoecker (1991) presented other criticisms of case study methodology, including:

- the objectivity of the researcher may be difficult to maintain given small sample sizes;
- assessing accuracy is difficult due to a reliance on retrospective (and often biased) reports;
- an inability to assure accurate measurement of dependent and independent variables;
- reliability and validity are difficult to assess;

- no built-in mechanism to allow for ‘scientific distance’ (for example, the use of experimental controls) to protect against the potential bias of the researcher;
- lack of rigor (pp. 90-91)

Mazumdar and Geis (2001) offered additional criticisms:

- variables may not be identified;
- lack of one or more hypotheses;
- lack of replicability;
- lack of representativeness;
- case may be non-representative and even unique (p. 259)

Despite criticisms, many argue that the application of quantitative research standards to largely qualitative case study research is unjust and more so, irrelevant (Mazumdar and Geis, 2001; Agar, 1986; Kirk and Miller, 1986; Lincoln and Guba, 1985; Morgan, 1983). Mazumdar and Geis (2001) state “at their core, these [critics of cases studies] are attempting to apply the lens, logic, language, terminology, and concepts commonly used in quantitative, statistical methods to an approach that is not statistical in nature” (p. 259).

6.4 The Research Sample

Historically, individuals with intellectual disabilities have been underrepresented as participants and informers in research. Almost two decades ago, Norlin (1995) speculated that this exclusion, in part, was due to a lack of interaction with and understanding of this population by researchers. Carey, McKechnie, & McKenzie (2001) conducted a review of the research and identified several ways researchers have previously “gained access.” These included using personal connections (Lofland & Lofland, 1984), persistence (Whyte, 1943), luck (Berg, 1989), and persuasiveness (Palys, 1997). Researcher mindset was

emphasized as a critical element contributing to a researcher's success in recruiting and engaging participants in study. Carey, et al. (2001) emphasized the need for researchers to:

- have respect for participants and their life worlds;
- strive to develop and maintain trust of participants and their families;
- recognize and exhibit flexibility with regard to the vacillating roles of researcher and participant; and
- work to establish rapport and reciprocity with participants and their families. (pp. 331-332)

For this study, participant recruitment and selection were accomplished purposefully and conveniently. Purposeful sampling served as a means to include individuals diverse in gender, age, and ability. Convenience sampling enabled ease of access to a community I was already engaged with through participation in Special Olympics. Access was further facilitated through the disclosure of my personal and professional experiences. This included my sharing about my experiences as a sibling of an individual with I/DD, as a former special educator and manager of a group home for individuals with I/DD, and as a Special Olympics volunteer.

Four participants took part in this study - two females and two males. Three of the four participants had previously taken part in a pilot study two years earlier. In the fall of 2007, a recruitment email was sent through an email listserv for the local Special Olympics organization. All three participants from the pilot study met criteria for this dissertation research and were asked of their interest to participate again. Criteria included:

- the formal identification of I/DD,
- between the age of 16 and 25, and

- the ability (verbal and/or physical) to articulate experiences and respond to interview questions.

Additionally, rapport and trust were fairly established by that point. A parent of a participant from the pilot study assisted in making the connection with the fourth participant.

6.5 Overview of Research Design

The research process is outlined below, followed by a more in-depth discussion:

1. Prior to study design and data collection, a review was conducted of relevant literature to become familiar with seminal research and literature in the areas of IDD, ELI, and qualitative methodology and analyses.
2. Potential committee members were approached and provided a brief research prospectus and a formal dissertation committee was established.
3. Following successful written and oral comprehensive exams and a proposal defense, an IRB application was submitted and approved. Documentation of IRB approval can be found in Appendix A.
4. Potential participants were contacted via an individual email to their parents.
5. Meetings were scheduled with participants and their parents in individual homes for the purpose of explaining the intent of the study and protocol. After explaining the study, participants were engaged in conversation to assess their understanding of potential participation. Although participants and their families were offered an opportunity of extended time to consider participation, consent was provided immediately by all four participants and their parents. At the end of each meeting, dates were scheduled for interviews, documents were acquired, and teacher contact information was provided by parents

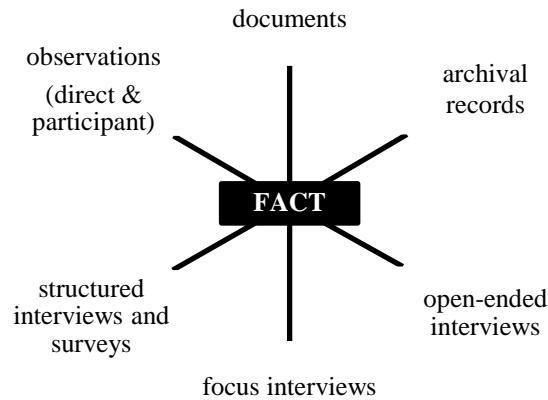
6. Data collection methods are discussed more in-depth below, but generally included:
 - a. individual semi-structured interviews of participants and family participants;
 - b. semi-structured focus interviews with participants' teaching staff;
 - c. school, home, and community participant and non-participant observations;
 - d. photovoice method;
 - e. document collection and review.
7. Interviews were transcribed by the researcher.
8. Interview transcripts, observation field notes, photos, and collected documents and photos were coded initially using Atlas.ti and then by hand to identify common themes. Rationale and procedures for analysis are provided more in-depth in section 6.8.
9. Case narratives were constructed and also coded by hand to identify additional themes.
10. Case narratives were then shared with participants and family participants to assess accuracy of interpretations and reporting.
11. The final dissertation report was drafted.

6.6 Data Collection. Four methods were employed in this study for collecting data: interviews, observations, photovoice process, and document collection. In conducting case study research, Yin (2009) makes a strong argument for the employment of multiple research methods as a means toward truth (Figure 4), stating,

The use of multiple sources of evidence in case studies allows an investigator to address a broader range of historical and behavioral issues. However, the most important advantage presented by using multiple sources of evidence is the development of converging lines of inquiry, a process of triangulation and corroboration...Thus, any case study finding or conclusion is likely to be more

convincing and accurate if it is based on several different sources of information. (p. 116).

Figure 4. *Yin's Convergence of Evidence*



Note. Reprinted from *Case Study Research: Design and Methods* (p. 117), by R. K. Yin, 2009, Thousand Oaks, CA: Sage Publications.

The following section provides a rationale for each data collection method and a description of the process involved in their use. The section concludes with a discussion of the researcher as an instrument in research process.

6.6.1 Interviews. Narrative interviewing refers to an engagement of study participants by the researcher to express experiences and opinions related to a particular topic in open and free flowing dialogue. Although the researcher may probe with direct questions, the interview functions more as a conversation between researcher and participant (Bates, 2004; Jovchelovitch & Bauer, 2000). Bates (2004) lauded the use of narrative interviewing in studies related to everyday life information seeking studies and stated, “the technique of narrative interviewing stimulates storytelling and encourages interviewees to describe an event(s) as they saw it, in their own language, using their own terms of reference, and emphasizing actions or participants which they regard as being significant” (p. 16).

While recognized as an effective technique in capturing and sharing underrepresented

voices, several challenges have been identified in its use with people who have I/DD. For example, some with I/DD experience an inarticulateness stemming from receptive and expressive communication problems. Other factors affecting articulation include low self-esteem, shyness, and few opportunities for social interaction, feelings of oppression, and learned helplessness or habits of compliance. Booth and Booth (1996) identified the challenges researchers sometimes encounter when interviewing individuals with I/DD:

1. Unresponsiveness: Studies related to the efficacy of various question formats showed difficulty on the part of individuals with intellectual disabilities to answer open-ended type questions. The narrative research process relies on opportunity for individuals to take the lead on free flowing dialogue, though this difficulty often requires the researcher to take a more direct and interactive approach than he/she might normally.
2. A concrete frame of reference: The narrative process has both referential and evaluative components with expectation that respondents will be able to construct meaning from past events and consider their impact on present or future situations. This expectation presents challenges for individuals with intellectual disabilities who typically have difficulty thinking abstractly.
3. Problems with time: Individuals with intellectually disabilities are more typically oriented in the 'here and now' and experience difficulties with conceptions related to time/date, presenting a challenge to the researcher in gathering accurate and authentic life stories. (pp. 56-57)

Lloyd et al. (2006) also addressed complications related to the credibility of participant response and identified the following challenges participants with I/DD

sometimes exhibit that may present issues for the researcher:

- poor or inconsistent memory for events;
- lack of insight or awareness;
- confabulated or meaningless responses;
- poor temporal orientation;
- difficulty in responding to abstract or socially reflexive questions or those relating to unfamiliar situations;
- tendency toward acquiescence when more direct questions are used. (p. 1394)

Awareness and consideration of strategies to address and account for these limitations are prudent. Lloyd et al. (2006) propose the following:

1. Interview participants on more than one occasion to determine consistency or inconsistency in storytelling.
2. Construct and reconstruct questions when necessary, paying particular attention to phrasing, use of abstract or confusing terminology, and sentence structure.
3. Meet participants prior to the interview to establish rapport and better gauge language skills in order to adapt questions or method if necessary.
4. Use pictures and photographs to aid participant comprehension.
5. Consider alternative techniques to engage participant dialogue.
6. Discuss findings with participants after the analysis for concurrence, if possible and modify, if necessary.
7. As a researcher, be cognizant of and own your perspectives and positions rather than artificially inserting them into the experiences of those studied. (pp. 1397-1398)

Goodley (1996) addressed issues of researcher bias or contamination in assessment and retelling of narratives from individuals with language deficits and cognitive impairments. Given the sometimes complicated nature from which these individual stories are shared, the researcher must take a more active role in bringing out the story, as either interpreter or biographer. “Such roles run the risk of researchers imposing their own assumptions, understandings and ambitions upon the stories that emerge. In turn, if the life story is taken as the basis from which sociological understanding emerges, whose understandings are presented?” (p. 345) Aligned with Lloyd et al., Goodley calls for researchers to employ a measure of critical self-awareness throughout the narrative process to better account for this possibility. Despite the challenges, Booth and Booth (1996) assert that they are not insurmountable.

It is possible to use narrative methods to give a voice to people who lack words, and to gain a measure of access to the lives of even the most inarticulate and unresponsive informants. They may yield a much poorer harvest of material than would be obtained from studies involving better informants but enough, nonetheless, to make the effort worthwhile in a literature that is still largely ‘void of the experience it would presumably portray.’ (p. 59)

Lloyd et al. (2006) concurred,

Indeed, the limited amount of research conducted within this field thus far suggests that it is possible to elicit perspectives and experiences verbally from individuals with expressive language difficulties that even in situations where this is accompanied by progressive cognitive impairment (e.g. dementia); a voice can still be found. (p. 1388)

One such means to rich data may be obtained through attention to silent dialogue, “silence may be as telling as talk. When using narrative methods with people who have learning difficulties, researchers must learn to read the spaces between the words” (Booth & Booth, 1996, p. 57). Silence could indicate a lack of understanding on the part of the respondent, but also could indicate hesitancy to answer a question, uncertainty, or avoidance. Reasons for non-responsiveness are rarely evident, though Booth and Booth (1996) encourage researchers not to be discouraged.

The clues are usually personal and idiosyncratic, and are picked up only by getting to know the informant. For this reason, interviews with inarticulate subjects should normally be spread over several sessions, and where possible supplemented by time spent with the person in other settings and situations. (p. 64)

Attention to body language, eye contact, and demeanor may also reveal information to better piece together the respondent’s story.

As a researcher engaging with this unique population, consideration and reconsideration of manners, methods, and questions used to generate dialogue is essential. Booth and Booth (1996) note that there is little room for assumptions as to what individuals understand. They state, “our experience is that even the most inarticulate people generally discern a great deal more than their conversation reveals” (p. 60). Interviews with individuals who have language challenges must be “self-developing”, meaning interview methods and processes should continually be refined through multiple interactions with the individual to more fully understand their experience (Tremblay, 1975, p. 690). Strategies might include rephrasing questions into smaller or simpler parts with yes/no or one word type response, providing a menu of response options to agree or disagree, eliminating all

alternatives until “truth” is distilled, developing different hypothetical scenarios for respondent to accept or reject, or progressively adapting to trigger an authentic response (Booth & Booth, 1996, p. 61-66).

In consideration of analysis of narrative responses, Bates (2004) identifies three perspectives that bring to light the “social reality of the narrator”:

1. the sequential and temporal structure of narratives (to understand the linear sequencing of actions which comprise the story);
2. the focus, or perspective (orientation) of the narrative (to understand the views and perceptions of the interviewee and how they evaluated the situation); and
3. how the interviewee tells or reports the narratives or episodes, which includes their use of language, tone, etc. (pp. 15-28)

As evident, the use of the narrative approach for individuals with intellectual disabilities serves to break from traditional research methods and the deficit model of disability which have for far too long neglected the perspectives and authentic experiences of those studied. Furthermore, as a data collection tool for ELI needs and practices Bates (2004) asserts,

The use of narrative or discursive techniques is particularly relevant to studies of everyday information behavior where one of the central aims is to understand, conceptualize, and theorize everyday information needs and information seeking of individuals from their own perspective, and is most pertinent for studies which focus on disadvantaged or marginalized members or groups in society. (pp. 16-17)

In this study, one-on-one interviews were scheduled and conducted with each participant, their parents (separately), their teachers, and in one case – an older sibling. Prior to each interview, participants and secondary participants (parents, teachers, and sibling)

were asked permission for the audio recording of the interview and informed of their right to not answer questions. Participants, in particular, were also reminded that they may end their participation in the study at any time, if they so choose.

Each interview was semi-structured, consisting of pre-planned questions, impromptu questions, and the allowance of time for individuals to share what they felt relevant.

Interview questions revolved around participant histories, strengths and challenges, likes and dislikes, interests and hobbies, activities, and routines (See Appendix B for the interview protocol). Questions regarding participant perceptions of information, information practices, relied on resources, and challenges were also posed to participants, parents, and their teachers.

At the interviews each teen or young adult participant was given a large pad of paper, index cards, and markers. As questions were asked, the participants had the opportunity to respond by drawing pictures to represent their responses – with or without words. Two participants actively engaged in this method of data collection and two participants exhibited disinterest, preferring to answer questions verbally.

6.6.2 Observations. One primary fallacy of observation as a methodological tool for data collection is that it merely requires a keen eye (Patton, 2001, p. 261). The rigor involved in the preparation to conduct systematic research observation is as multifaceted and involved as any other analytical investigative process. Components of such preparedness include disciplined focus, descriptive writing, the ability to isolate moments of meaningful actions, interactions, contextual influences, etc. from trivial minutia and "background noise", understanding and application of triangulated methods to capture a more holistic view, and the ability to self-reflect regarding the inherent strengths, limitations, biases, and

understandings you - as the researcher - bring to your study (Patton, 2001, p. 261).

Observation techniques range in levels of engagement and interaction of the researcher with participants within an environment. Spradley (1980) identifies five types of observation techniques: nonparticipation, passive participation, moderate participation, active participation, and complete participation. The involvement of the observer varies to the extent in which he/she can engage and become naturally immersed within the setting.

Patton (2001) advises,

The ideal in evaluation is to design and negotiate the degree of participation that will yield the most meaningful data about the program given the characteristics of the participants, the nature of staff-participant interactions, the socio-political context of the program, and the information needs of intended evaluation users (p. 267).

Additionally, elements such as research objective, scope, and setting will determine the degree in which the researcher can engage as an observer. For the purpose of the current study, I engaged at a moderate level - observing, asking questions, assisting as necessary, and participating in activities when seemed appropriate and not disruptive to instruction or aim of activity.

There are a number of advantages to employing observation as a data collection tool. Patton (2001) identifies six. First, observation situates the inquirer directly in the context of the study. First hand observation enhances understanding and increases potential for a more descriptive explication of that which is studied. Secondly, direct observation frees the inquirer from relying on another's written or verbal descriptive to inform his/her understanding. A third advantage is, as an outsider, the inquirer may see things that have become have become unapparent, invisible, or taken for granted in the daily routine of the

participant. Fourthly, opportunities for the inquirer to observe instances and interactions that otherwise may not have become evident during a more formal interview session. Fifth, direct observation allows the inquirer opportunities to assess the observed through his/her own lens and constructed understanding as opposed to second hand description and assessments conflicted by another's selective perspectives. Finally, the inquirer is able to pull from his/her own store of knowledge, impressions, and internal reactions - sometimes subliminal - in reflection and introspection of the observed.

Important to identify, there are a number of limitations in using observation as a methodology tool. The researchers own limitations as an observer, in terms of attention and observation skills, could affect data collection. There may be instances in which some observed information is of a private nature and not available to report. Establishing rapport between researcher and some participants is not always easily achieved. Finally, the researcher may be viewed as intrusive, upsetting the natural flow of the everyday experiences of the individual studied (Cresswell, 2003, p. 187).

In this study, observations were conducted on multiple occasions for each participant. And the researcher assumed two different roles, depending upon the context/setting of the observation. Observation sites included participant schools, school-related community and vocational outings, and after school and evening classes and activities. During these observations the researcher acted as a non-participant. Minimal interaction occurred between participant and researcher.

Additional participant observations were conducted that provided opportunities for the researcher to engage in activities with the participants. Examples of these occasions included participation in a pottery class, bike rides, home visits, computer activities, grocery

shopping, lunch outings, and community walks/talks. When appropriate, audio recordings were made of conversations that occurred during lunch, dinner, or car rides. Each time, participants were asked for permission to record the conversation and participants were reminded of their right not to respond.

6.6.3 Photovoice. Photovoice is a participatory research method in which participants document their perspectives, experiences, and other aspects of their lives through photography. Originally endorsed by Wang and Burris (1997) as way to engage community members in community improvement efforts, the method has gained increasing popularity in disability scholarship as a means to represent previously unheard voices in research. Participant photography serves both as a process to elicit voices and as an extension of voice. Disability rights advocates promote the methodology as a way to “buck” the hierarchy of credibility that has for far too long excluded individuals in matters relevant to their own lives. Jurkowsky (2008) identified other advantages, including:

- a more authentic representation of individuals with I/DD and their experiences;
- increased validity of findings as a result of data derived from primary source;
- the development and improved efficacy of programs, supports, services, and policies related to persons with I/DD as a result of these findings; and
- a sense of pride and increased confidence observed as a result of an individual’s opportunity to be engaged in and contribute to research, acquire new skills, influence positive change, and have his/her voice heard and valued. (pp. 7-8)

As with more traditional data collection methods, there are also challenges involved in photovoice methodology. Jurkowsky (2008) cited the following challenges:

- the process can be time consuming due to the need for relationship and trust

building and ongoing engagement between researcher and participant through the photovoice process;

- ethical issues may arise with regard to a participant's understanding of research purpose and consent process, as well as the participant's understanding of appropriate times and places for photo taking;
- challenges for researchers in the involvement of individuals who are non-verbal and/or have significant cognitive challenges with regard to eliciting critical thought and discussions about the process and their photos;
- difficulty assuring accurate representation of individuals who are non-verbal and/or have significant cognitive challenges;
- Potential for technology difficulties with equipment impacting quantity and quality of photos;
- Inability to completely control for outside influence on photo content from over-involved family or support staff. (pp. 8-9)

Member-checking and one-one-one assessments by independent researchers in the form of participant interviews may help to address and counter the negative influence of some of these challenges (Jurkowsky, 2008, p. 9).

In this study, each participant received a digital camera at the beginning of the study to be used for data collection and in compensation for participation. Time was allotted with each participant to provide instructions and for camera set up and practice. Participants were provided with four envelopes. Inside each envelop were simple instructions for four days of camera activity (Appendix C). Instructions were read to participants and shared with their parents. In short, participants were asked to take a series of photos that represented their

daily routines, their likes and dislikes, and their perceptions of information resources. When participants completed four days of photo taking activities, time was scheduled the following week to share and discuss photos. Although participants took photos of objects and people, to maintain confidentiality of participants, only the photos of objects are provided in each narrative.

6.6.4 Document collection. Document analysis is pertinent as it provides an additional layer of insight into the lives of those studied that might not otherwise be available. With regard to individuals with disabilities, documents may consist of school records such as individual education plans, medical history information, behavioral modification plans, transition plans, and habitual plans of care, case management plans, and private documents such as journals, diaries, and artwork. Creswell (2003) identifies a number of benefits and limitations in the use of document analysis as a data collection method. Benefits include,

- Documents enable a researcher to obtain the language and words of participants.
- Documents can be accessed at a time convenient to the research – an unobtrusive source of information.
- Documents represent data that are thoughtful, in that participants have given attention to compiling as written evidence.
- As a method, document analysis saves a researcher the time and expense of transcribing. (p. 187)

Limitations in relying on documents include,

- they may be protected information unavailable to public or private access;
- requires the researcher to search out the information in hard-to-find places;
- requires transcribing or optically scanning for computer entry;

- materials may be incomplete;
- the documents may not be authentic or accurate. (p. 187)

Documents acquired for this study included individual education plans, transition plans, and person-centered plans. These documents provided information regarding each participant's academic and behavioral strengths and areas of need, educational, vocational and life goals, and noted adaptations, modifications, supports, and/or services. Marie's family also provided a narrative of participant strengths, challenges, and vocational interests. This document was used as a communication tool for vocational support staff. Jack's mother provided copies of daily schedules, reward sheets, and participant constructed and typed stories.

6.6.5 Researcher as an instrument. In acknowledgement of what many have referred to as "the myth of objectivity," a statement of positionality has been included in this work in section 6.8.2. Noblit (2004) defined positionality as "being explicit about the groups and interests [the critical ethnographer] wishes to serve as well as his or her biography" (p. 198). This includes disclosure of any personal information that may have influenced the research process and outcome, including one's race, gender, class, previous experiences and/or profession, and ties or commitments to others. Making public one's positioning with the acknowledgement of potential biases and assumptions lends to the development of trust with the reader, thereby increasing the credibility and dependability of findings. Tisdell (2008) explains,

Paradoxically, by making the subjectivity clear, the research becomes more objective.

Thus, the dichotomy between subjectivity and objectivity is replaced by an examination of the dialectic between the two and is dealt with directly which

increased the dependability of the research. (p. 335)

6.7 Data management

The following measures were taken to secure the collected data:

6.7.1 Audio content. Interviews were recorded using a digital recording device owned by the researcher. Once interviews were completed, the audio content was immediately transferred to an encrypted password protected file on the researcher's password protected laptop. Additionally, backup copies of all audio were saved in an encrypted password protected file on an external hard drive located in the researcher's home.

6.7.2 Interview transcripts. All audio content was later transcribed by the researcher using downloaded transcription software, Express Scribe. Transcribed interviews were saved within the same password encrypted file containing audio on the researcher's password protected laptop. Additionally, backup copies of all transcribed documents were saved in an encrypted password protected file on an external hard drive located in the researcher's home.

6.7.3 Physical documents. Physical documents acquired during the data collection were scanned into pdf documents. The original documents were then stored in a locked file cabinet in the researcher's home. Electronic copies of the documents were saved in an encrypted file on the researchers, password protected laptop, with backup copies saved in an encrypted file on an external hard drive kept at the researcher's home.

6.7.4 Photos. Digital photographs taken by participants were first transferred onto a USB flash drive and shortly after (same day) transferred into an encrypted password protected file on the researcher's password protected laptop. Backup copies of photos were also stored in an encrypted password protected file on an external hard drive kept at the researcher's home.

6.8 Analysis

With data collected and stored securely, much time was spent considering different strategies and tools for mining the collected data. Resources consulted included Charmaz's (2006) text, *Constructing Grounded Theory* and Saldana's (2009) text *The Coding Manual for Qualitative Researchers*. The researcher also participated in short courses on two different qualitative analysis software tools, NVivo and Atlas.ti.

Steps toward analysis began with the employment of Atlas.ti. This tool was chosen over NVivo as it allowed the researcher to upload and code audio content. By coding audio, researchers are easier able to make note of voice inflections and paused silences revealing emotions such as nervousness, joviality, anger, reflectiveness, or sadness on the part of the interviewee. After experimenting with the coding of audio, efforts were abandoned due to extensive time involved in advantageously using the function. While the researcher still employed Atlas.ti for first round coding of interview transcripts, photos, observation field notes, and acquired documents, the process was perceived to be more time consuming than hand coding and potential benefits offered through the various functions of the software went unrealized due to the huge learning curve involved. Additionally, the researcher often felt too deeply immersed in the text and process, losing sight of common themes and big picture concepts. The researcher's frustration in using the qualitative analysis tool was validated by Yin (2009) who cautioned against their use stating,

Most case studies pose a more serious challenge in efforts to use computer-assisted tools: Verbatim records such as interviewees' responses are likely to be only part of the total array of case study evidence. The case study will typically be about complex events and behavior, occurring within a possibly more complex, real-life context.

Unless you convert all of your evidence – including your field notes and the archival documents you might have collected –into the needed textual form, computerized tools cannot readily handle this more diverse array of evidence. (p. 129)

Yin (2009) also emphasized “...nearly all scholars express strong caveats about any use of computer-assisted tools: You must still be prepared to be the main analyst and to direct the tools; they are the assistant, not you” (p. 129).

The following three sections outline specific steps taken for each of the three research questions, starting with the defining of key terms followed by the process of analysis.

6.8.1 Research question one. What are the everyday life information needs of teens and young adults with I/DD?

6.8.1.1 Definition of terms. Given the highly subjective and contextualized nature of the terms *information* and *need*, researchers engaged in inquiry on how and why individuals acquire information must first clarify their own conceptions of these two terms in order to avoid audience confusion and misinterpretation (Wilson, 1981, p. 659; Dervin, 1983, p. 158) For the purpose of this study, *information* is conceptualized broadly as a particular understanding that may be sought, received, expressed, and/or perceived through multiple means and recognized in inestimable manifestations. It is an understanding made known through sight, sound, smell, taste, touch, movement, and intuition, facilitated by human action and inaction, interactions and observations, experiences and reflections. Similarly, the term *information need* is applied assuming a wide girth, characterized as (1) an unawareness of relevant knowledge or (2) the recognition of a gap in knowledge. Additionally, the perception of information need may materialize as a result of hindered or barred access to generally accessible information-infused environments (physical or digital)

impacting one's ability to meaningfully engage in determined and unanticipated ways as information recipients, users, constructors, or providers.

6.8.1.2 Analysis process. Areas of information need began to emerge during review of interview transcripts, field notes, and acquired documents. Using a qualitative analysis software tool (Atlas.ti), the uploaded documents were coded with labels reflecting information type and context. This strategy was informed by Wilson's (1997) positioning of *information need* as a "subjective experience that occurs only in the mind of the person" and therefore, something not easily assessed. As an alternative, Wilson recommended that an information needs assessment focus on "activating mechanisms" triggering the need for information (p. 552). A second review and handcoding session enabled the refining, relabeling, or in some instances the elimination of codes. Codes were then extracted from the original documents with findings from each of the four case studies pasted into a single word document, presented in matrix form to enable cross comparisons. Identified areas of information need were listed, row-by-row, in the first column. Four adjacent columns were each assigned a participants' name for brief descriptive notations regarding types of information sought and context.

With the matrix complete, a third round of coding was conducted to delineate the source of the reported "information need" using color-coding to distinguish between *expressed needs* (red) and *ascribed needs* (blue).⁹ *Expressed* information needs, reflected wants or "felt" needs that were either (1) stated by the participant and/or (2) demonstrated by the participant. Important to note, some caution is warranted in the latter assumption of "felt" needs due to the interpretive nature of assessment. As with first round coding,

⁹ This classification of need type is adapted from a taxonomy of social need presented by Jonathan Bradshaw (1972, 1994) frequently referenced as a framework for understanding need within the context of social and economic justice issues.

inferences were made through the assessment of activating mechanisms (Wilson, 1997) with attention to context, participant action or behavior, purpose served or outcome. *Ascribed* information needs were those needs inferred and reported by another as important or necessary to the individual's life and well-being. This included information needs (1) attributed by the parent (or older sibling, in Jack's case), teachers, or the researcher, and/or (2) supported by an in-depth appraisal of related scholarship. The matrix of identified information needs is provided in Appendix D. The final stage of coding involved the winnowing of total information need types into relational categories. Each category was assigned a label reflective of the information needs presented within and purpose served.

6.8.2 Research question two. What are the everyday life information practices of teens and young adults with I/DD? What tools/resources/strategies do teens and young adults use to address their everyday life information needs?

6.8.2.1 Definition of terms. *Information practice* refers to one's intentional engagement and passive customs with information. Intentional engagement includes purposeful action to acquire, consume, create, and share information. Examples may include:

- asking questions of others or seeking answers online,
- visiting the library to find a particular book,
- delivering that same book to a friend who may share a common interest or have a particular need,
- participation in a class to acquire new knowledge or learn a new skill,
- keeping a datebook,
- creating and sharing a meme.

The action is done with a degree of forethought and intention to address a particular want or need. Our passive customs, on the other hand, relate to everyday habits, behaviors, and routines that place us in a position to be recipients of useful information. For instance:

- scanning over a newspaper or flipping through a magazine while waiting for an appointment at the doctor's office,
- watching television at the end of the day,
- eavesdropping on conversations on the bus ride to work,
- listening to the radio while in the car,
- glancing over a community bulletin board entering the grocery store,

These seemingly benign actions are done with little forethought or anticipation, yet situate us for serendipitous encounters with information while simply living life.

6.8.2.2 Analysis process. Analysis began with an informal assessment of participants' perceived information horizons¹⁰ to determine the types of resources and tools that participants recognize in their everyday environments as informative. Participants were provided a camera and asked to "take a picture or pictures of the places you go, the people you might talk to, or things that you might use to find answers to your questions or learn new things." Photos, taken on digital cameras, were then reviewed with participants to gain context and copied to a USB flash drive to be uploaded to the researcher's computer. Analysis involved the review and coding of participant photos, interview transcripts, observation field notes, acquired documents. Using Atlas.ti, content was tagged using broad terms (i.e. "practice", "tools", and "resources") and extracted categorically by handcoding, case-by-case, for the purpose of creating running lists (see Appendix E) to specify types of

¹⁰ Information horizon is a conceptual framework and methodology developed from Sonnenwald's (1999) research to assess an individual's perception of available information resources as a means to increase understanding of influential factors that affect decision-making in information seeking activities.

information practice (i.e. listening to audio content), tools (i.e. cd player), and resources (i.e. library).

6.8.3 Research question three. What are the everyday life information challenges of teens and young adults with I/DD?

6.8.3.1 Definition of terms. An information barrier refers to a restriction in one's access to information. For the purpose of this study, barriers are divided into five categories: *cognitive, psychological, physical, economic, societal, and institutional*. *Intellectual barriers* refer to limitations in knowledge and skills impeding one's access to and engagement with information. *Psychological barriers* are self-limiting factors (for example, depression, low self-efficacy, fear) that make it difficult for one to act purposively with regard to their information needs. *Physical barriers* refer to unaccommodating tools, resources, and environments that make it physically impossible for individuals to access and share information. *Economic barriers* refer to the inaccessibility of information due to prohibitive financial costs. *Societal barriers* are barriers created by societal perceptions and unawareness of information need. *Institutional barriers* relate to the denial of access to information as a result of rigid bureaucratic systems, structure, and/or processes.

6.8.3.2 Analysis process. Areas of information challenge emerged primarily from the review of interview transcripts and observation field notes. Using Atlas.ti, content was initially coded using one code, "challenge." Areas identified were then extracted and placed into a word document for categorization. Upon review of extracted content and consideration of previous literature related to information barriers, the following categories were established: intrapersonal barriers, physical barriers, economic barriers, societal barriers, and institutional barriers. The table located in Appendix F was created for the

purpose of sorting challenges into the most relevant category and for cross-comparison of case studies.

6.9 Issues of Trustworthiness

Establishing trust is paramount in research. Quantitative researchers have traditionally relied on measures of internal and external validity, reliability, and objectivity to ensure the soundness of their research. While these criteria serve as effective touchstones for assessing statistically driven research, qualitative researchers have found them lacking. Lincoln and Guba (1985) proposed four alternative criteria for qualitative studies: credibility, transferability, dependability, and confirmability. The following four sections outline each criterion and provide an explanation of their application within this study. Attention is drawn specifically to techniques employed for the purpose of strengthening this study's methodological integrity and increasing readers' trust.

6.9.1 Credibility. Credibility refers to a shared perception of truth from the viewpoint of the researcher, study participants, and the reader. Several steps were taken in this study to increase the likelihood of credible results including the use of prolonged engagement, persistent observation, triangulation, and member checking.

6.9.1.1 *Prolonged engagement and persistent observation.* Prolonged engagement and persistent observation are complimentary processes undertaken in research for the purpose of understanding the scope and depth of the subject matter studied (Onwuegbuzie, Jiao, & Bostick, 2004, p. 219). Specifically, prolonged engagement (scope) refers to a committed investment of time in the research setting to gain an appreciation for the culture, value system, and social context in which study participants live. Persistent observation (depth) is the researcher's narrowing of attention on attributes and dimensions relevant to the

specific topic of study.

Within this study, prolonged engagement enabled the development of rapport and trust with participants and their families and allowed for opportunities to observe and engage with participants in multiple setting, activities, and roles. Persistent observation, with attention focused on the information experiences of each participant, provided a more attuned understanding of their information needs, prioritized practices, and challenges that inhibited access. Field notes were taken during observations and after interviews, with heightened attention on identifiable instances of and context surrounding observed or reported occurrences of information need, practice or challenge. Formal data collection took place over a six month period. In total, over one hundred and twenty-five hours were spent collecting data, with a minimum of thirty hours per case study (as represented in Table 6).¹¹

Table 6. *Timetable of Data Collection Period*

Introduction of study to participant and parents to gain formal consent	1 – 1.5 hours (each)
Interview with participant's parents and one sibling (separately)	1.5 - 2 hours (8 interviews)
Group interview with teachers and transition specialists ¹²	1.5 - 2 hours (2 group interviews)
Initial interview with participant	2 – 3 hours (each)
Introduction of photovoice process, camera set up and practice	1.5 hours (each)
Photovoice interview with participant	1.5 - 3 hours (each)
School observations ¹³	6 ½ hours x 2 days (each)
Observation (participant/non-participant) of recreational/leisure activities	8+ hours (each)
Final interview ¹⁴	4 hours (each)

¹¹Beyond formal data collection, the participants and I maintained friendly relations through participation in Special Olympics, phone calls, emails, and occasional social outings.

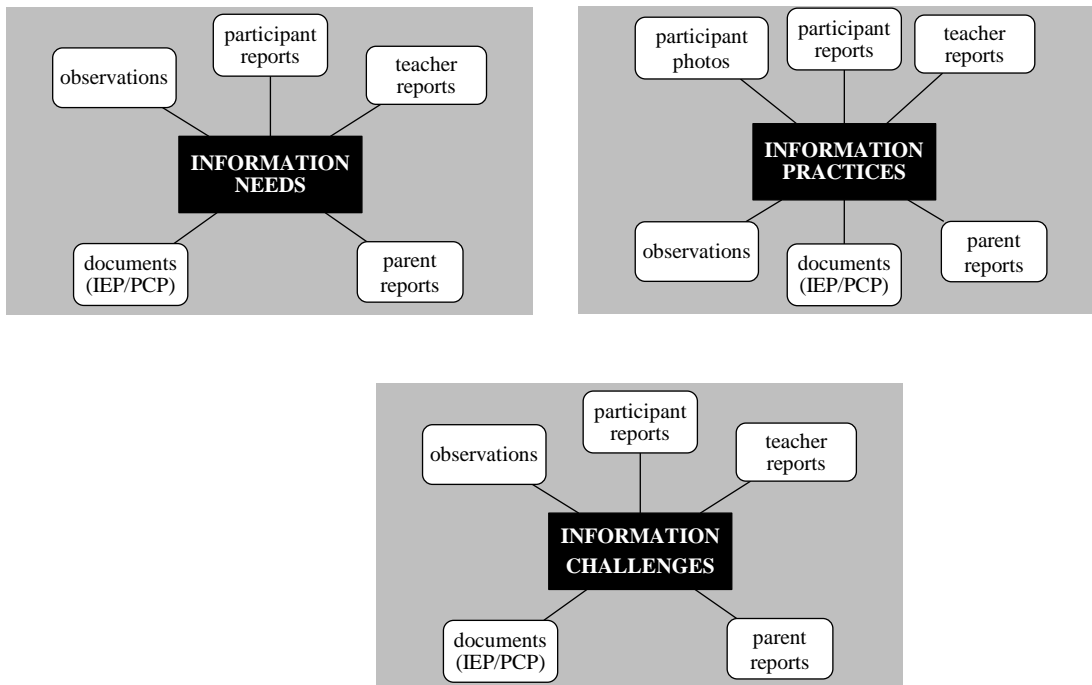
¹²Three of the four participants shared the same set of teachers at some point in their high school experience. Therefore two group interviews were conducted. During the interview with teachers of the three participants, time was allotted to discuss each participant separately. The decision to conduct group interviews was made to accommodate teacher schedules and conserve time.

¹³Three participants were high school students. The fourth participant graduated from high school the previous year.

¹⁴Each interview was broken into approximately 45 minute segments allocating time for short breaks and lunch.

6.9.1.2 Triangulation. Yin (2011) defined triangulation as “the goal of seeking at least three ways of verifying or corroborating a particular event, description, or fact being reported by a study” (p. 81). Yin also emphasized the strengthening of credibility when verification is attained not only through multiple sources (i.e. confirmation by three or more individuals), but also by multiple means (i.e. confirmation by observation, participant statement, and document analysis) (p. 81). The following figures present the generalized convergence of evidence leading to the identification of information needs, practices, and challenges in this study.

Figure 5. *Convergence of Evidence*



6.9.1.3 Member checks. Member checks involve soliciting feedback from study participants for the purpose of verifying accurate portrayals of their lived experiences and perspectives. In this study, member checks were conducted with study participants, parents, and one older sibling after findings were compiled and incorporated into separate case narratives.

Presented in word format, the case narratives were first sent to participants' parents and one sibling for review. The documents were delivered as an attachment to an email that included a rationale for case narrative use and a request for confirmation, rejection, and corrections of the information presented. Although anonymity was assured, recipients were also informed of their right to censor any information presented in the case narratives that they felt uncomfortable sharing publicly. Overall, their returned responses were positive and in agreement with information presented and interpretations made. Additional information and life updates were provided by all and minor corrections were offered relating to the presentation of certain facts and proof edits.

Participant member checks were scheduled as one-on-one interviews lasting a minimum of four hours each, allowing for breaks approximately every thirty to forty minutes. During this time, case narratives were read aloud with participants to confirm accuracy of presented information. Sessions were audio recorded and participants were informed of their rights at the start of each session, including the right not to participate in this part of the study, the right not to respond to any questions asked, and the right to censor any information that they provided earlier and now preferred not to share publicly. When reading aloud the case narratives, one participant requested that certain information not be shared publicly and another participant chose not to respond to some of the questions.

The use of case narratives for the purpose of member checking proved to be an especially effective method with participants. With their lives presented in the context of a story, participants were able to quickly confirm, reject or clarify information presented, diminishing concerns of participant acquiescence. Additionally, the process unexpectedly elicited many additional comments and thoughtful reflections from participants and all

displayed an observable excitement or pleasure in hearing their lives retold.

6.9.2 Transferability. Transferability refers to the ease with which one is able to generalize research findings and is highly dependent on in-depth descriptions of place, time, context, and culture (Lincoln and Guba, 1985, pp. 297-298). “Thick description,” as described by Denzin (2001)¹⁵, was used in this study as a means for specifying data collection methods, sharing findings through case narratives, and describing analytical procedures. Additionally, data analyses documents are provided in the appendices thereby increasing opportunities for other researchers to generalize and integrate similar processes into new initiatives.

6.9.3 Dependability. Dependability is concerned with the consistency of findings over time, with an understanding that some amount of change is expected. Thorough audits of subject matter and regular documentation of such change is necessary to assure claims of dependability (Lincoln and Guba, 1985, p. 299). Although formal data collection occurred over a six month period, the relationship forged between researcher, participants and their families facilitated an ongoing and regular exchange and documentation of information regarding issues relevant to the study, strengthening confirmation of findings.

6.9.4 Confirmability. The goal of confirmability is to demonstrate that findings are obtained and reported with a high level of neutrality. Emphasis is placed on original sources as evidence and the full disclosure of logic as to how data is interpreted (Lincoln and Guba, 1985, p. 300). Peer debriefing is one strategy implemented in this study to increase confirmability. This involved sharing research processes and products, including analyses with a colleague who serves as a critical eye. Meetings occurred on a regular basis and

¹⁵Denzin (2001) defined “thick description” as having the following characteristics: (a) It gives the context of an action, (b) it states the intentions and meanings that organize the action, (c) it traces the evolution and development of the action, and (d) it presents the action as a text that can then be interpreted. (p. 53)

throughout all stages of the research process and included:

- advisement on initial reviews of related research to ensure appropriate and relevant coverage of the literature,
- a critical review of the study design, implementation, and evolution to provide feedback, offer suggestions, and troubleshoot challenging processes,
- ongoing audits of case narratives, emerging and final codes, analyses, and final reporting
 - as an outside check for personal biases and assumptions,
 - to offer advisement on alternative ways to consider and represent findings, and
 - to review final report for clarity and completeness.

Additionally, “thick descriptions” of analytical procedure provide the reader a step-by-step account of data coding and categorization, supported by the included data analyses documents.

6.10 Ethical Considerations

6.10.1 Participant risk minimization. Case studies involving individual lives pose a number of risks to the participants. Three risks of particular relevance when engaging individuals with I/DD include the potential for emotional distress post-study, inaccurate representation of participant lives and experiences, and the disclosure of identifying information.

6.10.1.1 Potential for emotional distress. One risk sometimes cited is the potential of participant emotional distress due to mismatched expectations of the post-study researcher/participant relationship. While it is easy to presuppose that participants with I/DD

may be more inclined to desire continuation of relationships after a research process (and indeed research does indicate that this population has considerably fewer social relationships than non-disabled individuals and may be more vulnerable to disappointment of the severance of relationships), this assumption contributes to a paternalistic view that situates individuals with I/DD in a position of lesser control and devalues individual preferences and opinions. Furthermore, such instances are a part of everyday life and something all individuals must learn to adjust for and move forward. While unethical to exploit any cultivated relationship for the sake of research, to “safeguard” against these occurrences is to assume a position of authority and knowledge that is unwarranted and unearned. That said, Stalker (1998) promoted precautionary measures to reduce emotional risks, such as direct communication and negotiation between participant and researcher on the degree of engagement possible or impossible once research has concluded. Further, Booth and Booth (1996) advise extended disengagement time, with allowance for the participant to acclimate, post-study.

6.10.1.2 *Misinterpretation.* An additional risk to the participant is the potential for their words to be misinterpreted or for the original message to be expanded by the researcher to more clearly convey the researcher’s understanding of the participants implied meaning. Stalker (1998) advised a researcher/participant validation period to seek confirmation of expressed words and researcher interpretation.

6.10.1.3 *Identity disclosure.* In studies involving a small number of participants, it is not unusual for large amounts of data to be collected and shared, increasing risk of identity disclosure. Precautions must be taken to ensure participant anonymity. This includes the use of pseudonyms of participants and significant individuals in their lives, and the non-

disclosure or slight modification of any identifying physical, situational, and locale characteristics. Additionally, once the study is complete, the researcher must make every effort to destroy all identifiable print and electronic data.

6.10.2 Precautions to minimize participant risks. Efforts were made to minimize participant risks during the study. Due to the nature of sample selection, relationships between participants and researcher had already been established and only strengthened as a result of increased time spent. Severance of ties is not a threat due to mutual engagement in a common and active community and quality of relationships developed. Although individual participants exhibited different levels of desired contact, with some wanting/seeking more time and others less, boundaries were negotiated and expressed over the course of the study and remain unchanged after the study.

Member-checking and triangulation of collected data were implemented in the study to reduce the potential for misinterpretation or inaccuracy of findings. This involved the sharing of individual case narratives with the participant and their parents (separately) to confirm accuracy of expressed comments, interpretations, and re-told life experiences.

To reduce risk of participant identification, potentially identifiable information – including information related to physical, situational, and locale characteristics were slightly altered in the drafting of the narrative. Further, participants and significant individuals that appear in the narratives were given pseudonyms, chosen by participants themselves, to increase assurance of anonymity. Upon final reporting and defense, all potentially identifying print and electronic data will be deleted or destroyed.

6.10.3 Positionality. Beyond the data collection methods, data management strategies, and analytical tools, it has been said that the researcher is an instrument of research. Piantanida

and Garman (1999) go so far as to assert, “The researcher is as much a part of the inquiry as the intent of the study and inquiry process. In fact, the researcher’s thinking lies at the heart of the inquiry” (p. 24). Every decision made, participant selected, interview question formed, observation conducted, option excluded, and meaning made is done so by an individual or individuals inextricably fettered to his/her own history and view of the world. Acknowledged or not, subjectivity and bias are unavoidable.

With this in mind, several efforts previously mentioned help to minimize researcher influence over the process and results. An additional measure often offered in qualitative studies is a disclosure of positionality. Positionality refers to one’s sense of self and place in time and space. For the researcher, statements of positionality allow for the disclosure of personal or professional information that may be viewed by outsiders as corruptive to the integrity of the research process and results if left unrevealed. Revelations may or may not include the sharing of one’s knowledge areas, values, beliefs, experiences, professional and/or social status, ability/disability, nationality, gender and so on (Banister et al., 2011, pp. 91-92). These disclosures are particularly important in inquiry efforts toward the empowerment of marginalized populations. Often referred to as “emancipatory research”, studies such as these, by nature, run a high risk of being perceived as biased or agenda driven.

Along with disclosures, statements of positionality should reflect persistent self-assessments and a recognition on the part of the researcher as to his/her influence on the process and outcomes. In qualitative research, the researcher’s role is often one of altering dynamics, highly dependent on and influenced by context and perception and the projection of the relationship between and by researcher and participant (Ngo, 2010, pp. 111-122;

Mertens and McLaughlin, 2004, p. 108). As Ngo (2010) experienced while conducting an ethnographic study of Lao American students at an urban public high school, the intentional and detached identity that many researchers attempt to portray in data collection efforts is difficult to maintain. She stated, “During my research I developed relationships with students...where we were engaged with each other as human beings, sharing moments of silliness and sadness, as well as hopes and fears.” Although she had done what she could to prepare for the study, the human intimacy experienced and connections formed were unexpected and at times, unsettling. In attempt to characterize her complex and shifting role as researcher, Ngo reflected,

I am once again confronted by the inadequacy of our discrete categories for identity.

My interactions, conversation and positions...cannot be described by stable, cohesive categories of “researcher,” “mentor,” “confidante,” “adult,” or “friend.” ...I was all of this and more, something that was “not quite the Same, not quite the Other.”¹⁶

(p.121)

The tensions inherent in negotiating the line between insider/outsider roles in research initiatives are well documented. While the underpinnings of social science are grounded in the work of those who have absorbed insider identities within the research setting, Lincoln and Guba cautioned that by “going native” researchers may risk their ability to be objective. Kanua (2000) however, points to the self-reflective “native researcher” as advantaged in that he/she is “grounded in implicitly and situated at all moments” within the research process (p. 441).

The following chapter invites the reader into the lives of four young people with

¹⁶ This is a reference to work by Trinh T. Minh-ha, a Vietnamese-American filmmaker, anthologist, composer, and post-colonial theorist. Trinh’s draws attention to the tensions and fluidity that exist between insider/outsider positionality in research.

I/DD. In doing so it also draws the reader into my world. The histories and lives shared are not simply the product of data collection activities; they are a reflection of relationships formed and lives intertwined by common experiences, understandings, and frustrations. As a younger sister of a sibling with I/DD, I learned from a young age that the world is not always a kind and just place for individuals with I/DD. Eighteen months older, my sister was first identified with “mental retardation” when she entered kindergarten and was soon placed in a self-contained special education class. I was seven when I first heard the word *retard* hurled as an insult carelessly across the school lunch room. I have little memory of my parents sharing information about my sister’s cognitive challenges at this early age; still, I remember this day and I knew that this word, somehow, related to my sister. It stung.

Growing up, I watched as my sweet-natured and overly trusting sister endured false friendships, bullying from school mates, and harassing prank phone calls. In school, I saw her grow in confidence with incredible teachers who helped to develop her reading, writing, and life skills, only to lose these same skills a year later when placed with a less than motivated teacher whose idea of academic instruction largely consisted of showing videos and coupon clipping. I watched my parents advocate eloquently and not so eloquently, addressing insensitive remarks, ignorance, and prejudice from educators, medical professionals, and others in our community. These early experiences influenced my educational and professional trajectories, leading me to pursue an undergraduate and graduate degree in Special Education. During this time, I also served as a group home manager for individuals with I/DD and upon degree completion, I worked as a special education teacher for a number of years. Apart from my LIS doctoral program, I spent a year

in the LEND training program¹⁷ and have enjoyed long term involvement with Special Olympics as a coach.

I feel my personal and professional experiences have greatly enhanced my role as a researcher. In this dissertation research, my positionality afforded me an understanding of the challenges individuals with I/DD and their families face. Through sharing my background and personal experiences, I feel that I was able to more easily connect with participants and their families. Rapport, trust, and meaningful relationships were developed over a short time and I was entrusted with stories perhaps not otherwise shared. My educational background in K-12 education, disability studies, and library and information science provided me a strong understanding of theory and practice, informing all stages of the research process from study design through analyses and reporting. My teaching experience enabled me the skills to communicate information and engage participants in the research process in meaningful ways. My background in special education and previous teaching experience also afforded me a working knowledge of special education procedures including the IEP and transition processes and related documents. My professional background also contributed to my credibility with school district personnel and educators, affording me access to schools, classroom instruction, and community-based activities.

While I consider my positionality a strength, I also recognize how my previous experiences and viewpoint pose the potential for bias as a researcher. For this reason, many measures were taken to ensure the trustworthiness of the study's findings, including data triangulation, "thick" descriptions, member-checks, peer-debriefing, and reflective

¹⁷ LEND is an acronym for Leadership Education in Neurodevelopmental and Related Disabilities and is a federally funded program that provides interdisciplinary leadership training at undergraduate, graduate, and postdoctoral levels through University Centers for Excellence in Developmental Disabilities (UCEDD).

journaling. Despite these insurances, a claim of objectivity would be both inaccurate and diminishing to my lived experience and those who share my community. One only has to look at the recent statistics on adult life outcomes to understand the injustice individuals with I/DD face on a daily basis. This research is personal and subjective; however stating so makes it no less accurate or less trustworthy.

Chapter 7 Case Studies Introduction

You never really understand someone until you consider things from his point of view...until you climb inside of his skin and walk around in it.

Harper Lee, *To Kill a Mockingbird*

This chapter invites the reader into the lives of Jack (age 17), Marie (age 23), Ben (age 21), and Bella, (age 19) as a means to enhance understanding of the everyday life experiences and needs of young people with I/DD and the significance of cognitively accessible information. The case narratives will reveal several similarities between the four participants. They live with their families in the same small community and all have well-educated and involved parents. Three of the four participants have attended the same high school and all regularly take part in common activities through several local non-profit organizations. Having said this, the narratives will also reveal that Jack, Marie, Ben, and Bella are four highly unique individuals with distinct interests, strengths, talents, preferences, challenges, and needs; and their shared label of I/DD offers only a limited degree of commonality.

All four individuals played a central role in the research process, contributing to data collection, offering considerable time and input, and opening their daily lives for observation and study. Beyond interviews and observations, the four participants also initiated contact to share information about their lives and experiences through email, text messages, phone calls, Facebook and mail. Toward the construction of their narratives, all took responsibility

for creating and assigning pseudonyms for their self and others depicted in their stories, and two participants shared drawings about their lives incorporated into their narratives. Finally, all took part in member-checking activities to ensure accurate representation of their lives and perspectives.

The four case narratives rely upon “thick descriptions” to capture and share individual histories, intricacies of everyday life, and the viewpoints of individuals seldom represented in the research literature. While family and teacher participants helped to provide the narrative structure, it was through the voices and participation of Jack, Marie, Ben, and Bella that connections were formed and meaning found.

7.1 Introducing Jack

“Can I tell you a story?” he asked. This was my introduction to Jack and a question I soon became accustomed to hearing during my visits with the eighteen year old. Jack is a storyteller. At 6’1 and 210 pounds, he brings his tales alive, stepping into his characters with animated voice and grand gestures – a lunged chop at an imaginary beanstalk or a gentlemanly bow to the fair maiden. With enthusiasm unmatched, Jack welcomed me into a world of beanstalks, magical harps, a huffing and puffing wolf, and a host of other familiar characters.

When not sharing his stories, Jack can often be found walking about in whispered voice crafting and re-crafting his stories in his mind. “I like telling stories to myself,” he tells me. However, it would be an understatement to say that these storylines and characters are simply a preferred pastime. Rather, they have become an interwoven and often consuming facet of Jack’s everyday life. Jack has autism. Fixation on a particular interest area is typical of many individuals with autism. If left to Jack, storytelling will dominate free time, attention, and conversation to the exclusion of all else.

Jack’s Individual Education Plan (IEP)¹⁸ specifies his primary area of eligibility for special education services as Autism Spectrum Disorder (ASD).¹⁹ ASD can be defined by a set of behavioral characteristics ranging from mild to severe. Identifiable characteristics

¹⁸ An IEP is a federally mandated document individually constructed for each public school student who receives special education and related services. It is a collaboratively composed plan of action, reviewed yearly, identifying goals and short term objectives detailing methods for measured achievement toward desired academic and behavioral growth. The collaborative team charged with this process may include the special education teacher, parent(s)/guardian(s), district administrator, transition facilitator (for students 16 years of age), and the student.

¹⁹ A 2012 CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network report on the prevalence rate of ASD estimates 1 out of every 88 children are on the spectrum. ASD crosses all racial, ethnic, and socioeconomic groups and displays an occurrence four to five times higher in boys (1 out of 54) than girls (1 out of 252).

may include:

- early language delay
- difficulties with social interaction
- poor eye contact
- repetitive use of language
- repetitive routines and/or behaviors
- self-stimming behaviors such as hand-flapping, twirling of objects, spinning, etc.
- fixations on objects and/or special interest areas
- splinter skills – referring to an uneven profile of abilities with considerable strengths in one or two skill sets
- sensory issues – difficulty filtering sensory input, such as bright light, certain noises, types of touch, various tastes and textures, etc.
- strong rote memory skills/difficulties with abstract concepts

Characteristics may present themselves in a variety of manners and to varying degrees and are not, necessarily, collective in their manifestation. They may range from a subtle quirkiness in personality to a complete disconnect from the social world. When asking Jack to share a little about his autism, he responded, “My autism means that I am a good boy!”

Jack lives at home with his mother, Andromeda and older brother, Perseus. Jack’s father lives out of state and is not active in his life. Jack attends the local high school and receives instructional and behavioral support through the special education program. As a single parent, Andromeda works two jobs. She is also active in local advocacy efforts for

individuals with I/DD. Jack's brother Perseus, attends college and also contributes to the family income through part-time work. Given the extent of Jack's need for supervision and behavioral support outside of the school day, the family receives fifty-five hours of home support each week. Support is provided by four direct care providers, with only one providing support at any given time. They assist Jack with self-care needs, life and vocational skill development, and provide transportation to and from many of his extracurricular activities. Three out of the four care providers are male. Andromeda commented on the benefit of having male care providers as positive role models for Jack, noting that they, along with Perseus, have been especially helpful in dealing with issues surrounding puberty and self-care as Jack transitions into young adulthood.

During initial interviews, I began learning about Jack by asking a question: "What words describe Jack?" I presented this question to Jack, his mother, brother, and teachers. These were their responses:

Jack: brave, concerned, good, smart, steady

Andromeda (Jack's mother): exuberant, kind, polite, fun

Perseus (Jack's brother): innocent, energetic, opinionated, adorable, comfortable in his own skin

Jack's teachers (combined response): joyful, exuberant, polite, flexible, and affectionate

Jack's Individual Education Plan (IEP) and Person-Centered Plan (PCP)²⁰ provide a snapshot view of Jack and a glimpse into his everyday life. His IEP states:

²⁰ Person-centered plan (PCP) is a life planning model collaboratively designed around the individual, his/her interests, strengths, and needs. These plans and processes are constructed and implemented in separation from the educational environment. The PCP team is typically comprised of the individual, his/her family members and/or any other significant relations in the person's life, a home care provider(s), and led by an appointed case manager.

Jack is friendly, assertive without being aggressive, and shows willingness to compromise. He demonstrates a well-developed thought process, a good use of vocabulary, a great sense of humor, logical thinking, enthusiasm, and a love of learning. Math and Reading are considered relative strengths for Jack. Ms. Aurora [Jack's teacher] reports that Jack continues to develop his team playing skills. During his leisure time, Jack enjoys playing with Legos, Wii, Mickey [Mouse], playing the violin, and playing the sports of tennis, racquetball, swimming, and yoga.

Jack, Andromeda, and a care provider identified additional areas of special talents and traits, reported in Jack's PCP:

Jack: Telling stories, watching movies, playing on the computer, swimming, tennis

Andromeda: He tells great stories, he tries to please, and he follows written directions well.

Care provider: Jacks' got a great memory, vocabulary, enthusiastic personality; he has a remarkable talent for storytelling, great rhythm, good musical ear, quick learner at violin. Excellent skills in narrative innovation, a fine swimmer, excellent in problem solving strategies.

In 2007, Jack took part in a comprehensive evaluation measuring his IQ, academic aptitude, and adaptive behavior skills. His evaluating psychologist provided the following summary statement:

Jack was functioning within the Very Low range of intelligence on the DAS-II.²¹

²¹ The DAS-II refers to Differential Ability Scales 2nd Edition and is a norm-referenced test individually administered to assess cognitive ability in areas of verbal and visual working memory, immediate and delayed recall, visual recognition and matching, processing and naming speed, phonological processing, and

He showed a significant weakness on spatial abilities. As measured by the WIAT-II,²² Jack's performance was Borderline in Reading and Mathematics, and Extremely Low in Written Language. The ABAS-II²³ rating scale completed by Jack's teacher and mother indicated that his adaptive functioning was generally within the Extremely Low range. Ms. Aurora, classroom teacher, stated that these test results still appear to be accurate. She did, however, just complete the KTEA²⁴ and the results of this test yielded a grade equivalent of 6.2 in reading, a 3.5 grade equivalent in writing, and a grade equivalent of 5.8 in Math.

7.1.1 Jack's early years. Once upon a time, a baby was born –Jack. Andromeda, Jack's mother, reminisced on Jack's birth and first year of life as joyful, yet unremarkably ordinary. At 15 months of age during a routine doctor's visit, Jack's pediatrician discovered a lump at the base of Jack's spinal column. The following days included ultrasounds, MRIs, CAT scans, and an assortment of other tests until finally a diagnosis: cancer. More specifically, neuroblastoma, a tumor that develops in tissues from the sympathetic nervous systems and one of the most common forms of pediatric cancers. Discovered early, doctors informed Andromeda that Jack's prognosis was good. Despite the encouraging news, life had changed. Andromeda recalls,

Jack's father had walked out a month before and life was in a shambles. I had to

understanding of basic number concepts. It is designed to be administered to children between the ages of 2 years 6 months to 17 years 11 months.

²²The WIAT-II refers to Wechsler Individual Achievement Test 2nd Edition. This assessment assesses academic achievement in areas of Reading, Math, Writing, and Oral Language of individuals aged 4 through 85.

²³ABAS-II refers to Adaptive Behavior Assessment System – 2nd Edition. This assessment is a behavior rating scale evaluating areas related to conceptual, social, and practical skills. It is typically completed by a parent, caregiver, and/or teacher for individuals aged birth to 89 years.

²⁴The KTEA refers to the Kaufman Test of Educational Achievement. This test assesses academic achievement in areas of Math, Reading, and Written Expression for individuals aged 4 ½ to 25 years.

come home every night to assure Perseus that Jack wasn't going to die. You know, when you tell a 10 year old that his baby brother has cancer, it is very scary. After multiple surgeries and six months of chemotherapy, Jack was declared cancer-free. Still for Andromeda, fears lingered.

It was New England winter....Jack was at home. We had nurses come into the house to check his blood level. His counts were terrible and I wasn't taking chances. He didn't go out - people have colds. If somebody came into my house and sneezed, I said "There's the door. Get out. Sorry." Pneumonia is scary. Your whole lifestyle changes.

During this time, Jack had also stopped talking and was beginning to exhibit defiant and challenging behaviors. Andromeda initially attributed his behavior to months of coddling a child experiencing the trauma of cancer and treatment.

He was spoiled. I knew that. You know...he was only two and it is not the end of the world here. We have time to fix him. Though the more I tried, the harder it got...I just thought "I must be the worst mother on the face of the earth. How come this kid can't get it?" And then one day his preschool teacher said to me "Maybe he should be tested, maybe there's something else going on here."

When the answer finally came, Andromeda recalls the following conversation with the pediatric psychiatrist

Doctor: "Has anyone ever said Asperger's to you?"

Andromeda: "No, what is that?"

Doctor: "It's a form of autism."

Andromeda: "Autism! He doesn't have autism! He plays, he can engage. He

doesn't sit and rock and bang his head. He's here! You know he might zone out a little, but..."

7.1.2 Jack in childhood. Shortly after, Andromeda enrolled Jack in a kindergarten program for young children with special needs. She described her son at this time as a young boy with a "zest for life" who skipped the school hallways and greeted everyone "with all of his exuberance." He was placed in a classroom with a new teacher, who Andromeda described as young, but experienced in working with children with special needs and managed her classroom with structure and a somewhat rigid demeanor. She recalled an encounter when dropping Jack off at his classroom one morning. Jack had gone ahead of her and ran excitedly down the hallway to greet his new teacher.

She was visiting with another parent and she strictly said, "I'm talking to a parent and you must not run. Now go back to the end of the hall and walk down again."

She and I butted heads many times. I ended up saying to her, "I understand that Jack needs structure and he needs things to be orderly, but you can't take his spirit away. I believe that it is because of his spirit that he is alive today and I don't know if he might need it again. I can't let you rob it from his life. I would think that you would be excited that you have this student who is happy to be here and happy to see you. For any parent that you may be talking with, it would give them a good feeling to know that you have a child in this classroom who is so happy to be here, especially when some are coming in kicking and screaming and their parents are basically dragging them down the hallway. So don't you turn my child into one of those children."

After several meetings with the teacher and school administrator, Andromeda and

the teacher began to develop a mutual respect for one another and a strong partnership in support of Jack.

Through the school system, Jack and Andromeda also began receiving in-home support for two hours every other week and first became familiar with the use of schedules as a behavior management tool.²⁵ She recalled, “It started out very basic, he was five. He wasn’t reading, so she (support provider) used picture schedules.” By the time Jack was eight, Andromeda had customized a personalized behavior management system for Jack through the use of schedules, clear rules and expectations, and incentives for positive behaviors. She commented,

He was thriving and life was good. I mean...it was different than the average eight year old life, but when you go from a kid who you are constantly chasing after, who can’t sit more than five minutes and who you can’t get to engage... you think you are never going to have any normalcy. For a while, I felt like a prisoner in my own home. It was scary to go out with him. You just never knew what he was going to do and so you were anxious and your anxiety would raise his anxiety and therefore the behaviors got worse...Now we could take him to see a play. He could read and he had a list of rule cards. You know...now we just had to point. He would read them, sit back down and smile. I would smile at him and we would just go on. We took him to Disney World, Washington D.C. Yeah we modified – we did everything outdoors. We took him to Mount Vernon, the Smithsonian - inside a little, but not too much. You begin to create your vacations around what he can do.

²⁵ Schedules - pictorial and text – have been found to be highly effective tools in providing support for persons with autism, who commonly struggle in situations presenting multiple and concurrent stimuli and when transitioning from task-to-task and environment-to-environment. Through visual cues, individuals are able to anticipate change through structure, predictable patterns, and clear expectations. Benefits include a reduction in stress and anxiety and increased independence.

He rode the metro, he stayed in hotels. You know, he did ok! So you feel lucky.

With this system in place, Jack experienced much success in his early years of schooling. By third grade he was learning to read and doing math. Although primarily taught in a self-contained special education classroom, Jack began participating in a general education classroom for a few hours every day. Andromeda commented on the significance of this experience.

It didn't dawn on me for all of the years. You don't really think about it. You are walking down the hallway and there are all these kids on either side of you and no one ever said anything to you. But now, when we walk down the hallway and he's been spending time in the classroom next door...and they all [the other students] start saying "Hi Jack! How are you today?" You start realizing what he has missed and what he is now getting.

The following year, Andromeda received notice that Jack's special education program was being relocated to a new school and that he would be assigned a new teacher. Andromeda recalled,

We were given a teacher who had never taught kids with autism before and seemed to know nothing about it. She didn't want to hear anything about schedules and rewards. In six months, I watched five years of growth go right down the tube. Aggressive behaviors were mounting at school and at home. Things were just spinning out of control. I started driving the school district crazy, because our lives were disintegrating before my eyes and I now knew what I could have and what I was losing. There was nothing worse than that.

School administration encouraged Andromeda to look for other programs that

might better accommodate Jack's needs.

What I found was that the ones who could handle his behaviors were not appropriate academically. Those programs who had strong academics didn't have the behavior things in place that Jack needed. And the ones that could do both were full. Well....I couldn't lose him and that's what brought us here.

The transition to a new city was challenging and finding the most appropriate placement for Jack took time. Once again, Jack was placed with a teacher who had little experience in working with children with autism. Jack's aggressive behaviors continued and Jack's school day was shortened to half-days. After consulting with a lawyer and weekly school meetings, Jack was allowed to return to school for full days. Although his new teacher received specific training on strategies for working with children with autism, challenges continued. Andromeda recounted

There wasn't a mistake this teacher didn't make. We were trying to teach Jack to go to a quiet spot when he became angry or frustrated. "Jack, this is your quiet spot." The closest place for Jack to go was down the hall. They had one of those rubber bats and pillows that he could take out his aggression without hurting anyone. One morning after months of going through "if you get angry or frustrated, don't hit – go to your quiet place," Jack was sitting at a table doing puzzles. The teacher was talking to someone else and Jack went up to say something to her. She said "Not right now Jack." He went back to what he was doing. We still don't know exactly what happened, but he got up to walk past her and she said, "Where are you going?" He said, "I'm going to my quiet space." She said "No you are not. You are not angry." Well...he hit her. Then he got to go. When she told me what

had happened, I just looked at her and she said, “I blew it.”

