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EXPLORING FACTORS THAT IMPACT QUALITY OF LIFE FOR ADULTS WITH AUTISM

A DISSERTATION APPROVED FOR THE
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

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This dissertation is dedicated to all of the individuals who took the time to contribute to this study. I hope that this research will contribute to greater understanding of autism and expand our knowledge and appreciation of neurodiversity.

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Abstract

The purpose of this study was to (a) explore factors that may impact the quality of life for adults with ASD, and (b) based on those results, offer recommendations for interventions designed to improve the quality of life for ASD individuals. In order to develop appropriate support services and interventions for adults with autism, we must first understand how these factors, and potentially others, impact their quality of life. The results of this study indicate that, as predicted, living status, level of education, job satisfaction, and perceived social support significantly predicted quality of life for individuals with autism. Of note is the significant impact of job satisfaction and perceived social support. This finding has important implications for the development of intervention services aimed at improving quality of life for adults with autism.

Keywords: Adults with autism, quality of life, autism spectrum disorder

Chapter 1: Introduction

According to Volkmar, Reichow, and McPartland (2014) an estimated two million adults in the United States living with autism spectrum disorders (ASD). As defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013), ASD is a neurodevelopmental disorder that typically presents early in an individual's development. The major characteristics of autism include deficits in social interaction and communication, as well as a limited range of activities or interests, and restrictive or repetitive patterns of behavior that significantly impact daily functioning (American Psychiatric Association, 2013). Individuals diagnosed with autism often have a diverse range of outcomes and abilities. Due to increased awareness and more efficient diagnostic tools, autism can often be identified early for many individuals. Early diagnosis and treatment can lead to better outcomes for individuals and their families. Early intervention strategies have been shown to improve behavioral problems, emotional distress, and to reduce problematic symptoms of autism for a wide range of individuals (Bishop-Fitzpatrick, Minshew, & Eack, 2014).

Although some symptoms and behaviors may improve as individuals reach adulthood, many individuals with autism continue to experience difficulties regarding relationships, complex social situations, employment, and education (Cederlund et al., 2008; Eaves & Ho, 2008; Henninger & Taylor, 2012; Kapp, Gantman, & Laugenson, 2011; Volkmar, Reichow, & McPartland, 2014). While there is research available that suggests that adults with autism should continue receiving support services, little is known regarding the efficacy of various support or treatment programs. As children

with autism transition to adulthood, they must take personal responsibility for continuity of services related to their diagnosis. As such, many adults get lost in this transition period and fail to re-establish services following secondary school (Volkmar, Reichow, & McPartland, 2014).

Research has repeatedly demonstrated that support services can be a key to helping individuals with autism increase their quality of life (Volkmar, Reichow, & McPartland, 2014). Quality of life is an important variable for adults of all ability levels as it correlates with psychological and physiological outcomes. The World Health Organization defines quality of life as "an individual's perception of his or her position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHOQOL Group, 1998). Overall, adults with autism have been shown to have lower psychological wellbeing compared to the general population (Henninger & Taylor, 2012; Howlin, Mawhood, & Rutter, 2000; Kanner, 1971). Many studies regarding outcome for individuals with autism focus on within person factors such as intelligence, language development, social functioning, and symptomatology (Ruble & Dalrymple, 1996). Although these factors tend to have high predictive value related to adult outcomes, they are individual qualities that are often difficult to change in a therapeutic setting. Thus, it is vital for evidence-based practice that we understand more regarding variables that are amenable to treatment for individuals with autism. Furthermore, in order to develop appropriate interventions for this population, the impact of other factors such as social support, employment satisfaction, education, etc. should be explored (Ruble & Dalrymple, 1996).

