Self-Determination: A Case Study of the Needs, Preferences, Goals, and Feelings of Secondary Students With Significant Disabilities in Their Transition to Adulthood

by Celeste Sadler

An Applied Dissertation Submitted to the Abraham S. Fischler College of Education in Partial Fulfillment of the Requirements for the Degree of Doctor of Education

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Statement of Original Work

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Abstract

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Keywords: self-determination, significant intellectual disabilities, severe, moderate, multiple, secondary students, adult independent living, transition, expression, quality of life

This applied dissertation was designed to give a voice to students with severe disabilities so that needs, preferences, goals, and feelings could be expressed. Research has shown that there are fewer opportunities to practice self-determination for more seriously impaired students with significant intellectual disabilities. Studies have also pointed out that not all components of self-determination are being offered to these students in general. In addition, few research studies are conducted with input from the students with significant intellectual disabilities themselves. This qualitative case study explored how these students view their present and future and attempts to report the findings regarding their transition to adulthood.

The writer supported student communication of needs, preferences, goals, and feelings through interviews, observations, recordings, technology, memos, and archival records of student produced documents. Students expressed their desires, opinions, and disagreements through self-determination activities regarding the school, home, and community. Self-determination behavior was observed in student input using interview data as a major source. As a result of this study, transition to adult independent living will be more successful and lead to a higher quality of life for these secondary students leaving the public school system.

Table of Contents

	Page
Chapter 1: Introduction	
Preface	
Importance	
Nature of the Problem	
Definition of Terms	
Supporting Evidence	
National and State Findings	
Impact	
Rationale	
Purpose of the Study	
Research Questions	
Background and Significance	10
Chapter 2: Literature Review	15
Introduction	15
Historical Perspective	16
Lead Researcher and Definition of Self-Determination	19
Definition of Disability	20
Disability Identity	
Transition to Adulthood	24
Self-Determination Theory	28
Past Research	
Communication Supports	37
Opportunity	42
Relationship of Quality of Life to Self-Determination	45
Quality of Life	45
Independence	62
Empowerment	66
Importance of Leisure	68
Decision Making	69
Ability to Communicate	70
Informed Choice	73
Influence	75
Dignity of Risk	76
Expression	
Patience and Beliefs about Assistance	80
Beliefs about Disability	81
Technology	
Perceptions and Experiences	
Similar Studies	
Research Questions Reviewed	
Conclusion	

Chapter 3: Methodology	91
Aim of the Study	91
Qualitative Research Approach	91
Case Study Approach	97
Participants	102
Data Collection Tools	116
Procedures	124
Consent	145
Collection of Data	147
Data Analysis	148
Ethical Considerations	152
Trustworthiness	154
Potential Researcher Bias	155
Limitations	158
Chapter 4: Findings	160
Introduction	
Demographic Information for Participants	
Participant 1: Maria	
Participant 2: Rayann	
Participant 3: Vanesa	
Participants as a Group	
The Case Study Approach	
How Codes Were Determined During Analysis and Theme Development	
Coding Methods Used	
Within Case and Across Case Analysis	
How the Findings were Organized	
Themes Expressed for Needs Expressed Related to Independence	
Themes Expressed for Preferences Related to Beliefs, Interests, and Abilities	
Themes Expressed for Goals Related to Self-Regulation	
Themes Expressed for Feelings Related to Psychological Empowerment and Self-	
Realization	
Additional Themes Discovered	
Analysis of the Needs Expressed by Maria	
Analysis of the Needs Expressed by Rayann	
Analysis of the Needs Expressed by Vanesa	
Analysis of the Preferences Related to Beliefs, Interests, and Abilities for Maria	
Analysis of the Preferences Related to Beliefs, Interests, and Abilities for Rayann	
Analysis of the Preferences Related to Beliefs, Interests, and Abilities for Vanesa	290
Analysis of Goals Related to Plans, Problem Solving, and Self-Regulation for Maria	316
Analysis of Goals Related to Plans, Problem Solving, and Self-Regulation for Rayann.	324
Analysis of Goals Related to Plans, Problem Solving, and Self-Regulation for Vanesa	331
Analysis of Feelings Related to Psychological Empowerment and Self-Realization for	
Maria	339
Analysis of Feelings Related to Psychological Empowerment and Self-Realization for	
Rayann	359

Analysis of Feelings Related to Psychological Empowerment and Self-Rea	lization for
Vanesa	371
Maria Compared to Rayann	386
Maria Compared to Vanesa	408
Rayann Compared to Vanesa	431
Emergent Coding	451
Across All Cases	461
Additional Information	468
Archival Data for Triangulation	468
Additional Documents from Classwork	474
Member Checking	482
Memos	482
Summary of the Findings Related to the Research Questions	485
Conclusion	
Chapter 5: Discussion	491
Summary of the Findings	
Interpretation of the Findings	
Context of the Findings	
Implications of the Findings	
Limitations of the Study	
My Personal Thoughts for Future Studies	
Conclusions and Recommendations	
References	514
Appendices	
A Sample Picture Response Guides	571
B Premade Interview Guides	
C Permission to Use Unique Learning System	
D Permission to Use The Arc's Self-Determination Scale	
E The Arc's Self-Determination Scale	597
F Interview Protocol, Day One	606
G Coding Manual	
H Combined Theme Outline	
Figure	
Model of Self-Determination	33
Table	
Participant Demographic Data	162

Chapter 1: Introduction

Preface

Self-determination is one of the most important aspects of a successful transition from school to adult life for all students approaching graduation. Rick and John (2007) noted that even for college students "...transition from higher education into a 'graduate' job is a significant step in the life experience of a young person, something like a rite of passage..." (p. 517). Just as self-determination is important for college students with disabilities, self-determination is important for all post-secondary special education students planning the transition to adult life (Getzel & Thoma, 2008; Trainor, 2008). It is even more important for students with significant disabilities.

Self-determination is necessary for transition to adulthood since every grown person needs to feel independent and autonomous (Gitelson & McDermott, 2006). This is true for students without disabilities as well as students with disabilities. However, for the non-disabled, this evolution to adulthood happens naturally and gradually, as evidenced by young adults moving out of the family home (Young et al., 2008). They are expected not only to acquire a place of residence, but to also get a job or go to college, and to find a life partner. Parents are there to help with this transition, which usually happens for students without disabilities by the end of their twenties (Gitelson & McDermott, 2006). Even general education students that are English language learners do not feel that their level of self-determination is significantly different from their English speaking counterparts (LeClair, Doll, Osborn, & Jones, 2009). Intelligence was not as significant in predicting self-determination in all students as was the opportunity to make choices within real life situations (Shogren, Wehmeyer, & Palmer, 2007). A student with significant disabilities needs lifelong support and the opportunity to be a causal

agent in determining their present and future aspirations, especially as they approach graduation (Hartman, 2009).

Transition planning is necessary to make wise decisions to prepare for adult life (Shaw, Madaus, & Banerjee, 2009). It is age appropriate to construct the secondary student's perspective by asking questions, problem solving, and planning together (Gitelson & McDermott, 2006). Expression of self-determination, through choices, decisions, and planning, leads to a successful transition to adulthood (Rusch, Hughes, Agran, Martin, & Johnson, 2009; Shogren & Broussard, 2011; Trainor, 2008). Self-determination is the expression of needs, preferences, goals, and feelings about oneself.

Importance

The mere fact of having a disability and needing special education and services lessened the opportunity to practice choice making, decision making, and goal planning (Trainor, 2008). For individuals with disabilities, decisions to try new experiences usually depended on the degree of risk rather than potential opportunities and safety and has been a hindrance since the beginning of this human rights movement (Mitchell, 1988). Teachers and parents with good intentions were nevertheless the very ones who restricted the freedoms of students with disabilities in the interest of safety (Trainor, 2008). Teachers have expressed that teaching students about adult risk-taking activities was a sensitive issue best reserved for parents (Lamorey, 2010). Parents often felt they were their disabled child's safety net (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009). Students with disabilities needed more opportunities to practice self-determination for the important transition to adult independent living (Carter, Lane, & Pierson, 2006; Carter, Owens, Swedeen, et al., 2009; Carter, Owens, Trainor, Sun, & Swedeen, 2009; Swedeen, Carter, & Molfenter, 2010). The concept of self-determination was

applicable throughout one's lifespan, but was perhaps first expressed by students with disabilities, as with all children, during adolescence (Bianco et al., 2009; Heller et al., 2011; Palisano et al., 2009; Rapanaro, Bartu, & Lee, 2008; T. Ward & Stewart, 2008). Toward this expression of self-determination, this study aimed to support choice making, decision making, and goal planning.

Despite national interest to support self-determination, information regarding its perception "...is most often obtained from teachers and parents and not the students themselves" (Agran & Hughes, 2008, p. 70). The teaching of self-determination was important to the Individual Educational Plan (IEP) outcome goals of independence, community living, employment, transition to adulthood, and quality of life for individuals with severe intellectual disabilities (Agran & Hughes, 2008; Branding, Bates, & Miner, 2009; J. Martin, Van Dycke, Christensen, et al., 2006; Valenzuela & Martin, 2005). Self-expression was necessary for self-determination (Bianco et al., 2009; Heller et al., 2011) and was best produced by the individuals at stake.

Nature of the Problem

Students with significant intellectual disabilities needed to learn how to express self-determination so that they could apply it to their everyday life and in their transition to adulthood (Carr, 2008; Iwasaki & Mactavish, 2005; McGuire & McDonnell, 2008; Nota, Ferrari, Soresi, & Wehmeyer, 2007). These students had difficulty expressing and defending themselves verbally and needed extended response time (Van Laarhoven, Johnson, Van Laarhoven-Myers, & Grider, 2009). They often did not make their preferences clear (Valiquette, Sutton, & Ska, 2010). Their lack of involvement and expression forced people who knew them well to speak on their behalf, often without seeking their approval (Dunn, Clare, & Holland, 2010; Jingree, Finlay, & Antaki,

2006). This resulted in their giving up and learning to be helpless, relinquishing personal control to other people (Carr, 2008). The ability to communicate was a vital part of quality of life and a human need (Olney, 2001; Snell, Chen, Allaire, & Park, 2008; Valiquette et al., 2010).

Definition of Terms

Significant disabilities. For the purpose of this study, the newest definition of significant disabilities was utilized. Scores on an IQ test did not adequately describe the classifications of these participants and tended to reduce student potential to a number on an objective test (Roach, Elliott, & Berndt, 2007). This method of classification has become outdated, lending support to the reasoning behind this qualitative study and its appropriateness to students with significant intellectual disabilities (Riches, Parmenter, Llewellyn, Hindmarsh, & Chan, 2009; Vakil, Lifshitz, Tzuriel, Weiss, & Arzuoan, 2011). On objective tests, students with intellectual disabilities tended to select the first answer rather than look for other options (Vakil et al., 2011). Quantitative measures did not truly describe what individuals with significant intellectual disabilities knew about their life experiences, but objective measures remained the chief method of how we determined intellectual disability (Dennis et al., 2009).

In 2010, the American Association on Intellectual and Developmental Disabilities (AAIDD), formerly known as the American Association on Mental Retardation, created an operational or functional and observable definition of intellectual disability that suggested "...developing a new classification system in light of the movement away from coding on the basis of IQ levels," (p. 2). This qualitative study aligned itself with the more innovative thoughts toward disability. While numerical scores can be useful, they in no way captured the entire picture of the abilities and potentials of all individuals with disabilities.

In line with contemporary wisdom, the participants in this study had significant intellectual disabilities as defined by "...the proposed criterion of significant deficits in at least two adaptive behavior domains [American Psychological Association] (APA) vs. significant deficits in one or more adaptive behavior domains (AAIDD)," (American Association on Intellectual and Developmental Disabilities, 2010, p. 1). Significant disabilities can therefore be operationally defined as "...a disability characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18," (American Association on Intellectual and Developmental Disabilities, 2010, p. 2). In the case of these particular participants, they also had multiple disabilities which included physical, sensory, communicative, and other health impairments, which substantially increased the severity of their disabilities. These students fell well within the significantly intellectually disabled classification.

Self-determination. There were many ways to define self-determination and to classify its components. Studies conceded there were components with threads that ran throughout the core principles (Thoma, Pannozzo, Fritton, & Bartholomew, 2008). Thoma, Pannozzo, Fritton, and Bartholomew (2008) identified seven major components of self-determination: (a) choice making, (b) decision making, (c) goal setting and planning, (d) problem solving, (e) self-advocacy, (f) self-awareness, and (g) self-evaluation and self-regulation. All of these basic components led to the establishment of an internal locus of control, meaning that a person behaved according to an inner driving force rather than because of an external reward. Studies have shown that usually choice making was taught, but the other components were often ignored (Thoma et al., 2008). This study explored the multiple core themes that defined self-determination.

Transition. A student goes through many transitions in the course of their education. For example, students transition from home to preschool, preschool to kindergarten, kindergarten to elementary, to middle school, to high school, and finally to adulthood. This study focused on the most momentous transition: when a student approaches leaving the school system upon graduation.

Supporting Evidence

The Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 (Federal Register, 2006) stated that all educational agencies were required to include students with disabilities in the decision making process when transition to post-secondary adult life was discussed during an IEP meeting. Despite this law, professionals and parents were not adequately addressing the needs of students with low incidence disabilities, meaning severe disabilities that occur infrequently, to participate in IEP meetings (K. Powers, Geenen, & Powers, 2009). Students with significant disabilities were not providing meaningful input into the planning of their goals and outcomes for post-secondary life (K. Powers et al., 2009). A landmark research effort by Thoma, Pannozzo, Fritton, and Bartholomew (2008) discovered that most studies about self-determination have been aimed at high incidence disabilities, which are commonly occurring milder disabilities, since teachers had the mistaken belief that intellectual ability was a prerequisite.

National and State Findings

Unfortunately, national studies since 1990 have shown that even though student achievement rose with their level of self-determination, teaching methodology also showed a gap in understanding and teacher preparation to develop needed skills in students with disabilities (Thoma et al., 2008). The same was true for individual states. Morningstar and Liss (2008)

reported that "...it seems that approximately [two] 2 years after the passage of IDEIA, SEAs [State Education Agencies] recognize the importance of addressing the new mandates but have not fully developed procedures to guide local practices" (p. 53). Apparently even federal mandates such as the IDEIA were still not enough to effect change in how schools support self-determination in students with disabilities.

Wehmeyer and Powers (2007) both agreed with the federal government that selfdetermination was important since:

The findings from Congress for the Vocational Rehabilitation Act, the Individuals With Disabilities Education Act, and the Developmental Disabilities Act all emphasize that the goals of the United States properly include providing individuals with disabilities the tools necessary to (a) make informed choices and decisions; and (b) achieve equality of opportunity, full inclusion and integration into society, employment, independent living, and economic and social self-sufficiency. It is not a coincidence that the goals of the United States are to provide the tools to make choices and decisions (e.g., to be self-determined) and, then, achieve integration, employment, self-sufficiency, and so forth (p. 1).

Chambers et al. (2007) said in their review that students with disabilities rated the importance of self-determination higher than both groups of family members and professionals. This fact was not surprising. Self-determination affected the student personally and directly.

Impact

The importance of adequately and directly addressing self-determination skills in transition planning affected the lives of students with severe disabilities more dramatically than for more able-bodied and more able-minded, high-incidence students. Even something as simple

as personal choice was dependent on cognitive level, social skills, and parental perception of readiness (R. Smith, Morgan, & Davidson, 2005). The implication was that self-determination came easier to those who were more cognitively able to take advantage of its opportunities to live more independently. Remembering what Thoma et al. (2008) explained, self-determination was not only for those other students with less severe disabilities. It was for all students. It was an injustice to ignore students with the most severe disabilities who needed to have a say in how they wanted to live their lives. The denial of quality of life for students with low incidence disabilities affected not only the students (Angell, Stoner, & Fulk, 2010; Goodwin, Peco, & Ginther, 2009; Hogansen, Powers, Geenen, Gil-Kashiwabara, & Powers, 2008; Trainor, 2005) but also their families (Bianco et al., 2009), teachers (Thoma et al., 2008), and the communities in which they lived (R. Martin, 2006; Palisano et al., 2009).

Rationale

Students with significant disabilities not only had the law supporting their self-determination, but also had the human right of dignity of choice, happiness, and quality of life. If no one spoke up for their rights, they would have no voice. For this long-ignored group, it was time to notice their needs and support their life goals, notions most people take for granted. Those individuals who knew them best can interpret and translate their meaning into text that could be decoded and analyzed. Even the law required that their assessments be performed by professionals and others who were most familiar with the individual (Federal Register, 2006). This study explored how giving an opportunity for people with moderate, severe, and multiple disabilities to express themselves could be revealed.

Purpose of the Study

The purpose of this case study was to describe and understand how self-determination could be expressed by specific students with low-incidence disabilities at one high school in the Southeastern United States. Self-determination was defined in its original terms as making choices and decisions, without undue influence from others, which will affect quality of life (M. Ward, 1988). Even our nation's constitution highlighted the right to pursue happiness in life and that included individuals with significant disabilities. This study worked from an advocacy/participatory theoretical base within the qualitative interpretive community of disability theories (J. Creswell, 2007), specifically self-determination theory. Through collaboration with specific students experiencing the phenomenon of living with a disability within this case study, a fuller picture emerged to understand the expressions of self-determination for students who had more severe limitations.

Research Questions

When parents provided opportunities for decision-making throughout childhood, transition to adulthood was easier (Gitelson & McDermott, 2006). To develop independence it was important to be able to make choices and learn how to deal with the consequences (M. Ward, 1988). Teachers should support students as they explore their abilities and options for the future. What needs, preferences, goals, and feelings are expressed in students with significant intellectual disabilities? What needs are expressed related to independence? What preferences are expressed based on beliefs, interests, and abilities? What goals are expressed related to self-regulation? What feelings are expressed related to psychological empowerment and self-realization? I anticipated being able to answer these questions from the prospective of what was

important to them. The findings discovered how students with significant disabilities described the way they wanted to live their lives.

Background and Significance

Students who have self-determination skills had more meaningful involvement during the planning of the end result for the transition to adulthood (Agran & Hughes, 2008). The major concern was that students with severe disabilities were not being offered the opportunity to practice self-determination, nor were they systematically asked for an opinion on their own lives (Carter, Owens, Trainor, et al., 2009). Studies revealed that even students with mild disabilities were not consistently offered opportunities to practice self-determination skills as a routine or during transition meetings (Carter, Owens, Swedeen, et al., 2009; Carter, Owens, Trainor, et al., 2009; Trainor, 2005).

Major issues. Well thought out and planned transition goals took time to develop and even more time if the student had severe impairments. Students with significant disabilities needed extended personal contact to build support for self-advocacy due to communication and cognitive difficulties. For example, not many young people knew what type of job they preferred without any previous experience or knowledge of existing jobs. Families were often consulted by all young students looking for advice in job choices and support for future plans (Michaels & Ferrara, 2006) and students with disabilities were no different. Parents needed to be included to support their child's needs for self-determination.

Informed choice was an additional issue for this study. Having the opportunity to choose was not enough. One must also know what the available choices are (Storey, 2005). Technology can place a student in a work setting where they can safely test the boundaries of the environment and experience the dignity of being able to take their own risks in making decisions, learning the consequences of their actions, and preparing for the transition to their future (Salend,

2009; Skouge, Kelly, Roberts, Leake, & Stodden, 2007; Suárez, 2009). In addition, the Internet can be used with support to search for possible accommodation ideas that enable students with significant disabilities to be empowered to participate in independent living or in supported employment, which is employment assisted by agency support staff. This experience with technology can help increase self-awareness, provided informed choice, and offered opportunities to practice self-determination so that the students with disabilities could build background knowledge with which to communicate it to others. Even though this study did not employ the use of assistive technology or use of the Internet to acquire participant responses, it could have been made available. The participants involved in this stuy were adequately verbal to respond to interview questions.

Self-determination needed to be practiced to be learned. Mere awareness of what it meant to be self-determined was not going to bring it into realization. Bigby, Clement, Mansell, and Beadle-Brown (2009) noted that besides the high level of support needs for adult clients of residential services, attitudes on the part of staff toward facilitating their needs for community involvement were crucial. If adults in supervisory roles did not believe in the value or possibility that individuals in their care were both capable and willing to make choices, the opportunities to practice this skill would not occur. Practice in interacting with community workers in natural environments, such as Community Based Instruction (CBI), aided in retention of skills since performance was a real-life application. Having the chance to practice and apply the skills of self-determination so that students could express themselves was the main issue of this research study.

The organization. The organization in which this study took place was a large public high school located in the southeast part of the United States that served students in general

education as well as a small group of students with significant disabilities. At this school 16% of the students were working toward a special diploma as compared to the state average of 13.9%. There were three classes of students with moderate to severe disabilities with whom I interacted directly in the classroom throughout the day. Besides the approximately 30 students that I taught, there was another set of about 20 students with higher functioning and also working on special diplomas, of which only a few have moderate intellectual disabilities.

The setting. The setting for this study was in a high school which served a mostly Hispanic community (87% of students). The faculty and staff were also overwhelmingly Hispanic. The socioeconomic level was low-middle to middle class. The school was located in a safe suburban neighborhood of a major urban city. The school had been classified as a Title I school based on the 59% of students who qualified for free or reduced lunches. However, it had high marks in achievement and was a valued educational institution in the community. The special education department had consistently earned high marks during district audits and other program evaluations. The school made satisfactory efforts to include students with significant disabilities in school activities and clubs with nondisabled peers.

The majority of the school building was over 50 years old with some new construction including the latest technology. The setting for the study participants was in the newest classroom that was equipped with state-of-the-art technology. There was an interactive whiteboard affixed to the front wall of the classroom that was mounted low to accommodate students in wheelchairs or students of short stature. The students changed classes within this new building and to a main building classroom and back. The Best Buddies Club fostered frequent interaction with general education students. In class were several student computers, laptops, and tablets, and the teacher computer was connected to the interactive whiteboard that was used for

group lessons and discussions. The classroom had wireless Internet service as well as access to online curricular programs. The interview study occurred in the classroom after school hours. Memos were taken directly after interview sessions.

Role of the researcher. I was an experienced long-term teacher at this school and was in a position to observe and listen to students. I was able to observe communication about individual self-determination during class, in the school setting and community, and later during transition meetings. I was an active participant and advocate in the study, taking memos and providing interpretations for observations of interviews while bracketing personal experiences (J. Creswell, 2007). My participatory role was appropriate, since working with these students for multiple years had provided much background information on the manner of communication for each student. It was expected that not only students, but parents, teachers, and community members would have experienced a benefit from the students' expression of self-determination.

Ability to conduct research. Teachers verbally agreed that they did not fully understand what self-determination meant to their students and cooperated with this research study. At times, clarification was needed from the student and others who knew the participant well; however, opinions of others were given less weight. In some cases, parents or siblings needed to help decipher what the participant was communicating. I had established close ties to parents over the years. Since parents were supportive of other research related to National Board Certification and gave their consent for their children's participation, there was no problem anticipated to receive parental consent to satisfy Institutional Review Board (IRB) requirements. All participants were made aware of the ability to terminate participation in part or in full at any time. Since one student could not legally give her consent, I asked for her assent both before the research began and each time I recorded data. Family members had already expressed an interest

in this research to improve the quality of life for their children and had no issues with giving consent when needed. As was expected, quality of life was an important aspect of goal planning for parents of children with disabilities (Brewin, Renwick, & Fudge Schormans, 2008) and for teachers who believed they could make a difference in the student's life. (Nota & Soresi, 2009). Parental consent and teacher cooperation was achieved.

Chapter 2: Literature Review

Introduction

Self-determination is an important attribute of any student throughout his or her life, especially as graduation day draws near. Most students glide into adult life seamlessly with just minimal support. For a student with significant disabilities, much support is needed throughout his or her life and opportunities to experience self-determination must be on-going. Current literature supported the finding that more needs to be done to ensure that all students, even those with the most severe disabilities, are able to realize goals they have chosen for themselves so that there can be a smooth transition to adult independent living (Michaels & Ferrara, 2006; Skouge et al., 2007; Thoma et al., 2008; Valenzuela & Martin, 2005).

The purpose of this review was to shed light on previous related research on self-determination and secondary students with significant intellectual disabilities. Literature was included that investigated self-determination for younger children, as a foundation for future skills to be learned, or literature was described that explored adults with significant disabilities who have already experienced the transition to adulthood. Since there were considerable differences in the number of individuals with severe and moderate disabilities as compared to those with mild disabilities, some literature had to be included that was geared to a higher functional level, mainly because there was an abundance of literature pertaining to more verbal special education students. The goal was to investigate literature that addressed how self-determination portrayed, contextualized, and elaborated on the transition to adulthood for these individuals with low incidence disabilities. Literature that was quantitative was also examined since there was such a great quantity of information that was objective and measurable as opposed to qualitative and descriptive.

Most literature was supportive of the importance of self-determination skills in the adult lives of these individuals with severe to moderate intellectual disabilities and multiple disabilities. A major question was the ability to communicate and express needs, wants, and interests and the ability or willingness of others to understand, to offer the opportunity for self-expression, and to support their communication efforts. In the past, these individuals were written off as unable to be tested or unable to communicate and their participation has been ignored in research. The ethical issues of benefit to the person, validity of responses, and consent to be a participant in research were valid points that were addressed. The abundant amount of quantitative research on individuals with disabilities was one rationale for selecting a qualitative method. What scant qualitative data on self-determination that existed had come mostly from professionals and parents, but not from the individuals who were living with a disability. This study intended to enlighten the professional and private sector on the needs and abilities of these individuals to communicate some degree of control over their lives and participate in choices over decisions that impacted where they worked and how they wanted to live their lives.

Historical Perspective

The earliest mention of people with disabilities having a right to self-determination was depicted in a chapter written by Benget Nirje in Wolfensberger (1972). Nirje wrote that not only were those with impairments thought of as incapable of self-determination, but they were also treated as not entitled. Self-determination, also called self-sufficiency (Interstate Research Associates, 1988), was equated with self-advocacy. It was defined as "...people taking control, without undue external influence, over what affects their lives" (Interstate Research Associates, 1988). The important element here is without external influence (M. Ward, 1988). Individuals with disabilities were commonly given orders and fewer opportunities to decide for themselves

(Jingree et al., 2006). Individuals with significant disabilities were particularly at risk for denial of choice and control over their lives due to their dependency on others for care (Finlay, Antaki, & Walton, 2008).

The concept of offering self-determined choices to those with disabilities was a relatively new idea, coming on the heels of the 1954 Brown vs. Board of Education case and the Civil Rights Movement of the 1960's, which imposed that laws related to equity be specifically written in to enforce equality (M. McLaughlin, 2010; Mitchell, 1988). Also during the 1960's government funding and an interest in research was set into motion by President John F. Kennedy, whose sister had intellectual disabilities (Russo-Gleicher, 2008). Many people with disabilities derived inspiration from Martin Luther King, Jr. and the movements for women's rights and gay rights during that time (Caldwell, 2011). It was not until the late 1980's that the idea of independence and self-determination for individuals with disabilities was more widely discussed among education professionals (Mitchell, 1988). Historically, individuals with disabilities have always been denied the dignity of being able to translate their dreams into an effective action that can shape their lives and give their life a purpose (T. Ward & Stewart, 2008). They have always been treated as less valuable, lacking in equality, and of less moral significance to society, which in turn has subjected them to gross injustices of their human rights (T. Ward & Stewart, 2008).

Historically, children's rights were a comparatively novel concept. In the past, children were thought of as developing or becoming, not actually being a human being yet (Wickenden, 2011). Hart (1991) gave a historical perspective on the emergence of children's rights. For hundreds of years, children were regarded as property and are still the most vulnerable members of a family (S. Hart, 1991). Children were considered to be no more than commodities, economic

assets and valuable resources for parents' old age. Once they turned six, they were expected to be employed and subject to the same punishments for crime as adults (S. Hart, 1991). There was a reluctance for parents to get to close to their children for fear they would not survive to adult age. Only since the twentieth century did children's rights emerge and the theme of self-determination began to be applied to them, balanced with protectionism (S. Hart, 1991). All children were considered vulnerable, but those with disabilities were even more so.

It was not until 1975 that the Education for All Handicapped Children Act guaranteed children with disabilities a right to obtain a free and appropriate public education (Jiménez, Graf, & Rose, 2007). Historically, children's institutions in communities were established both to protect the disabled and to be protected from the disabled (Pote, Mazon, Clegg, & King, 2011). It was typically thought that institutions could best care for these individuals and that leaving them at home was a hardship on the family suffering from this "tragedy" (Ferguson, 2008). Common practice was to exclude children with disabilities from public schools to protect the children without disabilities from having to see them or otherwise come in contact with them (Skiba et al., 2008) even to the point of viewing the intellectually disabled as being a menace to society (Ferguson, 2008). Giving more credence to this practice was the tendency for children with disabilities to be more susceptible to other conditions, including behavioral, which tended to be poorly understood by others (J. Hart, Cramer, Harry, Klingner, & Sturges, 2010; Hayes, McGuire, O'Neill, Oliver, & Morrison, 2011). As adults they were housed in institutions not of their choice and kept dependent on others for all their needs (White, Lloyd Simpson, Gonda, Ravesloot, & Coble, 2010). Disabilities were considered a medical issue which lay within the individual and not as a result of the environment or a society that did not adjust to their needs (White et al., 2010). All authority and decision-making about them was carried out through

medical professionals and the individual was a passive observer (White et al., 2010). Some of these divisive sentiments still linger and social isolation and policies are still an issue for students with disabilities, who are considered oppressed in the United States (Anastasiou & Kauffman, 2011). Self-determination relates to human rights with an added aspect of children's rights.

In addition to children's rights, self-determination definitions have also been closely tied to concepts that define quality of life (I. Brown & Brown, 2009; Chou et al., 2007; Gerber, Baud, Giroud, & Carminati, 2008; Luecking, Gumpman, Saecker, & Cihak, 2006; Mactavish, MacKay, Iwasaki, & Betteridge, 2007; McGuire & McDonnell, 2008; S. Miller & Chan, 2008; Nota & Soresi, 2009). Social support appeared to be a stronger influence over quality of life for individuals with or without disabilities (Bramston, Chipuer, & Pretty, 2005). Choice was the central element of self-determination, which related to quality of life and human rights. Choice was included in the definitions of quality of life, but opportunities for choice depended on whether society offered them to individuals with disabilities or not (I. Brown & Brown, 2009).

Lead Researcher and Definition of Self-Determination

Presently, the literature base on self-determination has a prolific source and a specialist on the topic. Michael Wehmeyer can be considered the lead researcher in self-determination due to his development of a well-known standard measure for self-determination, *The Arc's Self-Determination Scale*, and numerous studies on the topic (Wehmeyer, 1999, 2005; Wehmeyer et al., 2008; Wehmeyer et al., 2009; Wehmeyer, Garner, & Yeager, 2006; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007; Wehmeyer, Palmer, et al., 2011; Wehmeyer & Powers, 2007; Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1997; Wehmeyer et al., 2012), for which he is still a prolific writer, many times listed as a joint researcher within the studies of others (Agran, Cavin, & Wehmeyer, 2006; C. Chambers et al., 2007; D. Davies, Stock, King, &

Wehmeyer, 2008; Heller et al., 2011; Nota et al., 2007; Nota, Soresi, Ferrari, & Wehmeyer, 2011; Shogren et al., 2007; Tanis et al., 2012; Thompson, Wehmeyer, & Hughes, 2010), and referenced in a number of other professional articles. Even though his studies have focused on quantitative measures, he agreed at the Division on Autism and Developmental Disabilities (DADD) 13th International Conference on Autism, Intellectual Disabilities & Developmental Disabilities at Miami Beach, FL, that all research on self-determination, including qualitative, is beneficial to the literature base (personal conversation, 1-19-2012). Observation, he went on to say, is a key way to investigate students with significant cognitive disabilities.

For the purposes of this study, the seminal research definition from Ward (1988) was used as a guide to stating the meaning of self-determination more simply and from its original meaning. Initially, self-determination was linked with children's rights (Wrightsman, Rogers, & Percy, 1975) and developed later to include children with disabilities. Other researchers after Ward (1988) have patterned their definition of self-determination following his leadership as a person living with disabilities (Agran & Krupp, 2011; Behnke & Bowser, 2010; M. Jones, 2006; Leake & Boone, 2007). The definition of self-determination from Wehmeyer, however, was often referenced, even if it was not the first ever (Branding et al., 2009; Shogren & Broussard, 2011).

Definition of Disability

Defining disability was complicated. The public policy regarding disability was intertwined with custom and factors that were affected by policy and practice (Shogren & Turnbull, 2010). Social elements, changing definitions of disability and core conceptualizations of disability policy were some of these factors. There were two aspects of these core principles of policy related to disability and they were person-referenced, as in self-determination, and

system-referenced, as in support delivery (Shogren & Turnbull, 2010). Consequently, education policy backed the notion that personal self-determination required support from the school system. Still, there were systemic barriers to real inclusion based on definitions of what a disability involved.

It was important to note that researchers and policy makers have defined and created models of disability, usually without consulting individuals who actually live with disabilities, except as passive objects of interviews or observations (Anastasiou & Kauffman, 2011). Individuals with physical disabilities have added insight into model development, but it was unclear if individuals with intellectual disabilities have contributed much to its advancement. While the goal of this study was not to develop a model of disability from the standpoint of a person with intellectual disabilities, the hope was to have more interactive, rather than passive, interview sessions and observations to gain a more precise perspective of their perceptions. Personal experiences can sometimes help people to think beyond their own experiences to consider how living life, for example, with an intellectual disability, can be (Anastasiou & Kauffman, 2011) and that was one of the objectives of this study.

There were several models of disability depending on the viewpoint and purpose of the definition (Mitra, 2006; Riches et al., 2009; Zascavage & Keefe, 2007). Each disability model might have had a different perspective depending on the context. Disability could be looked at from the major models of a medical perspective, a legal perspective, a social model, or the Nagi model (Mitra, 2006) which described functional limitations relating to the life skills including family, work, community, and self-care roles. According to Mitra (2006), Nagi delineated disability in 1991 as being defined by the society in which the person with disabilities lived. If functional skills were adequate to the family, community, and society in which the person lives,

the person was not exhibiting a disability. Riches, et al. (2009) described disability as a dynamic state due to multiple interactions between activities people with disabilities would like to access, and environmental and personal factors such as opportunity, attitudes, and the specific life and living background of an individual. The effect of disability on an individual's life had much to do with supports that were offered or not offered. It was important to note that opportunity was one of those supports that can have major consequences for the model of self-determination.

The other qualitative study previously mentioned (Zascavage & Keefe, 2007) found four themes that emerged, some being similar to the preceding referenced studies. Zascavage and Keefe (2007) envisioned through their study the themes of medical, materialistic, administrative, and social barriers models. Typically, the medical model involved the negative view of disability as something to be pitied, mourned, and medically treated. Medical models tended to lump all disabled into distinct categories and ignored the differences among individuals within the category, for example, cerebral palsy, Down syndrome, or brain injury (Stevenson, 2010). Each person in a category exhibited individual characteristics just as others did in categories that were not related to disability, for example, women or men. One positive outcome of this view was that, since the medical model was based on short term care or conditions, people with disabilities were able to become their own experts about their specific situation to enable informed decisions about their care (White et al., 2010).

The materialistic model involved contributing to society in the way of employment and life skills, a similar concept to the Nagi model. If an individual was employed and had independent life and family skills, the disability was minimized. The environment was the key to the nature of their contribution. Employment can neutralize the effect of the disability.

The administrative model (Zascavage & Keefe, 2007) advocated positively for removing physical barriers, offering least restrictive environments, and providing free appropriate public education (FAPE), but it also tended to formulate administrative decisions, which were made by able-bodied persons, over policy and opportunities for the quality of life that affected others with disabilities (Zascavage & Keefe, 2007). The administrative model was similar to the legal model (Mitra, 2006) in that it involved legislative action and government mandates. However, input from the individuals themselves who were living with a disability were still not considered. While it was true that other outside sources of advocacy can be considered self-advocacy for these individuals with disabilities, some control should be offered to those who were agents for themselves (Zascavage & Keefe, 2007). The administrative model had a legal component, even if individuals with disabilities were not necessarily asked for input.

Laws and policies can be in place, but social habits and barriers still prevail and still, most importantly, affect the definition of disability. The social barriers model explained how students with disabilities are moved into the fringes of our society whether in the classroom, the school building, the community, or through the curriculum (Zascavage & Keefe, 2007). The newer social model of disability (Anastasiou & Kauffman, 2011; Dhillon, Wilkins, Law, Stewart, & Tremblay, 2010; McKenzie & Macleod, 2012), which was first developed by leaders with disabilities, lent support to the global human rights agenda of the United Nations (Stevenson, 2010). Disability was only recognized as such by the society or environment in which one lived. For instance, the transition from school to employment was not as difficult as transitions between educational placements because the environmental accommodations were not as serious a hardship from the viewpoint of employers (Shaw, 2006). The community should therefore be more easily able to absorb these individuals socially into their working climate. It all

came down to how one defined disability and in what situation individuals with disabilities found themselves.

Disability Identity

Parents who have children with disabilities often did not discuss their disability with them, possibly to avoid harming their self-confidence and possibly due to feelings of guilt on the part of the parents. Studies have shown this practice to be a disservice to them because it viewed disability as something to be ashamed of and hindered their sense of identity (Caldwell, 2011). It was difficult to self-advocate for special needs if one did not have a disability identity. From an early age, most children with disabilities learned that they were different and excluded from many of life's formative experiences, leading to the feeling that having a disability was negative and shameful (Caldwell, 2011). This may have caused the need within a person to deny or hide their disabilities.

Even though they may be accepted by their families, people with disabilities needed to be accepted by the society around them. To accept oneself, one must recognize personal limitations, but be okay with them and realize they did not take away the fact that they are a person. Once a person understood their limitations, they knew how to ask for supports when and if they needed them. Awareness of what their particular disability required for independence was an essential step to transitioning to an adult world that was most likely unfamiliar with the needs of people with any disabilities at all.

Transition to Adulthood

The typical routine of the average student completing high school and going on to postsecondary education or employment was not experienced by the vast majority of students with disabilities (M. Davies & Beamish, 2009; Rusch et al., 2009). Consider that teenagers with

disabilities probably did not get the opportunities to practice age appropriate jobs such as babysitting, washing cars, or delivering papers as their counterparts without disabilities (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009). As a teacher, it was very disappointing to see all the hard work involved in preparing students with disabilities to have quality of life as an independent adult and to see them sit at home with nothing to do but forget all that was taught (C. Hughes, 2008; Taylor & Hodapp, 2012). Experience in job training before graduation was often lacking (Ali, Schur, & Blanck, 2011; M. Davies & Beamish, 2009). Once a child was away from the protection of the IDEIA after the public school years, transition support dropped off dramatically (Bianco et al., 2009; Neubert & Moon, 2006; Rusch et al., 2009). For example, if students did not have employment before graduation, they were at risk for continued unemployment (Agran & Krupp, 2011; Fabian, 2007; Sabbatino & Macrine, 2007). Many times the student's best resource for employment was not through the service agencies but through their own parents (Ankeny, Wilkins, & Spain, 2009). The response to this dilemma was in the IDEIA's enforcement of the emphasis on post-school outcomes to become post-school results (Etscheidt, 2006). It was not enough to plan transition. It must become a reality.

A review of the literature showed how strongly successful transition was linked to self-determination (Holden & Hamblett, 2007; Janus, 2009; Lubbers, Repetto, & McGorray, 2008; Morningstar & Liss, 2008; Neubert, 2008; Neubert & Moon, 2006; Povenmire-Kirk, Lindstrom, & Bullis, 2010; K. Powers et al., 2009; Rusch et al., 2009; Swedeen et al., 2010). Transition services addressed in the IEP must refer to areas of postsecondary education or adult education, employment, independent living, or community participation (Etscheidt, 2006). The areas listed have to do with the student's future and decisions needed to select their own path in life. Not being involved in decisions about their future tended to reduce motivation to be involved in their

own development (Agran & Hughes, 2008). High school students with disabilities have reported that they like to make their own decisions and did not appreciate teachers or others making decisions for them (Agran & Hughes, 2008). It is a human need to have a say in where you work, where you live, what you want to learn, and where you want to go (R. Martin, 2006). What tended to happen in the job market was that students were selected based on best fit for the job rather than by the best job to fit the student (Cobigo, Lachapelle, & Morin, 2010).

Since all special education students were required to have transition meetings before graduation, it was imperative that students were prepared to give meaningful responses, hopefully with assistance from both the school and the family (Angell et al., 2010; Lindstrom, Doren, Metheny, Johnson, & Zane, 2007). Ideally, these responses should be prepared in advance of meetings to facilitate efficient use of time for all IEP team members. Even high incidence, high functioning special education students often felt unprepared to discuss their own transitions at IEP meetings (J. Martin, Van Dycke, Christensen, et al., 2006; J. Martin, Van Dycke, & Greene, 2006). It was no wonder that students with more severe disabilities often did not participate meaningfully in their own IEP meetings where transition was being discussed (Carter, Owens, Trainor, et al., 2009).

Attitudes, activities, awareness, and experiences needed by adolescents to achieve independence were supported by the practice of self-determination (Carter, Owens, Trainor, et al., 2009; Swedeen et al., 2010). An attitude of learned helplessness can inadvertently be created when students with significant disabilities received excessive support from paraprofessionals, for example (Causton-Theoharis, 2009; Causton-Theoharis & Burdick, 2008; Giangreco, Yuan, McKenzie, Cameron, & Fialka, 2005). Teachers can be guilty of the same behavior: overbearing support that did not fade when no longer needed (Causton-Theoharis, 2009). The student needed

to believe in and be aware of his or her own abilities. Through activities such as structured interviews, discussions, and pictorial support, students with significant disabilities can develop self-awareness of their likes, interests, and strengths needed to participate in transition planning. Subsequently, teachers have to be patient listeners. Frustration caused by inability to communicate can be easily interpreted as challenging behavior by those on the receiving end of the interaction (Nota et al., 2007; Stoner et al., 2006), making it especially imperative to provide a way to communicate for these individuals so they can participate in self-determination experiences.

Furthermore, students with significant disabilities needed to experience their own independence to realize that it was possible. Based on their past experiences of regularly being told no (Jingree & Finlay, 2008), they needed to become accustomed to having opportunities for personal control and to telling themselves it is okay to voice an opinion that may be different from others. Actually, some individuals with significant disabilities may have difficulty differentiating their own opinions from those of others and the motive behind other's behavior (Törnqvist, Thulin, Segnestam, & Horowitz, 2009). It is vital that professionals recognize their attempts to express independent thought and support it by writing it into their transition statement.

One major milestone to becoming an adult was employment, which was where transition to work is unequivocally important (Carter, Owens, Swedeen, et al., 2009). Students with significant disabilities needed extra parental support and the belief from their parents that they can succeed with their help (Lindstrom et al., 2007). For instance, if parents did not assist their child with disabilities in planning transportation to work, the placement at work was at risk for termination. In addition, many parents had fears that their child could be harmed at work and

were not willing to allow the child the dignity of that risk, and in some cases, any risk at all (Angell et al., 2010; Dunn et al., 2010). Learning from mistakes is real life learning. Parents needed to be ready to let their child go so they can experience the significance and the pride of having a job during their adult development (R. Martin, 2006). This was especially true for females who were often more protected and consequently denied more opportunities for transition to employment (Hogansen et al., 2008; Leake & Boone, 2007). Hopefully, parents saw the long term value of self-determination in their child and aligned themselves with the direction of this study, even if their child had severe disabilities affecting their ability to experience employment. Youth with disabilities who communicated to their parents can help the parents learn how to listen to their child (Mill, Mayes, & McConnell, 2010) so that they can discover a purpose in their life.

Self-Determination Theory

The earliest works by major theoretical researchers, Ryan and Deci (2000), related self-determination theory to student needs for independence, a sense of interconnectedness, and internal locus of control. In fact, Deci, Koestner, and Ryan (2001) found evidence that extrinsic rewards, such as prizes for a job well done, inhibited the intrinsic motivation that supports self-determination theory and the need for an internal locus of control. Self-determination theory drove researchers to conclude that intrinsic motivation was what was behind a person's desire to be autonomous. For a person with significant disabilities, this need for autonomy can easily be disregarded due to an inability to communicate this feeling to others. Hence, there was the need to fully examine the concept of self-determination for all disability levels.

Theoretical constructs of self-determination discriminated the difference between intrinsic and extrinsic motivations (Vansteenkiste, Lens, & Deci, 2006). According to their

studies, choice motivations that were intrinsic can be exemplified by personal growth, relationships, or a sense of belonging to the community. On the other hand, extrinsic motivations to choose had an effect on something that was separate from the self, as revealed in their article. In applying self-determination theory to academic settings, parents who raised their children more autonomously, providing support with encouragement and affection without becoming overly protective and controlling, had the most self-motivated, investigative, and attentive children (Caldwell, 2011; Roth, Assor, Niemiec, Deci, & Ryan, 2009).

Application to individuals with disabilities. Self-Determination Theory (SDT) formed the basis of this study. SDT pertained to psychological states such as autonomy, competence, and relatedness (Jang, Reeve, Ryan, & Kim, 2009). However, as Nota et al., (2011), explained "our own research on self-determination with youth and adults with disabilities has focused less on motivational aspects, as does SDT, and more on cognitive, social, environmental, and behavioral components leading to the development of self-determination as a dispositional characteristic or, more specifically, to the expression of self-determined behavior" (p. 247). The behavior of the expression of self-determination was the topic of this study. To practice expression was how one becomes self-determined. For the purposes of this study, internal and intrinsic motivation were merely another positive effect of exercising self-determination. As SDT was applied to appropriateness to individuals with disabilities, this study explored the components of self-determination that emerged from the cognitive, social, environmental and behavioral factors of self-determination theory.

Components of self-determination. Self-determination can be thought of as having these components: (a) choice making, (b) decision making, (c) goal setting and planning, (d) problem solving, (e) self-advocacy, (f) self-awareness, and (g) self-evaluation and self-

regulation, even though other elements have been studied (Agran & Hughes, 2008; Shogren et al., 2008; Wehmeyer, 1999; Zhang, Katsiyannis, Singleton, Williams-Diehm, & Childes, 2006). Although choice making was seen as the central element that initiated all other components of self-determination, other elements were also vital (Agran & Krupp, 2011). Choice making may appear easy, but it was very difficult for individuals with intellectual disabilities (Antaki, Finlay, Walton, & Pate, 2008). Most educators described self-determination as choice making and put less emphasis on the other components (Thoma et al., 2008). Thoma, et al. (2008) also discovered in their research that most teachers felt they did not understand all the components involved in teaching self-determination. The mismatch between understanding what self-determination is and how to teach it, coupled with the emphasis from the school district to promote self-determination in students, was the main motivation for exploring this topic.

Choice making is an excellent way to start teaching about self-determination and is easy to introduce in the early grades (J. Kleinert, Harrison, Fisher, & Kleinert, 2010). Beyond choosing what foods to eat or what clothes to wear, a young child benefited by choosing which of two or three activities to participate in at school. However, self-determination cannot stop with teaching choice-making skills, as was often done in classrooms (Thoma et al., 2008). At some point, a child needed to begin practicing decision making skills that involved more significant consequences.

Enabling a student to make a decision and experience the consequences was in line with experiential learning in a realistic natural environment (Dunst, Bruder, Trivette, & Hamby, 2006). Other students can also benefit by incidental learning gleaned from watching what happened to other students when they made decisions during whole class lessons (Campbell & Mechling, 2009). Teaching the dignity of risk came into play when students were allowed to

make mistakes, be corrected, solve problems, and survive with their self-concept intact (Dykens, Schwenk, Maxwell, & Myatt, 2007). One tenet of good teaching is to tell students that everyone makes mistakes and to assure them that even teachers make at least one mistake a day.

An excellent way of supporting self-awareness, self-expression, and self-advocacy was through the arts (Mason, Steedly, & Thormann, 2008; Stephenson, 2006). Allowing for creativity involves several components of self-determination, as an example, when students chose the medium of art they will use, decided how they will portray their idea, and planned the steps to construct the end product (Mason et al., 2008). Technology, again, assisted students with disabilities to explore and discover who they were as a person through computer-supported art (DeSantis, 2012). Art and music can be added to self-expression as a message in itself. Of course there were many other ways to embed these components regarding self-reflection, but these were a few examples.

Research noted the lack of information on development of self-regulation skills in students with intellectual disabilities due to the presence of communication disabilities and questionable accuracy of present measures that exist (Varsamis & Agaliotis, 2011). Self-regulation included paying attention to the task, choice of goals, sticking to a plan of action despite distractions, seeking help or approval, and positive self-reinforcement (Nader-Grosbois & Lefèvre, 2011). The protective aspect of having an intellectual disability can preserve a positive self-concept that might improve goal orientation (Varsamis & Agaliotis, 2011). Even a young child with disabilities can look back at their creation with pride that they knew how to identify their interests, figure out how to show it to others, and can judge if they did the task to their satisfaction or if they needed to do something different next time.

Taking pride in one's work can lead to employment success and employment lead to less dependency on others for financial support (Brady, Rosenberg, & Frain, 2008; Storey, 2007). In fact, the need for economic independence was a major reason equity was offered at all to special education students (M. McLaughlin, 2010). The issue of benefits to students came as an afterthought and now the focus is outcome based. Self-determination elements improved the outcomes of transition to adulthood (Wehmeyer et al., 2007). This study examined the components of self-determination noted here and any others that were present as the study proceeded.

Model of self-determination. Self-determination can be thought of as a model with three interactive aspects: personal capacity, opportunity, and supports (Nonnemacher & Bambara, 2011). It came from a background of political (human rights) and psychological (personal control) origins (Wehmeyer, 1999). Through motivational psychology, personal control over one's life has come to be understood. The support aspect of the model is where educators impact student self-determination.

The aspects of self-determination were interdependent. Personal capacity was predisposed by the education received and amount of personal development achieved.

Opportunity was subject to experiences and environmental support. Lastly, support came in the form of accommodations that enabled the self-direction found in personal control (Nonnemacher & Bambara, 2011). A simplified model from the one offered by Wehmeyer (1999) that corresponded to this study can be depicted as such:

Figure. Model of Self-Determination

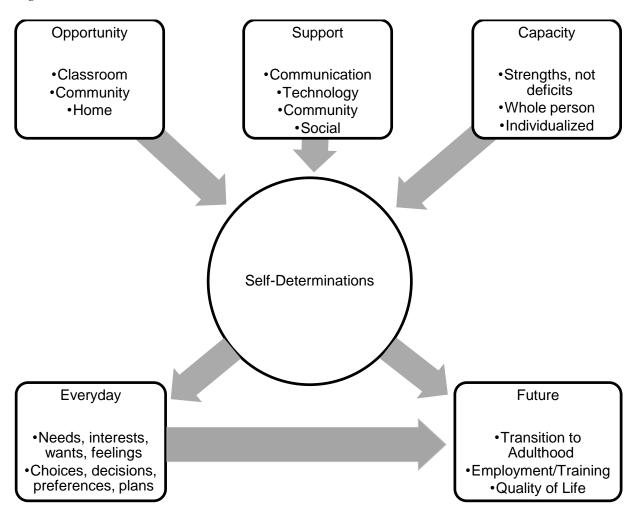


Figure. The relationship between aspects of self-determination as interpreted by the researcher.

Past Research

There has been much research in the area of self-determination, but most of it has been directed at milder disabilities (Thoma et al., 2008). Thoma, et al. (2008) attributed this phenomena to the teacher belief that students with lower ability levels could not express self-determination. There has been some question as to the validity of objective measures that gave a true global perspective of their capabilities in context to the environment of students with significant disabilities (Iacono, West, Bloomberg, & Johnson, 2009). In addition, measures of self-determination were not addressed on alternate assessments designed for standardized

assessment of students with severe or multiple disabilities (Roach et al., 2007). Perhaps that hints at the difficulty of measuring self-determination strictly in objective terms without considering the situation under which the test was given. For example, measuring everyday language objectively is difficult. According to one research study, "...the present investigation may indicate a difference in the severity of everyday language difficulties and the limitations this may place on communication, that are not always identifiable using formal assessments," (Wetherell, Botting, & Conti-Ramsden, 2007, p. 107). Even though qualitative measures were complex and more difficult to analyze for a conclusion, they needed to be included in future research.

Researchers typically considered individuals with communication difficulties as being unable to be interviewed and prefered individuals that can easily articulate and reflect on their life situation (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). In individuals with severe to profound intellectual disability, strengths lied in understanding receptive communication with others rather than in expressive communication from within themselves (Belva, Matson, Sipes, & Bamburg, 2012). Even though these individuals were probably listening actively, it may appear to others that they had nothing to say in return. In fact, many researchers have questioned the social value of studying individuals with intellectual disabilities at all (McDonald, Keys, Henry, & MacLean Jr., 2008; Russo-Gleicher, 2008). Consequently, these individuals were rarely allowed to be the subject of any type of research (Carter, Swedeen, Walter, Moss, & Hsin, 2011; Johnson, 2009; McDonald et al., 2008; O'Donovan, 2010; Williams & Heslop, 2006). Of course, protections needed to be in place to protect dignity, provide benevolence, and guarantee justice for any research participant (Noble & Sharay, 2008).

Special education has historically used quantitative research to measure behavioral objectives (Dennis et al., 2009). For a student with severe limitations, an objective measure did

not provide a complete picture of the child (H. Kleinert, Browder, & Towles-Reeves, 2009). These students cannot be reduced to a score on a piece of paper, even if it was an alternate assessment supposedly geared to their cognitive level. The current practice of objective assessment serves to place barriers to restrict learning when used to predict or determine success and points to qualitative investigations as a way to look at learning and development in a different way (Lebeer et al., 2012). Applying cognitive theory to students with significant disabilities tended to emphasize and intricately describe all the tasks these students cannot do and to assign labels that insinuated infantile behavior even when the students may actually be young adults (H. Kleinert et al., 2009). Nowhere was credit given in standardized testing for life experiences gained since infancy. Parents were shown their child's deficiencies, but not recommendations for improvement (Lebeer et al., 2012). In the early stages of intellectual measurement of individuals with significant disabilities, the term "untestable" was often used (H. Kleinert et al., 2009). If one were to work with these individuals, it can clearly be seen that they did know something about their environment, if only researchers could prove what it was, albeit through methods that were distinctively qualitative as opposed to quantitative. Often a child was found to be more capable than the strict interpretation of IQ results would show (Lebeer et al., 2012). Even though quantitative research was more highly thought of in scientific terms, this group of individuals with complex and challenging disabilities was more suited to the newer qualitative methods of investigation, especially if one wanted to observe self-expression. An emancipating advocacy approach to research, which respects the dignity of the whole human being and not the sum of their impairments, would be necessarily qualitative to reflect needs and wishes based on life experiences (Stevenson, 2010). Quantitative assessment can be seen as a barrier in itself to the inclusion of individuals with disabilities with mainstream society.

Most of the prior methods of research regarding individuals with significant disabilities have been quantitative and do not deal with the experiences of those who live with a disability (Lebeer et al., 2012). There was a weakness here because of the varied and specific types of disabilities encountered with individuals who have more serious disabilities. Furthermore, the testing environment and the situation on the particular day and time of the measurement affected the evaluation and resulted in unusually high or unusually low scoring (Couzens, Cuskelly, & Haynes, 2011). All of the abilities of these individuals cannot be tallied up and summarized on a computer printout, ignoring what can be accessed through direct observation or thorough openended interviews. Objective, standardized measures tend to reduce these individuals to a score using methods of measurement that may not be accessible to them due to the individual nature of their disability. If a student cannot speak nor control their movements upon command, they cannot indicate an answer without extensive support, invalidating independently given responses. Multiple handicapping conditions make it very difficult to assess quantitatively what the student knows and is able to do (H. Kleinert et al., 2009).

To understand the whole person and where they are in their environment, prior methods of qualitative approaches were stronger evidence (Roach, 2005). Disability is a social measure that depends on the supports in the surrounding environment. If a person can live independently, the effect of the disability on functional life skills was inconsequential. The focus is on real life experiences and abilities in the natural world. For individuals with significant, multiple disabilities, observation and personal interaction were superior ways to explore what they know about self-determination and how they can apply it to their lives to produce the desired outcome.

Communication Supports

The introduction of the idea of an individual with disability needing supports was different than the traditional medical model of disability and was the more modern thrust from the AAIDD (Lightfoot & LaLiberte, 2011). Support to be included and connected to society is a civic duty, not a favor extended to those with disabilities (Gomez, 2011). Society can be judged by the way they care for their members in need. Everyone needs a friend they can lean on for support and to communicate their troubles to in times of hardship. Support is a vital element to communication.

The idea of friendship may be experienced very differently for individuals who need extensive support to communicate with others. Most support offered to individuals with disabilities came in the form of a salaried caretaker or government assistance. These support caretakers were usually middle-aged women and their clients were usually young adult males (Björnsdóttir & Jóhannesson, 2009). Opportunities to interact with people that were not paid to be in their lives should be offered to individuals with disabilities (Gomez, 2011). Many researchers have found that an individual with significant disabilities only socializes with other members of the family or peers with disabilities nearly all of the time (Bailey, Parette Jr., Stoner, Angell, & Carroll, 2006; Cheslock, Barton-Hulsey, Romski, & Sevcik, 2008; Törnqvist et al., 2009). When the situation turned to communication with unfamiliar others, communication became difficult. One benefit of independent communication was having true friendships with people outside one's family and the support of a friend when one needed to talk.

Families are a person's first form of support. Genuine interest in what young people with disabilities are saying about their lives will help guide families (Mill et al., 2010), as well as professionals, to determine the degree of support needed to become a more independent adult.

Youth with disabilities felt it was important that families understood and supported their point of view (Mill et al., 2010). Family support made it easier to overcome the issue of disagreeing with the people one depended on for existence.

Research showed teachers viewed individuals with communication disorders as having the highest level of support need (McLeod & McKinnon, 2010). Families of children with severe communication difficulties also fiound a high level of support was necessary for others to understand and interpret what their children were saying (Bailey et al., 2006). Augmentation and alternative communication (AAC) devices might not be consistently used at home because the family understood the child with disabilities without the device, but felt AAC was needed to communicate within the community (Bailey et al., 2006). Remembering to consistently send the AAC devise to back to school in the morning when it was barely used at home can become a daily, but necessary burden.

Everyone needs support at one time or another during their adult lives and individuals with disabilities are only different as to intensity of support needed (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2012). Even individuals with mild disabilities benefited from visual support, for example, in making decisions (Bailey, Willner, & Dymond, 2011). Support for independence enabled free-will and autonomy. Individuals with disabilities needed reminders that all people need support and no one can live completely alone.

Autonomy can be thought of in degrees, not expecting perfect consequences, but a degree of willfulness in the direction of one's decision-specific actions (Lotan & Ells, 2010). Autonomy for these individuals did not mean complete independence as no one is completely independent of all outside forces. Individuals with disabilities should be allowed a degree of understanding, a degree of voluntariness, and a degree of rationality, without demanding perfect control over their

lives (Lotan & Ells, 2010). It was understood that due to the presence of a disability, some dependence was necessary, but with support, autonomy can be protected to the extent possible.

The present direction of ethical treatment is to challenge professionals who are accustomed to unilaterally making decisions for their clients with disabilities in daily living and future options (Lotan & Ells, 2010). If society values self-governance and self-expression, it will create an environment that supports it. In any society, complexities of interdependent relationships will cause any individual, with disabilities or not, to be dependent on others for their autonomy. It is common for any adult to ask for advice before making important decisions. What a person decides "...includes being able to decide how and how much one wants or needs to be involved in actually making the decisions, what information one needs to make certain decisions, and who will make those decisions" (Lotan & Ells, 2010, p.116). Furthermore, support conditions must exist that gives one the self-confidence to voice an opinion that may conflict with significant others in their life that they are dependent upon (Lotan & Ells, 2010). This study was ethical regarding unorthodox responses or conflicting opinions of all others, including myself, and offered necessary support for genuine communication to take place.

The balance between dependence and independence is a slippery slope of extremes for individuals with disabilities (Bianco et al., 2009). At any fleeting moment of independence, an unexpected barrier can cause a downward slide back into dependence on others, usually the family, for assistance. For example, an individual with intellectual disabilities can be an efficient worker in supported employment, but the moment the expected support was not there when needed, the situation can deteriorate rapidly and the individual can make an important mistake, causing others to believe the employee needed to be terminated. Another example of unanticipated failed supports was the turnover rate of caretakers for supported living which can

take a toll on frustration levels for their clients with disabilities who have gotten used to one person to assist them (Bianco et al., 2009). The aspects of independence that an individual can conquer are very individual and depend on the specific person's abilities in a specific location (Nota et al., 2007; Willner, 2011). Capacity should be determined over time and be decision specific and assumed to be present unless proven otherwise (Willner, 2011).

The degree of support needed was very individual and depended on what brain function was *not* impaired. The brain is a highly uncharted territory and most research is done after a specific area of brain damage occurs so scientists can interpret the consequences or behaviors related to the loss of function, and even those specific areas may affect healthy brain areas that are connected (Fonseca et al., 2009; van Asselen et al., 2009). The brain is all connected. Since ethical issues forbid direct observation of brain function in humans, researchers have used mice in hopes of shedding light on what happens between neural circuits in the human brain to link behaviors and brain damage (Desai et al., 2011). Using IQ alone or giving IQ scores special significance did not reliably produce correct, characteristic, or intuitive findings related to cognitive functioning (Dennis et al., 2009). Even individuals with severe intellectual disabilities can appear to function surprisingly well when least expected.

In a brain that has dysfunction, some parts of the brain work perform well and near average levels and some parts do not, especially in adults with intellectual disabilities (Danielsson, Henry, Messer, & Rönnberg, 2012). For example, executive-loaded working memory was at near-typical levels for both those with intellectual disabilities and those without (Danielsson et al., 2012). The study by Danielsson et al., 2012, showed that ability to learn may be more important than intelligence in executive functioning. Interestingly, students who have disabilities tended to underestimate the extent of their disability due to difficulty conceptualizing

its full impact and tend to retain a positive self-concept (Varsamis & Agaliotis, 2011). The suggestion here was that individuals with disabilities may have higher goals than can be reasonably accomplished and support will be needed to approximate their preferred life goals. Educators should strive to provide their students with as much independence as is possible, depending on their unique abilities.

Technology like SMART Boards[©], iPads[©], and the iPod Touch[©] can support learning about one's support needs (Schweder & Wissick, 2011). Educators need to keep in mind that children perceived whiteboard instruction as teacher driven and they would like to have more student-driven interactive activities, which was what the boards were designed for (Yáñez & Coyle, 2011). Students with disabilities benefited significantly by computer aided instruction that provided informed choices for different types of support that were available for different types of needs: employment, housing, and independent living (DeSantis, 2012; Mazzotti, Test, Wood, & Richter, 2010). Use of the Internet helped students view the possibilities of the outside world, if it was in an accessible format with accessible devices.

Communication support technology can give a voice to students who cannot use speech. Student-made digital presentations can assist in generalizing the ability to request appropriate supports in IEP meetings or meeting with vocational rehabilitation counselors. Participation was enhanced and support needs can be communicated cleanly and specifically with support from recent technological advances in speech simulation (Valiquette et al., 2010; Wennberg & Kjellberg, 2010), even for high incidence, commonly seen disabilities (Marino, Marino, & Shaw, 2006). It is common for people to view a person who has serious physical and communicative difficulties as also having low intelligence and not able to make use of technology, when technology can actually prove them to be wrong, once communication is supported (Zascavage

& Keefe, 2007). Advocacy for transition to adulthood was another issue often overlooked by individuals who needed to use AT to practice self-determination (Behnke & Bowser, 2010; Wehmeyer, Palmer, et al., 2011). The ability to communicate has become more important than ever in this technologically connected society. State-of-the-Art teaching cannot ignore the potential of technology for those with communication needs.

Opportunity

One tenet of this study was to examine the importance of having the opportunity to practice self-determination skills for transition to adulthood. For this opportunity to enable positive outcomes after graduation, meaningful opportunity must be provided for self-determination (Agran & Hughes, 2008; H. Kleinert, Miracle, & Sheppard-Jones, 2007; J. Martin, Van Dycke, D'Ottavio, & Nickerson, 2007). These opportunities must be available throughout the environment of the person with disabilities, including the school, home, and community (Caldwell, 2011; Kampert & Goreczny, 2007; Lysaght, Ouellette-Kuntz, & Morrison, 2009; James Martin, Woods, & Sylvester, 2005; McGuire & McDonnell, 2008; M. McLaughlin, 2010; Mill et al., 2010; Swedeen et al., 2010), including a culturally diverse perspective that might be relevant to the proposed community to be studied (Leake & Boone, 2007).

The student must have an active role in the decision making regarding expressed interests and preferences (Agran & Hughes, 2008; Kampert & Goreczny, 2007; Mill et al., 2010) and not exclusively during IEP writing. In addition, this opportunity to be involved in decisions that were made about them should not be restricted to only students with higher levels of intellectual functioning, just because it was easier to communicate with them (I. Brown & Brown, 2009; Dincer & Erbas, 2010; Ogletree, Bruce, Finch, Fahey, & McLean, 2011; Törnqvist et al., 2009). A particular facet of this research was to explore how aware students with intellectual disabilities

were of their actual involvement in choice-making and decision-making as it applied to them personally in various situations.

Daily practice in all the components of self-determination should be the goal, even if not accomplished completely or correctly. Self-monitoring, for example, was discovered to be one component that was often neglected in lesson activities (Agran & Hughes, 2008). It is not important if the students practice all components daily, or make optimal choices, decisions, or plans, but that they were practicing these skills and learning from their mistakes. Practice can come in the form of naturally occurring opportunities during the course of a regular school day as well as directly and systematically (Angell et al., 2010).

Educators need to get over the apprehension of periodically giving up control to the students and embedding opportunity for expression of choice during the day (M. Jones, 2006; McGuire & McDonnell, 2008). In personal conversations, teachers said the concern is the noise level and misbehavior. Appearances can be deceiving and a quiet classroom did not necessarily mean the best learning is taking place. Lower achievement, motivation, and self-esteem has shown a relationship to excessive teacher control (Thoma et al., 2008). As teachers, we have to ask ourselves if it was more important to have classroom control or a healthy learning environment (Reese, 2007), especially for students who needed to practice communication skills. Where the teacher was trying to develop expressive language skills, what might have seemed like chaos can actually be quite organized and purposeful. Furthermore, with students who use assistive devices to communicate, teachers have a duty to initiate conversations and create interactive situations (De Bortoli, Arthur-Kelly, Mathisen, Foreman, & Balandin, 2010). Studies have already shown that these students were higher in language reception than in expression (Belva et al., 2012). Educators should teach to this important expressive language skill that will

be needed in their adult life, regardless of how it appeared to others who do not understand the methodology involved in teaching communication skills.

However, educators felt more comfortable with the status quo of teaching academic content. Teachers worried about how they appeared to the school administration and were reluctant to allow student choice and free expression (M. Jones, 2006). Just as special education students needed a modified curriculum, they needed a modified environment. Prepackaged discipline plans that worked in general education may not mold themselves well to the needs of these unique learners (Lane, Pierson, Stang, & Carter, 2010). The current trend being to focus on student engagement would support the giving up of control and the allowance of shared power with the student to increase motivation to learn (Jalongo, 2007). As for the impression administrators may have toward classroom control in a self-determined class activity, educators may be in the position of having to prove best practices through research studies on self-determination. Routine classroom discipline may be more familiar and habitual, making teacher directed activities the less controversial path for instruction and, therefore, the least stressful. Educators may say they agree self-determination is important, but still not actually demonstrate it with students in the classroom for a number of reasons.

The lack of time spent teaching self-determination and the reported lack of confidence in teaching self-determination skills to students with disabilities were the chief reasons this study was needed: to ensure teachers provide students the opportunity to have their voices heard and seriously considered (I. Brown & Brown, 2009; Caldwell, 2011). It was understood that with high level decisions, a student with disabilities would need extra advice from family, teachers, mentors, or counselors, just as others do when they are making important decisions with life changing results (Lotan & Ells, 2010). Self-determination does not mean to choose whatever you

want or to have complete independence and absolute control, but to make an informed choice that produces a positive outcome, even if not always completely successful (Thoma et al., 2008).

Relationship of Quality of Life to Self-determination

Choice was often referred to in literature as it relates to self-determination and quality of life (I. Brown & Brown, 2009). However, I. Brown and Brown (2009) discovered the literature base to be lacking in studies pertaining to defining choice and how to effectively support others to make those choices. Personal control has been shown to have a positive effect on quality of life and a sense of empowerment for the individual as well as their family, who is also intricately involved (Van Haren & Fiedler, 2008). Behavioral challenges often effect quality of life for individuals with disabilities and can become a barrier to social inclusion, which is necessary for life satisfaction (Murphy, 2009). On the other hand, if individuals with behavioral issues along with intellectual disabilities had more choices in their life, their behavior may improve since they may feel more in control of what happens to them (Williams & Heslop, 2006).

Quality of Life

There were several ways to describe quality of life. A study by Chou et al. (2007) listed the eight components of quality of life to be: (a) emotional well-being, (b) interpersonal relations, (c) material well-being, (d) personal development, (e) physical well-being, (f) self-determination, (g) social inclusion, and (h) rights. Other researchers (Claes et al., 2012) have also listed eight areas, but refered to quality of life as belonging to the three factors of independence, social participation, and well-being. Under independence they listed the two domains of personal development and self-determination. For social participation they detailed three domains: interpersonal relations, social inclusion, and rights. On the last factor of well-being, they specified that it related to the domains of emotional, physical, and material well-being. In spite

of all available definitions, it was agreed that quality of life was variable in how it was described and measured (Chou et al., 2007; Claes et al., 2012). Self-determination was closely tied to having a good quality of life and both topics were mentioned concomitantly in numerous studies (Agran & Krupp, 2011; Ali et al., 2011; Bramston et al., 2005; C. Chambers et al., 2007; Cheslock et al., 2008; Chou et al., 2007; Gerber et al., 2008; Hanson-Baldauf, 2011; Heller et al., 2011; Luecking et al., 2006; Mactavish et al., 2007; McGuire & McDonnell, 2008; Nota et al., 2007; Shogren & Broussard, 2011). The consideration of what quality of life means was personal and best described by the person experiencing it (Moyson & Roeyers, 2012). This study limited the components of quality of life to those that seemed to be major issues as to self-determination for these participants, as they emerged during the study.

Right to communicate. We have an innate need to communicate (L. Powers et al., 2007) and a right to expression that is written into free speech legislation. The pursuit of happiness was written into our Declaration of Independence as an unalienable human right. Natural rights are what make us human and we are realizing that children also have this right to express their wishes and be included in social activity (Kirova, 2006). Ethics of care, human rights and participation have to do with removing isolating barriers when applied to individuals with disabilities (McKenzie & Macleod, 2012). Few social groups have suffered the abuses of euthanasia, forced sterility, and institutionalization for as long as individuals with disabilities have and these injustices are still occurring today (Stevenson, 2010). To ignore these individuals with severe difficulties in communicating is violating their human rights and their dignity.

Studies show on a global scale that simply legislation on human rights did not make it happen without advocacy (Johnson, 2009; Karr, 2011). Society has a responsibility to offer extensive

communication support and then listen at the moment communication is attempted, whether it is written into the law or not, as a matter of ethical treatment.

The dignity that comes with being listened to as a respected adult should not be withdrawn because the person with disabilities behaves as a child or likes childlike objects or activities. Adult-aged individuals with intellectual disabilities should be offered age-appropriate experiences, but not at the sake of removing juvenile experiences which they enjoy and which make them the unique individuals that they are (Forster, 2010). For example, these individuals should not be ostracized because they like children's cartoons or rocking to calm themselves down. Activities or objects that actively engage or regulate behavior should not be restricted from an individual with intellectual disabilities strictly on the basis of age-inappropriateness, as it could be seen as limiting freedom of expression. The disability itself limits the choice of meaningful activities in which they can engage as adults, so therefore limiting access to toys that connect with the individual is constraining their personal freedom. Age-appropriateness should serve to open up opportunities to be respected as an adult and not used to deny individuals with disabilities to be themselves among others (Forster, 2010) and to express their preferences.

To communicate with a person who has severe intellectual disabilities one may need to use age-inappropriate language to be on a level which they can understand meaningfully, but at least communication is taking place (Forster & Iacono, 2008). Furthermore, there has to be some emotional attachment on the part of caretakers to maintain persistence needed to elicit communication from a person with severe communication impairments (Forster & Iacono, 2008). A researcher cannot be completely detached from participants during interviews with individuals who need such intense communication support. The right to communicate is an important aspect of quality of life and validates one's very existence.

Choice. Choice is a component of quality of life as well as a component of self-determination (I. Brown & Brown, 2009). To have personal control over what happens to oneself is crucial to a sense of quality of life (Nonnemacher & Bambara, 2011). The positive sense of mind that comes when a person knows that they can take care of himself or herself is essential to the feeling of autonomy. Making a decision and experiencing the consequences, whether good or bad, is a mark of adulthood. To a member of a marginal group that has historically been considered as having the mind of a child, it is a sense of pride that they have earned the respected identity of an adult.

Choice may need to be more fully supported in individuals with intellectual disabilities since it may be difficult conceptually. Even in adults without disabilities, too much information about choices is confusing, not used maximally, and may not be wanted (Nieboer, Cramm, van der Meij, & Huijsman, 2011). Processing choices takes time and requires cross analysis which can cause confusion and self-doubt (Nieboer et al., 2011). Research had little information to enlighten policy makers on best practices to stimulate individuals with intellectual disabilities in ways to make better choices using available information (Nieboer et al., 2011). Active support in choice making for individuals with intellectual disabilities was difficult to define and maintain over the long term (Beadle-Brown, Hutchinson, Whelton, Harcombe, & Tilston-Viney, 2008). Other barriers to free choice were required choices that depended on personnel to supervise an activity or which item to purchase after required spending on services from a limited means of government funding. Choices may have been influenced by other factors such as proximity or familiarity rather than the use of relevant information.

Freedom of choice nevertheless was an important aspect of quality of life and opportunities needed to be offered. One way to support choice for those who have adequate

communication skills was to offer sentence completion opportunities (Dykens et al., 2007). Sentence completion may hold potential in giving the individual conceptual support, but free choice in the way they complete the thought prompt. For others, support for communication can be significantly enhanced if investments were made in access to technology for the most severe cases of disability, if only society would believe in their ability to use it (Mansell, 2010). This study discovered other ways to support choice-making in individuals with severe disabilities.

Employment. The fact of having a job increased one's quality of life and social integration (Heller et al., 2011; Kins, Beyers, Soenens, & Vansteenkiste, 2009; Laurenz, 2005; Luecking et al., 2006; R. Martin, 2006; S. Miller & Chan, 2008; Nota et al., 2007). For most young people, having employment was a mark of the transition from childhood to adulthood (Janus, 2009; Kiernan, Hoff, Freeze, & Mank, 2011). Students with severe intellectual disabilities need to be employed with community and social support, increasing their sense of empowerment and locus of control (Luecking et al., 2006; Luecking & Luecking, 2006; R. Martin, 2006; Nicholas, Luecking, & Luecking, 2006; Nota et al., 2007). Few studies have investigated what kinds of jobs people with disabilities want as opposed to deficits, gaps, and barriers to their employment (Ali et al., 2011). Employment or a lack of can be the gateway to further adult independence such as living on one's own, developing adult relationships, and accessing the community (Janus, 2009; Trainor, Carter, Owens, & Swedeen, 2008).

Productivity was another aspect of work that needed to be addressed. In lieu of employment, which may be problematic during a recession, productivity can mean volunteer activities, housekeeping, and personal projects (Lysaght et al., 2009). Employment and productive activity have been linked to enhanced mental health and unemployment may be more detrimental to mental health than a physical disability (Lysaght et al., 2009). Community

when it was volunteer work and unpaid. Ali, et al. (2011) discovered that people with disabilities generally would like any job, even if unpaid. The social aspect of employment with the general public seemed to be more important to quality of life than the financial.

Access to health care. Since most people get health insurance through their jobs, individuals with disabilities tended to be left out (Musumeci, 2011). Less access to healthcare lowered quality of life. Although educators try to convince potential employers that hiring individuals with intellectual disabilities is practical and safe, in reality they tended to have a higher risk for falls (Willgoss, Yohannes, & Mitchell, 2010). An employer would have to make some additional concessions for safety that make employment undesirable. Health care remains an important issue throughout life with ongoing consequences for those who cannot access it (Eidelman, 2011). Unemployed individuals with disabilities were harder hit by lack of health insurance. Serious health problems and medical bills were often the cause of financial hardship in families of children with disabilities.

Most health care policies and Medicaid regulations did not consider that individuals with lifelong health concerns needed continuous health benefits since they were often in and out of hospitals frequently, necessitating reactivating coverage more often than allowed (Musumeci, 2011). As patterned in society, the tendency to overlook the needs of the severely impaired continues until old age. There was much less research on elderly people with lifelong cognitive disabilities (Boulton-Lewis, Buys, & Tedman-Jones, 2008). Research did show that the risk of falls which can cause fractures increases with age in people with disabilities (Willgoss et al., 2010). In addition, since people with disabilities were living longer, consent for health care and health communication had become more difficult for nurses (Sowney & Barr, 2007). For

instance, when a person with intellectual disabilities needed emergency room care, the unfamiliar and stressful environment of the hospital setting can inhibit already limited communication skills (Lunsky, Gracey, Gelfand, & Taylor, 2008). Improved self-determination skills may have some benefits even as individuals with disabilities became elderly and needed to communicate informed decisions on healthcare.

Individuals with disabilities are living longer than ever now (Jobling & Cuskelly, 2006). Even though individuals with disabilities have more secondary health concerns, they experienced more barriers to obtaining needed healthcare (Minnes & Steiner, 2009). In addition they were less knowledgeable about their own bodies and their own state of health. Women with disabilities were especially prone to having little knowledge about their own bodies (A. Brown & Gill, 2009). Even though understanding a patient's perspectives on healthcare was an important facet of healthcare reform, very little data was available from individuals with disabilities (Parish, Moss, Richman, & Taylor, 2008). Physician availability, amount of time spent with the individual with a disability, and lack of knowledge of syndromes and services were cited by parents as some of the most serious barriers to appropriate healthcare (Lin, Lin, Chu, & Lin, 2011).

Social inclusion. As humans, we are social beings and people with disabilities need social contact as much as anyone else and perhaps more (Murphy, 2009). Hall (2010) expressed concern that the notions of individuals with intellectual disabilities to have paid employment, independent living, and community participation are very difficult to achieve. Even if all those adult goals are fulfilled, individuals with disabilities will have a difficult time interacting with others on an equal level of respect with full social inclusion. Social inclusion, as with other aspects of quality of life, requires a supportive environment.

Individuals with Down's syndrome were generally known for having very sociable personalities, but research has shown that not to be necessarily true (Cebula, Moore, & Wishart, 2010). When it comes to the social cognition of understanding the thoughts and feelings of others and the social give and take in conversation, it proved to be notably difficult (Cebula et al., 2010). In addition, they may have difficulty recognizing emotional states in others, with the impact of not being able to use this knowledge to guide their own behavior (Cebula et al., 2010). While it may seem like students with Down's syndrome did not have as much need for social skills improvement, they did indeed get into social trouble when they did not understand where the social limits were to their behaviors, what was acceptable behavior in various social situations, and they had a low affective response to distress in themselves and others. As students with Down's syndrome grew older, the developmental gap between them and students in general education classes widened, including socially (Cebula et al., 2010). These differences could indicate future problems in interpersonal relationships, mental health, and, ultimately, quality of life when they become an adult and do not feel connected to the rest of society (Cebula et al., 2010).

It certainly was an important aspect of self-determination and quality of life to feel a sense of belonging and social connectedness (Nota et al., 2007). Individuals with intellectual disabilities needed to be supported to have the opportunities to make social contacts so they could participate in the community (H. Kleinert et al., 2007). Furthermore, this social contact must be appropriate. Appropriate social support did not mean an older woman from support staff to accompany a young adult man to social events (Björnsdóttir & Jóhannesson, 2009), but an age appropriate person that would share the same interests. Development of true friendships was also a source of difficulty for individuals with intellectual disabilities. Often the only consistent

social contact they had after transition to adulthood were hired service providers, who had a high turnover rate (Bianco et al., 2009).

Even before transition, social contact with their peer group was affected by their limitations and can result in isolation. During their school days, students with disabilities were more susceptible to being bullied for being different (Caldwell, 2011). General education students casually tossed around the "R" word without regard to the fact that the word "retarded" might be sensitive to people who have intellectual disabilities and their siblings in mainstream classes (Caldwell, 2011; Eidelman, 2011; Siperstein, Pociask, & Collins, 2010). One social club that made a point to include individuals with intellectual disabilities in high school with non-disabled peers their age was Best Buddies[®]. On their web page, bestbuddies.org, was information regarding how club members can help end use of the "R" word through their advocacy. Best Buddies[®] was designed specifically to benefit individuals with ID and other high school clubs were rarely inclusive of people with disabilities. Belonging to a club, seeing friends as they change classes, and having lunch with peers in general education can help offset feelings of isolation and exclusion (J. Jones & Hensley, 2012).

Even in educational institutions that supported clubs such as Best Buddies, ideal friendship relationships were typically not fully formed. Best Buddies encouraged students in general education to make weekly contact with their paired buddies, either by sharing lunchtime with them, calling them on the phone, or visiting with them after school hours. Individuals with disabilities reported that they got more benefit from club membership than their non-disabled peer they were matched with (Hardman, Clark, & Kliewer, 2006; Neubert, 2008). Girls were generally more accepting of disabilities than boys (Litvack, Ritchie, & Shore, 2011), but participation was low for all general students. It took more effort to become a true friend to a

person with disabilities and most people did not put forth the sustained energy that it took to reach out to include them in their lives. In addition, students with significant disabilities such as intellectual disabilities and autism who were placed in inclusive settings rarely experience visits from friends or phone calls, even with the use assistive communication devices (Chung, Carter, & Sisco, 2012). Interactions observed were mainly between the individual with disabilities and their service providers, rather than with their age appropriate peers. The responsibility to socially include and befriend these individuals stays with the general education student peers.

To be the global society we want to become, we must recognize and have respect for cognitive diversity on an equal level with other kinds of diversity such as ethnic, gender, or religious (O'Donovan, 2010). People with intellectual disabilities have knowledge in their own right, their knowledge should be included in what defines all of knowledge, and they should not be overlooked as potential knowledge-givers (O'Donovan, 2010). They too have something to say. All in all, social interaction suffered immensely after students with disabilities left school and became idle. Inactivity, especially after exiting the school system, was common for individuals with more significant disabilities and can lead to other unwanted outcomes like depression, disorganized thinking, regression, and behavior problems (Taylor & Hodapp, 2012). Hare, Searson, and Knowles (2011) have found in their case study that adult individuals with disabilities who lived away from home became upset when they felt they were not listened to and their resultant anger was often interpreted as mental illness, contributing to the cycle of dismissal of their feelings and denial of more access to social experiences.

Transportation. Another barrier to transition for all young adults was transportation (D. Chambers, Rabren, & Dunn, 2009). Especially in the town which this study took place, a large city can be car-dependent without a satisfactory replacement in public transportation. Even

though transportation was most cited by individuals with and without disabilities as a barrier to successful adult transition, it was rarely addressed in transition planning (D. Chambers et al., 2009). Lack of transportation can affect access to employment, religious activities, recreation, and health care, as well as personal shopping needs (D. Davies, Stock, Holloway, & Wehmeyer, 2010). Quality of life depended on the ability to travel to be included in community activities and social interactions. While public transportation offered low priced and reliable service, complexities of bus routes and safety with unfamiliar community members was a concern. Even if family or agencies provided transportation, much depended on their availability and schedules and was often not readily available, having an effect on perceived quality of life.

Community involvement. An additional aspect of quality of life was community involvement and access, especially after leaving the school system, when supports fail due to complex and multiple service agencies that were not obvious at first to individuals with disabilities or their parents. Community involvement as applied here entailed access to the community. Involvement with the community was one of the most frequently expressed desires by individuals with intellectual disabilities (Kampert & Goreczny, 2007).

Under protection of the IDEIA, students got all their support from one location, the public school. Even though the IEP stated that the district must coordinate post-school services, collaboration among agencies was a rarity (Dutta, Kundu, & Schiro-Geist, 2009; Etscheidt, 2006). When mandatory education services were over, students were left with a maze of agencies that were not connected to each other. Quality of life was affected when a sudden withdrawal of individualized personal support for community involvement occured.

When asked what leisure or recreational activity individuals with intellectual disabilities participated in most, they usually replied video games, a solitary activity, as opposed to non-

disabled individuals, who went to the mall, movies, concerts, restaurants, and sporting events (Kampert & Goreczny, 2007). They also mentioned listening to the radio or watching TV, more activities that did not involve going into the community. Interaction with others without disabilities can assist learning of appropriate social behaviors and can serve to dissolve some of the negative social stigma that comes with having a disability. Social support can enable individuals to cope with daily stress, occasional crises, and life stage transitions (Kampert & Goreczny, 2007).

Recreational centers and organizations can offer a higher quality of life for individuals with disabilities by providing for social interaction during sports activities, lessons in the arts, or computer club meetings (H. Kleinert et al., 2007). Special Olympics had been one option for recreation, but it was segregated and the community usually did not have many other options to offer individuals with severe disabilities (Storey, 2008). Social networks developed because there was an expectation of long term future contact and that was not typical of volunteer assistance with Special Olympics (Storey, 2008). Activities like art, dance, drama, swimming, skating, and computer use offered additional community and social interaction with which to develop friendships (H. Kleinert et al., 2007). What was needed was integrated recreational services, with transportation provided, that were based on individual preferences and include non-disabled as well for true and sustained community involvement (Storey, 2008).

Another community institution that has offered personal involvement for individuals with disabilities was faith-based organizations (H. Kleinert et al., 2007; Vogel, Polloway, & Smith, 2006). It may be that because of having a child with disabilities, families looked to faith organizations for support and spirituality needs, along with a sense of community for each

member of the family. Due to cultural underpinnings of the community in which this study took place, religion had some significant influences.

When all else fails, most families found they were required to step in to resolve the lack of community involvement and coordination of service agencies for their child with significant disabilities (M. Davies & Beamish, 2009). When an individual with disabilities leaves the school system, they enter the adult services system where the rules are different. They are expected to advocate for themselves or seek their own support resources. Without trusted support from key persons in their lives, individuals with disabilities are left out of the loop when school has ended.

All students experienced a time of uncertainty immediately after graduation where they were unsure of their future direction, but for students with intellectual disabilities, the time period was extended (Test et al., 2009). It is very common to see an adult with intellectual disabilities that is unemployed or underemployed. Work and community experiences need to be provided during high school. There was no substitute for real practice in the real world to prepare these individuals to take their place in mainstream society (M. Davies & Beamish, 2009). Community experiences were of utmost importance to a smooth transition at school completion and fostered self-determination (Kampert & Goreczny, 2007).

Housing. Although many individuals with significant disabilities resided with their parents after graduation, the need still existed for community housing (Fisher & Purcal, 2010) and community living (Bigby, 2008). Many parents felt a sense of loss and guilt at having to consider outside living arrangements for their child with disabilities (Roper & Jackson, 2007), but these individuals can actually prefer living among their friends, being independent with support, and feeling like a true adult (Roper & Jackson, 2007). Perhaps if there were more satisfactory options, supported independent living would be a more viable choice.

Technology can offer hope and support here also, with homes that are adapted to individual needs. For example, smart phones can enable a home network of wireless devices to be controlled by one person through a home server. These smart houses can control actions such as the operation of household items, electronics, security cameras, and computers (Storey, 2010). Devices can be installed through the electrical wiring of the house or wirelessly. Technology can even track movements or location in and around the house and give health alerts to service providers. Systems can also be put in place to give auditory or visual reminders to take medicine or perform some other task such as food preparation. Assistive robotic devices have been developed for house cleaning, to aid in drinking and eating, and in picking up or moving objects and in operating appliances. All of these devices can be operated by a person with significant disabilities by voice, sip-n-puffs, eye gaze, remote controls, or smart phones, which double as communication devices for the general population. Even though these innovations were designed for persons with dementia, they can be applied to individuals with significant disabilities (Storey, 2010).

Given the fact that most individuals with intellectual disabilities continued to live at home after graduation, it was important to get their input as to satisfaction with their lives as they were now. Many individuals living with a disability would like to be allowed more independence at home, including more participation in household tasks (Harr, Dunn, & Price, 2011). Having a person with disabilities doing tasks for himself or herself may take more time, but it creates more independence within them. Parents who did too much for their children did not support their functional development so that the child can find their own independence within dependence (Harr et al., 2011).

Postsecondary education. Personal development and continuing education were also indicators of a quality of life. Students with significant disabilities needed continuous review to combat difficulties in retention. Individuals with intellectual disabilities had a high incidence of impairment in working memory as well as short term memory loss (Gathercole & Alloway, 2006). In addition, for some conditions, memory skills faded with age rather quickly. For example, individuals with Down's syndrome had a high prevalence of dementia after age 40 (Hanney et al., 2012). For students with intellectual disabilities, retention of learning can be solidified by living the experience. Research has shown that when compared to typically developing children, older mental age peers with disabilities may have an advantage of long-term knowledge and experience when it comes to recall and executive functioning (Henry, 2010). This may indicate that real life experiences indeed did help retention for individuals with intellectual disabilities. Continuing education and personal development through physical involvement ensures that these individuals did not forget what they just learned at school.

Little research has been done on the quality of postsecondary education and offerings from institutions of higher education for individuals with intellectual disabilities (Dutta et al., 2009). Ideally, universities should coordinate, collaborate, and share information regarding post-secondary options for both degree and non-degree programs, vocational rehabilitation agencies, and independent living centers. Appropriate transition services for post-secondary education or training should also be assisted by local school boards, special education programs, and state government entities (Dutta et al., 2009). After 30 years since the start of national legislation for their educational rights, basic needs of students with disabilities and equal academic environments are still not a reality for the overwhelming majority of these students (Dutta et al., 2009).

Love relationships. Few adults with disabilities reported having a love interest (Carr, 2008) or sexual experience (Bernert & Ogletree, 2013; Roebroeck et al., 2009). Some adult topics, such as sex, were deemed too risky to be discussed (Wilkenfeld & Ballan, 2011), even by parents at home (Lamorey, 2010). The capability of individuals with disabilities to consent to sexual relations has been examined and has changed since the early twentieth century (Lyden, 2007). Attitudes to sexuality were measured in a survey (Cuskelly & Gilmore, 2007) and described a lack of privacy in institutional settings and a withholding of sexual information. When asked, individuals with disabilities understood the barriers to sexual consent, social and environmental obstacles which were highly influenced by family and religious beliefs (Healy, McGuire, Evans, & Carley, 2009). Caretakers and other professionals involved in the care of individuals with disabilities also offered their personal beliefs and opinions, influenced by the paid supervisor's gender, in sexual education and health practices (Wilson, Stancliffe, Parmenter, & Shuttleworth, 2011). Most caregivers were female, but most individuals with disabilities were male, tending to promote a more restricted experimentation among men, for example, in a discotheque situation (Wilson et al., 2011). In addition, prerequisites for sexual expression and relationships seemed to be enforced by the self-determination goals of financial independence and home ownership, rarely achieved by individuals with disabilities (Healy et al., 2009). Given those requirements, fewer non-disabled adults today would qualify, but that principle should never prohibit their sexual freedoms.

In spite of all of the controversy, sexual freedom for adult individuals with disabilities was protected under state, national, and international law (Lyden, 2007). Lyden (2007) also explained that New York law, one of the strictest, only stated that the individual must understand the significance and the social morality aspect of their own actions, but there was no defined

measure of this competence and intellectual disability alone did not prove inability to provide consent. New Jersey, however more lenient, did not require understanding of the risks and consequences of sexual activity to give consent, only stipulating that the person with disabilities understood they can refuse to give consent (Lyden, 2007). These laws vary from state to state.

In addition to freedom of sexual expression for an adult individual with disabilities, there was the conflicting matter of related health issues (Scheepers et al., 2005). There was a lack of appropriate sexual education along with a lowered access to sexual health resources evident in the lives of most adults with intellectual disabilities (Scheepers et al., 2005). The issue of discrimination of sexual abuse from sexual freedom was key for individuals with disabilities who may not be able to distinguish between the two (Healy et al., 2009) and needed to be taught. Again, these individuals were on the outside looking in when it came to some of the most meaningful interactions of adult life (Arias, Ovejero, & Morentin, 2009). Individuals with disabilities were in the position that no one wanted to discuss their sexual needs (R. Brown & Pirtle, 2008) and most of all, their own parents (Evans, McGuire, Healy, & Carley, 2009)). Even in the documentary film, "Monica & David," about a local couple with Down Syndrome that got married, the parents were hesitant to talk about their sexual relationship (LaVant, 2011a, 2011b).

Little attention has been given to a common occurrence in the lives of other working adults and that was the issue of providing support for parenting for those individuals with disabilities (Lightfoot & LaLiberte, 2011). This group was at high risk for losing their children to child welfare agencies who historically did not provide supports for parents with disabilities (Lightfoot & LaLiberte, 2011). These individuals have been subjected to forced sterilization and have lost custody of their infants as recently as 20th century United States (Lightfoot & LaLiberte, 2011). Most states had laws detailing the removal of children from parents with

disabilities, but had few references to offering support so that these parents can keep their children (Lightfoot & LaLiberte, 2011). The focus of the withdrawal of children has been on the parental disability specifically and not on the more difficult to assess ability to parent. Parent support should be a factor in this decision just as it is in non-disabled parenting. For most working parents, day care services, housekeeping services, tutoring, and even home food delivery services were commonly used as formal supports. Informal supports could include grandparent babysitting, carpooling, or play group activities with other parents of young children. The idea here was to have equal access to opportunities for inclusion in the parent community which filled in the gaps caused by environmental demand.

Independence

Functional independence comprised all body functions, activities, and participation and was affected by culture and child-rearing practices (Chen, Tseng, Hu, & Koh, 2010). According to Chen, et al., American culture seemed to emphasize early independence (2010). However, in this country, the role of a parent of a child with disabilities was complex. It seemed a child with disabilities increased their dependence on their parents upon adulthood for support, rather than becoming more independent as in their non-disabled counterparts (Bianco et al., 2009). It can be a confusing world to a parent who is trying to encourage adult living, but is needed to put the plan into action. This creates ambiguous stress within the family, which makes it difficult to point to a specific cause (Roper & Jackson, 2007). Educators need to recognize in parents the feeling of the loss of a dream when they bring a child with disabilities into the world. As educators, we need to support the family with their grieving, as well as the student with disabilities, to see the positive level of independence special education can give.

Giving up control. Educators, along with parents, stressed independence as being an important quality for students with disabilities to exhibit (Shogren & Broussard, 2011). Independence can mean two different things to educators and to parents. Teachers have to gently introduce the idea of self-determination to parents if it is new to them. Most parents of secondary students have worked very hard to get where they are now through the system. It was not easy to give up parental control and hand it over to their child with disabilities. Sometimes teachers felt the same way.

Family expectations. Even though they wanted independence, Latino parents were not accustomed to expecting equity and advocacy on the part of their child in their interactions with school personnel (M. Hughes, Valle-Riestra, & Arguelles, 2008). They expected to be the voice for their child and to keep them close to home in line with cultural expectations as Hughes, et al. (2008) alluded to in their article. Sometimes in Hispanic families, children with disabilities were expected to ask for family assistance in decision making, since this culture tended to regard life from a collectivist rather than an individual viewpoint as most Americans did (Valenzuela & Martin, 2005). Parents worried about their child's independence when they were no longer around to protect them (Resch et al., 2010). On the other hand, it was possible that some people may have had a hidden agenda regarding a child's independence, such as keeping them at home because they depended on the government check for their child. Parents may actually need this income and were afraid of losing all or part of the child's social security benefit.

One significant barrier to independence was the benefit to others if the person with disabilities remained dependent. Parents may have felt like they would be able to keep their child closer to home and protected so that they did not have a need to worry and were more in control (Brotherson, Cook, Erwin, & Weigel, 2008; Heiman, Zinck, & Heath, 2008; K. Powers et al.,

2009). Ethnically diverse families, especially when they had girls with disabilities, often expected the child to stay at home and help around the house (Leake & Boone, 2007; Povenmire-Kirk et al., 2010). Some parents mght have worried that government assistance might be cut if there was proof that a child was more independent that previously thought (O'Day & Stapleton, 2009). Paraprofessionals also may have believed their job was in jeopardy if the student no longer needed their support and they had essentially worked themselves out of a job (Causton-Theoharis, 2009). These dependency enabling effects caused a lower quality of life, learned helplessness, lower self-esteem, and general passivity (Inman, Loge, Cram, & Peterson, 2011), the opposite of the goals of self-determination.

Freedom from outside influence. Independence was complicated when students depended so completely on parents for interpretation of their expressions (Angell et al., 2010). Children were socialized at home and conditioned by parental response, whether positive or negative (Roth et al., 2009). Given that parental authority, it was difficult to be certain student decisions were free of outside influence (K. Powers et al., 2009). If parents did not approve of their child's free choices, it was unlikely a child would want to disappoint them and would likely acquiesce to the parent's wishes (Roth et al., 2009). Parents were forced to walk a fine balance between offering support and allowing independence.

Independent responses. Another question was how to be sure a person with severe disabilities was understood authentically when they attempted to be independent. Everyday interactions with individuals who had severe communication disorders were more difficult to analyse statistically, but they were still important (Finlay, Antaki, Walton, & Stribling, 2008). Finlay, Antaki, Walton, and Stribling (2008) elaborated that there were countless ways that caretakers and others interacted with people with severe disabilities that shaped how control and

choice were exercised by the way their responses were recognized and considered when it came to terminating or continuing an interaction. The danger was that it was easy to mistake the intent of the communication for compliance to participate in an activity that was viewed as necessary on the part of the caretaker. These factors led one to question the independence of their responses.

It was important to remember that no adult was completely independent whether they havd disabilities or not. Many adults seek advice both personally and professionally when they needed to make an informed decision and they did not know what to do. Asking for advice remains a healthy action to take for anyone. The difference may be in the degree of support needed.

Action speaks volumes. Independent communication was especially important in employment settings, once a job was obtained. Individuals with severe communication difficulties should be allowed to show their task choices and decisions by actions, and not by words (Cobigo, Morin, & Lachapelle, 2007). Direct observation was superior to interviews with parents or professionals in achieving the true picture of their expression (Cobigo et al., 2007). Some questioned the student's understanding of abstract representations of a job task and the performance of the actual task that was selected during assessments, but observation showed they made the connection (Cobigo et al., 2007). The key to informed decision-making was to provide enough information, not vocational experience (Cobigo et al., 2007). Through their actions, individuals with intellectual disabilities were able to communicate wise decisions independent of others.

Empowerment

A relatively new concept for individuals with disabilities, the recognition of empowerment needs perhaps began with the movement for independent living which included the Veteran's Administration support (L. Powers, Sowers, & Singer, 2006). This shift from institutional services to community services offered the first real chance for individuals with disabilities to make meaningful life choices about the services and supports needed to be in charge of their own future (L. Powers et al., 2006). Medical models were replaced by an emphasis on individual supports to enable quality of life within the community. Rather than inadvertently advocating a learned helplessness, the opposite of self-determination (Kampert & Goreczny, 2007), educators should be offering support for individual empowerment. Personal control has been shown to have a positive affect on quality of life and a sense of empowerment for the individual as well as their family, who were also intricately involved (Van Haren & Fiedler, 2008).

Even for parents, empowerment was important to their sense of control and being in charge of the future of their family and child with disabilities (Resch et al., 2010). It was difficult to address empowerment for the individual with disabilities without referencing the family, where all support begins. Families can usually be counted on to have the best interest of the child with disabilities in mind. Research has shown that students with disabilities who had the most involved families had the best developed self-determination (Morningstar et al., 2010).

Grandparents can be of special significance when it comes to family support of the individual with disabilities and especially in emotional support for the mother of the child (E. Miller, Buys, & Woodbridge, 2012). Families can be an excellent voice for the person with disabilities, as long as they also consider their child's wishes as well, a difficult concept for family-dominated

Latinos that were encountered in the participant's community (M. Hughes et al., 2008; James Martin et al., 2005). This study explored some of the contrasts between what the family wanted and what the student with disabilities wanted, since even families often did not believe their child had the skills to develop self-determination (Van-Belle, Marks, & Martin, 2006).

There was a mismatch between the student with disabilities and the environment in which they must function (Zascavage & Keefe, 2007). Society fails to remove those barriers that restrict social inclusion and even while emptying institutions, isolation still exists (Zascavage & Keefe, 2007). Various types of disability effected opinions regarding the ability to be empowered with self-determination. Students with visual impairments were often neglected when thinking about self-determination and independence (Levin & Rotheram-Fuller, 2011). Hearing impairments can lead others to believe affected individuals cannot speak for themselves. Sign language can be empowering (Toth, 2009), if instructors have some proficiency in using it. If not, students that had the capacity to recognize print and visually discriminate between pictures have been shown through research to benefit from assistive technology like the Apple iPod Touch[©] or the Apple iPad[©] (van der Meer et al., 2011). Individuals with significant physical disabilities, especially when it involved the ability to speak, were often not considered in decisions made about them. Empowerment needs to be examined in all the specific and varied ways it affects an individual's ability to voice their opinions and make decisions about living their life. Involving students in the direction of research concerning their best interests in future planning had the potential to ask the most important questions that might have been overlooked had professionals and families been interviewed (L. Powers et al., 2007).