Jack was soon moved to a new school and placed in a self-contained classroom for students with severe and profound autism. Andromeda shared,

I had a lot of concerns when I first saw his classroom. He (the teacher) only had two students and one was going to high school the next year. The other student was severely autistic and non-verbal. The big goal on his IEP was to keep his shoes on for the whole day. You know, I had Jack. Jack reads, does math. I said to the teacher, “I’ve heard that you are a great guy and that you do great work, but I don’t think you’ve really worked with anyone like Jack. Jack has academic goals and I know that you know a lot about autism and behavior problems, but do you really know about teaching math, reading comprehension, social science, science or any of that?” He said, “No, not really.” “That’s my concern and then it becomes warehousing Jack. I don’t want Jack to become warehoused. I want him to learn. I don’t want babysitting. I want an education. This is free and appropriate public education. This is not warehousing him and let him stim for seven hours. It’s not ok.” I continued saying to his teachers, “Jack needs to be academically challenged” and I kept being told that we can’t bring him into those classrooms until his behaviors get better. “He could hit and hurt someone and we are going to be liable, because we know about his behaviors.” I said, “His behaviors are not going to get any better as long as he stays in this classroom. The lesson of the day is how to dress Mr. Bear. He had that when he was three! He’s 10! Do something.”

Although Jack’s placement remained, he was allowed to participate with one-on-one supervision in a program at the same school for students with milder forms of learning

challenges. With increased opportunities to be intellectually challenged and behavioral supports in place, Jack's behavior significantly improved. The following year, district administrators transferred Jack from the self-contained program to his home middle school, which offered a similar advanced program for students with learning challenges. Although there were occasional setbacks, overall, Jack did well and continued in the program throughout the remainder of his middle school years.

7.1.3 Jack as a young adult. Now a senior in high school, Jack, in many ways, lives the life of the typical teenager. He attends school, is involved in numerous afterschool activities and sports, has two part-time volunteer jobs, and is looking forward to prom. He also struggles with acne, can be moody, and grapples for increased independence and control. Perseus, Jack's older brother, commented,

Jack wants to be independent, but I think he also understands just how dependent his lifestyle is on Mom and that he's pretty happy with the way things are. Like anyone, I suppose, he would like to be calling all the shots. But, at the same time, he still wants to be catered to. Like most people! He doesn't really want to do the work that comes with independence, which I think is one of the more typical characteristics of being 17 years old. I mean...my brother understands that he doesn't want to cook but he still wants to decide what is for dinner.

The need for and movement toward increased autonomy is a defining characteristic of young adulthood. Unlike many teens, however, Jack's ability to lead a completely independent and self-determined adult life is still uncertain. As of now, much of his day is monitored and his need for support and supervision, still necessary. Andromeda commented,

One of his care providers said something really interesting to me the other day. He said “You know, it has to be really hard for Jack, because he really is a teenager. And...well....all teenagers do things that they really shouldn’t do. Like me, when I was in high school, I could get away with anything. I mean Jack doesn’t ever do anything terrible. He just does little things. But he always has someone with him – watching him. He can’t get away with anything.” I said, “You know, you’re right. I never thought of it that way. He really can’t. The littlest thing he does gets reported.

Despite an occasional pushback against his highly sheltered and supervised life, Jack seems content and maintains his “zest for life.” Central to Jack’s continued success has been his own determination to do well, Andromeda and Perseus’ steadfast advocacy and support, a team of dedicated teachers and support providers, and lastly, a well-laid plan. This plan includes ongoing assessments of Jack’s strengths and needs, the identification of relevant and measurable long and short term goals with explicit steps toward achievement, and behavioral support mechanisms. All of which are communicated through Jack’s IEP/Transition and PCP annual reports.

7.1.3.1 *An assessment of abilities and needs.* Table 7 presents a compilation of evaluative statements taken from Jack’s individual education plan, transition plan, and person-centered plan.

Table 7. *Assessment of Jack's Abilities and Needs*

Social/Emotional	<p>IEP: Jack is a very friendly and engaging student. He has a great sense of humor. He sometimes finds it hard to transition to a new activity in the classroom. At times, Jack can become overwhelmed with emotion that causes him to have a verbal outburst. The outburst can be a loud voice, refusals, raising of his arm, etc. It is best to give Jack choices, and to tell him the consequences of his choices. Then give him some time to decide. For the most part, he is able to re-direct himself when he feels settled. This can take between five and twenty minutes.</p> <p>PCP: Jack tries to please. Structure is very important, physical activity scattered through his day is vital to his success. Written schedules are important, rewards or choices, following responsibilities, encourage him to meet the responsibility. The person working with him should keep his/her words literal and not give into his demands.</p>
Academics	<p>IEP: Jack has demonstrated a terrific work ethic. He participates in class well. He enjoys role-playing situations. For note taking he relies on the word processor. Jack scored the following grade levels: 6.2 reading recognition and comprehension; 3.5 in writing. He enjoys reading comic strips. Math is his favorite subject and [he] enjoys his assignments.</p> <p>PCP: Jack likes money and numbers. He could learn more money management skills. That it takes money to eat, live, drive, rent movies, etc.</p>
Life Skills & Work Behavior	<p>IEP: Jack has shown much background knowledge and enthusiasm for learning basic safety skills in Life Science class. He currently does jobs when given a detailed list. He works for reward or down time. He performs household chores at home for spending money. He also volunteers at the public library shelving books alphabetically. He earns money for each shelf. Like all teens, he can be rigid when asked for flexibility on the job. He is working toward increasing his stamina, delaying gratification and seeing himself as being part of a team.</p> <p>PCP: Jack follows written directions well. He has a great memory, vocabulary, enthusiastic personality. He has a remarkable talent for storytelling, great rhythm, good musical ear, quick learner at the violin. Excellent skills in narrative innovation, a fine swimmer, excellent in problem solving strategies</p>

7.1.3.2 Annual goals. Jack's IEP and Transition goals (Tables 8 and 9) focus on skill development during the school day and his PCP goals (Table 10) emphasize instruction outside of the school day.

Table 8. *Jack's Individual Education Plan Goals*

Conventions of Grammar and Language Usage**Goal 1: Functional Reading**

- Expand comprehension skills with age appropriate learning materials at reading level by applying (1) context clues, (2) key word techniques, and (3) paraphrasing skills.
- Read and comprehend information found in a variety of print and non-print material to (1) understand warranties, instructions, and manuals, (2) understand bills, bank statements, credit card applications, mail orders purchases and non-prescription medicine directions, (3) gain information from a variety of pamphlets, and (4) obtain information from the newspaper concerning current events, events, weather, sports, entertainment and classified ads.

Goal 2: Functional Written Communication Skills (with the use of a word processor)

- Compose a 5 sentence or more paragraphs using (1) a topic sentence, (2) supporting details, (3) appropriate logical sequence, (4) sufficient elaboration, and (5) a concluding statement.

Goal 3: Functional Expressive Communication Skills

- Apply basic subject-verb agreement rules and appropriate use of adjectives when speaking.
- Acquire and apply appropriate telephone skills for use within an employment environment to (1) greet and serve customers, (2) secure information about the status of an order, (3) order needed materials and equipment from a supplier, (4) give directions to a place of employment, and (5) take messages given by customers.
- Give directions to complete a task/job within a work environment by (1) presenting information in a logical order and (2) presenting information in sequence terms using terms such as first, second, etc.
- Demonstrate appropriate conversational skills when communicating with peers by (1) using acceptable voice levels and tones for a variety of settings, (2) using socially acceptable vocabulary, (3) refraining from making inappropriate remarks when talking to peers of the opposite sex.

Financial Management**Goal 4: Financial Management for Independent Living**

- Identify important sections of bills, statements, and invoices Identify important sections of bills, statements, and invoices
- Demonstrate the skills involved in paying bills
- Identify methods in paying bills: cash, money order, check
- Complete a money order
- Determine when to pay bills
- Demonstrate an understanding of the purpose of banks and other financial institutions and the responsibilities associated with them: (1) writing checks, (2) balancing a checkbook, (3) bank statement reconciliation, (4) responsibilities of checking and saving accounts, (5) using the ATM machine, and (6) debit cards.
- Prepare a budget based on a specific income and determine adjustments needed.

Occupational Preparation**Goal 5: Develop self-determination skills for participating in transition planning and making a successful adjustment to adult life.**

- Identify through role-playing an understanding of a minimum of five of the six styles of communication (passive, aggressive, assertive, formal, informal, non-verbal).
- Develop a basic understanding of laws related to disability rights: Fair Labor Standards Act, with a minimum of 70% accuracy.

Goal 6: Actively participate in career development activities to determine a career goal.

- Examine various career pathways and identify a minimum of 2 potential careers of interest.
- On a minimum of two occasions, demonstrate the ability to locate information about careers of interest.
- Participate successfully in multiple school-based activities to complete a minimum of 75 hours of

the 300 hours of the work requirement: school-based enterprises.

- Participate successfully in paid and non-paid community based activities to complete a minimum of 60 hours of the 240 hour requirement: community based training, community service.

Goal 7: Develop job seeking skills necessary to secure employment in chosen career pathway.

- Describe or demonstrate successful interviewing strategies: proper behavior; with minimum of 70% accuracy.
- Update Work study portfolio by adding a minimum of 5 new items to it relating to this year's work experiences.

Goal 8: Develop the work behaviors, habits, and skills in the area of job performance needed to obtain, maintain, and advance in career pathway.

- State a minimum of 2 reasons for maintaining high standards for quality and quantity of work and recognizes strategies for obtaining these standards: time on task, self-evaluation of work, work evaluations by supervisors.

Community, Home, and Workplace Health and Safety

Goal 9: Develop the skills needed to exhibit safety measures and procedures in a variety of situations in the community, home, and workplace.

- Identify a minimum of 3 factors in the home, the community and on the job site that can lead to accidents and demonstrate the ability to point out dangerous situations in 2/3 role-plays.
- State strategies for ensuring safety in 8/10 situations at home, in the workplace and in the community.

Goal 10: Obtain the skills needed to exhibit skills associated with providing simple first aid and obtaining medical treatment when needed.

- Distinguish between simple and serious injuries, with a minimum of 70% accuracy.
- Identify a minimum of 5/7 simple injuries and demonstrate the proper procedures for providing simple first aid for these injuries (minor cuts, insect bites, simple burns, puncture wounds, nosebleeds, bruises, sprains).
- Interpret common warning labels on prescriptions and non-prescription medications and demonstrate the appropriate response to warning labels, with a minimum of 70% accuracy.

Goal 11: Develop the skills needed to practice healthful living and good nutrition.

- State common practices that help prevent illnesses and germ spreading, with a minimum of 70% accuracy.
- Describe methods for avoiding 5/6 minor injuries during exercise routines and provide care for these injuries if they do occur: blister, bruise, cramp, ligament damage, sprain, muscle strain.
- Identify foods that are a high risk for contamination/spoilage and state proper methods for handling, preparing, and storing these types of foods, with a minimum of 70% accuracy.

Social Skills

Goal 12: Social Skills

- Jack will use schedules (prepared in advance when possible) to acclimate himself to changes that may cause him to feel uneasy.
 - When Jack feels angry, anxious, upset, etc., he may request to use the quiet place as an alternative to having an outburst.
 - Jack will use words to express or negotiate changes that he feels necessary to help him feel calm.
 - Jack will earn choice rewards approximately every two class periods for: Following his schedules, completing class work and making good behavior choices.
 - To help him learn delayed gratification, Jack will work toward earning a weekly choice on Fridays for maintaining the above-mentioned good behaviors, a minimum of four days per week.
-

Table 9. *Jack's Transition Plan Goals*

Instruction: Jack will (1) engage in choice making activities and increase his tolerance for the potential of not getting what he desires, (2) participate in a self-advocacy workshop to reinforce concepts taught in his Occupational Preparation class, (3) engage in a computer class to advance his technology skills, (4) further his awareness about career choices and appropriate work behaviors through participation in the Occupational Preparation classes.

Community Experiences: (1) Jack will participate in weekly recreational and leisure time activities with family and support provider. (2) Jack and his family will investigate additional age-appropriate, community-based recreational, leisure, and social activities with peers. (3) Jack will continue to engage in violin lessons and swimming lessons. (4) Jack will continue to volunteer his time at the public library as a shelf reader.

Employment: (1) Jack will participate in school-based vocational training experiences. (2) Jack will develop his work habits, learn new skills, and gain exposure to the world of work through participating in 2-3 community-based vocational training placements. (3) Jack will tour 2-3 places of employment with his class and participate in periodic presentations about the world of work from supervisors and managers in the community.

Adult Living Skills: (1) Jack and his family will investigate supported living options following high school. (2) Jack will obtain a state-issued picture ID card.

Daily Living Skills: (1) Jack will develop his cooking and baking skills. (2) Jack will continue to make gains with his cleaning skills in the home and school. (3) Jack will develop his independence doing laundry using written interactions. (4) Jack will improve his ability to shave himself.

Functional Vocational Evaluation: Jack will participate in informal vocational assessments to identify his interests, work values, temperament, skills, etc. and receive situational assessments at his community-based vocational training sites.

Table 10. *Jack's Person-Centered Plan Goals*

Goal 1: Jack would like to participate in activities safely in the community.

1. Jack will independently tell an adult where he is going when in the community. Staff will remind Jack before going into the community of this goal to ensure Jack's safety while in the community.
2. Jack will identify adults in the community that are of authority at least two times a week with less than one prompt. Staff will show Jack adults in the community that are of authority and could possibly help him if he becomes lost or has a problem. That could include sales associates, police officers, fireman, etc.
3. Jack will demonstrate safety skills in the parking lots, streets and high traffic areas with one or less prompt or gesture given. Staff to provide prompts or signs for Jack to look for cars pulling out, backing up, walking don't walk signs, etc. Jack will respond after one or less prompts.
4. Jack will decrease his volume of verbalizations with one or less prompt or gesture given. Staff will firmly remind Jack to lower his voice as necessary.
5. Jack will select from a list one community activity of his choice once a week with one or less prompts given. Staff will provide opportunities for Jack to explore community activities previously unavailable. Modeling to be provided as needed Jack will participate after one or less prompt.
6. Jack will learn how to differentiate between a stranger and a non-stranger and when it is appropriate to yell for help when being approached by a stranger in an inappropriate manner independently at least once a week. Staff will teach Jack what constitutes a stranger and an inappropriate approach and when it is ok to yell for help or run from a stranger.
7. Jack will demonstrate safety skills in parking lots, streets and high traffic areas with one or less prompt

or gesture given. Staff to provide prompts or signs for Jack to look for cars pulling out, backing up, and walk and don't walk signs etc. Jack will respond after one or less prompts.

8. Jack will learn how to dial 911 and when it is appropriate to dial 911 with no more than 1 prompt. Staff will teach Jack when it is appropriate to utilize 911.

Goal 2: Jack would like to increase his independence in all areas of his life while knowing that staff or his mother is close by for assistance as needed.

1. When there is a knock at the door, Jack will ask "who is it?" and determine if he knows the person before answering. If he does not know the person, he will contact someone else in the house to assist him. Goal will be practiced at least once per week, unless it happens indirectly. Staff will model and prompt as needed and observe Jack's handling of the situation.
2. Jack will initiate taking a bath daily with no more than one verbal prompt per occasion. Staff will allow Jack to complete as much of this task as possible on his own, before assisting him with personal care. Home and community supports and personal care cannot be completed at the same time.
3. Jack will independently follow his complete bathroom routine when using the toilet with one or less prompt or gesture given. Staff will provide prompting assistance when necessary. Jack will follow his schedule.
4. Jack will set a time for a reasonable amount of time before using the bathroom and finish up quickly after the timer has expired upon entering the bathroom per occasion with two prompts per occasion. Record # and type of prompts given. Use least intrusive prompt first and work up prompt hierarchy.
5. Jack will independently attempt brushing of his hair successfully with one or less prompt or gesture. Staff will model appropriate brushing and provide guidance when needed. Jack will attempt brushing following model after one or less prompt. Record 3 of prompts given
6. Jack will independently complete and attend to each task/activity on his schedule per occasion with 2 or less prompts. Staff will refer to schedule and give prompts if needed to keep Jack on task.
7. Jack will choose appropriate clothing for the day with less than 2 prompts per day. Staff will assist Jack in finding out the weather and assist with choosing clothes when needed.
8. Jack will assist in making out a schedule of activities to be completed each day. Staff will facilitate planning and encouragement to Michal to complete the schedule with the least amount of assistance.
9. Jack will assist in completing a list of small purchase items for him to purchase once. Per week. Staff will facilitate planning and encouragement to Jack to complete the small purchase list with the least amount of assistance.
10. Jack will complete a small purchase in the community with staff assistance once per week with no more than 2 verbal prompt per occasion. Staff will assist Jack in completing a small financial transaction – providing appropriate money, waiting for change, and receipts.
11. Jack will demonstrate focus to tasks that require focus in five minute timed intervals per occasion. Staff will be instruct Jack that after five minute timer is up, he will be given one minute to be unfocused and then return to the task.

Goal 3: Jack needs to learn reasonable control of his emotions as a way to negotiate his wants and needs.

1. Jack will practice alone time in the house in five minute intervals at least once per day with at least one verbal prompt per occasion. Staff will inform him that they are going outside for five minutes and will be there if Jack needs assistance.
2. Jack will initiate brushing of his teeth daily with no more than one verbal prompt per occasion. Staff will allow Jack to complete as much of this task as possible on his own, before assisting him with personal care. Home and community supports and personal care cannot be completed at the same time.
3. Jack will independently use his words before becoming upset with one or less prompts. Staff will provide prompting, assistance when necessary and encourage use of emotions words before the onset of Jack becoming upset.
4. Jack will identify 3 basic emotions correctly 2 out of 3 times a day independently. Staff will teach Jack with different teaching techniques the basic emotions. The emotions of happy, sad, angry, mad will be

the first ones to start with.

5. Jack will demonstrate knowledge of the proper way to show affection to family members and other people given his relationship with them per occasion with 1 or less prompt. Jack will learn proper ways to show affection to family members and other people given his relationship with them. He will learn when physical contact is appropriate according to his family style and social norms, and gender.
6. Jack will negotiate changes to his schedule without resorting to behavior with no more than two prompts per occasion. Staff will assist in teaching Jack ways to negotiate and avoid behavior.
7. Jack will receive personal care services daily throughout the plan year. Aide will provide physical assistance with bathing, dressing, grooming, and or light housekeeping if necessary. Although aide will be providing physical assistance during these activities, aide will still encourage participation from Jack during all steps and allow him the ability to make as many decisions as possible (like when dressing, etc.).

Goal 4: Jack would like to continue with the summer work and wellness programs.

1. Jack will assess bus schedule at least three times per week and determine the bus stop and time to begin waiting with no more than two prompts per occasion
 2. Jack will be respectful of others while waiting for the bus and while on the bus with no more than two prompts per occasion. Staff will assist in teaching and modeling for Jack ways to act in this environment.
 3. Jack will use his augmentative communication device to determine the weather daily and will choose clothing accordingly with no more than two prompts per occasion. Staff will assist in teaching Jack ways to seek and determine this information and what to wear.
 4. Jack will type his daily schedule for the day into his augmentative communication device daily with no more than two prompts per occasion. Staff will assist in teaching Jack how to do this.
 5. Jack will transition from task to task daily using his schedule with no more than two prompts per occasion. Staff will assure Jack does this and assist as needed.
 6. Jack will maintain focus to each task daily with no more than two prompts per occasion. Staff will assure Jack does this and provide prompting as needed.
 7. Jack will tolerate learning new tasks daily as they relate to his future independence no more than two prompts per occasion. Staff will encourage Jack by reminding him of how learning will help him be more independent and provide prompting as needed.
 8. Jack will explore vocational opportunities as they apply to his interests at least three times per week with no more than two prompts per occasion. Staff will assist Jack with his exploration through modeling and education and provide prompting as needed.
 9. Jack will thoroughly clean up his area after lunch and snacks daily with no more than two prompt per occasion. Staff will assure Jack does this and provide prompting as needed.
 10. Jack will complete all steps in making a light lunch or snack daily with no more than two prompts per occasion. Staff will assure Jack does this and provide prompting as needed.
 11. Jack will follow a short shopping list at least twice per week and will seek out products with attention to price and nutritional value with no more than two prompts per occasion. Staff will assist Jack through modeling and education and provide prompting as needed.
 12. If someone is late to meet Jack, Jack will read a social story about how this sometimes happens and what to do to cope with this with no more than two prompts per occasion. Staff will provide Jack this social story and provide prompting as needed.
-

When presented with an abbreviated list of his goals during an email exchange, Jack was asked to identify three goals that he believed were most important for his growth and independence. The list included:

- functional reading and writing skills;
- money management skills and banking practices;
- expressive communication/conversation/telephone skills;
- healthy emotional response;
- home, workplace, and community safety skills;
- basic first aid, illness prevention, and emergency procedures;
- transportation options and practices;
- hygiene/grooming/self-care;
- personal schedule/time management/independent work skills;
- shopping / purchasing skills;
- meal preparation and clean up;
- rights and self-determination; and
- career development, job seeking skills, and work behaviors;

Jack replied:

Hi Dana!

The 3 things I pick are: Reading & writing skills, Telephone skills, & Rights! Why I pick them is so I can communicate with people I love & so I can be a good boy & so I know what I have the right to do! CATCH YOU IN A WHILE CROCODILE!

Yours Truly,

Jack!

In a following email, Jack was asked to comment on areas of less importance. He responded, “There is nothing I would take off this list!” When later presented with the list a second time during a face-to-face meeting, Jack confirmed his two earlier responses

stating, “I haven’t changed my mind.”

7.1.3.3 Behavioral interventions. Jack relies on two behavioral interventions to help monitor his emotion and guide his behavior: schedules and incentives.

7.1.3.3.1 Schedules. He described his schedules as “the routines” and shared, “They tell me what to do and when. When I don’t have my schedule, I lose track.” Jack’s schedules have become essential to his everyday life success, grounding him to the present by creating a structured and predictable world and outlining daily expectations (Figure 6 and Figure 7). With built in incentives for meeting expectations and accomplishing daily tasks, Jack’s schedules also serve as motivation and present opportunities for personal choice and control.

Figure 6. *Example of Jack's Morning Schedule*

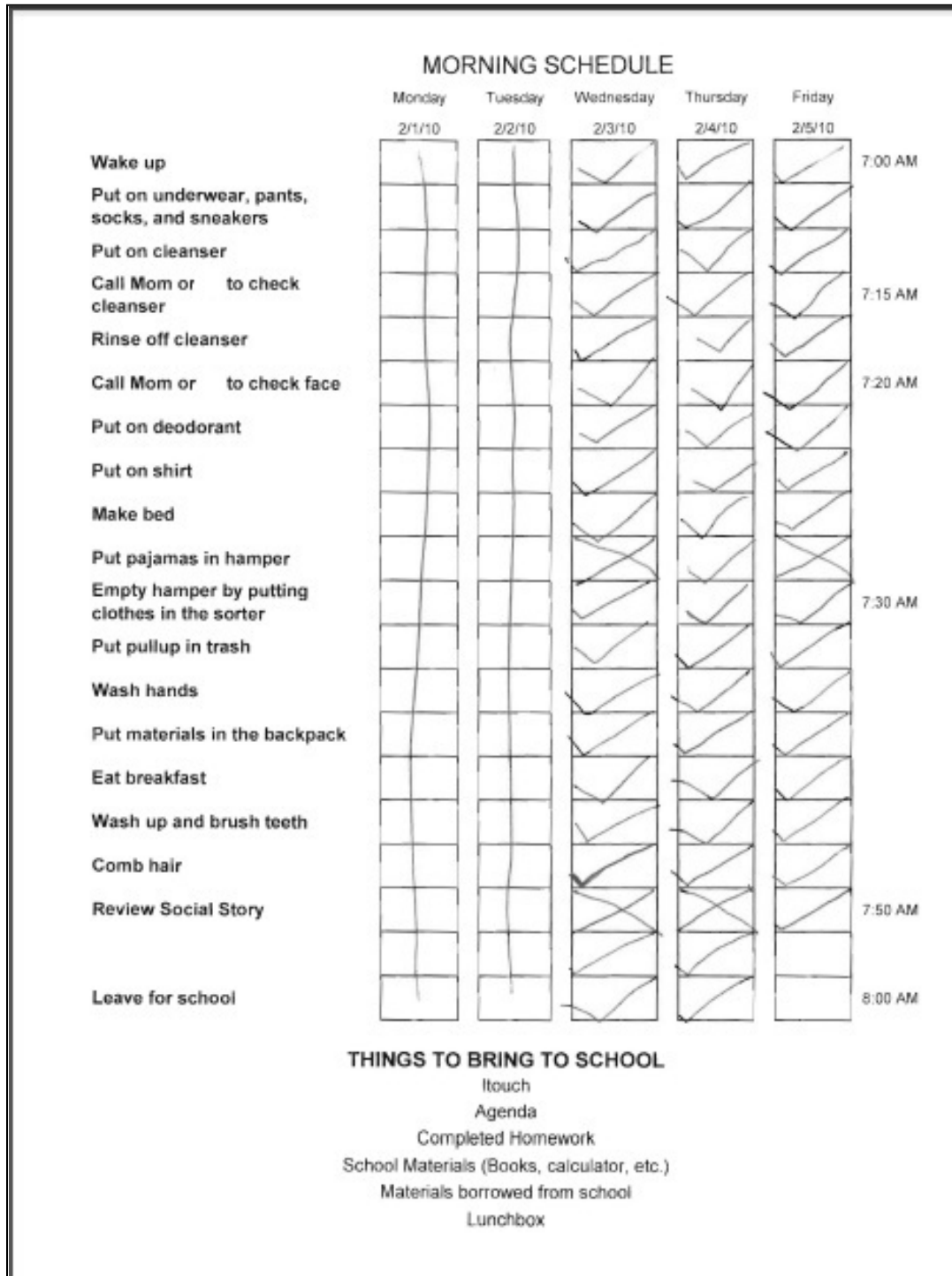
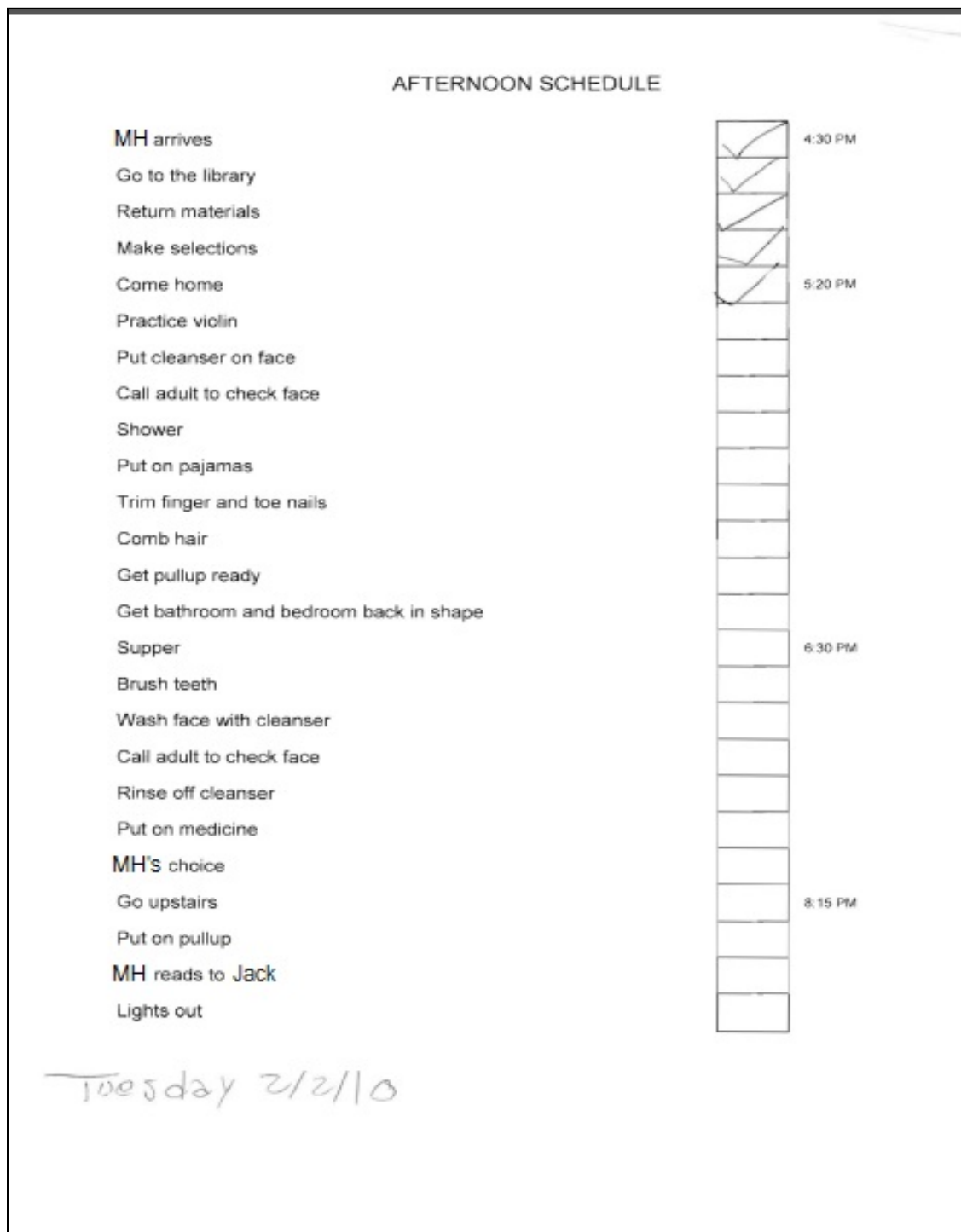


Figure 7. *Example of Jack's Afternoon Schedule*



Andromeda shared, “Even though the things on the schedule are things he likes to do, they are not necessarily things he would go and do if someone didn’t tell him to.”

When asked if Jack’s own wants ever conflict with activities on the schedule, Perseus commented,

If Jack is unhappy about the schedule, he will say he is unhappy about it, but ultimately he knows that this is not a battle that he is going to win. It’s a type of resignation I think most teenagers have when dealing with parents. He will try to negotiate his way, though.

7.1.3.3.2 *Incentives.* Tapping into what motivates Jack has been an effective way to encourage and reward positive behaviors. Andromeda shared,

Friday’s are movie night. If Jack gets seven stars, he can rent a movie and plan a weekend activity. With five or six stars, he can rent a movie. With four stars, he can choose a movie from the bookcase.

When earned, Jack and his evening care provider take turns choosing the movie. With this process is also a message, Andromeda explained,

It’s about trying to be a good friend. Being a good friend and sometimes letting your friend choose and then your friend will let you choose. I’ll explain to Jack, “Other people don’t like to watch preschool shows” and he’ll say “I wish they did, Mom.” “Yes, I know you do, Honey.”

Similarly, Jack is drawn to websites and online video clips aimed at younger children.

When free computer time is earned, Jack’s preferences include Disney Playhouse and Nickelodeon’s Little Einsteins, Dora the Explorer, and Handy Manny.

Food is a particularly strong motivator for Jack. During his annual PCP review,

Jack was asked the question “What is important to you?” He responded, “Getting food for free, Friday’s watching movies; go out to Chili’s, chicken fingers, cheese fries, and chocolate chip cookies, mountain cake.” Jack’s teachers all agreed and will often use food as an incentive. Mrs. Snow White shared,

Popcorn is a powerful tool. Earning popcorn on Friday makes him...it's like if he gets out of hand I'll say “Well you know you are going to mess it up for Friday popcorn.” It really draws him right back in and it's like “Ok, I don't want to mess it up.”

7.1.3.3.3 *Challenges.* At times, Jack’s family and teachers struggle to find an appropriate balance in using such strong incentives, acknowledging both benefits but also drawbacks. For instance, while Jack is highly motivated to earn free time on the computer, shutting down and transitioning to a new activity can be difficult. Ms. Aurora commented,

We know that computers are a little addiction for him. Once he is on, it’s hard to get him off. If he won't get off, then we have to resort to turning it off or unplugging it which can result in a major melt down.

Jack confirmed stating, “Sometimes it makes me mad when they tell me to shut it off because I’m having such a good time.” Similarly, while tapping into Jack’s fixation on fairytale and preschool characters has proven to be an effective strategy for behavior management, Jack’s family and teachers continue to grapple with questions of age appropriateness. Andromeda explained,

Jack wants to watch preschool shows and there is a reason why Dora the Explorer is aimed at people 3-5 years old. Then children are done with it. We are not done with it. He continues to talk in that voice and act out these stories. This is a child

that if you let him watch something that he likes once, it is playing in his mind for a month – at least.

Jack also shared his thoughts on this topic, “Ever since I’ve grown up, I’ve liked preschool stuff, even though my mom says that I’m too old for it. Mom says preschool is three to five years old and I’m way older than that!” When asked if he agreed with his mother, Jack stated, “Yes, I believe my mom. She never lies. But still, I like Dora and Little Einsteins...and even Barney... Nothing stops me from liking them!”

In spite of challenges, there seems somewhat a resignation to the power these stories and characters hold within Jack’s life. To illustrate, Andromeda recalled a conversation she had with one of Jack’s middle school teachers. Meeting to discuss behavior management strategies and rewards, the teacher stated, “Well, he can’t go to Disney online and he can’t talk about Mickey Mouse because the kids will make fun of him.” Andromeda replied,

Jack really doesn’t care what kids think about him. If you don’t make the choices and rewards match with what he wants – he has no motivation to meet the requirements for you. He doesn’t really care. He doesn’t care about the grade. He doesn’t care about what the other kids think. He cares about getting what he wants.

You need to have a choice and rewards that he wants.

Although it took a couple of months, Jack’s teacher eventually relented. She and Jack began exploring Disney online together and collaborated to determine his choices and rewards. Andromeda shared, “Something just turned around...she did a 180 and we had three terrific years at that school.”

In addition to tapping into what motivates Jack, Ms. Aurora emphasized the

importance of maintaining consistency with Jack. “You have to be so careful. If you do something once, then he expects it.” She shared the following example,

There was one time he brought in four dollars for treats. He bought eight treats - one of every kind. I thought to myself, this isn't a good idea. But he was in line and there were people around him. We had to move along, so I let him buy the treats. He ate seven of them and gave one to Mr. Hercules. After, he sat down and said "I'm never going to buy that many treats again my stomach hurts." The next day, he wanted to buy four treats. I thought that might still be too many. He said “No-no, you let me do that yesterday.” You have to think about what precedent you’re setting for him. You may have to change later and that’s upsetting to Jack. So ...I don't always think that fast on my feet. He knows what he wants and he will express himself and tell you he's disappointed when he can't have his way. But, he is also willing to work it out. The way I got around it was by saying, “You better hold it together because if you have a fit, your mom is going to want to know why. If I tell her it’s because I wouldn't let you buy eight treats, then she’s going to say “Well, don't let him buy any.” Jack then said, “Well... you don't have to listen to her.”

Although Jack has gained greater control over his anger as he has matured, his PCP reported “Jack has hit, kicked and thrown things in past situations at school that have escalated to crisis level” and “there is still potential for such behavior from Jack in the school, the home, and the community at any time.” One eruption early in Jack’s high school years occurred after he was denied a request to use the restroom. His teachers reported that this was a frequent request and often disruptive to instruction. When denied, Jack attempted to climb out of his second story classroom window. When asked about the

incident, Jack shared, “Well...I flew into a rage. I felt like hitting her.” Unable to calm Jack, the classroom teacher called for school security. Jack recalled,

He (the security guard) pushed me onto the floor and I couldn’t get up. I felt frightened and I kicked trying to get loose, but he held my legs down. That made me even more frightened. I was really scared and I yelled for help but nobody came to help me. I had no choice but to give up. It was the most frightening moment I’ve ever had.

7.1.3.3.4 *Choice, control, and voice.* Jack’s school support team commented on the significant change they observed in Jack when they increased opportunities for him to make decisions during the school day,

Ms. Aurora: Things were very different when he first came. Now our focus is on his responsibilities, his freedoms and his decision-making. It’s not so much someone else telling Jack what to do, but it is Jack deciding what he can and can’t do and what he should and shouldn’t do. I think that power is liberating for him.

Ms. Ariel: It’s the technique that is used to get him to be more flexible that I think is what is so key...but in saying that, there are some things that no matter what you do or say, he is not going to follow through.

Mr. Hercules: Jack doesn’t really want to do the new things and so his first response is always going to be “Oh I’ve never done that or I’m not going to do that!” You can kind of talk him into things, but he’s going to make sure he gets that out first. To let you know how he really feels about things.

Ms. Aurora: And sometimes he’ll say “Oh, I’d be honored!” or “It would be my pleasure!” In his mind, he thinks one thing and we are presenting him with

something else. Then when he really thinks about it - when he is presented with “if this, than that” - he can make a choice.

Ms. Ariel: Yes, choice is so critical and integral to everything.

7.1.4 Jack and high school life. Jack continues to receive the majority of his instruction and support through his high school’s special education program; however, he attends one mainstream class, Computer Skills. Three times a week, Jack also spends a portion of his school day at different community sites to develop work skills. His two primary teachers are Ms. Aurora and Ms. Snow White. Jack also receives one-on-one support from Mr. Hercules, a teaching assistant and Ms. Ariel, Jack’s transition specialist.

Jack begins his day in Ms. Aurora’s classroom. It serves as a homeroom where Jack checks in with his teacher throughout the school day. He prefers not to use a locker and instead stores his backpack, lunch box, and jacket at his designated workspace in a back corner of the classroom. His workspace is a desk with privacy shields. Various schedules and reminder notes are taped inside. One reads:

Figure 8. *Jack's Choices*

Reminder:
You have choices.
If your first choice is
not working,
choose something else.
Do not waste your choices on being
angry.

A lunch schedule is also posted, presenting activity options for Jack after finishing his lunch to occupy his remaining lunch period.

Figure 9. *Jack's Lunch Options*

<u>MONDAY</u> Lunch room Choice 1 – iTouch / Choice 2 – imagination*
<u>TUESDAY</u> Lunch club If lunch club is cancelled, then imagination
<u>WEDNESDAY</u> Lunch room Choice 1 – iTouch / Choice 2 – music
<u>THURSDAY</u> Lunch room Choice 1 – iTouch / Choice 2 – book
<u>FRIDAY</u> Must be earned: CIC or LMC** for computer time. If you did not earn computer time – then lunch room.

A transition schedule for moving between 5th and 6th periods reads:

Figure 10. *Jack's Rules for PE*

Before Adaptive PE: <ul style="list-style-type: none">• Walk laps around small gym and wait for Mr. Hercules to arrive• When Mr. Hercules arrives, report to weight room for further instructions from Coach. During Adaptive PE: You may earn a bathroom break at the end of 6 th period. Do this by: <ul style="list-style-type: none">• Participating and listening to Coach• No hitting, yelling at other TAs or touching people.• Listen to all of your teachers, Coach and substitutes. <p>* If you do not follow these rules you will leave class at 2:55 with the rest of the class.</p>

Ms. Aurora's classroom, in many ways, is similar to most high school classrooms. Fifteen to twenty desks grid the central space and face a front white board where class rules and a daily schedule are posted in the top left corner. However unlike other classrooms, the space is equipped with kitchen appliances, cabinets, a sink, and counter space. A

washer and dryer are located in an attached alcove separated by long curtains. Two long tables with benches are positioned in the back of the room.

7.1.4.1 First period: Health science. The first period bell rings and Ms. Aurora begins instruction on human sensory systems. Seven male students occupy the center desks with textbooks open. Each takes a turn reading a passage from his text, pausing occasionally to respond to questions presented by Ms. Aurora. Although Jack begins the class seated with his peers, within the first ten minutes he stands and begins to pace the perimeter of the room. As he paces he whispers quietly to himself. This does not appear to disturb the others and Ms. Aurora makes little notice of it other than to occasionally ask Jack a question. Although he responds on-topic, his answers convey a limited level of engaged awareness. For example, when reviewing a previous lesson on preventative measure to protect the skin, Ms. Aurora asks “Jack, why did you choose to wear shorts today?” He pauses and with a puzzled look, responds, “So I won’t be naked, of course!” A little later the topic turns to sense of smell. Again, Ms. Aurora calls on Jack.

Ms. Aurora: “Jack, how many smells can the nose detect?”

Jack: “Three.”

Ms. Aurora: “No, please go check your book.”

Jack quickly returns to his desk, glances at his textbook, and comments enthusiastically “1000! Wow! The nose is sure powerful!” Toward the end of class, students are asked to provide written responses to chapter review questions. As the seven young men pull out a piece of paper and begin writing, Jack moves to a classroom computer to complete the assignment. He moves through each question, quickly identifying the appropriate answer from his text and types his response with relative ease. Saving his work, he finishes at the

sound of the second bell. As he is rushing out the door, Ms. Aurora hands to him a piece of paper with printed instructions for the next class.

7.1.4.2 Second period: Computer skills. First to class, Jack confirms instructions with his computer skills teacher and sits at a computer facing away from his peers at separate computer stations. Mr. Hercules takes the adjacent seat and begins reviewing the instructions with Jack. Jack's task is to create a spreadsheet of volunteer contact information for the upcoming prom. He works in parallel to the other students who are watching a short video on computerized special effects and are later instructed to experiment at their computer stations with online tools.

As per his written instructions, Jack is provided free computer time after completing twenty-five minutes of work. As he begins to type the URL for YouTube, he is reminded by Mr. Hercules that the site has been blocked by district administrators. The dialogue below followed:

Jack: When will the administration turn it back on? I'm VERY angry with them.

Mr. Hercules: Have you written your letter to them?

Jack: No.

Mr. Hercules: You need to write your letter, Jack. Explain to the administration why it is important for you to have access to the site.

Jack: I'll say I miss Little Einsteins.

Mr. Hercules: Well, you need to say why it is important.

Jack: I'll say that I get a break from my work and I need it for my break. I'll say it nicely first and if they don't do it, I'll write an angry letter. I'll show them a thing or two! Who do they think they are?

7.1.4.3 Third and fourth periods: Life skills. Jack returns to Ms. Aurora's classroom for Life Skills, his third and fourth period class as Ms. Aurora is assigning tasks to each student in preparation for "Teacher's Treat." "Teacher's Treat" is a day once a week in which the school faculty may purchase baked goods for themselves and their students. Through this experience, Jack and his classmates develop and practice skills in shopping, money management, food preparation and handling, dish washing and laundry skills, customer service, sales, and collaboration. Jack is assigned to fold kitchen towels. He completes his job quickly and returns to ask Ms. Aurora for his next task. The following exchanges occur between Jack and his teacher over the course of the two class periods:

Ms. Aurora: Jack, would you rather do the receipts or help with the dishes?

Jack: I AM NOT doing receipts! I've already done too many!

Ms. Aurora: Well it is either receipts or wash dishes.

Jack: I'll do receipts.

Jack: What should I do now Ms. Aurora? Remember, I'm NOT doing dishes!

Ms. Aurora: Don't you mean I would rather not do dishes?

Jack: I would rather not do dishes, Ms. Aurora. I'll help Poseidon with the snack preparation.

Ms. Aurora: Ok, but wash your hands first.

Jack: Ms. Aurora, I just washed my hands and I am NOT doing it twice in one period. I WILL NOT wash my hands twice in one period!

Ms. Aurora: Jack, it might be better to say ‘Remember Ms. Aurora, I just washed my hands.’”

Jack: Remember Ms. Aurora, I just washed my hands.

Ms. Aurora: Jack, can you please put those dishes away?

Jack: What did I tell you, Ms. Aurora? I WILL NOT do dishes!

Ms. Aurora: Jack, what might happen if you say something like that to a boss?

Jack: Oooh....alright Ms. Aurora.

Jack puts away the dishes and the bell rings. As Jack leaves for lunch he looks at Ms. Aurora and says “You sure are beautiful, Ms. Aurora.”

7.1.4.4 Lunch. Jack’s lunch period is spent with the general population of students. By preference, he eats alone at a table at the far end of the cafeteria. After finishing his lunch, he begins to walk the open space next to his table. As he walks, he quietly whispers a story to himself. Although he occasionally pauses with a dramatic pivot or sword swing, others in the crowded cafeteria pay no mind.

7.1.4.5 Fifth period: Math. Fifth period is spent with Ms. Snow White and Jack’s classmate, Poseidon. The two students work quietly at their separate desks on a review packet in preparation for an upcoming math assessment. After a few minutes of work, Jack stops and looks over to Poseidon. “I’m in the lead!” he gloats. With a look from Ms. Snow White, Jack gets back to work but not before saying, “I love you, Ms. Snow White.” She responds with a smile and says, “I love you too Jack.” As Jack progresses through his packet, he whispers quietly to himself and appears to be counting on his fingers. When later asked, Jack explained that his counting was not related to his

computations stating, “No, I just was counting the words in my story.”

7.1.4.6 Sixth period: Adaptive PE. Jack participates in an adaptive physical education²⁶ (PE) class with approximately twelve male students and one female student. As they enter the gym, the students begin to walk the perimeter. Some, including Jack, talk to themselves as they walk and/or engage in self-stimming behaviors (repetitively flapping hands, snapping fingers, etc.) When asked, Jack shared that he was telling himself a story and counting his words. A teaching assistant from another classroom guards the door and explains, “Some have been known to bolt.” The students walk for approximately fifteen minutes until their PE teacher, Coach Mick arrives. He instructs the students to sprint back and forth across the gym floor a few times and then removes balls, hoops, a small trampoline, and other items from a storage closet and allows the students time to freely engage with the items. Some of the students, including Jack, return to their walking. For a short while, Coach Mick shoots baskets with three of the students and then comes to the side of the gym to initiate conversation. He shares that he is a retired high school coach recently hired to teach the adaptive physical education course. Except for a season of coaching Special Olympics in high school, he explains that he has little previous experience working with individuals with disabilities.

7.1.4.7 Seventh period: English. Jack returns to Ms. Snow White’s classroom for English, his last class of the day. He sits with Poseidon and Ms. Snow White at a small table reviewing proper uses of punctuation. After a short while, Ms. Snow White assigns the students ten sentences to rewrite inserting the correct punctuation. Jack quickly moves

²⁶Adaptive physical education is a federally mandated program enacted under IDEA 1990 and is defined by the National Consortium for Physical Education and Recreation for Individuals with Disabilities as “physical education which has been adapted or modified, so that it is as appropriate for the person with a disability as it is for a person without a disability.” Although national standards for certification in adaptive physical education exist, only fifteen states currently require certification for the position.

to the computer, smiles and says, “Mr. Hercules, DO YOUR DUTY!” His command is met with a gentle but firm, “Yes Jack?” Rephrasing, Jack tries again. “Mr. Hercules, would you please log me in?” When finished, Jack and Poseidon read quietly at their desks until dismissed. Before leaving, Jack turns to Mr. Hercules and says, “I’ll teach that District Office with a letter!” and rushes out the door. In a later conversation, Andromeda shared that Jack did write a letter. Sent through email to the school district’s superintendent and board members, Jack explained that he earns computer time for appropriate behavior, that he is no longer able to access favorite sites, and that he would like for the filter to be removed. Upon sending, Andromeda warned Jack, “You might not get the answer you want...but you should get some answer.” After a few weeks and a second email, Jack finally received the answer he hoped for. The filter was removed.

7.1.4.8 Homework. When asked about Jack’s homework, Perseus shared, Well, don’t tell him I said this, but he doesn’t have homework...at all. He is very happy about the fact that he doesn’t have homework, but I think it limits his independent quest for knowledge. I think it is difficult for educators when it comes to my brother simply because he is so in the middle of the autism spectrum. He is not at the bottom end so he is not really challenged by what some of his classmates are challenged by. He becomes bored... but yet, he is not at the high end of the spectrum so he is not expected to do more. He doesn’t have the same requirements that a normal student might have. I do think that a lot of people have lower expectations...he is very smart.

7.1.4.9 Vocational experiences. As part of his transition program, Jack is required to spend a portion of his school day in work-related experiences. In the beginning,

Andromeda had hoped that Jack would be able to gain experience volunteering in his own school library. Although he had previous experience shelving books in their local public library, she shared,

They won't let him work in the library and I don't know why. He is a really good library worker and he has letters of recommendation from the head children's librarian at public library. They [the librarians] let our kids empty their recycling, but I'm not going to let him do that. I've made it very clear that he is not to do janitorial work. It is not ok with me at all. At all.

She continued,

I mean, they have these days where they bake. They do a "Teachers Treat Day" every week. So the 9th graders go food shopping on Monday for the ingredients that they need. Then on Tuesdays, they bake and other classes help with cleaning up from the baking. The class periods are only so long – it is a life skills type of program. I said, "I don't have a problem with him coming in and drying dishes or folding aprons or putting things in a washing machine or washing dishes or wiping down tables in the classroom after people have baked. I have no problems with that. I have a really big problem with Jack wiping down a cafeteria table - where he is out in the main venue and that's how people see him. That is not ok with me and I don't want him doing it. I don't want him cleaning up bathrooms or working with the janitors. I agree everyone needs janitors. I think his skills are a lot higher than that and I have higher expectations." I think they were a little surprised when I said that. They said, "The janitors have always been so willing to have our children." I said "Of course they are, but it is not what I want for Jack."

Jack's brother added,

He's very smart. So when my mom comes home from the IEP meetings and they are talking about him becoming a janitorwell he can do more. It just seems very limiting. Not to mention the fact that he's seventeen. Why would you want to limit someone's potential?

Eventually, Jack was allowed to work in his school library and now volunteers every day before first period. He shared, "I reorganize the shelves so that the books are straight." Additionally, Jack has four off-campus volunteer positions. They include making frosting for a local pastry shop, data entry for a community non-profit agency, and reading stories to young children at two preschools. With supervision from his teaching assistant, Jack travels to and from his worksites using the city's public transportation system.

7.1.4.10 Mentorship. Jack also spends an hour once a week with a mentor, Dr. Purple, a faculty member from a local university who specializes in storytelling. Together they work to develop Jack's public storytelling skills through the presentation of Jack's original stories and new stories introduced by Dr. Purple. One goal of their work is to prepare Jack for opportunities to participate in community storytelling events and competitions.

In summarizing Jack's high school experience, Andromeda reflected "Things are going well there... Jack has a lot of opportunities, though we're still breaking down some walls." She also readily admits, "I'm probably one of the most challenging parents they've had." Because of her advocacy and involvement in Jack's schooling, Andromeda was asked of her own intentions after Jack graduates.

You know...I don't know. I'm really worried about the kid that doesn't have the parent that can go to bat. The parent who doesn't speak English, for instance. I want to make it a better place for them. For those parents who aren't the loudest or squeakiest or volunteer the most hours, because not everyone can do that. Not everyone knows how to do that or has the time. People shouldn't be railroaded and people have a right to an education.

7.1.5 Jack and social interactions. Contrary to common perceptions of individuals with autism as anti-social, Jack often shows an inquisitive and engaging interest in others. While riding the city bus to and from his work-study sites, Jack occasionally chats with the other passengers and asks questions about their lives. Mr. Hercules shared one conversation between Jack and a young man with a cast on his arm sitting across the aisle.

Jack said "Hey what's wrong with your arm? How did you hurt it?" And the guy said something like, "Oh I fell and hurt my arm." So Jack then says "Oh! Well you need to be more careful." Jack was kind of loud and people around him started laughing, though not necessarily laughing at him. They were just kind of laughing at his comments.

Perseus reflected on Jack's unintentional, yet common attention-drawing behaviors.

Jack's gotten past the point where it bothers him when people look at him. He didn't like the idea of standing out, but after years of positive reinforcement saying, "You know Jack, if they want to stare then that is really their problem. I think you are great. Mom thinks you are great. Most people think you are great and the other people – they just don't get it. Which is the honest truth." Somehow it feels reassuring when people come in and say, well we think he is pretty adorable too.

You know he likes to skip sometimes. He always has, which I think is more socially acceptable when you are a little boy than when you are a teenager. He'll skip in a parking lot or when we go on a trail and people will look. It doesn't faze him. You know – sometimes I'll giggle and he will ask me what I'm giggling about. I just tell him “you know pal – you are one of a kind.” He takes it at face value - like that's a good thing.

At times Jack's unawareness of social norms can create discomforting situations for others unfamiliar with Jack. Mr. Hercules shared of another bus ride in which Jack boarded and sat down next to a young college woman. The bus was crowded and “Jack kind of squishes her a bit” trying to keep his feet out of the aisle and clear of standing passengers. To Mr. Hercules, the young woman appeared uncomfortable, “Like, we don't know each other that well for you to be leaning on me like this.” He went on to reflect, “I don't think Jack necessarily understands the boundaries...like...I'm touching you so that means I'm a little too close.” Despite Jack's unawareness of certain social norms, he shows discriminating attention to other details that often “gives him a little edge”, as Ms. Ariel explained, illustrating with an example:

Ms. Ariel: At a luncheon the other day, Jack was talking to the waitress and she was wearing a nametag.

Ms. Aurora: Jenny.

Ms. Ariel: Yes, Jenny. So as soon as he made his order, he said “Thank you, Jenny!” He was the only student that identified her by name.

Ms. Aurora: He's off in his own world and yet he notices things that we ignore, you know?

Mr. Hercules concluded, “I don't know...Jack is not really a person you would fear. He's actually kind of inviting. He is so friendly and will say things in a way that you feel you can talk to him.” He ended by sharing a postscript to the original bus story of the young man with the arm cast.

So, another person gets on the bus also with a cast. He's an older gentleman and he doesn't quite realize...I guess you know with Jack you can't really tell what's going on [that Jack has autism]. The guy gets on and he looks kind of stressed and dealing with his own issues. Jack says "Oh my gosh, another guy! Your arm is broken too! Why is your arm broken?" The guy said “I was climbing mountains.” He was joking but just trying to brush Jack off - trying to be sarcastic. So Jack says "What mountain were you climbing? How high was the mountain? Was it greater than fifty feet?" And a whole bunch of other things. He just went down this list of questions to get to what had happened. Finally the guy kind of realized and Jack goes and sits with him. They end up having this long discussion about his fall and breaking his arm. So... I guess Jack just has his own way of being social with people.

7.1.6 Jack and friendships. When asked about friendships, Jack did not mention friends of the same age, but instead identified his long term care provider as his best friend and three additional care providers as good friends. Perseus commented,

He is not really interested. He has one friend at school and they share several classes. I've met Poseidon, he is a sweet boy. Though for the week that he was out of school because of the snow...he didn't really mention him. My brother is not very social. Plus, we have several people who come here. He sees his care

providers as his friends. He doesn't really see them as people who come here and are getting paid to come here. They are people he hangs out with. But as far as other kids at school, he can really take them or leave them. I hate to say it this way but he is really focused on himself. You know when Poseidon got him a Hanukkah present it didn't dawn on him that he should get Poseidon something in return. It is sort of a disconnect...a part of the autism.

7.1.7 Jack and the opposite sex. Mrs. Aurora, Mr. Hercules, and Perseus have all noticed Jack's emerging curiosity and interest in girls. Ms. Aurora shared,

Every once in a while he will notice what some girl is wearing and he will say "Mary, that shirt is beautiful!" and it makes her blush. It's just a shirt that she has worn before but all of a sudden he is noticing it. Maybe it's her shape.

Mr. Hercules added,

I don't know if it is just a playful affection toward girls, but sometimes in the hallway he will reach out and brush their shoulder. So...I don't know if that is just somebody in range for him to touch and to kind of have a connection with or if it is actually something physical.

Perseus shared,

I think he is interested, but I don't think he knows what it is about them that interest him. Even though he is 17, it's more that you start noticing girls and you can't quite figure out why you've started noticing girls. I don't think he can explain it and he certainly doesn't ask questions. He used to go to dances – like they have at the ARC. There was one girl that he asked to dance and she kept saying no. It wasn't incredibly constructive and I think it bothered him, you know. But, I think it

was more of that he doesn't quite understand what is going on. I don't think it is embarrassing. Maybe it's that he is not quite sure what to ask or who to ask. I'm not sure it even crosses his mind that he should ask someone....I think he understands that they are not interested in the same things that he is interested in. Like Tuesday during lunch, they have a social thing and there are girls there and they will talk to him. But, they are not really interested in talking about Mickey Mouse. I think he understands that. I don't think it bothers him. But I do think it creates a distance.

When asked if issues related to relationships, sexuality, sex, and sexual health were addressed through curriculum, Ms. Aurora and Mr. Hercules offered the following comments:

Ms. Aurora: We didn't put him in health class this year. Usually 10th graders go into health, but he'll probably be in school a little later and I'm not really sure if everything in health would apply to him. So we put it off - until another day.

Mr. Hercules: When we talked about it in Life Science... what little we talked about it...

Ms. Aurora: We get a little more graphic.

Mr. Hercules: So, he knows certain things. He knows the rules so...

7.1.8 Jack of many trades. Outside of the school day, Jack participates in numerous activities scheduled around his interests and needs as determined by long and short range goals identified in his IEP and PCP. They include violin lessons, physical recreation, a theater arts class, and volunteer work at the local public library. While enjoyment and skill development are two positive outcomes of these activities, they also foster

opportunities for increased self-awareness in areas of strengths, capabilities, and challenges explored through a variety of roles and experiences.

7.1.8.1 The musician. At the encouragement of his mother to learn a musical instrument, Jack chose the violin and has taken lessons once a week for the past two years. Andromeda recalled their early conversation,

I'm thinking keyboard, guitar, even drums. I said, "What instrument do you think you would like to learn?" He said, "I want to learn the double bass." I said, "The double bass?!" He said "Yes, because I want to play Peter and the Wolf. I want to do Peter's Theme." I said, "Jack, I don't think I can find anyone to teach you the double bass but there is someone who could teach you how to play the violin." He said, "Well that is a good start!"

Jack's instructor teaches using the Suzuki method. With this method, new students learn to play by ear before an introduction to musical notation. Environment plays a central role in a student's success, with encouragement and collaboration emphasized over competitiveness. Jack's practice sessions are built into his daily schedule except for Fridays. His violin and bow are marked with blue tape, indicating appropriate placements for fingering and bows. Andromeda commented, "It's amazing that someone with his fine motor problems can actually do this." When practicing, Jack keeps an open binder with instructions, sheet music, and a reward schedule on a table in view. He begins with practice drills, moves on to memorized pieces, and then plays newly introduced and more complicated compositions. When playing these more challenging songs, Jack will occasionally pause, closes his eyes and take calming breaths before beginning again. In response to the comment "Jack, you have many talents!" Jack smiled and responded with

confidence, “Yes, I know!”

7.1.8.2 *The thespian.* Jack attends a theater arts class through a community art center once a week developed specifically for youth with developmental disabilities. Three instructors lead the class and five to six peer volunteers partner with participants to socialize and provide assistance, if needed. A large, laminated picture schedule is displayed on an easel in the center of the room. During an observed class session, participants were charged with the task of assigning characteristics (special powers, emotions, occupations, habits, funny quirks, etc.) to their earlier crafted papier-mâché masks. Instructors presented various options using pictures pasted to small index cards to assist in their choice-making. Rather than partnering with a peer volunteer, Jack picked up his mask representing Zeus, and sat between Perseus and his care provider. At times during the class, Jack would affectionately lean on or drape his arm around one or the other. Although he seemed somewhat disengaged with the class activity, Jack consistently responded on topic when asked questions or as something came of interest. During the final sharing segment of the class, Jack appeared at ease as he stood confidently in front of the class and animatedly acted out his character’s traits.

7.1.8.3 *The athlete.* Jack participates in many recreational sports including swimming, bowling, tennis, and racquetball. He also enjoys going for walks with his brother. Integrating physical activity into Jack’s day has become a priority for Andromeda. She explained,

It started when we moved here and he saw the tennis courts. He wanted to play.

He said “Let’s play some tennis.” So I said ok! We went out and bought a couple of cheap rackets and a bag of balls and we just started hitting the balls. Around the

time of puberty, behaviors were getting - not quite crazy but kind of slipping off and I noticed there was something about playing a sport like tennis or racquetball and the concentration and running and hitting the ball. The negative behaviors decreased. The ability to focus increased. Then when it started getting cold we stopped and I saw a rise again. Just a physical activity and running - it does something. The teacher came to me after three or four weeks of picking up racquetball and she wanted to know what medicine I had put him on.

Of their walks together, Perseus commented, “Jack is very competitive...we will go for a walk and that's the joke, because for over half of the walk we end up running.” Jack's teacher, Ms. Aurora agreed.

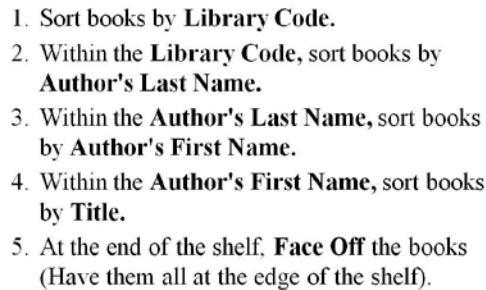
Jack has got a thing about competition. When students are in gym and someone else is winning, Jack will get mad and he might even whack one of them. Then there was the thing with Special Olympics. We were looking at some of his pictures on his camera and we noticed that when he didn't win first place, he would put his foot up on the first place pedestal. So... he is not happy for the other person when they win. He is not a gracious loser. Sometimes it scares and intimidates the other kids.

Of competition, Jack shared, “I like competition when I win, but when I lose it makes me upset!” Mindful of this, Andromeda is cautious in selecting Jack's physical activities and often opts for individually-oriented sports, such as swimming, over team sports.

7.1.8.4 *The library volunteer/patron.* Once a week, Jack volunteers in the children's department at the local public library. His responsibilities include straightening

the shelves and rearranging misplaced books. Although this is a volunteer position, Andromeda pays Jack \$4.00 per shelf. In learning his job, Jack followed the following visual prompt created by Andromeda:

Figure 11. *Jack's Shelving Guide*

- 
1. Sort books by **Library Code**.
 2. Within the **Library Code**, sort books by **Author's Last Name**.
 3. Within the **Author's Last Name**, sort books by **Author's First Name**.
 4. Within the **Author's First Name**, sort books by **Title**.
 5. At the end of the shelf, **Face Off** the books (Have them all at the edge of the shelf).

After finishing his work, Jack is able to spend time exploring the shelves for his own interests. As with many of his other activities, routine and rules are in place for choosing books. Andromeda explained,

One of the care providers came out with something really good that we've been doing. When Jack goes to the library, he picks two books that he has never seen before, two books that he has seen before and two books that he can learn something from.

Without this structure in place, Jack is inclined to choose the same books repeatedly. When asked of the impact of libraries in Jack's life, Andromeda commented, Huge. Huge! Not only does it give him a skill that he is good at (shelf reading), but we can branch off into new interests through the library. The library has opened Jack up to different things. If he has an interest, he can go further into it. Like mythology...he got one of the Eyewitness books on ancient Greece and when we

finished that he saw one that was on Ancient Egypt. So there is Egyptian mythology too. So he branched out that way and then he went on to China.

Of the librarian's engagement with Jack, Andromeda shared,

The public librarians are awesome with Jack. They adore him. Everyone in that library does. When he hears about a book they don't have – they order it for him. If he is reading a series and a new one comes out, they make sure he gets it. It's the attitude that they have that makes the difference. They are open to him. They have patience. When he comes up to that desk to ask a question, he is treated with respect.

7.1.9 Jack and leisure activities. Of all Jack's scheduled activities, he particularly enjoys free time at home. Perseus shared, "My brother doesn't really get bored, most of the things he enjoys to do are here at home. He's perfectly content being here because he can entertain himself a lot better than going somewhere else." When given the opportunity, Jack will often choose to play out his stories in the family living room using items such as a stuffed Mickey Mouse toy and a large tinker toy castle as props. Reading and writing stories, playing games on his computer and Wii, and baking are other preferred activities regularly scheduled into his week.

7.1.9.1 The reader. When asked to share some of his favorite activities, Jack replied "When I'm at home, I like to read my books. When I'm not at home, I like to go to the library, go to bookstores, and use my money to buy things – if I have enough." When asked, "What kind of things do you like to buy?" Jack replied, "Books! I have a lot of them." Perseus agreed, "Jack likes to read books, but he mostly reads the same books over and over again. Mostly children's stories." Jack also enjoys listening to audio books.

During one home visit, Jack shared a small clip from an audio book he was listening to on mythology. Andromeda and Perseus also make time to read to Jack every day. A copy of an abridged version of Great Expectations sat on his night stand. Andromeda shared,

We still read to him every day. We've read all of the Magic Tree House books in order. That was important to him. Initially we started thinking that we didn't need to read them in order. Then we came to one where there were references made to previous books. He looked at me and said, "What are they talking about?" I said, "I don't know, I think we need to read these in order." He said "I think you are right." He can tell you about something that happened in Magic Tree House Book numbergive you the title....

Perseus agreed, "His memory is amazing. He will pull something he remembered out of a book or movie or whatever....it will take me a minute to say oh yeah - that did happen - a week ago or whatever." Perseus also shared,

He used to be opposed to being read aloud to and would put up a fight if the book was a chapter book. He used to prefer to read himself...but now...I'm not sure if it is just an acceptance thing. I think he actually enjoys listening.

7.1.9.2 The writer. Over the past few years, Jack has started composing stories on his computer, using clip art to illustrate and various font options (underlining, bolding, size, italics) for emphasis. Perseus explained, "It actually started out where he would tell the story from memory and someone else would do the typing. They usually are fairy tales and Disney-type of stuff, but he does change things up slightly." Jack's mother prints his stories and Jack places them in a binder that is kept on the bookshelf with his other favorite books. When asked if Jack often chooses to read his own stories, Perseus commented, "To

be honest once he sort of puts them on paper he doesn't look at them very often.” Mr. Hercules also commented on Jack’s writing.

Yeah he writes a lot. He loves to write. One of the first stories that he wrote was single space four pages. He brings in all of his fairy tale stories and his vocabulary in those stories is just amazing. I mean the words that he uses are so...appropriate. He has a great vocabulary. The thing that I find interesting about his stories is that when he writes, he tries to write as he really sees things. It’s really cool. He might start off with all lower case letters for “bigger” and then as he wanted to emphasis words, he would change the size and font. Like... (Mr. Hercules demonstrates) it grew bigger and bigGER and BIGGER!”

7.1.9.3 The gamer. Jack’s favorite computer and Wii games all involve a racing element. Mario Brothers is a favorite Wii game and Perseus shared that Jack can become easily agitated if not playing well.

He can become frustrated, but usually there is someone here playing with him. We just pause the game and tell him, “It's just a game Jack. It is not something to get that frustrated about. He is competitive though and he wants to win.

Beyond playing to win, these games also offer Jack opportunities to showcase his gaming skills and to teach others. Perseus commented,

Jack likes to show people what he knows. I remember he was here with one of his care providers and he wanted to play a game that she had never played before and so he was pretty enthusiastic in terms of showing her how to do it.