Not surprisingly, nearly all of the available research on quality of life has been conducted from the view of "neurotypical" or normal developing individuals. This perspective emphasizes the importance of social relationships, living status, education, and employment as the major pillars of adulthood, which, in turn, supposedly contribute to the development of quality of life. Although these factors may contribute to higher quality of life for neurotypical adults, it is unknown how these factors impact quality of life for adults with autism. Clearly, there is a need for information regarding what, if any, effect these factors have on quality of life specifically for individuals with autism. To this end, the following questions served as a guide for the current research:

1. Do level of education, living status, job satisfaction, and perceived social support significantly predict overall quality of life for adults with autism?
2. Does level of reported autism symptoms mediate perceptions of quality of life for individuals with autism?
3. Based on the findings of the current research, what types of support services or interventions are likely to best meet the needs of adults with autism?

Chapter 2: Literature Review

Autism Spectrum Disorders: An Overview

As mentioned previously, autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by the presence of impairment in an individual's social and communication interactions, as well as restricted and repetitive behaviors, interests or activities (American Psychiatric Association, 2013). ASD now subsumes diagnoses that were previously known as infantile and childhood autism or psychosis, atypical autism, pervasive development disorder, childhood disintegrative disorder, as well as Asperger's disorder (Kurita, 2011). Based on the current diagnostic criteria, symptom severity and associated outcomes may vary widely for individuals with a diagnosis (American Psychiatric Association, 2013). It is generally agreed that the onset of ASD may occur before diagnosis given the range of severity of symptoms in some individuals. Most research indicates that at least some symptoms are present in early childhood such as the absence of joint attention (sharing enjoyment or attention regarding an activity with another person), restricted behaviors, and difficulty with meaningful communication. Although language delay is often a hallmark of autism, it is not always present in each case (Lauritsen, 2013; American Psychiatric Association, 2013). Nevertheless, the presence of language by five or six years of age is a significant predictor of prognosis (American Psychiatric Association, 2013). Because the presence of a language delay is a significant predictor of prognosis, children with ASD who have significant language delays tend to have worse outcomes compared to children who display some communicative phrases by age six (American Psychiatric Association, 2013). For example, individuals with language delays are at higher risk of

behavioral problems, academic issues, and psychological disorders as they age (Howlin et al., 2000). Although some individuals may be able to compensate for some behaviors typically associated with autism, social and communicative impairments tend to be pervasive into adulthood.

Prevalence rates of autism are estimated to be 1% of the general population (American Psychiatric Association, 2013). According to the Center for Disease Control and Prevention, one in 68 children have been diagnosed with ASD according to data collected in 2010. This represents a 30% increase from 2008 statistics that indicated one in 88 children were diagnosed with ASD. Current statistics also reveal that males are approximately five times more likely to be diagnosed with ASD compared to females (Centers for Disease Control and Prevention [CDC], 2014). Thus, there appears to be a growing number of individuals who are impacted by autism, and similar rates of autism can be estimated for adults.

Current research suggests that the range of symptoms associated with autism represent a continuum or spectrum (Ring, Woodbury-Smith, Watson, Wheelwright, & Baron-Cohen, 2008). For example, several studies have been conducted that have failed to differentiate Autistic disorder, Asperger's disorder, and Pervasive Developmental Disorder, not otherwise specified (PDD NOS) (Lauritsen, 2013). In the previous version of the Diagnostic and Statistical Manual, DSM-IV, each of these diagnoses had unique diagnostic criteria, leading to some debate regarding the transition to ASD in the current version the DSM-V. Nevertheless, according to Tsai (2012), approximately 9% of individuals who had previous diagnoses of PDD NOS did not meet the DSM-V diagnostic criteria for ASD based on symptoms evaluated using the Autism Diagnostic

Interview. Overall, however, there does not appear to be enough research to support the previous, separate differential diagnostic categories. Still, this diagnostic shift presents challenges to current and future research as previous studies have focused on disorders related to developmental delays (e.g., Asperger's disorder, classic autism, infantile autism, etc.) separately. (Kurita, 2011; Tsai, 2012). Because there is so much overlap among these previously separate diagnostic categories, it is important to examine research on any or all of the conditions. Therefore, for the purpose of this study, research examining any of these former diagnostic categories was considered for review.