Importance of Leisure

Even educators were not aware of the importance of leisure skills (T. Rose, McDonnell, & Ellis, 2007) and were not specially trained in how to provide leisure education. Most individuals with disabilities were taught in special education classrooms where teachers used highly structured methods that did not encourage conversation, choice, and decision-making (Danneker & Bottge, 2009). An individual with severe intellectual disabilities may need unstructured free time before they will speak out on their own. These students tended to shut down all responses when pressured for an answer during class activities and lessons and needed extended response time (Antaki et al., 2008). Even though appearances of an orderly, scholarly class may look efficient to administrators, free time was where these students can become who they are and where they can express themselves freely (McGuire & McDonnell, 2008). They are not the traditional pencil-and-paper students. They need to be actively involved in what they are learning. For any class that focuses on communication, i.e. an English language learning class, a higher level of noise or conversation showed students were actively learning by talking and not passively taking directions from the teacher (Soto-Hinman, 2011). The more structured the environment, the less freely elicited speech one received from an individual with significant impairments (Cheslock et al., 2008). If educators did not provide unstructured leisure time when they were not giving directions and were in complete control of the environment, students with disabilities would not be able to access the opportunity to express themselves freely (McGuire & McDonnell, 2008).

During non-teacher directed free time, a student with disabilities can practice choicemaking and decision-making. Of course, these opportunities should not be ignored during structured classroom lessons either, but they were even more significant to communication and language development when verbalizations were freely offered. Many classroom confrontations and behavioral problems can be eliminated by simply listening to what the student was trying to say and giving them the respect of empathizing with them while trying to solve their immediate problem (Hare et al., 2011; Williams & Heslop, 2006). Sometimes just giving them a choice of two options both teacher and student can deal with in the situation will suffice. For example, if a student did not want to or could not remain seated during an activity, allowing them to walk in a certain area while they can still hear and participate may be all that is needed. Or, a choice between two locations in the class that were appropriate for the activity could work for the student. The point was to listen to the student, respect their wishes, and make an accommodation that all participants could work with. This was a solution that could work for both unstructured leisure activities or during structured lessons and could enable the student to feel validated. It was unknown and difficult to diagnose more specifically how many individuals with intellectual disabilities also have mental health issues (Williams & Heslop, 2006). Applying the concepts of self-determination during leisure activities could lead to more uninhibited expression and improved behavior.

Decision Making

The choice of jobs extended to individuals with disabilities was affected by individual preference, availability of employment within a geographic area, and the opportunities offered by agencies. Community rehabilitation programs, as well as schools, need to consider the individual's strengths, abilities, and interests in job placement (Brooke, Revell, & Wehman, 2009). The student should be content in the job selection and support of the agency involved (Brooke et al., 2009). Advocates of the person with disabilities should insist that the job fits the student and not that the student fits the job. Ideally, support personnel should look for ways to

allow the client of employment services to voice their preferences and seek ways to modify the work environment to suit the worker with disabilities.

The question of ability in thought processes of individuals with significant intellectual disability was another side of the discussion concerning decision making (Lotan & Ells, 2010). All thought is to a degree. No matter the level of cognition, as a human being, an individual must be allowed decision making opportunities with a substantial degree of freedom. Even though individuals with intellectual or development disabilities had questionable mental capacity to be autonomous, their degree of voluntariness and understanding should be considered on a decisionspecific basis (Lotan & Ells, 2010). "The ability of persons with cognitive and/or physical impairment to self-govern is dependent in a large measure on the society of which they are members" (Lotan & Ells, 2010, p. 114). Ethical practice led to consciousness-raising initiatives for people without disabilities to restructure their own value systems and beliefs toward those with disabilities (Lotan & Ells, 2010). The consent to conduct research was a difficult obstacle to overcome for individuals with disabilities, even if the research held much positive potential. Molinari, Gill, Taylor and Charles (2011) alleged "this lingering distrust in research demonstrates the critical need to educate the general public, especially decision-makers for individuals with intellectual and developmental disabilities, on the benefits and imperative nature of researching the needs of these individuals...," p. 393. These individuals must be allowed decision making status in all important life issues, including the decision whether or not to participate in research, as a matter of fairness and of human dignity.

Ability to Communicate

Without the ability to successfully communicate needs, wants, and interests, students with severe intellectual disabilities were trapped in a body that could not make a statement in

their own defense (Finlay, Antaki, & Walton, 2008; Jingree et al., 2006; Olney, 2001). Even when given the chance to communicate, students with significant disabilities were often not successful in doing so in their everyday lives (Carter, Owens, Trainor, et al., 2009). In fact, many question the ability of individuals with severe and multiple disabilities to communicate at all, leading researchers to quantitatively prove that these individuals can indeed benefit from communication intervention (Snell et al., 2010). The advent of alternative and augmentative communication (ACC) has changed our concept of what communication is and has enabled many individuals with communication disorders to interact with others (Rowland, 2011). People with cerebral palsy commonly experienced the ability to produce thoughts they cannot express for their entire lives and can benefit from the newest speech technologies.

Communication was the key to open expression and problem solving, even between parents and youth, and was perhaps more open with mothers than with fathers (Heiman et al., 2008). This expression was highly dependent on the opportunity to communicate (Bigby & Fyffe, 2009). If these students were not given the chance to communicate and people to interact with that understood their idiosyncratic communication styles, it was unlikely they would be successful in getting their thoughts across to unfamiliar others. Research has shown that individuals with severe and profound communication difficulties can still make their needs known by reaching, body orientation, facial expressions, leading gestures, eye gaze, and vocalizations (Cascella, 2005; Finlay, Antaki, Walton, & Kliewer, 2007; John & Mervis, 2010; K. McLaughlin & Cascella, 2008). As living human beings, it is in their nature to attempt to communicate, if only others would take more notice of their attempts.

For those students who have severe difficulty in communicating with others, Symbolic interaction theory (Russo-Gleicher, 2008) was applied in developing interview questions,

understanding and interpreting the interactions between individuals with disabilities and professionals, and in explaining the findings. This theory explained how caring or accepting attitudes develop between caretakers and individuals with disabilities under their supervision and how the language between them develops. Patience is a virtue when it comes to truly listening to an individual with severe communication limitations. Attachments should go beyond the responsibilities of the job in order to advocate for the person's communication needs (Russo-Gleicher, 2008).

Even students who can communicate fairly well report that teachers often did not support their efforts to express self-determination and did not understand how to teach it (Shogren & Broussard, 2011). For those with severe communication disorders, technology can be used to support expression and empowerment (Bunning, Heath, & Minnion, 2009). Students with severe disabilities need life-long support to communicate choices, preferences, and decisions (Bigby & Fyffe, 2009).

Expression for students with significant disabilities can also come in the form of reading and writing, although not traditionally associated with this level of disability, it was indeed possible (Browder et al., 2009). Historically these students were considered incapable of reading in general and were offered only survival reading instruction, meaning safety and information signs (Browder et al., 2009). I have been guilty of this line of thinking also as it was taught to me in university classes years ago. Recent changes to NCLB have forced educators to look at ways to offer equal opportunities to general education by teaching reading as a skill and not merely as sight word memorization. Attempts at writing can illuminate thought processes that may not be able to be brought forth by other means, due to additional specific impairments like physical or sensory. All education should lead to increased quality of life and reading or writing for

expression is no different. The system has ignored the need for reading for personal interest in these students. Reading text aloud should be with the students, not reading to the students. Active involvement by on-going comprehension checks and the asking of predictive questions maintains participation in and a connection with the story. Perhaps reading stories about self-determination can lead to improved literacy, greater self-awareness, and personal enjoyment of literature (Konrad, Helf, & Itoi, 2007). Finally, improved reading can lead to more enjoyment using a computer, shopping, or filling out forms as an adult.

Informed Choice

Once given the opportunity to choose, a student with disabilities must have enough background information to make an informed choice (Hanson-Baldauf, 2011; Lotan & Ells, 2010; Mazzotti et al., 2010; Nicholas et al., 2006; T. Smith, Polloway, & Smith, 2007). This became an issue when the opportunity to experience different choices was not available nor given enough time to develop (Wehmeyer et al., 2012). An excellent way to demonstrate possibilities for the opportunity to be independent was to listen to other individuals with disabilities talk about their supported employment jobs or to visit them at their supported living homes to show the potential reality they can experience as an adult. Without ever seeing the possibilities with their own eyes, they may not be able to picture themselves as an independent adult with disabilities. These experiences can help provide the needed background information to make life changing choices.

According to an additional study, students with significant disabilities often chose yes answers or the second of two given choices even if they have sufficient language abilities (Cobigo, Morin, & Lachapelle, 2009). It is not always easy to decipher a true answer given with good effort. At times, they will give outlandish responses as they grow from a fantasy based

orientation to a reality based orientation (Harrington & Harrigan, 2006). The personal choice has to be feasible and realistic in relation to their specific abilities (Agran & Krupp, 2011). Another issue was that the permission to make a free choice was often not offered, as in the case of some students who have one-to-one paraprofessionals, which was another denial of opportunity (Causton-Theoharis, 2009). It was an unspoken understanding that the parents have the last word and some students with disabilities such as Down's syndrome had become accustomed to giving up their rights (Carr, 2008). Choice is a learned activity.

The reality of students with disabilities having access to real life practice with employment in the community was not easy to achieve (Carter, Owens, Swedeen, et al., 2009; Heller et al., 2011). Technology can bring the practice of virtual job experience into the classroom so that students can make better decisions for positive adult outcomes (Standen & Brown, 2006). Using technology, a student with disabilities can experience something like being a school bus driver, without the hazards of real life practice. For some individuals with severe disabilities, this experience was enough and would be the closest to being in the least restrictive and appropriate environment while still being tailored to the unique interests of that person (Standen & Brown, 2006).

Informed choice also came into play when exploring living situations for adults with disabilities (Nota et al., 2007). Necessarily with some family involvement and support, adult service clients will need to choose and plan where they will live for the long term, after parents are deceased. Since IDEIA protections drop off at graduation, it is in the individual with disabilities and the parent's best interest to plan for residential needs before leaving the school system (Etscheidt, 2006). In addition, a plan needs to be in place for continued monitoring of their satisfaction with the residential placement (Resch et al., 2010). A person with disabilities

should be an involved and informed participant in all these living situation decisions, including choice of roommate (Wiltz, 2007). Where mobility was a challenge, students could benefit from digital representations of living options to provide experiential opportunity (Moisey & van de Keere, 2007). The options for continued living support should be determined by the individual, even if it comes down to reading eye gaze as a response, for the dignity of the human being (Hopkins et al., 2011; R. Martin, 2006).

Often it was not only the students with disabilities who did not understand all their options, it was the parents too and even the educators (Rowe & Test, 2010). Studies have shown that parent involvement was a predictor of future transition success (Rowe & Test, 2010). The wide variety of adult services and available supports can be confusing to both parents and teachers. Since many barriers to improved parent involvement in transition planning involved transportation or time issues, computer based training for parents can be beneficial (Rowe & Test, 2010). Informed choice needs to include parents and teachers for the most effective transition outcome (T. Smith et al., 2007).

In the work site where I teach, an online curriculum geared specifically to students with significant disabilities was available and was in use (Edyburn, 2006). The Unique Learning System and News2You curriculum addressed self-determination and offered graphic worksheets that enabled students to choose preferences and assist in adult life planning (Newton & Dell, 2009). Many of the activities embedded in the online program corresponded to concepts of self-determination and assisted with providing informed choice.

Influence

These students were highly influenced by the reaction of others to their attempts at communication (Roth et al., 2009; Törnqvist et al., 2009). Service providers strived to make

attempts to listen to the desires of their service user. Individuals with disabilities needed to be looked upon as partners in a person centered support delivery (Antaki, Walton, & Finlay, 2007). There had to be interplay between offering suggestions and deciphering what the other person truly wanted and chose to do. Service providers, not unlike teachers, offered communication support, but subconsciously used their own impressions of the individual, eventually concluding with false statements (Jingree et al., 2006). Often educators erred on the side of caution or best judgment due to the nature of their students' disabilities. Individuals with significant disabilities needed to be given respect for the dignity of risk and recognize it as part of the learning process (Sikma, 2009; Thoma et al., 2008). If students with significant disabilities tried something they discovered they did not like, they had the experience to know their dislikes and learned from their mistakes. Care had be taken in this research to ensure undue influence did not occur during interviews.

In addition, students with disabilities were often not taught how to stand up for themselves and direct their own activities (Agran & Hughes, 2008). Even if they did voice an opinion, it was easy to enforce the will of the supervising adult or convince them to change their opinion to suit administrative needs (Dunn et al., 2010). There were few, if any, objectives specifically written into educational plans that called for the instruction of self-advocacy or self-determination for students with disabilities (Agran & Hughes, 2008) so teachers needed to instruct students on how to politely, but firmly disagree. Students with significant disabilities needed to know it is okay to say "no" or "later" and not be scolded or chastised for being defiant.

Dignity of Risk

Personal control also meant experiencing the consequences of one's choices. Support may have been needed to understand what the options were. Problem solving skills could be

learned to resolve issues in their lives. More hands-on experiences helped them understand their disability and how it affected their life and their attitudes. Professionals and parents needed to understand how to balance support and opportunity to explore and discover the results of their actions (Peralta & Arellano, 2010). If the risk of serious injury was low, it may be worth more in learning than repeated reminders.

One way to safely allow students with significant disabilities to explore the environment and possible accommodations was through technology, possibly using virtual reality software (Cobb, 2007; Standen & Brown, 2006). Since boys were more prone to be risk takers, virtual environments to teach street crossing, for example, can be an excellent way to experience crossing a busy street without injury, in hopes of transference of skills to real life situations (Bart, Katz, Weiss, & Josman, 2008). In addition to bringing in difficult to access locations, students can experience the consequence of their actions without actually being harmed. The software can even be set for the view from a wheelchair for increased reality (Cobb, 2007; Inman et al., 2011). The interface of virtual reality software had to be oriented to the cognitive and physical needs of students with significant disabilities and transfer of learning had to be considered (Cobb, 2007). Input devices such as joysticks may be of use and, of course, practice improved performance. For parents and professionals who feared harm will come from allowing students with significant disabilities to experience dangerous situations, technology can provide dignity of risk, without actual injury.

Expression

Students with significant disabilities expressed themselves in idiosyncratic, unconventional ways (Petry & Maes, 2006). They tended to be passive in their expressions and agreed to everything said to them (Jahoda et al., 2009). Parents, other care givers, and the

individual became frustrated when communication was unsuccessful, which can lead to behavior problems (Antonsson, Graneheim, Lundstrom, & Astrom, 2008; R. Martin, 2006; Snell et al., 2008) or the giving up of control (Garcia-Iriarte, Kramer, Kramer, & Hammel, 2009; Goodwin et al., 2009).

Spontaneous communication. Pictures were a major way individuals with severe language difficulties could communicate. Research has shown that the use of pictures to communicate not only improved the success of the thought exchange, but also developed the ability to communicate more spontaneously (Kravits, Kamps, Kemmerer, & Potucek, 2002). When educators structured the classroom environment so that the interactions were questions directed at students, they ran the risk of missing important interactions initiated by the student, however nonverbal (Finlay et al., 2007). Research has shown that a variety of direct instruction, natural environment, and incidental learning can be the optimal way to improve language and spontaneous speech in a single case study of a child with autism and Down syndrome (Kroeger & Nelson, 2006).

Intelligibility. Another issue for expression of individuals with significant disabilities was intelligibility. One can never assume communication is too difficult, and therefore impossible, because of the severity of the disability. Being understood depended on many environmental factors such as familiarity of the listener with the speakers idiosyncrasies of speech, the listening environment itself, and the ability of the listener to predict what the other person would say (Flint & Klein, 2006). Sometimes the listener needed a point of reference to make sense of the conversation. At other times, a parent may have had to be called to interpret especially difficult and specific words being repeated for obvious significance to the person who

uttered it. Lastly, the environment had to be conducive to listening clearly, as in control of distracting sounds.

English as a second language. One factor that affected communication in the community of these participants was the ability to speak English. Most available participants were of Hispanic origin, but native language interference affected a student who spoke Arabic (Palmer, El-Ashry, Leclere, & Chang, 2007). For the potential participant who used Black English, it would not have been a problem for me for the most part. This city was noted for having a diverse population, but in the particular population of the community, Spanish was the predominant language. Most paraprofessionals who were employed at the school where this study took place were second language speakers. It was difficult for them to understand Standard English accents and Black English accents (Haddix, 2010). At times these students needed language intervention to be understood by others.

Behavior problems. Much frustration expressed in poor behavior can be diffused if only communication could be successful and the individual felt as if their voice was heard and their wishes considered. If not, some students with disabilities may even turn this frustration about not being able to communicate onto themselves in the form of self-injurious behaviors (Jasper & Morris, 2012). Furthermore, students with severe and profound intellectual disabilities can and did exhibit signs of depression which can lead to difficult behaviors like self-injury, but also included aggression, and irritability (Hayes et al., 2011). These researchers qualified their findings by adding that frequent loss of attachment figures in these institutionalized participants may be a contributing factor to their depression, which added credence to the use of familiar persons to conduct research on individuals with severe disabilities. Singh et al. (2006) lamented in their studies that to reduce undesired behaviors of clients, staff needed to "...anticipate and

respond to each individual's needs as if they are able to see the world through the eyes of that individual," p. 546. Finally, professionals must not lose sight of the communicative nature of challenging behavior and respond appropriately to it as a legitimate form of expression (Hayes et al., 2011).

Video recordings were an appropriate way to capture expressions that might go unnoticed without them (Finlay et al., 2007). Delayed response times could cause gestures to occur after seemingly appropriate wait time has passed. The resultant frustration on the part of the individual trying to communicate can cause anger and behavioral outbursts. Computer assisted instruction improveed behavior (Mazzotti, Wood, Test, & Fowler, 2012) as well as opportunities to be self-determined (Pierson, Carter, Lane, & Glaeser, 2008). Replay of the video recording to the individual would detect discreet gestures passed over the first time, if it had been needed.

Patience and Beliefs about Assistance

One other issue for students with communicative difficulties was the pace of the American lifestyle, especially in urban areas. Patience needed by listeners got lost amid the rush of shoppers paying the cashier, for example. It was difficult in everyday life to resist the temptation to speak for the person with disabilities while other regular customers were waiting in line at the register. Involving children with disabilities in decision-making took time, tolerance, and the attitude that the child was competent to participate (Franklin & Sloper, 2009).

Paraprofessionals working with students who have severe disabilities often did not share the same views as the educators they worked with. Independence for the students went against the reason for their employment, to assist students (Lane, Carter, & Sisco, 2012). If students were too independent, the belief was that their job might be in jeopardy so paraprofessionals

rushed in to enable dependence (Lane et al., 2012). Teachers needed to include paraprofessionals in the teamwork necessary to support self-determination.

Beliefs about Disability

It was precisely the beliefs about the abilities of individuals with disabilities that kept them from becoming a part of the mainstream of life. Meissner (2011) noted that "What is necessary is the kind of purposeful listening relationships that encourage awareness and suspension of the assumptions and beliefs that reinforce gridlock and the exploration of an understanding more aligned with the purpose of developing individualized supports," p. 384. In other words, if authority figures did not block these individuals from participating in their own adult lives by withholding support, they would be able to access a higher quality of life. Support should be viewed not as a status quo dependent need for care, but as a partnership that provides individualized support to enable a progressive quality of life that is in line with a more modern view of the range of possibilities available to people with disabilities (Meissner, 2011).

In addition to others' beliefs about disability, there was the belief the individual has about his or her own disability that could sabotage attempts at successful interactions. These evaluative beliefs about themselves may be one of the hardest concepts for an individual with a significant disability to comprehend (Hebblethwaite, Jahoda, & Dagnan, 2011). Even harder may be their ability to link negative self-concepts with learned helplessness. Educational professionals needed to support positive feelings to combat an overpowered mind-set.

Technology

Technology has developed to the point where it can give a voice to the voiceless (Behnke & Bowser, 2010; Bunning et al., 2009; Cheslock et al., 2008; Cilesiz, 2009; Cote, 2007; Doyle & Giangreco, 2009; Jiménez et al., 2007; Mazzotti et al., 2010; Shaffer, 2007; Skouge et al., 2007;

Smedley & Higgins, 2005; Standen & Brown, 2006). The use of technology has shown a positive correspondence to enhanced self-determination (Wehmeyer, Palmer, et al., 2011). As special educators we have an obligation to listen to our students, no matter how difficult it may be (Rapanaro et al., 2008; T. Rose et al., 2007). Even students with moderate intellectual disabilities can benefit from text-to-speech technology (Douglas, Ayres, Langone, Bell, & Meade, 2009). In 2004, the lead researcher for self-determination noted that in spite of the popularity of technology in classrooms, students with disabilities were more likely not able to have access, either due to physical absence of equipment or cognitively unavailable content (Wehmeyer, Smith, & Palmer, 2004).

Research has shown that even with communication technology that attempts to support participation for students with significant disabilities, if the teacher did not ensure its use within the dynamics of the classroom, the device may sit unused and useless to the student (Hemmingsson, Lidström, & Nygård, 2009). The simple fact of needing assistive technology for self-expression was, in itself, a barrier to communicative opportunities (Myers, 2007). Another barrier to full inclusion in classroom conversations was lack of knowledge about assistive technology (AT) and awareness of its optimal use by the teacher (Zascavage & Keefe, 2007). There should be more to using AT than for standardized assessments. In addition, students and teachers alike sometimes complained of the burden of carrying (AT) equipment from place to place as needed (Hemmingsson et al., 2009) and this happened even in special education classrooms.

On top of everything else, the use of assistive technology did not necessarily or satisfactorily substitute for real, full, or freely elicited communication (Naraian, 2010). There were countless limitations and situations that have multiple social contexts, such as at home,

during lessons, or during social activities demanding spontaneous conversation, that depended on the perspective of the AAC user. The mere use of assistive technology did not mean that a person with severe disabilities can voice their opinion or tell a story. Family input and capacity based on relationships were often not considered in the selection of appropriate AAC technology specifically to meet an individual's needs (Naraian, 2010). The ultimate goal of communication technology should not be to assess ability, but to include by membership a person with expressive limitations as a part of society.

Student independence in creating their own view of themselves had much to offer them through support and development of language using technology, even when they had some speech abilities (Cheslock et al., 2008). Students with significant intellectual disabilities were often assumed to be able to verbally defend themselves merely by the fact that they could speak clearly. For adults with mild to moderate cognitive disabilities and functional, but restricted language capabilities, technological assistance was rarely considered. Usually a lower level of assistive technology was employed due to lack of confidence in their ability to use technology and the attitude among educators that adults were beyond the window of opportunity to learn how to use the devices at an older age (Cheslock et al., 2008). With the advent of mobile communication devices, its application for individuals with cognitive and expressive disabilities was not lost on educators (Hopkins et al., 2011; Newton & Dell, 2011; van der Meer et al., 2011). Light-weight and inconspicuous, devices like the iPod Touch® and the iPad® Tablet offered a way to blend in with peers who shared an interest in these popular types of mobile interactive tools.

As innovative as technology had been in serving the needs of students with significant disabilities, including communication, there still exist barriers in the provision of Internet access

and accessible applications (Newton & Dell, 2009). In the everyday situations within the classroom, there can be a number of access interruptions. The Internet itself may be down for the entire school. The district may have put restrictions on a website or software installation a teacher needed to provide an appropriate education. Documents and data may be lost due to school system maintenance so that all network computers were configured the same. Each of these barriers became particularly problematic for a special education teacher who needed specialized access (Newton & Dell, 2009). In spite of these downfalls, technology had phenomenal potential to provide a voice to represent the disabled world.

While advances in technology were popular among education professionals, in itself, it was not the answer to effective teaching unless used effectively (Petrilli, 2010). Most technology that claimed to have accommodations for disabilities did not address cognitive disabilities, even though they were the largest segment of the disabled population (Keeler & Horney, 2007). Perhaps web developers understood intellectual disabilities the least. It was up to educators to make sure technology was used to its fullest advantage for the individual student with disabilities.

Perceptions and Experiences

This qualitative study examined the expressions of participant perceptions and experiences of students with significant intellectual disabilities (Goodwin et al., 2009; Hogansen et al., 2008; Palisano et al., 2009). There was not an abundance of qualitative studies in which students themselves were interviewed, who were living the experience of having a disability (Thoma et al., 2008), however one was found to be in especially close resemblance (Shogren & Broussard, 2011). In that study, only participants, aged 26 to 56, with adequate verbal skills who attended one conference were selected, which was a different sample than this study employed.

A gap in the literature had been noted since the beginnings of our awareness of self-determination, namely that most information about self-determination came from professionals, not from lived experiences of those who had grown up with a disability (M. Ward, 1988). The expression of self-determination was so important it was a federal mandate that students give input into their own Individual Educational Plans (Agran & Hughes, 2008; Eisenman, Chamberlin, & McGahee-Kovac, 2005; J. Martin, Van Dycke, Christensen, et al., 2006; Valenzuela & Martin, 2005).

Similar Studies

Studies done in the past that were similar to the design of this research were from Thoma, et al. (2008), Angell et al. (2010), Agran and Hughes (2008), and Shogren and Broussard (2011). The purpose of the study by Thoma, et al. (2008) was to gain a better understanding of how preservice special education teachers defined and described self-determination as it applied to secondary transition planning. This study was important to mine because it shed light on the need to understand what self-determination was before teachers can teach it and put goals into practice. This study made me realize that the answer may lie within the students with disabilities themselves to express what their self-determination means to them. The researchers observed how a restrictive, oppressive environment can restrict growth in self-determination by students. Just because a classroom was quiet and orderly did not mean the students were actually learning what they needed to know. Educators should not strive for excessive classroom control, but opportunities to allow students to practice self-determination, even when the results were not always perfect. The article also supported my belief that all students can experience selfdetermination on some level and they have a right to be given the opportunity. The authors concluded that other components of self-determination, besides the choice component, needed to

be built-in to the school experience for more successful transitions to adulthood.

Angell et al. (2010) also did a similar inquiry where personal interviews were conducted with adults with disabilities, however mostly physical and mostly due to cerebral palsy. Some participants were in their 30's and 40's and had even married and graduated from college. They exhibited a range of intelligibility levels from readily intelligible to unintelligible to the unfamiliar listener and using augmentative alternative communication (AAC) to converse. But, the participants seemed to be higher cognitively than the participants that worked within this present study.

Similarities were that the study by Angell et al. (2010) used qualitative data and focused on expressions of self-determination from individuals with disabilities themselves. In addition, the study showed the value of negative experiences and failure in learning behaviors that facilitate self-determination. Plus, this study brought into perspective how important it was that individuals with disabilities learned what accommodations to ask for and under what conditions to ask for additional assistance (Angell et al., 2010). Being that these individuals were better able to express themselves, they felt they could become the spokespeople for other younger individuals with disabilities that were to come behind them that might not be able to express themselves as well. These adults discussed how important parental support was, but cautioned about overprotecting young people and instead encouraging them to take risks and live the lives they desired. They talked about the need for self-determination practices throughout the school years and beyond. Advocacy from verbal adults with physical disabilities was invaluable to the study of self-determination, even though equal access meant more than ramps and widened doorways.

Angell, et al. (2010) explored the meaning of self-determination to adults who hoped to

offer their advice to others with disabilities growing up behind them. The researchers created a list collected from their literature review of traits of self-determined individuals which was helpful to explore and describe its meaning. Their article discussed how teachers were given manuals, models, and curriculum to teach self-determination, but nowhere was there information describing examples of individuals with disabilities who had experienced the adult transition process. The goal of their study was to extend practical advice to teachers and to share their adult voices to assist others who were not as able to communicate. This study was an important contribution to the one I proposed.

Agran and Hughes (2008) had a similar study because they used interviews to get students' opinions about their involvement in their IEP. Most studies ask adults' opinions: teachers, parents, or support staff. The study was not entirely qualitative, however, using surveys to collect data and perform quantitative analysis. They also had middle school participants as well as high school and this study used only older students as participants. In addition, the participants were learning disabled and therefore more verbal. Structured individual interviews were used in addition to the surveys and were conducted in a quiet area as were the ones I did. They used a much larger pool of participants, some of which were able to write their responses. The reason this study adds to my knowledge was because the researchers asked the important questions regarding IEP involvement and skills taught, and they explored student reactions to choices they made. The researchers discovered that students were still not being taught to selfregulate or self-evaluate their behavior, even though they were taught other self-determination skills. Few knew how to read their IEPs and few actually spoke up during their IEP meetings. Transitional IEP development was an important topic in this study so it was relevant to my research.

Shogren and Broussard (2011) also explored self-determination using a similar methodology as this study and was probably the most similar to mine. The researchers interviewed individuals living with an intellectual disability as I did. One difference was that this study only used participants that could express themselves in a conversational setting. The communication support offered was for the interviewer to describe what self-determination meant personally to enable the interviewee to respond more appropriately, relating the concept to their own life. It was not as open-ended as this research. In fact, giving examples restricted the participants' thinking and they responded too closely to the scenario suggested. The study I conducted used other types of support like pictures, symbols, and gestures, to name a few, that attempted to make responses for all participants more independent and genuine. In addition, this study's participants were older and had already made the transition to adulthood. Even though the pilot study tested interview questions on adults that have already made the transition, the participants were of high school age anticipating transition and were comparable.

Research Questions Reviewed

Individuals with significant disabilities can express themselves in varying degrees of competency. Through one-to-one interviews and interpretations, among other data collection methods, this study explained how. The overarching research question that reflected the fundamental characteristics of self-determination was what needs, preferences, goals, and feelings are expressed in students with significant intellectual disabilities?

Several sub-questions displayed the component aspects of self-determination. What needs are expressed related to independence? Specifically, what needs are expressed associated with personal care, family functions, or interaction with the environment?

What preferences are expressed based on beliefs, interests, and abilities? In particular, what preferences are expressed connected to recreation and leisure time, community involvement and

interaction, post-school directions, and personal expression?

What goals are expressed related to self-regulation? Essentially, what goals are expressed having to do with interpersonal cognitive problem solving, goal setting, and task performance?

Last, what feelings are expressed related to psychological empowerment and self-realization? In effect, what feelings are expressed explicitly regarding relationships with others, self-worth, and self-awareness?

The future dreams of adulthood for specific and individually unique students in this case study with significant intellectual disabilities was documented in its authentic state. It was difficult to predict what issues would be brought up by these participants, but a review of the literature indicated a broad array of independence issues experienced by individuals with various types of disabilities and served as validation for their concerns about becoming an adult.

Conclusion

Most literature taken all together was quantitative. This includeed literature in the field of special education, where individuals with disabilities were evaluated, categorized, and labeled so instruction can be assigned. This practice was naturally isolating and separatist and tended to view individuals with disabilities as something that needed to be medically fixed. Disability should be looked at as being within the range of human existence and as preserving of their status as an individual worthy of quality of life. There were very few qualitative studies of individuals with intellectual disabilities and even fewer studies involving individuals with serious communication difficulties since they were so challenging to interview. This study intended to fill that gap.

This study made qualitative use of interviews, observations, memos, and archival documents to get a clearer picture of self-determination and what it is for these students. Very little was known about what concepts these students had regarding independence since they were

so challenging to understand (Franklin & Sloper, 2009), even by their families (M. Hughes et al., 2008). Historically, these individuals were the last ones considered to be participants by researchers (Russo-Gleicher, 2008), probably due to their language difficulties and the time it took to elicit a response, but also due to their protected status. It takes an extremely patient researcher (Russo-Gleicher, 2008) to ask more probing questions and give extra response time for answers, even for parents (Lyons, O'Malley, O'Connor, & Monaghan, 2010). More qualitative research all together needs to be conducted to explore communicative behavioral phenomena with this particular group of special individuals, who have much more to say than what can be collected from objective assessments.

Chapter 3: Methodology

Aim of the Study

The aim of this study was to explore self-determination in individuals with significant intellectual disabilities by giving them the opportunity to express needs, preferences, future goals, and feelings about themselves. Participants in this study had communication difficulties which sometimes caused them to be misunderstood by others. The complex obstacles of cognitive impairments paired with communicative impairments made them a group left out of most research studies in the past (Lebeer et al., 2012; McDonald & Kidney, 2012). I aimed to describe and understand how self-determination can be portrayed by individuals living with a disability by the expressions of needs, preferences, feelings, and life goals for the future.

Qualitative Research Approach

In order to study unconventional participants, a researcher will have to use an appropriate methodology which will also be unconventional. Quantitative methodology calls for finite responses such as yes or no, this or that, and right or wrong. Just because a participant has severe communication skills does not mean, for example, that they should be limited to a choice of three possibilities to provide clear and exact explanations, if their preferred choice was not offered. Traditional ways of knowing will not work to explore the knowledge of participants who have been traditionally kept out of the social mainstream. I chose a qualitative approach because I wanted to capture the genuine thoughts that these particular individuals had about their lives. Due to multiple and significant disabilities, typical standardized testing is not going to reveal enough information to tell a complete story of living with a disability and the attempt to express one's needs and desires through self-determination.

Comparison of qualitative and quantitative methodologies. To compare the two methodologies, Chenail (2011b) noted that typically "...qualitative studies are most likely exploratory, naturalistic, subjective, inductive, ideographic, and descriptive/interpretive and quantitative studies are most likely confirmatory, controlled, objective, deductive, nomothetic, and predictive/explanatory", p. 1713. The goals of this study were to discover what these individuals understood about their lives in the environment in which they found themselves and then to describe and interpret what they have expressed so that others can better understand their needs, preferences, and goals. The point was to encourage free communication and not controlled responses. There was no way to predict exactly what the participants would express and that was the intention. Each individual had a separate and unique case story.

The theoretical underpinnings of quantitative research as compared to qualitative research are divergent. Quantitative studies are reliant on variable theory whereas qualitative studies rely on process theory (Maxwell, 2010). The focus for qualitative studies is on events, processes, and situations that link them together and the how and why, rather than whether and to what extent (Maxwell, 2010). A quantitative measurement can be very exact and still create incorrect results. Qualitative methodologies have an equivalent status to quantitative studies, albeit not as time-honored. The appropriate methodology to describe and understand participant expression is one that supports logic over statistics, essence over scores on a test, and the totality of the situation over specific measurements. The precision of hard data, as used in quantitative methodologies, will not be appropriate if one wants to see the meaning behind the big picture. Maxwell (2010) wrote "qualitative researchers have often had their work evaluated in terms of a 'scientific' frame that sees numbers as a key indicator of valid and generalizable research...," p. 475. This

qualitative study was as rigorous as a quantitative study, only in an alternate realm of reality and in a different (wider) conceptual lens.

Choice of methodology. A qualitative approach was an unsurpassed technique to best inform and add to the literature on the life experiences of students with a moderate to severe intellectual disability. The qualitative method was an appropriate strategy because it enabled me to capture communication from this marginal group so that their voices will be heard. Openended interview questions (J. Creswell, 2007) were a suitable avenue to offer an opportunity to convey thoughts and feelings that cannot be observed using objective measurements. A qualitative approach is a newer, more innovative process to creatively explore complex interactions that a quantitative method could never develop (Yin, Hackett, & Chubin, 2008).

A qualitative study was better able to answer the research questions regarding what individuals with intellectual disabilities expressed as needs, preferences, and goals for transition to adulthood. An exploratory study would have had too many variables to quantitatively measure for an accurate picture of their collective communications and would indicate the reverse method as superior (Yin, 1997). No design choice is perfect, but it has to fit the interests, goals, and objectives of the study (Chenail, 2011b). Because of the individual nature of each student with significant disabilities, collecting normative, large group data would be counterproductive to the intent of this study, which was to discover and analyze particular thoughts and general themes.

Previous methodology. Most literature on students with significant disabilities is historically quantitative (Braden & Shaw, 2009; Crisp, 2007) and what little qualitative data that is available usually involves teachers or parents and is not from the children themselves (Dunn et al., 2010; Jingree et al., 2006). In addition, most studies that have examined the topic of student self-determination investigated the matter as it relates to students with milder disabilities (Agran

& Hughes, 2008). Of the qualitative studies that I located, very few addressed understanding the form of communication from students with severe speech and language disabilities, possibly because it is more difficult to document. The studies that did address communication added greatly to the literature, but few components of self-determination were explored (Thoma et al., 2008) and none involved high school aged students with significant disabilities. There was a need to add to the qualitative literature base the full scope of self-determination topics for these particular types of high school students with disabilities.

Present quantitative data. School systems already use quantitative studies of individuals with significant disabilities and these students do take standardized testing, such as the Florida Standards Alternate Assessment (FSAA). With a focus on academic skills, the more functional skills of adaptive behaviors are not evaluated (H. Kleinert et al., 2009) and the level of precision, comparable to measures for general education students, is not there (Kettler et al., 2010). In addition, these standardized assessments have to be given on a one-to-one basis. The teachers must mark the answer sheet for the students. Some may not be able to indicate their answers without specific supports, making FSAA measurement data questionable for pure objectivity (Roach, 2005). To evaluate the quality of this objective measure is to completely trust the evaluator to interpret the responses, albeit given training in how to support responses and still be as objective as possible. Quantitative measures were not appropriate to this study due to inherent inaccuracies in how knowledge is viewed for these students.

Complete objectivity with this group of participants, even with quantitative assessments that are specifically designed for them, is largely impossible since they are so dependent on the evaluator and the situation at the moment of testing, in addition to their unique disability. This brings the issue back to the value of a qualitative study: one in which the individuals, themselves,

are allowed to express, in context to their environment, what they understand in their lives. The insistence on statistical accountability (Elbaum, Gattamorta, & Penfield, 2010) and no child left behind (H. Kleinert et al., 2009) does not serve the purpose of adequately preparing students with disabilities to live independently and with quality of life (Lowrey, Drasgow, Renzaglia, & Chezan, 2007). In addition, the extensive use of quantitative assessment shows a gap in research methodology and demonstrates a reluctance to move into more modern qualitative methods, perhaps a topic for other studies.

Relevance. In special education there is at times a huge mismatch between students' cognitive abilities and their ability to get their message across to another person. It is very difficult to precisely measure an observation of their communicative efforts. One special education researcher said it well, "Each child and adult, no matter how profoundly affected is more human than disabled [italics in original quote]", (Crisp, 2007, p. 138). Each person is only one of a kind and the person should be placed before the disability. The participants were members of a unique group of individuals who had very specific, situation-based disabilities that cannot be captured using a status quo quantitative methodology. One aspiration of this study was to bring them to the table to discover what they say they need, not what others say without their presence. A qualitative methodology was in line with the intent of the study and the research questions, which were to capture the expressions of these individuals in a way that closed-response surveys are too restricted to reach.

Appropriateness. In the field of education, the value of a study comes from relevant and appropriate methods (Kelly & Yin, 2007). These participants cannot access traditional standardized assessment instruments with equal opportunity to their non-disabled peers.

Qualitative data was more appropriate to include their point of view and to engage them in

guiding their own lives. Historically, quantitative data on these individuals has served to separate them for education purposes and not to include them for social interaction.

Specific strategy. Since each individual with disabilities had distinct characteristics that will affect what they describe, a case study method was utilized to delve deeply into the needs, preferences, goals, and feelings of each unique participant. The major source of data was gathered by a series of video recorded interview sessions. All sessions used an interview protocol as a guide to assist in comparing within, between, and across cases and to keep all data consistent. Other types of data were collected, such as archival materials, researcher memos, and details regarding participant member checking to strengthen the analysis of the recordings and to triangulate the findings. The particular strategy of this qualitative inquiry was through use of the case study approach. This case study design was bound by place, time, and context (J. Creswell, 2007) with the theoretical underpinnings of self-determination.

Qualitative studies are typically small in terms of number of participants and case studies are more so. The nature of the various disabilities exhibited by these participants made it difficult to research their life situations authentically using a large sample. Each person's life situation was unique. In a qualitative report, action is described in context to the situation (Stake & Munson, 2008). Emphasis is more on the ordinary rather that the exceptional occurrences, not best or worst case scenarios, but useful insight to what is happening (Stake & Munson, 2008). A case study design was a fitting methodology to fully explore expression regarding their personal choices and plans for the future and it was not designed to be applicable to other students, even for those who also have significant disabilities.

Intended outcome. The intended outcome was to discover what individuals with significant intellectual and expressive difficulties were trying to express about their needs, wants,

feelings, and plans for their future adulthood. What was discovered can be utilized for training for IEP meetings where transition to adult living is discussed. Archival data forms documenting needs, preferences, feelings, and life-long goals could be incorporated into the writing of transition plans for all students. Short, vivid presentations make the IEP writing process simpler, clearer, and more accurately reflect what the participant legitimately wanted to express about their life. It is intrinsic among all people "...to be the primary determiner of their thoughts, feelings, and behavior," (Wehmeyer, Abery, et al., 2011). The results of this study could assist others with significant intellectual disabilities as they attempt to express their own self-determination.

Case Study Approach

A case study design was appropriate for these individuals with significant intellectual disabilities who also exhibited communication impairments. The individual time spent on each participant was necessary to get an in-depth look at their lived experiences in living with a disability amid the society they found themselves in. Studies have shown that individuals with intellectual and communication difficulties can understand more than they can express (Belva et al., 2012). It was expected that their understanding of full sentences would be better than their ability to respond intelligibly. With extended time and investigative questioning, a complete picture of their expression was achieved. Since the most influential barrier to entrance into the mainstream is social (Zascavage & Keefe, 2007), it is important to examine how the world outside of disabilities affects theirs and to hear the effects from their point of view. By truly listening to the participants' unique form of communication, a case study approach answered the research question of what individuals with disabilities express as needs, preferences, feelings, and goals for the future as an independent adult.

Background of the case study. Historically, the case study approach is well known in the field of medicine by Freud's work in psychology, by case studies in the area of law, and by the use in political science of case reports (J. Creswell, Hanson, Clark Plano, & Morales, 2007; Kvale, 1999). Case studies can trace their origins through anthropology and sociology. In fact, the beginnings of case study development can be said to be in prehistoric times, when tribes gathered around campfires to tell stories (Benjamin, 2006). Storytelling is still a useful tool to define and shape our existence related to the culture of society (Benjamin, 2006). Language is transferred to the young through storytelling. Language constructs and sustains culture (Benjamin, 2006). Everyone has a story and individuals with intellectual disabilities can tell their story in their own way; the story of where they fit in with our society.

Development of case studies can be categorized as exploratory, explanatory, or descriptive, but perhaps a more general approach for the field of education, where the emerging case analysis can be reviewed at multiple stages would fit this study more (J. Creswell et al., 2007). A definition of a case study is one where the researcher uses multiple data collection methods associated with the issue in a bounded system to discover the context in depth. The boundaries for this study were time, place, and context. In this multiple, collective case study, three cases were explored to discover the themes than run within, between, and across all cases to illustrate the issues in self-determination. The interpretation of text data came from what was discovered about the issue or the individual experiencing the issue had a unique understanding. The goal was to find common themes that transcended the cases to make broad interpretations that resolved some of the issues.

This case study was bound by age, disability level, and location. The sample age range was from 14-22, but participants over 18 were given priority. Shogren, Wehmeyer, Palmer, and

Paek, (2013), have found that increased levels of self-determination correspond with increasing age, giving relevance to the selection of participants by age. The category of exceptionality was intellectual disability, but the focus was on the moderate to severe levels. Data was further explored to confirm that responses were stable across various settings within the school site. The case studies represented three different cognitive/communicative levels, as compared and contrasted within this complex disability classification.

A case study method was a relevant tool to answer the research questions. Narratives that the interviews generated were the stories that expressed their very own identity (Naraian, 2010). Case studies delved deep into the life experiences and expressions of participants and were what was missing from the research on these particular types of individuals. The intention of a case study was to reveal more variables that needed additional attention and to provide examples for later generalization while considering alternate perspectives (Baker & Lee, 2011). Case studies are able to make a comment on society by exploring collected data (Yin & Heald, 1975) or by creating a scenario of the future, describing where one has been and planning where one wants to go (Benjamin, 2006). However, the most important concern of a case study is to analyze what was said and what was behind what was said (Yin & Heald, 1975).

From an early work of the lead researcher in case studies, Robert K. Lin (1975), a case study works best with a mixed collection of cases to analyze and cross analyze. The characteristics of the cases and not the conclusions or results were what was analyzed (Yin & Heald, 1975). The particular group of potential participants for this study had a wide variety of disabilities at different levels of severity which affected their environment in countless ways, making this study method suitable. Reliability of a case study was accomplished with triangulation of the data (Yin & Heald, 1975). Another way to strengthen the data was to ask for

confirmation with the participant as to the correctness of their recorded statement (Yin & Heald, 1975), although this was a little difficult to do in this particular case study. With extensive time and patience expended on support of their attempts at expression, their thoughts and stories were interpreted and told to others in this report so that they too can gain "...an appreciation of feelings of being and not being heard" (Chenail, 2011a, p. 260).

How a qualitative case study shapes data. The collective case study design was selected to delve deeply into the full meanings represented by a small number of representative case participants in this exact setting, namely, a single high school in the Southeast part of the United States. As explained by Yin and Gwaltney (1982) in one of their seminal studies, since a case study cannot be manipulated, more than one case can provide for some replication to an observation. One important feature of a case study is that because it explores an event in a real life context, it generates rich data with multiple interest variables that match a pattern rather than generate a few data points (Yin, 1997). A classic case study might focus on a single individual or individuals, as in this study, and can handle the blurring between real life and the context within which it occurs (Yin & Davis, 2007).

There can be some weaknesses to using a case study approach. Case studies are not meant to predict or generalize results to others, even under similar conditions, and cannot calculate expected results for others due to the small size of a typical case study sample (Kelly & Yin, 2007; Stake & Munson, 2008). This study did not produce rich sources of numerical data as in a quantitative study. Qualitative case studies can only show that individuals are unique in some ways and similar in other ways (Stake & Munson, 2008). A significant weakness in a case study approach is that there could be a bias as to who is selected, what topic is selected, specific interview questions that are asked, and researcher's preconceptions. Any method selected will

have some weaknesses and awareness of that will temper the quality of all results while still improving knowledge and making the qualitative research worthwhile. Another area of trouble was the severity of a communication disability. Communication impairments involve speech, language, and gestures (Carlsson et al., 2007), difficulties with which some participants exhibit.

There were overlying neurological conditions that precluded my ability to get the rich data for the purpose of this study. Even though intellectual disability was the primary category in which these participants belonged, some had neurological overlays, speech and language disabilities, and other health conditions as a secondary disability. Neurological impairments showed up in word-finding difficulties and difficulty responding or understanding what is said to them, as in an interview situation. Problem solving skills were also affected by neurological conditions (Carlsson et al., 2007) and came up as an issue in this study, since it was one of the components of self-determination.

It is extremely difficult to find methodology that assists researchers unsure of their ability to understand all of the speech of a participant with communication disorders and some researchers have found no literature at all on the topic (Carlsson et al., 2007). This was a diverse group that was rarely selected for research participation and were invisible even among qualitative studies that involved individuals with disabilities. Due to the extreme challenges they present for most researchers, any valid and reliable communication rendered from an interview study was an improvement over what scant data exists presently. In special education, it is the small steps that count and sometimes all the ones we get.

Previous case study. Bigby (2008) did a case study using methodology very similar to this study where she interviewed middle-aged and older adults with intellectual disabilities. The participants had just moved from an institutional setting to houses in a community setting. They

were asked how they felt about their quality of life. She chose small purposeful sample cases of high, medium, and low levels, depending on the level of care needed for supported living in each house. The researcher wanted to examine the nature of social relationships 5 years after moving out of an institution and into the community with agency support. The similarities between this study and mine were that it explored transition, used interviews in a case study design, and investigated the future for participants with similar disabilities to the present case study. Bigby's (2008) study made use of NVivo software to assist in data analysis, which was what I did also. The differences are that this transition had already occurred with older individuals, and the interview with participants was not the only data collection tool used. Her study relied heavily on staff and family member reports and not solely on the participants' views of their social life. The participants in my pilot study had already transitioned after high school so that was yet another similarity which made her study useful to mine.

Participants

The purposeful sample of participants in this case study was special education students from one high school in the Southeast region of the United States. They ranged in age from 14 to 22 years. The number of males and females invited into the study was approximately the same. Their primary classification was a severe to moderate intellectual disability, coupled with physical limitations, deafness or auditory impairments, visual impairments, communication impairments, neurological impairments or other health impairments. There were six classrooms of approximately 10 students from which I invited the participants. From these groups, selected students participated in this case study, depending on a representative sampling, ability to communicate, and parental or participant consent. There were just enough consenting

participants in the selected sample of individuals with moderate to severe intellectual disability to complete the study.

A purposeful sampling method is a criterion to reaching theoretical saturation of data (Guest, Bunce, & Johnson, 2006). Considering the level of disability these participants were experiencing, a small number of study cases along with multiple data collection sessions was the most appropriate approach to get full answers to the research questions. Since the participants had moderate to severe disabilities, they exhibited extreme or deviant sampling. Due to the difficulties involved in gaining access to participants with disabilities, a purposeful sample of students in the same small environment that demonstrated stratified cognitive/communicative levels was the preferred way to get answers to the research questions. A random sample will not work with a group with such small numbers and individual needs. A non-random sample allowed me to target participants with the potential to offer rich data to lived experiences (Mammen & Sano, 2012).

The demographics of the participants in this school area were mostly community members from various Hispanic backgrounds, and the faculty and staff were also mostly of Hispanic origin. Instruction is conducted in English and all instructors, including myself, use Spanish for clarification when needed. For the most part, the students were acclimated to an American culture, including language. There were a few English only speaking students (but they understand Spanish) and a few African-American students, some of whom also understand a little Spanish. There were two students, a brother and sister, who spoke Arabic as well as English and also know a little Spanish, having grown up in this community. Sadly, the brother passed away during the time of the design of this study. The students came from low-middle to upper-middle class homes and were generally provided with all material needs from their families.

Some families received government assistance due to income or to having a child or children with disabilities. There were very little cultural or economic differences between the faculty members and the parents of these students.

Interview setting. Permission from the school principal was obtained to use two classrooms during after school hours since they are familiar to all the students. Parents were allowed to wait in the neighboring classroom where they could be made comfortable with the school television, computer access, and ability to use personal devices. The building was new and it is pleasant and comfortable. Parents did not take advantage of the adjoining classroom and preferred to pick their child up after interviews each time.

In the interview room, shades were drawn and the window in the door was covered. A "Do Not Disturb" sign was placed on the outside of the door while interviews were being conducted. A few times, parents did not heed my sign and knocked a few minutes early, necessitating our interviews to stop because I had lost participant attention. My personal video camera, microphone, and tripod was set up on a nearby tabletop to capture images of the participant's entire body so that body language could be deciphered. The camera could have been re-trained on the participant who might have needed to move to the interactive whiteboard, tablet, iPhone, or other devise to clarify a point, however, that only happened once or twice and it was insignificant to the data collection. Nevertheless, the entire body of the participant was shown to pick up any gestures or body language that might have been meaningful to the targeted interview question.

To increase comfort and not give the impression the session was like a job interview, we sat around the corner of the table and used comfortable chairs (King & Horrocks, 2010). The room appeared to be almost soundproof, but was tested to see if others can hear from outside the

room. Outsiders could not hear us, but we could hear them, at times being distracting to the participant. Every effort was made to conceal the participant's identity from others as they entered the room.

Parents were not present and did not wait in the adjacent room as described earlier. Interviews were completed so that responses were free of outside influence. Refreshments were available to both participants. A bathroom was located inside each classroom for participants if needed. The room was newly constructed with new seating and equipment. I kept track of time by using the timer on the computer taskbar and kept meetings to one hour or less. There were some outside distractions from other people or noise from traffic that distracted two participants, but I was able to redirect them quickly (Orbach et al., 2000). My phone rang once because I had a daughter having car trouble that I had to communicate with. I realized that phone interruptions are not professional, but participants were forgiving and their parents called them also at times, towards the end of interviews. Interruptions were kept to a minimum, however. The participants were comfortable in the room as they have been exposed to it as a routine during school hours before its actual use for interviews. Parents were notified when interviews were over if they were not outside the interview room waiting for their child. Parents met the agreement to bring their child home immediately after a session is completed. This was important because I was not allowed to provide rides home. Only once or twice did a parent arrive late and it was because of communication problems with the other parent or the caregiver was not available to pick up as planned. Participants were entertained meanwhile by their choice of devices to use: interactive whiteboard, iPads, or computers.

Actors. Since interviews are conversations, the principle actors in this study were each participant selected for the three case studies, plus myself. The relationship between the

participants and myself was paramount to achieving the rapport needed to obtain clear, accurate answers. Based on the experience I have had communicating with each of the participants, I was able to achieve a truly connected interaction which was unique to each participant's communicative style. The participants have known me for a number of years and have established a relaxed pattern of interpersonal relationships with me.

Parents also played a role in this research as they had to be able to provide a ride home after interview sessions and be sure their child was present at school that day. It is against school policy for employees to take students home so parent cooperation was a must. In addition, a positive attitude on the part of the parents supported their child's self-determination efforts. Due to the participants' level of dependence, any support person in their life played a supporting role in this study.

Events. Participants entered the classroom and sat in the interview area. This area had comfortable seating, a small side table, and a setup for video recording with a tripod and separate microphone. Participants were placed so that the camera could capture full body responses and the audio could pick up all conversation. There was a test trial of the equipment with a student in general education and later with the participant and myself to make certain there was a full view and the volume was adequate. I had already experienced audio failure during the pilot study so I purchased a professional microphone to be sure it would not happen again. Participants were given time to practice the interview situation at hand, meaning in that room, at that table, after school, and with me. Having never been formally a research participant or having to answer questions from an authority figure as a separate individual, they each needed to try it out.

Next I turned on recording devices and began the introduction of the first interview session. The participant was prepared for the interview by listening to me explain why they were

there and what would be asked of them. A warm-up interview session was conducted in an attempt to demonstrate how I would probe for more information from them and how to appropriately respond with more than one word answers, if possible. Consent issues were reviewed in the introduction and periodically during the interviews.

That having been said, it is uncertain that another researcher who was unfamiliar with the participants would have the same conclusions I came up with. An outside researcher would have to get to know the participants and their parents for an appropriate time before the interviews begin. In addition, it would be much more difficult to be permitted access to the students if a researcher was a non-employee of the local school system. I felt this study could be successfully duplicated by another researcher even if the results were different. That would only add credence to the strength of a case study since each case was only one of its kind. I happened to be in a unique situation that brought unique perspectives typical of a case study where each person's experience was individual. As with other qualitative studies, this qualitative study cannot be exactly duplicated to strengthen validity, but it can provide descriptive information about themes that run within, between, and across separate cases. The actors in this case study needed to maintain a close relationship between themselves and I throughout the study. It was this very closeness that gave this study validity since it takes time for a researcher to get to the point where the communicative interactions between the participants and the researcher are truly understood and fully communicated.

During the hour or less of interview activity, the participant had a chance to change or agree with what was said. Each subsequent session briefly reviewed the previous area of questioning and introduced the present interview area to be explored. In addition, the participant

was given a chance to add anything that was not previously mentioned, but may be important for me to know. I praised the participants for their assistance and prepared them for the next session.

On the final interview participants were debriefed and I made closing statements thanking participants for their assistance and explaining what will happen next. Participants were given one last chance to change or add to their interview statements. I described how participants can contact her to ask any follow-up questions. They received information on how this research will be used and how they could hear the results. Participants were privately given a gift card during school for their participation. Similarly, the parents were given contact information so they could also hear the results of the study and ask any questions that may come up in the future regarding this study. I congratulated the participants for explaining their plan for adult living and made her parting comments. This was not a formal goodbye, since they still have classes with me even up to the completion of this report. Regarding this study, I plan to keep in contact with the participant that is presently graduating.

Process of the interviews. As the participants took part in the study, they came to understand that answers can be refined, how their answers are kept confidential, and their right to stop the interview, if needed. Sessions never lasted more than an hour. Interview questions evolved as each session progressed in an attempt to clarify and better describe participant responses that answered the research questions. Opportunities to review the previous session were given at the beginning of each subsequent interview, which were eight in total. The data became saturated after eight sessions. Many trials were needed because it was necessary to repeat previous questions to check for consistent responses and to perform member checking of previously collected data. In addition, the interview question list was extremely long to cover all self-determination components.

Due to the unique situation of each participant, other visual or auditory aides were available during these recorded interview sessions as a communication aid. Some examples were the use of the interactive whiteboard, tablets, smartphones, or low tech devices like picture books and bulletin boards. Through a process of supporting communication, rich text of their expressions were developed. High tech communication aides and devices were not necessary or used during the study since the text data collected was sufficiently rich, making the content development process observable. All participants had appropriate language ability on their own.

The purpose of the study was revealed to potential participants. They were told that the study was to find out what people with disabilities say about their choices, decisions, future adult plans, and feelings about becoming an adult. It was described to them that the results of this study will help teachers and school systems to plan education that helps students with disabilities who transition or "go on" to adult life after graduation. I told them that one benefit from this study is that they may learn more about themselves and be more able to express that to others. I also had to remind them that they may not agree with their families, but that it is okay to have their own individual opinions and that they are important to this study.

I explained to them that they will be given a copy of the research at completion and I will read a basic story about the results to them that they can keep. They were told that it is possible that the results may be published in an educational publication, but their identity will be concealed. I made it clear that their participation is voluntary and they may quit anytime or ask for a break if interview sessions are long. If they could not tell me they were tired or were hesitant to tell me something, I offered breaks periodically, reading facial expressions and body language if necessary. They were reminded that any information revealed in the interview sessions was confidential, only between the participant and me, unless they talk about hurting

themselves or others. Any research information they gave me was kept in a locked location at my home and will be destroyed at the end of the study. Periodically during the interviews and before each session, this consent information was repeated.

Types of data. This study incorporated three types of data: interviews, archival data, and member checking. Most of the rich data came from open-ended questioning. As participants answered questions, I wrote memos to note antecedent behaviors, mood states, my impressions or biases, and any other conditions or observations that may have affected the interviews. In addition, archival data in the form of student work products was collected for documentation. Some of these documents were completed directly after the last interviews and some were collected from other teachers who used them for classwork. These data collection methods provided rich data, but are not generalizable to all individuals with disabilities and are not exact numerical measurements. However, these types of data revealed a graphic accounting of participant understandings.

Participant selection criteria. Four students were selected for participation in this case study since they represented typical case sampling (Glesne, 2005) of lower, middle, and upper level cognitive abilities within the significantly intellectually disabled range, so that vivid data related to self-determination could be collected from these major ability groups. Ability to communicate was relevant to participant eligibility, although it was a secondary dynamic. Care was taken to ensure that interviews were not perceived as communication tests rather than genuine conversation about their needs, preferences, goals, and feelings (Carlsson et al., 2007). However, the ability to communicate was a factor to consider in inviting participants into each representative case level of the study. I had to select students who were able to provide meaningful data to answer the research questions. Some possible participants had some verbal

skills, but low cognitive skills or unreliable communication effort. Others had high cognitive skills, but very poor communication skills, especially if they do not use their assistive devices. Availability and use of assistive technology became a major issue for inclusion. Participants that were excluded were those that had mild intellectual disabilities and high level verbal skills or students that did not communicate consistently or did not use their communication devices reliably or successfully. The sample was a stratified purposeful representation (J. Creswell, 2007; Grayman, 2009). Selected participants provided rich data that attempted to describe the layers of lower, middle, and upper cognitive/communicative abilities within the severe to moderate range of significant disability. This form of sampling was stratified to facilitate comparisons among and within the layers of representative cases (J. Creswell, 2007).

Participant selection also depended on the particular students who would be attending during the chosen school year. Students who were expected to have good attendance during the selected school year were considered to participate first. Because these students are in this program for multiple years, their ability levels and attendance records were well known. Every effort was made to obtain a representative sample that demonstrated maximum variation within the category of severe to moderate intellectual disability (J. Creswell, 2007).

Parents who were supportive of the research, gave consent, and could provide transportation after the interviews had their child invited into the research program. The age of the student was also a factor in selecting participants. This research could not be completed if the student would be graduating before all the data can be collected. Secondly, youth was a factor. The younger students had less exposure to lesson content regarding transition to adulthood and self-determination. They were developing their answers to questions about future planning and needed more practice with choice-making, decision-making, and problem solving. There were

more candidates who were older as a result, but it was possible for a younger student to be selected to participate. In addition, it was more enriching for data collection to have older participants who could see more immediate results in their actions. Being closer to transition to adulthood, they had more of an interest and motivation in sharing their dreams, hopes, and plans for the future.

To fulfill the purpose of this study, a participant had to have certain qualities:

- 1. Documentation of significant intellectual disability
- 2. High school age
- 3. Have interest in being a participant (consent or assent)
- 4. Attend the school at the researcher's site
- 5. Have arrangements for a ride home after school when interviews are completed Exclusion criteria:
 - 1. Participants who may not be available for the length of the study
 - 2. Individuals with mild intellectual disability and adequate communication skills
 - 3. Participants who rarely communicate beyond yes or no responses or one-word repetitive responses (i.e. "Mom", "Go", "Eat") even with assistive devices
 - 4. Participants without consent or assent

No participant was approached for assent or consent until the IRB and local review board had granted approval.

Approvals. After obtaining IRB approval, authorization was acquired from the local school board. The Research Review Committee (RRC) conducted their review only after university IRB consent. Applicants had to fill out the required forms (Anonymous, 2011a, 2011b). The local school board regulations specified that "a request for experimentation from

people outside the public school system, or from persons seeking university degrees, must be submitted to the Research Review Committee" (The School Board of Dade County, 1993, p. 2). An outside researcher "... who is not a current M-DCPS employee must first obtain a security clearance from the district" if a visit to a school will occur (Anonymous, 2011b, para. 4). An official letter with the RRC approval number and the expiration date of the approval was submitted to the principal before any study could begin. After university approval, I spoke to the person who could grant me local permission to conduct my study. The objectives of the RRC were to protect students' privacy rights, protect them from harm, and to minimize the effects of research on the learning environment (T. Chebbi, professional email communication, February 27, 2013). I understood that since my participants had disabilities and would be video recorded, I needed to go through additional scrutiny.

Recruitment. For the first step in recruitment, I asked for an appointment with the Principal of the school to discuss my study. I requested that the Principal consider me to be an outside researcher asking for permission to access teachers who are working with students earning a special diploma. This ensured that the participant had significant disabilities, but did not indicate which had moderate to severe intellectual disabilities. I explained to the Principal that I would not ask to know their names, only the number of teachers with students working on a special diploma. My intention was to anonymously pass out invitations to these students' parents to participate in a research study. Teachers that have classes exclusively with students working on special diplomas were asked to pass out copies. In addition, teachers were asked to collect archival data if their student was selected to participate. All students in the targeted sample received the invitation in a sealed envelope addressed to their parents. The first 12 students who met the criteria received invitations to the study. The students were accustomed to

carrying home letters sealed in this way for IEP meetings and had no problems delivering them to their parents via their book bags.

A short survey included in the research invitation flyer assisted in identifying which potential participants met the inclusionary criteria and in what way. The survey inquired about the parents' understanding of the communicative and intellectual abilities of their child. The survey helped me, or possibly an outside researcher, decide which level of ability a participant may belong to and assisted with selection. Upon consent, participant records were accessed to confirm eligibility as stated. There was a permission clause that allowed me to access student assessment and evaluation data, used only for the purposes of providing evidence that the participant actually met the inclusion criteria. To remain confidential, the information had the participant's identity removed and was assigned a pseudonym. This inquiry was designed to explore a representative sample within this group of participants with significant intellectual disabilities and excluded milder disabilities.

Parents were instructed to fill out and return the survey forms if they wished their child to be included in the study. Invitations also stated that the included consent and assent forms would be signed in person at the school. They were told in advance through this invitation that their child may or may not be selected to participate in the study. Their child had to meet the representative sampling needs of the study. The form stated that if selected, parents of possible candidates would be contacted to confirm a conference date and time that is after school hours. Most importantly, they were informed that their child, if selected, must attend the meeting with the parent. During these conferences, parents could ask any questions or ask for clarification of any issues that may concern them. Furthermore, participants had a chance to ask questions also.

The meaning of the consent and assent forms was reviewed before signing took place. Finally, parents needed to promise to be able to provide a ride home after research sessions.

After survey forms were returned, the first four parents of possible candidates were contacted to confirm a conference date and time. If attempts to recruit had failed for the first four, the next set of participant parents would have been approached and so on until I found four willing participants/parents that met the criteria previously described who had formally agreed to assist with my research. Notification that assessment data would be accessed during the course of this research were added to the consent forms. Benefits and possible risks to the participants or their parents were reexamined. All actors in this research, parent, participant, and I, observed each other's signatures. As it turned out, only four participants and parents responded. Two had no legal guardianship established and could sign for themselves and two had guardianship; one because her mother put it into place and the other because she was under aged. However, the under aged participant did not give assent and was dropped from the study, leaving the final number of participants to be three.

Each participant had two weeks to return the forms and schedule a conference before another would have been selected in their place. I was available to answer questions and was prepared to make three follow up calls, if required, for each participant. Forms were available in Spanish and translated by an interpreter, when needed. The two adult participants signed for themselves within a week and the parent who held guardianship did the same, with her daughter giving assent. Pictures were used in the consent/assent forms to improve participant understanding for low reading abilities. Informed consent was an ongoing process for the participant throughout the study.

Briefly, once IRB was approved, the steps to recruitment of participants were:

- 1. Obtain an official list of the number of teachers with students working toward a special diploma from the school registrar.
- 2. Request the teachers of possible participants to pass out the invitations into the study to selected students working toward a special diploma and to be sure they get placed into student book bags. Indicate to teachers that they may be asked to collect archival data on selected participants for a specified time period during the study.
- 3. Select from the returned invitations three or four participants who have significant intellectual and possibly some communicative disabilities as reported by their parents. Verify disability level with parental permission to access assessment data. Request permission from parents to view participant work.
 - 4. Set up conference dates with participants and parents.
 - 5. Follow consent procedures during conferences as indicated previously.

Data Collection Tools

Since this was a qualitative case study, I used interviews, memos, audio and video recordings, pictures, and archival records of student work samples for data collection. The use of multiple data sources added strength to the collection process (J. Creswell, 2007) and helped define the case. Blank samples of student work forms are presented in the appendices. These worksheets came from the online curriculum in use by the local school system and permission was granted for its use. The permission letter is also presented in the appendices. Pictures were used as an aid to understanding the interview questions, when needed. Pictures were also used for the survey questions in the archival documents seen in the appendices. The main source of data, however, was recorded interviews. I designed the interview questions and began addressing the preliminary research questions to the pilot cases first and then to the participant cases. Once

this study was approved, I began compiling a history of expressed needs, preferences, goals, and feelings for those with severe communication difficulties to assist with interview protocol.

Framework of data collection protocol. The major phase of the collection process was through individual interviews. Being that the interview protocol was an extremely crucial tool to establish consistency and validity, it had to be carefully developed. I was aware that the interview questions I chose had a direct effect on the relevance to the research questions and could steer the study away from what the participant actually wished to express. I had to be vigilant in being honest with myself and had to use other data collection methods such as member checking, recording memos, and using other data/documents that participants produced in order to express themselves.

Instruments. The main instrument of this study was the researcher-developed interview protocol derived from the Arc's Self-Determination Scale (Wehmeyer & Kelchner, 1995). Student interview questions were open-ended, had uniform preliminary questions for all participants, and were short, but direct. As the interview process developed with multiple trials, each component of self-determination was addressed and the questions were developed to address them. The interview form changed as the data shaped the study.

Beyond that, I adapted some close-ended questions that are found in the online course materials, Unique Learning System® and News2You®, approved for students with significant disabilities in this school district. These materials were used on a regular basis in conjunction with the course I teach on self-determination. The online course contained worksheets, surveys, and reading materials designed to teach self-advocacy and independence. Some samples can be seen in the appendices of this study. Responses to the materials were used to corroborate theme discovery. The Unique Learning System® curriculum follows the most recent adoption of Core

Curriculum standards to ensure students in special education are receiving a comparable scope of education topics to those covered for students in general education. Besides modeling after subject matter from the Unique Learning System® curriculum and the Arc's Self-Determination Scale, I consulted the content of the Modified Annual Self-Determination Checklist (Anonymous, 2006) adopted by the local school district to form interview questions if they were relevant to the research questions.

Types of data collection. Data came from videotaped interview responses mostly, but I also used pictures to assist in communication, related artifacts, and memos taken after interview sessions (J. Creswell, 2007; Glesne, 2005; King & Horrocks, 2010). Interview data was the prime source since it came directly from the participants' immediate thoughts, but it can be unreliable if it is difficult to decipher. Although observations have been a chief evaluation tool for individuals with significant disabilities (Cobigo et al., 2007), they are open to interpretation by the observer. I chose interviews as the chief evaluation method because I wanted to offer participants an active rather than a passive role to communicate needs or preferences. Memos assisted me in describing the context of the data collection, my impressions of their effort to answer, and future areas that needed more elaboration, but showed researcher bias. Archival documents demonstrated how students can record their own thoughts, but with the understanding that there might have been extensive assistance from others that could influence responses. No one source of data can stand alone without other information. Using all these data collection methods has strengthened the results and these methods were used to triangulate all information sources.

Communication aids. Picture cards and graphic worksheets I made available assisted those with limited language abilities, speech impairments, short term memory deficits, high

on-topic responses. Picture support was used both to assist participants in understanding interview questions and to respond with on-topic explanations. Some examples of picture supported responses can be seen in the appendices that follow this chapter.

Recording devices. Video recordings of an interview are more appropriate for students who need to use gestural communication. These videos showed body movements from head to legs (Katz et al., 2012) to fully capture non-verbal expressions. Even students who speak well in comparison needed to be video recorded to enable reading expressions or body language.

I purchased a small digital video camera with a tripod and microphone for use in this research. These videos were used to collect data to be transcribed for analysis. Data collection using video was consistent with the qualitative approach of this study. Through creating their own living stories of themselves, they became more self-aware to be able to know how to communicate the kinds of goals they would like to determine for themselves.

Interview protocol. The interview questions were created to support open-ended responses, using words such as who, what, where, when, why, and how (Chenail, 2011a). From these preliminary questions, follow-up questions were created to delve further into the participant's expressions of needs, preferences, goals, and their feelings about themselves. An interview protocol used with a pilot study was especially useful to researchers who were very close to their participants and wanted to advocate for them (Chenail, 2011a) while making efforts to be as objective as possible. The pilot study allowed me to ask interview questions in the same way as for the actual interviews, ask for feedback to clear up confusions or difficult questions, judge the time it takes to conduct an interview, assess the value of a question and the range of responses it can produce, establish that interpretations can be analyzed, and to re-word, revise,

and pilot again if necessary (Chenail, 2011a). During question development, features of Microsoft Word® were used to track changes and create an audit trail for the refinement process.

The interview protocol environment was designed after the National Institute of Child Health and Human Development (NICHD) interview protocol. Widespread evidence has shown that the NICHD protocol is the most effective technique to get complete, quality information from interviews with children (Hershkowitz, Fisher, Lamb, & Horowitz, 2007; Lamb, Orbach, Hershkowitz, Esplin, & Horowitz, 2007; Pipe, 2010) and the technique seems to be crosscultural. The NICHD protocol is still a work in progress and much depends on investigators being true to its principles and continuous review to self-assess its use. Still, recognizing that children are easily influenced and are often inaccurate in answering interview questions, the NICHD protocol increases the value of child interviews and it is the best protocol tool to date (Lamb et al., 2007). The NICHD also takes into consideration the ethical concerns of causing distress in children relating and remembering unpleasant memories. Even though the NICHD focused on interviews with children regarding sexual abuse, there is much to offer in their methodology of open-ended questioning for adult individuals with intellectual disabilities who are easily persuaded and how to get objective, truthful responses to sensitive questions asked of vulnerable individuals. I expected that additional communication difficulties would require an adaptation of any interview protocol to adapt to unique ability levels (Webster & Carter, 2010).

Research has shown that open-ended questions are a better assessment of verbal intelligence in children with disabilities because they can give responses freely as opposed to responding yes or no to specific questions (Dion & Cyr, 2008). Instead of identifying or recognizing answer options, the participants were allowed free expression of specific areas of needs, preferences, goals, and feelings. Yes or no questions can lead to inaccurate responses

when more precise information is not available. The offering of option posing questions provided some information from the interviewer as opposed to focusing on information from the interviewee and could have affected the veracity of the data. Action based cues worked particularly well with young children, for example, asking a child to tell about an event (Lamb et al., 2007). Recall of detail was enhanced by an open-ended format of interview questioning and more detail was revealed in the beginning of the interview rather than the end when it is more subject to outside influences (Dion & Cyr, 2008).

Type and level of questioning. Interview questions for individuals with disabilities was flexible and repeated until data saturation. Due to linguistic and language differences, some questions did not translate well into English, or students may not have developed the background language needed to understand the interview questions (Ojeda, Flores, Meza, & Morales, 2011). I allowed them to switch to Spanish if it helped them describe something better, even if they were equally proficient in both languages. If I did not understand it, I either negotiated the meaning with the participant or asked a co-worker to translate later. The types of questions asked were, at first, background/orientation questions, and then questions about experiences/behaviors, opinions/values, feelings, knowledge, and sensory questions (King & Horrocks, 2010). Additional methods were used to assist participants to describe experiences in more detail or to relate to a situation that they can identify with in their real life. I slowed my usually fast speech to a pace the participants can better keep up with. I kept the cognitive load at a low level by using vocabulary words that are easier to understand and using less complex sentence structure. I used my experience and training with English language learners and my knowledge of the Spanish language system to select words and phrases that were more readily understood by second language speakers. Students with disabilities should be allowed to use the medium easiest for them to express themselves (Gulati, Luce-Kapler, Medves, & Paterson, 2011). In addition, I avoided giving examples to prevent influencing their answers.

Specific questions. The exact questions were derived from The Arc's Self-Determination Scale (Wehmeyer & Kelchner, 1995) which can be found in Appendix E. The research questions were directly related to the four sections of the scale. Interview questions were open-ended versions of the survey and sentence completion type items of the assessment. Modeling the interview questions after this scale completely covered all the essential components of self-determination. Additional questions to each major area were added to probe for deeper, more detailed meaning.

Secondary forms of data. Simultaneously, secondary data collection techniques such as researcher observations were recorded using memos written immediately after interview sessions. Besides all interviews being recorded, personal thoughts, predictions, or biases were documented in memos to block out researcher partiality. This collection method ensured that no details were forgotten during the course of an interview session. Immediate recording of personal notes ensured that an accurate story was written. Subsequent notations were used throughout this study and it has always been a typical way to collect data for this cognitive level (Volpe, DiPerna, & Hintze, 2005) and for second language learners (Baker & Lee, 2011). Some thoughts were demonstrated nonverbally by the participants, which necessitated the use of video. Memos clarified and classified nonverbal gestures, as well as member checking, to be sure I received the correct message for documentation.

Archival data. There were two sources of archival data collection used as additional secondary data. The first type was shown in Appendices A and B and the other source of archival data was an additional extended survey based on the initial ones mentioned. The extended

surveys were collected from all teachers working with the three participants during the selected time period of this study. This data was collected only for the duration of this study and only for the study participants, even though all students produced the same artifacts as part of their coursework.

All physical data and routine class work produced by, for, and about the participants was collected during the specific time of this study. Scans of both surveys were entered into the NVivo 10 software for analysis. These documents took the form of worksheets with visual checklists, their writings, or statements dictated to the teacher. Rich data was collected from these other teachers in additional situations, allowing comparison to increase validity. At times, homework was examined to investigate the difference in expression that comes from their home environment. This type of communication from the students was important to this study because it came from the home environment and was sampled for their student portfolio. Portfolios can be used in IEP meetings to show present levels of functioning and will drive the writing of improved transition plans required to be created during high school.

Permission to use material was obtained from the school district adopted online learning program, Unique Learning System® and News2You®, with the request that they be informed of the results of this study. These adapted worksheets with illustrated, uncluttered pages and short term writing tasks were unsurpassed for use with participants with significant intellectual disabilities so they can participate in describing themselves. I have been teaching from this curriculum using worksheets such as these for about five years. The participants were accustomed to using the discussion stories and accompanying comprehension questions. These adult discussions helped the students form opinions, create ideas, and guide adult thinking toward how to plan for their future. The Unique Learning System® and News2You® online

curriculum was adopted by our district because it parallels our local curriculum emphasis on selfdetermination and adult transition needs.

Student work was assessed by categorizing all archival data. Just as the interview data was sorted by hand at first, the archival data was sorted at first by hand to get a feel for what the data was revealing. Next, the archival data was entered directly into the NVivo 10 software for analysis. The scanned archival documents were analyzed using the editing tool for selecting a region of the Adobe Portable Document File (PDF) to code. Archival data that answered the research questions regarding self-determination and transition were analyzed by coding and theme exploration and merged with the memo summaries and the interview data analysis.

Procedures

By applying specific interview questions that addressed the interest of this study, I was able to collect the data and analyze the themes within, between, and across the cases. After IRB approval, a pilot study was conducted to discover the optimal questions to elicit responses on the topic of self-determination of needs, preferences, goals, and feelings of the participants. After all interview data was collected, I transcribed the audio into Microsoft Word® files. Results were analyzed by hand and with software. Secondary data was also analyzed by software and compared to the interview analyses for each participant to check for validity. Member checking was performed to check reliability. Coding was conducted to develop themes and an outline was used to reduce the themes, presented in Appendix H. Once the themes were reduced, the final report was written.

The procedure of using a pilot study first was advantageous because it gave me a chance to try out new interview skills as an inexperienced researcher. Using an interview guide for use with children who are victims of child abuse, I was able to design a format that would assist me

in providing support to collect open-ended responses with less constraints put on them by the method of interrogation. Open-ended responses are best practices for collecting qualitative data.

The participants in the pilot study were also well known to me since they were all former students at the same school. They were chosen because they were a similar age, not so much chronologically, but developmentally. The research participants were aged 19-21 and the pilot participants were aged 28-35. They shared similar characteristics, but two had mild intellectual disabilities and two had moderate; however, all had a significant intellectual disability that affected communication skills. Two spoke English only, one spoke Spanish also, and one also spoke Vietnamese. One had Autism and epilepsy, two had Down syndrome, and one had a mild disability from undetermined causes with a mild hearing loss. They had no mobility issues and one was even able to use special transportation services independently to get to work. There were four participants instead of three: two males and two females, which was different from my study participants. They all still lived at home and only one had paid employment. They were selected for ease of access since they lived in my neighborhood and school was out for the summer at the time. I had to wait to obtain access to them however, until the IRB approved my study at the beginning of the school year. Meanwhile, I was able to get preliminary permission from the pilot participants as well as their parents, who had become personal friends of mine over the years. The same confidentiality and anonymity was given, even between pilot participants and their parents, who were not told what their adult child said. Questions were tested and recording equipment was checked. One interviewed with me at home, and the rest interviewed in the same room in which the study took place. The main difference was age, sex, and the fact that they had graduated several years ago and had already experienced adult transition. All were appropriate for selection as pilot participants.

Answers to research questions. A case study design was the most logical way to discover how an individual interprets his or her life. What needs, preferences, goals, and feelings

were expressed in students with significant intellectual disabilities? The questions created for the interview protocol were a preliminary exploration into what these individuals with significant intellectual disabilities were saying about their lives and how they want to live them. By their answers, I knew what topics needed to be more thoroughly investigated. Each participant had some interview questions that applied specifically to their lifestyle. Through one-to-one interviews and observations, among other data collection methods, this study explained what they wanted in their lives.

Sub-questions. What needs were expressed related to independence? Interview questions began with introductory questions about recent activities or thoughts and then progressed to situations that may happen in the future, as these may be more difficult to conceptualize. Since the concepts of self-determination are broad, more sub-questions under the main sub-questions were needed. What needs were expressed related to personal care? What needs were expressed related to family functions? What needs were expressed related to interaction with the environment? Participants needed to be oriented to or reminded of the concepts of now, in the past, and in the future. By asking about what they now need or do not need, the stage was set to introduce more complex questions about future needs.

What preferences were expressed based on beliefs, interests, and abilities? This subquestion was also broken down further. Specifically, what preferences were expressed related to recreation and leisure time? What preferences were expressed related to community involvement and interaction? What preferences were expressed related to post-school directions? What preferences were expressed related to personal expression? Again, participants were introduced to this topic by a discussion of present preferences and preferences they had as a child to guide them into future thinking. Participants needed support to think of themselves as adults since they were aware they are dependent on others both to have their needs met and to allow them access to their preferences.

What goals were expressed related to self-regulation? The answers to this sub-question filled a gap rarely addressed in self-determination. Furthermore, what goals were expressed related to interpersonal cognitive problem solving? The ability to solve personal problems within oneself is another component that is hardly ever dealt with directly. What goals were expressed related to goal setting and task performance? High goals were made more manageable by the ability to break a large task into smaller achievable steps.

What feelings were expressed related to psychological empowerment and self-realization? Having a positive attitude toward oneself leads to more positive outcomes in general. Additionally, what feelings were expressed about relationships with others? What feelings were expressed about self-awareness? Knowing yourself is another essential characteristic of self-determination.

It does no good to express needs, preferences, goals, and feelings if none of it transfers to the ability to live life as independently as possible. This study answered the question of what individuals with intellectual disabilities ask for and hope to do as an adult. The self-determination to guide one's life reflects itself in a better quality of life for individuals who will always need support from the society around them to be independent and feel fulfilled. By answering all these research questions, this case study added to the sparse qualitative literature that seeks to understand significant intellectual disability from the point of view of those who live with it and are approaching adulthood.

Steps to research. The following steps were performed in this study:

1. Begin after IRB approval

- 2. Explain study to participants and guardians
- 3. Explain assent and consent forms
- 4. Provide schedule of video recorded interviews
- 5. Conduct interviews of 3 case study participants
- 6. Collect documents (memos, observations, student made materials)
- 7. Transcribe interviews, verify with participants
- 8. Code transcript data
- 9. Analyze data within cases, between cases, and across cases; analyze with software
- 10. Build theme development from codes
- 11. Write final report

Steps involved in forming data. Since the interview itself is the main research instrument, it was developed based on former protocol models and depended on specific interview questions. The data was also dependent on which participants were selected and what they said during interviews. I proceeded to shape the data using the following steps:

- 1. Format interview protocol questions that answer the research questions.
- 2. Obtain consent or assent from pilot study participants and/or legal guardians.
- 3. Select representative sample of pilot study participants.
- 4. Conduct a pilot study to evaluate the questions for appropriateness to outcome goals.
- 5. Construct a revised interview protocol based on results of the pilot study.
- 6. Obtain consent or assent from participants and/or legal guardians.
- 7. Select representative sample of participants.
- 8. Conduct interviews.
- 9. Analysis results.

10. Write a final narrative report of findings.

Interview setup procedures. After school interviews were arranged in advance with the parents, providing for the student be picked up afterwards. I thought it was going to be complicated to get access to the participants, since parents usually had difficulty being able to leave their jobs to pick them up after school. Most of the students ride special buses to get home and live farther away than general education students. Some parents, however, picked up their children daily. In these three cases though, parents had few problems being able to pick their child up afterwards. Two were housewives and one was a teacher with a similar schedule to mine.

Because I used after school interviews, participants were compensated by giving them a \$25.00 gift card to be used to their discretion. This opportunity to choose what to spend the card on supported the concept of self-determination and the component of choice making. The gift cards were given out discretely after the closing of interview sessions.

First, the research began with the interview warm-ups. During the sessions, interview questions were refined and adapted to improve the depth of the responses. The initial interviews examined preliminary data and uncovered ways to support communication for individual student needs. Students were familiar with the interview process, since it is not often done individually with them and never for formal research.

Soon after the school year got fully underway, I made arrangements to gather video documentation. For participants who used gestural expressions, movement can be picked up on the monitor for later transcription. I used a small digital video camera with a stand for use in this research and it was dependable to collect data as needed. The camera was connected to the computer and read by the software analysis program NVivo 10.

The interviews were actually educational or therapeutic to the participants who felt that at last someone was asking their opinions and listening to them (Chenail, 2011a) and they were learning how to respond to an interview. It was a rare event for someone to interview them for anything, let alone for important research that could help them and others. They may never get this opportunity again to respond freely for qualitative research.

With the change to a new classroom last year, I was able to find a quiet place to interview. I set up comfortable chairs adjacent to one another where the participant felt relaxed enough to give full attention to the interview questions. Recording devices were setup ahead of time to make a smooth transition for the participant so that the details of record collection did not interfere with the spontaneity of the conversation.

Participant preparation for interviews. Before interviews begin, I used advance organizers by explaining that I was going to ask them questions about themselves and their dreams for the future, as has been discussed in class. The aim, I told them, was to record their opinions and not those of someone else. Participants were reminded before and throughout interviews or other forms of data collection that their participation was voluntary and that they can stop completely or stop for breaks when they wanted to do so. Due to the nature of individuals with significant disabilities, interviews needed to be conducted on a one-to-one basis in a quiet area, ensuring good effort and privacy. When responses began to weaken due to fatigue or distraction, I could usually tell from the participant's body language when they needed a mental break. Efforts were made to avoid sound interruptions during the audio recordings of participant interviews, as this not only distracted the participant, but also made the transcriptions more difficult to record. To obtain rich data (Glesne, 2005), an hour was set aside for each interview and participants were interviewed until response saturation was achieved. Participants

never expressed that an hour was too long and rarely took breaks that were offered. A possible reason for that may be that our classes were on a two-hour block schedule and one hour may have seemed short to them.

Phases of interview development. NICHD protocol supports the use of a pre-substantive phase where the researcher introduces the topic and describes the child's role in the interview (Dion & Cyr, 2008; Hershkowitz, Lanes, & Lamb, 2007). During the pre-substantive session, a supportive environment was established, which is an important foundation for individuals with intellectual disabilities. Questions were adapted to the participant's developmental level and ability. Communication roles were conveyed and participants were trained to provide full information on topics. Since these participants are rarely interviewed for any purpose, this was an essential step for them to learn expectations. A neutral event was queried first as an introduction and warm-up and participants were reminded that it is okay to say "I don't know" or "I don't understand" or to correct the interviewer. By the end of this phase, the participant had practiced providing more detail in response to probing questions to prepare themselves for the actual interview questions.

The order of questioning protocol was an open prompt, more focused prompts, a free recall phase, follow-up, and more open-ended prompts. The interview began with an open invitation to provide information, for example, the request to tell me about what the participant needs every day. Next, I gave a cued invitation, for example, referring to something the participant already said and asking for more information. By using something the participant had already said, the question probes built upon what the interviewee had actually said and lessened the effect of suggestive and leading questioning (Hershkowitz, Fisher, et al., 2007). Then, a directive question was asked regarding a prior statement and asking for more specific detail, for

example, times, days, or occasions. At this point, options were given to select answers from, but only after open-ended questioning did not produce the needed details to answer the research questions. These more focused prompts were used at the end, if target information was not forthcoming, since there was an increased risk for faulty information when posing options or suggestive questioning (Lamb et al., 2007; Rabionet, 2011). During free recall, interview data was confirmed with the participant. Each interview ended in open-ended questions with an invitation to add anything else not mentioned before.

Interview protocol designed for disabilities. There was very scant research on an interview protocol specifically designed for individuals with intellectual disabilities, but some were discovered with appropriate characteristics. One study alluded to the finding that children with disabilities are not completely assisted by the current protocol used to interview young people, (Olafson, 2012). Furthermore, this study supported the idea that the standard single interview sessions commonly used are inadequate (Olafson, 2012). Olafson (2012) instead calls for the use of flexibility to reach every child that is interviewed. Webster and Carter (2010) in their interview study that specifically targeted individuals with significant disabilities pointed out the increased value of a short form adaptation of the interview process. It must be noted, however, that even though the Webster and Carter (2010) study included students with communication impairments, they excluded students with physical or other health impairments, which this study did not do. Another older, but major study on interviews with children who were possible victims of sexual abuse was very appropriate (Orbach et al., 2000). Using the approach that both children and individuals with intellectual disabilities, as a group, are vulnerable, socially immature, and easily led, the similarities were valid and the NICHD protocol was appropriate when modified.

Interview protocol designed for children. From the seminal research on the NICHD Investigative Interview Protocol (Orbach et al., 2000), the interview for a child should be conducted in at least two phases. Consequently, the first essential phase occurred before the target interview questions were asked, as a way of guiding the inexperienced person to what is expected and what will happen in an interview situation. The second phase was the actual openended questions that answered the research questions.

During the pre-questioning phase, a topic unrelated and neutral to the study was queried. Three alternate topics were addressed: (a) their birthday, (b) what they did yesterday, and (c) what happened in class or at home today. The first phase prepared the participant for what to expect and the extent of detail being explored. Participants were reminded that what they think is unique and only they can tell their stories, thereby projecting a sense of empowerment to the interviewees (Orbach et al., 2000). In addition, participants were told that only personal experiences should be reported as clearly and truthfully as possible. Reminders were given that they should admit they do not know or do not understand, and that it is okay to say my interpretation of what they said was incorrect and that those responses were welcomed if needed. I was aware that participant's responses were shaped by the adults in their lives and I took care to minimize this effect.

Narrowing down of questioning. At the questioning phase, the participants were asked about the topics under investigation in four sub-parts beginning with overarching questions concerning needs, preferences, goals, and feelings and getting more specific as the last of each section was reached. Participants were asked to explain about additional aspects of self-determination including their needs, wants, preferences, interests, strengths, abilities, plans, goals, and feelings about themselves in as much detail as possible. This was followed by a

confirmation phase where participants were asked to listen to a repeat of what they just said and to indicate if it was correct or not. Some direct yes or no questioning was needed at this phase, but then it ended with open-ended questions again.

Interview sessions ended with a debriefing phase where participants responded to questions asking for any other new information. This was also a chance for the participants to ask me a question and for me to thank them for helping with this study. I told them that they can go back to their parent now and asked what they were planning to do when they left. These steps were patterned after the NICHD interview protocol with slight adjustments to the purpose of this research (Orbach et al., 2000) and can be summarized as such:

- 1. Pre-interview warm-up
- 2. Interview
 - a. Broad overarching questions
 - b. Narrowing of topic
 - c. Specific topic
- 3. Confirmation or Direct Questioning for missing details
- 4. Debriefing

Memos. I used memos to record any potentially biased thoughts after the interviews that might have weighed in on future topic selection and analyses. I jotted down condensed memos as I interviewed (Suzuki, Ahluwalia, Arora, & Mattis, 2007) and expanded on them later. These notes served as an audit trail and showed my growth in a chronological order as I attempted to discover the themes. I realized the consequence of recognizing data that was expected and then ignoring what was not expected or giving it less importance based on my values, beliefs, or what is customary. This reflexive journal assisted in recognizing pre-conceived thoughts, feelings, and

perspectives (Chan, Fung, & Chien, 2013) derived from experience in working with students with significant disabilities and the attempt to "know what they mean" by certain ways of communicating. In my role as interviewer, I was the one to guide the situation, topic, and direction of the interview (Suzuki et al., 2007) By keeping a record of my thoughts during this qualitative process, I was able to check for errors in judgment and kept an open curiosity about the topics (Chan et al., 2013).

Potential interview questions for the study were tested on colleagues to discover ambiguous inquiries or difficult requests. Colleagues outside of this research were more objective and did not have such strong feelings toward the success of this study. Double checking with colleagues regarding the value of the questions along with the data from the pilot study strengthened the results. This recursive process (Chenail, 2012a) can assist researchers in bracketing themselves (J. Creswell, 2007) to control preconceptions and in demonstrating that the expectation of the unexpected is always a possibility (Chenail, 2011a). Bracketing is the practice of putting aside one's own beliefs and using an open mind to discover what a participant brings to the interview without prejuding from what one already knows about the topic (Chan et al., 2013). After IRB approval and the pilot study was completed and analyzed, the study moved into the actual collection of data for this research. The data continued to be collected until no new questions or no new characteristics of the themes were being developed (Guest et al., 2006).

Interview aids. One of the main issues for independence all along has been social support for individuals with disabilities and understandably that support was extended to the interview environment. The problem was to discover how much support and what type was best for full, detailed, true-life interview data. Any additional support techniques had to be employed only after attempting free responses from open-ended questioning to guard against information

contamination (Hershkowitz, Fisher, et al., 2007; Lamb et al., 2007). Some participants needed cognitive or visual support to participate in a full interview session (Webster & Carter, 2010). Often individuals with severe intellectual disabilities relied more on visual recognition than verbal recognition and were aided by picture images as a memory aid (Johansson & Terenius, 2002).. Never having been interviewed before, and much less for research purposes, these participants especially needed an environment that supported communication (Orbach et al., 2000) for individuals with significant disabilities. There was a delicate balance between supporting communication and interpreting what they were saying. Adults commonly ask young children or individuals who cannot speak to answer yes or no and otherwise leading questions in an attempt to understand their communicative efforts. The use of interview aids provided more options in guided questioning when more support was needed after initial questioning.

Studies have shown mixed results regarding the use of dolls, pictures, or media while interviewing children and adults with disabilities (Olafson, 2012). The question involves the effect of directed leading questions that may limit free disclosure and additional details (Olafson, 2012). Indications are that individuals with disabilities need more interviewer support in the way of graphic elements, more interview sessions, shorter sessions, simpler question formats, and a slower pace. Consequently, this study made use of graphic worksheets commonly used in the classroom to aid in discussion regarding self-determination, but only after open-ended questioning had finished.

I knew that children and individuals with disabilities will have difficulty eliciting complete accounts of their stories, so focused questions with visual support were used when needed at the end of interviews. I tried re-interviewing after thinking about questions during the week and gathering their thoughts to clarify contextual responses, but I did not get any new

information. At any rate, picture and object support, physical context restatements, and mental context restatements aided memory and recall in children and individuals with disabilities in an interview setting (Orbach et al., 2000).

Extended interview sessions. Due to the nature of participant abilities, it was difficult to tell how many interviews will be needed to saturate the data. Studies showed, however, that just one interview will not suffice in the case of children, (Faller & Nelson-Gardell, 2010; Olafson, 2012), and especially if they have disabilities. A single interview gives a participant only one chance to express themselves. If the situation was not optimal for the participant on that particular day and time, the data will also not be optimal. Since the study by Faller and Nelson-Gardell (2010) found that 8 interviews were optimal, with most (95%) of the new information revealed by the 6th session, it seems reasonable to conclude that about 10 interviews were needed for this study intended for individuals with significant disabilities. While it was understood that repeated interview sessions may produce data that is influenced by suggestive questioning, multiple non-suggestive questioning did not contaminate the data (Faller & Nelson-Gardell, 2010; Olafson, 2012). Furthermore, research demonstrated that interviews conducted close together, as in once a week, were more accurate and provided more detail (Faller & Nelson-Gardell, 2010; Olafson, 2012). In addition, a few questions were repeated to establish some level of reliability (Webster & Carter, 2010). More research needs to be conducted to more accurately determine the number of interviews needed and developmental guidelines depending on age and disability levels of children (Olafson, 2012).

Consent and legal issues. Consent was an important issue in conducting research with individuals with significant intellectual disabilities. Participants for this study were aged 18 or older, meaning there were issues regarding the transfer of rights for a person with significant

disabilities. It cannot be assumed that because one is a parent of a child with disabilities, that guardianship is automatic. Explained in common terms, Nangle (2010) posted on an informational website for parents:

Many people assume that because their child has a disability they are automatically the child's legal Guardian. However, every person over the age of eighteen is presumed to have the legal rights of an adult no matter what their abilities. In Florida, a person that is 18 years old or older is considered to be competent and have all their legal rights, until a court determines otherwise. Even if the person has very limited abilities and has a history of making poor choices, they are still legally able to make all decisions for themselves. Only a court can take away a person's right, (para. 2, 3)

Before seeking consent from a participant's parent(s), it had to be determined if they had legal guardianship or had become their child's guardian advocate. Very few parents of students at this research site had obtained guardianship or submitted evidence of guardianship status (S. Alvarez, personal conversation, January 10, 2013). Some participants were officially permitted to sign a legal document for themselves. Even so, without parental support, this consent alone did not guarantee legal access to the participant and was not correct ethically. The exact information regarding consent for each participant occurred before the study began, but the parent had to agree to make their child available, regardless of legal guardianship status.

Guardianship process. In Florida, the process of guardianship begins with the filing of a petition to appoint a guardian advocate with both the individual and the parents having required notice (Alley, Gilden, McIntosh, & McLain, 2007). Next, a hearing will be set to consider the petition and determine the individual's condition. If the court determines that a guardian

advocate is necessary, a written order with relevant facts, findings, and conclusions of the law upon which the decision was based will be entered (Alley et al., 2007).

Letters of guardianship are to be placed in the student's cumulative folder if transfer of rights has occurred. This document:

shall be issued to the guardian and shall specify whether the guardianship pertains to the person, or the property, or both, of the ward. The letters must state whether the guardianship is plenary or limited, and, if limited, the letters must state the powers and duties of the guardian. If the guardianship is limited, the letters shall state whether or not and to what extent the guardian is authorized to act on behalf of the ward with regard to any advance directive previously executed by the ward, (Florida Statutes, 2012a).

If a participant had a legal guardian, letters of guardianship would have been examined for information on the level of guardianship and whether it was plenary or limited as described above. The local review board would have been consulted regardless to determine by whose authority is consent to participate in research given for each participant in this study. Even if a participant has become a ward with a legal guardian, Florida statutes state that the guardian cannot:

- (4) Without first obtaining specific authority from the court, as described in s. <u>744.3725</u>, a guardian may not: ...
- (b) Consent on behalf of the ward to the performance on the ward of any experimental biomedical or behavioral procedure or to the participation by the ward in any biomedical or behavioral experiment. The court may permit such performance or participation only if:

- 1. It is of direct benefit to, and is intended to preserve the life of or prevent serious impairment to the mental or physical health of the ward; or
- It is intended to assist the ward to develop or regain his or her abilities...,
 (Florida Statutes, 2012b).

It was possible that I might not have been able to obtain consent permission from the guardian and may have had to ask the court, even if the transfer of rights to the parent had already taken place. Being that this study was not a biomedical or behavioral experiment, this ruling did not apply. This study was intended to assist the participant to develop independent abilities and was exempted. Whatever way legal consent was established, the person signing for it had to be informed of possible negative effects of the study as well as benefits.

Consent scenario. Regarding guardianship and consent, authority defers to the person in charge of the participant's health care. Since parents of students with intellectual disabilities turning 18 were asked by the U.S. Social Security Administration to update their information in order to continue receiving Supplemental Security Income (SSI), it supported the notion that the parents had the authority to give consent for these possible participants. According to SSI guidelines, as long as a student is 22 years of age or younger and still attending school on a regular basis, they are still considered to be a child under their benefits (Anonymous, 2013) even though the information update is still required. Guardianship for these adults with disabilities as it applies to consent for research was said to revert to the parent caretaker, as per personal conversation with the lawyer for the local school district (T. Chebbi, personal conversation, May 10, 2013). However, in consulting with the university lawyers with authority for the study, without legal guardianship, participants can sign consent for themselves. Consequently, participants over 18 were asked for consent if they did not have established guardianship and

parents were asked for legal consent for those with legal guardianship. Participants over 18 with guardianship were asked to sign for assent.

From the group of parents who returned surveys to accept the invitation, students were selected who meet the criteria of moderate to severe intellectual disability. Once identified, the following steps took place:

- 1. Introduce and read consent or assent guide to participant before the parent meeting
- 2. Ask the participant for consent or assent to participate in research
- 3. Setup conference with the parent to schedule a face-to-face meeting including participant
- 4. Meet with parent and participant to discuss details of the study (confidentiality, ethical concerns, consent, capacity to consent (Dye, Hare, & Hendy, 2007), possible benefits/detriments) and get permission to access participant cumulative folder.
 - 5. Share contact information should the parent or participant have questions
 - 6. Observe simultaneous signatures of the consent and assent documents
- 7. Witness parent signature of agreement to provide participant with a ride home After all documents were signed, they were sent to the IRB for final approval.

During the consent scenario, participants were read a description of what the research would entail. Understanding was evaluated by having participants retell key parts of the appropriate consent or assent agreement or signal agreement after several reviews of key issues of privacy and voluntariness. Parents were included as their involvement is also necessary, being the likely driver after interview sessions for any one of the participants. Participants and parents were given a schedule of interview sessions held after school and lasted for an hour each session. Participants were aware they will be video recorded and audio recorded for accuracy. They were

made aware that they were able to say whatever they wanted about family disagreements, what made them angry, or personal problems without worry of their parents finding out, unless they told me to tell their parents, or in case they were a threat to themselves or others. They were assured that I would not reveal these confidential statements to others. Their names were hidden and they were given a pseudonym. Parents were reminded that I cannot divulge the content of their child's interview session nor reveal to them other participants, of whom they know. I only used my home computer to input data and it was password protected. Again, after consent documents were signed, they were submitted to the IRB for approval.

Informed consent. A guide to giving consent was available that was written at the level of understanding from a parent's point of view rather than an education professional's view. Institutional jargon was not used. This guide was reviewed with the parent whether they were the legal guardian or not since they had a need to know and I needed their assistance in this study. I had no way to know beforehand which parents had legal guardianship. Even if there was no guardianship, the participant was still dependent on others for care and transportation.

An informed consent guide geared to the parents of potential participants was as follows: Your child has been invited to participate in this research study that will explore how individuals with intellectual disabilities describe needs, preferences, feelings, and goals for their future. Your child will not be punished or suffer in any way if you refuse their participation or do not agree with its benefits. I will not use your child's name and will assign him or her to a number. I will take every precaution possible to ensure your child's anonymity, but it is still possible people who know him or her well will recognize your child by what they say. Your child may say something you do not agree with or be embarrassed by. There may be parts of the interview that will make them sad or embarrassed about their disability. Those are the risks that may surface

during this study. The research will benefit your child because they will learn more about themselves and how to ask for what they want and need, but others may find out they took part in the study or they may say something personal. I will need to take videos of your child to verify the data and only I will review them. The video will be destroyed at the end of the study.