7.1.9.4 The baker. One day during Teacher’s Treat, Jack became frustrated because the brownies that he had hoped to purchase quickly sold out. Coming home still

upset, Andromeda said to Jack, “You know, you could get the recipe and we could bake it here. Then you could have it whenever you want!” So began a weekly tradition of Saturday baking. “We’ve made banana bread from scratch, a carrot cake and cream cheese frosting, also from scratch. He likes it and it is fun!” Jack now is able to bake many of these treats with minimal supervision. Andromeda shared, “You know, he gets this sense of accomplishment from baking sweets. Everyone tells him how delicious they are and he gets a sweet every day. So it is a win-win for him.”

Jack’s new interest in baking inspired Andromeda and his transition specialist, Ms. Ariel, to seek other baking opportunities for him. He since has volunteered at a local bakery where he learned to make chocolate croissants and currently volunteers once a week at a pastry shop preparing their daily batch of butter cream frosting .

7.1.10 Jack and household responsibilities. Beyond preferred home activities, Jack is also expected to contribute to many of the household chores. These include cleaning his room and bathroom, emptying trash, meal preparation, laundry and grocery shopping. These responsibilities are assigned with dual intention – out of family obligation and in preparation for the future life. Andromeda commented,

He does a little bit of vacuuming, but he’s not real great at it. It’s something we’ll work on. We haven’t gotten to dusting or even sweeping or mopping the floor. I have time though....I know he’s 18....but he is also still a child.

When pointing out that many eighteen year olds struggle with household chores, Andromeda responded, “Yeah, but the difference is that they are going to go to college, get out, get their own apartment, and pick up on these things. Jack is not going to pick up on it that easily.” To help Jack in the development of these skills, Andromeda breaks tasks into

steps, sets explicit guidelines, and creates reminder prompts.

7.1.10.1 Shopping. Saturdays are grocery shopping days. Jack develops a weekly shopping list from a checklist template created by Perseus and uploaded to Jack's iTouch. The checklist consists of regularly purchased grocery items and weekly decisions are made systematically. For instance, Jack will note the number of apples he has at home. He then will add to his list the number apples equaling to four. So, if Jack has one apple at home, he will add three apples to his list. If he sees an unopened milk container in the refrigerator, he will not add milk to his list.

While shopping, he searches for each item and enters the price directly into his iTouch. For unpackaged produce, Jack uses the scale to determine price. As he shops he typically displays a friendly courteousness to others. Once when blocking another customer's path, Jack moved his cart, gave a deep bow and said, "After you, Madame." He completes his shopping with little assistance and determines the amount of money needed before moving into the checkout lane. Of shopping, Perseus commented,

Jack wasn't thrilled about doing his own grocery shopping. But I do think he gets a sense of satisfaction, although I don't think he would admit it. He just sort of accepts that this is how things are going to be because my mom is so constant.

7.1.10.2 Meal preparation. Jack prepares one family meal a week. He shared, "I'm an expert at cooking breaded chicken." With two complete meals in his repertoire, Andromeda commented,

We plan on growing that so he'll have a variety of things that he can prepare. Jack knows how to make ziti with sauce and a green vegetable. He knows how to make a full chicken dinner with sweet potatoes and a vegetable. Jack knows what a meal

should look like.

7.1.10.3 Laundry. Jack completes a load of laundry twice a week. Through the week, Jack follows a process to determine when items need laundering. Andromeda explained “He knows that when you take off clothes, pants can be worn twice but they shouldn’t be worn back to back days and shirts – as soon as you wear it, it needs to go in the hamper.” Signs are posted in the laundry room with steps for sorting, though Andromeda commented, “Jack knows how to sort from lights, darks, cold....he gets all of that now.”

7.1.11 Jack and self-care. As with all of Jack’s activities and responsibilities, self-care tasks are also integrated into his schedule. Processes and rules for each task are made explicit. This includes tasks such as brushing teeth, combing hair, putting on deodorant, trimming finger and toe nails, and washing. Like many teens, Jack struggles with acne. Andromeda commented,

So it’s, “Put the cleanser on and call someone.” Then, he was doing a good job of putting it on, but he wasn’t doing such a great job of washing it off. So then it was, “Call someone after you have rinsed off.” Sometimes when I say something to him about washing his face – he’ll say, “I did!” and I’ll say, “Jack I know you didn’t wash your face. If you go to school and you have cleanser on your face the kids are going to laugh at you. If you don’t do a good job washing your face and your acne gets out of control - then you will have marks on your face for the rest of your life.”

Andromeda regularly uses a straight talk approach when explaining things to Jack and commented,

Jack’s teacher says that sometimes it surprises her that I talk to him just matter of

fact. I'm not good at all of this...you know, I'm an accountant! I'll say to Jack, "This is what you need to do and this why you need to do it." I rarely say, "Because I said so" because there is a reason why I'm saying what I'm saying. Sometimes I really need to think about it, but I always tell him why. I give him choices and I'm blunt. I tell him that my rules are to make his life better. The same way I tell him to look both ways before he crosses the street. It's because I want to keep him safe.

7.1.12 Jack's future. When Jack was questioned about his plans for after high school, he stated, "I know I don't want to go to college. Perseus gets too much homework when he's there. I've had enough with homework. I don't really know what the future will have in store...whatever it will bring!" When asked of his hopes for the future, Jack responded, "I hope that I'm allowed to do what I want, like have computer time and keep getting those preschool movies." As for Andromeda's hopes for Jack's future,

I want him to be happy...doing thing that he likes to do. He loves being in the library. He loves to bake. It could be a variety of things. I don't know anyone who graduated from college who did the same job until they retired, you know.

She later added with a laugh, "He won't be a janitor. I can assure you that!" As for where Jack will live, he stated, "I'd like to stay here and live where I am now." Andromeda anticipates that Jack will eventually live in some type of group living facility.

I've heard about something recently...a place where you have your own bedroom and kitchen, but there is a big community room almost like a duplex. There would be four people living there with staff. If you needed time off on your own you could be on your own, but if you wanted to be with a lot of people, you could. I

think that would be the best for Jack. He would have a lot of support, but he could still reach a certain level of independence. We've got time though...I'm thinking maybe in his thirties he should start living out in an independent type setting. Someplace that he will be able to live for the rest of his life. That type of familiarity. We don't have a big family so I need to know that there will be people that will take care of him.

Although Jack is eighteen and will be graduating in another year, Andromeda commented, "I don't see him moving out anytime soon....maybe in another fifteen or twenty years." Still, concerns of the future loom for both Jack and his mom. Jack confided, "I worry about what I'll do when I'm the only member of my family still alive. Like when both Mom and Perseus have died." Similar thoughts trouble Andromeda, as well. She shared,

If I died tomorrow, I have no doubt that Perseus will take care of Jack. Perseus sees Jack living with him in the future. My concern is the day something happens to Perseus. Alzheimer's runs in my family. Maybe they will have a cure for it by then, but maybe they won't...and maybe Perseus won't even know who Jack is...so those are my big concerns.

Until that time comes, she continues to lay the groundwork for Jack's future and is hopeful. Still, Andromeda moves forward with no false expectations. The challenges of living with autism are life-long and Jack continues to struggle with anger control. Andromeda shared, "Jack's temper is a challenge and it always will be. His own control of his temper has gotten a lot better, but that exuberance...when he is angry, is pretty powerful. When asked what she considers to be Jack's biggest challenge as he moves

forward, Andromeda shared,

Jack is trusting of everyone. That is a big challenge. He trusts everyone. Everyone is his friend. And you know, in his world right now...that is true. He is in a really nice little world. I'm not sure he will always have that. So there is a fear there.

As for now, Andromeda shared, "You know...we are happy. Everyone is happy and it's all ok. It is a nice little life."

7.2 Introducing Marie

Figure 12. *Marie's Self-portrait*



I first met Marie during her senior year of high school. She was twenty years old. Sitting in their living room, I explained the intent of the pilot study I was conducting to Marie and her parents. She sat silently next to her mother on a piano bench, her body positioned away from the conversation and slightly hunched forward. As I spoke, Marie stared at the floor. She did not speak during my half hour visit, though when I asked of her interest in participating in the study, Marie gave a tight-lipped smile and nodded. Still, her eyes remained on floor. Marie's inhibited behavior gave me pause. I wondered to what extent she understood the purpose of the study and her own involvement.

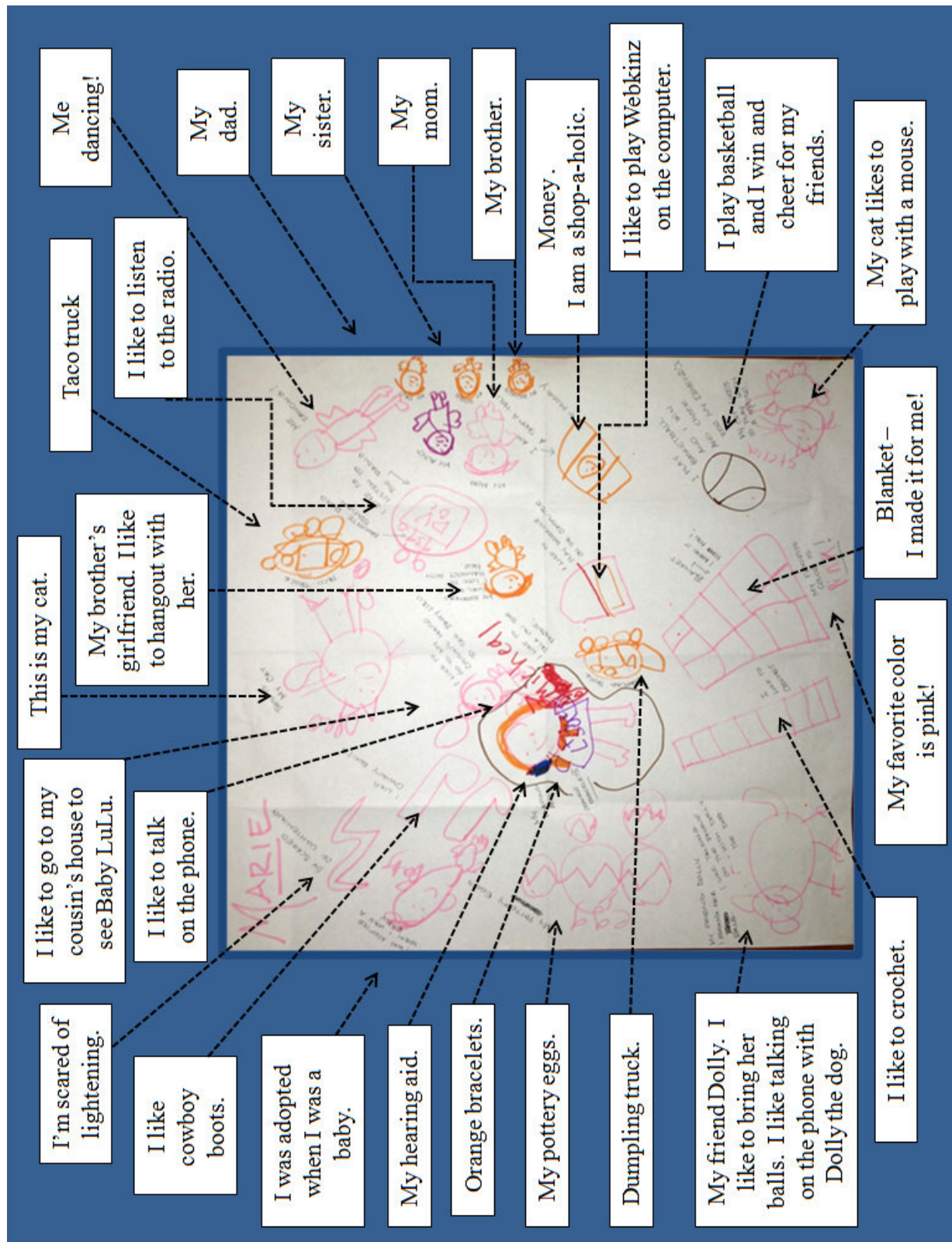
As I stood to leave, Marie abruptly left the room only to return a few seconds later. She handed me an informational flier for a program that her mother had mentioned during our conversation. In the bottom corner was a name and phone number, handwritten in fresh smeared ink. "Here, call her if you want to know more. I go there. She knows me." I took the paper, said "thank you", and finally, she raised her eyes to mine and gave me the

same tight-lipped smile and nod. My hesitancies vanished. I had a partner in research.

At age 23, Marie lives at home with her parents, Mr. and Mrs. Ice Cream. She is the middle child of three. Marie's younger sister, Faith, currently attends the local high school and her older brother, Tim, lives in an apartment in their same town. Both of Marie's parents are well-educated. Mr. Ice Cream works as a researcher and Mrs. Ice Cream was a former special educator but is now a homemaker. They live in a modest but comfortable home in a middle class neighborhood.

Marie was diagnosed at an early age with I/DD, epilepsy, and a hearing loss. She readily acknowledges her challenges; however, "disabled" is not an attribute typically self-proclaimed. Rather, when asked, Marie identifies herself as a dancer, a knitter, a swimmer, a country music fan, and a shop-a-holic. She will also often share about her love of babies and animals, Willie Nelson, and all things pink. Marie has countless interests and hobbies. Leading an active and engaged life is clearly a priority. Upon first meeting, she can be shy and hesitant - though it does not take long to see that this is an individual with a stubborn determination, fearless spunk, and heart of gold. In short, Marie is not someone marginally defined. Through her collage of drawings and dictated annotations (Figure 133), photos, and expressed thoughts and reflections, Marie offers the reader a window into her life.

Figure 13. *Marie's Life in Pictures*



When asked to describe Marie, her parents and former teachers used similar terms: outgoing, friendly, confident, and generous. They also characterized Marie as bossy, manipulative, impulsive, and unpredictable. Given these converging traits, Mr. and Mrs. Ice Cream often worry about Marie's vulnerability to harm and exploitation. "Marie can be friendly to a fault," her father explained, "Just in the way she is so quick to trust. I mean, she's quite willing to walk off with someone to see their workplace or check out their friends." Her mother similarly expressed concerns, particularly with regard to Marie's generosity. Mrs. Ice Cream stated,

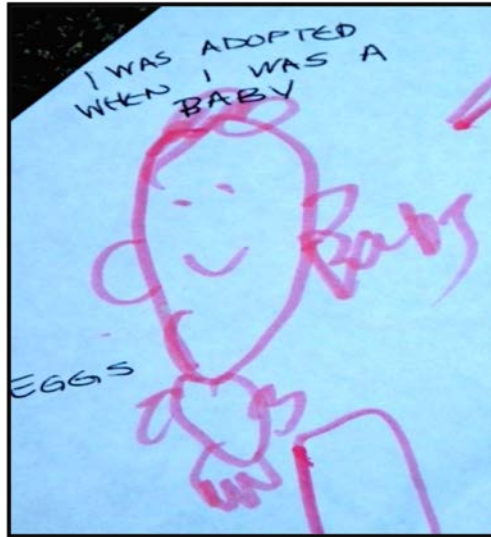
Sometimes it's embarrassing because she'll go to such extremes. Marie can't stand for someone to come into the house without giving them something. Or, she can't stand to go anywhere without taking gifts to people. There is no telling what she might give away...we sometimes don't know what's been given away. I worry that it's because she thinks that people love her only because she gives them something.

She later concluded, "Here's the thing...with a mind as different as Marie's you can't always predict what is going to pop into it. She doesn't think like everybody else. But...she does think - just not like everybody else."

7.2.1 Marie's early years.

Ok...I gotta tell you a sad story. You know I got two moms, right? My birth mom gave me coke [Coca Cola] when I was a baby. She didn't know how to take care of me. Left me by myself at home a lot. One time the neighbor heard me crying and screaming. She the one who broke into the back of my mom's house. She gave me to a policeman and they put me in childcare and my mom got mad. They try to teach her....but she don't learn.

Figure 14. *Marie as an Infant*



Diagnosed with a failure to thrive, Marie spent her first few years of life in and out of the hospital. Failure to thrive refers to the insufficient intake, absorption, and/or expenditure of calories to sustain developmentally targeted growth. Although more prevalent in underdeveloped countries, between five to ten percent of young children are diagnosed each year in the United States. Leading risk factors include impoverished environments (financially and educationally) and familial neglect and/or abuse. Biological factors are less common contributors. Long term developmental impacts may include continued low growth rate, cognitive delay, and poor academic performance (Cole and Lanham, 2011). In addition to the failure to thrive diagnosis, Marie also struggled with uncontrollable seizures and was identified as having a mild to moderate hearing loss.

Seeking to adopt their second child, Mr. and Mrs. Ice Cream learned of Marie's possible availability after Marie was removed from her birth mother's home and placed in a therapeutic care facility for children with developmental disabilities and behavioral disorders. Mrs. Ice Cream recalled,

Marie was about two years old when we started visiting her and she had been there for pretty much a year before. Her birth mother visited her several times and they tried to work with her on appropriate behavior and childcare, but that never really worked out. When we first got Marie, she came as a foster child so she could leave the hospital while they were terminating her mother's parental rights.

As for Marie, Mrs. Ice Cream shared,

The doctors put her on seizure medication, started her with a hearing aid, and did all kinds of evaluations. Initially they thought that as soon as someone started taking care of her, Marie would grow and be normal and everything like that. But...I could tell...I was a special education teacher and had worked with a lot of children. Marie has always been very bright looking and alert, but also very active. We had to watch her 24/7. It was also really hard to get her to eat and, of course, if you can't get her to eat, you can't get her to grow. We went everywhere and asked all kinds of questions and never really got answers.

Of this time in her life, Marie recollected, "I got real sick when I was little. I won't eat no vegetable cause I think it was nasty. The hospital people said, 'If you don't eat your vegetables, we gonna force you!'"

Shortly after bringing their new daughter home, Mr. and Mrs. Ice Cream enrolled Marie in preschool. "We thought that it was better for her to be in the mainstream setting, to be out as much as she could and do things with other kids," her mother explained. Because of Marie's size and developmental delay, she was placed in a classroom for younger children. She also began receiving speech and occupational therapies. "She did really well that year," Marie's mother commented and her seizures were finally under control.

In the spring of her fifth year, Marie's doctors recommended that Marie be weaned off medication to ascertain whether she had outgrown her seizure condition – an occurrence not uncommon for children who experience seizures in early life.²⁷ Mrs. Ice Cream recalled with surprise, “Marie blossomed and started talking more! We didn't realize what an impact the medicine was having on her learning and language.”

Unfortunately, their excitement was short lived. Traveling home from a summer vacation, the Ice Cream family stopped at a restaurant for dinner. Without warning, Marie had a seizure. Once back at home, the seizures continued, sometimes occurring several times a day. Her mother lamented, “We really hated that she had to go back on seizure medication. She was doing so well.” Finding the right combination of medication was a long and arduous process, Mrs. Ice Cream explained. At one point, Marie experienced an adverse reaction to one of medications (since withdrawn from the market) and was admitted to the hospital.

The doctors thought it may have been an allergic reaction to her medicine but she was on so many, they didn't know which one was causing the problem. They had to take her off all of them again and the seizures just went out of control. It probably took us close to a year to get her back on track.

7.2.2 Marie in childhood. At age six, Marie began kindergarten and was identified for special education services. Her elementary school followed an inclusion model, meaning that Marie received resource support within the general classroom setting alongside her same-aged peers. However, unlike her peers, Marie did not follow the typical K-5 grade level trajectory. Instead, she spent multiple years in some grades, while skipping others. Marie's mother explained,

Marie had a great teacher in third grade. The next year she was placed with yet another

²⁷ eMedicine Health reports that only thirty percent of children diagnosed with epilepsy early in life will continue to experience seizures into adulthood. Accessed on March 6, 2012 from http://www.emedicinehealth.com/seizures_in_children/article_em.htm

great third grade teacher. This teacher liked her so much that she asked to have Marie again the following year. So Marie spent three years in third-grade. It was inclusion and she was in the classroom with these kids and she was happy.

Mrs. Ice Cream described Marie during these early years as a friendly, yet energy-demanding child who had a tendency to wander. “Marie knew every student...everyone...and she knew everywhere to go. So, she would just go. Everyone [in the school] knew Marie and would just send her on back to class.”

Although Mr. and Mrs. Ice Cream were, for the most part, pleased with Marie’s inclusion in the regular classroom setting, they worried that not enough attention was being paid to Marie’s individual academic needs. Her mother commented, “She really couldn’t read or write or do math. They had to at least try to teach her these things,” Marie’s parents requested that Marie be pulled out of class on a regular basis for one-on-one instruction.

Her special education teacher worked really hard and eventually Marie was able to recognize some words on her own...but you know...she never holds these things in her mind for very long. The teacher also taught Marie to use the calculator. Even though she doesn't really understand the processes, she could still do the math if she had the calculator.

Looking back, Mrs. Ice Cream views Marie’s early schooling in a positive light, stating,

I think that it was really great that she was in the inclusion program because...it's not like somebody with a learning disability who might be really bright yet realize....you know, be embarrassed about not being able to do the academic things that their peers are doing. Marie was just happy to be there and to socialize with everyone. She made volcanoes and lighthouses and all kinds of projects that everyone else did – she did that. Other kids

worked with her and it was really great. So I'm sure she really learned a lot more than she would have if in a special education classroom the entire time. I mean, she might not have been able to learn to read and write - but she learned about the world. It also made her social skills a lot better too...I'm sure better than they would have otherwise been.

Once in middle school, Marie's time in general education classes lessened. Marie spent four of seven class periods in a self-contained resource room with other students similar in educational ability and need. Instruction centered on the development of functional everyday life skills. For the remaining three class periods, Marie attended elective courses,²⁸ physical education, and health with other grade level students. When asked of a favorite middle school memory, Marie recalled a parenting assignment for health class in which every student received an infant doll that simulated characteristics and needs of a living baby. Students were instructed to take the doll home and care for the "baby" over a short period. Marie explained,

It was for practice...like learning how to do stuff...like how to be a good parent for when you have a real baby. You put this key in to get the baby to stop crying. My friend broke his baby and had to pay for it, but I did not break mine. Dang, I saved my folks money!

Marie took part in extracurricular activities, as well. She attended many of the middle school dances and served as manager for the school volleyball team. When asked about her responsibilities, Marie shared, "I helped out people. I had to tell them what to do...pass out water bottles...stuff like that."

Of Marie's middle school experience, Mrs. Ice Cream commented, "The teachers couldn't have been better and Marie made it a point to know everyone - the principal, the assistant principal. Whenever I was there, she would introduce me to all of these people."

²⁸ Elective courses are those chosen by students according to their interests. Marie participated in art, home economics, and choir.

Marie's mother also recalled Marie's initiative when it came time for her eighth grade educational team to review annual IEP goals.

It was January and Marie's IEP meeting was coming up. Marie's teacher had just left to take another job and a person from the district was to be in charge of it. Marie knew that the regular class teachers are usually asked to come to all of these meetings. So, Marie went from class to class that morning and said to all of the teachers 'Today is my IEP meeting. Are you going to be there?' They all told her that they had not heard about the meeting...you know, I guess there was a breakdown from having the teacher leave. So Marie said to each of them, 'Well, you need to be there!' and they all showed up!

When Marie was asked about her participation in IEP meetings, Marie's face turned to disgust. "Dang, I hated those things! They're boring and they talked for ages!" Of Marie's involvement, Mrs. Ice Cream commented, "Marie has always been a little silly [during the meetings]...acting shy or like she can't talk. She'll sometimes act like she doesn't know what is going on – but she does."

7.2.3 Marie as a young adult. Mr. and Mrs. Ice Cream provided copies of Marie's individual education and transition plans from her last year of high school and her current person-centered plan.

7.2.3.1 *An assessment of Marie's abilities and needs.* Table 11 offers a general summary of Marie's current strengths and challenges.

Table 11. *Assessment of Marie's Abilities and Needs.*

Social/Emotional	<p>IEP: Marie loves people and is very outgoing. She has matured a great deal since first coming to the high school. While she is still very much aware of what is going on, she reacts to situations in a more appropriate way. She respects her supervisors and follows instructions.</p> <p>PCP: Marie feels that she is smart, friendly, and funny. Marie's parents say that she is smart and friendly, a hard worker, and a good athlete. Marie says she has had a great year in school. She is also very excited about being a senior and is looking forward to graduating from high school. She likes her life and doesn't have any complaints. Marie's parents say that in the past she has had behavioral issues like mild aggression and temper tantrums but over the past year they have declined. She will continue to need the support of her family and friends long term. She says that her family, pet, Special Olympics and school are important to her. Marie's parents say that they think her family, pet, Special Olympics, dance, and music are important to her. Recently, Marie began making jewelry and she has quite a talent for jewelry making. Marie has gotten involved with Social Ministries and she had the opportunity to go to camp this summer with her friends from the program. Marie wants to date and keep doing Special Olympics.</p>
Academics	<p>IEP: Marie is very interested in learning to read and improving her math skills. She has made progress but needs continual review. She reads around the first grade level and can solve simple math problems with assistance. Marie can write legibly but needs to improve on her spelling skills. She enjoys using a computer and can use a calculator. She needs to improve on using functional reading and math.</p> <p>Transition: Marie is a senior in the self-contained class for students with moderate developmental disabilities. She has participated in PE classes with her same age, non-disabled peers in the past. Her classes focus on functional academics, vocational skills and daily living skills.</p> <p>PCP: Over the past year, Marie has learned to sign her name in cursive and she is very proud of her new ability. Marie's parents say that she is doing well in school. Marie's parents say that Marie is smart and friendly and can follow simple directions when she wants to and can read and write some. They would like for her to continue to expand on her reading skills.</p>
Life Skills and Self Care	<p>Transition: Marie lives with her family. She reports that she feeds the animals at home and cleans the cats' litter box, cleans her room, puts her clean clothes away, and cooks with supervision. She reports that her parents do the majority of the cleaning, cooking, and laundry. Marie's parents manage her finances. She is unsure of whether or not she would enjoy living in a group home.</p> <p>PCP: Marie would maybe like to live in a group home one day with her friends. Marie's parents say they she is beginning to develop her independent living skills and would like for her to possibly move into a group home one day.</p>
Community Access	<p>Transition: Marie enjoys Special Olympics soccer, swimming, and bowling. She also enjoys going to movies with friends and family, doing a variety of arts and crafts, and reading. She presently receives case management services and is enrolled in the School to Work program through Vocational Rehabilitation.</p> <p>PCP: Marie's parents say that Special Olympics is important to her and would</p>

like for her to keep participating in the organization as it provides great access to her peers in a social setting.. Marie will continue to require case management services to assist her with coordination, monitoring, and linking her to services.

Employment

IEP: Marie thoroughly enjoys going out on jobsites. She is a good worker and is starting to show signs of being able to work more independently.

Transition: Marie reports interest in clerical work, light cleaning, child care, sales, plant care, and making arts and crafts. She has mastered these and other skills at school and community based vocational training sites. She has been a terrific salesperson for the school store, folded, stuffed, and labeled envelopes, cleaned tables and windows, and vacuumed. Once Marie knows the routine, she works independently, but requires supervision to ensure that she does not get distracted and that she maintains an appropriate work rate.

PCP: Marie enjoys staying busy and it is extremely important to her that she obtain a job in the community upon graduation to help meet financial needs now that she is an adult. Marie's parents say they would like for her to get a community job. Marie's parents say that she is a hard worker and would like for her to obtain community employment. Marie will need a job coach to assist her with a community based job.

7.2.3.2 Annual goals. Marie's annual individual education goals and transition goals from her final year in high school are outlined in Tables 12 and 13. Table 14 provides a list of Marie's most recent person-centered plan goals.

Table 12. *Marie's Individual Education Plan Goals*

Annual Goal 1: Marie will be able to read, write, and perform math skills as it relates to her functional living.

1. Marie will be able to identify 30 of the following with 90% accuracy:
 - Common signs
 - Vocational words
 - Grocery words
 - Restaurant words
 - Dolch Sight words
2. Marie will match the above functional words to picture icons with 100% accuracy.
3. Marie will read stories written at the first grade level and answer questions about each with 90% accuracy.
4. Marie will write the following using familiar words correctly in 4 out of 5 trials:
 - Phrases
 - Sentences
 - Simple messages
 - Letters
5. Marie will tell time in 15 and 5 minute intervals with 100% accuracy.

6. Marie will read and write numbers from 100 to 1000 with 90% accuracy.
7. Marie will count nickels and dimes to \$1.00 with 100% accuracy.
8. Marie will count combinations of pennies, nickels, and dimes with 100% accuracy.
9. Marie will solve simple addition and subtraction problems using counters with 90% accuracy.

Annual Goal 2: To improve social / emotional behavior as they relate to school, home, and being out in the community.

1. While working in the classroom or jobsite, Marie will follow the rules as dictated by the teacher/supervisor 100% of the time.
2. She will respect the property of the other students and staff 100% of the time.
3. Marie will remember to ask permission to stop and speak to people in the halls between classes and/or group activities 100% of the time.
4. She will remember to not listen to other people's conversations and will wait until the other parties are through talking to speak 100% of the time.

Annual Goal 3: Marie will improve on her vocational skills and increase the amount of time she can work independently.

1. Marie will attend at least one new jobsite during the school year.
2. She will be able to do the following accurately in 4 out of 5 trials.
 - Collate up to 10 times at one time
 - Wipe tables in the cafeteria
 - Help out with the school store at least once a week
 - File alphabetically by the first letter
 - Run errands to the office, media center, etc unassisted
 - Help pot plants and weed designated areas on campus
 - Make simple jewelry from scratch to sell at the school store
 - Fill out a simple job application
 - Demonstrate appropriate interviewing skills

Table 13. *Marie's Transition Goals*

Goal 1: Marie will become a lifelong learner and attend classes in including, but not limited to, compensatory education, art and crafts, and areas of interest.

Marie will:

1. Explore community college for compensatory education options
2. Explore local arts centers for classes of interest
3. Receive instruction in vocational skills and behaviors
4. Receive instruction in functional academics

Goal 2: Marie will utilize community support services to get assistance with vocational training, money management, and daily living skills after graduation. She will access the community with assistance from community support personnel and her family.

Marie will:

1. Identify rights for self-determination as an adult.
2. Identify voter registration process and requirements
3. Identify voting locations
4. Locate and access community advocacy services
5. Practice appropriate interpersonal skills in order to obtain services and/or access to resources
6. Follow through with agreed upon timelines and activities with service provider
7. Develop a network of service providers and/or friends to meet personal needs

Goal 3: Marie will work with assistance from community support personnel as an adult. Her position will utilize her outgoing personality.

Marie will:

1. Identify a variety of jobs she would be interested in pursuing
2. Complete elements of successful interviews
3. Develop a resume
4. Follow oral instructions for a work task
5. Exhibit good judgment regarding solving problems with or without notifying her employer
6. Practice behavior that is inherent in keeping a job
7. Evaluate herself and her work at work
8. Complete tasks unsupervised
9. Maintain a work rate over an extended period of time
10. Follow established work routines

Goal 4: Marie will live with maximum independence while receiving assistance with home maintenance and her grooming and clothing.

Marie will:

1. Maintain her personal grooming and hygiene
2. Dress appropriately for the situation and/or occasion
3. Maintain clothing including washing and drying
4. Follow a daily or weekly cleaning schedule
5. Follow basic home security practices
6. Perform floor maintenance include sweeping, mopping, vacuuming
7. Pick up items around the residence and return to proper setting

Goal 5: Marie will manage her money with assistance from a community service provider as an adult.

Marie will:

1. Tour several group homes in the area
2. Identify strengths and limitations of various supported and independent living options
3. Open checking and savings accounts
4. Plan and use simple weekly, monthly and annual budgets
5. Manipulate money including selecting coins or bills to total a specific amount.
6. Use public transportation system
7. Incorporate the amount of time needed for public transportation into planning

Goal 6: Marie will participate in a functional vocational evaluation in order to identify areas of interest and strengths.

Table 14. *Marie's Person-centered Plan Goals*

Long range outcome: Marie will receive case management services to arrange, coordinate, link assess needs, and review progress toward goals and monitor services as needed.

1. Marie will meet with her case manager at least monthly for the next 12 months. Marie will communicate with her case manager to inform her case manager of changes in her status and life.
2. Marie will receive support from her case manager to coordinate services for the next 12 months and she will have a current person centered plan for the next 12 months.

Long range outcome: Marie will maintain optimal health by continuing to access medical service; attend her medical, dental and mental health appointment. Marie will follow through with medical advice including medication protocols. Marie will also maintain optimal health by getting proper nutrition, eating nutritional meals and getting proper hydration. Marie will improve her overall health by getting regular exercise at least 3x a week.

1. Marie will attend her appointment and will follow thru with medical advice.
 2. Marie will continue to exercise and keep her body in good physical shape and will be conscientious of proper eating habits.
-

7.2.4 Marie and high school life. Marie's high school years were busy. Although much of her time was spent in the special education resource room, she participated in a mainstream physical education class and a few elective classes with her same-age peers. She also became involved in a school clubs and served as the manager for her school's cheerleading squad. When asked about her high school activities, Marie recollected,

I worked on reading and writing. Oh yeah! One time I had to do a lot of pages about Martin Luther King. It took me hours to do it and Ms. Rabbit said that if no one do it, they get a freakin F. I did double. I did a poster and I got extra credit...I did PE, art, school store, and cheerleading (as a manager) too. Oh! And I took this class that I learned how to stop people from smoking and how to avoid it. You gotta stand a feet away from them. Yeah, I learned that...it's good I warned you!

When visiting with Marie's former teachers, Mrs. Rabbit and Ms. Bic, about classroom content, they emphasized a focus on functional skills and experiential learning. As an example, they shared about the student-managed school store. During lunch period, Marie and her classmates

took charge, selling pencils, paper, snacks, and other small items. Ms. Bic recalled,

We would often send Marie out with a basket of small items. She would walk around and talk to people she knew and would go up to people she didn't know and ask if they would like to buy anything. She was a littleshe always had her own agenda and you know. She sold a lot of stuff! She was a good salesperson.

When mentioning Ms. Bic's comments to Marie, she smiled and declared, "Yeah, I was!" Other experiential learning opportunities included vocational skill development at various locations in the community. Marie identified the following work sites and offered these comments about her experiences:

Fitness center: "I did cleaning and stuff. We cleaned equipment to make sure people don't get sick."

Animal shelter: "I didn't like it cause they won't let me walk the dog or pet the cat. They just want me to do the boxes."

Business office: "I did recycling. I like that job best cause you get free soda."

During time in the resource room, Marie's class would often partner in learning activities with a class of students down the hall. This neighboring class served students with more involved physical and cognitive challenges. Over the course of these shared learning activities, Marie developed a special friendship with a young lady named Carly. Carly was born with severe cerebral palsy and had significant learning challenges. Marie enjoyed spending time helping Carly. She shared, "Carly couldn't eat by herself so I used to feed her ice cream with my fingers cause she couldn't use a spoon." At times Marie's involvement with Carly detracted from her own learning. Ms. Bic recalled, "We often had to remind Marie 'You are here to learn too and we want you to enjoy it. You have to stop helping Carly so much.'" When asked about

Ms. Bic's comments, Marie replied with frustration, "Yeah – they kept telling me that. It distracted me." Asked to explain, Marie expanded, "I got distracted cause they kept telling me that and they was interruptin' me when I was trying to help Carly."

Marie's teachers also spoke of Marie's involvement as manager of her school's cheerleading squad. Mrs. Bic commented, "Her mother helped her pursue it. Marie wasn't shy about trying anything. I think that girl was just born with confidence." Marie shared a few memories of her time as manager. One recollection involved an afternoon when the cheerleading coach asked Marie to pass along a message to the squad. Marie recalled, "Coach told me to tell them that she was going to be late and to start practice." At the gym, Marie had difficulty getting the attention of the girls. She shared, "I kept tellin' them what the coach said but they just ignore me. They don't listen and I tell them 'Coach gonna get mad.' Coach came and made them run laps cause they didn't listen to me." Of a happier memory, Marie shared of a time when the cheerleading coach asked for her to fill in for the school mascot. Marie commented with what seemed a proud smile, "One of the persons was sick so my teacher said 'You need to put this costume on. Man, I was burnin' up in there!'"

Reflecting on Marie's high school experience, Ms. Rabbit reflected, "Overall, Marie loved high school. She loved everything about being here. I think she probably misses it." Ms. Bic, followed, "Yes, I think Marie had somewhat of a crisis of confidence after she graduated."

7.2.5 Marie as an emerging adult. At age 20, Marie graduated from high school receiving a certificate of attendance. The transition to life after high school has been somewhat difficult. Shortly after Marie's high school graduation, her friend Carly passed away. Marie keeps a framed picture of Carly on her bedroom wall and often talks of their friendship. She shared of her loss,

It was sad. My mom told me. She had a stroke and seizure like me – twice. She liked pink so we bought fake pink flowers and real pink flowers. We put them all around her graveyard – decorated it – made a heart.

The same year, Marie experienced two major health scares. While riding in the car with her mother and sister, Marie had a seizure. She recalled,

We went through Wendy's drive-in and I got chili. I had a seizure and it spilled on me. It went flying everywhere and it was really hot! The car still smell like chili. Dang! One of my mom's friend's asked 'Why this car smell like chili? My sister told my mom to pull over and my sister busted out crying. My mom had to rush me to the hospital and I had to go to the emergency room.

Three months later, Marie suffered a small stroke. The following excerpts came from multiple conversations with Marie as she shared of this experience and the following weeks.

There was a blood clot in my brain. I heard about it, they told my parents. I was in the hospital for a long time. I woke up and I don't know my math or reading. It took a while for me to learn again. My family helped me.

I was in the hospital and people were visiting. I was like 'Oh my God!' My mom and dad had to feed me because I had a stroke and I can't feed myself. The lady, the nurse, she gave me a shower. I had a lot of sticky stuff in my hair.

They took a lot of x-rays. I never done that before. I was scared and I bust out crying.

They called the nurse and she had to run and give me another IV. I had three IVs.

They gave me blue dye in my leg and I had this nasty stuff coming in my mouth and I can't talk for days. I don't like it. I had a heart monitor on and so I can't leave the hospital.

I was in a wheel chair. It fun when it happens – the wheelchair people push you all around.

Although Marie recovered quickly, she continues to experience residual effects from the stroke. Mrs. Ice Cream observed, “Marie doesn’t seem to remember as well and she seems to get upset about things more easily.” Marie agreed, “Yeah – I do.” Marie’s mother also shared,

You know...there are a lot of issues in taking care of Marie and making sure she is ok. She had gotten really, really, really good right before the stroke. I found her to be very trustworthy. Now her behavior is not as predictable. I can’t really trust her to be here by herself now. And, we had just gotten to where we had a good working relationship, but now it seems more oppositional.

The characteristics described by Mrs. Ice Cream are not uncommon of others who have experienced a stroke. The American Stroke Association reports post-stroke impacts on individuals may include memory loss, communication difficulties, paralysis and/or muscle spasticity, seizures, increased fatigue, and emotional and behavioral changes (American Stroke Association, 2012).

Marie often talks about the seizure and stroke with regard to the continued impact on her life. Whether conversing about possible employment, living independently, or trying new activities, Marie will commonly say, “I can’t – cause a’ my stroke and seizures” or “My stroke doctor say I can’t do that.” Mr. and Mrs. Ice Cream commented separately that Marie will, at times, share this information to her advantage. Her father explained,

When Marie had a stroke, she lost some functioning in her right hand. She went to therapy and now her right hand is just as strong as her left hand. It functions fine. She will bring it up though [the right hand weakness], whether it’s true or not and tries to get

people to do things for her. Marie is very good at getting people to do things for her, if they don't know her.

Mrs. Ice Cream agreed, observing,

Sometimes Marie does things on purpose, to get attention or to get people to do things for her. She's a bit of an expert at manipulation...even when she was a little kid. I think maybe it relates to what she went through at an early age....Marie is very good at getting her way for someone who is supposed to have such limited intelligence.

She continued, pointing to contradictory IQ assessment reports received when Marie was younger.

She's never done well on IQ tests. She was tested when she was younger and she had no intelligence at the time of that testing. She didn't do enough to score. "No logical thinking skills," they told us, and "no reasoning skills." I was pretty sure...I meant the thing is...Marie had imaginary playmates at a young age. How do kids who have no intelligence have imaginary playmates? You've got to have some kind of thinking going on. You know, I also didn't really need a report that said my child had no intelligence...no reasoning skills. I thought...they couldn't possibly have just said that.

Soon after graduation, Marie began working at a sheltered workshop.²⁹ She recalled, "I didn't do nothin' there. It was so boring...I don't go there anymore." Unsatisfied, Marie's parents removed her from the program and have since structured a weekly routine centered on Marie's interests, vocational development opportunities, local events in the community, and

²⁹ Social Security Online (<https://secure.ssa.gov/apps10/poms.nsf/lnx/0302101270!opendocument>) defines a sheltered workshop as "a private non-profit or State or local government institution which provides individuals who have physical and/or mental impairments with services designed to prepare them for gainful work in the general economy. These services may include (but are not limited to) physical rehabilitation, training in basic work and life skills (how to apply for a job, attendance, personal grooming, handling money, etc.), training on specific job skills, and/or providing actual work experience in the workshop."

home life. As highlighted earlier, Marie is a young lady who proudly proclaims a life of multiple identities. She is a dancer, an artist, an athlete, a community volunteer, a friend, a girlfriend. The following few sections highlight these aspects of her life.

7.2.5.1 Marie, the dancer.

Figure 15. *Marie Dancing*



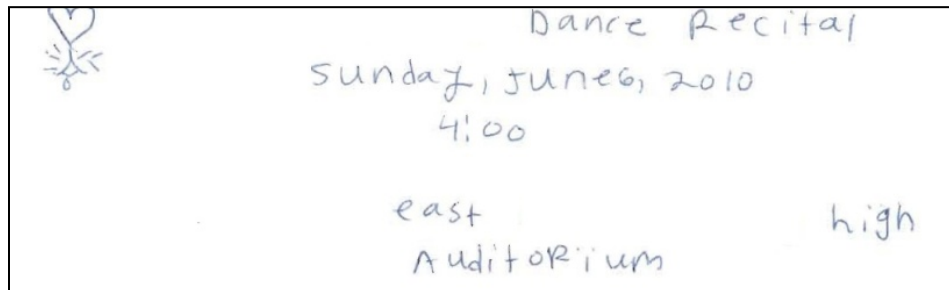
Dancing is my passion. I like it...just fun!

Marie loves to dance. She keeps a portable stereo and a stack of compact discs on the dresser in her bedroom and the center of her room is cleared for dancing. When in need of an audience, Marie will often call friends and family, leaving messages of music playing and sounds of soft shuffling dance steps in the background. Framed photos fill a wall in her family home, displaying pictures of Marie and her siblings from childhood to present. In many of the photos, Marie is poised in various dance positions and brightly colored recital costumes. She commented, “You know the dance teacher? She makes the costumes for the recitals. They’re rockin’ awesome!”

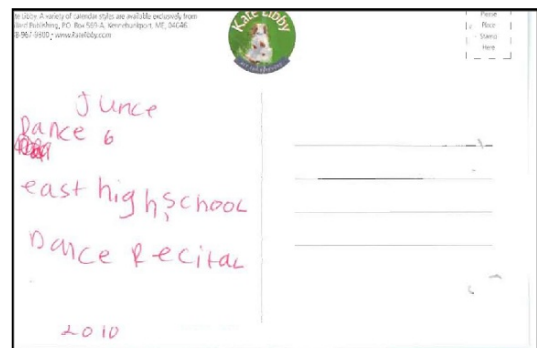
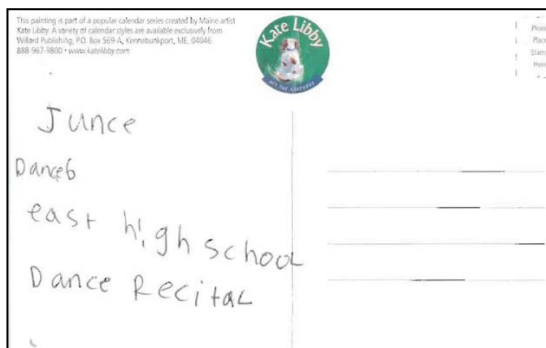
Marie has taken lessons from the same dance studio for numerous years. Her classmates are other teens and young adults. Marie is the only individual with a disability and shared that

she sometimes has difficulty remembering her dance steps. Though like water off a duck's back, she shrugged, "If I don't remember my steps, I just ask the dance teacher or other students for help. They're cool." Each spring, the dance studio hosts a year-end recital. Marie proudly invites friends and family to the performance with homemade invitations...

Figure 16. *Dance Recital Invitations*



...followed with more invitations....



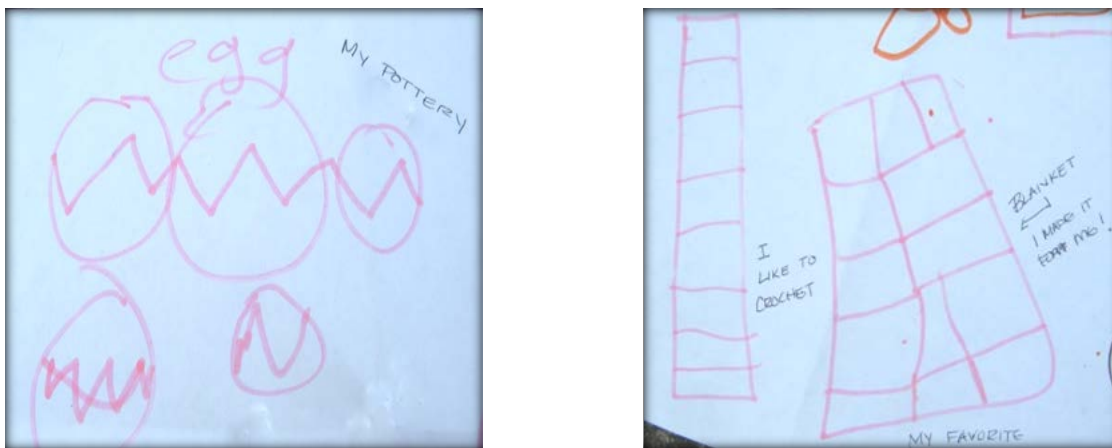
On recital day, Marie gracefully danced on and off the stage throughout the class performance. Her choreographed movements were slightly different than her peers, yet beautifully interwoven into the larger dance ensemble.

7.2.5.2 Marie, the artist. Marie is a creator. She knits, crochets, makes jewelry, sews, sculpts, and makes pottery. Once a week, Marie participates in a sculpting class. She is joined by two other students who also have I/DD and led by their teacher, Mrs. Nelson. Step-by-step, Mrs. Nelson guides the three students as they mold and piece together bits of clay into whimsical

creations – dragons, magical trees, a menagerie of animals from Noah’s ark, spiders, and other creatures - which are later painted and fired in the kiln.

Marie enjoys her sculpting class and thinks fondly of Mrs. Nelson. When learning that Mrs. Nelson wanted to expand student enrollment for the program, Marie initiated her own efforts to help with the recruitment. “I asked people I know, so I helped Mrs. Nelson find people for her camp...She don’t have enough money, so I try to help her find people.”

Figure 17. Marie's Pottery and Crocheted Blanket



In addition to sculpting, Marie is an avid knitter and known to carry a ball of yarn in her purse. She typically has more than one project going at a time. One of Marie’s current initiatives is a small lap blanket that will go to the grandmother of her boyfriend, once complete. “She been in the hospital, so I just want to do that for her.” This is not unusual. More often than not, Marie creates with intention - always with a recipient in mind. She rarely keeps an item for herself. Recently, Marie contributed two pieces of her pottery and a selection of her knitted scarves and blankets to a silent auction benefiting the local Arc³⁰ organization. All items sold and Marie was pleased to learn that she had earned over \$50 for the organization.

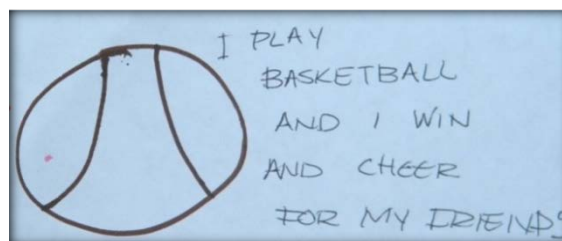
³⁰Founded by parents of individuals with I/DD in the 1950s, the ARC is national non-profit organization that advocates and provides services and programs for persons with I/DD.

7.2.5.3 *Marie, the athlete.*

I been in Special Olympics 15 years now. I got an award. You know Stacey (the Special Olympics coordinator)? She gives me a heads up about basketball, Special Olympics and stuff - send me emails.

Marie is an athlete. Depending on the season, you will find her out on the basketball court practicing drills with teammates, swimming laps in the city pool, cycling on the local bike paths, or running sprints on the track. She also serves as an assistant coach for her father's soccer team. When asked of her favorite sport, Marie made a swimming motion and stated with confidence, "Yeah - I'm fastest in the backstroke." Swimming is the one sport that she participates in year round. At the end of each season, the athletes compete in state-wide competitions. While Marie and her teammates enjoy the competitions, what they most look forward to is the celebratory dance where they can socialize with their teammates and catch up with old friends from across the state. The athletes often arrive at these dances in their finest attire. It is not unusual to see formal gowns, suits and ties, and the occasional fedora.

Figure 18. *Marie and Basketball*



7.2.5.4 *Marie, the volunteer.* Marie participates in a wide variety of volunteer opportunities. She enjoys assisting former teachers in their classrooms with younger students and often returns to her high school to assist in making jewelry, to be later sold in the school store. Marie also volunteers as a representative of the local Arc organization distributing

promotional materials from an information booth at local events. Many of these events include community road races. Prior to these events, Marie can often be found circulating through the crowd of runners and bystanders passing out the printed materials. She will also direct runners to the race starting point or may inform a runner of the “no headphone” policy if she observes someone breaking the rule. In addition to mingling among the runners, Marie enjoys visiting the other informational booths to collect what she refers to as “freebies” - pens, pamphlets, socks, sample energy bars, water bottles, etc. - all of which she quickly re-distributes to friends and family. “You know I like the freebies!” she proudly admits.

Once a year, Marie volunteers for the Knights of Columbus Tootsie Roll Fundraiser. Wearing a yellow plastic apron with red lettering that reads “HELP MENTALLY HANDICAPPED CITIZENS,” Marie positions herself outside a local grocery store to hand out candy, share information about the fundraiser, and collect donations from shoppers as they enter and exit the store. Of the experience, she shared excitedly, “One year I raised \$1000 and got my picture taken!” Money collected through the fundraiser is later distributed to community programs serving individuals with intellectual disabilities.

7.2.6 Marie and vocational activities. Beyond volunteering, Mr. and Mrs. Ice Cream continue to seek other opportunities for Marie to develop work skills. For a short while, Marie participated in a job club for individuals with I/DD offered through the local Department of Vocational Rehabilitation (VR). Club members met weekly with VR counselors to learn and practice job-seeking skills. “I practiced filling out applications and that kind of stuff,” Marie recalled. She also took part in a horticulture program offered through Goodwill Industries.³¹ The program was developed for young people with I/DD to gain gardening and landscaping

³¹Goodwill Industries is a non-profit organization that provides various community-based programs for individuals with disabilities and others who experience employment difficulties.

skills with all produce grown delivered to community food kitchens.

In a document generated by Mrs. Ice Cream for the purpose of sharing with a vocational rehabilitation counselor, Mrs. Ice Cream reported,

Some jobs Marie has been particularly interested in the past include working at a retirement center or nursing home, the senior center, working with young children, helping in offices and schools, working with animals, working to get animals adopted, working in a cafeteria, or bagging groceries. She is a persuasive sales person.

Sometimes her interests revolve around who she knows that works there. Actually, Marie's first job ambition as a young child was to be a dolphin trainer after she watched a video in which dolphin trainers and dolphins worked in the water with children with special needs.

7.2.7 Marie and social activities. Many of Marie's friendships and social relations revolve around two programs: Social Ministries and Special Olympics.

7.2.7.1 Social Ministries. Social Ministries is a faith-based program designed to provide social opportunities for young people with and without I/DD. Events scheduled three to four evenings a week with activities consisting of shared meals, games and crafts, sing-alongs, community service projects, special interest groups, and bible studies. Marie commented, "I took a sign language class there and now I can sign for people who don't hear." Her father later clarified, "Well...Marie knows some signs and she'll attempt to sign to both hearing and non-hearing people, but it's pretty limited."

The program also offers gender support groups referred to as Girls Night and Boys Night. Marie explained these evenings as,

You mix it up - boys and girls – we hangout first together, eat dinner, and then split up.

Girls talk about girls' stuff and boys' talk about boys stuff. We talk about it and then we draw it. I talk about my boyfriend and I say he buys me stuff.

Led by program staff and student volunteers, conversations during these evening groups revolve around social and health issues. For example, during one observation a young lady shared of an experience in which she felt excluded by a group of high school classmates. "It really hurt my feelings. I mean all I said was 'Hey guys' and they just looked at me and didn't say nothin'. So I walked away and told my teacher." As she told this story, her voice quivered. Marie then shared of a time she felt bullied by a classmate. She explained,

The cafeteria lady told that girl, "You don't got enough money to get milk. Then she (the classmate) got mad at me and pushed my lunch (tray) on me. My whole clothes got soaking wet cold. Then she blamed it on me. The lunch lady think it was my fault.

One by one, the other young women in the group recounted school experiences of feeling bullied or excluded. As each shared their story, the others offered advice and words of support and care.

7.2.7.2 *Special Olympics.* Beyond an organization for individuals with I/DD to stay fit and active, the local Special Olympics functions as an important social lifeline for Marie, her fellow athletes, the families, and volunteer coaches. They are a tightly-knit community who enjoy spending time together, share celebrations, and provide support in times of need – an extended family, per se. As with all families, there comes the occasional drama. Whether it be about a new relationship between athletes, spats on the basketball court, or health concerns of others, Marie is often in the know and always ready to share the latest news. Her regular recipients commonly exercise a cautious ear, as it is not unusual for Marie to take creative liberties in the retelling of news. For the most part, Marie's sharing seems well-intentioned, with news she feels may be helpful to the recipient. At times, it also seems a strategy to connect with

others when feeling bored or lonely. And other times - it is simply about the gossip.

7.2.8 Marie and dating. Marie and Michael have been in a relationship for approximately two years. Michael is her first boyfriend and prior to meeting Michael, Marie's experience with the opposite sex had been somewhat limited and unpleasant. She shared,

Boys be mean...one dared me one time to go upstairs and forced me to kiss him. I got scared. I told him I be right back and I went to the bathroom. I told my parents. They told his parents. His parents ground him for a week. My dad told me don't go with any boys. They won't be nice. Just be a friend.

Marie initially chose to keep her new relationship a secret from her family; though after a few weeks she shared the news to her mother and a bit later, her father. They met while working at the same sheltered workshop, shortly after Marie graduated from high school. When asked to comment on Michael, Marie smiled and said,

He's my boyfriend. He outgoing. He buy me presents – like the one I wear right now. He bought me this cross necklace, a purse, watch, sunglasses, three teddy bears, and two piggy banks. We hang out and dance. His mom a great chef. I love his grandma, Ms. Jackson.

Although they have few opportunities to see each other, outside of Special Olympics, the young couple keep in contact regularly through phone calls and text messaging. Marie recently revealed that Michael told her that he wanted to kiss her and someday have a baby together.

Marie: I told my mom and sister, but I didn't tell my dad. I not going to kiss him – cause I don't want have baby right now.

Dana: I think it is smart that you don't want to have a baby right now. Though...you know, there's actually a bit more involved in making a baby than just kissing.

Marie: I know....Sex...right?...But I don't know what that means...nobody told me that. Mrs. Ice Cream also spoke of Marie's emerging curiosities about sex and recalled an evening when Marie had returned home from a Girls Night session. The small discussion group focused on the topic of women's health issues. Once home, Marie went online to learn more and stumbled onto a site with graphic sexual content. Mrs. Ice Cream commented, "You know, we try to monitor but you never know what she might find online." When Marie was later asked about the incident, she replied quickly stating, "Oh yeah... I was asleep and I didn't know what I was doing – what I was typing. It was just a mistake."

7.2.9 Marie and home life.

What are you doing today? Oh nothin'... just hanging out.

While Mr. and Mrs. Ice Cream continually seek opportunities to keep Marie engaged and active, the lack of daily structure and social engagement once provided by the school day and sheltered workshop has been challenging. Her father commented on this life adjustment,

Marie is often not around people for long parts of the day. I don't think she likes not being able to socialize. When she was in high school, she'd be around others from the time the bus picked her up until 4:30pm. Now there are several hours a day without the social interaction. It's a different scenario. She's happiest when she has the social interactions.

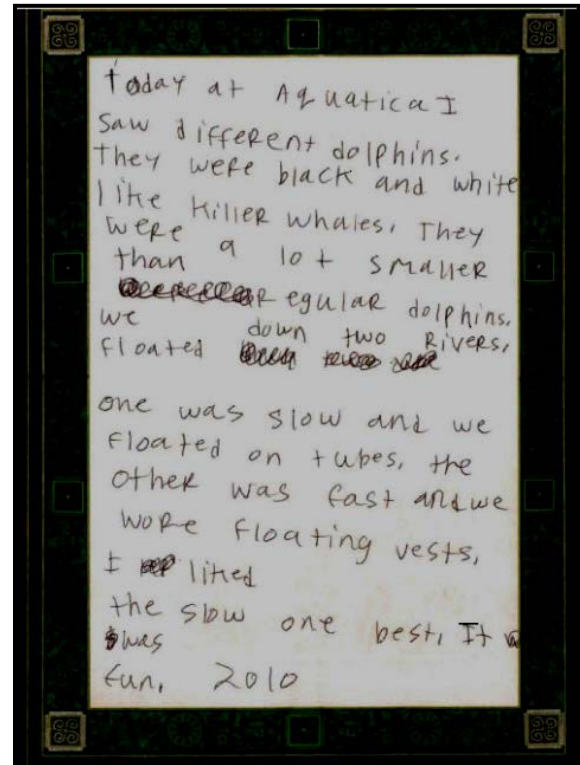
When mentioning her father's comments to Marie, she added, "Yeah, I get bored. If I'm bored doing nothing, I say 'Dude I'm bored!'" Marie occupies herself by playing with her cats, listening to music and dancing in her room, watching television, playing Wii, and spending time on her laptop. Marie also enjoys walking and riding her bike around her neighborhood, sometimes stopping in to visit favorite neighbors and their pets. Mrs. Donahue, Marie's next

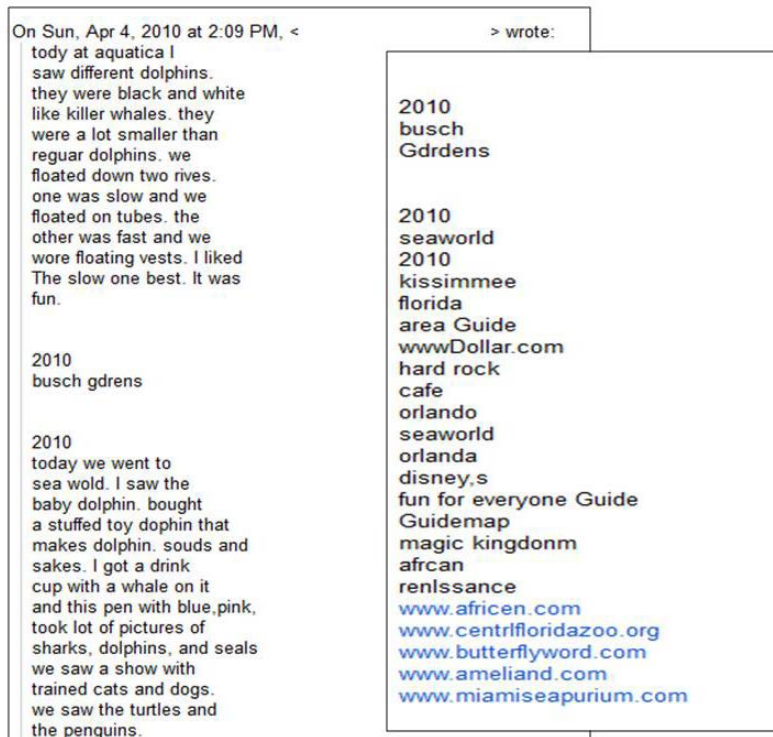
door neighbor, receives frequent visits from Marie, along with a daily delivery of her mail and a newspaper. Marie explained, “It’s because Mrs. Donahue slipped and broke her bone and she had a car accident and broke two shoulders. I don’t want her to get hurt again so I help her.” Marie speaks often and fondly of Mrs. Donahue and the two have formed a special friendship over the years. It was Mrs. Donahue who first taught Marie how to knit.

Another way Marie combats boredom is by reaching out to friends and family. She has her own cell phone and will sometimes leave multiple voice messages when unable to connect. Her parents have expressed concern over the frequency of Marie’s calls and have made efforts to limit her use of her phone by establishing strict guidelines for calling. Mrs. Ice Cream commented, “Marie has a bad habit of calling people a lot. She’s supposed to check with me before, but she’ll often wait until I’m not here and then call.”

In addition to phone calls, Marie enjoys corresponding through mail and email. She keeps a small notebook in her desk drawer to record and retrieve addresses and email addresses. She also records website addresses and stores a collection of business cards inside the notebook. Marie’s mailings and emails vary. Some contain a simple greeting, others a list of words or the url of a favorite website or online video clip. When wanting to convey a longer message, Marie will verbally relay her messages to a transcribing family member and later copy by hand or type the message into an email. Below are examples of letters and emails received:

Figure 19. Letters and Emails from Marie

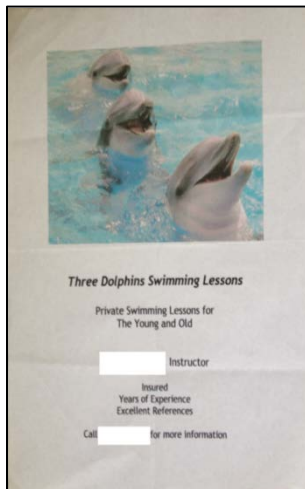




With postal mailings, she often inserts clipped articles, coupons, movie listing times, or advertisements she feels may be of interest to the recipient. For instance, when learning that we were interested in adopting a puppy, Marie mailed the following items to me in a greeting card:



Similarly, when planning a trip to Florida, I received the following items in the mail from Marie:



7.2.10 Marie's future. There are many unknowns about Marie's future right now in terms of employment and living arrangements. Although she prefers a busy lifestyle and receives great joy in helping others, Marie seems in no hurry to get a job.

Dana: Do you think you might have a job someday?

Marie: I don't know yet

Dana: If you could work anywhere, where might you like to work?

Marie: I can't work.

Dana: But if you could?

Marie: I gotta ask my stroke doctor.

Dana: Ok...but let's say your stroke doctor says that it's ok for you to work. What might you like to do?

Marie: I don't know.

Dana: Would you like to work with people? Maybe children?

Marie: No.

Dana: Animals? Perhaps in a pet store or animal shelter?

Marie: No.

Dana: Do any of those ideas sound interesting?

Marie: Ehhh....I don't know.

Likewise, conversations related to moving out of the family home have been received with similar disinterest with multiple reasons for staying put.

Marie: I can't move to a group home because I help my neighbor, Mrs. Florin with her cat.

Marie: Mrs. Donahue have problems. She needs me.

Marie: No...I can't move because if I do my cat get mad if no one around.

Dana: What if he could live with you?

Marie: He can't move back and forth – he'll die.

Marie: I hate group homes. Nasty food! I taste it before. My boyfriend don't want to go either.

Mrs. Ice Cream shared,

We started talking to her about moving into a group home setting when she was 17. She was all for it saying, "I would get a room and I would be able to visit you. So I would have two rooms!" So that to her was very appealing. But when it came to the point that they started calling us about placing Marie, she had cold feet and did not want to go. So while she would like a second room, I don't think she envisions being away from her parents that much at this point.

Recently, however, Marie's thoughts of the future have included Michael. With great excitement she shared,

Guess what my boyfriend want to do so bad? He want to get an apartment someday. Get

married and have kids. My mom don't want me to tell my dad. Cause he want me to get a job first and then get married and then move into an apartment. Guess what my colors gonna be? Red and pink. His favorite color and my favorite color!

Time will tell what the future holds, but for now Marie seems content with daydreams.

7.3 Introducing Ben

There is a common saying among parents of children with autism, “If you’ve met one person with autism, then, you’ve met one person with autism.” Meet Ben. At twenty-three years old, Ben lives at home with his parents, Mr. and Mrs. Kimmel. His younger brother, Jimmy, (age 21), attends college in another state. Diagnosed at age three, Ben exhibits many of the classic characteristics shared by others with autism,³² including poor eye contact, language challenges, anxiety with change, difficulty with the abstract and exceptional strengths in rote and visual memory skills. That said, Ben is also a young man unique unto himself, possessing a day-brightening spirit, a sincere joy for life, and an endearing affection toward his friends and family. He leads a full and busy life that includes two part-time jobs, participation in sports, a girlfriend and an active social calendar, and many interests and hobbies. And, although he finds security and comfort in rituals and routines, he also shows an engaging eagerness to take part in new experiences. Ben’s father described Ben in this way,

Ben is happy. He is very caring and kind. He misses people when he doesn’t see them. He misses his brother. In a lot of ways, he doesn’t fit that stereotype of autism as being sort of cold and remote or unobservant and not interested in people. Ben is very, very much interested in people and he is very warm.

On first impression, Ben’s language challenges may lead some to assume a low level of intellect. He generally speaks in short sentences and has difficulty with reciprocal conversation. Whether initiating or responding in conversation, Ben will string together a somewhat fractured

³² Identifiable characteristics of many individuals classified with autism include early language delay, difficulties with social interaction, poor eye contact, repetitive use of language, repetitive routines and/or behaviors, self-stimming behaviors such as hand-flapping, twirling of objects, spinning, etc., fixations on objects and/or special interest areas, splinter skills – referring to an uneven profile of abilities with considerable strengths in one or two skill sets, sensory issues – difficulty filtering sensory input, such as bright light, certain noises, types of touch, various tastes and textures, etc., and strong rote memory skills / difficulties with abstract concepts.

dialogue, taking tangential turns – sometimes leaps – along the way with topics related by means sometimes only known to Ben. For example, when asked “What is your favorite television show?” Ben responded,

Stephen Raichlen. I need to make Philly cheese steak. I need to make sandwiches. I need to cut with knife, fork...oh, don't get burn with the fire. It get hot. I like Disney movie, Alice in Wonderland. Is it a girl?”

Similarly, when asked “What did you eat for lunch today?” Ben stated,

Ham sandwiches. You need mustard and mayonnaise. Yellow and red makes orange.