Despite the belief on the part of many that autism is related to childhood vaccines, repeated studies have failed to establish any links between vaccinations and autism. Although it is beyond the scope of this review, it is of note that approximately 30% of individuals diagnosed with autism are also diagnosed with a seizure disorder (Howlin, 2000; Lord, Cook, Leventhal, & Amaral, 2000). Some research suggests that individuals with autism have a slightly increased mortality rate when compared to the general population; however, most increased mortality is associated with individuals diagnosed with epilepsy and those with lower IQ (Howlin, 2000; Levy & Perry, 2011). This higher mortality rate also coincides with individuals with other developmental disabilities characterized by below average IQ. There is also some evidence of differences regarding differential symptomatology in males and females, which suggests that females may display fewer symptoms of social impairment compared to males (Lai et al., 2011). Current statistics reveal that males are diagnosed with ASD at much higher rates than females (CDC, 2014).

Theory of Mind and Outcomes for Individuals with Autism

Premack and Woodruff (1978) described theory of mind as the ability to infer mental states both in oneself and others. This process involves the ability to "reflect on the content on one's own and other's minds" (Baron-Cohen, 2001, p. 174). It is now widely accepted that individuals with autism have differently developing theory of mind compared to individuals without autism. The ability to predict and understand behavior is an important component in the development of social skills, which is often identified as a deficit for individuals with autism (Baron-Cohen, Leslie, & Frith, 1985). There are several tests designed to assess theory of mind in children and these tasks involve the ability to make distinctions between subjective perception and objective reality and mental and physical states, the ability to judge what others think versus what they think or know, and being able to infer an individual's desires or know when they are thinking based on their gaze. When children with autism complete these tasks, they often perform less well than individuals without autism or compared to individuals with other disabilities such as Down's syndrome. This evidence seems to indicate that children with autism may demonstrate some difficulty in reflecting on their own state of mind (Baron-Cohen, 2001). In this same report, Baron-Cohen reported that individuals with high functioning autism or Asperger's disorder were often able to pass theory of mind tasks as they reached adolescence. This would seem to suggest that although theory of mind development may be delayed for children with autism, it is not impossible for them to develop the necessary frame of reference to report on their own mental state.

In fact, more recent research on theory of mind in older individuals and individuals with high functioning autism indicate that individuals with autism

performed as well as the non-autistic control group on theory of mind tasks (Scheeren, de Rosnay, Koot, & Begeer, 2013). Specifically, they examined performance on advanced theory of mind tasks in which individuals were asked mental state questions based on various stories that required individuals to reflect on emotion, intention, deception, sarcasm, and emotional display rules. They failed to find any group differences on any story. In addition, they found that adolescents had better performance than younger children regardless of whether they had an autism diagnosis (Scheeren, de Rosnay, Koot, & Begeer, 2013). Furthermore, White et al. (2009) found that a large number of children with high functioning autism performed as well or better on advanced theory of mind tests compared to a non-autistic control group. Thus, there appears to be a lack of research evidence that supports the conclusion that adolescents and young adults with autism have impaired theory of mind functioning.

Although relatively few studies regarding theory of mind for adults with autism exist, there appears to be evidence that as individuals with autism develop, their theory of mind also improves, although at a potentially slower rate than individuals without autism. This seems to indicate that individuals with autism have the capacity to self-reflect on their state of mind in an accurate and valid manner. In the past, researchers have made the case that due to the supposed lack of theory of mind, adults with autism cannot accurately report on their own emotional state (Gerber, Baud, Giroud, & Galli Carminati, 2008). However, there is a growing field of evidence that contradicts this assertion (Scheeren et all, 2013; Shipman, Sheldrick, & Perrin, 2011; White et al., 2009). In addition, it could be argued that whether or not an individual possesses an "adequate" theory of mind, their ability to engage in self-report is a valid reflection of

their internal experience and is an important source of information in order to develop support services for adults with autism.

