2014

Quality of Life in Emerging Adults with Autism Spectrum Disorder

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QUALITY OF LIFE IN EMERGING ADULTS WITH AUTISM SPECTRUM DISORDER

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

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November, 2014
Acknowledgments

Over the past 21 years I have been blessed to know, teach, coach, and embrace individuals with a diagnosis of Autism and their families. Most of all, I have learned from these families. I am grateful for each and every family who left a lasting impression on me and holds a special place in my heart. Thank you to all of you from Michigan, New York, Rhode Island, Massachusetts, and Virginia for enriching my personal, professional, academic and research life.

Dr. Judy Brown, my mentor, friend, and cheer leader…. You have believed in me from the first anthropology class that I took in 1994. You have stuck by me, encouraged me, and guided me. I owe you more than you can ever imagine. Much love and gratitude are in my heart for you.

Thank you to my advisor and chair of my dissertation, Dr. Barbara Myers. Your patience, sense of humor, guidance, support and persistence has been so very helpful from day one! I look forward to our dissertation-free friendship! I would also like to thank the rest of my committee, Dr. Geri Lotze, Dr. Terri Sullivan, Dr. Norm Geller, and Adam Sima for their support, suggestions, and interest. A special thank you goes Dr. Paul Wehman, your dedication to the field of disability research and supported employment is inspiring. You have shaped my research interests and have provided such encouragement over the years—Thank you!

Over the past 8 years, I have received the support of so many friends, family and loved ones. I am thankful for my work family, school family, friends who are like family; this includes my best buddies Jen, Don, Jeff, and Lorraine. You have been interested in my work, you have supported me when I needed it, and you have lifted me up when I have felt defeated. Chris, you make me laugh, make me relax when I am at the end of my rope, and help me not to lose perspective. Thank you. I am so indebted to you all.

Mom, thank you for pushing me and believing in me from Kindergarten through today! You have taught me to be independent, hard-working, and have a big heart. Thank you!!! I love you Mom!!! John, you have always been my school idol. I have always wanted to be as good as you were at school, and to accomplish the things that you did. I have always been proud of you and proud to be your sister. Thank you for believing in me.

Greg and extended Carr family, you all were with me through most of the ups and downs of this journey —I appreciate you for all the support and listening that you have done over the years.

Morgan and Peter, you have only really known a “mom who was in school” and working on some sort of writing…. You never complained about the time that I had to put towards my work and school, Thank you both! You are both smart, talented, and I am so proud of you both. I love you with all of my heart!
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>v</td>
</tr>
<tr>
<td>List of Figures</td>
<td>vi</td>
</tr>
<tr>
<td>Abstract</td>
<td>viii</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Review of Literature</td>
<td>6</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>6</td>
</tr>
<tr>
<td>Comorbidities and autism spectrum disorders</td>
<td>8</td>
</tr>
<tr>
<td>Communication and social development</td>
<td>10</td>
</tr>
<tr>
<td>Social interaction problems in people with ASD</td>
<td>13</td>
</tr>
<tr>
<td>Repetitive, perseverative, and stereotyped behavior</td>
<td>14</td>
</tr>
<tr>
<td>Disability identity</td>
<td>16</td>
</tr>
<tr>
<td>Transition into early adulthood for individuals with ASD</td>
<td>18</td>
</tr>
<tr>
<td>National Longitudinal Transition Study 2</td>
<td>20</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>21</td>
</tr>
<tr>
<td>QoL in individuals with ASD</td>
<td>23</td>
</tr>
<tr>
<td>Transition to adulthood and quality of life</td>
<td>29</td>
</tr>
<tr>
<td>Proposed Study</td>
<td>32</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>32</td>
</tr>
<tr>
<td>Education, Employment, and QoL</td>
<td>32</td>
</tr>
<tr>
<td>Social and Communication Abilities and QoL</td>
<td>34</td>
</tr>
<tr>
<td>Independence and QoL</td>
<td>35</td>
</tr>
</tbody>
</table>
Specific Aims and Hypotheses ........................................................................................................... 36
Method .................................................................................................................................................. 37
Participants ........................................................................................................................................ 37
Procedure ........................................................................................................................................... 39
Measures ............................................................................................................................................... 40
  Quality of Life (QoL) .......................................................................................................................... 40
  Woodcock-Johnson III ....................................................................................................................... 41
  Autonomy subscale of the ARC Self-Determination Scale .............................................................. 43
Results ................................................................................................................................................. 45
  Data Preparation ............................................................................................................................... 45
    Hierarchical multiple regression analyses .................................................................................... 46
Discussion ............................................................................................................................................ 55
  Study Hypotheses ............................................................................................................................. 56
    Degree of disability, Hypothesis 1 ................................................................................................. 56
    School success, Hypothesis 2 ......................................................................................................... 57
    Employment, Hypothesis 3 .............................................................................................................. 58
    Social and communication, Hypothesis 4 ...................................................................................... 59
    Autonomy, Hypothesis 5 .................................................................................................................. 60
Study Limitations ................................................................................................................................ 60
Contributions of This Study .................................................................................................................. 64
Future Research ..................................................................................................................................... 65
References ............................................................................................................................................ 69
Vita ......................................................................................................................................................... 85
List of Tables

1. Prevalence of Autism in 8-Year Olds in 2010 by Demographic Category.......................... 2
2. Participant’s ages during each wave of the NLTS-2 ...................................................................... 38
3. Demographic Characteristics of Participants.............................................................................. 38
4. Questions Utilized in QoL Subscale Development (Questions 12, 13, and 14).......................... 42
5. Woodcock-Johnson III Assessment Domains ................................................................................ 43
6. Arc: Self- Determination (Autonomy subscale) ........................................................................... 43
7. Measures ........................................................................................................................................ 44
8. Correlation matrix of study variables ............................................................................................. 47
9. Frequencies (rounded to the nearest 10), means and standard deviations for study variables . 48
10. Correlation Matrix for hypothesis 1 study variables of ≅ 230 young adults with Autism..... 49
11. Hypothesis 1: Hierarchical Regression Analysis Summary for degree of disability variables predicting Quality of Life in young adults with Autism of Tables......................................................... 49
12. Correlation Matrix for hypothesis 2 study variables of ≅ 200 young adults with Autism..... 50
13. Hypothesis 2: Hierarchical Regression Analysis Summary for school success variables predicting Quality of Life in young adults with Autism................................................................. 51
14. Correlation Matrix for hypothesis 3 study variables of ≅ 220 young adults with Autism..... 52
15. Hypothesis 3: Hierarchical Regression Analysis Summary for employment experience variables predicting Quality of Life in young adults with Autism ......................................................... 52
16. Correlation Matrix for hypothesis 4 study variables of ≅ 230 young adults with Autism..... 53
17. Hypothesis 4: Hierarchical Regression Analysis Summary for social and communication variables predicting Quality of Life in young adults with Autism ......................................................... 54
18. Correlation Matrix for hypothesis 5 study variables of \( \cong 170 \) young adults with Autism..... 55
19. Hypothesis 5: Hierarchical Regression Analysis Summary for autonomy variables predicting Quality of Life in young adults with Autism......................................................... 55
20. Comparison of 2 participants with Low and High Quality of Life scores......................... 65
List of Figures

Page

1. Prevalence of Autism from 1970-2013 .......................................................... 1
Abstract

QUALITY OF LIFE IN EMERGING ADULTS WITH AUTISM SPECTRUM DISORDER

By Staci Carr, M.S, Ed.M.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2014

Director: Barbara J. Myers, Ph.D.
Associate Professor
Department of Psychology

This study is focused on exploring quality of life in young adults in the autism spectrum and the factors that contribute to their own perception of satisfaction with their lives. Autism Spectrum Disorder is a neurodevelopmental disability that is associated with deficits in social interaction and communication and with restricted and repetitive behaviors (American Psychiatric Association, 2013). There has been a documented increase in the diagnosis of Autism Spectrum Disorders (ASD), making it to be one of the fastest growing diagnosed disabilities in children (Hartley-McAndrew, 2014). In the United States, the prevalence of ASD is approximately 1 in 68 children, with 1 in 42 among boys (CDC, 2014). With this increase in recognition of the disorder, adult outcomes have become an increasing priority for this population. While the concept of quality of life has been used in the field of intellectual disabilities for decades, the
factors contributing to quality of life of persons with autism spectrum disorder (ASD) have received relatively little attention. The aim of this study was to examine the influences of degree of disability, social and communication ability, academic success, employment, and independence and autonomy on quality of life in young adults with high-functioning autism. Participants ($N \approx 230$) were individuals from the dataset of the National Longitudinal Transition Study 2 (NLTS2) who had a diagnosis of autism spectrum disorder (ASD) (Cameto, et al., 2004). Results indicated that employment, social involvement, communication (being able to communicate, converse, and understand), and autonomy were significant in predicting higher quality of life. Factors found not to contribute to QoL included degree of disability (Woodcock-Johnson III) and education. This study helps to shed light on the development of higher quality of life in young adults with ASD and highlights areas for future research and training with these members of society.

Key Words: Autism, Emerging Adults, Quality of Life, Outcomes
Quality of Life in Emerging Adults with Autism Spectrum Disorder

Autism has become the diagnosis on every parent’s mind. It shows up on magazine covers (e.g., *Time*, May 6, 2002; May 15, 2006, June 2, 2008; *Wired*, January 11, 2010; *Parents*, April, 2012). When Kanner first described the disorder in 1943 (Kanner, 1943), it was seen as an exceedingly rare condition, with a prevalence of 2 to 4 in 10,000. Today, the webpage of the national organization *Autism Speaks* (http://www.autismspeaks.org) proclaims that “Autism affects 1 in 68 children, 1 in 42 boys.” This prevalence is supported by the Centers for Disease Control and Prevention (CDC, 2014), and it represents about a hundred-fold increase from the initial estimates (Figure 1).

![Autism Spectrum Disorders](image)

*Figure 1. Prevalence of Autism from 1970-2013.*
The higher prevalence estimates come about through a combination of factors: better awareness of autism spectrum disorder (ASD) by parents and professionals, a widened definition of characteristics of the disorder, improved diagnostic tools, more professionals able to make diagnoses, the availability of services for the disorder, and diagnostic substitution (i.e., children are now diagnosed with autism who previously were diagnosed with intellectual disability) (Ouellette-Kuntz, et al., 2014). Whether the incidence is actually increasing is a controversial question (Lord & Cook, 2013). Table 1 represents the prevalence by demographic category.

Table 1

<table>
<thead>
<tr>
<th>Prevalence of Autism in 8-Year Olds in 2010 by Demographic Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Boys</td>
</tr>
<tr>
<td>Girls</td>
</tr>
<tr>
<td>Race</td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Black</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
</tr>
<tr>
<td>Hispanic</td>
</tr>
</tbody>
</table>

The picture that “autism” most often brings to people’s minds is a young child with autism who is receiving intensive intervention to reduce his symptoms and bring out optimal functioning. What is forgotten is that each child with autism becomes a teenager with autism and then an adult with autism, as this disorder is lifelong (Seltzer, Krauss, & Shattuck, 2003). Our field knows far too little about the adults in our world who have autism spectrum disorders and, in particular, does not know enough about their quality of life as they move into adulthood. This
study is focused on exploring quality of life in young adults in the autism spectrum and the factors that contribute to their own perception of satisfaction with their lives.

Adults, as with children, in the autism spectrum show a wide range of strengths and problems. Autism is a spectrum disorder, meaning that it affects each individual differently, the intensity of the symptoms varies widely, and the form and presentation of symptoms change over time. The core symptoms of autism can be folded into two categories: persistent deficits in social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). Impairments in social communication and interaction, for example, can include abnormal eye contact, deficits in nonverbal and verbal communication, difficulty in play and making friends, and differences in social-emotional reciprocity. The second category, restricted and repetitive behaviors, also varies across the spectrum but may include stereotyped or repetitive hand movements (e.g., clapping, finger flicking, flapping, twisting), insistence on sameness, adherence to routines, preoccupations with obscure topics and items, and atypical reactivity to sensory input (American Psychiatric Association, 2013).

With this range of abilities and problems, the daily life and opportunities of adults in the autism spectrum can also show a wide range. Severely affected adults might have little or no speech, and this limits their communication with others and the kinds of social lives they are able to lead (American Psychiatric Association, 2013). Inability to following simple directions may cause problems in daily life and lead to increased problem behavior. Adults with high levels of stereotyped behaviors might have challenges getting and keeping a job if their repetitive hand movements or vocalizations are seen as disruptive or inappropriate. The intellectual level of people with autism also varies from those with very low measured intelligence to those with
genius-level capabilities. Intellectual capability is of obvious importance for success in school, college, and many jobs, though it is not a guarantee of either success or failure in life (Wehman, et al., 2013).

Possessing good social skills is critical to successful functioning in life. These skills enable individuals to know what to say and how to behave in diverse situations. The extent to which children and adolescents possess good social skills can influence academic performance, behavior, social and family relationships, and involvement in extracurricular activities. With a full repertoire of social skills, individuals will have the ability to make social choices that will strengthen their interpersonal relationships and facilitate success in school, employment, and life.

Quality of life (QoL) is a person’s perception of satisfaction in daily life. Quality of life typically includes the concepts of well-being, functioning, life-satisfaction, health, and disability. It also refers to “aspects of life that make life particularly fulfilling and worthwhile” (Quilty et al. 2003, p.406). Having, or not having, a disability does not determine quality of life. There can be many factors that contribute to quality of life, including, but not limited to, financial stability, employment, physical and mental health, education, recreation and leisure time, social belonging, and degree of independence. The relative importance of these factors can vary from one person to another and impact QoL differently.

Quality of life research spans decades and topics. Much research addresses how specific health conditions, such as cancer, HIV, Alzheimer’s, or stroke, impact a person’s quality of life. The use of quality of life (QoL) measures is an integral part of mental health evaluations (Drotar, 1998; Feingold, Hilari & Byng, 2009Sheir-Neiss, Melnychuk, Bachrach, & Paul, 2002; Weinberg & Williams, 1978). In contrast to clinical ratings of impairment, QoL assessments are based on the subjective global views of the individual. In addition, QoL assessments can be
further refined to specifically reflect the individual’s impression of his or her functioning (i.e., health-related quality of life; HRQoL) as opposed to the more global indicators or other specific measures (e.g., life-satisfaction). As a result, QoL measures provide valuable information for the clinical profile of individuals, as well as provide direction to intervention practices (Quilty L. C., Van Ameringen, Mancini, Oakman, & Farvolden, 2003).