Mustard. You need a spoon first. Stir it with a spoon. So mix red and white makes pink, so red and white makes pink like clouds. We read sentences about books....about colors.

Mrs. Kimmel speculates Ben's thought process akin to sorting a stack of scrambled pictures. As Ben engages in new experiences, he actively seeks patterns in an attempt to integrate new information with existing schemas in effort to make meaning of the situation. “When Ben was young, you could just see how his brain was developing by how he would ask questions.” Mrs. Kimmel illustrated, using an example related to Ben's interest in travel. “Ben loves hotels. He always says, “I like to stay at the Double Tree” or “I want to go to the Hilton.” She continued, explaining that before a hotel stay, Ben will often ask, “Does the hotel have TV? Does it have computer? Does it have a bed?” He will also go to the Internet in search of answers, looking up various hotel websites to compare similar and different features from hotel to hotel. Upon arrival at a hotel, Ben works through a mental checklist as he examines his room, “No TV. No computer. Right?” Similarly, he might begin drawing comparisons, “Double Tree has eggs...Holiday Inn has grits, Frosted Flakes, Apple Jacks...”

Mrs. Kimmel's description conveys similarities to renowned autism expert, Temple

Grandin's (2006) own description of her thought processes as a woman with autism. She states,

Being autistic, I don't naturally assimilate information that most people take for granted. Instead, I store information in my head as if it were on a CD-ROM disc. When I recall something I have learned, I replay the video in my imagination.... If I let my mind wander, the video jumps in a kind of free association.... Each video memory triggers another in this associative fashion. (p. 8)

While Grandin identifies herself as a visual thinker, she suggests that individuals with autism will typically exhibit one of three types of thinking styles: visual thinking, pattern thinking, and word thinking.³³ She also notes, however, that some individuals may show strengths in more than one style of thinking. Ben, for instance, displays a strong interest in numbers and has extraordinary gift for visual memorization. Mrs. Kimmel shared,

I remember when we first moved here. We were shopping at a grocery store and then we went to a different one. Ben started shifting around the cereal boxes and I thought, "What the heck is he doing??" Then I realized that he was putting the cereal boxes in the same order that the other store had them arranged.

Also known for having an impish sense of humor, Ben's orneriness is easily revealed through a twinkle in his eyes and a huge smile. Mrs. Gilbert, one of Ben's high school teachers, described Ben saying, "He is just beyond cute...and funny!" Ben's father also commented on Ben's playfulness stating,

Sometimes Ben will do things wrong on purpose, just to get your reaction. It's his own way of making a joke....never malicious or harmful, but sometimes it may appear like he's not understanding something or that he's not cooperating. It's actually not that at all.

³³ For more information also see: <http://www.smithsonianmag.com/science-nature/Temple-Grandin-on-a-New-Approach-for-Thinking-About-Thinking.html#ixzz2BwKevvIT>

It's just his own way of interacting or soliciting a reaction from you.

Mrs. Kimmel recalled a few of Ben's antics. She started by sharing that Ben often enjoys calling friends and family while waiting for or traveling on the city bus to and from work. She continued,

The other day - it was so funny - I had three friends over for lunch and Ben called pretending to speak in a girl's voice. He said "Hellooooo!" and I knew it was him because he always likes to call me before he gets on the bus. Sometimes I will say to him, "Hello, this is Pizza Hut." So now he will call me and say "Mommy, it's Pizza Hut!" Other times he will call and then ask, "Mommy, why did you call me?" And I'll say, "No Ben, you called me!" and he'll say, "No, you called me!" and I'll say, "Oh no I didn't!"

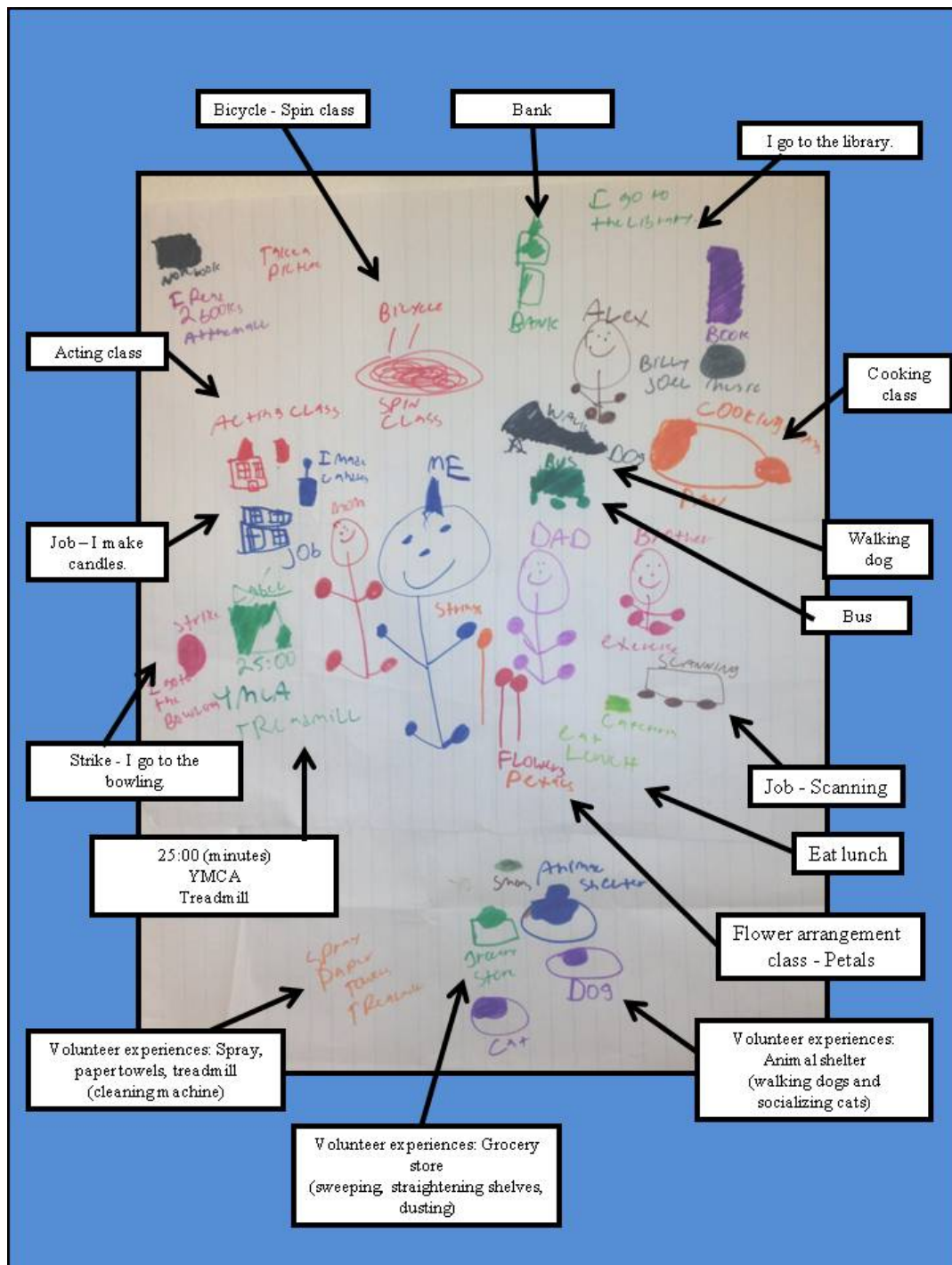
While Ben typically displays a happy-go-lucky demeanor, when under stress he has difficulty expressing his discomfort and explaining the cause. His father shared,

Ben doesn't deal with it [his feelings] directly, in terms of expressing, "Hey I'm upset." He won't tell you why he is upset. He doesn't act out in terms of being physical, such as hitting or any sort of destructive behavior. He doesn't throw a tantrum. What he does do, though, is this verbal self-stimming. He talks about people – the same people - totally out of context. Like Fred, a boy who has been in a lot of Ben's classes over the years, or Fred's parents and other people that he has known over the years-- including some that are no longer alive. Ben will just start this whole litany, bringing them up and naming them and putting them in situations totally unrelated to what he's doing at the moment. That's a sign that he's stressed out.

Although Ben struggles to share his life, perspective, and troubles in words, he lives each

day with an earnestness and authenticity rarely found in our digital age of carefully constructed personas. In an effort to share his life with the reader, Ben created the visual in Figure 20 as a representation of his life and selected the photos embedded in the life narrative.

Figure 20. *Ben's Life in Pictures*



7.3.1 Ben's early years. Described as a “very happy baby” by his father, Ben’s first two years of life were typical, from the perspective of the new parents. Mr. Kimmel shared, “Nothing set off alarms right away that something was wrong.” As Ben grew into toddlerhood, his language came slow. Mr. Kimmel recalled, “He didn’t speak. I mean, he had his words for things, but they weren’t the right words.” Ben also began exhibiting somewhat unusual behavior. Mr. Kimmel recalled,

One of the things I remember is that he would go into our backyard and lie on his stomach, get dirt and just pick it up and have it fall in front of his eyes. Now looking back on it, I understand that is a fairly typical behavior for autistic people. But back then, he was our kid and maybe he's a little strange, but it didn't really register until he was three and a half.

During this time, Ben’s younger brother, Jimmy, was born. Mrs. Kimmel described these early years as stressful. “I had two in diapers, two everything! I was home and didn’t have any help.” Ben had grown into an active little boy who loved to run. Leaving the house to run errands with the two boys became almost impossible for Mrs. Kimmel. “Ben was really fast! He would run all over the place.” This included store stock rooms (“I went into so many stock rooms that I didn’t even know existed!”), into the middle of the clothing racks (“He liked to pull the tags off clothing”), and out into parking lots. Mrs. Kimmel shared,

I’d be at the cashier and Ben would just run out. He liked to stare at the license plates and with the cars backing out...oh it was just so stressful. I would just sweat at the thought of going shopping. It was horrible. People used to ask me, doesn’t your kid ever calm down?

In addition to these comments from others, Mrs. Kimmel also endured tense

conversations with her parents when visiting from her home country. Although they now have come to understand Ben's autism, at the time...

My father would said, 'How come you don't know how to teach your kid!!' And my mother blamed me and said "How come we've never heard of autism before. You just come here and you make up all those names!" I was so stressed out."

A turning point came during a *Mommy and Me* class with Ben. Mrs. Kimmel described watching the other mothers and their small children sitting in a large circle. "They were all doing what they were supposed to be doing and here was Ben, running out to the sand pit." She found him sifting sand through his hands, mesmerized in its movement. "One of the teachers said to me, 'I think there is someone in the school district that you might want to talk to. And then that person told me to go to my pediatrician.'" With this referral, Mr. and Mrs. Kimmel were soon introduced into the world of autism. Mr. Kimmel recollected,

My wife took Ben to a doctor who first mentioned the word autism. He used it very gingerly. I guess he didn't want to take any sort of liability associating a diagnosis that wasn't thorough. We had never heard of autism. Back then they didn't have the Internet, so just finding out about it was very slow discovery process.

Ben was initially diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), sometimes referred to as "atypical autism." PDD-NOS is one of five categorizations under the umbrella category of PDD³⁴ and often applied to individuals who do not fully exhibit indicators necessary for a formal diagnosis of autism. Given his young age, Ben's physicians were hesitant to apply the categorization of autism and instead opted for a broader diagnosis of PDD-NOS. Mrs. Kimmel shared, "Their rule at that time was that before

³⁴ The other four categories of PDD include autism, Asperger's syndrome, Rett's syndrome, and Childhood Disintegrative Disorder. Although Autism Spectrum Disorder (ASD) is often used interchangeably with PDD, ASD primarily encapsulates autism, Asperger's syndrome, and PDD-NOS within the spectrum.

you are five years old, they don't diagnose you with autism.”³⁵

Shortly after the diagnosis, Mr. and Mrs. Kimmel enrolled Ben in a preschool class for children with cognitive disabilities. Mrs. Kimmel recalled,

It was a cross-category class with mostly Down syndrome children. Ben was very different than these other kids. These kids, again, they were sitting in a circle, nice and imitating the teacher and Ben doesn't imitate. He would run around and do all kinds of crazy things.

One day during an unexpected school visit, Mrs. Kimmel entered and saw Ben strapped to a chair. The teacher explained that Ben had taken off his pants and diaper pull-ups in front of the other children when running to use the bathroom. In effort to prevent him from doing this again, she had tied him to the chair. Mrs. Kimmel was told, “We don’t even allow the children to take off their shoes at school” and later, “We prefer to change all of the children’s diapers at the same time – it’s just easier for us.” With frustration in her voice, Mrs. Kimmel shared,

I was so upset. I had just gone through six months of toilet training... you know, not having him wear diapers and just running around the yard. I would turn on the sprinkler and do all kinds of things. I had put in a lot of work to have this kid, who doesn’t talk, be toilet trained and the teacher tied him to the chair so that he won’t have an accident on the floor! I said “No! I just spent the last six months doing this and you just put him right back to where he was before.”

Not long after the incident, Mrs. Kimmel attended her first conference on autism and sat in on a lecture by a top specialist in the field. His message resonated with her as he emphasized the importance of trying to understand life from the perspective of the

³⁵As of 2012, behavioral markers of autism can be identified in children as early as eighteen months of age with a fairly conclusive diagnosis by the age of two (<http://www.cdc.gov/NCBDDD/autism/facts.html>).

individual with autism.

He was talking about how structure can make their lives easier and how we can learn their culture. He said, “Just pretend someone from Russia coming over here. Do we expect them to know the same things we know and to speak the same language? No. We’ve got to meet them half way. We need to learn some Russian.”

The speaker also showed videos of an internationally renowned autism center known for effective therapeutic interventions for individuals with autism. Mrs. Kimmel stated, “I came home, put a ‘For Sale’ sign in the yard, and we moved.”

7.3.2 Ben’s childhood. Once relocated, Ben was assessed through the center and began receiving behavioral and speech therapies. He also attended a special kindergarten class at his neighborhood elementary school for children with autism. Mr. Kimmel described young Ben, at that time, as a “difficult” child. He shared,

Ben was very very restless and at times anxious. He would just go off and you had to keep your eye on him all of the time because you never knew what he was going to get into. This was when he was three, four, five, and six years old, not just as a toddler. You know, he could cover a lot of ground and do a lot of damage.

Although Ben’s behavior continued to draw stares from others, Mrs. Kimmel began to develop a support system of parents who also had children with autism. She shared, “We used to say how sometimes we wished that our kids had Down syndrome, just so people would understand. Ben looked so perfectly normal. He doesn’t have any special features. He just runs.”

In contrast, Ben’s younger brother, Jimmy, was described as an exceptionally calm and quiet child. Mrs. Kimmel noted, “Jimmy was so normal compared to Ben. With Ben there was

lots of screaming, biting, and everything else. Jimmy was just a sweet little boy. He did everything...but he just didn't talk." During one of their early assessment meetings for Ben, Mrs. Kimmel asked the clinician in partial jest, "By the way, I have this three year old that doesn't talk...can he get an assessment too?" The clinicians agreed. When they met again to discuss results, the Kimmels received some unexpected news. Jimmy also had autism. Mrs. Kimmel recollected her shock, "I knew he had a speech delay and I just thought that he might need some speech therapy. I could not believe what they had said. I just stood there and I actually threw up!" Twenty-plus years later, Mrs. Kimmel laughs as she shares this story. However in the moment, she admitted, the news was devastating.

Yeah...I had a pretty violent reaction. Now I know more about autism. I know the characteristics and that they exhibit in different ways and to different degrees. I have no doubt about the diagnosis, but when I was a new parent...I didn't even think about it. You are just so busy with one; you don't really have time to think about the other guy. And they were so different. Even to this day – like day and night. I'm not saying it's good or bad, but they are just very different. You don't see them as having the same thing.

Less affected cognitively and socially, Jimmy received therapies at the center though was enrolled in the general education setting with pull-out support when it came time for him to begin school. Ben continued his elementary and middle schooling through the self-contained autism class. He thrived in the structured environment. His mother shared, "It was very predictable. They [the teachers] go in and they already had a whole list of things that were going to happen that day, that week, that month...everything. Ben just loved to know all of that." Mr. and Mrs. Kimmel began integrating many of the same techniques at home. Developing Ben's

oral and written language skills was also a key component in decreasing Ben's behavioral challenges. Mrs. Kimmel stated, "Once Ben started to learn, he learned a lot...I mean, he couldn't sit down and chat with you, but he could tell you what he wanted. So then he didn't have to be upset anymore." Mr. Kimmel stated similarly,

As I look back on Ben, it's astounding to think that there was a time when we thought he would never talk. Now we can't get him to stop talking! (laughing). It's also very hard to think back to when Ben had behavioral issues, because, generally, he is such a happy, easy-going kid. But, back when he was preverbal, he just wasn't getting his needs met.

In addition to language delay and behavioral challenges, the avoidance of eye contact is a common behavioral marker of autism. However for Ben, this trait did not emerge until mid-childhood. Mrs. Kimmel recalled, "Before, Ben would say 'Mommy, Mommy!' And he would hold my chin and make me look him in the eye. That's how he was. Now I can't get him to look at me in the eye. He will not even look a dog or cat in the eye." Ben also stopped looking at himself in mirrors. His mother shared, "We used to have a room full of tall mirrors and he would look at himself and act out in front of them. But now, it's almost impossible to get him to look at himself." Mrs. Kimmel speculates that this change may have been triggered by a traumatic event that occurred during the summer of Ben's ninth year. While at a community swimming pool, Ben slid down a water slide and unintentionally crashed into a young girl. The girl's father immediately reacted, thinking that Ben had been roughhousing. Mrs. Kimmel recalled,

He just jumped on Ben, pushing him and screaming. Ben had never had anyone be mean to him in his whole life. After that, Ben came home and just said over and over again, "I'm sorry, I'm sorry, I'm sorry." You couldn't even talk to him for months. He was so

scared. For years after, he would hold my hand wherever we went. It could be a coincident – but it was such a perfect coincident.

Although Ben eventually overcame this frightening incident, Mrs. Kimmel stated, “The eye contact just never came back.”

7.3.3 Ben’s transition into high school. When it came time for Ben to transfer to high school, it was originally planned for Ben to continue on his track into a high school autism program. However, tensions brewing between the parents and the high school teacher prompted Mr. and Mrs. Kimmel to consider an alternative program. This program served students similar in cognitive ability to Ben, though was intended for a wider category of students with the I/DD label. Mrs. Kimmel explained,

At that time, the autistic class was having a lot of problems - teacher and parent issues. They were hating each other. I didn’t want to be a part of any of it. I also thought Ben would enjoy this other class so much more. The autistic classroom was so boring for him. Not much social things going on.

Unfortunately, early impressions of Ben’s new teacher, Mrs. Stein, were not favorable. Although the special educator had many years of teaching experience, she seemed uninformed about autism and expressed reluctance to take Ben as a student. Mrs. Kimmel shared, “Ben’s middle school teacher went with me to convince the teacher. Mrs. Stein said to me, ‘Well...I don’t know...what do I do if he has a melt down?’” While Ben had many outbursts as a young child, these behaviors had completely disappeared over the years and Ben had matured into an easy-natured and jovial individual. With assurance that Ben would not present difficulties, the teacher agreed to a one month trial period. With little surprise to Mr. and Mrs. Kimmel, at the end of the month Mrs. Stein raved “Oh, we love him!”

7.3.4 Ben as a young adult.

7.3.4.1 An assessment of Ben's abilities and needs. The following assessment of Ben's strengths and challenges are derived from two documents, Ben's final IEP and his current PCP. Though, typically, a transition plan is developed for each student identified for special education services by the age of 16, as mandated by IDEA 2004, in preparation efforts for post-school life, Mrs. Kimmel reported that she did not receive this plan from Ben's team of teachers.

Table 15. *Assessment of Ben's Abilities and Needs*

Social and Communication	<p>IEP: Ben is a very sociable young man who loves being around people. Through teacher observation, it has been found that he usually begins a conversation with a random statement and does not reciprocate questions. Ben frequently jumps from one topic to another and avoids eye contact while speaking. He recognizes when he needs help, but does not always do it in an appropriate manner. He demonstrates great empathy for people when they are hurt or sick, but needs help when it comes to social problems (i.e. someone who may pick on him or act aggressively towards him.) He also frequently comments on activities or people in the room or repeats what others are saying. This behavior as decreased in the past year, but is still present. Ben would benefit from strategies to help him initiate a conversation, increase verbal exchange to maintain a conversation, and request for help. It is clear that Ben is very interested in his surroundings. He enjoys talking about things he observes and has improved in his ability to express himself. For example, when it comes to describing objects, he is inclined not to use adjectives.</p> <p>PCP: Ben requires some support to communicate his needs. Ben will often answer a question with a "yes" even if he means "no." When Ben is not familiar with a person, he is likely to need additional time to communicate his needs. Even with people that Ben is familiar with, he is likely to not be descriptive enough when describing his needs.</p>
Reading	<p>IEP: According to informal testing and daily assignments, it is clear that reading is one of his strengths. However, although he has the ability to pronounce words at the third and fourth grade levels, he does not always comprehend their meaning. With the aid of pictures and repetition, he is able to improve on his ability to comprehend more complex words. While he is adept at following written schedules and directions, Ben would benefit greatly by increasing his vocabulary and sentence complexity. He should continue to learn new word concepts to help his overall receptive/expressive language.</p>
Money and Time	<p>IEP: Math is a relative strength for Ben. He identifies coins, counts groups of pennies, nickels, dimes and quarters up to \$1.00 with 100% accuracy. He adds groups of dimes plus pennies, dimes plus nickels, nickels plus pennies with 100% accuracy. He also adds values of 5 (e.g. .25, .75) plus nickels with 80% accuracy. He needs practice paying for items in community environments. Presently he either hands the cashier his wallet or all of his money. He tells time to the hour with 100% accuracy, half hour with 96%</p>

accuracy, quarter after the hour with 100% accuracy, quarter till with 50% accuracy, and to five minute increments with 75% accuracy. He cannot figure elapsed time consistently.

Vocational Skills

IEP: Ben works at [a bookstore] one day per week. He dusts the shelves and books, faces books, sweeps and washes the windows. He independently gets his daily schedule and with guidance from staff chooses the order in which he will complete the tasks. He is a thorough duster, doesn't consistently face the books without reminders, requires assistance washing windows and requires assistance sweeping. He has a wonderful attitude towards work. He doesn't stay on the topic of conversation and engages in 2-3 incidents of echolalia per work session. This has reduced, but is still present. Ben helps at many job tasks at school as well. He posts the notices on the school marquee almost independently. He independently gets the letters, puts them on the marquee with no adult supervision. An adult checks the sign after he is done, and the only mistake he consistently makes is putting punctuation marks in upside down. He has shown dramatic improvement in this task this year. A year ago, he required adult supervision through the entire process and constantly asked if he was doing the job correctly. He also helps put staff mail in over 100 mailboxes. He does this task slowly but accurately. He also completes clerical tasks (tri-folding, stuff envelopes, sealing envelopes, labeling) with very little supervision needed. While he is working on vocational tasks in school, Ben frequently verbalizes or remarks on something in the environment. This slows his work rate and some students get upset and feel like Ben is talking about them. Ben has a very positive attitude about most jobs and is very eager to do a good job.

PCP: Ben currently works part-time at a university. He makes copies, converts books and papers to PDF files, shreds confidential information, retrieves books from libraries and runs errands. He said that he likes it because he likes to help others and he likes interacting with the students and professors. He also likes working on the computer. Ben also works at a conference center that employs people with intellectual and developmental disabilities. The center houses several small businesses and also holds conferences for community organizations. Ben makes candles that are sold online and at various conferences. Ben volunteers at an animal shelter where he walks the dogs and socializes the cats. Ben also volunteers at a retirement community. He walks the resident's dogs for them. In the past, Ben has tried many different jobs. Restaurant jobs were difficult for Ben because of the amount of social interaction it included. Ben said that he likes working at the university the most and hopes to work there forever.

Self-care

PCP: Ben requires support to brush his teeth thoroughly. This is in part because he does not like to look in mirrors. Ben requires support to prepare his food. He is not able to safely use the stove. Ben can use the microwave but requires support to punch in the correct time and to ensure he doesn't put his fork in the microwave. Ben requires written and visual schedules to understand what is expected of him. When there is an unexpected change to the schedule it is important that staff show Ben the change by putting a line through it and writing in the new schedule item. It is important that Ben can visually see how much work is left to do and how much is finished. Ben requires support with learning all new household tasks. Once he has learned the task he can be independent with very predictable and routine tasks. He requires supervision when performing these tasks. Ben requires support to regulate water temperature. He will sometimes take showers that are too hot and leave his skin red and irritated.

Safety

PCP: Ben requires support to evacuate the house in the event of a fire. In the past, Ben has stayed seated in the kitchen when there was a small fire on the stove. Ben requires support to avoid actions that will endanger himself. Ben can cross the street safely most of the time but if he sees someone he knows, he is likely to dart across a busy street without looking. Ben does not always distinguish between strangers which is a safety risk. He is likely to open the door to a stranger, take rides from strangers and also is likely to give money or personal information away to strangers. Ben is at risk for being taken advantage of financially. He is also not always able to make safe choices when in the home or the community. Ben is not at risk of wandering away. He prefers to stay with staff at all times. Ben is able to stay home alone for a short period of time. Mom said she would feel safe leaving him alone for up to two hours. When he is left alone, she gives him a written list of rules to follow. The rules include not opening the door for anyone and going outside if he sees smoke or hears the fire alarm. Other rules include not using the kitchen. Ben can be left alone in the community in very protected settings. He rides the bus alone every day. The bus driver knows Ben and his mother watches him get on the bus and staff is waiting to get him off the bus. Other than that, Ben is never left alone in the community.

7.3.4.2 Ben's goals and objectives. From the above assessment, Ben's annual IEP and

PCP goals were determined, as detailed below:

Table 16. *Ben's Individual Education Plan Goals*

Goal 1: Ben will improve his pragmatic language skills to increase opportunities for more appropriate social communication.

1. Ben will, in four out of four consecutive sessions, follow a visual script to do the following:
 - Initiate conversation with no more than one verbal reminder
 - Initiate conversation independently
 - Stay on topic for three consecutive turns with no more than one verbal reminder
 - Stay on a topic for three consecutive turns independently
2. Ben will utilize a portable communication system (i.e. the iTouch) to be able to ask for help, follow a schedule and/or to do list, and learn new skills on a job site or in the classroom in four out of four consecutive sessions:
 - with verbal prompts
 - independently
3. Ben will be able to role play various social situations (i.e.: eating in the cafeteria) with at least one other student in three out of four attempts without visual cues.

Goal 2: Ben will increase his receptive/expressive vocabulary skills within contexts of functional language activities (i.e. computer, recipes, schedules, menus).

1. Using visual cues (i.e. pictures), Ben will use adjective and noun phrases to complete sentences during spelling and other written language activities. (letter writing, story writing, etc.)
2. Ben will comprehend and use ten new descriptive concepts (i.e. texture, size, classification) during functional language activities in five out of five sessions.
3. Ben will comprehend and use at least thirty new vocabulary words within various written contexts (reading

materials) and functional language activities in five out of five sessions without visual prompts.

4. Ben will be able to answer “wh” questions about functional texts (i.e. recipes, store fliers, labels) in five out of five trials during small group instruction without visual prompts.
5. With the aid of a newspaper and/or the Internet, Ben will pick out at least one story to discuss in a small group setting using a minimum of three complete sentences, in five out of five trials.

Goal 3: Ben will tell time and pay for small purchases independently.

1. Figure change from purchases in amounts up to \$10.00 with 95% accuracy.
2. Count coin values of 5s (e.g. .25, .75) with 95% accuracy.
3. Pay for purchases independently (counting money out of pocket or wallet, count, give correct amount to cashier and receive change) with 90% accuracy.
4. Figure elapsed time in nine of ten trials.

Goal 4: Ben will work quietly with minimal guidance in a paid position.

1. Alert staff or supervisor when he is in need of assistance within four of five trials.
2. Work for 1.5 hours continuously on the same task without a break in four of five trials.
3. Refrain from commenting on other people during work sessions in four of five trials.
4. Work independently on familiar tasks without asking for help or directions in four of five trials.
5. Work in at least two school and/or community worksites per week.

Goal 5: Ben will demonstrate knowledge of what it takes to stay healthy in terms of eating habits and avoiding sickness.

1. Ben will be able to name the five food groups in five out of five trials.
2. Ben will be able to associate any food item with its correct food group in four of five trials.
3. Given a list of food items, Ben will be able to use them to plan a balanced meal in three out of five trials.
4. Using visual prompts, Ben will be able to help prepare a balanced meal in three out of five trials.
5. Ben will identify what the weather is like each day and name the appropriate clothing to wear in three out of five trials.
6. Ben will be able to identify common illnesses and what it takes to prevent them in three out of five trials.

Table 17. *Ben's Person-Centered Plan Goals*

Long Range Outcome 1: Strengthen and develop skills related to job duties.

1. Ben will monthly determine the steps to complete new tasks that are introduced to him and he will write down and follow the steps to complete the task with no more than two verbal prompts per occasion.
2. Ben will maintain his attention to a work/academic activity in the presence of distracting stimuli daily with no more than one verbal prompt on each occasion.
3. When at work, Ben will recognize when others are busy working or talking with someone else, and he will not interrupt them, on a daily basis by not requiring more than one verbal prompt per occasion.
4. When out in the community or on a job site, Ben will remember to say goodbye or end a conversation before walking away independently per occasion.

5. Ben will improve his communication skills at least three times per week, by expressing his wants and needs to staff when at a job site, independently, per occasion for three consecutive months.
6. Volunteering/working at the library or any other job site where Ben has to learn how to use the equipment, Ben will learn the names of the equipment and how each one functions with no more than two verbal prompts per occasion for three consecutive months.
7. Ben will independently put away his work items before leaving work at least two times per week.

Long Range Outcome 2: Ben will develop and strengthen daily living skills.

1. Ben will learn the skills needed to leave a message for the person he has called, at least three times per week with no more than one verbal prompt per occasion for three consecutive months
2. Ben will indicate that he has enough money to complete a purchase, independently, at least one time per week for three consecutive months.
3. When at a restaurant, Ben will appropriately order his food by:
 - Looking at the cashier
 - Speaking clearly
 - Stating what he would like to eat and then what he would like to drink
 - Ensure he gives the cashier the correct amount of money
 - And wait for his food/change with no more than two verbal prompts at least two times per week.
4. Ben will count to make sure he receives the accurate amount of change back after making a purchase at least two times per week with no more than two verbal prompts per occasion.
5. Ben will daily learn to identify time in intervals of 15 minutes in order to inform staff of the time he needs to be somewhere or an activity will take place with no more than two verbal prompts per occasion.

Long Range Outcome 3: Ben will develop and strengthen social skills. Ben will strengthen his communication skills. Ben will strengthen his community access skills.

1. Within no more than one verbal prompt, Ben will introduce himself and the person he is with (ex. Staff) to new people he encounters.
2. Ben will complete at least one writing activity daily with 100% accuracy for three consecutive months.
3. Given an activity or game, Ben will follow the rules for the activity he is participating in at least three times per week, with a written prompt, for three consecutive months.
4. Ben will practice making eye contact for at least five seconds, two times per week with no more than 1 verbal prompt per occasion.
5. Ben will accurately answer questions the first time he is asked on a daily basis with no more than two verbal prompts per occasion.
6. Ben will clearly state his name or other information when asked on a daily basis with not more than two verbal prompts per occasion.

Long Range Outcome 4: Ben's family will have periodic breaks from care.

1. Ben's family will receive a periodic break in care as needed throughout the plan year.

Long Range Outcome 5: Develop work appropriate social skills.

1. Ben will volunteer at a place of his choice in the community or by walking his neighbor's dog at least two times per week with no more than one verbal prompt per occasion.

7.3.4.3 Support providers. Ben receives approximately forty hours a week of support services funded through a Medicaid waiver program and provided through a local non-profit support agency for individuals with I/DD. These services consist of a one-on-one personal care and vocational support provider. Mrs. Kimmel reported that finding long term, conscientious, and dependable support staff can be difficult due to the position's low pay, poor benefits and the agency's recruitment of college students who tend to move on after graduation. She also lamented,

As Ben gets older, people have lower expectations that he can learn. I always feel like it is such a waste of money if people are not going to really help him. That's why I try to get him to be more independent.

At times, her frustrations in finding quality support staff have prompted her not to take advantage support services. She shared,

I was planning to visit family (overseas) for three weeks and hadn't had any support staff for so long because I had been so disappointed in some of the workers. I just decided that we were going to let Ben do things for himself.

While Ben was not completely left on his own, he did experience an uncommon level of independence after school before his father returned from work, with family friends on call to help if needed.

Although Mr. and Mrs. Kimmel have been exceedingly pleased with Ben's most recent support provider, Sabrina, they learned a few months ago that she was leaving the agency. After four years of employment (one year with Ben) without receiving a raise³⁶ and a sudden decision on the part of her employer to reduce health benefits, Sabrina was forced seek employment elsewhere. Ben and his parents were sad to see her leave, as they had developed a close

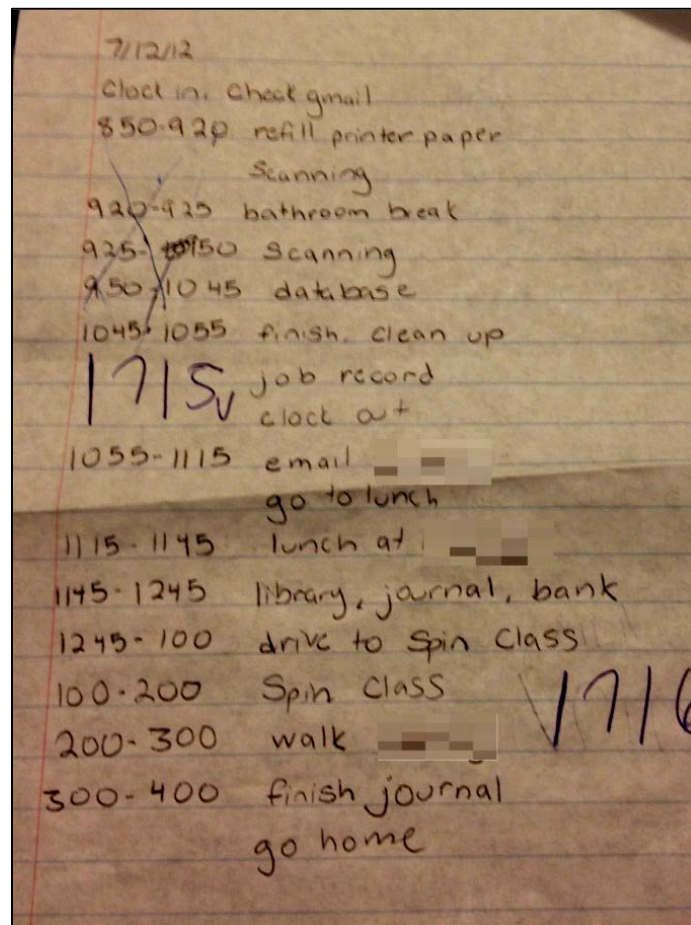
³⁶Sabrina is contracted and paid through the support agency.

relationship over the past two years. On two occasions, Ben even traveled with Sabrina on weekend trips to visit her family in a neighboring state.

Sabrina's departure has been hard on Ben. He misses her and has had difficulty understanding the circumstances. Further upsetting, lack of a support provider in the interim meant that Ben was unable to work for a short time. Substitutes within the agency are hard to come by. Unfortunately, finding a suitable replacement has been complicated by a new Medicaid regulation requiring support providers to have three years of disability-related experience, greatly narrowing the pool of qualified applicants. Moreover, a starting pay rate of ten dollars an hour and poor health care coverage serves as a weak enticement to the position.

7.3.4.4 Interventions. Central to Ben's success and own sense of well-being has been the employment of tools and strategies to ease anxiety and to help Ben cope with everyday life chaos. As Mrs. Kimmel stated, "It's about developing trust." The establishment of daily routines, for example, have allowed Ben a sense of life stability and purpose. When Ben is able to anticipate and rely on the structure of his day, he experiences less anxiety. In effort to prepare Ben for the disruption of non-routine life events, such as a doctor's appointment, family vacation, or birthday party, a calendar of upcoming events kept on his desk in his bedroom, where he regularly refers to it. In addition to his calendar, daily handwritten schedules are developed and implemented throughout Ben's day to facilitate smooth transitions from one activity to the next. These schedules also enable Ben to anticipate change and allow him a level of autonomy and success as he monitors his time and moves himself through the tasks or activities. When complete, Ben creates an X over the accomplished action listed on the schedule. Figure 21 is an example of a schedule developed by Ben and his support provider at work.

Figure 21. *Ben's Schedule*



Of Ben's schedules, his mother shared that although she would prefer not to impose rigid timeframes on Ben's activities, she has found that when she does not specify time, "Ben tries to multitask. He will try to do everything at the same time because he just loves to get things done."

While Ben prefers a structured and predictable day, Mr. and Mrs. Kimmel have observed great maturation over the past few years in terms of Ben's adaptability. Mr. Kimmel shared, Ben is much more able to adjust and take verbal things (i.e. changes in his schedule), whereas before, everything had to be written down. If we changed a schedule item on him, reversed an order, or added something new, Ben would go and get the schedule and

make you actually erase or cross it out. He's become increasingly flexible in that way. Mr. Kimmel also commented on Ben's enthusiasm for new opportunities. "If it is part of his routine, he looks forward to it. That said, you can almost make anything a part of his routine and I think he would like it and look forward to it."

In addition to frequently referencing his calendar and daily schedules, Ben regularly tracks the activities of his loved ones. Mrs. Kimmel shared,

Before Ben goes out to school, he asks me, "Where are you going today?" and I have to tell him, "Let's see...I am going to play tennis and have somebody over for lunch." Then he will say, "Who are you playing tennis with?" and "What are you going to eat for lunch?"

Ben also stays informed of and encourages the interests of his family members. Mr. Kimmel explained,

If he knows you like American Idol, he will remind you that it's on at eight o'clock tonight and he will keep reminding you until you go do it. He knows where everyone in the house is at any given moment and sort of tracks everything. He knows exactly what your routines are. If you do something late, he will remind you.

With a laugh, Mr. Kimmel admitted, "Ben is a bit of the control freak. He's happy when he's in control. In a nice way." Mrs. Kimmel confirmed her husband's assessment, expressing the same amusement.

Ben likes to think that he has control over me. If I say I'm going shopping, he will come home and check the freezer. Then he'll say, "I want this and barbeque that and you cook that tomorrow." He will plan my whole day! I have to say, "No, no. Wait and see!"

In addition to frequently monitoring his calendar and schedules, Ben often seeks verbal

confirmation. Mrs. Kimmel emphasized the importance of providing Ben reliable information. “If we say to Ben that something is going to happen, then we do what we can to make sure it happens. I think that is what made Ben really trust us.” Along the same line, when responding to Ben’s requests or questions about upcoming life events, Mr. and Mrs. Kimmel consciously avoid the use of “maybe” and similar vague answers. Mrs. Kimmel shared,

We try to say either “yes” or “no.” I tell people, ‘Don’t tell Ben ‘I don’t know’ or ‘Maybe.’ Those are not good enough for him. He wants a definite answer. You can say no. It doesn’t hurt his feelings, but you can’t say “maybe” or he’s going to keep asking.

In recognition that there are times when answers cannot be immediately provided, Mr. and Mrs. Kimmel employ a “wait and see” approach, a strategy often used by his teacher, Mrs. Stein. Mrs. Kimmel explained how this developed.

I would ask Mrs. Stein on a Friday, “Where is your field trip?” and she would say, “I don’t know.” Or, I would ask, “Where are you going to eat lunch?” and she would say, “I don’t know.” This was a huge difference from what Ben was used to (from previous autism program). So, what Ben learned was “We will wait and see.”.... So now I use it. Ben will ask in the morning, “What’s for dinner?” and I say “Wait and see!” I figured, if he can wait and see at school, then he can wait and see at home.

7.3.5 Ben and high school life. Multiple visits to Ben’s school, home, work settings, and on community outings have presented a variety of opportunities to observe Ben engaged in a wide range of experiences. Important to note, over the course of data collection, Ben graduated from high school. The following section portrays an overview of Ben’s everyday school and post-school life, formed from a compilation of observations, Ben’s final individual education plan, his most recent person-centered plan (PCP), interviews with Mr. and Mrs. Kimmel and Ben’s

teachers, and self-reports by Ben through words, drawings, and photos.

7.3.5.1 Early mornings. Ben is an early riser. Always awake before his parents, Mrs. Kimmel laughed, “I think he sleeps with one eye open!” Mr. and Mrs. Kimmel have established a rule that Ben not leave his room until 6:30 am, so he uses his early mornings to draw, paint, and look at books. Down the stairs by 6:31am, Ben grabs the morning paper from the driveway, empties the dishwasher, and prepares his breakfast. Whether cereal, a bagel and humus, or tortilla with cheese, Mr. Kimmel shared,

Ben always decides what he wants for breakfast the night before and he will tell us to make sure that there’s not going to be any problems. We don’t have to make it for him – he’ll get it himself - but he just wants to make sure that he is not going to be disappointed.

Breakfast in hand, Ben heads back upstairs to the family computer located in a common loft area. With an eye on the clock, he may watch a favorite YouTube video or send emails out to friends and family before preparing himself for the day. “He’s very good at getting ready in the morning,” Mrs. Kimmel shared with the caveat,

The biggest challenge we have now is shaving. We’ve tried all different kinds of electric shavers. It’s very hard - the grooming part- like combing his hair and things like that. He won’t look at himself in the mirror, so it’s like pointless when you can’t see yourself.

In deciding what clothes to wear each day, Ben tunes into the local weather report. Keeping informed of the weather also helps Ben to anticipate possible changes in his schedule or routine. Of his weather monitoring, his father commented,

In general, Ben is pretty tuned into the weather, in terms of temperatures and whether it is going to be sunny, rainy, snowy, or whatever. He has very vivid memories of hurricanes

and ice storms and when the power has gone out. It's very hard for him to entertain himself if he doesn't have the TV or the computer or something like that and he'll get anxious when he sees that there's bad weather coming. He is also very sensitive to when there might be a delay of school or school cancellation because of ice or snow, and that sort of thing.

At eight o'clock, Ben is dressed, ready, and waiting to head out to the school bus stop. Of his preparedness, his mother commented "Ben is perfect punctual. At 8:10 he is, whoosh, out the door!"

7.3.5.2 *On the bus.* "Good morning, Bus Driver!" Ben would say as he boarded his school bus each morning. His mother shared, "I've tried to teach him to say "Good Morning Mrs. So-and-So!" but it's always the same, "Good morning Bus Driver!" For his first few years of high school, Ben and his younger brother, Jimmy, rode together on the same bus. This changed when Jimmy was offered the opportunity to participate in a program at another high school in the district. Mrs. Kimmel commented,

I think it was a good thing that Jimmy had some experience seeing Ben take the bus. He would sometimes tell me that Ben talked too much on the bus, so then I would remind Ben, "Now don't talk too much today."

Without Jimmy on the bus, Mr. and Mrs. Kimmel decided it would be better for Ben to begin taking the smaller school bus that transported many of his classmates with I/DD. Ben was not in agreement with this decision. Mrs. Kimmel recalled, "The first day Ben took the special bus, he came home and said 'No! I'm not taking that bus. I want Bus 11 (Ben's old bus).'" She went on to speculate, "I think because there were very few kids on his new bus and the regular bus had all the pretty girls. He likes girls and I think people were nice to him."

7.3.5.3 In the classroom. Ben's days during high school were largely spent with classmates similarly identified for special education support services in a self-contained program. Two special educators, Mrs. Stein and Mrs. Gilbert shared teaching responsibilities in separate classrooms. Added support staff included two teaching assistants, Mr. Barker and Ms. Hanna, and Ms. Trebec, a transition specialist responsible for vocational-related activities. Ben spent most of his instructional time in Mrs. Stein's classroom, though transferred to Mrs. Gilbert's room for math class. The high school day consisted of seven course periods, of which Ben participated with mainstream peers in one elective class, choir, and a physical education class.

Evident from classroom observations, discussions with Ben's teachers, and a review of Ben's IEP, instruction in Mrs. Stein's class focused primarily on functional everyday life and vocational skills. Whereas educators of general education core courses must abide by established state curriculum standards, no similar content oversight occurs within self-contained special education classrooms serving students with I/DD. Instead, curricular emphasis is typically determined at the discretion of individual teachers and influenced by student IEP objectives. Observations in Mrs. Stein's classroom presented opportunities to observe a review of weekly spelling words, a class discussion on global warming and pollution prevention, a viewing of a YouTube video about homelessness, a menu review of a local diner to solicit student orders in preparation for lunch outing, and a guest lecture from a local vocational rehabilitation specialist and a manager of a retirement community on potential job opportunities and interviewing skills. Instructional sessions were generally presented in a whole-group, teacher-centered approach, with Mrs. Stein positioned at the front of the classroom. Individual seatwork consisted of worksheets with fill-in-the blank type tasks and word banks. Mrs. Gilbert's math class consisted of students stuffing and sealing envelopes with mailers to be

distributed later by the school district. Mrs. Gilbert explained that this was a typical classroom activity which presented opportunities for students to strengthen and generalize basic math skills.

Ben seemed engaged and displayed a happy and easy-going demeanor in the classroom setting. When teachers posed questions, he eagerly raised his hand to contribute an answer. His responses were, at times, on point, though more frequently, tangential to the topic. Ben also often wove humor into his responses. For instance, when presented with a menu of lunch items to be decided upon for the class outing, Ben responded by feigning much consideration (“Ummm,”) before his announcement, “I think I’ll have...pork shoulder!” Pork shoulder was not an item on the menu, but rather a reference to an episode of Barbeque University, one of Ben’s favorite shows. When redirected to his options, Ben quickly scanned the menu and voiced a selection. When provided instruction for seatwork, Ben often looked to his peers for behavior cues on such things as taking out paper and pencil or turning to a particular workbook page. Overall, Ben was attentive and followed directions with only one exception. When students were directed to view the video on homelessness, Ben sat flipping through a computer game catalog. He went unnoticed by Mrs. Stein, who sat at her desk computer. Interestingly, Mrs. Stein presented minimal introduction to the video and provided no follow-up to contextualize the viewing. In later examination of the video clip, comments from viewers on the site suggest that the video was created as a hoax, with the central subject of the clip falsely portraying himself as a homeless person.

When provided free time, Ben and his classmates enjoyed playing games using the SmartBoard touch screen, positioned at the front of Mrs. Stein’s classroom. Wheel of Fortune was a favorite game among the students. Two separate observations allowed opportunities to observe students engaged in this game. Each time, Ben was appointed to control the laptop and

touch screen. Ms. Trebec commented that Ben is often eager to take charge of the classroom technology.

He adores technology and he's very good at it. He'll always jump in and won't let you do it, because he wants to do it. When we have a dance class and we use the Smartboard to play music, I can never get it to work, but Ben gets it to work every single time. So now when I'm about to do something, he'll say "Let me do it" and he'll go and do what needs to be done. Which is really nice because I can never seem to get it to work.

The other students remained in their seats, taking turns to call out letters after prompting from the teaching assistant who sat in the back of the classroom. The following dialogue illustrates their process:

Mr. Barker: Ok Nora. You're first. Let's see... choose O...yeah, choose O.

Nora: I choose O!

Mr. Barker: Ok, Ben, now go touch the O. Yeah, good.

Mr. Barker: Matt it's your turn. Ok...Matt...choose T! T!

Matt: T!

Mr. Barker: Ben, touch the T.

Once enough letters revealed an obvious answer, the teaching assistant would call out the final answer. And so the game continued....each letter, each final answer, and each game. In moments when Mr. Barker became occupied in conversation with another adult, the students would yell back, "Mr. Barker, Mr. Barker! What letter should I choose?" and Mr. Barker would look to the screen, call out a letter and return to his conversation. In a later conversation with Mrs. Stein, she shared how fortunate she felt to have Mr. Barker as an assistant and indicated that he was currently in school to become certified as a special educator.

7.3.5.4 Choir. Ben's choir class consisted of approximately twenty-four students, four of whom (including Ben) came from the resource room. During class, the instructor led students in vocal exercises and two songs. Ben sang along with his classmates, though at times seemed unfamiliar with the lyrics. Unlike their peers who held binders with sheet music, curiously, Ben and his three classmates sang without binders. Ben was quick to raise his hand in response to questions posed by the instructor, during the fifty minute class. As before, his answers were not always accurate; however, they were always acknowledged respectfully by the teacher. Toward the end of class, the teacher called upon the students to divide into gender groups to practice different sections of a musical piece. All of the male students were instructed to gather around the piano. For unknown reasons, Ben and his male classmate remained at their seats and observed the activities from a distance until the class was dismissed.

Of Ben's participation in choir class, Mrs. Kimmel commented, "Ben can't sing very well but the teacher says he is really good." Impressed with Ben's knowledge of classical music, Ben's choir teacher shared a story with Mrs. Kimmel of Ben's recognition of a musical piece played in class one day. Ben recognized the melody immediately and shouted, "Snow White music!" Unsurprised, Mrs. Kimmel responded, "All the Disney movies have classical music and Ben remembers everything." She continued by recalling a family road trip memory of listening to a Disney soundtrack of classical music when Ben and Jimmy were quite young.

I looked back and at certain points, Ben would start crying. I zipped it (the music) back and remembered the number, 7:59. When I played it again at 7:59, Ben started crying again. When I got home and watched the movie, that was exactly when the whale opened his mouth. You play the music and Ben plays the movie in his head. He has an incredible visual and sound memory.

7.3.5.5 Physical education. When starting high school, Ben was originally enrolled in an adaptive PE course with his peers from Mrs. Stein's class. Mrs. Kimmel soon advocated for Ben to be transferred into the general PE course, telling his teacher, "Ben can move. He's not crippled." The request was granted and Ben was transferred into an all-male PE class. Not long after, Mrs. Kimmel learned that Ben was spending the majority of his time with the female class. Mrs. Stein explained, "We put Ben with the boys, but he kept migrating over to Coach T's class and nobody seemed to care. When we found out they said "Oh he's fine!" Of learning about Ben's participation with the female students, Mrs. Kimmel commented, "No wonder there have been so many girls in the community saying hello to him! Wherever we go, someone always says 'Oh! We know Ben!' and Ben loves it!" She also shared, "Ben loved the class. He learned to ice skate and got to go on field trips...He had a good time."

To Ben's disappointment, his participation in the class was short-lived. After displaying what was perceived as romantic affection toward a young female teacher (unaffiliated with the PE class), Mrs. Stein decided to remove Ben from class out of concern that he may display similar affection toward female classmates. She explained,

Ben came in every single day to see her (the teacher) and you could hear him shout "Hi Ms. G!" from down the hallway. Then he started getting inappropriate. He kissed her a couple of times on the temple and would give her lingering hugs. That's when he stopped going to PE with the girls. We thought "Hmm...maybe we don't want to have something like this happening in PE with the other girls."

It is uncertain if these concerns were shared with Ben's parents as Mrs. Kimmel provided an alternate explanation, indicating that the reason behind Ben's transfer was due to a protest from one of Ben's male classmates who also wanted to join the girls' class. With good humor,

Mrs. Kimmel commented, “I think so many guys must have envied Ben!”³⁷

Observation of the PE course yielded little information about instruction and class activities; however, it did provide some insight into Ben’s interaction with his mainstream male peers. Without instruction, the young men divide among themselves into groups scattered across the gym. Some played a half-court scrimmage of basketball, others shot baskets, and a few groups gathered in clustered conversation. Ben and two classmates from Mrs. Stein’s room occupied a corner of the gym, taking turns shooting baskets. During the class period, the other students did not engage positively or negatively with Ben and his classmates, nor did Ben or his classmates engage the students. That said, little interaction occurred between any of the student groupings within the gym. Ben’s PE teacher appeared occupied on a separate initiative across the hall from the gym. He provided no instruction that day, though intermittently checked in on the students until dismissing them to the locker rooms at the end of the period.

While waiting outside the gym for the dismissal bell, Ben took notice of a female student also waiting. Although they did not speak, she smiled at Ben and then looked down. Ben kept his eyes on the young lady until she looked up again. He then quickly looked away, though glanced back often. When the bell rang, she waved goodbye to Ben with a smile and he waved back as she passed by.

7.3.5.6 Community-based activities. In addition to classroom instruction, the teaching staff and students traveled out into the community several times a week. Bowling and shopping (grocery store, mall, craft stores) appeared to be regular activities. While it was explained by Mrs. Stein that the intent of these outings was to provide students opportunities to generalize skills emphasized during classroom instruction, when joining the class on two separate outings

³⁷As an aside - while true that Ben can be affectionate and was observed giving occasional hugs and light kisses on the cheek or forehead to friends and family outside of school, at no time was he ever observed exhibiting inappropriate or aggressive affectionate behavior toward anyone at any time over the course of data collection.

(bowling and to a craft store) all opportunities to handle money, make decisions, and interact with business employees were monopolized by the teacher staff. In contrast to Mrs. Stein's original explanation, these two outings appeared scheduled primarily for recreational purposes, out of routine, and to meet the preparation needs of the teachers rather than the instructional needs of the students.³⁸ Additionally, students spent much time sitting and waiting during non-instructional transitions as the teaching staff engaged in preparations, in waiting for the bus, loading and unloading, and travel time. Upon their return, on both occasions, no attempt was made to initiate new or follow-up instructional activities. Perhaps this was due to anticipation for the bell to ring signaling a transition to another class or the end of the day, despite what appeared allowable time.

7.3.5.7 Vocational training experiences. Two times a week, Ben and a few fellow classmates traveled with a teaching assistant by school bus to various worksites for the purpose of strengthening job skills. Tasks include fronting shelves at a local grocery store,³⁹ cleaning animal cages at an animal shelter, folding napkins at a cafeteria, and delivering newspapers to patient rooms at a hospital. Two opportunities availed chances to accompany Ben and his classmates on these outings. A description of Ben's senior year work-study experience as an office assistant is also included.

7.3.5.7.1 Fronting shelves. Upon arrival to the grocery store, Mr. Barker informed the clerk at the courtesy desk of their arrival as the three students waited quietly behind him. Assigning each student a separate work location within the store, Mr. Barker conducted an initial rotation between the three students and then left them to work independently as he walked down

³⁸Multiple classes participate in the weekly bowling trip. Beyond limited instructional value, it appeared the activity served as an opportunity for physical and occupational therapeutic interventions for students with physical challenges.

³⁹Fronting refers to positioning products on the front edge of shelves in effort to present an orderly and fully stocked appearance.

to another store within the same shopping strip. Before leaving Ben, Mr. Barker asked that he skip glass items, indicating that Ben had previously dropped an item. Ben worked quickly, pulling items to the front of the shelf and positioning them forward facing. As he moved down his aisle, he talked quietly to himself taking note of the items that he liked and did not like (“Yuck!”) and identifying ingredients from familiar recipes. He appeared to enjoy his work. When customers approached, Ben stepped back to allow their access to the shelved stock, sometimes greeting them with a friendly “Oh, excuse me!” At one point, a classmate walked down the aisle indicating that he had a question for Mr. Barker. Rather than return to his aisle, he continued wandering the store until Mr. Barker returned, approximately 30 minutes later. At that point, Mr. Barker indicated that it was time to leave and informed the students that they would be traveling to a nearby shopping mall before returning to school. Before leaving, Mr. Barker stopped by the courtesy desk to let management know they were leaving.

7.3.5.7.2 Newspaper delivery. Ben and a classmate began their shift in the volunteer workroom. With assistance from Mr. Barker, they unpacked and loaded stacks of newspapers onto a rolling cart. Wearing assigned hospital uniforms (a red knit shirt with an embroidered hospital logo and khaki pants), they then took turns pushing the cart through the hospital hallways, walking quickly, as if in competition. Mr. Barker followed behind. Before entering a room, Ben and his classmate reviewed signage posted on each patient’s door. White and blue signs signified room entry was limited under restricted conditions. For these rooms, a newspaper was left on a cart outside the room. For rooms without restriction, Ben and his classmate took turns entering. Their entrance announcement was made without directed eye contact toward the patient. Instead, each quickly introduced themselves with “Hello, I’m _____. Would you like a paper?” Without waiting for an answer, a newspaper was placed on the patient’s bed or side

table before the deliverer moved quickly out and into the next room. They spent approximately an hour at the hospital delivering to two units before loading the bus to return to school.

7.3.5.8 Office assistant. During his senior year, Ben began a volunteer work-study position as an office assistant a few afternoons a week for an academic department at a local university. His primary responsibility was the digitization of the department's thesis and dissertation print collection. This consisted of scanning each document, page by page, to create a pdf which was then catalogued and made electronically accessible to university students and researchers. Although Ben had a support provider available for assistance, he quickly learned the technology and became proficient in the task. Over the year, his responsibilities expanded as staff and faculty became more aware of his availability and service capabilities. New assignments included such tasks as providing copying services for faculty, assisting office staff with alumni mailings, demagnetizing videotapes for disposal, and the retrieval of materials from campus libraries.

7.3.5.9 The school library. The high school library appeared to be underutilized by Ben, his classmates, and teachers. Ben's teachers offered the following dialogue with regard to their general use and promotion of the library for instruction and leisure reading interests:

Mrs. Stein: Personally, I haven't used the library much this year. In the past, I would take a group now and then to check out books. Of course the reading levels are quite high, where we have some kids just reading at the elementary level. I don't think they have books with high interest level vocabulary.

Mrs. Stein: Our librarian, she is like the sweetest person in the entire world.

Mrs. Gilbert: Yeah, you are not going to find anyone more accepting.

Mrs. Stein: If she were given a list of books that we wanted her to purchase, she would

buy them in a second.

Mrs. Gilbert: We've done several jobs for them, like water the plants and dusting the shelves...but that keeps not working out very well. She is very, very receptive and welcoming to our kids, though.

7.3.5.10 *Peer and romantic relations.* Ben appears to have enjoyed his time in high school. He smiled as he flipped through his yearbook, pointing to friends and teachers and sometimes commenting to the individuals in the photos with an “Oh hi, Nora!” or “Oh that’s Mike. I see you at practice Saturday Mike.” Of Ben’s peer relations with his classmates, Mrs. Stein and Mrs. Gilbert shared the following comments,

Mrs. Stein: The kids are funny about Ben. He seems to get on their nerves.

Mrs. Gilbert: He used to get on Alex’s nerves because if Ben thinks you want to hear the answer “yes,” he will say “yes.” Alex thinks that’s the same thing as lying. But now Alex knows and he’ll say “Hey Ben, does the sky fly in Venus?” and Ben will say “Yes” and then Alex will start laughing. I have to say, “Alex, that’s really kind of making fun.”

Mrs. Stein: I don’t think they quite understand Ben. I think they think he is doing things on purpose rather than it just being a part of his autism. He likes to imitate people. I don’t really know if that is his personality or his autism.

On observation, although Ben is friendly with his classmates outside of school at common activities or events, he seems to initiate and engage in conversation more so with his peers and other adults without I/DD. One exception is Sally, Ben’s girlfriend. The two have been dating for a number of years. Sally lives in another town and their opportunities to see each other are limited to a few times a month. Sally was Ben’s prom date two years in a row. Mrs. Trebec, Ben’s transition specialist, described watching them dance during Ben’s senior prom.

He was so cute dancing with Sally. She would start doing a line dance – it was elaborate and long, but Ben just kept watching her and learned it and was doing it in sync across from her. It was awesome. He danced the whole time and was really cute with her.

They make a cute couple.

Of Sally, Mrs. Stein commented, “She is a little higher functioning than Ben in some ways. Ben’s mother says she talks about marrying him all the time. Pushy little things like that...” Sally will often post affectionate messages on Ben’s Facebook page, including marriage proposals. When asked about Ben’s feelings toward Sally, Mr. Kimmel shared,

They don’t see each other on a regular basis. I think if Ben hasn’t seen Sally or talked to her for a while an alarm goes off in his head and all of a sudden, he’ll want to talk to her, see her, engage with her. He also has other girls that he’s interested in. If he sees them, he’ll want to hold their hands and be with them...but still, Sally seems to be the primary interest. It is not central to his life – just sort of a nice thing. There was a more intense period early on, where he was talking about her more frequently and wanting to see her, but that’s become less and less.

7.3.5.11 Parent/Teacher tensions. Ben’s parents expressed great frustration over Ben’s high school experience. From the beginning, communication with Mrs. Stein had been difficult. Not long after the start of his freshman year, Mrs. Stein informed Ben’s parents, “I don’t do email.” Further, handwritten notes and documents sent to the teacher were often disregarded or misplaced. In preparation for Ben’s IEP, Mrs. Kimmel shared,

I used to write about Ben’s learning style and where he is with counting and money and this and that. I thought if I have something in writing, maybe she will have time to look at it. Each time I went in, she said “Oh could you send me another copy, I don’t know

what happened to it.” After two to three years of this, I just gave up.

In review of Ben’s annual education goals, the Kimmel’s at times felt some of Ben’s established objectives were not relevant to his learning needs. Mr. Kimmel stated, “For the longest time, telling time kept showing up on his IEP. We thought, “This is ridiculous! He absolutely gets it. Ben is really into time.” Mrs. Kimmel confirmed, “Ben tells time better than me...to the second! In fact, he keeps all of our clocks synchronized at home - that’s how good he is. Why should we worry about his telling time?” Confounded by the continued appearance of time-related goals on Ben’s IEP the first few years, came to the conclusion that Mrs. Stein and Mrs. Gilbert were misinterpreting Ben’s playfulness with numbers as not understanding. Mr. Kimmel shared, “Sometime Ben will see a clock and it will say 2:24 and he’ll say “addition!” Or he will see 5:55 and say “Three way tie!” We finally figured out that they didn’t realize he was playing with them.”

Although Ben’s parents requested to have the goal removed from Ben’s plan, Mrs. Stein asserted that the goal was still warranted due to Ben’s difficulty understanding quarter concepts (i.e. quarter to twelve). Mrs. Kimmel responded, “You know, Ben saying 11:45 is really good enough for me.”

When asked about the instructional content emphasized at school, Mrs. Kimmel stated, “I’m afraid that I don’t really know what goes on at school.” She then spoke of attending Open House events during Ben’s first two years of high school only to find herself one of the few parents in attendance. “Mrs. Stein didn’t have anything prepared. I didn’t really learn anything about Ben’s day at school. Now I know why other parents don’t go. It was such a waste of time.” Discouragement only grew when the Kimmel’s received reports from a therapist who occasionally worked with Ben during the school day. Mrs. Kimmel shared, “She told me ‘I’m

afraid to go to his class because I always come back so depressed. I never see much being done. Ben is always sitting at the computer watching YouTube or doing blotches of paint.” As for homework, Mrs. Kimmel shared,

For the longest time, they would send work like “1, 2, 3, __, __, __, 8, 9, 10.” I’m like, “Ben has done that since second grade. Even when he couldn’t even say it, he could do it. But the teacher kept sending it.

Highlighting a disjuncture between Ben’s enthusiasm for discovery and the scope of instruction emphasized in his classroom, Mrs. Kimmel stated,

It is so disappointing. Ben is very curious. He knows so much about all kinds of things. Maybe he can’t sit here and tell you about it, but if he sees a pyramid, he will say “I want to go to Egypt!” He never went to any regular class. Nobody every taught him that kind of thing. They will not teach him about Egypt, the pyramids, the Nile River, or anything like that...they just don’t think about it or they just don’t understand.

Mrs. Kimmel further lamented her disappointment when learning that a new iTouch intended for Ben’s instructional use at school had been locked in a cabinet, untouched for months. When questioned, Mrs. Stein informed her, “I don’t know how to use it.” Similarly, when the classroom was equipped with interactive SmartBoard technology and Mrs. Stein was offered training through the district for its instructional use, she declined the opportunity and commented to Mrs. Kimmel, “You know, I’m just not motivated to learn how to use it.”

Ben’s trips to walk the mall with Mr. Barker and his classmates during time intended for vocational experiences have also raised the ire of the Kimmels. Mrs. Kimmel stated, “Everybody tells me, ‘Oh I saw Ben today at the mall. It’s so frustrating.’” In an effort to find additional ways to develop Ben’s job skills, Mrs. Kimmel began presenting Mrs. Stein with the

possibility of a school job for Ben. While in the school office one day, she saw stacks of paper waiting to be shredded.

I asked Mrs. Stein, “Why don’t you let Ben come and do it?” She said to me, “Oh I won’t remember to send him. There is no way I’ll remember.” So I said, “You know what, you don’t really have to remember. All you need to do is tell Ben, “Ben, every Tuesday at 3pm, go to Ms. So-and-So’s office....How about if you put it on the blackboard? Ben will remember from then on. She said, “Ok, I’ll see,” but she never did it.

Despite many frustrations, Mrs. Kimmel acknowledged that Ben’s high school experience has not been entirely negative. She stated, “I treat school as a social place where Ben can be with a lot of his normal peers. Alone, I cannot create that by myself. So, in that way, school has been a perfect and safe place for Ben to learn to survive on his own.” Still, after three years, Mr. and Mrs. Kimmel scheduled a meeting with the school district’s director of special education to request for Ben’s transfer back into the autism classroom. Mrs. Kimmel recalled speaking with the director,

I don’t want you to fire this teacher. I don’t want to ruin someone’s life if everybody else is fine with this. Can’t I just have my child removed from her class? It has been too much of a fight.

Their request was denied. Mrs. Kimmel soon learned that she was not alone in her frustration. “Since then I’ve learned that other parents were just afraid to complain. As soon as their children graduated they wrote a huge letter to the superintendent, but still nothing ever changed.”

7.3.6 Ben as an emerging adult. During Ben’s last year of school, Mr. and Mrs. Kimmel began piecing together a life for Ben, post-graduation, with the support of Ben’s transition

facilitator and teachers. Ben's case manager from the Kimmel's contracted support agency was also an integral part of these discussions, as the agency who would assume a primary responsibility for the provision of home and vocational support, life goal development, and implementation in support of Ben everyday life needs, interests, and desires. Since graduating from high school, Ben has acquired two-part time jobs, participates in volunteer work experiences, continues his relationship with Sally, and has maintained many of his same recreational and leisure activities, as detailed below.