Consent can be withdrawn at any time up until the end when I begin to write the study results. A copy of the study will be given to you at completion and it may one day be published in a research journal. You can contact me at any time if you have questions.

During analysis, however, I found it easier to assign each participant another name rather than a number. This was not specified, but was inconsequential to the study. Psuedonyms made the reading easier and were also used for everyone else participants mentioned during interviews.

Informed assent. In one case the participant needed to sign an assent form. The same aspects of informed consent were addressed to that participant and the participant was informed before the parent. Selected students were asked individually in a private work room if they would like to participate in this research. A participant guide to informed consent/assent with pictures was read out loud, completely covering the information needed to make a wise decision in their best interest. Since the participant was the main actor of the research and their competence came into question, it was most important for them to be clearly informed, to the greatest extent possible, of the risks and benefits of participation. A simplified explanation of what they can expect to occur was given along with time to ask questions, clarify information, or verify understanding. Informing participants of their rights regarding consent was expected to take about 15 to 20 minutes and it was actually less. Afterwards, parents joined the conversation and I went over the consent/assent guide with the participant present to respect their right to know what was going to happen.

An informed assent guide geared to the cognitive level of potential participants was as follows: You were invited to take part in a study about the way people with disabilities talk about their lives. You will be asked about your needs, preferences, feelings, and goals. You will be asked to talk about things you need to have, preferences you make, your plans for the future, and how you feel about yourself. We will talk about 10 times for about an hour each time and it will be after school. If you get tired, you can let me know. We can interview later. Sometimes I will get tired or I will have to stop early and I will let you know too. I will video record you, but everything you say is only between me and you. I will not tell anyone else, including your parents, what you say unless you tell me to or unless you talk about hurting someone. No one will know who you are because I will give you a number instead of a name. Even other people in this study will not know you are in the study too. You do not have to do these interviews and you can stop for a break or stop completely if you do not want to do it. I will not force you to talk with me and you can say "not now, later" also. I have to ask your parent's consent too, but even if they say yes, you can always say no. This study will help teachers and other students with disabilities prepare for living as an independent adult. I hope it will help you too, but there is some risk that people will read this report and figure out who you are, even if I call you by a number. I hope this study will make you learn more about yourself so you can tell others what you need in the future. It is okay if you do not agree with me or your parents because your ideas help the study and I want your opinions. At the end of the interviews, we will talk about everything that happened and you can say more if you want. We will discuss if you want me to tell other people important parts of what you said that made you feel emotional. I may need to go back and ask you what you said in certain parts and that might be frustrating. I might ask you something sad or embarrassing about your disability. But, I am not going to force you to do

anything. When I finish, I will give you a copy of this study and read to you the parts that talk about you. It might be published in a study or college magazine one day, but no one will know it is you. I will repeat this many times during this study so you will not forget all this important information. You can ask me any question at any time.

Consent

Twelve students with severe to moderate intellectual disabilities were invited into the study by a colleague. Of those, only four responded to demonstrate an interest in the study. Parents had to be queried first to determine if they had obtained court-ordered guardianship if their child was over 18 years of age. Two participants did not have parental guardianship and consented independently. One adult participant had full guardianship and her parent gave consent while she gave assent. The fourth possible participant was under age 18 and consequently her parent signed for consent. However, after hearing the above informed assent guide, she did not give assent because she did not want anyone to see her in the interview videos and I respected that. She was dropped from the study. The resulting sample consisted of three females who represented lower, middle, and higher intellectual levels within the severe to moderate range of functioning. After a pilot study from September 1, 2014 to October 17, 2014, video recorded interviews of the participants were conducted from November 1, 2014 to December 17, 2014.

Signatures. The parent signed the consent form where legal guardianship was established and the participant signed the assent form. Both observed each other sign, simultaneously. These participants needed more time with their signatures, but there were two witnesses, the parent and myself, that made consent more legitimate for an audit trail. It was made clear that consent can be withdrawn, but not after all data was collected and I moved on to the report stage. If a

participant was to withdraw, the participant and parent were told the data collected up to this point will be used.

Participants who had the right to sign for themselves did so, but the parents also participated in the above process after consent was obtained confidentially by the participant. These two participants also were made to understand that consent can be withdrawn, but not after all data was collected and I moved on to the report stage. If a participant was to withdraw, the participant was that told the data collected up to this point will be used. Parents were similarly informed in case participants needed reminders in the future. Also, participants and their families understood that I must (and can decide if or when to) reveal content that could cause serious harm to self or others.

Consent reminders. I reminded the participants of their option to stop or delay interviews as per the assent agreement. As a special education professional, I must "...be particularly attentive to fragmentation, contradictions, or inaccuracies in the person's statements..." (Carlsson et al., 2007, p. 1365) as a sign of fatigue in participants. Even if they were not aware of their own fatigue, I suggested some time off to rest from interviewing.

All interviews were recorded for transcription and accuracy. To confirm data, other coteachers who worked with these students reviewed parts of the interview transcripts independently from me to provide an expert review. The data collection method was also important to my coworkers for their use in planning lessons and the writing of valid transition goals for students they teach.

The use of pictures helped confirm what students are trying to express. Knowing the students well and what they liked to talk about assisted me in deciphering the messages. Parents, who know them best, were always available by phone for interpretation when needed. Students

were interviewed multiple times to provide practice in answering questions about themselves and to discover if the data was consistent over time. Multiple interviews also allowed participants to think over what they wanted to say the next time. Once the answers were fully developed and no new knowledge was gained from the interviews, they ceased. By this time, I had all necessary information to communicate clearly what each participant wanted to say about her transition plan to adulthood, and the end point in time for the case study was reached.

Text transcriptions. Due to the difficulty of understanding the expressions of individuals with significant disabilities who also had communication impairments, it did not serve the purpose of this study to hire a transcriber. Participants who cannot speak especially intelligibly needed a transcriber that understood their unique mode of verbal and gestural communication witnessed in the videos. The time spent attempting to interpret their meanings would frustrate most transcribers who are not accustomed to communicating with individuals who cannot fully communicate their desires. To that end, I transcribed the data myself and asked colleagues for clarification of material that was difficult to figure out. I transcribed all nuances of the participant's speech patterns: pauses, emotional overtones, intonation, and body language (Suzuki et al., 2007). It was more accurate to ask participants themselves (J. Creswell, 2007; Glesne, 2005; King & Horrocks, 2010) what they were trying to express in the videos rather than succumb to an outside transcriber unfamiliar with their communication modes.

Collection of Data

The data collection consisted of transcripts of video recorded interviews and archival documents. Some archival documents were included in the original proposal and some were included later when they were developed in the Unique Learning System® learning program used for this study. The original documents were collected right after the end of each interview

session as part of the session. Some assistance was needed to transcribe their answers, which is common practice for this population of students. Special education teachers are considered trustworthy to collect data by transcribing answers and they are expected to do so for standardized testing using alternate exams. The later documents were collected by another colleague in a different environment in an attempt to capture their thoughts in a separate situation.

Data Analysis

The analysis of the data collected in this case study was a description of the case and theme revealed from transcribed text (J. Creswell et al., 2007). Themes can be defined as "...recurrent and distinctive features of participant's accounts, characterizing particular perceptions and/or experiences, which the researcher sees as relevant to the research question" (King & Horrocks, 2010, p. 150). The coding system used some elements of open coding, predetermined codes, and emergent coding. Each case was analyzed across themes and across cases. The focus was on issues within the case to assist with understanding the research problem. There was a grouping of contextual situations across more than one case. Using multiple sources of data besides the interview, the research included data organization to produce a description of the cases and case-based themes (J. Creswell et al., 2007).

Theme exploration and coding procedures. An embedded analysis (J. Creswell, 2007) was performed to look at the specific aspects of self-determination within this case. A compilation of all data from the multiple sources discussed was first coded into themes by hand to understand where the study was leading and to categorize what theme topics were emerging. Data was examined first line by line (Chenail, 2012b) and segment by segment to employ constant comparison (Schaeffer, Leventhal, & Asnes, 2011) to themes previously identified and

to explore the need to identify a new theme (Chenail & Duffy, 2011). In addition, data was scanned for units of undivided, whole meaning (Chenail, 2012b). Furthermore, I lent credibility to my coding system by double coding, or coding the same material again at a later time in the study (Baxter & Jack, 2008).

As a new researcher, I used both low-tech and high-tech means to analyze my data so as to be recursive and self-reflective to achieve a complete investigation. Low-tech coding by hand allowed me to get a better feel for each person as a whole (Auld et al., 2007) before I attempted to use any software like NVivo 10 that I was not familiar with. I assembled the data representations on paper to perceive the whole picture. Next, using the features of Microsoft Word®, I analyzed the content into meaningful units, highlighting starter codes (Chenail, 2012a). I listened to the transcripts again to discover themes not noticed using other methods. The participant's data was coded individually developing the context and description of the case. Next, codes were developed for themes in a within-case analysis. Codes for themes that are similar or different were used for a cross-case analysis. Finally, codes for assertions and generalizations were analyzed across all cases (J. Creswell, 2007).

As an experienced special educator, I took extra care to bracket myself from preconceived notions as I decided which themes were emerging and important for describing the essence of what was communicated. As the instrument of analysis, I had to be certain that I did not dismiss issues or topics that I did not expect to come up or that I did not deem significant in my experiences (Chan et al., 2013). What may not seem important to me may be very important to a particular participant and this outlying view could not be discarded.

The use of memos to take note of researcher bias enabled the reflexivity necessary to keep researcher influence out of data analysis (Chan et al., 2013). Having an open acceptance to

all interpretations was crucial to having an accurate analysis of the data collected. In addition, an on-going literature review until the final report stage demonstrated the intention to stay neutral until the results were discussed (Chenail, Cooper, & Desir, 2010).

Qualitative description. After obtaining a global sense of the meaning of the themes the data was revealing, the software program NVivo 10 was utilized to analyze the interview transcripts, archival documents, and other student work products. From this, both hand-sorted themes and computer sorted themes were compared and synthesized, allowing the text materials to be fully analyzed as objectively as possible. The software program served to validate the findings discovered by manual categorization of the topics discovered (Glesne, 2005). Details defined as words or phrases that described needs, preferences, goals, and feelings were further defined by reference to the present or the future. Interviewer question type were coded along with text from the participants in the analysis of the results. The purpose of the qualitative analysis was not to repeat, paraphrase, or count the number of like responses, but to analyze as a whole, the meaning of each unit of thought within the spoken context (Chenail, 2012a).

Data analysis software. Effective use of data analysis software was a learning experience. I took online classes on how to use the software before I purchased it and afterwards. I previewed NVivo 10 and used that program since my university recommended it. I was extremely proficient in computer use and did not foresee problems in learning how to apply any software; however, I respected the intricacies of NVivo 10. I understood that any software analysis program is only as good as the data entered and the themes that were selected for coding. As it turned out, NVivo 10 challenged all my computer proficiencies.

Findings and interpretations. The intended outcome of this strategy was to bring out expression from individuals with significant intellectual disabilities, who often had a difficult

on their unique capabilities and difficulties. The more severe the disability the more variably and individually it is experienced. Similarities and differences between and across the cases illuminated the issues they encountered when they attempted to use self-determination to explain needs, preferences, feelings, and goals for their transition to their adult life. Suggestions were developed as to the best ways society can support their efforts to be independent adults. The findings and interpretations of this study will help others with significant intellectual disabilities use self-determination to improve their quality of life.

Protection of vulnerability. To make sure the communication of non-participation was clear at any time during the study, I watched for expressions and body language that showed what they wanted. Vocal inflections, facial expressions, and eye contact was also noted, especially if as to show fatigue or disagreement. Body movements were coded in the analysis phase to cross reference with other forms of expression (Katz et al., 2012). Participants were offered a break or asked if they wanted to stop the interview if they showed the slightest sign of discomfort or other personal need. I understood that their willingness to please me could cause them to delay or ignore their own needs.

Negative responses. If the participant had communicated the desire to discontinue three times during the interviews, we would have revisited informed consent and considered the participant for dismissal from the study. If the participant demonstrated a negative desire to leave an activity to participate in an interview, that wish would have been respected. The indication of "later, not now" would be taken as a request for postponement and they would have remained in the study as long as they came back within a week. If the participant was reluctant to enter the interview room 3 times, again we would have revisited consent and considered the participant for

dismissal from the study. To ensure the participant would not change their mind later and ask to re-join the study, a form would have been drawn up with their signature declining participation in the study and it would have been explained to them what that meant. Once they signed out of the study, someone else would replace them and they could not come back. However, this situation did not arise and all participants stayed until the end.

All of these sources of data were analyzed with computer software to validate manual data coding and to provide a clear audit trail (Glesne, 2005). This study collected a tremendous amount of rich information about these students who may not have had a chance to voice their opinions with such attention before this research. The data collected flowed smoothly between digital sources, like my personal computer, USB devices, the digital camera, and the data analysis software NVivo 10, making the analysis faster and more accurate. All digital sources of data were also compared to the initial hands-on analysis to explore how much agreement was found among all the information collected.

Ethical Considerations

Even if I have been given consent by a participant's parents, it in no way implied that the person must comply with interview requests at any time. If a participant decided to quit participation in the study altogether or a student decided she needed a break from questioning, the person would be free to exercise that choice. In addition, identities were concealed by using false names for confidentiality. This strategy was important because these families know each other well. If this study is published, de-identification of participants is crucial. Anonymity was achieved by removing identifying information.

Data storage. All data was entered and saved electronically using Microsoft Word® and backed up in at least three locations. Data was backed up on jump drives, an external hard drive,

and on my personal computer. NVivo 10 also served as a storage device for data. A separate file indicating ownership of data collected was stored securely in a separate place (my home) in case the information was needed to be traced back to the source as in an audit. At the research site I guarded video data by never leaving the camera unattended during or before and after interviews. Video and written data was secured during the study in a locked cabinet along with my purse. The devices used to record the data were also stored in the same locked location. When I needed access to the data, I returned to the locked location alone, placed the material in my car immediately, and brought it home to be examined. I live alone so there were no observers while I analyzed data. The next time I collected data, I retrieved the materials from the car alone, and placed it again in the secured storage area at the work site. No one else ever had access to these materials.

Data destruction. Data collected by videotaped interview will be destroyed 36 months after the completion of this study. These will be in the form of digital files that I will delete completely from all devices. All paper documents submitted as part of this data collection will be shredded. Paper data includes student archival worksheets and other data completed in class or during interviews, memos, or observations that became a part of this study. Video recordings or any other digital material produced by the participant solely for this study will also be completely deleted. The only data remaining will be the data that will be presented in the study results. Data destruction after research completion is a requirement for an employee of the local school system when "...such studies are conducted in such a manner as will not permit the personal identification of students and their parents by persons other than representatives of such organizations and if such information will be destroyed when no longer needed for the purpose

of conducting such studies" (Lowe Tribble & Associates, 2003, p. 133). At the writing of this report, I still have all collected data, but it will be destroyed as detailed above at the proper time.

Trustworthiness

All informational data gleaned from this study was reviewed by each participant for reflexivity and credibility during interviews and also during member checking. This practice is common in this field because we are constantly asking for students to repeat something we did not understand. I repeated and reworded their statements to obtain the true meaning of the communication. Many times it took several guesses and at times frantic gesturing until finally I had to allow them to show me want they wanted, but I did not stop until I found out what the message was. Usually the student was patient enough to wait for me to figure it out.

Responses were repeated back to the participants to verify the accuracy of the interaction. Participants agreed or refined responses to give a clear answer. Pictures, worksheets, or gestures were used during this study to aid communication. Other teachers and family members were called on to decipher difficult passages during the writing of interview transcriptions or to confirm what was found, without advance information of the subject matter of my writings. All these techniques for collecting interview data strengthened trustworthiness.

To confirm data, other co-teachers who work with these students reviewed parts of the transcriptions independently from me to provide an expert review. The data collection method was also important to my coworkers for their use in planning lessons and the writing of transition goals for students they teach. Sometimes they did not understand the Spanish used either and I had to use my own interpretations along with theirs.

Member checking. One technique for verifying data in a qualitative study was member checking. Each participant was given a chance to hear their responses again to confirm that was

what they meant to say. I also asked participants to verify that my interpretations of what they said was correctly recorded. I was able to understand their communicative efforts well enough to represent their thoughts as accurately as possible given language and communication impairments. Participants were reminded of what they said in previous sessions and that they could change or clarify what they have said earlier, after they have had time to think about it. This technique added credibility to my study (Missiuna, Moll, King, Stewart, & Macdonald, 2008) and has been used in other studies with participants who have disabilities (Palisano et al., 2009). The recursive nature of the interview protocol was evidenced by repeated references to what was said previously and by offering opportunities to change their story during each interview session. Member checking confirmed themes that were discovered to be representative of other participants during the inquiry process.

Triangulation. The data collected from all sources was used to triangulate the findings. Data sources from the interview sessions, member checking, memos, and archival materials was explored to discover themes that ran through all resource materials. Themes were organized according to the most common to the least common topic in order to corroborate the evidence.

Potential Researcher Bias

Another important way I demonstrated trustworthiness was by being aware of my own personal feelings toward my students. Over the years I have become personally involved with my students and they with me, as is what happens in close professionally caring relationships (Folkestad, Folkestad, & Taylor, 2008). I was very interested in seeing them be successful communicators, and I might have read more into their expressions than was really there. I asked my peers to review the findings to see if they agreed that it interpreted the data accurately. I described the situational context clearly for increased understanding of the background that

framed the interview, observation, or case. I looked for negative case examples in my work setting by having discussions with other faculty who hold differing opinions from mine (Glesne, 2005) and by noting responses that did not fit with other codes and themes. I respected any request for keeping a conversation confidential and off the record, especially if it was sensitive personal information unknown to their parents. This confidentiality was especially important when the topic was the cognitive ability of these students, and I needed to check for personal bias. I felt like each student could communicate needs, preferences, feelings, and goals at some level. Advocacy was the personal filter through which I interpreted the results and opposing views were expressed and included in the analysis.

I defended against the influence of early or late interview data collection and did not grant it more importance than other data collected (Suzuki et al., 2007). I used member checking and peer checking to confirm my analysis. I assigned numbers to quantify the weight of interview data and to review my perceptions until a clear and true picture was produced to the best of my ability. Language can never truly replicate the complexity of the human experience. No scientific measures are without error and qualitative measures are no different.

As my own instrument of measurement, I understood that my choice of interview questions was what framed this investigation. I made every attempt to be as complete and thorough as possible to capture the essence of each participant's life story. I tried to explore both positive and negative aspects of each individual's lives and perceptions. While qualitative measurements are not black and white, they do give a global perspective of a participant's thought processes. Taking advice from a number of sources, I compiled a comprehensive interview protocol that attempted to answer the research questions.

I am aware of my own researcher bias, since I sometimes spend as much as eight years with these students from the time they enter in the ninth grade and leave as seniors. I have also chosen my advocacy/participatory theoretical point of view to coincide with natural environments of study and to be an active participant in the disabled community to achieve social justice (Lincoln, 2005). On the one hand, my involvement gave my study the validation of having prolonged engagement with the participants, but on the other hand, I had to bracket myself from them to become an objective observer (J. Creswell, 2007). I had many years of experience which influenced my thinking toward those with disabilities. I have already changed some of my perceptions by reading recent research and I support the more modern philosophical underpinnings of disability rights. I made every effort to select a case study participant by typical example of the case rather than by considering my relationship with the parent or any other factor. Through the use of memos, I questioned my own perceptions, including before and after interviews. Through consulting with co-teachers, I obtained their peer review of my findings. If my colleagues also could not interpret the recordings, I consulted with the parents, but only for the segment in question, not entire interviews. Audio recordings from the videos of interviews were relied upon rather than personal memory. The form of the interview questions were the same for all participants, giving the content trustworthiness. There was a sufficient number, variety, and realism of picture representations made available for a student to adequately communicate. If I did not fully understand any Spanish that was spoken, I obtained assistance from a co-worker. I requested the assistance of a professional Spanish-English interpreter for the invitations to the study and the consent forms. Even though I am a firm advocate of selfdetermination for these students, I did not let my feelings affect the way I interpreted what they were trying to say. I did not exaggerate the data to support my beliefs. All attempts possible were made to keep researcher bias out of this study. As their teacher and a researcher, I was not perfect in bracketing myself from emotional responses to what they were saying and in refraining from using those teachable moments, but those episodes were brought out during analysis.

Limitations

During the short extent of time on this study, I did not want to define this study by conducting formal interviews with the teachers, parents, or all the students who were stakeholders in this research. Their input would have contributed to a deeper understanding of self-determination in real life terms as it relates to the various students' future plans. However, the focus of this study was not on the authority figures who associated closely with them. It was understood that the data collected related to these particular individuals and were their personal truths, not to be applied to all individuals with disabilities, even if it was the same disability label (Anastasiou & Kauffman, 2011; Kelly & Yin, 2007).

Another important limitation was that these individuals had access to technology to support communication that other researchers might not have available to them. In addition, a researcher would have to have expertise in using technology to its best advantage and the extensive time it takes to prepare the technological devices. Furthermore, the ability to use software to analyze the data and referencing software to write the report was a huge advantage that not all researchers possess. Access to technology might not have been typical of the classroom research experience.

To undertake this study in depth, I had to collect rich data from only a small number of participants. I was mostly be able to observe participants while they were in my class and less while they were in others, so I was not be able to get a more global picture of how they see themselves in other settings. As studies have shown (Lindstrom, Hirano, McCarthy, & Alverson,

2014; Papay & Bambara, 2014; Shogren et al., 2013), environment has a huge influence on self-determined behavior. Social science research is never an exact science, and one can never know everything. Readers, who have come to understand my point of view, will need to interpret the data through the filter of this human observer.

Chapter 4: Findings

Introduction

In this qualitative case study to explore needs, preferences, goals, and feelings of secondary students with significant intellectual disabilities, the research questions focused on what they expressed about their transition to adulthood after high school completion. The subquestions included: needs expressed based on independence; preferences based on beliefs, interests, and abilities; goals related to self-regulation; and feelings related to psychological empowerment and self-realization. This chapter is organized in terms of these specific subquestions as expressed in each of three participant interviews. Although there were many common areas mentioned, each participant had a unique perspective of their life at present and for the future.

Fifteen overarching findings and supporting evidence for these findings will be presented in this chapter. These 15 major findings are:

- 1. Participants expressed dependency needs for their parents, caregivers, and adult supervisors for self-care, cooking, medical needs, and safety.
- 2. Participants expressed a lack of awareness of their own disability and conditions and also a lack of awareness toward environmental supports necessary to achieve independence.
- 3. Participants preferred to express positive beliefs about themselves, others, their fantasies, and their rights as humans and adults.
- 4. Participants had preferred interests in assistance from parents or support persons, in independence, in friends and a social life, and in lifestyle choices including jobs, living situations, leisure time, friends, post-secondary education, travel, and foods.

- 5. Participants preferred to be optimistic about their abilities in job, education, and learning skills, self-expression, self-advocacy, socialization, emotional control, low risk choice-making, travel with support, and living in independent housing.
- 6. Participants were able to express goals for plans to work, to live as an adult, and to enjoy their leisure time; goals for problem solving with parents and co-workers; and goals for self-regulation to deal with difficult people and situations.
- 7. Participants expressed feelings about psychological empowerment through self-advocacy, self-confidence, protection of their self-image, and use of technology.
- 8. Participants expressed feelings about self-realization by being self-aware of how they felt, what their adult preferences were, their dislikes, who will give support, and how they feel about religion.
- 9. Information was missing because of no experience, drifting off topic, language issues, automatic responses or repetitions, not knowing the answer, poor effort, contradictions, and efforts to please the researcher by changing their answers.
- 10. Extra information was expressed to take the focus off of themselves, reject blame, give excuses, or to express anger, sadness, or anxiety.
- 11. Participants were happy with being who they were and did not feel that their disability got in the way of what they wanted.
- 12. Participants did not understand the financial level needed to become independent and were not interested in becoming completely independent.
- 13. Participants expressed a high level of interest in becoming entertainers, probably due to participation in the annual school talent show featuring students with disabilities.
 - 14. All participants mentioned the concept of respect as being very important to them.

15. All participants mentioned wanting peace in their lives, which was a surprisingly philosophical comment to make about life for these individuals.

Additionally, I must inform the readers that that my findings look a little different than the typical report of findings because my participants give very short answers. Usually a qualitative researcher would be able to quote entire paragraphs from participants without having to show the interview prompts. My participants often give very telescopic or one word responses, causing me to have to show the prompts used to probe for more information so that readers can make more sense of our conversations and understand how the responses were developed.

Demographic Information for Participants

All participants happen to be female and all were former students of the investigator. Having been in my classes for multiple years, all were familiar with the discussion topics related to self-determination that had been presented to them in the past. All participants had moderate to severe intellectual disabilities and/or other health and physical conditions related to disability. The following table shows essential traits of each participant:

Table

Participant Demographic Data

Name	Age	Sex	Level	Job Experience	Culture Ha	s Assistant	Ambulatory	Religious
Maria	20	F	Middle	Yes	Hispanic	No	Yes	No
Rayann	21	F	High	No	Middle Eastern	Yes	No	Yes
Vanesa	19	F	Low	No	Hispanic	Yes	Yes	Yes

Note. Brief description of basic characteristics that influenced the direction of this study.

Participant 1: Maria

Maria was 20 years old and the only one who was participating in a job training program. Even though she scored a full scale IQ of 50 on the WAIS-IV, her temperament and impaired judgment caused her to appear lower functioning in a classroom setting. In addition, the report of her ability to fluently and automatically perform cognitive tasks was anywhere from moderately to severely impaired. This was evidenced by her score on the Florida Alternate Assessment which put her level at participatory in all areas except reading, where she scored a low supported level of the three possibilities which are participatory, supported, or independent. This would seem to conflict with the some of the psychologist's results showing mild intellectual disability which was most likely not accurate. The psychologist also did not notice any delusions or obsessions that were evidenced at school and observed by all her teachers.

This participant was born in Spain, but was now independent in English. She had the most trouble with language and would sometimes revert to Spanish when she couldn't find the right word. She exhibited slight pronunciation difficulties in both languages and was diagnosed with dysarthria as a small child. I noticed some mumbling during the interviews and a more pronounced use of vague descriptor words like here, there, this, that, and counting to communicate how she did things. She had no physical limitations and her functional level within this group can be described as in the middle between the other two participants. Records showed she has petit mal seizures, but with nightly medication, she was able to control her epilepsy.

At first glance, she would appear to be without any disabilities, but upon speaking with her, cognitive difficulties become apparent. She had a vivid imagination, embellished experiences, and actually believed her own fantasies. She was reluctant to take responsibility for her own actions and was quick to blame or see fault in others. She was easily frustrated at work

training and needed encouragement to start and finish her work at school and to start activities at her after school recreational program.

At work training, her supervising teacher reported that she can do limited tasks, was easily frustrated (although she was improving), needed guidance and supervision, still cried when corrected or redirected, and had trouble counting. She was impatient and did not like to wait. She was caught sitting, not working, three times and then stopped idling. She was the only child at home and often complained that her parents botheredher and would not allow her to sleep. Her mother has said in the past that she usually slept all weekend and that she was obsessed with using her iPad and computer. Her mother was surprised that she liked cleaning so much during work training because she did not help out around the house very much. On a positive note, she was friendly and very aware of what goes on around her. She expressed herself well and used the contemporary language of her non-disabled peers in the school. She was able to read and write at a kindergarten level and was better in language arts than in math or science. I considered her to represent the middle level of ability for this study.

Participant 2: Rayann

Rayann was 21 years old and used a wheelchair due to a genetic neurological condition called Ataxia-Telangiectasia, which becomes progressively worse with time. Her older sister and younger brother passed away from the same condition when they were much younger than Rayann. The best measure of her intellectual potential was the WISC-IV Verbal Comprehension index score of 47, falling within an extremely low range. Her physical disabilities likely played into a lower score than was evident in class. On the Florida Alternate Assessment, she scored in the supportive level of intellectual disability, between participatory and independent. She read at a second grade level and performed math at a first grade level. She can be described as having a

moderate intellectual disability. She was classified as orthopedically impaired and received physical therapy.

As a child she was able to walk and she did not like to be seen in her wheelchair. She had a one-to-one Paraprofessional at school to assist her in the bathroom, with eating, and with writing when she gets tired. At home she also had a caretaker for personal assistance. Her parents were divorced and remarried and she had half-siblings from both. She lived with her father and her mother remained in Lebanon. Records showed the participant was born and grew up in Florida. She spoke Arabic at home and was independent in English at school. She was never educated in Arabic so therefore could only read and write in English.

Her functional level was high as compared to the other two participants. She expressed herself well verbally and in writing. Her handwriting was shaky due to poor muscle control, but her sentences were clearly articulated. She was able to transfer from the wheelchair to a regular chair, if supported, and she preferred to participate in class from a student desk. She was very cooperative during the study and was eager to have her voice heard. She was hesitant to give her own adult consent at first, but once she was sure her father did not disapprove and actually supported her expressing herself in this study, she was happy to participate. She was self-aware and realistic, for the most part, in describing her life goals. She described her mother in an idealistic manner, from the point of view of someone unaware or in denial regarding her mother's absence and ability to take care of her. She stayed on topic and did not make up answers just to express her fantasies or just to give any answer that came to mind. Even though she frequently said she did not know as a first response to many interview questions, with further prompting and explanation, I found her to be willing and serious about giving me what she thought was the best or a corrected answer. She exhibited a higher level of spirituality and ethics

due, perhaps, to her religious training and experience, which was not evident in the other participants. Of all the participants, she was best able to express what she needs, what she preferred, how she feels, and how she plans to live her life as an adult.

Participant 3: Vanesa

Vanesa was 19 years old and her mother received guardianship. Of the three participants, she was lower functioning in most areas except for her ability to clearly pronounce fairly sophisticated words. She wrote her name with great difficulty and had very little functional reading skills, but she contributed well in class discussions if called on to speak. Due to cerebral palsy, she had difficulty walking, fell easily, and had seizures that were controlled with medication. Previous psychological testing placed her at a full IQ of 34 on the Leiter International Performance Scale-Revised. On the Florida Alternate Assessment she scored at a middle participatory level, with reading slightly higher than math and science at the low supported level. Even though psychological testing at young ages placed her at a moderate level of intellectual disability, her current functional level at the present age was more akin to severe. At home she had a nurse for a caretaker and she helped her with dressing skills. She lived with her mother, who was a teacher, and her brother, who also went to the same school as she did. She was eager to do this study and continued to ask to "do the microphone" long after all the data was collected. She was eager to please during the entire study and would apologize when she knew she was off topic. She had a habit of going off topic in the middle of a conversation and randomly asking others about their family members or friends or erratically talking about a favorite memory of hers. Since she knew my daughter from her summer internship program, she would often bring up her name and I would have to bring her back to our previous conversation. Even though outside the research situation, this participant often broke out into laughter, she

seemed to laugh more when fatigued, and neither of us recognized it as such when it happened. When offered a break to rest, she would ask to go on with the interview. On the other hand, she was able to provide some well thought out and consistent answers when I least expected it. She truly was speaking for those at her level who cannot due to communication impairments.

Participants as a Group

Though each of these cases was unique, I was able to capture full rich content that intertwined all participants. They all knew each other, had been classmates throughout their school years, and had spent all day together in school This study was also aided by good communication abilities of all the participants that were invited into the study. The three responding participants represented the cognitive ability groupings of students with moderate to severe intellectual disabilities and were a good representation of high, middle, and low level intellectual abilities.

The Case Study Approach

The aim of this study was not to generalize findings to all students with severe to moderate intellectual disabilities, but to explore each unique case to discover needs, preferences, goals, and feelings toward their transition to adulthood after high school is over. Themes were developed within each case and between and across all cases to enhance understandings of general similarities and find negative cases through differences (Miles, Huberman, & Saldaña, 2014, p. 101). The purpose was to reveal how each participant sees themselves presently in their everyday lives and to describe their dreams for the future so that others can understand them. The attempt was to explore stratified cases, the theory being that most themes will be expressed at all levels (Miles et al., 2014, p. 296), but it was definitely more difficult to interpret at lower communicative or functional levels. Having more than one case is all that is necessary to perform

a cross case analysis (Yin, 2003, p. 133) and this study had three. Verification was comparable to quantitative studies since a case study researcher can get closer to the participants and can be corrected during the study to discover variables that were left out (Denzin & Lincoln, 2011, p. 310). In fact, two separate rival themes were discovered during analysis, namely missing information and extra information, which were discussed at the end of the planned comparisons.

Interview Questions. Participants were each asked 120 questions covering needs, preferences, goals, and feelings that were designed to explore all components of selfdetermination. Interview questions were patterned after Wehmeyer's ARC's Self-Determination Scale, which used a higher language and experience level than the participants were accustomed to. This scale is included in Appendix E. These close-ended questions were adapted to be openended and to better suite a qualitative interview format with participants with more significant intellectual disabilities. Other open-ended questions were added to more specifically address all components of self-determination and to update exploration of technology use by the participants. In addition, probing questions were asked to ensure I had collected rival explanations (Yin, 2003, p. 112). Two or three cases were enough to develop rival theories since the themes were unique to the individual. I therefore needed to be flexible with how certain I was to be in coding them due to their specific life experiences (Yin, 2003, p. 51). Multiple case studies are equivalent to experimental replication (Yin, 2003, p. 47). Appendix F includes the exact questions that were asked of each participant. If information was not forthcoming from the participants, additional questions were asked to more deeply delve into the topic at hand. At times, I had to provide background information before the participants were able to respond appropriately and on topic.

Archival documents. To triangulate the interview data, student documents were utilized.

Included in Appendices A through B are the worksheets that were completed at the last interview session. Additional student work by the participants was collected from the participants' teachers within the time boundaries of this study. These documents were valuable since they represented each participant's expressions outside the scope of the interview situation and in other environments. They were completed with the assistance of other educators who work with the participants and were not influenced by me. All documents came from the Unique Learning System Curriculum approved by our school district and with the company's approval (see Appendix C).

How Codes Were Determined During Analysis and Theme Development

The codes used to analyze this data were predetermined using a combination of the research questions, a basic outline of questioning from the ARC's Self-Determination Scale, and from the literature. The attempt was to make the analysis as complete as possible looking at all components of self-determination. Additional codes were developed as needed and as they emerged. Coding was aided by using the NVivo 10 software program. NVivo is a code-based program that assists with retrieving codes to support theory building (Glesne, 2005).

Researcher as theme developer. In as much as the NVivo program assisted with assigning description codes and separating the data into parts, the analysis of meaning comes from the researcher. Having difficulty using the software efficiently and understandably, I found myself having to go back and hand code both descriptive and in vivo coding. I discovered I could make use of the software with the basic use of text searches for key words across participant transcripts and that helped tremendously. The time bound nature of this study made it impractical to take the classes I needed to learn to use NVivo well enough to query different variables and

get a result I could understand. After all data was sorted into nodes, I developed themes by combining the topics into an outline form using sub-topics.

Initial coding. I followed the advice of Miles, Huberman, and Saldaña (2014, p. 85) by doing an initial coding of the first participant and then coding again after the initial analysis of the other participants to increase internal validity. When I began with the first participant, I noticed repetitive types of responses were emerging due to cognitive functioning. I was not sure how it would affect my analysis as it progressed so I coded them also. For example, I saw a pattern where if I was to ask a participant "what do you say", two of the three would give an automatic response of "thank you." At that moment I felt that incidents such as that would not have been meaningful, but other saved response types may have some bearing on the results. I continued to code to response type. Ultimately I acknowledged that automatic language is related to "don't know" and was later coded there. There is a reason behind all response types because it relates to their cognitive and communicative abilities and is therefore important. Every effort to document their voices is crucial for this group. Many idiosyncrasies were noted such as blaming others, language difficulties, repeating key words, and fantasy ideation. I often got contradictory responses that needed to be examined for their true meanings. Also, students with disabilities, more than most people, perseverate on previous questions or response patterns and have difficulty addressing the question at present. I had to go back and re-examine all my coding to include emerging data. Contrary to the advice of Miles, Huberman, and Saldaña (Miles et al., 2014, p. 86), who suggested not to code simultaneously and not to code trivial data, I erred on the side of valuing all communication of these participants who are marginal members of this society and were rarely heard from.

Objectivity. Other dimensions of this study involved being an insider attempting to examine the cases as an objective researcher and came to light during the process of exploring the transcriptions (Unluer, 2012). While it can be useful to know the participants well if they have significant disabilities that may hinder expression, being too close to the cases presents its own set of problems. Part of the analysis needed to be reflexive of my own biases and reactions to what participants were saying. I thought it needed to be noted when I felt they were too easily persuaded to change their answers to please me. I also found it very difficult to bracket myself and refrain from those teachable moments regarding content we have gone over in class over the years. I found it especially difficult to be objective and non-judgmental when I had to listen to their fantasies, like describing a date they had with a rock star. Being an insider (Unluer, 2012), it was helpful to be able to judge when participants were perseverating on previous interview questions, giving answers they think I wanted to hear as their teacher, or making up fantasy stories or false accusations regarding others. On the other hand, it hindered analysis because no doubt I used my judgment to decide which data was important to include as meaningful. To be honest I felt I needed to code my own reactions as "I went into a teacher mode", "I misunderstood", or "I gave up." Sometimes I did not realize I responded that way until I went back and examined the transcripts.

Coding for research questions. While performing the first level analysis of the second and third participants, I realized I was double coding for the same concepts by using the ARC's Scale and the research questions separately. During the coding of the second and third participant's data, I discontinued using the codes from the ARC's Scale and added those facets to the research question coding. Specifically, I added autonomy from the ARC's Scale to needs; self-realization and psychological empowerment to feelings; and self-regulation to goals. Acting

on beliefs, interests, and abilities remained in the preferences category of coding. That left coding by the four aspects of this study according to the research questions regarding needs, preferences, goals, and feelings. To be sure I was consistent, I re-coded the first participant using the reconfigured research question codes.

Archival data. In addition, I found it necessary to add new codes for the archival data since the topics there did not fit into any of the predetermined codes so far. Those new codes analyzed survey type questions illustrated by responses such as: not interested, so-so, I want to learn, I do this now, like sometimes, or I'm happy with what I do now. After level one coding of the interview questions, I coded the entire content of the archival documents to describe the data. Then I analyzed only the short answer/sentence completion items by examining open-ended statements without the question cue, which were listed again later into In Vivo coding. These documents provided some insight into the participants' thoughts outside of the interview situation since they were completed during other classes. The first set of archival documents were part of the original research design. These survey type documents were useful in triangulating the data for veracity and consistency. In the end, however, I did not use the theme coding on the documents for analysis. I used the documents to triangulate what they said in interviews to what they produced on paper to achieve some measure of validity.

Coding Methods Used

Several coding methods were used to analyze the data in this study. First I used predetermined codes because I wanted to tie the results back to the literature review, the research questions, and Wehmeyer's Self-Determination Scale. The initial analysis was the elemental method called Descriptive Coding (Saldaña, 2013, p. 87) because I wanted to show the meaning of the ideas, concerns, and interests participants were expressing using interviews grounded in

participant experiences. Descriptive coding can be explained as what was heard or seen by the researcher based on what the participants have experienced on a daily basis (Saldaña, 2013, pp. 88, 90).

Because I used NVivo 10 to analyze my data, the next natural step was to use the grammatical method of Sub-coding (Saldaña, 2013, p. 77) since the software is set up to use parent and child nodes as in an outline setting. This method corresponds directly with two of the research sub-questions which have two or three sub-topics of their own for the areas of preferences and feelings. I used this method during descriptive coding and later during second level coding for themes. Sub-coding also lends itself well to within case and across case analysis (Saldaña, 2013, p. 80) and was also applied to the second level coding.

Another elemental coding method that emerged was In Vivo Coding since I wanted to honor and focus on the voice of the young person with a disability whose views were often marginalized by those who made decisions for them (Saldaña, 2013, p. 91). I wanted to capture the terms they used in their everyday life about their everyday life. Participants often said "I don't know", "What's that?", or "I forgot", allowing In Vivo coding to capture something significant to the person expressing it (Saldaña, 2013, p. 92).

The second level coding method that I used was Theming the Data (Saldaña, 2013, p. 175). Participants had to construct the meaning of what I was trying to explore. Individuals with intellectual disabilities are eager to please and are easily persuaded. I had difficulty wording the questions so that they could better understand how to answer. Sometimes they did not have the background information or the experience to answer questions about becoming an adult. I needed to step back to see the whole story. This method enabled me to discover explanations, threads, and an overarching theme based on my interpretations. I discovered what was similar and what

was different between and within the cases. I reduced the number of themes (Saldaña, 2013, p. 176) to get the essence or the big picture of what all the data was saying.

Within Case and Across Case Analysis

Capturing data from only three case participants, I needed to improve validity and reliability. This was accomplished by utilizing within case and across case analysis. Miles, Huberman, and Saldaña (2014, p. 247) explained that within case and across case analysis is a "thematic narrative" that employs estimated variables interpreted to be similar or different by respecting individual cases. These variables are deemed to be the most important in measuring or determining the outcome in a qualitative case study.

How the Findings were Organized

The results for each participant were displayed by the four research sub-questions and their resulting theme development. Some sub-questions also had two or three branches stemming from them. Each participant in this case study had a unique story to tell even though there were many similarities within the cases. To analyze differences, I described each participant's distinctive views and compared them to each of the other participants and then across all cases. Next I showed the results from the analysis of the archival documents and compared them to what each participant expressed to check for validity outside of the interview situation. Then I investigated reliability using member checking for triangulation of the data. I did not expect there to be a perfect match between what participants said in interviews and what was expressed in archival documents, but member checking assisted with accuracy.

Themes Expressed for Needs Expressed Related to Independence

After initial first level coding with NVivo 10, I performed second level coding by hand to develop themes. I looked for the meaning behind each segment of coded text and reduced it to these main categories that all participants had talked about for these specific topics:

I. Needs

- a. Family functions/personal care attendant
 - i. Cooking meals
 - ii. Cleanliness (body and clothing)
 - iii. Medicine, doctor appointments, first aid
 - iv. Safety at home and community
 - v. Disability and conditions
 - 1. Dressing
 - 2. Eating
 - 3. Health
 - 4. Intellectual
- b. Independence in the Environment
 - i. Snack preparation
 - ii. House keeping
 - iii. Communication (verbal and electronic)
 - iv. Community and social access
 - v. Financial support
 - vi. Family support
 - vii. Transportation

The topic of personal care attendant was added because it emerged with two participants and was not covered in topics from the ARC scale. To include need areas for severe disabilities, I

explored interview questions on dressing, eating, health, and intellectual need awareness. In addition, electronic communication was added to update the standard scale's emphasis on use of the post office.

Themes Expressed for Preferences Related to Beliefs, Interests, and Abilities

Each facet of preferences was explored separately to correspond with the research subquestions. The following are the common themes discovered for preferences:

II. Preferences

- a. Beliefs
 - i. About self
 - ii. About others
 - iii. Fantasies
 - 1. Boyfriends, husbands, and babies
 - 2. Walking or standing alone
 - 3. Being a professional entertainer or artist
 - 4. Travel independently
 - iv. Rights
- b. Interests
 - i. Assistance from parents or support person
 - ii. Independence
 - iii. Friends and social life
 - iv. Choices
 - 1. Living
 - 2. Job
 - 3. Leisure
 - 4. Friends

- 5. Food
- 6. Post-secondary education and training
- 7. Travel

c. Abilities

- i. Job, education, and learning skills
- ii. Self-expression
 - 1. Can contact friends
 - 2. Can support friends
 - 3. Can participate in social activities
 - 4. Can express what they want/ask for support
 - 5. Can appropriately control emotions
 - 6. Can make choices independently
- iii. Can live in independent housing
- iv. Can travel with support

Fantasies were expressed uniquely by each participant, but emerged as a commonality for all participants. Choices originated from the format of the interview that derived from the research questions based on the literature. Abilities in self-expression were a given because all participants were verbal.

Themes Expressed for Goals Related to Self-Regulation

An area often overlooked for students with significant disabilities was the question of how they would like to plan for the future and solve problems. These areas had themes that were held in common:

III. Goals

a. Plans

- i. Job
- ii. Living
- iii. Leisure
- iv. Education
- b. Problem solving
 - i. Parent permission and support
 - ii. Support on the job
- c. Self-regulation
 - i. Dealing with difficult people/making new friends
 - ii. Dealing with difficult situations

Themes Expressed for Feelings Related to Psychological Empowerment and Self-Realization

This area was broken down into the two facets of this research question. Because interview questions were open-ended, some topics were unique to these cases. Themes that emerged regarding feelings were as follows:

IV. Feelings

- a. Psychological empowerment
 - i. Self-advocacy
 - ii. Confidence
 - iii. Technology use
 - iv. Protection of self-image
- b. Self-realization
 - i. Self-awareness
 - 1. Conditions
 - 2. Disability

- 3. Feelings about themselves
- ii. Adult preferences
- iii. Difficulties, dislikes, and non-interests
- iv. Religious feelings
- v. Support people

Additional Themes Discovered

To give weight to all the language produced by these participants, additional themes were coded. Having a communicative or cognitive disability made it an obligation for me as a researcher to attempt to capture all meanings which may be hidden to others who did not know them as well. The additional themes also attempted to describe why information was missing and why it was additional or unexpected.

V. Missing Information

- a. Why missing background information
- b. Why off topic
- c. Why question not answered

VI. Extra Information

- a. Why take focus off self
- b. Why not interested in being more independent
- c. Why high level of interest in being an entertainer

The entire theme outline can be found in Appendix H for the reader's reference. Data analysis was be presented for each case to show how each theme was expressed by all participants. The purpose was to tell the story of each participant and how they were similar or dissimilar from the other cases in this study. Reliability and validity were increased by multiple methods of

comparison. Incidentally, all participants were twice as likely to express independence as opposed to dependence during In Vivo coding of their voices alone.

Analysis of the Needs Expressed by Maria

Needs related to family functions and/or personal care attendant. Maria was the only participant who did not have a personal care attendant. However, she did talk about needs related to family functions in the home. When asked about cooking, Maria replied that her mother does that:

Researcher: Ok how about cooking? Maria: I don't do cook. My mother does.

Researcher: But do you wanna know about cooking?

Maria: I know how to do a sandwich.

She had difficulty throughout the study with separating what her mother does from what she does independently. However, this person would not go hungry when it comes to food preparation if left in the house alone. As with all participants, she did not use sharp knives or heating elements, which was an important point for these participants when they are looking for a job in food preparation.

Maria stated she had good self-help skills in the bathroom and observations at school confirm that. She can bathe, use the toilet, and dress herself independently. It was unclear how she assists herself with doing the laundry:

Researcher: How do you care for your clothes?

Maria: Well, every day when I go to my house, my mom always do. She wet it with

water.

Researcher: Um hm Maria: Put it with water—

Researcher: Not your mom though, what do you do?

Maria: I put it with water on my shirt.

Researcher: Ok

Maria: I put some soap. Researcher: Um hm Maria: And it's wet Researcher: Um hm Maria: It's a little bit wet. And then I take it outside and it's to, to, to dry.

Researcher: Um hm

Maria: I put the two shirts outside and wait to dry.

Researcher: Um hm Maria: And that's it.

Researcher: Ok, what do you do when your clothes are dirty?

Maria: Dirty? Researcher: Um hm

Maria: Well, when they're dirty, my mom puts some spray—

Researcher: Uh-uh, not your mom, what do you do?

Maria: That's it.

Researcher: When your clothes are dirty? Maria: Um, I take it outside is is dirty.

Researcher: Outside where?

Maria: Um, outside, whi-sis dirty, the pants is dirty,

Researcher: Um hm Maria: Um, I wash it. Researcher: Um hm

Maria: Whi-sis wash it, wash it.

Researcher: Um hm

Maria: And I wash it by myself.

To Maria's credit, "outside" may mean out of her room or bathroom, or that the laundry room is outside of the house, or it could also mean she uses a clothesline, which she mentioned. She had Spanish language interference and language difficulties in both languages. I could not get her to express this detail adequately. In any case, her mother was involved with her independence in laundry skills.

As was expected, medical care was not something that Maria did independently. Her idea of independence was actually taking the pill. She did not understand what the medicine was and what to do to remember to take it:

Researcher: Do you do the medicine by yourself without reminders?

Maria: Well...

Researcher: Do you ever forget to take your pill at night or in the morning?

Maria: Yea

Researcher: You forget sometimes?

Maria: Yea

Researcher: How do you remember to take your pill?

Maria: Because always busy

Researcher: But how do *you* remember to take your medicine by yourself?

Maria: Every, um, I drink it

Researcher: Do you forget sometimes?

Maria: I forgot sometimes

Researcher: But how do you remember it? What do you do to remember your pill?

Maria: I say, um, I get some medicine

Researcher: Um hm Maria: Get some water... Researcher: Um hm Maria: And then I drink it

Researcher: And you never forget?

Maria: Never

Researcher: But if you do forget, how do you, how do you get help to remember to take

that pill?

Maria: I don't know

As evidenced by this excerpt, Maria often contradicted herself, making it difficult to tell what was actually happening. Since contradictions were common, I had to err on the side of caution and found medical care to be dependent on the family.

Maria had a poor understanding of how doctor appointments for her were made and was unable to directly answer the interview questions at hand:

Researcher: How do you *make* doctor appointments? Maria: I have, sometimes I go to doctor's appointment.

Researcher: You go sometimes, right?

Maria: Well I go to the...

Researcher: And how do you *make* doctor appointments?

Maria: Well, I go to doctor's appointment every week when I go back to school.

Researcher: Um hm, every year that means...

Maria: Every, every year

Researcher: Ok

Maria: Not every Sunday or...

Researcher: Ok how do you, how do you, uh, take care of your doctor appointments?

That means your, the, the *cita*, the *cita* with the *medico*?

Maria: They say like, a doctor said, um, who you calling, Maria! (says her real name)

Researcher: Um hm

Maria: And then they say my name.

Researcher: But how do you get there to the doctor?

Maria: You get in the car.

Researcher: Ok, how do you get in the car? Maria: You pressing your seatbelt on.

Researcher: Uh huh

Maria: And then put your seatbelt on, you go to, to the doctor...

Researcher: Do you drive yourself?

Maria: No, my mom drives

Researcher: Oh, your mom drives, ok, and how does she know to get there?

Maria: She drives and then she, she...

Researcher: But how does she know about the appointment? Who makes the

appointment?

Maria: I think my mom

Researcher: Your mom makes the appointment?

Maria: Yea

Researcher: She makes the phone call?

Maria: The phone call

Researcher: And then do you know about the appointment?

Maria: No

Researcher: She just calls you when it's time to go?

Maria: Yea when it's time to go.

Maria had poor time concepts and that fact alone made her dependent on her mother to make her appointments with a doctor. Furthermore, she depended on her mother to give her a ride to the doctor on the correct day and time and to remind her of when to get ready.

The same dependence was evident in responses concerning first aid care:

Researcher: How do you take care of simple first aid?

Maria: What's that?

Researcher: Like if you have a cut or something like that, how do take care of, if you

have a little cut, how do you take care of that?

Maria: Well one time I was shaving...

Researcher: Um hm

Maria: And my mom was really upset!

Researcher: Mmm!

Maria: I got cut over here (points to leg)

Researcher: Um hm

Maria: And my mom was like, mom stop cutting me, please, I'm getting blood

Researcher: Who cut you? You cut yourself or mom cut you?

Maria: I cut myself

Researcher: Oh, ok, so then what happened?

Maria: And my mom was so mad!

Researcher: Wooh!

Maria: She, she cut me here. I got hurt here and there and then I was so mad. I got a

Band-Aid here, Band-Aid there, and I'm, I'm so...

Researcher: Ok, and who put the Band-Aid?

Maria: Me

Researcher: Very good, by yourself.

Maria: Yea

Researcher: Ok, so if you have a cut, you put a Band-Aid on it right?

Maria: Yea

As evidenced here by my statements, I was rewarding conversation about independent living and that increased participants' willingness to please me and say what I wanted to hear. From the excerpt above and knowing the participant so well, it appeared the mother responded to the need for first aid and allowed her daughter to actually place the Band-Aid on the cut. It was also evident how the participant turned the blame around and put it on her mother.

Safety at home and in the community was a serious concern for Maria and her family.

Maria was an attractive young woman and her disabilities were hidden. She can be easily persuaded to trust unfamiliar others. She was largely dependent on others for safety at home, in the community, and in case of emergency:

Researcher: What if you're home alone and you, and you're alone, and your phone rings

and it's somebody you don't know on your phone?

Maria: I say, um, I don't know you, I really don't know...

Researcher: Um hm

Maria: I really don't know you. Wrong number.

Researcher: Um hm

Maria: Ok

Researcher: What if they ask you if your mom and dad are home, what do you say?

Maria: They're not home now.

Researcher: You tell them they're not home now? You tell them?

Maria: They're not home now, come on, c-come later.

Researcher: What if they say I'm gonna come now cause you're home alone, so I'm gonna come over to see you now. I like when you're all alone. I'm gonna come over to

see you now. What do you do then? You want to be safe, right?

Maria: Yea, I wanna be safe. Researcher: What do you do?

Maria: Wooofff! Don't be all alone....

Researcher: Do you ever, do you ever tell people that you're home alone when they call?

Maria: No, because every day um, my mom goes shopping

Researcher: Yea?

Maria: She goes shopping to Winn Dixie.

Researcher: Uh huh

Maria: She come back to home and then I don't be alone.

Researcher: But when you're alone and somebody calls, what do you say to them?

Maria: Um, excuse me, um, I'm really busy right now...

Researcher: Um hm

Maria: Um, I-I'm busy now...

Researcher: Um hm

Maria: Please stop oping the door please...

Researcher: Um hm

Maria: Please stop oping the door, you open the door one more time, I'ma call the police

Researcher: Ok, very good

I have always taught my students that when they are alone and someone on the phone asks if their parents are home, to tell them either that they are sleeping, taking a shower, or that their father is a policeman and he cannot come to the phone right now. Since they do not retain what they were taught, I was not certain if Maria had safe phone skills and found her to be dependent.

Many of my students had a poor understanding of their own disability and conditions.

Where Maria was independent in eating and dressing, she was more dependent in the areas of being aware of her own health conditions and her own type of disability. When asked if she had seizures, this was her reply:

Researcher: Do you have any health conditions?

Maria: No

Researcher: Do you have any seizures?

Maria: Well, one time my mom got a seizure...

Researcher: Not your mom...you Maria: I don't got a seizure.

Researcher: Never had a seizure?

Maria: Oh, one time I got a seizure.

Researcher: Ok, and how do you take care of that?

Maria: One time I got a seizure. They were doing my brain.

Researcher: Uh huh

Maria: And they was doing here, here...

Researcher: Uh huh Maria: Here, here...

Researcher: They were testing you. Maria: ...and here and I was relaxing

Researcher: Yea

Maria: And I said I, I, don't move, don't move, don't move

Researcher: They said don't move.

Maria: And then they took it off, and took it off, and took it off

Researcher: Uh huh

Maria: And then I was better for the whole year. Researcher: You were better for the whole year.

In addition, during the conversation about medicine, Maria admitted that the medication she takes was for seizures and now she did not have any more. Subsequently, when asked what her disability was she responded: "I don't have sib-abilities."

Needs related to independence in the environment. Maria can prepare cold foods and snacks for herself whenever hungry. She also expressed that she sometimes makes a sandwich for a free time activity. She was able to use the microwave under questionable independence:

Researcher: Who does the timer on the microwave?

Maria: My mom, she, she, she do it.

Researcher: Um hm Maria: She do it.

Researcher: So if she's not there to put the timer on, how are you gonna heat your pizza? Maria: I do the timer, and then I do the timer, and then it's, em, you have to wait for ten,

two minutes to get ready.

Researcher: But you do your own timer, right?

Maria: Yea

Researcher: Or does your mom do the, the timer?

Maria: My mom do the timer

Researcher: Do you take turns or do it by yourself...?

Maria: No we take turns.

Researcher: So if she's there or not, you can still do it.

Maria: Yea

Researcher: So if mother is not there, who does the timer?

Maria: Me and my dad.

Researcher: What if your dad's not there either and you're hungry and want some warm

pizza. Then what do you do?

Maria: I do it myself. Researcher: The timer?

Maria: Yea

Researcher: Ok so if mom's there, she does it?

Maria: Yea

Researcher: Would you rather do it alone or would you rather have mom do it?

Maria: Yea mom do it. I don't want to be alone. I don't want to be alone.

Maria often expressed that she did not want to perform particular adult activities alone. This was a significant find in her case, especially since she frequently stated that she wanted to live independently.

Housekeeping for Maria meant a spray bottle and wipes. She did use spray often to clean at work training, but she used this word excessively during interviews. Being unclear in my mind if she was embellishing her story or just did not have the language to express it, I found her to be dependent in housekeeping:

Researcher: What housework do you do at home?

Maria: Well, I do clean. Researcher: Cleaning what? Maria: Cleaning...my room.

Researcher: Ok, tell me how you do that.

Maria: I get the spray, get the napkin, spray all this, all that.

Researcher: All what?

Maria: And then there's, spray my room, I go another place, my mom's room and I spray,

I spray, I spray, I spray all that and then I'm done.

Another excerpt of the conversation:

Researcher: What do you do about the stinky towels in the kitchen?

Maria: If it be stinky...

Researcher: What do you do? Maria: Then you, you take it off.

Researcher: You take it off, right? And put it in...?

Maria: In the dryer.

Researcher: It's gonna be still stinky in the dryer. All that does is get it dry.

Maria: Oh, put it in the bathroom.

Researcher: In what part of the bathroom do you put it in?

Maria: In, in *my* bathroom.

Researcher: In what place in the bathroom do you put dirty towels?

Maria: I put it in *my* bathroom.

Researcher: What part of the bathroom, though, do you put it in?

Maria: Every day w-, I take a shower and then I put in my bathroom (gestures reaching

up and going across). Researcher: On the floor?

Maria: On the floor.

Researcher: Just throw it on the floor? Maria: Yea is is dirty? It's, it's, it's...

Researcher: And you leave it there on the floor?

Maria: Yea

Researcher: You do?

Maria: Yea

Researcher: How does it get clean like that?

Maria: You get a spray!

Researcher: A spray. And then what happens?

Maria: You got a spray (gestures low side to side movement toward floor) and then it

come off (gestures side to side movement on her hand)

Researcher: Um hm

Maria: It come off, if not... (slaps legs then gestures with palms up)

Researcher: So you're telling me that you get the dirty towels from the kitchen, take them

to the bathroom and throw them on the floor and spray them?

Maria: Yea

Researcher: And they get clean that way?

Maria: Yea

Researcher: Is that true?

Maria: Yea

Researcher: It is?

Maria: Yea

While not the best interview methodology, the above quote illustrated the difficulty in getting the participants to give a straight answer and the ensuing researcher fatigue it was beginning to cause. Fatigue continues below:

Researcher: What do you do in there, in the living room, to keep it clean?

Maria: Um, you get the spray

Researcher: Everything's with a spray? Always a spray and that's it?

Maria: Um. the towel

Later I tried to give more background information before giving the question:

Researcher: Let's say there's stuff all over the sofa and you have somebody coming to,

you have visitors coming to see you.

Maria: Yea

Researcher: And there's stuff all over the sofa. How do you help clean that? What do you

do?

Maria: I get the spray

Researcher: The spray for everything?

Maria: And I clean it anaall over the sofaaaa... (gestures spraying the sofa)

Researcher: Does the spray get rid of the things all over the sofa?

Maria: Yea

The following was another attempt to provide more information so that Maria could give me an informed response:

Researcher: Let's say there's, there's magazines there, there's sneakers that're thrown in

the living room, there's a blanket thrown there and a pillow in there

Maria: Yea

Researcher: Or the pillows are off the sofa they're on the floor and--

Maria: I have pillow.

Researcher: How do you...? How do you...?

Maria: I have pillows everywhere. Researcher: In the living room?

Maria: Everywhere.

Researchers: Are they in the right place?

Maria: Yea

Researcher: How does it get in the right place?

Maria: Like orders (gestures with chopping motions using both hands)

Researcher: How do you get it in order?

Maria: Like one here one there (gestures with both hands in a downward motion)

Researcher: Uh huh

Maria: One here (gestures with both hands in a downward motion)

Researcher: And who does that?

Maria: One there, myself

Researcher: There you go, you straighten the pillows up, right?

Maria: One there, one there, one there, one there (gestures with both hands in a

downward motion)

Researcher: No spray needed for that, right?

Maria: That's how my mom do it! She's doing like duh duh duh duh (gestures putting

pillows in order from one side to the other)

Researcher: Oh your *mom* did that?

Maria: Duh duh duh (continues gesture of putting pillows in order)

Researcher: But what do you do there in the living room?

Maria: I do one two three four (gestures putting pillows in order from one side to the

other)

Researcher: So you do it too?

Maria: Yea

Admittedly, I became fatigued and teased her about using spray, but she also revealed that she was probably describing what her mother does to clean house and not her. For my last attempt to get her to describe how she helped around the house, I have the excerpt:

Researcher: What if there's dust in the living room?

Maria: I say oooo th-this is a a room in here?

Researcher; Um hm Maria: Is dust in here?

Researcher: So, what do you do about that?

Maria: It stink.

Researcher: And what do you do?

Maria: I put some spray in there.

Researcher; Um hm Maria: And ss- wooo!

Researcher: Ok, ok let's discuss now the bedroom.

Even after showing my displeasure of hearing the word "spray" again in describing how she helps around the house, she continued to perseverate on that word. Sometimes I decided to just move on to the next topic since I was running out of time and I was not getting anywhere.

Maria's verbal communication abilities were considered to be good by all her teachers.

Even so, there were still areas of her communication skills that needed improvement. She often expressed herself by counting as if to explain the steps to completing an activity:

Researcher: What grooming do you do by yourself?

Maria: Well...

Researcher: Do you know what grooming is?

Maria: No

Researcher: For example, what do you do about your hair, to groom your hair, what do

you do with your hair?

Maria: I brush it.

Researcher: Ok that's...and then what do you do?

Maria: Like, like this, one, two...

Researcher: Uh huh Maria: Three, four... Researcher: Uh huh

Maria: six, seven, and nine

Researcher: Uh huh

Maria: And then I, and when it's done, you, it's done,

Researcher: Uh huh Maria: It's done.

Maria liked to send and receive texts as do other non-disabled young people her age. This was where the objective measure of self-determination needed to be updated and to put less emphasis on the postal service. When asked about her ability to write and respond to texts, she attempted to explain it:

Researcher: Tell me how you do text.

Maria: You write in, in the phone and then like this (wiggles her fingers as if to type) and then is you, I write on the phone, I said I'm, my buddy gave me a text and she said she was sick.

Researcher: Um hm

Maria: And she don't answer and that's why.

Researcher: How did you know you had a text? How did you know she gave you a text?

Maria: Be-, she said are you are sick, she said that. Researcher: But how did you know she gave you a text?

Maria: I don't know

Researcher: Do you have your own telephone?

Maria: Yes

Researcher: What does your phone do when you, when you get a text?

Maria: Um, my buddy is sick.

Researcher: She's sick but what does your phone do to let you know you have, a text

came in?

Maria: I I press it, I press it.

Researcher: Um hm Maria: And then I say...

Researcher: How do you know when to press it?

Maria: You press it with your fingers!

Researcher: How do you know when to press it?

I was trying to lead her into responding that her phone makes a sound signal when a text arrives,

but it did not work so later in the conversation we said...

Maria: Sometimes my mom gives me text and, and, uh I have, I love you.

Researcher: Yea

Maria: And then and then every day, I say, mom, I'm working. I can't text you now, mi

amor.

Researcher: At work? (laughs)

Maria: I can't text her in, in work, only when I come back. Researcher: And how do you know your mom gave you a text?

Maria: Sh-

Researcher: How do you know?

Maria: She, she give me like, uh, I love, like I love you or something.

Researcher: But how do you know she gave you a text when you're at work? How did

you know you have a text? Maria: Like I love you.

Researcher: Ok what tells you, you have a text? Maria: She always give me text everyday w---

Researcher: But how do you know they're coming in?

Maria: I got a hundred texts last night.

Researcher: But how do you know you have a text when you're at work?

Maria: In work, um, I go work every day, I clean...

Researcher: That's something else. I'm talking about the text now. That your mom will

text you in the middle of your work day just to say I love you, right?

Maria: Yea

Researcher: And how do you know she did that?

Maria: I don't know

Researcher: You just look at it or does it make a little noise to tell you?

Maria: Make, make noise

Researcher: It makes a noise and tells you!

I had to support her verbal communication by offering two possibilities to choose from regarding text notifications. To her credit, she knows about the give and take of electronic conversation and how it was not allowed while on the job. Knowing her reading and writing levels displayed in class, I was still not sure of the legibility of the texts she was able to produce so, considering all factors, I found this excerpt to be under needs for independence. She was able to produce some written words as evidenced in archival documents, however, they needed to be deciphered.

A major issue for people with significant disabilities was the ability to get out into the community to be with others. Maria understood that she was dependent on her mother to transport her for shopping or visiting friends. Parents were the ones who set up community and social contacts for Maria. The following were her words only from In Vivo coding, taken out of a conversation we had about how she makes contact with friends:

Um her mom calls me.

And then I can go to the house.

And then, and then, she, she said I can go to the house and she said ok.

Um my mom drives.

I said mommy tan I go? And she say okay.

This was a typical response from Maria regarding how she gets around the community and participates in social activities. Few In Vivo codes were quoted because they were usually so fragmented and the meaning depended on knowing what the question was.

Being dependent on their parents up to this point in their lives, students with intellectual disabilities often cannot express how they will get financial support when they become adults.

When Maria was thinking realistically, she gave me an honest answer about where her money came from:

Maria: My mom give me money to me and then I, I get the money and I put it in the

wallet.

Researcher: Um hm

Maria: And then I go to the store.

Most of my students, when asked where money comes from, will respond that it comes from the bank. Like many students that were much younger than these, if they did not see the process of how adults work, get paid, and then deposit money into the bank so they can withdraw it when needed, they will think the bank provides money spontaneously. Maria was no exception:

Researcher: But where does your family's money come from?

Maria: I don't know

Researcher: How does your family get money?

Maria: From the bank

Researcher: Who puts it in the bank?

Maria: My mom

Researcher: Where does she get it from?

Maria: She gets the [c]redit card, sshh (gestures swiping motions)...

Researcher: How do people get money in life?

Maria: In the bank, man, in the bank!

Clearly, Maria did not understand the workings of a bank and will not be able to handle her own money in a bank account without the support of her parents. Whereas she did understand that people get paid for work they do, she did not associate income with bank deposits:

Researcher: So how do people get money?

Maria: What they get to work

Researcher: When they go to work and they get paid on the job.

Maria: On the job

Researcher: So if you want money what do you have to do about that?

Maria: I need to work really hard.

Researcher: And get a...?

Maria: Money

Researcher: From a...?

Maria: Bank

Researcher: No, Not from the bank. Maria: Work really hard, money...

Researcher: If you want to solve that problem of not having any money you need to go

out and get you a what?

Maria: A job

Researcher: There you go!

It was very difficult to remain scientific and not go into a teacher mode when there was an obvious misconception. Regardless of interview errors, I can determine that Maria was not able to completely support herself financially and manage her expenses without family or caregiver assistance.

Maria dreamed of living on her own one day and being independent. When she really thought about it, she knew this dream was dependent on family support and asking for help politely:

Researcher: Ok you want to live on your own one day, right?

Maria: Yea

Researcher: So what do you need to know about living on your own?

Maria: I need to be impendent.

Researcher: To be independent. What do you need to know about that, about being

independent?

Maria: Um, I need to be, be nice to my family.

Researcher: Um hm

Maria: Don't be rude to my family.

Researcher: That's true, but what do you need to know about, more about, to live independently. What do you need to know more about? I need to know more

about...what? To be independent?

Maria: (sighs) I don't know

Maria had difficulty expressing what she had to learn to be more independent. She was unable to predict what difficulties she would have in living independently since she had always had help. Typically our students require a government controlled agency to supply a caretaker to live independently.

Besides being dependent on her parents for generalized support and for rides in the community, Maria was dependent on her family to travel long distances. The following were her words using In Vivo coding:

I love New York

I ask mommy, I wanna go to, um, something specials please

I want, I want to go to the, to Spain

Mexico?

I go on a plane

We go to the airport

On a train

By using the word "we" with airport, she was demonstrating that she knew someone had to take

her there to get a flight to Spain. The train did go to the airport in town, but I was not sure Maria

knew that, nor knew how to use it on her own.

Analysis of the Needs Expressed by Rayann

Needs related to family functions and/or personal care attendant. Rayann was very

dependent on personal assistants. She had a caretaker at home and one-to-one paraprofessional

assistance at school. These assistants helped her with eating, using the restroom, and transferring

to a student seat in class. To be fair, Rayann was found to be independent for being able to ask

for the physical assistance she needed. On other occasions, when she could have been more

independent by putting forth more effort, she was found to be dependent. For example, Rayann

was totally unaware of the meaning of *halal* foods and how they were prepared:

Researcher: Ok, I have a question about the hamburgers. Are they cooked in a certain

way?

Rayann: Yea

Researcher: Different than the way Americans eat hamburgers?

Rayann: (nods)

Researcher: How are they cooked in a different way?

Rayann: I don't know. I never cook. (laughs)

Researcher: Well, isn't there a Muslim—

Rayann: I don't know yet.

Researcher: But isn't there a Muslim way of doing it that's different than the American

way? No?

Rayann: I don't know what, what they call it in Eng-, I'm from--, yea, I forgot what they

call it in English, but in Arabic, it's called halal.

Researcher: Can you spell halal? Can you spell it?

Rayann: No

Researcher: But it's halal.

Rayann: (nods)

Researcher: Ok, I'll have to look that up. See what it means...

Rayann: And I can't eat hamburgers here because it's not halal for me

Researcher: Not halal, ok, that's what it is. I know it was something different about the

hamburgers. Rayann: Yea

Researcher: Different than the American way of cooking it.

Rayann: Yea

Researcher: Ok, let's see, does she use a certain kind of uh, oil to cook it in that's

different?

Rayann: M-maybe

Researcher: Maybe it's the oil that it's cooked in or something like that, or it doesn't

touch other foods maybe...

Rayann: Maybe

Researcher: Uh huh. You don't know what the uh, what the tradition is on that?

Rayann: No

Researcher: Um hm

Rayann: I just eat it (big smile)

In spite of her professed interest in cooking, she did not have the curiosity to see how the food was prepared or to ask what *halal* was and what it meant. She was content to have her stepmother cook for her and just trusted others to provide the permissible foods to her. In addition, she expected to be able to cook *halal* one day, as witnessed by her comment "I don't know yet."

Rayann was assisted with body and clothing cleanliness. Truthfully, she was noticeably dependent for personal care assistance such as dressing, due to physical impairments:

Researcher: How do you do with getting dressed? What dressing do you do by yourself?

Rayann: Sometimes I put the pa-pajamas

Researcher: The pajamas, you can do the pajamas

Rayann: Yea

Researcher: Ok anything else?

Rayann: No

Researcher: Shoes?

Rayann: No

Researcher: Socks?

Rayann: No

Researcher: But pajamas you can do

Rayann: (nods)

Researcher: That's good. You can do pajamas!

All the same, she could try to do a little more for herself. Caretakers often found it is easier to do an activity for a client rather than wait for them to do it on their own. Sometimes their clients did the task poorly, as well as slowly, but at least it was completed by the person with a disability. Because she can ask for this assistance, she was making a willful choice or decision to get help for herself and to control what happened to her in a beneficial way. When it was not a beneficial decision, she was found to be dependent in cleanliness:

Rayann: My helper brushes my teeth, but I, I sometimes I tell her no.

Researcher: Hm, that you want to do it what? Later?

Rayann: Yea

Researcher: Uh huh, so you tell the order of things, right?

Rayann: Yea

Researcher: Does she listen?

Rayann: No, because I have to brush my teeth, but sometimes I get lazy.

Researcher: Oh that you don't even want to do it sometimes?

Rayann: No

Researcher: (laughs) and then what happens?

Rayann: And then she does anyway Researcher: She does it anyway, right?

In addition to a lack of awareness of what made permitted foods halal, Rayann was unaware of what kind of medicines she took and why:

Researcher: What do you take for medicine?

Rayann: Pills

Researcher: And what are they for?

Rayann: I don't know I just take them! (laughing) I don't know what they're for.

Researcher: No one told you what the pills are for?

Rayann: Maybe someone told me but I forgot

She was capable of being aware of what her medicine was for and what the medicine was called.

She was aware her condition had a name and she named one of the other medicines she takes.

She also knew what that medicine was for. As mentioned in the literature, she has become complacent and has learned to be helpless and dependent on others.

Rayann was dependent on others for doctor appointments, taking medicine, and first aid. In addition, she tended to say "I don't know" when she really did know the answers, if probed further. This was how she responded when questioned about appointments:

Researcher: How do you handle doctor appointments?

Rayann: I don't know what you mean.

Researcher: Well you had one the other day. How did you handle that? Who takes care of

that?

Rayann: Takes care of what?

Researcher: Of doctor appointments

Rayann: My help-, my, my helper was with me. Researcher: Um hm, and then what happens?

Rayann: I don't know (smiles)

Researcher: (laughs) Rayann: (laughs)

Researcher: That was on Halloween. Remember that day?

Rayann: Yea

Researcher: What happened that day? Rayann: They gave me shots with...

Researcher: Uh huh Rayann: Medicine Researcher: Uh huh Rayann: On them Researcher: Uh huh

Rayann: And they pinched them here

Researcher: Uh huh Rayann: In the fingers

Researcher: In the fingers, yea

Rayann: Yea

Researcher: Ok, then your helper made the appointment, and how did you get there?

Rayann: M-m-my helper drove m- in her car

Researcher: She drove you in her car, ok. That's how you take care of that! And that's

your treatment for your hands, right?

Rayann: Yea

Later in the conversation she said bleomycin was the name of the medication that was injected into her hands for her skin condition and she knows it was the last treatment that worked. The skin condition was something that has been very stubborn and she wore gloves every day to cover it, which may account for her increased awareness. However, she was found to be dependent in both making doctor appointments and awareness of all medicines she takes.

It was unclear if Rayann would be more independent if medical items she needed were placed within her reach. She did not even know where first aid supplies were kept in the house:

Researcher: Ok, how do you take care of simple first aid? Do you remember that?

Rayann: No I don't know

Researcher: That means if you get, how about if you get a little cut?

Rayann: I put a Band-aid? Researcher: Yourself?

Rayann: (nods, then shrugs her shoulders) Nnn- (laughs)

Researcher: But you can right?

Rayann: Yea I could

Researcher: If you could reach it you could put it on?

Rayann: (nods)

Researcher: Can you reach the Band-aids at home?

Rayann: Yea, but I, I don't know where they...it, I don't know

Researcher: Ok, you don't know where they are?

Rayann: No

Researcher: Does the helper do that too?

Rayann: Yea

As for safety at home and in the community, Rayann felt she was perhaps more safe than she actually was. The mere fact that she lived in a large city and was female presented at least some dangers, not including the fact that she had physical disabilities. As was each member of her family, Rayann was a very attractive young woman. Here was what she said in In Vivo coding when asked how she would address the issue of dating safety with her father:

Don't worry. I'm gonna be safe.

He, he's a good guy.

He would do nothing to hurt me.

While this might be true with some potential dating partners, it certainly cannot be said for all. It was typical for my students to be more trusting of others than they should be, just because they wanted to be liked so badly. Using a wheelchair did not guarantee personal safety in a big city.

Rayann was at least aware of one important thing her condition affects. Her condition also affected coordination, strength, and balance, but she only mentioned one aspect:

Researcher: What is your disability?

Rayann: I forgot what it's, I forgot what it's called

Researcher: Ok, what we're going to do is then, tell me about your disability then.

Rayann: Like what?

Researcher: Um, what, what, um, what limitations does it put on you? Do you know what

limitations are?

Rayann: (shakes head no)

Researcher: How does it limit you? How does it stop you from doing what you want to

do?

Rayann: I don't know what you mean

Researcher: Well, let's see. There's some things that other people can do that maybe give you a hard time, that you wanna do, things like, things you used to do all the time that

you don't do anymore

Rayann: Walk

Researcher: Ok it affects your walking. Ok so your disability affects your walking.

Rayann: Yea

Researcher: What else does it affect?

Rayann: Just walking

Researcher: That's the main thing, just walking, right?

Rayann: (nods)

Since she did not name other activities her condition affects and could not remember what it was called, she was found to be dependent in disability awareness. To her credit, she has mentioned off the record, that her balance was affected and that she had difficulty keeping her hands steady. Her condition had a long name and was difficult to pronounce. An easy way to name it was to call it A-T. Rayann was unaware that her condition can also cause brain cell destruction.

Needs related to independence in the environment. Beyond being independent at home, it was important to be independent in the living environment. Rayann expressed wanting to feed and cook for her own baby, but she needed assistance to feed herself. She will not be able to feed a baby without extensive support. When I asked her what kind of job she wanted, she asked me if being a mom was a job. I said yes, that it was one of the hardest jobs in the world.

Then I continued the interview as such:

Researcher: What would help you get the job done?

Rayann: My husband

Researcher: Your husband? You better believe it!

Rayann: (laughs)

Researcher: He will help you too.

Rayann: My kid

Researcher: Your kid, um hm. Ok, how can your husband get the job done? How could

he help you?

Rayann: By carrying him Researcher: Carrying--

Rayann: While I make the food

Researcher: Carrying the baby while you make the food

Rayann: Yea

Rayann would be very dependent on family or spousal support to help her care for and prepare food for a baby. It may not even be advisable or possible to have children given her genetic condition (Mets, Tryon, Veach, & Zierhut, 2015). The above quote was included in another reference when I coded for fantasy thinking. In any case, here it showed she was dependent on others for food preparation and feeding a child.

Housekeeping was another area in which Rayann was dependent. She would like to help out around the house, but wanted to do it her way, which may be unrealistic:

Researcher: What kind of household chores do you do at home?

Rayann: Nothing Researcher: Nothing? Rayann: (shakes head no)

Researcher: Which household chores do you wish you could do?

Rayann: Um, I wish I could help

Researcher: With what?

Rayann: With cleaning and...I don't know

Researcher: Cleaning what?

Rayann: The table

Researcher: Like wiping the table?

Rayann: Yea

Researcher: Um hm, what else?

Rayann: I don't want to do it sitting down. I want to do it standing up. Researcher: I know, I know. But it's possible to do it sitting down, isn't it?

Rayann: Yea but...I still, I don't know

Researcher: You'd rather do it standing up right?

Rayann: Yea

Having done household chores from a wheelchair myself, I have tried to explain to her in the past that she could still wipe a table from a sitting position, but she insisted she wanted to stand.

She admitted that she did not do household chores so she was found to be dependent in this area.

This particular quote was used again later in this chapter in another category.

Even though Rayann was the representative case of the highest language and cognitive level in my study, she still had difficulty expressing herself. The same held true for students with mild intellectual disabilities as was noted in the literature. They still needed assistance with communication and Rayann demonstrated it:

Researcher: What if you don't know the price of something in the store?

Rayann: I don't know

Researcher: Yea, you don't know the price! So what if you don't know the price? What

do you do about that?

Rayann: I don't know what to do. Researcher: Well, you gotta find out...

Rayann: Yea

Researcher: ...so you can pay. So how do you solve that problem? You don't know the

price.

Rayann: I don't know

Researcher: You never go to the store and say, hmmm, I really like that? I want to buy it.

I don't know how much it costs though.

Rayann: I look at the price

Researcher: And what if it's not there. You look at the price. That's...sometimes it's there. Sometimes it's not there. If the price is not there, what do you do? With the salespeople in the stores?

Rayann: Tell the employees there the...they're not there?

Researcher: And then what do you do?

Rayann: I don't know

Researcher: You *don't* know the price. So what do you do?

Rayann: No, I don't know (laughs) what to do

Researcher: Besides telling them, hey, there's no price over there, you, you gotta find

out...so what do you do?

Rayann: Don't know the answer

Researcher: Well, what I would do if, if, if there's no price there, and you tell them, the employees, there's no price over there, the next thing to do would be to ask what? Hmm, I like this. I want to buy it, but there's no price on it. Then what do you do? You say

what...?

Rayann: Can I buy it?

Researcher: They'll say I don't know if you have any money. What do you have to ask them? What...? There's no price here ma'am. And you gotta ask them what...?

Rayann: I don't know

Researcher: I'll tell ya. What's the price? You say what's the price? You ask them how much does it cost.

Rayann: Yea

Researcher: You're making it complicated, more, harder than it has to be. Right?

Rayann: Yea

Researcher: But you can talk. What's the price? Rayann: No! Because I can't think straight!

Rayann: Oh you can think straight! You're making it more complicated than it...

Rayann: Not now

Researcher: Naaa, you're thinking straight. You're getting it complicated. You're making

it more complicated. It's just a simple question. You ask them. What's the price?

Rayann: (laughs)

Researcher: Because I know you do that and you can, right?

Rayann: Y-y (laughs)

Researcher: Right? I know you can.

Talking with salespeople in stores was something our classes practiced once a week. Stores have stopped putting price tags on items and have begun using bar codes, making the prices harder to discern for my students, unless they knew where to search and how to ask for help. Rayann has been using this skill for at least five years. In spite of this fact, she still needed extensive communication support in this interview situation.

Rayann mentioned school activities for many of her community and social access activities. She was dependent on others to assist her in mobility skills and in making social contacts possible. She shopped occasionally with her family, but it was difficult to get her out due to her heavy wheelchair and no access to a family lift van. The school was usually the provider for her community travel through Community Based Instruction (CBI) and social access:

Researcher: How do you go shopping at the mall?

Rayann: I go with my class?

Researcher: With your class, ok. How else do you go to the mall to go shopping?

Rayann: In the bus

Researcher: On The bus? What kind of bus?

Rayann: School bus!

Researcher: Oh the school bus! Rayann: When we go to CBI

Researcher: Oh, CBI bus. Do you go with the family?

Rayann: No

Researcher: You never go to the mall with the family?

Rayann: Yea but not in the school bus (laughs) Researcher: Not in the school bus no, no, no...

Rayann: (laughs)

Researcher: ...no, no. So how do you go shopping at the mall with your family?

Rayann: In the car Researcher: Ok

Rayann: We used to but now not, not every d--, I don't know Researcher: You used to go to the mall more than you go now?

Rayann: Yea

Researcher: What made the change?

Rayann: I don't know

Researcher: Was it a new baby...?

Rayann: Maybe

Researcher: ...that made things change?

Rayann: Maybe

Researcher: How about before the baby? Was it different then? You went to the mall

more often?

Rayann: I go with my stepmom.

Researcher: Ok

Rayann: My dad is always working

Researcher: He is, isn't he?

Rayann: Yea

It appeared Rayann did go out shopping with the family and that she either minimized it or she did not go out very often. She may not realize the effect having a new baby had on the ability of her stepmother to pick up and go with a baby and a young woman with a wheelchair.

Additionally, she did not realize the effort it took for teachers and family to get access to a lift bus or lift van for her because everything was always done for her with no effort on her part.

Financial support was not well understood by Rayann. She knew her father gave her money because he loved her, but she was unaware of how much it took to generate enough money to meet her needs and had no idea where financial support realistically came from:

Researcher: You need money. What do you do?

Rayann: Ask my dad can I borrow money

Researcher: There you go. Ok, ok and what is something that you're saving up for? Do

you have some money at home saved?

Rayann: Yea

Researcher: Ok what is something that you're sa--

Rayann: I have money in my wallet

Researcher: Yea you have some money. What are you saving it up for?

Rayann: An apartment Researcher: (gasps) Really!

Rayann had no idea of how much money it took to rent an apartment and to keep up with payments from a steady income. Rayann had no intention of securing continual support for herself financially and was found to be dependent. In addition, she had just been awarded Medwaiver services and did not know the potential benefits it can provide for her adult life.

Transportation was a major issue with Rayann because she used a heavy electric wheelchair. She must change to the manual chair to use a private car for travel, but then she cannot push it herself and I knew she did not like to be so dependent. Sometimes mobility interfered with her social life:

Researcher: How do you plan weekend activities?

Rayann: With, we talk about planning, but I don't know if it's gonna happen...

Researcher: Who talks about it?

Rayann: I, me

Researcher: You said we talk about it, so who's we?

Rayann: Me and Lilly Researcher: Yea, ok

Rayann: We talked about it today, but I don't think it's gonna happen...

Researcher: You don't think it's gonna happen?

Rayann: No

Researcher: Well, why do you think that? Rayann: I don't know if they're gonna take me

Researcher: Who?

Rayann: My dad and my step mom Researcher: Mm hm, what about Lillian?

Rayann: Maybe, I don't know

Researcher: Well you could get the other little chair and they can just put you in the back

of the car, you know, with the little chair...

Rayann: Yea, I could go, but I don't know if, if they will take me...

Researcher: Mm hm, did you ask her about that? Did you talk to Lillian about that?

Rayann: No, we talked about it today Researcher: Today, oh just today

Rayann: Yea

Researcher: Well you gotta sit down and make a plan, right?

Rayann: Yea

Researcher: You gotta plan that out

Rayann: Yea

Researcher: How could you plan that out?

Rayann: Yea

Researcher: If you want it to happen, you gotta make a plan. It's just gonna be a dream if

you don't plan it out. Do you know what I'm saying?

Rayann: I know

Researcher: Do you want it to be a dream or do you want it to come true?

Rayann: I want it to come true

Researcher: You gotta make a plan, ok, and it'll happen. Not only today but, let's say, let's make a real quick little plan. How you would do this with Lillian. How would you

do this? Use your imagination. How would you plan this out?

Rayann: My dad or my stepmom

Researcher: Um hm Rayann: Could take me

Researcher: That's step one, that you try, clear it with them and if they're busy, what do

you do?

Rayann: I, I won't go?

Researcher: You won't go? You're gonna just give up like that?

Rayann: Uh huh I... Researcher: (laughs)

Rayann: I, I, I send someone else to take me...

Researcher: Someone else, right?

Rayann: Yea

Rayann had a large family support base and could ask any one of them for assistance. In addition, her friend, Lillian, in Best Buddies had known her since at least middle school and had taken her out in the past. Rayann's father had a heavy work schedule and other family members to support, but Rayann was also reticent to contest her father's authority due to cultural and religious influences. I realized the above excerpt was a bit structured, but it was difficult not to go into that teacher mode when I knew they could give me a better response. I felt like this was her chance to express herself since time was not on our side.

Analysis of the Needs Expressed by Vanesa

Needs related to family functions and/or personal care attendant. Vanesa was another participant who had a caretaker, but at home, not at school. Her home nurse assisted her with bathing and dressing skills. Vanesa walked unaided, but had difficulties with stiffness in her legs.

She fell easily if bumped into. Even though she was thin, she liked to eat. She can prepare snacks and other cold foods, but she was dependent in preparing heated foods:

Researcher: Do you make warm foods?

Vanesa: Yea

Researcher: How do you prepare your warm foods?

Vanessa: With meatballs

Researcher: Yea

Vanesa: And then with, with, with cheese on...

Researcher: Uh huh, and then what do you do?

Vanesa: Um, and then make, um, with the, make the meatball, when it's done you, you

put, um, you put, uh, thingy, the oven fort- forty forty-five minutes

Researcher: Um hm Vanesa: And then...

Researcher: Which oven is this?

Vanesa: Mmmm...

Researcher: The big house oven or the little microwave oven?

Vanesa: The big house oven

Researcher: Do you do it by yourself?

Vanesa: Yea!

Researcher: Really? No one helps you? Vanesa: Oh, yea, my mom helps me.

As stated previously, Vanesa had a nurse at home to assist her with bathing and dressing. Her mother assisted her in the bath also, but it was unclear to what degree based on what Vanesa said:

Researcher: Tell me about taking a bath.

Vanesa: Wash my hair clean.

Researcher: Um hm, who does that?

Vanesa: My mom

Researcher: Ok, what do you do for yourself though, by yourself?

Vanesa: Oh

Researcher: With the bath? By yourself. What do you do by yourself in the bathtub? Or

in the shower?

Vanesa: In the bathtub?

Researcher: Or in the, do you take a tub bath or a shower?

Vanesa: Oh bath, bath

Researcher: In the tub or in the shower?

Vanesa: In the shower

Researcher: Ok, how do you do a shower by yourself without mom there? How do you

do it?

Vanesa: You clean my, my, on my leg

Researcher: Um hm

Vanesa: And I like this (gestures washing leg while sitting)

Researcher: And you do it yourself?

Vanesa: Yes

Researcher: Ok what else do you do for yourself?

Vanesa: By myself?

Researcher: By yourself, in the shower...

Vanesa: I put my, my arms (gestures washing arm)

Researcher: Um hm

Vanesa: And then I put the other arm (gestures washing other arm)

Researcher: Um hm, um hm Vanesa: Because it gets safe

Researcher: Um hm, you wash yourself...

Vanesa: Yea

Researcher: How about your hair?

Vanesa: Oh, my hair? Researcher: Yea Vanesa: Is...

Researcher: Who does that? Vanesa: My mom, oh!

Researcher: Do you ever shampoo your own hair? Vanesa: Yea like this (gestures washing hair) Researcher: You can shampoo your own hair?

Vanesa: Yea

Vanesa seemed not fully aware of why she had a personal assistant at home and what she actually did for her. There was an area of confusion between us about which assistant I was talking about. She did not have her own one-to-one assistant at school, but there was one in her class for another student. This assistant often helped other students too, and that was possibly from where the confusion stemmed:

Researcher: What's difficult for you to do?

Vanesa: It means that, that you, that you be my, my assistant.

Researcher: Yea? You have an assistant for things that are hard? Is that what you're

trying to say? Vanesa: Yea

Researcher: Ok the assistant helps you with things that are hard?

Vanesa: Yea

Researcher: What does the assistant help you with that's hard for you?

Vanesa: Um (laughs) get, get like, get like a stamp then you put the piece of paper and

then and then I write it down.

Researcher: Um hm

Vanesa: Yea

Researcher: You know what I thought you were going to say just now? You need a helper

to help you get dressed. Because you were going to say dressed, weren't you?

Vanesa: Uh, yea

Researcher: So is it hard to get dressed?

Vanesa: N-n-no. No, no. Researcher: Um hm Vanesa: I dress by myself. Researcher: Oh you do? Oh...

She often returned to repeating her ideas about writing something down on a piece of paper. It might be her go-to phrase when she did not know what to say or she was getting fatigued, but did not want to end the conversation. It was also evident that I was leading the conversation toward reality since her mind did tend to wander off topic. Vanesa maintained her story and denied having help with dressing. She ended with a firm "I dress by myself," but said something different further along in the conversation:

Researcher: Ok so it's not hard for you to get dressed. What's hard for you to do then?

You have an assistant...?

Vanesa: Put...

Researcher: What does she help you with? Vanesa: Take um take off of my shoes, off Researcher: That's hard for you to do?

Vanesa: Yea

Researcher: It's hard for you to take off your shoes so you get, you get help taking off

your shoes? That's one thing, right? Am I saying it right?

Vanesa: Mmm, yea

Researcher: So what's hard for you to do is take off your shoes is hard for you. What else

is hard for you?

Vanesa: Take off your shirt

Researcher: Take off the shirt is hard for you?

And further through the conversation:

Researcher: What else is hard besides take off? What else is hard for you to do?

Vanesa: Take me a shower

Researcher: Taking a shower is hard. You have a little help with that.

Vanesa: Yea

Apparently, assistance stopped at getting dressed and she had learned how to dress herself.

Vanesa participated in doing the laundry, but was found to be dependent due to some contradictions in her answers:

Researcher: You said you put the clothes in the washer. You do it by yourself?

Vanesa: Yea

Researcher: Ok, after they come out of the washer then what happens? Because they're

still wet then. Vanesa: (laughs)

Researcher: How do you get them dry? Vanesa: You can dry like 10 minutes

Researcher: Where?

Vanesa: In the washing machine

Researcher: Washing machine just washes with water.

Vanesa: Yea

Researcher: Now it's all wet. Now what do you do?

Vanesa: Now? Now you that take out

Researcher: And where do you put it? When it's wet?

Vanesa: Um

Researcher: How do they get dry?

Vanesa: Um, you, you p-, you, uh, you put, you put the, oh, you put (laughs), you put a- a

um, a a shirt and a shorts and then you fold it...

Researcher: Do you have a dryer? Vanesa: Yea, my mom has the dryer

Researcher: Who puts the clothes in the dryer?

Vanesa: My mom

Researcher: Do you ever help her with that? Vanesa: Yea, I will help her, like, like put away

Researcher: Put away where?

Vanesa: In the washing machine (laughs)

Vanesa was completely dependent on her mother for medical care and doctor appointments. She participated in taking medicine by cooperating in swallowing pills. She did not administer medication to herself independently:

Researcher: What do you do to take care of your medical needs? You know what medical

needs are? Vanesa: No

Researcher: Like medicine?

Vanesa: Oh!

Researcher: How do you take care of your medicine?

Vanesa: You put the pill Researcher: Um hm Vanesa: Inside my mouth Researcher: Um hm

Vanesa: And then I drink milk with it

Researcher: Uh huh

Vanesa: And then it's better

Researcher: Yea with milk, you take it with milk, right?

Vanesa: Yes!

Researcher: Ok, and when do you take your pill?

Vanesa: I, at night

Researcher: At night? Only one time at night? That's it?

Vanesa: Yea

Researcher: That's pretty good.

Vanesa: (nods)

Researcher: Do you do it by yourself or...?

Vanesa: Mmm

Researcher: How do you remember that pill? Vanesa: My mom helps me by myself. Researcher: Helps you remember to take it?

Vanesa: Yea, all night

Researcher: Um hm. Do you ever go get the medicine yourself?

Vanesa: Yea

Researcher: You get it yourself?

Vanesa: Like this...(gestures opening a bottle) and then (gestures taking a pill with a

drink)

Researcher: And you don't ever forget it?

Vanesa: No

Researcher: You have a good memory, huh?

Vanesa: Yea

Researcher: Does your mom ever help with medicine?

Vanesa: Yea

Researcher: Ok, so like tonight, when it's time for your pill, what's going to happen tonight when you have to, when you have to have your pill? What's going to happen

tonight? Who gets the pill?

Vanesa: My mom

Researcher: Ok she gets the pill?

Vanesa: Yea

Researcher: And then what happens?

Vanesa: And then (laughs), and then we, wuh, oh, and then when I bad dream, I take my

pills.

Researcher: Oh, a bad dream? You have bad dreams? Don't like that...

Vanesa: (nods)

Her mother was also the one that made doctor appointments for her:

Researcher: How do you keep your appointments?

Vanesa: Oooh! I know I know... Researcher: Oh you do, ok. Vanesa: Mmm

Researcher: How do you keep your appointments?

Vanesa: Eat the medicine and, and you swallow it the pill.

Researcher: Um hm

Vanesa: Like this (gestures swallowing a pill)

Researcher: Um hm

Vanesa: Like that and then that's it.

Researcher: Let's say you have to go to the doctor. Who makes the appointments?

Vanesa: My mom

Researcher: Ok and how do you keep them?

Vanesa: The receipt

Researcher: Um hm you keep the receipt.

Vanesa: Yes

Researcher: Um hm, how do you get there to your appointments?

Vanesa: Um, to, I forgot.

Researcher: Ok, if you have to go to the doctor, who reminds you to go to the doctor

appointment? Vanesa: My mom

Researcher: Your mom reminds you.

Vanesa: Yes

Vanesa was very trusting of everyone and very friendly to everyone, hugging almost anybody she saw. She was also very pretty and small in stature. Safety in the community and at home was an area of concern for all her caretakers. It was unclear from her statements if she truly knew how to be safe if she was alone at home:

Researcher: How do you keep safe in your house? Let's say mom is not there. How do

you keep safe in your house if mom is not there?

Vanesa: Oh, you, you lock the door. Researcher: Lock the door. What else?

Vanesa: And then you come in

Researcher: You come in. How about the phone?

Vanesa: The phone? Oh.

Researcher: If the phone rings? How do you keep safe if the phone rings?

Vanesa: Call someone

Researcher: Someone's calling you and you're home alone. How do you answer the

phone? Or do you answer the phone?

Vanesa: Get some privacy Researcher: Privacy?

In addition, Vanesa was dependent on others for assistance in dealing with difficult people in her environment:

Researcher: Let's say your friend is a bully, and, but you like that person, and they're

bossy to you. They always tell you what to do, they treat you mean...

Vanesa: (nods)

Researcher: But you think they're your friend and you like them and your mom doesn't

like them. Vanesa: No

Researcher: What do you about that?

Vanesa: Sad

Researcher: Um hm, and what do you say, what do you do about that?

Vanesa: Get mad

Researcher: Ok, about what?

Vanesa: About, about be kind to you

Researcher: Um hm

Vanesa: Be kind to your friends.

Researcher: Um hm, but they're not being kind to you, but do you still like them?

Vanesa: Yea

She would need her mother's advice on who to be friends with because she liked others even if they were mean to her. Vanesa was easy prey in our special classes and had often been the target of student bullies. She did not defend herself physically and cowered down when intimidated.

Vanesa was surprisingly aware of her condition because she said it once in a conversation. She was not, however, able to describe what it was. Undoubtedly, she has heard the word spoken at home or at school since it was part of her vocabulary:

Researcher: What do you need to know about seizures though? What do you need to

know about it?

Vanesa: I need to know about it is...get the CP you have to cole (call?)

Researcher: Um hm Vanesa: Bac-, bacteria?

Researcher: Bacteria, about bacteria, um hm

Vanesa: Right

Researcher: That's a good thing to know about bacteria.

Vanesa: Oh yea

Researcher: What does CP stand for?

Vanesa: CP stand for?

Researcher: Um hm, um hm, why did you say CP just now?

Vanesa: Mmm, because CP stand for healthy issues

Researcher: What kind of, healthy issues? Does it mean Cerebral Palsy?

Vanesa: Yea

Researcher: Uh huh, I see, because you have Cerebral Palsy...

Vanesa: Yea

Researcher: You want to know more about that, right?

Vanesa: Right

Researcher: That's your health issue.

Vanesa's vocabulary was unusually precocious, probably because her mother was a teacher and she heard conversation like those about "bacteria" all the time. She seemed to throw those big words out when she did not have the answer to a question. Being able to pronounce big words did not mean she understood them. Later in the interview, this was what she said:

Researcher: What do they call the disability that you have? What do they call it? I have...

Vanesa: I have, inte- tsk I have, hmmm, I don't know (shrugs shoulders)

Researcher: Well, before you said, last time you said, I have CP.

Vanesa: Oh! I have CP!

Researcher: Ok, what does CP stand for?

Vanesa: Um P, V?

Researcher: CP, what does it stand for? Vanesa: CP is be nice to each other

She was found to be dependent in understanding her own disability.

Needes related to independence in the environment. Vanesa could also prepare cold foods and snacks for herself if hungry, but needed help with heating elements.

Researcher: How do you make your own meals by yourself?

Vanesa: W-with, with, with peanut butters

Researcher: Peanut butters Vanesa: Yea, sandwich

Researcher: A sandwich! And then what happens? How do you make that? Vanesa: With, with, uh, with the peanut butter on, on, on the knife to spring

Researcher: Um hm, peanut butter spread on what?

Vanesa: Spread on the, on the bread Researcher: And then what do you do? Vanesa: And then we eat it (laughs).

Researcher: Ok, just like that, peanut butter and bread

Vanesa: Yea

Researcher: No jelly?

Yea (laughing) yea jelly, he!

Researcher: Oh Vanesa: (laughing)

Researcher: Tell me about the jelly then.

Vanesa: (still laughing) To, to sp-, to, to spread like, um, like, like to, to, to eat it

Researcher: Um hm

Vanesa: It gets i-it, it gets mel-ting

Researcher: Melting? Um hm, oh do you heat it?

Vanesa: Yea!

Researcher: That sounds good

Vanesa: To heat it up and you're done Researcher: Ok, do you heat it up yourself?

Vanesa: Yes!

Researcher: Tell me how you heat it up yourself.

Vanesa: Like this and then...

Researcher: Um hm

Vanesa: (makes a click noise) you're done! Researcher: And how, where do you heat it?

Vanesa: On, I, I eat it on the, on a toaster oven (laughs) Researcher: Toaster oven. Do you turn it on yourself?

Vanesa: Yea

Researcher: Tell me how you do it, the toaster oven.

Vanesa: With both hands Researcher: Um hm

Vanesa: Like this (makes a sound effect as she turns a crank in the air)

Researcher: Uh huh, and what are the steps that you take to turn the oven on?

Vanesa: You take the oven off

Researcher: Uh huh Vanesa: And it burns Researcher: Ooooo

Vanesa: And when you done, you poock it back on again

Researcher: Um hum

Vanesa: Yea

Researcher: What temperature do you put it on?

Vanesa: S-Six minutes

I was unclear if she had gotten burned before because she mentioned "it burns," but I was sure someone must have been in the vicinity when she was using heating elements. The risk was too great that she would start a fire without some supervision nearby. I erred on the side of caution because I knew how much she wanted to please me by saying she did things by herself and burns are traumatic.

Housekeeping was a safer form of independence for Vanesa. Her mother still provided assistance in keeping the kitchen clean:

Researcher: What housework do you do in the kitchen?

Vanesa: The plates, the, the door (drawer?)

Researcher: Um hm

Vanesa: And then, and then put the cups in the, in, in the kitchen (laughs)

Researcher: You put the dishes away?

Vanesa: Yes

Researcher: You put the dishes away. Who washes the dishes?

Vanesa: My mom

She also gets assistance in cleaning the floor:

Researcher: How about the floor? Vanesa: Oh yeah! The floor to clean Researcher: How do you do that?

Vanesa: Like this (bends over out of sight of the camera and makes low sweeping

motions from side to side)

Researcher: Um hm Vanesa: And then...