Many researchers recommend using a combination of subjective and objective measures to assess overall quality of life in adulthood (Burgess & Gutstein, 2007). An “objective” assessment of a person’s quality of life can tell about that life from a well-informed family member or professional and will take into account the factors that are important to “most” people, and this can be very helpful. However, it may not tell us how an individual judges his quality of life. Subjective measures may include satisfaction ratings and personal opinions about feeling safe and secure, experiencing quality relationships and being included by others, environmental factors, family life, opportunities for personal development, physical health, recreational opportunities, and feeling that one’s rights have not been violated (Verdugo, Schalock, Keith, & Stancliffe, 2005). Because people might overestimate their quality of life for social desirability, the validity of subjective ratings may be questionable (Willey, 1999). Thus, both subjective and objective measures may be useful when assessing particular populations, including those with autism.

The question of quality of life becomes especially salient as young people transition from their school years into emerging adulthood. This is a time of major transition for every young person, but it takes on special challenges for those who must deal with the differences brought on by disabilities. As youth with autism leave the structure and consistency of a high school setting and life at home, where the majority of their day was consistent and planned out, they are faced
with increased unstructured time and decreased support. The variability of services and inconsistency of postsecondary opportunities for youth with autism can be challenging and can lead to social withdrawal and problem behaviors (Schall, Wehman, & McDonough, 2012). The natural transitions that all youth face may impact the quality of life of individuals with autism in a more extreme way.

Little is known about the predictors of quality of life in emerging adults with autism. The proposed study aims to provide a preliminary investigation into these important areas by exploring young adults aged 19-23 diagnosed with autism spectrum disorder (ASD). It will seek to identify the roles played by a number of factors available in a pre-existing dataset including severity of disability, educational success, employment status, social involvement and communication, and an individual’s level of independence in predicting the quality of life of young adults in the spectrum.

**Review of Literature**

**Autism Spectrum Disorder**

Autism spectrum disorder comprises a range of complex neurodevelopmental disorders. According to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (American Psychiatric Association [APA], 2013), Autism Spectrum Disorder, or ASD, is comprised of two primary characteristics: impairment in social communication and social interaction, and presence of restricted or repetitive patterns of behavior. Individuals with ASD vary widely in their abilities, interests, and strengths, and so characteristics of the disorder are expressed differently in every individual. Some individuals with ASD may exhibit only mild characteristics of autism, while others display the characteristics in an extreme manner.
Until the 2013 release of the DSM-5, the DSM-IV (2000) defined autism spectrum disorder to consist of four separate disorders: autistic disorder, Asperger’s disorder (AS), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS). More recently, researchers found that these distinct diagnoses were not consistently applied across different treatment centers or clinics. That said, anybody diagnosed with one of the four pervasive developmental disorders from DSM-IV will still meet the criteria for ASD in DSM-5 (Wing, et. al, 2011; American Psychiatric Association [APA], 2013). For an individual to meet criteria, characteristics must be present during a child’s early development. However, the characteristics may not be recognized until the individual is older and is placed in social situations that exceed his or her social abilities, such as school (Jordan, 2013). During the school years the social and developmental gap between typically developing children and those who may meet criteria for autism grows. The CDC recent findings report that only 44% of children with an ASD diagnosis were diagnosed by age 3 (CDC, 2014).

A considerable degree of variability in symptom severity exists, which makes for a diverse profile in performance across all aspects of life (e.g., education, employment, friendships, independence). The deficits among individuals with autism often result in uneven academic achievement, with students performing much higher or lower than intelligence tests would predict (Jones et al., 2009; Mayes & Calhoun, 2003). Furthermore, studies suggest that the severity of deficits in core areas of functioning including, social, communication, and behaviors can vary over time and settings (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004), and thereby differentially affect students’ performance in school and eventually employment. Additionally, nearly half of the children with an ASD diagnosis (46%) had above-average intelligence (IQ over
an interesting finding in itself. In 2002, only about a third of children with ASD were thought to have above-average intelligence. These results from the CDC indicate that the DSM-V criteria is capturing fewer individuals with Intellectual Disability (ID) (CDC, 2014). Ultimately, it is this variability in autism symptoms, within and between subjects, and over time, that can make it difficult to determine appropriate interventions, supports, and environments for individuals with autism to be most successful.

**Comorbidities and autism spectrum disorder.** Some, but not all, individuals with ASD have low intelligence as measured by cognitive functioning. The comorbidity for having ASD and intellectual disability (ID) is recently estimated to be as low as 41% (CDC, 2009) or as high as 70% - 75% (Ozonoff, Rogers, & Hendren, 2003), with half of the ID group functioning in the mild to moderate range and the other half in the severe to profound range. As part of the core characteristics of autism, individuals with ASD have language delays or differences. About 40% of children with ASD are non-verbal and do not talk at all during childhood; others may speak, but not until later in childhood (Howlin, Savage, Moss, Tempier, & Rutter, 2014). An estimated 25%–30% of children with autism have some words at 12 to 18 months of age and then lose them, in a pattern called regressive onset. Still others speak a lot but in odd or atypical ways (Howlin, Savage, Moss, Tempier, & Rutter, 2014). Individuals with average or superior intelligence may understand and use language fluently, but still use atypical prosody or intonation (Howlin, Savage, Moss, Tempier, & Rutter, 2014; Weismer, Lord, & Esler, 2010).

Autism Spectrum Disorders are often comorbid with a diverse group of medical conditions. It is estimated that about 10% of children with an ASD have an identifiable genetic, neurologic, or metabolic disorder, such as fragile X syndrome, Down syndrome, or
tuberous sclerosis. Fragile X syndrome is linked to between 2% and 6% of all children diagnosed with an ASD; the cause is gene mutation of an X chromosome (NIMH, 2011).

One percent of the general population has Down syndrome, while 5-7% of individuals with Down syndrome also are diagnosed with an ASD (Moss et al., 2013). One to four percent of individuals with an ASD have tuberous sclerosis (CDC, 2011), a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs and has a consistently strong association with ASD (NIMH, 2011).

One in four individuals with ASD develops seizures (Tuchman, 2011), with prevalence peaking in early childhood and again in adolescence. One study conducted on 120 adults with an ASD diagnosed in childhood found that 38% had had epilepsy at some time over their lifespan, while 16% were in remission (Ballaban-Gil & Tuchman, 2000).

Prevalence for seizures is found to be higher with increasing age, lower mental abilities, and severe language disorders; thus, while individuals with Asperger’s or high functioning autism have a low incidence, 5-10%, the prevalence of seizures increases to 30% in classic autism and further increases in disintegrative disorder and Rett syndrome, with values of up to 90% (Coleman, 2005). Obsessive and compulsive behaviors are frequently observed in individuals with ASDs; however there is controversy regarding whether an additional diagnosis of Obsessive Compulsive Disorder (OCD) is justified (Russell, Mataix-Cols, Anson, & Murphy 2005).

A number of studies have indicated a risk of mood disorder, particularly depressive disorder, among adolescents and adults with ASDs (Lugnegård, Hallerbäck, & Gillberg, 2011; Mazefsky, Conner, & Oswald, 2010; Simonoff, Jones, Pickles, Happé, Baird, & Charman, 2012). Youth with ASD who are found to be depressed present heightened
symptoms of ASDs, including more stereotypies and preoccupations, greater social withdrawal, hyperactivity, and agitation (Coleman, 2005). The comorbidity between bipolar disorder and ASD ranges from 5% to 21% (Ozonoff, Rogers & Hendren, 2005). Symptoms of over-activity and inattention are frequent in Asperger's Disorder, and indeed, many individuals receive a diagnosis of Attention Deficit/Hyperactivity Disorder prior to the diagnosis of Asperger's Disorder (Mayes et al., 2012).

The comorbidity rate of Tourette syndrome and ASD is 4.3-8% (Baron-Cohen et al., 1999). The differentiation between stereotypic movements of ASD and tics associated with Tourette’s is that stereotypic movements are voluntary, rhythmic, and often longer in duration while tics are involuntary, non-rhythmic, sudden, and often have a rapid onset and offset. The prevalence of autism is higher in blind than in sighted children (Brown et al. 1997; Hobson & Bishop, 2003).

Thus autism is a behaviorally defined disorder characterized by a broad constellation of symptoms. The issue of ASDs and co-morbidity is challenging, particularly when it comes to psychopharmacological treatments when co-morbid conditions exist (Effat, 2009). Individuals with ASD display great variability in behaviors, skills, preferences, functioning, and learning needs, and these change over the course of the life span (Heflin & Alaimo, 2007). The following section will describe the characteristics of social/communication and repetitive and stereotyped behavior in those diagnosed with ASD.

**Communication and social development.** Communication abilities among individuals with ASD vary from total lack of spoken language to highly sophisticated spoken and written ability (APA, 2000; Paul, 2007; Heflin & Alaimo, 2007). Communication is often the first domain of concern identified by families whose children are later diagnosed with autism (Goin-
Kochel & Myers, 2005). Some children initially develop early language skills but lose language between 18 and 24 months (Richler et al., 2006; Goin-Kochel & Myers, 2005), in a pattern known as regression. Others never develop language, or may develop language in which true reciprocal conversational exchanges do not occur. Such language may be characterized by labeling (instead of requesting), echolalia (echoing speech), abnormal prosody or inflection (unusual tone of voice or inflection), or improper use of pronouns (Corsello, 2013). In addition to expressive and pragmatic impairments, children with autism often demonstrate deficits in receptive communication. That is, they have difficulty understanding and responding to what others are saying.

Communication impairments appear as deficits or differences in both verbal and nonverbal language skills. For individuals who use language, they may use it instrumentally (i.e., to request something they want) rather than socially (Boucher, 2003). The inability to sustain a conversation with others, and the use of repeated words or idiosyncratic language, are characteristics of deficits in spoken language for children with autism (Manning-Courtney et al., 2013; Plumb & Wetherby, 2013). For individuals with autism whose speech is developed, there may be an abnormal pitch, rate, rhythm, or stress associated with verbal communication (McAlpine, 2012; Zager & Alpern, 2010); these issues constitute prosody problems. Problems with nonverbal communication include a lack of gestures, signaling, and facial expressions (Rozga, et al., 201).

In typical communication, people are “endowed with information-processing capacities for extracting linguistic rules and using them to encode and convey information” (Bandura, 1989, p. 17), but in ASD, this is challenged by difficulties with both semantics and pragmatics (VanBergeijk, et al., 2008). Children with autism do not naturally pick up the unspoken rules of
language structure and of what others mean when they are talking in the way that typically developing children do. Autism interferes with the ability to categorize and to understand abstract concepts in language, such as inference, idioms, and sarcasm, thereby impacting both communication and social relationships. Being able to recognize and repair breakdowns in communication requires high levels of joint attention, and thus deficits in joint attention add to the difficulty in communicating with others (Zager & Alpern, 2010). For persons with ASD, conversation may be self-centered on a topic of personal interest, and they may demonstrate a resistance to change the topic. Their resistance may be interpreted as “signs of disinterest, frustration, and anger” (Adreon & Durocker, 2007, p. 272). The underlying social communication differences may improve or change over time, but they do not go away.

Carrying on a conversation requires a multitude of skills, most of which come naturally to children and adults without ASD. In a conversation, it is necessary to understand how to initiate the interchange, take turns, demonstrate respect for the speaker, show interest in the speaker, and recognize previous knowledge of others involved in the conversation. These skills are difficult for many who have ASD. An inability to pay attention or maintain shifting attention has been reported in ASD, and this affects the individual’s orientation to social information in the environment (Keehn, Lincoln, Muller, & Townsend, 2010). Successful communication requires interaction between the networks of a multidimensional system (Keehn, et al., 2010). Individuals with ASD who are high functioning often speak using a formal or advanced vocabulary and not realize that this is different from the speech of their peers or that others find this odd or off-putting (Adreon & Durocker, 2007). Difficulty in modulating volume is also consistent among individuals with an ASD diagnosis. They may not be aware of how loudly or how softly they are speaking. Further discomfort for themselves and others may come about as
they may stand too close, fail to engage in reciprocal back-and-forth conversation, interpret language literally, and not understand the humor or sarcasm that is clear to others their age (Adreon & Durocker, 2007). Individuals with ASD are typically unaware of these problems and do not “read” the discomfort of others (Schwarzkopf, et al., 2012).

**Social interaction problems in people with ASD.** Problems with communication are related to problems with social interaction. The success of interactions with people requires bringing together non-verbal and verbal information (O’Conner, 2012). Communication requires expressing one’s own thoughts and emotions as well as understanding the thoughts and emotions of others. The expression of emotions is demonstrated through facial and body movements, speech prosody, and voice quality (O’Conner, 2012). Atypical prosody (e.g., unusual stress, rhythm, and intonation) adds social and communication barriers to communication and interaction that already contains speech that is grammatically and pragmatically peculiar (Paul et al., 2005). Difficulties are further compounded when the individual with ASD has difficulty in understanding the mental state of the other speakers from their vocal and facial expressions (Rubin, Prizant, Laurent, & Wetherby, 2013).

Children with autism are often not very social. They may demonstrate a low level of interest in other people, little affection towards familiar caregivers, abnormal eye contact, and a disinterest in reciprocal interactions (Williams & Gray, 2012). In addition, children with autism usually have deficits in imitation, joint attention, and imaginative play. These deficits constitute communication impairments as well as social interaction impairments (Hwang & Hughes, 2000). As the child grows older, if language or functional communication skills do not improve, he will fall further behind his peers, until the adolescent or adult is markedly different from others (Breitenbach, & Armstrong, 2013).
Compounding the communication problems, individuals with autism may also show deficits in the ability to understand that other people have different points of view (i.e., theory of mind). This interferes with their ability to understand the social language and intent of others. Children with autism have varying ability to initiate, respond to, and maintain social interactions (Matson, Dempsey, & Rivet, 2009). Social skills in adults with ASD, however, have been given far less study (Matson and Nebel-Schwalm, 2007; Matson et al., 2012).