7.3.6.1 Office assistant. Ben currently works two hours every weekday morning in an academic department at a local university. His position began as a volunteer assignment to gain job skills while in his final year of high school. After graduation, Ben was hired on as a part-time employee and is shadowed in this position by a support provider. Although Ben's work responsibilities vary, his main task is the digitization of the department's collection of student theses and dissertations. Ben scans each document, page by page, creating a pdf, which is then cataloged and made electronically accessible to university students and researchers. Additionally, Ben supports departmental faculty and office staff by providing copying services, filing, data entry, running campus errands, collecting and returning materials from libraries, demagnetizing electronic materials in preparation for disposal, shredding documents, stocking office supplies, and keeping inventory of items in low supply. With each new task or unfamiliar piece of equipment, Ben is quick to learn, only needing a short demonstration and practice period before becoming proficient. Once on task, Ben becomes highly focused and works with speed. He requires little direction, independently tracking his progress in a notebook where his schedule and work assignments are recorded. An area in which Ben has required more direct assistance has been in acclimating to professional norms of the work place. Ben's support provider

provides modeling, instruction, and prompting on such things as appropriate ways to greet and address faculty and co-workers, how to send professionally-worded emails, and recognizing appropriate times for interruptions and knocking on faculty office doors. Ben's happy nature is infectious among his colleagues and he is well liked by office staff and faculty who have taken time to get to know him. Although his services are still underutilized by faculty, those few who have advantaged Ben's assistance have come to rely on his expediency and attention to detail.

The following comments were noted in his recent person-centered plan:

Ben currently works part-time at a university. He makes copies, converts books and papers to PDF files, shreds confidential information, retrieves books from libraries and runs errands. He said that he likes it because he likes to help others and he likes interacting with the students and professors. He also likes working on the computer...

Ben said that he likes working at the university the most and hopes to work there forever.

7.3.6.2 Candle making. Ben also works four afternoons a week as a candle maker for a non-profit organization that provides employment opportunities for individuals with I/DD. He makes approximately eight candles each day in various scents and colors. His support provider reports that Ben works with little assistance other than encouragement to stay on task. His candles are later sold over the organization's online site.

7.3.6.3 Volunteer experiences. In effort to develop and diversify Ben's work skills, Mr. and Mrs. Kimmel often seek opportunities for him to volunteer in his community. Ben walks dogs and socializes cats at the local animal shelter on a weekly basis. He especially loves the cats and when asked about his work Ben said, "Get some toys. He's hairy, tail, feet claws, whiskers...yeah white. I play with the cat. He need a toy...string." Ben also regularly walks the dog of a family friend. Less frequently, Ben volunteers at his YMCA cleaning exercise

equipment. Of this job, Ben shared “I use a paper towel, spray it, clean it, and throw it away in trash.” As of day of service in honor of Martin Luther King Jr. day, Ben greatly enjoyed assisting in the delivery of meals to the elderly for the Meals on Wheels program. He has also volunteered at his neighborhood grocery store. Of this experience Mrs. Kimmel shared,

They tended to have Ben do more things on the backend – straightening shelves, dusting, sweeping. One time they let him help put up the Christmas display and he really liked that. We were trying to see if we can get him more on the front side, do some bagging but Ben wasn’t quite there yet in his customer facing skills, I guess.

While Ben enjoyed working at the store, Mrs. Kimmel shared that these opportunities are often hard to come by and dependent upon store management.

It has been very, very difficult. A lot of stores do not like our kids to go there. They always say there are liability issues....or policy against it. One manager was very nice; he let Ben learn how to bag groceries. But others, they just want you to go away. They don’t want you to do anything with the customer and not really interfere with anything. They think you can’t learn anything and are always talking about the liability.

7.3.6.4 *Personal needs activities.* In between his work and volunteer positions, Ben and his support provider take time to run personal errands including shopping, a trip to Ben’s bank to withdraw cash for the week, a stop at a photo kiosk to print photographs, and a weekly visit to the public library. When asked about his visits to the library, Ben stated that he likes to look at the “Billy Joel cds, books, computers, and LeVar Burton’s Reading Rainbow (dvd).” Mrs. Kimmel stated that Ben tends to gravitate toward number and alphabet books. She also commented on Ben’s comfort with the library,

Ben has been to the library ever since he was a baby. You can just tell him “Go find ...”

and there he goes. He has it memorized. I don't think he ever goes to the computer to check. He is amazing. He has an incredible visual memory.

7.3.6.5 *Social/Recreational activities.* Ben takes great pleasure in his busy lifestyle. Mr. Kimmel commented, "If it is part of his routine, he looks forward to it. That said, you can almost make anything a part of his routine and I think he would like it and look forward to it." Some of Ben's regular activities include weekly classes in cooking, theater, and flower arrangement, weightlifting and a spin class at the gym, and a standing Friday lunch date with friends. Two organizations responsible for filling much of Ben's calendar are a faith-based social program for individuals with I/DD and Special Olympics.

7.3.6.6 *Social Ministries.* Ben participates in many of the activities offered through the faith-based, non-profit organization. Every other week he attends an evening program of dinner, crafts, games, and songs. These evenings are always well attended and inclusive of both young people with and without I/DD. On other evenings, the organization offers special interest clubs, Bible study, and gender-separate discussion groups on social and health issues. Staff also regularly organize community outings and host a dance each year. Another highlighted annual event is the talent show. Ben participates each year, recruiting different friends to perform the Chicken Dance with him on stage. One of Ben's favorite things about the program is their overnight camp each summer. Campers with I/DD are paired with staff and other campers without I/DD and travel by bus out-of-state to the campsite. When asked about camp activities, Ben listed, "Ropes course, hiking, rafting...brrr...the water is cold!"

Although the Kimmel family is not particularly religious, Mrs. Kimmel commented that Ben's involvement in the faith-based program has prompted an interest in God, noting that Ben will occasionally watch televangelical programs.

7.3.6.7 Special Olympics. Ben has been active in Special Olympics, year-round, from the time he was a young child. He participates in almost every sport offered, including soccer, swimming, basketball, softball, track, and cycling and his evenings and weekends are often occupied by practices, games, or other related sporting events. In opportunities to observe Ben engaging with fellow athletes and participating in a range of Special Olympics sporting events, it is a rare occasion to see Ben without a smile. Of his son's involvement with the organization, Mr. Kimmel shared that Ben's enjoyment has little to do with the competitive aspect and is more so related the opportunity to be active and with friends.

He doesn't really care how well he does or whether his team has won or lost. He just enjoys it. It's been such a part of his routine. He knows exactly where and when things are and we've come to depend on him. We'll sometimes forget, "Is swimming at four o'clock or four thirty?" and he will remember all of that.

7.3.6.8 Bicycling. Ben and his father enjoy bicycling and ride every Saturday morning, when the weather allows. Each time, they travel the same route always stopping by a neighborhood café for a cookie. On weekdays, Ben is encouraged to ride on his own. Before leaving, he and his mother negotiate the route. Depending on the route, Ben is reminded at what point during his ride he will need to switch gears. Ben has proven to be a safe rider, though has experienced some difficulty in the past. His mother shared,

One time Ben's tire blew up. He came home and the inner tube was just all around the tire. I don't even know how he made it home. I think he must have tried to ride it all the way home. He said "My tire got squishy."

From then on, Mrs. Kimmel insisted that Ben take his cell phone on his rides and is instructed to call his mother if his tire gets "squishy" again. Regardless, Ben now stops and calls

halfway through his ride to inform his mother that he has reached his mid-point destination and is on his way back home.

7.3.6.9 Interests and leisure activities. Without doubt, Ben is a young man with much energy who enjoys his active lifestyle. At the same time, he is also very content to be at home and has many interests that occupy his time. His father shared, “Ben can easily keep himself entertained at home though my wife is good about pushing new things into his routine to get him outside.” Ben’s interests include painting, food, travel, and photography. He also has a love of technology and spending time on the computer is one of his favorite ways to spend his leisure time.

7.3.6.9.1 Painting. Ben is a painter. “He can spend hours during the day doing his art,” his father shared. Ben models his painting style after Bob Ross, an artist whom he became familiar with by watching the PBS show “The Joy of Painting.” From the Ross’s show, Ben has acquired techniques for mixing colors, gained familiarity with different types of paint brushes, and has perfected his brush strokes to create different effects. While Ben occasionally creates Ross-like landscapes following videotaped instruction, step-by-step, most of Ben’s paintings depict colorful cloud-like creations. Off canvas, colors often capture Ben’s attention and he is quick to identify them by name – lavender, titanium white, crimson, azure. When viewing a sunset during a drive one day, Ben pointed to the sky and said “Burnt sienna – huh?”

7.3.6.9.2 Food. Described by his mother as a gourmet eater, Ben enjoys ordering exotic foods when eating out. “Traveling with Ben is very easy. We can go to any country, anywhere and he really enjoys the food.” Laughing, Mrs. Kimmel also shared, “Ben knows a lot about food. The other day he tells me that he wants elk loin! I’m like – where am I going to get elk!” His interest, in part, can be attributed to a determined mother who exposed her children to

a variety of foods at very young age after observing many older children with autism exhibiting negative food-related behavior. “I told myself, my kid is going to eat everything.”

In recent years, Ben has become a fan of Chef Steven Raichlen, host of the PBS show Barbeque University. He watches Raichlen’s show, owns all of his cookbooks, and often brings up different recipes, ingredients, and cooking techniques in conversation. Although Ben enjoys his cookbook collection, his father shared that Ben is more inclined to explore Raichlen’s recipes and videos online.

Ben doesn't actually spend a lot of time pouring through them looking at recipes. He likes the pictures, I think, but he would much rather search and do things online rather than do something as static as looking through a book. It’s not as immediate...not as interactive.

When asked about Ben’s abilities in the kitchen, Mrs. Kimmel shared, “A lot of time he just wants to sit there and tell me how to do it. He’ll tell me, ‘Mommy, I want Beer Can Chicken. You need to caramelize the pineapple...and now put some paprika on it.... Though if I cook, he will stir.” Mr. Kimmel highlighted a few items previously prepared by Ben but also conceded, “We probably haven’t done enough cooking with him” and expressed safety concerns.

The things that Ben has made are more mixed packaging type items, like brownie mixes, macaroni and cheese, spaghetti...So it’s not very sophisticated. He doesn't have a wide variety of things that he knows how to make. You know...Ben’s ability to use knives or to know when something is boiling and having to turn it down.... We just haven't pushed it very aggressively...so, maybe that's our fault or maybe more of our issues than his issues.

7.3.6.9.3 Travel. One interest area largely expanded and facilitated through online activities is travel and geography. Mrs. Kimmel provided the following example

Ben is very curious about places. He will say, “I want to go on a double-decker bus in London.” Or, “I want to go to Stonehenge.” For winter break he said that he wanted to go to New York City. He wanted to see Broadway and Radio City. He sees a cactus and says, “I need to go to Phoenix” or “I need to go to Arizona.” He studies all of these things on the computer. He knows a lot. Whatever he is thinking, he types and there it is! It is just so incredible.

Fascinated by highway signs, Ben was excited to discover a website that catalogs highway exit signs. Mr. Kimmel shared, “Ben will find pictures of exit signs from where my parents live in California and he'll want to show us.” Google Maps has become another favorite website. In demonstrating how the site works, Ben entered the name of the studio where one of his favorite game shows, *The Price is Right*, is produced. After pinpointing the location on the map, Ben eagerly showcased different features of the site by navigating to photographs of the area, webcam displays, local weather, bicycle trails, etc.

7.3.6.9.4 Photography. During times of celebration, sporting events, and other fun occasions, Ben is seldom without his camera in hand. He enjoys taking pictures and has become skilled in centering focal points and capturing crisp images. When back at home, he transfers his pictures from his camera to his computer using a USB cable. His father shared, “Ben used to just change the memory card from the camera to the computer, but he was taking it in and out so many times that it was starting to break the mechanism.” Ben also regularly captures pictures, using both his camera and his computer’s screenshot function, of his computer screen displaying multiple thumbnail images of favorite websites.

Ben saves his pictures in electronic folders that he has titled “2010 Bowling” or “2010 Highway 83” or other names that have meaning for him. Because of the large quantities of

images saved, Mr. and Mrs. Kimmel log into the computer once a week to delete some of Ben's pictures. Mr. Kimmel shared, "Ben used to be upset about it, but now he kind of expects it. He can literally save between 500 and 1,000 pictures a day." Previously, Ben would print many of his pictures on his home printer. His father noted, "It wasn't long before we were spending large amounts of money on replacement ink cartridges." An alternate plan was soon devised.

We made this rule that Ben has to email me the pictures. I select two a month that I print out for him and he gets them on the first of the month. He cherishes these pictures. He'll then spend the whole next month sending me new pictures. It's almost like by restricting him - he sort of looks forward to it. He spends time on it and thinks about what are the right pictures to send.

Ben hangs some of his photos on his bulletin board in his room and the others he places in a binder where he can view them easily.

7.3.6.9.5 Technology. As evident in the previous discussion, Ben's interests are largely facilitated through his use of technology and exploitation of the Web and televised media. Ben is drawn to technology and has shown a natural adeptness. His father shared,

Ben is very savvy and sophisticated when it comes to technology. He has no fear. He will go in and try this or try that. He figures out the new software. He figures things out much faster than anyone else in our family - including me. It is because he is so curious. He'll just keep trying stuff.

Ben's skill with technology extends to the family television and digital recording device. When having difficulties programming television shows through their digital recording device, Ben is the first person his parents call for help. Ben's father stated, "We almost don't ever deal with the television because he just does it all on his own." His mother also confirmed,

He just has it all figured out. None of us can figure it out. We say, “Ben, the TV is broken. Come fix it please!” and Ben just comes and fixes it. Sometimes I say “Can you show me how you fixed the TV?” and he will say “No!” He doesn't want to show me.

Mrs. Kimmel continued by sharing a story of receiving a phone call from Mrs. Stein, who had hosted an event for students at her home one day. “She told me, “You know, it’s funny, my TiVo is recording one of those kids shows.” And I thought, “Oh, I bet I know who did that!” Without anyone noticing, Ben had programmed Mrs. Stein’s digital recording device to record an entire season of “Barney and Friends.”

7.3.6.9.6 Online activities. Spending time on the computer, particularly in online activities, is one of Ben’s most preferred past times. His father shared, “It’s something that motivates him. Something that he really enjoys. It has become an activity that he could probably spend as much time as we would allow him to do.” Much of Ben’s time online is spent searching for and viewing episodes of his favorite game shows - Jeopardy, The Price is Right, Ben Stein’s Money, and Supermarket Sweeps. He rarely watches them on television anymore. His mother shared,

I think with TV now, it’s just not under his control enough. Like...he may want to watch a Jeopardy show from 1996. On the computer, he can just call it up, but with the TV he can’t. Or, if he wants a cooking show or whatever...Ben is very good at searching. On the computer he can get exactly what he wants as easily.

Ben’s father stated similarly, “I think the reasons Ben likes computers so much because he’s totally in control and everything is on-demand. He can pick exactly what he’s looking at and manipulate it.”

The Kimmels also commented on how the Web has encouraged Ben to be more self-

directed in exploration of his curiosities and interests. Mr. Kimmel stated, “Ben is very curious and has an infinite capacity of interest. The Internet has become a whole gateway to things and allows Ben to express his curiosity and to follow trails.” Mrs. Kimmel agreed, adding,

The Internet has really fostered Ben’s independence in seeking things he wants. Ben is not someone who can really ask or explain things well, but he will run into things (online) that he learns. He has learned so much about all kinds of things.

In addition to pursuing his own interests, the Web has also offered new opportunities for Ben to encourage and support the information needs and interests of his loved ones. Ben’s father shared,

If Ben knows that we are interested in something or even if he detects that we have an interest, he will sometimes search it and come and show us. It doesn’t so much sustain his interest. It is just a way of interacting with us.

Finally, the Web has allowed Ben to maintain connections with friends and distant relatives. He sends emails regularly. His messages consist of short statements with brightly colored fonts or highlighted words, and often with an attachment or two of photos displaying his computer screenshots. Ben also has a presence on Facebook. His online social interactions on the site are few. Instead Ben primarily uses the site as somewhat of an online photo album where he can go and enjoy photos posted by his friends and upload his own to share.

7.3.7 Ben’s future. Mr. and Mrs. Kimmel look toward the Ben’s future with a mix of hope and hesitation. In terms of employment, it is assumed that Ben will continue on in his part-time positions at the university and candle making with similar levels of support. Ben’s future living arrangements are less certain. While Mr. Kimmel commented, “Right now, it’s easy for us to keep him at home,” he also acknowledged a looming reality. “We are not going to be around

forever. It's not sustainable for Ben to be so dependent on us."

In preparation for Ben's eventual move out of the family home, Mr. and Mrs. Kimmel have explored a number of possible options, including group homes, apartment living with one or two roommates and day-only support staff, and adult foster care. Implicit in their considerations is the certainty that Ben will always require some level of supervision and guidance. Although Ben possesses many of the functional skills necessary to live independently, in question are his abilities to effectively cope with the unexpected, recognize and respond appropriately to dangerous situations, and sufficiently communicate a need for help. Mr. Kimmel commented,

Ben has the skills to live independently...or they are emerging...doing things like the dishes, doing the laundry, making his bed. And, his ability to entertain himself and his sensitivity to his schedule and routine - these things would probably serve him well for an independent lifestyle. What my wife and I worry most about are things out of the routine, something that Ben hasn't been prepped or trained for. How would he react? His mom seems to have a lot of reluctance to leave him at home for any length of time. Not because he's unable to entertain himself, but if something unexpected comes up. Would he call us? Would he know that something was different? Would he recognize a situation where there might be danger? Sometimes he surprises us in that he's very aware. He notices things. He's observant. If there were something unusual or different or out of the routine, he would probably notice. Whether he would react appropriately...we would hope that he might call us. Ben is more comfortable using a cell phone now, so that is a great comfort to think that he would at least call us. But could he explain what's going on or what was happening?

Securing a future supported living arrangement that allows Ben opportunities to be engaged and connected in his community is a high priority for Mr. and Mrs. Kimmel. Mr. Kimmel stated, “Ben is social and he likes people. His mom and I both recognize that number one - Ben needs to get out. He needs to be with people. He enjoys that. It’s important that he not be isolated.” That said, Mr. Kimmel also spoke of Ben’s naivety and potential for exploitation, conceding a fear that many aging parents experience when transferring the guardianship of an adult child with I/DD to others. He said,

One thing that worries us is that Ben is such a social person. He enjoys people, but that the whole sense of good and bad...that somebody that might harm him...that somebody who might take advantage of him, that’s a concept that is completely lost on him. So thinking about whether or not could Ben live in an assisted living or group home ...we would have to have a really high degree of trust in the people he was with because of that and that's a big concern. I'm sure a lot of parents with special needs children worry about that... It would just be very easy to take advantage of them.

For the time, Mr. and Mrs. Kimmel are content to have Ben at home. Mrs. Kimmel shared, “I like living with Ben. He’s very easy to live with and he’s fun!” When the time does come for Ben to move out, his father speculates, “I think Ben is adaptable enough that where ever it is, he’ll be fine. Our concern is that it is sustainable, that he will be protected, and that he’ll enjoy it.”

Love and pride show through when Mr. and Mrs. Kimmel speak of their two sons. A year before his high school graduation, Jimmy was accepted into a prestigious preparatory school and now attends an equally prestigious military academy. Ben’s success shines through his accomplishments at work, his independence in the community, his friendships, and his smiles.

Ben is happy in his life. Thinking back on Ben's trials and accomplishments over the years, Mrs. Kimmel commented,

You know - if you look at Ben now - you would not think he was the kid running around, hiding, screaming, hitting. I could never imagine that he would be like this - so calm. He really is such an amazing kid.

Similarly, Mr. Kimmel reflected,

Looking back, Ben has changed a lot over the years. He's done a lot of things I thought he would never be able to do. He has turned into a great person, given his limitations...but you know, I guess we all have our own limitations.

7.4 Introducing Bella

Bright blue eyes, hair pulled back into a bouncing ponytail, freckled nose and cheeks, and a smile - sweet and genuine. This is Bella. In many ways, Bella epitomizes our cultural notion of the all-American teenage girl. Step into her bedroom and you will find posters of Orlando Bloom, Taylor Swift, and Backstreet Boy Nick Lachey hanging above an unmade bed occupied by a few lovingly worn stuffed animals. Across the room, past a pile of yesterday's clothes, Bella's bookshelf sits overstuffed. "I have a lot of random books," she points out. Bella's collection includes all of the Twilight and Harry Potter series, autobiographies by Barack Obama (Dreams of My Father) and Mia Hamm (Go for the Goal), The Magic Tree House series, numerous books on pet care, dog pedigrees, and horses. While visiting, meet Lopez. Lopez is Bella's pet gerbil who sleeps hidden beneath a pile of wood shavings in his cage on an upper desk shelf, which sits next to the bookshelf. "He can keep me up all night," Bella says. "Gerbils are nocturnal. He has a wheel but he keeps knocking it over. Smart gerbil. Not." Bella's computer also sits on her desk. The screen displays her iTunes library, an eclectic mix of music that includes Bruce Springsteen, Journey, Taylor Swift, Adele, U2, and Jason Aldean. Bella shares her large L-shaped room with her little sister, Victoria, who claims the smaller end. "Whatcha doin' Pest?" Bella says as she hurls a balled up pair of socks in Victoria's direction as she enters the room. Bella's light-hearted tone betrays her action and words. In leaving the room, Bella comments, "Me and my sister, we hate to clean our room."

At nineteen, Bella is in her sophomore year of high school. She is the second oldest of four and lives at home with her mother, father, her younger sister Victoria and brother, Emmett. Hermione, Bella's older sister, attends college out of state. In addition to Lopez, Bella's gerbil, the family shares their home with two dogs and two cats. Bella's father, Mr. Potter owns his

own business and works out the home. Mrs. Potter is a former social worker and now a homemaker. Diagnosed with multiple sclerosis thirteen years ago, she uses a walker and sometimes a wheel chair because of increasing mobility difficulties. Despite challenges, Mrs. Potter continues to be actively involved in daily family life as primary liaison of their busy household. She also continues to assist in transporting the children to their various activities in the family car, converted with hand controls.

When asked to share a bit about Bella, Mr. Potter began, “Bella is social and sweet-natured. She has a fun personality...you know? She just has a little spark to her. She is a genuinely nice person and caring, a friendly-type of person. She rarely has a bad day.” Mrs. Potter described Bella similarly, highlighting her compassionate nature.

Lately she's really been thinking a lot about Haiti [the 2010 earthquake] and what we can do to raise money for Haiti. Each day she comes home from school with ideas. She'll say 'I was thinking we should have a bake sale' or 'I was going to do a collection.' Anytime she sees someone hurt or in pain...she is just very warmhearted that way.

Ms. Anne, one of Bella's teachers, also described Bella as an exceptionally empathetic and loving individual.

Bella's empathy is really incredible. She just shows so much compassion. She'll really listen to your situation, and remember and she'll want to hug you. Bella has been told so many times that she gives really good hugs and it gives her great confidence. We call it healing with a hug.

In sharing these comments with Bella, Bella smiled and said confidently, “Yeah...that sounds a lot like me. I have a big heart and I'm not afraid to use it!”

In an annual meeting to review Bella's Person-Centered Plan (PCP), Bella had the opportunity to reflect on her other strengths. When asked, “What are my special talents/traits? What do I like and admire about myself?” Bella stated:

- making friends
- helping a classmate who broke her ankle
- good horseback riding skills

She also responded to the questions “What is important to me? What are the people/activities/things/places that matter to me in everyday life?” Bella’s answers can be summarized with one word: family. The PCP document reported:

- Bella stated that her parents and her older sister are important to her.
- Bella stated that she likes to mess with her brother.
- She enjoys watching her brother play lacrosse.
- Bella likes going Christmas shopping with her dad.
- Bella enjoys going to the beach with her family.
- Bella loves her pets.

Ms. Rosalie, Bella’s school transition specialist also spoke of the importance of family in Bella’s life. “I’d describe Bella as very family-oriented. She goes to every one of her brother's lacrosse games and is always talking about her sisters. Though I also think she and Victoria have a very typical sibling relationship.” When asked about her siblings, Bella spoke of missing her older sister, Hermione. She also commented on her relationship with younger siblings, Emmett (17) and Victoria (13). “Emmett’s my only brother. I’m really close to him. Not Victoria. There’s a big giant age difference and she kind of bosses me around. She treats me like I’m two. Always telling me what to do. Don’t do this and don’t do that.” When asked to take pictures of things she enjoys, Bella’s family and pets were central subjects.

In addition to photographing things that she enjoys about her life, Bella was also asked to include photos of things she does not enjoy. She offered the following two photos under this

category, a math workbook and a handwriting workbook. Of math, Bella shared, “I never was good at math. I hate it. I will never like it. I just don’t get it. I get frustrated and...I don’t know...with math homework, I just feel like giving up.” Similarly, when asked about the handwriting workbook, Bella commented, “I hate it because they always tell me to go slow and steady and I already go really, really slow.”

Diagnosed with an intellectual disability and ADHD in early childhood, Bella has struggled academically throughout her schooling. She receives special education (SPED) support services and her current individual education plan specifies a primary area of eligibility under the category of Educable Mentally Disabled (EMD). EMD is a classification sometimes used by school officials to justify the provision of support services for students who have IQ scores that fall between two and three standard deviations below the mean, with scores generally ranging between 50-70. Other Health Impairment (OHI) is listed as a secondary area of eligibility on Bella’s IEP. OHI is a category applied broadly to cover a variety of health issues that may affect student learning, for instance ADHD in Bella's case.

7.4.1 Bella’s early years. New parents often experience a moment of anxious anticipation as they await the sound of a piercing cry signaling their newborn’s healthy entrance into the world. For Mr. and Mrs. Potter, this wait may have seemed excruciatingly long. Bella’s first few breaths did not come easily. Mrs. Potter explained,

When Bella was first born, her APGAR⁴⁰ scores were quite low and she was having some trouble breathing. They [the birthing team] didn't take any extraordinary measures, just suctioning her and such. Initially, they just had a little trouble getting her going.

⁴⁰ APGAR is a system developed by Dr. Virginia Apgar to quickly assess the health of a newborn infant immediately after birth.

Reflecting on Bella's first two years of life, Mrs. Potter recalls young Bella as a late bloomer who experienced digestive problems and frequent ear infections.

She was constantly spitting up and it just always seemed like there was always something digestively wrong with her. She also started having chronic ear infections. Though, through all of this we just assumed that Bella was close to "normal." She was reaching her developmental milestones...at the late end of normal, but she was reaching them.

Bella also commented on her early challenges with ear infections. "I was the queen of ear infections in my family! Every time I went somewhere, I'd get an ear infection. I had so many ear infections as a baby, I just couldn't think straight." Bella's mother shared,

It was around the same time when toddlers typically begin to develop speech and we noticed that Bella was really, really lagging with her speech. Because of all her ear infections, we and the pediatricians just thought, 'well...it's probably affecting her hearing and just related to that.'

At 18 months, Bella underwent surgery to have tubes placed in her ears. Myringotomy is a common surgical procedure for children prone to chronic ear infections due to the buildup of fluid in the middle ear. As the months went on, Bella's parents began to notice other marked differences between Bella and her same aged playmates. Mrs. Potter recalled,

We were in a little playgroup with other one and two-year-olds. The other little girls were just more engaged and interested in playing with different things than Bella was. Even compared to her older sister Hermione, who was more on the speedy side of her developmental growth. Bella's speech was still lagging and in terms of simple puzzles, naming shapes and things like that, she just seemed behind the curve.

Although concerned, Bella's parents remained hopeful that their young daughter would

eventually gain ground. Mrs. Potter recollected, “Nobody ever thought about labeling. There were no red flags until she was three and started preschool. Then the differences really became apparent.”

7.4.2 Bella’s childhood. By kindergarten, Mr. and Mrs. Potter knew that Bella was struggling with something more than just a speech delay. After a battery of assessments, Bella's parents received what they refer to as their “wake-up call.” Mrs. Potter stated, “It was the first time anyone had presented to us that Bella was mentally retarded. Even though we knew that she wasn’t where she was supposed to be - it just really hit us.” Further, Bella was also diagnosed with ADHD and placed on medication. Her mother recalled, “The teachers were concerned and we were too. Bella was just very flighty and she would take off and wander away.” In hearing her mother's recollection, Bella responded with a laugh, “Oh yeah...hey, I still do that!” Mrs. Potter continued on,

She was so impulsive and had a poor attention span. The pediatrician went ahead with the diagnoses (of ADHD) and that’s also where she got the label Other Health Impaired (OHI) rather than MR (mental retardation), so that she would have a wider range of options.

Over the next few years, Mr. Potter’s job took the family to three different states until planting roots in their current town. With each move and a new school, Bella underwent additional evaluations, in order for new school officials to determine the most appropriate classroom placement. Each evaluation report confirmed previous findings of a mild to moderate intellectual disability. Still, Bella maintained the single label of OHI and educated with same-aged peers in a general elementary classroom. She was, however, frequently pulled from class for one-on-one instruction and received heavy support while in the classroom. Bella also

repeated second grade "just to see if we could give Bella a little more time to catch up," Mrs. Potter shared.

In thinking back on her elementary school years, Bella shared fond memories of some of her favorite teachers and experiences.

Ms. Mehra...she was from India. So that was kind of cool. Ms. Davis was probably the first teacher I grew really attached to. And then there was Mrs. Pearson. In elementary school, the classes had different names. So we were the penguins. They called us the Pearson's Penguins and we had to waddle around like penguins. I swear to God! How embarrassing was that! It was actually kind of fun though.

Mrs. Potter also reflected on these early years and commented, "Through it all, Bella's personality was always sweet and compliant. The teachers always loved her. She tried really hard in school." Despite efforts, Bella continued to struggle. Mrs. Potter shared,

She just got to a certain level with her reading and handwriting....you know, they worked so hard and we would work really hard with her at home on letter formation and real basic math. Bella just never seemed to get past any first grade kind of level. Now, her understanding and her verbal abilities were always way beyond what she could do on paper. She has a good wealth of knowledge. In fact, a couple times she scored almost normal on a few things, but then scored way down in other areas.

7.4.3 Bella and early adolescence. When it came time for Bella to transition to middle school, Bella's teachers and parents met to discuss options and determined that Bella would be better served under the primary category of Educable Mentally Disabled (EMD) with OHI shifted to a secondary category. The decision was also made to send Bella to a school other than her home middle school. Although closer to her house, the EMD program had only boys at the time of

Bella's transition. Mrs. Potter explained, "We requested a transfer to another middle school that had more girls because we didn't want Bella to be the only girl in her class."

At her new school, Bella participated in three general education classes (two elective courses and a physical education/health course) each semester and spent the remaining four course periods in a self-contained special education classroom with instructional emphasis on the development of independent life skills and functional literacy and math. Mrs. Potter recalled,

Bella did okay, though we noticed that some of her peers (in the special education program) were further along in their writing and math skills. Bella's reading and writing weren't improving much, but she was gaining knowledge. She had these little social studies tests and she would remember things. She has an amazing memory. We all felt that she was doing well enough in that setting, so we left her there.

With the help of her yearbook to prompt memories, Bella shared about her classes and some of her middle school experiences.

I took Global Connections. I did sculpting for a while. I made a whistle to look like a dog and gave it to my dad. My dad still has all my artwork that I made over the years! I loved my sculpting teacher. Let's see...I also took theater. It was fun. I did Alice in Wonderland and was in the jury. I took P.E. and health. Oh yeah, in health we had to take home these baby dolls! Every time they cried, we had a key to shut it up. It was such a pain in the ass to carry around school. I was so glad it was over. It was really such a pain in the ass. It cried during class! You didn't get any sleep at night and you're like a zombie. I'm glad I did it though - it was life changing.

When asked of her thoughts on the possibility of children in her future, Bella laughed and stated with clear certainty, "No. I'll never do that again!"

Bella also recalled a few less favorable memories from middle school. Turning to the faculty section of her yearbook, she pointed to a picture of an older man whose face was crossed out multiple times in dark black ink.

He was my teaching assistant. Yeah...I tried to get him fired. He was just very...um...
...like...during lunchtime, you were supposed to hang out with your friends. He just followed you everywhere and wouldn't leave you alone. I just kind of got tired of it. He was annoying.

She also later commented, "I do have another memory from middle school. It's not a very good one." After quiet hesitation, Bella said, "I got picked on in middle school." She turned to a few different pages showing photos of three girls. Like the teaching assistant's photo, all were barely visible beneath dark inked Xs, repeatedly crossed over their faces. "Yeah..." she said with somewhat a scornful laugh, "Bella with a marker in her hand can be a dangerous thing!" When asked if she wanted to share more about these girls, Bella slowly pieced together her experience.

It was one of my friends...and her friends. I knew her because we went to elementary school together. Um...I was just hanging out with them and they started talking trash to me. Being mean and stuff. I didn't know what to do...I just kind of stormed off and hanged out with the popular kids. Yeah...they were kind of nice...but um... yeah, being picked on wasn't fun - at all. I just kind of shut it off. I had just gotten my braces off and still had my retainer, so I didn't speak to anyone for two days. It was kind of weird not having any friends. I did tell the intern working there and we sat down and talked about it. But...yeah...life was kind of tough.

7.4.4 Bella as a young adult. Bella described her move into high school and first year as a

freshman, “Hell.” When asked to explain she said,

It was just hard. You don’t know much of the teachers and just getting to class on time. The school work, the homework...it just throws you a curveball. I didn’t understand the workload and just juggling all of it...it was difficult. I had to drop a lot of my classes cause they just weren’t working. It took me these past few years to realize, I hated my freshman year.

Bella shared that she struggled socially and had difficulty making friends at her new school.

Lots of my friends went to the other high school. I wasn’t a social butterfly. I was very quiet and conservative. I’ve changed a lot over the past few years. I’ve grown so much and came out of my shell. I used to be shy. I didn’t want to talk to nobody.

Mrs. Potter also spoke of Bella’s challenging first year.

When she started high school, she was going to be with many of her peers from her middle school. So, this was the higher functioning special education class that integrated with some of the regular classes. Well, within the first few weeks of school we knew that Bella was just way over her head and it became uncomfortable for her. She felt completely lost and overwhelmed. She was unhappy and we were unhappy for her, because she would just come home and have these assignments that there was no way she could ever do. Expectations were just too great.

Bella’s parents and teachers decided to move Bella into a program that served students with more significant cognitive challenges. Housed within the same school, the “new” program placed less emphasis on academics and mainstreaming, and focused primarily on independent life skill development and vocation preparedness. When asked how Bella felt about the move, her mother shared “She was actually relieved. It was a positive thing. Obviously we want her to

do the best that she can, but it was all just too much for her.” Within her new class, Bella became a star student. Mrs. Potter commented,

Bella’s happy and enjoys the classroom. She’s actually the helper a lot of the time, because she’s, obviously, one of the highest functioning in that class. She was just talking yesterday about how both of her teachers always say, “Bella is our second brain. She helps us remember so many things.” So Bella feels important and feels like she’s really a help in the classroom.

While Bella’s confidence has increased, she expressed some frustration of often feeling like she is being treated as a child by one of her teachers. This was also reported in her PCP review document. In the same document, Mr. and Mrs. Potter noted concerns that Bella’s IEP directives are not being followed at school and reported, “Bella spends time making jewelry for the school store instead of working on math curriculum.” As for her academic growth, Mrs. Potter stated,

Bella is just not really getting any better. There are certain basic things that she can do. In terms of life skills training there’s probably more that she will learn in time, like telling time. I’m not sure that she’ll ever understand money very well. Her handwriting is probably worse than back in elementary school, because we are just not focusing on it so much anymore.

Bella’s teachers acknowledge that Bella’s learning challenges have been complicated to address. Ms. Renee commented, “With Bella, it’s a bit frustrating because you think she has gotten something and then it’s just gone...there’s such a big gap between her strengths and weaknesses. She has such splinter skills.” Ms. Anne spoke of inconsistencies in Bella’s school performance and brought up her tendency toward anxiety.

Bella has this general background knowledge that is higher than a lot of our kids. When she first came to us she was with students higher in ability. I taught her class and sometimes she would just get so nervous. We would be reading and I'd try to be so patient because I could see the anxiety on her face. I talk a lot to her about it, because it happens to me too. I call it "going stupid." I'll say "I know how you feel." Sometimes I'll point to a word and she won't get it, but then she will say a synonym of the word minutes later and show this incredible understanding. Even in making choices...she just gets that deer in the headlight look. We say "whatever you say is right...it's really whatever you want." But she freezes up. She has also kind of learned that if she just sits here long enough, somebody will answer for her and she'll be out of it.

Bella also seems cognizant of her difficulties in making choices and responding off-cuff. In conversations over the course of the data collection, Bella occasionally made the following comments when asked various questions about her life, "Ugh, my brain's not working today" and "Gosh, I just can't think straight."

Agreeing on appropriate academic expectations for Bella has been a difficult process for Bella's parents and teachers. Ms. Renee recalled a tense transition-planning meeting attended by all and reflected,

I think Bella's dad feels a bit bad that she is where she is....that they expected her to be a little higher or that she wasn't in the right program when she came to us. When we met for her transition meeting, he was laying out these huge ambitious plans...but then Mom was saying to him, 'This is Bella. Think about Bella, where she is right now. Is she really going to get there?' I was so glad Mom was there. She's incredibly accepting. I think it's a good balance.

Despite challenging discussions, Mr. Potter concedes “The teachers and ladies at the school, they do love Bella. I think they are doing the best they can for her, but I think it’s limited still.”

7.4.4.1 An assessment of Bella’s abilities and needs. Bella’s IEP and PCP present brief narratives of her current level of academic and functional performance and indicators of well-being and necessary supports. The following descriptions are derived from these narratives.

Table 18. *Assessment of Bella’s Abilities and Needs*

Reading	IEP: Bella reads, relying mainly on her ability to recognize words from sight. She is able to, at times, decipher a word using word attack skills. She is most successful when words are accompanied by a picture
Comprehension	IEP: She usually understands material that is presented orally, but seems to have difficulty focusing on auditory means of comprehension. She needs verbal prompting when it comes to higher order skills such as getting the main idea and summarizing reading material.
Writing	IEP: Bella is able to copy words from paper and the board. She has difficulty converting from upper case to lower case... She usually does very well on spelling tests if she has been practicing, but needs to improve on her everyday spelling skills (writing down notes, emails, etc.). She also needs to improve her ability to sequence words in a sentence.
Math	IEP: Bella is able to count objects up to 10 unassisted. She needs help staying focused and counting beyond 10 independently. She is able to copy numbers but is unable to add and/or subtract without a calculator.
Money	IEP: Bella can count by 5’s and 10’s consistently, but requires assistance when adding groups of different coins together. She can pay for items using the next dollar method for amounts up to \$10.00 PCP: Bella needs assistance with understanding the concept of money.
Telling Time	IEP: Bella cannot consistently tell time. She frequently confuses the hour and minute hands. PCP: Bella has difficulty with telling time.
Computer Skills	IEP: Bella is developing into an avid keyboard user and is quite knowledgeable about the computer and different aspects of the Internet (i.e. sending emails, Facebook, YouTube).
Vocational Skills	IEP: Bella is enthusiastic about most community and school based job sites. Bella has recently begun working at the hospital again, delivering newspapers to patients. She forgot some aspects of the job over the summer but is regaining those skills quickly. This position requires some problem solving and interaction with patients and Bella has excelled in both. Bella is very focused at the hospital and works for up to one hour without a break. She needs intermittent reminders to focus on work while at school. PCP: Bella’s family would like for her to continue vocational training while she is in school to prepare for a job once she graduates.

	IEP: Bella shows an interest in healthy living and has been quite active in different types of sports through Special Olympics. She is fun to be around and has a great attitude toward winning and losing.
Health/Safety	PCP: Bella is generally healthy, but she is overweight. Bella has skin eczema. Bella's family would like to see Bella have more success with physical fitness. In the event of an emergency, Bella might not respond well in stressful situations in terms of knowing what to do in the event of a fire, calling 911, etc.
Social	PCP: Bella can be shy at times. If Bella does not know the answer to a question she may become nervous. Bella enjoys discussing topics that she knows a lot about and is interested in. Bella stated that she would like to meet new friends and attend more social groups. Having an active social life is important for Bella (family comment).
Independence	PCP: Bella's family would like to see Bella gain independence to live apart from her family one day. Bella would do well with having staff assist her with daily living skills. Needs assistance with long term vocational and residential placement.

7.4.4.2 Goals and objectives. From the above assessment, Bella's annual IEP (Table 19), Transition (Table 20), and PCP (Table 21) goals were determined, as summarized below:

Table 19. *Bella's Individual Education Plan Goals*

Goal 1: Bella will demonstrate the ability to create readable sentences using a keyboard.

- Proper casing of letters
- Appropriate spacing between words
- Correct spelling

Goal 2: Bella will demonstrate the ability to read and write at her level as it relates to her daily schedule.

- Identification of days of the week and months of the year
- Following simple written instructions
- Reading and following a simple recipe
- Spelling 10 basic sight words correctly each week
- Reciting and writing personal information from memory
- Completing simple job applications with and without using a personal information sheet as a reference

Goal 3: Bella will demonstrate the knowledge of eating healthy foods and exercising

- Identification of food groups
- Appropriate portion size
- Reading and understanding labels
- Healthy meal preparation
- Development of healthy eating habits

Goal 4: Bella will participate in school and community based job sites.

- The development of work skills
- Maintaining sustained focus

- Accurately completing assembly tasks
- Requesting assistance in timely manner

Goal 5: Bella will pay for items using dollar bills and coin combinations, use schedules, newspapers, and basic charts to find information, and tell time to the quarter hour.

- Identifying values of coin combinations
- Purchasing items using the “next dollar method”
- Using a variety of information resources to answer questions

Goal 6: Bella will interact with a variety of people in the community in a mature manner.

- Autonomously asking and answering questions
- Conversation turn taking
- “Stranger danger”
- Home safety practices

Table 20. *Bella's Transition Goals*

Instruction: Bella will receive direct instruction in (1) vocational skills and (2) functional academic skills and (3) attend a choir class to develop her musical skills, interests, as well as to socialize with her general education peers.

Community Experiences: Bella will (1) demonstrate knowledge of rights for self-advocacy, including when to stick up for herself and expressing her emotions, (2) attend and discuss cultural events in the community including musical and art events, (3) show respect for other’s privacy and protect her own, (4) engage in conversation with people in the community at appropriate times and maintain an appropriate rate, (4) participate in Special Olympics sports, and (5) participate in therapeutic horseback riding.

Employment: Bella will (1) identify and practice skills inherent in getting and keeping a job, (2) complete work tasks with minimal to no prompting, (3) maintain a work rate for extended periods of time, (4) work with fellow students, co-workers, and job coaches as a team, graciously accepting constructive criticism, and (5) participate in a variety of school and community based vocational training sites to determine vocational interests and develop job skills.

Adult Living Skills: Bella will (1) explore different living options and determine what types of support she will need in those settings (2) keep a basic budget and practice paying bills, (3) participate in the different aspects of citizenship such as voting, recycling, and community involvement.

Daily Living Skills: Bella will (1) shop for and prepare simple healthy snacks and meals, (2) have a weekly exercise schedule, (3) do her own laundry, including sorting, washing, drying, folding, and putting away.

Table 21. *Bella's Person-Centered Plan Goals*

1. Bella will receive case management services. (a) Bella will receive case management to assist her in transition planning while in school and to plan for what she wants to do following graduation. (b) Support Broker will assist Bella and her family with applying for Medicaid and SSI. (c) Support Broker will assist Bella’s family with applying for guardianship, if needed. (d) Bella will be an active participant in the case management services she receives through the plan year, including creation and updates to her person-centered plan, goals, and visits with her Support Broker at least once a month.
2. Bella will receive assistance with becoming more connected to the community. Support Broker will assist Bella with finding more social opportunities in the community to enhance her social and communication skills.

When asked about her participation in IEP and PCP meetings, Bella stated, “I decided not to go to them. I let my parents do the talking. I don’t feel comfortable being around a bunch of meetings. I get kinda squirmy. I just don’t feel like going.” Of individual goals determined by her parents and teachers, Bella stated that she felt all were very important.

7.4.5 Bella and high school life. Bella does not attend her home school, but rather travels across town to a school that has an established special education program to support students with I/DD.

7.4.5.1 In the classroom. Bella’s school days are largely spent within a self-contained classroom. Or, as Bella noted, “All freakin’ periods...except when we have PE and choir together.” Although Bella’s daily schedule follows a typical seven course period day, it fluctuates often depending on school events, class activities, and community outings. Ms. Renee and Ms. Anne, Bella’s core teachers, divide instruction and case management responsibilities with support from two teaching assistants and Ms. Rosalie, the school transition specialist.

Bella’s classroom is a large room with cabinets and a counter covering the back wall. A full size refrigerator sits at the far end of the cabinet space next to a kitchen-sized sink. The right front corner of the room has three computer stations and a sitting area with bookshelves and beanbags. The following class rules are posted on a side wall:

1. Copy schedule.
2. Follow directions.
3. Use manners.
4. Do not interrupt.
5. Respect others and their property.
6. Work quietly.

7. Finish work on time.
8. No talking out loud.
9. No bossing others around.
10. Keep hands and feet to self.
11. Be honest.

Rows of desks, four-by-four, face the front wall where a Smart Board with touch screen capabilities takes center stage. A laptop sits on the teacher's desk to the left of the board, used to display content on the board for instruction and fun. Bella shared, "We all love it. We check the weather from the laptop. It's actually really cool. We play games like Wheel of Fortune and watch movies."

7.4.5.2 Instructional content. Unlike core courses within the general education setting that are bound by a state-mandated curriculum, instructional content for self-contained special education classes is largely determined at the discretion of the individual teacher guided, ideally, by student IEP goals and objectives. Content emphasized during observations in Bella's classroom included a review of weekly spelling words, a class discussion on global warming and pollution prevention, a viewing of a YouTube video about homelessness in their community, a menu review of a local diner to solicit student orders in preparation for lunch outing, and a guest lecture from a local vocational rehabilitation specialist and a manager of a retirement community on potential job opportunities and interviewing skills. Students also spent one course period, math, stuffing and sealing envelopes with mailers to be distributed later by the school district. Ms. Anne explained that this was a common classroom activity and an opportunity for students to strengthen and generalize skills such as one-to-one correspondence and to develop other work skills including collation, following directions, and teamwork. During each class session, Bella

appeared focused and engaged. She asked on-topic questions and contributed to class discussions. When asked a question, Bella sometimes had difficulty providing an immediate answer. However, when provided opportunity to initiate questions and responses, Bella did so with more ease.

7.4.5.3 Lunch. Bella and her classmates eat lunch together in the school cafeteria with supervision and assistance from a teaching assistant. To avoid the crowd of students, they are allowed to arrive early to make purchases and claim their table. When class activities delay lunch, Bella's classmates and teachers will often eat "family style" at a large table in the classroom. The teaching staff plans for these occasions in advance. Ms. Anne, Ms. Renee, and the two teaching assistants bring in casseroles and other food items, sometimes requesting contributions from the student families, as well. In joining a lunch gathering, it appeared customary practice for the teaching staff to administer place settings and food distribution as students wait to be served in their seats.

7.4.5.4 Choir. Bella attends choir class with three classmates and approximately twenty other students. Mr. Cowell is the choir director and his classroom is a fairly large room with chairs arranged in rows on a graduated platform, shaped in a semi-circle. A piano and a music stand are positioned floor level and mid-center. Unlike the other students who enter the classroom and retrieve a binder from a side shelf before sitting, Bella and her three classmates go directly to their seats without taking a binder. Mr. Cowell begins the class by asking students to open their listening logs and record their thoughts on a selection music played from a small stereo at the front of the room. He prompts them with reminders to pay attention to musical qualities such as rhythm, dynamics, pitch, and timbre. As the other students jot notes in their binders, Bella and her three classmates sit and listen. Bella examines her fingernails. "What you

hear?" the instructor asks when turning off the music. Many raise their hands to respond, including one of Bella's classmates. After a few minutes of discussion and then reminders of upcoming events, Mr. Cowell leads the class in vocal exercises. They spend the remaining class period practicing, as a whole group and in sectionals, three different songs. As they sing, the students with binders refer to sheet music provided inside. Mr. Cowell provides Bella and one classmate sheet music for one of three songs.

Of choir class and Mr. Cowell, Bella commented, "I love that class. Mr. Cowell is really nice and so funny. He even taught me some dance moves." Ms. Rosalie, Bella's transition specialist also spoke of Bella's participation and enjoyment of the choir class.

Bella loves chorus. She's so confident in there. Whenever Mr. Cowell asks a question, she'll raise her hand to answer. He'll ask a question about her weekend or he'll say "Who did something fun this weekend?" and she will start talking. Sometimes she will go on for 15 minutes... well not that long, but she does have a tendency to go on and on. She has a little crush on him.

Perhaps true. While at a coffee shop one day, Bella encountered Mr. Cowell and stopped for a brief chat and hug. While walking away she said with a smile, "I bought him a chocolate rose for Valentine's Day. It was for a school fund raising thing." In feigned outrage, Mrs. Rosalie later commented, "I actually bought him the flower and here she gets all the credit! She was so happy though. She giggled for about an hour after."

Occasionally, Bella and her classmates do not attend the choir classes. She also shared that they only participate in some of the concert events, providing the explanation,

Yeah, they were trying to get ready for their concert so I've been staying in Ms. Renee's room first period. So...yeah, our schedule has been sort of like weird. I, pretty much me

and two boys and a girl, we've just been stuck in our classroom for work.

When questioned about these instances, Bella replied, “Well...I mean...I guess we need to focus on our work....” Of the concerts she has participated in, clear excitement evinces through her voice and eyes as she recalls the events. “Yeah, we had a dress rehearsal and wore these long dresses and the guys had to wear a tux. It was pretty cool.”

Bella’s annual transition report documents her attendance in choir class as a “transition activity” and states “Bella will attend a choir class to develop her musical skills and interest as well as to socialize with her general education peers.” However, on a segment of the document requiring a signature as evidence of a general education teacher’s participation in the IEP/Transition process, the signature space is left blank except for a statement that reads, “Bella does not participate in the general setting.”

7.4.5.5 Physical education. Bella also participates in a physical education class with her general education peers and commented, “Yeah...it’s not my favorite class.” When asked to share a bit about the class, she said,

We did rollerblading. It wasn’t fun. I was kind of...it just wasn’t my favorite thing. We also did lacrosse and salsa dancing. The guys had to come and invite us, so it was kind of different. You had to partner with a guy. I danced with my brother’s friend. He didn’t mind. Yeah...not one of my favorite classes.

An observation of Bella in PE yielded little information in terms of other class activities, but did offer some insight into Bella’s engagement with the other students. On this particular day, the students (all female) were instructed to run laps around a practice field and then wait for the instructor who appeared twenty minutes into the class session. Bella ran and walked the laps and sometimes paired with a classmate to chat. When finished she sat quietly within the larger

group of students as they waited for the teacher to arrive. Although Bella did not engage in the group's conversation, nor was engaged by the other students, she appeared at ease and seemed to enjoy listening to their conversations and being a part of the group. Once the teacher arrived and took attendance, she informally conversed and joked with the girls and then dismissed them early without further activity.

7.4.5.6 Community-based activities. Portions of Bella's time during the school day are spent off campus participating in community-based activities. These activities include weekly bowling trips, shopping for gifts at the mall, shopping for groceries or craft supplies for classroom projects, and visits to museums and other local attractions. While it was explained that the intent of these outings are to provide students opportunities to practice social and functional life skills (money skills, decision-making, problem solving), neither areas were specifically emphasized during the two observed outings (bowling and craft store). All opportunities to handle money on both occasions were done by the teacher staff. With exception to voicing preferences on purchased materials or choosing a bowling ball, the majority of decisions made were also determined by the teaching staff. This may not be the case for other unobserved outings. However, the purpose of these two trips appeared to be scheduled primarily for recreational purposes, out of routine, and to meet the preparation needs of the teachers rather than the instructional needs of the students.

7.4.5.7 Vocational experiences. In addition to community-based activities, Bella and many of her classmates travel off-campus to gain work experience as part of their transition program and individual goals. Bella shared, "I get paid from the school for my work. We have Voc. Rehab, so I get paid. It was like...eighty dollars? I forgot. The first one I got, I put in the bank and the second one I still have. I gave it to my mom to keep it safe." Two of Bella's off-

campus jobs include delivering newspapers to patients at a hospital and feeding horses and cleaning stalls at a horse stable.

Newspaper delivery. Once a week, Bella and a classmate travel by school bus with Mr. Tucker to the local hospital to deliver newspapers to patient rooms. Wearing assigned hospital uniforms (a red knit shirt with an embroidered hospital logo and khaki pants); they begin their shift in the volunteer workroom unpacking and loading stacks of newspapers onto a cart. As they roll the cart from room to room, the two classmates look to signage posted outside each room to determine delivery options. White and blue signs indicate room entry is limited under certain conditions. For these rooms, a newspaper is left on a cart outside the room. For rooms without restriction, Bella and her classmate take turns entering each room, introducing themselves as a volunteer and offering the newspaper. Although Bella breezed confidently into the rooms, her self-introductions were spoken with such speed (Hi I'm Bella. Would you like a newspaper?) that they were often met with a "Huh?" and "What was that?" No instructional attempt was made by the teaching assistant to improve Bella's entrance. Before leaving the hospital, Bella, her classmate, and Mr. Tucker eat lunch in the hospital cafeteria. Her mother commented, "She seems to really like the hospital job. I think because it's so social and she really likes to have lunch there." Bella shared, "I like this job [at the hospital] because it's a good workout!"

Horse stables. Bella's passion for animals, particularly horses, prompted Ms. Rosalie (Bella's transition specialist) to seek opportunities for Bella at a local stable. Bella shared a bit about her job, "I work at a barn on Friday. Ms. Rosalie drives me. I feed the horses and clean their stables. It's kind of fun. I really love it there. I get to be around the horses...so it's sort of cool!" Ms. Rosalie highlighted Bella's adeptness in this position,

Bella knows a whole lot about horses. She rides every Saturday. She loves the horses and knows every single one. I'll make a mistake, like I was about to give one someone else's food and Bella will say "No Ms. Rosalie. That's Stanley." She knows all of the different names of the brushes and how to use them. She has no fear when she is grooming the horses.

She also commented on some tasks that do not come as easily for Bella.

When we are feeding the horses, counting out the number of buckets we need is nearly an impossible task for Bella. Counting out four buckets and laying them where they need to go. She did it today and I was so thrilled. But every other time, I'll say four buckets and she will do "one, two, three, four, five, six, seven, and just keep going."

7.4.5.8 The school library. Bella shared, "I go to the library almost every day during lunch to use the computers - check my email and just mess around on them." Presented with the following questions:

- Do you ever go for lessons on using the computer?
- Do you ever go for lessons about other library resources and how to find information?
- Do you ever go for assistance with school projects or homework?
- Do you ever go to explore and check out books?
- Do you ever go to read magazines?
- Does your librarian ever come to your classroom?

Bella replied "No" to each and stated, "I just go to use the computers." Bella was also asked about her interactions with her school librarian. She shared that she does not often speak with the librarian and had difficulty recalling her name. Despite Bella's limited use of school library resources for academic and personal purposes, when asked to share her thought about the role

and importance of libraries and librarians, Bella asserted, “I think they are really important. They help people find information.”

7.4.5.9 *Pep rallies and school sports.* Bella lights with excitement when talking about the extracurricular activities of high school life, particularly pep rallies and school sporting events. Of a recent school pep rally, she said,

We had a shorter day on Friday because there was a pep rally. It was for all the spring sports. So yeah, it was pretty cool! The student government had shirts that were glowing.

It was really awesome. Papers came down from the top - like streamers. It was just really awesome and our band is so good. It was just really fun! It was pretty awesome.

On Friday evenings, Bella can be found sitting in the high school bleachers cheering on her school football team. Of the previous season, Bella shared, “Yeah...football last year was a pretty depressing year. Our football players...one died of a heatstroke and the other died in a car crash.” Bella also attends many of her brother Emmett’s lacrosse and soccer games and speaks fondly of his teammates, “They’re kinda like big brothers to me.” Bella’s mother confirmed, “Bella really likes to go to his games and everybody knows her there.”

7.4.5.10 *School dances.* Although Bella does not regularly attend school dances, she spoke excitedly about her school prom. “It’s a lot of fun. I get to hang out with my classmates and girly-up. I’m usually a tomboy and just like to wear jeans and t-shirts.” Her father also commented about the events.

Ms. Renee and the ladies at the school, they’ve really taken Bella under their wing. For prom, we just gave them the money and they got her the dress and everything. They were really into it, which is nice. Bella has been to two proms now. She always gets invited.

Of the two proms, Bella attended one with a date and the other with a group of classmates. When asked about her date, she simply stated, “Ummm....it was different.”

7.4.5.11 Clubs. Bella has been active in a school club that formed in response to the 2010 Haiti earthquake. After learning about the tragedy, she shared that she felt compelled to help and originally promoted the idea of hosting a bake sale at school to raise money for the victims left injured and homeless. “I said ‘Let’s do a bake sale, but yeah...my idea kind of got squashed.’ Shortly after presenting her ideas, Bella learned of an initiative by students who also felt moved to help. Ms. Anne recollected,

Even before we heard the announcement of the club, Bella wanted to spearhead a fundraiser and then we heard that another group was doing the same thing. We said, ‘Bella, why don’t you just go to that meeting?’

Ms. Renee expanded,

Bella couldn’t wait to volunteer. We went to the meeting. Bella was accepted into the group and she asked appropriate questions. Sometimes she has a tendency to...well...she doesn’t really realize it, but sometimes she tends to dominate. It will be just a free association sort of thing.

Of her involvement in the club, Bella shared,

It was kind of just perfect! So now I’m on it. We are doing, like, fundraisers and selling Band-Aids and stickers and these wristbands. We are pretty much reaching a goal to make...I don’t know how much money. I’ve really lost track. I collect money from classes. I go to the rooms with sticky notes. So we see if the teachers have money or not. It’s kind of nerve wracking because I try not to disturb the classes. So yeah, that’s the hard part, because the teachers are teaching. And my email fills up with messages and

I'm just like ugh! The process of getting it...it gets a bit stressful. But, I like to check to see what's going on. So... it's just kind of awesome to be on the committee. Kind of cool!

7.4.6 Bella and friendships. As emphasized in her Person-Centered Plan, Bella often struggles in social situations and has difficulty developing and maintaining meaningful friendships. Social isolation and loneliness are common experiences for many with I/DD. Mr. Potter commented on Bella's advantage, in terms of her ability to "pass" socially over others with I/DD who sometimes have behavioral and/or physical differences that set them apart.

As far as people with mental retardation go, some folks can be off-putting unless you're around them and understand them and you are comfortable with them. With Bella, if you just walking down the street and you just saw her, you wouldn't say there is something off, but then when you get to know her you would realize - oh yes, there is. A lot of people think that she is higher functioning than she really is because she is so social and she can talk about things. She has a good personality, she doesn't have anything glaring, like physically, that might put people off.

Indeed, numerous studies have shown that youth with more observable differences experience higher degrees of social alienation. However, having the advantage has not shielded Bella from social struggles. Her mother shared,

Bella's social life has been kind of a problem all along. It's just been hard to find a good fit. For the longest time, Bella seemed normal enough that it looked like she should be able to fit in and join with the regular kids, and she did for a while. She did soccer and her dad would coach.

As Bella and her teammates grew older and their interests and skills diverged, Bella's

mom conceded, “It became time to recognize, you know, we may need to go to Special Olympics, and it’s been really great! So... part of it has been us, just coming to terms with letting go...with Bella fitting in as normal. ”

Mr. Potter also spoke of Bella’s difficulty in forming and maintaining friendships. “She doesn't really make great connections with friends. She doesn't really ever want to have friends over.” Mrs. Potter added,

There are times when Bella can't... she just doesn't seem to interact. She interacts and socializes with adults and wants to hang around with us or our friends or her teachers, more so than her peers. It just seems that she has trouble connecting with her own age group. Her social life has been kind of the problem all along. So, she is very connected to the TV, the computer, the iPod.

Bella’s school placement has also played a part in Bella’s difficulties forming lasting friendships. Mrs. Potter commented,

She was pretty good friends with this one girl, but she was quite a bit higher functioning than Bella academically. And then when they got to high school, her friend stayed in the higher track and Bella dropped down. They've lost touch completely. It was the same with another girl who is now actually at another high school in the higher class.

In terms of Bella’s classmates and the potential for friendships, finding compatible individuals have also been a challenge. Her mother explained,

We've tried arranging get-togethers with people from her class, but it hasn't seemed to work out very well. There are only a couple of girls in her class. One, Bella seems to really like, but she's allergic to cats and she doesn't want to come over to the house.

We've offered to take her to football games in the fall, but for some reason she couldn't

go. Not sure exactly what the deal is. It's just never really worked out. And then, there is a girl that Bella has known over the years and done things with. But, they really don't seem to get along anymore. It is not really that they don't get along; it's just that they don't interact when they're together. She doesn't seem to want to see her much.

Mr. Potter spoke of Bella's friendship with one young man that she has known for a number of years,

There is one boy, Ron, and Bella does some stuff with him. But even when they are together, they are not really talking. They are just kind of sitting there and half the time he's texting. He is a little higher functioning. We go to the football games together sometimes and it's not like they are having these great in depth conversations. But still, I know it is nice just to have the companionship. Just the fact that they are there together, I think that is a good thing. So, she still wants to do stuff with him now and again.

When asked of Bella's interest in boys, Mr. Potter reflected,

You know, I think she is smart enough to know or to want certain things, but she is not quite old enough to really enjoy... I don't know ...it is kind of hard to put a finger on it. She likes the social part, but she is not really good at it.

In recent months, Bella has become acquainted with another young man who plays on her Special Olympics softball team. His name is George and, according to Bella, he is both a "ham" and a "gentleman." When asked to share a little about their friendship, Bella commented,

He was on my softball team and we exchanged numbers. He's super nice and just kind of a fun guy to hang out with. We usually talk on the phone for like an hour catching up and stuff. He always finishes my jokes.

Bella giggled when asked if George was a boyfriend and said,

Funny, my parents asked me the exact same thing! No, he's just a friend who happens to be a guy. Besides, he's really tall and I'm short so it's like...weird. He's just a really good friend. One time there was this other guy from another team and he was messing with me and stuff. George started getting all protective. Like...that's why I like him, because he such a good friend and he always protects me. He's so caring of others. Yeah...he's a good guy. Fun to hang out with...but just a friend.

7.4.7 Bella and home life. Bella returns home each day on a school bus. “The first thing she does is come right to the refrigerator, fix herself a snack, and ask, “What's for dinner?” It's like clockwork!” Bella's mom shared with a smile. Bella confirmed this with a “Yep! She's got me pegged!”

7.4.7.1 Homework. Homework expectations have decreased over the past few years. Bella's mother explained,

She usually has a packet of spelling words. They have to write the word three times over and sentences. They haven't been sending math home for a long period of time. Which is good because it's really frustrating when they do.

Bella's response to the question of homework was “Sometimes I do. I don't have math homework anymore. Thank God for my mom. She saved my sanity!”

7.4.7.2 Chores. Bella earns an allowance for completing household chores. These include emptying the dishwasher after school, changing her sheets, putting away her clean clothes, feeding the pets, and cleaning Lopez's cage. “UGH! That's the only part I don't like about owning a gerbil - it reeks!” She also helps her father prepare some of the evening meals. Mr. Potter shared, “Bella wanted to learn how to cook, so I've been teaching her things. She is my little apprentice cook.” Mrs. Potter also spoke of Bella's emerging culinary interests, “She

helps her dad with dinner...with the chopping, stirring, etc. She really enjoys it and takes great pride in what she helps to make.” Of favorite dishes that Bella and her father prepare, Bella stated, “We make shrimp pasta. It’s pretty complicated. You have to peel the shrimp and I’m the queen shrimp peeler of the family. No one can do it like me!” Bella also mentioned another favorite family dish, bacon carbonara. After “zipping” her mouth to indicate that this was a secret family recipe, Bella proceeded to list all of the ingredients and process. She then said, “The best part is that I get to eat while we cook!”

7.4.7.3 *Helping Mom.* While discussing chores, Bella referred to her mother’s MS and feelings of added responsibility. She also spoke of an increasing tension between herself and her grandmother.

It’s kind of hard, especially since I’m always home so much, As soon as I get home I help my mom out, pretty much, as much as I possibly can. I warm up her food and make sure she has a glass of happy wine. I’m twenty one, so sometimes my dad lets me have a little too.

Bella continued, “My dad is always there to help too, because she falls. Twice a day. She’ll just stretch and her legs won’t work and she falls. So I have to call my dad and he has to come pick her up.” Of struggles with her grandmother, Bella’s voice rose with frustration,

She thinks I don’t do anything in this house. It’s like BS! Excuse my language. I help my mom a lot. 90% of the time I help my mom out. My grandma’s like...’You’re being lazy. You don’t do anything around here.’ Now, I may have the attention span of a peanut but I have the work ethic of a horse. She just doesn’t appreciate that and it drives me nuts. She always makes me feel really uncomfortable sometimes. When she’s around me, I kind of be nice. I kind of shut off my tongue with my grandma about it all.

I don't talk to her much. When she's around me, her and I fight.

Mr. Potter spoke with resignation about his wife's MS, how they have coped with it as a family, and Bella's response.

You know...we all just kind of just go with it. We all know. The kids, they all know that she is getting worse. But it is what it is. We all know it's there. We talk about it sometimes and Bella knows a little bit. I mean...she knows what it is and if she sees something she may mention it, but we all just try to be helpful. Bella has become very helpful...more so in just the last year or two in terms of being a part of the family and helping out and wanting to help out. She wants to do things. Now...will she come to the kitchen, let's say if the kitchen needs to be picked up and just start doing it? No. But you know, my fully functional 18 year old and 16 year olds, they won't do that either. But Bella, when asked, she's quite willing to jump when asked, definitely. She is always willing to pitch in.

When hearing her father's comments of her helpfulness and obvious pride, Bella giggled and said, "Ahhh...you're getting me all emotional now! Yeah...man, I love that little booger."

Bella's feelings about her mother's health weigh heavy. When asked if she has ever spoken to anyone about her worries, Bella's voice softened and a few tears came to her eyes. "I love my mom...I don't really like to talk about it much though. I just kind of shut it off...but whatev'." After a few moments of silence, she went on,

My grandpa had ALS, so that's another thing that changes your personality in life. I was only ten when he died, so I don't remember much. I talked to one of the technology experts at my school and a person who works at my church. I just told him about my grandpa, pretty much. I've kept it in so much...so I told him. It took a weight off my

shoulder. It's definitely hard. I can't get sick cause my mom's immune system can't fight it off. So I try to stay healthy. Oh...I also talked to a psychologist up in the CIC⁴¹ room at school. One of my friends from school - he was in a choral concert - I introduced him to my family. He asked me why my mom is in a wheelchair. It just...kind of made me appreciate how I am the backbone. We go somewhere, I always push her. I take care of my mom every single day. I don't know....It's kind of hard so I don't really talk about it much.