Researcher: And you do that?

Vanesa: Yea Researcher: Ok

Vanesa: My mom helps me to do my room and the, and the floor

The following excerpt was included as being significant because it was possible that she believed that her job around the house was to play video games and that was her job skill. It was not clear if Vanesa felt that way, but she kept talking about the TV in reference to cleaning up the living room. Perhaps she was told to watch TV so her mother could do the housework around her:

Researcher: What housework do you do in the living room?

Vanesa: TV, remote control

I took that comment and others as evidence that she did not clean the living room without supervision.

While Vanesa had excellent pronunciation and vocabulary, she often did not make sense when she spoke. Her cognitive level caused her to drift off topic or to previous unrelated topics. She needed assistance to stay on topic. Here was an example of her answers to probing questions about speaking to and dealing with salespeople in stores:

Researcher: How do you buy food at Publix?

Vanesa: My mom goes to Publix.

Researcher: Um hm Vanesa: And...

Researcher: You have CBI sometimes, don't you? How do you do it in CBI?

Vanesa: Ooooh, Home Depot

Researcher: Or there. How do you buy things at Home Depot on CBI?

Vanesa: Santa Claus (laughs) Researcher: Santa Claus helps you?

Vanesa: Noooo!

Researcher: That's what you said!

Vanesa: Nooo!

Researcher: Ok, how, tell me how you buy things. How do you deal with the salespeople

in the stores? What do you say to them? What do you do with them?

Vanesa: Christmas decorations

Researcher: That's not a person now. How do you talk to people in stores that work there in the store? How do you talk with them? How do you deal with them? People that work in the stores and you want to buy semathing.

in the stores and you want to buy something...?

Vanesa: Oooh

Researcher: How do you talk with them? How do you deal with them?

Vanesa: By the kitchen?

Researcher: Maybe, but what do you say with, to them, when you want to buy something

and what do you do? Tell me the whole story about that.

Vanesa: Uh, to buy...I don't know, I forgot

She mentioned she had help from her mom in going to Publix and that she went to Home Depot on CBI trips at school. She was not able to communicate successfully how she spoke to store personnel during that specific line of questioning at that moment. In her defense, I asked her multiple questions at a time and that is not ideal methodology from a special education teacher, but in my defense, I was trying to get her to give me more information by guiding her toward what I wanted to hear. Another example of an off topic response is:

Researcher: How do you choose an activity to do with a friend?

Vanesa: A friend?

Researcher: Yea, something to do with a friend, an activity, that's fun...

Vanesa: A family?

Researcher: Not family, friends. How do you choose something to do with a friend?

Vanesa: A friend is, is to know about the future...

Vanesa was not independent in speaking up for herself in a restaurant, according to her responses below:

Researcher: You got the wrong order sitting in front of you. What do you do? What do

you say?

Vanesa: Sssay thank you

Researcher: So you eat whatever they give you?

Vanesa: Yea

Researcher: Even if it's a mistake? You eat whatever they give you? Ok, um, what if you're eating and you need some ketchup and they don't have any ketchup on the table?

Vanesa: (laughs)

Researcher: What do you do about that problem?

Vanesa: (laughs) Ah! On the plate!

Researcher: There's no ketchup on the plate and you don't see a bottle anywhere. You're eating a hamburger, let's say, for example, eating a hamburger and you don't have any ketchup.

Vanesa: I forgot the ketchup, aaahhh!

Researcher: So what do you do about that problem in the restaurant? You're in the restaurant now. And you have a hamburger and maybe you have French fries too, but you know what? You need ketchup. What do you do? What do you say?

Vanesa: You say thank you.

Researcher: And that gets you ketchup? That's how you get ketchup by saying thank

you?

Vanesa: Yea

Researcher: Really? That's how it works?

Vanesa: Yea (clears throat)

Researcher: You're sitting in the restaurant at the table. They give you a hamburger and they give you some French fries, but they didn't give you any ketchup and you *really* wanna have ketchup on your French fries and on your hamburger. What do you say?

Vanesa: You say thank you. Oh! You say you welcome.

Researcher: You don't say anything about the ketchup? You don't ask for ketchup?

Vanesa: Yea but...

Researcher: How do you ask for ketchup?

Vanesa: Ask for ketchup?

Researcher: How do you do that?

Vanesa: You can eat it.

Researcher: Yea you can eat it. Ok next question.

She often automatically would respond "thank you" or "you're welcome" when asked what she would say about some topic. She was not thinking about the question and needed support to express herself verbally. She has been experimenting with texting, however:

Researcher: Do you ever do texting? Do you ever text?

Vanesa: I, Oh I text my mom's iPad

Researcher: Oh! On the iPad. Who did you text?

Vanesa: Myself (laughs)

Researcher: To yourself and what did you say?

Vanesa: Um, she, s-, wait, she said I miss you, I and I...

Researcher: Who said that?

Vanesa: Me!

Researcher: Who said they miss you though?

Vanesa: My mom

Researcher: Oh she text you? Your mom text you?

Vanesa: Yea

Researcher: And how did you get that text?

Vanesa: I text from my phone, (laughs) like this (gestures texting)

Researcher: Uh huh

Vanesa: And then that's it.

Later in the conversation she proceeded to demonstrate to me how she texts using her own phone. I also noticed that it was not working so there was a doubt in my mind if she really could text. I knew all she can write correctly most of the time is her first name:

Researcher: And how do you do that? How do you call Julie?

Vanesa: Call, call with the speaker Researcher: With the speaker phone?

Vanesa: Yea

Researcher: Have you done speaker phone with her?

Vanesa: Yea

Researcher: And how do you know what her phone number is?

Vanesa: It's 373 wait 995

Researcher: Wow and how do you use the phone? How do you do that on the phone?

Vanesa: You wanna see me?

Researcher: All right, go get the phone.

Vanesa: (gets up to get her phone from a nearby desk) (places book bag on top of the

desk)

Researcher: Getting the phone...

Vanesa: (opens her book bag hanging on back of the desk) Wait, uh wait...

Researcher: Uh huh Vanesa: ...Sadler, I'm...

Researcher: We're waiting for the phone... Vanesa: Yea! You...(reaches into her book bag)

Researcher: We are waiting...

Vanesa: I got this...too (takes out her cell phone and puts it on the nearby desk)

Researcher: Nice!

Vanesa: Sadler! Wait, come on, I'm getting... (laughs)

Researcher: All right, come sit down. Vanesa: And then Sadler, and then you...

Researcher: Um hm

Vanesa: You, you text on the phone. Researcher: You text on the phone too? Vanesa: Yea (laughs)

Researcher: That's great! I didn't know you could do that!

Vanesa: Yea, I only do it at home. Researcher: You do it at home, right?

Vanesa: Um hm

I interpreted this section as being dependent because she said she only texts at home. To me that means that she texts at home because she needed help with it. Using a speaker phone was more on her ability level.

Vanesa knew she was dependent on her mother for financial support. We ask students to bring spending money for each CBI trip. This was her answer for where she gets her money:

Researcher: What do you do when you need money?

Vanesa: Get the cash register.

Researcher: It doesn't belong to you.

Vanesa: Oh

Researcher: What do you do if you need money?

Vanesa: I ask for the wallet Researcher: From who?

Vanesa: For the cash register. Oh yea!

Researcher: What if you're home and you need money? When you're home?

Vanesa: On my home?

Researcher: You're home and you need money. What do you do?

Vanesa: I ask mom.

Researcher: You ask your mom, right?

Vanesa: Right!

Researcher: That's a good answer.

Vanesa: Yea

Researcher: Ok and when do you ask mom for money?

Vanesa: To buy pizza

Researcher: To buy pizza, what else? Vanesa: Ha—(clears throat) hamburgers

Researcher: Hamburgers? And when else do you ask her for money?

Vanesa: Chicken

Researcher: But when do you ask her for money? When? When do you ask her for

money? Vanesa: Um

Researcher: When do you think, hm, I need some money? When do you think that?

Vanesa: When? I think that?

Researcher: Yea

Vanesa: You-you need some help. Researcher: When you need some help? Vanesa: Yea

Vanesa also knew she needed her family's support to be independent, even if she was not forthcoming in her off-target answers:

Researcher: Who always helps you with things?

Vanesa: Oh! The president!

Researcher: The president!? (fakes crying)

Vanesa: No (laughs), wait, wait, help, uh probably a bank

Researcher: You don't have any family [Vanesa]?

Vanesa: I, I, I do have a family

Researcher: Would they help you, do you think?

Vanesa: Yea

Researcher: Who would help you in your family?

Vanesa: My mom

Researcher: Oh she, she would help you...

Vanesa: Um hm

She was not really interested in living in her own house away from her mother. Vanesa, her mother, and I have attended parent group meetings about supported living arrangements. I knew her mother was interested in her living independently one day, but Vanesa expressed that she will stay at home:

Researcher: How about living in your own house?

Vanesa: Own house? Yes

Researcher: Not with mother, in your own house. How about that?

Vanesa: Oh, yea

Researcher: What do you think about that?

Vanesa: Um, about like...

Researcher: Living in your own house...

Vanesa: Yea

Researcher: Without mother, in your own house

Vanesa: Um hm

Researcher: What do you think about that?

Vanesa: I thinking about, about how she want to stay in my house.

Researcher: Which house? Vanesa: My mom's house.

Researcher: Um hm

Vanesa: And then, and then I have to go sleep by myself.

Researcher: Where? Vanesa: My room.

Researcher: Your room where, whose house?

Vanesa: My mom's house.

Vanesa trusted her mother to look after her best interests. She expressed a dependence on living at home with her mother. She did not appear that she was prepared mentally to live independently.

To get around the community, Vanesa depended on others. She talked about going shopping with her mother and going to CBI on the school bus. After graduation, everything changes:

Researcher: How are you gonna travel around Miami after you graduate? No more school

bus!

Vanesa: No?

Researcher: Nope! Once you graduate your high school no more bus,

Vanesa: Wh—

Researcher: No more school bus

Vanesa: From here?

Researcher: From here, no more yellow school bus, so how are you going to get around

Miami after you graduate?

Vanesa: Go to FIU

Researcher: How are you going to get there?

Vanesa: (laughs)

Researcher: That's possible, ok, that's fine but how are you going to get there?

Vanesa: You can open the door

Researcher: Of what? Vanesa: Of to go to FIU

Researcher: How are you going to get to the door of FIU?

Vanesa: Go inside

Researcher: How are you going to get there? From your house to FIU? How are you

going to get there?

Vanesa: Mmm, uh, you can call 911 Researcher: That's for emergencies

Vanesa: Oh! I forgot Researcher: Um hm

Vanesa: Sorry Sadler, I forgot

Researcher: But who's gonna help you get from your house to FIU if you wanna go

there?

Vanesa: My mom

Researcher: There you go! Vanesa: I forgot! (laughs)

Researcher: Your mom will help you with that!

Vanesa: I forgot Sadler, I forgot, I forgot

Researcher: That's ok, we got it now, don't we?

Vanesa: Yea

This report of the results had so far explored the needs of the three participants in this case study. Those were the areas where the participants showed dependence. Next I discussed the subsequent theme of preferences for each case.

Analysis of the Preferences Related to Beliefs, Interests, and Abilities for Maria

Preferences related to beliefs for Maria. Maria had a very positive attitude toward herself. She believed she can accomplish anything she wants:

Researcher: Let's say there's something that you, you want to do and people are telling you you can't do that and you think you can. What stops you from doing the things you want to do that you know you can do it?

Maria: I tell him yes I can. I can do something whatever I can do.

Researcher: Um hm

Maria: Because I'm [Maria] and I, I can do everything. I love to go shopping and get my clothes

She had confidence in herself and could defend herself verbally. She stood up for her beliefs:

Researcher: Let's say they tell you, aaa, you can't sing, you can't dance in the talent show. You can't do that. You're no good. And you, you think you can do it. You can dance and sing in the talent show and they think, aaa, you can't dance and sing in the talent show. You're no good.

Maria: Yes I can do it! I can dance! And you can't beat me! Researcher: Um hm, so you, you speak up for yourself?

Maria: Yea!

Researcher: What else do you tell them?

Maria: You dance bad. You dance like a chicken.

Researcher: What if they say, oh no, you dance like a chicken. You can't do that. You

think you can dance. You can't dance!

Maria: I can dance better than you. You want a dance competition? And bring it on!

The yearly Best Buddies Talent Shows that I have created and presented to the entire student population at our school has thoroughly increased my students' self-confidence. The general education students have been so supportive every year, applauding loudly with their cell phone lights beaming in the darkness. I am partly guilty of inflaming the overconfidence in their talents. What happened in the talent show was not what will happen in reality and my students did not see the difference. They believed that what they saw in the media was possible for them also.

Maria believed that she was never to blame for anything and that it was always someone else's fault. Here was one of many examples of this type of thinking that I have collected:

Researcher: Do you ever do anything wrong like that?

Maria: No

Researcher: You ever make mistakes?

Maria: No

Researcher: You never make any mistakes?

Maria: No...

Researcher: You mean you're perfect?

Maria: M-Yea

Researcher: Ah! We all make mistakes. We all make mistakes.

Maria: Oh, my mom always makes mistakes.

Researcher: Not, not your mom, it's about you. Think about a mistake you made a long, a while back, think about any mistake you've made in the past. How'd you feel when you

made a mistake?

Maria: I never makes mistakes.

Maria did not like to be corrected and got emotional when she was, as observed in the classroom by all her teachers and by her teacher at work training in the hospital.

Maria also believed that she was safe and strong. She believed she could defend herself against danger and could fight back:

Researcher: What if you're home alone and someone breaks into your house. What would

you do?

Maria: I give them knuckle sandwich.

Researcher: A knuckle sandwich! (laughs)

Maria: I say, hey, stop breaking my house! I hit you back!

Researcher: Ok, what if it's a great big man and you can't beat him. What would you do

then?

Maria: Stop breaking my house!

Researcher: Uh huh, he broke in the door. He's get-, he's coming in the house and you're

alone.

Maria: He better....

Researcher: What would you do?

Maria: You better stop, you better stop breaking my house! This is my house!

Truthfully, I taught her the words "knuckle sandwich" because that was how I would tease them when they would ask for lunch too early. But, she did believe she could beat an intruder. She did not feel like she was in any real danger in the community, while her parents frequently expressed worry for her safety, even during supervised school outings.

Maria often used the word "brave" to describe herself. I was unsure if the frequent use of the word was a Spanish language interference or a perseveration, even after conferring with her other teachers of Hispanic heritage. After speaking with my colleagues, I believe it was just an automatic, habitual response she used, possibly due to limited vocabulary or cognition. She used brave in reference to work skills, conflicts with friends, and reaching her goals. In Spanish, *bravo* can mean anything from aggressive, grumpy, upset, or what English speakers mean by courageous. It did not always match with what she was talking about:

Researcher: What do you do if people treat you like a child and you feel like an adult? Maria: Hey, I'm not a child! I'm a big adult, ok, adult! Stop calling me a baby, man!

Researcher: Um hm Maria: I'm a, I'm brave!

And later in the interviews:

Researcher: Why do you say it's great to be who you are/?

Maria: Because I go to my house and, um, I do like take a shower, I eat breakfast, um, I

get on the bus on time, um, I brush my hair, I did the bed, I do everything.

Researcher: Um hm. What do you like about being who you are? I like being me

because...?

Maria: I'm brave

Researcher: You're brave! That's a great thing to say. You're brave, what else?

Maria: I'm great Researcher: At?

Maria: The Best Buddies

Researcher: You're great at Best Buddies? You are!

Maria: Yea

Referring to her goal of living with a friend when she is an adult:

Researcher: How do you know how well you're doing working toward this goal? How do you know you're doing—?

Maria: Because I'm brave

Researcher: You're brave, right?

Maria: Yea

On being independent:

Researcher: How do you know how well you're doing on working toward this goal of, of

riding the bus?

Maria: Because I'm brave

Researcher: You're brave and how do you know how well you're doing working toward

that goal of being independent and riding a bus by yourself?

Maria: I don't need no help.

Researcher: How do you know, how do you know you're doing a good job?

Maria: Because I'm brave

Researcher: Because you're brave, ok.

On encouraging herself:

Researcher: Let's say you're not able to do certain things on the job. How do you feel

about that?

Maria: Real good

Researcher: Um hm, it doesn't bother you?

Maria: No

Researcher: Ok. How do you encourage yourself?

Maria: I'm brave

And on being a good worker:

Researcher: Why are you such a good worker? What makes you so good at working?

Maria: Because I'm really, really brave

I interpreted all these excerpts to mean that Maria believed she had both inner strength and physical strength. She believed she was independent and could take care of herself.

As for Maria's beliefs about others, she believed that people liked her and that she could cooperate with her friends, but that they were mean if they did not agree with her. Here is a conversation about how her friends feel about her:

Researcher: How do you think she felt when you gave her that gift?

Maria: She felt warm

Researcher: Warm inside, right?

Maria: Yea

Researcher: So what do you think people, uh, feel about you?

Maria: Because I'm the best.

Researcher: That's right, that's why they feel the way they feel, but how do you think

they feel about you? How do your other, your other friends feel about you?

Maria: Feel good

Researcher: Um hm, you said they felt warm when you gave them that gift? And how

about your other friends, how do they feel about you?

Maria: Good

Researcher: How about [Alicia]?

Maria: She feel um good

Researcher: How about [Jevon]? Maria: [Jevon's] gone, what is...

Researcher: No, but how do you think he feels about you?

Maria: Good

Researcher: How about your other friends, how do they feel about you?

Maria: Real good

Researcher: Ok, let me name someone, h-how does um, let me think, how does [Vanesa]

feel about you?

Maria: [Vanesa] talks too much

Researcher: How do you think [Vanesa] feels about you?

Maria: Crazy

Researcher: She thinks, she's crazy about you, you mean?

Maria: Yea

Researcher: Like, she likes you a lot, you mean?

Maria: Yea, she starts talking too much duh duh (gestures mouth talking with her

hands)

Researcher: Yea, but how do you think she feels about you?

Maria: Good

Researcher: That she likes you?

Maria: Yea

Researcher: Crazy about you or just likes you?

Maria: That likes me

Researcher: Ok, ok, are you trying to say that she's crazy or crazy about you? I'm not,

I'm, I'm not sure about that. Maria: She talks too much

Researcher: You said something about crazy and [Vanesa]. You mean [Vanesa]?

Researcher: [Vanesa] is crazy or [Vanesa] is crazy about you?

Maria: She's crazy about me

Researcher: Ok, that's what I'm trying to find out, about you, ok?

Maria: Yea

But if her friends did not agree with her, she will get upset:

Researcher: What do you do when you don't agree with others opinions or their ideas?

Maria: What's that?

Researcher: Their opinions or ideas, let's say, ok, you love Beyonce and you love, who's that, who's that other girl you said you loved, you love Vanessa Hudgins and you love

Beyonce? Maria: Yea

Researcher: And your friends, they, they can't stand them. They'd rather listen to Taylor

Swift. And you just don't like Taylor Swift. You like Beyonce. You like Vanessa

Hudgins. And they don't like, they think, they think...

Maria: They, they (laughs)

Researcher:...they go to you, ew, you like Vanessa Hudgins? You like Beyonce? Oh no,

no, Taylor Swift is a much better singer. And they don't agree with you...

Maria: They really *mean*! (laughs)

Researcher: They're mean? So how are you gonna handle that?

Maria: I gonna crying

Researcher: You're gonna cry? (laughs) Does that solve the problem?

Maria: No

Researcher: No right?

Maria: They gonna hurt my feelings!

Maria seemed to have no problems working well with others in job training:

Researcher: So how well do you work with, with other people like him?

Maria: Maybe one year

Researcher: So how do you do that? How do you work with someone like that?

Maria: I don't know

Researcher: Well is, do you, do you get along well? Do you fight?

Maria: Yea, we get al--, no, we get along well

Researcher: Ok. You get along well?

Maria: Yea

Researcher: How do you get along well with him when you're working with him?

Maria: We, we friends, mmm, I text to him.

Researcher: Um hm

Maria: And he text me back.

Researcher: Wow! So you talk with him and...

Maria: Text

Researcher:...and, and you work with him?

Maria: And text

Researcher: And text, um hm

Maria: Yea

Researcher: So no problem working with somebody else, right?

Maria: No

Maria was unique in that she expressed numerous fantasies about her life as she dreamed it would be. It was difficult for me as her long-time teacher to accept her accounts and allow her to continue believing in her fantasy world. Nothing I said made her think about her real life as a

real adult with disabilities. I teach about the realities of having a boyfriend and marriage often in my classes. I even invited a married couple with Down's syndrome as guest speakers to give students a reality check. Maria persisted with her fantasies:

Maria: I wanna have a, um, a wedding.

Researcher: You wanna have a wedding or go to a wedding?

Maria: Go to a wedding

Researcher: Ok, you want to go to a wedding.

Maria: Yea

Researcher: And what would you do there?

Maria: Dance or something or get...

Researcher: You wanna dance at a wedding?

Maria: Or get married.

Researcher: You wanna get married?

Maria: Or get married.

Researcher: Tell me about that. Maria: Um, I'm gonna be the wife.

Researcher: You wanna be the wife. How would it be? Tell how that would be.

Maria: It's gonna be love. (gestures drawing a heart in the air)

Researcher: Yea? What else?

Maria: Um, I'm gonna have a boyfriend, Logan.

Researcher: Logan?

Maria: Yea

Researcher: You already have somebody in mind, don't you?

Maria: (laughs) (nods)

Researcher: I don't know Logan, do I? Maria: (laughs) From Big Time Rush! Researcher: From Big Time Rush?

Maria: (nods)

Researcher: Oh, he's a big movie star?

Maria: (nods)

Researcher: You better get in line for that man!

Maria: (laughs)

Researcher: I think all the girls are going to marry him.

Maria: (laughs)

Researcher: You gotta have a real boyfriend! Right?

Maria: (nods)

Researcher: Like Justin Beiber, all the girls are in line for Justin Beiber.

Maria: (laughs)

Researcher: You're gonna be in a long line for that!

Maria: (laughs)

Researcher: No, you gotta find a real boyfriend, right? How would you find a real

boyfriend?

Maria: Kendall broke my heart!

Researcher: Kendall?

Maria: Yes

Researcher: Who's Kendall? Maria: From Big Time Rush

Researcher: Oh, I don't know who that is...

Maria: He broke my heart, man! Researcher: How did that happen?

Maria: He likes another girl.

Researcher: Ah boy!

Maria: He likes another girl.

Researcher: Um hm Maria: But not me

Researcher: Um hm, but you don't even know him. To get married you have to know

somebody well, right?

Maria: Yea

Maria had fantasies about how she will get around locally and how she will travel out of town:

Researcher: What type of transportation do you plan to use after graduation?

Maria: Um

Researcher: You know what that means, transportation?

Maria: Who's that?

Researcher: How you're going to get around in Miami? How you're going to travel?

Maria: I want to go to...

Researcher: But how are you going to get around in Miami, from one place to another,

how you gonna get there?

Maria: I want to go to Pitbull to Miami.

Researcher: And how you gonna to get there?

Maria: In a limo

Researcher: In a limo ok, that's to go see Pitbull, right?

Maria: Yea

Researcher: But what if it's everyday traveling? Every day things you have to do as an

adult, how are you going to travel around in your everyday life in in Miami?

Maria: I go in the plane.

Researcher: In Miami? Planes take you so far away. You just wanna go around in Miami. How are you going to get around the city of Miami when you're an adult and you finish school?

Maria: M-maybe Big Time Rush have a city. They have a city I watch it.

Researcher: That's a TV show though. Let's get down to real life. How, how are you going to move around in Miami in your real life? Let's say you finish school you graduated. How are you going to travel around Miami in your real life? What's your

plan?

Maria: Uh I get dressed Researcher: Um hm

Maria: Wash my teeth, my mom drives

Researcher: Oh your mom's gonna drive then? You're planning on getting a ride with

your mom to get around?

Maria: I go to like a Vanessa City

Researcher: Ok, let's say your mom couldn't drive you and you wanted to get out in Miami and go and travel and maybe go shopping. What would you do then if your mom

couldn't take you?

Maria: Fine I go walking.

She appeared indignant when things did not go her way and claimed to be able to do things on

her own anyway. Maria also dreamed about being a big star herself and believed it was a right:

Researcher: How about the rights you have to live, for your life? What are the rights you

have? What are the right you have about your life?

Maria: I wanna, I wanna be a artist.

Researcher: Yea, ok

Maria: I wanna be a artist.

Researcher: What other rights do you have to live?

Maria: I wanna be a stuper star.

Researcher: Ok. What other rights do you have?

Maria: That's it.

It was partly my fault, because I asked her about her dream life, but Maria spoke again later in our interviews about wanting to be a super star:

Researcher: If anything was possible, I mean anything was possible, what would you

like?

Maria: I want to be a star.

Researcher: You want to be a star.

Maria: Yea, a stuper star. Researcher: A super star.

Maria: Yea

Researcher: Yea?

Maria: Yea

Researcher: Tell me more about that.

Maria: I wanna be on TV, be in the screen and s-, and, and sing some songs.

Researcher: And sing, you want to be a singer.

Maria: Yea

Researcher: A super star singer.

Maria: Yea

Researcher: Wow! Maria: That's it.

Researcher: What kind of songs would you sing?

Maria: Uh um, Demi Levato Researcher: Demi Levato?

Maria: Yea

Researcher: Those kind of songs?

Maria: Yea

Researcher: Um hm, anything else?

Maria: That's it.

Leading Maria into the last question of our interviews, I asked her about her dream life. This question coming after the previous excerpt, I was still hoping for a more realistic answer, but did not get one. Saying the words "let it go" was the wrong choice on my part if I wanted to get a more realistic answer:

Researcher: What is your dream life?

Maria: Don't know, I wanna be the colors of the wind.

Researcher: The colors of the wind.

Maria: Yea

Researcher: That's nice. Maria: Yea, that's it

Researcher: Naaa na na, tell me all about your dream life. If you have the, your life, the way you dream it to be, what your dream be like? How would you dream about your life?

Maria: I can't stop the dream.

Researcher: Don't stop the dream, let it go, tell me about your dream.

Maria: I, I want to be like Elsa.

Researcher: Like Elsa?

Maria: Yea

Researcher: How's Elsa? Maria: She wears like a blue.

Researcher: Um hm

Maria: And, and a pony tail and she has purple eyes and she has a little scarf, a little

purple. I wanna be like her.

Researcher: Like her, that's your dream?

Maria: Yea, that's my dream. Researcher: You like her?

Maria: Yea

Researcher: Anything else?

Maria: No

Researcher: All right.

Maria: Yep!

It may be important to note that we were planning to use the music from the movie "Frozen" in the next talent show, so in a way, her dream was a reality to her. Maria also believed herself being able to travel to various places independently, cost

being no real issue, because her parents would pay for it if she was nice:

Researcher: You said you like to travel.

Maria: Yea

Researcher: Ok, where do you like to travel? To go where?

Maria: I wanna travel and to, to pig bull's concert.

Researcher: People's concert?

Maria: Like pig bull

Researcher: Oh Pit Bull concert!

Maria: Yea

Researcher: You wanna go to a Pit Bull concert?

Maria: Yea

Researcher: Wow!

Maria: Far away from here

Researcher: That would be nice, wouldn't it?

Maria: Yea

Researcher: And how would you plan that?

Maria: I w-, I w- with my brain

Researcher: You need to think about that, right?

Maria: Yea

Researcher: What's step one, first you do what?

Maria: Be nice Researcher: To who?

Maria: To me

Researcher: Yea? To a Pit Bull concert?

Maria: Yea

Researcher: You're not nice to yourself?

Maria: My mom s-, my dad ding me crazy at home.

Researcher: Does your mom say that to you, be nice to me?

Maria: Yea

Researcher: Oh, your mom is telling *you* that?

Maria: M-my mom is telling me that.

Researcher: You have to be nice to mom first, then what?

Maria: Don't be mean to mom.

Researcher: To who?

Maria: To, to, don't be mean with my mom. Researcher: Don't be mean to your mom?

Maria: And I say I'm sorry, I'm sorry, I'm sorry

Researcher: Yea, you gotta get on her good side, right? Maria: And then I'm sorry and then she say ok, I can go.

Researcher: Ok, how are you gonna go there? Alone or with somebody else?

Maria: No, I gonna go with a friend. Researcher: Ok. Which friend?

Maria: Uh, with [Lorena]

Researcher: With [Lorena]!

Maria: Yea, we're gonna go together. I'm gonna buy two ticket, one for me, one for

[Lorena].

Researcher: Nice

Maria: And then we're gonna go together. We're gonna go together.

Researcher: And what city would the concert going to be in?

Maria: I don't know it's far away

Researcher: Is it in this city or another city?

Maria: Another city Researcher: Ooo far away

Maria: It's far.

Researcher: You don't wanna do it in Miami, right?

Maria: No

Researcher: You wanna go to a different city?

Maria: Yea, different city Researcher: Oh I see.

Deep down Maria knew she needed her mother to drive her around and was interested in local

travel in the community:

Researcher: How about traveling? Do you travel by yourself?

Maria: I don't know, it's too far, it's too far.

Researcher: Well, do you know how to, how to get help with that?

Maria: It's too far.

Researcher: How do you get help with that if you want to go somewhere?

Maria: It's too far.

Researcher: Ok, it's too far, but how do you get help with that then?

Maria: I want to go to Vanessa Hudgins, but my mom say no, it's too far. It's too far. Researcher: Ok, that's pretty far, Vanessa Hudgins. Let's say it's everyday stuff. You want to go to the store and get some, and get some, and get a new blouse at the store. You

need a need blouse to wear at the store. Right? Can you do it by yourself?

Maria: No

Researcher: With help? Can you do it with help?

Maria: I can go with my mom.

Researcher: With your mom, you can go. Once you're there you get it yourself, can't

vou?

Maria: Yea

Researcher: You just have to get a ride there.

Maria: With my mom.

Researcher: You just need to get a ride, right?

Maria: Yea

Researcher: Getting a ride is the, is the problem, getting a ride.

Maria: Yea

Maria offered some ideas as to what she felt her human rights were. There was some English-Spanish confusion due to homonyms like rights/rice/write, but I finally communicated to her what I wanted to know about:

Researcher: What are the human rights that you have?

Maria: Don't know

Researcher: You don't know what your human rights are?

Maria: No

Researcher: Human rights, you don't know what that is?

Maria: Rice

Researcher: Not rice, rights. Derechos, derechos humanos, human rights

Maria: Human rights

Researcher: Yea, what are your human rights? I have a right to...

Maria: Write, write

Researcher: No I don't mean escribir. I don't mean that, I mean a right, a derecho, a

derecho...

Maria: Listen to me!

Researcher: You have a right to be listened to.

Maria: Yea

Researcher: Ok, you have a right for people to listen. You have a right to be listened to.

You have a right...what else? What else are your rights?

Maria: Pay attention

Researcher: Uh huh, pay attention to me. You have a right for, for people to listen to you.

Maria: Yea

Researcher: Right. Any other things you have a right to?

Maria: No

Researcher: I have a right to have...

Maria: No curse

Researcher: Uuum, we can't always help that though, right?

Maria: Yea

Being in my class for more than three years, Maria had participated in discussions regarding human rights and her rights as an adult. She was able to verbalize some of the concepts we had discussed in class.

Preferences related to interests for Maria. Maria's interests were age appropriate for her, at 20 years of age. As are all young people seeking a life independent from their parents, she was aware she will need their support for the transition. With the condition of the American

economy, young people without disabilities will also need assistance from their families, only with Maria, it will be more so:

Researcher: What are you doing now to be independent from your parents?

Maria: Be nice to them.

Researcher: Be nice to them...

Maria: I say thank you, thank you very much Researcher: Um hm, for supporting you, right?

Maria: Yea

Researcher: But what are you doing right now to be independent from your parents so

you can live on your own one day? Maria: Be, uh, be nice, don't be mean.

Researcher: Um hm Maria: Don't be mean. Researcher: Um hm

Maria: Be nice to each others.

Researcher: Yes, well what kind of, what kind of things are you doing though, to help

you be independent, independente, you know, independent?

Maria: I want to be a doctor.

Researcher: Ok, but how are you going to be independent from your parents then to, to,

to be a doctor? You gotta be independent.

Maria: I ask my mom. I say mom, I wanna be a doctor.

Researcher: Um hm

Maria: And she say okay, and okay, I be a doctor.

She will also need help selecting a realistic job for her abilities. She knew she must be nice to her parents to get what she wanted. This holds up in the literature because individuals with disabilities were aware that their choices in independence depended on family support. Maria knew she needed assistance from her parents to get the job or something close to the job that she preferred. To clarify her goal of being a doctor, she later said she would actually like to work with a veterinarian, which would be a viable option for her ability level:

Maria: I know one thing independent...

Researcher: What?

Maria: I wanna be, um, a doctor.

Researcher: Yea? You like that kind of a job?

Maria: Yea, I wanna be a doctor. Researcher: Tell me more about that.

Maria: I wanna be a doctor work, with pets.

Researcher: Oh, with pets?!

Maria: Yea

Researcher: Like a pet doctor?

Maria: Yea, to help. Researcher: Wow!

Maria: To help little pets.

Researcher: Aw! Maria: Little pets

Researcher: I didn't know that about you.

Maria: I love little pets.

Researcher: Tell me more about that. Maria: I love little pets, they really nice.

Researcher: Aw!

Maria: I give it to them and give it to my people.

Researcher: You, you what? You're good to them? What did you say?

Maria: I'm really nice.

Researcher: You're nice to them? Maria: I give it to the people. Researcher: Give it to them?

Maria: Yea

The above quote demonstrated reliability because she repeated the same ideas, giving more

details about her thoughts on independence and what it meant to her.

Maria was interested in doing things as an adult:

Researcher: How about mom and dad, where are they going to live

Maria: Far away from there (laughs)

Researcher: Oh yea you wanna live with Logan by yourself

Maria: Yea

Researcher: Oh that's a new story now. I thought you wanted to be with mom forever. So

you want to get married one day with Logan

Maria: Yea

Researcher: And have your own place to live

Maria: Yea

Researcher: Oh I didn't know that you're telling me now

Maria: And have babies

Researcher: And babies uh huh

Maria: And babies

Researcher: And babies, how many babies

Maria: One hundred (laughs) Researcher: That's a lot of babies

Maria: (laughs) Researcher: Woo! Maria: (laughs) Researcher: You better have some, a lot of money you better marry, you better marry a

rich man

Maria: Ok are we done

Researcher: Is Logan rich? Change the subject now? Change the subject?

Maria: Yea

Researcher: Am I making, Are you getting embarrassed?

Maria: He dimme he got a lot of money

Researcher: He better have a lot of money for a hundred babies.

Maria: Yea

Researcher: Does he have a job?

Maria: Yea Researcher: Ok Maria: Ok that's it

Researcher: All right wanna change the subject now.

Maria: Yea

Researcher: Ok I got that story straight.

Maria mentioned Logan at least five times during the interviews. I believed her fantasy about as many times. Part of the reason for that was because I thought she was talking about an ex-student of mine named Logan that attends an adult recreational facility that is associated with the one Maria attends. I thought she must have traveled to the other facility in the camp van. Another reason I believed her fantasy boyfriend was because I just forgot she mentioned him before. At the end, I could tell Maria was getting uncomfortable with her storytelling and wanted to change the subject, possibly before I remembered and figured it out. I think I might have been a little fatigued and all the interviews seemed to merge together in my mind during this time.

Maria was interested in doing things by herself. This was especially true when it came to shopping. She would like to go shopping without her mother and to do whatever she wanted at a mall:

Researcher: What is something you prefer to do all by yourself?

Maria: I want to go shopping. Researcher: By yourself?

Maria: Yea

Researcher: You like doing that, huh?

Maria: Shopping

Researcher: Tell me more about that. How you want to shop by yourself. Tell me more

about that.

Maria: I br- I bring um I go to the, the house and bring money. Researcher: Bring money and then what are you gonna do?

Maria: I'll bring my purse with me.

Researcher: Uh huh, get your purse. Then what are you gonna do?

Maria: And go in my mom's car. Researcher: Go in your mom's car.

Maria: Yea

Researcher: Um hm. Then what are you gonna do? Maria: I go to the store and then get something.

Researcher: Uh huh, by yourself

Maria: Yea

Researcher: Nobody with you.

Maria: No

Researcher: And then what are you gonna do in the store by yourself?

Maria: Get a some makeup.

Researcher: Makeup Maria: Yea and that's it.

Researcher: Ok, tell me. I want you to tell me all the things you wanna do when you're

shopping all by yourself.

Maria: I wanna get some makeup. I wanna get s-, um, um, get some frozen.

Researcher: Some frozen what? What?

Maria: The frozen, man!

Researcher: Frozen movie, the movie?

Maria: Yea

Researcher: Something with frozen on it.

Maria: Yea

Researcher: Ok, you gotta go shopping, see which one you want...

Maria: Yea

Researcher: When you see it, you know it, right?

Maria: Yea

Researcher: What else you wanna do when you go shopping?

Maria: Uuum

Researcher: By yourself? Something you can't do now but you love to do?

Maria: Maybe a snack or...

Researcher: Got out and get a snack, those are great answers!

Maria: Maybe a movie

Researcher: Maybe see a movie, those are all great answers!

Maria: Or CD

Researcher: You buy a CD on your own...

Maria: Yea, that's it.

Researcher: Those are all great answers, I love it!

Maria: Yea

Maria neglected to mention where her mother was going to be after she got to the mall, but
Maria may not know how to tend to personal safety with unfamiliar people. She also did not
discuss where she will get the money and how she will get home. Consequently, this was found
to be an interest in being independent.

She was also interested in forming and maintaining friendships of her choice on her own:

Researcher: What else do you do independently? Like an adult does, besides shopping?

Maria: Talk to my buddy on the phone.

Researcher: Talk to who? Maria: Buddy on the phone

Researcher: Your buddy on the phone. That's adult too. Adults do that. What else do you

do that's adult, that's independent?

Maria: Listen to music.

Also what was really important to Maria was access to music. She spent all of her classroom free time listening to her favorite artists and role playing their lives. She participated in music as a social activity with like-minded friends who did the same.

Following the lead of the research questions, another commonly mentioned topic was choices. Choices were coded into several categories: living, job, leisure, friends, food, post-secondary education and training, and travel. In that order, here were some of the quotes from Maria:

Researcher: What you could do for a place to live?

Maria: I wanna live in a hotel.

Researcher: In a hotel?

Maria: Yea

Researcher: You like that idea, right?

Maria: Yea

Researcher: Who with? Who do you want to live with?

Maria: Me and my friend.

Researcher: Ok Maria: That's it.

Researcher: That's what you...

Maria: I wanna live...

Researcher:...want to do in the future?

Maria:...and then mom can stay home in there.

Researcher: Um hm, that's in the future when you get older...for later.

Maria: Yea, when you get older.

By saying "mom can stay home in there" Maria meant that mom can stay home and she can live in a hotel with her friend. She repeated these thoughts throughout and even with occasional contradictions, I believe living in a hotel was her most well-defined interest regarding her future living situation:

Maria: I wanna live far away from here.

Researcher: Yea? Tell me more. Maria: I wanna live in a hotel.

Researcher: Nice! Ok, and why do you like hotels?

Maria: Because they big hotels and they are tall, tall buildings.

Researcher: Um hm

Maria: They have tall buildings and I wanna live there.

Researcher: Ok, why do you wanna live there?

Maria: With a friend.

Researcher: You want to go live with [Alicia] someplace

Maria: Yea

Researcher: Ok where do you want to live with [Alicia]? Maria: Uh, [Alicia] and me we're gonna to live in a hotel.

Researcher: Oh, in a hotel ok because I was wondering if she wants to live with her mom,

in her mom's house.

Maria: She says she wants to live in a hotel.

Researcher: She might want to get out and live in a hotel too. I know, I was thinking the

same thing, ok. Maria: In a hotel.

In some comments she contradicted herself, so to clarify, I questioned her about a previous statement concerning who she wanted to live with, a boyfriend previously cited (many times), or family she mentioned wanting to live nearby or with her in the same house:

Researcher: Where are you gonna live if you get married with Logan? Where you gonna

live?

Maria: We're gonna live in some house (laughs).

Researcher: Ok, so how about mom and dad? Where are they going to live?

Maria: Far away from there (laughs).

Researcher: Oh yea, you wanna live with Logan by yourself.

Maria: Yea

Researcher: Oh, that's a new story now. I thought you wanted to be with mom forever.

So you want to get married one day with Logan?

Maria: Yea

Researcher: And have your own place to live?

Maria: Yea

Researcher: Oh, I didn't know that, you're telling me now?

Maria: And have babies

Researcher: And babies, uh huh

Maria: And babies

Maria was not unlike many other teenage girls and young adults with the same aspirations.

Statements made after this excerpt described her fantasy of having a hundred babies and that her future rock star husband would give her lots of money to support her, but that was another topic that was already mentioned.

When questioned about being independent, Maria had this to say concerning her interest in choosing the job she preferred:

Researcher: What kind of help do you need to make a choice as far as which job is the

best job for you?

Maria: Um, Publix, I wanna work...

Researcher: What kind of help, do you need any kind of help to, to decide on a job for

you, to choose a job? Maria: Um, I love Publix. Researcher: Um hm Maria: Um, Winn Dixie

Researcher: Winn Dixie, um hm Maria: Uh, I love two jobs.

Researcher: Um hm. One or the other would you would like, right?

Maria: Uh

Researcher: Ok, what kind of help do you need to choose which one to work at? What

kind of help do you need to, to choose that?

Maria: In Publix

Researcher: Yea, but what kind of help do you need to choose which one?

Maria: I—

Researcher: Everybody needs help in life.

Maria: Aaah, I do by myself?

Researcher: Really? You don't need any, any help...? Maria: I don't need no help, I don't need help, I c—

Researcher: Ok

Maria: I do by myself.

Researcher: You're independent, ok, ok, ok.

She talked about one simple thing she was interested in that would make her a happy adult:

Researcher: Like when you graduate and you finish school, what would make you a

happier, even happier, adult, when you finish school?

Maria: I wanna work on the job.

Researcher: Have a job.

Maria also mentioned various jobs she wanted that are the typical ones special education teachers encourage. She talked about working at grocery stores, department stores, fast food restaurants, schools, and even talked about wanting to work with her dad. However, I was most impressed with her unique answer about hospital related work that did not include working with people like she does at work training. She mentioned that they would not allow her to work with animals at Project Victory in the children's hospital. I think the job she wanted to do most was to work with

Individuals with disabilities have more than the usual amount of leisure time to manage.

An important question to ask was what they liked to do in their free time. These were some of the most frequently mentioned activities Maria said she liked to do:

Researcher: How do you choose your free time activities?

pets, since she specifically pointed it out on several occasions.

Maria: Free time? Researcher: Um hm

Maria: I ask mom I want free time.

Researcher: But how do you choose those things you want to do? Maria: I ask mom I want to go to the computer. I need a break. Researcher: You choose computer. What else do you do?

Maria: Um, I use my tablet.

Researcher: You, and use your tablet...
Maria: Mom, I wanna use my tablet please.
Researcher: So you do have a tablet?

Maria: Yea

Researcher: I thought you didn't have a tablet.

Maria: I have one at home.

Researcher: Oooh I thought! Well, I was confused about the table and the tablet...

Maria: Yea

Researcher: tableta

Maria: Yea

Researcher: And then tablet, it got me confused, I'm American, you know, it got me

confused. Maria: Yea Researcher: So you have a, you have a tablet at home?

Maria: Yea, I have games.

Researcher: I didn't know that. So you choose, you, so, how do you choose those things

to do?

Maria: I put is the, is I use computers, I just tap and every day I use tablet and I go to my

tablet, um, um, put it on and then I put movies. Researcher: So when do you choose computer?

Maria: In the night Researcher: Um hm Maria: When I sleep

Researcher: Ok, is it in your room?

Maria: Yea

Researcher: Ok, and when do you choose to use the tablet?

Maria: In my room

Researcher: But when do you choose to use it, when?

Maria: In the night Researcher: At night

Maria: Yea

Researcher: At the same time you're using the computer?

Maria: Yea

Researcher: At the same time?

Maria: Yea

Researcher: You have the computer on, tablet on

Maria: Yea

Researcher: Some people do that, I guess.

Maria: Yea

Researcher: That's possible. Ok, how do you choose other free time activities?

Maria: Um, I go to the kitchen. Do me a sandwich. I go to the kitchen, do a sandwich.

Researcher: Um hm

Maria: I put some sandwich, put some in my room and, and, and eat it and then free time.

Researcher: You eat that while you're having free time?

Maria: Yea

Researcher: Ok, besides computers and tablets, what else do you like to do in your free

time?

Maria: Maybe sing

Researcher: You like to sing?

Maria: Yea

Researcher: And how do you do that at home?

Maria: I go on the computer and sing.

Researcher: Oh, you sing along with the music that you hear?

Maria: Yea

Maria's strong interest in her tablet was probably the chief source of friction between her

and her mother. The attraction of technology has not been lost on people with disabilities. As

seen in the literature, television and movies were, and still are, a major source of selfentertainment for this group. Now young people access movies and music through Internet connected individual devices.

Another of Maria's interests was participating in activities with her friends. A *Quinceañera* or *Quince*, for short, is a Latin American birthday party for a 15 year old girl held to mark her passage into womanhood:

Researcher: What do you do with your friends at home?

Maria: I don't know

Researcher: They don't visit you at home?

Maria: (shakes head no)

Researcher: Oh, is that what it is?

Maria: [Lorena] visited me.

Researcher: Ok, what did you do with her?

Maria: Um, she loves to dance. Researcher: So what did you do? Maria: And she dance too, I dance too.

Researcher: That's what you did, you danced with her.

Maria: Yea, oh...

Researcher: I don't know [Lorena].

Maria: She's my best friend, um, she's my best friend.

Researcher: From where?

Maria: From far away, I don't know, I know her house, I went to—

Researcher: You know her house?

Maria: I know her house, one time I went to a party...

Researcher: Um hm

Maria: She was having a *Quince*...

Researcher: Oooh!

Maria: And then I had fun.

Maria realized that through common interests, she can make new friends:

Researcher: How did you become friends with [Belinda]?

Maria: When I was, when I was 16. Researcher: When you were 16.

Maria: I was 16, I was, when I was 18. I'm 20. When I was 18, I was her friend.

Researcher: And how did that happen?

Maria: I was, one time I went to bowling and, and, sh—and I invited her, she give me a

present.

Researcher: And after that what happened?

Maria: I went Mom, um, can I invite [Toronica] ([Veronica]) to bowling please and she

said yes.

Researcher: And then, what happened?

Maria: And she said ok Researcher: And now? Maria: I have a new friends.

Researcher: You have a new friend because you did something together with them

Maria: Yea

Researcher: Like bowling, right?

Maria: Yea

Participating in activities together was the major tenet of membership in Best Buddies, a club I have sponsored at our school for 15 years:

Researcher: How about new friends? How do you find a way to make new friends?

Maria: Uh like [Belinda]?

Researcher: Is, I don't know [Belinda].

Maria: She was here, she was here last night (referring to Best Buddies Parent's Night

Meeting).

Researcher: The Best Buddy girl?

Maria: Yea

Researcher: Ok, you have new friends through Best Buddies.

Maria: Yea Researcher: Ok

Maria: I call her last night.

Researcher: Uh huh, so you find new friends with social clubs?

Maria: Yea, I call her last night. Researcher: You did? That's good!

The easiest way to practice self-determination skills with people who have even the most severe of disabilities was through choosing what food they wanted to eat. Many times they did not even get to choose that most basic aspect of human rights. These participants were all verbal so hopefully they might speak for others:

Researcher: How do you deal with people in a restaurant?

Maria: I go get a plate, I get some food.

Researcher: Um hm

Maria: I get like shrimp or pizza or something. I get some pizza. I eat it and then it smells

so good!

Researcher: Um hm

Maria: And delicious, look like pepperoni.

Researcher: Like pepperoni pizza...

Maria: Yea

Researcher: And then what happens?

Maria: You wanna go to a second, second food?

Researcher: To get seconds? Uh huh

Maria: You can get dulces (sweets)...chocolate or, or chocolate or ice cream

Researcher: Um hm

Maria: I get some chocolate, get some ice cream.

Researcher: Um hm

Maria: And *natilla* (pudding). I get *natilla* and I eat it and it smell good!

And for breakfast:

Researcher: What if it's, your mom is not there and it's CBI and you go into a restaurant,

like maybe Denny's. Mom is not there and you have to do it by yourself?

Maria: I do it by myself.

Researcher: How do you do that?

Maria: I go in the, I say order, I need, um, some food.

Researcher: You order.

Maria: I'll order, please I need a food.

Researcher: You order it and how do you order food?

Maria: Um, I get some pancakes.

Researcher: But how do you know what pancakes they have?

Maria: They have like strawberry pancakes.

And for lunch:

Researcher: How does she know which restaurant that you want to go to? This is about

you now, not about your mom.

Maria: I say, um, tan I pick some no no no no no no no (points from side to side)

Researcher: Hm?

Maria: Tan I pick Wendy's, tan I pick Burger King, buh, buh, um, that restaurant I say,

one, two.

Researcher: So how do you decide?

Maria: I, I, I decide in my head, in my head.

Researcher: Um hm

Maria: I say Wendy's, Wendy's and I pick Wendy's.

Researcher: That's your favorite?

Maria: Yea

Researcher: Ok and why did you pick Wendy's?

Maria: Because it's awesome.

Researcher: It's awesome? What makes Wendy's so awesome? Maria: Because they have, it's a new Wendy's and it's so big.

Researcher: Oh, that's the new one.

Maria: Yea the new one.

Researcher: Wow Maria: The new one.

Researcher: How about the foods they have there?

Maria: Burger King?

Researcher: You said Wendy's was your favorite though...

Maria: Yea, Wendy's

Researcher: Ok, why is there, do you like their foods?

Maria: Because they have, um, wraps, they have hamburgers, they have, they have salad,

they have, like apple, and it's so good!

Researcher: Those are the things that you like, the foods that you like, the foods?

Maria: Yea, I like that.

Researcher: Ok. That's why you picked it, right?

Maria: Yea

Researcher: They have your favorite foods there.

Maria: Yea

And at work training when students were paid for volunteering with a free breakfast:

Researcher: So what do you eat then?

Maria: I eat like eggs, um, bacon, some juice... Researcher: And you, you pick that yourself?

Maria: Yea, by myself.

Researcher: Ok, it's what you want to eat!

Maria: Yea

And last, at home:

Researcher: What do you choose to eat at home?

Maria: I eat like a chicken nugget, like a chicken nugget.

Researcher: Um hm, um hm

Maria: Microwave, I put it in the microwave like two minutes.

Researcher: Um hm

Maria: And then, and then I take it out and I put some ketchup.

Researcher: Ketchup, you like it with ketchup.

More significant than merely choosing her favorite foods, Maria had interests in post-secondary education and training for a job:

Researcher: How do you find out what training or what classes or what schools you can

go to after you graduate? How do you find out?

Maria: I wanna, I want to go to FIU.

Researcher: FIU, oh you told me that before.

Maria: Yea

Researcher: That's a good program.

Maria: Yea, but my mom s-, she's, my mom said I need two more days.

Researcher: Years Maria: Two more years Researcher: Years, uh huh Maria: Yea, because I'm 20

Researcher: Um hm

Maria: Next year I'll be 21 and then I have 22.

Researcher: Um hm

Maria: I need two more years.

The last coded interest was in traveling, whether in the community or further away. Here is expanded text from a previous In Vivo quote:

Researcher: What would help you be able to go out more often in the community? What

would help you?

Maria: I want, I want to go to the, to Spain.

Researcher: That's pretty far, too. What would help you get out and travel? What would help you travel more? You said New York, you said Spain. What would help you get to

those, to those places?

Maria: Mexico?

Researcher: Yea, what would help you get to those places?

Maria: I go on a plane.

Researcher: And how would you, what would help you get, get a ride on a plane? What

would help you?

Maria: We go to the airport.

Researcher: Ok, but what would help you get a ride on a plane more often?

Maria: On a train.

Researcher: Train too, ok.

I used mostly quotes with both of our statements since I had difficulty getting enough text and participants needed extensive support to pull conversation from them. I wanted the reader to see how the conversation was flowing. In addition to expressive difficulties, Maria did not discriminate community locations from travel abroad. Next I redirected her into the previous query about local travel:

Researcher: Ok, now those are, this, those are all really far away trips though. Let's say it's the everyday stuff around the community here, right around Miami. You want to go maybe go to the movie more, once a week maybe, or you wanna go bowling once a week, you wanna go more often with your friends...

Maria: I like to go...

Researcher: Your mother can't always take you.

Maria: I love to, I like to go movies.

Researcher: Uh huh Maria: Movies, bowling Researcher: Um hm

Maria: M-movies bowling and that's it.

Researcher: Ok, and you want to go more often than you do right now, right?

Maria: Yea

Researcher: Do you?

Maria: Yea

Researcher: Ok, but mom can't take you all the time

Maria: No

Researcher: So what's another way you can go out and do those things without...mom?

Maria: I go with a friend.

Researcher: A friend could pick you up.

Maria: Yea

Researcher: In their car

Maria: Yea

Researcher: Take turns

Maria: They knock on the door.

Researcher: Um hm

Maria: To is it? And I'm going, and, to is it? Sih that's her? And I open the door.

Researcher: And go with your friend.

Maria: Yea

Researcher: That's an excellent answer.

Preferences related to abilities for Maria. Maria expressed that she had adult abilities and was not a child, with which I must agree. People commonly think of my students as being children in adult bodies, which is true, but only to a point. They are able to do many things that no child can do:

Researcher: Why don't you come up with some ideas of something new you want to try?

Or I wanna try to cook something on my own without any help one day...

Maria: I love to cook.

Researcher: You do? What do you like to cook?

Maria: Mmm, yesterday my mom cook some pizza and tecretas (croquetas).

Researcher: And what?

Maria: Tecretas

Researcher: What's that?

Maria: It's like when you eat it, it's so good! Researcher: What kind of food is that?

Maria: It's em my mom, my mom em, she always buy *croquetas*.

Researcher: Croquetas?

Maria: Yes

Researcher: *Cro-quetas*, ok Maria: And it's so good

Researcher: Yea

Maria: And then it's delicious and I eat it and it's delicious.

Researcher: Well, have you ever learned how to make *croquetas* yourself?

Maria: Yea

Researcher: You wanna learn how to make that?

Maria: Yea

Researcher: That'll be a great thing to learn how to make.

Maria: Yea

Researcher: So you wanna learn how to make some new foods?

Maria: Yea

Researcher: Ok that's one thing you can say right there.

Maria: Yea

Maria felt confident that she caould learn how to cook a favorite food and I believe she can learn this too. With the sizable Latin population in this community and the number of cafeterias, restaurants, and grocery stores that serve croquets, this was a marketable skill.

Maria also knew she had the ability to be a good worker because she had experience in work training:

Researcher: What makes you a good worker?

Maria: I work real hard

Researcher: You work hard, what else?

Maria: Easy job

Researcher: What's that? What do you mean?

Maria: Easy job is you have to work real hard an excellent job and work every day.

Researcher: Um hm. What's easy then? Is it an easy job? What do you mean by easy job?

Maria: Easy is you need to work in the hospital every day in time.

Researcher: Um hm

Maria: And work everyday

Researcher: And that's an easy job?

Maria: Yea

Researcher: Right

Maria: Yea

Researcher: So it makes your, it means you're a good worker at that. You're good

because it's easy? Is that what you're saying?

Maria: Yea

Researcher: It makes you a good worker? What else makes you a good worker? Why are

you such a good worker? What makes you so good at working?

Maria: Because I'm really, really brave.

Researcher: Yea you're brave, uh huh, what else?

Maria: That's it.

Maria preferred to be who she is because she does everything:

Researcher: Tell me what's the best thing? Why are you happy to be who you are?

Maria: Because I love to be who I am.

Researcher: What's the best thing about being who you are?

Maria: I love, uh, uh, I like to be in my life.

Researcher: What is the best thing about being you?

Maria: Being great!

Researcher: Being great? What's a great thing about being you? Tell me what the great

thing is, about being who you are.

Maria: Be good.

Researcher: But what are the good things about being the person that you are?

Maria: Great!

Researcher: It's great to be who you are?

Maria: (nods)

Researcher: Why do you say it's great to be who you are/?

Maria: Because I go to my house and, um, I do like take a shower, I eat breakfast, um, I

get on the bus on time, um, I brush my hair, I did the bed, I do everything!

Maria could express herself when it came to dealing with friends, participating in social activities, expressing what she wanted, controlling her emotions when she needed to calm down, and making choices independently. This was how Maria described her ability to call one of her best friends:

Researcher: Ok how do you talk on the phone with, with friends?

Maria: I talk to [Veronica].

Researcher: How do you do that?

Maria: I say, I say hello, to is it? [Veronica], it's me, [Maria], please.

Researcher: And how do you call her?

Maria: In my cell phone.

Researcher: And how do you do it?

Maria: I pressa the button. Researcher: Which buttons?

Maria: I say, I say, uh, I see [Veronica] n-number. I say hello, it's me [Maria] your best

friend, hell, and she's there.

Researcher: Um hm. Well, now days you don't have to know the number. It just tells you

the name. Maria: Yea

Researcher: The name shows up on your phone? You just find her name?

Maria: Yea

Researcher: And then what do you do?

Maria: And then she talks to me.

Researcher: Did you, are you going to call her? You see her name on the phone, right?

Maria: Yea

Researcher: So what do you do then?

Maria: And, and she's there, I say...

Researcher: She's there? Well you gotta call her first...

Maria: And she's there and she say, what you want? Are you dee me crazy now?

Researcher: But how do you call her though?

Maria: Eh, eh

Researcher: You see her name on the phone. How do you call her?

Maria: In in the phone

Researcher: And then what do you do?

Maria: And I say well, you...

Researcher: Now tell me, tell me the steps you do, like I don't know...

Maria: I get the phone.

Researcher: Uh huh, Ok here we go.

Maria: I get the phone. Researcher: Yep

Maria: Um, I put some numbers...

Researcher: Uh huh

Maria: I put some numbers...

Researcher: Uh huh

Maria: I call her on the phone. Researcher: There you go

Maria: And then I say hello, this is me, [Maria], your best friend. What you want right

now? You dee me crazy?

Researcher: At least she talks though, right?

Maria: Yea, everyday

Researcher: At least she talks, doesn't she? Better than being quiet.

Maria: Yea, quiet

Maria was able to use texting successfully:

Researcher: When do you check your texts then?

Maria: One in the morning. I text me one in the morn-, she texts me one in the morning.

Researcher: When do you check for texts? When do you check it?

Maria: Um, um, I turn it on.

Researcher: Um hm

Maria: And then when I turn it on, I, I press the little thing on the, like this

Researcher: Um hm

Maria: And I say I press like m-mommy and then she give me uh, I say "love"

Researcher: You know how to do that then, don't you? You know how to push the button

and then it says mom and then you read it

Maria: Yea and it says "love (participant's name)" Researcher: Well that's a, that's a mom for ya, right?

Maria: Yea

Researcher: But you know how to do texts, you can handle that, no problem.

Maria: Yea

Maria supported her friendships. She talked about a friend in general education classes that she got to know through Best Buddies:

Researcher: You have such a great time with her.

Maria: Yea

Researcher: Is that what you're trying to tell me?

Maria: Yea

Researcher: Anything else?

Maria: Sometimes in the weekend, she text me in the weekend.

Researcher: Really? That's nice!

Maria: She, she always doing, I say, Happy Thanksgiving, and she's at Thanksgiving.

Researcher: And what do you do for...yea? You answer her back then?

Maria: Yea

Researcher: That's what a good friend does. That's what you're able to do for a friend.

Maria: Yea

Researcher: As a friend to someone else, you can text them right back.

Maria: Yea

Researcher: So you make a good friend, don't you?

Maria: Yea

Researcher: I see that.

The above excerpt demonstrated an excessive use of yes-no questioning on my part, but I fell into this technique because I had a problem getting more information at times. In the next quotes, she was more expressive. She was able to support her friends emotionally when they needed it:

Researcher: What if they're mad, but you don't know why? All of a sudden, they're just mad and you don't know why they're mad.

Maria: Please, stop fighting!

Researcher: But what if you want to find out why they're mad? You wanna know why

they're mad. What do you do about that?

Maria: I tell them sorry.

Researcher: You could say s- whatever I did sorry, right?

Maria: Yea, sorry.

Researcher: And what would you do?

Maria: Please stop, don't fight, you're friends, man!

Researcher: Um hm

Maria: You're friends. Stop fighting!

Researcher: So you go up to her and try to make up with her, right?

Maria: Yea yea

Researcher: And talk to her, right?

Maria: Yea

Researcher: Good, that's good, that's what I hear you saying to me, right? I did get it

right?

Maria: Yea

Even in the above quote, Maria still had problems accepting any negative feelings of others toward her. She kept putting herself outside the situation as if she was talking to other people about their anger. It was also possible there was an English language problem and I still used too much yes-no questioning.

Maria was able to participate in social activities:

Researcher: What else do you do for school related activities?

Maria: I love to play basketball.

Researcher: Basketball!

Maria: Yea

Researcher: And where do you do that?

Maria: Um, um, I play, I sh--, I do like that, dribble, dribble.

Researcher: Um hm Maria: And then I shoot it.

Researcher: And where does this happen?

Maria: In the park

Researcher: In the park! Ok...what are some other activities that you do with your

friends?

Maria: Um, we go outside.

Researcher: Where is this? Where do you go outside?

Maria: They play around. Researcher: Where?

Maria: Um, we do like um, Frisbee. Researcher: Where does this happen?

Maria: In the park

She was able to express what she wanted:

Researcher: What do you do when you need a ride to go somewhere of your choosing,

that, where you want to go?

Maria: What's that?

Researcher: What do you need? What do you when you need to get a ride to go

somewhere that you wanna go?

Maria: Um

Researcher: How do you get a ride to get there?

Maria: On the, on the car?

Researcher: Ok, how do you get that car? How do you get that ride in the car?

Maria: I go in my mom's car.

Researcher: And how do you get to ride in your mom's car?

Maria: I ask mommy tuh I go in your car please?

Researcher: Ok, you ask for a ride, right?

Maria could control her emotions by calming herself down to self-regulate:

Researcher: How do you calm down or relax?

Maria: I calm down in the chair. Researcher: You sit in the chair?

Maria: Yes

Researcher: Then what do you do to calm down or to relax?

Maria: (gives a deep breath)

Researcher: You breathe deep like that?

Maria: Yea

Researcher: Ok, that's a good way to relax or calm down. Let's say you're really angry.

How do you calm down if you're really angry?

Maria: I um, um, I go to the bathroom and I sss, I put water on myself and then I say calm

down.

Researcher: You put water on your face?

Maria: Yea

Researcher: Um hm. That's another good way to calm down. Wash on your face, calm

down, Maria: Yea

Researcher: Go to the bathroom, breathe a little, breathe a little bit

Maria: Yea

Researcher: Very good. How do you relax?

Maria: (breaths) I breathe out...

And later in the same conversation:

Researcher: How good are you at asking for a break before you get upset? You know what I mean? I mean you don't want to work and work and work until you start worrying, I'm so tired I'm getting upset. So how good are you at asking for a break before you get to the point where you're so upset that it affects your job? How good are you at asking for a break when you're getting...?

Maria: Drink some water, drink some water

Researcher: Water would help, but how good are you at asking for a break on the job

before you get too too upset?

Maria: Calm down

Researcher: Are you good at asking for a break before you get too upset? How good are

you at doing that?

Maria: I calm down first.

Researcher: Calm down first and then what do you do?

Maria: (breathes) I relax.

Researcher: Ok

Maria: And then it calms me down.

Researcher: Uh huh

Maria: It calms me down.

She was aware of her own emotions and ways to deal with them.

Maria assured me that she could make independent choices. She was able to name some

things she chooses. These were some of her examples:

Researcher: Do you ever decide to put things on your walls and it's your choice?

Maria: I put a cat, um, a picture of me, um, of the weeks

Researcher: Of the weeks? Is it a calendar?

Maria: Yea

Researcher: So you put a calendar on the wall?

Maria: Yea

Researcher: Who decided to put the calendar on the wall?

Maria: Me

Researcher: You did that!

Maria: Yea

Researcher: What else did you decide to do in your room?

Maria: Um, do my bed

Researcher: The way, you mean, you mean, like the sábana, where the sheet...?

Maria: Yea

Researcher: You put it yourself? You decided?

Maria: Yea

Researcher: You decided what color to get?

Maria: Yea

Researcher: What color did you pick?

Maria: I pick pink

Researcher: You like the room in pink?

Maria: Yea

Researcher: What else did you decide to do in your room?

Maria: I pick a pillow.

Researcher: Ok, how did the pillow look? Maria: It look like Troy Bolton (laughs)

Researcher: Like what? Maria: Like Troy Bolton. Researcher: Who is that?

Maria: Like high school musical!

Researcher: Troy what?

Maria: Like a...

Researcher: What's that? Is that Troy's last name?

Maria: B—

Researcher: Boyton? Maria: No like a Z. Researcher: Troy... Maria: Like a Z.

Researcher: That's Zack?

Maria: Yea, Zack

Researcher: Ef, ef— Maria: Zack Efron

Researcher: Oh, you mean that played Troy in high school musical?

Maria: Yea

Researcher: So what do you have like that in your room?

Maria: I sleep with it.

Researcher: Oh is it, what is it, a pillow?

Maria: A pillow.

Researcher: Oh who picked that out?

Maria: Me

Researcher: Ok what else do you do in your room like that...

Maria: I I...

Researcher: ...to decorate it yourself? Maria: Um I have um teddy bears.

Researcher: And you put them there yourself? You decorated them yourself?

Maria: Yea

A typical action that an adolescent would take shows that Maria was like many other young people. It was important to her to be able to decorate her room her way. In addition to more mundane choices, Maria spoke about knowing how to spend her own money. The following excerpt was quoted before, but it explained her thinking totally and was found to be interest in being independent and for independent choices:

Researcher: What is something you prefer to do all by yourself?

Maria: I want to go shopping. Researcher: By yourself?

Maria: Yea

Researcher: You like doing that, huh?

Maria: Shopping

Researcher: Tell me more about that. How you want to shop by yourself. Tell me more

about that.

Maria: I br-, I bring, um, I go to the, the house and bring money. Researcher: Bring money and then what are you gonna do?

Maria: I'll bring my purse with me.

Researcher: Uh huh, get your purse. Then what are you gonna do?

Maria: And go in my mom's car. Researcher: Go in your mom's car.

Maria: Yea

Researcher: Um hm. Then what are you gonna do? Maria: I go to the store and then get something.

Researcher: Uh huh, by yourself?

Maria: Yea

Researcher: Nobody with you?

Maria: No

Researcher: And then what are you gonna do in the store by yourself?

Maria: Get a some makeup.

Researcher: Makeup Maria: Yea and that's it.

Researcher: Ok, tell me, I want you to tell me all the things you wanna do when you're

shopping all by yourself.

Maria: I wanna get some makeup. I wanna get s-, um, um, get some frozen.

Researcher: Some frozen what? What?

Maria: The frozen, man!

Researcher: Frozen movie, the movie?

Maria: Yea

Researcher: Something with frozen on it?

Maria: Yea

Researcher: Ok, you gotta go shopping, see which one you want.

Maria: Yea

Researcher: When you see it, you know it, right?

Maria: Yea

Researcher: What else you wanna do when you go shopping?

Maria: Uuum

Researcher: By yourself? Something you can't do now, but you love to do?

Maria: Maybe a snack or...

Researcher: Go out and get a snack, those are great answers!

Maria: Maybe a movie.

Researcher: Maybe see a movie, those are all great answers!

Maria: Or CD

Researcher: You buy a CD on your own.

Maria: Yea. That's it.

Researcher: Those are all great answers, I love it!

Maria: Yea

Lastly, Maria asserted that she was able to live in independent housing. As quoted before,

she knew she needed to be independent to live on her own:

Researcher: What do you need to know about living on your own?

Maria: I'm going to live on my, on my own.

Researcher: On your own?

Maria: Yes

Researcher: Ok, you want to live on your own one day, right?

Maria: Yea

Researcher: So what do you need to know about living on your own?

Maria: I need to be impendent.

Analysis of the Preferences Related to Beliefs, Interests, and Abilities for Rayann

Preferences related to beliefs for Rayann. The next participant in this study had strong beliefs about herself, others, and feeling safe. She also expressed some fantasies that she seemed to believe would come true. At the end of this section will be examples of her beliefs concerning what her rights are. To begin, Rayann believed in herself:

Researcher: What do you do when you, when, when others tell you, you can't do something that you know you can do? And they say you can't do that and you think you can do it?

Rayann: I'll tell him. I'll tell them, oh yes I can!

Researcher: That's right!

Rayann: (laughs)

Researcher: And they say oh, you can't do that by yourself... and what do you say? Rayann: You'll never know if I can...do that by myself. You'll never know un-until you

see me.

Researcher: That's right! You gotta speak up like that. I like that.

Rayann believed she was a good friend and could support others emotionally:

Researcher: What if they're having a bad day? What do you do as a friend if they're

having a bad day?

Rayann: Write them a, um, uh, tell them it's okay. It's uh, gonna get better.

Researcher: Um hm, that's nice. Rayann: And make them feel good.

Researcher: That's nice, that's very encouraging, that's nice.

She had strong religious feelings due to her Muslim upbringing. Her belief system caused her to worry about being punished by God for eating food that was not permitted, that was not *halal*:

Researcher: What if it's food you're not supposed to be eating? And they're trying to get you to eat it and they don't understand that you're not supposed to be eating that kind of food? That's not Muslim food.

Rayann: I'll explain.

Researcher: Uh huh, and they, finally they listen to you, finally, and they go, oooh,, now I

get it and then how do you feel then?

Rayann: Safe

Researcher: Safe! Yea, what else?

Rayann: I don't know

Researcher: Ok maybe a little relaxed, right?

Rayann: Yea

Researcher: You can relax and they understand you, right?

Rayann: Yea

Rayann generally felt safe, however, even if she were to be alone with the opposite sex:

Researcher: Let's just say you have, you have a love interest in [Nelson].

Rayann: Ok

Researcher: And you wanted to visit with [Nelson] and your family was worried about

that. What would you do? Rayann: I don't know what's...

Researcher: (laughs) It's gonna happen one day...

Rayann: Yea?

Researcher: You better be ready for it...

Rayann: Yea

Researcher: What are you going to say? Rayann: Don't worry. I'm gonna be safe.

Researcher: Um hm, that's what they're worried about. What else would you say so they

can feel better about that? Rayann: He, he's a good guy.

Researcher: He's a good guy. He is a good guy and he's...

Rayann: He would do nothing to hurt me.

Researcher: He wouldn't do anything to hurt you.

Rayann felt strong. She felt she had inner strength as well as outer strength:

Researcher: Are there any big problems you wish you could change?

Rayann: Like staying away from my mom?

Researcher: That's a problem, that's a problem. You don't want to have that problem.

Rayann: No

Researcher: That's a big—

Rayann: I wanted, I wanted to be with her. Researcher: Yes, I know that's a big problem. Rayann: When I was little, but now I'm grown up.

Researcher: And now? Rayann: I don't know now.

Researcher: Is it the same or different now?

Rayann: Different.

Researcher: You don't feel as strongly about that as you used to when you were a little

girl?

Rayann: I don't feel like crying...

Researcher: You don't cry about it as much?

Rayann: Mmm, but I do, I do wanna still be with her.

Researcher: Um hm

Rayann believed she had to always do the right thing, even if it meant not having one of her dreams come true:

Researcher: We were saying that you were trying to go see John Cena and that was a barrier there of how much money it costs. Oh, we discussed that problem, maybe you could use the Medwaiver money to do things. Maybe you could use that money right? Everyone would be safe.

Rayann: Because I don't want to say anything in the video that's not true.

Researcher: No

Rayann: I wanna sound, I wanna sound serious.

Researcher: Serious. It is true that you have Medwaiver. That wouldn't be a lie. What do you...? What lie do you mean, that wouldn't be the truth, that you would say in the video?

What would that be? Rayann: I don't know

Researcher: You'll still say the truth, I know you.

Rayann: Yea

Researcher: You'll say the truth. You have honor. You have honor. You'll say the truth

Rayann: That's my dream. Researcher: Your dream? Rayann: To see him. Researcher: Yes

Rayann: To meet him.

Researcher: To meet him. You gotta do it for [Baqir] too. Tell them that. Tell them my brother and I wanted to go. He passed away now. I wanna meet him for [Baqir]. That'll

get 'em. That'll get 'em right in the heart, right?

Rayann: Yea, but I don't know if it's right to say something to make them feel bad

Researcher: Do you want to get his attention?

Rayann: Yea, but I want to get his attention and still feel good.

Rayann believed in some fantasies about herself and her abilities. The following overlapping quote was also referenced for support, incidentally. She had dreams like many other young women do:

Rayann: I go to the living room sometimes.

Researcher: Uh huh Rayann: And...

Researcher: Well, how are you going to learn more about being a mom then?

Rayann: From my mom

Researcher: Ok, and how would you learn from your mom about being a mom?

Rayann: By taking care of a baby.

Researcher: Um hm, and how would you learn that?

Rayann: By carrying him.

Researcher: Carrying. That's a big job, carrying them around, what else?

Rayann: Putting, putting them in the...I don't know what it's called...

Researcher: What do they do there?

Rayann: Walking

Researcher: Oh the baby walker? Rayann: The rocking chair Researcher: The, the...rocking?

Rayann: Yea

Researcher: Oh the rocking chair or walking?

Rayann: No rocking

Researcher: Like rocking chair, like rocking back and forth?

Rayann: (nods)

Researcher: Oh yeah, ok so there with the rocking chair...

Rayann: Yea

Researcher: Is it a baby bouncy chair? And the babies bounce in it?

Rayann: No

Researcher: Is it for the mother and the baby or just the baby?

Rayann: Just the baby

Researcher: Ok, it's got the, is it a little bouncy chair or something? A little chair?

Rayann: You put it on the floor. Researcher: The walker, the walker?

Rayann: Not the walker

Researcher: But it rocks, oh like a baby cradle that's kinda bouncy, like a baby cradle?

Rayann: I don't know, (laughs) it's not bouncy.

Researcher: It leans back?

Rayann: Yea

Researcher: And you can feed 'em there?

Rayann: (nods)

Researcher: And they can have little toys hanging in front of them?

Rayann: Yea that

Researcher: Yea like a little cradle?

Rayann: Yea

Researcher: Yea, ok, very good. Ok, ok, what do you prefer to use to help you, there you go (gets a drink), get the job done? What helps you get the job done? I can give you some examples if you need to hear some. What would help you get the job done?

Rayann: My husband

Researcher: Your husband? You better believe it!

Rayann: (laughs)

Researcher: He will help you too.

Rayann: My kid

Researcher: Your kid, um hm, ok, how can your husband get the job done? How could he

help you?

Rayann: By carrying him. Researcher: Carrying—

Rayann: While I make the food.

Researcher: Carrying the baby while you make the food.

Rayann: Yea

The reason the above passage was found to be a fantasy was because she did not stay in the living room long enough to watch her stepmother care for her baby brother, but wanted to learn from her mom, who lived in another country. Also, she would need support to be able to physically carry a baby safely due to her muscular condition. In addition, she got help at school and at home to feed herself foods that require a fork or spoon. It was unclear how she would be able to feed her baby an entire meal without becoming fatigued. She thought her child was going to help her. She would have to wait a long time before a child could help her with anything. Rayann wanted an able bodied husband to help her and believed she could find one, possibly in her parent's home country. The logistics of finding an equal partner for Rayann who met her requirements was complicated. He also should be a Muslim so the family will more easily approve, which was extremely important to Rayann. She was especially reticent to do anything without her father's approval, even when it came to participating in this study. Most of all, it may be difficult for Rayann to become pregnant or to carry to term. Her genetic condition may affect her ability to have children, even with family support. I had to find this comment as a fantasy, not knowing if she knew about this aspect of her health condition. Deep down, however, she knew how difficult it would be to have a married life. Knowingly, she conveyed her dreams and hopes for the future:

Researcher: Like what kind of relationship do you want to be in?

Rayann: Like a boy and a girl. Researcher: Like a boy and a girl?

Rayann: Yea

Researcher: Tell me more.

Rayann: Together

Researcher: Yea, um hm, a lot of kids in high school are like that and want to be close

together.

Rayann: Just doing everything with each other. Researcher: Doing everything with each other...

Rayann: Yea

Researcher: Give me some examples.

Rayann: Like, like a boy tells you a joke and you laugh.

Researcher: Oh, that's a good part in life, making each other laugh!

Rayann: Yea

Researcher: And share a joke, um hm, what else?

Rayann: Uh, um, I don't, I know I can't do that, but I know another boy and girl can. I

like it when they stay close like a girl lays her head in his shoulder.

Researcher: Yea and they stay close you mean?

Rayann: (nods) Researcher: Yea

Rayann: Yea, it would be nice if it happens to me.

Researcher: You're still young, ok.

Rayann: (laughs)

Researcher: You got a long way to go.

Rayann: But I still dream of it.

Researcher: Sure all girls dream about that.

Rayann: I daydream.

In spite of all her dreams of young womanhood, she had an understanding of the barriers she faced in actually achieving this particular dream. This demonstrated one reason why I categorized Rayann as my participant with the highest intellectual ability.

Another statement Rayann made that may or may not have been made in earnest was about walking:

Researcher: How confident are you in your abilities?

Rayann: Um, I'm, uh, the only thing I'm confident in is walking.

Researcher: You're confident you can walk.

Rayann: But, sometimes I'm not confident of doing the r-right thing.

Either she meant she can walk with assistance, which she can do, or she meant she knows she can walk one day, which is not going to happen realistically, unless there is a new medical innovation. I found this to be a fantasy because I have heard her make similar statements before and I know she believed she can walk in Lebanon. Also, she went on to the next topic without qualifying her previous statement so I took it as her truth so she could go to Lebanon.

Rayann believed she had certain rights. Being born in the USA, she had acculturated to an American lifestyle:

Researcher: How about your American rights...

Rayann: Emmm...

Researcher: ...we talked about? Rayann: I have a right to get my way?

Researcher: You have a right to get your way, with what though?

Rayann: Don't know, (laughs) I don't know.

Researcher: You don't know?

Rayann: No

Researcher: You don't know what you want to get your way with?

Rayann: Getting a apartment.

Researcher: That's a, you keep saying that, that's an important thing for you, isn't it?

Rayann: Yea

Researcher: You keep on saying that.

Rayann: Yea

Researcher: You have a right to have your own place.

Rayann: That's what I want.

Researcher: That's what you really want, right?

Rayann: Yea

Researcher: Your own place to live. Rayann: Yea, with my husband and kids. Researcher: And you have a right to do that?

Rayann: Yea

Researcher: You do have a right to do that!

Rayann: Um hm

Researcher: Ok, what else do you have a right to do?

Rayann: I have a right to be respected.

Researcher: A right to be respected and to feel what? Rayann: I don't know what you're looking for (laughs) Researcher: Well, you have a right to feel in what way?

Rayann: Happy? Researcher: Yea! Rayann: (laughs)

Researcher: Americans say we have a right to uh, to be happy, right? You want to be

happy and get what you want, your choices that you want.

Rayann: Yea

Researcher: Anything else you have a right to do?

Rayann: No

Researcher: That's all the rights you have? You have no more rights than that?

Rayann: I don't know (laughs)

Researcher: Can you think of one more right you have and we'll go on to the next

question? What's...just tell me one more right that you have...

Rayann: I have the right to say who I wanna be with.

Researcher: To say who you wanna be with, you have a right to do that too.

On a lighter note, Rayann had these comments later in the discussion:

Researcher: What do you have a right to have? I have a right to have...

Rayann: I can't think of nothing right now

Researcher: Ok no lunch for you anymore then, no more lunch for you

Rayann: (laughs) lunch! Researcher: Uh, what?

Rayann: I have a right to have lunch (laughs) Researcher: (laughs) ok what else? Things like that

Rayann: I don't know

Researcher: What other rights do you have besides lunch?

Rayann: School?

Researcher: A right to go to school ok

Rayann: Right to have teachers Researcher: A right to have teachers

Rayann: And friends

Researcher: And friends, whose friends?

Rayann: *M-My* friends!

Researcher: Your own friends, right?

Rayann: Yea (laughs)

Researcher: Ok, who picks out your friends?

Rayann: Me!

Researcher: Friends you pick yourself.

Rayann: (laughs)

Researcher: You have a right to have friends that you pick yourself. Ok

Rayann: (laughs) yea

Significantly, the last thing she said in our conversation about her rights was something I want to re-emphasize: "I have a right to be respected."

Preferences related to interests for Rayann. Rayann was keenly aware that she needed assistance with daily living. When asked what she wanted in a support person, she said, "A person who, who, who got my back." Rayann had a support person at all times, at home and at school and it was very important to her that the person be "respectful," "give me what I want," and "when I want it." She also stated "I need help to walk" and was particularly interested in walking in her parent's home country:

Researcher: You know Lebanon and, and America are different. Very different. Different services there to help you than here. You may not have the same services there that you have here.

Rayann: I don't know.

Researcher: Can your chair go all around Lebanon? Is it easy to get around Lebanon with

your chair?

Rayann: I go walking.

Researcher: You go walking? Who helps you go walking in Lebanon?

Rayann: Sometimes my dad. Researcher: In Lebanon?

Rayann: We don't take, I don't take my helper with me to Lebanon.

She was also interested in financial support from her family. Rayann knew where her financial support came from even though she was unclear in my opinion on how much or how hard her father worked to earn it. She was also unconcerned at times of how she can earn her own money:

Researcher: What work have you done to earn money? Rayann: My dad gives me, from his job, I don't know...

Researcher: Ok, do you have to work to get that money that he gives you?

Rayann: No

Researcher: It's like an allowance?

Rayann: He just gives me, uh, because, because he loves—I don't know...

Researcher: Yea, he did it because he loves you?

Rayann: Yea

She also was unaware of all the expenses her father took care of, including taking care of his present family plus alimony. Raynn said this about how she will get monetary support:

Researcher: How can you meet Muslim men then?

Rayann: I'm looking for... Researcher: (laughs)

Rayann: I'm, I'm still looking.

Researcher: You're still looking. How are you looking? Rayann: I don't know where I'm going to look for...

Researcher: Um hm

Rayann: ...maybe in Lebanon

Researcher: And how are you going to get over there? Rayann: I, I don't know where I'm going to look for him.

Researcher: Mmm. You never know in life, right?

Rayann: (nods)

Researcher: Well, a lot of young girls don't know what, where they're gonna meet their husbands either. A lot of young girls don't know that. You never know till it happens.

Rayann: No

Researcher: I understand that. No one knows till it happens. But you're looking and

you're thinking. Rayann: Yea

Researcher: You have your eyes open looking, right?

Rayann: Yea

Researcher: Ok, let's say you already met this person then, then what's going to happen?

Rayann: I'm gonna be happy.

Researcher: Yea? Rayann: (laughs)

Researcher: Let's say you met this, a man that's Muslim, that you're father likes him,

he's happy, that's important too and you're happy...

Rayann: (laughs)

Researcher: Ok, then what happens?

Rayann: I'm gonna get, I-I'm gonna have a wedding.

Researcher: A wedding ok, that's a lot of money. Who's gonna put up the...

Rayann: But first the engagement.

Researcher: First the engagement, who's gonna, who's gonna help you with that? That's

a lot of money.

Rayann: Maybe my parents.

Researcher: Ok, they're gonna be your support. A lot of dads pay for their daughter's

weddings. It happens. That's what we do.

Rayann: Yea

Researcher: Nothing wrong with that kind of support.

Rayann: (laughs)

Rayann was interested in a husband that will be able to provide for her financial needs:

Researcher: What do you have to have to live like to get groceries and do the rent and all

that stuff? What do you have to have?

Rayann: Help?

Researcher: Help, um hm, ok, and how are you going to get that?

Rayann: I'll ask.

Researcher: Ok, ask who? Rayann: My husband. Researcher: Yea?

Rayann: To drive me there.

Researcher: To drive you there, there where?

Rayann: To the grocery store.

Researcher: Ok. And how are you going to pay for it?

Rayann: With my money.

Researcher: Um hm, and when the money runs out, then what are you going to do?

Rayann: Or my husband's. Researcher: Ok. Or his money.

Rayann: (laughs) Researcher: All right.

She was also interested in her strong network of family support to realize her dreams:

Researcher: Who's gonna support you in in reaching your goals? Who's gonna support

you in that?

Rayann: My husband

Researcher: Your husband is one

Rayann: My mom

Researcher: Your mom is another person that's going to support you

Rayann: My dad

Researcher: And your dad

Rayann: And then...

Researcher: Anybody else

Rayann: No, nah

Researcher: How about other people in the family?

Rayann: My sister Researcher: Um hm

Rayann: Brother, brothers! Researcher: Two brothers

Rayann: Yea, No actually three brothers

Researcher: Three brothers, Sure! Anybody else?

Rayann: My aunt Researcher: Uh huh Rayann: And uncle Researcher: Uh huh Rayann: (laughs) and

Researcher: People I've already met that I know...

Rayann: And my cousin

Researcher: Oh that's what I'm waiting to hear, the cousin (laughs)

Rayann: (laughs)

Researcher: I'm waiting to hear that. I know I met her and she's a good support for you

Rayann: Yea

Researcher: I know.

Whenever I have planned club activities either for the Talent Show or for other activities, I usually saw her cousin who attended the events or took her to them. For that reason, I tried to get her to name her cousin as a supporter because I knew it actually happened. Rayann also had an interest in family support to become a mother:

Rayann: And one time in Lebanon...

Researcher: Hm um

Rayann: [Yamin] was sleeping

Researcher: Who?

Rayann: My little brother. Researcher: Oh, uh huh... Rayann: On my lap... Researcher: Um hm Rayann: And they looked at me and, and they said something like, you're gonna make a

great mom someday.

Researcher: They did? Who said that?

Rayann: Something like that? Researcher: Who said that?

Rayann: I d- s-, Maybe she was my, my aunt...

Researcher: Really? There's a good support person right there that'll support you because

you want to be a mother one day.

Rayann: Yea

Researcher: And she'll support you.

Rayann: Yea

Researcher: And she believes you can do it.

Rayann: Yea

Researcher: There you go.

She was interested in everything being acceptable regarding family harmony because she wanted

to have her family nearby:

Researcher: What if they say, but you, but we don't want you to leave the family. Then

what will you say?

Rayann: I can't stay here forever.

Researcher: There you go. What else would you say?

Rayann: I have to move out.

Researcher: Uh huh, and then what else would you say? What if they go, but we're never

gonna see you again? What are you gonna say?

Rayann: You can come visit.

Researcher: Ok, but we won't see you anymore in your room anymore. Then what will

you say?

Rayann: I'll come visit you, too.

Researcher: There you go! (laughs) Those are good arguments!

Rayann: (laughs) yea

Researcher: Excellent! That's what you do!

Rayann was interested in being independent. In this case she talked about walking

independently:

Researcher: What's something that maybe you get help with right now, that people help

you with right now, that you would rather do it by yourself?

Rayann: I can't think of nothing.

Researcher: Nothing that you prefer to do all by yourself? I wish they would let me do...

Rayann: I...

Researcher: ...blank, by myself? What would that be?

Rayann: I wish I could walk but...

Rayann: What?

Researcher: Is it a secret?

Rayann: No

Researcher: Because you know I'm recording you (laughs).

Rayann: (laughs)

Researcher: You wish you could draw?

Rayann: I wish I could walk, but the people have nothing to do with it.

Researcher: The, what people?

Rayann: I wish I could walk by myself.

Researcher: Draw? Rayann: Walk.

Researcher: Walk. Oh, to walk by yourself. Sure you do. You wish you could walk by

yourself, but the people what? Rayann: But you and all the people... Researcher: All the people like at school?

Rayann: ...have, have nothing to, did nothing to, did nothing to me to, for me to stop

walking.

Researcher: It happened by itself, right?

Rayann: Yea

Researcher: Yea, but you wish you could walk more, right?

Rayann: Yea

Researcher: Get out of the chair more often too, right?

Rayann: (nods)

Researcher: Um hm, maybe use it less.

Rayann: (nods)

Researcher: That would be nice, right?

Rayann: (nods)

Rayann was interested in being more independent in child care:

Researcher: How are things when they're busy with the baby? How's things with you? Are you more independent when they're with the baby? Do things more on your own?

Rayann: (nods)

Researcher: Yea? Think so? Rayann: I rock the baby's chair!

Researcher: You rock the baby in the chair?

Rayann: Yea

Researcher: And help him out?

Rayann: (nods)

Researcher: Well that's nice!

Rayann: Try to get him to stop crying. Researcher: How good are you at that?

Rayann: Very good.

Researcher: Really? That's good practice for you.

Rayann: Yea

Researcher: Tell me more about that.

Rayann: And one time I remember we were at the mall with my stepmom and I was carrying my little brother. He was sitting on my lap and I was holding on to him but the, the chair stopped and he fell and I...

Researcher: Uh oh!

Rayann: ...but I, I was still holding on to him. But he...no I remember, I fell not him!

Researcher: Oh ho, ho, you fell!

Rayann: Yea

Researcher: So you took the fall for him, huh?

Rayann: Yea

Researcher: How was the baby?

Rayann: He was okay. Researcher: He was okay?

Rayann: (nods)

Researcher: So you took the fall, right? Rayann: That's what I remember.

Researcher: That's what a good mother does, right?

Rayann: (nods)

Having friends and a social life was another area in which Rayann was interested in being

independent in. She knew how to develop new friendships:

Researcher: What if you just met them and you don't know them very well? How do you become friends with the person?

Rayann: Keep calling them in their cell phone.

Researcher: Keep calling them, keep in touch, it takes time to make a friendship, right?

Rayann: (nods)

Researcher: What else do you do? Rayann: Do stuff with them.

Researcher: Do stuff with them like...?

Rayann: Color.

Researcher: Color, what else?

Rayann: Take pictures.

Researcher: Take pictures, that's a good one.

Rayann: Go somewhere with them. Researcher: Go somewhere with them

In addition to all these interests, Rayann was interested in making her own choices in

living, working, free time, friends, foods, post-secondary education and training, and in travel.

This was what Rayann said about where she was interested in living:

Researcher: What are some things you could do to make yourself happier?

Rayann: I could get an apartment and live w-with my husband.

Researcher: That would make you happier

Rayann: And kids. Researcher: And kids.

Rayann: And not worry about nothing.

She has said before that she did not like to worry. Rayann was also interested in friendly

neighbors:

Researcher: What people do you want to live near?

Rayann: Live near?

Researcher: Yea, like what people do you want to live near?

Rayann: My friends

Rayann included in her family when it came to her interests in living a dream life:

Researcher: If anything was possible, what would you like? And what is your dream life?

Rayann: An apartment.

Researcher: An apartment, what else is your dream life?

Rayann: With my husband...

Researcher: Um hm Rayann: ...and kids Researcher: Um hm Rayann: Alone.

Researcher: Alone, and your parents? No parents around?

Rayann: I, I don't know that yet.

Researcher: Not maybe *in* your apartment, but maybe not so far?

Rayann: (laughs) Yea. Like what?

Researcher: Husband and kids in your apartment, ok. How about the rest of your family?

Rayann: Next door maybe. Researcher: Maybe next door.

When it came to a job and working, Rayann had two different choice preferences. I am

not sure how serious she was about this first choice because of how she talked about it:

Researcher: You ever think about having a job in the future?

Rayann: Maybe

Researcher: Maybe, what do you think about?

Rayann: Being an artist.

Researcher: Oh, artist, you did say that before, like the artist?

Rayann: Yea

Researcher: You really like that, art.

Rayann: Yea

Researcher: So what, what do you do in your free time to help you be a better artist?

Rayann: I don't draw too much these days.

Researcher: Why is that?

Rayann: Because I'm, I'm too lazy now.

Researcher: Oh ho (laughs) too lazy! Can't be a lazy artist!

Rayann: I'm so lazy now!

Researcher: Why are you so lazy now?! (laughs)

Rayann: I don't know

Researcher: Maybe in the summer or something when you have a lot of free time? You

could do it then maybe?

Rayann: Maybe

Researcher: So when do you do...draw, now, and, and use colors and all? When do you

do it?

Rayann: I don't do it now.

Researcher: Ok, that's a fair enough answer.

Rayann has outlived both of her siblings, but was showing signs of physical and mental decline.

She did not do many activities she used to do and enjoy in the past.

While she did not have a strong interest in being employed as an artist, she was interested

in a job in her long range plans, if it was being a mother:

Researcher: In ten years I want to have a job in...what?

Rayann: Is being a mom a job? Researcher: Oh it's a big job! Rayann: Then I wanna be a mom.

Researcher: A mom in ten years? That's a big job! A homemaker?

Rayann: Yea

Researcher: So you want to be a homemaker in ten years?

Rayann: (laughs)

Researcher: Woo! That's a lot of work. You better believe it!

Rayann: Yea

Rayann also has developed a strong interest in being an entertainer since I have been asking her

to perform in our annual Best Buddies Talent Shows:

Researcher: What is something about working that you have tried and you liked?

Rayann: Singing on stage, you remember?

Researcher: Um hm, um hm Rayann: I was nervous the first...

Researcher: Whooo! Everyone's nervous, but I make 'em do it! Rayann: But when I, when I did it, I, I felt like, I felt good.

Researcher: You did! Because you know, I don't do that, you know...

Rayann: Because I was nervous at first... Researcher: I said, oh my goodness...

Rayann: ...but then I wasn't.

Researcher: That's how it is, that's how show biz is.

Rayann: (laughs)

Researcher: Once you start, you know...

Rayann: Yea

Researcher: ...you get over that.

Rayann: Yea

Researcher: Yea. Why do you think I make the kids do it and I don't do it? (laughs)

Rayann: (laughs)

Researcher: Because I know (laughs)

Rayann: Yea

Researcher: Ok, that's part of show biz you have to get over, right? So you tried doing that and you liked it? Being on stage? Even though you got nervous, you liked it?

Rayann: I liked it with all my heart!

Researcher: Really?! Rayann: Yea (laughs)

Researcher: Oooh! We gotta do it again, (laughs) ok.

For her leisure time, Rayann had many interests. She liked to use the computer and find

the music she liked to listen to. She really enjoyed watching her favorite soap opera in Arabic:

Researcher: Well what do you choose for free time?

Rayann: Computer

Researcher: On the Computer, you like computers, right?

Rayann: Yea

Researcher: Because you like it, you pick computers, cause you like it. What else do you

pick for your free time? Rayann: At home or here?

Researcher: Either way I don't care.

Rayann: Watch TV. Researcher: Watch TV. Rayann: Use my laptop.

Researcher: You use your laptop.

Rayann: Or tablet.

Researcher: You have a tablet?

Rayann: No, my brother.

Researcher: Oh

Rayann: And my sister.

Apparently, Rayann had some access to a tablet because she mentioned it. And for her listening

interests:

Researcher: How do you find out what your options are or what's out there for you to do

for your free time?

Rayann: Listen to music.

Researcher: Listen to music, how do you know what music is out there? All kinds of

music. How do you find out about the music?

Rayann: Computer?

Researcher: Oh, what do you do with that?

Rayann: I'll find out if there there's any new song.

Researcher: How do you do that? Rayann: I go to the computer.

Researcher: And?

Rayann: I don't know, and type the title of the song.

Researcher: Ok, and then what happens?

Rayann: Some sometimes it doesn't work because of the Internet.

Researcher: Mm hm. And when it works?

Rayann: I, I, it pops up?

Researcher: It pops up and then you can do it.

Rayann: Yea

Researcher: You can do it, you can find the songs.

And also for her interests in TV programs:

Researcher: What were you watching?

Rayann: Some Arabic show in *Panet*, but I changed that now to Power Rangers.

Researcher: Before you had a Arabic...song...

Rayann: Arabic show Researcher: Arabic show Rayann: I watch it on Panet. Researcher: Panex? What's that?

Rayann: Panet.

Researcher: Spell it, P-L... Rayann: It's a program Researcher: Called Planet?

Rayann: No Panet

Researcher: Spell it, spell it

Rayann: P-A-N-E-T Researcher: Panet Rayann: Yea

Researcher: Is that an Arabic word, Panet?

Rayann: It's a Arabic program.

Researcher: And that word Panet is a Arabic word, too?

Rayann: Yea, maybe

Researcher: There's an Arabic channel on TV?

Rayann: (nods)

Even though she cannot read or write in Arabic, she spoke it fluently. Rayann was interested in choosing her own friends and meeting new people. She had her own preferences when it comes to friends:

Researcher: Who do you prefer to hang out with at the mall?

Rayann: [Jill].

Researcher: [Jill]? Anybody else? Rayann: No (gasps) y-yea, but...

Researcher: What? You don't know their names?

Rayann: No (laughs)

Researcher: Well, tell me about them then.

Rayann: I don't know

Researcher: All the Best Buddies?

Rayann: (nods) Researcher: Ah hah!

Sometimes I really had to structure the interviews to pull the information out from participants when it was not forthcoming. I understand this practice was not completely scientific, but they all needed some form of communication support. Usually they hesitated when they did not know what I wanted them to say or what I wanted from them. On another standpoint, having a large family, Rayann had many relatives to pick from for companionship:

Researcher: Who do you prefer to hang out with at home?

Rayann: My sister.

Researcher: Your sister! You have one sister? Um hm. Rayann: No, I have two. The other one passed away.

Researcher: I know. Your older sister passed away. You have two little sisters now,

right?

Rayann: I have the one sister and one brother here, but two brothers with my mom.

Researcher: Two brothers with your mom? I didn't know that, um hm, but when you're

in Miami here, you have to hang out with your one sister, right?

Rayann: (nods)

Researcher: Ok, ok that's good. Good answer. Rayann: I have, no, I have two brothers here. Researcher: Cause you have the baby too, right?

Rayann: Yea (laughs)

Researcher: And one sister, and two brothers.

Rayann: No three, m- m-...

Researcher: Ok

Rayann: ...the little baby

Researcher: Yea

Rayann: And [Kareem] and [Baqir] (points up) Researcher: Yea that passed away, that one?

Rayann: Yea

Rayann was interested in and knew how to make new friends:

Researcher: How will you make new friends in new situations? New friends, not here.

Someplace new. Rayann: Try?

Researcher: Try, how do you—

Rayann: Try my best.

Researcher: Try your best. By doing what?

Rayann: To make new friends. Researcher: By doing what things?

Rayann: Talking to them. Researcher: Talking to them.

Rayann: I don't know

Researcher: Well, how do you get to know them better?

Rayann: Get their phone numbers.

Researcher: That's one thing. Ok and then you call them on the phone and you talk with

them. Then, what are things you could say?

Rayann: My name.

Researcher: Uh huh, what else could you talk about on the phone?

Rayann: Your day? Researcher: Your day?

Rayann: How is your, how was your day...

Researcher: Oh, how was your day, um hm. You can share that with them, how was your

day, uh huh. What else would you do?

Rayann: I don't know

Researcher: Well, you're always either working or at home and you want to get to know them better. So what could you do to get to know them better? All you, all you do is see them at work or else you call them on the phone. You want to get to know them better.

So what do you do? What do you say?

Rayann: I wanna be your friend?

Researcher: Um hm, and how could you do that?

Rayann: I don't know

Researcher: What kind of things could you do together?

Rayann: Go out...

Researcher: That's one way. Rayann: ...to the mall.

When it came to food, Rayann had specific requirements due to her religion. However,

there was one American food she liked when it was cooked at home in the approved way:

Researcher: Do you ever get warm foods?

Rayann: Yea

Researcher: Well how do you get it? Rayann: My stepmom cooks it Researcher: Um hm and then?

Rayann: I don't know

Researcher: Ok what does she cook?

Rayann: Hamburgers Researcher: Um hm Rayann: Sometimes pizza

Researcher: Mmmm! What's your favorite food that she cooks?

Rayann: Hamburgers

Researcher: Oooo you like hamburgers!

Rayann: Yea (laughs)

Researcher: You're an American girl

Rayann: (we both laugh)

Later she said she can eat meat if it was cooked *halel*. This conversation was quoted previously.

Further along in the conversation she talked about another of her favorite foods:

Researcher: What kind of foods do you eat? Rayann: Um, I, e-, there's a salad called *tabule*. Researcher: I've had that before. It's really good.

Rayann: I like that.

And at the end of the conversation about food:

Researcher: Besides hamburger, what's your favorite foods?

Rayann: Mmm, that's American! (laughs)

Researcher: That's American, yea! (laughs) But cooked the Muslim way,

Rayann: (nods)

Researcher: *Halel*, right?

Rayann: Yea

Researcher: Yea, what else? Rayann: I like chicken. Researcher: Chicken Rayann: Mashed potatoes Researcher: Um hm

Rayann: French fries
Researcher: French fries

Rayann: I can't think of nothing else.

Researcher: How about fish?

Rayann: Yea

Researcher: I thought you liked fish.

Rayann: (nods)

Researcher: Because you get that a lot at school.

Food was an important issue for Rayann and I wanted to be sure to get her voice out so she could explain what kind of foods she had to eat and explore what she understood about it.

Rayann had definite post-secondary interests in choosing a college. After telling Rayann about a new college in a nearby city for students with disabilities that offered dormitory-type apartment living, she had this to say about it:

Researcher: What are steps you should take to meet this goal? What are the little steps you're gonna take to get to that goal of having your own apartment? What are you going to do first, second, and third?

Rayann: I go to the school, the one that you told me about.

Researcher: Um hm, the college.

Rayann: Yea, but I don't think I'm going to that school.

Researcher: Um hm

Rayann: Th-they're gonna pick one and, and send me there.

Researcher: Um hm. Who's gonna pick one?

Rayann: My dad and my stepmom.

Researcher: You showed them the paper?