**Repetitive, perseverative, and stereotyped behavior.** The second core domain of ASDs concerns atypical behavior. Repetitive, perseverative, and stereotyped behaviors are noticeable by others and can be disruptive in family and school situations. As infants, children with autism may excessively mouth items or demonstrate an aversion to touch. As they grow older, children may exhibit stereotyped hand and finger movements (e.g., wiggling fingers in front of their eyes), use objects inappropriately (e.g. interest in a part of a toy, such as the wheels of a toy car), demonstrate repetitive actions (e.g., lining objects up), and have inappropriate interests (e.g., bus schedules). Stereotyped movements such as pacing, spinning, running in circles, flipping light switches, rocking, hand waving, arm flapping, and toe walking are common. Body mannerisms such as rocking back and forth, moving hands in odd ways, blinking eyes, waving fingers in front of the eyes, or other uncommon movements sets the person apart from peers (Stratis & Lecavalies, 2013). These behaviors may address the sensory needs of the individual (Harrop, McConachie, Emsley, Leadbitter, & Green, 2014), but they mark him as odd and may bring forth peer victimization or bullying from other youth (Cappadocia, Weiss, & Pepler, 2012; Twyman, Saylor, Saia, Macias, Taylor, & Spatt, 2010; van Roekel, Sscholte, & Didden, 2010; Zablotsky, Bradshaw, Anderson, & Law, 2014).
Stereotyped movements appear to be less frequent among older individuals. Self-injurious behaviors and compulsive behaviors appear comparable across age groups, but ritualistic/sameness appears to be more frequent among older individuals (Lam & Aman, 2007). Militerni (2002) and colleagues found a different pattern in the age-related differences in restrictive and repetitive behaviors. In a comparison of younger and older children with ASD, they found younger children were more likely to exhibit motor and sensory repetitive behaviors, and older children were more likely to exhibit complex repetitive behaviors (Militerni, Bravaccio, Falco, Fico, & Palermo, 2002).

Individuals with autism frequently demonstrate unusual responses to sensory input. They may demonstrate either hyper-sensitivity or hypo-sensitivity to sounds, textures, tastes, and visual stimuli. Children may sniff objects obsessively. Subtle sounds, such as the buzz from fluorescent lights, or subtle textures, such as tags inside clothing, may feel aversive. Some individuals with autism seem not to feel pain or to notice when they are cold. Related symptoms include self-injurious behavior (e.g., self-biting, head banging) and feeding or eating problems (Matson, Hess, & Mahan, 2013). Children with ASD reject many foods and may be compulsive about the presentation of food (e.g., foods should not touch on the plate).

Anxiety frequently exists for individuals with ASD, and their anxiety is associated with significantly impaired functioning (Bellini, 2006;) (Vasa, Luther, Mazurek, & Kan, 2013). The anxiety becomes a part of the need for repetition and sameness. This often presents itself as individuals having the need to adhere to a strict routine and difficulty adapting to change. Along with restricted ranges of interest, there is an apparent anxiety in many of these individuals with respect to new situations, experiences, and changes in routine (Lecavalier, et al., 2013). For example, an individual may insist that the car to school follow the same route every day or that
items on kitchen shelves be arranged in an unchanging way. To cope with these anxieties, individuals with an ASD frequently involve themselves in ritualistic, OCD-like behaviors, or self-stimulation, such as rocking or hand flapping (Attwood, 2003). Unfortunately, although these behaviors often do help to decrease levels of anxiety, they may also cause these individuals to be negatively targeted by non-disabled peers (Garnett, Atwood, Peterson, & Kelly, 2013; Wing, 1981). If these rigid behaviors remain throughout adolescence and into adulthood, they pose a challenge in school, relationships, and jobs.

**Disability identity.** Developing and creating identity is an ongoing process from childhood though adolescence and into adulthood. For individuals with disabilities this process can be particularly challenging. Research on students with disabilities in post-secondary education has increased dramatically in the past thirty years since the passage of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, yet there remains a large gap in studies that address identity development in people with disabilities. Over the past decade, a small sampling of unpublished dissertations has addressed the experiences of people with learning disabilities in relation to identity status, often through narratives and group dialogues (Cain, 1997; Ferri, 1997; Skolnikoff, 1999). Skolnikoff described the experiences of adults with learning disabilities she interviewed as placing them on the margins, often due to being hesitant about revealing a hidden disability. The participants in Skolnikoff’s study were asked to describe their experiences in relation to their disability and interactions with others. She likened the resulting stories to those of people with differing sexual orientations who are constantly required to make decisions regarding whether to reveal in every situation. This process was seen by the researcher as harmful to the participant’s identity development, and, in fact, she stated that she
felt that the participants did not appear, from their narratives and responses to her questions, to have integrated disability into their identity.

Ferri (1997), and Cory (2005) interviewed students and requested that their participants provide stories about their experiences as people with disabilities. Ferri stated that most of the participants in her study tended to minimize or hide (as much as possible) their disabilities, specifically in reaction to negative experiences and interactions with non-disabled people (including family, friends, and faculty), and, instead, used other identities to describe themselves, such as gender, race or sexual orientation. Cory’s findings are similar. He found that a desire to pass or hide the disability is a common and logical desire, stemming from past experiences. He also found that students will work to keep this information a secret to the greatest extent possible. He asserts that students with invisible disabilities do not necessarily perceive themselves as disabled, therefore categorizing them together as a group is not logical to the students (Cory, 2005). Do and Geist (2000) used their own personal experience and experiences of other individuals with disabilities to illustrate how non-disabled people communicate their attitudes to people with disabilities both verbally, through statements of pity or inspiration, focusing on the disability and not the person, and non-verbally by “passing” (persons) through as if they are not able to function like others (i.e., passing a student with a disability from grade to grade without assessing knowledge). Do and Geist then suggest ways to communicate with people with visible disabilities that are non-stereotyping and that may serve to encourage people with disabilities to accept themselves and their bodies by using person-first language and treating the individual, not the disability. In the same way, Matthews and Harrington (2000) suggest a paradigm for communication with persons with invisible disabilities. However, neither of these articles offers a model for integration of disability into identity.
Individuals with autism often begin to develop a sense of identity related to their autism when they are able to make contact with others with the same disability (Bagatell, 2007; Holland et al., 1998). The diagnoses of Asperger Syndrome and high functioning autism began in the 1980’s. A recent development for this group is a sense of identity in the “Aspie World” (Bagatell, 2007). Through self-advocacy and self-determination in local groups (e.g., Autism Society Chapters, Autism Speaks, etc.), individuals with autism can feel comfortable meeting together and addressing their unique interests. Caldwell’s (2011) research supports this claim. He conducted in-depth qualitative interviews with 13 leaders in the self-advocacy movement with developmental or intellectual disabilities. Through careful analysis, he found five major themes, including connection with the disability community, reclaiming disability and personal transformation, disability acceptance, and integration into one’s life.

Higher functioning individuals with an autism diagnosis (HFA or AS) tend to fall into two camps. They may try to fit into the neuro-typical world though experimentation of trying things that will help them “take the edge off” social situations and “pretend to be normal” when they need to. Alternately, they may embrace their diagnosis and be “all-in” with developing a sense of pride in their autism. They may endorse a new way of looking at how their diagnosis offers an understanding of experiences and behaviors (Bagtell, 2007). Whichever camp resonates with the individual, researchers and practitioners should consider the process of disability identity that a person goes through and arrives at as a key component of development.

**Transition into early adulthood for individuals with ASD.** Young children with ASD have received much attention in research and as targets of intervention, due to the consistent finding that early and intensive intervention leads to the best possible outcomes for persons with ASD (Dawson et al., 2010, Kluth & Shouse, 2009). That said, the manifestation of ASD is
different during adolescence than during childhood. Adolescents with ASD have a unique experience, as they must deal with the typical difficulties that accompany bodily changes and peer relationships in adolescence (Brown & Klute, 2003) while at the same time possessing core deficits that make social relationships and communication difficult. The challenges that are associated with adolescence and the impact they have on the transition from school to adulthood for individuals with disabilities are only recently attracting the attention of researchers and professional personnel (Wehman, 2013). The transition from school to post-secondary education and employment is often difficult. Individuals diagnosed with an autism spectrum disorder experience struggles when transitioning to adulthood, especially in the areas of achieving independence and accessing community supports and services (Wehman, Smith, & Schall, 2009). The impact of having an ASD diagnosis and the characteristics that go along with the diagnosis greatly impact young adults’ independence in every aspect of their lives, including independent living, community integration, social relationships, and community networking (Schall, Wehman & McDonough, 2012).

The U.S. Department of Education counted in 2010 a total of 6,608,446 children and youth who were receiving special education services, with 10% of this group between 14 and 21 years of age; 417,000 of those students had an Autism diagnosis, (U.S. Department of Education, 2010). For those who graduate from high school, only 10% of these young adults with disabilities are employed upon exiting school, and fewer go to college and complete a degree (Newman, et al., 2011). Outcomes for youth with ASD show that most live with their parents, and many continue to require intensive community support services. Thus, these young adults are not achieving community independence (Hendricks &Wehman, 2010).

Individuals with ASD across the spectrum are reported to experience poor outcomes in

This study will use the dataset from the National Longitudinal Transition Study 2 (NLTS2) to investigate the relationships among student, family, and social factors as they relate to quality of life. The design for the NLTS2 is summarized next as a context for this study. The interested reader is referred to Wagner, Newman, Cameto, and Levine (2005) for an in-depth description of the design and procedures for the NLTS2.

**National Longitudinal Transition Study 2.** The NLTS2 is a longitudinal study of youth with disabilities that was commissioned by the U.S. Department of Education’s Office of Special Education Programs. The study was conducted by SRI International and Westat to obtain information on a variety of topics related to adolescents and young adults with disabilities (e.g., school experiences, employment, independent living, and social adjustment). At the beginning of the study in December, 2000, youth in the sample were students ages 13 through 16, in the seventh grade (or higher), and receiving special education services. Five waves of longitudinal data collection spanned 2001 to 2009. The study aimed to identify and sample a nationally representative sample of students with disabilities. NLTS2’s first wave of sampling identified local education agencies (LEAs) based on four categories each for the LEA’s enrollment size (small, medium, large, or very large), geographic region (Northeast, Southeast, Central, or West/Southwest), and socioeconomic status (SES; high to very low). Data were collected from multiple sources, including youth, their parents/guardians, teachers, principals, and school
records as youth transitioned from school to their post-secondary outcome. The three main data components of NLTS2 included parent/youth telephone interviews, direct youth assessments, in-person interviews with the youth, and school data. A follow-up simplified mail questionnaire was sent to those unable to complete the phone interview. Academic performance was measured at Wave 2, through a direct assessment by a professional using the Woodcock-Johnson III, and student interviews were conducted, if possible. Data were not collected from every participant for every variable; for example, the Woodcock-Johnson measures were conducted with just 170 youth (approximately). Overall, the NLTS2 is the largest and most representative longitudinal measure of adolescent and young adult participants with disabilities that currently exists.

Quality of Life

In everyday parlance, Quality of Life (QoL) has to do with people’s well-being, health, and happiness, but in scientific studies, it is a construct that is difficult to precisely define. Although there is a general agreement that QoL broadly encompasses multiple aspects of an individual’s life experience, there are almost as many QoL definitions as there are researchers defining it. For the purpose of this study, the World Health Organization (1997) definition will be used. Within the WHO framework, QoL is defined as individuals’ “perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1997, p. 3). This definition suggests that QoL is a subjective perspective on physical health, emotional health, independence, social relationships, and environmental interaction, all in relation to what is expected in that culture. This definition was chosen because it is largely inclusive in terms of groups of individuals for whom it would be applicable and because of its emphasis on the importance of subjective evaluations. These are characteristics that are well matched to this
study’s population and objectives. QoL instruments can be broadly categorized based on their rater (self or proxy) and whether they are generic or specific. Generic measures of QoL are designed to assess multiple areas of functioning deemed appropriate for the general public, while specific measures are intended to assess QoL within the context of a specific condition (Koot & Wallander, 2001).

Much of the research on QoL has focused on adults with specific health conditions such as schizophrenia (Tolman, Kurtz, 2012; Boyer et. al, 2013), aphasia, and stroke (Hilari & Byng, 2009; Ross & Wertz, 2003). Other research has examined QoL in individuals with chronic illnesses such as cancer (Wong et al., 2013), HIV/AIDS (Krause, Butler, & May, 2013) and cardiovascular disease (Schoormans, et al., 2013). The expansion of QoL research reflects a shift from conceptualizing disability and illness based on a medical model to a more holistic perspective. This, coupled with the ever-present pressure to allocate resources to ensure effective and efficient outcomes, has led to an increased interest in understanding factors that enhance QoL.

The importance of subjective ratings of quality of life—as opposed to ratings provided by parents or other proxies—has been highlighted by studies in which QoL outcomes were unexpected. For example, in an investigation of subjective QoL ratings of 53 adolescents who were born prematurely, investigators found that those who had been rated by their medical team as having more severe brain damage based on ultrasound during the neonatal period indicated more positive ratings of health-related QoL 18-19 years later as compared to the individuals with less brain damage in infancy (Feingold, Sheir-Ness, Melnychuk, Bachrach, & Paul, 2002). The expectation was that individuals who were identified as being more medically involved during the neonatal period would indicate that their QoL was worse than the group of adolescents who
were healthier as neonates. It is unclear why the individuals with more severe disabilities rated their QoL at adolescence more positively.

In another study that yielded unexpected results, Weinberg and Williams (1978) investigated the experience of 30 adults with physical disabilities who had had disabilities for a minimum of 6 years. The researcher asked, “If there were a surgery available that was guaranteed to completely cure your disability (with no risk), would you be willing to undergo the surgery?” Although the researcher was not directly asking individuals to rate their QoL, it was assumed that participants would wish to change their life if they perceived it to be of poor quality. Twenty-two (73%) of the participants indicated that they would not want to be cured, and that the disability had become an integral part of their life. The participants who first developed disabilities as adolescents or young adults were more likely to indicate that they would take the cure than those who had disabilities from birth or early childhood. It could be argued that the participants’ reluctance to want to change their life experience reflects a positive perception of their QoL, or perhaps they had simply adjusted to the life that they knew. Results of studies such as these lend credence to the importance of contextual factors in facilitating or inhibiting functioning, as there is not a clear, linear relationship between disease or disability and QoL.