With this in mind, Baron-Cohen et al. (2001) developed the self-administered Autism-Spectrum Quotient as a means for individuals with autism to report on their symptoms. The AQ was developed as a short, simple measure to assess symptoms associated with autism. The traditional assessments of autism include the Autism Diagnostic Interview Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS), which can be time consuming and difficult to score (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Baron-Cohen and his colleagues developed the AQ as a tool to administer to individuals with normal IQ to determine where they might fall on the autism spectrum. The AQ assesses five different areas including social skill, attention switching, attention to detail, communication, and imagination. When comparing individuals diagnosed with Asperger's disorder or high functioning autism with the general population, individuals with a clinical diagnosis were more likely to endorse scores above 32 on the AQ. The authors mention that the AQ is not meant to be a diagnostic tool; rather, they contend that the AQ is useful measure in determining the presence of autistic traits in individuals with normal intelligence (Baron-Cohen et al., 2001).

Outcomes for adults with autism. Although language development is a significant predictor of outcome for adults and children with autism, it is interesting that there are reports of differential outcomes when individuals with language disorders are compared to individuals with autism. Adults with autism typically report lower levels of social communication skills, friendships, independent living skills, and general

psychosocial functioning when compared to individuals with a developmental language disorder (Howlin et al., 2000). This seems to indicate that although language is a significant predictor of outcome, there are many other variables that impact adult functioning that have not been fully addressed in research.

Recent studies have moved towards a more systematic review of outcome variables, particularly the inclusion of more subjective measures. One of the arguments against the use of subjective instruments in autism research is that individuals lack the communication skills necessary to respond to questions about themselves (Gerber et al., 2008). However, individuals with high functioning autism likely have the cognitive and emotional awareness to be able to complete self-report measures regarding their psychological and physical wellbeing. For example, research conducted with children diagnosed with autism has shown that subjective assessments are valid forms of outcome measurement (Travenor, Barron, Rodger, & McConchie, 2013). They found that self-report measures completed by children diagnosed with autism demonstrated similar response sets to measures completed by the caregivers and parents of the children. In fact, children tended to report additional symptoms indicating that self-reports of autism symptoms may reflect higher amounts of autism behaviors. In addition, the aforementioned studies regarding autism and theory of mind seem to indicate that adults with autism likely have the capacity to report on their emotions and experiences accurately.

Studies of outcomes for adults with autism are unique compared to other studies of adult psychiatric disorders. Studies that examine outcomes for individuals diagnosed with depression or anxiety tend to rely on the use of self-report measures to monitor and

assess symptomatology. While earlier research with individuals diagnosed with developmental disabilities (DD), avoided self-report measures in favor of observation or reports from caregivers or family members (Bishop & Seltzer, 2012), more recently autism research has promoted the idea of utilizing self-report measures as effective tools for better understanding of perceptions of individual functioning for this population (Bishop & Seltzer, 2012).

To clarify, the idea of examining outcomes for individuals with autism is not a new concept. Henninger and Taylor (2012) described three different waves of autism research that began with vague rating criteria and moved towards more specific and integrated measures of successful outcomes. Outcome studies for adults with ASD prior to the early 2000s relied on narrow category ranges of "good" to "very poor." Needless to say this set of outcome criteria has been described as vague and not well defined (Henninger & Taylor, 2012).

Rutter was one of the first researchers to develop a scale for determining outcomes for individuals with ASD. He and his colleagues developed a rating system of "good, fair, poor, and very poor." These ratings were determined by assessing whether the individual "was leading a normal or near normal social life and was functioning satisfactorily at school or work, making social and educational progress in spite of significant, even marked, abnormalities in behavior or interpersonal relationships, or unable to live an independent life but still showing signs of some progress, or unable to live any kind of independence" (Rutter, Greenfield, & Lockyer, 1967 p. 1185). Many studies that relied on Rutter's measurement or a similar form of categorical rating have found that individuals with autism generally have poor or very poor outcomes.