Rayann: Yea

Researcher: Um hm

Rayann: And I told how you have to pick one.

Researcher: Yea and they only have a few things there, too.

Rayann: Yea

Researcher: It's a new thing they're starting up, you know.

Rayann: Yea

Researcher: Maybe one day it'll get better.

She understood the choice of college she was interested depended on family guidance and support. She would need a caretaker to live with her and assist her in getting to class, which was across the street in this case. Another barrier to this interest was that it was in a nearby city and not in her hometown. In addition the college had very limited fields of study and she might not be able to find the one she wanted to learn about.

The last category of interests that Rayann showed interested in was travel. She mostly expressed only one place of interest:

Researcher: Where would you like to travel to?

Rayann: Lebanon

Researcher: Somehow I knew you were going to say that! (laughs)

Rayann: (laughs) to be with my mom.

Researcher: Of course, yea.

She also wanted to travel to visit someone else:

Researcher: Ok, besides Lebanon, where would you want to travel to? Rayann: I wanna go, you, you know Mon Cena [John Cena] the wrestler?

Researcher: No, but that's ok. Rayann: I wanna go to meet him.

Researcher: To meet the wrestler? That would be cool, wouldn't it?

Rayann: Yea

Preferences related to abilities for Rayann. On the topic of jobs and education, Rayann had no job experience and very little job training. She had no experience in earning money at home and was given an allowance just to have spending money. I interpreted from what she said that if she had a choice she would graduate high school right now:

Researcher: What's something you want to learn more about? I want to learn more

about...what?

Rayann: I think I've already learned everything I wanna to learn, I want to learn.

Researcher: Maybe you're just ready to graduate now, right?

Rayann: Yea

Researcher: That's a sign that you're ready to graduate.

Rayann: Yea

Rayann knew she was able to express herself. This was definitely one of her greatest strengths.

These were examples of how well she was able to express herself with friends and family:

Researcher: What do you have to do to make friends?

Rayann: Talk

Researcher: Uh huh

Rayann: Talk to the people I wanna be friends with. Researcher: Ok. And how do you talk to them?

Rayann: Tell them my name.

Researcher: Um hm Rayann: I'm a good girl.

Researcher: Yea, that you're a good girl, uh huh...

Rayann: I respect you.

Researcher: Um hm. What do you tell them about yourself?

Rayann: Um

Researcher: Like your interests, what you prefer to do, your feelings, what do you tell

them about you? Rayann: I like to draw. Researcher: I like to draw.

Rayann: I want to be an artist when I grow up.

Researcher: Um hm Rayann: Nothing else.

Researcher: Ok

Rayann was able to speak with her mother even though she lived in another country:

Rayann: I want my mom.

Researcher: Your mom to be near you, to be close to you, right?

Rayann: (nods)

Researcher: Um hm, what else? Rayann: But just to visit me.

Researcher: Just to visit, or you know we have Internet now, you know, it makes contact

easier. You do the Internet, right?

Rayann: Yea,

Researcher: Um hm

Rayann: Not that much now.

Researcher: Um hm

Rayann: I don't use Facebook a lot.

Researcher: Or email?

Rayann: No

Researcher: How do you two keep in touch?

Rayann: We talk to each other.

Researcher: How? Rayann: On the phone.

Researcher: The phone, ok. By phone, she's a phone call away, right?

Rayann: Yea

Rayann was able to give emotional support to her friends:

Researcher: What if they were quiet and, and they don't talk too much?

Rayann: I'll tell them it's ok. You can talk to, with, to me.

If someone said something wrong about a friend of hers, Rayann would speak up and

defend that person:

Researcher: She telling you, don't talk to [Nelson]. He's not very nice. He's a pain. I

can't stand [Nelson] and you don't agree with her. What do you do?

Rayann: I'll stand up for him. Researcher: What will you do? Rayann: Tell, tell [Kaitlin] that's he's a, uh, he's my friend. Don't talk to him, mmm,

about him like that. Researcher: Um hm Rayann: And...

Researcher: She says, she'll say to you, you don't know him very well. I have him in my class and he's a real pain in class. You don't know him very well. He bothers everybody

in my class. Then what will you say?

Rayann: I don't know

Researcher: She'll say come over here with me. Don't sit by him. Sit by me. He's not very nice. Come on, don't talk to [Nelson] anymore. He's a real pain. Then what are you

gonna do?

Rayann: Yes, he *is* nice! Researcher: Uh huh

Rayann: And then I'll go and sit by him.

Researcher: You'll stand up for yourself, right?

Rayann: Yea

She was able to participate in social activities like family ceremonies and get-togethers with

friends:

Researcher: A social event could be somebody got married, having a wedding--

Rayann: Yea, my cousin is gonna get married.

Researcher: Ok, other things like that, you know what I mean? There's graduation, there's birthday parties, there's re-, even retirement for older people like me, um, events like that. I'm running out of ideas. Maybe an award ceremony. I don't know. Those are social activities, like social events or activities. So tell me more about the wedding.

Rayann: It didn't it didn't happen yet.

Researcher: Ok, but you talked about something happening in the future. Tell me more

about that. Rayann: Yea

Researcher: You would like to attend it, ok. Rayann: But I went to her engagement already.

Researcher: And how was that?

Rayann: Good

Researcher: What happened? Rayann: They were dancing.

Researcher: Nice

Rayann: They had music. Researcher: Um hm Rayann: And food

Researcher: Mmm, what kind of food?

Rayann: Strawberries Researcher: Mmm

Rayann: Covered with white chocolate

Researcher: Ooo

Rayann: And, and I don't remember if they had, maybe there, there was baklera, but I

don't remember the, yea maybe then baklera

Researcher: What's that?

Rayann: Baklera Researcher: Baklava? Rayann: Is a sweet

She insisted that particular dessert was pronounced "baklera", but when I looked it up on the Internet, I read that baklava is a common Arabic food in Lebanon, but I also saw it spelled "baklawa." At times she had difficulty with specific articulations. Rayann was able to understand what happens in a wedding and was able to describe the traditional foods that were served in her culture. She was also able to enjoy being with friends her age:

Researcher: Who do you prefer to hang out with?

Rayann: W-w...At school?

Researcher: Anywhere, I wanna hear the whole story.

Rayann: Um hm, Mr. [Reyes].

Researcher: Mr. [Reyes], ok, at school. Who else at school do you prefer to hang out

with?

Rayann: Mmm, students.

Researcher: Ok but which ones? (laughs)

Rayann: (laughs)

Researcher: There's a lot people, students, woo! We got a big school!

Rayann: Boys and girls.

Researcher: That's still a lot of, a lot of people...

Rayann: (laughs)

Researcher: ...you know! Be specific Rayann: I don't know the names.

Researcher: You don't know the names?

Rayann: No

Researcher: You just wanna be with everybody, is that what you're trying to say?

Rayann: Yea

Researcher: Everybody.

Rayann: Yea

Researcher: (laughs) I mean like tomorrow we're going to go to the, to the mall. Who do

you prefer to hang out with at the mall?

Rayann: [Jill]

Researcher: [Jill]? Anybody else? Rayann: No (gasps) y-yea but...

Researcher: What? You don't know their names?

Rayann: No (laughs)

Researcher: Well tell me about them then.

Rayann: I don't know

Researcher: All the Best Buddies?

Rayann: (nods)

It seemed that Rayann, like other young people in high school, had a high opinion of her

handsome teacher, but she was able to form friendships with others her age.

Rayann could definitely express what she wanted and could ask for support:

Researcher: Who do you want for a support person? A support person that helps you.

Who do you want to have for a support person?

Rayann: I want, I, I want for a support person a boy.

Researcher: A boy for a support person?

Rayann: Yea

Researcher: Ok, tell me more about that. Explain that to me.

Rayann: I don't know what to explain.

Researcher: Ok, why do you prefer a boy rather than a girl for a support person?

Rayann: It could be anyone. I just want support. Researcher: But what if it's a mean person?

Rayann: I don't want that.

Researcher: You don't want a mean person?

Rayann: No

Researcher: So what do you want to have in a, in a support person? They need to be what

with you?

Rayann: Respectful

Researcher: Respectful, what else? Rayann: Give me what I want.

Researcher: Give you what you want, what else?

Rayann: When I want it.

Researcher: When you want it, you need that, right?

Rayann: (nods)

Researcher: What else? How else should they be with you?

Rayann: Nice

Researcher: Nice, great to hear that. Nice to you, right?

Rayann: Yea

Researcher: What else?

Rayann: A person who, who, who got my back. Researcher: Who's got your back. Looks out for you.

Rayann: Yea

Rayann could appropriately control her emotions. She came from a household that held the idea of respect to be of utmost importance. They were taught to control their emotions even

during times of great sorrow as observed at her brother's funeral. Here was how Rayann

described how she calmed herself down at home:

Researcher: What else do you do to try to calm down when you get angry?

Rayann: I go to my room.

Researcher: That helps. And then what do you do with the door?

Rayann: Nothing

Researcher: You leave it open?

Rayann: Yea

Researcher: Well it is your room.

Rayann: Yea

Researcher: Um hm, and that helps you calm down?

Rayann: Yea

Researcher: Ok, what if you were like nervous or upset about something, or you can't relax? How do you relax yourself? You're thinking and thinking about something and

you're worried about something, how do you relax?

Rayann: I don't know what to tell you.

Researcher: What's, what's relaxing to you? What makes you feel relaxed?

Rayann: Music

Researcher: Music makes you relax. Anything else?

Rayann: Sleeping

Researcher: Sleeping, sure!

Rayann: (laughs)

Researcher: People do that.

Rayann: Dreams Researcher: Dreams!

Rayann: Makes me f-feel happy. Researcher: Oh yea, of course.

And when she was with her friends, this was how she calmed herself down:

Researcher: Let's say they're on CBI. You're on CBI together and maybe you're in a mall and you wanna go to this store and they wanna go to the other store. Ok, what do you do about that?

Rayann: Yea, I wanted to go to Justice.

Researcher: Justice, uh huh, yea!

Rayann: But, but it was time to go and I was real mad.

Researcher: So what did you do about that? What did you say?

Rayann: I tried to calm myself down.

Researcher: Tried to calm yourself down. And what did you say to people?

Rayann: Nothing!

Researcher: Nothing? You just tried to take it and calm yourself down?

Rayann: Yea

Researcher: Yea, I guess you knew there was nothing you could do about it, right?

Rayann: (nods)

Researcher: It was time to go.

Rayann: (nods)

And when she was upset with other people, she could still control her emotions:

Researcher: Nothing hard about working with other people?

Rayann: No

Researcher: You, you enjoy it, right?

Rayann: Yea

Researcher: You have no problem with that?

Rayann: As long as I get my way.

Researcher: That's right, what if you don't get your way, then what happens?

Rayann: Then I'll get mad.

Researcher: And then what happens? Rayann: Try to calm myself down.

Researcher: And what do you say though? They might not even know you're mad if you

don't say anything. What do you say? Rayann: I want this or I want that.

Researcher: Um hm. Because if you're mad they might now know. Right, do you show

your anger when you get mad? Do you show it or you just, you're just quiet?

Rayann: I'm not, I try to keep it quiet.

Rayann was able to make choices independently about personal items, how she decorated her

room, and how she spent her money:

Researcher: Who chooses the clothes you use every day?

Rayann: Me

Researcher: You do, ok.

Rayann: (laughs)

Researcher: Tell me how you do that? How do you choose your clothes?

Rayann: I match.

Researcher: You match them, um hm,

Rayann: (shrugs her shoulders)

Researcher: How about your gloves? Who chooses that?

Rayann: Me

Researcher: And how do you do that? Rayann: I t-tell my helper which one I want. Researcher: How many gloves do you have?

Rayann: I don't count them (laughs) Researcher: Oh there's a lot right?

Rayann: Yea

Researcher: Different colors, right?

Rayann: Yea

Researcher: So how do you know which gloves you want to wear?

Rayann: I tell [Carla] which, which color.

Researcher: Hm um, which color, right?

Rayann: (nods)

Researcher: Ok, how about the personal items that you use every day? Who chooses the

personal items that you use every day? Do you know what personal items are?

Rayann: What?

Researcher: Like toothbrush, hairbrush

Rayann: Yea, I know

Researcher: Um, ok, you know what that is? Ok, who chooses those things that you use

every day?

Rayann: M-m-my stepmom buys them.

Researcher: Uh huh Rayann: And I use them.

Researcher: Ok, all right, do you ever have a voice in which one you buy, she buys?

Rayann: No

Researcher: You ever tell her about what color or what, like what kind of brush, you know, how, if it's stiff bristles or soft bristles? You ever tell her what kind of brush you

want or what kind of toothbrush you want?

Rayann: Just clothes

Researcher: Just your clothes. What do you tell her about clothes?

Rayann: Which color

Researcher: Um hm, anything else?

Rayann: No

Researcher: Ok. Who chooses your hair style?

Rayann: Me (laughs)

Researcher: M-hm. Ok, and how does that happen?

Rayann: I don't know (laughs)

Researcher: You don't know how you choose your own hair style?

Rayann: Yea, I do.

Researcher: Oh, tell me about that then. Rayann: I tell [Carla] how to make it.

Researcher: Uh huh Rayann: And she does it.

Rayann can choose gifts she buys for other people. In fact, it was often hard to talk her out of something once she had her mind set on a gift for someone. Only if she buys clothing for herself that was too revealing did she not get to choose what she wanted to her spend money on.

Lastly, Rayann stated that she was able to live in independent housing:

Researcher: Well, why do you go to school?

Rayann: Because to learn.

Researcher: To learn so you can do what?

Rayann: Live by myself.

Researcher: Live by yourself, ok that's true. And what does it take to live by yourself?

Rayann: And with my husband and kids.

And another excerpt from the transcript:

Researcher: What are you doing now to be independent from your parents?

Rayann: I'm learning to be without them.

Researcher: Without them, good. Rayann: Without them next to me.

Researcher: Um hm Rayann: And around me.

Researcher: Um hm, that's being independent.

Rayann: I'm learning about that.

Another example was:

Researcher: Who do you need? Rayann: I need a husband.

Researcher: You need a husband.

Rayann: (laughs)

Researcher: Ok, who else do you need?

Rayann: I need to live a-alone.

Researchewa: You need to live alone.

Rayann: Sometimes I need to be my, be alone.

Researcher: Sometimes, you need to be alone sometimes, right?

Rayann: Yea

With the support of her future husband, Rayann stated that she could live independently. That may be true in itself, but realistically she might never be allowed to get married.

Analysis of the Preferences Related to Beliefs, Interests, and Abilities for Vanesa

Preferences related to beliefs for Vanesa. Vanesa believed in herself and others. I am not sure if she named the other two participants in this study as her friends because she knows they were in this study too or if she named them because they spent so much time together. Vanesa had also named them in other places in the interviews. It was obvious that they missed the bus and stayed after school with me for interviews. Plus, there was always [Veronica], everyone's best friend, to tell them the gossip on everything. This was how Vanesa expressed beliefs in herself:

Researcher: But what does she think about you?

Vanesa: Oh!

Researcher: She's your friend, right? [Rayann] is your friend?

Vanesa: M-Yea

Researcher: What does she think about you?

Vanesa: That she's proud. Researcher: She's proud, ok. Vanesa: And she excited...

Researcher: ... What does she say about you?

Vanesa: She says I'm friendly.

Researcher: That you're friendly! Well, that's true....

Researcher: ...but what does [Maria] think about you?

Vanesa: That, that she's best friend. Researcher: That you're her best friend?

Vanesa: Yea

Researcher: She thinks you're her best friend? Is that it?

Vanesa: Yea

Researcher: That's a nice thing!

Vanesa also believed her friends were kind to her:

Researcher: How did you and [Nelson] become friends?

Vanesa: I...

Researcher: Tell me that story.

Vanesa: (laughs) we be kind together, be...

Researcher: You were kind to him?

Vanesa: Yes Researcher: Ok

Vanesa: Being gentle. Researcher: Gentle

Vanesa: And being good friend.

I heard few references from Vanesa about fantasy ideation, but there was one good example of something she said that was far from reality:

Researcher: What housework do you do in the living room?

Vanesa: TV. remote control.

Researcher: Um hm

I believe some young people with disabilities actually believe their job at home was to entertain themselves and keep busy because parents encouraged it so they could take care of important business at home. I wanted to make sure to represent this line of thinking in the study. Vanesa mentioned another job many young people in Florida dreamed about having:

Researcher: What kind of job do you want to have in the future, long time from now

when you're getting older? What kind of a job do you want to have?

Vanesa: Oh, to go to Disneyland.

Researcher: You wanna work in Disneyland? You wanna work there?

Vanesa: Yea

Researcher: That's the kind of job you want to have in ten years?

Vanesa: Um hm

Researcher: Wow, that would be a good job, wouldn't it?

Vanesa: Yea

This dream job was just that: a fantasy job. Disney World in Florida was too far away unless she moved to Orlando and it was still doubtful she would ever get hired by such a competitive company. In addition to this fantasy, Vanesa believed she had the ability to play instruments, but on an iPad:

Researcher: You want to say anything else about yourself?

Vanesa: Um, play instruments?

Researcher: Which instruments do you want to play?

Vanesa: A drum.

Researcher: You wanna learn how to play drums?

Vanesa: Yea

Researcher: Wow, that's good to learn. That's fun, huh?

Vanesa: It's not hard, it's easy.

Researcher: And how do you play drums? Do you have a drum set?

Vanesa: No, no, no.

Researcher: How do you play drums then?

Vanesa: My, my brother has a drum set with the stick.

Researcher: Well, I didn't know that!

Vanesa: Like, wait, it's like, wait, like this (bangs on the table)

Researcher: I didn't know that. He plays it?

Vanesa: Yea

Researcher: And you? What do you do too?

Vanesa: I listen to music on my....

Researcher: How about the drums though?

Vanesa: Oh the drums?

Researcher: Yea

Vanesa: Yea the drums, the guitar. Researcher: He has a guitar, too?

Vanesa: Yea

Researcher: Tell me about the guitar and the drums. I wanna hear more about that.

Vanesa: The guitar and, and the drums?

Researcher: Um hm

Vanesa: Is to pretend to...keep your voices down.

Researcher: Um hm. Do you ever play the drums at home?

Vanesa: Sometimes.

When I told Vanesa's brother at school one day that I did not know he had a drum set and could play the drums, he told me it was not true. He said his sister was talking about the iPad. I found these statements about instruments to be fantasies because it was nothing like playing a real instrument. She mentioned instruments frequently so I know she believed she could play:

Researcher: You're good at counting? Uh huh, what else?

Vanesa: Um I thinking... Researcher: You're thinking? Vanesa: About...instruments Researcher: Instruments? Vanesa: Like piano.

Researcher: Uh huh Vanesa: Or like guitar.

Researcher: You like the piano and the guitar?

Vanesa: Yea (laughs) yea

Researcher: Is that something you want to learn more about?

Vanesa: Yea

Researcher: How good are you at piano? How good are you at playing the piano?

Vanesa: It's, it's very easy.

Researcher: Um hm

Vanesa: To play the piano.

Researcher: And you're good at that piano? Yea?

Vanesa: M-yea

Researcher: Do you have a piano at your house?

Vanesa: No, no, no.

Researcher: Where do you practice piano? Vanesa: No, my brother has the piano. Researcher: Your brother has the piano?

Vanesa: Yea Researcher: Ok Vanesa: My mom. Researcher: Um hm

Vanesa: She has the iPad. Researcher: Um hm

Vanesa: And she has music in her iPad?

Researcher: iPads have pianos in there too. Is that the piano you do too?

Vanesa: M-yea

Researcher: I have a, a piano in my iPad.

Vanesa: (laughs) Researcher: Do you?

Vanesa: No, my mom has it. Researcher: In the iPad? Vanesa: No, the r-...

Researcher: The real piano?

Vanesa: Yea and, and the red iPad, she has.

Researcher: What? Vanesa: My mom

Researcher: Has a piano in the iPad or just iPad?

Vanesa: Just iPad. Researcher: Ok

Vanesa believed she had skills in entertaining, which was found to be a fantasy of hers:

Researcher: Yea, what's your favorite song?

Vanesa: Uuummm, Adele?

Researcher: You like Adele, don't you? Wanna do Adele again one day?

Vanesa: Yea, do it. Researcher: All right

Vanesa: Oh, wait, wait, are we gonna do it over here or over there? (indicating

auditorium)

Researcher: Practice here, show over there. Vanesa: Oh yea, I forgot, aaahhh, I forgot! Researcher: Ok, we're gonna practice over here.

Vanesa: I forgot.

Researcher: And your favorite song is...?

Vanesa: Adele. Researcher: Adele.

She also said in archival documents that one skill she had was acting. She probably remembered a Christmas play we did one year and performed it for our students in the special education department. All the students needed full support to remember their lines so I found this belief of hers to be a fantasy. She did not really say she believed she could be a professional entertainer, but she did believe she could sing a song by Adele for the talent show. She did know the words for the song, but must use the song playing in the background for support while she sings.

Vanesa had some beliefs about her rights. I was not clear if she understood the concept of rights, especially at the end of the conversation, but I wanted to respect her voice as representative of students with a severe intellectual operating level:

Researcher: What do you have a right to do? I have a right to...what?

Vanesa: To go to the Best Buddy meeting.

Researcher: I have a right to go to the Best Buddy meeting, what else? I have a right to...?

Vanesa: To see [Yolanda].

Researcher: To see [Yolanda], to see her—

Vanesa: Help... Researcher: Hm?

Vanesa: Helps [Norma] to help her.

Researcher: Uh huh

Vanesa: See [Yolanda's] food.

Researcher: Yea Vanesa: Yea

Researcher: Are you trying to say you have a right to, to be with [Yolanda]?

Vanesa: Yea

Researcher: You have a right to your, to your friends.

Vanesa: Yea

Researcher: To pick out like [Yolanda] for a friend.

Vanesa: M-yea

Researcher: What else do you have a right to do?

Vanesa: I...like um...

Researcher: I have a right to... Vanesa: To, to go to the buses.

Researcher: To go to the buses and get a ride home from school.

Vanesa: From school. Researcher: Um hm

Vanesa: Or...

Researcher: You have a right to what, what else?

Vanesa: Go t-, go to the tree.

Researcher: Tree? Vanesa: Yea

Researcher: Um hm. Which tree is this? Vanesa: Oh, outs-, outs-, outside...

Researcher: Um hm Vanesa: Mmm, yea

Researcher: Which tree outside, at this school, or at home, or at the park?

Vanesa: At the, at the park (laughs)

Researcher: Oh, at the park. I wouldn't know that tree. It's at the park.

Vanesa: Sorry, Sadler!

Researcher: That's ok. That's ok. It's part of your life.

Vanesa frequently had a difficult time staying on topic. The friend she was referring to,

[Yolanda], had profound physically disabilities, but moderate to severe intellectual disabilities

and many of our students were drawn to her because she required so much attention from her

one-to-one paraprofessional and teachers. She could not speak, but understood everything going

on around her in both languages. I think this excerpt reflected her desire to bask in some of the

attention [Yolanda] received and she felt she needed to talk about her friendship with her. I

cannot explain the tree comment, however. Vanesa also had some idea of her human rights:

Researcher: You have a right to...what?

Vanesa: To eat it.

Researcher: You have a right to eat food, to eat your sandwich, yea, is that what you're

saying?

Vanesa: Yea (laughs)

Researcher: That's true, you have a right to eat your sandwich. All right, what do you

have a right to have? I have a right to have...what?

Vanesa: Oh, coke.

Researcher: I have a right to have coke.

And later on:

Researcher: I have a right to have what?

Vanesa: Oh! Play video games.

Researcher: I have a right to play video games.

Vanesa had a difficult time staying on topic, even if she knew the concept. I believe if she was fully rested and guided, she could give better examples of her rights.

Preferences related to interests for Vanesa. Vanesa knew her needs and was interested in assistance from her mother and caretaker at home:

Researcher: What happens to you when you got to go to the doctor? What happens?

Vanesa: You need some help to go to the doctor.

Researcher: Good, who helps you?

Vanesa: My mom.

Researcher: Ok there you go.

When speaking of her home nurse, Vanesa said:

Researcher: What else do you want in a helper? They gotta be nice, what else?

Vanesa: Put my clothes on.

Researcher: Help you with your clothes, what else?

Vanesa: Pants, shoes. Researcher: Um hm. Vanesa: Socks.

Researcher: All those things.

Vanesa was interested in being independent and liked to think that she was:

Vanesa: I put on, I put my shoes on my socks.

Researcher: Um hm. Vanesa: And...

Researcher: Um hm, by yourself?

Vanesa: Yea

Researcher: You dress yourself all the way?

Vanesa: Yea

Researcher: No help?

Vanesa: No help, I dress myself all the way with no help.

Researcher: No help.

Contrary to what she said previously and contrary to the fact that I knew her mother hired a nurse to help her bathe while she was still at work, Vanesa showed she was interested in being independent:

Researcher: You take a shower by yourself completely with no help?

Vanesa: No help.

Researcher: You take a shower with no help?

Vanesa: No *help* (whispered)

Researcher: And you shampoo your hair, no help?

Vanesa: No help.

Vanesa was interested in her friends and having a social life:

Researcher: How do you make friends with people your own age?

Vanesa: Shake hands.

Researcher: You shake hands. Vanesa: Give them a hug. Researcher: Give them a hug.

Vanesa: (laughs) And give them the kiss (makes two smacking sounds)

Researcher: Um hm Vanesa: (laughs)

Researcher: But people you don't know, you give them a kiss?

Vanesa: Yea, on the cheek not on the mouth.

Researcher: Not on the mouth.

Vanesa: Oh (laughs)

Researcher: But still you don't know them.

Vanesa: No...no.

It was very difficult for students like mine to know when they are crossing a line socially and they tended to be overly friendly to people they did not know. However, Vanesa had good social skills otherwise and was interested in making friends in a more appropriate way:

Researcher: How do you make new friends with people that are your age? How do you

make new friends?

Vanesa: We sit at the table by the cafeteria.

Researcher: Um hm

Vanesa: We eat at the table (laughs)

Researcher: You have lunch with them. That's a good idea.

Vanesa explained her interest in a club she belonged to:

Researcher: How do you take part in youth groups?

Vanesa: What's youth group?

Researcher: Well, it could be Tamiami, it could be Peer Link, it could be Best Buddies, any type of group that does activities with young people. How do you take part in that?

Vanesa: Best Buddies?

Researcher: Yea, how do you do that?

Vanesa: That, that you mean, you meet the buddy?

Researcher: You meet the buddy, um hm.

Vanesa: And, and then, and then (reaches for her drink)

Researcher: Um hm

Vanesa: You, you wait to my buddy. Researcher: You wave? Like that?

Vanesa: No, you, you wait (gestures waiting)

Researcher: You wait?

Vanesa: Yea

Researcher: Who do you wait for?

Vanesa: For my buddy.

Researcher: Then what are you gonna do? Vanesa: Walks (looks down at drink)

Researcher: Walks, all right. Take a drink, take a drink. Go ahead.

Vanesa: And...

Researcher: Take a drink and we'll talk, ok?

Vanesa: And...

Researcher: And what do you do when you walk?

Vanesa: She hold my hand.

Researcher: And then what happens?

Vanesa: Um and then we...I forgot, I forgot the words.

Researcher: You walk together?

Vanesa: Oh, we walk together in the same group. Researcher: In the same group, ok, that's good.

Vanesa was interested in making choices about her future living situation, job, leisure activities, friends, food, post-secondary training, and travel. Despite her mother's interest in supported living for adults with disabilities, Vanesa was interested in staying home:

Researcher: I wish I lived near...what? Vanesa: Um I wish I live near is...

Researcher: Near, close to. I wish I lived close to...what?

Vanesa: In my house.

Researcher: You're gonna be living in your house.

Although Vanesa repeatedly said she wanted to remain living with her mother in the future, at the end of our interviews she did mention apartment living with a friend, not a boyfriend:

Researcher: What's something important in your life that you want to change, something big in your life that you wanna change?

Vanesa: Like change your address?

Researcher: Change your address? That means you want to move. So you want to move?

You want to get a new house? Is that what you're saying?

Vanesa: Yeee-a

Researcher: You wanna get a new house?

Vanesa: Yea

Researcher: So where do you want to live?

Vanesa: I live in the apartment.

Researcher: You want to live in an apartment?

Vanesa: Yea

Researcher: You do? Who do you want to live with in the apartment?

Vanesa: With some friends.

Researcher: With some friends? Like who do you want to live with? Which friends?

Vanesa: Like [Spencer].

Researcher: You want to live with [Spencer]?

Vanesa: With, go to the apartment.

Researcher: Um you want to live with [Spencer] as a friend or as a girlfriend?

Vanesa: As a friend!

Researcher: Not as a girlfriend?

Vanesa: No

Researcher: So you don't want to be his girlfriend?

Vanesa: I, um, I gonna be as a friend.

She repeated this sentiment in the last interview question, lending credence to the conclusion that she was at least thinking about having her own place to live one day:

Researcher: When you think of yourself, finishing high school, graduating, going on to be an adult, how do you want to live your adult life? What's your dream about living an adult life?

Vanesa: Apartment.

Researcher: Apartment! There you go, what else?

Vanesa: Living a dream home.

Researcher: Living in a dream home? How would that be? Who would be there?

Vanesa: [Spencer].

Researcher: Yea maybe [Spencer].

Vanesa also was interested in being employed. She mentioned several jobs she might like to have. Here is an example:

Researcher: What kind of job do *you* wanna have?

Vanesa: A school.

Researcher: A school job?

Vanesa: M-yea.

Researcher: You want a school job?

Vanesa: Yea.

Researcher: That's a good answer.

Many of our students talked about wanting to work in school because they did not want to leave a place where they felt comfortable and had extensive social contact with people with and without disabilities. In addition, Vanesa mother was a teacher and that was an influential factor. Here is another example of Vanesa's job interests:

Researcher: What other school work do you do right now that will help you get a job?

Vanesa: Mmm, like I forgot I don't know.

Researcher: Ok, ok. Vanesa: Oh! A s-, a job? Researcher: Yes, um hm.

Vanesa: Oh, um, at the computer, just like yours.

Researcher: The computer will help you get a job, it sure will!

Vanesa: Yea

Researcher: It will! Computers are the future!

Vanesa: To do numbers, words.

Researcher: Yes! Vanesa: Letters. Researcher: Yes.

Vanesa: And alphabets.

Researcher: That's very good, very good answer.

This example was included because I remember a time when special education teachers were told that our students would never learn how to use a mouse and that computers were not as important for them. This proved they were just like any other student in high school with interests in computers. However, most of Vanesa's job interests revolved around working in an educational setting:

Researcher: What kind of a job do you want to have when you're, when you're an adult?

Vanesa: A teacher.

Researcher: You wanna be a teacher?

Vanesa: (nods)

Vanesa tried to express that she wanted a job with peace and quiet:

Researcher: You like to have somebody to tell you what to do?

Vanesa: Mmm yea.

Researcher: So you can hear it and you can follow the directions?

Vanesa: Yea.

Researcher: Very good. What else? Vanesa: Answers peace and quiet. Researcher: Answer peace and quiet?

Vanesa: Yea.

I had to read between the lines in the above quote, but I thought that I had captured a very profound statement from a person with such serious cognitive disabilities and it was remarkable.

Vanesa had various interests in leisure time activities. Since this is the group of people who will have the most leisure time in their adult lives, it was important that we get their input:

Researcher: How do you decide what to do in your free time? For fun?

Vanesa: Fun game?

Researcher: But how do you decide which fun game to do?

Vanesa: Play with the computer.

Researcher: That's what you pick? To play the computer?

Vanesa: Yea

Researcher: You like to play with computers?

Vanesa: Yea

Researcher: That's why you chose that one, because you like it?

Vanesa: Yea

Researcher: What else do you choose to do in your free time?

Vanesa: To go outside. Researcher: Outside, and? Vanesa: To go inside. Researcher: Inside, too?

Vanesa: Yea

Researcher: Ok, doing what? For free time?

Vanesa: Doing the dishes.

Researcher: That's what you do in your free time for fun?

Vanesa: Yea

Researcher: You love washing dishes?

Vanesa: Yea

Researcher: For fun?

Vanesa: Yea

Researcher: You can come over to my house and do my dishes then if you like it so

much!

Vanesa: Sadler!

Researcher: Is that what you do for fun?

Vanesa: Yea

Researcher: What do you that's fun? Vanesa: Oh wash--, washing the plates.

Researcher: That's for fun?

Vanesa: Yea

Researcher: Well computers are fun, going outside is fun, what else is fun?

Vanesa: Playing kickball.

Researcher: Playing kickball is fun?

Vanesa: Um hm.

Researcher: Tell me more about kickball.

Vanesa: You, you kick the ball.

Researcher: Um hm, then what happens? Vanesa: And then, and then you score.

Researcher: Um hm, and what made you pick kickball to do for fun?

Vanesa: Playing outside, not inside.

Researcher: In--, Outside, not inside. What made you decide to pick kickball to do? Why

did you pick kickball to do?

Vanesa: To play it. Researcher: To play it?

Vanesa: Um hm.

Researcher: Why do you want to play kickball?

Vanesa: Because it's a lot of energy.

Researcher: A lot of energy.

Vanesa: Um hm.

I questioned her interest in washing dishes for fun, but it was possible she liked playing with water. It was very difficult to separate the pleasing-the-researcher statements from the true-feelings statements. She also mentioned she liked putting together goody bags in her free time, but this may be an example of free association due to her cognitive level.

Vanesa had interests in friends and social activities:

Researcher: How do you decide what to do with one of your friends, for fun?

Vanesa: Oh! Play games.

Researcher: Ok. You like to play games, what else?

Vanesa: Um, let's see, play instruments.

Researcher: Play instruments with your friends, ok. What else do you like to do with your

friends?

Vanesa: Play, uh, play, play Internet access.

Researcher: Play Internet...access?

Vanesa: Yea.

Vanesa was interested in weekend social activities:

Researcher: How do you know what you want to do on the weekends?

Vanesa: Go to Dolphin mall. Researcher: You like doing that?

Vanesa: Yea (laughs) Researcher: What else? Vanesa: Go to the store.

Researcher: Um hm, tell me more.

Vanesa: Go to buy shoes.

Researcher: You like buying shoes?

Vanesa: Socks Researcher: Um hm Vanesa: Um, pants

Researcher: Um hm, you like doing that? Vanesa: And a jacket and a, and a shirt.

Researcher: Um hm

Vanesa: And, and my earrings too.

Researcher: You like to go shopping on the weekends?

Vanesa: Yea, I go shopping with my mom.

She was also interested in going shopping with her friends:

Researcher: Tell me more about that, about hanging out with your friends tell me more

about that.

Vanesa: Going out to eat.

Researcher: Nice, ok.

Vanesa: Going to the stores.

Researcher: Uh huh

Vanesa: Going shopping, going Kmart, Oh! Going to buy shoes.

Researcher: Nice Vanesa: And socks

Researcher: Um hm, so you're doing this with your friends, right?

Vanesa: Um hm, yea

Researcher: That's fun, all right.

Vanesa was interested in contacting her friends, but used an adaptive method of communication

which people without disabilities also often used:

Researcher: How do you call [Kaylee]? Vanesa: Call, call with the speaker. Researcher: With the speaker phone?

Vanesa: Yea

Researcher: Have you done speaker phone with her?

Vanesa: Yea

After a bit of confusion, Vanesa stated her interests in picking out her own friends:

Researcher: Who picks out your friends?

Vanesa: Mmm (points to herself) Researcher: You do, right? Vanesa: Yea, I forgot.

Researcher: You forgot, but you got it right now? You pick out your own friends right?

Vanesa: Yea

Researcher: They don't tell you who to be friends with, you did that yourself!

Vanesa: Yea, I did that by myself.

Researcher: There you go.

Vanesa had her own ideas that interested her regarding social activities that were meaningful to

her:

Researcher: What social activities do you want to go to?

Vanesa: What's soshos activ-?

Researcher: Activities. Well it could be a wedding, it could be a birthday party, it could

be a graduation. It could be um...

Vanesa: A birthday party.

Researcher: You want to go to a birthday party?

Vanesa: Right here or over there? (gestures this classroom and possibly her afterschool

park program)

Researcher: Well, anybody's party. I mean do you like to go to weddings, birthday parties, graduations? Do you like to go to reunions? Do you like to go to, um, meetings? Do you like to go to, um, games? What kind of social activities or events do you like to go to?

Vanesa: Games!

Researcher: Games what kind of games? Vanesa: Um, wait. Like play blocks.

Researcher: Play...blocks?

Vanesa: Um hm

Researcher: Um hm. That's a social activity? That's a social event?

Vanesa: Yea

Researcher: Where do you play block, blocks?

Vanesa: You, you can build something. Researcher: Where do you do that?

Vanesa: The form

Researcher: Yea. The forms. Where do you do that?

Vanesa: A, a farm! (laughs) Researcher: Farms? Oh.

Vanesa: (laughs)

Researcher: You can build farms out of blocks?

Vanesa: Yea!

Researcher: Ok, where do you do that?

Vanesa: The house. Researcher: Um hm Vanesa: The barn. Researcher: Um hm

Vanesa: And different places I like to go to.

It was possible that Vanesa was recalling playing a block activity with others at her after school parks and recreation program, but I cannot be sure from her statement above.

Even though Vanesa was a slim young woman, she liked to eat and had a varied list of favorite foods:

Researcher: You're going to eat there at the restaurant. How do you do that?

Vanesa: Pizza.

Researcher: You're gonna order pizza. What are you going to do?

Vanesa: Pepperoni.

Researcher: How do you order pepperoni pizza at the restaurant?

Vanesa: Call the place.

Vanesa was not a picky eater and was interested in many different restaurant foods:

Researcher: What other kinds of other restaurants do you like?

Vanesa: Mmm, wait Carrabbas.

Researcher: Carrabbas? Vanesa: Carrabbas. Yea!

Researcher: You like Italian food, don't you?

Vanesa: (laughs)

Researcher: (laughs) What else?

Vanesa: KFC Researcher: KFC Vanesa: Subway Researcher: Subway

And later in the conversation:

Researcher: Tell me more about that.

Vanesa: Eat food.

Researcher: Oh, do they have good food there? At Dave & Buster's?

Vanesa: Yea

Researcher: Mmm, they do, don't they?

Vanesa: (laughs)

Researcher: Where else do you want to go?

Vanesa: Bur- wait burgers.

Researcher: They have hamburgers there?

Vanesa: Uh, yea hamburgers, yea. Researcher: At Dave & Buster's?

Vanesa: Um hm.

She also liked hot food:

Researcher: Ooo, you like *jalapeños*? That's a hot food!

Vanesa: Yea, and it's spicy!

Researcher: Yes! Vanesa: (laughs) Researcher: It is.

Vanesa: (laughs) And hot!

Researcher: It is.

Vanesa stated, incidentally, that choosing her own food was an important decision. To her, it probably was. Eating was one of the primary choices for self-determination and one they were most commonly allowed to do independently, as long as there were no other health issues.

She was interested in choosing post-secondary education sites. She talked about living on a college campus:

Researcher: When you're like 30 years old, 40 years old? Then where do you want to

live?

Vanesa: In in c-college.

Researcher: You wanna live in college?

Vanesa: Yea.

Later in the conversation, she talked about her interests in schooling after graduation:

Researcher: How about when you graduate from [Northeast] and you leave the school.

What kind of a job do you want to have?

Vanesa: To FIU.

Researcher: To FIU? How about after FIU and you finish FIU? What kind of a job do

you want to have?

Vanesa: [Northeast] (laughs)

Researcher: Well, now that's going backwards. You gotta, from high school, college,

after that you have to get a job.

Vanesa: Oh!

Researcher: That's going backwards, back to high school, right? What kind of a job do

you want to have?

Vanesa: Oh! College, college.

Vanesa was interested in further learning, like the class in "kinology" that her brother takes:

Researcher: What class does he take that you want to learn more about? Kinology? What

was that class?

Vanesa: Oh, reading! Reading.

Researcher: Reading? You want to learn more about reading?

Vanesa: Yea

Researcher: You wanna be a better reader?

Vanesa: Yea

Researcher: That's a good thing to learn more about!

Just to clear up any confusion, "kinology" was her attempt to pronounce technology. Vanesa was a very precocious speaker for her cognitive ability level.

Vanesa expressed interests in travel:

Researcher: Where would you like to travel to?

Vanesa: A farm (laughs)

Researcher: A farm? You like being in the country on the farm, right?

Vanesa: Yes

Researcher: You said that twice now. You want to visit a farm one day?

Vanesa: Oh, yea.

Researcher: What kind of a farm? Tell me more about the farm you want to visit.

Vanesa: A cow moo-ooo! (laughs)

Researcher: You want to see cows and listen to them moo at the farm?

Vanesa: (laughs) yea

Researcher: What else you wanna do at the farm?

Vanesa: A pig.

Researcher: You want to see the pigs, um hm.

Vanesa: (laughs) Yea Researcher: What else?

Vanesa: Pony.

Researcher: You like ponies? How about riding ponies?

Vanesa: What? What's that?

Researcher: Riding the pony, taking a ride on a pony. How about that?

Vanesa: Oh, yea. I, I like to sit down in the pony.

Researcher: Yea?

Vanesa: Oh yea, chica, chica, chica like that (makes sound effects and gestures

holding the reins)

Researcher: You want to travel to like a horse farm?

Vanesa: Yea

Researcher: And ride the po-, the ponies and the horses, right?

Vanesa: Yea

Researcher: That would be fun, wouldn't it?

Vanesa: Yea

Vanesa, her mother, and I once attended a birthday party for one of the other students that was held at a petting farm. She was probably talking about wanting to go back there. She also talked about her interests in local travel around the city:

Researcher: How are you gonna travel around Miami after you graduate? No more school

bus!

Vanesa: No?

Researcher: Nope! Once you graduate your high school no more bus.

Vanesa: Wh—

Researcher: No more school bus.

Vanesa: From here?

Researcher: From here, no more yellow school bus. So how are you going to get around

Miami after you graduate?

Vanesa: Go to FIU.

Researcher: How are you going to get there?

Vanesa: (laughs)

Researcher: That's possible, ok, that's fine, but how are you going to get there?

Vanesa: You can open the door.

Researcher: Of what? Vanesa: Of to go to FIU.

Researcher: How are you going to get to the door of FIU?

Vanesa: Go inside.

Researcher: How are you going to get there? From your house to FIU? How are you

going to get there?

Vanesa: Mmm. Uh, you can call 911. Researcher: That's for emergencies.

Vanesa: Oh! I forgot. Researcher: Um hm

Vanesa: Sorry, Sadler, I forgot.

Researcher: But who's gonna help you get from your house to FIU if you wanna go

there?

Vanesa: My mom.

Researcher: There you go! Vanesa: I forgot! (laughs)

Researcher: Your mom will help you with that! Vanesa: I forgot Sadler, I forgot, I forgot.

Researcher: That's ok. We got it now, don't we?

Vanesa: Yea.

Preferences related to abilities for Vanesa. Vanesa stated her various abilities. They were related to jobs and education, self-expression, participation in social activities, emotional control, and living independently. Even though she had no job experience, she felt she had some abilities for working and learning:

Researcher: How do you do school activities?

Vanesa: To do work?

Researcher: It could be work, it could be fun things.

Vanesa: Science?

Researcher: Science, you like science in school?

Vanesa: Math.

Researcher: You like math in school?

Vanesa: Reading. Researcher: Reading.

She was also interested in improving her abilities in math:

Researcher: What do you want to learn more about...?

Vanesa: Oh! Um...

Researcher: You said reading, anything else? How about math?

Vanesa: Math is easy. Researcher: Math is easy?

Vanesa: Yea

Researcher: Good, why do you like math?

Vanesa: 2 + 2 = 5

Researcher: There you go.

Vanesa: Sss- Wait, 6 + 9 = 10

Researcher: You like math, right? You want to know more about reading, and you want

to know more about, about math too? You want to know more about math, too?

Vanesa: Yea

Vanesa had never participated in work training, but she stated she had abilities in class work

training:

Researcher: What job training have you done, or work training?

Vanesa: Work training? Researcher: Um hm

Vanesa: Like you trace you, like tracing?

Researcher: Could be tracing. Vanesa: Tracing the paper?

Researcher: It could be tracing the paper, it could be.

Vanesa: Yea

Researcher: What else?

Vanesa: Ah this one? (reaches over for classwork from the inbox)

Researcher: Um hm Vanesa: That?

Researcher: Like classwork?

Vanesa: Yea, like... Researcher: Classwork.

Vanesa could express herself very well considering her cognitive ability level. She was able to

make contact with friends:

Vanesa: You, you text on the phone. Researcher: You text on the phone too?

Vanesa: Yea (laughs)

Researcher: That's great! I didn't know you could do that!

Vanesa: Yea, I only do it at home. Researcher: You do it at home, right?

Vanesa: Um hm

Researcher: What kind of a phone is that?

Vanesa: It the iPhone.

Researcher: Oh, that's a nice one! You can do good texts on that phone!

Vanesa: It's the ap—ap—apple.

Researcher: And how do you use the apple phone to make a, a phone call?

Vanesa: To call messages.

Researcher: You know how to do that? Tell me how.

Vanesa: Like this (moves her thumbs quickly over the screen and then turns it around to

show me, the screen is black) (laughs)

Researcher: Um hm. um hm.

I gave her the benefit of the doubt that if the phone was working, she would be able to use it to contact friends with minimal assistance.

Vanesa was able to give her friends emotional support.

Researcher: Like [Kaitlin], you know [Kaitlin]. They used to fight all the time. [Nelson]

and [Kaitlin] used to fight all the time. Vanesa: N-no fighting! No fighting! Researcher: They did, they did fight, ok.

Vanesa: (laughs)

Researcher: Let's say [Kaitlin] says to you, why do you like [Nelson]? He's, he's so, he's

such a pain! Vanesa: (laughs)

Researcher: And then she says, I don't like [Nelson].

Vanesa: (laughs)

Researcher: And you like [Nelson]...

Vanesa: He's big.

Researcher: She's says no, he's just a punk!

Vanesa: Sadler!

Researcher: What, what would you say to [Kaitlin]?

Vanesa: Be nice!

And later in the conversation:

Researcher: Let's say one day you're in Dolphin Mall and you're walking around with [Kaitlin]. Ok, and here comes [Nelson], down, down the, the mall, ok, here comes [Nelson] walking towards you and you, you get, look [Kaitlin] there's [Nelson]! And she goes don't talk to him!

Vanesa: (laughs)

Researcher: I don't like him and he's mean.

Vanesa: (laughs)

Researcher: Don't walk, don't say hi to him, come over here, don't talk to him and you want to say hi to him. She won't let you do it. She doesn't agree with you. You think he's a nice guy and she thinks he's not nice.

Vanesa: No!

Researcher: So what do you do? What do you say to [Kaitlin]?

Vanesa: I like, oh! Like chi! (laughs) (gestures by moving hand as if to throw)

Researcher: But what do you say?

Vanesa: Like like...I like [Kaitlin] a blonde girl. Researcher: But [Kaitlin] doesn't like [Nelson]...

Vanesa: No!

Researcher: She thinks he's a creep and you think...

Vanesa: A creep

Researcher: ...he's a great guy.

Vanesa: Yea

Researcher: She's thinks he [not] very nice, what are you going to say to [Kaitlin]?

Vanesa: Uh, wait, uh, [Kaitlin], uh, you are a creep and...

Researcher: How about [Nelson]? Vanesa: Uh [Nelson] is a great guy

Researcher: So are you going to tell her that?

Vanesa: Yea

Researcher: Ok, you're gonna speak up to her and tell her that?

Vanesa: Yea (laughs)

Vanesa was able to participate in social activities. One of her favorite free time activities was

playing sports with other people:

Researcher: Where do you do kickball? Vanesa: Out front of the, of the tree. Researcher: In front of the tree, where? Vanesa: Behind where, uh the grass.

Researcher: Behind the grass, at what place do you do kickball?

Vanesa: Uh, at the field.

Researcher: At the field, so you're not home when you do kickball, are you?

Vanesa: Uh uh (meaning no)

Researcher: Are you at [Northeast] when you do kickball?

Vanesa: Um hm Researcher: You are? Vanesa: Um hm

Researcher: You do kickball here, too?

Vanesa: Um hm

Researcher: Where else do you do kickball?

Vanesa: Like, like to kick the ball?

Researcher: Where? Where do you play kickball?

Vanesa: On, on the field. Researcher: On the field. Ok.

Vanesa could ask for support when needed:

Researcher: Where do you wanna live when you're an adult in the future?

Vanesa: I stay home by myself.

Researcher: Um hm

Vanesa: Yea

Researcher: Ok, ok, who's gonna help you to, to plan where you're gonna live in the

future? Who's gonna help you with that plan?

Vanesa: That plan is...

Researcher: Who helped you with your plan?

Vanesa: Take me a shower.

Researcher: No, your plan for the future. Where you're gonna live?

Vanesa: Oh!

Researcher: Who helps you with that plan? Who helps you plan your future? Where

you're gonna live?

Vanesa: I live by myself.

Researcher: Ok, but who's gonna help you with that plan?

Vanesa: Um, my mom.

Researcher: Yea, your mom's gonna help you. She's your support person.

Vanesa: Yea

Researcher: She's gonna support you, with help, you get there, where you want to be in

your life. That's a good answer.

When she needed a ride, she was able to ask for support:

Researcher: You gotta pick up a box that's, that's sent *to you*. Maybe it's a present for Christmas. You can't just, it comes in a box, but it's in the post office now because it wouldn't fit in your mailbox. You have to go pick it up at the post office and you don't have a license. So, how are you gonna get there?

Vanesa: Uh, um, uh, oh, to ask for help.

Vanesa knew how to control her emotions when she was upset:

Researcher: When you're upset, how do you calm down?

Vanesa: Calm down?

Researcher: Yea, how do you calm yourself down?

Vanesa: I breathing a lot.

Researcher: Breathe a lot, that's a good answer. What else do you do to calm down?

Vanesa: Hmmm. Breathe a little bit.

Researcher: Um hm

Vanesa: Um, respect un another.

Researcher: Ok, how do you relax? What do you do to relax?

Vanesa: To relax? Researcher: Yes

Vanesa: Um, respect our neighbors? Researcher: What makes you relax?

Vanesa: Um relax to... Researcher: Yes

Vanesa: To breathe down.

Researcher: To breathe down, uh huh.

Vanesa: Yea

Researcher: What else makes you relax?

Vanesa: Um re-...to behave

Researcher: Yea...

Vanesa: Ask you a question?

Researcher: Ok, if you're really, um, nervous...

Vanesa: Oh! Nervous, tired.

Researcher: Or tired, how do you relax?

Vanesa: Go to bed.

Researcher: Go to bed is a good way to relax, very good. Ok, if you're really mad, how

do you calm down? Vanesa: I really mad?

Researcher: Yea, if you get really *mad*, how do you calm down?

Vanesa: I remember the computer (laughs)
Researcher: Yea the computer gets you mad.

Vanesa: (laughs)

Researcher: How do you calm down?

Vanesa: Calm down. Researcher: Um hm Vanesa: When I breathing.

Researcher: Oh, breathing that helps you really calm down.

Vanesa: Yea Researcher: Ok

Vanesa: Or asking for help.

Researcher: Ask for some help? That would do it, too.

Due to her cognitive level, Vanesa was expected to have some off topic responses, but for the most part, she was able to explain how she was able to control her emotions.

Vanesa was able to make choices independently:

Researcher: Who's gonna pick that food at the food court? Who's gonna decide what you

eat?

Vanesa: By myself?

Researcher: Really! By yourself?

Vanesa: Yea

Because Vanesa gave some conflicting answers, I probed her further and got this for a response:

Researcher: Who's gonna pick out what you eat at the field trip? Who's gonna pick out

what you're gonna eat? Your buddy or you?

Vanesa: My, my buddy...no, me (laughs) (looking directly at researcher, possibly reading

expression)

Researcher: (laughs)

Vanesa: Me

Researcher: Are you sure about that now?

Vanesa: Yea

Researcher: Ok! It's you.

Since the general education students in Best Buddies were directed to allow their buddies to select their lunch food and to assist them, only if needed, to pay, I was confident she picked out her own food the day of the field trip. She also can decide what to spend her personal money on:

Researcher: What do you yourself do with that money on your birthday? What do you

spend it on? What do you buy with it? Vanesa: Oh! Buy the, buy the purse. Researcher: You bought a purse with it?

Vanesa: Yea

Researcher: And who decided that?

Vanesa: By myself.

Researcher: You bought a purse and decided it yourself.

Vanesa: Um hm.

Researcher: That's good.

Vanesa stated she can be by herself:

Researcher: What kind of atmosphere or situation would you rather live in? Like in your house, how do you want it to be in your house where you, where you live? How do you like it to be?

Vanesa: Stay here by myself.

Researcher: You wanna be by yourself, what else?

Vanesa: Mmm. Prob- probably...hear music in my, my radio.

Researcher: Excellent you want to have music in the radio playing in your house.

Vanesa: Yea

Researcher: Ok, how about the people around you? How do you want that to be? You said you wanted to be alone, no people around you?

Vanesa: Alone.

Researcher: You wanna be alone, no people around you, with music playing, ok.

Vanesa expressed various ways she was able to live independently:

Researcher: What else are you doing besides that to be independent from your parents?

Vanesa: Uh...

Researcher: To do things by yourself?

Vanesa: Like cooking food.

Researcher: Yea? You do that? Great! So you can feed yourself? You can get your own

food ready? Vanesa: Yea Researcher: Yea? Vanesa: Yea

Researcher: Great! That we discussed the first day, didn't we? That was very good.

Vanesa: Yea, first day.

Researcher: So you take care of yourself in the bathroom. You can, you can take care of yourself in the kitchen. What else are you doing to be independent from your parents?

Vanesa: Laundry room?

Researcher: Ok, what do you do in there to be independent? What do you do in there by yourself? In the laundry room?

Vanesa: Um, who made the star? Like a week that star ago. (looks at a star on the wall)

Researcher: Meee, but I want to know about the laundry room.

Vanesa: Oh! A laundry room is like...

Researcher: Yea Vanesa: Is like, is like...

Researcher: You said you're independent in the laundry room.

Vanesa: Yea, is like, um, is like put your shorts away.

Researcher: Uh huh

Vanesa: And then put in the laundry room and then... Researcher: Excellent, that's independent! Excellent!

Analysis of the Goals Related to Plans, Problem Solving, and Self-Regulation for Maria

Goals related to plans for Maria. In spite of having an unrealistic dream job, Maria was able to describe how she would attempt to support herself so she could live with a friend. Here is how she described her plan:

Researcher: You want to live with [Alicia]...

Maria: Yea

Researcher: ...after you graduate? So what steps are you going to take to reach this goal

of living with [Alicia]?

Maria: Maybe w-, I can go dance.

Researcher: That would help you get to live with [Alicia]? To go dance?

Maria: Yea

Researcher: Ok, how would that help you? How would that help you? How would

dancing help you to go live with [Alicia]?

Maria: A dance competition.
Researcher: A dance competition?

Maria: Yea

Researcher: And then what would happen?

Maria: I can dance.

Researcher: And then what would happen?

Maria: I can have a partner.

Researcher: A partner? Who would the partner be?

Maria: [Alicia] and me

Researcher: And how would that get you to be able to live with [Alicia]?

Maria: I don't know. I live with her and, and I dance with her.

Researcher: Uh huh, is that like for a job?

Maria: Yea, for a job.

Maria described the steps involved in getting closer to her goal, albeit in vague terms:

Researcher: How do you know you're, that you're getting closer and closer to the time when you can live with somebody like [Alicia] in the future? How do you know you're

doing good? How do you know you're doing better, progressing?

Maria: You need to get better and better.

Researcher: And better and better and take steps.

Maria: Take steps.

Researcher: So how do you know you're getting close to that goal by those steps?

Maria: You need to take time.

Researcher: Takes time, it takes time to do it, it does.

Maria stated that her goal of having a job was as easy as asking her mother for a ride to the

interview, asking for a job, and getting it:

Researcher: What are the steps you should take to meet this goal of working in Publix?

Maria: Um, I wanna do, work on foods.

Researcher: But what are the steps you need to take to get there to this job at Publix?

What do you need to do first?

Maria: My mom has to take me, to drive.

Researcher: To drive you to...

Maria: Publix.

Researcher: Publix, and then what do you do?

Maria: I get in.

Researcher: Um hm. How do you get in so quick?

Maria: I say hello, my name is (says name). I'm from [Northeast]. I need a job please.

Researcher: Um hm, and then what happens?

Maria: And I got in. Researcher: Ok, all right.

She had a simple plan to explain the steps it took to achieve the goal of riding a city bus

independently:

Researcher: What are the steps you would take to meet this goal of using a bus to get around in Miami?

Maria: Get your, uh, wash my teeth, put my clothes on, brush my teeth, wash my clothes,

and get my purse, and like that, and get on.

Researcher: And get your purse.

Maria: And then I'm ready.

Researcher: And how are going to get this bus?

Maria: I get on.

Researcher: How do you know when, where it's going to be? How do you know what

time to be there and where?
Maria: You need to be on time.

Researcher: You need to look at the time, know what time the bus comes.

Maria: Yea, what time the bus comes. I say, wait, wait, wait, wait, I have to wait.

Researcher: You have to wait for the bus.

Maria: The...

Researcher: Where do you wait for the bus?

Maria: Because there's people.

Researcher: There's people coming and where do you wait for the bus?

Maria: In the building. Researcher: In the building...

Maria: In the front.

Researcher: In the front and what do you look for to ride a bus?

Maria: You look for the bus and say, the city? And then it say, tis that's the city?

Researcher: Uh huh

Maria: And then I go. I go, this is the city?

Researcher: Uh huh

Maria: And I go, I go, uh, see it.

Maria knew how to plan a visit with a friend:

Researcher: You can't just *go* over to her house. You gotta make a little plan, right? Tell me the steps you did to get to their house and plan this out where you can go visit your friends on the weekend.

Maria: In the weekend, I go to her on Sundays. Researcher: But how did you plan all that out?

Maria: In the calendar.

Researcher: Oh you get the calendar out?

Maria: Yea

Researcher: Ok, now we're getting warm here. What did you do with the calendar?

Maria: It said Sunday, go to [Veronica's] house.

Researcher: Oh, you plan it on the calendar. And then what el--, what else did you do

with it?

Maria: And then on Sunday we go to [Alicia's] house.

Researcher: Um hm

Maria: And then that's it, the calendar.

Researcher: And how did [Alicia] know that you were going to come on, on Sunday?

How did [Alicia] know about it?

Maria: I go to her house—

Researcher: How does *she* know about it?

Maria: Because she has a room.

Researcher: Yeaaa...?

Maria: A room and she has a, a phone.

Researcher: A phone, and how does the phone help her know about the plan?

Maria: Um, her mom calls me.

Researcher: Oooh.

Maria: And then I can go to the house.

Researcher: Oooh.

Maria: And then, and then she, she said I can go to the house and she said ok. Researcher: And she said ok and then, and then what do you do to get the okay?

Maria: And she say yes.

Researcher: And they said it's okay to come to our house, right? They say ok come to the

house and you put it on the calendar, right?

Maria: Um hm

Researcher: Ok, it's on the calendar. They know you're coming over. Now how do you

get over to her house?

Maria: Um, my mom drives.

Researcher: How does she know about it?

Maria: I said mommy tan I go? And she say okay.

Researcher: Now that's how you plan it.

Maria: Yea

Knowing how to use a calendar was an important way for students with disabilities to be able to plan their lives.

Goals related to problem solving for Maria. A major source of problems expressed by

Maria have to do with parental permission and control.

Researcher: What kind of situation or what kind of atmosphere around you do you prefer

to live in?

Maria: I want to live in a hotel.

Researcher: You do? You've said that before, didn't you? You wanna live in a hotel,

right?

Maria: I am so tired of my mom. She ding me crazy every...

Researcher: What? Tired of what? Maria: She is, I can't sleep last night.

Researcher: Really? You're tired about your mom, you said?

Maria: She scream at me in my face! Researcher: Your mom got mad at you? Maria: Yea, on my tablet and then, aaagh!

Researcher: Uh huh

Maria: I said mom don't scream at me.

Researcher: So you want to live on your own so you don't have to hear your mom scream

anymore, right?

Maria: I want to live in a hotel alone.

Researcher: Alone?

Maria: Yea.

There was some tension at home about Maria's constant use of the computer and tablet:

Maria: My dad is ding me crazy. Researcher: Tell me more about that.

Maria: He, he don't let me to use the computer.

Researcher: Um hm

Maria: He scream at me in my face, man!

Researcher: Oh boy.

Maria: I say dad stop, really stop.

Researcher: Um hm

Maria: He don't want, he don't lets me.

Maria solved family problems by going to her room:

Researcher: What gets in the way of doing your best?

Maria: My mom get in my way.

Researcher: She does?

Maria: Yea, do this sandwich, do--, and every day, she do, what's... My dad cooks. Yesterday he cook barbeque and I say, sorry, you want a barbeque, and I'm, dad, you

want a barbeque? Hell and I say no!

Researcher: You said you didn't want barbeque?

Maria: No

Researcher: Who said they didn't want barbeque?

Maria: Me

Researcher: Uh huh

Maria: And I say no, I don't want, ding me alone!

Researcher: Oooeee bar-, that's not good because you know he, he's trying to cook

barbeque and...right?

Maria: And, and my mom don't leave me alone.

Researcher: They don't leave you alone?

Maria: (shakes head no)
Researcher: What do they do?
Maria: I want to be alone.
Researcher: Uh huh

Maria: I close the door.

Researcher: So your, your parents are, are bothering you?

Maria: Yes

Researcher: About what things? Maria: They don't leave me alone.

Researcher: They don't leave you alone?

Maria: No

Researcher: What are they always doing then? They're always what?

Maria: Bothering me.

Maria solved problems on the job by adapting the task to her ability level:

Researcher: What helps you keep the job, keep yourself straight on the job, where you

don't get mixed up and do the job right?

Maria: I put some—

Researcher: What helps you?

Maria: I put some tape. Researcher: Tape?

Maria: Yea

Researcher: Tape helps you keep everything straight?

Maria: Yea

Researcher: What do you, what do you tape?

Maria: The stuff.

Researcher: You tape it down.

Maria: Yea

Researcher: So it doesn't move?

Maria: Yea

Researcher: Is that what it is?

Maria: Yea

Researcher: And that way you can put things in it maybe?

Maria: Yea

Researcher: Is that what you're doing?

Maria: Yea

Researcher: So you don't get mixed up, is it, it stays right where it is?

Maria: Yea

Using tape to keep her job straight was a low-tech adaptation that can be used to support any employee with disabilities.

Goals related to self-regulation for Maria. Maria had her own ways of dealing with difficult people and difficult situations:

Researcher: How do you make friends with people your own age?

Maria: My friends? Researcher: Yea

Maria: [Veronica's] annoying.

Researcher: You're saying, you're saying it's annoying?

Maria: No [Veronica's] annoying. Researcher: Oh [Veronica's] annoying.

Maria: She's talks so much. Researcher: Aye yay yay!

Maria: I cannot in my head, she talks so much! I...she's my best friend and then she talks

so much *every day*! Researcher: I know. Maria: *E-very day*! Researcher: I know.

Maria: Do this, do that, do this, do that...

Researcher: I know.

Maria: Go to lunch, go to this, go to that. She, she...

Researcher: I had her last year. Maria: She's making me crazy.

Researcher: But she's still your friend? Maria: Yea, but she's talks so much. Researcher: So how do you deal with her?

Maria: I tell her please, please stop, please! Enough!

Researcher: Uh huh, does it do any good?

Maria: (shakes head no)

Researcher: I think that's just the way she is.

Maria: Yea

Researcher: Ok well, you've had her for a friend for a long time, right?

Maria: Yea, yea.

Maria talked about her father being hard to deal with, but did not say anything about how she solved that problem. Apparently she did not appreciate the hard work her father did:

Researcher: What's hard for you to do? Maria: My dad is making me annoying.

Researcher: Your dad is hard for you to deal with?

Maria: (nods) Researcher: Yea?

Maria: Yea.

Researcher: Tell me more about that. Maria: Um, when I went to sleep...

Researcher: Um hm

Maria: ...my dad is snoring, kuh, kuh (makes snoring noises)

Researcher: Oh, aww! Maria: He snores so much. Researcher: Um hm

Maria: He gets, um, I go to work on, I work first and then he sleep because he, he's tired

from work.

Researcher: Does he work at night or in the day?

Maria: In the day. Researcher: Um hm

Maria: He works in some, some house and then when he gets in the house, he goes home

to sleep and then he, he snores so much. Researcher: He works, work hard huh?

Maria: Yea really hard.

Researcher: He must work really hard.

At times Maria expressed that she would be compliant with what her parents wanted her to do:

Researcher: So what you're telling me is that if your parents don't want you to learn

about that, that you will listen to them and do it their way?

Maria: Yea their...

Researcher: Is that what you're saying?

Maria: Yea

Researcher: You would do it their way?

Maria: Their way.

Researcher: You wouldn't argue with them about that?

Maria: No

Researcher: They say no, no, no, no job for you with little pets and little puppies. You're

going to work with, in an office.

Maria: Yea

Researcher: And you would just do that then.

Maria: Yea

Researcher: You would listen to their advice and you just do it.

Maria: Yea

Researcher: Ok, that's an honest answer.

Maria had a plan to deal with difficult situations at work training:

Researcher: Can you think of, of a better way of handling that so you can listen to people

correct you better? Can you think of a way you can do it better?

Maria: Yea

Researcher: So you can do better, be a better listener when they correct you?

Maria: W-work, Work real hard, work.

Researcher: Work harder, yea. Maria: Yea, work real hard.

Researcher: Um hm

Maria: And listen to the teacher.

Researcher: Yea, that would help, wouldn't it?

Maria: Yea

Researcher: Those are good answers.

Maria: Yea

Researcher: Very good.

Maria found it difficult at times to change specific routines:

Researcher: What if you have to get dressed, eat, and then do your teeth in a different

order? How do you handle that kind of change?

Maria: I eat first.

Researcher: No, what if you change the order of how you do things?

Maria: Ave no!

Researcher: You don't like that?

Maria: No

Researcher: You want your same routine, right?

Maria: Yea, same routine.

Researcher: Um hm, ok, all right.

As long as Maria had a tablet available, a change in plans for leisure time was no problem:

Researcher: How do you handle changes? Let's say you plan to go outside, and all of a sudden, uhp, now it's raining! You can't do that now. It's raining, you can't do that now.

You have to do something different. Inside maybe.

Maria: Yea

Researcher: How do you handle that change?

Maria: Go, I go to my tablet, free time.

Researcher: Do you get upset about that change?

Maria: No

Analysis of the Goals Related to Plans, Problem Solving, and Self-Regulation for Rayann

Goals related to plans for Rayann. Job, living, and leisure plans were discussed during the interviews. Rayann had been quoted previously for wanting a job as a mom, but this excerpt from the aforementioned passage also explained how she was preparing for a job at school:

Researcher: What school work do you do now that will improve your chances of getting a

job?

Rayann: Homework.

Researcher: Homework will help, it will. Anything else?

Rayann: Signing. Researcher: Signing?

Rayann: And signing our name.

Researcher: Signing your name, uh huh, ok. Anything else?

Rayann: No

Researcher: All right, next question, um, let's see here. What are your long range career

plans? Career means job. What are your long range plans?

Rayann: I don't know.

Researcher: Ok, like in ten years. In ten years, I want to have a job in...what?

Rayann: Is being a mom a job? Researcher: Oh, it's a big job! Rayann: Then I wanna be a mom.

Rayann described her plan for living independently, parts of which was also portrayed in the coding under interests:

Researcher: That's step one, finish school, graduate, right?

Rayann: (laughs) yea

Researcher: What's step two?

Rayann: Go to one school you told me about. Researcher: Um hm. Like higher education.

Rayann: Yea

Researcher: That's what we call it.

Rayann: Yea

Researcher: Ok next? Rayann: I don't know.

Researcher: Well, why do you go to school?

Rayann: Because to learn.

Researcher: To learn so you can do what?

Rayann: Live by myself.

Researcher: Live by yourself, ok, that's true. And what does it take to live by yourself?

Rayann: And with my husband and kids.

Researcher: But you're...yea, and are you going to live on air?

Rayann: No

Researcher: You have to have what to live?

Rayann: Yea, air?

Researcher: Yea, air, I know, air to breathe, but what do you have to have to live, like to

get groceries and do the rent and all that stuff? What do you have to have?

Rayann: Help?

Researcher: Help, um hm, ok, and how are you going to get that?

Rayann: I'll ask.

Researcher: Ok, ask who? Rayann: My husband.

Researcher: Yea

Rayann: To drive me there.

Researcher: To drive you there, there where?

Rayann: To the grocery store.

Researcher: Ok, and how are you going to pay for it?

Rayann: With my money.

Researcher: Um hm, and when the money runs out, then what are you going to do?

Rayann: Or my husband's. Researcher: Ok, or his money.

Rayann: (laughs)

Researcher: All right, ok, so, so far you said you're gonna graduate high school, then go

on to higher education after that.

Rayann: Yea

Researcher: And then where does the husband come in? How are you going to get this

husband?

Rayann: Uh, I have to meet, meet him first.

Researcher: Ok, and how are you going to do that?

Rayann: Maybe in Lebanon. Researcher: Maybe in Lebanon.

Rayann: I don't know where I'm going to meet him.

Researcher: Could be in America too, right?

Rayann: Maybe.

Rayann had a strong interest in planning her future living situation:

Researcher: You want to get married, have a husband and you said something else that

you wanted. Do you remember what you said?

Rayann: Kids?

Researcher: Kids, ok, like how many?

Rayann: Two Researcher: Two Rayann: Yea Researcher: Uh hm

Rayann: A girl and a boy.

Researcher: Oh, yea, a lot of people do that, want a boy and a girl.

Rayann: (laughs)

Researcher: You're like everybody else in this world, right?

Rayann: Yea

Researcher: Like any other young girl.

Rayann: I wanna name my daughter the same as my mom.

Researcher: Really! What's your mom's name?

Rayann: [Sadira]

Researcher: Oh, yea, [Sadira], I remember that. And if you have a boy, you're gonna

name him what?

Rayann: I don't know yet.

Researcher: Your fa-, the, the father might wanna give the name. The, your husband

might wanna name that one.

Rayann: Yea

Researcher: Yea, that's what happens. Rayann: But I'm gonna name the girl.

Researcher: Yea, that's what's gonna happen. Most likely, yea. That's a nice plan for the

future!

Rayann: Yea

Researcher: I like that plan! And you have the s-, steps all lined up, that's what you do!

Rayann: I can see my future now.

Researcher: You can see it because you have to plan it.

Rayann: Yea

Researcher: If you don't plan it, it's just a dream.

Rayann: (laughs) I don't like to, I don't like to dream it, I like to live it,

Researcher: Live it! You're right! Rayann: That's better to live it...

Researcher: Oh, yes Rayann: ...than dream it.

Rayann often said that she did not know the answers to many interview questions, but with more probing, she was able to develop an answer. This question was about planning to attend a pool party:

Researcher: You're worried about the party being on the same day as the Lebanon, Lebanon trip. So if you ask your dad, when's the trip for Lebanon, you know that date, what you do next is find out what? About [J-Jillian]? The other what?

Rayann: I don't know.

Researcher: She said some day. You gotta to ask her what?

Rayann: What day? Researcher: Is?

Rayann: Is the pool party.

Researcher: And then what are you going to do after that?

Rayann: I don't know.

Researcher: Let's think about that. You have the date for Lebanon on this side. On this side you have the date for [Jillian's] party. Ok, how are you going to solve that problem?

What do you have to find out?

Rayann: If they're both on the same date?

Researcher: That's your next step! To find that out!

Rayann: (laughs)

Researcher: You have to develop a plan like that, right?

Rayann: Yea

Researcher: And it might work out, you don't know.

Rayann: Yea

Researcher: All right.

Later it was evident in the conversation that Rayann did know how to form a leisure plan:

Researcher: Let's say you want to go visit [Jillian]. How would you plan that?

Rayann: I ask someone if they could take me.

Researcher: Um hm, and then what do you do? Let's say they say yes, then what do you

do?

Rayann: I'll tell him, I'll tell them the address?

Researcher: But you know you're going to go to visit their house.

Rayann: Yea! For their house

Researcher: So you ask them the address?

Rayann: Yea!

Goals related to problem solving for Rayann. Problem solving themes consisted of parent permission concerns and support on the job. When it came to parental permission, Rayann had this to say:

Researcher: What if your family doesn't like your choice of friends? What do you do?

Rayann: I'll explain to them that they're...they're good friends.

Researcher: Um hm, but we don't like that friend of yours. He's gonna be a bad influence

on you. Then what do you say?

Rayann: No, they're not.

Researcher: Um hm. What if they say, but they're not Muslim? We don't like them.

They're not Muslim. Then what do you say?

Rayann: It doesn't matter. Researcher: Um hm.

Rayann: If they're not Muslim...

Researcher: Um hm

Rayann: ...I can be friends with them.

In Rayann's family it was of utmost importance that the children respect their father. It was especially difficult for individuals with disabilities to get angry at someone they were so dependent on:

Researcher: What do you do if you're angry at someone you care for?

Rayann: Try and talk to them.

Researcher: You try and talk to them, right?

Rayann: Yea

Researcher: What if you're angry at your *dad* and you care for your dad a lot, but he makes you mad sometimes? How do you feel about that? What do you do about that?

What do you do about that if you're mad at your father?

Rayann: I can do, um, something for others that are, are angry, but my, uh, dad, I can't do

nothing!

Researcher: (laughs) well I can understand that!

Rayann: Yea

Researcher: So if you're mad at your dad, what happens? What do you do if you're mad

at your dad?

Rayann: I get nervous.

Researcher: You get nervous.

Rayann: (laughs)

Researcher: What do you say when you're mad at your dad?

Rayann: Don't, don't be mad.

Researcher: No, if you're mad at him, what do you say?

Rayann: Um, if I said, if tell him, then he'll be, if I tell him I'm mad at you, he'll, he'll

be, I don't know...

Researcher: Do you ever tell him that?

Rayann: No

Researcher: Oh, you never tell him that, right?

Rayann: No

Researcher: Because you're afraid to tell him, right?

Rayann: No, I'm not afraid of my dad, I—

Researcher: What else—? Rayann: I don't know

Researcher: How do you feel about telling him about, that you're angry? How do you feel

about telling your dad you're angry? Rayann: Try to tell him I'm angry. Researcher: You try to tell him, right?

Rayann: Yea

Researcher: Like in a nice way, right?

Rayann: (nods)

Rayann would like to use videos to support her work:

Researcher: Let's say you have the whole house to take care of and the kids. Ok, there's some things that might help you, for example, it could be a schedule, a chart, a list, pictures, or, or videos. What helps you get the job done? What would help you get the job done so you don't forget what to do?

Rayann: I don't know

Researcher: Well, how do you remember things you have to do for a job? How do you

remember the steps in a job? Rayann: Put them on video?

Researcher: Do you like watching videos to help you remember what to do? Right, what

else? Helps you get the job done? Rayann: Remembering yourself.

Researcher: Remembering yourself, but what if you forget, what helps you remember?

Rayann: See something that helps you remember.

Researcher: What would that be that thing you see that helps you remember?

Rayann: I don't know what m—

Researcher: Would you rather it be written down where you can read it, or you want it to be said to you, or do you wanna see a picture or a video of it, of reminders? How would you rather get reminders?

Rayann: A video

Researcher: You'd rather get reminded by videos?

Rayann: Yea

Goals related to self-regulation for Rayann. Dealing with difficult people and

situations came up as themes for Rayann. This was how Rayann dealt with people that were

difficult:

Researcher: What do you do if people treat you like a child and you feel like an adult? Rayann: I'll tell them I'm not a child, I'm a, ad-, I'm adult and I like to be treated like one.

Researcher: That's right you speak up, right?

Rayann: Yea

Rayann did not give up on difficult people:

Researcher: How do you get along with people that are hard to get along with?

Rayann: Keep trying.

Researcher: Keep trying, right.

Rayann: Yea

Researcher: That's all you can do.

Rayann: Yea

Researcher: And if you keep trying, what happens?

Rayann: I'll get my way.

Researcher: You'll get your way, right? If you keep trying.

Rayann: Yea

Researcher: You'll melt that ice and get through, right?

Rayann: Yea

Researcher: That's right, ok.

When she had difficulty getting information, Rayann used the Internet:

Researcher: What if you want to know something about Lebanon, for example? Can you

use a computer like that?

Rayann: (nods)

Researcher: How do you use a computer to find out about Lebanon?

Rayann: If I don't know where is, where is Lebanon, I can go and I can know that. I can

type.

Researcher: Um hm Rayann: And they tell me.

Researcher: You make a search... Rayann: What I want to know?

Researcher: Right, you can search for things and find out information.

Rayann: Yea

Rayann solved the difficult situation of wanting to ambulate in a mountainous area using the help

of her father:

Researcher: Is it easy to get around Lebanon with your chair?

Rayann: I go walking.

Researcher: You go walking? Who helps you go walking in Lebanon?

Rayann: Sometimes my dad. Researcher: In Lebanon?

Rayann: We don't take, I don't take my helper with me to Lebanon. Researcher: That might be one of the problems, right? Do ya think?

Rayann: (nods)

When she had stage fright, Rayann got over that difficult situation:

Researcher: What is something about working that you have tried and you liked?

Rayann: Singing on stage, you remember?

Researcher: Um hm, um hm Rayann: I was nervous the first...

Researcher: Whooo! Everyone's nervous, but I make 'em do it! Rayann: But when I when I did it, I, I felt like, I felt good!

Researcher: You did! Because you know, I don't do that, you know...

Rayann: Because I was nervous at first... Researcher: I said oh my goodness...

Rayann: But then I wasn't.

Researcher: That's how it is, that's how show biz is.

Rayann: (laughs)

Researcher: Once you start, you know...

Rayann: Yea

Researcher: ...you get over that.

Rayann: Yea

Researcher: Yea! Why do you think I make the kids do it and I don't do it? (laughs)

Rayann: (laughs)

Researcher: Because I know (laughs)

Rayann: Yea

Researcher: Ok, that's part of show biz you have to get over, right? So you tried doing that and you liked it? Being on stage? Even though you got nervous, you liked it?

Rayann: I liked it with all my heart!

Researcher: Really?! Rayann: Yea (laughs)

Researcher: Oooh! We gotta do it again, (laughs) ok!

Rayann had the self-discipline to regulate herself and persevere during times of duress:

Researcher: What will happen if you keep trying even after you get something wrong? Like, you're doing a job or doing an assignment in school and you keep trying, and keep trying, and you get something wrong, and you keep trying, and trying to fix it. What's gonna happen?

Rayann: I don't know how to explain it.

Researcher: Let's say you're doing something, an assignment at school you're doing, something for like a, like a math problem at school and you keep on getting it wrong. Well, you got it wrong and you keep trying, and trying, and trying, and then what finally happens?

Rayann: I don't know

Researcher: Do you get it right or do you give up and say I, forget it, forget about it?

Rayann: Right?

Researcher: Do you, do you keep, do you get it right or do you forget about it?

Rayann: I get it right.

Researcher: You keep trying till you get it right?

Rayann: Yea

Researcher: Ok, that's good.

It was true that Rayann did try until she got what she wanted from what we have observed in school.

Analysis of the Goals Related to Plans, Problem Solving, and Self-Regulation for Vanesa

Goals related to plans for Vanesa. Goals that emerged were jobs, living situation, and leisure time. Vanesa never had work training, but she had this to say about learning how to have a job:

Researcher: What classes do you take now, do you do now, that help you learn about a

job you want to do one day?

Vanesa: Learn how 'bout the job...

Researcher: Yea

Vanesa:...that I do one day?

Researcher: Yea, what classes do you take now that help you learn about getting a job?

Vanesa: And, oh yeah! Researcher: Uh huh

Vanesa: Uh, wait [Reyes].

Researcher: Um hm

Vanesa: Learn to do the job...

Researcher: That's right, Mr. [Reyes].

Vanesa: Yea Researcher: Ok

Vanesa: Oh, [Thomas]!

Researcher: And Mr. [Thomas] too, right?

Vanesa: Yea

Researcher: You learn about getting a job in those classes, right?

Vanesa: And [Garcia] too.

Researcher: And Miss [Garcia] too.

Vanesa had notions about classes she wanted to take:

Researcher: Let's say you're in a, in a school meeting with a teacher...

Vanesa: Um

Researcher: ...and you want to take a different class and your mom wants you to have an,

another class that you don't wanna take, you wanna have this different class...

Vanesa: Yea

Researcher: ...and you don't agree, what do you do?

Vanesa: You get, you get attitude.

Researcher: Um hm, you get an attitude and then what happens? Vanesa: And then you, you ask for, for a-, you ask for adults.

Researcher: Adults? Vanesa: Adults

Researcher: You have to ask for adults?

Vanesa: Uh

Researcher: For help, um hm, you ask an adult for help, right?

Vanesa: M-yea

Researcher: That's a good answer.

Vanesa: Yea

Vanesa had distinguished plans for her goal of getting a job:

Researcher: Let's say there's a job opening in something that you wanna do, that you

like...

Vanesa: Yea

Researcher: How do you handle getting a job there?

Vanesa: Get some, some business cards. Researcher: Some business cards? Uh huh

She also had a plan for her living situation:

Researcher: Where do you want to live after graduation?

Vanesa: I had to live my mom's house.

Researcher: You're gonna live at your mom's house after you graduate?

Vanesa: Yea

Vanesa waivered back and forth on her living plans for the future:

Researcher: Who helps you plan your future where you're gonna live?

Vanesa: I live by myself.

Researcher: Ok, but who's gonna help you with that plan?

Vanesa: Um, my mom.

Researcher: Yea, your mom's gonna help you. She's your support person.

Vanesa enjoyed making plans with her mother for the weekend:

Researcher: How do you plan what to do on the weekend?

Vanesa: Oh the weekend you go shopping.

Researcher: Um hm. And how do you, how do you, uh, pick out those things? How do

you know what you want to do on the weekends?

Vanesa: Go to Dolphin Mall. Researcher: You like doing that?

Vanesa: Yea (laughs) Researcher: What else? Vanesa: Go to the store.

Researcher: Um hm, tell me more.

Vanesa: Go to buy shoes.

Researcher: You like buying shoes?

Vanesa: Socks. Researcher: Um hm Vanesa: Um, pants.

Researcher: Um hm, you like doing that? Vanesa: And a jacket and a, and a shirt.

Researcher: Um hm

Vanesa: And, and my earrings too.

Researcher: You like to go shopping on the weekends?

Vanesa: Yea, I go shopping with my mom.

She planned to put together goody bags in her free time:

Researcher: How do you decide what to do in your free time?

Vanesa: Um, a goody bags, something.

Researcher: Goody bags?

Vanesa: Yea

Researcher: What about goody bags?

Vanesa: That they put the goody bags, the bracelet.

Researcher: Um hm Vanesa: The ring. Researcher: Um hm

Vanesa: And things like that. Researcher: Who does that?

Vanesa: Myself.

Researcher: You do it?

Vanesa: Yea

Researcher: In your free time?

Vanesa: Yea

Vanesa had some great ideas on how to plan a party for a friend:

Researcher: You want to plan a party for one of your friends, how do you do that?

Vanesa: Get invitations.

Researcher: Get invitations, then what?

Vanesa: Get Balloons. Researcher: Balloons.

Vanesa: Piñatas, you know those piñatas?

Researcher: Piñatas?

Vanesa: P-tchew! (gestures hitting a piñata) (laughs)

Researcher: Yea, you hit it with a stick?

Vanesa: (laughs)

Researcher: Piñatas. You're getting good ideas there!

Vanesa: Yea (laughs)

Researcher: What else, to plan a party for a friend, what else?

Vanesa: Um, Oh! Those chips!

Researcher: Chips.

Vanesa: Sauce with the dip and eat it. Researcher: Wow, what a great party!

Vanesa: Yea (laughs)

Researcher: That would be a great party you're planning there!

Vanesa: Yea

In spite of Vanesa's severe cognitive disabilities, she appeared to have experience with and knew how to plan a nice party.

Goals related to Problem Solving for Vanesa. Vanesa got along very well with her mother and was not the kind of person that was going to put demands on her family for

permission. The most serious problem I could find for Vanesa was being able to respond to messages from her mother saying that she missed her:

Vanesa: Um, she s-, wait, she said I miss you, I and I...

Researcher: Who said that?

Vanesa: Me!

Researcher: Who said they miss you though?

Vanesa: My mom.

Researcher: Oh, she texted you? Your mom texted you?

Vanesa: Yea

Researcher: And how did you get that text?

Vanesa: I text from my phone, (laughs) like this (gestures texting)

Researcher: Uh huh

Vanesa: And then that's it.

Vanesa knew if she had a problem with needing money, she could go to her mother:

Researcher: What if you're home and you need money? When you're home?

Vanesa: On my home?

Researcher: You're home and you need money. What do you do?

Vanesa: I ask mom.

Researcher: You ask your mom, right?

Vanesa: Right!

Researcher: That's a good answer.

Vanesa: Yea

Researcher: Ok, and when do you ask mom for money?

Vanesa: To buy pizza.

Researcher: To buy pizza, what else? Vanesa: Ha—(clears throat) hamburgers.

Researcher: Hamburgers? And when else do you ask her for money?

Vanesa: Chicken.

Researcher: But when do you ask her for money? When? When do you ask her for

money? Vanesa: Um

Researcher: When do you think, hm, I need some money? When do you think that?

Vanesa: When? I think that?

Researcher: Yea

Vanesa: You, you need some help. Researcher: When you need some help?

Vanesa: Yea

If Vanesa needed a ride, she knew how to ask her mother about it:

Researcher: Who helps you get there?

Vanesa: My mom.

Researcher: And how does she know about the movie?

Vanesa: Mmm, it's funny (laughs)

Researcher: It's funny. And you want to go to it, so what do you do?

Vanesa: Mom, c-can I go to the movies?

Researcher: That's what you do. You ask her, right?

Vanesa: Yea

As small and simple as these tasks were, many of our students with lower functioning did not assert themselves at all. Vanesa was selected for this study because she could verbalize almost any word with excellent pronunciation, even if the words were not applied appropriately at times.

Vanesa could express which supports she would like to access to assist her in getting her work done on a job:

Researcher: What you would like to use to help you get your work done?

Vanesa: Um hm

Researcher: And you said you like to do videos to help you get your work done.

Vanesa: Yea

Researcher: Ok, how about, also it could be a picture, it could be a list, it could be a chart,

schedule...

Vanesa: What's a schedule?

Researcher: I have one over there, see over there, on that purple board over there? Where it says schedule? It has breakfast, then it has bathroom, then it has lesson, then it has change class. My schedule. See? By the refrigerator over there?

Vanesa: Um hm

Researcher: That tells you what to do during the day. What we're going to do all during the day.

Vanesa: Oh yea.

Researcher: You like, do, do schedules help you get your job done?

Vanesa: Yea

Researcher: They do? Schedules help you? Or a chart or a list of what to do? This is number one, do this, number two, do that, number three, do this, or it could be pictures...

Vanesa: Photos?

Researcher: Photos could help you. You like photos?

Vanesa: Yea

Researcher: They help you get your job done?

Vanesa: Yea

Researcher: You look at the photo and you follow it?

Vanesa: Yea

Researcher: It helps you get your work done?

Vanesa: Um hm

Never having worked, I had to offer her a list of suggestions, but through this structured interview question, she was able to select her best options.

Goals related to self-regulation for Vanesa. Self-regulation was coded to dealing with difficult people and dealing with difficult situations. Vanesa was an especially friendly young woman and did not like when her friends got mad at her. This was how she solved that problem:

Researcher: Ok, let's say you have a friend, let's say it's [alina]. And [Dayana] gets mad at you.

Vanesa: Yea

Researcher: And you don't know why she's mad. She's just mad. You don't know why.

What do you do about that problem?

Vanesa: That...

Researcher: Your friend [Dayana]'s acting like she's made at you.

Vanesa: That, uh...

Researcher: And you don't know why...

Vanesa: Uh, that she's, uh, she's frustrated.

Researcher: She's frustrated with you and you don't know why. So what do you do about

that problem?

Vanesa: You get a big trouble.

Researcher: Yea, it's big trouble, isn't it? You don't like [Dayana] getting mad at you, do

you?

Vanesa: No

Researcher: So what do you do about it? What do you say, what do you do when she's

mad at you?

Vanesa: You're saying, you say thank you.

Researcher: Um hm, what else? Vanesa: And you say...uh...

Researcher: Ok, [Dayana] is mad at you.

Vanesa: M-yea

Researcher: And she's your friend...

Vanesa: Um hm

Researcher: And you don't know why she's so mad. What do you ask her?

Vanesa: I said [Dayana], why you go so mad?

Researcher: There you go! You ask her why you so mad at me?

Vanesa: Yea

Researcher: And you try to find out. Ok, and then she tells you what, why she's mad.

Vanesa: Yea

Researcher: She says oh you, you, you hurt my feelings. And what do you say to her?

Vanesa: You say stop it. Researcher: Um hm When Vanesa encountered the difficulty of how to invite a friend over for a visit, this was what she planned to do:

Researcher: You want them to come over to visit you? How are you going to let [Kaylee]

and [Spencer] know you want them to come and visit you?

Vanesa: Ask my friend.

Researcher: Ask your friend, and how do you ask them?

Vanesa: You say hello and thank you.

Researcher: Yea, and how do you contact them?

Vanesa: Talk, talk, talk them my phone.

Researcher: With your phone! That's what I wanted to hear you say!

Vanesa: (laughs)

Researcher: With your phone! You call on the phone and say come on over.

Vanesa: Yea

Researcher: There you go! Ok.

As quoted previously and found to be goals related to plans, Vanesa knew her mother would help

her in dealing with difficult situations:

Researcher: Who's gonna help you to to plan where you're gonna live in the future?

Who's gonna help you with that plan

Vanesa: That plan is

Researcher: Who helped you with your plan?

Vanesa: Take me a shower

Researcher: No your plan for the future where you're gonna live

Vanesa: Oh!

Researcher: Who helps you with that plan? Who helps you plan your future where you're

gonna live?

Vanesa: I live by myself

Researcher: Ok but who's gonna help you with that plan

Vanesa: Um My mom

Researcher: Yea your mom's gonna help you. She's your support person.

Vanesa: Yea

In new situations, Vanesa knew how to handle the difficulty of making new friends:

Researcher: What do you do if you're new at school or new at the job and you want to

have friends? Vanesa: Be kind.

Researcher: Be kind, what else?

Vanesa: Be gentle. Researcher: Be gentle.

Vanesa: Yea

Researcher: Um um

Vanesa: And be behave. Researcher: Behave.

Vanesa was a gentle soul and was always well behaved. She was well liked by others.

Analysis of Feelings Related to Psychological Empowerment and Self-Realization for Maria

Feelings related to psychological empowerment for Maria. The themes that emerged

from empowerment were self-advocacy, confidence, technology use, and protection of self-

image. Maria was outspoken when it came to advocating for herself at home:

Researcher: But you told your mother just now, for example, I want to be alone mom,

and so how do you do that?

Maria: I say mommy, I want to be alone. Researcher: And then what happens?

Maria: Please give me privacy.

Researcher: And then?

Maria: Give me privacy, I, mm, please. Researcher: And then what happens?

Maria: I want to be alone please, please for a moment, I need a break.

Researcher: So what do you do about that? What happens next? When you say that what

happens next? Maria: Go away!

Researcher: And then what happens?

Maria: Mmm

Researcher: When you want to be alone, where do you go and what do you do?

Maria: Go to my room.

Researcher: And then what do you do?

Maria: Close the door.

Researcher: And you have your...privacy?

Maria: Privacy.

Maria tried to convince her friends to do things her way, but if she was unsuccessful, she went

her own way to advocate for what she wanted:

Researcher: How are you gonna solve that problem? Yea, they're your best friends. You love those two friends, right? You don't want to just break up with your friendship with them because you didn't get your way?

Maria: No

Researcher: How are you gonna speak up to them? What are you gonna say?

Maria: I'll be, I'll be brave.

Researcher: Be brave, I'm trying to ask you how you speak up for things that you really

want and need.

Maria: You talk, you talk.

Researcher: You talk! How? What do you say?

Maria: Are you want to go to the limo? And I say are you going and I say ok.

Researcher: But what if they don't want to do the things that you want to do. How do you

talk to them?

Maria: They want to be boring.

Researcher: Um hm

Maria: They want to be lazy.

Researcher: Um hm, so let's say they wanna go, they wanna go to see sports and you

wanna go shopping. So what do you say? What do you do about that? Maria: I say go sh-, mmm, I go shopping and they go to sport. Good bye!

Researcher: So you go alone?

Maria: Yea I go alone.

Researcher: They go their way and you go your way?

Maria: Yea

Researcher: That's how you solve the problem?

Maria: Yea

Researcher: Either you vote and see who wins, if you can't ever get your way, ok, then

I'll go here and you go there?

Maria: Yea

Researcher: That's how you solve that problem?

Maria: Yea

Researcher: That's what you're saying, right?

Maria: Yea

While it was not an ideal solution, both sides got what they wanted, except her friends would not have the pleasure of her company if they did not agree with her.

Maria was absolutely devoted to a few specific musical artists. This was how she handled her friends that did not feel the same way about her favorite performers:

Researcher: What do you do when you don't agree with others opinions or their ideas?

Maria: What's that?

Researcher: Their opinions or ideas, let's say, ok, you love Beyonce and you love, who's that, who's that other girl you said you loved, you love Vanessa Hudgins, and you love Beyonce.

Maria: Yea

Researcher: And your friends, they, they can't stand them. They'd rather listen to Taylor

Swift. And you just don't like Taylor Swift. You like Beyonce. You like Vanessa

Hudgins. And they don't like, they think, they think...

Maria: They, they (laughs)

Researcher:...they go to you eeww, you like Vanessa Hudgins? You like Beyonce? Oh,

no, no, Taylor Swift is a much better singer. And they don't agree with you.

Maria: They really *mean*! (laughs)

Researcher: They're mean? So how are you gonna handle that?

Maria: I gonna crying.

Researcher: You're gonna cry? (laughs) Does that solve the problem?

Maria: No

Researcher: No right?

Maria: They gonna hurt my feelings!

Researcher: They're just, so, what they, ok, they hurt your feelings. They don't, they say eeww! Beyonce's ugly! Vanessa Hudgins is ugly! They sing terrible! Ok, and they want you to listen to Taylor Swift like, like they like. So you don't, you don't have the same, you don't agree with them on that.

Maria: They need to be nice to them.

Researcher: Yea

Maria: Be nice! They, they, they sing really beautiful!

Researcher: But they say no, they sing terrible! And they're ugly too. And they don't sing good. They don't agree with you on that, on that. They have different ideas and different opinions than you do.

Maria: Yea

Researcher: So what do you do about that?

Maria: I, uh, [Veronica] and [Alicia], please stop saying Beyonce ugly please. She's nice

man, come on!

Researcher: So you talk to them?

Maria: Yea, I talk to them.

Researcher: Ask them please, don't talk bad about my favorite stars. I, I love them that's,

you know, don't talk bad about things that I like.

Maria: Ok

Researcher: That's what you're saying to me?

Maria: Yea

Researcher: You tell them please, don't do that to me?

Maria: Yea

Researcher: That's, that's a good way to handle it.

It was true that Maria was fanatical about music stars. She has been observed at school looking at teen star magazines and crying for the people she saw in the pictures.

As quoted earlier under speaking up for her beliefs, she had confidence she could dance

like a famous rock star and would defend her abilities:

Researcher: Let's say they tell you, aaa, you can't sing, you can't dance in the talent show. You can't do that. You're no good. And you, you think you can do it. You can dance and sing in the talent show and they think, aaa, you can't dance and sing in the talent show. You're no good.

Maria: Yes I can do it! I can dance! And you can't beat me! Researcher: Um hm, so you you speak up for yourself?

Maria: Yea!

Researcher: What else do you tell them?

Maria: You dance bad. You dance like a chicken.

Researcher: What if they say, oh no, you dance like a chicken. You can't do that. You

think you can dance. You can't dance!

Maria: I can dance better than you. You want a dance competition? And bring it on!

Researcher: (laughs) There you go! Have confidence, right?

Maria: Yea

Researcher: There you go!

To emphasize how much Maria felt empowered by her ability to dance well, the following excerpt was coded more than once and was repeated:

Researcher: How would dancing help you to go live with [Alicia]?

Maria: A dance competition

Researcher: A dance competition?

Maria: Yea

Researcher: And then what would happen?

Maria: I can dance.

Researcher: And then what would happen?

Maria: I can have a partner.

Researcher: A partner? Who would the partner be?

Maria: [Alicia] and me.

Researcher: And how would that get you to be able to live with [Alicia]?

Maria: I don't know. I live with her and and I dance with her.

Researcher: Uh huh, is that like for a job?

Maria: Yea for a job

Maria was confident that she never made mistakes. Even after I explained that everyone makes mistakes, that even I make a least one mistake a day, she had this to say:

Researcher: You ever make mistakes?

Maria: No

Researcher: You never make any mistakes?

Maria: No...

Researcher: You mean you're perfect?

Maria: M-yea

Researcher: Ah! We all make mistakes. We all make mistakes.

Maria: Oh, my mom always makes mistakes.

Researcher: Not, not your mom, it's about you. Think about a mistake you made a long, a while back, think about any mistake you've made in the past. How'd you feel when you

made a mistake?

Maria: I never makes mistakes.

Maria felt she had the ability to do anything she wanted to do:

Researcher: Let's say there's something that you, you want to do and people are telling you you can't do that and you think you can. What stops you from doing the things you want to do that you know you can do it?

Maria: I tell him yes, I can. I can do something whatever I can do.

Researcher: Um hm

Maria: Because I'm [Maria] and I, I can do everything.

Maria felt she could speak up for herself when it seemed no one wanted to listen to her:

Researcher: How, how can you get other people to listen to you?

Maria: They need to listen because always busy, and busy, and busy, and busy, and busy. Researcher: Ok, that's true, so how are you going to get them to stop a minute and listen

to you? What are you gonna do?

Maria: Look at me!

Researcher: What else you gonna do?

Maria: Hey! Listen to me man!

Researcher: Ok

Maria: I'm gonna scream!

Researcher: (laughs) That's speaking up right?

Maria: Yea

Researcher: So that's how you get, what you, people to listen to you, you just raise your

voice and that's...

Maria: Yea

Researcher: Listen to me I really...

Maria: Need to talk

Researcher: There you go! And I want...

Maria: To talk!

Researcher: There you go!

Maria used technology for a variety of interests, namely games, music, and movies:

Researcher: So you have a, you have a tablet at home?

Maria: Yea, I have games.

Researcher: I didn't know that. So you choose, you, so, how do you choose those things

to do?

Maria: I put is the, is I use computers, I just tap and every day I use tablet, and I go to my

tablet, um, um, put it on and then I put movies.

And later in the conversation:

Researcher: How do you do that at home? Maria: I go on the computer and sing.

Researcher: Oh, you sing along with the music that you hear?

Maria: Yea

Researcher: I bet you do, um hm.

And again later:

Researcher: What can you do on a smart phone?

Maria: My phone?

Researcher: A smart phone.

Maria: Smart phone, I watch like Vanessa Hudgins.

Researcher: The same things?

Maria: Um, like Grease. Researcher: Um hm Maria: That's it.

She made numerous references to using a computer, tablets, and her phone all through the

interviews. Technology use was one of the ways Maria felt empowered.

When Maria felt the least bit faulted for anything, she blamed others to protect her self-

image:

Researcher: We had a meeting last week, right? How did you know about that? Who told

you?

Maria: Myself

Researcher: You must have read my mind then [Maria], right?

Maria: Yep

Researcher: You must've read my mind.

Maria: Yea

Researcher: Hmf! Hm, hm! Now how did you really find out about the meeting?!

Maria: It was not my fault.

Researcher: Not your fault? (laughing)

Maria: Nope

Researcher: No, it's not your fault. How did you find out about the meeting? How did

you, how did you get the information about, that there was a meeting?

Maria: [Veronica] told me

Researcher: And how--, Oh, [Veronica] told you!

Maria: (laughs)

Researcher: She's a good friend! She reminded you.

Maria: (laughs) She told me. She told me there was a meeting today!

Researcher: And that's the truth! It came out, right?

Maria: (laughs) She told me (laughs)

Maria's job coach at the hospital once came to me concerned about Maria's negative comments about her parents. She blamed her mother often during our conversations for many things:

Researcher: Do you have any seizures?

Maria: Well, one time my mom got a seizure.

Researcher: Not your mom...you! Maria: I don't got a seizure. Researcher: Never had a seizure? Maria: Oh, one time I got a seizure.

It was her mother's fault, according to Maria, that she cut herself shaving:

Maria: Well, one time I was shaving.

Researcher: Um hm

Maria: And my mom was really upset.

Researcher: Mmm!

Maria: I got cut over here (points to leg)

Researcher: Um hm

Maria: And my mom was like, mom stop cutting me, please. I'm getting blood.

Researcher: Who cut you? You cut yourself or mom cut you?

Maria: I cut myself.

Researcher: Oh, ok so then what happened?

Maria: And my mom was so mad!

Researcher: Wooh!

She often said her mother was driving her crazy because there was a conflict about her excessive use of technology at home with her computer and tablet. Maria talked about what would make her happier from a bulletin board posting of activities independent adults do:

Researcher: Ok, what else do you see over there that would make you happy?

Maria: Ummm, time? Get a... Researcher: It says free time.

Maria: Free time.

Researcher: Tell me about your free time.

Maria: Um, when I go to sleep I have a free time. Researcher: Yea, that's when you rest, relax.

Maria: Yea

Researcher: But what would make you happier about your free time?

Maria: I said uuuh...