**QoL in Individuals with ASD.** The majority of research in the field of ASD has focused on causes of the disorder, deficits in various domains, and treatments for atypical behavior or deviant behavior, with a positive outcome being measured in terms of specific skill gains or amelioration of aberrant behavior. There is also a fairly broad base of literature investigating the impact of ASD on families, with an emphasis on the negative impact in terms of increased stress, anxiety, and depression among caregivers (Hastings 2003; Openden, Symon, Koegel, & Koegel,
Less attention has gone to learning about quality of life in individuals with ASD themselves, but there is a small body of research examining the QoL of individuals with ASD.

Researchers and professionals do generally agree on core domains that comprise quality of life. Schalock's (2000) comprehensive review of papers on quality of life from the prior 30 years identifies eight core domains and their underlying indicators. The core domains include: self-determination, social inclusion, material well-being, personal development, emotional well-being, interpersonal relations, rights, and physical well-being. Schalock's (2000) framework has been widely adopted by studies that have investigated the quality of life of disability populations. This framework outlines quality of life domains in a manner that fuses a social model of disability with individuals’ commitment to self-determination and self-advocacy. This structure also rejects a deficit model of disabilities and favors a viewpoint that embraces strengths and difficulties, as well as diversity.

Individuals in the autism spectrum at all levels of functioning have trouble with social relationships. This is true both for lower-functioning individuals, who might be unable to maintain eye contact or relate to others as individuals, as well as for higher functioning individuals who are awkward or inappropriate in their social overtures with peers (Hsiao, Tseng, Huang, & Gau, 2013). Research shows that social support greatly enhances the quality of life of people with ASD (Hillier et al. 2007; Renty and Roeyers 2006, 2007; Weidle et al. 2006). Renty and Roeyers’ (2006, 2007) conducted studies of QoL in adults with ASD, looking at their degree of disability, how much informal social support they actually received, and how much social support they perceived they received. Their findings concluded first that degree of disability (i.e., level of autism traits and intellectual ability) was not a significant predictor of quality of life.
Further, they found that perceived availability of informal support was significantly related to quality of life, whereas received informal support was not. In other words, the perception that support is ready and available when needed was linked to a higher personal quality of life, while getting actual support was not. Also, they found that higher quality of life was associated with less discrepancy between needed and received formal support.

A study that focused specifically on the social aspect of quality of life was conducted with 14 adolescents with high-functioning autism and Asperger’s Syndrome and 15 of their typically developing peers, as well as with mothers of the participants, who rated their children’s quality of communication life (Burgess & Turkstra, 2010). Results indicated that ratings for both groups were generally positive, though ratings for the AS/HFA group were significantly lower than that of the control group. Of note, the ratings the individuals with the disorder gave themselves were higher than their parental ratings.

Presson (2000) measured QoL in adults who were moving into a group home in Sweden. This longitudinal study used ratings of behavior and independence skills on the Adolescent and Adult Psycho-Educational Profile (AAPEP; Mesibov, Schopler, Schaffer, & Landrus, 1988), a test administered to adolescents and adults with ASD to assess skills that are important for adult living (e.g., vocational and functional communication skills). The participants were 7 adults with ASD. The AAPEP was administered to each participant prior to moving into the group home and then 5 more times, at six-month intervals. There were improvements from time 1 to time 6 in all skills. The investigator argued that improvements in the individuals’ skills reflect perceptions of greater independence and satisfaction, and therefore serve as indicators of QoL. This is not a conceptualization of QoL that others have used, and it is possible that changes on the AAPEP were the result of practice effects rather than true changes in QoL in this small sample study.
In a second longitudinal study of QoL of adults with ASD, Garcia-Villamisar, et al. (2002) measured changes in QoL ratings on the Quality of Life Survey over a span of five years. The participants were 26 males with ASD who worked in a sheltered workshop (SHW) and 21 who worked in a variety of settings with employment support or supported work (SPW). The two groups were matched for ages and non-verbal IQ. Responses to the QoL interview were provided by the individual with ASD, if possible, or a job coach if the individual did not have the ability to communicate effectively. At the beginning of the study, participant groups had equal ratings of QoL, but at the end of 5 years the SPW group had more positive ratings than both their own initial scores and those of the SHW group, which did not change over time. The authors did not indicate which aspects of the supported employment might have led to more positive QoL ratings but generally concluded that supported work in a natural setting provided a better quality of life for adults with ASD than does work in a sheltered workshop.

A third study examined QoL in young men with Asperger Syndrome (AS) (Jennes-Coussens, Magill-Evans, & Konin, 2006). The authors compared quality of life ratings (WHOQOL-BREF Version; WHO, 1997) of 12 young men with AS in comparison with 13 typically developing (TD) peers. Participant ages ranged from 18-21 years. In addition, participants completed a Perceived Support Network Inventory (PSNI; Oritt, Paul, & Behrman, 1985) and were interviewed regarding other aspects of their lives such as friendships. The WHOQOL includes domains such as physical health and social relationships. Participants with AS rated their overall QoL lower than did their typically developing peers. Quality of Life scores were also significantly lower for individuals with AS than TD for the social domain. However, the total social support scores on the PSNI were not significantly different between groups. It is notable that the AS group had lower ratings on the social domain on the QoL instrument, but
similar social support scores on the other instrument. This finding suggests that although they had similar numbers of supports, the AS group was less satisfied with the quality of their relationships. The view of social network was positively related to ratings of QoL. There were a number of similarities between groups, including levels of education, employment, living arrangements, number of social relations, and frequency of participation in leisure activities, although there were some differences in the types of activities in which the two groups participated. The young adults with ASD in this study were better functioning and more independent than most with ASD. It is interesting that given the many similarities between the AS and TD groups, participants with AS still rated their overall QoL lower than did their typically developing peers.

Kamp-Becker (2010) and colleagues similarly examined health-related quality of life (HRQOL) in a cross-sectional study of twenty-six adolescent and young adult males with ASD. Compared to the reference sample of healthy controls, their sample scored significantly lower in three of the four WHOQOL-BREF domains. They did not find a significant difference in the Environment domain. In contrast, when compared to the sample with schizophrenia spectrum disorder (SDD), the sample with ASD scored significantly better on all of the HRQOL domains, except the “social relations” domain. These results are consistent with other studies comparing QoL in individuals with ASD with other samples.

Another recent study compared health-related quality of life (HRQOL) of youth with ASD with typically developing peers. Potvin (2013) and team used self and parent-proxy reports to measure health-related quality of life among those in the sample. They conducted a cross-sectional study of children with high-functioning autism (n = 30) and peers (n = 31) using the Pediatric Quality of Life Inventory 4.0 Generic Core Scales. They found that children with high-
functioning autism had significantly poorer health-related quality of life than peers whether reported by themselves ($p < .001$) or their parents ($p < .001$), although disagreement (intra-class coefficient = −.075) between children and parental scores suggested difference in points of view between parent and child. It is consistent with other study findings that children with high-functioning autism experience poorer health-related quality of life than those without autism.

Additional evidence about QoL in individuals with ASD may be found in the body of literature written by adults with autism, in which they describe both the struggles of having ASD and also the positive aspects of their lives (Gerland & Tate, 2003; Grandin, 2012; Grandin, 1996; Jackson, 2002; Williams, 1992). For example, Temple Grandin, arguably the most widely-known individual with ASD in the United States, cites her strong visual-perceptual skills, which result from her ASD, as the reason for her professional success (Grandin, 1996; Grandin, 2012). In general, in this autobiographical literature, many of the individuals with ASD who are able to reflect on their life experience describe it as different but not of poor quality.

As evident from this review, a number of recent studies have examined QoL in individuals with ASD, including some that have focused on higher functioning adolescents and emerging adults with HFA/AS. These studies recognize that social life is changing at this age and that some adolescents and young adults with HFA/AS are in mainstream settings with same-age peers, such as vocational settings and college. A few points may be derived from the review of QoL literature, however, including that there are often differences between self vs. proxy ratings, with the “self” ratings generally more positive than proxy ratings. Further, QoL ratings are generally lower for those with ASD than those without, although the differences may be relatively small.
**Transition to adulthood and quality of life.** In our society, graduation from high school is considered a key turning point in the lives of young people. Not only does it mark the transition from high school into college or the workforce, but it also symbolizes the transition from adolescence to emerging adulthood and increased independence (Syed & Seiffge-Krenke, 2013). For many adolescents, finishing high school marks the start of autonomous decision-making in daily life.

Griffin et al. (2010) are interested in how schools can encourage teenagers to begin exploring notions of adulthood as early as possible, during high school at the latest. In her research, Griffin aimed to obtain detailed descriptions from high school students as they approached graduation of what transitioning into adulthood meant to them as well as their decision-making strategies during this transition period. They collected data on typically developing high school students’ perceptions of: (1) socio-cultural information, i.e., their beliefs about societal norms and appropriate adult behaviors and goals, (2) self-information, i.e., self-awareness, skills, and personal goals, and (3) task information, i.e., environmental opportunities and requirements.

Griffin and colleague’s findings indicate that students have stronger goals and higher levels of thinking during this transition time if they perceive themselves as becoming adults and have a richer representation of adulthood. In other words, planning for adulthood and thinking like an adult is more likely to occur when young people see themselves as transitioning into adulthood. These results suggest that in order for students to make the most out of their high school years in terms of preparation for adult life, they must practice being an adult before they actually become an adult. These authors recommend that during their high-school years, students should be encouraged to think about adulthood, explore their options, and set some goals. This
advice is good not only for typically developing students, but for those with autism spectrum disorders as well.

In their path of “practicing adulthood,” students use high school and experiences associated with it as a “rite of passage experience” (Collinson, 1998). Students appreciate being trusted with greater responsibilities while still needing guidance from adults. Ellis and colleagues (2009) assert that teachers, parents, and other professionals working with adolescents should encourage youth to begin taking on more adult responsibilities as well as provide them with guidance during this transition period. However, many schools focus exclusively on academic achievements and pay little attention to other skills that are essential for adult life. Consequently, many students leave high-school unable to handle adulthood (Syed & Seiffge-Krenke, 2013).

The seemingly independent choices of young adults are affected by societal expectations, and these, in turn, affect societal interaction with them. As adolescents go through this transitional period, they must decide what adulthood means for them, what kind of adults they would like to become, and how they envision interacting with society. In a seminal early study that helped shape the construct of emerging adulthood, Arnett (1994) examined college students’ perspectives of their transition to adulthood. Two research questions guided this study: (1) what characteristics are necessary in order for a person to be considered an adult? and, (2) where on the adolescence/adulthood continuum do college-age students perceive themselves to be? The participants ($n = 346$) filled out a 40-item questionnaire with items such as “support self financially,” “employed full-time,” “established relationship with parents as an equal adult,” and “accept responsibility for the consequences of your actions.” Students were asked to indicate whether or not they felt each item was necessary for adulthood.
Arnett found that, on average, college students did not consider several behaviors commonly associated with adulthood as necessary to being an adult, such as completing secondary or post-secondary education, marrying, becoming a parent, and being employed full-time. On the other hand, most college students did view moving out of the parental home, financial self-sufficiency, and running their own households to be important markers of becoming an adult. Arnett also compared these students’ answers to their current living situation, revealing that many students were uncertain about their own adult status. For example, although 66% of participants considered financial self-sufficiency to be a mark of independence, only 5% of them indicated that they supported themselves without any parental support at all. While 55% of participants considered the ability to run a household to be a mark of adulthood, most did not have responsibility for food preparation or living expenses in their own household.

Arnett concluded that these participants are in what he termed the emerging adulthood stage. He posited that this is the period between the time when young people consider themselves to have begun the transition to adulthood and the time when they consider themselves to have completed and become full-fledged adults. According to Arnett, “Adult status is conceived by them mainly in terms of independence and self-sufficiency and, during the process of emerging adulthood, they gradually pursue these ends” (p. 223).

This research highlights that becoming an adult does not mean simply reaching a certain age. It includes developing life skills and achieving certain life circumstances that mark the difference between adolescence and adulthood. This process takes time and effort. Wehm (2013) suggests that schools should offer curriculum and experiences to help adolescents begin the transition to adulthood and that this training is needed for both typically developing youth
and those with disabilities. Schools can also offer opportunities to develop and practice life skills while providing scaffolding in that process (Hayes, & Hosaflook, 2013).

**Proposed Study**

**Statement of Problem**

Adolescence through emerging adulthood is a period of transition during which there is typically a substantial increase in the ability to think abstractly, conceptually, and flexibly (Syed & Seiffge-Krenke, 2013). It is a time when young people increase their ability to reflect upon and evaluate their life experiences (Arnett, 1994). This is a time when social cognition and social skills become increasingly important if a young person is to fit in to the social environment of school, work, and community. Communication skills are needed to support social participation.

Individuals with ASD have substantial and longstanding difficulties in these domains (Rubin, Prizant, Laurent, & Wetherby, 2013). Young people expect to become more independent than when in high school; they expect to drive, get a part time job, buy their own music and clothes, and manage their money, at least to some extent. Adolescents and young adults with ASD are often greatly limited in each of these areas. They may be limited in their ability to participate in everyday activities of life; hence, this likely limits their quality of life. The relations among these factors are unknown, however. There is much evidence that QoL is reduced for individuals with health conditions and disabilities compared to healthy and non-disabled peers as it is typically defined; however, the predictors of this lowered QoL for young people with ASD are not known.