7.4.7.4 Television. Of afterschool and weekend leisure activities, Bella's mother commented, "Well, there's a lot of TV watching." Bella's father confirmed, She comes home from school or on the weekend and plops in front of the TV set. You know...it's something to keep her busy. She gets lonely, but she also doesn't want to go do things or cultivate friendships. I'll say "Hey let's call so and so or let's go do this or that" and she'll say "No. No. I don't want to."

When asked about the types of shows she enjoys, Bella listed the talk show Ellen, the comedy sitcom Scrubs and reality shows America's Next Top Model and American Idol. Out of all, Bella identified ESPN Sports Center as her favorite show to watch and then exclaimed, "Oh boy, I sound just like my dad!" As a family, the Potters are loyal to their home college football and basketball teams and enjoy evenings and weekends watching the games together as a family. Bella also will often watch televised sporting events on her own. Mr. Potter contemplated,

I think with sports, it's live and you're in the moment. It's like you are a part of it. Bella gets real enjoyment from watching sports on television. Sometimes I have to tell her, 'Bella, you are not watching a live game. That's ESPN Classics. That's like a ten-year-

⁴¹CIC is an acronym for Career Information Center which is a high school program that provides information on post-secondary options, including information about higher education institutions, vocational schools, and military service.

old game or that happened last weekend. But still, she's just really into it.

7.4.7.5 Pop culture. Bella also stays current on celebrity gossip and teen trends by watching tabloid news shows, surfing celebrity news blogs, and flipping through the pages of People Magazine and Seventeen, which she keeps in a stack next to her bed. Her mother commented, "If there's any celebrity news, Bella can tell you about it.... which celebrity is having a baby, who is breaking up with whom..." Bella also keeps up on popular literature and her overstuffed bookshelf conveys the heart of a true bibliophile. Mrs. Potter shared,

Bella loves having books...carrying books around. She sort of reads them, but it's hard to say how much. One of the requests on her Christmas list that she really, really wanted to have was Mia Hamm's book Go for the Gold. She loves having that one. She used to check it out from the library all the time, but now she has her own. She also wanted the Obama books. Audacity of Hope was on her birthday list. And the Twilight books...my goodness! Anything to do with Twilight, she's just crazy about.

Bella is a confirmed Twi-hard. Giggling, she shared, "Yep, I'm on Team Jacob. Edward just seems like a lunatic." Mrs. Rosalie also commented on Bella's love of Twilight, "She told me that she and her father are listening to the audio book. That poor man! What a good guy!" Beyond areas of pop culture, Bella also stays attuned to local and world events. Ms. Rosalie shared,

I find that we have our biggest conversations when we are either talking about the choir teacher or when we are listening to NPR. We listen to NPR every Friday morning when we're driving to the farm. You know, with this whole oil spill thing [Gulf oil spill]...we've been talking about it so much. I'm just sick about what happened and Bella just feels so much empathy about everything.

Of Bella's main channels of information, Mr. Potter commented,

Most of the stuff she probably gets from school and the rest of it she'll pick up from watching TV in the evenings. She will watch local news and some of the Hollywood news. She is on the internet, as well...cruising around Facebook and other areas. You know, she just likes being a part of it all.

He later concluded,

Now, I don't know if she really gets all of it, though she really likes keeping up on it all. Having all that information and being able to bring it up and mention things. Just joining in on the conversation here and there when she can. Again...Bella just likes being a part of it all.

7.4.7.6 Computer use and online activities. Bella's parents have recently purchased her a laptop, which she often carries around the house and surfs while watching television. When asked about her online activities, Bella shared that she has a Facebook account, often searches for information of interest (she gave the example of looking at game schedules and scores of her favorite sports teams), scans celebrity news sites, checks her email, watches videos, listens to music, and shops. Her favorite websites are bookmarked and she explained, "I pretty much put them there so if I need anything I can just go there and pick it out." Bella also has a regular practice of clearing her search history when online. When asked if this was to protect her privacy, she countered, "No, not really, it's just that I like to clear stuff before I do stuff again. I don't know why... I just like to do that for some reason." Bella was also asked how she acquired many of her computer and online skills. She responded, "Oh, just by messing around." When asked if she ever receives instruction about technology and the Web from school, Bella commented, "Yeah, at school I learned that you can change your settings to keep things private,

so that people don't see what you're posting when you don't want them to."

7.4.7.7 Facebook. Like many young adults, Bella spends a fair amount of time on Facebook. She shared that she does not post often, but rather goes to the site "just to see what everybody is up to." Bella's Facebook profile is private, only providing her birth date and political affiliation to those unconnected. She has just fewer than one hundred "friends." These include family members, family friends, her own friends, teachers, and schoolmates. Bella commented that Facebook is an easy way for her to stay in touch with her older sister, Hermione and other distant family members. "Yeah, I took one summer to track them all down!" Mrs. Potter also spoke of Bella's use of the social networking site.

Bella loves to be a part of all that and saying that she is a part of all that and having the connection. But to actually send emails and post messages on Facebook, it's hard for her. Bella will write things on Hermione's wall, like "Love you Bella. Where are you" and other random things. Hermione says she gets a kick out of reading her posts and that it always cheers her up to see a message from Bella. And Bella, she is just thrilled when Hermione responds. She'll also say, "Somebody friended me!" and come and show us. Having that connection is really exciting for her. The actual messaging is hard, but she really likes being a part of it.

Mr. Potter also mentioned Bella's Facebook use.

She "friends" people all over the place, a lot of our family members, cousins, aunts and uncles. She's having all these conversations all the time with people we don't always know...but she's doing it. I don't know if that's a good thing or a bad thing, or if she is annoying people or what. We've never gotten any phone calls from people asking her to stop. I think she will see someone online and write some little note. Maybe they will

have two or three little exchanges and that will be it. She can't write complete sentences really, but with some of these programs now, you type it and it gives you suggestions. I don't know if she uses that tool on Facebook and other sites or not.

7.4.7.8 *Searching for information.* Mrs. Potter commented on Bella's determination and success online in terms of searching and finding information, despite weak literacy skills.

If it's something she is interested in, she'll find it. Sometimes she'll ask us for help with spelling, but a lot of time she will just pull out her laptop and trial and error, just on her own. She finds all kinds of things. One time, she knew she wanted a grooming kit for Christmas. She was frantically searching and I asked, "What are you looking for Bella?" She would say nothing. She worked and worked at it and finally she said, "Look Look!" My mother was visiting. She was amazed and said, "Did she do that all by herself?" I said to her, "Mom, she can do more on the computer than we can. Believe me."

Bella spoke with excitement of her recent online success in finding a new pair of tennis shoes.

They're pink, like for breast cancer and they have ribbons on the side. My grandmother was actually diagnosed with breast cancer and my next-door neighbor too. So it kind of hit me like....I just found these shoes and I was like, "Perfect!" My mom ordered and paid for them and I had to pay the shipping....well, I actually still owe her money.

When asked if Bella ever independently purchases items online, Mr. Potter explained that although they have tried to teach Bella how to use gift cards and iStore credit for online purchases, they have had little success.

You know, it may take a normal person - say five times to remember something. With Bella, you have to tell her 100 times and maybe she will get it. She received a \$25.00 gift card for her birthday and we set up store credit for her, but then we had to change the

password because she would log on and just buy all sorts of stuff without any concept of price. All of a sudden, I'm getting these \$30 iTunes receipts in my email. So we had to cut that off. Now she just gives us a list of things and we'll buy the things for her. I think she'll eventually learn, over time, but for now we don't give her the access.

Cell phone use. At age nineteen, after months of begging, Bella received her own cell phone. Her father recalled,

Bella was dying to have one. She saw everyone else with a phone and wanted to be a part of all that. She doesn't really have anyone to call but home and her brother and sisters....but she has one and she's happy.

Mrs. Potter agreed,

She loves having it. We do get a lot of random phone calls now. If she's at Special Olympics, she'll call every 10 minutes or so. Or if she is at one of Emmett's games with her dad, she will just keep calling, just to call.

On a recent birthday, Bella's parents upgraded her phone to an iPhone. With enthusiasm, she showed off her new phone and said, "I'm getting better at working it, but it's taking time. I don't know how to put music on yet." Bella has learned to take pictures and videos though and proudly presented her collection. "I send them to my aunt. We constantly text." Taught to use the text feature by her brother on her first phone, Bella now describes herself as a "text junkie." Although her messages often contain missing and misplaced letters, Bella's intent comes through. The following is a screen shot of text messages sent by Bella.

Figure 22. *Bella's Text Message*



When asked about the importance of her laptop, cell phone, and other technology tools in her life, Bella stated, “Well, my laptop means the world to me. I just love it. It’s all just so...so cool.” Mr. Potter also commented on the benefit of technology in Bella’s life beyond recreation and information finding. “I bought all that stuff for her...an iPod, the laptop. It keeps her connected in the world...so she doesn’t go crazy. Seriously. It keeps her from being lonely. It keeps her connected and she loves it.”

7.4.8 Bella, out and about. Mr. and Mrs. Potter regularly seek opportunities to keep Bella connected and physically active, though admit it is difficult. The challenges are many, starting with Bella’s shyness and resistance to try new things. Another challenge has been the limited availability of social and recreational options for young people with I/DD in their community. Finally, one only has to consider the daily responsibilities and stressors that come with managing a busy household, owning a business, coping with a chronic health condition, and parenting four children - one of which has I/DD, to recognize that Mr. and Mrs. Potter’s days and energies are

stretched thin. Mr. Potter commented,

I feel bad about it. We can't always get out and do stuff with her much. Bella will watch TV all day long if we let her. Sometimes I'll say "Bella, let's go take a walk." She might squawk about it but when I come up she's ready to go. So...does she really want to watch TV all day long? No, I don't think she does. I guarantee that if she had something else to do she wouldn't watch a second of it.

A few activities have sparked Bella's interest over the past few years - Special Olympics, horseback riding lessons, and teen programs through The Arc⁴² and a similar non-profit organization.

7.4.8.1 Special Olympics. Bella participates in three seasons of sports: soccer in the fall, basketball in winter, and softball during spring months. "My favorite is softball. I play catcher and have to wear a chest protector to protect my ribs. My legs get like all jello-y with always squatting and when I take my helmet off - I definitely have helmet head!" She also shared, "Special Olympics has changed my life for the better, I think. I used to be anti-social and now I have more confidence...like for me to talk to George. I used to not be like that." Mrs. Potter also commented on Bella's participation in Special Olympics, "It's been wonderful for Bella. She just loves it and it's an area where she can be one of the better players. That's been a positive thing for her."

7.4.8.2 Horseback riding lessons. On Saturday mornings, Bella can be found in equestrian garb at a local horse stable for riding lessons. She shared,

We get to choose which horse do we want to ride and I always like Spring. She's more high energy. Very high maintenance. Very energetic. Though she is actually easier to ride than the other horses. Sometimes have to use the reigns to slow her down and they

⁴² The Arc is a nation-wide, non-profit advocacy and support agency for individuals with I/DD.

taught us how to use our heels to make sure our horse is listening.

For each lesson, Bella is responsible for grooming, feeding, tacking and untacking Spring before and after the session. She moves about the horse and stall with expert care. “You have to always keep your hand on the horse so they know where you are and won’t get spooked and kick you,” she explained. Bella’s riding lesson is shared with by two other students and consists of instruction and practice on various maneuvers and trots. Again, Bella shows comfort and confidence atop the horse. Leaving the stables, Bella commented on her horse, “Spring has a really fast trot, but that's what I love about her!”

7.4.8.3 Social clubs. In hopes of fostering friendships, Mr. and Mrs. Potter have encouraged Bella to participate in social events offered through the local ARC organization. Mrs. Potter shared, “She used to go to Friday Teen Night and seemed to enjoy going. She’d probably like doing more of these events, but they are kind of expensive.” The rising costs of ARC programming has been a common concern among many parents of young people with I/DD in this small community. For many of their programs, parents are reasonably expected to cover the cost of the scheduled activity (for example bowling, a movie, dinner out, or a trip to an amusement center, etc). However, they are also charged a monthly programming fee. This is a fee that is required whether the child participates in all activities or just one a month. Transportation for these activities is rarely provided and sometimes “programming” equates to an email on a listserv indicating a gathering place, such as a park, with no planned activities and minimal ARC staff oversight. One parent stated, “Well I could do that!”

For a few years, Bella regularly attended a social program offered through a religious-affiliated non-profit organization. Although the program provided numerous types of opportunities for young people to engage and was inclusive of participants with and without

disabilities, many of the events are scheduled on weeknights and located in a neighboring town a half hour drive away. Mrs. Potter shared that Bella initially enjoyed attending these events, but after time her interest waned. “She just got to where she didn't really feel like doing it anymore.” Bella’s teacher, Ms. Anne, also commented on the program and Bella’s decision to leave.

Bella used to be involved in this really great program. She got to meet new kids and she loved it for a few years. But then she mentioned to me several times, “You know it’s really religious and that is just not what I believe. It just makes me uncomfortable.” Part of me was thinking, but it is such a great social thing for you to do. I wasn't pushing either way, but she finally told her mom and dad that she didn't want to do it because the religious stuff made her uncomfortable. I told her, “That’s a very grown up decision to make and you have made it very maturely.”

When asked about the program Bella’s only statement was, “Yep, I dropped out. I dropped out and I never looked back. I don’t really have anything else to say about it.”

In addition to the above activities, Bella is often persuaded out on errands and activities with her parents, especially her father. He shared, “We actually do a lot of stuff together. You know, we have our little routines. We have fun.” In agreement, Bella said, “Yeah, I’m a daddy’s girl. I admit it! I always have been, always will be. I’m lucky. We’re like two peas in a pod.”

7.4.8.4 At the gym. One of their routines involves early morning workouts at a local fitness club a few mornings a week before the school day. Bella’s father recalled,

When I first started taking her, I kind of wanted to figure out a routine for her. One that she could do on her own and get the benefit. I’m there for myself as well and we only have an hour. I took time to show her how the machines work, to get her going. You

know, I used to make her do certain stuff, but that wasn't good for either of us. Now, I just let her do her own thing now. The way I figure, some exercise is better than no exercise. Now she knows how to set the time to 45 minutes. She can't tell time really, but when it stops, she knows she has to go jump in the shower and get ready for school.

Bella commented, "I hate working out...well, it's not that bad. The waking up part is just so hard. I'm not a morning person." When asked of the types of exercise machines she prefers, Bella stated, "I like to do the elliptical and sometimes I try the treadmill. I take my iPod and listen to music." With a smile, Mr. Potter confirmed, "Yeah, she's got the headphones blaring, bopping along, and she is dancing and having a good time. You know, people know her there now." He also acknowledged the positive impact Bella has had in his own reluctance to exercise.

Sometimes she'll say, I'm not going today and I'll get her up. Other times, I don't really want to go. I'll just want to sleep in the car while she works out and she will say 'Come on Dad! It's good for both of us!' So, it's a good thing. It's worked out well for both of us.

In hearing her father's comment, Bella scoffed with a smile and said "Yeah, that's true. Sometimes I have to drag his sorry ass in!"

7.4.8.5 On the music scene. Bella and her parents also enjoy checking out their local music scene and catching a concert when their favorite bands come to town. Mr. Potter shared, Bella loves it and I like to get out too. Sometimes Bella's mom doesn't always want to get out ...so we'll go to those kinds of things together - which I don't know if it is a good thing or a bad thing, but for right now it seems ok.

Last summer, Bella discovered that her favorite country singer was scheduled to perform

in a nearby town. She recalled,

There was this thing on the computer that I found showing the concerts and I was like “YES!” I really begged my dad and kept saying, “Did you get the tickets? Did you get the tickets? Come on Dad! This is the only time he’s going to be here!” He found some tickets on Craig’s List. I wore my mom’s old cowboy boots and we drove the pickup truck. It was such a blast. It was a very bonding moment - just me and my dad.

During the concert, Bella filmed short clips of the performance using her cell phone.

“My dad put it on my iPod for me and I watch it every single day when I get home from school. Of course I got nothing better to do after school!”

7.4.8.6 Bella’s independence. While out, Bella enjoys a certain level of independence.

Mr. Potter commented,

She likes to go off on her own. When we go to the grocery store, she has certain things that she wants. She might not tell you that, but as soon as you hit the door, she’s off doing her own thing. She’ll come back with three or four things she wants and dumps them into the cart.

Mr. and Mrs. Potter spoke with appreciation of Bella’s increasing ability to assist on errands and do more things on her own. Mr. Potter shared,

Now that she is getting older, it’s actually nice because I can say “Hey Bella, will you go get the milk?” and she’ll go get it. Now, there’s a 50/50 chance that she’ll come back with the wrong thing or won’t be able to find it at all.

Mrs. Potter highlighted Bella’s own pride in being able to assist and act independently and told of a time in which she sent Bella into the grocery store alone with a list and a \$20.00 bill while she waited in the car.

It was for deli sandwiches and I was pretty sure she could handle it. You know...I felt pretty safe about sending her in there. She and her dad go in and order subs all the time. They probably know her at the counter. Bella came back to the car with the sandwiches and she was so proud of herself.

While Mr. and Mrs. Potter are intentional in their encouragement and support of Bella's ability to be more autonomous, it does not come without hesitation and concern. Mrs. Potter shared,

There are a lot of times where her dad is more likely to just send her off on her own than I am. Sometimes I think, "No, she is not ready for this." I guess maybe he pushes her a little bit more than I do.

Mr. Potter agrees that he places a great deal of trust in Bella's ability to do more, but he also concedes that much trust is also placed on others to do the right thing. Whether at the grocery store or the concession stand at a high school football game, "I'm counting on the people at the counter to give Bella the proper change back or not to sell her something that she doesn't want." He then gave an example.

We were at a Christmas benefit to see an indie band and I gave Bella \$10.00 to get a Christmas ornament for her older sister. It had a little mp3 that you could download off the web. Bella came back with the ornament and a CD. I don't know if she didn't understand or what. It wasn't a big deal. I would never give her so much money that if she came back without it...you know, I wouldn't be mad at her.

Beyond concerns of someone taking advantage of Bella financially, greater concerns weigh heavier on her parents' minds and hearts. Bella is an admitted "wanderer." "Yep, I always have been!" she laughed. Mr. Potter confided,

It's one of the things I worry about. We lost her at a festival one time for forty-five minutes. I try to keep an eye on her, but you can turn your back for one second and she'll be gone. With kids getting abducted, I worry about it.

Mrs. Potter also expressed concerns over Bella's safety and lacking self-advocacy skills.

We worry that she could be easily taken advantage of. She is not a fighter -- well sometimes, here at home -- but out and about, no. She is just so trusting and timid. She can easily be intimidated, We worry that she could be taken advantage of and wouldn't know how to stand up for herself or even know that she was being taken advantage of.

Bella's father spoke of Bella's tendency toward acquiescence and fears that she might not always reveal occurrences of harassment or abuse.

I worry about Bella not being able to tell people no and things like that. Sometimes if something bad has happened, she will clam up. It might just be something trivial but she won't say anything. You can tell right away when something is wrong though. She wears it on her sleeve. We always tell her, "No matter what happens, Mom and Dad love you. We're just trying to instill that in her that there is nothing that could possibly happen to her out in the real world that she couldn't tell us about. So you know...yeah...that's what I worry about when we are dead and gone...that something bad could happen to her.

7.4.9 Bella's future. With prospects of high school graduation on the horizon, Bella was asked, "What's next?" She responded, "I don't really know yet. Traveling I guess." Bella shared that her graduation present was a trip to visit her sister and then to her father's home state and college alma mater which happens to be one of Bella's favorite college teams. "I've never been. I'm pretty excited."

Although Bella's parents have likely spent her entire lifetime thinking about her future and the question of "What's next?" for Bella, the future seems less an area for much thought. When asked questions related to future possibilities, including college, where she might live, and employment, Bella responded similarly with an "I don't know" and "I'm not really sure." Mrs. Potter reflected,

I don't know if Bella really knows what it all entails. We sometimes will talk about the future with her. She used to say things like, "I want that kind of car or I want to have my own apartment, but it's been a few years now. She doesn't really say those things anymore. You know, we've talked with Bella about driving as being something that's really hard to do. "Bella, there are a lot of things to remember... rules. It just might be something that's too hard for you." She seems okay with that. You know, she likes to think that she would be independent and she likes the idea of going out and doing things on her own. But there's also a certain part of her that wants to be at home with us. She says that she is a daddy's girl and wants to be around family. I mean...right now she is still pretty young.

Bella had the opportunity to tour a college campus with a program specifically for individuals with I/DD located an hour away from her home. Post-secondary programs for students with I/DD are emerging in large numbers across the U.S. Although designed to emulate a typical college experience, most are largely non-degreed and somewhat segregated. Still, they offer new opportunities and exciting possibilities for individuals with I/DD than ever before. After visiting the program, Bella said with excitement, "It was beautiful!" Of particular interest were thoughts of apartment life, study groups that met outside, and parties. She said, "Yeah, maybe I'm ready to be on my own. Kind of like my sister...you know. Spread my wings away

from my family.” A number of months later, when asked about potential plans to enroll in the program, Bella shared that she had reconsidered and decided that it was not for her.

Although Bella has not yet shown great interest in a future career, her father has started exploring possibilities and spoke with discouragement on the availability of options and vocational supports. He recalled one conversation with a county vocational rehabilitation counselor responsible for placing individuals with I/DD into jobs.

I said, “So, what are you doing to find people jobs?” And he said to me, “Well my goal is to keep twenty-five people employed in our county this calendar year.” So I asked, “How many clients do you have in all?” “I have over two hundred.”

Undeterred, Mr. Potter asserted, “When she’s twenty-one, I’m going to take her out there and find her that job.” When asked about the types of jobs he sees for Bella, Mr. Potter stated with unapologetic candor,

You know it has to be something simple. Even though it looks like she has more on the ball - when you get right down to it, she doesn't. I mean, she can't tell time, she can't make change, anything number-related, she just can't. She can't make change for a quarter. It has to be simple and it has to involve interacting with people, but not in one of those closed workshop environments.

He presented the following possibilities: a candy striper passing out magazines, working at a stable or farm, working at the animal shelter, for a landscaper or in a nursery, for the ARC office or for Habitat for Humanity. He later added, “You know, if she could get a job bagging groceries, I'd be happy as a clam!” His suggested ideas infer, that for Bella, desired work outcomes are less about earning an income and more so about being productive, purposeful, making contributions, and belonging. The following responses are Bella’s thoughts on these

possibilities:

- **Candy striper:** “Kind of, sort of.”
- **Stable, farm, and animal shelter:** “Sort of, kind of...you pretty much get to work around animals. Farms are kind of hard though.”
- **Landscaper or working in a nursery:** “No.”
- **Office work:** “Nope.”
- **Habitat for Humanity:** “Not really.”
- **Grocery store:** “Kind of, sort of.”

In terms of where Bella might live in the future, Mrs. Potter shared,

We’ve talked to her a little bit about the possibility of Bella living in some sort of group home, making comparisons to when her older sister went away to college. “Bella, you know once you’re an adult you won’t want to stay living with mom and dad forever.” So we’re trying to get her to think along those lines. I think part of her wants to be grown up and to experience those kinds of things. On the other hand, it’s very comfortable here at home for her. She’s very attached, especially to her daddy.

Bella also indicated that she would “sort of” like to continue living with mom and dad, but she also said that she could see herself living in an apartment with a roommate. When asked about the possibility of getting married, she replied, “No....I don’t know. Maybe.” And of having children? “Nope.” In final reflection of Bella’s future, Mr. Potter commented, “She really wants to get out and do things. She wants to work. She wants to live a full life. And that’s what we want for her. Just to have a happy life.”

Chapter 8 Results

The proof of the pudding is the eating.

Miguel De Cervantes, Don Quixote

The purpose of this study was to explore the everyday life information needs, practices, and challenges of four young people with I/DD, ranging in age from seventeen to twenty-three years old. Data collection methods included semi-structured and focus group interviews, participant and non-participant observation, and document review including photovoice products, participant art work, and IEP and PCP annual reports. This chapter presents findings organized by the three research questions:

1. What are the everyday life information needs of emerging adults with intellectual disabilities?
2. What are the everyday life information practices of emerging adults with intellectual disabilities? What tools/resources/strategies do they commonly use to address their everyday life information needs?
3. What are the everyday life information challenges of emerging adults with intellectual disabilities?

8.1 Research Question One

What are the everyday life information needs of teens and young adults with I/DD?

Identified ELI needs are organized into two categories: *expressed information needs* and *ascribed information needs*. Expressed information needs are information needs (1)

stated by the participant as significant to his/her wants and needs and/or (2) demonstrated by the participant through his/her prioritized and self-directed action toward access. *Ascribed* information needs are those inferred and reported by another⁴³ as important or necessary to the individual's life and well-being. While the participant may have engaged in information practices toward addressing ascribed information needs, they did so out of compliance and not their own preferred volition.

Collectively, twenty-nine topics of ELI need emerged from review of the four case studies, as represented in Table 22. A comprehensive list that includes categories and sub-categories of identified ELI needs can be found in Appendix G.

Table 22. *Areas of Identified Everyday Life Information Need*

1. Academic endeavors	15. Health and development
2. Communication skills	16. Relations
3. Community access	17. Responsibilities
4. Consumer information	18. Schedule development/maintenance
5. Correspondence skills	19. Self-care skills
6. Creative endeavors/expressions	20. Self-determination/self-advocacy
7. Curiosities, interests, hobbies, and pastimes	21. Sexual literacy
8. Emotional health/coping skills	22. Social life /recreational activities
9. Employment	23. Social skills
10. Financial literacy/money management	24. Spirituality/religion
11. Future planning	25. Sports/physical activities
12. Identity	26. Technology skills
13. Independent life skills	27. Transliteracy skills
14. Personal safety	28. Volunteering/service to others
	29. World, national, community awareness

As the case narratives illustrate, the ELI needs exhibited by Jack, Marie, Ben, and Bella are unique to their own interests and life circumstance. Table 23 presents a case-by-case cross section sample of identified ELI needs, expressed and ascribed. In spite of individual variability, the ELI needs presented in the four case studies are highly consistent with other research on ELI needs of young people (Table 24).

⁴³(1) attributed by family or teacher participants or the researcher, and/or (2) supported by an in-depth appraisal of related scholarship.

Table 23. *Case-By-Case Sample of Identified Everyday Life Information Needs*

Jack	Marie	Ben	Bella
Curiosities, interests, hobbies, & pastimes <ul style="list-style-type: none"> • Fairytales/Mythology • "Preschool" materials • Violin • Story-writing/storytelling 	Curiosities, interests, hobbies, & pastimes <ul style="list-style-type: none"> • Dancing • Crafts - knitting, pottery, sewing • Shopping 	Curiosities, interests, hobbies, & pastimes <ul style="list-style-type: none"> • Food • Game shows –trivia • travel • Photography • Painting 	Curiosities, interests, hobbies, & pastimes <ul style="list-style-type: none"> • Music • World events • Sports • Pop culture and celebrity gossip
Emotional health/coping <ul style="list-style-type: none"> • Schedule tracking • Self-monitoring and regulation • Breathing techniques • Self-advocacy • Choice-making* 	Volunteering / Service to others <ul style="list-style-type: none"> • Finding/sharing coupons, news articles, books • Seeking/sharing online information on pet adoption, humorous videos 	Personal safety <ul style="list-style-type: none"> • Situational awareness* • Appropriate response* to dangerous situations • Appropriate response to minor and major injuries* 	Belonging (“a part of it all”)⁴⁴ <ul style="list-style-type: none"> • Facebook • Sports • Teen trends/culture • Cell phone
Independent life skills <ul style="list-style-type: none"> • Meal preparation* • Baking • Laundry • Shopping • Self-care needs* 	Women’s health issues / sexual self⁴⁵ <ul style="list-style-type: none"> • Intimate relations • Sexual literacy • Self-advocacy 	Emotional health / coping <ul style="list-style-type: none"> • Schedule monitoring • Seeking verbal confirmations • Weather monitoring • Social/Personal connections 	Technology skills <ul style="list-style-type: none"> • Skill development • Trouble shooting • Transliteracy • Online shopping / consumer safety • Online safety

Table 24. *Comparable Findings on Youth ELI Needs*

1. **Academic endeavors** - formal education or curriculum needs, self-actualization (Walter, 1994); course related (Latrobe & Havener, 1997); school-related subject information (Shenton & Dixon, 2003a); schoolwork (Agosto & Hughes-Hassell, 2005); school work (Meyers et al., 2009)
2. **Community access** - transportation (Agosto & Hughes-Hassell, 2005)
3. **Consumer information** - consumer information (Shenton & Dixon, 2003a); goods and services (Agosto & Hughes-Hassell, 2005); consumer information (Meyers et al., 2009)
4. **Creative endeavors and expressions** - creative performance, creative consumption (Agosto & Hughes-Hassell, 2003)
5. **Curiosities, interests, and hobbies** - intellectual stimulation (Minudri, 1974); leisure activities (Walter, 1994); interest driven (Shenton & Dixon, 2003a); hobbies (Meyers et al., 2009)
6. **Emotional health/coping skills** - response to problems (Shenton & Dixon, 2003); bullies (Meyers et al., 2009); self-awareness / self-regulation- emotional awareness (Walter, 1994) emotional security (Minudri, 1974); self-image, affective support (Shenton & Dixon, 2003a); emotional health (Agosto & Hughes-Hassell, 2005)

⁴⁴This section encompasses multiple ELI needs – technology, world, national, and community awareness, social skills, communication skills, relations, and recreational activities.

⁴⁵Additional ELI needs relate to self-advocacy, self-determination, communication, and relations.

7. **Employment** - career information (Shenton & Dixon, 2003a); career, job information (Agosto & Hughes-Hassell, 2005)
8. **Future planning** - living options/post-secondary education (Shenton & Dixon, 2003a); college (Agosto & Hughes-Hassell, 2005)
9. **Health and development** - health, nutrition (Minudri, 1974); nutrition, general health issues; AIDS prevention drug, tobacco, and alcohol abuse (Walter, 1994); medical diagnosis, illness, medical condition (Shenton & Dixon, 2003a); health (Latrobe & Havener, 1997); health (Agosto & Hughes-Hassell, 2005);
10. **Identity** - self-awareness (Walter, 1994); self image (Shenton & Dixon 2003); self-image, sexual identity, heritage/cultural identity (Agosto & Hughes-Hassell, 2005)
11. **Money management / financial literacy** -personal finance (Agosto & Hughes-Hassell, 2005)
12. **Personal safety** - safety (Minudri, 1974); Crime avoidance, traffic rules, emergency procedures (Walter, 1994); bullies, dangerous strangers (Meyers et al. 2009); physical safety (Agosto & Hughes-Hassell, 2005)
13. **Relations (friendships/family/romantic/workplace)** - interpersonal skills (Walter, 1994); personal relationships – conflict (Shenton & Dixon, 2003a); relationships (Latrobe & Havener, 1997); friend/peer/romantic relationships (Agosto & Hughes-Hassell, 2005); relationships (Meyers et al., 2009)
14. **Responsibilities** - responsibilities (Shenton & Dixon, 2003a); daily life routine, civic duty (Agosto & Hughes-Hassell, 2005)
15. **Schedule development/maintenance** - routine, personal information (Shenton & Dixon, 2003a); daily life routine, time/date (Agosto & Hughes-Hassell, 2005)
16. **Self-care skills** - personal hygiene (Walter, 1994)
17. **Sexual literacy**- sex education (Walter, 1994); sexual safety, sexual identity (Agosto & Hughes-Hassell, 2005)
18. **Social life /recreational activities** - social life (Agosto & Hughes-Hassell, 2005); social events (Meyers et al., 2009)
19. **Spirituality/religion** - ethics and values (Walter, 1994); religious practice (Hughes-Hassell & Agosto, 2005)
20. **Sports/physical activities** -sports (Meyers et al., 2009)
21. **Technology**- self-actualization (Agosto & Hughes-Hassell, 2005)
22. **Volunteering/service to others** - empathy (Shenton & Dixon, 2003a)
23. **World, national, community awareness** - social system knowledge (legal, economic, etc.) (Walter, 1994) - Multicultural awareness (Walter, 1994); current events, pop culture, fashion, school culture, social and legal norms (Agosto & Hughes-Hassell, 2005); pop culture (Meyers et al. 2009) Fashion (Meyers et al. 2009)

8.2 Research Question Two

What are the everyday life information practices of teens and young adults with I/DD?

What tools/resources/strategies do teens and young adults use to address their everyday life information needs?

Preliminary steps in answering this question began with a review of photographs taken by the participants. Jack, Marie, Ben, and Bella captured photos of both similar and different types of tools and resources in response to the prompt: “Take a picture or pictures of the places you go, the people you might talk to, or things that you might use to find answers to your questions or learn new things.” Their photo collections included:

advertisements	magazines	televisions
books	newspapers	telephones
calendars	people	videos
clocks	schedules	
computers	signage	

Important to note, participants completed photovoice tasks apart from the researcher. The degree to which they were prompted in this task (if at all) is unknown, yet other forms of data collection support their collected photo responses.

Analysis of interview transcripts, observation field notes, and acquired documents revealed other tools and resources frequently accessed by the participants, as well, which were categorized into four groups: *trusted individuals*, *group membership*, *physical objects*, and *technology/digital objects*. The category of *trusted individuals* refers to persons frequently consulted, including those individuals known on a personal level, as well as those perceived to have credible knowledge relevant to the participant's needs, for instance a store clerk or a city bus driver. *Group membership* encompasses organizations and agencies that facilitate opportunities for information exchange for purposes of academic achievement, vocational and life skill development, leisure and recreation, fellowship and camaraderie, or charity and service. *Physical objects* refer to physical representations of information including items that are mass-marketed for consumption, items that are mass-marketed for user-modification (i.e. calendars or address books), and items that are created for personal use (i.e. schedules and reward sheets). Last, the category of *technology/digital objects* represents (1) technological equipment necessary for the facilitation of information access and engagement in electronic/digital form, and (2) digital representations of information.

Table 25 presents a collective list of reported and observed information resources and tools employed by the four participants.

Table 25. *Information Resources and Tools Employed by Participants*

Trusted Individuals: family members, teachers, friends / peers, co-workers, home and work support providers, community service providers
Group Membership: school, social organizations, sports teams, work, service organizations
Physical Objects:
Published/Manufactured: books, magazines, newspapers, compact discs, digital video discs, software, ephemera
User-modified: calendars, agendas, cookbooks, journals
User-generated: schedules, reward sheets, work-logs
Technology and Digital Objects: computers, internet, online resources, gaming systems, mobile and landline phones, mp3 players, iPod/iTouch technology, calculators, cd players, cameras, television, radio

In review of other studies on ELI practices of young people, Jack, Marie, Ben, and Bella relied on tools and resources typical of their same age peers (Table 26).

Table 26. *Comparable Findings on ELI Tools and Resources*

1. Trusted individuals – peers, parents, teachers, professional coaches (Shenton & Dixon, 2003b); interpersonal peer sources (Meyers et al., 2009); peers, teachers, parents, relatives, physicians, and other individuals (Latrobe & Havener, 1997); friends/family, school employees, mentors, customer service staff, other teen (not friend), librarians, passers-by (Hughes-Hassell & Agosto, 2007)
2. Group membership – group tuition (Shenton & Dixon, 2003b); classroom instruction, clubs/social groups, community/governmental organizations, businesses, libraries (Latrobe & Havener, 1997);
3. Physical objects – newspaper, magazines, books (Amey, 1985) magazines, books/textbooks, print materials for libraries (Shenton & Dixon, 2003a); books and magazines – utilized but less popular (Meyers, Fisher, & Marcoux, 2009); books, magazines, newspapers (Latrobe & Havener, 1997); book, print ephemera, newspaper, magazine, school notebook (Hughes-Hassell & Agosto, 2007)
4. Technology and digital objects – Internet, CD-Rom, television (Shenton & Dixon, 2003a); telephones, instant messaging, email / TV and radio were also utilized but less popular (Meyers, Fisher, & Marcoux, 2009); electronic sources, videocassettes, radio (Latrobe & Havener, 1997); telephone, computer, tv, radio/CD player (Hughes-Hassell & Agosto, 2007), television, radio, movies, tape recordings (Amey, 1985)

Utilizing these tools and resources, along with their own internal resources Jack, Marie, Ben, and Bella engaged in a wide range of information practices, purposively and passively, to address their needs and enable meaningful experiences. Table 27 presents a collective representation of their information practices, followed by individual participant examples in Table 28, Table 29, Table 30, and Table 31. Table 31

Table 27. *Collective Everyday Life Information Practices*

Seeking and exploring information
<ul style="list-style-type: none"> • Questioning • employing search engines and catalog systems • “surfing” • employing user-centered online tools (drop-down menus, spell check, “did you mean?” function, suggested content) • scanning of reference materials, resources • environmental scanning • browsing
Acquiring information (physical and digital representations)
<ul style="list-style-type: none"> • borrowing from library or others • finding/obtaining online, from personal collection, gifts, community resources (bank, library, transportation, support agencies) • purchasing and/or downloading from retail or online site
Consuming information
<ul style="list-style-type: none"> • pleasure reading (print & digital content) of books, newspapers, magazines, websites/blogs • functional reading (print & digital content) of retail websites, signage, menus, bank statements, receipts, recipes • scanning/monitoring of weather, news, sports scores, self, others, environment • listening / viewing of television programs, online video clips, movies, performance, instruction, conversation • listening to audio books, radio programs, music
Programming, reformatting, and duplicating information
<ul style="list-style-type: none"> • recording – television programming • printing – photos and documents • scanning/digitizing – print documents • uploading/downloading photos, music, documents • burning compact discs and photos • hand-copying from a template

Creating, expressing, and transferring information

- verbal forms - conversation, formal and informal presentations
- recorded forms (print and digital) - handwritten notes, letters, journaling, creative reflections, emails, texts, instant messages, posts (social network sites)
- crafting and performance - painting, dancing, sculpting, photography, videography
- physical forms - sharing/loaning/gifting of books, magazine articles, newspaper articles, coupons, videos, compact discs, games
- digital forms - emails, texts, instant messages, posts (social network sites)

Collecting, organizing, storing informational content

- physical collections - books, videos, compact discs, games, magazines, dvds, ephemera
 - print recordings - personal contacts, business cards, urls, recipes, scheduled events
 - digital collections - contacts, frequently accessed URLs, personal digital documents, music, photos, videos
-

Table 28. *Examples of ELI Practice Exhibited by Jack*

- browsing of the shelves at the public library or local bookstore in search of new adaptations to his favorite fairytale stories
- monitoring behavior by referencing a reward sheet in anticipation of a desired activity
- using an iTouch to create or access his weekly grocery list for the purpose of shopping
- listening to audio books and those read by family members.
- writing and sharing stories
- engaging with a storytelling mentor to enhance skills
- engaging in work tasks including data entry, baking, storytelling to preschoolers
- participating in special interest classes to learn new skills (theater class, violin lessons)
- meal preparation
- engaging in online activities – academic responsibilities, email, video viewing, gaming

Table 29. *Examples of ELI Practice Exhibited by Marie*

- writing letters and emails
- clipping and mailing articles and coupons to others
- recording addresses and storing business cards for future reference
- seeking/collecting of music cds
- participating in special interest classes and programs to learn new skills (pottery, dance, job club, horticulture club)
- participating in peer group on the topic of women's health issues
- scanning environment to collect informational items to share with others
- sharing of information through volunteer activities and calling friends and family
- engaging in online activities – information searching, video viewing, gaming, Facebook, email
- connecting with others to learn new skills (knitting with neighbor)

Table 30. *Examples of ELI Practice Exhibited by Ben*

-
- seeking and viewing video clips for pleasure (game shows) and instruction (painting techniques)
 - engaging in photography and related activities (taking photos, uploading photos and organizing into named files, sharing photos through email and Facebook, printing photos)
 - engaging in work tasks, including data entry, reformatting of data, erasing of data (demagnetization of video), organization of informational content, gathering information resources for others, and email
 - programming of a digital video recording device for future retrieval of content.
 - monitoring weather in anticipation of change in schedule
 - expressing self through journal writing
 - seeking confirmation (I did good, right? I see you Tuesday, right?)
 - connecting with friends and family through phone calls and email
 - tracking and sharing television/radio programming schedules to share with others
 - creating and tracking daily schedule and task responsibilities

Table 31. *Examples of ELI Practice Exhibited by Bella*

-
- reading celebrity blogs and magazines
 - monitoring game schedule and sport scores of favorite teams
 - browsing shopping online
 - transferring music from laptop to phone
 - listening to audio books
 - clearing online browsing history
 - interacting on Facebook and monitoring Facebook activities of others
 - participating in school clubs including the sharing of ideas and accessing and exchanging information verbally and online
 - sharing information through text messaging and email
 - listening to news programs on the radio

The four participants' practices were as varied as their expressed ELI needs; nonetheless, their pursuits to consume, engage with, and share information also seemed directed toward similar ends and, commonly, in support of their most immediate needs, concerns, and pleasures. This included the engagement of ELI practices to support daily routines, responsibilities, interests, curiosities, preferred activities, interpersonal relations, and emotional well-being.

Parent and teacher participants, while generally supportive of participants' prioritized ELI needs and practices, placed high priority on information and informative experiences to enhance awareness, knowledge, and skills in support of participants' future lives. Classroom instruction and activities, community-based and vocational training opportunities, social and

recreational programs, volunteer activities, provisions of support provider services, and assigned household chores - all served as conduits for the exchange of information verbally, visually and experientially. Areas emphasized included independent life skills (i.e. cooking, laundry, household maintenance), career exploration and work behaviors, money management and consumer skills, hygiene and grooming, personal safety, and overall well-being (physical and emotional). For parents, particularly, concerns of “What happens when I’m gone” weighed heavy in considerations of their child’s ELI needs and experiences. In light of recent research reporting on the lowered quality of life experienced by many adults with I/DD, parent concerns are not without warrant.

8.3 Research Question Three

What challenges do teens and young adults encounter in attempts to address their everyday life needs?

Identified information challenges were organized by barrier type. Five categories of barriers were identified, including intrapersonal barriers, physical barriers, economic barriers, societal barriers, and institutional barriers. Table 32 presents an overview of challenges (1) reported by participants, family or teacher participants, (2) identified in acquired documents, and/or (3) inferred from observation. Table 33 presents comparable findings from other youth ELI research. For a case-by-case report of challenges, refer to Appendix G.

Table 32. *Everyday Life Information Challenges Experienced by Participants*

<p>Intrapersonal barriers:</p> <p>Cognitive: weak literacy skills, difficulty comprehending abstract/complex concepts, slower processing/recall rate, problem solving difficulties, poor memory, attention issues, limited perception of need</p> <p>Communication: receptive/expressive language challenges, auditory challenges</p> <p>Psychological: learned helplessness, weak self-advocacy skills, naivety, difficulty regulating emotion, limited self, social, situational awareness, impulsivity, shyness, anxiety, limited eye contact</p> <p>Physical barriers: limited access to transportation, restricted /limited access to technology, print-only sources of information</p> <p>Economic barriers: cost-prohibitive programming, limited job training / employment opportunities</p> <p>Societal barriers: social exclusion, societal perception and unawareness of need, lowered expectations of ability, discrimination/stigma, highly monitored life/controlled schedule, enabling attitudes of learned helplessness, prevalent tracking to sheltered workshop, professional disconnect, school / home disconnect in expectations</p> <p>Institutional barriers: tracking/segregation in school -leveled system, limited curriculum / instructional oversight, inadequate assessment tools for I/DD identification and administration of school support, stringent requirements by federal / state funding and oversight agencies, underfunded support personnel, state restrictions on vocational training hours during school day</p>

Table 33. *Comparable Findings on Everyday Life Information Challenges*

<p>Intrapersonal – culture/language barriers (Walter, 1994); anxiety (Shenton & Dixon, 2003b); embarrassment (Meyers et al., 2009); information overload, awareness (Julien, 1999), challenging reading level (Julien, 1999)</p> <p>Physical – weak collections (Farrell, 1974); insufficient materials (Minurdri, 1974); collections not relevant to needs (Agosto & Hughes-Hassell, 2005); mobility issues/transportation, adult restricted, access issues (Meyers, Fisher, & Marcoux, 2009); challenging access tools (Latrobe & Havner, 1997)</p> <p>Societal – insufficient instruction (Shenton & Dixon, 2003); ineffective information provider (Walter, 1994); inadequate service (Farrell, 1974); lack of properly trained staff/unawareness by staff (Minurdri, 1974); negative perception of libraries (Agosto & Hughes-Hassell, 2005)</p>
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8.4 Summary of Findings

Single case analyses revealed four rich and multifaceted lives led by individuals exhibiting a wide range of both formidable and whimsical ELI needs. Despite notable challenges, inherent and imposed, Jack, Marie, Ben, and Bella displayed high motivation and impressive initiative in their individual pursuits as information consumers, produces, managers, and providers, utilizing tools, resources, and strategies to their own advantage. Further, these findings parallel other studies on youth-ELI needs and practices and point to

additional topics of ELI need.

As a final point, analysis of ELI needs and practices considered within the context of participants' everyday lives contributed to a well-grounded understanding of ends served.⁴⁶

Collectively, findings suggest that Jack, Marie, Ben, and Bella engaged in the seeking, consuming, producing, managing, and sharing of information toward the following common ends:

- to explore, satisfy curiosities, and enjoy life's pleasures
- to embolden a stronger sense of self
- to develop and maintain meaningful relationship
- to belong
- to cope with unpleasant feelings
- to fulfill responsibilities
- to be of service to others
- to develop self-sufficiency and assert autonomy
- to acquire personal wants and needs
- to enhance physical well-being

A case could be made that their ELI initiatives are motivated out of a desire to (1) enhance the quality of their own everyday life experiences, and (2) enhance the everyday lives of others. This revelation is significant and underscores the meaning of cognitively accessible ELI and information services toward the development of self and, as such, the development of desired life worlds and positive adult life outcomes. The following chapter sets the stage for a proposed LIS model in support of emerging adults with I/DD and their ELI needs.

⁴⁶Wilson (1981), Dervin (1983), Chatman (1990), and Katz (1959) have all underscored the empirical and practical value of assessing information needs and behaviors within context and toward ends served.

Chapter 9 Discussion

Every story can enhance a life or destroy it.
Every story can lift us or depress us.
Stories sustain if not make a person's world.
And thus, the storyteller holds a certain power and responsibility.

Burton Blatt, *The Conquest of Mental Retardation*

9.1 Introduction

The current study contributes to a small but burgeoning body of research literature highlighting the under-addressed ELI needs of individuals with I/DD. It also draws attention to the need for a comprehensive model for LIS research and service in support of individuals with I/DD and their ELI needs across the life span. Whereas the I/DD field has given much attention to the transition-related needs of teens and young adults with I/DD, the LIS field has placed emphasis on the developmental processes experienced by teens and young adults and the need for information to support their identity exploration, changing relationships, maturing roles and responsibilities, and so on. A model is clearly needed that brings these two perspectives together. Targeting the developmental period represented by the current study participants, this chapter proposes an LIS model for research and practice in support of emerging adults with I/DD and their ELI needs. Each step of the model creation process is discussed below.

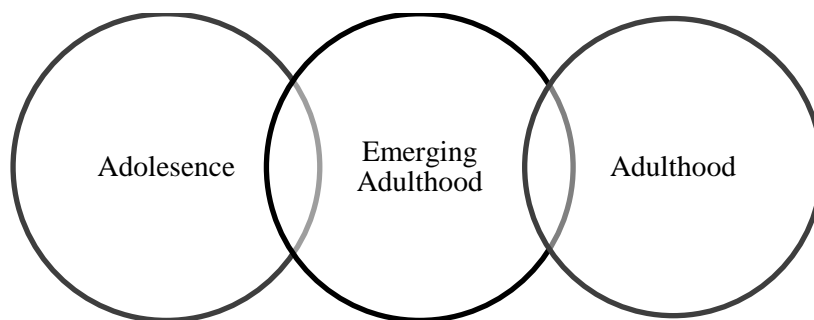
9.2 Toward the Construction of a Model

Five conceptual frameworks serve as foundational building blocks of the proposed model: Emerging adulthood, Person-centeredness, Self-determination, the Theoretical Model

of Urban Teen Development, and the Quality of Life Model. Each construct is discussed below as it relates to the findings from the current study and contributes toward the proposed model.

9.2.1 Emerging Adulthood. *Emerging adulthood* refers to the time period following adolescence. A relatively new classification within developmental theory, *emerging adulthood* was first introduced by Jeffrey Jensen Arnett in 2000. Two earlier classifications by Havighurst (1949) and Erikson (1963) delineated the developmental period after adolescence as *early adulthood* (age 18 to 30) and *young adulthood* (age 18 to 40), respectively. In recent years, their contemporaries have advocated for a more suitable classification arguing that societal life patterns and expectations of young people have changed since Havighurst and Erikson first characterized the life stage. Much of this change was attributed to increased opportunities for individuals to take part in post-secondary schooling and less restraining societal mores relating to sex. As such, young adults were now waiting longer to get married and moving into their adult roles at a slower pace than generations previously (Arnett, 2007, pp. 68-69).

Figure 23. Emerging Adulthood



Note. Reprinted from *Emerging adulthood: What is it, and what is it good for?* (p. 69), by J. J. Arnett, 2007, *Child Development Perspectives*, 1(2), 68-73.

Overlapping both late adolescence and adulthood, this period of life is often described as the “transition to adulthood.” Recognized as an in-between time, it is a period of readjustment as young people are negotiating both the freedoms of adolescence and the responsibilities of adulthood. This developmental dichotomy was highlighted in Perseus’ description of his brother Jack,

Jack wants to be independent, but I think he also understands just how dependent his lifestyle is on Mom and that he’s pretty happy with the way things are...Like most people! He doesn’t really want to do the work that comes with independence, which I think is one of the more typical characteristics of being 17 years old. I mean...my brother understands that he doesn’t want to cook but he still wants to decide what is for dinner.

Arnett (2007) characterized emerging adulthood as one of the more heterogeneous and least structured life stages and identified five common developmental traits exhibited by emerging adults:

- identity exploration;
- instability (in romantic partnerships, residence, and education and career paths);
- self-focus orientation (meaning not bound by family structure or obligation);
- feelings of “in-between”; and
- the recognition of expanding possibilities. (p. 69)

Although recognized as a turbulent time for all young people, it can be an especially stressful and uncertain time for teens and young adults with I/DD. While many of their neurotypical peers are heading off toward new opportunities and expanding their social networks, for young people with I/DD, the transition from high school means leaving behind

friendships, daily routines, and reliable supports and services toward a less certain post-school life with high unemployment, few social opportunities, and reduced and less reliable supports and services. This was especially evident in Marie's case study. Marie's former teacher described Marie as having a "crisis of confidence" after leaving high school and Marie and her parents described feelings of frustration, boredom, and loneliness during this period. These feelings are well documented in the research literature on transition outcomes (Stewart, et al., 2013).

Emerging adulthood serves as the first of five foundational building blocks in the proposed model. While not depicted visually, the construct establishes the basis for LIS focus during this particularly volatile time in the lives of young people with I/DD and is supported by the numerous ELI topic needs represented in the four case studies, including:

- coping and emotional health resources
- establishing/reinforcing social support networks
- navigating and securing necessary supports and services
- strengthening of work and securing employment,
- strengthening of independent living skills and residential living options
- managing money/financial literacy and consumer practices
- accessing the community
 - transportation options and practices
 - community resources and opportunities
- self-advocacy and personal safety
- problem solving /decision making

9.2.2 Person-centeredness. In his book, *A Way of Being*, Carl Rogers (1980) wrote,

“Individuals have within them the vast resources for self-understanding and for altering their self-concepts, basic attitudes, and self-directed behavior” (p. 155). At the core of his life work was the fundamental belief in the human capacity for self-actualization. Rogers believed that when provided the climate, resources, and opportunity to make meaningful life choices and engage equally with others, an individual is more likely to become “more autonomous and creative as the architect of his or her own life” (p. 183). He described this philosophy as being “person-centered.”

Over the last few decades, this way of understanding the human potential has evolved from a philosophical approach to a functional framework, adopted and now firmly embedded within the I/DD field. Represented in the four case narratives, person-centered life planning is seen as an effective way to promote personal growth and self-empowerment through the provision of resources, services, and supports, centered on an individual’s self-determined needs, desires, and interests. In a review of the I/DD research, numerous studies suggest a positive relationship between person-centered life planning and positive life outcomes. Claes, Van Hove, Vandeveld, van Loon, & Schalock (2010) cited the following identified benefits: enhanced social networks, closer family relations and friendships, increased participation in group activities, increased community engagement, increased opportunities for decision-making and choice, skill development, reduction in challenging behaviors, increased displays of engagement, increased opportunities for general education participation, improved academic performance, knowledge growth in the areas of leisure information, work, volunteering, retirement, and social support (p. 446-447).

As a philosophical construct for model integration, person-centeredness directs LIS focus on the unique individual with attention to his/her special interests, preferences,

strengths, support needs, priorities, everyday experiences and life goals. Moreover, person-centeredness emphasizes a strengths-based approach for all LIS initiatives directed in support of emerging adults with I/DD, honoring and capitalizing on an individual's capabilities and talents. Ideologically, this stands in stark contrast to the deficit model of disability that continues to dominate public perceptions of I/DD. As the case narratives clearly illustrate, Jack, Marie, Ben, and Bella are extraordinary individuals - creative, funny, kind, generous, ambitious, determined, talented, impassioned, empathic, and brilliant in their own unique and awe inspiring ways. This observation - in no way - underestimates the impact of their cognitive challenges but, rather, provides a more complete picture of these four young people. As Ben's father aptly noted "we all have our limitations." The difference, however, is that far too often individuals with I/DD live lives shadowed, structured, and confined by the meaning society has made of their limitations. As such, their strengths often go unnoticed, their contributions continue to be undervalued, and their potential is denied. Not surprisingly, two traits often observed in young people with I/DD are lower self-esteem and learned helplessness.

The impact of ELI access, in all forms, toward positive identity construction was underscored in the case studies of Jack and Bella. When Jack was asked about having autism, he responded, "It means I'm a good boy!" While society often views autism as a disabling condition, Jack has received a different message. For Jack, autism is a positive attribute and an important part of his identity. Bella, on the other hand, just wants to be a typical teen. This was highlighted by her desire for a cell phone. Her father shared, "Bella was dying to have one. She saw everyone else with a phone and wanted to be a part of all that." It can be argued that, for Bella, having a cell phone signifies a transitioning from

childhood to young adulthood and a positioning of herself among peers as like them. Similarly, despite significantly weak literacy skills, Bella actively acquires popular reading materials. Her mother commented, “Bella loves having books...carrying books around. She sort of reads them, but it's hard to say how much.” Regardless, the act of carrying books promotes a positive image as a “reader” and likely facilitates opportunities for meaningful connections with same-aged peers who share common interests, thus fostering Bella’s sense of self as a typical teen and sense of belonging among her peer group.

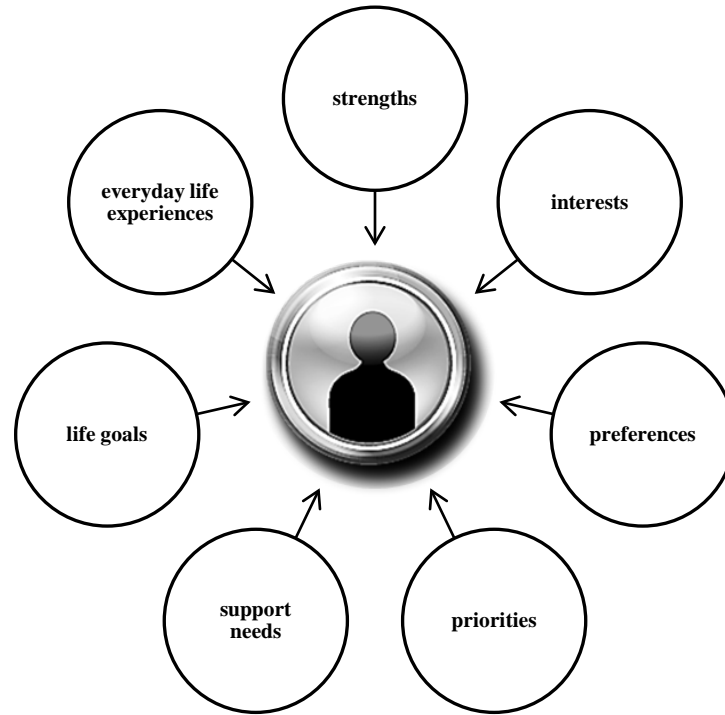
The importance of ELI toward self-actualization was also underscored in this study by the ways in which participants identified themselves in their everyday lives:

- Jack is a *storyteller, baker, and violinist*.
- Marie is a *dancer, potter, and shop-a-holic*.
- Ben is a *painter, photographer, and office worker*.
- Bella is a *Twihard, text junky, and her teachers’ second brain*.

These labels were not claimed happenstance. Rather, they are a part of their perceived identities - developed, rightly earned, and continually supported through ELI pursuits and practices.

Person-centeredness serves as the second building block of the proposed model as it draws LIS focus on the unique individual, his/her strengths, and ELI as means toward positive identity formation, individual capacity building, and personal fulfillment. Positioned centrally, person-centeredness is the core from which LIS research and practice should emerge – the individual.

Figure 24. *Person-centeredness*



9.2.3 Self-determination. Person-centeredness aligns closely with self-determination theory in that both emphasize the individual’s inherent tendency toward personal growth. Similar to Roger’s position, Deci and Vansteenkiste (2004) stated that self-determination is most likely to occur when an individual is provided “nutrients from the social environment.” They continued, “To the extent that they are denied the necessary support and nourishment by chaotic, controlling, or rejecting environments, there will be negative consequences for their activity and development” (pp. 23-24).

As with person-centered planning, self-determination has gained significant recognition in the field of I/DD as a means toward autonomy and positive life outcomes for individuals with I/DD. Field, Martin, Miller, Ward, and Wehmeyer (1998) defined self-determination as:

a combination of skills, knowledge, and beliefs that enable a person to engage in

goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults. (p. 2)

Within this study, Jack's school support team emphasized the significant change they observed in Jack when he was given more opportunity to make choices for himself and exert control in his life:

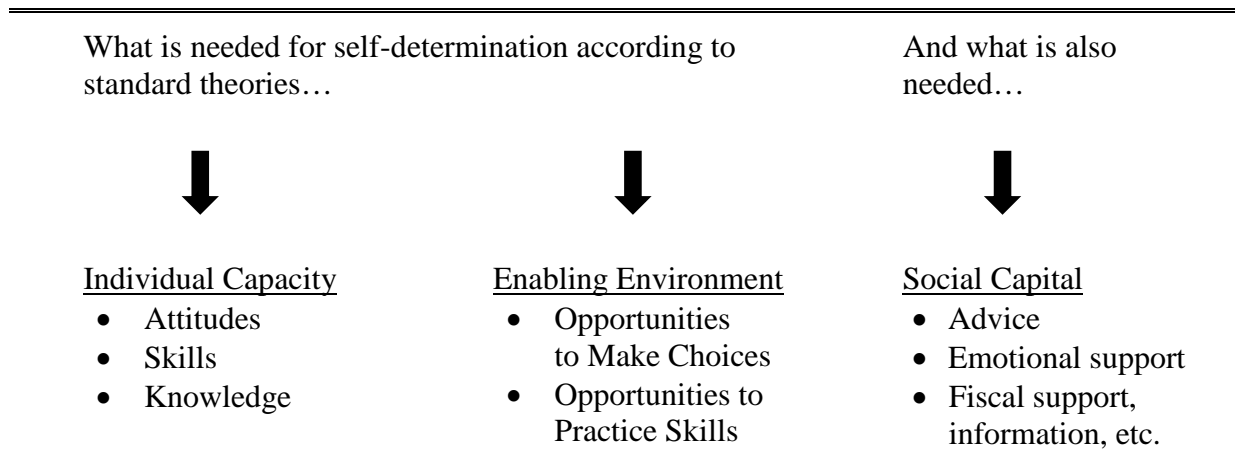
Ms. Aurora: Things were very different when he first came. Now our focus is on his responsibilities, his freedoms and his decision-making. It's not so much someone else telling Jack what to do, but it is Jack deciding what he can and can't do and what he should and shouldn't do. I think that power is liberating for him.

Ms. Ariel: It's the technique that is used to get him to be more flexible that I think is what is so key...but in saying that, there are some things that no matter what you do or say, he is not going to follow through....Choice is so critical and integral to everything.

While much of the I/DD transition-related literature focuses on instruction and enabling environments toward the promotion of self-determination, David W. Leake (2012) from the University of Hawaii recently argued that interdependent relationships and social capital have been greatly undervalued in scholarly discourse on self-determination. He attributed this neglect to a traditional Western emphasis on individualism and self-sufficiency. Quoting Sprague and Hayes (2000), Leake began the article, "The reason some of us are self-determined is that we are in interpersonal and social structural relationships that

empower us” (Sprague & Hayes, 2000, p. 681) and he goes on to state, “it can be cogently argued that the collectivistic value of interdependence is actually essential for self-determination in all cultures because interdependent social relationships yield the social capital that most people need to achieve their self-determined goals” (p. 34). The following figure was offered as a more accurate depiction of self-determination:

Figure 25. *Leake’s (2012) Representation of Self-determination*



Note. Reprinted from Self-determination requires social capital, not just skills and knowledge, (p. 38), by D. W. Leake, 2012, *Review of Disabilities Studies: An International Journal*, 8(1), 34.

The promotion of self-determined behaviors requires an emphasis on knowledge growth and skill sets related to decision-making, problem-solving, goal-setting, risk taking, safety, self-instruction, self-advocacy, self-awareness (Wehmeyer, Martin, and James, 2009, p. 102). As Leake notes, these behaviors are also contingent upon supportive relationships and enabling environments that foster opportunities for choice, self-control, risk-taking, and practice. Underlying all is that individuals with I/DD must believe that they have the right and power within them to be self-determined in their own lives. Self-determination relies on several core understandings about oneself and one’s place in the world including a sense of self, positive feelings of self-worth, feelings of inclusion and belonging, personal safety, a

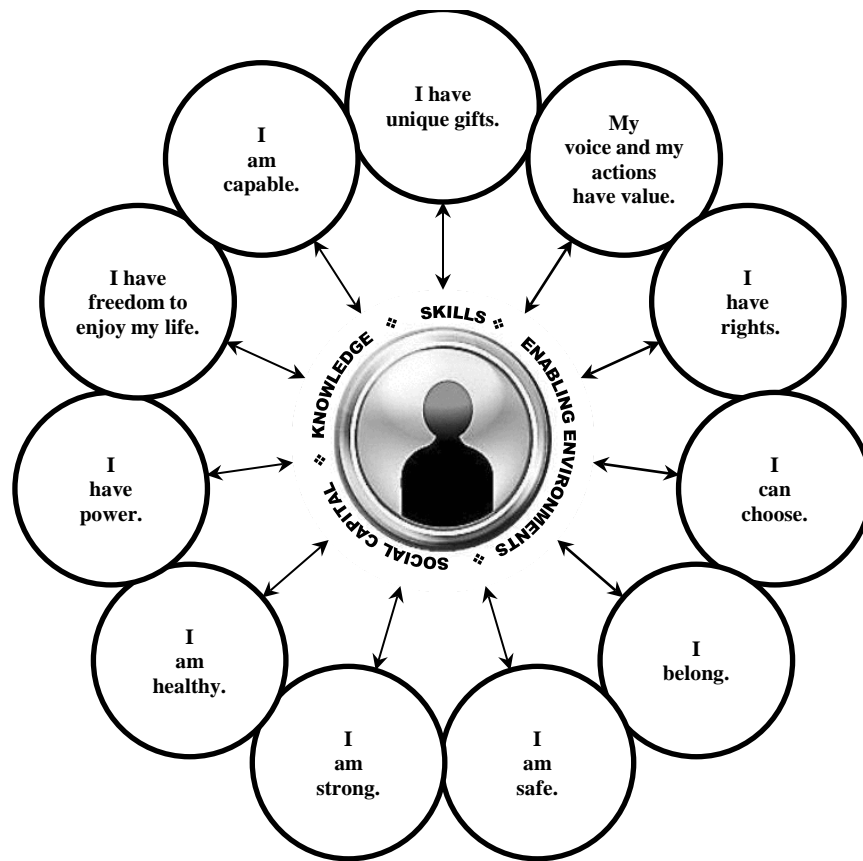
sense of purpose, self-efficacy, and so on. They are dispositions of empowerment.

All four participants in this study exhibited occasions of self-determined behavior, particularly in their ELI pursuits and practices. In both physical and online environments, Jack, Marie, Ben, and Bella displayed great curiosity, high motivation, and impressive initiative to explore and engage – as Bella’s father said, “just to be a part of it all.” At times, their ELI efforts were obstructed by environments and resources physically or cognitively inaccessible to them or presented such considerable barriers that meaningful engagement was inhibited. Other times their efforts were hindered by the well-intentioned yet limiting behaviors of others - myself included. To explain, Bella and I went to a coffee shop one day and I took the initiative to order for us. Bella quickly interrupted and expressed her desire to order and pay for her own drink. My intentions were well-meaning. I wanted to treat Bella as a gesture of appreciation for helping me with the study. I also knew that Bella struggled with money skills and I did not want to create a situation where she might feel discomfort or embarrassment. My assumption potentially denied Bella the opportunity to engage in an informative experience, contributing to enhanced skill development and feelings of self-sufficiency. Had Bella not asserted herself, the opportunity would have been lost. Although information was not directly delivered in the drink purchase, it was embedded in the experience of conversing with the sales clerk, making a decision on what to order, placing the order, determining the correct money amount due, and purchasing the item. These well-intentioned, yet limiting acts occur every day in the lives of individuals with I/DD and undermine empowered dispositions and potential for self-actualization.

Self-determination serves as the third foundational building block for the proposed model. Whereas person-centeredness draws attention to the unique individual with emphasis

on his/her inner strengths, self-determination is positioned with an outcomes-oriented focus for LIS research and practice. From the center out, knowledge growth, skill development, enabling environments, and social capital are depicted in a reciprocal relationship with empowered dispositions.