Researcher: Happier? What would make you happier about your free time?

Maria: I relax on the sofa in my free time.

Researcher: Um hm Maria: I relax. Researcher: Yea Maria: Mmm

Researcher: And you're happy with that—?

Maria: Yea

Researcher: ...but what would make you even more happy? What free time activities

would make you even more happy?

Maria: I play on my tablet.

Researcher: Your tablet! Because you love that tablet! Right?

Maria: Yea, that's my free time. Researcher: That's your free time.

Maria: Yea

Researcher: And it makes you happy, right?

Maria: Yea

Researcher: Anything else?

Maria: No

Keeping in mind that Maria was the only child living at home, she had all her material needs satisfied, and was well cared for and loved at home, her account had to be taken with some doubt.

Feelings related to self-realization for Maria. The categories coded in self-realization included self-awareness, adult preferences, difficulties/dislikes/non-interests, religious feelings, and people they have for support. Maria displayed self-awareness when she commented on her conditions, disability, and feelings about herself:

Researcher: Do you have any heart conditions?

Maria: No, no

Researcher: That you wanna know about? Maria: No, it do like boop, boop, boop.

Researcher: So do you have any heart conditions?

Maria: Yea, I have a h--

Researcher: Any heart problems? Maria: No, I don't have none.

Researcher: Do you have, how about your lungs? Maria: (breaths deep) I can breathe in home.

Researcher: Um hm

Maria: I breathe in home (breaths deep) Researcher: No problem with your lungs?

Maria: Mmm

Researcher: And your breathing?

Maria: Mmm

Researcher: How about your vision, when you see?

Maria: Yea I can...

Researcher: Any problems with your vision?

Maria: I can see.

Researcher: No problem?

Maria: No problem.

Researcher: Ok, how about hearing?

Maria: No

Researcher: Any...No what?

Maria: No earing.

Researcher: No hearing problems?

Maria: No

She was aware that she did not have any health conditions, even though she previously denied ever having a seizure condition. She was aware she has a seizure disorder, but denied it at first.

Maria said this about her difficulties at work training:

Researcher: You have to clean wagons?

Maria: Yea

Researcher: And you think it's hard?

Maria: No, it's not hard.

Researcher: It's harder than doing the sofa and the counters and the, um, where the coffee

area is? It's harder than that?

Maria: Yea

Researcher: Is it?

Maria: Yea

Researcher: Why is it, why do you think it's so hard to clean the wagons?

Maria: It's too, it's too, I can't get up in the wagons, sit down in the wagons, I can't s-s-

stand up.

Researcher: Like baby-sized wagons?

Maria: No, I, I'm cleaning.

Researcher: Uh huh

Maria: And then I can't get up in the seat.

Researcher: So you have to be down low to clean the wagons?

Maria: Yea, it's too hard.

Researcher: It's hard to get up after you get finished?

Maria: Yea

Researcher: It's that bending down low that bothers you?

Maria: Yea

Researcher: Oh I see.

Maria: Yea

Researcher: I get it now.

Maria found it hard to be friends with some people she had to associate with in her class:

Researcher: How do you feel about that?

Maria: It's really hard. Researcher: Cause why? Maria: It's difficult.

Researcher: She's difficult, right?

Maria: Yea

Researcher: And how do you feel about her when she does that *pollo pollo* all the time?

Maria: I tell her stop, this is not pollo now.

Researcher: You don't like it?

Maria: I don't like it.

Researcher: Does she stop?

Maria: Yea

Researcher: She does?

Maria: Yea

Researcher: That's good.

Maria: Yea

Researcher: It's hard to be her friend, right?

Maria: Yea

She was aware that it was not easy to be friends with everyone. Maria realized that it was hard for her to take criticism at work:

Researcher: How good are you at listening to what they're telling you when they're telling you you're not doing that right? How good are you at listening to them?

Maria: They make me mad.

Researcher: It makes you mad when they correct you?

Maria: Yea

Researcher: It's hard to listen to them when they correct you?

Maria: Yea

Researcher: What do you do about it?

Maria: I do like this (gestures folding arms across chest and pouting)

Researcher: Um hm, I know it's hard, right?

Maria: Yea

Researcher: It's part of life though.

Maria: Yea, part of life.

Her disability made it difficult to accept criticism at work and often caused her to cry inappropriately for minor infractions or corrections, as per job coach observational comments to me.

Maria expected to have difficulties with her parents when she wanted to have a relationship with the opposite sex:

Maria: It's going to be a fight.

Researcher: Ah! How are you going to handle that?

Maria: Myself.

Researcher: Like what would you do?

Maria: I go away.

Researcher: Go away? Does that solve the problem though?

Maria: Yea

Researcher: It just makes it go for another day. It's still going to be there. It's not going to

change things any.

Maria: No

Researcher: How would you solve that problem?

Maria: I tell my parents to...I stay there for a whole week.

Researcher: And then what would happen?

Maria: I say mom go away!

Researcher: Wooh! And then what would happen?

Maria: Go away! Tell mommy go to your house and go to live over there.

Researcher: (laughs) And where are you going to go then?

Maria: Over there.

Researcher: Over there, ok.

Maria: In the hotel.

Researcher: (gasps) I see! What we talked about before, right, that same hotel, right?

Maria: Yea

Researcher: And then you could live how?

Maria: By myself

Researcher: Mm hm, there you go.

Maria: Yea

Maria stated her strengths in reading as being:

Researcher: Let's say you can't read something and then and the teacher is asking you to

read this.

Maria: I don't know. No se.

Researcher: Um hm Maria: I don't know

Researcher: What do you use to help you read?

Maria: A magazine. Researcher: A magazine?

Maria: Yea

Researcher: Magazines helps you to read?

Maria: Yea

Researcher: What part of the magazine helps you to read?

Maria: Over here (points in the general area towards the board or door)

Researcher: What part of the magazine helps you to read?

Maria: Selena Gomez

Researcher: Yea? What helps you to read in the magazine, the words or the pictures?

Maria: The pictures.

Researcher: Pictures can help you to read, right? How do pictures help you to read it and

understand what it says?

Maria: I open the magazine and then I read it.

Researcher: Ok. You know, how do the pictures help you know the words, to read the

words?

Maria: I read it by myself.

Researcher: But if the word is too hard, how do the pictures help you?

Maria: I do by myself.

As her teacher, I knew that she read at a kindergarten level, probably making her able to pick out specific words from a magazine to make her think that she was at her instructional level of reading. She had a difficult time explaining how pictures helped her read, but maybe she did not have the language or cognitive ability to explain it. In addition, she appeared to go into her fantasy world when she looked at fan magazines and could imagine almost anything about reading them.

Maria was aware of what to do when she felt sleepy on the job and she cannot just go to bed as she did when she was home:

Researcher: It's hard for you to stay awake?

Maria: Yea

Researcher: Like when you're working, you get sleepy?

Maria: Yea

Researcher: So how do you make up for that? What do you do about that problem? Maria: I say mom, I'm, I'm working so hard, that's why I'm working so hard.

Researcher: Yea, but she won't be around when you're getting sleepy, when you're on

the job and you're getting sleepy, or in the class and you're getting sleepy.

Maria: Yea

Researcher: How do you make up for that? How do you keep yourself going?

Maria: I go home and sleep.

Researcher: Yea, but that's a long ways away. It's the morning, you're sleepy, and you're

at work. And how do you take care of that problem? What do you do?

Maria: I sleep at home.

Researcher: You can't, yea, but you're sleepy right now and you're at work.

Maria: I can't, I don't know how!

Researcher: How do you keep yourself awake? How do you keep awake when you're at

work?

Maria: Shr-, drink water.

Researcher: You drink water. That helps when you drink water?

Maria: Yea

Researcher: So you get up from your job and go get a drink of water?

Maria: Yea

Maria stated that she felt happy being who she is. Several times during our interviews she stated that she was terrific, capable, and that many people like her:

Researcher: How do you feel about yourself?

Maria: Good.

Researcher: Good. Tell me more about that.

Maria: I feel like, I feel good, like, like my heart is beating good.

Researcher: Um hm, you feel good about being yourself?

Maria: Yea

Researcher: And being who you are?

Maria: Yea

Maria would not change a thing in her life. She was content the way it was now:

Researcher: What is something in your life you would like to change?

Maria: What change?

Researcher: Something in your life, something about your life that you want to change,

what is it?

Maria: Don't know

Researcher: So everything is ok the way it is?

Maria: Yea

Researcher: Nothing you're unhappy about? You know unhappy? Like no alegre or no

contenta? Something you're not happy about in your life?

Maria: Don't know

Researcher: So you're happy with everything in your life right now?

Maria: Yea

Researcher: No problems? You wouldn't change anything?

Maria: No problems

Researcher: You wouldn't change a thing about your life right now?

Maria: Yea

Researcher: Is that what you're saying to me?

Maria: Yea

Researcher: Wouldn't change a thing, ok.

Despite the fact that she was happy with her life, there was one thing that would make her even

happier as an adult as was quoted earlier:

Researcher: What free time activities would make you even more happy?

Maria: I play on my tablet

Researcher: Your tablet! Because you love that tablet! Right

Maria: Yea that's my free time Researcher: That's your free time

Maria: Yea

Researcher: And it makes you happy right?

Maria: Yea

Maria felt that others liked her, even when she was not particularly kind to them:

Researcher: So what do you think people, uh, feel about you?

Maria: Because I'm the best.

Researcher: That's right, that's why they feel the way they feel, but how do you think

they feel about you? How do your other, your other friends feel about you?

Maria: Feel good.

Researcher: Um hm, you said they felt warm when you gave them that gift? And how

about your other friends, how do they feel about you?

Maria: Good.

Researcher: How about [Alicia]?

Maria: She feel, um, good. Researcher: How about [Jevon] Maria: [Jevon's] gone, what is...

Researcher: No, but how do you think he feels about you?

Maria: Good.

Researcher: How about your other friends? How do they feel about you?

Maria: Real good.

Researcher: Ok, let me name someone, h-how does, um, let me think, how does [Vanesa]

feel about you?

Maria: [Vanesa] talks too much.

Researcher: How do you think [Vanesa] feels about you?

Maria: Crazy.

Researcher: She thinks, she's crazy about you, you mean?

Maria: Yea

Researcher: Like, she likes you a lot, you mean?

Maria: Yea, she starts talking too much duh, duh (gestures mouth talking with her

hands)

Researcher: Yea, but how do you think she feels about you?

Maria: Good

Researcher: That she likes you?

Maria: Yea

Researcher: Crazy about you or just likes you?

Maria: That likes me.

Researcher: Ok, ok. Are you trying to say that she's crazy or crazy about you? I'm not,

I'm, I'm not sure about that. Maria: She talks too much.

Researcher: You said something about crazy and [Vanesa], you mean...

Maria: [Vanesa]

Researcher: [Vanesa] is crazy or [Vanesa] is crazy about you?

Maria: She's crazy about me.

Researcher: Ok, that's what I'm trying to find out, about you, ok.

Maria: Yea

She felt important with her best friend, even though she was so busy working:

Researcher: Do you feel important with [Lorena]?

Maria: No

Researcher: You don't think [Lorena] thinks you're important to her?

Maria: I do fe-peer aportant with her, but she always busy. She has a, um, she w-, she

works so hard. She's working (gestures work in sign language)

Researcher: Working, working, I know what you mean, but now we're gonna

have vacation for the winter, winter break.

Maria: Yea

Researcher: And she'll have some time then, right?

Maria: She's working at un banco, I think.

Researcher: Oh in a bank!

Maria: In a bank.

Researcher: Oh, even during Christmas?

Maria: Yea

Researcher: Oooh

Maria: She call me in the weekend! (laughs) Researcher: On the weekend she has free time!

Maria: Yea

Researcher: Maybe then?

Maria: In the weekend she was calling me. Researcher: How about on the weekend then?

Maria: Yea in the weekend.

My students often have difficulties understanding that others are not available to them every minute of the day. That was what was taught in Best Buddies. Their friends may have jobs and cannot talk to them all the time. They did not understand that just because they were not working themselves did not mean that their friends were also not working.

Maria expressed various feelings about herself. For one, Maria did not like to feel mad at her best friend:

Researcher: When you get *mad* at [Lorena] and you care for [Lorena] a *lot* and you get *mad* at her, then you feel what?

Maria: Saaad...

Researcher: Sad, yea, a little sad about that, right? Ok, how do you feel when people see you showing your feelings?

Maria: What's that?

Researcher: Let's say you're with a bunch, a bunch of people, bunch of people around you and, and something happens, and you're sad, and you're sitting there, and you're

crying, and people are seeing you cry. How do feel about people seeing you when you're

crying?

Maria: Disappointed. Researcher: Disappointed?

Maria: Yea

Maria was also aware that the loss of her pet made her sad:

Researcher: What stops you from being happy in your life?

Maria: My cat die.

Researcher: That wasn't happy, was it?

Maria: No

Researcher: That made you sad, didn't it?

Maria: (nods)

Researcher: When your cat died, you weren't very happy about that. Now that was a sad

thing.

Maria had adult preferences and preferred to be thought of as an adult:

Researcher: What do you do if people treat you like a child and you feel like an adult? Maria: Hey, I'm not a child. I'm a big adult, ok, adult! Stop calling me a baby, man!

Researcher: Um hm Maria: I'm a, I'm brave.

Researcher: How do you feel when they treat you like a little kid and you're, you're a

grown woman now? Maria: They mean.

Maria knew she preferred to access the community as an independent adult:

Researcher: What adult things do you do by yourself independently?

Maria: I go shopping. Researcher: By yourself?

Maria: By myself.

Researcher: That's an adult thing.

Maria: I do all by myself.

Maria realized that being adult meant having a job:

Researcher: When you graduate and you finish school, what would make you a happier, even happier, adult, when you finish school?

Maria: I wanna work on the job.

Self-realization also meant being aware of personal difficulties. Maria felt her parents

were a source of difficulty in her life:

Researcher: What things are hard for you to do?

Maria: It's the music from home. Researcher: The music from home?

Maria: Yea

Researcher: It's hard for you to do that?

Maria: Yea my my...

Researcher: Why do you say that?

Maria: ...My dad is always put music every day in the weekend.

Researcher: Yea?

Maria: And I can't sleep without it. It's getting my last nerve. Dad, please stop putting

music. It's getting my last nerve. Researcher: I thought you liked music.

Maria: I do, but he always put music, salsa, merengue, cant- (cantar means to sing)

Researcher: Makes it hard for you to sleep on the weekends?

Maria: Yea

Researcher: Um hm

Maria: I can't concentrate in my head.

Researcher: Mmm. You sleep a lot on the weekends?

Maria: Yea

Researcher: Um hm

Maria: I need to tell dad, put it down.

Researcher: Um hm Maria: I'm sleeping

Researcher: When does he put the music on?

Maria: Real loud

Researcher: But when what time of the day does he put it on

Maria: Maybe at 7 Researcher: Um hm ok

Maria: It's too early to put music in the night

Maria may not be aware of what time it really was. Perhaps her father was putting the music on to wake her up on the weekends, since I happen to know she sleeps a lot. People, more than anything else, gave Maria a hard time in life, as she repeated many times, in many different contexts, resulting in multiple coding of her statements:

Researcher: What gives you problems? Maria: [Veronica] give me problems

Researcher: (laughs) [Veronica] gives you problems?

Maria: Yea

Researcher: Um hm

Maria: She get on my last nerve. I can't take anymore. She ding me crazy.

Researcher: So it's the people that give you a hard time more than anything else? It's

people in your life...

Maria: Yea

Researcher: ...give you a hard time?

Maria: Do this, do that, do rrr, rrr, rrr, rrr, rrr, and she's ding me crazy.

Researcher: M-k, what gets in the way of doing your best?

Maria: My mom get in my way.

Researcher: She does?

Maria: Yea. Do this sandwich, do--, and every day she do, what's, my dad cooks. Yesterday he cook barbeque, and I say sorry, you want a barbeque, and I'm, dad, you

want a barbeque? Hell and I say no!

Researcher: You said you didn't want barbeque?

Maria: No

Researcher: Who said they didn't want barbeque?

Maria: Me

Researcher: Uh huh

Maria: And I say no, I don't want, ding me alone.

When asked about things that were hard for her to do, she usually mentioned people that were difficult, and usually someone in her family.

Sometimes Maria caused her own difficulties in life and that created situations she

disliked:

Researcher: What is the worst thing that can happen to you?

Maria: My mom hit me.

Researcher: Your mom would hit you, that's the worst thing to happen to you, right?

Maria: Yea

Researcher: Um hm, tell me more about that.

Maria: I hit her. She hit me back!

Researcher: Um hm

Maria: Like this poom! (gestures getting hit on the forearm)

Researcher: And you hit her too?

Maria: Yea

Researcher: Ooo, that was bad, right?

Maria: Yea

Researcher: That was a bad day, right?

Maria: I said, I said, mommy I'm sorry, I'm sorry, I'm sorry, I never do it again!

Researcher: Um hm Maria: Sorry, sorry.

Researcher: So you stopped, um hm.

Maria: Yea

Researcher: So the worst thing to happen to you is that your mother and you have a fight?

Maria: Yea

Researcher: You don't like that, right?

Maria: No

Researcher: That's the worst thing that can happen to you?

Maria: Yea, I say sorry.

Researcher: You don't like fighting with your mom.

Maria: No

Researcher: I didn't think so.

Maria: And my dad said, what's going on in here?

Researcher: He didn't like it either, did he?

Maria: No

Researcher: Uh uh (meaning no)

Maria: No

Researcher: He got upset, didn't he?

Maria: Yea

Maria did not like the idea of graduation and was not interested in leaving her friends:

Maria: (sighs) I'm gonna miss this school, I'm gonna mist it.

Researcher: You gonna miss this school?

Maria: Yea

Researcher: I know you are. You got two years to go though, right?

Maria: Yea

Researcher: You're gonna miss this school when you graduate. All the kids miss it. But what do you want to learn about now before you leave that will help you when you

graduate?

Maria: And I'll say bye to my friends...

Researcher: I know... Maria: Bye, see you... Researcher: I know Maria: Give them a hug.

Researcher: Yea, it's gonna be happy and sad.

Maria: Happy and sad.

Researcher: Both, when you graduate, right?

Maria: Only two more days.

Researcher: Years. Maria: Two more years.

When it came to religion, Maria was not very interested in going to church:

Researcher: Do you belong to any religious groups through the church?

Maria: I don't go to church. Researcher: Ok, fair enough.

Maria: I hate church. Researcher: Um hm. Maria: I don't like—

On the other hand, she was not above praying when she was in need:

Researcher: So both your neighbor's cat and your cat both died?

Maria: Yea

Researcher: At the same time?

Maria: Yea

Researcher: Wow, that was sad.

Maria: That was sad.

Researcher: So what are you, what are you going to do about that?

Maria: I'm going to go home and pray.

Researcher: Yea? Maria: I'm gonna pray.

Researcher: How about a new pet?

Maria: I'm gonna get a new pet because...

Researcher: How do you know you're going to get a new pet? What have you, what have

you done to get a new pet?

Maria: Because in the night I, I sleep and I, and I, I pray.

Maria knew what she wanted and needed in support people:

Researcher: What kind of a person do want to help you with [Veronica]?

Maria: Maybe [Norma].

Researcher: Maybe [Norma] will help you with [Veronica], yea.

Maria: Yea

Researcher: [Norma] would be a good support person, wouldn't she?

Maria: Yea

Researcher: Ok, tell me why you like [Norma] for a support person.

Maria: Because she's nice.

Researcher: She's nice, what else?

Maria: She's sweet.

Researcher: She's sweet, you want somebody that's gonna help you, that's gonna be

sweet... Maria: Nice

Researcher: ...that's gonna be nice to you, those are great answers.

Maria: Yea

Researcher: Anything else you want in a support person?

Maria: No

Researcher: And they have to be what, besides nice and sweet?

Maria: Don't be anger.

Researcher: Not get angry at you...

Maria: And don't be mean. Researcher: Not mean to you...

Maria: No

Researcher: Ok, that's some good answers.

Maria knew who her best support person was:

Researcher: Who's gonna support you in reaching your goal? Who's gonna support you

or help you to reach that—?

Maria: My mother.

Researcher: Your mother is always there for support, right?

Maria: Yea

Maria stated that her teachers supported her to learn about having a job:

Researcher: What class do you take at school that helps you with your job...

Maria: Uh uh

Researcher ...search? Maria: This class. Researcher: Uh huh Maria: Mr. [Thomas]. Researcher: Uh huh Maria: And Mr. [Reyes].

She knew that her mom would support her in learning how to use the city bus to get around:

Researcher: Let's discuss your everyday life in Miami, that how are you going to get around in your everyday life in Miami. You said, you said bus, bus is a good thing to take.

Maria: Yea

Researcher: But how are you going to know what time and where to take the bus?

Maria: My mom take the time, cause she... Researcher: Your mom will help you?

Maria: Yea

Researcher: Ok, so your mom's going to support you on that?

Maria: Yea

Analysis of Feelings Related to Psychological Empowerment and Self-Realization for

Rayann

Feelings related to psychological empowerment for Rayann. Self-advocacy,

confidence, use of technology, and protection of self-image were the themes that were coded for this topic. Rayann spoke up for herself successfully:

Researcher: Let's say you're working, and working, and working, and you're trying not to say anything, but you're starting to get upset. And if you wait longer, and longer, and longer, you're gonna start screaming. I'm tired of this! I wanna stop working! I can't take it anymore! How could you ask them for a break before you get too upset like that where you can't take it anymore and you start acting out? I can't take it anymore! How could you do it now?

Rayann: Ask for them nicely.

Researcher: Before you get up-, too upset?

Rayann: Yea

Researcher: Are you good at doing that?

Rayann: Yea Researcher: Ok

Rayann: And, and keep, and try to keep the problem, (gestures holding back) mmm, I

don't know how to say it!

Researcher: You trying, you're going like this (imitates gesture) try to keep it inside of

you?

Rayann: Yea

Researcher: Try to keep the problem inside you?

Rayann: Yea

Researcher: So it doesn't come out like that, right?

Rayann: Yea

Researcher: That's a very good answer. How can you ask them for a break before your work gets worse, and worse, and worse? Like you're getting tired of working and you don't want to, you don't want to say I'm tired, but you keep on working, and you get worse, and worse, and more, and more tired. How will you ask them for a break when you're like that, and your work is getting worse and worse?

Rayann: Can I please take a break?

Researcher: What else could you say? Because you're working so hard and...do you tell

'em why? Rayann: (nods)

Researcher: How do you tell 'em why you want a break?

Rayann: I'm so tired.

Since fatigue was a medical issue for Rayann, it was important that she learned how to speak up about it and inform others who may not be aware. She was aware her disability had medical conditions and that her sister and brother both had it. She was also aware that it caused her parent's divorce:

Researcher: Let's see what happens, because you're not a baby anymore. You're adult

now.

Rayann: Because you know he's, he, he needs me so bad.

Researcher: He does need you.

Rayann: No, what about my mom? She needs me too! Researcher: She does. Well, you gotta cut yourself in half...

researcher. She does. Wen, you gotta cut you

Rayann: Yea, one for my dad (sighs)...

Researcher: Well, one for your mom, right? That's one problem you got there, isn't it?

You shouldn't have that problem in your life. Ah, divorce is very hard. Yep.

Rayann: I get why they, they divorced, but I don't get why they have to keep me away.

Rayann had confidence in her abilities:

Researcher: How are you going to get the job you want when you have the ability to do

it?

Rayann: Um, I want to be an artist.

Researcher: Ok. And you have the ability to do that?

Rayann: Yea

Researcher: So how are you going to get that job?

Rayann: Show my artwork. Researcher: Show your artwork.

Rayann: I have to get an interview first. Researcher: An interview first, uh huh.

Rayann knew she wrote and expressed herself well on paper:

Researcher: How confident are you in doing the things you're able to do?

Rayann: I could do, I could draw good.

Researcher: You can draw good and you're confident about that.

Rayann: Nothing else.

Researcher: What are you the most confident about?

Rayann: I don't know.

Researcher: How about writing?

Rayann: Yea, I'm confident about writing.

She was persistent in school and at home until she got what she wanted. She was sure that eventually, she would get what she asked for:

Researcher: What if you have a problem and they're ignoring you?

Rayann: And helps me.

Researcher: And helps you. How about if they ignore you?

Rayann: I don't like that when they ignore me.

Researcher: That's right, uh huh, what if you have a problem with something?

Rayann: I talk to them.

Researcher: Ok, so they have to do what when you talk to them?

Rayann: They have to try to make me feel better. Researcher: That's right and they have to...?

Rayann: Listen.

Rayann felt empowered through the use of technology. Though her mother lived far away,

technology could make her seem close:

Researcher: Tell me how you email. If you wanted to email your mother, how would you

email your mother?

Rayann: I go to Facebook

Researcher: Oh, you would go to Facebook if you wanted to talk to your mom.

Rayann: Yea

Researcher: And then what would you do? Rayann: And then I write her a message. Researcher: Um hm, and then what happens?

Rayann: She gets it? Researcher: And then?

Rayann: And then she messages me back.

Researcher: That's what I wanted to find out. To get your reaction there, see?

Rayann: (nods)

Researcher: Between her and you. All right. Do you ever send her any pictures through

the Internet? Rayann: I did.

Researcher: By yourself?

Rayann: Yea Researcher: Yea? Rayann: A long time.

Researcher: A long time ago?

Rayann: (nods)

Researcher: Tell me more about that.

Rayann: I, I don't know

Researcher: Did you do it with Facebook Rayann: Yea, no I did it with my phone.

Researcher: Oh, with your phone. So you do emails on what?

Rayann: On Facebook! Researcher: On what device? Rayann: Laptop or computer.

Rayann also used technology for leisure:

Rayann: I use my dad's phone now.

Researcher: Oh, you have to use his phone?

Rayann: (laughs)

Researcher: Do you ever text with his phone?

Rayann: No, but I watch on his phone.

Researcher: Watch what? Rayann: Power Rangers.

Researcher: Oh yea, like shows, you mean.

Rayann: Yea

Researcher: You watch shows on his phone.

Rayann: Yea

Music was an important part of Rayann's life. She felt empowered by being able to access any

music she liked:

Researcher: How do you listen to the music that you like?

Rayann: I use the computer or the laptop.

Researcher: Uh huh, and how do you find the music on that?

Rayann: Write the title.

Researcher: With the title...

Rayann: Uh huh, and the singer.

Researcher: And the singer. And then what do you do?

Rayann: Listen to mu-, to music.

Researcher: Ok, what kind of music do you like?

Rayann: Every kind. Researcher: Yea? Rayann: (nods)

In fact, when Rayann was without her laptop, it was not a good situation for feeling empowered:

Researcher: How's it like without your laptop? How is it like in your, in your room

without the laptop? Rayann: Not good.

Researcher: (laughs) not good right?

Rayann: (laughs)

Rayann did not like to blame others unjustly. She wanted to look good in the eyes of other

Muslims. She wanted me to be sure I understood that a particular incident she experienced was

the fault of no one:

Rayann: But about that fall...

Researcher: About that fall? Tell me about that fall you had.

Rayann: That it was m-, it was my fault. My helper had nothing to do with it.

Researcher: No one's blaming anybody. It's ok. You wanted to make that clear, didn't

you?

Rayann: I'm just telling you (smiles) Researcher: Yea, you're just telling me.

Rayann: Yea

Researcher: Nobody was, nobody was mad right?

Rayann: No

Researcher: I mean they may be worried and scared, but they weren't mad right?

Rayann: No

Researcher: No one got in trouble for that.

Rayann: (shakes head no)

Researcher: Yea, ok, nothing else?

Rayann: (shakes head no)

Feelings related to self-realization for Rayann. Themes coded for self-realization were self-awareness, adult preferences, difficulties/dislikes/non-interests, religious feelings, and support people. I have already detailed how Rayann was aware of her conditions and disability.

Researcher: How do you feel about your own limitations? Do you know what limitations

are?

Rayann: No

Researcher: The things you're not able to do? How do you feel about the things you're

not...?

Rayann: I feel really, really bad!

Here is how she felt about her own limitations:

Researcher: About the things you're not able to do?

Rayann: Like walk.

Researcher: Like walk, that really bothers you, right?

Rayann: Yea

Researcher: That what you're saying—?

Rayann: Because I see everyone doing what, what they want...

Researcher: Um hm

Rayann: And I don't know...

Researcher: You just really wanna walk.

Rayann: Yea

Researcher: What if you wanna be somew—

Rayann: No, it, it doesn't bother me if I don't walk. It bothers me if people sees me and,

and think to themselves, she's, she's not like us.

Researcher: Aaaw, you don't want people to think you're different, is that what it is?

Rayann: I like to be the same.

Researcher: The same as everybody else, not different. Well, you are the same, you're,

we're all human here, we're the same, you mean, you mean about walking?

Rayann: (nods) But the walking doesn't, um, I, not walking. That doesn't bother me. It

bothers me what people think. Researcher: What people think?

Rayann: Um hm

Researcher: Um hm, and what do you think they're thinking?

Rayann: I don't like when they think she's not like us.

Researcher: Um hm, and they don't include you, you mean, is that what it is?

Rayann: I don't know

Researcher: That's she different, and they're not going to include her because she can't

walk, like that, you mean?

Rayann: Kinda

Researcher: Kinda, is that what, what you're trying to say?

Rayann: Yea

Researcher: Kinda like that? Um hm, you know you can't worry about what they're

thinking...

Rayann: I don't like people when they look at me with, with, w-, I don't know...

Researcher: With sad eyes? Like that? They look at you with sad eyes, is that what it is?

Rayann: No, I don't know

Researcher: You don't like when they look at you when you're in the chair. Is that what it is, no? I'm trying to get your story right.

Rayann: No, I don't look at, like when, wh-...I don't like them to look at me when I'm in

my, I don't like how they look at me when they're in, I'm in my chair.

Researcher: Uh huh. Because it makes you feel what?

Rayann: Bad!

Researcher: Uh huh, and how do you think they're looking at you? In what way?

Rayann: I don't know

Researcher: It just bothers you when they see you in the chair. And you wish what?

Rayann: That, that I can walk and...

Rayann needed a platform where she could publicly express how she felt about living from a wheelchair. Sometimes I had to include a long quote from her to demonstrate her feelings.

In addition, Rayann was aware she worried a lot and did not like it:

Researcher: You said before you don't like being worried. How do you feel about being

worried?

Rayann: Not good.

Researcher: Tell me more about that. How you feel about being worried?

Rayann: I, I, I don't know

Researcher: Tell me about being worried, and what happens when you get worried, and

how you feel about being worried and...

Rayann: Like when some, when someone's doing something and, and I'll be thinking of

something inside. Researcher: Um hm

Rayann: Like, I forget what, but I do think a lot.

Researcher: I know you think a lot about things and you worry a lot.

Rayann: Yea

Researcher: How do you feel about worrying a lot?

Rayann: I feel bad.

Researcher: You don't like it.

Rayann: No

Rayann had preferences for when she becomes an adult:

Researcher: What else is part of your dream life if anything was possible? If you could

have anything you want, what would you want in your adult life, besides that?

Rayann: Our own, our own room. Researcher: Your own room.

Rayann: With my husband and me. Researcher: Um hm, what else?

Rayann: Maybe! Because, I don't know, I'm not grown up yet.

Researcher: No

Rayann: I'm not old yet. Researcher: No, you're young.

Rayann: I don't know what's going to happen in the future.

Researcher: But what do you wish would happen in the future if you could have anything

you wish for?

Rayann: Get my own, my apartment.

Researcher: Um hm, ok.

Rayann: Yea

Researcher: With husband and child.

Rayann: Yea

Researcher: Children, children.

Rayann: Oh, yea

Researcher: Anything else?

Rayann: No

Researcher: That's the main thing?

Rayann: (laughs) Researcher: Ok.

She kept repeating this wish each time she was asked where she wanted to live.

Rayann expressed difficulties she has in life:

Researcher: How do you do it?

Rayann: I just hang the shirt and hang it in the...I don't know what it's called...

Researcher: Is it the closet?

Rayann: Yea, but the thing in the closet

Researcher: The, the closet r-rail? The rail in the closet?

Rayann: Nnn

Researcher: Or the closet rod that goes across? You put it up there?

Rayann: Yea, but not me, my helper. Researcher: Who puts it on the hanger?

Rayann: My helper.

Researcher: Can you put them on the hanger if you wanted to?

Rayann: Yea, I could but it's so difficult.

Researcher: Aw, yea.

Rayann: And then I'll get tired.

A part of Rayann might miss her brother sharing the room with her based on this comment:

Researcher: What keeps you from doing the things that you're interested in doing?

Rayann: I don't know the answer to that.

Researcher: Do you get to do the things you want to do? That you're interested in doing

most of the time?

Rayann: I, I like to get my own room.

Researcher: Your own room?

Rayann: No I, I, someone, I don't mind if someone's is s-sleeping with, in, in, in...

Researcher: In your room, with you, yea.

Rayann: Yea, I just want the room to be bigger. Researcher: You wish you had a bigger room.

Rayann: Yea

Researcher: Yea, maybe you'll get a bigger room one day.

Rayann: Yea

Rayann was able to do some household activities before that she cannot do now and did not like to do them anymore:

Researcher: Ok, do you, how about knives? Cutting food with knives?

Rayann: I don't like to cut thame (same?) knife.

Researcher: Um hm

Rayann: I've been like, since I was a little...no I, I remember I did cut some when I was

little, but now I don't want to.

Rayann was not an outdoor type person. She was not interested in living near a recreation center:

Rayann: I don't know what is recreation means.

Researcher: You know like YMCA, you know YMCA.

Rayann: Yea

Researcher: That was the song in the talent show your brother did.

Rayann: Yea

Researcher: Like the YMCA where they have sports and things to do and social events,

and sports events, and activities, play games and...

Rayann: Yea

Researcher: Maybe you'd like a recreation center? Like to live by one of those?

Rayann: No

Researcher: Ok, it doesn't interest you, all right. It doesn't interest you.

Rayann was no longer interested in doing her nails. She had been wearing gloves to cover a skin condition since I have known her:

Researcher: How about a nail salon where they do your nails? You want to leave near a

nail—?

Rayann: I don't do my nails now.

Researcher: You don't do your nails anymore? That doesn't interest you, does it?

Rayann: No

Rayann had strong religious feelings:

Researcher: Do they do their own, uh, religious group in the house or do they go

somewhere else to do it? Rayann: I don't know (laughs)

Researcher: Like a prayer group? You pray, do you pray with, out of the house with other

people?

Rayann: No, I pray inside the house. Researcher: Always in the house?

Rayann: Yea

Researcher: You ever go to, you never go to a place with other people and go pray with

other people?

Rayann: I did once in Lebanon. Researcher: Not in Miami?

Rayann: No

Rayann based her food choices on what was permitted in her religion:

Researcher: At home it's cooked the, the Muslim way and then other places it's not, it's

cooked the American way.

Rayann: Yea

Researcher: And you know you're not supposed to eat that way?

Rayann: Um hm

Researcher: Because it doesn't go with your religion, right?

Rayann: (nods)

Researcher: Ok ok. So that's it about the food you eat, does, it's, it's, uh...it's done the Muslim way for your religion and that's who picks the food is your religion picks the

food, basically, right?

Rayann: Y-yea

Rayann spent a lot of time worrying that she was not a good enough person:

Researcher: What would be the worst problem that would ever happen to you?

Rayann: I tell someone something and it's not the right answer.

Researcher: Um hm

Rayann: Because I get very, uh, cause I didn't tell the truth.

Researcher: Oh, and that worries you, I know it does.

Rayann: Yea

Researcher: You don't like being misunderstood, do you?

Rayann: No

Researcher: You don't like that now...

Rayann: I get worried a lot.

Researcher: I know you worry about things. I know, you hate to worry, right?

Ravann: Yea

Researcher: I know.

This feeling appeared to be based on her religion and wanting to go to heaven:

Rayann: Sometimes I get tired of that, worrying a lot. Researcher: I know, it's not fun to worry, right?

Rayann: Yea

Researcher: Um hm, what else do you worry about? Rayann: I want God to, to still love me, to still want me...

Researcher: Yea

Rayann: ...when I go to heaven.

Researcher: Right

Rayann: And I wanted to, that to happen even if I did, I do things by accident.

Researcher: By accident. So, uh, how do you feel about God forgiving you about what

you did by accident? How do you feel about that? Rayann: Sometimes I tell God to please forgive me.

Researcher: Ok, what do you, do you think God forgives you?

Rayann: Maybe, I don't know.

Researcher: You ask Him to forgive you, right?

Rayann: (nods)

Researcher: Do you think he does when you ask Him?

Rayann: M-yea

Rayann self-concept revolved around being Muslim:

Researcher: Ok, so you're saying that you, the way that you feel about yourself is that

you worry about doing the right thing?

Rayann: Yea

Researcher: You worry about that? You worry about being a good Muslim? You worry

about that? So how do you feel about being a good Muslim?

Rayann: Sometimes it's not easy for me.

Researcher: It's not easy.

Rayann: But I *like* being Muslim!

Researcher: Yea? What's hard about being Muslim in America?

Rayann: I don't know.

Researcher: What's hard about being a Muslim when you're in Lebanon?

Rayann: That's easy! But in America it's a little hard.

Researcher: Yes

Rayann: Because I can't eat, I can't eat everything. Over there I can eat everything!

Researcher: Cause everyone's Muslim, right?

Rayann: Yea, but here no.

Researcher: No, um hm, not everyone here is Muslim.

Rayann: Over there the KFC is *halal*.

Researcher: Really?

Rayann: Yea, and I remember when I was, when we were little, me and [Baqir] used to

sit on the floor and our dad would feed us.

Researcher: Aaaw! Those are some sweet memories!

Rayann: (laughs)

No matter what I would say to Rayann, she persisted in feeling worried about being good:

Rayann: I wanna go to heaven.

Researcher: Oooh!

Rayann: I don't want to go to hell.

Researcher: I don't think you're going to go to hell. I'm sure you're going to go to

heaven.

Rayann: Sometimes I, I think negative, negative.

Researcher: Negative? I know, you worry.

Rayann: And I'm tired of that.

Researcher: I know and I don't know how to help you with that, the way you worry. You know, there are some really bad people in this world and you are *nothing* like that. You

know who's waiting for you in heaven, don't you?

Rayann: (nods)

Researcher: Who's waiting for you in heaven?

Rayann: My brother and sister.

Researcher: Don't you think they're gonna help you go to heaven?

Rayann: Yea

Researcher: They're gonna say here, you grab this hand and I'll grab that hand and we'll take you up to heaven, like that. You have two hands to hold onto. I am sure. And you, also they watch over you, too. Make sure you, you do good things and good things happen to you.

Rayann: I just want Him to still want me to, with Him.

Researcher: Oh, I'm sure God wants you. You're such a good person. You're a good

person

Rayann: Yea, but sometimes I worry.

Researcher: About being a good Muslim, right?

Rayann: (nods)

Researcher: God knows it's hard to be a Muslim in America. Do you think He knows

that?

Rayann: (nods)

Researcher: What a hard time you have being a Muslim in America?

Rayann: (nods)

Researcher: I think God knows that.

Rayann: (nods)

Rayann was aware of who she can lean on for support and had a strong family support system.

This excerpt was quoted previously under interests in support people:

Researcher: Who's gonna support you in in reaching your goals? Who's gonna support

you in that?

Rayann: My husband

Researcher: Your husband is one

Rayann: My mom

Researcher: Your mom is another person that's going to support you

Rayann: My dad

Researcher: And your dad

Rayann: And then...

Researcher: Anybody else

Rayann: No, nah

Researcher: How about other people in the family?

Rayann: My sister Researcher: Um hm

Rayann: Brother, brothers! Researcher: Two brothers

Rayann: Yea, No actually three brothers

Researcher: Three brothers, Sure! Anybody else?

Rayann: My aunt Researcher: Uh huh Rayann: And uncle Researcher: Uh huh Rayann: (laughs) and

Researcher: People I've already met that I know...

Rayann: And my cousin

Researcher: Oh that's what I'm waiting to hear, the cousin (laughs)

Rayann: (laughs)

Researcher: I'm waiting to hear that. I know I met her and she's a good support for you

Rayann: Yea

Researcher: I know. How many cousins do you have?

Rayann: A lot

Researcher: A lot. Will they all support you or just the one cousin that I met?

Rayann: No I know they'll all support me

Researcher: All your cousins?

Rayann: (nods)

Researcher: You have a good support system there

This list did not even include the relatives she had in her parent's home county that she mentioned previously. Rayann had a large family support system.

Analysis of Feelings Related to Psychological Empowerment and Self-Realization for

Vanesa

Feelings related to psychological empowerment for Vanesa. The categories in this theme were self-advocacy, confidence, use of technology, and protection of self-image. Vanesa could communicate well enough to speak up for herself, even if she did not always apply her skills to the situation as necessary. She said she did speak up when she has pain:

Researcher: What do you do when you have a pain somewhere on your body? What do you do about it?

Vanesa: I, I get scared.

Researcher: First you get scared, right? Because you feel pain, you get scared and then

what do you? Vanesa: Relax.

Researcher: Try to relax. And if you still feel pain, then what do you do?

Vanesa: Call the doctor.

Researcher: There you go, call the doctor or else you could call what?

Vanesa: My mom.

Researcher: Your mom, right? If you have a pain, tell your mom. You gotta speak up,

right?

Vanesa: Yea

Researcher: Because she doesn't know where it hurts.

Vanesa: No

After giving Vanesa a background scenario of a teacher rushing her to go to lunch when she had to go to the bathroom first, she claimed she would speak up and say what she needed:

Researcher: But how do you say to the teacher, wait, I need something here? Let's go to lunch, come on, come on.

Vanesa: (laughs)

Researcher: Hurry up, but, but, what are you gonna do? What are you gonna say?

Vanesa: But, um, ar-

Researcher: Teacher, teacher, wait...

Vanesa: Wait!

Researcher: What are you gonna say?

Vanesa: Teacher, teacher, wait, uh, let's go to lunch, like, hurry, hurry, hurry

Researcher: But you have to go to the bathroom...

Vanesa: (laughs)

Researcher: What do you say?

Vanesa: Um, I need to go to the bathroom, go...

Researcher: Ok, you would say that?

Vanesa: Yea (laughs)

Researcher: You would tell 'em?

Vanesa: Yea!

Researcher: Yea, you have to speak up for yourself, right?

Vanesa: Yea

She tended to copy my background scenarios before I could get her to give me a well-thought out answer. Vanesa could advocate for herself in a restaurant:

Researcher: How do you ask them for the food in a restaurant?

Vanesa: Ask them for the food?

Researcher: Yea, how do you ask them for food in a restaurant?

Vanesa: Ask...please can I have some pizza and then...

Researcher: Good

Vanesa: And then I think, that's it and! Coke.

Researcher: Um hm Vanesa: Coke.

Researcher: And who do you tell that to?

Vanesa: To the pizza Researcher: It can't hear.

Vanesa: No!

Researcher: You said it to the pizza? Vanesa: Oh, thank you! And then...

Researcher: To who? Vanesa: To the pizzaaa!

Researcher: The pizza can't hear what you say. You mean to the people?

Vanesa: Oh, yea, yea (clears throat), to the people

Researcher: To the waitress or the waiter?

Vanesa: Uh, www-, uh, waitress.

Her cognitive level made her especially easily led, but I gave her the benefit of the doubt again.

Vanesa could express how she would be able to advocate for herself on a job:

Researcher: How do you like to learn a new job? You have to tell me which thing?

Vanesa: Talk (whispers)

Researcher: You said talk before.

Vanesa: Ok!

Researcher: You like people to talk to you?

Vanesa: Yea

Researcher: That came up again. That's a good way, ok.

Vanesa: Talk to your friends.

Researcher: Want...you want your friends to tell you what to do on the job?

Vanesa: Mmm-yea

Vanesa could advocate for what kind of job she might like to do:

Researcher: What kind of a job have you tried to do, like in school here, that you tried it

and you liked it?

Vanesa: Like [Thomas's] class?

Researcher: Yea

Vanesa: Ok, um, I like [Thomas's], the computer.

Researcher: The computer is a good work skill to know.

Vanesa: Um hm

Researcher: You tried the computer and you liked that, anything else?

Vanesa: I like that computer and the...(points to the laptop)

Researcher: Laptops? Vanesa: Laptops.

Researcher: You like using laptops, too?

Vanesa: Yea

Researcher: What else?

Vanesa: I like using headphones.

Researcher: Headphones.

Vanesa: I like using this, the...I forgot Researcher: On the side over there?

Vanesa: Yea

Researcher: That long thing? That's a speaker.

Vanesa: A speaker. Researcher: Um hm

Vanesa: And then, and then that computer and the table (points to computer table)

Researcher: Um hm

Vanesa: Yea

As thin as she was, Vanesa had a good appetite and could handle a knife with confidence:

Researcher: How do you cut food?

Vanesa: I cut food like this (makes noise and gesture)

Researcher: Um hm Vanesa: And I (noise)

Researcher: Ok

Vanesa: And then I cut the chicken.

Researcher: You cut chicken with a knife?

Vanesa: Yes

Researcher: By yourself?

Vanesa: Mm hm

Researcher: Very good.

Vanesa: With no, w-with no help, with no help.

Researcher: With no help?

Vanesa: Uh-uh (shakes head vigorously from side to side)

Researcher: That's excellent!

Vanesa: Yea

Researcher: Very good, independent.

Vanesa expressed self-confidence regarding job skills:

Researcher: What jobs are you good at?

Vanesa: I good at...I, I good at writing down piece of paper.

Researcher: Ok, anything else or is that it?

Vanesa: Mmm. That's it.

Vanesa mentioned writing on paper throughout the interviews. She was better at writing than she was at any other language arts skills because she can neatly write her personal information after a model (name, address, phone number, etc.). Vanesa talked about her abilities:

Researcher: How confident are you in your abilities?

Vanesa: What's abilities?

Researcher: Things you can do. So how, how good do you feel about the things you can

do? That's the question. Vanesa: Like play games?

Researcher: Yea, do you think you're good at games?

Vanesa: Yea

Vanesa felt empowered using technology:

Researcher: Ok, how do you listen to the music that you like?

Vanesa: Oooh! I know! I know!

Researcher: Tell me. Vanesa: Hannah Montana!

Researcher: How do you listen to Hannah Montana?

Vanesa: To...

Researcher: How do you listen to her?

Vanesa: To sing songs.

Researcher: Yea? How do you hear Hannah Montana?

Vanesa: Um

Researcher: Is it on that? (points to phone)

Vanesa: Yea!

Researcher: Well, how do you do that?

Vanesa: (sighs) It's...(sighs) ha--, it has, it has voice music. Researcher: It has voice music? On that phone right there?

Vanesa: Yea!

Researcher: So you listen to music on the phone, right?

Vanesa: Um hm

Researcher: Ok, how do you hear or how do you see the TV shows you like? Vanesa: Like that TV? (points to interactive board at the front of the classroom)

Researcher: Or even at home, your home TV. How do you see the TV shows you like?

Vanesa: The TV shows?

Researcher: Um hm, how do you see them?

Vanesa: Um Facebook

Researcher: You do Facebook?

Vanesa: Um hm

Researcher: How do you do that?

Vanesa: You...you put the Facebook on the iPad

Researcher: Nice

Vanesa: And then you put you put the Internet on the iPad.

Researcher: Wow, that's good.

Vanesa: Too...

Researcher: So you do Facebook, you do iPad, you're connected!

And later in the conversation:

Researcher: What makes you happy? Vanesa: When I listening to music. Researcher: You like music, right?

Vanesa: Yea

Researcher: What else makes you happy?

Vanesa: Makes you proud...

Researcher: Proud, what makes you proud, of yourself?

Vanesa: Listening to your iPad.

Researcher: Makes you proud of yourself? You feel proud when you listen to the iPad?

Vanesa: Yea

Vanesa could also use a tablet to write or take pictures:

Researcher: What can you do on a tablet? Vanesa: Like that i-P-...? (points to iPads)

Researcher: Like that iPad.

Vanesa: Oh!

Researcher: What can you do on a tablet like an iPad?

Vanesa: Like this, t-t-t- (makes typing sound and gestures typing on the table)

Researcher: But what can you do on it? You can type like that, right?

Vanesa: Yea

Researcher: What else can you do on an iPad, on a tablet?

Vanesa: On a tablet? Researcher: Yea

Vanesa: You get pictures taking.

Researcher: Um hm

Vanesa did not place blame on others, but she had this to say about making a mistake:

Researcher: How did you feel about that mistake when you did it wrong? How did you

feel?

Vanesa: I feeling... (laughs)

Researcher: How'd you feel about that?

Vanesa: I feeling like, like, like nor, like nervous.

Researcher: Nervous? You felt nervous?

Vanesa: M-yea Researcher: Yea?

Vanesa: I, I felt afraid about...

Researcher: Really? Vanesa: M-yea She gets very quiet and looks down when corrected in class. This may be how Vanesa protects her self-image.

Feelings related to self- realization for Vanesa. Self-realization included self-awareness, adult preferences, difficulties/dislikes/non-interests, religious feelings, and support people. Vanesa expressed self-awareness as such:

Researcher: What do they call the disability that you have? What do they call it? I have...

Vanesa: I have, inte-, tsk, I have, hmmm, I don't know (shrugs shoulders)

Researcher: Well before you said, last time you said, I have CP.

Vanesa: Oh! I have CP!

Researcher: Ok, what does CP stand for?

Vanesa: Um P, V?

Researcher: CP, what does it stand for? Vanesa: CP is be nice to each other.

Researcher: Yea, but that's not what it means. That's a *good* thing to have, be nice to other people. Ok, but if, you know, your mother said something about CP to you and you

went, oh yeah.

After attesting that she did not have any other physical conditions, Vanesa mentioned CP once, but was not able to verbalize that it stood for Cerebral Palsy. Sometimes Vanesa just repeated what she heard at home or at school without being able to process it. Basically Vanesa was always happy, but she was also happy about being who she is:

Researcher: How do you feel about yourself?

Vanesa: Oh happy? Researcher: Happy?

Vanesa: Yea!

Vanesa was happy when she could dress herself:

Researcher: When you get all dressed up by yourself, all alone by yourself, it makes you

feel what?

Vanesa: Happy. Researcher: Happy.

Vanesa: Yea

Researcher: Ok, so you're happy being who you are?

Vanesa: Yea

Researcher: You feel happy about yourself, right?

Vanesa: Yea

Researcher: Is that what you're saying?

Vanesa: Yea

Vanesa felt that her friends liked her:

Researcher: She's your friend, right? [Rayann] is your friend?

Vanesa: M-Yea

Researcher: What does she think about you?

Vanesa: That she's proud. Researcher: She's proud, ok. Vanesa: And she excited.

If a boy she was interested gave her a ring, here is how she would feel about herself:

Researcher: How would you feel about [Spencer] being your boyfriend?

Vanesa: Oh, like put it on, the ring?

Researcher: Yea, and then how would you feel about that?

Vanesa: I feel proud.

Researcher: Proud, what else? Vanesa: Or I feel happy.

Researcher: Happy?

Vanesa: Yea Researcher: Nice!

Vanesa could identify how to calm down when upset:

Researcher: If you're really *mad*, how do you calm down?

Vanesa: I really mad?

Researcher: Yea, if you get really mad, how do you calm down?

Vanesa: I remember the computer (laughs) Researcher: Yea, the computer gets you mad.

Vanesa: (laughs)

Researcher: How do you calm down?

Vanesa: Calm down? Researcher: Um hm Vanesa: When I breathing.

vallesa. When I breathing.

Researcher: Oh, breathing, that helps you really calm down.

Vanesa: Yea Researcher: Ok

Vanesa: Or asking for help.

Researcher: Ask for some help? That would do it too.

Vanesa expressed her adult preferences:

Researcher: What's your dream about living an adult life?

Vanesa: Apartment

Researcher: Apartment! There you go, what else?

Vanesa: Living a dream home

Researcher: Living in a dream home? How would that be? Who would be there?

Vanesa: [Spencer]

Researcher: Yea maybe [Spencer] Vanesa: Or maybe, oh! Maybe [Kaylee].

Researcher: Maybe [Kaylee], what would be your dream job?

Vanesa: Go to the, go to the shopping, go Publix

Researcher: Uh uh Vanesa: To buy stuff

Researcher: Going shopping

Vanesa: Publix

Researcher: Uh huh, that's part of your dream, having an apartment, you going shopping,

what else? What else is part of your dream life as an adult?

Vanesa: Go, go to different places

Researcher: Uh huh, go to different places

Vanesa: Or go to, tsk, go to the CVS pharmacy and get the medicine

Researcher: Go to CVS pharmacy and get your own medicine. What kind of job do you want to have? What's your dream job? What's a job you would love to have a job of

doing there?

Vanesa: CVS pharmacy

Researcher: Work in a CVS pharmacy? To work there you mean?

Vanesa: Yea

Researcher: You want to work in CVS? Work in a store like CVS?

Vanesa: Yea

Researcher: That's your dream job

Vanesa: Yea

Researcher: So you have your dream house or your new apartment, and [Spencer] is there, maybe [Kaylee], is there too, you go shopping you work in CVS. Is that your

dream? Vanesa: Yea

Researcher: For the future

Vanesa: Yea

Researcher: Did I get the story right?

Vanesa: Yea

Here she sounded sure she wanted an apartment, to live with friends, and have a job. At other times she said she wanted to keep living with her mother. This was how Vanesa expressed difficulties she experienced in life:

Researcher: What gives you a hard time in life? It's hard for me to...?

Vanesa: To, to s-, to, to graduated?

Researcher: To graduate?

Vanesa: Yea

Researcher: You think it's hard to graduate?

Vanesa: Um hm

Researcher: Ok, why do you say that?

Vanesa: (laughs) is...

Researcher: You mean like to finish school?

Vanesa: Yea (laughs)

Researcher: It's hard for you to finish school?

Vanesa: Yea

This was Vanesa expressing weaknesses:

Researcher: What's something that you can't do too good? I'm not very good at...what?

Vanesa: At writing the name (laughs)

Researcher: At writing your name? Ok, you're not very good at writing your name.

Vanesa: (laughs)

Researcher: So what do you do about that? How do you solve that problem?

Vanesa: Write, write on, write on the board. Researcher: You write on the board. That helps.

Vanesa: Helps, helps me think.

Researcher: Helps you think, writing on the board, ok.

Vanesa: Go, go to the movies together...

Researcher: What if somebody writes your name on a piece of paper and says, now copy

your name on that piece of paper? Can you do it that way? Would that help?

Vanesa: Some, um, sometimes I do and sometimes I don't. Researcher: Uh hm, what helps you write your name better?

Vanesa: Like, like on the sheet?

Researcher: On the sheet. What helps you write your name better on the sheet?

Vanesa: To, to copy the words.

Researcher: To copy the words! That's an excellent answer.

This was the most coherent statement she could make about what was hard for her. She usually had great difficulty staying on topic without going off on wild tangents. Sometimes I had to pull out what I thought she was trying to say:

Researcher: What's difficult for you to do?

Vanesa: It means that, that you, that you be my, my assistant.

Researcher: Yea, you have an assistant for things that are hard? Is that what you're trying

to say? Vanesa: Yea

Researcher: Ok, the assistant helps you with things that are hard?

Vanesa: Yea

After this relatively coherent statement, she went on to say that she did not need an assistant and dressed herself independently, which I happened to know was a false statement. And then, the next statement she made was that she had difficulty taking off clothes, but not putting them on. She also described difficulties bathing:

Researcher: What else is hard for you to do?

Vanesa: Take me a shower.

Researcher: Taking a shower is hard. You have a little help with that.

Vanesa: Yea

Researcher: What else is hard for you?

Vanesa: Um, get a soap. Researcher: Um hm Vanesa: And water. Researcher: Um hm

Vanesa: And wash my hair like this, chic, chicha, chich.

And turned right around and said washing her hair was not difficult. The difficulty I had in analyzing some of her statements will be discussed later.

Vanesa was a friendly, cheerful person and did not express understandable dislikes or non-interests. She rarely said anything negative about anything in her life. We have to remind her not to laugh all the time in front of people she does not know very well. We say that because it draws attention to her disability because she laughs for no apparent reason. In spite of acting perpetually ecstatic, Vanesa was able to describe a range of feelings that I never knew she had:

Researcher: How do you feel about yourself?

Vanesa: Oh, happy? Researcher: Happy?

Vanesa: Yea!

Researcher: What else?

Vanesa: Um, sad.

Researcher: Sometimes sad?

Vanesa: Yea

Researcher: When do you feel sad? Vanesa: If I have a headache.

Researcher: Don't like being sick, right?

Vanesa: No

Researcher: Having headaches, that's a sad time.

Vanesa: Yea

Researcher: What else makes you sad?

Vanesa: Nervous.

Researcher: When you get nervous. You don't like being nervous, right?

Vanesa: M-no

Researcher: What makes you get nervous?

Vanesa: Tired.

Researcher: Tired, all those feelings, right?

Vanesa: Yea

Researcher: What makes you get nervous?

Vanesa: A s-, a seizure.

Researcher: A seizure makes you get nervous.

Vanesa: Yea

Researcher: Not fun.

Vanesa: No

Researcher: What makes you get tired?

Vanesa: Go to bed.

Researcher: Well, when you go to bed, you feel tired, right?

Vanesa: Yea/

Researcher: Ok, ok, what makes you happy?

Vanesa: When I listening to music. Researcher: You like music, right?

Vanesa: Yea

Researcher: What else makes you happy?

Vanesa: Makes you proud.

Researcher: Proud, what makes you proud, of yourself?

Vanesa: Listening to your iPad.

Researcher: Makes you proud of yourself? You feel proud when you listen to the iPad?

Vanesa: Yea

Researcher: Um hm, how else do you feel about yourself?

Vanesa: Mmm

Researcher: Is that it or do you have more things to say?

Vanesa: I have more things to say.

Researcher: Good

Vanesa: Ah, I go change my clothes.

Researcher: Um hm, and how do you feel about being able to do that?

Vanesa: Oh, pull my pants up.

Researcher: And how do you feel about being able to do that for yourself, by yourself?

Vanesa: Oh, my shoes... Researcher: Uh huh

Vanesa: off...and my socks.

Researcher: And how do you feel when you do all that, about yourself?

Vanesa: You...

Researcher: Do you know what I'm saying?

Vanesa: Yea, you throw it in, you throw it in the washing machine.

Researcher: Um hm, and when you get all dressed up by yourself, all alone by yourself, it

makes you feel what?

Vanesa: Happy. Researcher: Happy.

Vanesa: Yea

Researcher: Ok, so you're happy being who you are?

Vanesa: Yea

Researcher: You feel happy about yourself, right?

Vanesa: Yea

Researcher: Is that what you're saying?

Vanesa: Yea

Parts of the above conversation were previously referenced, but I wanted to show the other excerpts in full context. I had no idea she could express so many sides of herself. At school she was always just a happy person. Vanesa expressed her feelings about being important:

Researcher: What are the things that make you *feel* like an important person?

Vanesa: Like dress, wait, dress up nice, like that.

Researcher: Um hm. It makes you feel like an important person when you dress up nice?

Vanesa: Yea

Researcher: Yea, ok. What else? Vanesa: Put on your shoes.

Researcher: Um hm, what else makes you feel important?

Vanesa: Go to the Best Buddy party.

Researcher: Um hm Vanesa: And eat pizza. Researcher: Um hm Vanesa: Yea to go... Researcher: That's good. Vanesa: ...to go new cafeteria.

Researcher: Um hm, that's important. Ok, who makes you feel important? Who's the

person that makes you feel important?

Vanesa: My mom.

Researcher: That's a good answer. Your mom makes you feel important, doesn't she?

Vanesa: Yea

Vanesa was able to express religious feelings:

Researcher: How do you take part in religious or church groups?

Vanesa: What is religious church group? Researcher: Like, do you go to church?

Vanesa: Yea

Researcher: So do they have like little groups in church?

Vanesa: Yea

Researcher: And what do you do there in the groups in church?

Vanesa: My mom. Researcher: Um hm

Vanesa: And me, some days I have to go to, to the big church.

Researcher: Uh huh

Vanesa: To, just like your desk, it's big.

Researcher: A big desk like mine, huh? Uh huh

Vanesa: (laughs)

Researcher: Well, are there any groups over there at church where they have young

people in the groups? Vanesa: Uh, One!

Researcher: There's one group there?

Vanesa: Yea

Researcher: And you belong to that group at church?

Vanesa: Mmm, sometimes. Researcher: With young people?

Vanesa: Yea

Researcher: And what do there do there? Vanesa: (sighs) They receive the priest.

Researcher: Um hm Vanesa: And get bread. Researcher: Um hm Vanesa: And eat it.

Researcher: Um hm. Yep, that's right.

Vanesa: And drink wine.

Researcher: That's right, in the Mass.

Vanesa: Prayer... Researcher: Um hm Vanesa: ...and, and pray

Researcher: And they pray, ok, very good.

Vanesa knew she needed people to support her:

Researcher: Who takes you to doctor appointments?

Vanesa: In the office.

Researcher: Yea? Who takes you?

Vanesa: (laughs)

Researcher: Who takes you?

Vanesa: Um, I don't know, I don't know, I don't... Researcher: Nobody at your house helps you with that?

Vanesa: Oooh, I know! Researcher: Who? Vanesa: My nurse!

Researcher: Oh, the nurse takes you sometimes, ok?

Vanesa: She takes me a shower.

Researcher: Uh huh

Vanesa: And she takes me, put my pajamas on.

Researcher: Uh huh

Vanesa: And put my socks and that's it. Researcher: Tell me more about that nurse.

Vanesa: Wash my teeth by myself.

Researcher: Hm um

Vanesa: Um

Researcher: Tell me more about the nurse.

Vanesa: I clean the toothbrush.

Researcher: Um hm

Vanesa: With water and I put it in there. Researcher: And then where's the nurse?

Vanesa: (laughs) She's in the car. Researcher: Oh, where's she going?

Vanesa: I don't know.

Vanesa wanted a nice person for support:

Researcher: I want a support person that is what?

Vanesa: Yea, uh (laughs) Researcher: Serious answer!

Vanesa: I forgot

Researcher: I want a, I want a helper that is...

Vanesa: Oh [Bianca]?

Researcher: That might be [Bianca], because [Bianca] is...

Vanesa: A nurse

Researcher: A nurse and she is... Vanesa: Taking a shower with me.

Researcher: Uh huh, because she's so what?

Vanesa: She's, she's nice.

Researcher: She's nice! You want a nice helper, don't you?

Vanesa: Yea

Vanesa made a comment on what she would rather do without assistance, but it was difficult to

follow at times:

Researcher: Maybe, you have a helper at home, right?

Vanesa: M-yea

Researcher: And mom helps you, your n-, the nurse right?

Vanesa: My nurse.

Researcher: The nurse helps you, your mom helps you. What's something that you do

now with help that you would rather do by yourself?

Vanesa: Brush my teeth.

Researcher: Brush your teeth, you do it by yourself?

Vanesa: Um hm

Researcher: What's something that you get help with right now that you wish you would

just, you would rather do it by yourself without help?

Vanesa: Just don't be lazy. Researcher: (laughs) um hm Vanesa: Go to, go to the concert.

Researcher: You want to go to the concert, um hm, by yourself?

Vanesa: Yea

Researcher: Um hm

Vanesa: And go different shows.

Researcher: You want to go by yourself to different shows and concerts?

Vanesa: Yea

Each participant had unique qualities and experiences that were analyzed by themes. Next I will examine how participants compare to each other across cases.

Maria Compared to Rayann

Needs. Maria and Rayann were similar in needs in that they both were dependent on their parents or family for support. Both needed assistance to be safe at home and in the community. To see a doctor they both needed help making the appointments and getting a ride. Both knew very little about simple home repairs. Maria had this to say:

Researcher: What if the water pipes break and there's water all over your house?

Maria: I say mom please, mop the floor, please.

Researcher: Uh huh, but the water's still coming out. What do you do if you're home

alone?

Maria: I call the...

Researcher: Home alone, your mom's not around and the water pipe in your house

breaks?

Maria: I call 911

Researcher: There you go.

While Rayann answered the same question in a similar way:

Researcher: What would you do? In the house, if there's a water leak in the house, what

would you do?

Rayann: I don't know.

Researcher: Go swimming? Rayann: No, no (laughs)

Researcher: (laughs) What would you do?

Rayann: Go buy another house? Researcher: Buy another house?

Rayann: Yea (laughs) Researcher: Yea? (laughs) Rayann: I don't know.

Neither talked about turning off the main water valve, turning off any other water supply to stop the leak, or using a bucket until help arrived. Other ways in which they were alike were that they both said they have a need to be listened to, need to be able to access technology, and need social access. Neither one had a clear concept of how hard their parents had to work to support them and how much they clearly needed their financial support. Maria did not know how money got into her parent's bank account:

Researcher: Where does your family's money come from?

Maria: I don't know

Researcher: How does your family get money?

Maria: From the bank.

Researcher: Who puts it in the bank?

Maria: My mom.

Researcher: Where does she get it from?

Maria: She gets the redit card, sshh (gestures swiping motions)

Researcher: You gotta pay for the credit card. How do you pay for the credit card? Maria: She goes to the redit card, she, she see her name (says mother's name)

Researcher: Um hm

Maria: And then she do like that (gestures putting in a credit card), she push the buttons ding, ding (gestures pushing buttons)

Researcher: But how do you pay for the credit card with the ding, ding, ding? How do you pay for the credit card?

Maria: She gets, she gets \$20 and then dute, dute (gestures money coming out of a

machine)

Researcher: How do you get \$20 though?

Maria: Oooh (moans)

Researcher: Nothing's free in life. How do people get money in life?

Maria: In the bank, man, in the bank!

Researcher: But who puts it in the bank though?

Maria: My mom.

Researcher: Where does she get the money from? Do know how people get money? Do

you know how they get money?

Maria: No

Rayann expected her father to give her an allowance and to pay the bill for all her wishes:

Researcher: What work have you done to earn money?

Rayann: My dad gives me, from his job, I don't know.

Researcher: Ok, do you have to work to get that money that he gives you?

Rayann: No

Researcher: It's like an allowance?

Rayann: He just gives me, uh, because, because he loves—I don't know.

Researcher: Yea, he did it because he loves you.

Rayann: Yea

She had no idea of how hard the long hours away from home were for him and how he also paid alimony to her mother. They both had an idea how they needed their families to support their choice making and to approve of their choices. Lastly they both knew they needed family support for travel within the community and for long distances.

The differences between the needs of Maria and Rayann were that Maria was ambulatory and physically within normal limits whereas Rayann used a wheelchair and was very dependent for physical needs. Maria was able to prepare and microwave simple foods for herself without help. Rayann needed assistance even to bring the food to her mouth, even though I have to give her credit, given her physical limitations, to be able to ask for assistance when hungry. Maria did not use the services of a personal attendant, but Rayann did. Maria could take care of self-care needs independently and Rayann needed personal assistance. Rayann knew she had a specific disability, which had a name, and Maria denied having a disability at all. This was mentioned because it was important to know what your disability is so one can ask for accommodations specific to needs. Maria claimed to do extensive household cleaning, while Rayann had no need to worry about it. Maria was athletic and participated in recreational activities after school for community involvement and Rayann had no interest in recreation in the community. Maria talked about how her mother was an athlete and that she also needed that outlet for physical movement. Rayann had no experience with working or work training and Maria had work training every morning. This difference made Maria much more aware of the need to work and

various job possibilities and it piqued her interests in alternate careers. Rayann could possibly participate in supported employment if it was a sit-down type job, but she did not feel a serious need to work. Maria's family was perhaps more supportive of her life choices to be more independent than Rayann's family due to family values and traditions. Lastly, Maria could ride any vehicle while Rayann needed a lift device or assistance in storing her wheelchair in the vehicle and help transferring herself into a seat.

Preferences. Both young women stood up for what they believed and spoke up for themselves successfully. They believed they were good friends to others and others liked them. Both verbalized that they could do anything they wanted to as far as life goals. They both believed they were good artists. They felt safe and felt they could tend to personal safety with unfamiliar and familiar others. They both felt they had inner strength to see their goals come to fruition. They knew what their friends liked and they found people to be friends with that were like them. They dealt satisfactorily with the problem of friends that did not agree with them. Maria and Rayann believed in a fantasy life for themselves. For both, those fantasies involved romantic interests, dreams of being an entertainer, and beliefs that they could travel independently. They also believed in their rights to respect, adult treatment, and privacy.

There were differences in what they believed in. Maria believed she could defend herself physically from attack and said she would strike someone who bothered her. Rayann believed she could talk her parents into allowing her to be in potentially unsafe company, but did not talk about physically defending herself. One fantasy Rayann had that Maria did not was to be able to walk independently. On the other hand, she would verbalize that she knew she could not walk as she once did as a child.

Both participants were interested in assistance from their parents or caretakers. They wanted to live alone, but have their family nearby. They were interested in financial support from their parents. They were both interested in becoming as independent as possible and in doing things by themselves. Friends and a social life also appealed to them and they wanted to choose what activities to do with friends based on what they both liked. They expressed many varied types of favorite foods, which is a basic level of self-determination. They both mentioned wanting to go on to college and were interested in faraway travel.

Although these two participants had many similar interests, Rayann had particularly limited job interests: either an artist or a mother. Maria mentioned both of those jobs, plus gave a huge number of other jobs she was interested in, one special one being to become a nurse in a veterinarian's office so she could help pets. There was a slight difference in their tastes in music. Maria was interested in the flashy choreographic music she watched on videos or music from Disney movies and Rayann liked songs that send a meaningful message.

Researcher: You want some music playing

Maria: Maybe we could put a screen and say [Alicia] and (says name)

Researcher: Yea Maria: In a hotel

Researcher: Um hm with some music playing.

Maria: Yea

Researcher: What kind of music?

Maria: Like Miley Cyrus

Researcher: Miley Cyrus, uh huh

Maria: Or Ariana Grande

Researcher: Ariana Grande, that's a nice atmosphere

Maria: Yea

For Rayann, she preferred Austin Mahad

Rayann: There's, there's this singer.

Researcher: Um hm

Rayann: Mmm, mmm, I don't know if you know him. He, his, his name is Austin Mahad

(Mahone).

Researcher: Oh, you showed me him before, Austin something.

Rayann: Yea

Researcher: Austin... Rayann: Mahad? Researcher: Mahad?

Rayann: It's, it's with a M.

Researcher: I remember him before, young boy.

Rayann: Yea Researcher: Ok

Rayann: And he, I heard this song by him.

Researcher: Um hm

Rayann: And I said that song was, is about me because the song said wait...the song said (sings) "you're all I ever need, baby you're amazing, you're my angel, come and save

me" because I'm an angel!

Researcher: That's part of your name, right?

Rayann: That name means I'm, my, my name means I'm an angel and that's what I

thought.

Researcher: Right!

Rayann: That's song was about me.

Researcher: It's in the song.

Rayann: Yea

Researcher: Beautiful! Rayann: (laughs)

Austin Mahone is in the genre of Justin Beiber, Arianna Grande, and Selena Gomez, which both girls liked, but his song "All I ever Need," had lyrics that were meaningful to Rayann. In addition to these differences, Maria was interested in a nearby public university and Rayann was interested in a special college with a modified curriculum that could house students with disabilities.

Maria and Rayann expressed some similar abilities. Neither one had ever earned money from working. Both were able to use friends' contact information to make phone calls or text. Both could offer support to friends when they were upset or arguing. They could actively participate in social activities they chose. Both of them had excellent language skills for their ability levels and could express almost anything they wanted to a familiar person. If they got upset, they both knew how to breathe to calm down or to get away from situations that caused duress. They could independently choose what they wanted to wear, what gifts to buy others, or

how to decorate their own room when allowed to or when interested. Both said they could live in independent housing.

Some differences in their abilities were that Rayann had no job experience and Maria had one year of experience in work training in a hospital setting. Rayann's job skills were untested and she was not interested in getting job training. Maria had much more experience in job training:

Researcher: What job training have you done?

Maria: I, I did clean-cleaning, mail room, clinical, upstairs.

Researcher: What's, what's upstairs?

Maria: Um, it's the, upstairs, it's the cleaning room.

Researcher: Cleaning room?

Maria: Yea, the cleaning room, where you go to the elevator, and, and I do that.

Researcher: Is it the room where they keep all the cleaning supplies?

Maria: Yea Researcher: Ooo Maria: I do that.

Researcher: What do you do in there?

Maria: I clean the wagons.

Researcher: Wagons? What wagons?

Maria: It's a big guss of wagons like one, two, three, four, five, six, seven, ten.

Researcher: Wagons? Maria: Yea, ten wagons.

Researcher: What are the wagons for?

Maria: It's for the kids.

Researcher: Like, oh toys, that can, like little kid's wagons?

Maria: Yea

Researcher: You clean the kid's toys and things?

Maria: Yea

Researcher: That's important.

Maria: Yea

Maria even had experience in learning how to work alongside others on the work site:

Researcher: What's easy about working with other people? What makes it easy?

Maria: Work with others?

Researcher: Yea, what's easy about working with others?

Maria: I don't know

Researcher: What's easy about working with [Jose]? Maria: I work around with um, with the bathrooms.

Researcher: Um hm

Maria: And then e-, we spl-, we s-, we sp- (gestures going in two different directions)

Researcher: Split? Maria: Split

Researcher: You split the jobs up?

Maria: Yea

Researcher: That makes it easier working with him? When you split the jobs up?

Maria: Yea

Researcher: That's what makes it easier?

Maria: Yea

Rayann spoke about one time that she practiced job skills, but also remarked that she never trains for child care to be a mother:

Researcher: What job training have you had?

Rayann: I helped, remember I used to help you fold the clothes? Researcher: Oh, that's a good job training. That's what moms do, too.

Rayann: Yea

Researcher: Do you have any other mom training like that, besides folding shirts? Mom

training? Rayann: No

Researcher: Do you ever read to little kids?

Rayann: (shakes head no)

Researcher: That's a mom's job too, right? Well you could!

Rayann: (nods)

Researcher: Couldn't you? Read to little kids?

Rayann: Yea

Researcher: You could. Ok.

The work training Rayann was talking about here happened in my class a couple of years ago. I had asked her to fold some Best Buddies T-shirts that were piling up in my class. It happened on possibly three occasions, nothing to speak of in the way of job training, but one of the few opportunities she was offered to do a job task and accepted the role. Rayann wanted to be a mother, yet stayed in her room and rarely came out to observe how her step-mother cared for the new baby, whom she has said she was crazy about:

Researcher: Do you watch your stepmom take care of the kids?

Rayann: I watch my stepmom taking care of the baby.

Researcher: And what are you learning there?

Rayann: Nothing.
Researcher: Nothing?!

Rayann: (laughs)

Researcher: You're learning more than you think you are!

Rayann: I, I, I'm always in my room! Researcher: Always in your room?

Rayann: Not always.

Researcher: Um hm, most of the time? Rayann: I go to the living room sometimes.

Researcher: Uh huh

Maria had some experience handling money by selling candy for a Best Buddies fundraising event, but Rayann did not. Maria enjoys a good dance competition with her friends and Rayann, because of her wheelchair, would rather perform in the talent show with a solo interpretive dance while seated. Maria could live in any supported living situation, but Rayann was only able to live in a residence that had wheelchair accessibility and accommodations.

Goals. In comparing Maria to Rayann, when it came to setting goals, they had many similarities. Both wanted to get married, have children, and live on their own. They had similar plans for leisure, which surrounded the use of technological devices. They had the language and cognitive ability to say how they would get what they wanted, albeit not in the most reasonable or realistic way, but a way nonetheless that could be adapted. Both talked about the thought process they used to see their future. Maria talked about imagination:

Researcher: How do you know if you're getting closer to working at Publix?

Maria: You need a little bit, your brain. Researcher: Your brain, to do what?

Maria: Thinking.

Researcher: Thinking, what else?

Maria: You're excellent.

Researcher: Excellent, uh huh.

Maria: Imagination.

Researcher: Imagination, you need imagination for that and to make a what...?

Maria: A plan.

Researcher: A plan! You've got it.

Rayann talked about her dreams from a previous quote:

Researcher: That's a nice plan for the future!

Rayann: Yea.

Researcher: I like that plan! And you have the s-, steps all lined up, that's what you do!

Rayann: I can see my future now!

Researcher: You can see it because you have to plan it.

Rayann: Yea

Researcher: If you don't plan it, it's just a dream.

Rayann: (laughs) I don't like to, I don't like to dream it, I like to live it.

Researcher: Live it! You're right! Rayann: That's better to live it...

Researcher: Oh yes! Rayann: ...than dream it.

Researcher: Yes, and how are you going to live it? By what? How are you going to make

your dream come, come true?

Rayann: Try my best.

Researcher: Try your best and go what? Number one, number two, what?

Rayann: In steps. Researcher: In steps! Rayann: (laughs)

Researcher: You gotta make a plan right?

Rayann: Yea

The difference in the plans between Maria and Rayann was mostly about job potentials.

Maria was planning to try for many different types of jobs, while Rayann was not. Maria

mentioned several job plans during the course of our interviews:

Researcher: How do you find out what kind of jobs you might like?

Maria: I wanna work with my dad.

Researcher: How do you find ideas for jobs? Maria: Um, I wanna work with Wendy's.

Researcher: At Wendy's?

Maria: Yea

Researcher: What classes do you take now that will help you learn about the job?

Maria: I wanna, I wanna to make a a pizza. Researcher: Learn how to make pizzas?

Maria: Yea

Researcher: What school work do you do that will help you, help you get a job?

Maria: I love to do math.

Researcher: Math will help you get a job one day, won't it?

Maria: Yea

Researcher: Ok, what else do you, what other school work do you do now that will help

you get a job?

Maria: Um, I love science.

Researcher: And science, ok. What else do you do now in school that will help you get a

job?

Maria: Um, A nurse? Researcher: Um hm Maria: A nurse.

Researcher: What about that? Maria: I love to work with nursing?

Researcher: Um hm Maria: A nurse.

And then seconds later in the same conversation:

Researcher: What school work do you do now that will help you be a nurse assistant?

Maria: Be a teacher.

Researcher: Ok, what work do you do now that will help you be a teacher assistant?

Maria: (burps) Researcher: (laughs) Maria: Oh, excuse me!

Researcher: That's all right (laughs)

Maria: Um, be nice

Researcher: Being nice, well, behaving right is good, a good job skill. You have to be

nice on the job.

And further along:

Researcher: What kind of a job do you want to have in 10 years? Ten years from now I

want to work at...? Maria: Burger King. Researcher: Um hm, ok.

Maria: I wanna work in Burger King. Researcher: For the next 10 years?

Maria: Yea, 10 years.

And then she mentioned:

Researcher: How do you prefer to learn a new job at work?

Maria: Um

Researcher: What helps you learn a new job?

Maria: At Denny's?

And still another job goal:

Researcher: To be a nurse's assistant and helping animals and you have to have a job interview, where the boss sits there and talks to you about what kind of a job you—

Maria: I wanna work with animals.

Researcher: Uh huh

Maria: And, and be on TV.

Researcher: With animals? Uh huh. Maria: Yea, yea, and help them.

Researcher: Um hm

Maria: I say...my mom say, hello, thing you doing [Maria] I'm working with pets.

Researcher: Um hm. Like that?

Maria: Yea Researcher: Nice.

The best quote from Maria that showed her various goals for jobs in one breath was:

Researcher: What changes do you need to live more independent? To be more

independent? What changes do you need? Maria: I want, I want to work in Publix.

Researcher: Have a job working in Publix. What else makes you more independent?

Maria: I want to work in Target, too.

Researcher: Um hm, you want to have two jobs to be to be more independent, right?

Maria: And Denny's, too.

Researcher: You're gonna be one tired woman, aren't you? Three jobs!

Maria: Yea, three jobs.

Researcher: So you really just wanna get a job, don't you?

Maria: Yea

Researcher: What other changes do you need to be more independent or to live better?

Maria: That's it.

Researcher: That's a big change. That's a good change to have a job.

Maria: Yea

On the other hand, Rayann had limited job interests. Her cognitive abilities surpassed her physical abilities, but realistically, she could perform a job where she could sit down and have breaks when she felt fatigued.

Researcher: What kind of things do you *want* to volunteer for in the future?

Rayann: Nothing.

Researcher: What are you learning now at school right that will help you get a job in the

future?

Rayann: I don't know

Researcher: Ok, what do you do in your free time now that will help you get a job in the

future?

Rayann: I don't, I don't know

Researcher: Like when you're home in your free time, what do you do to think about or

to learn about a job you could have in the future?

Rayann: I don't know the answer.

Researcher: Ok, you ever think about having a job in the future?

Rayann: Maybe

Researcher: What school work do you do now that will improve your chances of getting a

job?

Rayann: Homework.

Researcher: Homework will help. It will, anything else?

Rayann: Signing. Researcher: Signing?

Rayann: And signing our name.

Researcher: Signing your name, uh huh, ok, anything else?

Rayann: No

Researcher: What job interests have you looked into by visiting the people that are in that

job?

Rayann: I don't know

Researcher: Let's say you want to be a, maybe a homemaker, or, um, a babysitter even.

Ever gone to go visit a babysitter and see how she does her job?

Rayann: No

Researcher: How do you handle those kind of changes? When you have to change the

way you have to do things on the job?

Rayann: I don't know

Researcher: Haven't been through that before, have you?

Rayann: No

Researcher: You haven't experienced that yet.

Rayann: Not yet

Researcher: I knew you haven't experienced those things yet. That's part of why I'm

asking you. I'm trying to see what you know about life experiences.

Rayann: I don't know yet.

Having a work goal was so important in our special education department, that I even created an acronym we still use which complements our school mascot, the Eagle C.L.A.W. (Community Living and Working). Rayann may have developed a learned helplessness from having personal assistants throughout her day at school and at home and a father who gave her money for the asking.

Maria and Rayann expressed some similarities in how they solved problems in life. Both mentioned that they would have to defer to what their parents wanted. Maria admitted:

Researcher: They go eeew, but puppies are nasty. We want (you) to work in an office, but

you, but you want to work with puppies.

Maria: Yea

Researcher: And you don't agree with them, so how do you handle that?

Maria: Mmm, the cats is smell, this the...

Researcher: Yea

Maria: Go away you stink!

Researcher: Yea, but how would you handle that argument with your parents that they...

Maria: I say, mama that cat stink!

Researcher: Ok, let's say you want to learn about this certain job that you like.

Maria: Yea

Researcher: And they want you to learn about this *other* job, that you don't like it so much, but they want you to learn *that* job, and you want to learn this *other* job. How would you handle that argument? How would you handle that disagreement? What would

you do about that? Maria: I tell the nurse.

Researcher: They won't be around. This is between your parents and you.

Maria: I say mom, this is, this pee-yew, this dog is stink!

Researcher: Oh, so you're agreeing with them that the dogs stinks. You're going to agree

with them, right?

Maria: It stink man, go...

Researcher: So you're going to-

Maria: ... another, another dog is go away.

Researcher: So what you're telling me is that if your parents don't want you to learn

about that, that you will listen to them and do it their way?

Maria: Yea their...

Researcher: Is that what you're saying?

Maria: Yea

Researcher: You would do it their way?

Maria: Their way.

Researcher: You wouldn't argue with them about that?

Maria: No

Researcher: They say no, no, no job for you with little pets and little puppies. You're

going to work with, in an office.

Maria: Yea

Researcher: And you would just do that then?

Maria: Yea

Researcher: You would listen to their advice and you just do it?

Maria: Yea

Researcher: Ok, that's an honest answer.

Rayann also deferred to her parents' wishes:

Researcher: What are the little steps you're gonna take to get to that goal of having your

own apartment? What are you going to do first, second, and third?

Rayann: I go to the school, the one that you told me about.

Researcher: Um hm, the college?

Rayann: Yea, but I don't think I'm going to that school.

Researcher: Um hm

Rayann: Th-they're gonna pick one and, and send me there.

Researcher: Um hm. Who's gonna pick one?

Rayann: My dad and my stepmom.

Researcher: You showed them the paper?

Rayann: Yea

Researcher: Um hm

Rayann: And I told how you have to pick one.

Researcher: Yea, and they only have a few things there, too.

Rayann: Yea

Researcher: It's a new thing they're starting up, you know.

Rayann: Yea

Ways that Maria and Rayann differed in problem solving was in the way they talked to their parents. Maria was more forceful and Rayann was more respectful and chose her words more carefully. Here is how Maria would tell her parents she planned to be independent:

Researcher: What do you do if you want to visit a love interest and your family is worried

about it?

Maria: What's that?

Researcher: Ok I'm gonna...you have a love interest with some guy that you have romantic feelings toward him, and you want to go visit him, and your family is worried

about it. What do you do?

Maria: I go home.

Researcher: You go home and then what happens?

Maria: I say mom, I want, I went to a boy's house and my, and my mom say no.

Researcher: Um hm, and what do you do?

Maria: And my mom say, I'm sorry mommy, I'm going to a boy's house. I'm, don't be

mad at me. Don't be mad at me. I'm sorry. I'm sorry.

Researcher: Um hm, and then what happens?

Maria: She be mad.

Researcher: And how do you take care of that problem?

Maria: She be really upset.

Researcher: She would be. And how would you take care of that problem?

Maria: Talk to the boy, man Researcher: Talk to the boy?

Maria: Yea

Researcher: Who else would you talk to?

Maria: My dad.

Researcher: Um hm, your dad. What if he was worried about him, too?

Maria: Yea

Researcher: Then what happens?

Maria: And my dad, my dad would be screaming in to the boy and the boo-ooo, a bully...

Researcher: Then what's going to happen?

Maria: It's going to be a fight.

Researcher: Ah, how are you going to handle that?

Maria: Myself.

Researcher: Like what would you do?

Maria: I go away.

Researcher: Go away? Does that solve the problem though?

Maria: Yea

Researcher: It just makes it go for another day. It's still going to be there. It's not going to

change things any.

Maria: No

Researcher: How would you solve that problem?

Maria: I tell my parents to, I stay there for a whole week.

Researcher: And then what would happen?

Maria: I say mom, go away!

Researcher: Wooh! And then what would happen?

Maria: Go away, tell mommy, go to your house and go to live over there!

Researcher: (laughs) And where are you going to go then?

Maria: Over there.

Researcher: Over there, ok.

Maria: In the hotel.

Researcher: (gasps) I see!

I was taken back by her forceful response to her parents and it was obvious in that quote.

Rayann, on the other hand, was more diplomatic with her parents:

Researcher: What would you do if you want to be with a love interest and the family is

worried about it? What would you do?

Rayann: I don't know

Researcher: You don't know? Rayann: (shakes head no)

Researcher: Let's say, well, I know it's not true, but let's just say you had a, a romantic

interest in [Nelson], for example. I know you're just friends...

Rayann: Um hm

Researcher: ...right? Let's just say you have you have a love interest in [Nelson].

Rayann: ok

Researcher: And you wanted to visit with [Nelson] and your family was worried about

that. What would you do? Rayann: I don't know what's...

Researcher: (laughs) It's gonna happen one day.

Rayann: Yea?

Researcher: You better be ready for it.

Rayann: Yea

Researcher: What are you going to say?

Rayann: Don't worry. I'm gonna be safe.

Researcher: Um hm. That's what they're worried about. What else would you say so they

can feel better about that? Rayann: He, he's a good guy.

Researcher: He's a good guy. He is a good guy and he's...

Rayann: He would do nothing to hurt me.

Rayann's religious upbringing which emphasizes respect for your father might be the reason behind her softer defense.

There were few differences in how they sought support on the job because of the way the interview questions had to be structured to support both participants lack of background information on what job support possibilities there could be. They selected the same basic supports from the possibilities given.

In the area of self-regulation Maria and Rayann shared some similarities. They both spoke up for themselves when dealing with difficult people or situations. Previous quotes referred to those affirmations.

The differences in self-regulation were regarding being treated as a child when they felt like an adult. At first, Maria would protest being treated like a child, but then would acquiesce:

Researcher: What do you do if people treat you like a child and you feel like an adult? Maria: Hey, I'm not a child. I'm a big adult, ok, adult! Stop calling me a baby, man.

Researcher: Um hm Maria: I'm a, I'm brave.

Researcher: How do you feel when they treat you like a little kid and you're, you're a

grown woman now? Maria: They mean.

Researcher: What if they go to you, no they're not mean, they go, oh, here's a little toy here for a little girl. Here's a little, here's a little baby toy for you to play with. Here you go. How do you feel about that?

Maria: Nice

Researcher: You like it ok?

Maria: Yea

Researcher: What if it's like a little balloon, oh, here, your, your, here's a little balloon?

Maria: And they nice too.

Researcher: And, they're...yea, they're nice, uh huh.

Looking back, it was possible she took a clue from my "no, they're not mean" statement and was influenced to agree. Rayann persevered in declaring she was too old for baby toys:

Researcher: What do you do if people treat you like a child and you feel like an adult? Rayann: I'll tell them, I'm not a child, I'm a, ad-, I'm adult and I like to be treated like one.

Researcher: That's right, you speak up, right?

Rayann: Yea

Researcher: What if they go, oh, come here little girl. Here's a here's a little balloon for you, and a little toy, and a little balloon. Here you go, little girl. Play with the little kids over there, here, with the little balloon and the little toy. Go with the little kids over there.

How do you feel about that?

Rayann: Bad.

Researcher: What would you do? Oh, listen to the baby songs over there! Listen to the kids, listen! Look a baby song, listen, it's a cute little baby song, listen to the baby song

they're playing!

Rayann: I'll ignore them.

Researcher: (laughs) Yea! What else?

Rayann: I don't know what else.

Researcher: It's a merry-go-round song or "Mary had a little Lamb" song. It's cute. Look, a little baby song! Look! Listen to it! And they play it over, and over, the baby songs for

you over, and over, and over, baby songs...

Rayann: I'll tell them I'm not going to listen to it.

Researcher: Um hm Rayann: I'm an adult. Researcher: Anything else?

Rayann: No

Feelings. Maria and Rayann were alike in some of the feelings of psychological empowerment they felt. They both knew how to use 911 for emergencies to get them out of danger. They were both allowed to choose some items of clothing, how their hair is styled, the gifts they give others, and some aspects of their bedroom décor. They voiced disagreements in the school setting. They decided for themselves who their friends were. They were confident they could do things without help when, as their teacher, I knew that they could not. Both were persistent and fairly consistent about what they wanted in their lives. There were numerous quotes previously brought out that showed repeated requests for the same things in their lives regarding work, living, and free time. Both felt empowered with the use of all forms of

technology and it was readily available to them. Last of all, both tried to protect their self-image regarding who was to blame for a mistake.

Each person handled assigning blame in different ways to gain psychological empowerment. Maria blamed others numerous times during the interviews and here is a sample:

Researcher: How do you hear there's a meeting today? Who's telling you there's a

meeting today? Maria: I don't know

Researcher: We had a meeting last week, right? How did you know about that? Who told

you?

Maria: Myself

Researcher: You must have read my mind then [Maria], right?

Maria: Yep

Researcher: You must've read my mind.

Maria: Yea

Researcher: Hmf! Hm, hm! Now how did you really find out about the meeting?!

Maria: It was not my fault.

Researcher: Not your fault? (laughing)

Maria: Nope

Researcher: No, it's not your fault. How did you find out about the meeting? How did

you, how did you get the information about, that there was a meeting?

Maria: [Veronica] told me.

Researcher: And how--, Oh [Veronica] told you!

Maria: (laughs)

Rayann was the opposite and did not want to blame others for something she did:

Rayann: But about that fall...

Researcher: About that fall. Tell me about that fall you had.

Rayann: That it was m-, it was my fault. My helper had nothing to do with it.

Researcher: No one's blaming anybody. It's ok. You wanted to make that clear, didn't

you?

Rayann: I'm just telling you (smiles)
Researcher: Yea, you're just telling me.

Rayann: Yea

Researcher: Nobody was, nobody was mad right?

Rayann: No

Researcher: I mean they may be worried and scared, but they weren't mad, right?

Rayann: No

Researcher: No one got in trouble for that.

Rayann: (shakes head no)

Researcher: Yea, ok, nothing else?

Rayann: (shakes head no)

The difference in Rayann's style of placing blame was that it was probably influenced by her desire to be honorable in the eyes of the members of her faith.

Maria and Rayann were alike in some areas of self-realization. Both felt they were happy to be who they are. They recognized all types of feelings and emotions in themselves and could express how they handled them. They could describe their own personality traits. They definitely articulated their adult preferences for their transition to life after high school. They described living preferences, job choices, and their desire to access the community. They recognized the fact that they needed support people in their lives to do what they planned as adults.

Differences in how both participants expressed self-regulation were in the areas of difficulties, dislikes, non-interests, and religious feelings. In a previous quote, Maria expressed the worst thing that could happen to her:

Researcher: What is the worst thing that can happen to you?

Maria: My mom hit me.

Researcher: Your mom would hit you? That's the worst thing to happen to you, right?

Maria: Yea

Researcher: Um hm, tell me more about that.

Maria: I hit her, she hit me back!

Researcher: Um hm

Rayann's response to the same question was different:

Researcher: What's the worst thing that you never want that to happen to you ever?

What's your worst nightmare?

Rayann: I don't want people to treat me bad?

Researcher: Um hm

Rayann: Like being mean to me. Researcher: Being mean to you.

Rayann: Ignoring me.

Researcher: That's a bad one, right, ignoring you?

Rayann: Yea

Researcher: Being mean to you?

Rayann: Yea

Researcher: That's your worst nightmare, right?

Rayann: Yea

Researcher: Um hm, acting like you're not even there, right?

Rayann: (nods)

Researcher: Not good.

Maria expressed many more dislikes than did Rayann. She expressed over and over how she did not like others to curse. For sports she did not like golf or jump rope. She repeatedly said she did not like her parents "bothering" her and most of all did not like how her best friend talked so much. She took offense to things that were dirty or smelled bad. Speaking of one of her best friends, Maria had this to say:

Very nice, very, a little nice, but sometime, she's get a little bit rude. She curse sometimes and I don't like everybody's cursing sometimes. Every day when she go to school, she curse.

Another way her parents bothered her was:

Researcher: You don't want to buy anything with your money?

Maria: N---

Researcher: Like saving up for something?

Maria: No, I don't like to buy.

Researcher: You don't like to buy things then?

Maria: No

Researcher: How come? Maria: I don't like shopping.

Researcher: You don't like shopping? Not everybody likes shopping, right?

Maria: My mom talks in the shopping in all the times. In the phone, in the phone, in the

phone...

Researcher: Ok. Well moms shop a lot.

Maria said repeatedly how much she liked shopping, but apparently not with her mom, who was needed to drive her there.

Rayann did not like using a knife, doing housework sitting down, support people that were mean or ignored her, not getting what she wanted, being with people she did not know, falling down, worrying about doing the right thing, and people thinking she was different because she uses a wheelchair. Here were a couple of examples of things Rayann did not like:

Researcher: Which household chores, chores do you wish you could do?

Rayann: Um, I wish I could help.

Researcher: With what?

Rayann: With cleaning and...I don't know.

Researcher: Cleaning what?

Rayann: The table.

Researcher: Like wiping the table?

Rayann: Yea

Researcher: Um hm. What else?

Rayann: I don't want to do it sitting down. I want to do it standing up. Researcher: I know, I know. But it's possible to do it sitting down, isn't it?

Rayann: Yea, but...I still, I don't know.

Researcher: You'd rather do it standing up, right?

Rayann: Yea

And this was what Rayann said gave her problems:

Researcher: What gives you problems? I have problems with...?

Rayann: I don't know

Researcher: Everybody's got problems, right?

Rayann: Yea but...

Researcher: I've got problems too (laughs)

Rayann: B-, f-, I don't know where they come from (laughs) Researcher: Where they come from? But you have them?

Rayann: M-yea

Researcher: You have problems sometimes?

Rayann: Yea, sometimes.

Researcher: I don't care where they come from, what are they? What are the problems?

Rayann: I don't get what I want.

Researcher: You don't get what you want sometimes, that's a problem?

Rayann: That's a problem.

Another area of differences for Maria and Rayann was how they felt about religion. Maria did

not like going to church:

Researcher: Do you belong to any religious groups through the church?

Maria: I don't go to church. Researcher: Ok, fair enough.

Maria: I hate church.

Rayann had strong religious feelings:

Researcher: You worry about being a good Muslim? You worry about that? So how do

you feel about being a good Muslim?

Rayann: Sometimes it's not easy for me.

Researcher: It's not easy.

Rayann: But I like being Muslim!

Researcher: Yea, what's hard about being Muslim in America?

Rayann: I don't know

Researcher: What's hard about being a Muslim when you're in Lebanon?

Rayann: That's easy! But in America it's a little hard.

Researcher: Yes

Maria Compared to Vanesa

Needs. These two participants expressed some of the same needs. When asked for clarification, both Maria and Vanesa admitted that their mothers helped them prepare meals.

Maria said:

Maria: You put it in the microwave like two minutes.

Researcher: Uh huh

Maria: And then when it stop, it's ready.

Researcher: Who does the timer on the microwave?

Maria: My mom, she she she do it.

Researcher: Um hm Maria: She do it

And Vanesa said:

Researcher: How do you prepare your warm foods?

Vanesa: With meatballs.

Researcher: Yea?

Vanesa: And then with, with, with, with cheese on...

Researcher: Uh huh, and then what do you do?

Vanesa: Um, and then make, um, with the, make the meatball, when it's done you, you

put, um, you put, uh, thingy, the oven fort-, forty, forty-five minutes...

Researcher: Um hm Vanesa: And then...

Researcher: Which oven is this?

Vanesa: Mmmm

Researcher: The big house oven or the little microwave oven?

Vanesa: The big house oven.

Researcher: Do you do it by yourself?

Vanesa: Yea!

Researcher: Really, no one helps you? Vanesa: Oh, yea, my mom helps me.

Both were able to prepare a sandwich if they were hungry. They both needed supervision in taking medicine and seeing a doctor. To be completely certain that they would be safe at home,

someone would have be there so that they would not be by themselves in case of an intruder or other emergency. They were both aware of dialing 911, but it was not clear if in a real life situation, they would be able to perform safely because of inconsistent responses. This was how Maria said she would handle a break-in:

Researcher: What if you're home alone and someone breaks into your house what would

you do?

Maria: I give them knuckle sandwich. Researcher: A knuckle sandwich! (laughs)

Maria: I say, hey, stop breaking my house. I hit you back!

Researcher: Ok, what if it's a great big man and you can't beat him? What would you do

then?

Maria: Stop breaking my house!

The above quote was repeated, but it served both analyses purposes; within case and across case.

Vanesa was a little slower to respond, creating a degree of doubt:

Researcher: What if someone's trying to break into your house? Then what do you do?

Vanesa: Break my house?

Researcher: Break into your house.

Vanesa: Sadler!

Researcher: Break the door down and go in your house.

Vanesa: Oh

Researcher: What do you do?

Vanesa: You call the emer-, you, uh, you call the emergency.

Researcher: Call the emergency. And what is that?

Vanesa: That's...

Researcher: How do you call the emergency?

Vanesa: Oh, emergency? Ooo...

In addition, both young women attested to helping with household chores. They both communicated well, considering their intellectual disabilities, and were both accustomed to using technology to contact others and for entertainment. Both needed access to social and community activities apart from their parents, but with their parents was acceptable to them also. They needed financial, family, and transportation support to be more independent.

There were also some differences noted. Maria was much more independent than Vanesa.

She doid not need a personal care attendant, but Vanesa had a nurse at home that also picked her

up from school on some days. Maria was completely independent in the bathroom, but Vanesa

needed occasional reminders and assistance with her clothes. Maria bathed herself and Vanesa

received assistance. Maria did not seem to be able to identify that she had a disability, but

Vanesa was able to utter the initials "CP" to possibly indicate she has been listening to her

mother calling her condition CP, standing for Cerebral Palsy. These quotes were presented

previously.

Preferences. The categories coded for preferences were beliefs, interests, and abilities.

Maria and Vanesa can be compared similarly when it came to their beliefs. They tended to feel

they could do anything. In addition, Maria was not worried about the things she could not do:

Researcher: Let's say you're not able to do certain things on the job. How do you feel

about that?

Maria: Real good.

Researcher: Um hm, it doesn't bother you?

Maria: No

Researcher: Ok. How do you encourage yourself?

Maria: I'm brave.

Vanesa gave an off topic response to the same question, but did not appear bothered by her

inabilities:

Researcher: How do you feel about that? Being able to do many different things? How do

you feel about that?

Vanesa: Like you, like you can go to the jewelry store...

Researcher: Um hm

Vanesa: ...to buy something...

Researcher: Um hm

Vanesa: ...or, or you can buy the ring.

Researcher: You could, um hm, all right.

Later Vanesa was able to respond more clearly in a previous quote about preferences regarding

beliefs in abilities, here in its entirety:

Researcher: How confident are you in your abilities?

Vanesa: What's abilities?

Researcher: Things you can do. So how, how good do you feel about the things you can

do? That's the question. Vanesa: Like play games?

Researcher: Yea, do you think you're good at games?

Vanesa: Yea

Researcher: How good are you at games? Tell me more about that.

Vanesa: Dominos?

Researcher: How good are you at dominos?

Vanesa: I good at counting.

Researcher: You're good at counting? Uh huh, what else?

Vanesa: Um I thinking... Researcher: You're thinking? Vanesa: About...instruments Researcher: Instruments? Vanesa: Like piano. Researcher: Uh huh

Researcher: Uh huh Vanesa: Or like guitar.

Researcher: You like the piano and the guitar?

Vanesa: Yea (laughs) yea

Researcher: Is that something you want to learn more about?

Vanesa: Yea

Researcher: How good are you at piano? How good are you at playing the piano?

Vanesa: It's, it's very easy.

Researcher: Um hm

Vanesa: To play the piano.

Researcher: And you're good at that piano? Yea?

Vanesa: M-yea

Researcher: Do you have a piano at your house?