Unfortunately, these categories lack empirical clarity and require a large amount of interpretation to derive any meaningful information (Henninger & Taylor, 2012).

Kanner identified symptoms of what we now understand to be ASD in 11 children ranging in age from two to eight years of age. He then conducted follow up interviews with the families of each of these children 28 years after his initial account of their symptomatology. In this sample of children with ASD, eight were male and three were female. Four of the eleven children spent much of their development living in institutions and, as reported by Kanner, had "lost all of their luster" after admission (Kanner, 1971, p. 143). These four cases were reported to have very limited social interaction and were described as living in isolation. After taking measures of IQ, they were found to be far below average and their skills of independent living were essentially nonexistent. One of the cases described by Kanner went on to work on a farm and appeared to exhibit happiness and an ability to learn and participate in daily activities and chores despite not developing meaningful speech. Two other cases were considered to be "successes" by Kanner as evidenced by their abilities to achieve employment, attend school, and participate in various community activities. Although these two individuals still lived at home with their families, it appeared that they were able to live near-normal lives compared to their peers (Kanner, 1971).

Kanner's description of individuals with ASD was rare for its time. Prior to the 1970s, studies focused on the etiology of the disorder (Kanner, 1971). Kanner's paper was one of the first reports of outcomes in adults diagnosed with autism as children. Most research regarding outcomes for individuals with ASD prior to the 2000s were case descriptions with little or no uniformity regarding variables.

The next wave of outcome research focused on more precise definitions of successful outcomes and involved a more comprehensive view of possible outcome measures. According to Henninger and Taylor (2012) successful adult outcomes expanded from simply avoiding being institutionalized to having social relationships, occupational involvement, and independent living skills. To this end, Howlin et al. (2000) developed an Overall Outcome Rating to measure outcomes for adults with autism. Howlin and colleagues included language, friendship, and independence as the primary measures for outcome. They found that a large majority of adults with autism had poor or very poor outcome according to their scale. Other research that used similar rating scales generally revealed that adults with autism had worse outcomes compared to other adults (Henninger & Taylor, 2012). In a similar attempt to create a more precise definition of success for adults with autism, Billstedt, Gillberg and Gillberg (2005) also developed a rating measure. They defined good outcome as "being employed or in higher education/vocational training, and if over the age of 23 years, living independently, if 22 years or younger, having two or more friends/a steady relationship (p. 354)." They also defined a poor outcome as "obvious very severe handicap and unable to lead any kind of independent existence, no clear verbal or non-verbal communication" (p. 354). In their study of 108 adults with autism, 57% were considered to have a "very poor" outcome based on their rating scale and none had "good" outcome. It is noteworthy that the results of this study may be limited given that only 10% of the sample reported having a normal IQ range. Cederlund et al. (2008) conducted a study comparing outcomes of adults diagnosed with autism to adults diagnosed with Asperger's syndrome. The authors examined employment, relationship,

independent living, and psychiatric outcomes in both populations and found that although there were more individuals in the Asperger's group that were found to have "good" outcome, "poor" outcome was reported in more individuals than expected.

The third and current wave of outcome research according to Henninger and Taylor (2012) focuses more on "person-environment fit." This wave has emphasized the importance of including personal values and expectations. Much of the research conducted to date has looked at objective ratings of outcomes based on relationship status, employment, involvement in recreational activities and ratings given by parents or care takers of adults with ASD (Wilson, 1998). There is a gap in the literature regarding adults' perceptions of their own needs and satisfaction with their current living situation. For example, adults with autism may have different values when it comes to social relationships, support, and community involvement. Also, traditional views of success may not fully apply to adults with ASD; however, this aspect of adult outcomes has not been fully explored. Moving forward, more research that takes into consideration individuals' views of success and how their experience aligns with their desires and abilities seems warranted (Henninger & Taylor, 2012).