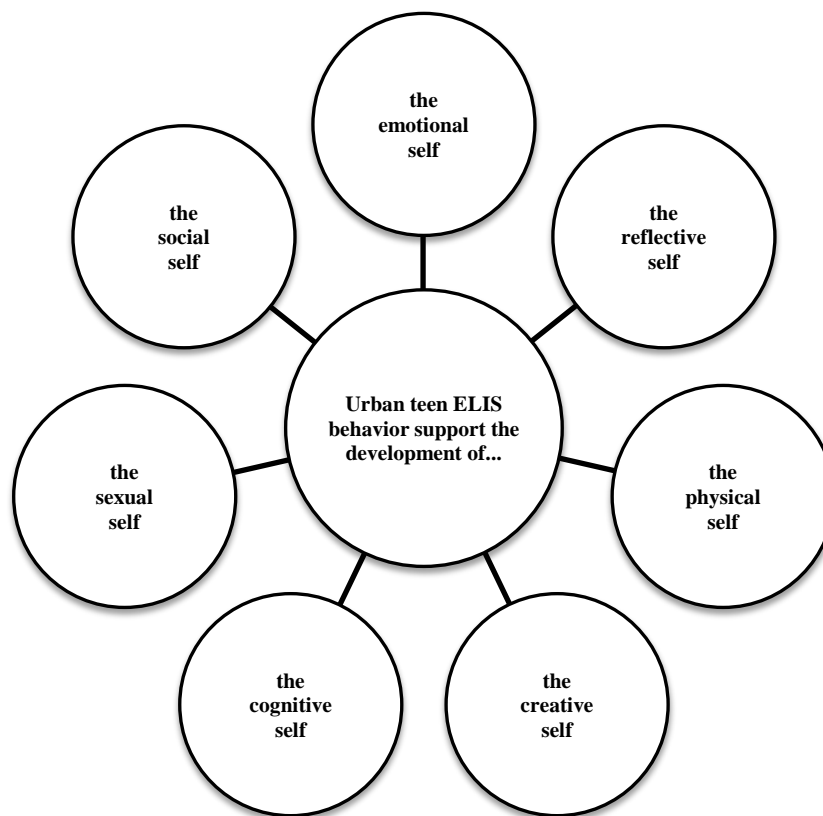
Figure 26. *Self-determination*



9.2.4 The Theoretical Model for Urban Teen Development In 2005, Hughes-Hassell and Agosto reported findings from a three year study on the ELIS needs and behaviors of urban teenagers. Using participant activity logs and semi –structured individual and group interviews, the researchers engaged twenty-seven teen participants (aged fourteen through seventeen) from the Philadelphia metro-area in the task of constructing a common list of ELIS needs and behaviors of urban teens. In review of their findings, Hughes-Hassell and

Agosto posited that the “teen ELIS is as much a process of self-exploration as a process of world exploration that helps them to understand the world and their positions in it as well as helping them to understand themselves now and to understand who they aspire to be in the future” (p 53). Grounding their work in Havighurst’s developmental tasks of adolescence,⁴⁷ Hughes-Hassell and Agosto’s findings informed the construction of a theoretical model of urban teen development comprised of seven areas of teen development. A total of twenty-three corresponding developmental tasks that are enabled by urban teen ELI behavior are distributed among the seven developmental areas (Table 34).

Figure 27. *Theoretical Model of Urban Teen Development*



Note. Reprinted from Modeling the everyday life information needs of urban teenagers. (p. 37), by Hughes-Hassell & Agosto, 2007), Lanham, MD: Scarecrow Press, Inc.

⁴⁷Havighurst, well regarded as an educational theorist, characterized six major life stages and proposed corresponding developmental tasks for each stage.

Table 34. *Developmental Tasks of Urban Teen Development*

Social self	(1) developing stable and productive peer relationships; (2) understanding and negotiating the social world;
Emotional self	(1) establishing emotional and psychological independence from his or her parents; (2) developing increased impulse control and behavioral maturity; (3) seeking emotional health and security; (4) establishing relationships with adults other than parents/guardians;
Reflective self	(1) developing a personal sense of identity; (2) establishing adult vocational goals; (3) adopting a personal value system; (4) developing a sense of civic duty; (5) establishing a cultural identity; (6) questioning how the world works;
Physical self	(1) adjusting to a new physical sense of self; (2) developing physical self-sufficiency; (3) seeking physical safety and security;
Creative self	(1) expressing artistic preferences; (2) expressing aesthetic preferences
Cognitive self	(1) adjusting to new intellectual abilities; (2) adjusting to increased cognitive demands at school; (3) expanding verbal skills; (4) understanding the physical world
Sexual self	(1) learning to manager his or her sexuality; (2) learning to recognize and accept his or her sexuality

Note. Reprinted from Modeling the everyday life information needs of urban teenagers. (p. 37), by Hughes-Hassell & Agosto, 2007), Lanham, MD: Scarecrow Press, Inc.

In consideration of the proposed model, Hughes-Hassell and Agosto's Model of Urban Teen Development is significant for many reasons. Principally, the model aligns with core principals guiding this study. Both initiatives reflect a person-centered philosophy and approach to research. Additionally, both acknowledge teens and young adults centrally, as (1) multifaceted individuals with complex lives, and (2) as experts on adolescent experiences and therefore, essential contributors to the research process. Finally, both serve as emancipatory mechanisms toward the personal growth and empowerment of two historically marginalized, underserved, and underrepresented populations.

In addition to a shared philosophy and approach to research, a side-by-side comparison of the current study findings and empirical research findings informing the development of Hughes-Hassell and Agosto's model revealed the identification of similar

ELI need topics, despite a slight variance in categorizations and word choice (Table 35).

Table 35. *Comparison of Everyday Life Information Needs*

ELI NEEDS TOPICS FOR PARTICIPANTS WITH I/DD	URBAN TEEN ELI NEEDS TOPICS
academic endeavors	academics
consumer information	goods and services
creative endeavors and expressions	creative performance
curiosities, interests, hobbies, and other pastimes	philosophical concerns, creative consumption, fashion
emotional health / coping skills	emotional health
employment	career
future planning	college
identity	self-image, sexual identity, heritage/cultural identity
financial literacy / money management	personal finances
personal safety	physical safety, sexual safety
health and development	health
relations (friends, peers, romantic, family, co-workers)	friend, peer, romantic relationships, familial relationships
responsibilities	job responsibilities, civic duty
schedule development / maintenance	daily life routine
sexual literacy	sexual safety
social life	social activities
spirituality / religion	religious practice, philosophical concerns
sports / physical activities	social activities
volunteer /service to others	civic duty
world, national, community awareness	current events, pop culture, school culture, fashion
community access	self-actualization
communication skills	
correspondence skills	
independent life skills	
self-care	
self-determination / self-advocacy	
social skills	
technology use	
transliteracy skills	

The parallel findings strengthen Hughes-Hassell and Agosto's hypothesis that "teenagers have similar information needs across socioeconomic, ethnic, cultural, and geographic boundaries" (p. 55), and to the extent of these four participants - mild to moderate cognitive differences. They also lend support to Hauser-Cram et al.'s (2009) posit that teens and young adults with and without I/DD experience similar developmental trajectories (p. 589). While the disability literature centered on this age group focuses heavily on the

transition-related needs of young people with I/DD, this current study offers evidence to suggest more attention is warranted toward their developmental needs and processes in the everyday – as teens and young adults. Just as their neurotypical peers are engaged in the tasks of self and world exploration – so too are Jack, Marie, Ben, and Bella. Table 36 highlights examples of participants’ individualized ELI needs and practices contributing to the developmental processes of self and world exploration.

Table 36. *Examples of ELI Pursuits Toward Personal Development*

ELI NEED	ELI PRACTICE	DEVELOPMENTAL AREA AND TASKS
JACK Access to YouTube during the school day	Letter writing to his school admins. advocating for access to YouTube during the school day.	<ul style="list-style-type: none"> • Social self: understanding and negotiating the social world • Emotional self: developing increased impulse control and behavioral maturity; seeking emotional health and security • Reflective self: developing a personal sense of identity • Physical self: developing physical self-sufficiency • Cognitive self: expanding verbal skills
MARIE Women’s health and social relationship issues	Participation in peer group on women’s health issues Online searching for info. on women’s health information Conversations with parents about intimacy.	<ul style="list-style-type: none"> • Social self: developing stable and productive peer relationships • Emotional self: establishing emotional and psychological independence from her parents; seeking emotional health and security; establishing relationships with adults other than parent/guardians • Physical self: adjusting to a new physical sense of self; seeking physical safety and security • Sexual self: learning to manage her sexuality; learning to recognize and accept her sexuality • Reflective self: developing a personal sense of identity
BEN Work-related information to support professional behavior, skill development and task completion	Acquiring new technical skills in support of work responsibilities	<ul style="list-style-type: none"> • Social self: developing stable and productive peer relationships; understanding and negotiating the social world • Emotional self: establishing emotional and psychological independence from her parents; establishing relationships with adults other than parent/guardians • Reflective self: developing a personal sense of identity; establishing adult vocational goals • Physical self: developing physical self-sufficiency • Cognitive self: adjusting to new intellectual abilities and increased cognitive demands, expanding verbal skills; understanding the physical world
BELLA Info.to support relationships and affective needs including sense of self and belonging	Engagement on Facebook including posting, emailing, chatting.	<ul style="list-style-type: none"> • Social self: developing stable and productive peer relationships; understanding and negotiating the social world • Emotional self: establishing emotional and psychological independence from her parents; establishing relationships with adults other than parent/guardians • Reflective self: developing a personal sense of identity • Physical self: developing physical self-sufficiency • Cognitive self: expanding verbal skills

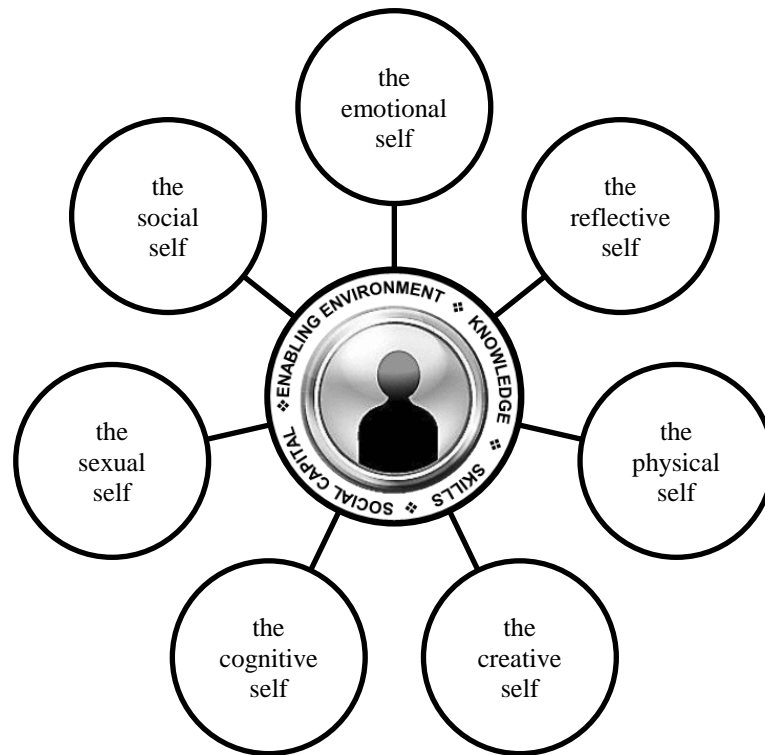
While participants in the current study shared common ELI needs and practices as participants in Hughes-Hassell and Agosto's study, there was one notable distinction in the area of self-actualization. Self-actualization refers to one's ability to reach his or her fullest potential and relies on the acquisition of meaningful ELI resources, services, and supports to promote knowledge growth, skill development, and empowered dispositions. While neurotypical teens and young adults are, generally, able to access the information and acquire knowledge, skill sets and dispositions necessary to achieve self-actualization through traditional information channels and everyday experiences (i.e. print and digital resources, information communication technologies, daily interactions and observations, after school jobs and household responsibilities), young people with I/DD have greater difficulty. Participants in this study struggled with illiteracy, difficulties with the abstract, attention and impulse control issues, anxiety, weak self-advocacy skills, and so on, influencing the quality of their ELI pursuits. They also encountered considerable ELI obstacles unrelated to personal challenges. Obstacles in the form of decreased opportunities, denial of information, and overly complicated, excluding, and/or unreliable systems, supports, and resources -- byproducts of societal misperceptions of what it means to have I/DD. Along the same vein, teens and adults with I/DD are regularly subjected to child-like treatment and there seems a societal tendency to want to quantify their abilities and "functioning" in age equivalents.

To assume that because Jack has I/DD and enjoys "preschool" shows that he also has the capacity and understanding of a preschool age child, is not only incorrect but denies the sum of his experiences and wisdom gained in his eighteen years of life to the severe detriment of his potential. As an emerging adult with I/DD who towers over 6 feet tall, attends school, holds down two jobs, contributes to the family household, and has a wide

range of interests beyond preschool shows – little suggests that Jack is not engaged in the same developmental processes as his same age peers or that he has less need for access to information. Clearly he and each of the study participants are exploring both the external world around them and their internal worlds.

The integration of Hughes-Hassell and Agosto's model plays a critical role in drawing LIS attention to the multi-dimensional aspects of being an emerging adult with I/DD and the significance of cognitively accessible ELI in support of personal growth and self-actualization. As shown in Figure 27, Hughes-Hassell and Agosto's original model positions seven selves around a central orb representing the facilitative relationship between teen ELI behaviors and each developmental domain. The proposed model incorporates all seven "selves" around the individual to reflect their inclusiveness (Figure 28). Hughes-Hassell and Agosto spoke of the interrelatedness of the seven areas, stating "the seven areas of teen development are not mutually exclusive. They often overlap, as some information needs support the development of multiple 'selves'" (p. 38).

Figure 28. *Developmental Aspects of Emerging Adulthood*



Another alteration to the original model is an adjustment for the differing maturity levels presented by young people with I/DD at this life stage. Hughes-Hassell and Agosto drew from Havighurst's developmental life stages; however, his classification of the life stage following adolescence ("early adulthood") proved unsuitable for the proposed model given the wider age span he attributed to this period (age 18-30). Table 37, thus, incorporates the developmental tasks of adolescence and the developmental characteristics of emerging adulthood (EA) identified by Arnett (2007).

Table 37. *Developmental Tasks of Emerging Adulthood for Individuals with I/DD*

Social self	(1) developing stable and productive peer relationships; (2) understanding and negotiating the social world;
Emotional self	(1) establishing emotional and psychological independence from his or her parents; (2) developing increased impulse control and behavioral maturity; (3) seeking emotional health and security; (4) establishing relationships with adults other than parents/guardians;
Reflective self	(1) identity exploration (EA); (2) establishing adult vocational goals; (3) adopting a personal value system; (4) developing a sense of civic duty; (5) establishing a cultural identity; (6) questioning how the world works; (7) adjusting to “in-between” feelings of adolescence and adulthood; (8) exploring life possibilities (EA)
Physical self	(1) adjusting to a new physical sense of self; (2) developing physical self-sufficiency; (3) seeking physical safety and security; (4) exploring career paths (EA); (5) leaving the family home (EA)
Creative self	(1) expressing artistic preferences; (2) expressing aesthetic preferences
Cognitive self	(1) adjusting to new intellectual abilities; (2) adjusting to increased cognitive demands at school; (3) expanding verbal skills; (4) understanding the physical world; (5) exploring educational paths (EA)
Sexual self	(1) learning to manage his or her sexuality; (2) learning to recognize and accept his or her sexuality; (3) developing intimate relations (EA)

9.2.5 Quality of Life

Quality of life has been described as “the degree to which a person enjoys the important possibilities of his or her life” (Renwick, Brown, & Raphael 1994, p. 201) and emerged in the I/DD field during the mid-1980s as a sensitizing notion to conceptualize life quality of individuals with I/DD. The following five principles provide the philosophical base of the QoL model.

1. Quality of life is composed of those same factors and relationships for people with I/DD that are important to those without disabilities;
2. Quality of life is experienced when a person’s needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings;

3. Quality of life has both subjective and objective components, but is primarily the perception of the individual that reflects the quality of life he/she experiences;
4. Quality of life is based on individual needs, choices, and control; and
5. Quality of life is a multidimensional construct influenced by personal and environment factors, such as intimate relationships, family life, friendships, work, neighborhood, city or town of residence, housing, education, health, standard of living, and the state of one's nation (Schalock, Brown, Brown, Cummins, Felce, Matikka, Keith, & Parmenter, 2002, p. 460).

Felce (1997) described QoL as a “potentially unifying concept” and spoke of the powerful influence a model might have in the lives of individuals with I/DD, describing the framework as a means “to bring together developmental change: in individuals and their identities; in the nature of their circumstances, experiences, and lifestyles; and in their own perceptions about themselves, their circumstances, experiences, and lifestyles.” On a broader scale, Schalock, Bonham and Verdugo (2008) describe the QoL model as an “an agent of social change that at its core makes us think differently about persons with I/DD and how we might reform policy and practice to enhance QoL-related personal outcomes” (p. 181). Over the last fifteen years, the QoL framework has evolved from a sensitizing notion into an empirically validated tool for measuring life quality and adult life outcomes and conceptually strong construct for goal setting and guiding the provision and evaluation of services and supports for individuals with I/DD.

Structurally, the QoL model is comprised of eight life domains and corresponding key indicators characterizing optimal well-being (Table 38). Although indicators can vary from person to person, across the lifespan, and between and within geographic and cultural contexts,

the framework has proven consistently sound when tested across different cultures and countries, applied and understood for all individuals - with or without I/DD.

Table 38. *Quality of Life Framework: Core Domains and Key Indicators*

Emotional well-being: Contentment, self-concept, lack of stress
Interpersonal relations: Interactions, relationships, supports
Material well-being: Financial status, employment, housing
Personal development: Education, personal competence, performance
Physical well-being: Health and health care, activities of daily living, leisure
Self-determination: Autonomy/personal control, goals and personal values, choices
Social inclusion: Community integration and participation, community roles, social supports
Rights: Human (respect, dignity, equality) and legal (citizenship, access, due process)

Note. Reprinted from “Quality of Life Model Development and Use in the Field of Intellectual Disability,” (p. 19) by R. L. Schalock, K. D. Keith, M. A. Verdugo, & L. E. Gomez, 2011, in R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disabilities [Electronic Resource]: From Theory to Practice*. Dordrecht: Springer Science+Business Media B.V.

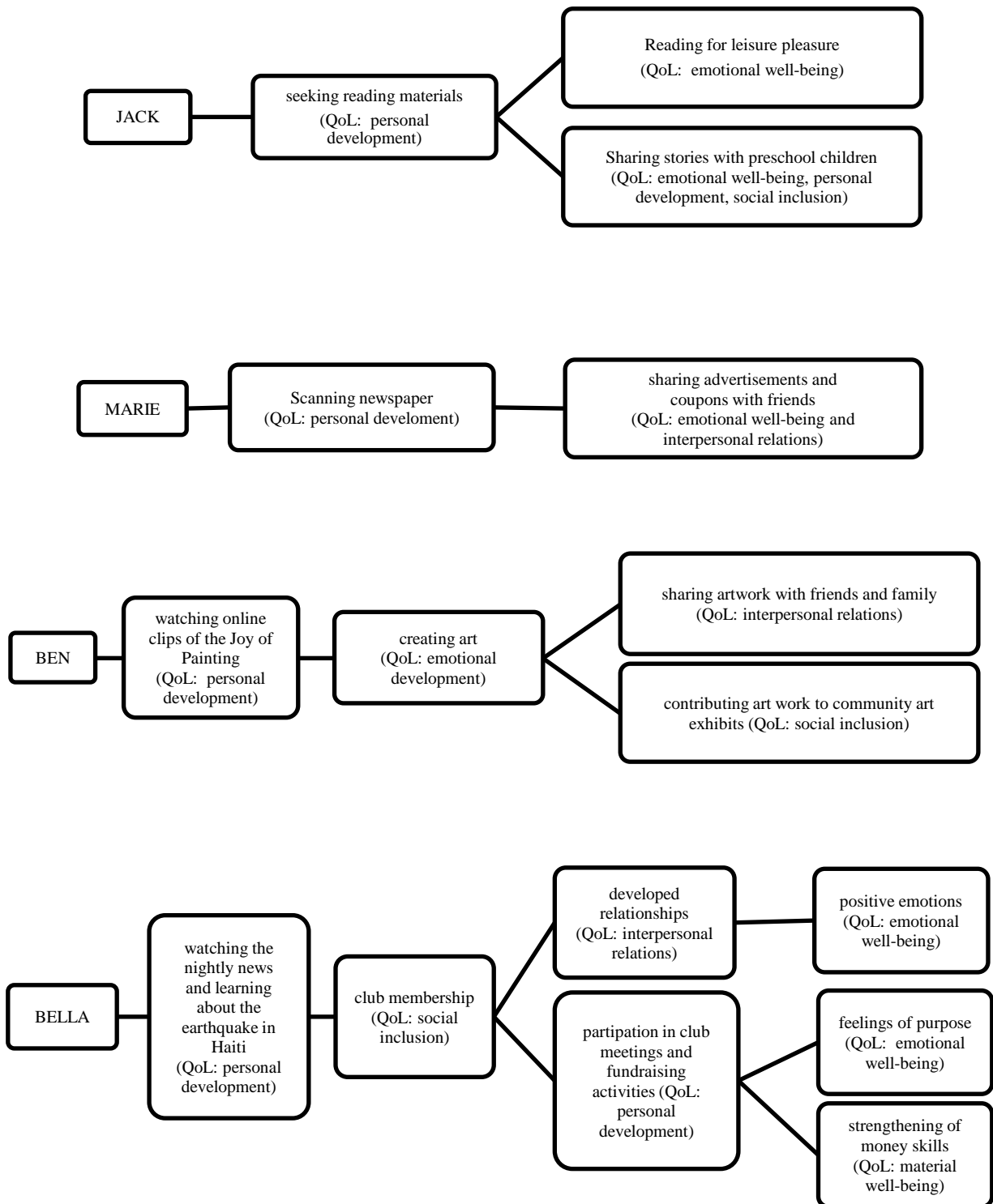
Several variables have been linked to enhanced quality of life and improved life outcomes including: one’s level of self–determination, opportunities for choice, social networks, living status, health status, community integration, life satisfaction, and the reduction of challenging behavior (Claes et al., 2012, p. 97). While intrapersonal characteristics, environmental factors, and support services are generally understood to influence individual life quality and adult life outcomes, a recent study by Claes et al. (2012) found that when removing the variable of severe and profound I/DD from intrapersonal characteristics, only environmental factors and support services were predictive of life outcomes.

The QoL framework is well-suited for integration into the proposed model in that it offers a comprehensive and empirically sound landscape from which to consider and support ELI needs and practices of emerging adults with I/DD. Schalock et al. (2002) offer five principles for its conceptual application within systems:

1. The primary purpose for applying the concept of quality of life is to enhance an individual's well-being.
2. Quality of life needs to be applied in light of the individual's cultural and ethnic heritage.
3. The aims of any quality of life-oriented program should be to collaborate for change at the personal, program, community, and national levels.
4. Quality of life applications should enhance the degree of personal control and individual opportunity exerted by the individual in relation to their activities, interventions, and environments.
5. Quality of life should occupy a prominent role in gathering evidence, especially in identifying the significant predictors of a life of quality and the impact of targeting resources to maximize positive effects. (p. 463)

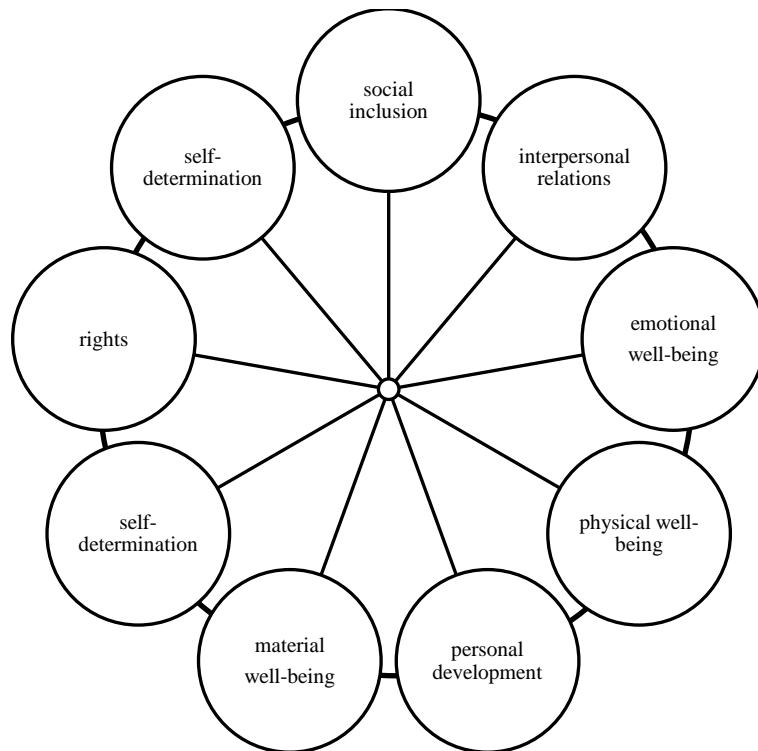
Applied as a lens from which to consider the ELI pursuits and practices exhibited in this study, the case narratives offer multiple examples illustrating the potential influence on and across different life domains. Four examples are provided in Figure 29.

Figure 29. Case Narrative Examples of ELI Influence on Quality of Life



The QoL framework (Figure 30) is represented as a radial structure with each life domain positioned separately, yet also linked to other domains to reflect their interdependency - meaning, that the enhancement of one life domain may influence other life domains, as shown in the previous case narrative examples.

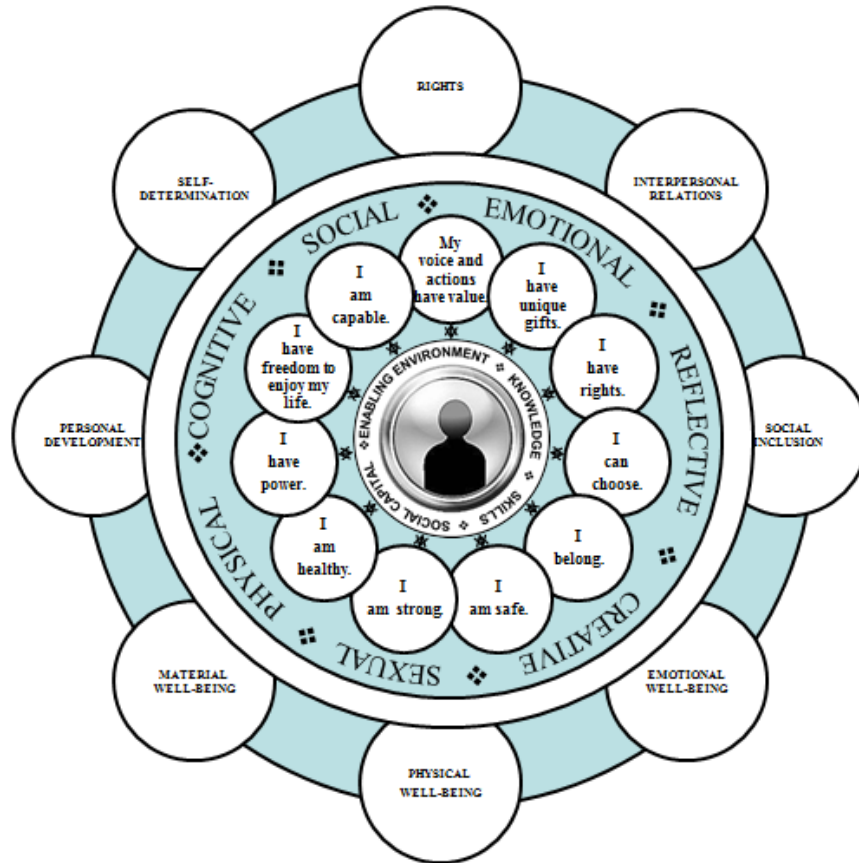
Figure 30. *Quality of Life*



9.3 Proposed ELI Model for Emerging Adults with I/DD

The completed model, as shown in Figure 31, proposes a person-centered, outcomes-oriented approach in supporting the ELI needs and initiatives of emerging adults with I/DD. For the LIS community, this means high emphasis is placed on an individual's potential rather than his/her limitations. While personal challenges are not ignored, the model asserts a strengths-based focus for LIS initiatives in support of emerging adults with I/DD, capitalizing on an individual's capabilities and strengths, interests, and life priorities in recognition of the whole person.

Figure 31. *Proposed ELI Model in Support of Emerging Adults*



As a framework to inform LIS initiatives, research and practice are grounded in the following principles and attitudes:

1. Everyone has potential.
2. All individuals have the innate desire to grow, to explore, to be of value, to belong, and to be positively acknowledged.
3. Individual differences are to be valued and celebrated.
4. The recognition and “owning” of strengths allow for individuals to define themselves by their abilities and interests rather than their limitations and thus, enable empowered dispositions and self-determined behaviors.
5. When individuals are acknowledged for their strengths and capabilities, they have

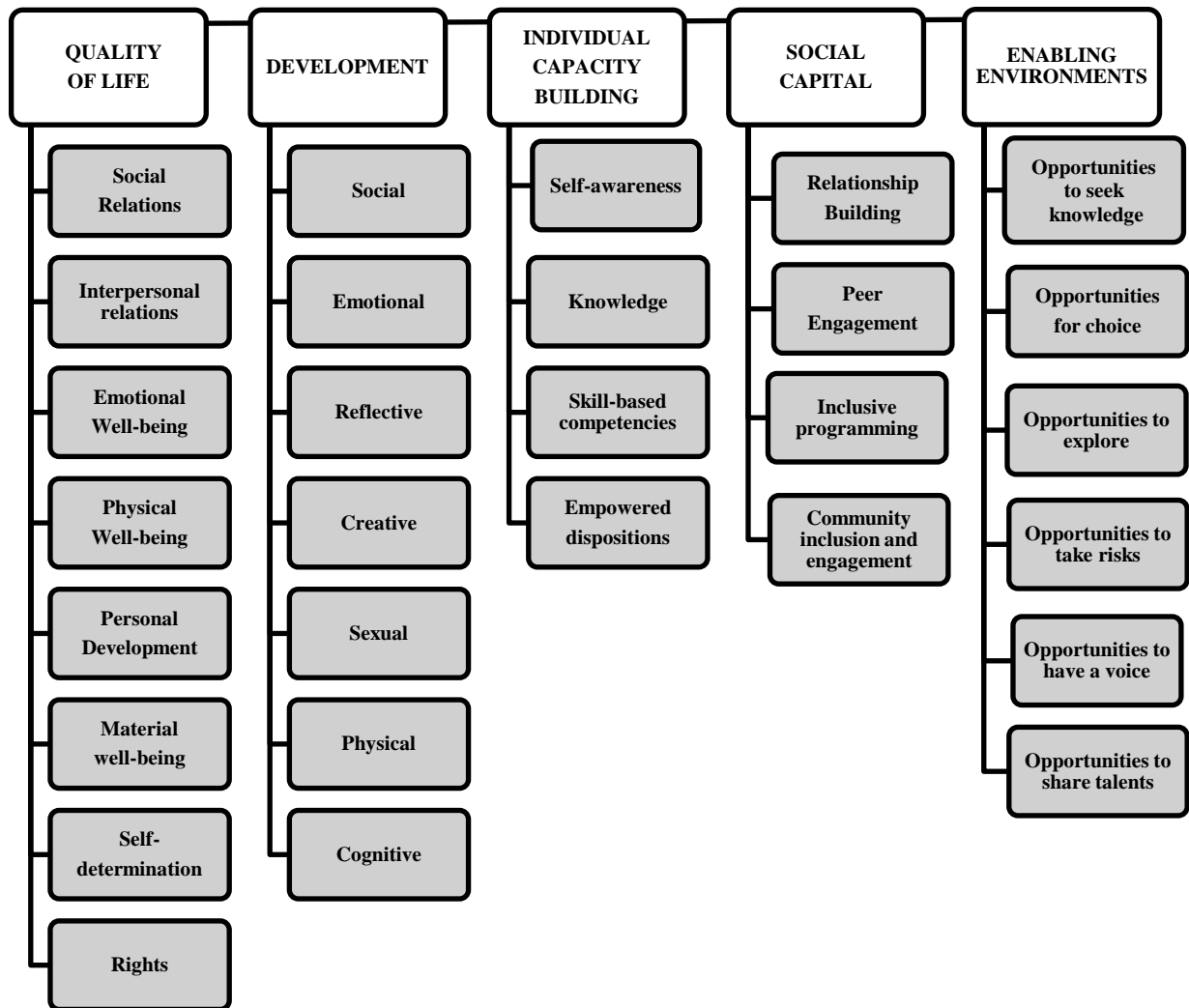
more confidence to take risks, to explore, and to be self-determined in their lives.

6. The provision of LIS services, supports, and resources should complement an individual's strengths, interests, and priorities rather than compensate for his/her perceived limitations. This involves reaching out and engaging individuals as active participants in the process. They are the experts on their lives and can provide valuable input to inform collection development decisions, program design, and service delivery.
7. The way in which LIS service and support are made available is as important as the information resources, themselves. Individuals are more likely to return to the library and advantage services, programming, and resources if they feel valued, respected, and engaged. The onus of service, outreach, and support falls squarely on the LIS community. They must meet individuals as they are and where they are in life's journey, unconditionally.
8. The goal of LIS initiatives should be to help individuals enhance their everyday lives and to self-actualize. This includes the provision of resources, supports, and services that promote self-awareness, knowledge growth, skill-development, and empowered dispositions.
9. LIS research and practice should emerge as collaborative and participatory initiatives. Emphasis is placed on building relationships and community bridge building.
10. LIS research and practice are about enhancing lives and creating possibilities.

Given these understandings, Figure 32 targets five specific areas for LIS attention toward addressing and supporting the ELI needs and initiatives of emerging adults with

I/DD. Target areas include gaining a familiarity with the literature on adult life outcomes and quality of life issues faced by individuals with I/DD, becoming informed on the developmental processes of emerging adulthood, asserting goals of individual capacity building, fostering opportunities for individuals to increase their social capital through inclusive programming and peer and community engagement, and finally creating an enabling environment inclusive of accepting and empowering attitudes of library staff, cognitively accessible resources, and service delivery and programming that enable individuals to explore, seek knowledge, develop skills, engage with resources, make connections, have a voice, share their talents, and flourish.

Figure 32. *Target Areas for LIS Attention*



Chapter 10 Implications and Limitations

While this study and proposed model provide countless jumping off points for research and practice, the study was an exploratory initiative and the model will require an interdisciplinary research agenda for validation and amplification. Still, lessons can be learned through the inquiry process and research findings. This chapter outlines implications for LIS research, pre-service education, and practice, concluding with a discussion of oft cited limitations of qualitative studies as they relate to this dissertation research.

10.1 Implications for Research

Perspectives from individuals with I/DD on matters pertaining to their lives are largely absent from the research literature. This study could not have been possible without Jack, Marie, Ben, and Bella. Their contributions clearly demonstrate that participatory research is possible and should be more fully integrated into LIS scholarly practice in studies related to the I/DD community. Still, the replication of this research may be challenging (as are most qualitative studies) given the varied contexts, personalities, and priorities involved. As highlighted in the four case narratives, the participants' everyday life needs were complex and nuanced. The strengths of this type of research lie in the case study methodology, affording multiple data collection methods and flexible strategies to gain in-depth understanding and richly descriptive accounts of the unique individual life experience. Several considerations and effective strategies employed in this study are outlined below.

10.1.1 Conceptions of ELI and ELI needs. The ways of becoming informed are innumerable. Conceptions of ELI for research will require unbinding from traditional

restraints of the written word. Information access expands parameters of LIS service, technology, and print and is inclusive of meaningful participation in everyday and digital environments in which informational content is embedded in experiences and engagement with others. This understanding informed observations and analyses of data in this study. Similarly, ELI needs are highly subjective and nuanced. Their identification requires a researcher to impose parameters as means for considering their origins and reporting findings. In this study, a distinction was made between *expressed ELI needs* and *ascribed ELI needs*. *Expressed ELI needs* represented the participants' stated and demonstrated needs and desires for information. *Ascribed ELI needs* represented ELI needs identified by others and/or highlighted in the I/DD research literature.

10.1.2 Familiarity and the development of trust. Reliance on convenience sampling, prolonged engagement in the research field, and a “native” status contributed to an easy rapport with participants (parents and teachers included) and the establishment of trust, increasing the opportunity for rich dialogue. For researchers with less experience in the I/DD community, prolonged engagement in the research setting and with participants will be particularly important to develop mutual familiarity and confidence. Further, authentic representation of individual lives will rely on a researcher's openness to engage with and commit to participants in meaningful and self-revealing ways.

10.1.3 Data collection methods. In this study, it was discovered early that a “one size fits all” approach toward data collection would not be effective given the participants' unique personalities, preferences, and challenges. Communication difficulties, attention issues, poor memory, difficulty with abstract concepts, shyness, and a tendency toward acquiescence were some of the challenges encountered. A researcher planning to engage in similar

participatory research initiatives must consider strategies for approaching these types of challenges. Traditional data collection methods will be insufficient and require some modification. In this study, tapping into participants' interests and preferred activities facilitated an easier flow of conversation than early interview efforts. Activities that were integrated into interviews included art projects, bicycling, computer activities, lunch dates, shopping, and nature walks.

Participant photography, art work, and computer activities were also effective ways for participants with communication difficulties and shyness to share information in alternate forms. The use of photovoice as a data collection tool was especially helpful in engaging participants early on and learning about their daily lives. However, some flexibility is needed in terms of the photovoice method and expectations of participants. While guidelines were established as parameters for picture taking, participants did not consistently follow instructions. That said, photos and the interviews that followed were still richly revealing in that they were independently directed by the interests and priorities of participants. The use of photos, including school yearbooks and Facebook photos, also prompted what seemed an easier recall on the part of the participants of past experiences and feelings.

Prolonged engagement in the research setting is essential. In this study, extended time with participants allowed for persistent observation and afforded multiple opportunities to ask questions in the moment and to later rephrase questions to seek clarity, ensure response consistency, and confirm accuracy of interpretations.

10.1.4 Document analysis. IEP and PCP documents proved especially helpful in gaining familiarity with participants' strengths and challenges, learning styles and preferences. The

documents also provided topic areas of ELI need and served as strong supporting data for the triangulation of findings.

10.1.5 Thick description and case narratives. “Thick description” as a methodological tool proved especially beneficial for many reasons. First, the strategy provided a canvas for assimilating coded data (observation field notes, interview transcripts, and gathered photos and documents) and constructing the case narratives. The case narratives, as stand-alone documents, then became an additional mechanism for thematic analysis, data collection, and study validation. The sharing of case narratives with individual participants and family members generated additional information and provided the opportunity for individuals to confirm or correct reporting and interpretations. While print documents were provided to family members, the case narratives were read aloud to study participants individually. This method was especially effective in that it generated more in-depth life storytelling and prompted deeper reflection. With their lives presented in the context of a story, the four participants were also able to quickly confirm, reject or clarify the information presented. As a method for decreasing concerns of participant acquiescence, this process of sharing proved especially effective. An undetermined but hopeful benefit of using thick descriptions and crafting of case narratives is that the participants’ stories will not only challenge stereotypes of I/DD, but will also evoke a connection and familiarity with the reader.

10.2 Implications for LIS Preparatory Programs

Jaeger, Bertot, and Franklin (2010) draw attention to an under-emphasis on diversity issues in LIS pre-service curriculum, suggesting that many practitioners entering the field are ill-prepared when it comes to understanding and supporting the information needs of individuals with I/DD (p. 179). The proposed model and identified target areas for LIS

attention establish a basis for pedagogical focus for MLIS programs with emphasis placed on preparing students who are not simply informed, but transformed with knowledge, skills, and dispositions to provide proactive and strengths-based LIS support.

10.2.1 Curricular content. Curricular content should focus on developing a strong knowledge base of I/DD-related issues. Table 39 provides suggested topic areas for course emphasis and cross-curricular LIS infusion.

Table 39. *I/DD Topics for LIS Course Emphasis and Cross-curricular Infusion*

Prevalence and Etiology
Philosophical perspectives and models of I/DD
Historical foundations
Theoretical frameworks and principles of practice
<ul style="list-style-type: none"> • Self-determination • Normalization • Person-centeredness • Strengths-based instruction • Least restrictive environment • Inclusion • Self-advocacy • Cultural competency • Evidence-based practice • Multiple intelligence • Constructivism • Universal design • Transliteracy (information, visual, media, digital literacies)
Critical issues
<ul style="list-style-type: none"> • Quality of life • Employment • Lifespan/aging • Gender and Sexuality • Race and culture
Legislation and public policy
<ul style="list-style-type: none"> • Americans with Disabilities Act (ADA) • Telecommunications Act • Developmental Disabilities Assistance and Bill of Rights Act • Rehabilitation Act • Social Security Act • National Voter Registration Act • Individuals with Disabilities Act (IDEA) • Architectural Barriers Act (ABA) • Ticket to Work & Work Incentives Improvement Act (TWWIIA) • Workforce Investment Act (WIA) • Olmstead Act • Rosa's Law
I/DD supports and services - state and local

Additionally, LIS pre-service educators and students may benefit from interdisciplinary academic partnerships with faculty and students in academic programs from more traditional I/DD service-related professions. Collaborative learning opportunities are beneficial for many reasons:

- contributing to skill development and strategies for working with the I/DD population;
- enabling LIS students a greater awareness of the I/DD professional scope of practice;
- offering opportunities for LIS students to share knowledge about their profession and potential contributions; and
- fostering collaborative attitudes and encouraging professional and community partnerships.

Pre-service training programs for collaborative LIS initiatives may include special education, rehabilitation counseling and psychology, social work, occupational and physical therapies, and speech pathology. Additionally, pre-service LIS educators may benefit from reaching out to their state UCEDD (University Centers for Excellence in Developmental Disabilities Education, Research, and Service) program for educational partnerships. Authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and funded by the Administration on Intellectual and Developmental Disabilities (AIDD), UCEDD programs disseminate disability research and information and provide training, technical assistance, and other services for individuals with disabilities, their families, community organizations, and governmental agencies. Presently, there are sixty-seven UCEDD organizations in the United States, with at least one center in each state.

10.2.2 Field experience. Field experience and service learning opportunities in real world settings that afford opportunities for skill development through meaningful engagement with individuals with I/DD, their families, and community organizations will also benefit pre-service LIS students. Beyond traditional school and public library service learning experiences, other potential partnerships may include the local Arc organization, state Developmental Disabilities councils, vocational Rehabilitation and employment services, and Special Olympics. Students may connect with organizations to conduct action research projects in the form of organizational information needs assessments and collection development initiatives. With these opportunities, journaling and professional mentoring relationships will encourage students to be inquisitive and self-reflective in their practice.

10.3 Implications for LIS Practice

As a historically underserved population, Holmes (2008) found that many individuals with I/DD are not active patrons of libraries. She concluded “the reasons for this discrepancy could be numerous, but one very basic reason could be that people with DD...do not view the library as a viable resource” (p. 538). This was clearly represented in the current study by all four participants who reported what seemed an underutilization of their school libraries and minimal interaction with their school librarians. Comments from teachers about their promotion and instructional use of library services and resources were particularly revealing:

- Personally I haven't used the library much this year. In the past I would take a group now and then to check out books. Of course the reading levels are quite high, where we have some kids just reading at the elementary level. I don't think they have books with high interest level vocabulary.
- Our librarian, she is the sweetest person in the entire world.

- You are not going to find anyone more accepting.
- If she were given a list of books that we wanted her to purchase, she would buy them in a second.
- We've done several jobs for them, like water the plants and dusting the shelves...but that keeps not working out very well. She is very, *very* receptive and welcoming to our kids, though.

These comments suggest a limited perception and expectation of librarians and libraries.

While a welcoming library environment is a start, it does not equate to quality service that purposefully provides legitimate access to information and purposefully works to address the information needs and wants of *all* individuals.

The actualization of the proposed model in practice will require additional efforts outside the scope of this research dissertation project; however, several steps can be taken toward enhancing LIS service in support of individuals with I/DD.

10.3.1 Engaging the I/DD community. LIS practitioners will benefit from engaging individuals with I/DD, their families, and local organizations that serve the I/DD community in discussions to gain a clearer understanding of the ELI needs, desires, practices, and challenges of this population and how best to respond and provide support. Further, library advisory boards should include members from the I/DD community (individuals with I/DD and family members) and efforts should be made to become familiar and partner with service organizations that support the I/DD community. Collaborative partnerships may include the local health and human service department, group home agencies, vocational rehabilitation and employment services, the local Arc organization, and Special Olympics.

10.3.2 Policy, practice, and collections. While mission statements often reflect tenets of

intellectual freedom and access for all, these principles are often less evident in library policy statements, practices, and collections when it comes to supporting individuals with I/DD. Again, soliciting input from I/DD community will be an important step. Services and collections should be regularly assessed to ensure relevancy and inclusive access. This includes the regular review and revision of library policy statements outlining practices relating to:

- the acquisition of materials and management of collections that provide for multiple modes of access;
- technology access and online resources;
- adaptive equipment including assistive technology and furniture that accommodates wheelchairs;
- library space arrangement for physical access; and
- professional staff development to ensure responsive reference services, inclusive and targeted programming, and proactive outreach.

10.3.3 Inclusive and targeted programing. Library service and programming in support of individuals with I/DD should be informed by I/DD community and reflective of the understandings and dispositions outlined in section 10.3. While interest driven programming should be inclusive to all members of a community, individuals with I/DD will also benefit from targeted programming in response to identified ELI needs. Examples of specific programs geared toward the I/DD community may include informational sessions on community safety, health and wellness, and citizenship roles and responsibilities. Programs may also focus on specific skill development areas relating to information literacy/bibliographic instruction, technology use, and community resources relating to

function and access. LIS practitioners will benefit from consulting and/or partnering with local special educators on how to effectively design programs, communicate information, and engage the I/DD community.

10.4 Limitations

While this study provides a starting place to extend LIS initiatives, study limitations are inevitable in all inquiry efforts. The following areas address often cited limitations of qualitative inquiries as they relate to this dissertation research.

10.4.1 Small sample size. As expected with case study research, the small sample size may be considered, by some, as a limitation in the study. However, as Stake (1995) countered, generalization is not the goal of case study research.

The real business of a case study is particularization, not generalization. We take a particular case and come to know it well, not primarily as to how it is different from others but what it is, what it does. (p. 8)

10.4.2 Lack of participant diversity. All participants came from similar backgrounds and socio-economic levels. Conducted in a different setting, the priorities, experiences, and needs of emerging adults with I/DD will likely vary across community settings, socio-economic levels, geographic locations, and cultures.

10.4.3 Participation. While participants' were actively involved in many aspects of the study, they did not take part in the study design, analysis, and production of the final document. As a participatory research initiative, this exclusion may be viewed by some as a limitation.

10.4.4 Subjectivity of researcher. As Stoecker (1991) notes, a small sample size may influence objectivity as a result of relationships formed over the course of study (p. 90).

While several steps were taken to safeguard the accuracy of findings, my native status in the community of I/DD, without question, contributes to a level of subjectiveness.

Chapter 11 Conclusion

If we are to achieve a richer culture, rich in contrasting values,
we must recognize the whole gamut of human potentialities,
and so weave a less arbitrary social fabric,
one in which each diverse human gift will find a fitting place.

Margaret Mead, *Sex and Temperament in Three Primitive Societies*

The purpose of this dissertation research was to explore the everyday life information needs, practices, and challenges of teens and young adults with I/DD. Major findings from the study include:

1. The participants exhibited a wide range of both whimsical and formidable ELI needs.
2. The participants employed multiple tools, resources, and strategies to their advantage.
3. The participants encountered both inherent and societally imposed challenges inhibiting ELI access and meaningful engagement in physical and online environments.
4. The participants displayed similar ELI needs and practices as their neurotypical same-age peers.
5. The participants exhibited ELI needs specific to their everyday life challenges and transition to adulthood – specifically the need for cognitively accessible information to support skill-based competencies necessary for self-actualization.
6. The participants exhibited ELI needs consistent with their neurotypical peers

reflecting both self and world explorations in support of developmental processes of emerging adulthood.

7. The participants displayed high motivation and exhibited great initiative to engage as information consumers, producers, managers, and providers.
8. The participants prioritized their ELI pursuits toward the enhancement of their own everyday life experiences and toward the enhancement of the everyday lives of others.
9. School and public libraries were underutilized and played a minimal role in supporting the ELI needs of Jack, Marie, Ben, and Bella.

11.1 Final thoughts

The four case narratives paint complex portraits of everyday life for young people with I/DD and highlight a confounding range of ELI needs. These needs are made more significant by the formidable barriers they encounter in their daily lives - barriers inhibiting access to information, limiting opportunities for knowledge growth and skill development, and negatively influencing the development of self and the development of desired lifeworlds. Ross Todd (2000) described the influence of information access toward the facilitation of knowledge as a process of “*inward forming*” or *in-formation*. He stated that teens and young adults “need to be able to engage with their information world, construct their own understanding and meaning, and use their knowledge in making lifestyle decisions” (p. 165). For many young people with I/DD, however, the opportunity to make lifestyle decisions - big or small - is a luxury not commonly afforded. Additionally, the competencies, resources, and opportunities necessary for strategic decision-making and problem solving are often unrealized and the dispositions required, too rarely observed.

These challenges point to a significant disparity between participants and their neurotypical peers in meaningful access to information to the detriment of self-development, everyday life quality and future life outcomes.

The LIS community is in the position to empower young people with I/DD and to positively influence lives – to be as Deci and Vansteenkiste (2004) described, “nutrients from the social environment.” David Lankes (2011), professor at Syracuse University's School of Information Studies and one of the most vocal advocates for libraries and librarians, asserts that “the mission of librarian *should* be to improve society...to make it a better place for all.” He argues that it is not enough to inform. “New librarianship” should be about *transforming* lives and facilitating the creation of knowledge. Lankes stated, “We are in the business of not simply informing someone, but making sure they are more knowledgeable so that they can act, so that they can change the world around them.”⁴⁸

The right to information is understood as a fundamental human right. The United Nations Universal Declaration of Human Rights (1948) states that all individuals have the right to “seek, receive and impart information and ideas through any media and regardless of frontiers” (Article 19). Both the International Federation of Library Associations and Institutions (1999) and the American Library Association (2006) assert the principles of intellectual freedom that include free and equal access to information for all individuals, without discrimination and regardless of medium. The World Wide Web Consortium (2009) emphasizes a “Web for All” philosophy stating:

The social value of the Web is that it enables human communication, commerce, and opportunities to share knowledge.” One of W3C's primary goals is to make these

⁴⁸Interestingly, Lankes refers to the traditional model of librarianship is a deficit model. He refers to this approach as aspirational advocacy.

benefits available to all people, whatever their hardware, software, network infrastructure, native language, culture, geographical location, or physical or mental ability.

The significance of ELI for enhanced quality of life is also highlighted in the Developmental Disabilities Assistance Act and Bill of Rights (Department of Health and Human Services, 2000). It states,

The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to

- (A) make informed choices and decisions about their lives;
- (B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;
- (C) pursue meaningful and productive lives;
- (D) contribute to their families, communities, and States, and the Nation;
- (E) have interdependent friendships and relationships with other persons;
- (F) live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and
- (G) achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual. (Administration on Developmental Disabilities, 2000)

In 2010, the United States Department of Justice issued an advanced notice of proposed rulemaking to gather public input into possible revisions of the Americans with Disabilities Act, specifically title II and III. The statutes broadly prohibit discrimination on the basis of


disability by State and local government entities and in places of public accommodation, though do not specifically address digital environments of public accommodations. While these admirable tenets and initiatives explicitly convey a message of inclusivity, the prerequisites and conditions necessary for information access and meaningful engagement in information-rich environments continue to largely exclude individuals with I/DD. Certainly, the everyday life challenges and information needs experienced by young people with I/DD are significant and issues of access and equity, complicated. However when such a disparity in life quality exists, continued inaction by the LIS community is not an acceptable option. More research is needed. The possibilities for exploration are many and have powerful and long range implications for our youth with I/DD.

In supporting all individuals with I/DD, “new librarianship” is about expanding possibilities and enhancing individual potential. It is about recognizing and advantaging information in its multiple and diverse forms and expanding information horizons through traditional, digital, and human resources. It is creating inclusive and enabling environments where information is embedded in meaningful experiences and interactions. It is about fostering feelings of belonging, acceptance, safety, respect, and self-determination. It is about empowering emerging adults with the knowledge, skills, and empowered dispositions so that they may change their own worlds, create their own meaningful outcomes and live lives of quality. Undoubtedly, the world is a better place because Jack, Marie, Ben, and Bella are in it. I believe we owe them more.

Appendix A

IRB Approval Letter

Figure 33. *IRB Approval Letter (page 1 of 2)*

 <p>THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL</p>	<p>OFFICE OF HUMAN RESEARCH ETHICS Medical School Building 52 Mason Farm Road CB #7097 Chapel Hill, NC 27599-7097 (919) 966-3113 Web site: ohre.unc.edu Federalwide Assurance (FWA) #4801</p>
<p>To: Dana Hanson-Baldauf School of Info and Libr Science CB: 3360</p>	
<p>From: Behavioral IRB</p>	
<p>_____ Authorized signature on behalf of IRB</p>	
<p>Approval Date: 12/23/2009 Expiration Date of Approval: 12/22/2010</p>	
<p>RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110) Submission Type: Initial Expedited Category: 7.Surveys/interviews/focus groups,6.Voice/image research recordings Study #: 09-2273</p>	
<p>Study Title: Everyday Life Information Needs and Practices of Young Adults with Intellectual Disabilities</p>	
<p>This submission has been approved by the above IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal.</p>	
<p>Study Description:</p>	
<p>Purpose: To explore the everyday life information needs, practices, and challenges of young adults with intellectual disabilities.</p>	
<p>Participants: 4 primary participants--individuals with intellectual disability, between the ages of 16 and 25; and an unspecified number of secondary participants--their caregivers (parents or guardians), teachers, and case managers.</p>	
<p>Procedures: Conduct case studies employing participant observations, semi-structured interviews, and document analyses. Primary</p>	
<p>Regulatory and other findings:</p>	
<p>The IRB has determined that decisionally impaired subjects may be enrolled in this research with the consent of a legally authorized representative (LAR). The following individuals may give surrogate consent for another to participate, in order of priority: (1) a court appointed guardian, or (2) an agent pursuant to a health care power of attorney, or (3) in some circumstances, a person appointed under a durable general power of attorney. If one of these three LARs is used, the PI should obtain a copy of documentation granting this authority. If the first three LARS do not exist, and as long as there is no evidence to the contrary, the following members of the immediate family</p>	

page 1 of 2

Figure 34. *IRB Approval Letter (page 2 of 2)*

may give surrogate consent, again in order of priority: (4) spouse, (5) adult child, (6) parent.

This research, which involves children, meets criteria at 45 CFR 46.404 and/or 21 CFR 50.51 (research involving no greater than minimal risk). Permission of one parent or guardian is sufficient.

Investigator's Responsibilities:

Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to submit for renewal and obtain approval before the expiration date. You may not continue any research activity beyond the expiration date without IRB approval. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.

When applicable, enclosed are stamped copies of approved consent documents and other recruitment materials. You must copy the stamped consent forms for use with subjects unless you have approval to do otherwise.

You are required to obtain IRB approval for any changes to any aspect of this study before they can be implemented (use the modification form at ohre.unc.edu/forms). Any unanticipated problem involving risks to subjects or others (including adverse events reportable under UNC-Chapel Hill policy) should be reported to the IRB using the web portal at <https://irbis.unc.edu/irb>.

Researchers are reminded that additional approvals may be needed from relevant "gatekeepers" to access subjects (e.g., principals, facility directors, healthcare system).

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule), 45 CFR 164 (HIPAA), 21 CFR 50 & 56 (FDA), and 40 CFR 26 (EPA), where applicable.

CC:

Sandra Hughes-Hassell, School Of Info And Libr Science

Marcia Tauber, (School of Information and Library Science), Non-IRB Review Contact

Appendix B

Sample Interview Questions

For Participants:

Questions will occur and develop during one-on-one formal sessions and informally during course of observations. Formal interview sessions will develop from (but not limited to) the following questions and imperative statements:

- 1) Please tell me about yourself.
- 2) Please take me through your day. What did (will) you do today/yesterday/tomorrow?
- 3) What do you like to do for fun?
- 4) How do (did) you find out about (the activity/experience/etc)?
- 5) How do you get to this activity (and other related participant information seeking questions)?
- 6) The word information can mean many things. What does “information” mean to you? How do you get information? What type of information is important to you? Do you have any difficulties finding the information you need? Can you explain?
- 7) Can you please tell me about your school library/public library? What do you do there? What are the responsibilities of a librarian?

Questions will be revised if necessary to aid in comprehension. During the course of this interview, participants will also be asked to create a collaged picture of him/herself and lifeworld – daily activities, special people, interests, etc. It is hoped that this component will aid the interview process by presenting an outlet for the individuals to express and share information in an additional way.

Informal interview sessions will occur during observation sessions and will emerge directly from natural environment and experiences. Examples may include:

- 1) Please tell me about _____.
- 2) How did you find out about _____?
- 3) How will you find out about _____?

For Family Member and Teacher Participants:

Questions will occur and develop during one-on-one formal sessions with influential individuals in participant's life including parents, special education teacher, and case manager. Formal interview sessions will develop from (but not limited to) the following questions and imperative statements:

- 1) Please tell me about _____. (Additional questions will emerge from information derived from responses. Expected responses may include information regarding disability, interests, activities, dislikes, behaviors, strengths, challenges, etc.)
- 2) Please tell me about a typical weekday/weekend day in the life of _____.
- 3) What types of information do you feel are important in the everyday life of _____?
- 4) Tell me about a time when _____ initiated a search for information. What happened? Where did he/she go to seek information? What resources did he/she consult? (books, newspaper, person, etc) What challenges did _____ encounter? How were (or Were) these challenges resolved?
- 5) Related to the everyday life information needs of _____, who typically initiates an information search? If participant, what sources does he/she typically consult? What challenges does he/she encounter in his/her search for information?
- 6) What could information/library service practitioners do to better meet the information needs of individuals with intellectual disabilities?

Appendix C

Photovoice Activities

DAY ONE

Hello (participant name)!

I want to learn more about you and the different things you do during your day.

Please take pictures of the places you go and the activities you participate in during your day today.

For example,

- If you spend time on the computer, you could take a picture of the computer
- If you go to Pottery House, take a picture of the project you are working on.
- If you have basketball practice, take a picture of the basketball, or the court, or the basketball net.
- If you go to Job Club, you could take a picture of the building.

You may take as many or as few pictures as you like, but there are a couple of important things to remember.

1. If you choose to take a picture of another person, it is important to first ask them if you may take their picture. Some people do not like to have their picture taken and it is important to respect their feelings.
2. Please remember to save these pictures either on your camera or on your computer. Try not to delete any pictures. I will want you to show me these pictures the next time we meet.

Thank you for your help! I look forward to seeing your pictures!

Dana

DAY TWO

Hello (participant name)!

Today I would like for you to think about the things you do when you have a question or are curious about something. How do you get answers to your questions or learn new things?

There are many ways we can find out new information. We might:

- ask someone we trust
- try to find the answer on the computer
- look in the newspaper
- look at our calendar
- look in a book
- take a class

Where are the different places YOU go to find answers or learn new things?

Please take a picture or pictures of the places you go, the people you might talk to, or things you might use to find answers to your questions or learn new things. Remember to save these pictures on your camera or on your computer for me to see the next time we meet. Thank you!

Sincerely,

Dana

DAY THREE

Hi (participant name)!

Today I want to learn about the things that are **MOST** important to you. Please take pictures of people, places, and things that are important to you. This might include...

- activities you like to participate in
- things you like to eat
- favorite pets
- important people in your life
- a favorite book
- a place you like to visit

Remember, if you choose to take a picture of another person, it is important to first ask them if you may take their picture. Some people do not like to have their picture taken and it is important to respect their feelings.

Also please remember to save these pictures either on your camera or on your computer. Try not to delete any pictures. I will want you to show me these pictures the next time we meet.

I look forward to seeing your pictures!

Best,

Dana

DAY FOUR

Hi (participant name)!

Today I want to learn about things that you DON'T like. This could be anything and might include...

- a chore you don't like
- a type of food that you don't like to eat
- a sport you don't like playing
- a television show or book you think is boring

Sometimes there are people that we do not like or care for very much. It is very important not to take any pictures of people today. This may cause hurt feelings.

Please take pictures of the places, activities, or things that you DO NOT LIKE.

Please remember to save your pictures on your camera or on your computer. I will want you to show them to me the next time we meet.

Thank you!