**Education, employment, and QoL.** Over the past decade, increased attention has been given to a population of students with ASD who are transitioning from high school to post-secondary activities. A large portion of young people with ASD have intellectual disability or
other limitations that keep them from pursuing academic work after high school (i.e., college). These individuals hopefully are able to transition into supported employment or other job-related activities despite their cognitive ability (Wehman, 2013). Students with ASD who attend college are individuals with average to superior intelligence and with special interests and talents (Prince-Huges, 2002; Camarena, et al., 2009). The college setting provides these students with an opportunity to develop their special interests and academic skills. In both school and work settings, however, many individuals with ASD struggle with negotiating the social interactions and conversations with others that are necessary for their success in those settings. Adults with ASD report pervasive difficulties in fitting in to many aspects of their lives, including “schooling, expectations, friendships, life, and society” (Portway & Johnson, 2003, p. 437). For young adults with ASD who are intellectually and academically capable of doing well in college, social struggles can impact their perceptions of personal success and have a negative impact on their overall view of school. Their self-evaluation of success or failure in the social realm can influence their decision to remain enrolled in college or to drop out (Harpur, Lawlor, & Fitzgerald, 2004) and ultimately, their quality of life. Thus, some students with ASD choose to leave college solely based on their inability to cope with the social demands (Harpur, Lawlor, & Fitzgerald, 2004).

The challenges that individuals with ASD face in securing employment, friends, economic independence, and freedom to function at the highest possible level (Smart, 2001) suggest a relationship between these milestones and QoL. Chan, Wang, Muller, and Fitzgerald (2011) propose that “lack of employment opportunities and work incentives excludes people with disabilities from full community participation, significantly affecting the quality of
their lives” (p.3). Together, these findings suggest that relationships exist between education and QoL as well as employment and QoL.

**Social and communication abilities and QoL.** Competence in getting along with others in adult settings is dependent at least in part on the quality of social skills that an individual possesses. Social skills can vary by situation or context. An individual with ASD may demonstrate social skills that family members understand and accept but may be less competent when interacting with peers and unfamiliar adults. Some researchers (Billstedt, Gillberg, and Gillberg, 2011) have found that certain symptoms of autism lessen as an individual enters emerging adulthood. However, while improvement in communication skills may be seen, the social use of language is generally more resistant to change, and interpreting social information and participating in reciprocal social interaction often continue to be areas of significant difficulty (Farley et al., 2009; Seltzer et al., 2004). These lingering social deficits impact adult outcomes and are thought to be significant contributors to the patterns of unemployment and underemployment, paucity of friendships and romantic relationships, and low rates of independent living that have repeatedly been shown for adults with ASD (e.g. Billstedt et al., 2011, Farley et al., 2009, and Howlin et al., 2004). Outcomes are highly variable (Levy & Perry, 2011), but even high functioning individuals with ASD often seem to “function well below the potential implied by their normal range intellect” (Marriage, Wolverton, & Marriage, 2009, p. 326).

Social functioning in adolescents and adults with ASD is studied through looking at peer relationships, friendships, and patterns of participation in social activities. Baron-Cohen and Wheelwright (2003) reported that many adults with ASD have friendships, but that these friendships tended to be less close and had less importance for the adults with ASD compared to
a group of neurotypical (NT) adults. The adults with ASD were also less likely to enjoy social interaction simply for the sake of social interaction. Orsmond, Krauss, and Seltzer (2004) reported their participants had difficulty defining the term friend; few were considered to have a true friendship, and even those who did still reported feeling lonely. Liptak, Kennedy, and Dosa (2011) and Shattuck, Orsmond, Wagner, and Cooper (2011) found that many adolescents and young adults with ASD did not tend to get together with friends or talk to friends via email, instant message, or telephone. Research suggests that many adolescents with ASD are able to take advantage of social support, for example, Humphrey and Lewis (2008) found the students in their study who had peer support and real friendships tended to have a much more positive sense of self; however, not all do so. Similarly, Lasgaard, Nielsen, Eriksen, and Goosens (2010) found that while adolescents with ASD were lonelier than a control group, perceived social support from family, peers, or friends was protective against loneliness. Thus it is proposed that social relationships are predictors of QoL in young adults in the autism spectrum.

**Independence and QoL.** The deficits associated with ASD hinder daily life functioning in emerging adulthood. A minority of individuals with ASD live independently. Few individuals have social and intimate relationships, and education and employment levels are low, even when general intelligence is within the normal range (Howlin, Savage, Moss, Tempier, & Rutter, 2014). As they move from adolescence and into adulthood, individuals with ASD find themselves still living in their childhood bedrooms and needing their parents’ help for everyday functioning; this world can be very small and the freedoms quite constrained. For this age group, independent activities would include earning money, going out with friends, choosing how to spend money and time, going out to restaurants and movies, and making decisions about clothes and hairstyle. The typical steps into autonomy seem to be unattainable. Research available today
fails to tell, from the young adults’ point of view, what this lack of independence means to them. It is likely that this lack of independence greatly impacts the young person’s feelings of self-confidence, self-worth, and ultimately their QoL.

**Specific Aims and Hypotheses**

The objective of the current study is to explore the predictors of Quality of Life for late adolescents and emerging adults with Autism Spectrum Disorders. The results of this study may provide a contribution to families, service providers, educators, policymakers, and third party payers in understanding the needs of the young adult population with ASD by identifying the areas of potential impairment or strength that have predictive capacity of future independence and success. Additionally, results may assist in developing direction for educators regarding the skills they should be teaching adolescents with ASD so that they can maximize their potential for a high quality life in adulthood.

The aims and hypotheses for the current research are:

**AIM 1:** To examine the influence of degree of disability on QoL of young adults with ASD.

- **HYPOTHESIS 1:** Individuals who have higher ability level will report higher QoL. Specifically, participants who score higher on Woodcock-Johnson III (subscores: applied problems, calculation, and passage comprehension), and have a greater ability to communicate with others (ability to communicate, ability to converse, and ability to understand others) will report higher levels of QOL, over and above the influence of age and gender.

**AIM 2:** To examine the influence of school success on QoL of young adults with ASD.
• HYPOTHESIS 2: Individuals who have more educational success (higher grades in high school, high-school diploma, involved in post-secondary education) will report higher QoL, over and above the influence of age and gender.

AIM 3: To examine the influence of employment on QoL in young adults with ASD.

• HYPOTHESIS 3: Individuals with higher levels of employment (not employed, non-competitively employed, competitively employed) will report higher levels of QoL, over and above the influence of age and gender.

AIM 4: To examine the influence of social involvement and communication on QoL of young adults with ASD.

• HYPOTHESIS 4a: Young adults who participate in more active social activities (number of groups involved in, number of groups relied upon to make decisions, invited to social events) will report higher levels of QoL, over and above the influence of age and gender.

• HYPOTHESIS 4b: Young adults who have better communicative ability (communication ability, conversation ability, ability to understand others) will report higher levels of QoL, over and above the influence of age and gender.

AIM 5: to examine the influence of independence and autonomy on QoL of young adults with ASD.

• HYPOTHESIS: Young adults with greater sense of autonomy (The Arc’s Self-Determination Scale, Autonomy subscale) will report higher levels of QoL, over and above the influence of age and gender.

Method

Participants
Participants were individuals from the dataset of the National Longitudinal Transition Study 2 (NLTS2) who had a diagnosis of autism spectrum disorder (ASD) (Cameto, et al., 2004). Ages by wave are shown in Table 2. The original Wave 1 sample included approximately 900 students whose primary disability was autism spectrum disorder. (We note that all sample sizes must be rounded to the nearest 10, per the requirements of the IES.) Participants were lost across waves; the details for the losses at each wave are not publicly available. At Wave 4 participants were between the ages of 19 and 23. This represents the final year in high-school and post high-school, the developmental period of interest in this study. The dataset was examined for participants with little or no missing data for our relevant variables. Approximately 230 youth had sufficient data for inclusion. Some variables had fewer respondents, and these are noted in the Results. The ethnicity of the sample is comparable to the general population. Demographics are provided in Table 3.

Table 2

*Participant’s ages during each wave of the NLTS-2*

<table>
<thead>
<tr>
<th>Wave 1</th>
<th>Wave 2</th>
<th>Wave 3</th>
<th>Wave 4</th>
<th>Wave 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>2003</td>
<td>2005</td>
<td>2007</td>
<td>2009</td>
</tr>
<tr>
<td>13-16 years</td>
<td>15-19 years</td>
<td>17-21 years</td>
<td>19-23 years</td>
<td>21-25 years</td>
</tr>
</tbody>
</table>

Table 3

*Demographic Characteristics of Participants (N = 230*)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n*</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>200</td>
<td>87</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>180</td>
<td>78</td>
</tr>
<tr>
<td>African American</td>
<td>30</td>
<td>14</td>
</tr>
<tr>
<td>Hispanic</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Asian</td>
<td>10</td>
<td>4</td>
</tr>
</tbody>
</table>
Procedure

Data in the NLTS2 were collected by project staff from multiple sources using a variety of different instruments. In this study, data from the Parent Interview or Parent–Youth Interview, Student’s School Program Survey (SPS), and the School Characteristics Survey (SCS) were used. Prior to the study beginning, at Wave 1, the project staff achieved active consent (a positive indication of consent) from all parents. Either active consent (written consent on a consent form) or passive consent (not indicating a refusal to participate) was sought at at subsequent waves for youth over 18-years of age or from parents of younger participants prior to any assessments taking place. For analysis purposes, students were assigned to a disability category on the basis of the primary disability designated by the student’s school or district. In Wave 1, the Parent Interview was conducted by telephone with a parent or guardian (hereafter...
referred to as parent); when a parent could not be reached by telephone, selected questions were
asked via a mail survey. In Waves 2 to 4, the Parent Interview was replaced with the Parent-
Youth Interview. Parents continued to respond to certain interview questions regarding family
and youth characteristics and expectations. In addition, youth were interviewed (either by phone
or mail) regarding work, extracurricular activities, postsecondary school, and other experiences.
If youth were unable to respond to the interview questions, parents continued to respond to key
questions. In addition, youth who could not respond by telephone but could complete a self-
administered questionnaire were mailed one. For this analysis, when parent and youth responses
to the same questions were available, the youth response was chosen.

For the current study, Wave 4 youth-report data were used for variables regarding social
supports, employment, independence, and the outcome variables of self-image, support, and
QoL. Wave 4 was chosen because it represented the age group of interest for this study,
demerging adults. Academic performance and intellectual capacity data drew upon school data.
The Institutional Review Board of the Virginia Commonwealth University (VCU) approved the
study.

Measures

Quality of Life (QoL). The NLTS2 did not administer a standardized QoL scale. A QoL
scale was developed for this study by utilizing combined responses from three sets of questions
that were asked of the youth. Youth answered a series of items that measured Personal Feelings,
Self-Image, and External Support. The total quality of life measure is a composite of 3
subscales: personal feelings, self-image, and external support. The items that make ups these
subscales consists of Likert-type variables measure on 4, 3, and 5 point scales, respectively. The
total subscale was based on the sum of the items in each subscale, scaled so the that each
subscale has a range of 0 – 10, such that the higher values of the subscale reflect higher aspects of QoL. The total QoL score is the sum of the scaled subscales.

Several participants in the sample had missing values for one or more of the items that were used to create the subscales. In order to retain participants that had a small number of missing items, an ad hoc method of imputation was performed. This method considered the value of the missing item(s) to be the average of all the items for a participant within a subscale. However, this method was only applied if the number of missing items was relatively small. Specifically, this method was applied if participants had 2 or less missing values from the personal feelings subscale, 3 or less missing items from the self-image subscale, or 1 missing item from the external support subscale. Participants with more missing items than these were deemed missing for the Quality of Life scale. Internal reliability (Cronbach alpha) for this transformed scale was .75. The range of potential scores was from 1 to 30, with higher scores representing higher quality of life.

**Woodcock-Johnson III.** The Woodcock-Johnson III was used as a measure of degree of disability. The Woodcock-Johnson Tests of Cognitive Abilities, Third Edition (WJ-III COG; Woodcock et al., 2001) is a revised version of the Woodcock-Johnson Tests of Cognitive Ability, Revised (WJ-R COG; Woodcock & Johnson, 1990). The WJ-III COG is administered individually and can be used with individuals between the ages of 2 and over 90. The standardization of the WJ-III COG was conducted nationally using 8,818 typically developing participants between the ages of 2 and 90, from over 100 different geographical communities in the United States. Examinees were randomly selected within a sample controlling for census region, community size, sex, race, Hispanic, type of school, type of college/university, education of adults, occupational status of adults, and occupation of adults in the work force. As a result,
the norm sample is considered to be representative of the United States population (McGrew & Woodcock, 2001).

The Woodcock-Johnson III consists of seven measures. The three included in this study, Passage Comprehension, Applied Problems, and Calculation, are described in Table 5. The median reliability coefficient alphas for all age groups for the standard battery of the WJ III ACH for subtests ranged from .81 to .94. A shortened version of the WJ III was conducted during Wave 2 (youth were 15-19 years of age) in person by trained professionals. It was not re-administered at later Waves. Data are available for approximately 170 participants.