In 2011, Billstedt and colleagues returned to their sample of adults with autism to conduct additional follow up measurements related to quality of life. Based on newer research regarding person-environment fit, the researchers included a measurement to take this aspect into account. When this factor was included in their analysis, quality of life was higher than predicted based on previous studies (Billstedt, Gillberg, & Gillberg, 2011). While many of the individuals who took part in the study still had high dependence and lack of employment, their overall outcome was better than expected.

Focusing on the person-environment fit seems an important step in moving towards evidence-based interventions for adults with autism. As mentioned previously, language acquisition, IQ, and severity of symptoms are factors that are not readily amenable to change. Instead, it may be beneficial for research to focus on factors within the community that can be implemented to enhance adult outcomes, particularly in the areas of education, employment, residence, and social support.

Psychological outcomes. Overall, historical research has demonstrated that psychological outcomes for adults and children with ASD are poor (Farley & McMahon, 2014; Howlin et al., 2000; Kapp et al., 2011; Levy & Perry, 2011). Some experts believe that as children with autism transition to adulthood, they may become more aware of their social and behavioral differences. This increased awareness may result in distress and, without appropriate intervention; these difficulties may lead to mental health problems in adulthood. This is evidenced by the fact that individuals with autism who have normal or above average IQ are more likely to experience symptoms of depression (Kapp et al., 2011). In addition to experiencing symptoms of depression, adults with autism often struggle with anxiety as well as other mood disorders (Howlin, 2000; Levy & Perry, 2011; Mazurek, 2014). Eaves and Ho (2008) conducted research with a group of 48 young adults diagnosed with ASD. They found that over half of the cohort reported general emotional difficulty, and the remaining half of the individuals reported struggling with anxiety and/or OCD. Additionally, ten individuals reported having depression (Eaves & Ho, 2008). This research echoes other studies that have reported high levels of depression and anxiety in this population.

Behavioral problems are also a common source of distress for families of individuals with ASD. Behavioral issues are more common in children; however, research indicates that individuals with lower IQs may experience an increase in behavioral problems as they reach adolescence (Levy & Perry, 2011). Some of the behavior issues reported by families include sensitivity to change, OCD-like behavior, inappropriate sexual behavior, tantrums, and self-injury (Levy & Perry, 2011). Generally, individuals with autism do not have increased involvement with the legal system; however, there is a limited amount of research that indicates there may be more inappropriate sexual behaviors in this population. For example, adults with ASD are more likely to engage in sexual behaviors in public or may appear to interact inappropriately with others due to their social deficits (Howlin, 2000).

Even for individuals with high functioning autism spectrum disorders (HFASD), outcomes have not been shown to be significantly better than individuals with more impaired functioning. In a study of Japanese adults diagnosed with high-functioning autism, Kamio, Inada, and Koyama (2013) found that participants reported lower psychological and social wellbeing than the general population. In one study examining outcomes for adult males diagnosed with Asperger's Syndrome, the authors found that despite having average intellectual ability, a majority of their sample experienced "restricted" or "poor" outcomes based on measures of their psychosocial functioning (Cederlund et al., 2008). Although there is some evidence that suggests that the symptoms typically associated with ASD decrease with age (repetitive behaviors, aggressiveness, agitation, self injury etc.), other research indicates that psychiatric symptoms tend to worsen with age (Howlin et al., 2000).

Clearly, there is a need for greater understanding of the impact of societal, cultural, and individual factors on adults with autism. As the research discussed previously suggests, adults with autism continue to experience inferior outcomes compared to adults with other types of developmental disabilities as well as the typically developing population. It is also important to note that adults who report higher ratings of quality of life typically display fewer psychological difficulties and are generally more satisfied with their health, employment, living environment, and relationships (Kamio et al., 2012; Renty & Roeyers, 2006; van Heijst & Geurts, 2015). Many adults with ASD continue to face challenges that hinder their success despite possessing qualities that would typically lead to accomplishments such as specialized interests, high IQ, and high achievement. In order to develop evidence-based practice for improving psychological wellbeing, it is vital to understand factors that impact quality of life for adults with ASD.