Vanesa: No, no, no

Researcher: Where do you practice piano? Vanesa: No, my brother has the piano. Researcher: Your brother has the piano?

Vanesa: Yea Researcher: Ok Vanesa: My mom. Researcher: Um hm Vanesa: She has the iPad. Researcher: Um hm

Vanesa: And she has music in her iPad?

Researcher: iPads have pianos in there too. Is that the piano you do, too?

Vanesa: M-yea

She was confident she could count as well as play the piano on the iPad. Both young women believed that people liked them and that they could and did stand up for their friends. They felt strong, safe, and confident. They both had fantasies about performing in the annual talent show as well as anybody else without disabilities. There were quotes referring to those statements in their case analyses. They both talked about their beliefs in respect from others. The following quote was referenced before, but I felt it illustrated the confidence she had in her abilities well. Maria said it this way:

Researcher: Not rice, rights. Derechos, derechos humanos, human rights.

Maria: Human rights?

Researcher: Yea, what are your human rights? I have a right to...

Maria: Write, write.

Researcher: No, I don't mean escribir. I don't mean that. I mean a right, a derecho, a

derecho.

Maria: Listen to me!

Researcher: You have a right to be listened to.

Maria: Yea

Researcher: Ok, you have a right for people to listen. You have a right to be listened to.

You have a right, what else? What else are your rights?

Maria: Pay attention.

Researcher: Uh huh, pay attention to me. You have a right for, for people to listen to you.

Maria: Yea

Vanesa mentioned respect on numerous occasions and here are a couple of examples:

Researcher: Why do your friends love you?

Vanesa: Because they, they my f-, my, my, they, uh, they my friends.

Researcher: But why are they your friends?

Vanesa: Oh, because they, they r-, they respect you.

Researcher: What makes you a good worker?

Vanesa: Hm! (laughs) To, to re-, to respect of others.

Researcher: Um hm Vanesa: Things

Researcher: Ok, that makes you a good worker.

Vanesa: Yep

Although Maria and Vanesa have much in common in the area of beliefs, they had one difference. Maria believed people who did not agree with her were mean, but Vanesa gave signs that she could be easily persuaded:

Researcher: I'm being [Kaitlin] now. I don't know why you like him. He's a creep, he's

mean

Vanesa: Yea

Researcher: What are you gonna say? Vanesa: He's a creep, he's mean.

Researcher: So you're gonna agree with what [Kaitlin] says then? You're gonna agree

with her? Vanesa: Yea

Researcher: So you go along with whatever she says?

Vanesa: Yea

Maria was previously quoted regarding her beliefs about people who did not agree with her.

Other than this difference in beliefs, no other differences were significant in this specific area.

These two participants shared some interests in common. They both were interested in assistance from their families or support person. They were interested in being independent with spending money and living on their own, but they were still interested in having their family living nearby. They both liked to think they could do almost anything by themselves. They both had an interest in friends and a social life and did not mind if social activities included the family sometimes. They knew they depended on parents to take them to activities. Maria and Vanesa were interested in making their own choices about their living situation, jobs, leisure activities, friends, foods, post-secondary education and training, and travel. Previous quotes have mentioned all these topics.

The main significant difference between interests for Maria and Vanesa was what they chose for free time activities. As referenced before, Maria liked dancing so much, she wanted to do it for a living. Even though she talked about dancing for a career, I think it will end up as a pastime activity for her. Here is evidence from parallel responses:

Researcher: What steps are you going to take to reach this goal of living with [Alicia]?

Maria: Maybe w-, I can go dance.

Researcher: That would help you get to live with [Alicia]? To go dance?

Maria: Yea

Researcher: Ok, how would that help you, how would that help you, how would dancing

help you to go live with [Alicia]? Maria: A dance competition. Researcher: A dance competition?

Maria: Yea

Researcher: And then what would happen?

Maria: I can dance.

Researcher: And then what would happen?

Maria: I can have a partner.

Researcher: A partner? Who would the partner be?

Maria: [Alicia] and me.

Researcher: And how would that get you to be able to live with [Alicia]?

Maria: I don't know. I live with her and, and I dance with her.

Researcher: Uh huh, is that like for a job?

Maria: Yea, for a job.

Vanesa was set on playing instruments for her leisure time:

Researcher: You want to say anything else about yourself?

Vanesa: Um, play instruments?

Researcher: Which instruments do you want to play?

Vanesa: A drum.

Researcher: You wanna learn how to play drums?

Vanesa: Yea

Researcher: Wow, that's good to learn. That's fun, huh?

Vanesa: It's not hard, it's easy.

Researcher: And how do you play drums? Do you have a drum set?

Vanesa: No, no, no

Researcher: How do you play drums then?

Vanesa: My, my brother has a drum set with the stick.

Researcher: Well, I didn't know that!

And later in the interviews:

Researcher: What other important choices do you make?

Vanesa: Like you can make like choices, like, like, like play instruments.

Researcher: Um hm

Vanesa: Play those instruments.

Researcher: Um hm Vanesa: Play guitar. Researcher: Um hm Vanesa: And play violin. Researcher: Nice!

Because the interview questions were structured toward the research questions and because they

had similar mindsets, participants gave similar answers. There were no other significant

differences in interests.

Maria and Vanesa expressed some mutual abilities. Neither one had actual job

experience. They could both contact friends independently and could offer emotional support to

friends. They were able to socialize appropriately during activities and social events. Both could

express what they wanted and could ask for support if needed. When they needed to calm down,

they both used the technique of deep breathing. If given the opportunity, they can both make

independent choices. Both claimed to be able to live in independent housing.

One of the differences between Maria and Vanesa were that Maria had actual job training

and knew herself as a worker better than Vanesa did. Also, Maria was able to give a wide variety

of possible jobs she might like and Vanesa did not have the background information to give as

many examples. Another difference in their abilities that was important to know was that Maria

had no physical difficulties and Vanesa had an awkward gait, poor balance, and fell easily due to

cerebral palsy. That fact affected Vanesa's ability to be more independent in self-care.

Goals. Goals were coded as plans, problem solving, and self-regulation. Both Maria and

Vanesa planned for themselves the goal of getting a job, deciding where to live, and selecting

what they wanted to do in their leisure time. Maria talked about plans for getting a job which

merely involved getting dressed, getting a ride from her mother, and getting hired easily:

Researcher: How do you know if you're getting closer to working at Publix?

Maria: You need a little bit, your brain.

Researcher: Your brain, to do what/

Maria: Thinking.

Researcher: Thinking, what else?

Maria: You're excellent.

Researcher: Excellent, uh huh.

Maria: Imagination.

Researcher: Imagination, you need imagination for that and to make a what...?

Maria: A plan.

Researcher: A plan! You've got it. What would be your plan be to get a job at Publix?

Maria: Get dressed. Researcher: Um hm Maria: Wash your teeth. Researcher: Um hm

Maria: I go in the car, my mom.

Researcher: Um hm

Maria: My mom take me and then I'm in Publix and I got in.

And her plans for living with a friend:

Researcher: How do you know that you're getting closer and closer to your goal of living

with [Alicia] in a hotel one day? How do you know you're getting there?

Maria: This is hard.

Researcher: Are you making a plan for that?

Maria: Yea, making a plan.

Researcher: What's your plan to do that? What do you do first?

Maria: I get dressed first.

Researcher: Um hm, and then what happens? Maria: Get my sh-, um, my little shoes in home.

Researcher: Um hm

Maria: Get a, brush my hair first and then, um, [Alicia's] mom knock.

Researcher: Um hm

Maria: And then she's there.

Researcher: Um hm

Maria: And then we can go to the hotel.

Researcher: Ok, good enough.

And finally how she planned visits with her friends, which was a better answer than the first two

because it was more realistic:

Researcher: Tell me the steps you did to get to their house and plan this out, where you

can go visit your friends on the weekend.

Maria: In the weekend, I go to her on Sundays. Researcher: But how did you plan all that out?

Maria: In the calendar.

Researcher: Oh, you get the calendar out?

Maria: Yea

Like Maria, Vanesa also talked about her plans for employment:

Researcher: Where do you want to live after graduation?

Vanesa: I had to live my mom's house.

Researcher: You're gonna live at your mom's house after you graduate?

Vanesa: Yea

Researcher: Um hm, what about when you're older? When you're like 30 years old, 40

years old? Then where do you want to live?

Vanesa: In in c-college.

Researcher: You wanna live in college?

Vanesa: Yea

Researcher: Um hm

Vanesa: Um, I like, I like TJ Maxx.

Researcher: TJ Maxx?

Vanesa: Yea

Researcher: For what? To do what there?

Vanesa: To do beds. Researcher: To do beds?

Vanesa: Yep

Researcher: You mean like for a job?

Vanesa: (nods)

The following quote was also referenced in her case analysis for interest in living choices and adult preferences, but compared positively to Maria. Immediately after the previous excerpt, we talked about where Vanesa would live:

Researcher: When you think of yourself, finishing high school, graduating, going on to be an adult, how do you want to live your adult life? What's your dream about living an adult life?

Vanesa: Apartment.

Researcher: Apartment! There you go, what else?

Vanesa: Living a dream home.

Researcher: Living in a dream home? How would that be? Who would be there?

Vanesa: [Spencer]

Researcher: Yea, maybe [Spencer]. Vanesa: Or maybe, oh! Maybe [Kaylee].

Researcher: Maybe [Kaylee], what would be your dream job?

Vanesa: Go to the, go to the shopping, go Publix.

Researcher: Uh uh Vanesa: To buy stuff.

Researcher: Going shopping.

Vanesa: Publix

Researcher: Uh huh, that's part of your dream, having an apartment, you going shopping,

what else? What else is part of your dream life as an adult?

Vanesa: Go, go to different places.

Researcher: Uh huh, go to different places.

Vanesa: Or go to, tsk, go to the CVS pharmacy and get the medicine.

Researcher: Go to CVS pharmacy and get your own medicine. What kind of job do you want to have? What's your dream job? What's a job you would love to have a job of doing there?

Vanesa: CVS pharmacy.

Researcher: Work in a CVS pharmacy? To work there, you mean?

Vanesa: Yea

Researcher: You want to work in CVS? Work in a store like CVS?

Vanesa: Yea

Researcher: That's your dream job.

Vanesa: Yea

Researcher: So you have your dream house or your new apartment, and [Spencer] is there, maybe [Kaylee] is there too, you go shopping you work in CVS. Is that your

dream? Vanesa: Yea

Researcher: For the future?

Vanesa: Yea

Researcher: Did I get the story right?

Vanesa: Yea

Vanesa made weekends plans with her mother:

Researcher: How do you plan weekend activities?

Vanesa: What is weekend activities?

Researcher: Like Friday night, Saturdays, Sunday, when there's no school.

Vanesa: Um hm

Researcher: How do you plan what to do on the weekend?

Vanesa: Oh, the weekend, you go shopping.

Researcher: Um hm. And how do you, how do you, uh, pick out those things? How do

you know what you want to do on the weekends?

Vanesa: Go to Dolphin Mall. Researcher: You like doing that?

Vanesa: Yea (laughs) Researcher: What else? Vanesa: Go to the store.

Researcher: Um hm, tell me more.

Vanesa: Go to buy shoes.

Researcher: You like buying shoes?

Vanesa: Socks. Researcher: Um hm Vanesa: Um, pants.

Researcher: Um hm, you like doing that? Vanesa: And a jacket and a, and a shirt.

Researcher: Um hm

Vanesa: And, and my earrings too.

Researcher: You like to go shopping on the weekends?

Vanesa: Yea, I go shopping with my mom.

As for problem solving, Maria and Vanesa were alike in the two areas found to be getting parental permission and finding support on the job. Both, at least sometimes, deferred to their parents' wishes when they did not give permission for something they wanted. Previous quotes demonstrated how they mentioned complying with parental decisions. Maria even talked about complying with her friends' decisions:

Researcher: What do you do if your friends want to do something different from what

you want to do?

Maria: They like shopping.

Researcher: And what if you don't want to do that?

Maria: I say, oh, I don't like shopping, boo hoo, let's do something else.

Researcher: You switch to something else, right?

Maria: Yea they wanna do something else? Oh, let's go to the limo, man.

Researcher: Um hm

Maria: And they say, okay, let's go to the limo, bye.

Researcher: Well, then you get, you agree with them then, see? You agree with that.

Vanesa would also comply with her friend's wishes:

Researcher: You want to go see the movie with [Spencer].

Vanesa: Yea

Researcher: You want to go see "Little Mermaid," but [Spencer] wants to go see

"Terminator." Vanesa: Oooh!

Researcher: So what do you do? Vanesa: Thank you, [Spencer].

Researcher: So what do you..., where you gonna go, which one you gonna go to?

Vanesa: Oh, "Terminator."

Researcher: You're gonna go to "Terminator" with [Spencer]?

Vanesa: Um hm

Researcher: So you don't mind he's not...saying, no "Little Mermaid."

Vanesa: (shakes head no)

Researcher: Go with [Spencer], see "Terminator?" What he wants to do?

Vanesa: Sit down and then watch a movie.

Researcher: Which one? Vanesa: "Terminator!"

Researcher: With [Spencer]?

Vanesa: Um hm

Researcher: And you don't mind?

Vanesa: (shakes head no)

Researcher: That's ok. That's because you're a good friend, right?

Vanesa: Yea

Maria described how she would get support on the job:

Researcher: What's easy about working with [Jose]? Maria: I work around with, um, with the bathrooms.

Researcher: Um hm

Maria: And then e-, we spl-, we s-, we sp- (gestures going in two different directions)

Researcher: Split? Maria: Split.

Researcher: You split the jobs up?

Maria: Yea

Researcher: That makes it easier working with him? When you split the jobs up?

Maria: Yea

Researcher: That's what makes it easier?

Maria: Yea

Vanesa detailed how she would like to be supported to learn a new job:

Researcher: How would you rather learn a new job?

Vanesa: A new job at work?

Researcher: Yea, how would you rather learn about something new?

Vanesa: You can write it down on a piece of paper.

Researcher: You like to have it written down on a piece of paper?

Vanesa: Yea, and a pen.

Researcher: Um hm, anything else? Vanesa: Um...to...ask for help.

Researcher: Ask for help? Very good, someone could tell you what to do. You like to

have somebody to tell you what to do?

Vanesa: Mmm, yea

Researcher: So you can hear it and you can follow the directions?

Vanesa: Yea

Researcher: Very good.

The difference between Maria and Vanesa in problem solving was that Maria was more likely to

raise her voice or storm off to solve problems like being angry at someone:

Researcher: How do you solve that problem of not having any money?

Maria: I don't, I ask mom, I don't have no money, I'm broke.

Researcher: She says, I don't have any money either. So what are you gonna do about

that?

Maria: I'm mad at you. I'm out of here.

Researcher: You're out of there? You just give up and say forget it?

Maria: Forget it, forget it!

Vanesa would probably recoil to smooth out the situation:

Researcher: Do you ever get mad at people?

Vanesa: M-m-yea

Researcher: Who do you get mad at?

Vanesa: (laughs) At, at, um, at like I get mad at, at, at [Reyes], get mad at [Reyes] get

(laughs)

Researcher: Mr. [Reyes] got mad?

Vanesa: (laughs)

Researcher: Or you got mad?

Vanesa: I got mad (laughs). I don't know.

Researcher: At Mr. [Reyes]?

Vanesa: Yea! (laughs)

Researcher: Ok, and you love Mr. [Reyes], right

Vanesa: Yea!

Researcher: So what do you do when you get mad at Mr. [Reyes]?

Vanesa: I w-, I watch him.

Researcher: You watch him and then what happens?

Vanesa: And then I sit down at my desk.

Researcher: Um hm

Vanesa: And then do my homework.

Researcher: Um hm Vanesa: And then I go... Researcher: Um hm

Vanesa: Yea

There were no other significant differences in how they said would get support on the job. Previous quotes showed evidence in the case analysis of each participant. All of it was speculation because neither one was getting paid to work.

Maria and Vanesa had some likenesses in self-regulation under the categories of dealing with difficult people or situations. Both said they would ask for help with a difficult person.

Maria had this to say:

Researcher: Who do you want to have for a support person for you?

Maria: What's that?

Researcher: A person that helps you when you have trouble, helps you. Who do you want

to have for a support person?

Maria: [Veronica] is leaving me crazy.

Researcher: Hm?

Maria: She leaving me crazy.

Researcher: Who?

Maria: [Veronica].

Researcher: You need support and you need help with that?

Maria: Yea, I cannot take anymore. She is ding me crazy in school.

Researcher: Um hm

Maria: And I can't take anymore. At lunch she talks so much.

Researcher: Um hm Maria: Oh, my God! Researcher: Um hm

Maria: I can't take anymore. She making my head like (gestures round and round near

her head).

Researcher: What kind of help do you want to have with [Veronica] then?

Maria: I'm going to tell her to calm down.

Researcher: Um hm Maria: And stop talking.

Researcher: Well, who do you want to help you with [Veronica]? With that problem you

have with [Veronica]?

Maria: Uh...

Researcher: What kind of a person do want to help you with [Veronica]?

Maria: Maybe [Norma].

Researcher: Maybe [Norma] will help you with [Veronica], yea.

Maria: Yea

The person Maria mentioned that she would go to for support was one of our one-to-one

Paraprofessionals that helped all students when needed. Simultaneously, Vanesa said:

Researcher: How would you be able to work with other people in there, whether they're nice or whether they're not nice, when you have to work with them? How would you do it?

Vanesa: You, you s-, you stay away to the class.

Researcher: Stay away? When do you stay away from them?

Vanesa: S-say goodbye to them. Researcher: Say goodbye to them?

Vanesa: Yea

Researcher: But you have to work with them though sometimes.

Vanesa: Um hm

Researcher: And what if they're, what if they're not nice, and you have to work with

them, and they're not very nice? How are you going to do that?

Vanesa: They, they teach kids.

Researcher: Um hm Vanesa: How they nice.

Researcher: Who teaches them how to be nice? Who teaches them?

Vanesa: The class.

Researcher: The class? On how to be nice?

Vanesa: Yea Researcher: Right. Vanesa: Yea...hoh!

Given Vanesa's cognitive and communicative difficulties, I believe she was trying to say that she depended on the teacher for help to make the other students behave nicely.

In a difficult situation in the community, they both refrained from getting upset and would ask for assistance. Maria said:

Researcher: You're looking for something in a store and you can't find it, what do you

do?

Maria: I'll tell her help, help. Researcher: To who, to who?

Maria: To the lady. Researcher: What lady? Maria: From, from the store.

Researcher: The lady from the store?

Maria: Yea

Researcher: Does she work there?

Maria: Yea

Researcher: You ask her for help, right?

Maria: I need some help please, I need to buy something, please help me.

Researcher: That's perfect. You speak up and you ask for help, that's perfect. Ok, what if

you're gonna buy something and you don't know the price? Then what do you do?

Maria: I need some help.

Researcher: And what do you say?

Maria: Please, I need some help. I need some help, please.

Vanesa also said:

Researcher: Ok, let's say you can't find the olive oil. What do you do?

Vanesa: You can eat it (laughs)

Researcher: No, but you're looking for the olive oil. You can't find it.

Vanesa: Oh!

Researcher: What do you say to the people in the store that work there?

Vanesa: You say, thank you!

Researcher: Did you find the olive oil already?

Vanesa: Yea!

Researcher: Well, how do you, no, you didn't find it. You couldn't find the olive oil. So

how do you get help to find the olive oil in the store?

Vanesa: Can I please find the olive oil? Researcher: Ok, who do you tell that to?

Vanesa: To...to the manager. Researcher: There you go!

Both participants would self-regulate and control their temper by asking store employees for assistance when they could not find something.

Differences in self-regulation were that Maria would speak up about a wrong order:

Researcher: Ok what if they give you, they give you the wrong food?

Maria: And and...

Researcher: What do you do then?

Maria: I ask the lady hey take it away, take it away, I don't like that Researcher: Uh huh you say it's the wrong food, you tell them.

And Vanesa would eat whatever she was served:

Researcher: Let's say you're in the restaurant, and you order pepperoni pizza, and they gave you fried chicken. It's the wrong food. What do you do? What do you say?

Vanesa: Thank you!

Researcher: You're gonna eat fried chicken then?

Vanesa: No, not fried chicken!

Researcher: But you, but you wanted to order pizza, with the pepperoni pizza!

Vanesa: Yea!

Researcher: And they gave you fried chicken. What do you do?

Vanesa: You eat it.

Researcher: You eat the wrong food?

Vanesa: Yea (laughs)

Researcher: Well, you maybe like chicken too, but you really wanted to have pepperoni

pizza.

Vanesa: Oh, yea

Researcher: You got the wrong order sitting in front of you. What do you do? What do

you say?

Vanesa: Sssay thank you...

Researcher: So you eat whatever they give you?

Vanesa: Yea

Feelings. Feelings were coded by psychological empowerment and self-realization. In some ways, Maria and Vanesa felt the same way. For feelings of self-advocacy, confidence in themselves, and love of technology they were both very similar as evidenced by previous quotes. However, they felt differently when it came to the protection of their self-image. From previous references concerning beliefs she preferred to hold about herself and the case analysis for feelings of psychological empowerment, Maria had this to say about mistakes:

Researcher: How do you feel about doing things wrong?

Maria: Don't know

Researcher: Let's say you did something wrong. You made a mistake on something, did

it wrong. Maria: Yea

Researcher: How do you feel about that?

Maria: Don't know

Researcher: You ever did anything wrong before?

Maria: No

Researcher: And made a mistake?

Maria: Oh, I know, um, [Dayana] got, she was, I was in the hospital, she was stealing the key, and then she put it in the pocket, and then she steal it, s-she was taking it home. That

was wrong.

Researcher: Who? Maria: [Dayana] Researcher: [Dayana]?

Maria: Yea

Researcher: Yea, that was the wrong thing to steal the key, wasn't it?

Maria: Yea

Researcher: Ok, but did, what if you do something wrong like that? What if that was you?

Do you ever do anything wrong like that?

Maria: No

Researcher: You ever make mistakes?

Maria: No

Researcher: You never make any mistakes?

Maria: No...

Researcher: You mean you're perfect?

Maria: M-Yea

Researcher: Ah! We all make mistakes. We all make mistakes.

Maria: Oh, my mom always makes mistakes.

Researcher: Not, not your mom, it's about you. Think about a mistake you made a long, a while back, think about any mistake you've made in the past. How'd you feel when you

made a mistake?

Maria: I never makes mistakes.

Vanesa gave mixed answers, but in the end, did not blame anyone for influencing her choice of

friends:

Researcher: Who picks your friends?

Vanesa: [Dayana]?

Researcher: Yea, but who picked [Dayana] for your friend?

Vanesa: Oh [Kaylee], [Kay-]...

Researcher: [Kaylee] told you to be friends with [Dayana]?

Vanesa: Uh...

Researcher: She told you to do that?

Vanesa: Yea

Researcher: To be friends with [Dayana]?

Vanesa: Yea

Researcher: Are you sure she did that?

Vanesa: Nooo! (laughs) Researcher: Oh, ok. Vanesa: I forgot.

Researcher: You forgot, ok, who picks out your friends?

Vanesa: Mmm (points to herself)

Researcher: You do right! Vanesa: Yea, I forgot.

Researcher: You forgot, but you got it right now? You pick out your own friends, right?

Vanesa: Yea

Researcher: They don't tell you who to be friends with. You did that yourself!

Vanesa: Yea, I did that by myself.

In fact, Vanesa never blamed anyone else and frequently apologized for forgetting, drifting to another topic, or not knowing the answers by saying "I forgot."

For self-realization, several areas were coded for self-awareness, adult preferences, difficulties/dislikes/non-interests, religious feelings, and support people. Maria and Vanesa had comparable feelings regarding self-realization under the category of self-awareness. Both were aware of their specific health conditions such as seizures, allergies, and both knew they were otherwise healthy. Both were happy to be who they are. This was supported by previous quotes under the individual case analyses.

One difference in self-awareness was under the category of disability awareness. Maria was previously quoted as saying she did not have a disability, but Vanesa was able to elicit a response regarding "CP," professional jargon for Cerebral Palsy. The other difference was in the category of feelings about themselves, specifically about being someone's girlfriend. Maria said:

Researcher: How do you feel about having a boyfriend?

Maria: I have Logan.

Researcher: You have Logan?

Maria: Yea

Researcher: You already have a boyfriend named Logan?

Maria: Yea

Researcher: Ok, I didn't know that. How do you feel about Logan?

Maria: Good

And Vanesa felt a little differently about being a girlfriend:

Researcher: How do you feel about having a ring on your finger from your boyfriend?

Vanesa: I get I get s-s-scared Researcher: A little bit scared

Vanesa: Yea

Researcher: Yea a little bit scared

Vanesa: Yea

Researcher: How come you're a little bit scared about that? What are you scared of? Are

you a little bit scared of having a boyfriend?

Vanesa: Yea

Both participants voiced similar desires to live independently as an adult, be employed, and access the community. Both preferred to be treated like an adult. The exact interview question was used to demonstrate. Maria said previously:

Researcher: What do you do if people treat you like a child and you feel like an adult? Maria: Hey, I'm not a child. I'm a big adult, ok, adult! Stop calling me a baby, man!

Researcher: Um hm Maria: I'm a, I'm brave.

Researcher: How do you feel when they treat you like a little kid and you're, you're a

grown woman now Maria: They mean.

And Vanesa also said previously:

Researcher: What do you do if people treat you like a child and you feel like an adult?

Vanesa: Oh! People treat me like a child? Researcher: And you feel like an adult.

Vanesa: Like in...

Researcher: What happens?

Vanesa: You, you be nice to, to me.

Maria seemed more interested in being treated like an adult than Vanesa was. Although Maria once expressed an interest in a child's balloon toy, she declared she was an adult and too big for baby toys. Vanesa actively spoke about wanting to spend her money on toys.

As for difficulties, dislikes, and non-interests, there were few commonalities. The major common area was non-interests. Both were not interested in specific physical activities. For Maria it was golf and bending down to work and for Vanesa it was roller skating.

Maria and Vanesa talked about different things that bothered them or gave them difficulties. According to Maria, people made her life more difficult as mentioned previously:

Researcher: All right what gives you problems?

Maria: [Veronica] give me problems.

Researcher: (laughs) [Veronica] gives you problems?

Maria: Yea

Researcher: Um hm

Maria: She get on my last nerve. I can't take anymore. She ding me crazy.

Researcher: So it's the people that give you a hard time more than anything else? It's

people in your life?

Maria: Yea

Researcher: Give you a hard time.

Maria: Do this, do that, do, rrr, rrr, rrr, rrr, rrr, and she's ding me crazy.

Researcher: M-k, what gets in the way of doing your best?

Maria: My mom get in my way.

Researcher: She does?

Maria: Yea. Do this sandwich, do--, and every day she do.

And Maria mentioned people in her family on several occasions previously quoted in her case analysis under goals for self-regulation and throughout our conversations:

Researcher: What's hard for you to do? Maria: My dad is making me annoying.

Researcher: Your dad is hard for you to deal with?

Maria: (nods) Researcher: Yea?

Maria: Yea

Researcher: Tell me more about that. Maria: Um, when I went to sleep.

Researcher: Um hm

Maria: My dad is snoring, kuh kuh kuh (makes snoring noises)

Researcher: Oh. Awww! Maria: He snores so much. Researcher: Um hm

Maria: He gets, um, I go to work on, I work first, and then he sleep because he, he's tired

from work.

Researcher: Does he work at night or in the day?

Maria: In the day. Researcher: Um hm

Maria: He works in some, some house and then when he gets, um, the house, he goes

home to sleep and then he, he snores so much.

Researcher: He works, work hard, huh?

Maria: Yea, really hard!

Researcher: He must work really hard. Well, what's, what's hard for you to do as far as what's hard for you to do things? What, what things are hard for you to do? That's what I

really mean. What things are hard for you to do?

Maria: Um, uh, I don't know

Researcher: What things give you a hard time when you try to do it?

Maria: My mom.

In Vanesa's opinion, self-care can be difficult:

Researcher: What else is hard for you to do?

Vanesa: Take me a shower.

Researcher: Taking a shower is hard. You have a little help with that?

Vanesa: Yea

Researcher: What else is hard for you?

Vanesa: Um, get a soap. Researcher: Um hm Vanesa: And water. Researcher: Um hm

Vanesa: And wash my hair like this, chic chicha, chich.

Researcher: Wash your hair, is that hard for you to wash your hair?

Vanesa: (shakes head no)

Researcher: Uhp, then I don't want to hear about it. I want to hear the things that are hard

for you. Vanesa: Oh

Researcher: What's hard for you?

Vanesa: Oh, like, like this is hard (gestures washing hair)

Researcher: Ok, scrubbing your hair.

Vanesa: Um hm

Vanesa also said:

Researcher: Yea what's, what's difficult for you to do?

Vanesa: It means that, that you, that you be my, my assistant.

Researcher: Yea, you have an assistant for things that are hard? Is that what you're trying

to say? Vanesa: Yea

Researcher: Ok, the assistant helps you with things that are hard?

Vanesa: Yea

Differences in what the two disliked were the feelings they had about other people seeing them express different negative emotions. Maria was sorry about showing anger:

Researcher: You're mad. You can't help it. You can't help being mad and people are all

around you looking at you when you're mad. How do you feel about that?

Maria: I say I'm sorry, I'm sorry, I'm sorry, I'm sorry, I say sorry, sorry, sorry.

Researcher: Ok, you don't want to be mad in front of everybody?

Maria: No, no...

Researcher: You don't like that?

Maria: No

Vanesa felt nervous when other people saw her express sadness:

Researcher: Let's say you were in the cafeteria and you were crying. And people were seeing you showing your feelings that you were crying and sad in the cafeteria. How do you feel when people see you show your feelings in the cafeteria, and maybe you're crying or something, and they're all looking at you? How do you feel about that? Vanesa: Nervous.

Maria and Vanesa both made a religious reference during the interviews. Even though

Maria said she is not religious, she once talked about praying:

Researcher: So both your neighbor's cat and your cat both died?

Maria: Yea

Researcher: At the same time?

Maria: Yea

Researcher: Wow, that was sad.

Maria: That was sad.

Researcher: So what are you, what are you going to do about that?

Maria: I'm going to go home and pray.

Researcher: Yea,

Maria: I'm gonna pray.

Researcher: How about a new pet?

Maria: I'm gonna get a new pet because...

Researcher: How do you know you're going to get a new pet? What have you, what have

you done to get a new pet?

Maria: Because in the night I, I sleep and I, and I, I pray.

Vanesa talked about church activities:

Researcher: You belong to that group at church?

Vanesa: Mmm, sometimes.

Researcher: With young people?

Vanesa: Yea

Researcher: And what do there do there? Vanesa: (sighs) They receive the priest.

Researcher: Um hm Vanesa: And get bread. Researcher: Um hm Vanesa: And eat it.

Researcher: Um hm, yep, that's right.

Vanesa: And drink wine.

Researcher: That's right, in the Mass.

Vanesa: Prayer... Researcher: Um hm Vanesa: ...and, and pray.

The difference between Maria and Vanesa was that Maria did not attend church and did not like it, but Vanesa attends church, was involved, and could describe church activities.

In the last category of self-realization called support people, Maria and Vanesa had some similarities in what they wanted in a support person. Both wanted someone that was nice to them and listened. The difference between them was that Vanesa actually had a specific support person to help her at home and Maria did not have an assigned support person.

Rayann Compared to Vanesa

Needs. The basic categories under needs consisted of self-care and knowledge of health or safety and level of independence. Rayann and Vanesa had many similarities in this area. Both had personal care attendants at home. They needed assistance with food preparation, self-care, medical needs, and safety at home and in the community. They were both aware they had a disability and made attempts to name them. Numerous quotes were given in each of their case analyses.

The significant difference in self-care and knowledge was that Rayann also had a one-to-one care professional during school and Vanesa did not. Vanesa was able to ambulate to get herself to the bathroom and did not need assistance to eat. On the other hand, Rayann was more able to stay on topic while talking about assistance:

Rayann: I used to do surgery and when I was little, but that didn't work.

Researcher: Oh. It didn't work, um hm. Ok, no more treatments any more then, only for

your skin.

Rayann: This is the last treatment that works.

Researcher: Is what? Rayann: Is the...

Researcher: For your skin? Rayann: You know, bleomycin. Researcher: Um hm, it's a medicine.

Rayann: Yea Researcher: Yea

Rayann: They put that in the shots. Researcher: And that's what helps you?

Rayann: Yea

Researcher: Very good. What do you do when you have pain?

Rayann: I take medicine. Researcher: Um hm

Rayann: I don't know what medicines.

Researcher: Um hm, but you have pain sometimes?

Rayann: Yea

Researcher: Uh hm. And how is that? How is that pain? Where is it?

Rayann: Here (shows hands)

Researcher: Oh, in the hands yes, sometimes, your skin right?

Rayann: And I have one here in my...(gestures feet)

Researcher: Uh huh, on the foot?

Rayann: Yea

Another difference was that Vanesa wandered off topic randomly as evidenced by previous

quotes as well as this one regarding assistance:

Researcher: What if you have pain?

Vanesa: P- paa...

Researcher: What if you have a pain?

Vanesa: Pain?

Researcher: How do you take care of pain?

Vanesa: Um

Researcher: Do you know what pain is?

Vanesa: Um hm

Researcher: Like duele? You have a pain somewhere on your body? How do you take

care of that?

Vanesa: It hurts people.

Researcher: No, I'm talking about you.

Vanesa: Sadler!

Researcher: What if you have a pain? How do you take care of pain? What do you do

when you have a pain somewhere on your body? What do you do about it?

Vanesa: I, I get scared.

Researcher: First you get scared, right? Because you feel pain, you get scared, and then

what do you? Vanesa: Relax.

Researcher: Try to relax. And if you still feel pain, then what do you do?

Vanesa: Call the doctor.

Researcher: There you go, call the doctor, or else you could call what?

Vanesa: My mom.

Researcher: Your mom, right? If you have a pain, tell your mom. You gotta speak up,

right?

Vanesa: Yea

Researcher: Because she doesn't know where it hurts.

Vanesa: No

Researcher: And you gotta tell her. You gotta explain to her where it hurts.

Vanesa always tended to say the first thing that came to mind. Rayann was more able to give a coherent response.

In the category of independence under needs, Rayann and Vanesa shared some common characteristics. They could both communicate well verbally and could communicate electronically using various devices like iPads, computers, and smartphones. They were both able to attend and participate successfully and appropriately in social activities. Both depended on the family for financial support and had no job training experiences except what little they participated in at school. They both depended on their families for support of their life choices. They both depended on services or family for transportation to access the community.

Rayann and Vanesa also expressed some differences in independence. Rayann said she was completely dependent on others to prepare and provide food to her, even in bringing some foods to her mouth. Vanesa only needs occasional reminders to use the bathroom, had no problems feeding herself, and ate well for such a small person. Rayann could communicate better due to higher intellectual functioning and better reading and writing skills for use with technological devices. Rayann was completely dependent in housekeeping, but Vanesa helped her mother, with supervision, to do housework.

Preferences. This category was divided into beliefs, interests, and abilities in the research question. Under each category were several sub-categories. Both shared similar beliefs in themselves; that they were strong, safe, and could do anything. They both stood up for their friends when they were attacked verbally. Previous quotes showed those beliefs. They both knew they were nice to others and respectful.

One disparity between Rayann and Vanesa was that they felt differently about others. If someone disagreed with Rayann, she would immediately speak up:

Researcher: What do you do when you do not agree with other's opinions or ideas?

Rayann: I tell them

Researcher: Um hm. What do you say?

Rayann: I don't agree

Researcher: You say I don't agree with you right

Rayann: Yea

And later for the same question:

Researcher: What if somebody tells you, tsk, that Austin, he can't sing. He's no good. He's ugly, and he can't sing, and I don't like Austin, and you don't agree with him. What

do you say? What do you do?

Rayann: I'll try to stand up for him.

Researcher: Um hm

Rayann: And say, and disagree, tell, tell him, he's a nice guy, and he writes good songs!

Researcher: Um hm. You'd speak up?

Rayann: Yea

Researcher: Good, you do speak up for things. Rayann: I'll, I'll stand up for him if that happens.

Researcher: That's what you do. You speak up for yourself.

Rayann: Yea

But Vanesa, at times, would go along with other people, as was previously referenced in the between case analysis of Maria and Vanesa:

Researcher: Do you understand what I'm saying? You and [Kaitlin] don't agree about

[Nelson]. You like [Nelson], [Kaitlin] doesn't like [Nelson].

Vanesa: Uh uh (meaning no)

Researcher: She says [Nelson] is a terrible person

Vanesa: (laughs)

Researcher: I don't like him. He is mean.

Vanesa: (laughs)

Researcher: He, he's creepy, he's mean. Vanesa: (whispers to herself, inaudible)

Researcher: And you think he's a terrific guy, a great guy. So what do you say? What do

you do? What do you tell [Kaitlin]?

Vanesa: [Kaitlin], he's mean, but he's a great guy.

Researcher: No, no, no, he's not a great guy, she's gonna say.

Vanesa: (laughs)

Researcher: He's not a great guy, I don't know why you like him!

Vanesa: Sorry, Sadler, I messed up on...

Researcher: No, I'm being [Kaitlin] now. I don't know why you like him. He's a creep,

he's mean. Vanesa: Yea

Researcher: What are you gonna say? Vanesa: He's a creep, he's mean.

Researcher: So you're gonna agree with what [Kaitlin] says then? You're gonna agree

with her? Vanesa: Yea

Researcher: So you go along with whatever she says?

Vanesa: Yea

anesa. 1 ea

Researcher: Is that what you're gonna do?

Vanesa: Yea (laughs)

Researcher: She says don't talk to [Nelson] anymore!

Vanesa: Yea (laughs)

The difference was that Vanesa could easily be persuaded to change her mind, but Rayann had a stronger mindset in her beliefs and was more consistent.

Both young women had some fantasies about their future. Both had the fantasy of working in entertainment and other fantasy jobs that did not match their abilities, like being a mother, artist (visual or musical), or a college instructor. Both had the fantasy of attending college, which should be available to students with significant disabilities, but realistically, there are no programs in our area yet since Free Appropriate Public Education (FAPE) ends at age 22 and there is no other funding available for these students.

Some differences in fantasy ideation were in the areas of romantic interests, ambulation, and travel. Rayann definitely wanted to get married and have a family. Vanesa was unsure about the idea of getting married, but liked the idea of having a boyfriend to kiss on the cheek and hold

hands with. Rayann fantasized about walking, but Vanesa walks. Rayann believed she could travel overseas independently to a place that had limited services for people with physical and intellectual disabilities. Vanesa did not fantasize about faraway travel. There were many instances of the quotes to support these participants' fantasies in their case analyses.

Both participants mentioned their rights to respect, adult treatment, and privacy. The only differences that emerged here were the times when Vanesa talked off topic about random topics that were not related to meaningful human rights:

Researcher: What else do you have a right to do?

Vanesa: I...like um...

Researcher: I have a right to... Vanesa: To, to go, to the buses.

Researcher: To go to the buses and get a ride home from school.

Vanesa: From school. Researcher: Um hm

Vanesa: Or...

Researcher: You have a right to what? What else?

Vanesa: Go t-, go to the tree.

Researcher: Tree? Vanesa: Yea

Researcher: Um hm. Which tree is this?

Vanesa: Oh, outs-, outs-, outside.

Researcher: Um hm Vanesa: Mmm, yea.

And later in the same conversation:

Researcher: I have a right to have what?

Vanesa: Oh! Play video games.

Researcher: I have a right to play video games. I have a right to have what?

Vanesa: (laughs) To (laughs) to, to respect other people. Researcher: Um hm, what else do you have a right to have?

Vanesa: Have neighbors at the door.

Researcher: Neighbors at the door, anything else?

Vanesa: Or to see the windows shut.

Researcher: Um hm

Vanesa: And then and then you go inside.

Researcher: M-k

Vanesa: To, to see the, t-, to see the talent show.

Researcher: Ok

Vanesa often was unable to give me an on-topic response and many times her responses were found to be as such.

In the research sub-question regarding preferences related to interests, there were the categories of assistance from others, independence, friends and social life, and choices. Rayann and Vanessa were similar in their interests in support from their parents or a support person. Both had paid support workers and family support. Both were interested in doing things by themselves. They both wanted to be involved with friends in social activities and in Best Buddies. They were interested in making choices about their living situation, a job, leisure time activities, friends, foods, post-secondary education and training, and travel. Several previous quotes were noted in their individual case analyses.

Where the two were different included their preferred living situation, specific job interests, certain foods, particular colleges, and certain travel destinations. Rayann preferred her own home with her husband and children. Vanesa preferred to stay at home, but did mention having her own place to live at times. Specifically, Rayann only mentioned three job preferences: a mother and an entertainer or artist. Vanesa talked about working in department stores, drug stores, schools and colleges, and at Disney or with computers. Rayann was committed to selecting foods to eat that met with her religious guidelines and Vanesa had a wide range of foods she preferred, including hot and spicy foods, as mentioned under preferences related to interests in her case analysis:

Researcher: Eat at a what?

Vanesa: Jala-, um, to eat jalapeño, you know what, you know what...

Researcher: Jalapeños?

Vanesa: Yea!

Researcher: For a job?

Vanesa: Yea

Researcher: Ooo, you like jalapeños? That's a hot food!

Vanesa: Yea, and it's spicy!

Researcher: Yes! Vanesa: (laughs) Researcher: It is!

Vanesa: (laughs) And hot!

Rayann wanted to go to a college that offered dormitory style living and Vanesa wanted to go to a local college or university. Another difference was that Rayann wanted to travel to Lebanon and Vanesa only wanted to travel within Miami or to a local farm to see animals. I believe what Vanesa was referring to was a party we (her mother, other students, and I) once went to on a farm with petting animals. The following quote was used in coding for travel interests for her case analysis:

Researcher: Where would you like to travel to?

Vanesa: A farm (laughs)

Researcher: A farm? You like being in the country on the farm, right?

Vanesa: Yes

Researcher: You said that twice now. You want to visit a farm one day.

Vanesa: Oh, yea

Researcher: What kind of a farm? Tell me more about the farm you want to visit.

Vanesa: A cow moo-ooo! (laughs)

Researcher: You want to see cows and listen to them moo at the farm?

Vanesa: (laughs) Yea

Researcher: What else you wanna do at the farm?

Vanesa: A pig.

Researcher: You want to see the pigs, um hm.

Vanesa: (laughs) Yea Researcher: What else?

Vanesa: Pony.

Researcher: You like ponies? How about riding ponies?

Vanesa: What? What's that?

Researcher: Riding the pony, taking a ride on a pony. How about that?

Vanesa: Oh, yea, I, I like to sit down in the pony.

There were some similarities to the abilities they expressed. Both had no job training or experience earning money. Both were very verbal and could contact family and friends, with some support when needed. They expressed that they were able to lend emotional support to friends. They were both very well-mannered and able participate in social events appropriately.

They could express themselves well and ask for support when needed. They both knew techniques to calm themselves down when upset. They both made choices about clothing, hairstyle, and how they chose or did not choose to decorate their bedrooms. Both said they would be able to live in independent housing.

Differences in their abilities included how they expressed themselves and how independently they were able to live. Rayann expressed herself more connectedly, even though she often said she did not know the answers. Vanesa often went off topic and gave random, but clearly pronounced, sophisticated words that she did not know the meaning of, and did not apply appropriately to the question at hand. Rayann said she was able to live independently, but in reality needed much support for her physical limitations. Vanesa was less confident in her ability to live independently although she was more mobile:

Researcher: If you were to live in your own house, mom's over here and you're over there in your own house, what would you need to know more about to live by yourself? Vanesa: Uh Hm, to, to help someone to live near...

Vanesa often reverted back to saying she wanted to live near or with her mother.

Goals. Plans, problem solving, and self-regulation made up the three sub-divisions of the coding for goals. When questioned, both Rayann and Vanesa had plans to get a job, find a desired living situation, and select leisure activities they enjoyed. They both talked about how they would get support from family to reach the goals of their own place to live and a job, which would solve the problem of how they were going to get where they wanted to be in life. Rayann talked about steps for her plan:

Rayann: I have to finish here first.

Researcher: (laughs) You're gonna finish here first, that's step one, finish school,

graduate, right?

Rayann: (laughs) yea

Researcher: What's step two?

Rayann: Go to one school you told me about.

Researcher: Um hm. Like higher education?

Rayann: Yea

Researcher: That's what we call it.

Rayann: Yea

Researcher: Ok, next? Rayann: I don't know

Researcher: Well, why do you go to school?

Rayann: Because to learn.

Researcher: To learn so you can do what?

Rayann: Live by myself.

Researcher: Live by yourself, ok, that's true. And what does it take to live by yourself?

Rayann: And with my husband and kids.

Vanesa also had steps to her plan for independent living, although it included her mother:

Researcher: What steps are you taking to, to meet this goal of living with your mom? But

you do, you live with her right now, don't you?

Vanesa: Mmm

Researcher: You live with her right now?

Vanesa: Yea

Researcher: How about living in your own house?

Vanesa: Own house? Yes.

Researcher: Not with mother, in your own house. How about that?

Vanesa: Oh, yea

Researcher: What do you think about that?

Vanesa: Um, about like...

Researcher: Living in your own house...

Vanesa: Yea

Researcher: Without mother, in your own house?

Vanesa: Um hm

Researcher: What do you thinking about that?

Vanesa: I thinking about, about how she want to stay in my house.

Researcher: Which house? Vanesa: My mom's house.

Researcher: Um hm

Vanesa: And then, and then I have to go sleep by myself.

Researcher: Where? Vanesa: My room.

Researcher: Your room where, whose house?

Vanesa: My mom's house.

The one difference was in specific leisure time activates they planned to participate in.

Rayann planned to use her laptop to watch her favorite Arabic show and to listen to her favorite

music. Vanesa planned recreation activities like outdoor sports and recreation, plus her own specific favorite movies and music on various devices.

Problem solving goals were vastly similar in both Rayann and Vanesa. Both mentioned they would accept parental decisions about their adult lives. However, both would persist in asking for what they wanted even if they got resistance from their parents. Rayann said:

Researcher: Let's say they're gonna have some job training, and you wanna take *this* kind of job training, your family says no you should take *this* kind of job training, and you don't agree on which training you should have for a job. How do you handle that disagreement?

Rayann: Get ideas

Vanesa had this to say:

Researcher: You want to take a different class and your mom wants you to have an-, another class that you don't wanna take. You wanna have this different class.

Vanesa: Yea

Researcher: And you don't agree, what do you do?

Vanesa: You get, you get attitude.

Both would seek help from others on the job and said they used aides such as schedules, charts, and visuals as were suggested in structured questioning. Both would ask for help to support them on the job.

In the area of self-regulation the topics coded were dealing with difficult people and situations. Rayann felt this way about a difficult support person:

Researcher: What if you have a problem and they're ignoring you?

Rayann: And helps me

Researcher: And helps you. How about if they ignore you?

Rayann: I don't like that when they ignore me

Researcher: That's right, uh huh, what if you have a problem with something

Rayann: I talk to them

Researcher: Ok so they have to do what when you talk to them?

Rayann: They have to try to make me feel better Researcher: That's right and they have to...?

Rayann: Listen

And about difficult people:

Researcher: How do you get along with people that are hard to get along with?

Rayann: Keep trying.

Researcher: Keep trying, right?

Rayann: Yea

Researcher: That's all you can do.

Rayann: Yea

Researcher: And if you keep trying, what happens?

Rayann: I'll get my way.

Researcher: You'll get your way, right, if you keep trying?

Rayann: Yea

Researcher: You'll melt that ice and get through, right?

Rayann: Yea

Vanesa handled difficult people by talking to them also:

Researcher: What do you do about that problem?

Vanesa: That...

Researcher: Your friend [Dayana's] acting like she's mad at you.

Vanesa: That, uh...

Researcher: And you don't know why. Vanesa: Uh, that she's, uh, she's frustrated.

Researcher: She's frustrated with you and you don't know why. So what do you do about

that problem?

Vanesa: You get a big trouble.

Researcher: Yea, it's big trouble, isn't it? You don't like [Dayana] getting mad at you, do

you?

Vanesa: No

Researcher: So what do you do about it? What do you say, what do you do when she's

mad at you?

Vanesa: You're saying, you say thank you.

Researcher: Um hm, what else? Vanesa: And you say...uh

Researcher: Ok, [Dayana] is mad at you.

Vanesa: M-yea

Researcher: And she's your friend.

Vanesa: Um hm

Researcher: And you don't know why she's so mad. What do you ask her?

Vanesa: I said [Dayana], why you go so mad?

Researcher: There you go! You ask her why you so mad at me?

Vanesa: Yea

Researcher: And you try to find out.

Regarding difficult situations, Rayann had this to say:

Researcher: What are the bad things that happen when people don't listen to you?

Rayann: I'll get really mad.

Researcher: You'll get mad, what else?

Rayann: Start yelling.

Researcher: Start yelling, you're gonna have to, right?

Rayann: (nods)

Researcher: Um hm, what if they say, no, this is good food. Come on eat, and they start *feeding* it to you, and it's not Muslim food, and they're feeding it to you, and you're trying to say, no, no, and they don't listen to you. Oh, be quiet, come on, this is good food, eat it. What are the bad things that will happen if they did that and didn't listen to

you?

Rayann: They'll get in trouble.

Researcher: Um hm, how will they get in trouble?

Rayann: By our parents.

Researcher: By your parents, and how will they know?

Rayann: I'll tell them.

Eating the correct foods that were *halal* was extremely important to Rayann's sense of safety:

Researcher: What if it's food you're not supposed to be eating, and they're trying to get you to eat it, and they don't understand that you're not supposed to be eating that kind of food that's not Muslim food?

Rayann: I'll explain.

Researcher: Uh huh. And they, finally they listen to you, finally, and they go, oooh, now I

get it, and then how do you feel then?

Rayann: Safe.

Vanesa talked about her own difficult situation:

Researcher: What's hard for you to do then? You have an assistant...

Vanesa: Put...

Researcher: What does she help you with? Vanesa: Take, um, take off of my shoes, off.

Researcher: That's hard for you to do?

Vanesa: Yea

Researcher: It's hard for you to take off your shoes, so you get, you get help taking off

your shoes? That's one thing, right? Am I saying it right?

Vanesa: Mmm Yea

Feelings. The research sub-questions were the topics psychological empowerment and self-realization for the category of feelings. Under psychological empowerment, Rayann and Vanesa had numerous similarities for self-advocacy, confidence, and use of technology. Both knew about the use of 911 in an emergency, felt they had the chance to make choices, could

speak up for what they wanted, could get food provided to them if they were hungry, and could express emotions with self-control.

The difference in psychological empowerment between Rayann and Vanesa was that Rayann was more aware of her desire to be truthful and blameless in the eyes of others and in her faith. She worried a lot about following the Muslim teachings and being able to go to heaven:

Researcher: What would be the worst problem that would ever happen to you?

Rayann: I tell someone something and it's not the right answer.

Researcher: Um hm

Rayann: Because I get very, uh, cause I didn't tell the truth.

Researcher: Oh, and that worries you, I know it does.

Rayann: Yea

Researcher: You don't like being misunderstood, do you?

Rayann: No

Researcher: You don't like that now.

Rayann: I get worried a lot.

Researcher: I know you worry about things, I know, you hate to worry, right?

Rayann: Yea

And later on in the conversation about worry:

Researcher: What else do you worry about?

Rayann: I want God to, to still love me, to still want me—

Researcher: Yea

Rayann: --when I go to heaven.

Researcher: Right

Rayann: And I wanted to, that to happen even if I did, I do by things by accident. Researcher: By accident. So, uh, how do you feel about God forgiving you about what

you did by accident? How do you feel about that? Rayann: Sometimes I tell God to please forgive me.

Researcher: Ok, what do you, do you think God forgives you?

Rayann: Maybe, I don't know

Researcher: You ask Him to forgive you, right?

Rayann: (nods)

Researcher: Do you think he does when you ask Him?

Rayann: M-yea

Vanesa did not express anything she was worried about during our interviews and did not worry about protecting her self-image.

Self-realization was separated into the areas of self-awareness, adult preferences, difficulties/dislikes/non-interests, religious feelings, and support people. Rayann and Vanesa both had self-awareness concerning their conditions, disabilities, and feelings about themselves. Both knew they had a disabling condition and knew that is had a name. They knew they needed support from others to be more independent. They were able to describe how they learned best given structured interview questions. Both could tell what they were good at and what they needed help with. There were several quotes regarding strengths and weaknesses in their case analyses. They knew what made them angry and what made them happy. They could give some of their own personality traits. Both were happy being who they are.

The difference in self-awareness was that it was unclear if these two participants knew they had an intellectual disability along with a physical disability. They knew what supports they needed in life, but did not specifically compare themselves to non-disabled others. Rayann said:

Researcher: What is hard for you to do?

Rayann: It's hard for me to walk? Researcher: Hard for you to walk.

Rayann: I need, uh, uh, uh, I need help to walk

Researcher: You need help to walk. Rayann: I can't think of nothing else.

Vanesa could not give a true example of something that was hard for her to do:

Researcher: What is hard for you?

Vanesa: What is hard?

Researcher: What's hard for you?

Vanesa: Oh, hard? Researcher: Yea

Vanesa: Is pretend be nice to...all the students

Researcher: To be nice to all the students is hard for you?

Vanesa: M-yea

Researcher: Really? What makes it so hard to be nice to everybody? What makes it so

hard about that?

Vanesa: (laughs) nice to, nice, nice to, wait, nice to [Spancer] and—

Researcher: Yea, but you already are nice to them.

Vanesa: ...[Pierre]!

Researcher: This is a different question. What, what things are hard for you to do? That's not hard for you to be nice, because you're always nice...to everyone, you are! What's a hard thing for you to do?

Vanesa: Like, like you eat at the restaurant?

Researcher: You have no problems eating in a restaurant either. What's a hard thing for you to do? What gives you problems?

Previous quotes proved they made those statements.

Vanesa: Be nice?

Researcher: That's not true!

Both young women had similar feelings about adult preferences. They both knew they wanted to live independently, have a job, access the community, and be treated like an adult.

The only differences were that Vanesa waivered at times between wanting to be treated like an adult and wanting child-like articles like toys or balloons:

Researcher: When do you think, hm, I wanna buy something. When do you— Vanesa: Oh! Toy! A toy!

And later in the same conversation:

Researcher: Are you saving money for something?

Vanesa: Yea

Researcher: For what?

Vanesa: For you give me the dime.

Researcher: I'm saving money for...what?

Vanesa: A dollar?

Researcher: Because one day I want to buy a...?

Vanesa: A toy.

And when Vanesa was asked about being treated like a baby:

Researcher: Like people go, oh, come here little girl, here's a little baby toy for you, and

how do you feel about that, because you think you're an adult?

Vanesa: Oh! You say thank you.

Researcher: And they're giving you a baby toy, come here little girl, come here, here's,

you're just a little girl...

Vanesa: And...girl!

Researcher: Here's a baby toy for you.

Vanesa: Oh!

Researcher: How do you feel about that?

Vanesa: You say thank you.

Difficulties, dislikes, and non-interests were similar in Rayann and Vanesa. They both felt that they had difficulties. Rayann had a more serious difficulty:

Researcher: That's the hard part about being you, is that right? You miss your mom and all that. Ok, I'm going to ask you then, now, what's the worst thing about being you?

Rayann: Not getting what I want.

Researcher: Which is your mom, right?

Rayann: Yea

Researcher: That's the worst part about being you, what you just said, that you can't go

visit her when you want to, right? Am I saying the story right?

Rayann: Yea

And Vanesa had a difficulty which was serious in its own way because she could not write without a model to copy from:

Researcher: What gets in the way...of doing your best work?

Vanesa: Uh...

Researcher: Or doing your best on anything?

Vanesa: Writing like... Researcher: Writing?

Vanesa: Yea. Like writing down.

Researcher: Um hm

Vanesa: The, the piece of paper.

Vanesa repeated this theme about writing on a piece of paper so I must assume it was important to her to be able to write. For dislikes, both did not like falling down. Rayann said:

Researcher: What is the worst thing that can happen to you?

Rayann: Uh, falling, fall down. Researcher: Falling down?

Rayann: (nods)

Researcher: You hate to fall down, don't you?

Rayann: Mmm, b-, it happens to me. Researcher: It happens sometimes.

Rayann: Yea

Vanesa also did not like to fall because she also had a physical disability:

Researcher: What would you say?

Vanesa: Mmm, to, to, to see, to see many choices like, like, I cannot go to skate. I will

fall down.

Researcher: Right, So what do you do about that?

Vanesa: I get up.

And then in the same conversation:

Researcher: You don't, you don't want to go roller skating?

Vanesa: I'm scared.

Researcher: Right. And so how are you going to tell [Reyes] that, what are you going to

do?

Vanesa: I get—

Researcher: He's not listening to you. How do you get him to listen to you?

Vanesa: I cannot go to the, to the roller skates.

Researcher: Yea

Vanesa: But I freak out (laughs)

Researcher: You freak out, right, so you tell him, right?

Vanesa: Yea!

Both did not like to have bad feelings. Rayann did not like to be lonely or scared:

Researcher: How do you feel about being...lonely?

Rayann: I feel really bad (laughs)

Researcher: You don't like being lonely either, right?

Rayann: No

Researcher: How do you feel about being afraid?

Rayann: I feel kinda scared.

Researcher: Is that a good feeling or a bad feeling?

Rayann: Bad feeling.

Vanesa did not comment about loneliness, but did say something about anger:

Researcher: What do you do if you're angry at your mom?

Vanesa: Oooh!

Researcher: You care about her, right, a lot?

Vanesa: I big trouble (laughs)

She also did not like the feeling when she made mistakes:

Researcher: How did you feel about that mistake when you did it wrong? How did you

feel?

Vanesa: I feeling (laughs)

Researcher: How'd you feel about that?

Vanesa: I feeling like, like, like, nor, like nervous.

Researcher: Nervous? You felt nervous?

Vanesa: M-yea Researcher: Yea

Vanesa: I, I felt afraid about...

Researcher: Really? Vanesa: M-yea

There were no commonalities in what the two participants were not interested in. On the topic of non-interests, Rayann said:

Researcher: What kind of things do you want to volunteer for in the future?

Rayann: Nothing.

But, Vanesa named several things she wanted to volunteer for even though most of them were random insignificant thoughts. Rayann was not interested in recreation:

Researcher: Maybe you'd like a recreation center? Like to live by one of those?

Rayann: No

Vanesa attended a recreation facility every day and felt differently about it:

Researcher: So I wanna live near what, what service?

Vanesa: Apple Store.

Researcher: The Apple store!

Vanesa: (laughs)

Researcher: That's fun! What do they have in the Apple Store that you like?

Vanesa: iPhone.

Researcher: iPhone store! Yes!

Vanesa: (laughs)

Researcher: You could live near that. That would be fun. That's nice. Anything else?

Vanesa: Uh, oh! P-. At the...

Researcher: Park? Is that what you were going to say? Park?

Vanesa: Uh, park, yea.

Researcher: You wanna live near a park?

Vanesa: Yea

Researcher: That would be nice too. Which park?

Vanesa: Outs-, outside over there (points in the direction of the afterschool park program)

Researcher: What's that park called?

Vanesa: FIU-ooo (laughs)

Researcher: It's near FIU, it's near it, it's called what t-, t-.

Vanesa: T-, t-

Researcher: What's that park called that you go to?

Vanesa: Tamiami Park.

Researcher: Tamiami Park, you want to live near, near that park?

Vanesa: Yea

Both young women had physical therapy, but Rayann did not care to live by a facility:

Researcher: How about, um, like a therapy service, where they give you therapy?

Rayann: I get therapy in school.

Researcher: Did you get it in the community when you do that too or where you house is,

around your house?

Rayann: No

Researcher: You just get it at school?

Rayann: I'm, maybe, what, I don't think those people are for therapy.

Researcher: You don't think those people have therapy? What do you mean?

Rayann: That comes to my house.

Researcher: They don't give you therapy at your house?

Rayann: I don't know

Researcher: You're not sure what that service is called?

Rayann: Um um (shakes head no)

Researcher: Do you want to live by those services, where they come to your house? You

want to live near their services?

Rayann: (shakes head no)

Researcher: Does it interest you to live near those services?

Rayann: No

Researcher: You don't care about that.

Rayann: (shakes head no)

And Vanesa said:

Researcher: Do you wanna live near where you have like physical therapy?

Vanesa: Yea

Researcher: Like for your le-, therapy for your legs.

Vanesa: Um hm

Researcher: You want to live near that?

Vanesa: Yea

Rayann and Vanesa both had religious feelings and talked about them during our interviews. Vanesa was very generic about religion, only saying that she went to church and participated in the Mass. Rayann was driven by her religion regarding appropriate foods and how to live a respectable Muslim life. There were many quotes about religion by Rayann and it worried her so much that she commented more than once about how she did not like that feeling of being worried.

Lastly, both Rayann and Vanesa realized they were dependent on their care-givers. They talked about them in the interviews often. They also mentioned how the school and teachers would give them support.

The major difference between Rayann and Vanesa on the topic of support persons were that Rayann had two, one at school and one at home, and Vanesa only had one at home. Vanesa claimed she could do most personal care by herself, but her home care giver was hired specifically to assist her with self-care.

Emergent Coding

As I was analyzing all the interview data, I noticed I was collecting information that was either not answering the questions or was other information I had not asked for. Being that participants such as mine who have significant intellectual disabilities were rarely asked to contribute their knowledge to research, I thought it best to honor every word they said. I wanted to capture the meaning of why the information was missing or why they gave me extra information. I named two other categories discussed below.

Missing information. I coded three sub-categories under missing information which were why was information missing, why participant was off topic, and why the question was not answered.

I deduced that one reason information may have been missing was because of lack of background information to answer the question. Many of the research questions that were based on the standardized ARC's Self-Determination Scale were designed for higher functioning students that had more experience with working at a job for instance. The participant in this study that had the most experience with working because she participated in job training every morning was Maria. Even so, she never earned money from actual employment. Maria could not tell me realistically how she was learning about jobs at school:

Researcher: What kind of activities do you do in school that help you learn about your

iob?

Maria: Um I do like, um, magzines.

Researcher: Magazines?

Maria: Like you a quo—reading time like.

Researcher: And how's reading time, magazines, how does it help you learn about a job?

Maria: I read like, like, uh, do like, Justin Beiber, um, do like, Selena Gomez, and...

Researcher: Those are movie star magazines, right?

Maria: Yea

Researcher: Do they help you learn about a job?

Maria: Yea

Researcher: Yea, how do they help you learn about a job?

Maria: I read it.

Researcher: You read it.

The participants with the least experience in working or work training stated the following two quotes. Rayann, who had limited interest in having a job outside the home, said:

Researcher: What school work do you do now that will improve your chances of getting a

job?

Rayann: Homework.

Researcher: Homework will help. It will, anything else?

Rayann: Signing. Researcher: Signing?

Rayann: And signing our name.

Researcher: Signing your name, uh huh, ok, anything else?

Rayann: No

And Vanesa, who had the most significant cognitive limitations of the three participants, said:

Researcher: What classes do you take now, do you do now that help you learn about a job

you want to do one day?

Vanesa: Learn how 'bout the job...

Researcher: Yea

Vanesa: ...that I do one day?

Researcher: Yea, what classes do you take now that help you learn about getting a job?

Vanesa: And, oh yeah! Researcher: Uh huh

Vanesa: Uh, wait, [Reyes].

Researcher: Um hm

Vanesa: Learn to do the job.

Researcher: That's right, Mr. [Reyes].

Vanesa: Yea Researcher: Ok

Vanesa: Oh [Thomas]!

Researcher: And Mr. [Thomas] too, right?

Vanesa: Yea

Researcher: You learn about getting a job in those classes, right?

Vanesa: And [Garcia] too.

Researcher: And Miss [Garcia] too. Um hm.

Maria brought in her fantasy job, Rayann thought that signing her name was enough to train for a job, and Vanesa merely mentioned her teacher's names as job training classes when that was not actually being taught regularly to her. Job training for these students needs to happen at an actual work site as in on-the-job training. These students do not transfer class discussions or classwork to real life work skills unless they have hands-on practice. Consequently, many questions about job expectations and job knowledge left missing information.

Moreover, the standard assessment from which the interview questions arose was outdated in that there was a focus on use of the post office, which was decreasing in use for this younger population in the study. That would account for lack of knowledge on how to answer post office related questions. In my set of questions, I was compelled to add questions about more modern forms of communication like email, texting, and devices used to contact others. However, feeling compelled to stay with the content of the standardized measure, I inquired participants about their use of the post office. Maria was first:

Researcher: Know what the post office is?

Maria: Oh the mail over there? (points toward the hallway door towards the office

perhaps)

Researcher: Well it's in the community. It's not really in the school. How do you, how do

you go to the post office and use the post office in your community?

Maria: You, you, you open the door.

Researcher: What door?

Maria: The door in the office. Researcher: Post office door? Maria: Yea, you open the door. Researcher: Open the door, ok.

Maria: I open the door. Researcher: Um hm

Maria: Get some papers and then I see some mail.

Researcher: Um hm

Maria: And then I, I go to the hospital and give the mail to Ms. [Reuben] and...

Researcher: Oh, you have a post office at the hospital where you work?

Maria: Yea

Researcher: And you, do you do the mail there?

Maria: Yea

Researcher: Oh, I didn't realize that.

Maria based her response on personal experience, because she did not give correct answers when questioned about home mail service:

Researcher: To get it to arrive at [Veronica]'s address? What do you put on there?

Maria: Thank you?

Researcher: That's not her address.

Maria: I don't know her address, I don't know.

Researcher: Then how do you get the mail to her house if you don't know her address?

Maria: I don't know her address.

Researcher: Does somebody help you do that? Maria: I don't know. I don't know her house.

Researcher: Have you ever mailed [Veronica] a letter through the mail?

Maria: Yes

Researcher: How did you do that?

Maria: Um

Researcher: If you don't know her address?

Maria: I don't know her address. I think her mom does.

Researcher: Mmm, yea, so how did you get her address to mail the letter to her?

Maria: I did it with paper.

Researcher: Ok. But you have to write something on there, her address.

Maria: Yea

Researcher: How did you get her address?

Maria: I don't know. I write it with my address.

Researcher: But it's going to go to your house then, it isn't going to go her house. It's not going to go to her. It's going to go to you then. You want a letter *from* you to her. So how

do you get it to her? Does someone help you?

Maria: My mom.

Rayann, representing the highest functioning participant of this study, also had little experience using the post office:

Researcher: You want to mail a box.

Rayann: Yea

Researcher: Because a box won't fit in your mailbox.

Rayann: Hey...yea.

Researcher: You want to mail a box to Lebanon. What do you do?

Rayann: Put the address.

Researcher: Put the address on the box.

Rayann: A stamp. Researcher: Uh huh Rayann: And mail it?

Researcher: Not in your mailbox. You gotta go to the post office.

Rayann: Yea

Researcher: So how you gonna get there?

Rayann: I don't know

Researcher: How are you gonna mail this box to Lebanon?

Rayann: Take it to the post office?

Researcher: You got it. And how are you gonna do that? You've done that before,

haven't you? Rayann: No

Researcher: You've never mailed a box to your mom?

Rayann: No

Researcher: Never, never, mailed a box or anything else to Lebanon?

Rayann: I, I told someone else to do it.

And lastly Vanesa, who had difficulty giving relevant responses said this about picking up a box that came in for her at the post office:

Researcher: How are you gonna get it? Vanesa: To, to pick up the, the box.

Researcher: Who's gonna help you go get the box?

Vanesa: The mail (laughs)

Researcher: They don't help you with that...no, no, no, no, no

Vanesa: (laughs) You're funny (laughs)

Researcher: Well it's true! Vanesa: (continues laughing)

Researcher: Who would help you go get mail from the post office and pick up your box

for you? Who would help you with that?

Vanesa: The...

Researcher: Who always helps you with things?

Vanesa: Oh! The president.

Researcher: The president!? (fakes crying)

Vanesa: No (laughs) wait, wait, help? Uh, probably a bank.

Researcher: You don't have any family [Vanesa]?

Vanesa: I, I, I do have a family.

Researcher: Would they help you, do you think?

Vanesa: Yea

Researcher: Who would help you in your family?

Vanesa: My mom.

Feeling that this post office topic was not particularly related to the participant's way of life, I did not refer to it until I coded for missing information. Participants had little background experience in using the post office as independently as possible.

Another area of concern for missing information was the question of why the participant was off topic. Sometimes they were just answering a previous or a different question. I discovered that aspect when I used In Vivo coding and only looked at what the participants said and not what I asked. These students tend to perseverate more than students without disabilities and have difficulty changing topics rapidly to adapt to the situation at hand. They often changed the topic and I went with them to attempt to discover something they wanted to say that I had not thought to ask. Usually, however, participants were only drifting away from the topic to discuss something not under investigation or their mind just drifted away due to attention deficits.

Vanesa was the participant who was most guilty of that due to her functional level. Here is one

example from Vanesa:

Vanesa: I put, I always, I put the key in the door.

Researcher: Besides making the bed, what else do you do?

Researcher: The key?

Vanesa: Yea

Researcher: You put the key for your door? Vanesa: My mom's...door, to be locked. Researcher: You lock your mom's door?

Vanesa: Um hm Researcher: Yea Vanesa: Um hm

Researcher: And then...Why do you do that?

Vanesa: Because my mom is, my mom is open the door to, uh, to get some privacy

(laughs and covers mouth)

Researcher: Oh for privacy, yea for privacy, ok, that's not that's not house cleaning

though, that's something else.

Vanesa: Yea

Vanesa gave many off topic or inappropriate responses like repetitively stating she would solve problems by staying away:

Researcher: You don't agree with [Kaitlin] on that. So how do you feel about that?

Vanesa: I, I feel proud of [Kaitlin]. Researcher: Proud of [Kaitlin]? Um hm Vanesa: And I, I proud of, of [Nelson]. Researcher: Proud of both of them. Vanesa: Yea (laughs)

Researcher: But she doesn't *like* [Nelson]. She's saying eew, I don't like [Nelson].

Vanesa: (laughs)

Researcher: Why do you like [Nelson]? You shouldn't like [Nelson], he's no good, she's

telling you that.
Vanesa: Um (laughs)

Researcher: And you don't agree with her, how do you feel about that?

Vanesa: Mmm, I feeling, uh, I feeling like, ungracious about...

Researcher: Ungracious, uh huh

Vanesa: About, about [Nelson] and then I feeling about [Kaitlin]...

Researcher: Um hm, she doesn't agree with you.

Vanesa: No

Researcher: And what do you think about that? Vanesa: (laughs) To, to, to stay away [Kaitlin] and

Researcher: Um hm

Vanesa: And, and, um, and [Nelson], both

Researcher: Ok

Vanesa had the uncanny ability to use complex words without knowing their meaning. She also came up with the most amusing responses:

Researcher: What do you do in your free time...

Vanesa: Oh!

Researcher: ...to help you learn about getting a job?

Vanesa: Paying, paying some taxes.

And:

Researcher: What school work do you do right now that will help you get a job?

Vanesa: Assessments...?

And she got her vocabulary from her mother apparently:

Researcher: What is something you do now with help that you would rather do it by

yourself?

Vanesa: Like community service?

Researcher: Like community service? Maybe.

I did not know where she was going here when she said this:

Researcher: Which adult could you ask for help?

Vanesa: Two things. Researcher: Two things?

Vanesa: Yea, to, to be kind, be nice. Researcher: Um hm, that's right.

I included the above quote to show the reader how difficult it was to code some of the material I collected in transcript data. Vanesa did her best work when she answered questions about a topic we were discussing in class, but it was equally difficult to question her about events that were not happening at the present time:

Researcher: How about discussions in class?

Vanesa: What's discussions?

Researcher: Talking about things in class, answering the questions.

Vanesa: Um

Researcher: What about that?

Vanesa: Yea

Researcher: What *about* that?

Vanesa: A-answering like, like different sculptures...

Researcher: Different sculptures? Uh hm, answering different sculptures...

Vanesa: Yea

And further along in the conversation:

Researcher: What else is it about working that you tried that you don't like?

Vanesa: I like pictures (looks around room) Researcher: But what is it you don't like?

Vanesa: Oh! I f— (looks at wall in front of her)

Researcher: I don't like...?

Vanesa: A flag, a flag (points to flag in front of her)

Researcher: Um hm Vanesa: Um hm

Another cause for missing information appeared to be the automatic repetition of responses such as "thank you" or "I don't know" without giving the question much thought. Sometimes participants were unsure of what I was asking and said they did not know because they wanted to get more clarification, upon which I provided more background information to set the question up for their answers. At other times I felt the participant did not want to think that hard at that particular moment and just said that they did not know. I also heard many contradictions that I believe were due to trying to please me with a better answer or one they thought I preferred to hear. Some contradictions were for other reasons like a change of mind or

they forgot what they said the first time. Sometimes they appeared unwilling to admit they were more dependent than they seemed.

Extra information. I also coded three sub-categories for extra information. Those categories were why the participant took the focus off themselves, why participants were not interested in being more independent, and why was there such a high level of interest in being an entertainer for all three participants.

I suspected than some of the reasons Maria tried to take focus for the fault off herself and place it onto someone else was to reject blame. I believe it demonstrated fear of failure and denial of disability. She blamed others as an excuse for her own behaviors. She also blamed others, mostly her parents, to mask her own anger at not getting her way to do what she wanted to do, even if it was unreasonable. Then there were times Maria blamed others and it appeared unrelated to her sense of self:

Researcher: And how did you become friends with them again?

Maria: Sometimes I be friends with [Veronica] but sometimes [Alicia's] getting duh little

confused.

Researcher: Uh huh

Maria: Last time, um, [Alicia] and [Veronica] they were being bad.

Researcher: Um hm Maria: In the park. Researcher: At the park.

Maria: She would, [Alicia] was stealing money,

Researcher: Um hm

Maria: \$3.00.

Researcher: Um hm

Maria: And then I don't know, [Veronica] was being in trouble and that's why no people

stealing money there.

Maria did not want to be blamed for anything and even once said that she never made mistakes.

The reason Rayann rejected blame it was to be truthful in her faith. She did not want to blame others for something that she did. Vanesa did not place blame on anyone during this study,

There was a reason I conjectured why participants were not interested in being more independent. Some of it can be contributed to learned helplessness. Participants became accustomed to everything being done for them so they habitually did not put forth the effort to take care of themselves. One participant, who tired easily, may have somewhat of an excuse, but she did not try even with things that she could do. There was always someone nearby who would jump to do things for them, even without being necessary or without the participant's asking. They all said they were happy with who they are and their life as it is. If they did not get something, even if it was expensive, they were content to keep asking until they got it or fantasized that one day they would.

These participants had a high interest in becoming entertainers. I believe I was the one who put that idea into their heads. Every year for the past 15 years, I have produced a talent show for Best Buddies. While it took a while to gain popularity with the general education population and it took time for the activities director to allow us to fill the auditorium, thinking that these students would have stage fright, it has now become a standard for the school and the club. General education students have come to love the show and vie for the opportunity to be invited to the show. They cheer loudly and show appreciation by responding passionately to the actions of the performers. Local media once came out to video the show and put it on the local news. Anthony Kennedy Shriver, the founder of Best Buddies, was once a celebrity member of the audience. I have the show recorded each year and pass out the DVD to each student so they can watch it over and over and relive the experience. They have now come to believe this fantasy of being a professional entertainer can be a reality for them. This was a unique finding to this study that probably will not come up in future studies similar to mine.

Across All Cases

Needs. All participants were dependent on others for health care and to ensure their personal safety. Two needed personal assistants and they represented students in the upper and lower ability range. In fact, the participant representing the upper ability level had two assistants, one at home and one at school. The participant who represented the middle range of ability was independent in self-care. The two participants in the middle and lower range were able to prepare snacks for themselves and heat some foods in the microwave with supervision. The participant in the upper level and the lower level were able to name their disability, but the participant at the middle range did not seem to be aware that she had a disability.

In the area of needs for independence in the environment, only the participant with the most severe physical disabilities, but the highest functional level, did not participate in housekeeping. All were proficient in communication whether verbal or electronic. They also were independent in seeking face to face social access, but needed assistance to access the community due to transportation needs. They all depended on the family for decision making support and financial support.

Preferences. All participants believed they speak up and stand up for beliefs about themselves and others. They all felt that they could do just about anything. They believed they have inner strength to deal with the world and two believed they had physical strength to defend themselves if needed. They felt safe in the world. All of them had fantasies about becoming an entertainer. Two believed they could become artists and one believed she could be a homemaker. One believed she could be a nurse and another believed she could be a teacher. One believed she could walk with help and wanted to stand alone to help with housework. Two wanted to get married and have children and one just wanted to hug and hold hands with a boyfriend. They all

believed they could travel independently with minimal assistance. All believed they had rights to respect, adult treatment, and privacy.

All three participants were interested in assistance from their parents or other caregivers. They preferred their families to help with financial support so they could live in an independent living situation, but with their parents nearby. They were interested in doing things by themselves. All were interested in having friends and a social life. Each one wanted to make their own choices regarding their living situation, what job they have, leisure activities, who they want as friends, what foods they prefer to eat, what post-secondary education and training they want to participate in, and where they want to travel.

Each one could name something they had the ability to do or to learn. Two of the participants named numerous tasks they were able to perform or to learn and they did not have the highest cognitive ability of this group. All were able to express themselves well. They could contact friends and support them emotionally. They could all participate appropriately in social activities and events. They could express what they wanted and ask for support if needed. They could appropriately control their emotions if desired by using breathing techniques and by removing themselves from stressful situations. They could make everyday choices independently regarding clothes, hairstyles, gifts they give others, how they decorate their rooms, and how they spend their money. They preferred to be able to live in independent housing with parents nearby for support if needed.

Goals. Participants across all cases communicated their goals of wanting to be employed one day after graduation. They were not consistent or realistic in how they would perform the steps to get a job, but they all named some measures they would take to prepare for a job upon further probing. For the most part, they expressed that they would rely on parental support to get

the job they really wanted. As for living as an adult, all mentioned plans to live on their own, but one did not feel as strongly about it. All of them did want to have their own residence, but still have their parents close by and sometimes two of them stated they wanted their parents to live with them. They gave conflicting responses at times. Only one, Rayann, was always sure she wanted to live on her own and visit her parents or have them visit her:

Researcher: What if they say, but you, but we don't want you to leave the family. Then

what will you say?

Rayann: I can't stay here forever.

Researcher: There you go. What else would you say?

Rayann: I have to move out.

Researcher: Uh huh, and then what else would you say? What if they go, but we're never

gonna see you again? What are you gonna say?

Rayann: You can come visit.

Researcher: Ok, but we won't see you anymore in your room anymore. Then what will

you say?

Rayann: I'll come visit you too.

Researcher: There you go! (laughs) Those are good arguments!

Rayann: (laughs) yea

They were all similar in planning for their leisure activities. The number one plan was to use various technological devices, like iPads, laptops, smart phones, and computers, to access music or movies in their free time. Two of the participants planned to continue recreational activities they enjoy presently. They all had plans and hopes of traveling to enjoy a recreational activity.

Maria said:

Maria: I'm gonna ask my dad.

Researcher: And what would happen, do you think, then?

Maria: I gonna ask him, dad please, I wanna go to Vanessa Hudgins concert, and then I

say, please, please, please.

Researcher: And then what will happen after that?

Maria: And he say yes.

Researcher: He will say yes?

Maria: Yea

Researcher: Who's gonna pay for it?

Maria: My dad.

Researcher: He'll do that?

Maria: Yea

Researcher: That's your plan?

Maria: Um hm

Researcher: That's a good dad. That might, that might work, that might be a good plan.

Rayann has this to say about what blocked an important recreational activity of hers:

Rayann: And she said, and she said, uh, she said, it's hard because John Ceno [Cena] has

his bodyguards with him.

Researcher: Yea, he always has that.

Rayann: And...I don't know

Researcher: That's not going to get in the way of you going to see him and being happy

watching his performance.

Rayann: Yea

Researcher: That won't get in the way, his bodyguards?

Rayann: I wanna meet him.

Researcher: Oh, maybe for not letting you meet him. Well...there's ways around that getting to meet him. Others meet him. What's your plan to get to meet John C-eno, is that

his name? What is your plan to meet him, if you, let's say you got to go to--

Rayann: And I write him letters...

Researcher: That's what I was going to say! Rayann: But I don't know if he gets them.

Researcher: He does. He has people that read it for him. You gotta make him a *really good letter*, you know, something that'll really get his attention.

Rayann: Because I didn't hear back.

Researcher: I know, big stars like that, they don't always write back. Maybe if you write to a, close to the date that he comes to do his performance, I'm, you could say, I'm gonna

be seeing you on this date and this time. Rayann: And I was so nice in that letter!

Researcher: And you were nice.

Rayann: I said, I, I told him all about me.

Researcher: Uh huh

Rayann: And I'm his big fan.

Vanesa said:

Researcher: What's something that you get help with right now that you wish you would

just, you would rather do it by yourself without help?

Vanesa: Just don't be lazy. Researcher: (laughs) um hm Vanesa: Go to, go to the concert.

Researcher: You want to go to the concert, um hm, by yourself?

Vanesa: Yea

Researcher: Um hm

Vanesa: And go different shows.

Researcher: You want to go by yourself to different shows and concerts?

Vanesa: Yea

Researcher: Ok, right now you get help with that, right now, but later on, you want to do

it by yourself? Vanesa: Yea

Researcher: Is that what you're telling me?

Vanesa: Um hm, um hm Researcher: Anything else?

Vanesa: N—And that, and, and the play those in-, play those instruments.

Researcher: Play doh's (those) instruments? (misunderstood)

Vanesa: Mmm, yea Researcher: What is that?

Vanesa: It's the trumpet. Like... (gestures blowing into a trumpet)

Researcher: Oh trumpet!

Vanesa: Yea

Researcher: So where do you see that? Vanesa: On the, on the, on the concert.

Researcher: Oh, in a concert! You went to a concert like that?

Vanesa: Um hm Researcher: Nice!

Vanesa: Um hm (laughs) I, I for-, I forgot.

Researcher: You forgot, but then you remembered it now.

Vanesa: I forgot...

Researcher: You want to go to a concert by yourself sometime, is that what you're

saying? Vanesa: Yea

Researcher: Ok, very nice.

Although they might not have provided the specifics on who, when, and how they planned to get there, they were able to express their plans to attend recreational events.

In the area of problem solving, their goals were similar regarding accepting parental decisions. They realized they needed parental guidance and advice on the best way to find solutions to future adult problems with being allowed to do what they wanted. Generally speaking, less important decisions did not need as much parental control as more important ones. As for the problem of getting support on the job if they had one, their answers were similar because of the structured questioning needed because of lack of background experience.

Goals related to self-regulation in dealing with difficult people or situations consisted of walking away or avoidance, speaking up, persistence in trying to reason with others, or

acquiescence to what others wanted. All of them expressed these themes at different times when questioned about various difficulties with others or in difficult situations.

Feelings. All participants across the board expressed some feelings of psychological empowerment and self-realization. They all felt like they could advocate for themselves by making choices, speaking up for themselves, being able to express disagreement, getting or requesting food when hungry, and calling 911 in case of emergency. They were confident they were able to do things without help even when they really were not. Sometimes they waivered between being able to do specific tasks and then not being able to do the same task later in the conversation. Usually, they all talked positively about things they could do. They all felt strongly about using technology to feel independent. Only two were worried about protecting their self-image and the other participant was not significantly aware of the psychological use for blaming others.

As for self-realization, they were all aware of some of the conditions they had, but only two were aware they had a named disability. Two of the participants could name personal shortcomings that give them problems and the other would only name people that gave her problems. All of them could name various strengths that they perceived they had. Given structured questioning, all could select ways they would learn a new task best. Each one could name some of their personality traits. They were able to express anger, but still like someone if they did not agree. They were happy to be who they were. All of them had similar adult preferences for living, working, community access, and being treated like an adult. They all shared difficulties with family members, friends, and writing. Maria had difficult explaining what she writes at work training:

Maria: Um, um, is she, is she is not there or she's not, um, I go to the back. Is she, she is there, I, I, I see her.

Researcher: Ok

Maria: I knock the, I look in the window and then she opens the door.

Researcher: Um hm

Maria: And then I sit down, gets the papers...

Researcher: Papers are mail?

Maria: Yea. They m-, they, they papers, they are mail.

Researcher: Ok. So you begin to work on the papers for the mail.

Maria: Yea

Researcher: And how do you do that?

Maria: Um, I do, I do like this (starts to write in the air then gestures sliding her right

hand to the right) and then I put my a pen, a pen right here, one, two, three.

Researcher: You're writing on the letters?

Maria: Yes, and then after that I went, and when I'm done with that, I go to the next one. Researcher: But I still don't understand what you're doing. Are you folding the letters

and putting them in an envelope?

Maria: Yea

Researcher: So you're stuffing the envelopes?

Maria: Yea

Researcher: Oh, that's part of your job?

Maria: Yea

Researcher: Do you fold paper and put it in the envelope?

Maria: Yea

Researcher: Oooh and what do you write on there?

Maria: Um, I do, um, like, like pens, like...

Researcher: But why are you writing on the letters? I don't understand.

Maria: I don't know.

Rayann has difficulty with writing her homework:

Rayann: My homework.

Researcher: Your homework!

Rayann: No. But someone does it, I just give them the answers.

Researcher: You give them the answers but you gotta think about the answers. And they

write it for you, right?

Rayann: Yea

Researcher: Ok, they write it for you, but you...

Rayann: Some, sometimes I write.

And later in the conversation:

Rayann: Sometimes when I'm write a letter th- that that doesn't make me happy, I just

erase it and do it again. Researcher: Um hm

Rayann: And make it perfect.

Vanesa talked about writing on numerous occasions:

Researcher: What gets in the way...of doing your best work?

Vanesa: Uh

Researcher: Or doing your best on anything?

Vanesa: Writing like... Researcher: Writing?

Vanesa: Yea. Like writing down...

Researcher: Um hm

Vanesa: The, the piece of paper.

All three did not like having negative feelings like sadness or anger. Two mentioned non-interests in specific physical activities in recreation and the third did not mentioned anything she was not interested in. Two reported to have religious feelings and one did not like going to church, however, resorted to prayer over her pet. Lastly, they all had the self-realization to know that their family, school, and assistants were their support system.

Additional Information

I was surprised to note that all three participants selected the same person as their best friend. Even though they have spent their entire school careers going to classes with the same students, just about, it was significant that they all picked the same person. This student's personality can be described as overly friendly, overly helpful, and into everyone else's business, but her own. She often told others what to do, even adults, and knew the gossip on everything. I suppose students in general education have the same affinity for friendship with the person they feel is the leader in attention getting behaviors and these students were no different.

Archival Data for Triangulation

Archival data consisted of survey evaluation forms produced by the Unique Learning System Online Curriculum that was approved by the local school district. The forms can be found in the appendices and additional forms were collected from their teachers during this time bound study. Participants answered the survey questions which generally aligned with the topics in the research questions. First I compared responses from the archival data I collected after

conducting all interviews and then I compared responses collected by their teachers on different forms. The purpose was to compare what they said during the interviews to how they answered the survey questions with me and then with their teachers. The attempt was to increase the validity and reliability of my interpretations of the interview data.

Maria's responses on paper. Maria said she enjoyed doing outdoor recreational activities, but then marked "so-so" instead of "like" on the survey of likes and dislikes. She repeatedly said she liked to clean, but then checked she liked messes. In the interview about her job she said she did not like working with children, but then marked she liked children. She once said she was afraid of storms and then said she liked storms on paper. Maria marked that she did not like skating and did not want to learn how to. She contradicted herself when she marked that she went to church. She also contradicted herself when she talked about how important it was for her to work in the medical field with animals and then when asked if she liked animals marked "so-so." When it came to recreational activities, Maria chose them for herself, but for costly items like clothing and haircuts, her parents decided and she was content with all the choices as reported on paper. Using a sentence completion type survey question, Maria admitted that her parents did most of the decision-making, but that she was happy with it. If she could change something, it would be that her parents would let her sleep more than they allowed her to now. For the worksheet on conversation style, Maria gave positive responses all the way down the page, even if the responses were contradictory, possibly indicating careless responses. On the sheet surveying work learning style, she was right on target with what she said during interviews. How she advocates for herself was validated by similar responses in the interviews, except for the item regarding how she interacted with friends. She marked that she only smiled at friends when they talked to her and not that she could talk and share information. I think she may have

been more attracted to the picture symbol of two friends, one talking and one listening, rather than the picture of only one person talking. On the worksheet about where she would like to live, she was true to her interview transcript except for naming places she wanted to live near. She mentioned wanting to live near the library, which was not mentioned before and she neglected to check stores as discussed verbally. For choosing a place to live she checked yes for all options, for all descriptions of independence levels, and that she liked all locations. I think she just wanted to get through with the paper at that point and was not thinking. When it came to being ready to live on her own, she checked yes for all items on both pages. She was consistent in work preferences on the documents and in conversation. She was also reliable when she noted the same personal strengths in short open-ended answers. She said she was amazing, smart, a good dancer, and a hard worker. For what she needed to improve on, she was inconsistent. She mentioned laundry and cleaning. In interviews she said she was great at cleaning and in another survey she said she does laundry. How she plans to improve her weaknesses was consistent, however, because she also said in interviews that she needed to think with her brain and use her imagination. There were some topics in the handouts that were not discussed in the interviews and could not be used for a comparison.

Rayann's responses on paper. Rayann was true to her word when she marked what she liked and disliked on the documents. Like the other two young women, she checked that she did not like skating. She marked that she also did not like team sports, Special Olympics, and swimming, possibly due to cultural concerns or it might be because of her physical limitations. She also did not like light indoor sports like ping pong or outdoor activities like camping or gardening. These facts coincided with comments she made during interviews. She did not like board games or card games and only liked to look at scrapbooks, not create them. These topics

were not asked during interviews. On paper she marked that her parents chose her clothes and hairstyle, but she chose everything else for free time activities and was happy with the choices being made. She claimed she made most of those choices about her personal life. Her short open ended answer was that she wished she could chose who she wanted to live with and that was validated many times in the interviews. She marked it twice that she would rather talk with people her age than with adults. She marked that she liked to talk to large groups of people and that she would talk to people she did not know very well. She did say in interviews that she found it easy to be friends and meet new people. She validated that she learned best by talking it out and by viewing videos. Rayann advocated well for herself and said so in the interviews and on paper. She told people who she was, signed her own name, and interacted with others independently. On paper she said she needed support to make decisions for herself and she sometimes said this in the interviews, especially when it came to traveling long distances. Rayann was consistent in saying where she wanted to live and in what setting. She gave all positive responses to living with a friend or in a group home, but did not like to live at home and was not sure she could get the help she needed if she lived alone. She was true to the interviews when she marked that she did not do housework, but could call for help in an emergency and needed help to know what to do in an emergency and help to lock the door. She checked that she needed help for personal care and meals. She noted that she makes healthy food choices, but did not do first aid for herself. She preferred to work in a clean environment, inside, staying in one place, sitting, with much supervision, wearing regular clothes, with no lifting, many people, different work, shown how to do things, with fast work. Rayann said people would say she was nice, respectful, knows herself, and knows where she wants to live. They would say she draws well, she was good at being on stage, and she was good at expressing herself and saying when

something was not right. Rayann said her weaknesses were that she needed to stand up to people better and if she kept trying, she would improve this.

Vanesa'a responses on paper. Vanesa also marked that she was neutral about liking to go outside. She liked both cleaning and messes. She agreed on paper that she liked being with all kinds of people. She liked exercising as well as relaxing. She marked that she liked skating when during the interview she clearly did not. She marked that she wanted to try hiking, but living in Florida all her life, I do not think she understands the balance needed to do so on gradient surfaces. She marked that she wanted to learn bowling, but I am sure she has had lessons before since she was a student in special education and it was very common to go bowling. In interviews she said she picked out her clothes and movies, but on paper she said her mother did and she liked the choices sometimes. She said friends pick out the videos she watches and that bore out in interview questioning. She marked that her parents pick everything else out for her, but that her caregiver picked out her hairstyle, her mother made most of the decisions, she was happy about them, and wished she could change her mom (which may be a random or repetitive thought). She responded positively to all questions about communication style. Vanesa validated knowledge of herself when she marked that she learned best by talking it out since she said that in interviews and I have personally observed it to be her learning strength, being that she was a non-reader. Pictures and working alongside another co-worker also assisted her, I have observed that also, and she mentioned those points in interviews. Vanesa said on paper that she advocated for herself independently, but only looked and smiled at her friends for interaction, which was completely not true. Other participants have said that she talked a lot and I observe her talking daily. Vanesa checked that she wanted to live in the suburbs, which she does presently, but in a group home and alone, which is impossible. She marked that she was interested in living near a

park, a grocery store, a laundromat, and a church, but did not mark that she wanted to live near friends, which she said is important to her in interviews. She marked all positive responses to the living options of at home, living alone, with a friend, group home, or care center and that she could take care of her needs in any of those places, can get help and services there, and that she liked all those locations. She did not discriminate one from the other. Even though she wanted to live near a laundromat, she later marked that she did not do laundry. She marked that she needed help for housekeeping in all areas except vacuuming and wiping the counters. Vanesa checked that she bathed herself daily, but needed help with dressing, grooming, meals, and first aid. She marked that she knew what to do when sick and kept her money in a safe place, which did not hold up in conversations. She would like to work in an environment that is clean and inside, where she can stay in one place, standing (she cannot stand for long periods of time), with much supervision, where she can dress up (not addressed in interviews), lifting (she is not very strong), with many people, same work every day, told what to do, and she wanted fast work, which was going to be difficult for her. She said people would say she was strong and healthy, a good friend, and that she was good on the tablet and computer. She did say often that she was healthy along with the other comments people would say about her that she also mentioned. For the short answer section, she said she was good at going shopping, which she mentioned, but she did not mention until this document that she was good at puzzles and coloring pictures, which was actually true for her level. She also commented in short answers that she could already tell time (she cannot), act (in our talent show), take medicine and get groceries as skills she already had. In reality, she needed assistance with all these skills. In the very next document, she commented that she needed to improve telling time skills, erasing the board (which she mentioned being able to do throughout interviews), telling people more about herself, and that she needed to do better

at working. She planned to improve by respecting other people and with more practice typing and using the mouse.

Additional Documents from Classwork

The following survey instrument was administered in other classes by other colleagues in the special education department of our school. The intent was to discover thoughts about themselves in an environment outside the interview situation and with other supervisory personnel. In addition, it was used as another way to triangulate data.

Classwork from Maria. In the community Maria marked that she went many places and liked to walk or jog, bike, swim, camp, picnics, amusement parks, garden, sled (no snow in Miami), watch TV and movies, shop, read, arts and crafts, visit friends, dance, play cards (not mentioned in interviews), and various other recreational activities that she mentioned she liked in interviews. She did check that she did not like church and that agreed with what she said in interviews. She said she traveled long distances by herself but needed help traveling to stores and going grocery shopping. She marked she was able to independently shop for clothes, go out to eat, and go into the community for fun when she spoke otherwise during interviews. She also contradicted herself when she said she attends church activities by herself. Perhaps her mother takes her to church, but she did not like it. She marked that she was independent in doing things with friends and that was mentioned verbally also. She said she could ask for rides by herself, walk safely along roads, and knew what to do if lost. Her parents, however, have told me they do not believe that she is safe in the community alone and have expressed their worries to the teachers many times. In the past she has gotten in trouble at work training for talking to strangers on the Internet so parental fear about Maria and strangers was valid. Lastly, for the community,

Maria knew who her support people were and liked to try new things, of which she was able to mention a few during interviews.

In the area of daily living, Maria marked that she would like to live with her family which she did say in interviews intermittingly along with saying she wanted to live on her own. She checked that she wanted to live alone and did not mark the hotel-appearing apartment picture cue on the same page. Maria checked that she can count money (has difficulty), budget, and buy things she needed or wanted by herself. Her documents agreed with what she said in interviews that she cooked, cleaned, and took care of health and medicine. She marked that she was independent in self-care and that was true by observation and by interview comments. She could manage herself by time and use of the calendar, also true to what she said. She checked that she could use the phone, which she talked about extensively in interviews.

In the area of lifelong learning, Maria marked that she learned best by reading and looking at videos and that she worked best alone. At the same time she wished she could read better, even though she marked she could read signs, menus, and application forms, books, magazines, and newspapers by herself. I believe she thought if she could flip through simple books and periodicals, she was reading. She said she was not interested in reading emails (although she marked being able to write emails) or writing notes, but talked about writing notes to her friends during our talks. She claimed to be able to use a calculator to add and subtract and balance her checkbook without help when in reality, she did need help.

In her personal life, Maria checked that she had no problems communicating with others, which was true. Her marked interests coincided with what she said in interviews, but she again contradicted herself about liking animals only so-so. She did admit on paper here that she did not like working with children. Here she claimed to like being outside instead of feeling so-so about

it like before. She responded positively again to all aspects of communicating with others in small groups or large, talking or listening, letting others start conversations or starting them herself. She marked she made choices, plans, moved around, and got support from others on her own and that held true in interviews.

For vocational employability, Maria marked that she had a job presently, which can be true if you count on-the-job work training that appeared to be like a real job to her. She did not agree on paper with wanting a quiet job because she marked loud. She marked she liked work that was the same here, but said in the other form that she liked work that was different every day. She said she liked to wear regular clothes for work on the previous form, but wanted to dress up for work on this form. She marked she needed help with grooming, but disagreed in interviews. She marked being independent in all other aspects of working, which was true to the interviews.

Classwork from Rayann. In the area of community living, Rayann concurred with interviews that she learned best by talking it out, watching videos, and working by herself. She wished she could tell time and use money better, which was not mentioned in interviews. She marked that she read signs by herself, but needed help reading menus, something we did not discuss. Rayann was actually one of our better readers and I think she can read, but was unsure which menu items she was allowed to eat. She claimed on paper to be able to read books, but had difficulty reading job applications, maybe because of lack of interest. She did mark that she was not interested in reading periodicals or emails, which held true in interviews. Rayann was not interested in writing job applications or emails, also true. She admitted she needed help with time and money skills, but used a calendar and calculator independently. She marked that she only went to a few places in the community and that corresponded to interview responses. She did not

like walking (in her case, using her wheelchair for walks), but liked bikes and wanted to learn how to swim, which she discussed wanting to do with her best friend and all girls. She did not like camping, picnics, or gardening, but liked amusement parks. That held true because she said she liked going to the fair with her Best Buddy. She wanted to learn sledding, but we did not talk about that in interviews. She liked all social activities on paper except playing cards, which we did not discuss. She did not like bowling and I have seen that for myself. She marked she did like to watch sports, but spoke of her interest in meeting the wrestler, John Cena. She admitted on paper that she needed help to travel long distances and to get access in the community. She marked that she was not interested in going grocery shopping, but said in interviews that she wanted to be a mother. She marked that she had friends in the community and people that visited her at home, but that she needed help to go out to visit a friend herself and that bore out in discussions. She could ask for help to get a ride, but needed help to be safe walking along streets. She marked that she needed help to choose what to do for fun, but I think it was because she needed help to get there. She had no interest in volunteering and said so. She would try new things with help and knew where to go for support, which she had mentioned.

In the area of daily living, Rayann was true to her interviews responses about where she wanted to live except for choosing in the country when she said in the city before. She was not interested in cooking, but said she wanted to prepare the food for her baby. She was also not interested in using appliances, washing dishes, or keeping her room clean, which she agreed with in conversation. She checked that she needed help with personal care and health needs, but she could pick out her own clothes and this agreed with interview findings. She previously marked that she was independent in calendar use and then said she needed help with important dates on

the calendar. She needed help answering and calling on the phone which she did not say in interviews.

For lifelong learning, Rayann concurred with interview statements that she learned best by talking it over and viewing videos. Again she said she wanted to tell time and use money better, but she made the same comments about reading abilities and interests. She again said she could use a calendar and calculator by herself.

In her personal life, Rayann had no problems communicating with others, which held true in interviews. She mentioned the same likes and dislikes and added that she did not like animals, which she says all the time when asked at school. She liked all social activities, but as for being outside she marked so-so. Again she marked that she did not like cooking, unless, as in interviews, it was to feed her baby. She liked all verbal interactions and did not like being quiet, which was verified in the other document. She did not like cleaning, which was verified. She liked all aspects of the give and take in conversations. She marked she was able to tell her needs, for which she was given credit in independence during interviews. She claimed to need help making plans with friends and in choosing clothes to buy which she talked about in conversations. She once said she chose her own hairstyles, but marked here that she needed help. She checked that she needed help with mobility, but had no problems interacting with others, which was true. She wanted to learn how to go to meetings to plan for her future, which we did not specifically discuss, but talked about it in a round-about manner

For vocational employability, Rayann marked that she went to school to learn about jobs and did not mark that she did not want a job, which may be closer to the truth. She wanted a clean, inside job, with few people around her. She wanted no lifting, sitting, but moving around, if that is possible to do at the same time. She wanted work that was different every day and slow

with much supervision. She wanted to be shown how to do things and to be able to dress up for work. She did not want to fill out job applications, make resumes, or go to job interviews. She checked that she needed help with dressing and being on time. She was not interested in following a schedule but yet can follow directions by herself. She marked she needed help getting out her work materials and that was true because they are kept behind her wheelchair where she cannot reach. She worked independently, but needed help to finish on time, probably due to fatigue issues. She marked that she fixed mistakes with help, but said in interviews that mistakes bothered her and she spends considerable time getting her work just right. She checked she was not interested in cleaning up her work area and that coincided with interviews about cleaning her room.