Table 4

* Questions Utilized in QOL Subscale Development (Questions 12, 13, and 14)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Feelings</td>
<td>(How often youth felt the following in the last week)</td>
</tr>
<tr>
<td></td>
<td>a) Enjoyed life</td>
</tr>
<tr>
<td></td>
<td>b) Depressed</td>
</tr>
<tr>
<td></td>
<td>c) That people disliked you</td>
</tr>
<tr>
<td></td>
<td>d) Hopeful about future</td>
</tr>
<tr>
<td></td>
<td>e) Lonely*</td>
</tr>
<tr>
<td>Self-Image</td>
<td>(How much youth thinks each of the following statements are like him or her)</td>
</tr>
<tr>
<td></td>
<td>a) You are proud of who you are</td>
</tr>
<tr>
<td></td>
<td>b) You are a nice person</td>
</tr>
<tr>
<td></td>
<td>c) You can make friends easily</td>
</tr>
<tr>
<td></td>
<td>d) You can tell other people your age how you feel when they upset you or hurt your feelings</td>
</tr>
<tr>
<td></td>
<td>e) You feel useful and important</td>
</tr>
<tr>
<td></td>
<td>f) You feel your life is full of interesting things to do</td>
</tr>
<tr>
<td></td>
<td>g) You can handle most things that come your way</td>
</tr>
<tr>
<td></td>
<td>h) You know how to get the information you need</td>
</tr>
<tr>
<td></td>
<td>i) You can get school staff and other adults to listen to you</td>
</tr>
<tr>
<td>External Support</td>
<td>(How much youth feels supported by people around him/her)</td>
</tr>
<tr>
<td></td>
<td>a) Adults care about youth</td>
</tr>
<tr>
<td></td>
<td>b) Parents care about youth</td>
</tr>
<tr>
<td></td>
<td>c) Friends care about youth</td>
</tr>
<tr>
<td></td>
<td>d) Family pays attention to youth</td>
</tr>
</tbody>
</table>

* Reverse-coded
Table 5

Woodcock-Johnson III Assessment Domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Assessment</th>
<th>Task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>Passage Comprehension</td>
<td>Youth reads a short passage and identifies a missing word.</td>
</tr>
<tr>
<td>Math</td>
<td>Applied Problems</td>
<td>Youth analyzes and solves problems in mathematics: youth decides the appropriate mathematical operations to use and which of the data to include in the calculation</td>
</tr>
<tr>
<td></td>
<td>Calculation</td>
<td>Youth performs mathematical calculations ranging from simple addition to calculus, but is not required to make decisions about what operations to use or what data to include.</td>
</tr>
</tbody>
</table>

Autonomy subscale of the ARC Self-Determination Scale. The NLTS 2 investigated four domains of youth’s self-determination by asking youth to judge and report the extent to which their behavior reflects self-regulation, self-realization, psychological empowerment, and autonomy (Wehmeyer, 1997). NLTS2 selected items from the Arc’s Self-Determination Scale (Wehmeyer, 2000) that address these topics and included them as part of an in-person interview with youth at Wave 2. For the purpose of this study, the Autonomy score was used as a measure of Independence. The other scores were too closely related to the Quality of Life outcome variable that is used in this study and thus were not included. The Autonomy Scale can be seen in detail in Table 6. Total scores can range from 2 to 60, with higher scores indicating higher feelings of autonomy. Data from this scale are available for approximately 170 participants.

Table 6

Arc: Self-Determination (Autonomy subscale)

<table>
<thead>
<tr>
<th>Items of the Autonomy subscale</th>
<th>Response Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal autonomy items:</td>
<td>I do not even if I have</td>
</tr>
<tr>
<td>I keep my own personal items together.</td>
<td>the chance</td>
</tr>
</tbody>
</table>

43
I keep good personal care and grooming.
I make friends with other kids my age.
I keep my appointments and meetings.
I plan weekend activities that I like to do.
I am involved in school-related activities.
I volunteer for things that I am interested in.
I go to restaurants that I like.
I choose gifts to give to family and friends.
I choose how to spend my personal money.

Autonomy in career planning items:
I work on schoolwork that will improve my career chances.
I do school and free time activities based on my career interests
I make long-range career plans.
I work or have worked to earn money.
I am in or have been in career or job classes or training.

Additional measures are described in Table 7.

Table 7

<table>
<thead>
<tr>
<th>Measure</th>
<th>Scored</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achievement</td>
<td>Woodcock-Johnson III as described above</td>
</tr>
<tr>
<td>High School Grades</td>
<td>Most recent grades rated as: 2 = Above Average; 1 = Average; 0 = Below Average or Failing at Wave 4 by parent report</td>
</tr>
<tr>
<td>High School Graduation</td>
<td>2 = High School Diploma 1 = GED or Certificate; ; 0 = Still in high school;</td>
</tr>
<tr>
<td>Post-secondary Education Status</td>
<td>2 = In post-secondary education (Vocational, Community College, 4 year); 1 = Still in Highschool; 0 = not enrolled in school</td>
</tr>
<tr>
<td>Employment Status</td>
<td>2 = Competitively Employed; 1 = Non-competitive employment; 0 = not employed</td>
</tr>
<tr>
<td>Belongs to a large social group</td>
<td>1 = yes; 0 = no</td>
</tr>
</tbody>
</table>
Number of groups of people relied upon to make important decisions

Includes friends, parents/guardians, girlfriend or boyfriend, siblings, religious figures, guidance counselors, teachers, coworkers, boss/supervisor, other; Each scored 2 = more than 1 , 1 = 1, 0 = no; final score was a tally of groups

Communication

Ability to communicate with others: Answered in Wave 2 by student’s teacher
1 = No trouble, 2 = a little trouble, 3 = a lot of trouble, 4 = does not speak at all

Conversation

Ability to engage in a conversation with others: Answered in Wave 2 by student’s teacher
1 = No trouble, 2 = a little trouble, 3 = a lot of trouble, 4 does not converse at all

Understanding

Ability to understand others: Answered in Wave 2 by student’s teacher
1 = No trouble, 2 = a little trouble, 3 = a lot of trouble, 4 = does not understand at all

Autonomy

Autonomy subscale of Arc Self-Determination Scale; higher numbers are better (2-60)

Results

Data Preparation

Analyses were conducted using SPSS 22. Relevant assumptions were first tested. A sample size of approximately 230 was deemed adequate given the number of independent variables to be included in each analysis (Tabachnick & Fidell, 2007). The assumption of singularity was met as each of the independent variables was not a combination of other independent variables. An examination of correlations (see Table 8) revealed that some variables were highly correlated. However, as the collinearity statistics (i.e., Tolerance and VIF) were all within accepted limits for all variables (i.e., VIF < 5 for all hypotheses, Tolerance > 1),
multicollinearity was ruled out (Coakes, 2005; Hair et al., 1998). No bivariate correlations surpassed .80 between any of the variables of interest. No extreme univariate outliers were identified. An examination of the Mahalanobis distance scores indicated no multivariate outliers. Residual and scatter plots indicated that the assumptions of normality, linearity and homoscedasticity were all satisfied (Hair et al., 1998; Pallant, 2001). The correlation matrix of all variables is shown in Table 8. Frequencies, means, and standard deviations are reported in Table 9.

**Hierarchical multiple regression analyses.** Hypothesis 1 stated that Quality of Life is predicted by degree of disability as measured by cognitive measures and communication. A three step hierarchical multiple regression was conducted with Quality of Life as the dependent variable. Age and gender were entered at step one of the regression to control for any effect these variables may have. Three cognitive measures, the Woodcock-Johnson-III subtests (Applied Problems, Calculations, and Passage Comprehension), were entered at step two. Three communication variables (Ability to Communicate, Ability to Converse, and Ability to Understand) were entered at step three. Note that for communication variables, higher values denote poorer communication ability, hence the negative betas. Intercorrelations between the variables are reported in Table 10, and the regression statistics are in Table 11.

The model at the first two steps was not significant (p > .05). With the addition of the communication variables in addition to age, gender, and the Woodcock-Johnson scores, the full model was significant $F(8,170) = 7.16, p < .001$, adjusted $R^2 = 0.11$; eleven percent of the variance in quality of life was predicted. Those with higher ability to converse with others had higher QoL. The analysis was conducted on a reduced sample size of approximately 170 participants, thus the $n$ for the full regression $\geq 170$. 

46
Table 8

Correlation matrix of study variables (n ≥ 230)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5◊</th>
<th>6</th>
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<th>8</th>
<th>9</th>
<th>10</th>
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<th>12</th>
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<th>14◊</th>
<th>15◊</th>
<th>16◊</th>
</tr>
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<tbody>
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<td>4</td>
<td>-.17*</td>
<td>.16*</td>
<td>.63**</td>
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<td>7</td>
<td>.21**</td>
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<td>-.07</td>
<td>.17*</td>
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<td>.06</td>
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<td>.04</td>
<td>-.03</td>
<td>-.18*</td>
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<td>-.07</td>
<td>-.02</td>
<td>-.08</td>
<td>.06</td>
<td>.19**</td>
<td>-.07</td>
<td>.09</td>
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<tr>
<td>12</td>
<td>.24**</td>
<td>-.13*</td>
<td>-.20**</td>
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<td>.23**</td>
<td>-.09</td>
<td>.06</td>
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<td>13</td>
<td>-.12</td>
<td>-.04</td>
<td>-.09</td>
<td>-.01</td>
<td>.01</td>
<td>.20*</td>
<td>-.16*</td>
<td>-.53**</td>
<td>.41**</td>
<td>.25**</td>
<td>.10</td>
<td>-.01</td>
<td>--</td>
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<tr>
<td>14◊</td>
<td>-.15</td>
<td>-.18*</td>
<td>-.12</td>
<td>-.09</td>
<td>.16*</td>
<td>-.09</td>
<td>-.08</td>
<td>.11</td>
<td>.29**</td>
<td>.08</td>
<td>.03</td>
<td>.09</td>
<td>.41**</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15◊</td>
<td>-.17*</td>
<td>-.17*</td>
<td>-.02</td>
<td>.00</td>
<td>.02</td>
<td>-.05</td>
<td>-.06</td>
<td>.18*</td>
<td>.26**</td>
<td>.08</td>
<td>.03</td>
<td>.06</td>
<td>.35*</td>
<td>.75**</td>
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</tr>
<tr>
<td>16◊</td>
<td>-.07</td>
<td>-.23**</td>
<td>-.06</td>
<td>-.05</td>
<td>.13</td>
<td>-.08</td>
<td>.02</td>
<td>.23**</td>
<td>.30**</td>
<td>-.05</td>
<td>.05</td>
<td>.04</td>
<td>.25**</td>
<td>.70**</td>
<td>.60**</td>
<td>--</td>
</tr>
</tbody>
</table>

*p < .05

**p < .001

◊ = n is reduced to about 170 participants

∆ = higher values denote poorer communication ability

Variables by Number

1. Quality of Life (DV)
2. Ability to communicate ∆
3. Ability to converse ∆
4. Ability to understand ∆
5. Autonomy (Self-Determination Scale)◊
6. Age
7. Belonging to large social groups
8. Current Education Status
9. Current Employment Status
10. Gender
11. Grades in High School
12. Groups relied upon to make important decisions
13. High School diploma Status
15. Woodcock-Johnson-III Calculations◊
Table 9

*Frequencies (rounded to the nearest 10), means and standard deviations for study variables*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Frequencies</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life</td>
<td>22.98</td>
<td>4.58</td>
<td></td>
</tr>
</tbody>
</table>

Woodcock-Johnson III

| Applied Problems                | 84.42       | 22.13 |     |
| Calculations                    | 92.03       | 24.63 |     |
| Passage Comprehension           | 83.38       | 25.42 |     |

High School Grades

| 2 - Above average  | 120          |
| 1 - Average       | 60           |
| 0 - Below average  | 30           |

Post-Secondary Education status

| 2 - In-post secondary | 20           |
| 1 - Still in high-school | 90          |
| 0 - Not enrolled      | 110          |

Employment Status

| 2 - Competitive     | 40           |
| 1 - Non-competitive | 100          |
| 0 - Not employed    | 70           |

Belongs to a large social group

| 1 - Yes            | 120          |
| 0 - No             | 100          |

Number of groups of people relied upon to make important decisions

| 2 - Two or more groups | 40           |
| 1 - One group         | 90           |
| 0 - None              | 100          |

Communication

| 1 - No trouble            | 140          |
| 2 - A little trouble      | 80           |
| 3 - A lot of trouble      | 10           |
| 4 - Does not speak at all | 0            |

Converse

| 1 - No trouble            | 60           |
| 2 - A little trouble      | 120          |
| 3 - A lot of trouble      | 40           |
| 4 - Does not converse at all | 10          |

Understand

| 1 - No trouble            | 70           |
| 2 - A little trouble      | 150          |
| 3 - A lot of trouble      | 10           |
| 4 - Does not understand at all | 0         |
Table 10

*Correlation Matrix for hypothesis 1 study variables of ≥ 230 young adults with Autism*

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality of Life</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Age</td>
<td>-.14*</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gender</td>
<td>-.12</td>
<td>.04</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. WJ-III Applied Problems◊</td>
<td>-.15</td>
<td>.08</td>
<td>-.09</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. WJ-III Calculations◊</td>
<td>-.17*</td>
<td>.08</td>
<td>-.05</td>
<td>.75**</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. WJ-III Passage Comp.◊</td>
<td>-.07</td>
<td>-.05</td>
<td>-.08</td>
<td>.70**</td>
<td>.60**</td>
<td>--</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>7. Ability to communicate with others</td>
<td>.03</td>
<td>.02</td>
<td>.06</td>
<td>-.18*</td>
<td>-.17*</td>
<td>-.23**</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Ability to converse with others</td>
<td>-.25**</td>
<td>.12</td>
<td>-.02</td>
<td>-.12</td>
<td>-.24</td>
<td>-.06</td>
<td>.40**</td>
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<td></td>
</tr>
<tr>
<td>9. Ability to understand others</td>
<td>-.17*</td>
<td>.06</td>
<td>.06</td>
<td>-.09</td>
<td>.00</td>
<td>-.05</td>
<td>.16*</td>
<td>.63**</td>
<td>--</td>
</tr>
</tbody>
</table>

*p < .05

**p < .001

◊ = n is reduced to about 170 participants

Table 11

*Hypothesis 1: Hierarchical Regression Analysis Summary for degree of disability variables predicting Quality of Life in young adults with Autism (N ≥ 170)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.30</td>
<td>.28</td>
<td>-.14</td>
<td>.03</td>
<td>.03</td>
</tr>
<tr>
<td>Gender (Male = 1)</td>
<td>-1.75</td>
<td>.97</td>
<td>-.08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td>.06</td>
<td>.03</td>
</tr>
<tr>
<td>Woodcock-Johnson-III Applied Prob.</td>
<td>-.02</td>
<td>.03</td>
<td>-.09</td>
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</tr>
<tr>
<td>Woodcock-Johnson-III Calculations</td>
<td>-.02</td>
<td>.02</td>
<td>-.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Woodcock-Johnson-III Passage</td>
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<td>.02</td>
<td>.04</td>
<td></td>
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</tr>
<tr>
<td>Comp.</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td>.17**</td>
<td>.11**</td>
</tr>
<tr>
<td>Ability to communicate with others</td>
<td>.78</td>
<td>.62</td>
<td>.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to converse with others</td>
<td>-2.65</td>
<td>.70</td>
<td>-.41**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to understand with others</td>
<td>.62</td>
<td>.87</td>
<td>.07</td>
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</tr>
</tbody>
</table>

**p < .001
Hypothesis 2 stated that Quality of Life is predicted by success in school. To test this hypothesis a four step hierarchical multiple regression model was conducted with Quality of Life as the dependent variable. Age and gender were entered at step one. Grades earned during high school (above average, average, or below average) was entered at step two. High school diploma status (Still in high school, standard high school diploma, GED or certificate, or no diploma) was entered at step three. Current education status (post-secondary education, high school or GED, or none) was entered at the final step. Intercorrelations between the variables are reported in Table 12, and the regression statistics are in Table 13. Hierarchical multiple regression analysis revealed that the model was not significant at any step. Thus, these measures of school success did not predict Quality of Life $F (3,190) = .36, p = 0.55$.