Dana

Appendix D

Case-by-case Report of Identified Everyday Life Information Needs

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	AREAS OF INFORMATION NEED			
	JACK	MARIE	BEN	BELLA
Academic endeavors	School / homework (observations; interviews - teachers, Perseus, Andromeda	School / homework report on MLK, Jr. (interview - Marie) smoking (interview - Marie)	School work (observation)	School / homework (observation; interviews - Bella; Mrs. Potter) Navigating school grounds "a map is your only friend" (interview - Bella)
Adolescent development	Puberty (interviews - Andromeda, teachers) Demonstrative behaviors toward female students (interviews - teachers)	Girls night (observation; interview - Marie) Computer activity (interviews - Marie, Mrs. Ice Cream)	Interactions with opposite sex (observation; interviews - Mrs. Kimmel, teachers)	
Citizenship Rights and Responsibilities <ul style="list-style-type: none">• Voting• Taxes• Laws• Community resources (access and function)	Jack's email "So I can be a good boy!" (document - email)			"Voting, recycling, and community involvement" (document - transition goal)
Collaboration	Jack's competitiveness (interviews - Perseus, Andromeda, teachers) Teacher treats (interview - teachers, observations)			Club participation (interviews - Bella, teachers) Special Olympics - team sports (interview - Bella)
Community access <ul style="list-style-type: none">• navigation - map and schedule reading• public transportation options and use• public transportation etiquette• community resources (access and function)• community events -	Public bus travels to/from work Schedule reading, etiquette (interview - Hercules; document - PCP goal) Community authority / helpers (police, fireman, sales associates, etc.) (document - PCP goals) Pedestrian safety (document - PCP goals) Stranger danger (document - PCP goals) Community activities/choice		Public bus travels to / from work (observation; interviews - Ben, Mrs. Kimmel) Bicycling road rules problem solving navigation (observation; interviews - Mr. and Mrs. Kimmel)	Scanning news sources television, radio, magazines, newspaper, online sources (interviews - Bella, Mr. Potter, teachers) Grocery shopping w/ family and alone (interviews - Mr. and Mrs. Potter) "Attend and discus cultural events in community" (document - transition goal) Community engagement / social activities

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
	JACK	MARIE	BEN	BELLA
	making (document - PCP goal)			(document - transition goal) Wandering tendencies (interview - Mr. Potter)
World, national, community awareness		Websites, newspapers, pamphlets, etc In support of interest and those of others (observation; document) Club participation (interview - Marie) Inclusion - elementary school (interview - Mrs. Ice Cream)	Environmental scanning Ben’s interests and others (observation; interviews - Mr. and Mrs. Kimmel) Current events from newspaper / internet (document - IEP goal)	Music events (interviews - Bella, Mr. Potter) News monitoring -TV / radio (interview - Bella, teachers, Mr. Potter) Sports (interview - Bella, Mr. and Mrs. Potter) Celebrity gossip (interview - Bella, Mr. Potter) Popular YA literature and other media (observation; interview - Bella, Mrs. Potter) "To be a part of it all" (interview - Mr. Potter) "Attend / discuss cultural events in community" (document - transition goal)
Conversation skills Turn-taking Styles of communication • Passive • Aggressive • Assertive • Formal • Informal • Non-verbal Social norms / etiquette Eye contact Self-awareness Public/private info Voice volume / tone	Bus ride interactions (interview - teachers) Voice volume awareness (document - IEP goal)	Sharing information about others private vs. public info (interview - Marie; observation)	Bus travels phone calls to friends / family (observation) Bus travels over talking (interview - Mrs. Kimmel) Initiation of conversations (document - IEP goal) Descriptive word familiarity and use (document - IEP goal) Introductions (document - PCP goal) Greetings and goodbyes (interview - Mrs. Kimmel; document - PCP goal) Relaying personal information (document - PCP goal) Eye contact (document analysis - PCP goal) Answering questions (document - PCP goal)	Conversation skills independently asking and answering questions turn-taking (document - IEP goals) Community engagement and social opportunities (document - PCP goal) Communication styles w/in context one-on-one in class in clubs (interview - teachers)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
Coping mechanisms <ul style="list-style-type: none">• Stress management / reduction• Bereavement• Community resources (access/function/ use)• Conflict resolution• Healthy emotion response• Self-awareness	Violin - breathing techniques (observations; interview - Jack) Letter to school district (observation; interviews - Jack, Hercules, Andromeda) Negotiation (observations) Choice-making (observations; document/notes; interviews - teachers, Andromeda) Schedule use to ease transitions (observation; document - IEP goal) Emotion identification, triggers, and use of descriptive language (document - IEP / PCP goals) Healthy emotion response techniques <ul style="list-style-type: none">– finding a quiet place when frustrated– using descriptive words to express feelings (document - IEP goals) Teacher modeling of appropriate responses (observations)	Girl's night support group (interview - Marie) Gifting (observation; interview - Mrs. Ice Cream) Loss of Carly (interview - Marie) Frustrations associated w/ memory loss (interview - Mrs. Ice Cream)	Schedule / calendar referencing (observation; interviews - Mr. and Mrs. Kimmel) Weather monitoring (observation; interviews - Mr. and Mrs. Kimmel) Seeking verbal confirmation <ul style="list-style-type: none">about upcoming events / schedule changesabout self-performance ("I do good?") (observation; interviews - Mr. and Mrs. Kimmel)	School support and resources Transition to high school Problems with TA in middle school Peer difficulties in middle / high school Counseling about mother and grandfather health issues (interview - Bella) Shyness (interviews - Bella, Mr. and Mrs. Potter) Boredom (interview - Mr. Potter) Problem solving / self-advocacy regarding middle school peer issues (interview - Bella) Self-advocacy about faith-based social club (interview - Bella, Mrs. Potter, teachers) Post-graduation transition (document - PCP goal) Expressing emotion (document - transition goal) Anxiety (interview - Bella, teachers) Relationship with grandmother (interview - Bella)
Correspondence skills <ul style="list-style-type: none">• Postal• Email• Cell phone• Calling<ul style="list-style-type: none">- Texting- Data access- Video/camera functions• Formal and informal etiquette / norms• Delivery systems (function and access)	Letter to district (observation; interviews - Jack, Hercules, Andromeda) Using cell phone / practicing calls (interview - Andromeda)	Emails (document) Phone calls (observation; interviews - Marie, Mr. and Mrs. Ice Cream) Texting messages/pictures (observation) Mail - dance recital invitations, birthday invitations (document) Notes to family when leaving the house (interview - Mrs. Ice Cream) Storing / accessing contact information (document; observation)	Emails (document - email; interview - Mr. Kimmel) Phone calls <ul style="list-style-type: none">leaving voice messageschecking in to report difficultiesconnecting with friends and family (observation; interviews - Mrs. Kimmel; document - PCP goal) Bus travel phone conversations <ul style="list-style-type: none">to connect w/ friends and family (observation; interview)	Facebook (interview - Bella, Mr. and Mrs. Potter, teachers) Cell phone <ul style="list-style-type: none">textingcallingsending photos (interview - Bella; observation) Email (interview - Bella, Mr. Potter)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
			- Mrs. Kimmel) While out bicycling to report difficulties to check in (interview - Mrs. Kimmel)	
Creative consumption	Video clips - preschool stories (observation; interview - Jack, Perseus, Andromeda) Gaming (observations; interviews - Jack, Perseus, Andromeda, teachers) Literature/audio books (observations; interviews - Jack, Andromeda, Perseus)	Television - adoption story, animal planet (interviews - Marie, Mr. Ice Cream) Gaming / Wii (observation; interviews - Marie, Mr. Ice Cream) Movies (observation; document - note) Web - YouTube (observation; interview - Marie) Music (observation; interview - Marie, Mr. Ice Cream) In response to boredom (interview - Mr. Ice Cream)	For entertainment: – music (observation; interview - Ben) online videos game shows cooking shows joy of painting (observation; interview - Ben, Mr. and Mrs. Kimmel) literature (observation; interviews - Ben, Mr. and Mrs. Kimmel) television programming (interviews - Mr. and Mrs. Kimmel)	Television (interview - Bella, Mr. and Mrs. Potter) Music (observation; interview - Bella, Mr. and Mrs. Potter) Literature (interviews - Bella, Mrs. Potter, teachers) Movie downloads (interview - Mr. Potter)
Creative endeavors / expressions	Story illustrations - clip art (document - stories; observations, interview - Jack) Violin (observation; interviews - Jack, Andromeda; document - transition goal) Storytelling (observations; email videos; interviews - Jack, Andromeda) Story writing (document; observations; interviews - Jack, Perseus, Andromeda, Hercules, teachers)	Pottery (observation; interview - Marie) Knitting / crocheting (observation, interview - Marie) Sewing (interview - Marie) Dancing (observation; interview - Marie) Talent show performance (observation; interview - Marie) Beading (interview - Mrs. Ice Cream)	Talent show performance (observation) Painting (observation; interviews - Ben, Mr. and Mrs. Kimmel) Flower arranging (document - schedule)	iPhone videos and photography (observation; interview - Bella)
Development and maintenance of healthy relations <ul style="list-style-type: none">• Friendships• Family• Romantic• Co-workers	Movie turn-taking "it's about how to be a good friend" (interview - Andromeda) Relations with opposite sex (interviews – Perseus, Hercules, teachers) Peer relations	Girls' night (observation; interview - Marie) Boyfriend relations (interview - Marie) Supporting interests / needs of others (observation; interview - Mrs. Ice Cream) Family / peer relations (interview - Mr. and	Supporting interests of others (interviews - Mr. and Mrs. Kimmel) Interactions w/ female peers (interview - teachers) Relationship with girlfriend (interviews - Mr. and Mrs. Kimmel, teachers)	Friendships w/ peers and adults (interviews - Bella, Mr. and Mrs. Potter) Family relations (interviews - Bella, Mr. and Mrs. Potter, teachers) Dating (interviews - Mr. Potter)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
	(interviews - Jack, Perseus) Appropriate shows of affection (observations; document - PCP goal)	Mrs. Ice Cream, teachers)		Relations w/ opposite sex "He is protective of me" (interview - Bella)
Exploration and curiosities	Online searches (observations) Literature (observations)	Online searching (observation; interview - Marie) People (observation) Community (observation)	Natural curiosities via: internet searching television experiences observations examples: food trivia / game shows travel / geography (observation; interviews - Mr. and Mrs. Kimmel)	Online shopping (interviews - Bella, Mr. and Mrs. Potter) Magazines (interviews - Bella, Mrs. Potter) Literature (interviews - Bella, Mrs. Potter) Online music exploration (interview - Bella, Mr. Potter)
Financial literacy <ul style="list-style-type: none">• Currency recognition and value• Money management / Budgeting• Consumer practices• Banking practices<ul style="list-style-type: none">- ATM use- Check writing- Balancing checkbook- Privacy issues- Debit cards- Bill pay- Money orders- Reading bank statements- Online banking practices	Shopping (observations; document-IEP; interviews - Jack, Andromeda, Perseus) Payment for tasks shelving, bringing in groceries (interviews - Andromeda) Savings (interview - Andromeda) IEP goals (document)	Shopping thrift shops garage sales (observation; interviews - Marie, Mr. and Mrs. Ice Cream) Negotiating (observation) Assistance seeking (observation)	Money skills making change coin values purchasing items independently (observation; interview - Mrs. Kimmel; document - IEP / PCP goals)	Philanthropic efforts / fundraising (interview - Bella) Online shopping tacking equipment gift cards shoes (interviews - Bella, Mr. and Mrs. Potter) Grocery shopping (interviews - Mr. and Mrs. Potter) Currency identification / value (document - IEP goal; interviews - Mr. and Mrs. Potter) Purchasing using "next dollar" method (document - IEP goal) Bill pay (document - transition goal) Keeping a simple budget (document - transition goal) CD purchase (interview - Mr. Potter)
Health <ul style="list-style-type: none">• Medical history• Prescriptions/medicine<ul style="list-style-type: none">- Label reading- Self-administration- Safety	Health science class content (observation) Nutrition - meal preparation (interview - Andromeda) Exercise/mental health benefits	Smoking dangers (interview - Marie) Wii fitness (interviews - Marie, Mr. Ice Cream) Seizure/stroke history (interviews - Marie, Mr. and Mrs. Ice Cream) Hospital recovery	Physical fitness spin class cardio / weightlifting Special Olympics (interview - Ben; document - schedule; narrative by support provider)	Mom's / grandfather's health (interview - Bella, Mr. Potter) Health club (interviews - Bella, Mr. Potter) Sharing health-related info w/ doctor

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
<ul style="list-style-type: none">• Illness prevention• Healthy living practices (nutrition, exercise, etc.)• Emergency procedures• Identification / response to simple and serious injuries• First aid• Community and online health resources(access / function)	(interview - Andromeda)	(interviews - Marie, Mr. and Mrs. Ice Cream)	Nutrition identification of food groups creating balanced meals meal preparation (document -IEP goal) Illness prevention (document - IEP goal)	(interview - Mrs. Potter) Nutrition and healthy life habits identification of food groups reading and understanding labels healthy meal preparation healthy eating habits (document - IEP goal) "Shop for and prepare simple healthy snacks and meals" (document - transition goal) Weekly exercise schedule (document - transition goal) Medical history - past surgery, medications (interview - Mrs. Potter) Prescription - administration, use, side effects (interview - Mrs. Potter) ADHD (interviews - Bella, Mrs. Potter) Personal health influence on mother's health (interview - Bella)
Identity development <ul style="list-style-type: none">• Capabilities• Strengths• Challenges• Personal / family history• Sense of place• Gender identity• Sexual identity	Disability-related "My autism means I'm a good boy" (document/email correspondence - Jack; interview - Perseus) Strengths - violin, storytelling (interviews - Jack, Andromeda; document - PCP / IEP) Challenges - anger management (interview - Jack; PCP / IEP reports)	Questions about birth mom (interview - Marie) Strengths - swimming (interview - Marie) Disability / health, physical, cognitive challenges – "You know I got something wrong with my brain" – "I can't do it b/c of my stroke doctor." (interview - Marie) Television - adoption story	Verbal confirmation work / volunteer performance (observation) Painting interests / gifting (observation) Friendships (observations)	Empathetic "I've got a big heart and I'm not afraid to use it" (interview - Bella) Strengths "It kind of made me appreciate how I am the backbone" peeling shrimp / "best in the family" "The teachers call me their second brain" (interview - Bella) Shyness "I wasn't a social butterfly."

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
	JACK	MARIE	BEN	BELLA
				<p>"I've grown so much and came out of my shell" (interview - Bella)</p> <p>ADHD (interview - Bella, Mrs. Potter)</p> <p>Cognitive challenges "brain freeze" / "brain not working today" (interview - Bella)</p> <p>Interests - "sports nut" (interview - Bella)</p> <p>Family connection "daddy's girl" (interview - Bella)</p>
<p>In response to the needs of others</p> <ul style="list-style-type: none">to understand/empathizeto helpto share information	<p>Gaming - offering information to another (Perseus interview)</p>	<p>Self - research project (interview - Marie)</p> <p>Knights of Columbus fundraiser (interview - Marie)</p> <p>Helping pottery teacher find new students (interview - Marie)</p> <p>Dogs and birds (interview - Marie)</p> <p>Coupons (document - mail)</p> <p>5k race rules (observation)</p> <p>Promoting The Arc activities/services (observation)</p> <p>Gossip (observation)</p> <p>Vacation options (document - mail)</p> <p>Assisting Mrs. Donahue (interview - Marie)</p> <p>Assisting Carly (interviews - Marie, teachers)</p> <p>Learning sign language (interview - Marie, Mr. Ice Cream)</p>	<p>Volunteer opportunities Meals on Wheels dog walking animal shelter (interviews - Ben; support provider; document - PCP goal)</p> <p>Acquiring information to share related to interests of family Prairie Home Companion American Idol road signs near family (interviews- Mr. and Mrs. Kimmel)</p>	<p>Mother's health (interview - Bella)</p> <p>Haiti club activities (interviews - Bella, Mr. and Mrs. Potter, teachers)</p> <p>Empathetic nature (interviews - Bella, Mrs. Potter, teachers)</p>
<p>Interests, hobbies, leisure activities</p>	<p>Fairytales (interviews - Jack, Andromeda, Perseus, Hercules, teachers; observations; document - stories)</p> <p>Mythology (interviews - Jack, Andromeda; observation - theater)</p>	<p>Animals (observation; interview - Marie)</p> <p>Dancing (observation; document - invitations; interview - Marie)</p> <p>Country music (interview - Marie)</p> <p>Babies</p>	<p>Travel (observation; interviews - Mr. and Mrs. Kimmel)</p> <p>Food (observation; interviews - Mr. and Mrs. Kimmel)</p> <p>Game shows - trivia (observation;</p>	<p>Music (interview - Bella)</p> <p>World events (interviews - Bella, Mr. Potter, teachers)</p> <p>Sports football, basketball, lacrosse (interviews - Bella, Mr. and Mrs. Potter,</p>

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
	class) "Preschool" related items (interviews - Jack, Andromeda, teachers; observations) Violin - musical skill development (interviews - Jack, Andromeda; observations) Story writing (document - stories; interviews - Jack, teachers, Andromeda) Storytelling (interviews - Jack, Andromeda; observations/email video) Literature exploration (interview - Jack; observation - library visit)	(interview - Marie) Crafts knitting, pottery, beading, sewing (observation; interviews - Marie, Mr. and Mrs. Ice Cream) Helping others (observation; interviews - Marie, teachers, Mr. and Mrs. Ice Cream) Online games (observation; interviews - Marie, Mr. and Mrs. Ice Cream) Wii - exercise tracking (interviews - Marie, Mr. and Mrs. Ice Cream) Shopping (observation; interviews - Marie, Mr. and Mrs. Ice Cream) Sign language (interviews - Marie, Mr. Ice Cream)	interviews - Ben, Mr. and Mrs. Kimmel) Photography (observation; interviews - Mr. and Mrs. Kimmel) Technology (observation; interviews - Mr. and Mrs. Kimmel; teachers) Painting (observation; interviews - Ben, Mr. and Mrs. Kimmel) Facebook - photos (observation) Music - choir class / Billy Joel (observation; interviews - Ben, Mrs. Kimmel) Literature exploration (observation; interview - Mr. and Mrs. Kimmel; document - schedule, narrative by support provider) Cooking, theater, flower arranging classes (interview - Ben; document - schedule, narrative by support provider)	teachers) Literature exploration (interview - Bella, Mrs. Potter) Celebrity gossip (interviews - Bella, Mr. and Mrs. Potter) Teen-related / pop culture content (interviews - Bella, Mrs. Potter)
Leadership skills		Sharing 5k race information (observation) Assistant for father's Special Olympics' soccer team (interview - Marie) Volleyball / cheerleading manager (interview - Marie)		Special Olympics softball catcher (interview - Bella)
Life skill development • Meal preparation / safe food handling • Laundry / clothing care • Shopping • Home maintenance • Home cleaning • Home repairs • Household	Meal preparation (document - IEP, transition, PCP goals; interviews - Jack, Andromeda) Safe food handling (document - IEP, transition, PCP goals; interviews - Jack, Andromeda) Baking (interviews - Jack, Andromeda, teachers;	Pet care (interview - Marie) Child care (interview - Marie) Shopping (observation; interviews - Marie, Mr. and Mrs. Ice Cream) Home chores - vacuuming, cleaning room (interview - Mr. Ice Cream)	Meal preparation (interviews - Mr. and Mrs. Kimmel; document - IEP goal) Household appliance / technology use (interviews - Mr. and Mrs. Kimmel) Shopping (interviews - Mrs. Kimmel; document - IEP / PCP goals)	Child care / health class (interview - Bella) Meal preparation (interviews - Bella, Mr. and Mrs. Potter) Reading recipes (document - IEP goals) "Shop for and prepare simple healthy snacks and meals" (document - transition

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
appliance use	document - IEP/PCP) Laundry (observation; document - transition goal; interviews - Andromeda, teachers) Shopping (document analyses - IEP / PCP goals; interviews - Jack, Perseus, Andromeda; observations) Home chores (interviews - Jack, Andromeda; document - transition goal)			goal) Laundry skills sorting, washing, drying, folding, putting away (document - transition goal)
Living options	Future living situation (document - transition goal; interviews - Jack, Andromeda)	Group home discussions (interviews - Bella, Mr. and Mrs. Ice Cream)	Future living options (interviews - Mr. and Mrs. Ice Cream)	Exploration of living options (document - transition goal) Assessment of supports needed (document - transition goal)
Personal wants and needs			Photo kiosk (document - schedule and narrative by support provider) Library use (document - schedule and narrative by support provider; interviews - Ben, Mrs. Kimmel) Banking - ATM (document - schedule and narrative by support provider) Shopping (document - schedule and narrative by support provider)	Online shopping (interviews - Bella, Mr. and Mrs. Potter)
Personal safety <ul style="list-style-type: none">Emergency proceduresIdentification and response to simple and serious injuriesInterpreting warning labelsFirst aidSafe touchStranger dangerHealthy and unhealthy relationsCommunity	Vulnerability to abuse/exploitation (interview - Andromeda) Community/pedestrian safety (document - PCP goal)	Potential for abuse/exploitation – "friendly to a fault" (observation; interviews - Mr. and Mrs. Ice Cream) Independence in the neighborhood/community (observation; interviews - Mr. and Mrs. Ice Cream)	Bicycle safety (observation; interview - Mrs. Kimmel) Recognition of dangerous situations and appropriate response (interviews - Mr. and Mrs. Kimmel) Communicating need for help (interviews - Mr. and Mrs. Kimmel; document - IEP / PCP goals) Vulnerability to abuse / exploitation	Stranger danger (document - IEP goal) Home safety practices (document - IEP goals) Wandering tendencies (interviews - Bella, Mr. Potter) "Trusting and timid" (interview - Mrs. Potter) "We worry she wouldn't know how to stand up for herself" (interview - Mrs. Potter) "Not being able to tell people no"

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
resources (access and function) • Self-advocacy • Rights • Self defense • Environmental scanning • Situational awareness • Self-awareness – recognition of internal feelings of discomfort			(interviews - Mr. and Mrs. Kimmel)	(interview - Mr. Potter)
Recreational / physical activities • Skill development • Game/activity rules or procedures • Sportsmanship • Equipment needs / use • Teamwork • Safety • Health benefits (physical and mental) • Practice / event schedule • Transportation options	Sports - skill development swimming, tennis, basketball, racquetball, walking/running (interviews - Jack, Perseus, Andromeda) Sportsmanship (interviews - Jack, Andromeda, Perseus, teachers) Health benefits (interview - Andromeda)	Camp activities (interview - Marie) Special Olympics (observation; interviews - Marie, Mr. Ice Cream)	Gym equipment use (interview - Ben) Dancing at the prom (interview - teachers) Special Olympics (observation; interviews - Ben; Mr. and Mrs. Kimmel) Camp activities (interviews - Ben, support provider, Mrs. Kimmel) Biking (interviews - Ben; Mr. and Mrs. Kimmel; observation) Schedule monitoring (observation; interviews - Mr. and Mrs. Kimmel)	Special Olympics (observation; interview - Bella) Health club (interviews - Bella, Mr. Potter) School dance - social norms (interviews - Bella, Mr. and Mrs. Potter)
Schedule development/main tenance	Schedule referencing (interviews - Jack, Perseus, Andromeda, teachers; documents - schedules, IEP/PCP) Choice-making (observation; document - notes; interviews - Andromeda, teachers)	Monitoring of community events (observation; document - mail) Calendar reference (observation; interviews - Marie, Mr. Ice Cream)	Calendar reference (observation) For independence (observation) Monitoring events for others schedule (observation; interviews - Mr. and Mrs. Kimmel) Schedule keeping (observation; interviews - Mr. and Mrs. Kimmel; document - PCP goal) Affective-related needs for life stability / consistency for direction understanding expectations to anticipate change In response to other's needs / interests	Monitoring of: local and televised sporting events music events favorite television programs (interviews - Bella, Mr. Potter) School schedule / calendar - constructing / reading (document - IEP goal) "Attend and discuss cultural events in community" (document - transition goal) Weekly exercise schedule (document - transition goal)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
			(observation; interviews - Mr. and Mrs. Kimmel) Monitoring weather for potential schedule change (interview - Mr. and Mrs. Kimmel) Experience new things (interview - Mr. Kimmel) Schedule creation / process (document- PCP goal)	
Self-care skills <ul style="list-style-type: none">• Hygiene• Grooming	Schedule reference for: washing face (interview - Andromeda; document - schedules) shaving (document - transition goal, schedule) bathing, brushing hair, brushing teeth (document - PCP goals, schedules) Washing hands (observation; interview - teachers) Choosing appropriate clothing by weather and occasion (document - PCP goals, schedules) Checking weather reports on iTouch (document - PCP plan)		Weather monitoring appropriate clothing potential schedule change coping w/ potential stress (observation; interview -Mr. Kimmel; document - IEP goal) Shaving, combing hair (interview - Mrs. Kimmel)	Referencing weather from online home page (observation; interview - Bella) Washing hair reminders to rinse thoroughly (interview - Mrs. Potter)
Self-determination <ul style="list-style-type: none">• Problem solving• Decision / choice making• Future planning• Goal setting• Awareness of resources (functions/access /use)• Rights• Negotiation skills• Social norms/etiquette• Self-advocacy• Rights• Disability related	Choice-making movie night, school notes (observation, document - transition goal; interviews - teachers, Andromeda) Negotiating changes in schedule (document - IEP) School district letter (interviews - Jack, Hercules, Andromeda) Articulating feelings / wants / needs (observation;	School - IEP Scheduling/planning/go al setting (interviews - Marie, Mrs. Ice Cream)	Advocacy for school bus preference (interview - Mrs. Kimmel) Technology control (observation; interviews - Mr. and Mrs. Kimmel; teachers) Wants / needs breakfast / meals paints (interviews - Mr. and Mrs. Kimmel) Independence in community bus bicycling (interview - Mrs.	Future planning living arrangement college possibilities employment (interviews - Bella, Mr. and Mrs. Potter) Difficulties w/ choice making (interviews - teachers) "Knowledge of rights for self-advocacy" (document - transition goal) Express emotions (document - transition goal)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
	JACK	MARIE	BEN	BELLA
laws / regulations (ADA, Fair Labor Standards Act, etc.)	interviews - Jack, Perseus, teachers) Appropriately asking for assistance (observation)		Kimmel) Asking for assistance (document - IEP goal)	Post-graduation plans (document - PCP goal) Applying for SSI and Medicaid (document - PCP goal) Active participation / input in PCP plan (document - PCP goal, interview - Mrs. Potter)
Self-monitoring and self-regulation <ul style="list-style-type: none">• Healthy emotional response• Impulse control• Cause / effect• Expectations• Social norms (w/in context)	Schedules (interviews - Jack, Andromeda, Perseus; document - schedules, IEP/PCP) Rewards systems (interviews - Jack, Andromeda; document) Visual reminders - school notes, schedules (document; interviews - teachers) Jack's email - "So I can be a good boy!" (document) Computer time (interviews - Jack, teachers) Teacher treats (interview- teachers) Personal safety assessment <ul style="list-style-type: none">environmental scanningsituational awareness of potential dangersself-awareness - internal feelings of discomfort (interviews - Andromeda)	Impulsivity (interview - Mr. and Mrs. Ice Cream) Personal safety assessment <ul style="list-style-type: none">environmental scanningsituational awareness of potential dangersself-awareness-- internal feelings of discomfort (interviews - Mr. and Mrs. Ice Cream)	Verbal confirmations (observation) Schedules - monitoring and referencing (observation; interviews - Mr. and Mrs. Kimmel) Personal safety assessment <ul style="list-style-type: none">environmental scanningsituational awareness of potential dangersself-awareness--- internal feelings of discomfort (interviews - Mr. and Mrs. Kimmel)	Classroom expectations / rules (document - photography) Self-awareness / communication (interview - teachers) Personal safety assessment <ul style="list-style-type: none">environmental scanningsituational awareness of potential dangersself-awareness--- internal feelings of discomfort (interviews - Mr. and Mrs. Potter)
Sense-making			Pattern-seeking hotels (observation; interview - Mrs. Kimmel)	
Sexual health <ul style="list-style-type: none">• Sexual development• Safe sex practices• Reproductive process• Birth control options (access/use)• Healthy intimate	Puberty (interviews - Andromeda, teachers)	Questions about sex (interview - Marie) Reproductive process (interview - Marie) Child care - health class (interview - Marie) Online searching / misinformation (interviews - Marie, Mrs. Ice Cream) Girls night (observation; interviews		Intimate relations (interview - Mr. Potter)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
relations		- Marie, Mrs. Ice Cream)		
Social acclimation <ul style="list-style-type: none">Social norms/etiquette w/in context (school, work, community, online)Common talking points (pop culture, local / world events)Teen trendsPositive peer relationsConversation skills	Turn-taking "About being a good friend" (interview - Andromeda) Hygiene and grooming (interview - Andromeda) Volunteering -giving back Positive work habits	Facebook - etiquette / norms (observation)	Consumer practices eye contact ordering food (document - PCP goal) Interactions with female peers (interviews - Mrs. Kimmel, teachers) Relations with classmates (interviews - teachers) Positive work habits	Twilight (observation; interviews - Bella, Mr. and Mrs. Potter, teachers) Celebrity blogs (interviews - Bella, Mr. Potter) Sports (interviews - Bella, Mr. Potter) News (interviews - Bella, Mr. Potter, teachers) Facebook monitoring (interviews - Bella, Mr. and Mrs. Potter, teachers) Club participation / extracurricular activities (interviews - Bella, Mr. Potter, teachers)
Spirituality / religion		Church with neighbor (interview - Marie) Faith-based social club (observation)	Faith-based social club (observation; interviews - Ben, Mrs. Kimmel) Televangelical programs (interview - Mrs. Kimmel)	Previous participation in faith-based social group (interviews - Bella, teachers)
Technology skills <ul style="list-style-type: none">UseWeb navigationOnline etiquette / normsOnline safetyWord processingEmailGamingSocial networksSearchesPhotographyTransliteracy (print, information, digital)	Story writing / illustrations (document; interviews - Jack, Andromeda) Games (observations) Computer class (document - transition goal; observation) Data entry (interview - Jack) Email (document) iTouch - for shopping (observation, interviews - Jack, Perseus) Wii - games (interviews - Jack, Perseus) Checking weather - iTouch (document - PCP goal) Schedule creation (document - PCP goal)	Email - receiving information about Special Olympics (interview - Marie) Email - connecting with friends and family sending messages attaching photos (document) Online searching (observation; interviews - Marie, Mr. Ice Cream) Online games (observation; interviews - Marie, Mr. Ice Cream) Facebook (observation) Cell phone use making calls texting attaching photos (observation) Wii - games (interviews - Marie, Mr. Ice Cream) Wii - health	Learn new skills related to interests painting techniques, techniques, computer functions (observation; interviews - Ben, Mr. and Mrs. Kimmel) Searching to satisfy curiosities hotels, road signs, Google maps (interviews - Ben, Mr. and Mrs. Kimmel; observation) Formal / informal email correspondence (observation; interviews - Mr. Kimmel, support provider) Photography (observation; interview - Mr. Kimmel) Facebook (observation)	Club participation - keeping informed via email (interview - Bella) Organization / search history clearing (observation; interview - Bella) Cell phone use making calls texting taking and sending photos videos (observation; interviews - Bella, Mr. and Mrs. Potter) Photography - transferring digital photos (observation, interview - Bella) iPod - transferring music, videos (interviews - Bella, Mr. Potter)

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
		(interviews - Marie, Mr. Ice Cream) Downloading music / burning compact discs (interviews - Marie, Mr. Ice Cream)	For entertainment purposes videos, games (observation; interviews - Ben; Mr. and Mrs. Kimmel) Learning new skills related to employment data entry copy machine use demagnetizer scanning creating pdfs (observation; document - IEP goal) Wheel of Fortune - Wii (observation; interviews - Ben, teachers) iTouch - to follow a schedule (document - IEP goal)	Online activities: shopping, searching, music access, entertainment, access to news, pop culture, Facebook, email (observation; interview - Bella, Mr. and Mrs. Potter, teachers) Keyboarding / word processing (document - IEP goal)
Time concepts			Referencing calendar (observation; interviews - Mr. and Mrs. Kimmel) Maintaining schedules (observation; interviews - Mr. and Mrs. Kimmel) In response to others interests / needs Mrs. Kimmel's Prairie Home Companion American idol (interviews - Mr. and Mrs. Kimmel) Elapsed time concepts (document - IEP goal) 15 minute time intervals for schedule keeping (document - PCP goal)	
Alcohol / Drug education		School program on smoking (interview - Marie) Responsible consumption of alcohol (observation)		Responsible consumption of alcohol (interview - Bella)
To support memory/promote recall • Strategies		Address book (document; interview - Marie) Calendar referencing (observation; interview -	Video to support hobby painting (observation; interviews - Ben, Mr.	Recall difficulties / anxiety-induced (interview - Bella, teachers) Personal information

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
	JACK	MARIE	BEN	BELLA
<ul style="list-style-type: none">Tools		Marie) Memory loss due to stroke (interviews - Marie, Mrs. Ice Cream)	and Mrs. Kimmel) Schedule / calendar reference (observation, interviews - Mr. and Mrs. Kimmel) Verbal confirmation (observation, interviews - Mr. and Mrs. Kimmel) iTouch use for schedule maintenance (document - IEP goal) iTouch use for step-by-step process (document - IEP goal)	(document - IEP goals)
Transliteracy (print, digital, visual, media...) <ul style="list-style-type: none">Comprehension of information presented in print / non-print materialsFunctional reading⁴⁹ skills – use of context clues, identifying key words, paraphrasingFunctional writing to convey information to another. Including topic sentences, supporting details, appropriate logical sequence, sufficient elaboration, concluding statement.	Story writing / sharing (document; observations) Academic endeavors (observations) Email correspondence (document) Digital literacy online activities / navigation (observation) Technology use: computers, iTouch, work-related equipment, cameras (observation, interviews - Jack, Perseus, Andromeda, teachers) --computer functions: data entry, creating files, saving documents / photos (observation; interviews - Jack, teachers)	Community events (document - mail; observation) Movie times (document - mail) TV schedule (interview - Mr. Ice Cream) Digital literacy online activities / navigation (observation; interviews - Marie, Mr. and Mrs. Ice Cream) technology use: computers, camera, cell phone (observation; interviews - Marie, Mr. Ice Cream)	Digital literacy online activities / navigation (observation) technology use: computers, iTouch, cell phone, Work-related equipment, cameras (observation) Computer functions: Creating files, saving documents / photos, creating pdfs (observation) Visual literacy in support of painting technique development cooking techniques (observation; interviews - Ben, Mr. and Mrs. Kimmel) Functional reading - different types of texts reading recipes (document - IEP goal) rule following using a written prompt for game or activity (document - PCP goal)	Digital literacy online activities / navigation (observation) Technology use - computers, iTouch, iPhone, cameras (observation; interviews - Bella, Mr. and Mrs. Potter) Visual literacy school map / "a map is your only friend" (interview - Bella) Using "schedules, newspapers, and basic charts to find information" (document - IEP goal)
Vocational skill development	Work skills data entry, bakery,	Sheltered workshop (interview - Marie)	Use of work-equipment	Job skill development working with

⁴⁹ Examples: instructions, manuals, warranties, bills, bank statements, credit card applications, mail order purchases, prescription/non-prescription, medicine directions, newspapers (for weather, TV schedule, movie times, community events, advertisements/classified ads), informational pamphlets, print / online phone directories

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCRIED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED	JACK	MARIE	BEN	BELLA
<ul style="list-style-type: none">• Career exploration• Job seeking skills• Application/interviews• Trades• Laws (ADA, Fair Labor Standards Act)• Conflict resolution, resources, processes• Positive work behaviors/habits• Interest inventories• Professional dress	<p>storytelling, shelving books (observation, document - transition goal; interviews - teachers, Andromeda)</p> <p>Use of work-related equipment: electric mixer computer / computer programs (interviews - Jack, Andromeda)</p> <p>Teacher treats Work demeanor / following directions (observation)</p> <p>Career exploration (document - IEP and transition goals)</p> <p>Assessment of vocational interests, work values, skills, etc (document - transition goal)</p>	<p>Fitness center (interview - Marie)</p> <p>School store (interviews - Marie, teachers)</p> <p>Animal shelter (interviews - Marie, Mrs. Ice cream)</p> <p>Business office / recycling (interviews - Marie, teachers)</p> <p>Job club (interview - Marie, Mrs. Ice Cream)</p> <p>Horticulture program (interviews - Marie, Mrs. Ice Cream)</p> <p>Volunteer opportunities (interviews - Marie, Mr. and Mrs. Ice Cream; observation)</p>	<p>computer, computer programs, copy machines, scanners, demagnetizer, heating device (candle making) (observation; document - PCP goal)</p> <p>Professional emails (interview - support provider)</p> <p>Positive work habits / behaviors (document - PCP goal; interview - support provider)</p> <p>Developing a trade / skill candle making data entry filing fulfillment-related tasks organizing / shelving books (observation; interview - support provider)</p> <p>Navigating campus (observation)</p> <p>Animal care (interview - Ben, support provider)</p> <p>Gym equipment care (interview - Ben, support provider)</p> <p>Meals on Wheels (interview - support provider)</p> <p>Volunteer opportunities (document - PCP goal)</p>	<p>horses hospital position coffee shop experience (interviews -Bella, teachers; observation; document - transition goal)</p> <p>Work interest inventory (document - transition goal)</p> <p>Job application completion personal information (document - IEP goal)</p> <p>Teamwork Accepting constructive criticism (document - transition goal)</p> <p>Work skills and requesting assistance when needed (document - IEP goal)</p>
To promote belonging and connections	<p>Email (document)</p> <p>Phone calls to g'ma (interviews - Jack, Andromeda)</p>	<p>Emails (document)</p> <p>Texting messages/pictures (observation; document)</p> <p>Spelling assistance from others (observation)</p> <p>Copying from print resources (observation)</p> <p>Dictating (observation)</p>	<p>Phone calls (observation; interview - Mr. and Mrs. Kimmel)</p> <p>Emails (document - email; observation; interview - Mr. Kimmel)</p> <p>Facebook (observation)</p>	<p>Club participation / email (interviews - Mr. Potter, teachers)</p> <p>Pop culture interests (interview - Mr. Potter)</p> <p>sports "they're like my brothers" "We're like two peas in a pod" (interviews - Bella, Mr. Potter)</p> <p>Literature (interviews - Mr. and Mrs. Potter)</p> <p>Texting (observation;</p>

EXPRESSED INFORMATION NEED (IDENTIFIED OR DEMONSTRATED)		ASCIBED INFORMATION NEED (IDENTIFIED BY ANOTHER)		
AREAS OF INFORMATION NEED				
	JACK	MARIE	BEN	BELLA
				interviews - Bella, Mr. and Mrs. Potter) Phone calls (interviews - Bella, Mr. and Mrs. Potter)
Personal responsibilities	Chores (interviews - Jack, Andromeda) Grocery shopping (observations; interviews - Jack, Andromeda, Perseus)	Chores (interview - Mr. Ice Cream) Volunteer responsibilities (interview - Marie)	Work and volunteer responsibilities (observation; interview - support provider; document - IEP / PCP goals, narrative by support provider) Dog walking (document - schedule, narrative by support provider) Chores (interview - Mr. Kimmel)	Pet care (interview - Bella) Assisting Mrs. Potter (interview - Bella) Chores (interviews - Bella, Mr. and Mrs. Potter) Homework (interviews - Bella, Mr. and Mrs. Potter) Family cooperation (interview - Mr. Potter)

Appendix E

Identified Information Practices, Tools and Resources

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
ADDRESS BOOK		<ul style="list-style-type: none"> - To record store and access postal and email addresses and phone numbers - To record store and access favorite website urls (observation; interview Marie)		
BOOKS (including audio books)	<ul style="list-style-type: none"> - For entrainment - To support interests - To fulfill academic obligations - To develop/strengthen vocation-related skills - To expand knowledge (observations interview - Jack Andromeda; documents - Jack's photo)	<ul style="list-style-type: none"> - Entertainment/to support leisure interests - To understand life events (book given in hospital) - In generosity and friendship – the seeking and sharing books that might be of interest to others (observation; interview - Marie; documents - Marie's photos)	<ul style="list-style-type: none"> - Entertainment - To support/expand interests and knowledge - In support of others - work-related responsibilities (observation; interviews - Ben family)	<ul style="list-style-type: none"> - To fulfill academic obligations - To expand knowledge - For entertainment - To support personal interests - To connect with family (Twilight and father) - To "be a part of it all" (observation; interviews - Bella family teachers; documents - Bella's photo)
CALCULATOR		<ul style="list-style-type: none"> - To fulfill school obligations - To perform simple calculations for personal needs (interview - Marie)		<ul style="list-style-type: none"> - To fulfill school obligations to perform simple calculations for personal needs (observation; interview - Bella)
CALENDAR		<ul style="list-style-type: none"> - To monitoring activities/events (observation; interviews - Marie family)	<ul style="list-style-type: none"> - To anticipate change and upcoming events - To confirm changes and upcoming events - To self-regulate/coping (desk calendar) (observation; interviews - Ben Mr. And Mrs. Kimmel; document - calendar Ben's photo of school calendar)	<ul style="list-style-type: none"> - To anticipate upcoming events/activities (document - Bella's photo)
CLASS PARTICIPATION	<ul style="list-style-type: none"> - To support interests - To develop/strengthen interest area skills - To fulfill academic 	<ul style="list-style-type: none"> - To support interests to gain/expand knowledge areas - To develop/strengthen 	<ul style="list-style-type: none"> - To share creative endeavors/expressions - To connect w/ others - For personal 	<ul style="list-style-type: none"> - To fulfill academic obligations - To develop/strengthen interest area skills

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
	<p>obligations (observations; interview - Andromeda documents - IEP/Transition/PCP Jack's school photo)</p>	<p>interest area skills (dance flower arranging pottery sign language)</p> <ul style="list-style-type: none"> - To share creative endeavors/expressions - To develop vocation-related skills (job club horticulture program) (observation; interviews - Marie family) 	<p>enjoyment</p> <ul style="list-style-type: none"> - To fulfill academic obligations - To develop/strengthen interest area skills (cooking class painting class flower arranging class theater class) (observation; interviews - Ben family) 	<p>(horseback riding lessons) (observation; interviews-Marie family)</p>
PARTICIPATION IN CLUBS ORGANIZATIONS AND EXTRACURRICULAR CLASSES	<ul style="list-style-type: none"> - To develop/strengthen special interest skills (violin Special Olympics swimming basketball) - To stay fit/healthy (physical/emotional health Special Olympics) - To develop and strengthen good sportsmanship skills (Special Olympics) - To connect and engage socially (The Arc program) (interviews Jack family) 	<ul style="list-style-type: none"> - To engage with others (Special Olympics social ministries summer camp) - To offer peer support (social ministries Special Olympics) - To develop work skills (job club horticulture program) - In support of interests (pottery flower arrangement class) - To contribute (volunteering for The Arc Knights of Columbus) - To support creative endeavors and expressions (pottery class flower arranging class talent show) - To develop life skills (cooking class) - To stay fit and healthy (Special Olympics) (observation; interview - Marie family; document - Marie's photos) 	<ul style="list-style-type: none"> - To connect w/ friends (Special Olympics social ministries) - To stay fit and healthy (Special Olympics spin class) (observation; interviews - Ben family; documents - Ben's photos) 	<ul style="list-style-type: none"> - To connect with friends (Special Olympics) - To overcome shyness (Special Olympics) - To develop strengthen and showcase skills (Special Olympics - softball) (observation; interviews - Bella family)
COLLECTING MISC. PRINT AND DIGITAL MATERIALS		<ul style="list-style-type: none"> - In generosity and friendship to others - in support of their interests and needs - To support possible future needs (observation; interview - Marie Mrs. Ice Cream) 	<ul style="list-style-type: none"> - To support interests and needs of others - To connect and engage with others (interviews - family) 	

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
COMMUNITY TOOLS	<ul style="list-style-type: none"> To support grocery shopping activities (use of produce scale) (observation; interviews - Jack family) 		<ul style="list-style-type: none"> To access personal funds (ATM) (interviews- Jack support provider; document - work document) 	
COMPUTER / INTERNET	<ul style="list-style-type: none"> To fulfill school expectations To express self through stories and emails to find illustrations for stories For entertainment (videos games) To support curiosities and interests To self-advocate To support vocational skill development To fulfill work obligations to connect with others (observation; interviews - Jack family teachers; document - IEP/Transition/PCP Jack's photo emails) 	<ul style="list-style-type: none"> For entertainment Diversion from boredom (online video clips games) For personal health information (sexual health nutrition) For obtaining information to support others (pet adoptions animal rescue sites birthday party planning; learning to sing Happy Birthday in Portuguese dance moves) To connect with others / share photos (email Facebook) (observation interviews - Marie family document - email Facebook communications) 	<ul style="list-style-type: none"> For entertainment and leisure time preference (game show video clips; online games Facebook photos) To fulfill work obligations (job) To connect with others (email Facebook) To fulfill academic obligations To support personal interest areas (travel food painting) To develop / strengthen / showcase skills (painting photography) To scan weather report (observation; interviews - Ben family teachers; documents - Ben's photos) 	<ul style="list-style-type: none"> Entertainment and leisure preference (online surfing games videos/movies Facebook) To access / listen to / share music To support curiosities and interests To support personal information needs (online shopping music concerts) To connect with others (email Facebook) To fulfill club membership obligations and stay informed (email Haiti / Peace club) To store and access photo To fulfill academic responsibilities To check weather (observation; interviews - Bella family)
COMMUNITY ENGAGEMENT AND TOOLS	<ul style="list-style-type: none"> To develop and strengthen vocational skills (school vocation-related activities volunteer opportunities) To develop and strengthen life skills (home responsibilities school community activities) To contribute to home upkeep To develop and strengthen skill development in interest areas To support grocery shopping activities 	<ul style="list-style-type: none"> To develop and strengthen work skills (volunteer school vocational training) To contribute and belong (volleyball and cheerleader manager volunteer opportunities) To develop and strengthen life skills (baking at home) To develop and strengthen appropriate social behaviors (interviews - Marie Mrs. Ice Cream teachers) 	<ul style="list-style-type: none"> To develop and strengthen vocational skills (school vocation-related activities) To develop and strengthen life skills (home responsibilities school community activities) To contribute to home upkeep To develop and strengthen skill development in interest areas To access personal funds (ATM) (interviews- Jack support provider; 	<ul style="list-style-type: none"> To develop and strengthen vocational skills (school vocation-related activities) To develop and strengthen life skills (home responsibilities school community activities) To contribute to home upkeep To develop and strengthen skill development in interest areas To increase confidence and overcome shyness To foster friendship

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
	<p>(use of produce scale) (observation; interviews - Jack family)</p> <ul style="list-style-type: none"> - To understand social norms - To develop and strengthen appropriate context-dependent social behaviors - To develop community navigation skills (city bus travels) (interviews - Jack Andromeda teachers; documents IEP/Transition/PCP) 		<p>document - work document)</p> <ul style="list-style-type: none"> - To understand social norms - To develop and strengthen appropriate context-dependent social behaviors (interviews - Ben family teachers; documents - IEP/PCP Ben's photos) 	<p>development (interviews - Bella family teachers; documents - IEP/PCP)</p>
iPod / iTouch	<ul style="list-style-type: none"> - To support life skill development (grocery shopping) - To access and share music (observation; interviews -Jack family; document - PCP) 	<ul style="list-style-type: none"> - To access / listen to and share music (observation; interview - Marie) 	<ul style="list-style-type: none"> - For entertainment - For academic support - For life skill development (interview - family; document - IEP) 	<ul style="list-style-type: none"> - For entrainment (movie watching) - To access transfer share music - To be / have as peers (interviews - Bella Mr. Potter)
MAGAZINES		<ul style="list-style-type: none"> - To support interests - To support the interests of another (observation; interview - Marie; document - Marie's photo) 		<ul style="list-style-type: none"> - To support personal interests and leisure interests - To connect and share common knowledge (pop culture) (interview - Bella Mr. And Mrs. Potter)
NEWSPAPER		<ul style="list-style-type: none"> - To be aware of local happenings and community events - To access movie times - To share information on pet adoptions - To access/share coupons and advertisements in support of needs of others (observation; interview Marie Mr. Ice Cream; documents - mailings) 	<ul style="list-style-type: none"> - To fulfill academic obligations - For enjoyment - advertisements / catalog) - Checking weather (observation; interview Ben Mr. Kimmel; document IEP Ben's photo) 	<ul style="list-style-type: none"> - To support shopping efforts (advertisements) - To access information to fulfill academic obligations (interview - Bella teachers; document - IEP / Bella's photo)
OTHERS	<ul style="list-style-type: none"> - To share information 	<ul style="list-style-type: none"> - To share and receive 	<ul style="list-style-type: none"> - To observe and 	<ul style="list-style-type: none"> - To address

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
	<ul style="list-style-type: none"> - To negotiate wants - To address uncertainties - To address curiosities - To support interests (storytelling baking) - to develop and strengthen job skills - To understand expectations and norms (observations; interviews - family teachers) 	<ul style="list-style-type: none"> information ("stroke doctor" about permission) - To try new activities - To develop new skills (knitting w/ Mrs. Donahue) - To gain and expand on knowledge - To address uncertainties - To connect and engage - For diversion from boredom (observations; interviews - family teachers) 	<ul style="list-style-type: none"> mimic social behaviors of others - To expand knowledge - To seek confirmation - To address uncertainties - To engage socially (observation; interviews - family teachers; documents - iep ben's photo) 	<ul style="list-style-type: none"> uncertainties to gain new information (school clubs) (interview - Bella; document - Bella's photo)
POSTAL Service		<ul style="list-style-type: none"> - To share information (dance recital pet information) - To connect (cards letters etc) (observation; interviews Marie Mrs. Ice Cream; documents - received letters cards postcards) 		
RECIPE REFERRAL	<ul style="list-style-type: none"> - To prepare meals to contribute to class activities (teacher treats) - To support personal interests - To develop self sufficiency - To develop and support vocation-related activities (interviews - Jack Andromeda teachers; document - IEP) 	<ul style="list-style-type: none"> - To develop life skills (cooking class) - Family engagement - In generosity and friendship to others (giving cookies/breads) (observation; interview - Marie) 	<ul style="list-style-type: none"> - To support interests - For entertainment - To develop life skills - To engage w/ family - To develop healthy eating habits (observation; interviews- Ben family; document - IEP) 	<ul style="list-style-type: none"> - To develop life skills of family engagement to contribute to family (interviews - Bella family; document - IEP)
USE OF REWARD SHEETS	<ul style="list-style-type: none"> - To self-regulate - Goal achievement (observation; interviews - Jack family teachers) 			
SCHEDULE REFERENCING	<ul style="list-style-type: none"> - To self-regulation - Goal achievement - To anticipate change - To assure life stability - For understanding expectations and 		<ul style="list-style-type: none"> - To self-regulation - To anticipate change - To assure life stability - To understand expectations and norms 	

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
	<p>norms (observation; interviews - Jack family teachers; documents - schedules IEP/PCP)</p>		<p>(observation; interviews - Ben parents; documents - IEP/PCP schedules)</p>	
SELF-CREATED PRODUCTS	<ul style="list-style-type: none"> For personal enjoyment To share information and creative endeavors (stories) (observation; interviews - Jack family teachers) 	<ul style="list-style-type: none"> For personal enjoyment (pottery knitting etc) To share creative endeavors (observation; interviews - Marie Mrs. Ice Cream) 	<ul style="list-style-type: none"> To share creative endeavors (painting) For personal enjoyment (observation; interviews - Ben family) 	
SIGNAGE	<ul style="list-style-type: none"> To prompt and remind of appropriate behaviors for awareness of options For task completion (step by step instructions) (interviews - Jack Andromeda teachers; observation; document - school / home signage) 		<ul style="list-style-type: none"> School wall quote (document - Ben's photo) 	<ul style="list-style-type: none"> Awareness of class rules (document - Bella's photos)
MAKING PHONE CALLS (LAND/CELL)	<ul style="list-style-type: none"> To connect w/ others (g'ma Chick) (calling only) To connect w/ family when out in community / personal safety (interview - Andromeda; document - email from Jack) 	<ul style="list-style-type: none"> To connect with others (calling / texting) To share and receive information To send photos (observation; interviews - Marie Mr. Ice Cream) 	<ul style="list-style-type: none"> To connect with others in friendship and for personal safety (biking) (calling only) To share and receive information (observation; interviews - Ben Mrs. Kimmel) 	<ul style="list-style-type: none"> To connect with others (calling / texting) To share and receive information To send photos To access and listen to music To record and watch videos To take / view / store / share photos To have / be as peers (observation; interviews -Bella Mr. Potter)
TELEVISION	<ul style="list-style-type: none"> For entertainment (interviews - Jack Andromeda; document - Jack's photo) 	<ul style="list-style-type: none"> For entertainment (iCarly Disney etc) As a diversion from boredom Connection w/ personal history (adoption story TV show) To support of interests (animal 	<ul style="list-style-type: none"> For entertainment To support personal interests / curiosities / skill development (food / cooking painting religion) To support interests of others (American Idol) (interviews - Ben 	<ul style="list-style-type: none"> For entertainment To stay informed (news celebrity gossip etc) To connect / share common interests w/ family (sports) As a diversion from boredom (interviews - Bella

INFORMATION TOOLS and RESOURCES	INFORMATION PRACTICES EXHIBITED BY:			
	JACK	MARIE	BEN	BELLA
		planet) (interviews - Marie family; document - Marie's photo)	parents)	parents)
USING PROPS	<ul style="list-style-type: none"> To share information/storytelling (observation; interviews - Jack Andromeda) 			
PLAYING WII	<ul style="list-style-type: none"> For entertainment To share information on game play To learn/practice good sportsmanship (interview - Jack Perseus; document - Jack's photo) 	<ul style="list-style-type: none"> To develop healthy habits (Wii fit) To develop game skills of diversion from boredom (interviews - Marie Mr. Ice Cream; document - Marie's photo) 	<ul style="list-style-type: none"> For entertainment (Wheel of Fortune) (observation; interviews - Ben teachers; document - Ben's photo) 	<ul style="list-style-type: none"> For entertainment (Wheel of Fortune) (observation; interviews - Bella teachers)

Appendix F

Identified Everyday Life Information Challenges

INTRAPERSONAL BARRIERS			
JACK	MARIE	BEN	BELLA
<p>Cognitive Lower literacy skills Difficulty understanding abstract / complex concepts Influencing Jack's ability to access process generalize apply judge source/quality of information (observation; interviews - family teachers; document - IEP PCP)</p> <p>Attention Discriminate attention issues Difficulty managing time Influencing Jack's ability to access process generalize apply judge source/quality of information (observation; interviews - Jack family teachers; documents - IEP/PCP)</p> <p>Psychological / Behavior Difficulty monitoring and regulating emotional response to positive and negative triggers Impacting Jack's awareness of information need problem solving focus / concentration in seeking / sharing / processing information; negatively impacting Jack's interactions w/ possible information providers. (observation; interviews - Jack family teachers; document - IEP/PCP)</p> <p>Awareness Limited perception of personal need Decreases opportunities for Jack to be more independent / self-sufficient (observation; interviews - Andromeda Perseus teachers) Limited self and social awareness of social norms and communication style influence Can negatively influence interactions and responses by others influencing scope and quality of information experiences <ul style="list-style-type: none"> Bus - personal space </p>	<p>Cognitive Weak literacy skills Slower processing of info Situational assessment and problem solving challenges <ul style="list-style-type: none"> Technology trouble shooting / viruses Difficulty accessing / finding accurate / relevant information <ul style="list-style-type: none"> Women's health Influencing Marie's ability to access process generalize apply judge source/quality of information. Increases Marie's dependence on others for assistance. (observation; interviews - Marie family teachers; document - IEP)</p> <p>Physical Hearing impairment May decrease full availability of orally presented information (observation)</p> <p>Communication Receptive / expressive communication difficulties May influence interpretation of information received and information shared. (observation; interviews - family teachers)</p> <p>Awareness Limited perception of personal need Self-awareness <ul style="list-style-type: none"> limited awareness of communication style influence May inhibit / lessen opportunities for information exchanges and decrease opportunities for Marie to be self-sufficient and have more autonomy (observation; interview - teachers) Naivety - "friendly to a fault" At increased risk for accepting misinformation as</p>	<p>Cognitive Lower literacy skills Difficulty understanding abstract / complex concepts Influencing Ben's ability to access process generalize apply judge source/quality of information (interview - Mrs. Kimmel)</p> <p>Awareness Limited perception of need Situational assessment and problem solving challenges <ul style="list-style-type: none"> Bicycling experience w/ flat tire Cooking Untrustworthy individuals (observation; interviews - Mr. and Mrs. Kimmel)</p> <p>Psychological / Behavior Lack of eye contact May make difficult to obtain information relayed through facial expressions Reliance on schedules to monitor / manage time-to avoid discomfort May at times increase dependency on others and decrease opportunities for self-sufficiency. (observation; interviews - Mr. And Mrs. Kimmel)</p> <p>Communication Expressive speech / echolalia Difficulty communicating information need and sharing information (observation; interviews - family teachers; document - IEP)</p> <p>Self-determination Learned helplessness Limited self-advocacy At times Ben waits for others to lead/ take action first decreasing opportunities for recognizing and acting on information needs. (observation; interview - Mr. And Mrs. Kimmel)</p>	<p>Cognitive Weak literacy skills Slower processing of info <ul style="list-style-type: none"> Information overload - club emails (interview - Bella) Problem solving challenges <ul style="list-style-type: none"> Technology troubleshooting /viruses online purchasing difficulties Influencing Bella's ability to access process generalize apply judge source/quality of information. Increased dependency on others for assistance. (observation; interviews - Bella Mr. and Mrs. Potter teachers; document - IEP)</p> <p>Psychological / Behavior Shyness Anxiety Word-finding difficulties Negatively influences information exchange and possibilities for self-initiated information seeking. (observation; interview - Bella teachers)</p> <p>Attention ADHD May contribute to incomplete or slower processing of information (interviews - Bella teachers; document - IEP)</p> <p>Awareness Limited perception of need (observation; interviews - Bella family teachers) Naivety - "trusting of everyone" Puts Bella at greater risk for accepting misinformation as truth (observation; interviews - Mr. and Mrs. Potter teachers)</p> <p>Self-determination Weak self-advocacy skills Learned helplessness Dependency / reliance on others <ul style="list-style-type: none"> Lack of involvement in IEP mtgs doctor appt Decreases opportunity for relevant information exchange and inhibits</p>

INTRAPERSONAL BARRIERS			
JACK	MARIE	BEN	BELLA
<ul style="list-style-type: none"> • Opposite sex -school / dance • Social stories • Letter to district • Computer access - "do your duty!" • Teacher treat day /classroom experiences <p>Naivety - "trusting of everyone" Puts Jack at greater risk for accepting misinformation as truth (observation; interviews – Jack Andromeda Perseus Hercules teachers; document – IEP)</p>	<p>truth (observation; interview s- Mr. and Mrs. Ice Cream)</p> <p><u>Behavior</u> Impulsivity impacts ability to process / consider information to make informed decisions and problem solve. (interviews – Mr. and Mrs. Ice Cream teachers; documents – vocational narrative)</p> <p><u>Self-determination</u> Learned helplessness Dependency / reliance on others</p> <ul style="list-style-type: none"> • Lack of involvement in IEP mtgs doctor appt • Hesitancies - "I can't b/c my stroke doctor said..." <p>Decreases opportunity for relevant information exchange and inhibit opportunities for increased access to information (interview - Marie Mr. and Mrs. Ice Cream)</p>		<p>opportunities for information access. (interview - Bella Mr. and Mrs. Potter teachers)</p>

PHYSICAL BARRIERS			
JACK	MARIE	BEN	BELLA
<p><u>Transportation</u> Dependency on others Decreases self-initiated opportunities for information engagement. (observation/personal reflection)</p> <p><u>Technology</u> Restricted / controlled access Computer / television restrictions limit opportunity for self-initiated information inquiries interactions (observation; interviews - Jack family teachers)</p> <p><u>Print-only sources of information</u> Weak literacy / comprehension skills The exclusivity of information in print denies access. (documents – IEP)</p>	<p><u>Transportation</u> Dependency on others Decreases self-initiated opportunities for information engagement. (observation/personal reflection)</p> <p><u>Print-only sources of information</u> Weak literacy / comprehension skills The exclusivity of information in print denies access. (observation; interviews – Mr. Ice Cream; documents – IEP)</p>	<p><u>Transportation</u> Dependency on others Decreases self-initiated opportunities for information engagement. (observation/personal reflection)</p> <p><u>Technology</u> Restricted / controlled access to iTouch (interview - Mrs. Kimmel)</p> <p><u>Print-only sources of information</u> Weak literacy / comprehension skills The exclusivity of information in print denies access. (observation; documents – IEP)</p>	<p><u>Transportation</u> Dependency on others Decreases self-initiated opportunities for information engagement. (observation; interviews – Mr. and Mrs. Potter)</p> <p><u>Print-only sources of information</u> Weak literacy / comprehension skills The exclusivity of information in print denies access. (observation; interviews – Mr. and Mrs. Potter; documents – IEP)</p>

SOCIETAL BARRIERS			
JACK	MARIE	BEN	BELLA
<p><u>Perception of need / gate-keeping:</u> Examples: Health class - sex education (interview - teachers) Minimal homework (interview - Perseus)</p> <p><u>Lowered expectations / misperceptions of ability</u> Limited job-training opportunities / "janitor work" (observation; interviews - Andromeda Perseus) Mismatched expectations and goals between school/family (interviews - Andromeda Perseus)</p> <p><u>Highly monitored life / controlled schedule</u> (observation; interviews - Jack family teachers)</p> <p><u>Enabling</u> Examples: Camera introduction - set up Library - book finding and job "check-in" (observation)</p>	<p><u>Lowered expectations / misperceptions of ability</u> Examples: Researcher hesitancy on participant understanding (personal reflection) Limited employment opportunities (interviews - Mr. And Mrs. Ice Cream teachers)</p> <p><u>Social exclusion</u> Examples: Cheerleading experiences Reports from social ministry program (observation; interview - Marie)</p> <p><u>Professional disconnect</u> Purpose of library and library services- information needs of youth with I/DD. Lower expectations of library services and resources (interviews - teachers)</p>	<p><u>Perception of need / gate-keeping</u> Limited scope of instructional content (interview - Mr. And Mrs. Kimmel) School bus option (interview - Mrs. Kimmel) Limited / restricted access to information sources available to others: choir class library (observation; interview - teachers) Class placement decisions- placement / removal from female p.e. Course (interview - teachers) Minimal school instruction on areas related to technology skill development Minimal school instruction on Trans-literacy skills (interview - Mrs. Kimmel)</p> <p><u>Lowered expectations / perceptions of ability and intent</u> Choir class groups Initial enrollment in adaptive PE (observation; interviews - Mrs. Kimmel teachers) Limited job training / employment opportunities (interviews - Mrs. Kimmel teachers)</p> <p><u>Highly monitored life / controlled schedule</u> (observation; interview - Mr. And</p>	<p><u>Perception of need / gate-keeping</u> Restricted access to information sources available to others - choir class library resources and services (observation)</p> <p><u>School / home mismatched expectations and goals</u> Math / jewelry making (interview - Mr. And Mrs. Potter)</p> <p><u>Professional disconnect</u> Purpose of library and library services- information needs of youth with I/DD-lower expectations of library services and resources (interviews - teachers)</p> <p><u>Lowered expectations / perceptions of ability</u> jewelry making comments by Bella (interviews - Bella teachers)</p> <p><u>Limited employment opportunities</u> (interviews - Mr. Potter teachers)</p> <p><u>Highly monitored life</u> (observation; interview - Bella)</p> <p><u>Enabling</u> School lunch - family style Preparation- serving Community outings Few opportunities for self-direction decision-making practice</p>

SOCIETAL BARRIERS			
JACK	MARIE	BEN	BELLA
		<p>Mrs. Kimmel)</p> <p><u>Enabling</u> School lunch / family style Preparation and serving Community outings Few opportunities for self-direction decision-making practice purchasing Wheel of fortune game (observation)</p> <p><u>School / home mismatched expectations and goals</u> Time telling goal-advantaging personal interests / passions (interview - Mr. And Mrs. Kimmel)</p> <p><u>Professional disconnect</u> Purpose of library and library services-information needs of youth with I/DD. Lower expectations of library services and resources (interviews - teachers)</p>	<p>purchasing Wheel of fortune game (observation) Vocational training opportunities Minimal instruction and/or redirection (observation)</p> <p><u>Social exclusion</u> (interview - Bella)</p>

ECONOMIC BARRIERS			
Jack	Marie	Ben	Bella
<u>Cost-prohibitive programming</u> (interview – Andromeda) <u>Limited job training / employment opportunities</u> (interviews - Andromeda teachers)	<u>Limited job training / employment opportunities</u> (interviews - Mr. And Mrs. Ice Cream teachers)	<u>Cost-restrictive programming</u> (interview - Mrs. Kimmel) <u>Limited job training / employment opportunities</u> (interviews - Mrs. Kimmel teachers)	<u>Cost-restrictive programming</u> (interviews - Mr. And Mrs. Potter) <u>Limited job training / employment opportunities</u> (interviews - Mr. Potter teachers)
All limit and/or prohibit opportunities for passive and active information engagement including the seeking acquiring applying processing and sharing of information.			

INSTITUTIONAL BARRIERS			
JACK	MARIE	BEN	BELLA
<p><u>Segregation in school</u> Limited/restricted access and exposure to information available via typical school experiences:</p> <ul style="list-style-type: none"> ▪ general education curriculum ▪ classroom instruction activities dialogue invisible curriculum / teen norms and trends <p>(observation; interview - Andromeda)</p> <p><u>State-level graduation requirements for diploma-seeking students</u> Issues of info relevancy with course coverage and requirements – information presented does not always align with post-school needs (interviews - Andromeda teacher)</p> <p><u>Educational oversight and hiring qualification standards</u> Issues related to quality / relevance / exposure to information. For instance qualifications of adaptive p.e. instructor may influence quality of inform received about personal health and importance of healthy habits (observation; personal communication; personal reflection)</p>	<p><u>Process of I/DD identification and administration of school support</u> Educational tracking segregation and misuse of labels (contributing to stereotyping / misperceptions) may negatively influence scope and quality of information exposure access and engagement (interview – Mrs. Ice Cream)</p> <p><u>Prevalent tracking to sheltered workshop</u> Limits and/or prohibits exposure / access / engagement with information necessary for job skill development and gainful employment (interview - Marie Mrs. Ice Cream)</p>	<p><u>Segregation in school</u> Limited/restricted access and exposure to information available via typical school experiences:</p> <ul style="list-style-type: none"> ▪ general education curriculum ▪ classroom instruction activities dialogue invisible curriculum / teen norms and trends. <p>(observation; interview - Mrs. Kimmel)</p> <p><u>Minimal classroom / instructional oversight</u> May impact scope and quality of instruction (observation; interview –Mr. and Mrs. Kimmel)</p> <p><u>Stringent requirements by federal / state funding and oversight agencies and underfunded support personnel</u> May impact the quality and employment longevity of support personnel and consequently the facilitation of meaningful and relevant information engagement (interview - Mrs. Kimmel support provider)</p>	<p><u>Segregation in school - leveled system</u> Limited/restricted access and exposure to information available via typical school experiences:</p> <ul style="list-style-type: none"> ▪ general education curriculum ▪ classroom instruction activities dialogue ▪ invisible curriculum / teen norms and trends <p>(interview - Mr. And Mrs. Potter)</p> <p><u>State restrictions of vocational training hours during school day</u> Limits exposure / access / engagement with information to support job skill development. (interview - Mr. Potter)</p> <p><u>Minimal classroom / instructional oversight</u> - Impacts scope and quality of instruction. (observation; interview –Mr. and Mrs. Kimmel)</p>

Appendix G

Identified Information Need Types

1. Academic endeavors
2. Communication skills
 - turn-taking
 - styles of communication
 - passive/aggressive/assertive
 - formal
 - informal
 - non-verbal
 - public/private info
 - voice volume /tone
 - cell phone use
 - etiquette
3. Community access
 - navigation - map and schedule reading
 - public transportation options and use
 - public transportation etiquette
 - community resources (access and function)
 - community events
4. Consumer information
 - consumer practices
 - reading / interpreting advertisement
 - shopping / purchasing behaviors
 - online shopping practices
 - consumer safety/rights
5. Correspondence skills
 - letter writing
 - email
 - document attachment
 - style functions
 - cc/bc use
 - management of contact information
 - formal and informal etiquette / norms
 - postal services (function and access)
6. Creative endeavors / expressions
7. Curiosities, interests, hobbies, and pastimes
8. Emotional health /coping skills
 - anger management
 - bereavement
 - conflict resolution
 - stress management
 - memory/recall strategies
 - problem solving
 - self-regulation/impulse control
 - healthy emotional response
 - community resources (access/function/use)
 - social norms (w/in context)
 - self-awareness - capabilities, strengths, challenges
9. Employment
 - identity development
10. Financial literacy/money management
 - career exploration
 - job seeking skills
 - application/interviews
 - skill development
 - laws (ADA fair labor standards act)
 - conflict resolution resources processes
 - positive work behaviors/habits
 - professional dress
11. Future planning
 - housing options
 - post-secondary education
 - employment
12. Identity
 - self-awareness - capabilities, strengths, challenges
13. Independent life skills
 - meal preparation/safe food handling
 - laundry/clothing care
 - shopping
 - home maintenance and repairs
 - household appliance use
14. Personal safety
 - identification and response to simple and serious injuries
 - interpreting warning labels
 - stranger danger
 - healthy and unhealthy relations
 - community resources (access and function)
 - self-advocacy
 - rights
 - self-defense
 - situational awareness
 - self-awareness – recognition of and response to internal feelings of discomfort
15. Health and development
 - medical history
 - prescriptions/medicine
 - label reading / safety precaution
 - illness prevention

- healthy living practices (nutrition/exercise)
 - identification / response to simple and serious injuries
 - first aid
 - community and online health resources (access/function)
 - developmental changes
16. Relations (friendships /family/romantic / workplace)
- making/maintaining friends
 - healthy relations
 - conflict resolution
 - social norms (home, school, work place)
 - problem solving strategies/resources
 - teamwork/collaboration
17. Responsibilities
- household chores
 - work duties
 - homework
 - pet care
18. Schedule development/maintenance
- time management
 - time/date
 - weather
 - community navigation
19. Self-care skills
- hygiene and grooming
20. Self-determination
- problem solving
 - decision/choice making
 - future planning / goal setting
 - awareness of resources (functions/access/use)
 - negotiation skills
 - social norms/etiquette
 - self-advocacy
 - rights
 - disability related laws / regulations (ADA Fair Labor Standards Act, etc.)
21. Sexual literacy
- sexual health
 - sexual development
 - safe sex practices
 - reproductive process
 - birth control options (access/use)
 - healthy intimate relations
 - community resources
22. Social life/recreational activities
- schedule development/maintenance
 - time management
 - correspondence skills
 - social skills
- community access/navigation
 - transliteracy skills
 - cell phone use
23. Social skills
- social norms/etiquette w/in context (school work community online)
 - teen trends
 - conversation skills
24. Spirituality/religion
25. Sports/physical activities
- skill development
 - game/activity rules/procedures
 - sportsmanship
 - equipment needs / use
 - teamwork
 - safety
 - health benefits (physical and mental)
 - practice / event schedule
 - transportation options
26. Technology skills
- use
 - web navigation
 - online etiquette/norms
 - online safety
 - word processing
 - email
 - gaming
 - social networks
 - searches
 - information literacy/trans-literacy
 - game systems
 - television systems / DVR devices
 - searching /programming / deleting
 - digital camera use
 - taking photos
 - transferring photos to computer
 - storing / organizing photos
 - cell phone use
 - calling
 - texting/forwarding photos
 - camera/video functions
 - accessing data/app use
 - storing/accessing contacts
 - setting adjustment
27. Trans-literacy skills (information, digital, functional print, etc.)
- library skills
 - technology skills
 - functional reading skills (i.e. instruction manuals, warranties, bills, bank statements , credit card applications, mail order purchases, prescription/non-prescription medicine, directions, newspapers - for weather TV schedule

- movie times community events
- advertisements/classified ads,
- informational pamphlets,
- print / online phone directories
- writing skills
 - use of context clues
 - identifying key words
 - paraphrasing
 - topic sentences
 - supporting details
 - appropriate logical sequence
 - sufficient elaboration
 - concluding statement
- 28. Volunteering/service to others
 - to understand/empathize
 - to assist
 - to share information
- 29. World/national /community awareness
 - history
 - geography
 - current events
 - pop culture
 - citizenship
 - rights and responsibilities
 - voting
 - taxes
 - laws
 - community resources (access and function)
 - teen trends / fashion

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