Classwork from Vanesa. For community living, Vanesa marked that she went many places in the community, which was true, and that she would like to learn walking/jogging (she has a physical disability), swimming, and biking, for which she could all do with support. She wanted to learn about camping, but liked picnics, parks, gardening, sledding (maybe she has visited other places to sled), and various other social activities including shopping and going out to eat. She marked that she wanted to learn how to play cards and bowl (which is a common recreational activity for our students). She mentioned on paper and in interviews that she liked to watch sports and go to church. She checked that she wanted to learn about vacations, but I know she participated in vacations with her mother. She claimed to be able to travel long distances by herself, but then marked that she wanted to learn how to travel within the community. She said she shopped by herself, but needed help eating out and going into the community for fun. It was true that she needed help to attend church activities and also that she made friends independently. She marked needing help visiting her friends and having company visit her at home. I am not

sure what she meant by needing help with company because she was very sociable. She checked that she needed help to go places, to walk safely along streets, and to choose fun things to do, which bore out in interviews. She knew she needed help if lost and needed help with support people. During the time of this study, her mother had to hire a new caretaker and it was possible that was what she was referring to, but I cannot be sure. She marked she wanted to learn how to volunteer and needed help to try new things.

In the area of daily living, Vanesa marked that she lived at home, but that she wanted to live by herself as an adult in a care center, which was a contradiction both on paper and in interviews where she waivered frequently between wanting to live on her own, but by her definition, in her own home with her mother. She checked she wanted to live in the country and to her credit, she did mention wanting to travel to a farm during interviews. She marked needing help counting money and budgeting, but that she was able to spend money by herself. She took care of food preparation needs and housekeeping with help and wanted to learn how to wash dishes. She marked, however, that she did laundry by herself, which was a contradiction in interviews and on the previous survey document. She handled emergencies by herself, but needed help when sick, which is a contradiction in itself. She marked that she needed help with taking medicine, bathing, and picking the right clothes to wear. Vanesa checked that she knows important dates on the calendar and tells time when she needs to go places, which contradicted what she said in person and on other forms. She said interviews that she used the phone by herself, but marked that she needed help on the present form.

For lifelong learning, Vanesa marked that she learned best by talking it over, by using pictures, and under the direct supervision of an adult, which was verified in interview conversations and in observations. Vanesa was happy with all her academic skills she has now,

but said in interviews that she wanted to read as well as Rayann. She checked that she read signs, menus, applications, and magazines with help, but that she read books by herself. That may seem true to her because she loved to look at books and may have considered this to be reading. She was not interested in reading emails. She marked that she wrote her name by herself and she can. She checked that she wrote notes, emails, and job applications with help. She counted money and bought things with help, but told time, used a calendar, and used a calculator by herself, which did not hold true in real life.

In her personal life, Vanesa checked that she interacted with her voice, wrote her name, but only smiled and looked when others talked to her, an obvious contradiction. She liked all activities and interactions with others, except being with animals. She claimed to not like people asking her questions, but was the only one to ask about continuing using the microphone to record our interview conversations. She also claimed to like listening better than talking.

Although she was a good listener in class and this was her learning strength, she demonstrated chattiness and talked about making conversations during the interviews. She marked that she needed to learn how to tell others what she needed and she had a point. Vanesa was easily persuaded. She marked being independent in asking for help, making plans, making choices, but needed help moving around the community, which was true. She needed help to go to meetings to plan her future and she said she would ask an adult for help in interviews.

As for vocational employability, Vanesa marked her understanding that she went to school to learn about jobs. She wanted a job that was clean, inside, quiet, with a few people, and she again said that she could lift on the job, which would give her difficulty. She said she wanted a job sitting, but on the other form she said standing. She verified she wanted to work staying in place, wanted fast work that was the same every day, with much supervision. She may not be

able to handle fast work as she marked here. She maintained that she wanted to dress up for work and be told how to do things. She checked that she filled out applications and resumes with help and wanted to learn how to interview. She wanted to learn how to wear clean clothes, groom herself, and tell time to get to work on time independently. She wore the correct clothes with help she reported. She wanted to learn how to follow directions and followed a schedule with help. She wanted to learn how to begin work right away, but got out her materials by herself. She wanted to learn how to finish her work on time and get back to work quickly when distracted. She wanted to learn how to fix mistakes and clean up her work area and asked for help with assistance. She checked that she was able to follow safety rules.

Member Checking

Each participant had a final interview to perform member checking with me. I reviewed their responses to each question and asked if I had their story correct. None of them changed their responses, but Rayann asked me to not include some of her responses in the final report and I respected her wish. In addition to performing member checking during the actual interviews, I used the last session to verify that I had accurate responses.

Memos

In looking over memos I wrote immediately after interviews, I saw a few significant details about my thinking. Memos were not directly analyzed, but threads of what I wrote weaved in and out through the analyses. In addition, some of the topics I wrote about are contained in the literature I had read. I noted that participants were enjoying the interview sessions because they were already asking when the next one will be. I also noticed early on that I was asking too many yes-no questions, but I did not know how to avoid it since I was not getting much information. I realized that it did not matter what order the information came in as

long as it was coming in. I also wrote that I was surprised that it did not matter the functional or academic level the participant had, the language level equaled everything out. I noted researcher fatigue early on and was unsure when to let a participant talk and when to bring them back to the research questions. Many times participants said they did not know, when I knew or thought they did.

I really felt like a novice interviewer because I kept interrupting, teaching along the way, and revealing what I knew about them without getting them to say it first. I attributed it to too much special education training: scaffolding and supporting participant answers. I was too excited to wait for the rich text. Sometimes I had to let lines of questioning go because I could not seem to get the participant back on topic, they were getting frustrated about repetitive, reworded questioning, or I felt they were not going to get what I wanted them to do. I was also worried about the time factor. Toward the last few interviews, I was seeing the same answers showing up repeatedly. Interviewing was a learning experience for me.

. After telling myself not to give in to the temptation to ask parents for verification of what their child was saying, I did. I asked Maria's mother if she really did that much housework around the house and her mother told me that she did very little around the house in the way of housework. She also said she spent all weekend sleeping and was obsessed with her tablet and the computer. Maria was much clearer describing activities I happen to know she actually did and she tended to get dramatic during our talks and complained often.

Rayann got emotional at times, but she did not cry. I did hear her voice crack though on sensitive topics. She was the most consistent in her answers and stayed on topic the best, but she also was the highest functioning. To get her to perform her best, I allowed her to talk longer on topics she was most interested in and moved quickly over topics she was not very interested in,

especially ones that involved physical activities she could not participate in. Just as the study was ending, Rayann gave her best answers ever. I did not know if it was because she got the idea of how to answer better, the content of the questions were richer, or I was getting better as an interviewer by letting her talk more than I did.

Vanesa had a difficult time staying on topic, but I also did not help her at one point while discussing the post office questions. I felt that that section was outdated and participants would not know how to answer it so I drilled them too much on that topic when I should have moved on. It was not that significant to spend that much time on. Vanesa got fatigued and I noticed she laughed more than usual when tired, but would not ask for a break or take one when offered. I did not want to drive Vanesa crazy by repeating the same questions and expecting different answers. I had to take what she said as much as possible and move on when I observed gaps in understanding and nonsense answers. It was difficult to ask the questions in terms she could understand without losing the intent of the question. For one session there were many interruptions, but it did not seem to matter much. Vanesa would often interrupt herself and blurt out off topic phrases, like asking me about my daughter, who she knew from internship at the park she attended. Vanesa was always especially eager to come to our interviews and asked to talk into the microphone long after the study was completed.

Memos were taken on the last interview day surrounding what happened during the written part of the surveys. Maria marked her answers all the same way down the line, possibly to just get it done and over with. She would mark yes before I even finished reading the question to her. I had to take the pen away until after I read the question so I could get her to contemplate the answers. She remained contradictory in her answers until the end. For Rayann, I only wrote for her after she became fatigued and then I would only transcribe what she was saying. Some of

her answers were right on target and confirmed what she said during interviews. All the memos confirmed what was happening during the interviews and agreed with the data analyses.

Summary of the Findings Related to the Research Questions

Needs. Each participant expressed their unique needs for independence. Maria was the most independent in caring for herself and participation in the environment. Rayann was next, in spite of significant physical limitations, because she had the best language and reasoning skills. Vanesa, representing the most significant cognitive disability, was least independent, although more able-bodied than Rayann. I had to give Rayann recognition for being able to ask for help since she was physically unable to do many tasks for herself. All participants, however, expressed their need for assistance and support from others to be independent. All felt that they were more independent than they were in reality. I found them all dependent on others for self-care, safety, health needs, housekeeping, community access, and financial support. This was an expected outcome and answered the research question regarding needs for independence.

Preferences. Participants also answered the research question about preferences related to beliefs, interests, and abilities. All believed in themselves and their abilities to do just about anything they wanted to. That belief system can be attributed to the way special education professionals treated students with significant disabilities at this school. The interests of these participants reflected interests of other young people without disabilities in that they were all closely attached to their technological devices and are not happy without them. They were all highly interested in making their own choices about where they will live, work, go to post-school education or training, who their friends are, what foods they eat, where they will travel to, and mostly what they want to do in their free time. Leisure time choices were especially important because this population had more of it than any other. They were rarely hired and typically spent

much time at home. They dreamed big, however, and had fantasies of fame and fortune with rudimentary explanations of how it could be possible. Dreams they had that were and should be possible were: their own place to live, a job of their own, and access to society and the community.

Goals. Participants' goals for getting what they wanted, solving problems, and self-regulation were captured by the corresponding research question. Even though participants generally knew how to use a calendar to schedule activities, they sometimes did not have concepts of days, weeks, months, and years while in conversation. They spoke of how they would solve problems in their interactions with others at home or on the job. The primary way they expressed they would get their way was to verbalize it to their parents or caregivers. If parents did not agree, usually participants would give in to parents' wishes. That would not stop them from continuing to ask for what they want in life, however. Parents were usually the gatekeepers to what their child with disabilities got to choose and participants knew it.

Feelings. The research question about feelings regarding psychological empowerment and self-realization was answered merely by allowing these marginal members of our society to have an outlet with which they could express themselves to the world. They were able to advocate for themselves, express confidence, and voice their adult preferences. They were happy to be who they were and to live the life they were in. Even though they had a child-like view of the world, they proved that they are not children (Forster, 2010). They observed what went on around them and had a range of feelings that were surprisingly well articulated. I was even able to record profound religious feelings that really surprised me.

Unexpected findings. I did not expect to find so much missing information or the extra information I was not asking for. Most missing information was due to lack of background

experience since the standard measure by Wehmeyer and Kelchner (1995) that I used to develop the interview questions was geared to a population with higher intelligence scores. In addition, my participants would drift off topic perhaps more than most people. Likewise, they would repeat key phrases and habitual answers and would perseverate on the previous questions without answering the current one. They also did not understand what I wanted at times and were too eager to please, changing answers based on my tone of voice. The extra information mostly came from one participant's attempts to deflect blame away from herself and on to others. It also came from a high interest level in becoming an entertainer, based, I believe, on their successful experiences in performing in our annual school talent show. Feeling compelled to give credit to all of their expressions, I added these two categories in the final analysis.

Unexpected results that were significant. I thought it was significant that all three participants mentioned that they wanted "peace" in their lives (Duignan & Connell, 2015). Maria talked about the right to peace and quiet, Rayann wanted peace at lunch, and Vanesa liked being told what to do peacefully. At this level of cognitive development, this was a very abstract concept that they seemed to understand and all have in common, making it a significant finding to me, as their teacher. The concept of peace related to the tranquility one can find in the home that created an atmosphere of close, caring relationships (Duignan & Connell, 2015). They all seemed to talk about a pleasant home environment that included a sense of this tranquility. I was surprised that they each mentioned something this deep and I thought I knew them all so well.

Another concept all three participants mentioned wanting in their lives was "respect." I was surprised at how often respect was mentioned throughout (Duignan & Connell, 2015; McDonald, 2012). They all talked about how they respected others and wanted others to respect them. I thought that was very insightful of them and it was actually an important quality to have

in life. I also believe it went beyond what I had been trying to teach them at school. I believe it also was taught at home.

In addition, all of them said they like being who they are and that they were good at being themselves. No one felt unhappy because of their disability, except Rayann who did not like not being able to walk, but was happy otherwise when she got want she wanted. She was happy to have so much personal assistance at home and at school and was content to let it continue. She was happy just to think about her dream life for the future. I tell students in class that the goal of all the teachers is to have them to become happy, independent adults. It seemed that they were already happy with themselves and had positive self-concepts. That did support research findings that students with significant intellectual disabilities have a protective factor because they did not realize how disabled they really were (Varsamis & Agaliotis, 2011). I was surprised to find it to be true in the participants that I know and care about. Now, we just have to help them become more independent or, as we say, as independent as possible.

When participants described how they wanted the environment to be in their home as an adult, I was impressed by how each one described it. All said they wanted to be surrounded by people they were close to, in addition to having peace in the house and in their lives. What really stayed in my mind was the way they described wanting to hear music being played in their homes. Music came up many times during our interviews and it appeared to be a significant finding to this group. The way they described the living environment of their dreams even made me find it appealing and I was amazed at how they were able to communicate it. I believe it was more important to them to live as they wished than to work as they wished. They may not ever get jobs, but they all have to be happy where they are living.

Expected results that were not significant. Wanting jobs that were unrealistic and out of reach without extensive modifications that would be unreasonable for the job requirements was expected. I believe it is fairly common for young adults to want to be entertainers, medical professionals, or teachers, not knowing what it takes to do so. The modifications it would take for these students to realize these job goals would be unreasonable and employers would not be willing to carve out a job placement especially for them in that manner (Luecking et al., 2006). It was difficult enough to get employers to hire our students even for entry level positions with support. I agree that supported employment should do more to find job placements that were more in line with student interest, but that did not always happen in the real world. We need to do more to place students near people that work in their dream jobs, but at an entry level. That was a finding that I already knew about.

Conclusion

After eight interview sessions for each participants, I collected a massive amount of text data to analyze. Each participant was verbal and expressive, considering their cognitive abilities. They represented a cross section of three levels of ability and characterized their classmates who can and cannot express themselves, but likely had the same thoughts and feelings about transition to adulthood after high school graduation. Perhaps male participants would have had slightly different stories to tell, but human need would make their stories very similar.

They all were aware of their dependence on family and others to satisfy survival and safety needs. They also knew they were dependent for interaction with the environment regarding community and social access, travel, and financial support. They felt somewhat independent in housekeeping, preparing snacks, and using technology. They believed they were able to do just about anything, had friends that liked them, and had rights to adult treatment and

respect. They were interested in independence with parents still available to them, in friends and a social life, and in making their own choices about their living situation, jobs, leisure activities, friends, what foods they like, where they would like to travel, and post-secondary education and training options. They expressed that they had abilities in job training, education, and learning new skills. Cognitive differences did not create significant variations for their abilities to express themselves to family and friends, in social activities, or in verbalizing choices. They were all sufficiently verbal to express abilities and any other topic of this study. They were able to express what they wanted, to express how they could control their emotions, and to express how they could make independent choices for their living situation. All expressed goals for how to get what they wanted, how to solve problems with parents and co-workers, and how to regulate themselves in dealing with difficult people or situations. They expressed feelings of psychological empowerment through self-advocacy, having confidence in themselves, protecting their self-image, and by being able to use technology. Through self-realization they were aware of their own feelings and abilities, their adult preferences, their difficulties, dislikes, and noninterests, their religious feelings, and most of all, who they could turn to for support.

Even though there were gaps in their responses where information was missing or extra information was offered that lead the interviews in a different direction at times, this study was successful in capturing what the participants thought about their transition to adulthood.

Chapter 5: Discussion

Summary of the Findings

The purpose of this case study was to describe and understand how self-determination can be expressed by specific students with low-incidence disabilities at one high school in the Southeastern United States. The research questions were as follows: What needs, preferences, goals, and feelings are expressed in students with significant intellectual disabilities? What needs are expressed related to independence? What preferences are expressed based on beliefs, interests, and abilities? What goals are expressed related to self-regulation? What feelings are expressed related to psychological empowerment and self-realization?

Utilization of a qualitative case study. Interviews were the main technique for capturing text data (Agran & Hughes, 2008; Baxter & Jack, 2008; Chenail, 2011b; King & Horrocks, 2010; Thoma et al., 2008) and archival documents with member checking (McDonald, 2012) was how information was triangulated. A case study design (Baxter & Jack, 2008; Unluer, 2012; Yin, 2003) was utilized to explore the unique experiences and thoughts of unique participants. Themes were coded by research question and by what participants brought to the interviews in their responses. Data was analyzed within each case, between cases, and across all cases to improve validity and reliability (Miles et al., 2014; Saldaña, 2013). In addition, data was triangulated by the archival documents and member checking. I compared what was said to what was marked on paper. Due to the fact that these participants have communication difficulties (Carter, Owens, Trainor, et al., 2009), the significant statements they did make and the comparison within, between, and across cases meant that there would be much material that would be repeated (Webster & Carter, 2010) and that was what happened. Furthermore, some themes overlapped because they could fit into more than one category (Saldaña, 2013).

Emerging themes were missing information and extra information to capture all utterances that could possible hold meaning for the participants (Angell et al., 2010; Lindstrom et al., 2007).

Preconceptions. First I felt it was important to discuss the preconceptions I had before I began this study (Chan et al., 2013). I thought all participants would want to live in their own residence and have a significant other (Arias et al., 2009) or a close friend to share it with. I also thought all participants would want a job in supported employment (Carter, Owens, Trainor, et al., 2009; Cobigo et al., 2010), where they would hold entry level positions with the support of a job coach, because this is what we teach.

Because they have such poor math skills, I expected that they would not comprehend how much money it takes to support oneself and they would not be aware of government funding they were eligible for (Storey, 2005). In addition, they did not comprehend what they really have to do to get and keep a job. They seemed to believe they can just walk into a business, ask for a job, and get it.

I knew that travel within the community would be an issue since most parents of females with disabilities did not trust a male provider of special taxi services, which was realistically what we had available in this locality. If an adult with disabilities lived in a supported living facility, they would have had van transportation services provided to them as part of the package (Laurenz, 2005). The van, with adult supervision, would take them during the day to jobs or activities at an adult center. As it is now, they would probably always need to rely on parents for transportation if they continued to live at home.

Most of our students did continue to live at home because parents seemed reluctant to give them up to a housing agency for special needs until it was too late and parents had already passed away (J. Mendez, personal conversation, Sunrise Community, Inc., Supported Living

Services, February 15, 2015). They assumed siblings would take in their child with disabilities, but that was not usually the case once the parents were gone. Contrary to most parents' opinions, adults with disabilities enjoyed living on their own (Marlow & Walker, 2015; Roper & Jackson, 2007) and could still come home to visit the family at will. The support check parents received for their child may also be a factor in why they did not allow their adult children to live in another home. Despite numerous attempts to provide information on these topics to parents, most did not take advantage of these opportunities. I expected participants to remain very dependent on what their parents decided for their lives.

Interpretation of the Findings

What I thought I would find when this study was designed meant that these participants, who were rarely part of any research that involved getting their verbal input, would finally get to have their voices heard. The case study design meant they each person would be able to reflect on their own thoughts about their life and the unique way they felt about it. Once a researcher strives to sample a population who has significant intellectual disabilities, there will be much variability in the types of disabilities that will be represented. Each will have a unique set of circumstances due to other conditions that will most likely be present, such as physical, sensory, or other health issues. I tried to sample a higher, middle, and lower ability case condition, but I had to limit myself to participants who could speak to be able to get rich text data.

This study was limited by poor participant interest since I had to invite them anonymously and parents did not recognize me as a university student they knew. I had another serious issue regarding consent and competency to consent to research since some potential participants were 18 or older and parents did not have legal guardianship established. It took 6 months to get IRB approval after going back and forth between the university and the local

school district. Finally, lawyers for the university declared my participants independent and competent to consent to research since the study was deemed beneficial and no serious harm would come to participants. A similar study had difficulties akin to mine (Nicholson, Colyer, & Cooper, 2013), but was approaching potential participants as an unfamiliar person. For me, once they had an idea I was the researcher, it made recruitment to my study easier. The study by Nicholson, Coyler, and Cooper, 2013, suggested one improvement that this study did not need: graphic information about the study to inform participants during recruitment. I used adapted consent forms with picture symbols of each aspect, which was a tremendous aid to understanding. Illustrated consent forms were approved by the IRB.

Lastly, this study was limited due to the lack of male participants who showed interest to the invitation into the study. All participants were female and aged 19 to 21. Even though the target sample was older students closer to graduation ages, I would have taken younger students to get a more widespread sample, especially if they were male. To complete this study in a timely manner, I was compelled to sample participants who were more verbal than most.

Meanings and understandings. Knowing the participants well and how they expressed themselves, I was able to interpret what they were trying to say. I knew how to give them background information so they could answer because I was able to give examples from what was happening to them now in their lives. Not all of them were interested in having a job, at least a job that was realistic and feasible. They all expressed a fantasy job they would like to have, namely an entertainer of some sort. One wanted to become a professional dancer, one wanted to become a professional singer or artist, and one wanted to become an instrumentalist using the iPad. The annual talent show they participated in no doubt influenced these responses.

All participants mentioned wanting to have a significant other in their lives, but one did not want to actually get married, but just wanted to hug and hold hands. For many of our students, it was enough just to have companionship and perhaps someone of the opposite sex to watch TV with and do other activities together. One participant mentioned wanting to get married and have her own apartment with her husband and children. The other wanted to marry a famous rock star, but also live with her best female friend. All gave inconsistent responses to who they would live with, ranging from staying at home with the family, having the family live with them in their apartment, and only having the family living nearby for support. Maria mentioned the same rock star as her boyfriend five times and I did not catch it until I analyzed the transcripts. That might have been a sign of researcher fatigue.

Archival documents differed from interview data at times, but not in areas of significance for transition planning to life as an adult. The differences could be attributed to not remembering what they said the first time or possibly liking more than one close-ended response on the surveys. Member checking also agreed with the data collected and was performed during the last interview meeting. All agreed that I had captured their story accurately and only one requested that I not use some information about family dynamics. I reported that fact because these participants usually did not question adult authority and were especially complacent and compliant.

Significance and substance within the literature. The findings agreed with and extended existing literature in that participants demonstrated the difficulty of getting accurate responses (Dincer & Erbas, 2010; Dion & Cyr, 2008; Iacono et al., 2009; Wetherell et al., 2007), yet the responses that did emerge were significant to the participant that provided them (Agran & Hughes, 2008). This study filled some of the gaps in the literature that did not include the views

of individuals that were living with a significant disability (Ali et al., 2011; Shogren & Broussard, 2011; M. Ward, 1988). Responses were geared to the research questions and patterned after the standardized measure (Wehmeyer & Kelchner, 1995). The interview technique was similar to the standards used for child abuse questioning (Dion & Cyr, 2008; Faller & Nelson-Gardell, 2010; Hershkowitz, Fisher, et al., 2007). The study findings fit in with distinctive population characteristics (Stevenson, 2010). Participants with lower abilities were able to give some input into their own future planning as opposed to what some professionals in special education believed (Thoma et al., 2008). They were able to feel a sense of control over what happens to them which matches the underlying theory of self-determination (Ryan & Deci, 2000). These participants did not have serious behavior problems, but it was possible that the results of this study will help their parents better understand them at home as noted in the literature (Heiman et al., 2008; Mill et al., 2010).

The findings also clarified contradictions in participant responses and in the literature (James Martin et al., 2005). I expected there to be some disagreement between what they said in interviews and what they said on a paper based closed-ended survey due to memory issues (Danielsson et al., 2012; H. Kleinert et al., 2009). In all fairness, it cannot be said that individuals without disabilities would be able to give completely reliable answers to interviews questions when compared to survey responses conducted at some point in the future (D. Chambers et al., 2009). These individuals cannot be faulted for being human and making mistakes.

Context of the Findings

How findings fit in with the literature review. The characteristics of the population under study was similar to those found in the literature with some differences. Few studies involved school-aged participants such as these, probably due to the difficulties of getting

approvals to do research from both the university and the public school system (Dye et al., 2007; Nicholson et al., 2013). I was in a position where I was an insider to both which gave me an advantage another researcher may not have, being that I was a classroom teacher and a doctoral student. This population consisted of students with significant intellectual disabilities in the moderate to severe range of functioning and preferably in the upper grades of high school, anticipating an upcoming graduation.

There were few qualitative studies in the literature with which to compare this study on self-determination and transition. One study gathered perceptions by pre-service teachers (Thoma et al., 2008) and another involved adults with physical disabilities who offered advice to those with disabilities coming up after them (Angell et al., 2010). I was able to find qualitative studies on self-determination of adults with significant disabilities who had already transitioned to their adult living situations (Shogren & Broussard, 2011), but none for those before transition. In my pilot study, I was able to sample adults I knew who had already graduated and that was helpful as a comparison.

Agreement with existing literature. Research has shown that for individuals with significant intellectual disabilities, it was common for others to make decisions on their behalf without consulting with the person living with a disability (Kampert & Goreczny, 2007). The seminal research study on self-determination defined it as "people taking control, without undue external influence" (Interstate Research Associates, 1988). People often spoke for them and I did also, even though I tried not to. I understood that this group of individuals was most at risk for denial of choice and loss of control over what happened to them (Finlay, Antaki, & Walton, 2008). In trying to support their communication efforts, I often interpreted what they were saying on the spot, and not during data analysis as I should. To counteract the effect of my exerting

control over them, I tried to verify that I had their story correct immediately after they expressed it (L. Powers et al., 2007). While not a hundred percent reliable since they were easily led (Orbach et al., 2000), it was better than not trying to interpret telescopic or off topic comments which may carry some meaning to them.

Other studies have shown that these participants characteristically demonstrated a learned helplessness (Causton-Theoharis, 2009), lack of awareness of their own weaknesses (Hebblethwaite et al., 2011), and a lack of background knowledge in both knowing what options were out there for them, and knowing how to respond to questions about situations they had yet to experience (Hanson-Baldauf, 2011; Lotan & Ells, 2010; Mazzotti et al., 2010; Nicholas et al., 2006; T. Smith et al., 2007). They did not have the information to make an informed decision about important life events that would happen in their not-so-distant future (Storey, 2005). They had adult interests, but still had a child-like world view due to living sheltered lives (Brotherson et al., 2008; Hogansen et al., 2008; Leake & Boone, 2007).

Even though the body of literature in the special education field recognized the enormous constraints language and communication (Finlay, Antaki, & Walton, 2008; Jingree et al., 2006; Olney, 2001) can have on the ability to control one's destiny, this study showed the participants could recognize and express a range of feelings within themselves. They did have difficulty at times staying on topic. In addition, they were often unsure of what I was asking of them or what I was talking about, resulting in many responses of "I don't know" (Saldaña, 2013, p. 92). With further probing, encouragement, and repetition, I was able to get some on target responses. Being understood for these participants depended on familiarity with their idiosyncratic manner of speaking and my ability to understand them (Flint & Klein, 2006).

An area often not considered during transition meetings was independent travel in the community (D. Chambers et al., 2009). These participants each expressed what travel meant to them and expressed a desire to do so independently. They understood that, as a last resort, they always had their parents who would give them a ride (D. Davies et al., 2010).

Contradictions with existing literature. I expected the participants were going to be more displeased than they were about living with a disability and their unmet needs for independence (Harr et al., 2011). For the most part, they were happy the way they were. Some possible reasons for this were relatively good health, social connectedness still being experienced while in high school, and perceived autonomy (Lehmann et al., 2013). Lehmann et al., 2013, further discovered that happiness was reduced as these individuals aged, associated with increased loneliness and less autonomy due to effects of aging on the body. These participants were not aware how much their lives would change when high school was over and isolation begins.

A study by Rose and Gerson (2009) found that participants recognized anger in themselves more often than staff who could not percieve these individual's innermost feelings. The study of anger contained approximately twice as many men as it did women which may account for the difference in self-reporting of anger, but did not differentiate between anger assessment differences of men and women. I was not able to find specific research on anger or unhappiness and women with disabilities, but I did find research comparing males to females and how socialization and sensitivity to socially supported behaviors affected suppression of anger in females (Karreman & Bekker, 2012).

I was surprised that one participant was not really interested in being more independent and preferred to rely on her assistants for support (Causton-Theoharis, 2009; Giangreco et al.,

2005; Inman et al., 2011). The literature on the topic of non-interest in employment was lacking, but this individual was extremely unique in this line of thinking. Most of these individuals held a high level of interest in being employed, even if it was unpaid volunteering (Lysaght et al., 2009). I thought all of them wanted to live in their own place, but one other participant did not really want to, possibly due to fear of being harmed in some way or that merely being close was satisfying enough (K. Ward, Atkinson, Smith, & Windsor, 2013). Another participant really believed in her fantasy life style as a professional dancer married to a rock star (Harrington & Harrigan, 2006) and I did not predict that she would make those statements in an interview setting. I did not realize she was so influenced by the media and their portrayal of women (Rifà-Valls, 2011).

All mentioned wanting their own apartment, but at varying degrees of sincerity. All were interested in having family nearby, even if they were living in their own residence (Lindstrom et al., 2007; Mill et al., 2010). Truthfully, if someone wanted to continue to live at home, it naturally follows that it would be perfectly acceptable and their choice. More and more adults have been delaying living on their own in recent times so it should be equally accepted for these participants (D. Chambers et al., 2009). In addition, needs should change with the person as time goes by (Meissner, 2011). Individuals with significant disabilities needed to see firsthand the possibilities and potential there was in the community to live on their own before they could be fearless about obtaining support away from home (Bigby & Fyffe, 2009). Living on one's own for the first time was an important decision requiring advice from multiple support sources in anyone's life (Lotan & Ells, 2010; Mill et al., 2010; Thoma et al., 2008).

I also thought all of them would want to get married, but one did not and only wanted a friend to hug and hold hands with (K. Ward et al., 2013). Having a special friend to confide in

and have companionship with builds emotional resilience while moving into adulthood (Williams & Heslop, 2006). Having a significant other did not always mean marriage.

I was surprised at the complexity of language they were able to produce at times.

Research showed little on self-regulation which included choice of goals, preserving through a plan of action, asking for help when needed, and a positive self-concept (Varsamis & Agaliotis, 2011) due to communication difficulties (Snell et al., 2010). I knew I had selected participants with adequate speech abilities, but they made comments beyond what I thought were within their abilities.

Solution or clarifications of contradictions in research. Capacity and competence were two aspects of independence that should not place comprehensive restrictions on individuals with disabilities to make choices and decisions because of the variability among members of this group (Meissner, 2011; Willner, 2011). Choice making was considerably lower for those with moderate and severe intellectual disabilities as opposed to mild (R. Smith et al., 2005). Use of communication technologies could assist these students to have their voices heard in IEP meetings where transition to adulthood was planned, giving them a voice in their own future (Skouge et al., 2007). What was even better than technology was the human act of listening and reading body language of individuals who could not communicate verbally (Flint & Klein, 2006). It takes a certain level of cognitive ability to use communication technology and it was still cumbersome at best when compared to natural communication with those who know them well.

Implications of the Findings

This study had the potential to improve and change the field of special education and its view of all the components of self-determination for individuals with significant intellectual

disabilities, who were rarely allowed to participate in research as an equal partner. This study was not about them; it was with them. The voices of those with the most significant disabilities were heard. Without their input, this study would not have been possible. I looked at all aspects of self-determination in a qualitative design, which was an area not tapped into previously at the time of this study.

Research methodology. This study held importance to the discipline by advancing qualitative research methodology with these participants. There were scant research studies in qualitative design (Nicholson et al., 2013), in addition to few case studies for individuals with significant intellectual disabilities (Yin & Davis, 2007). There were no pre-made interview formats patterned for use with this specific group of individuals using the topics in the objective measure of self-determination. While the interview question format was extensive, not always relevant to the present lifestyles, and tedious to administer, it was a starting point in consideration of an improved design.

Current theory and theoretical framework. The underlying theory was consistent with the theory of self-determination, which focused on internal motivation that was self-driven instead of external motivation which depended on outside influences (Ryan & Deci, 2000). It addressed the gap in research for these students and their voices. It improved understanding of the phenomenon of self-determination (Carter, Owens, Trainor, et al., 2009) by delineating exactly what these unique individuals who were living with a disability said that they need, prefer, plan, and feel about their future transition to an adult. Even though this study could not be exactly replicated (Baxter & Jack, 2008), it shed light on the life of individuals with significant disabilities and their views of the society in which they lived.

The findings were consistent with self-determination theory, which addressed internal motivation to control one's life situation (Ryan & Deci, 2000; Vansteenkiste et al., 2006). Participants came willingly to interview sessions and were eager to be heard because the conversation revolved around their needs and their lives. Breaks were rarely taken and short, if they were. Participants appeared to be motivated by an internal reward system and appeared to enjoy being interviewed. External rewards were given at the end of interviews to express appreciation for thinking and working hard on all eight sessions. Fruit juice was provided for each session, to ward off possible hunger or thirst and to make for a more pleasant interview situation. One participant, truthfully, was motivated to join the study because of the proposed reward of a gift card at the end. She was the same one that repeatedly expressed her love of shopping and she decided to earn the gift card by participating in the study.

This study advanced research methodology merely by adding to the sparse literature in qualitative studies (Agran & Hughes, 2008). Since the participants were unique, the findings added to the special education literature that included individuals with significant disabilities (Hall, 2010; Heller et al., 2011). In addition, it was rare that literature included school age students that were over the age of 18, but their competence to consent to research was still an issue due to their ability levels (Wehmeyer et al., 2008) and unestablished guardianship (Willner, 2011). Finally, the particular technique used to interview participants such as these was advancing the practice of open-ended questioning for research (Hershkowitz, Fisher, et al., 2007; Kirova, 2006).

Interest and relevance in findings. The results of this study may be important to the students with disabilities themselves, their families, teachers, pre-service teachers, the community, and potential employers. For the students themselves, it forced them to take a look at

themselves and what they really wanted in their adult lives (Nonnemacher & Bambara, 2011). Families also had a stake in what made their child happy in their adult life (M. Hughes et al., 2008; J. Martin et al., 2007). Self-determination was an important teaching area for teachers and pre-teachers and must be addressed when writing Individual Educational Plans (IEPs), especially transition IEPs held at the end of their high school career (Branding et al., 2009; J. Martin, Van Dycke, & Greene, 2006). Self-determination improved choice and decision making, quality of life, transition outcomes, and adult independence, which was the ultimate goal for special education (C. Chambers et al., 2007). In the local school district in which this study took place, there was very little information or guidance in how to teach or present self-determination concepts to students.

The community and potential employers also needed to increase awareness of self-determination so that these individuals could be placed on jobs and in homes of their preference (Lotan & Ells, 2010), leading to a higher quality of life and reduced behavior problems (Rapanaro et al., 2008). The community needs to give more of a chance for individuals with significant intellectual disabilities to have paying jobs (Carter, Owens, Swedeen, et al., 2009). Colleges and universities have an obligation to offer programs for them so they can be with appropriate age peers in a learning environment (Plotner & Marshall, 2014). In addition, colleges and universities, must offer programs, including access to dormitory living, and funding for those that are above the age of 22 when FAPE ends and they are no longer being served by the IDEIA (Bianco et al., 2009; Neubert & Moon, 2006; Plotner & Marshall, 2014).

Hopefully, educators will understand that it was beneficial to give up some classroom control so that these individuals could practice choice making and decision making (Lane et al., 2010; McGuire & McDonnell, 2008). Teachers may change the way they involve students in

choosing present activities and planning future directions (Thoma et al., 2008). Without student practice in this area, teachers were likely to get blank stares when they asked students what they wanted (R. Smith et al., 2005). This population was a group that was accustomed to being told what to do every step of the way in all facets of their lives (Myers, 2007). In the absence of direct instructions, they tended to become immobilized. Opportunity to practice self-determination was one of the biggest barriers to using it in one's life (McDonald, 2012; Skouge et al., 2007; Willner, 2011). It must be kept in mind that self-determination for this cognitive level did not mean complete control, but a degree of control to make an informed choice on high level decisions and to have their voice heard and given serious consideration (Lotan & Ells, 2010).

Limitations of the Study

Implementation issues. During the process of transcribing the interviews and while listening to the recordings, I noticed that I spoke too much and the participants too little. They should have had more time to speak, even though they needed much support to say more than "good" or "yea." It did not help the situation that I often resorted to yes-no questions to trigger their thought processes because, in a way, it was another impediment to their expression. Their cognitive abilities and language impairments were a detriment as expected. Still, I felt I had to accept what was said as truth and as the best they could do at the time. All had excellent verbal ability considering their assessed intelligence levels. Since it was my first experience interviewing for research, I understood that it was a learning process, especially when it came to getting the most accurate and meaningful responses from this group of participants. In hindsight I wish I would have spoken less and listened more.

In addition to being a better listener, I should have set up the questions better. The participants did not always have the background information to answer the questions. At times

they did not understand what I was asking of them or where I was going with the questioning. The objective measure from Wehmeyer and Kelchner (1995) was not geared to the cognitive and language level of these participants and I did not break down the meanings enough for them, nor did I make an outstanding attempt to apply difficult questions to their experiences. Researcher fatigue set in and at times I gave up on getting an accurate response, especially from my lowest level participant. Her mother, who was also a teacher, confessed to me that she felt the same way when she asks her daughter questions. I felt pressed for time and had to move on every so often.

It may not be entirely accurate to perform member checking by asking these participants to verify their responses to each question. The participants were eager to please, and even though I thought I made them comfortable and relaxed to answer the questions, they were extremely tuned in to my facial expressions, glances, and my every move. They needed much encouragement to go against what I told them they said. Their short term memory, tendency to agree rather than refute, and other disabilities often came into play.

As a novice researcher, I made several mistakes that caused implementation issues. I led the discussions a great deal of the time and spoke for them noticeably, not unlike others did as per research. I asked too many yes-no questions because I had difficulty getting them to talk more. Participants were sometimes too agreeable and then changed their stories often, possibly because they were trying to give me what they thought I wanted. Sometimes giving examples led participants to copy the exact example rather than to offer their own version of the example. This was also a problem that showed up during lessons in class, but I did not know how to avoid it since they needed more information to answer many questions.

Research design. A suggestion for change is to allow more time and shorter, more frequent sessions to get better answers when they are rested. Participants appeared fatigued at

times by breaking into giggles, yawning, or giving incomplete and short answers. However, when offered a break, they overwhelmingly declined and said they wanted to continue. When they did take a break, it was only for a minute or two and then they wanted to get right back to the interview. In addition, I should have planned better scenarios in advance to provide background information that enhanced leads to research questions. I did plan scenarios in advance and tried to offer each participant the same background information to ensure validity and reliability, but I think I could have developed better ones if I would have had more time. Last, I think if I would have done more analysis between interview sessions to prepare for possible changes in responses and verification of data collected, it would have improved the quality of data I collected. This was a time bound study and as such I was on a time limit. It was not easy to work as a teacher while performing research after school. I now understand the importance of a sabbatical, but that would have put me out of the classroom and away from the participants and would have affected my established relationship with them.

Validity issues. Internal validity was affected because I could only compare these three cases within, between, and across cases to increase the strength of this study. The population sample was very small due to their unique life experiences and the goal of exploring deep meanings in each participant's account. External validity was also affected because I had to generalize within limits since each case was unique. I cannot say with authority that these distinctive cases represent all individuals with significant intellectual disabilities, especially when many of them cannot communicate and were excluded from this study. I cannot even say they definitely represent upper, middle, and lower functional levels because each individual was just that: an individual. Communication ability was fluid between all levels and did not always depend on cognitive skills.

Reliability. As for measurement formatting, qualitative measures can never be exact, but cross analysis, member checking, and triangulation with archival documents can improve preciseness. Reliance instead shifted to trustworthiness, since my lifelong exposure to this disability level, familiarity with participants, caring for them over all these years, and passion to assist their communication about themselves, enhanced reliability of the study (Folkestad et al., 2008). Furthermore, I felt it was necessary to transcribe the interviews myself because no outside person could understand their manner of speaking and what they were trying to say better than I did. I had to use endless patience throughout the whole process of the study. I am not sure if another person would put as much care and interest into a study such as this.

My Personal Thoughts for Future Studies

Extension of previous research. The mantra of the disability group "nothing about us, without us" needed to be explored further by including participants with disabilities more often in research studies. Professionals need to maintain respect for the participants throughout (McDonald, 2012). To extend previous research, the goal should be to overcome obstacles to the invitation into the study and give more time to this marginal group of individuals so that the literature is enriched (Dye et al., 2007). I felt compelled to do this study because I thought no one else would put as much of themselves into the study as I did. This represents the culminating keystone product of my 42 years of teaching students with significant intellectual disabilities. As I retire from teaching, I hope that another special education professional takes up my campaign to allow these participants' voices to be heard through research as partners, not as subjects.

Suggestions for change. I needed more practice conducting pilot interviews and more time to conduct a strong qualitative analysis of the pilot text data before beginning the actual study. I was not aware just how important my tone of voice and leading questions influenced

participant responses. This study should have been broken up into smaller segments. Attempting to explore all components of self-determination was too ambitious for such a short time-bound study. I wanted to do it all in a time span that was too limited.

Future inquiry. Throughout this study I tried to talk as little as possible and allow the participant to express themselves freely, but I found they needed extensive communication support. If I was to do this study again, I would revise my interview questions, talk less after giving background scenarios to elicit the best responses, and extend the time and days spent in interview sessions. I would also bracket myself more by refraining from interrupting or talking over the participants and by guarding against leading questions. While it helped to know the participants so well that I could give them specific background scenarios based on what I know they have experienced, examples of what I wanted them to talk about could be limiting their open responses.

I needed to examine my own feelings about participants and their fantasies. As a teacher, I tried to bring them back to reality and get them to see what they were saying about the world. I had to stop myself from using teachable moments during interviews. On the other hand, as a researcher, I should not be negative toward participant ambitions. A researcher should listen without judgment and I found that to be very difficult. All exhibited some level of fantasy ideations and minimized how their limitations affected their ability to function independently, which may be due to their developmental ages (Walker, Gopnik, & Ganea, 2015; Zisenwine, Kaplan, Kushnir, & Sadeh, 2013). They had difficulties separating fact from fiction and spent long hours watching TV, using devices to play their favorite movies, and living a vicarious life. Even when they knew inside, that their fantasies were just that, and they have learned about reality, they still clung to their own interpretations and chose "...selective learning from

stories..." (Walker et al., 2015). As their teacher and club sponsor for Best Buddies, I felt partly responsible for their fantasies about becoming an entertainer since I produced a talent show each year, where general education students made up the audience members and always applauded their performances enthusiastically. The participants were not aware of the work and competition involved in the real world of the entertainment industry they spoke of. I tried not to be too discouraging.

As a teacher, it was moving to observe how they were able to talk about themselves and dream about independence when they became adults. Self-determination was easiest when students had the ability to express themselves and when their living environment supported their choices and ability to control what happened to them (J. Jones, 2012). As an experienced teacher, I had the confidence to know I was ethical in allowing a higher noise level in class activities because one cannot be quiet when one is expressing oneself. It was permissible to give up classroom control when a student was trying to exert some control over what happened to them in real time. This study was enhanced by participants who were able to communicate their thoughts.

Above all, what assisted these interviews were students having the opportunity to think about their future and discuss their plans in class activities previous to data collection. At this school, they knew that we treated our students with disabilities with respect and dignity. They did not fear me as a teacher and knew I was there to listen to them. When they focused on the actual questions, they recognized the fact that they were dependent on their parents, but that they would like to be more independent with support. Participants felt important because they were treated like adults and were given the opportunity to express themselves as adults.

Sometimes I had to provide examples of what the question meant or had to rephrase the questions into easier terms. I did not always get an answer on topic and sometimes had to accept that they did not know. At times I experienced researcher fatigue, gave up, and went on to the next question. Perhaps if I gave them more time or other opportunities to answer, I would have gotten more information, but perhaps not, considering their cognitive levels. It was difficult to tell at times if they were fatigued because they usually wanted to continue the interviews and would even cut short the breaks they were offered. They often admitted that they did not understand specific questions and asked for clarification. Knowing them well was very beneficial to the study and to getting the most out of them in the time frame that was available.

This sampling of individuals with significant intellectual disabilities did not include two demographics, which needed further examination. It did not include males and did not include others of varying economic levels. It was not clear if results on happiness would be different if the individuals were at lower economic levels. These participants all said they were happy with their lives, but that may be because all their material and medical needs were met. On the other hand, participants who were wealthy may also not be as happy since they may be more separate from family due to extensive outside caregivers. Also these participants were still in high school where they still maintained social contacts with the school community and consequently there was an effect on quality of life. In addition, males may have had different opinions about marriage and children.

There remains another group of individuals for whom research has yet to tap in to. To further research on the topic of expression of self-determination in individuals with profound intellectual disabilities, an interview method needs to be developed to capture responses of those participants. Perhaps those participants who could understand speech but are unable to produce it

could be invited to the study. Technology such as eye gaze software may need to be utilized in addition to other forms of assistive technology. If a participant could use their eyes to trigger a gaze-activated response that was prerecorded or could be scanned letter by letter or word by word, it would be possible to record their thoughts. The study may need to be a single case study to have time to provide all possible responses to simulate open-ended responses. Responses need to be made available for the participant to hear and select. In addition, the researcher would be aided by knowing the participant well enough to quickly narrow down appropriate open-ended responses to offer and to decipher responses by listening and watching with familiarity of their manner of communication.

Conclusions and Recommendations

More studies should include qualitative data collection measures so that these students can express unique situations, interests, problems. These students could express themselves and make choices or decisions if given the opportunity and communication support. New studies need to include males, other socioeconomic representatives, or students with more profound disabilities, possibly in a single case format or with assistive communication technology.

Participants might need more support to answer, such as building a more appropriate background scenario from which to respond. It was unclear if that would assist responses, but a more thoughtful pre-planned attempt to develop background information could yield more on-topic responses.

There should be more research into realistic life choices and interest in fantasies since this was a topic that emerged as a surprise to me. I was not aware of such strong beliefs in fantasy worlds through the viewing of popular media for example. More work was needed to assist individuals with significant intellectual disabilities to approximate job placements in

interest areas which come close to their fantasy job pursuit. Perhaps adult activity centers could put on community performances where they could get an audience, for example, to satisfy this need to perform on stage. Doctor's offices could hire clinical assistants to do routine work other employees might find tedious and mundane. These participants would be proud to do such tasks. Colleges and other educational institutions could educate these individuals in college classes and employ them to do specific tasks these individuals were able to do, while obtaining social access to people their own age or others without disabililities. Being close to their fantasy job may be all that is needed for quality of life.

This study indicated more research was needed into studying the key words "respect" and "peace" and the meanings to these types of participants. It may be interesting to study why participants might deflect blame so strongly and had such conflicts with parental control.

Another interesting topic would be how to counsel participants on realistic personal relationships with the opposite sex in light of consent, safety, and parental permission issues. Community travel remained a barrier for social inclusion and communities need to create safe and economical solutions to that concern. Possibilities for supported living need to be explored and how individuals with disabilities and their families can co-exist in that scenario. These individuals may not ever have a job, but they all will need someplace to live when their parents are gone. And lastly, there remained a significant need to provide more job opportunities in the community for lower ability levels and more studies would shed light on this important independence issue. Having a job continues to be the one most serious obstacle to adult independence for all young adults and the effect on those with disabilities is confounded immensely.

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Appendix A

Sample Picture Response Guides



Choices...Who Is Making Them?



Transition Passport / Personal Life / Evaluation Tools

Think about your life right now.

	Me	Parents	Together	Siblings or Friends	Caregivers
Who picks out the clothes you buy? Do you like them? yes no sometimes O O O O					
₩ Who chooses the movies you watch? Do you like them? yes no sometimes O ② O ④ O ♣					
Who chooses the videos you watch? Do you like them? yes no sometimes O O O O					
Who picks the TV shows you watch? Do you like them? yes no sometimes O O O O					
Who picks out the shoes you buy? Do you like them? yes no sometimes O O O O					
Who chooses the music you listen to? Do you like it? yes no sometimes O P					
Who plans your activities with friends? Do you like them? yes no sometimes O O O O					
Who picks out the clothes you wear? Do you like them? yes no sometimes O O O P					
Who chooses how your hair is cut/styled? Do you like it? yes no sometimes O P					
Who makes most of the decisions in your life? _					
Are you happy with the choices that are being n	nade?				
What would you change if you could?					



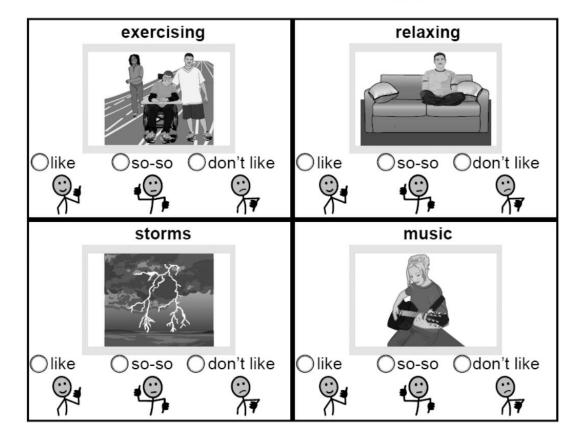
Likes and Dislikes



Transition Passport / Personal Life / Evaluation Tools

It is important that others get to know you and your preferences as they help you plan for your future.

Please circle your feelings about the items below and on the following pages:

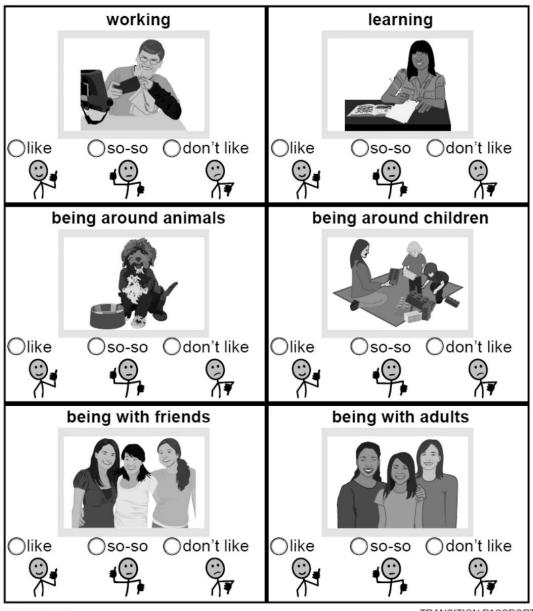




Likes and Dislikes



Transition Passport / Personal Life / Evaluation Tools



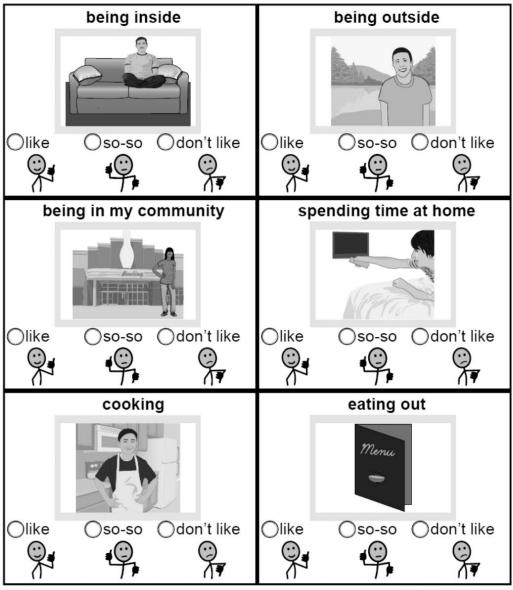
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Likes and Dislikes



Transition Passport / Personal Life / Evaluation Tools



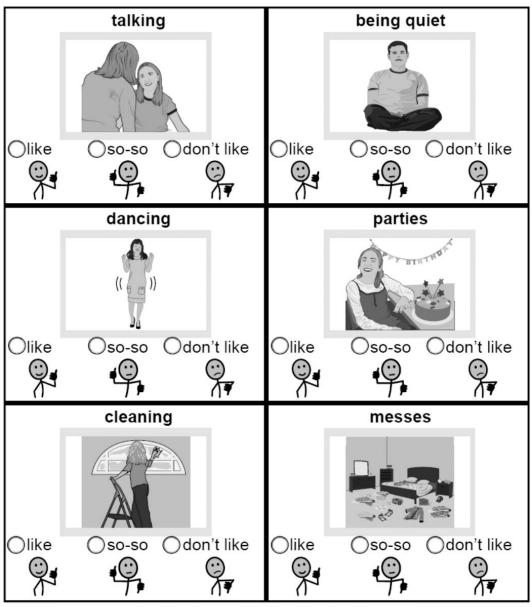
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Likes and Dislikes



Transition Passport / Personal Life / Evaluation Tools



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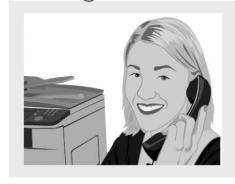
Work Environment Preferences



Transition Passport / Vocational / Evaluation Tools

○ clean





or



○ inside

○ outside

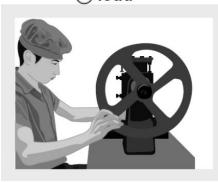


or

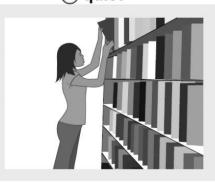


Oloud

O quiet



or



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Work Environment Preferences



Transition Passport / Vocational / Evaluation Tools

ostaying in one place





or



o same work

O different work

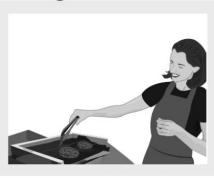


or



Ofast work

slower work



or



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Work Environment Preferences



Transition Passport / Vocational / Evaluation Tools

much supervision

Olittle supervision



or



Otold how to do things





or



Odress up

O regular clothes

○ uniform



or



or



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TRANSITION PASSPORT Vocational, Evaluation Tools, Work Environment Preferences



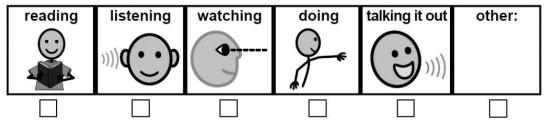
My Work Learning Style



Transition Passport / Vocational / Evaluation Tools

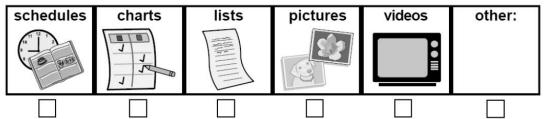


I learn best by:



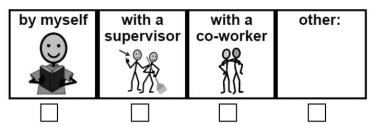


Things that help me learn:





🎢 I learn best when I work:





Where I Would Like to Live



Transition Passport / Personal Life / Evaluation Tools

Nam	ne:				- -
Date	e:		Age:		<u> </u>
_00	k at the sections below	v. Mark the choice tha	at best fits you.		
w	ould like to live:				
1.	In the city	In the country	In the suburb	s A nne	Other:
2.	On a quiet street	On a busy st	treet	Othe	er:
3.	In a house	In an apartn	nent	In a	trailer
	In a condominium	In a group h	ome	Oth	er:
4.	Alone Alone	With a roommate	With a boyfriend/		With a husband/wife
	With my family	With relatives	Other:		
	(You may mark more the	an one in this section)			
5.	Near public transportation	Near a grocery store	Near my job	- R	Near my doctor
	Near my bank	Near my church	Near the library		Near a laundromat
	Near a park	Near my family	Near friends	***	Other:



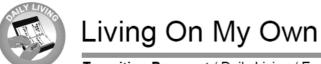
Choosing a Place to Live



Transition Passport / Personal Life / Evaluation Tools

Living Option		I care elf here?		get help I need it?		ne services I here?	Is th location	
Family Home	○ es	No ()	○ Ves	$ \bigcirc^{No} \bigcirc$	○ es	No O	○ es	№ ○
Live Alone	○ es	 ○	○ es	No O	○ es	No O	○ es	№ ○
Live with a Friend	○ Yes	No (○ Yes	No O	○ es	No (es O	No (
Group Home	○ es	No ()	Yes	No O	○ es	$\overset{No}{\bullet}\bigcirc$	es O	No (
Care Center	○ es	№ ○	○ es	No O	○ es	No (○ es	No O

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Transition Passport / Daily Living / Evaluation Tools

Am I Ready?	do myself	need help	don't do
take a bath or shower daily	\circ	\bigcirc	\circ
groom hair, face and teeth daily	\circ	\bigcirc	\bigcirc
get dressed	\circ	\bigcirc	\circ
make healthy food choices	\circ	\bigcirc	\bigcirc
make simple meals	0	\bigcirc	\bigcirc
know basic first aid	0	0	\bigcirc
know what to do when sick	0	\bigcirc	\bigcirc
keep money in a safe place	0	\bigcirc	\bigcirc
spend money wisely (needs vs. wants)	\bigcirc	\bigcirc	\bigcirc

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Daily Living, Evaluation Tools, Living On My Own





Transition Passport / Daily Living / Evaluation Tools

Am I Ready?	do myself	need help	don't do
dust	\bigcirc	\bigcirc	\bigcirc
vacuum	\circ	\circ	\circ
wipe counters	\bigcirc	\bigcirc	\bigcirc
do dishes	\bigcirc	\bigcirc	\bigcirc
do laundry	0	0	0
clean bathroom	\circ	\circ	\circ
lock door when alone	0	0	0
know who to call for help	\bigcirc	\bigcirc	\bigcirc
know what to do in an emergency	\bigcirc	\bigcirc	\bigcirc

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Rec-Leisure Survey



Transition Passport / Community / Evaluation Tools

	Activities	I like this	I want to learn
GHICKERY ME GAME TREVERY	board games		
	card games		
	bean bags		
	crafts		
	scrapbooking		
1	fishing		
	eating out		
63	movies/videos		
	shopping		
	bowling		
SALE	garage sales		

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Rec-Leisure Survey



Transition Passport / Community / Evaluation Tools

	Activities	I like this	I want to learn
CA	dancing		
	ceramics		
	photography		
	skating		
	parties		
	team games		
Special Olympics	Special Olympics		
0-	swimming		
	karaoke		
M	putt-putt golf		
	ping pong		
	foosball		

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Rec-Leisure Survey



Transition Passport / Community / Evaluation Tools

7	Activities	l do this now	I want to try this
	bike riding		
	camping		
Ž.	hiking		
	gardening		
	hanging out with friends		
	listening to music		
	picnics		
	festivals		
	going to church		
	volunteering		
4 A	working out		

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My Communication Style



Transition Passport / Personal Life / Evaluation Tools

	Yes 🙂	No 🚭	It's OK 🧐
I like talking to adults.	0	0	0
I like talking to friends.	0	0	0
I like talking to children.	0	0	0
I like talking to one or two people.	0	0	0
I like talking in a group of people.	0	0	0
I like meeting new people.	0	0	0
I like it when people ask me questions.	0	0	0
I like asking others questions.	0	0	0
I like listening to others.	0	0	0
I would rather listen than talk.	0	0	0
? I often do not know what to say.	0	0	0
I am afraid of saying the wrong thing.	0	0	0
I will start a conversation with someone.	0	0	0
I like to wait until someone talks to me first.	0	0	0
I need to get to know people first before I talk.	0	0	0



How Do I Advocate for Myself?



Transition Passport / Personal Life / Evaluation Tools

Read the questions in each of the four areas below. Circle how YOU answer each question.

Personal Life/ Communication How do I tell people who I am?	tell with my voice	use my VOCA device/ communication cards and/or voice	smile and get help	Other:
	IO SO PO	IO SO PO	IO SO PO	IO SO PO
Personal Life/ Physical Access How do I sign my name?	write my name	use a name stamp	write an "X" with help	Other:
	IO SO PO	IO SO PC	IO SO PO	10 S0 P0
Personal Life/ Social Skills How do I interact with friends?	talk and share information	use my VOCA device/ communication cards and/or voice to share information	smile and look at my friends when they talk to me	Other:
	IO SO PC	IO SO PC	IO SO PC	IO SO PO
Personal Life/ Problem Solving How do I make decisions for myself?	make choices and tell others what I need and want	point to objects or pictures to tell others my choice	smile, look or vocalize to show my preference between two choices	Other:
	IO SO PO	10 SO PC	IO SO PO	IO SO PO

Response rating scale: I = Independent S = With Support P = Participatory

Appendix B

Premade Interview Guides

Premade Interview Guide 1



What are some good things people might say about you?
What are some things that you do well?
What are some skills that you already have?

Premade Interview Guide 2



What is one thing you may need to improve?
What is your plan to improve this?

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Appendix C

Permission to Use Unique Learning System

Permission to Use Unique Learning System

Unique Learning System Reply Reply All Forward Unique Learning System Angela Arreche [angie@n2y.com]

To

Sadler, Celeste C.

Tuesday, January 31, 2012 2:11 PM

You forwarded this message on 1/31/2012 10:31 PM.

Dear Celeste

Yes, you may use our material for research in your dissertation as long as you share what is written with us.

Enjoy the day Angie

n2y, inc angela arreche account manager ph: 419-433-9800 x-1007 fx: 419-433-9810 n2y.com







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mhtml:file://C:\Users\Owner\Documents\Unique Learning System permissio... 6/9/2013

Appendix D

Permission to Use The Arc's Self Determination Scale

Permission to Use The Arc's Self Determination Scale

Page 1 of 1

Subject:

RE: my proposal

From:

"Wehmeyer, Michael L."

Date

Wednesday, November 13, 2013 7:25 PM

To:

'csadler345'

Celeste, I'm traveling, and don't have access to my computer, so this email will need to suffice as granting permission. I hold nonexclusive copyright to The Arc's Self-Determination Scale, and thus have the authority to grant permission for its. This email will constitute my permission for you to use items in and open-ended format from the scale in your interview process, as you describe.

Good luck,

Mike Wehmeyer

Sent from my iPhone

From: csadler345 [mailto:csadler345@aol.com] Sent: Wednesday, November 13, 2013 6:12 PM

To: Wehmeyer, Michael L. Subject: my proposal

Hi Dr. Wehmeyer,

I met you in Miami Beach at the DADD conference in 2012. I hope you remember me. I was doing a qualitative study on self-determination and we talked over lunch. I wanted to include a copy of your Arc's Self-Determination Scale in my proposal, but I have to get your permission first to use it. Could you send me a letter authorizing the use of your scale in my proposal? What I intend to do with it is to turn your test questions into open-ended interview questions plus add a few original questions of my own for my interview protocol. I wanted to make sure I address all components of self-determination and your test instrument does it best. Can you send it to me as an attachment? My proposal is digital and has to be submitted electronically. If you need to see how I used your test questions, I can email you my interview protocol. Your help will be appreciated. Thank you. Celeste Sadler

Nova Southeastern University

Doctoral Candidate

Saturday, November 23, 2013 America Online:

Appendix E

The Arc's Self-Determination Scale (Adolescent Version) is a student self-report measure of self-determination designed for use by adolescents with cognitive disabilities. The scale has two primary purposes:

- To provide students with cognitive disabilities and educators a tool that assists them in identifying student strengths and limitations in the area of self-determination; and
- To provide a research tool to examine the relationship between self-determination and factors that promote/inhibit this important outcome.

The scale has 72 items and is divided into four sections. Each section examines a different essential characteristic of self-determination: Autonomy, Self-Regulation, Psychological Empowerment and Self-Realization. Each section has unique directions that should be read before completing the relevant items. Scoring the scale (see Procedural Guidelines for scoring directions) results in a total self-determination score and subdomain scores in each of the four essential characteristics of self-determination. A comprehensive discussion and exploration of self-determination as an educational outcome is provided in The Arc's Self-Determination Scale Procedural Guidelines, as well as detailed scoring procedures and a discussion about the use of self-report measures in general. The scale should not be used until the administrator is thoroughly familiar with these issues.

The Arc's Self-Determination Scale (Adolescent Version) was developed by The Arc National Headquarters with funding from the U. S. Department of Education, Office of Special Education Programs (OSEP), under Cooperative Agreement #H023J20012. Questions used in Section One (Autonomy) were adapted, with permission from the authors, from the Autonomous Functioning Checklist. Questions used in Section 4 (Self-Realization) were adapted, with permission from the author, from the Short form of the Personal Orientation Inventory. Appropriate citations for both instruments are available in The Arc's Self-Determination Scale Procedural Guidelines. The Arc gratefully acknowledges the generosity of these researchers.



By Michael Wehmeyer, Ph.D., Kathy Kelchner, M.Ed., Principal Investigator Project Director

Self-Determination Assessment Project

Student's nan	20	
Student's nam	ie	

Date

School

Teacher's name



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by The Arc of the United States

Section On Autonomy	There are no disability limits	the answer on each questic right or wrong answers. Cho s you from actually performi as a personal care attendar	eck only one answer for eating the activity, but you have	ch question. (If your ve control over the
1A. Independence: Routine per	sonal care and family oriente	d functions	1A	. Subtotal
I make my own meals or snacks.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
2. I care for my own clothes.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
3. I do chores in my home.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
 I keep my own personal items together. 	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
I do simple first aid or medical care for myself.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
I keep good personal care and grooming.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
1B. Independence: Interaction v	with the environment		1B.	Subtotal
I make friends with other kids my age.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
8. I use the post office.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
I keep my appointments and meetings.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
I deal with salespeople at stores and restaurants.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
1C. Acting on the basis of pref	erences, beliefs, interests a	and abilities: Recreational ar	nd leisure time 1C	Subtotal
I do free time activities based on my interests.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
12. I plan weekend activities that I like to do.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
I am involved in school-related activities.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
 My friends and I choose activities that we want to do. 	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
 I write letters, notes or talk on the phone to friends and family. 	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
16. I listen to music that I like.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have

1D	Acting on the basis of pref Community involvement and		s and abilities:	1D.	Subtotal
17.	I volunteer in things that I am interested in.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
8.	I go to restaurants that I like.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
19.	I go to movies, concerts, and dances.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
20.	I go shopping or spend time at shopping centers or malls.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
21.	I take part in youth groups (like 4-H, scouting, church groups)	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
E.	Acting on the basis of prefe	erences, beliefs, interests	and abilities: Post-school dire	ections 1E.	Subtotal
2.	I do school and free time activities based on my career interests.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
23.	I work on school work that will improve my career chances.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
4.	I make long-range career plans.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
5.	I work or have worked to earn money.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
6.	I am in or have been in career or job classes or training.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
7.	I have looked into job interests by visiting work sites or talking to people in that job.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
F.	Acting on the basis of prefe	erences, beliefs, interests	and abilities: Personal expres	sion 1F.	Subtotal
8.	I choose my clothes and the personal items I use every day.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
9.	I choose my own hair style.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
0.	I choose gifts to give to family and friends.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
11.	I decorate my own room.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance
2	I choose how to spend my personal money.	I do not even if I have the chance	I do sometimes when I have the chance	I do most of the time I have the chance	I do every time I have the chance

	Section Two Self-Regulation	Your job is to tell what happend. Read the beginning a middle of the story. There	oene ind e are r	estions tell the beginning of a story and how the story ends. d in the middle of the story, to connect the beginning and the nding for each question, then fill in the BEST answer for the to right or wrong answers. a answer that you think BEST completes the story.
2A.	Interpersonal cognitive problem-so	olving		
33.	Beginning: You are sitting in a planning and teachers. You want to take a class was a cashier in a store. Your parents was Child Care class. You can only take one	where you can learn to work nt you to take the Family and	35.	Beginning: Your friends are acting like they are mad at you. You are upset about this. Middle:
	Middle:			
	Ending: The story ends with you taking will learn to be a cashier.	a vocational class where you		Ending: The story ends with you and your friends getting along just fine.
		Story Score		Story Score
34.	Beginning: You hear a friend talking about local book store. You love books and wa would like to work at the bookstore. Middle:	ant a job. You decide you	36.	Beginning: You go to your English class one morning and discover your English book is not in your backpack. You are upset because you need that book to do your homework. Middle:
	Ending: The story ends with you working	g at the bookstore. Story Score		Ending: The story ends with you using your English book for homework. Story Score

37.	Beginning: You are in a club at school. The club advisor announces that the club members will need to elect new officers at the next meeting. You want to be the president of the club. Middle:	Directions: The next three questions ask about your plans for the future. Again, there are no right or wrong answers. For each question, tell if you have made plans for that outcome and, if so, what those plans are and how to meet them. 39. Where do you want to live after you graduate? I have not planned for that yet.
38.	Ending: The story ends with you being elected as the club president. Story Score Beginning: You are at a new school and you don't know anyone. You want to have friends. Middle:	List four things you should do to meet this goal: 1) 2) 3) 4) 40. Where do you want to work after you graduate? I have not planned for that yet. I want to work List four things you should do to meet this goal:
	Ending: The story ends with you having many friends at the new school. Story Score	41. What type of transportation do you plan to use after graduation? I have not planned for that yet. I plan to use List four things you should do to meet this goal: 1) 2) 3) 4) 2B Subtotal

Directions: Check the answer that BEST describes you. Choose only one answer for each question. There are no right or wrong answers. 1 usually do what my friends want or I tell my friends if they are doing something I don't want to do. I tell others when I have new or different ideas or opinions or I usually agree with other peoples' opinions or ideas.		49. It is no use to keep trying because that won't change things or I keep trying even after I get something wrong. 50. I have the ability to do the job I want or I cannot do what it takes to do the job I want. 51. I don't know how to make friends or I know how to make friends or I know how to make friends. 52. I am able to work with others or I cannot work well with others. 53. I do not make good choices or I can make good choices		
I distally agree with other peop	nes opinions or lucas.	53. I do not make good choices or		
	r different ideas	I cannot work well with others.		
44 🖂 Luevellu assas with sassas a	on thou tell me I com I	The state of the s		
		I can make good choices.		
I tell people when I think I can tell me I can't.	do something that they	54. If I have the ability, I will be able to get the job I want or		
45. I tell people when they have hu	rt my feelings or	I probably will not get the job I want even if I have the ability.		
I am afraid to tell people when my feelings.	they have hurt	55. I will have a hard time making new friends or		
46. I can make my own decisions	. or	I will be able to make friends in new situations.		
Other people make decisions f	or me.	56. I will be able to work with others if I need to or		
47. Trying hard at school doesn't d	o me much good or	I will not be able to work with others if I need to.		
Trying hard at school will help	me get a good job.	57. My choices will not be honored or		
48. I can get what I want by workin	g hard or	I will be able to make choices that are important to me.		
I need good luck to get what I	want.	Section 3 Subtotal		

	Section Four Self-Realization	Directions: Tell whether you think each of these statements describes how you feel about yourself or not. There are no right or wrong answers. Choose only the answer that BEST fits you.					
58.	I do not feel ashamed of any of my emotions.	Agree	Don't agree	66. I don't accept my own limitations.	Agree	Don't agree	
59.	I feel free to be angry at people I care for.	Agree	Don't agree	67. I feel I cannot do many things.	Agree	Don't agree	
60.	I can show my feelings even when people might see me.	Agree	Don't agree	68. I like myself.	Agree	Don't agree	
61.	I can like people even if I don't agree with them.	Agree	Don't agree	69. I am not an important person.	Agree	Don't agree	
62.	I am afraid of doing things wrong.	Agree	Don't agree	 I know how to make up for my limitations. 	Agree	Don't agree	
63.	It is better to be yourself than to be popular.	Agree	Don't agree	71. Other people like me.	Agree	Don't agree	
64.	I am loved because I give love.	Agree	Don't agree	72. I am confident in my abilities.	Agree	Don't agree	
65.	I know what I do best.	Agree	Don't agree	Section 4 S	ubtotal		

The Arc's Self-Determination Scale Page 8

Scoring Step 1:	Scoring Step 3:	Sco	orir	ng :	Ste	p 4	4:									Scoring Step 5:						
Record the raw scores from each section: Autonomy	Using the conversion tables in Appendix A, convert raw scores into percentile scores for comparison with the sample	s sample. From the appropriate percentile down, darken the complete bar graph (See example in Scoring Manual):															Fill in the graph for the percentile scores indicating the percent positive responses.					
1A = 1B =	norms (Norm Sample) and the percentage of positive responses (Positive Scores):	One A	One B	One C	One D	One E	One F	One	Two A	Two B	Two	Three	Four	Total	%		One	Two	Three	Four	Total	%
1C =	Norm Positive Sample Scores			0	0	0	0	0	-	-	-	-	ш	-	100	ľ	_				'n	100
D =	Autonomy														- 90							_ 90
E =	1A =														90							00
F =	1B =														- 80							_ 80
Domain Total:	1C =														00							
	1D =														- 70							- 70
Self-Regulation	1E =																					
2A =	1F =														- 60	H						- 60
2B =	Domain Total:														00							
Domain Total:	Self-Regulation	\blacksquare	\vdash	-	-	-	_	_		-	-		\dashv	_	- 50		_				\vdash	- 50
sychological	2A =															н						
Empowerment	2B =	\blacksquare		\rightarrow	-	Н	_	_				-	-	_	- 40	l H	-	_		-	\dashv	- 40
s =	Domain Total:															ш						
Domain Total:	Psychological Empowerment	Н		\dashv	\dashv	\vdash			Н			\dashv	\dashv		- 30	H	_				\dashv	- 30
Self-Realization	3 =															ш						
=	Domain Total:														- 20							- 20
																						4.0
Domain Total:	Self-Realization														- 10							- 10
Scoring Step 2: Sum each Domain Total or a Total Score:	4 = Domain Total:	ndep:	ndep: unity	ioice:	olce: unity	chool:	olce: sonal	lutonomy	SelfReg: ProbSolve	fReg:	Self- ation	sych	Self-	Self- ation		L	omy	Self- ation	sych	Self-	Self- ation	
Self-Determination	Self-Determination Total Score =	Self	Indep: Community	إدة	Comm	PostS	Per	Auto	Prob	Go	Regul	Emp	Realiz	Self- Determination			Autonomy	Self- Regulation	Emp	Bealiz	Self- Determination	

Appendix F

Interview Protocols Day One Through Day Eight

Interview Protocol Day One

Interviewer: Tell me what you know about our meeting today. (wait for answer)

I understand that this is our first recorded interview and you do not know exactly what will happen. We are going to have a private relaxed conversation about you and your life, the way it is now and the way you wish it would be. The reason I am asking you these questions is because I want to know what you think so that I can help other people who have disabilities too. I have a video camera set up to record our conversation so that I can remember everything you say and so that I understand you correctly.

You do not have to answer any question that you do not want to answer. I will offer you a break part way through. You can ask for a break too. We will not talk for more than an hour in any interview. These interviews may be hard work and may cause you to think hard, but it will help others with disabilities to tell their stories and will let others know how you live your life. You might give me information about your home situation, but no one will know that you said it. We will meet for interviews about 10 times and you will have a chance to change your mind about anything you said. I am not sure how many interviews I will need, but when your story is complete, I will stop. I will go over what you said at the end and you can tell me if everything is correct. I may have to interview you more than ten times, just so you know.

I want to understand your life story and what it is like being you. I want to know the good things and the not so good things about being you in the everyday world we live in. I would like you to tell me about your life the best way you can and I will do my best to help you tell your story so that other people can understand. You are/were a student of mine and now I am a student too at a university. Teachers are always learning new things and that is why I am doing

this study. I have been your teacher all this time. Now I am asking that you be my teacher and show me how to feel things the way you do.

Let's practice how we will do our interview. I am going to ask you some questions and you are going to practice answering me. There is no right or wrong answer and this is not a test. We will practice three times. Are you ready? (wait for answer) (turn camera on)

Interviewer:

Scenario 1

Scenario 2

- 1. Tell me about your birthday. (if full response go to question 3, if not, go to question 2)
- 2. I need to know more about your birthday. Tell me more about your birthday. (repeat their response for verification, repeat question if needed, give extended response time)
- 3. Tell me more about ____. (something the participant mentioned about their birthday)

Now I am going to ask you about something else. Are you ready? (wait for answer)

- 4. Tell me what you did yesterday. (if full response go to question 6, if not, go to question 5)
- 5. Can you tell me more about what you did yesterday? (same as question 2)
- 6. Tell me more about ____. (something the participant mentioned about yesterday)

Scenario 3

- 7. Tell me everything that happened in class today/during your day today. (if full response go to question 9, if not, go to question 8)
- 8. Think about class today/your day. Tell me what happened from the time you came to school till ____/the time you woke up this morning till ____. (something mentioned in previous question)
- 9. Tell me what happened after ____/until you came to this meeting. (something mentioned in previous question)

- 10. Tell me more about ____. (something the participant mentioned about today)
- 11. And then what happened? (use this question as often as needed)
- 12. Before you talked about ____. Tell me more about that. (something the participant mentioned about class today)
- 13. What did we talk about today in class/What did you talk about with your family today?
- 14. What did you like about class today/What did you like about your talk with family today?
- 15. What is something that you did not like in class today/What is something you did not like about your talk with family today?

(have pictorial support materials ready)

- 16. Use these pictures to show me what happened in class today/at home today. (explain what the pictures are of)
- 17. Use these pictures to show me what we talked about in class today/what you talked about at home today.
- 18. Use these pictures to show me the best part of class today/your day today.

Now I am going to talk about something else again. I really want to know more about you and your life. It is important to tell me everything you can, both good things and bad things, both happy things and sad things. First I am going to ask you about what you need to be independent about taking care of yourself and your house. Everyone has certain things they need to do in their life to be on their own. Are you ready? (wait for answer) (note that flexibility should be used with question choices when needed to focus on the research questions)

1. How do you make your own meals?

(if incomplete answer, use model below to draw out more information each time needed)

I want to know more about you. Can you tell me more about how you make your own meals? Can you tell me more about ____? (specific topic participant mentioned)

And then what happens? What happens in the end?

- 2. How do you care for your clothes?
- 3. What chores do you do at home?
- 4. How do you take care of your personal items?
- 5. What do you do to take care of simple first aid?
- 6. What do you do to take care of medical needs?
- 7. What do you need to know about your medical conditions? What is your disability?
- 8. What do you know about being safe or what to do in an emergency?
- 9. What personal care do you do by yourself?
- 10. What grooming do you do by yourself?

Interviewer:

Now I would like you to look at some pictures I have that show some things people might need to do to be independent. Show me or tell me which things you need to do too. Take your time and look at all the pictures before deciding. I am not in a hurry.

Is there anything else you want to say about being independent? (wait for answer)

Is there anything else I should know?

Is there anything you want to ask me? (turn camera off)

You can always talk to me later in private if you want to. You told me a lot of things and that is really helpful. I want to make sure I got it all right. I am going to repeat some things you told me today and then I will ask you if I am correct. By the next time we interview, I will have listened to the recording. You can think about our interview until then to see if there is something

else you want to say or if you want to change something you already said. It is really important to me to get exactly what you said and what you meant.

How do you feel about this interview? Do you want to meet again next week? (wait for answer) Think about what we talked about until then. When I call you for an interview, you can say okay, no, or not now, later. What did you think about being interviewed? Did you get tired during the interview? Would you like to have a break/more breaks during the interview? I plan to see you next week to ask more questions and of course you can always see me during school (or call me, if pilot participant) if you want to talk or ask me questions. We are finished for the day. I am going to call your parents in now so you can go home. Thank you for your time and effort in answering all my questions the best you could. It was really helpful and you did a great job.

Do you want to continue these interviews next time? What are you going to do now that this interview is over? Thank you for helping me with my study and I will see you next week.

Interview Protocol Day Two

Interviewer:

Are there any questions about the last interview we had? Moving on, I am going to ask you more questions about your life. I want to understand your life story and what it is like being you. I want to remind you that I want to know the good things and the not so good things about being you in the everyday world we live in. I would like you to tell me about your life the best way you can and I will do my best to help you tell your story so that other people can understand.

Remember that I want your okay to do this interview. You do not have to answer any question that you do not want to answer. I will offer you a break part way through. You can ask for a break too.

Last time we talked about what you need to be independent about taking care of yourself and your house. Today we are going to talk about you and how you interact with what is around you. Are you ready?

- 11. How do you make friends with people your own age?
- 12. How do you use the post office? The bank? The ATM machine?
- 13. How do you use email or texting on the phone?
- 14. How do you keep your appointments?
- 15. How do you attend meetings?
- 16. How do you deal with salespeople at stores?
- 17. How do you deal with restaurant workers?
- 18. What do you do when you need money? What is something you are saving for?
- 19. What do you do when you need a ride to go somewhere of your choosing? What changes would help you go out into the community better?

20. What do you need to know or learn about living on your own?

Interviewer:

Now we are going to talk about things you do because it's what you prefer, it's what you believe, it's what you are interested in, or it's what you are able to do. Are you ready? (wait for answer)

21. How do you choose free time activities? (use the following pattern to get more detail for each question)

I want to know more about you. Tell me more about how you choose free time activities.

Can you tell me more about ____? (something specific the participant mentioned)

And then what happens? What happens in the end?

- 22. How do you plan weekend activities? What weekend activities do you like?
- 23. How are you involved in school-related activities? (pilot study: use community-related) What school or community activities would you like to be involved in?
- 24. How do you choose an activity to do with a friend? What activities do you do with friends?
- 25. How do you write letters or notes to family and friends?
- 26. How do you talk on the phone with family and friends?
- 27. How do you listen to the music/TV shows you like? What kinds of music/TV shows do you like?
- 28. What new things do you want to try?
- 29. What keeps you from doing things you are interested in? How do you plan to go around those barriers that keep you from taking action?
- 30. What do you do to calm down or relax?

Interviewer:

I would like you to look at some pictures that might help you tell me about things you do because it's what you prefer, what you believe, what you are interested in, or what you are able to do. Let's go over them and maybe you can tell me more about yourself. You can always change your mind later, but for now, tell me which pictures interest you today.

Is there anything else you want to say about what you prefer or are interested in? (wait for

Is there anything else I should know?

answer)

Is there anything you want to ask me? (turn camera off)

This ends our interview for today. Next week we will do another interview. At the end of all of our interviews, I will remind you of any questions I have asked you and how you answered. If what I said is not correct, I will change it. You can think about your answers and change them at the end if you want to. If you get tired in the middle of an interview, we can stop and take a short break or talk another day. If you do not want to do any more interviews, it is your choice. No one will be upset and nothing bad will happen to you. I will ask you each time if you would like to be interviewed and you can say yes, no, or not now, later. When you say no or later three times, I will think you want to stop the interviews. After three times you will have to tell me you want to be interviewed again because I will not ask you.

Remember you can always talk to me later in private if you want to. You told me a lot more things and that is really helpful. I still want to make sure I got it all right. It is really important to me to get exactly what you said and what you meant.

How did you feel about this interview? Do you want to meet again next week? (wait for answer) Think about what we talked about until then. When I call you for an interview, you can say okay, no, or not now, later. What did you think about being interviewed? Did you get tired

during the interview? Would you like to have a break/more breaks during the interview? I plan to see you next week to ask more questions and of course you can always see me during school (or call me, if pilot participant) if you want to talk or ask me questions. We are finished for the day. I am going to call your parents in now so you can go home. Thank you for your time and effort in answering all my questions the best you could. It was really helpful and you did a great job.

Interview Protocol Day Three

Interviewer:

This is now our third interview. Do you have any questions from the other interviews?

Do you understand what is going to happen? Tell me why I asked to talk to you today.

Remember that I want your okay to continue and I don't want you to feel uncomfortable or to get tired so we can take a break whenever you say. Are you ready to do the next set of questions?

These questions are going to be more questions about things you do because it is what you prefer, what you believe, what you are interested in, or what you are able to do. Ready?

31. How do you volunteer in things you are interested in? What are things you want to volunteer for? Can you tell me more about ____? (something participant mentioned)

- 32. How do you go to restaurants that you like? What restaurants do you like?
- 33. How do you go to movies, concerts, and dances? What kind of movies do you like? What concerts would you like to go to? What community places would you like to visit to dance?
- 34. How do you go shopping or spend time at the shopping center or mall? And then what happens?
- 35. How do you take part in youth groups? (community, religious, social)
- 36. What people, businesses, or services do you want to live near?
- 37. What do you want in a support person that will help you in your adult life?
- 38. Where would you like to travel to?
- 39. What social activities or events would you like to attend?
- 40. How do you find out what your options are for free time, living situations, school, work, or friendships? How do you know what is out there for you to do?

Interviewer:

These next questions are going to be about what your plans are after you graduate and leave high school. Even though you probably haven't had much experience with working, I want you to answer the best you can. Are you ready?

- 41. How do you do school or do free time activities based on your career interests? In other words, what do you do now in school or in your free time that will help you get the job you want? I want to know more about ____ (something participant mentioned). Tell me more about ____.
- 42. What do you want to learn more about? What is something you want to learn that will help you after you graduate?
- 43. What school work do you do that will improve your career chances? (pilot study use classes)
- 44. What are your long-range career plans? What job do you want to have in five years?
- 45. What work have you done to earn money?
- 46. What career or job training or classes have you done?
- 47. What job interests have you looked into by visiting or talking to people in that job?
- 48. What do you prefer to use or have to get the job done at work? What do you think will help you do a better job during the interview? Once work begins?
- 49. How do you prefer to learn a new job at work? How do you think you will learn best on a new job? What kind of atmosphere or situation do you prefer to work in?
- 50. How do you handle changes in the way you have to do things at work? Then what happens?

 How do you handle changes in your morning routine? What happens after that? And then what happens last? How do you handle changes in plans for leisure time? And what happens next? What happens in the end?

Interviewer:

Now I would like you to look at some pictures that you could use to help explain some of the things you prefer in your life. Some of the pictures are about how you prefer to do your job and some are about personal things that you prefer.

Is there anything else you would like to tell me about what you prefer?

Do you have any questions for me?

Interviewer:

That ends our interview for today. Remember if you get tired or need a break to tell me and we will stop. I will not reveal any of these private answers unless you tell me to. You can decide what or how much to tell your parents about today. I hope you have a great week and I am looking forward to talking to you again and I hope you are too. I am going to call your parents in now so you can go home. What are your plans for tonight? I appreciate all the work you are doing for me in this study. See you next week.

Interview Protocol Day Four

We are now on our fourth interview. Are there any questions about any of our other interviews? These next set of questions are going to be about your personal preferences. These questions may be a little easier for you because they are about things you probably know more about. Ready to start? (wait for an answer)

- 51. Who chooses the food you eat? Can you tell me a little more about that?
- 52. Who chooses what your daily schedule will be? Who decides on your morning routine?
- 53. Who chooses the clothes and the personal items you use every day?
- 54. Who chooses your hairstyle? And then what happens?
- 55. Who chooses the gifts you give to family and friends?
- 56. Who decorates your room?
- 57. Who chooses how to spend your personal money?
- 58. Who do you prefer to hang out with? Who picks your friends? How do you plan a party for a friend? How do you plan for a friend's visit? How do you plan to visit a friend?
- 59. What kind of atmosphere or situation do you prefer to live in? What changes do you need to live better or more independently?
- 60. What do you prefer to do all by yourself?

Interviewer:

This time we are going to talk about how you solve personal problems. I want to know what you think about when you are having trouble getting what you need or want. There are a lot of questions so tell me when you need to take a break and we can stop. Are you ready to begin?

61. How do you handle disagreements with your family over which job classes to take? Let's say you are in an IEP meeting or a planning meeting and your family wants you to take one

- course, but you want to take something else? What do you do about it? (if incomplete answer ask: And then what happens? And what happens in the end?)
- 62. How do you handle getting hired at a new job opening you are interested in?

 What would you do if you wanted to get hired at a new job opening that you like?
- 63. What do you do when your friends act like they are mad at you?
- 64. What do you do when something you need for work or school is missing? Think back to a time when you couldn't find something you needed for school. What did you do? Is there anything you would do differently now that you look back on it?
- 65. What do you do if your club or activity group needs a new leader and you want to do it?

 What do you do if your club or activity group needs someone to lead an activity and you want to do it? How do you show an interest in participating in an activity in your group?
- 66. What do you do if you are new at school or on the job and you want to have friends?
- 67. What are the good things that happen when others listen to you? What are the bad things that happen when others don't listen to you?
- 68. What do you do if people treat you like a child and you feel like an adult?
- 69. What do you do if your family doesn't like your choice of friends?
- 70. What do you do if you want to visit with a love interest and your family is worried about it?

 How are you able to have privacy?

Is there anything else you want to say about how you handle rough situations? Interviewer:

Now I would like you to look at some pictures that you could use to help explain some of your personal preferences and how you solve personal problems. Tell me if any of these pictures

describe what you are trying to say about what you prefer and how you solve problems. We can find other pictures if these don't show what you mean.

That ends our interview for today. Remember I will not reveal any of these private answers unless you tell me to. You can decide what or how much to tell your parents at the end of all of our interviews. I hope you have a great week and I am looking forward to talking to you again and I hope you are too. I am going to call your parents in now so you can go home. What are you going to do after this interview? I appreciate all the work you are doing for me in this study. See you next week.

Interview Protocol Day Five

Interviewer:

We are now about halfway done with our meetings. In our interview this time we are going to talk about your strengths. I want to know what you are good at and what you need help with. Everyone has things they are good at and things they are not so good at. I cannot do everything either and no one can do everything right or good. That is why we have school and work training. Are you ready to begin? (wait for answer)

- 71. What are you good at? (if incomplete response, go to next question) Tell me more about your strengths. Tell me more about your strength in ____. (something participant mentioned) What makes you good at ____? (something participant mentioned) What is the best thing about being you?
- 72. What is hard for you? What gives you problems? What gets in the way of you doing your best? What is the worst thing about being you?
- 73. What are you able to do on a computer? Tablet? Smartphone?
- 74. What is something about working that you tried and liked?
- 75. What is something about working that you tried and didn't like?

Interviewer:

Now we are going to talk about your goals. I want to know what your goals are and where you go for support. No one can do everything alone. We all need support to do the things we want to do in life. I would not be where I am today if I didn't have the support of my family, my teachers in school, and my friends. There is nothing wrong with asking for help because we all do it. We all have goals for ourselves for the future. The question is how do you plan to reach your goal? Where do you want to end up in life? All goals are just dreams put into action.

- 76. Where do you want to live after graduation/in the future? What are the steps you should take to meet this goal? Who sets this goal? Who will support you in reaching this goal? How do you know how well you are working toward this goal?
- 77. Where do you want to work after graduation/in the future? What are the steps you should take to meet this goal? Who sets this goal? Who will support you in reaching this goal? How do you know how well you are working toward this goal?
- 78. What type of transportation do you plan to use after graduation/in the future? What are the steps you should take to meet this goal? Who sets this goal? Who will support you in reaching this goal? How do you know how well you are working toward this goal?
- 79. Who do you want to live with in your adult life? What kind of family life do you want to have? What kind of meaningful relationship do you want to have? Who will support you in reaching this goal? How do you know how well you are working toward this goal?
- 80. What are you doing now to be independent from your parents?

Is there anything else you want to say about your goals for the future?

Interviewer:

Now we are going to talk about something else again. I want to know how you speak up for what you want or need. I also want to know how you feel about being able to get what you want or need. Are you ready to begin?

- 81. What do you do if your friends want to do something different than what you want to do?
- 82. What do you do when you do not agree with others opinions or ideas?
- 83. What do you do when you have new or different ideas or opinions than other people?
- 84. What do you do when others tell you that you can't do something that you think you can do?
- 85. What do you do when other people hurt your feelings?

- 86. Who makes decisions for you? What kind of decisions do you make every day? What kinds of important decisions can you make?
- 87. What will happen if you try hard at school or at work?
- 88. How do you get what you want at school or at work?
- 89. What will happen if you keep trying even after you get something wrong?
- 90. What do you have to do to work at the job you want?

Is there anything else you want to say about what you what you are good at?

Interviewer:

Now I would like you to look at some pictures that you could use to describe what your strengths are or what you are good at. Some of these pictures may show what is hard for you also. Other pictures might show some goals you might have for your adult life. Tell me if any of these pictures describe what you feel about being able to get what you need or want. We can find other pictures if these don't show what you mean.

That ends our interview for today. Remember if you get tired or need a break to tell me and we will stop. I will not reveal any of these private answers unless you tell me to. You can decide what or how much to tell your parents about today. I hope you have a great week and I am looking forward to talking to you again and I hope you are too. I am going to call your parents in now so you can go home. What are you going to do after this meeting? I appreciate all the work you are doing for me in this study. See you next week.

Interview Protocol Day Six

Interviewer:

Now we are going to talk about the way you feel about yourself. I want to know more about how you speak up for what you want or need. I also want to know how you feel about being able to get what you want or need. Are you ready to begin?

Interviewer:

- 91. What do you have to do to make friends? How easy or how difficult is it to make friends?

 What are you able to do as a friend for someone else? What kind of person are you able to be friends with? Who is someone you will always want to be friends with?
- 92. How do you work with others? How easy or difficult is it to work with others?
- 93. How do you make good choices? What kind of support do you need to make good choices?
- 94. How will you get the job you want when you have the ability to do the job?
- 95. How will you make new friends in new situations?
- 96. How will you be able to work with others when you need to?
- 97. How will your important choices be honored? What do you have a right to do? What do you have a right to have? What important choices can you make?
- 98. What makes you change your mind about a choice or a decision you made?
- 99. What is the worst thing that can happen to you? What is your worst nightmare? How would you get out of that situation?
- 100. How good are you at asking for a break? Before you get upset? Before your work gets worse?

Interviewer:

Now we are going to talk about how you feel about your own emotions. We all have emotions like being happy, sad, angry, worried, bored, lonely, excited, afraid, and many other feelings. I want to know how you feel about yourself. Are you ready?

- 101. How do you feel about your emotions? How do you feel about having these emotions?
- 102. What do you do if you are angry at someone you care for?
- 103. How do you feel when people see you show your feelings?
- 104. How do you feel about people if they don't agree with you?
- 105. How do you feel about doing things wrong?
- 106. How do you feel about being popular? How do you feel about being yourself?
- 107. Why are you loved? Who do you need? Who needs you?
- 108. How good are you at listening to someone that is correcting you?
- 109. How do you feel about your own limitations? How do you encourage yourself?
- 110. How do feel about your ability to do many things? What makes you a good worker? What do you wish people knew about you?

Is there anything else about how you feel about yourself that you would like to tell me? Interviewer:

Here are some pictures that may help you talk about the way you feel about yourself, how you try to speak up for yourself, and how you solve personal problems. If the right picture to describe your feelings is not here, we can find other pictures that are better. Tell me when you see the picture that has what you mean to say.

That ends our interview for today. Remember if you get tired or need a break to tell me and we will stop. I will not reveal any of these private answers unless you tell me to. You can decide what or how much to tell your parents about today. I hope you have a great week and I

am looking forward to talking to you again and I hope you are too. I am going to call your parents in now so you can go home. What are you going to do later on? I appreciate all the work you are doing for me in this study. See you next week.

Interview Protocol Day Seven

Interviewer:

Today we are going to continue talking about your feelings and how you feel about yourself. I want to know more about you to tell your true story so that other people can understand you better. Are you ready to begin? (wait for answer)

- 111. How do you feel about yourself? What are some steps you could take that will make you happier in your adult life? What barriers to happiness have you removed so far?
- 112. How do you feel about being important?
- 113. How do you make up for your limitations?
- 114. How do other people feel about you?
- 115. How confident are you in your abilities?
- 116. How do you prefer to participate in conversations? Who do you prefer to start talking? Who do you prefer to ask the questions? Who do you prefer to do the listening?
- 117. How do you feel about being in a relationship?
- 118. What do you do when you need to have privacy?
- 119. What is something in your life you would like to change?
- 120. If anything was possible, what would you like? What is your dream life?

Is there anything else you want to say about your feelings?

Interviewer:

Here are more pictures that may help you talk about the way you feel about yourself, how you try to speak up for yourself, and how you solve problems. If the right picture to describe your feelings is not here, we can find other pictures that are better. Tell me when you see the picture that has what you mean to say.

You did a terrific job on all those interview questions. That was a lot of work. I really appreciate all the time you took to answer all my questions. It will really help me to learn how to help other people that have disabilities like yours. I am going to write about the things you told me and try to get a picture of everything you are trying to say. Other people will understand people who have disabilities better after they read what I wrote. You will be helping all the other people like you by participating in my study. We will meet just one more time to look at all the things you have told me during all these interviews. You will have a chance to agree or change what you have said. After that, I will start to write and you cannot change any more of your answers. I will give you a copy of my study and read to you the parts about what you said. I will not tell anyone who you are and no one will know what you said unless you tell them. Do you understand everything I have said so far? Do you want me to repeat anything? Do you want to ask me any questions? You can contact me anytime to ask me about this study and we can talk about it in private. If you do not have any more questions, I am going to call your parents in now. I will contact you about when we can have our last meeting because I have a lot of reading and writing to do to get ready to talk to you. That will probably be in about 2 weeks. How do you feel about the end of our interviews? I am going to miss our talks, but we can keep in touch.

Interview Protocol Conclusion Day Eight

Interviewer:

Today is our last meeting for this study. I have taken all the things you have told me and have made a short story about it. This is the way I see it and I want to see if you agree or want to change your story.

I think what you are trying to say you need are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? You also told me what you don't need is: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

What you want is: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? Some things you don't want are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

What you prefer or rather have or do is: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? Some things you would rather not have or do are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

You are interested in: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? You are not interested in: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

Things you are good at are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? Some things you

are not so good at are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

Things you are able to do are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? Some things you need help with are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

You plan to: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? Things that you do not plan to do are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

Your goals are to: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out? Some goals you do not have are: (list topics participant talked about). Do you agree? Are there any other things you want to add to that list? Any things you want to take out?

You have told me how you feel about many things. The way I see that you feel about yourself is: (list topics participant talked about). Do you agree? Is there anything I have left out about how you feel about your life? Is there anything you want me to take out?

I have explained to you the story about you as I understand it. You and I have agreed on what you meant to say. Once you leave here there will not be any more changes. I will tell people what you said but I will not use your real name. I will give you and your family a copy of the report, but they will not know exactly what you said. Other people will have their stories in the report too. It is possible this report might be published in a college magazine one day. This report will help other people with disabilities be understood by the people they live and work

with. Your work on these interviews has helped me and others to understand what it is like to live with a disability. For all of your time and effort in this study, I want to give you a gift card for you and your family to enjoy. How do you feel about being finished with all of these interviews? I am going to miss talking with you about your life and understanding how you feel. Don't forget that you can contact me any time about this study. We know each other very well and we will always be a part of each other's lives. I hope being a part of my study helped you learn something about yourself that you will always take with you. I truly hope this study has helped you to have a happy adult life now and I want to send you off with my best wishes for you in the future!

Appendix G

Coding Manual

Coding Manual

Level One Coding

Descriptive coding was used initially to get a sense of what was being said about each interview question. Codes were predetermined and aligned with the research questions and subquestions. Some codes emerged as descriptive coding moved forward. These response type nodes were later coded into a later type of coding. Using NVivo 10 software, I was able to separate each elemental section as a stand-alone item of data.

In Vivo coding was employed using NVivo 10 to capture the voices of the participants without the questions. Many times participants were answering a previous question which did not make sense with the question at hand. I was able to get a different view of what was said when I only looked at what they were trying to say regardless of what question was asked. When data saturation was reached, I went into second level coding.

Sub-coding was appropriate for descriptive coding and theme coding during the second level. Due to the design of the research questions and sub-questions and to the setup in the NVivo 10 software that used parent and child nodes in coding, sub-coding was appropriate. However, I did not use this method during In Vivo coding because it did not rely on the research questions as much as on the actual responses to them.

Level Two Coding

Theming the data was the method used to discover the patterns within the codes. All the Descriptive codes and the In Vivo codes were reduced by hand to discover the major themes that ran within and across the cases. Results were reported as themes that answered the research questions with sampling that at times needed to include the question being answered.

Appendix H

Combined Theme Outline

Combined Theme Outline

I. Needs

- a. Family functions/personal care attendant
 - i. Cooking
 - ii. Cleanliness (body and clothing)
 - iii. Medicine and doctor appointments
 - iv. Safety at home and community
 - v. Disability and conditions
 - 1. Dressing
 - 2. Eating
 - 3. Health
 - 4. Intellectual
- b. Independence in the Environment
 - i. Food preparation
 - ii. House keeping
 - iii. Communication (verbal and electronic)
 - iv. Community and social access
 - v. Financial support
 - vi. Family support
 - vii. Transportation

II. Preferences

- a. Beliefs
 - i. About self
 - ii. About others
 - iii. Fantasies
 - 1. Boyfriends, husbands, and babies
 - 2. Walking or standing alone
 - 3. Being a professional entertainer or artist
 - 4. Travel independently
 - iv. Rights
- b. Interests
 - i. Assistance from parents or support person
 - ii. Independence
 - iii. Friends and social life
 - iv. Choices
 - 1. Living
 - 2. Job
 - 3. Leisure
 - 4. Friends
 - 5. Food
 - 6. Post-secondary education and training
 - 7. Travel
- c. Abilities
 - i. Job, education, and learning skills

- ii. Self-expression
 - 1. Can contact friends
 - 2. Can support friends
 - 3. Can participate in social activities
 - 4. Can express what they want
 - 5. Can appropriately control emotions
 - 6. Can make choices independently
- iii. Can live in independent housing
- iv. Can travel with support

III. Goals

- a. Plans
 - i. Job
 - ii. Living
 - iii. Leisure
 - iv. Education
- b. Problem solving
 - i. Parent permission and support
 - ii. Support on the job
- c. Self-regulation
 - i. Dealing with difficult people/making new friends
 - ii. Dealing with difficult situations

IV. Feelings

- a. Psychological empowerment
 - i. Self-advocacy
 - ii. Confidence
 - iii. Technology use
 - iv. Protection of self-image
- b. Self-realization
 - i. Self-awareness
 - 1. Conditions
 - 2. Disability
 - 3. Feelings about themselves
 - ii. Adult preferences
 - iii. Difficulties, dislikes, and non-interests
 - iv. Religious feelings
 - v. Support people
- V. Missing Information
 - a. Why missing background information
 - b. Why off topic
 - c. Why question not answered
- VI. Extra Information
 - a. Why take focus off self
 - b. Why not interested in being more independent
 - c. Why high level of interest in being an entertainer