Table 12

*Correlation Matrix for hypothesis 2 study variables of ≥200 young adults with Autism*

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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</thead>
<tbody>
<tr>
<td>1. Quality of Life</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Age (Male = 1)</td>
<td>-.14*</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gender</td>
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<td>.04</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>4. Grades in High School</td>
<td>.06</td>
<td>-.08</td>
<td>.09</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. High School Diploma</td>
<td>-.12</td>
<td>.20**</td>
<td>.25**</td>
<td>.10</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>6. Current Education Status</td>
<td>.07</td>
<td>-.24**</td>
<td>-.18**</td>
<td>.19**</td>
<td>-.53**</td>
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</tbody>
</table>

*p < .05

**p < .001
Hypothesis 2: Hierarchical Regression Analysis Summary for school success variables predicting Quality of Life in young adults with Autism (N ≥200)

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Age</td>
<td>.58</td>
<td>.27</td>
<td>-.15</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gender (Male = 1)</td>
<td>-.132</td>
<td>.96</td>
<td>-.10</td>
<td>.03</td>
<td>.00</td>
</tr>
<tr>
<td>2</td>
<td>Grades in High School</td>
<td>.30</td>
<td>.46</td>
<td>.05</td>
<td>.04</td>
<td>.01</td>
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<tr>
<td>3</td>
<td>High School Diploma</td>
<td>-.66</td>
<td>.56</td>
<td>-.09</td>
<td>.04</td>
<td>.00</td>
</tr>
<tr>
<td>4</td>
<td>Current Education Status</td>
<td>-.38</td>
<td>.63</td>
<td>-.05</td>
<td>.04</td>
<td>.00</td>
</tr>
</tbody>
</table>

*p < .05

Hypothesis 3 stated that Quality of Life is predicted by employment status. A two-step hierarchical multiple regression was conducted with Quality of Life as the dependent variable. Age and gender were entered at step one of the regression. Current employment status (competitively employed, non-competitively employed, not employed) was entered at step two. Intercorrelations between the variables are reported in Table 14 and the regression statistics are in Table 15.

The full model was significant $F (1, 220) = 4.90, p < .05$, adjusted $R^2 = .05$. Those who were younger and those with higher employment status (e.g., competitively employed) had higher QoL.
Table 14

Correlation Matrix for hypothesis 3 study variables of ≥220 young adults with Autism

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality of Life</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Age</td>
<td>-.14*</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gender (Male = 1)</td>
<td>-.12</td>
<td>.04</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>4. Current Employment Status</td>
<td>.12</td>
<td>-.19**</td>
<td>.00</td>
<td>--</td>
</tr>
</tbody>
</table>

**p < .001

Table 15

Hypothesis 3: Hierarchical Regression Analysis Summary for employment experience variables predicting Quality of Life in young adults with Autism (N ≥220)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.57</td>
<td>.25</td>
<td>-.15*</td>
<td>.04*</td>
<td>.04*</td>
</tr>
<tr>
<td>Gender (Male = 1)</td>
<td>-.156</td>
<td>.88</td>
<td>-.12</td>
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<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current Employment Status</td>
<td>.96</td>
<td>.43</td>
<td>.15*</td>
<td>.06*</td>
<td>.02*</td>
</tr>
</tbody>
</table>

*p < .05

Hypothesis 4 stated that Quality of Life is predicted by social ability and ability to communicate with others. A three step hierarchical multiple regression was conducted with Quality of Life as the dependent variable. Age and gender were entered at step one. Two variables that represent social ability (belonging to a large group, and number of groups relied upon to make important decisions), were entered at step two. Three communication variables (Ability to Communicate, Ability to Converse, and Ability to Understand) were entered at step
three. Intercorrelations between the variables are reported in Table 16, and the regression statistics are in Table 17.

The hierarchical multiple regression revealed that the model at each step was significant ($p > .05$). At step 1, gender and age ($F(2,220) = 3.89$, adjusted $R^2 = .03$) predicted 3% of the variance in QoL. With the addition of the social variables at step 2 ($F(2,220) = 11.54$, adjusted $R^2 = .11$), an additional 9% of the variance was accounted for. At step 3, an additional 7% of the variance in quality of life was accounted for by communication ability over and above age, gender, and social ability ($F(3,220) = 7.03$, adjusted $R^2 = .18$). Being younger, having larger social involvement, and having a higher ability to converse, communicate, and understand others predicted a higher quality of life.

Table 16

Correlation Matrix for hypothesis 4 study variables of ≥230 young adults with Autism

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality of Life</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Age</td>
<td>-.14*</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gender (Male = 1)</td>
<td>-.12</td>
<td>.04</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Belonging to a group</td>
<td>.21**</td>
<td>-.05</td>
<td>-.03</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Groups relied upon to make important decisions</td>
<td>.24**</td>
<td>-.09</td>
<td>.04</td>
<td>.06</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Ability to communicate with others</td>
<td>.03</td>
<td>.06</td>
<td>.02</td>
<td>.04</td>
<td>-.13*</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Ability to converse with others</td>
<td>-.25**</td>
<td>-.02</td>
<td>.12</td>
<td>.13</td>
<td>-.20**</td>
<td>.40**</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>8. Ability to understand others</td>
<td>-.17*</td>
<td>.06</td>
<td>.06</td>
<td>.11</td>
<td>-.08</td>
<td>.16*</td>
<td>.63**</td>
<td></td>
</tr>
</tbody>
</table>

*p < .05  
**p < .001
◊ = $n$ is reduced to about 170 participants
Table 17

Hypothesis 4: Hierarchical Regression Analysis Summary for social and communication variables predicting Quality of Life in young adults with Autism (N = 230)

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Age</td>
<td>-.53</td>
<td>.25</td>
<td>-.14*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gender (Male = 1)</td>
<td>-.158</td>
<td>.90</td>
<td>-.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Belonging to a large (social) group</td>
<td>1.72</td>
<td>.58</td>
<td>.19*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Groups relied upon to make important decisions</td>
<td>1.43</td>
<td>.40</td>
<td>.23**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Ability to communicate (with others)</td>
<td>1.39</td>
<td>.52</td>
<td>.18*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ability to converse (with others)</td>
<td>-1.86</td>
<td>.54</td>
<td>-.30**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ability to understand (others)</td>
<td>-.03</td>
<td>.70</td>
<td>-.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05

**p < .001

Hypothesis 5 stated that Quality of Life is predicted by level of independence or autonomy. A two-step hierarchical multiple regression was conducted with Quality of Life as the dependent variable. Age and gender were entered at step one of the regression and autonomy was entered at step two. Intercorrelations between the variables are reported in Table 18 and the regression statistics are in Table 19.

The full model was found to be significant $F (1, 170) = 9.03, p < .05$, adjusted $R^2 = .05$; five percent of the variance in quality of life was predicted by higher score on the autonomy subscale. It should be noted that this analysis was conducted on a reduced sample size of about 170.
Table 18
*Correlation Matrix for hypothesis 5 study variables of ≥170 young adults with Autism*

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality of Life</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Age (Male = 1)</td>
<td>-.14*</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gender</td>
<td>-.12</td>
<td>.04</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>4. Autonomy (Self-Determination Scale)◊</td>
<td>.25**</td>
<td>-.20**</td>
<td>-.05</td>
<td>--</td>
</tr>
</tbody>
</table>

*p < .05
**p < .001
◊ = n is reduced to about 170 participants

Table 19
*Hypothesis 5: Hierarchical Regression Analysis Summary for autonomy variables predicting Quality of Life in young adults with Autism (N ≥170)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.30</td>
<td>.28</td>
<td>-.08</td>
<td>.02</td>
<td>.02</td>
</tr>
<tr>
<td>Gender</td>
<td>-1.53</td>
<td>.99</td>
<td>-.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy (Self-Determination Scale)◊</td>
<td>.11</td>
<td>.04</td>
<td>.23*</td>
<td>.07*</td>
<td>.05**</td>
</tr>
</tbody>
</table>

*p < .05
**p < .001
◊ = n is reduced to about 170 participants

Discussion

The prevalence of autism diagnosis is on the rise across the lifespan (CDC, 2014). While research continues to target diagnosis and early intervention for children, work needs to focus also on those who are entering adulthood with respect to their quality of life. They are now out of...
school and many efforts to improve their functioning are finished. The mandate for school intervention is now ended, and the services young adults receive in their communities is highly variable but is often next to nothing. Our attention now needs to look at the quality of life that these young people have as they embark upon their adult years.

The purpose of this investigation was to examine the predictive value of (a) degree of disability, (b) educational success, (c) employment, (d) social and communication ability, and (e) autonomy on Quality of Life (QoL) in young adults with ASD. The reasons for examining these potential predictors of QoL were to add to the literature base and to suggest topics for consideration when providing support to this population. In this discussion, each of the study’s hypotheses will be addressed and findings will be explained within the context of relevant literature. Limitations of the current study will be outlined.

Study Hypotheses

**Degree of disability, Hypothesis 1.** Previous research revealed mixed results when assessing quality of life in those with disabilities. For individuals with physical disabilities, quality of life was not predicted by their disability (Weinberg & Williams, 1978). Those with medical issues such as cancer and cardiovascular disease did, however, experience lower quality of life due to their health condition (Wong, Lam , Wan , & Rowen, 2013). One study that investigated autism spectrum disorder specifically found that degree of disability was not a significant predictor of quality of life (Rentry & Roeyers, 2006).

It was hypothesized that degree of disability would be a significant predictor of quality of life in emerging adults with autism. Disability was measured by a cognitive measure (Woodcock-Johnson III) and by communication ability. Our prediction was that those who scored higher on the Woodcock-Johnson III would have higher quality of life. Additionally,
communication ability was used as a measure of disability, such that those who were able to communicate, converse, and understand others with little or no trouble would have a higher QoL. This hypothesis was partially supported.

In this study, the Woodcock-Johnson III did not predict quality of life. Findings examining intellectual ability and quality of life are inconsistent. Rentry and Roeyers (2006) found that a norm-based measure of cognitive disability was unrelated to QoL. Howlin and colleagues (2004), though, found that individuals with IQ scores above 70 were likely to demonstrate a more positive outcome. Though the Woodcock-Johnson measures did not predict QoL in this study, measures of intelligence and functioning are important to life. As expected, Woodcock-Johnson III was positively correlated with education and employment, such that having higher scores on the measures was related to better grades, enrollment in post-secondary education, and employment at a higher level.

When looking very specifically at communication ability, the measures of communication played a role in QoL. These results are consistent with clinical experiences. Those individuals who are more severely impacted in their communication (i.e., minimal expressive language, difficulty understanding others) spend less time with others and interact less with others. Thus, they do not have the same opportunities as those who communicate with ease. This leads to a more restrictive lifestyle, which in turn can impact quality of life (Krause, Butler, & May, 2013).

School success, Hypothesis 2. It was hypothesized that those individuals who had greater school success (e.g., higher grades in school, a high school diploma, enrolled in post-secondary education) would have higher quality of life. This hypothesis predicted that those individuals who were less impacted by their disability, such that they had higher grades,
graduated from school, and perhaps were attending a post-secondary educational setting, to be better functioning and thus that they would have a higher quality of life. Those emerging adults with autism who have a positive academic profile often have more opportunities, and it was expected that they would report higher quality of life. This hypothesis was not supported.

Although the schooling measures did not predict QoL, the data here affirmed that the high school diploma is not without importance in a young person’s life. Specifically, in this sample, this achievement is strongly correlated with higher level employment, and that employment indeed predicted QoL. Working in the community is a goal that individuals with and without disabilities want to achieve and view as a milestone of adulthood (Wehman, 2013). But higher education itself does not always equate to happiness and fulfillment. There are many aspects of higher education that many students with autism are not prepared to navigate, including less contact with teachers, higher expectations, less support, greater emphasis on independence, and increased social demands (Getzel, & Briel, 2006). Perhaps the demands of education reduced the positive aspects that schooling had to offer (Potvin, Snider, L, Prelock, Wood-Dauphinee, & Kehayia, 2013). Those who were stronger students and further along in their education may not have been more happy and satisfied, even though an objective measure of their situation would consider them to have higher quality of life.

**Employment, Hypothesis 3.** Our third hypothesis looked at employment as a predictor of quality of life for emerging adults with autism, and this hypothesis was supported. There is substantial research into the positive effects of employment for individuals with disabilities (Hendricks & Wehman, 2010; Wehman, et al., 2009; Wehman, 2013; Wehman et al., 2013). Satisfactory employment is a construct that predicts QoL for adults in general and for adults with autism in particular (Burgess, et al., 2010). Meaningful, paid employment is a source of pride
and meaning for people with and without autism (Grandin, 2012). Research has found that the lack of employment opportunities that individuals with autism experience impacts their community participation and perhaps quality of life (Chan, Wang, Muller, Fitzgerald, 2011). Our research supports previous findings that having a job had a significant positive effect on quality of life (Wehman, 2010; Wehman, 2013).

**Social and communication, Hypothesis 4.** The fourth hypothesis looked specifically at social opportunities and communication as predictors of QoL. These two areas are, by definition and diagnosis, the most challenging for individuals with autism. Two distinct areas, based on previous research, were considered. First the predictive value of belonging to a group was tested, and was found to be significant (Orsmond & Krauss, 2004; Liptak, et al., 2011). Next, the predictive value of social support was tested, as it was also a significant predictor. Prior research indicated that having a social support network that a person could rely on predicted higher quality of life (Rentry & Roeyers, 2006). Hypothesis 4 was fully supported.

When young people participate in a group (e.g., church youth group, autism specific group, scouts, club, etc.) they have contact with others and opportunities to practice and engage socially. Social interaction in a group can be easier to manage than individual friendships, as the group has social norms that require everyone to get along (e.g., “A Girl Scout is a sister to every other Girl Scout”). Individual friendships can be difficult for those with autism (Bauminger & Kasari, 2000). For example, even among those who have developed friendships, there often is great difficulty defining what a friend is. Children in the spectrum who had friends still reported greater feelings of loneliness compared to typically developing children (Bauminger & Kasari, 2000).
Communication is a social act. Being able to communicate, converse, and understand others facilitates more interactions and potential social encounters. Not surprisingly, conversation ability, in addition to social engagement in a group and support network, predicted quality of life.

**Autonomy, Hypothesis 5.** The final hypothesis targeted self-determination, particularly autonomy. This hypothesis was supported. Included in the concept of autonomy are independence and acting on the basis of beliefs, interests, and abilities. As children grow older, their need and desire to display autonomy, responsibility, and competence increases and leads to exploration and healthy development. This is true for all individuals; however, youth with autism tend to have fewer choices and fewer opportunities for self-management and exploration of independence (Heflin & Alaimo, 2007). Self-determination and opportunities for independence enhance quality of life for typically developing children and adults (Adleman & Taylor, 1990; Lishin, Bostanzhieva, & Provorova, 1990) and for special populations such as those with intellectual disability (Brown 1999; Felce & Perry, 1996), and learning disability (Heyman, 1990). This was found to be true with this sample of emerging adults with autism as well.

**Study Limitations**

This study was fortunate to have had access to the NLTS-2 study. This is a large and well-conducted study that provided a rich resource of data, far beyond what any individual researcher could achieve. However, there are limitations in the data available for the particular questions in this study, and so compromises had to be made.

A first concern is the sample characteristics. This sample was from a large national dataset that at the outset of the study included approximately 900 youth with a diagnosis of
autism. The original sample was well balanced across regions of the country, socioeconomic status, demographics, and so on. Unfortunately, by Wave 4 there were a great many participants who had dropped out of the study. The original sample of 900 was reduced to approximately 230, leaving less than 25% of the youth who were originally enrolled. It is not possible to know whether the drop-outs were different in systematic ways from those who were still taking part. Further complicating things, the sample of 230 was reduced to approximately 170 for many analyses. In particular, data were missing for the cognitive measure, the Woodcock-Johnson III (measured by professionals), and for the Autonomy measure (a self-report measure). This indicates that approximately one-quarter of the youth were not measured for these key variables, and there is no way to know why. A concern is that these measures might not be missing at random but rather that they represented participants who were different in some systematic way (e.g., lower functioning, less cooperative, or other reasons). It is also possible, of course, that the missing data happened at random due to everyday complications of research (e.g., youth were missing school that day, study personnel did not make it to their appointments, a box of measures was lost). While there was still sufficient power to conduct the desired analyses, caution should be used when interpreting and generalizing these results.

Another potential limitation has to do with the participants’ diagnosis. In this study, children were classified as having autism by the school district and that diagnosis was confirmed by parents. It is not clear how diagnoses were conducted or whether they were confirmed by a medical professional or psychologist. Their classification encompasses the full autism spectrum. This may result in under-representation of those individuals with a milder form of autism spectrum disorder who did not require special education services. Likewise, it could be that lower-functioning students who could have met criteria for ASD were classified instead as
having Intellectual Disability as the primary diagnosis. Further, it was not possible to consider comorbidities (i.e., multiple disabilities), mental health conditions such as depression or anxiety, or other complicating health conditions. Comorbidities are present for a large portion of the ASD population, yet this study was not able to take this into account. A presence of additional conditions could certainly impact quality of life.

A third limitation to this study relates to the measures that were available through NLTS2. It was not possible to select the instruments that would have been optimal. Most seriously, the study did not include a standardized Quality of Life measure, and so a measure of QoL was created for the study from available data representing personal feelings, self-image, and external support. These are important components of quality of life, but they are not all the aspects. Schalock (2000) suggested eight core domains that make up QoL, including self-determination, social inclusion, material well-being, personal development, emotional well-being, interpersonal relations, rights, and physical well-being. The measure created for this study, from variables available in the NLTS2 dataset, was not able to capture all of these domains.

Limitations exist for additional variables. The Woodcock-Johnson measures were not the best measure for cognitive and functional abilities, but this was the only IQ-type measure available. This measure had also been collected when the youth were four years younger, at Wave 2. A cognitive measure taken at Wave 4 may have yielded different results for individuals who were achieving gains (or losses) during this period. Additionally, one can speculate that those who did not have data on the Woodcock-Johnson-III may be those who were lower functioning. This speculation comes from looking at the mean scores on the measure, which were less than one standard deviation below the mean. The lowest-IQ youth were apparently not
tested. Thus, the study sample does not include representation of the entire autism spectrum from low to high functioning.

Many of the variables available for the study were categorical estimates with 2, 3, or 4 levels rather than validated measures. For example, the measures of ability to communicate, converse, and understand were provided by teachers at Wave 2. These communication measures were rough estimates and not validated measures of communication that might have been provided by speech-language therapists. It is unknown in what context communication was measured. There is certainly a difference between initiations of communication with adults versus peers. Similarly, it is not known whether teachers were thinking about communication in a one-to-one setting, in a small group, in the classroom, or in a family setting. The measure for high school grades was a simple above average, average, below-average scale, provided by the parents; too much data was missing to discern whether the participants were in inclusive classrooms or special classrooms. Perhaps, the measurement of “grades” is less relevant to this population. Academic success may be better measured by how well the Individualized Education Goals (IEP) are met. Thus, the measure of “school performance” is less than precise.

Social support data and social activity data were provided by the participants themselves. While self-report is important, it is unclear the accuracy of the participants’ understanding or perception of their own social functioning. The available measures regarding sociability were focused on the quantity or frequency of social participation rather than the quality. Previous research suggests that the quality of social interactions is more important than the number or frequency of interactions.

One of the core domains of an autism diagnosis included in the DSM- 5 is presence of restricted, repetitive patterns of behavior, activities, interests, etc. (American Psychiatric
Association, 2013). The data available did not specifically address behavior in this way. Rather behavior was associated with behavior disorder. Such behaviors often impact other areas of functioning including social interactions, independence, and inclusion in a variety of activities. A measure of how these restrictive and repetitive behaviors impact the individual with autism would perhaps add to the prediction of quality of life.

**Contributions of This Study**

It is known that individuals with autism are different than individuals without autism, and that there is much diversity along the autism spectrum. It cannot be assumed that these differences equate to deficiencies, inadequacies, or poor quality of life. It is possible and even likely that individuals with autism can have different life experiences from each other and from typically developing individuals and still have a high quality of life. This merits further study, particularly given the clinical goal of maximizing QoL in this population.

Our overall results give a beginning picture of what contributes to quality of life in individuals with autism, and this will be illustrated with two case examples. Table 20 illustrates two young men from this sample. Participant A has a relatively low quality of life. He presents as a 20-year old male with difficulty in communication, not belonging to a social group, not employed, still in high school, and with an average autonomy rating. Participant B presents as a 20-year old male who does not have trouble communicating with others, belongs to a social group, has graduated from high school, has a job, and has an above-average autonomy rating. His QoL score is high. Their cases demonstrate the three greatest predictors of QoL in this study: communication ability, employment, and autonomy.

Understanding the predictors of Quality of Life for the unique population of emerging adults with autism could potentially steer future intervention practices in schools and
communities. This is one of only a few studies that have investigated the value of specific life skills and events in predicting quality of life in emerging adults with autism. The results are important in terms of gaining increased understanding of QoL perceptions of emerging adults with autism. This study provided beginning evidence of predictors of QoL among this population. Past research has shown that individuals with autism have less positive perceptions of their own QoL compared to their typically developing peers, and so there is much room for improvement.

**Future Research**

Extensive efforts go into helping young children with autism spectrum disorders learn to talk and think and interact with others, and these efforts are bringing remarkable gains. What happens next—in adulthood—needs to be the focus for autism researchers, professionals, and families. Helping individuals with autism achieve a good quality of life can be seen as the ultimate goal of all the intervention work that is done during childhood.

Table 20

*Comparison of 2 participants with Low and High Quality of Life scores*

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Participant A</th>
<th>Participant B</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL Score</td>
<td>10</td>
<td>28</td>
</tr>
<tr>
<td>Age</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>Ability to Communicate</td>
<td>A little trouble</td>
<td>No trouble</td>
</tr>
<tr>
<td>Ability to Converse</td>
<td>A lot of trouble</td>
<td>No trouble</td>
</tr>
<tr>
<td>Ability to Understand</td>
<td>A little trouble</td>
<td>No trouble</td>
</tr>
<tr>
<td>Autonomy Score</td>
<td>≈ 30</td>
<td>≈ 50</td>
</tr>
<tr>
<td>Belongs to a group</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Current Education Status</td>
<td>High School</td>
<td>Not in school</td>
</tr>
<tr>
<td>Current Employment Status</td>
<td>Not employed</td>
<td>Employed (not-competitively)</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>Grades in High School</td>
<td>Average</td>
<td>Above Average</td>
</tr>
<tr>
<td>Groups relied on to make decisions</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>High School Diploma Status</td>
<td>Still in High School</td>
<td>High School Diploma</td>
</tr>
<tr>
<td>Woodcock-Johnson III Applied Problems</td>
<td>≈ 90</td>
<td>≈ 100</td>
</tr>
<tr>
<td>Woodcock-Johnson III Calculations</td>
<td>≈ 90</td>
<td>≈ 100</td>
</tr>
<tr>
<td>Woodcock-Johnson III Passage</td>
<td>≈ 80</td>
<td>≈ 80</td>
</tr>
</tbody>
</table>

Quality of life is difficult to measure for any population, and it is especially challenging for a group as diverse as individuals in the autism spectrum. Schalock outlined in his 2004 research a set of domains that contribute to quality of life for those with disabilities. These could provide us with the targets to measure, though that list of domains may or may not feel important to each person with ASD. The measurements themselves must be sensitive to the wide range of functional abilities, as well as the diverse interests and strengths, of individuals with disabilities. Future research should include both quantitative data and qualitative data to specifically address all aspects of quality of life. Both the objective indicators of life—jobs, housing, transportation—and the individual voices of people in the spectrum to gain a full understanding of the qualities making up their quality of life are needed for future research.

Future research needs also to pick up on recent advances in college attendance by those in the autism spectrum. Colleges are struggling to establish support services appropriate to their needs. These college students likely need coaching on how to navigate the college environment. At the same time, more young adults with autism are gaining employment, and their communities may try to provide support on how to engage socially and communicate effectively.
An important question in these efforts is whether such support services actually help the quality of life of the people they aim to serve.

The data that were available began to answer many of the questions posed for this study; however, several remain. This field needs to know more from the young adults’ point of view. In particular, it will be helpful need to know more about what their lack of independence, friendships, and romantic relationships means to them. How much does it bother them if they have few friends and no intimate partners? Do they hope to date and to marry; are they happier, or less happy, if they do? The majority of young adults with autism still live at home; it is not known whether these young adults find this to be acceptable, favorable, or upsetting. One can speculate, but more valid evidence could come from careful examination of interview transcripts from young adults with autism.

Research has found elevated rates of anxiety-related disabilities among individuals with an autism diagnosis, including social anxiety, generalized anxiety, separation anxiety, and panic disorder and agoraphobia. All of these mental health-related disabilities can have an impact on daily living, employment, community involvement, and social acceptance of people with autism, thus impacting QoL. Additional information is needed about comorbid diagnoses and if the presence of such disabilities predicts a lower quality of life.

A major barrier to the attainment of healthy physical well-being (one of the 8 core domains of QoL) by adults with autism is lack of supportive recreational, leisure, and physical activity programs. This likely contributes to the weight problems that many face. Orsmond (2004) found that adults with autism who experience major challenges in social interaction and communication may be less likely to participate in organized recreational programs with high social demands because those programs may not accept and understand their differences.
Consequently, adults with may become isolated from the community and may focus their pastimes exclusively on solo hobbies despite potential interests in participating in community recreational activities. Perhaps inclusion in leisure or recreational programs would predict a higher quality of life.

Future study has much to gain from delving more deeply into the answers available within the NLTS2 dataset; researchers are fortunate to have this rich resource available. In particular, a longitudinal look at the course of development--in a variety of arenas--could help delineate individual paths and clusters of paths that these young people took as they grew from early adolescence into early adulthood.

But these data could be enhanced by examining smaller samples of adolescents and young adults through qualitative interviews with the participants themselves and their family members. Such study could add depth to our understanding by putting faces and stories on the life course of these young citizens. Sometimes these individual stories can speak volumes, telling us what is behind our statistical analyses. In the end, achieving a good quality of life for individuals with disabilities is the goal of all the massive efforts put forth by dedicated parents, therapists, interventionists, teachers, job coaches, employers, and mentors. This is a worthy goal that deserves our targeted efforts.
References


Vita

Staci Elizabeth Carr was born on March 23, 1975, in Warren, Michigan, and is an American citizen. She graduated from Rochester High School, Rochester, Michigan in 1993. She received her Bachelor of Arts in Psychology *cum laude* from Oakland University, Rochester, Michigan in 1996. She received a Master of Education with a focus on Human Development and Psychology from Harvard University, Cambridge, Massachusetts in 1998. She received a Master of Science in Psychology from Virginia Commonwealth University, Richmond, Virginia in 2010. Staci received the Odyssey Award from Oakland University in 2004. The Odyssey Award recognizes alumni who seek to exemplify Oakland University’s motto “to seek virtue and knowledge.” She has taught Child Psychology, Psychology of Adolescence, and has been an independent study mentor for an undergraduate psychology student. Staci completed the Virginia Leadership Education in Neurodevelopmental Disabilities (Va-LEND) Program in 2011. Since 2010, Staci has been working at the Research, Rehabilitation, and Training Center (RRTC) at Virginia Commonwealth University as a Technical Assistance Coordinator for the Autism Center for Excellence while pursuing her Doctor of Philosophy degree in Developmental Psychology from Virginia Commonwealth University (VCU). She continues to present across the country on a variety of topics as it relates to Autism Spectrum Disorders and published a articles and book chapters with her colleagues at the RRTC.