Education

Individuals with disabilities are guaranteed certain rights in the United States under protection of three major pieces of legislation. The Individuals with Disabilities Education Act (IDEA) is a law that requires all students with disabilities to have equal access to primary and secondary schooling. One of the primary purposes of IDEA is to ensure that students engage in transition planning to attend postsecondary education or to pursue employment upon graduation from high school (Stodden & Mruzek, 2010). The Americans with Disabilities Act (ADA) was amended in 2008 and mandates that individuals with disabilities receive reasonable accommodations in postsecondary education and/or employment. The Rehabilitation Act of 1973 provides funding for

individuals with disabilities to receive employment training or job support. The overall goal of these laws is to allow individuals with disabilities to participate in their communities in the least restrictive way possible. As individuals transition from school to higher education or as they enter the work force, individuals must understand how to navigate the system to ensure provision of services (Shrogren & Plotner, 2012; Stodden & Mruzerk, 2010). This period of transition often leads to a gap in services when individuals leave high school and the protection of IDEA. Ideally, as individuals progress through the education system, they engage in transition planning that includes postsecondary goals such as finding steady employment, enrolling in college, or living independently. Unfortunately for individuals with ASD, this is often not the case.

In fact, students with ASD have lower rates of employment, independent living, and postsecondary education attendance compared to students with other types of disabilities (Shrogren & Plotner, 2012). One of the issues that may contribute to this difference in outcomes is the lack of appropriate goal setting for individuals with ASD in transition planning. Students with ASD have few or no goals related to integrated employment or postsecondary education when compared to students with other disabilities (Shrogren & Plotner, 2012). This difference is apparent even when individuals with ASD are compared to students with intellectual disabilities. It has been reported that students with ASD do not have high rates of participation in transition planning meetings with their educators and parents. Best practice in education indicates that students should take an active role in transition planning in order to empower them to pursue their goals (Hart, Grigal, & Weir, 2010). Engaging in goal setting and participating in educational planning typically leads to goals that are more realistic,

personally salient, and individualized to the student. This process is important for individuals with disabilities because it enables them to maximize their strengths and become aware of areas that are in need of growth. Thus, despite having legislation and well-established best practices, students with ASD continue to experience poor postsecondary outcomes (VanBergeijk, Klin, & Volkmar, 2008).

Cai and Richdale (2016) conducted a study regarding the experiences of university students diagnosed with ASD. They found that features of ASD, co-morbid diagnoses, transition preparation, disclosure of diagnosis impacted students' educational experiences, and services/support provided by the university. For example, social-communication difficulties that are the hallmark of autism may interfere with social interactions with both classmates and instructors, as well as increase stress during group projects or assignments (Cai & Richdale, 2016). As mentioned previously, adults with ASD often have co-morbid depression, anxiety, and OCD-like behaviors. Students' overall emotional wellbeing is likely to impact their academic performance. Although a majority of the students who participated in this study reported positive experiences with disability support services, many students with ASD do not chose to disclose their diagnosis in order to receive services. Some of the reasons that impact student's openness to disclosure are related to past educational experiences, lack of awareness, ambivalence about the benefits of reporting their diagnosis, and the belief that they no longer have a disability (Cai & Richdale, 2016). Another potential factor that leads to lack of disclosure is inadequate transition planning prior to college. Although higher education is a viable option for many students with ASD, research suggests that students are often ill prepared for the unique challenges and responsibilities that occur

in the college setting. According to the previous study, many students at university felt there was a lack of formal planning and institutional support (Cai & Richdale, 2016). Students who attend postsecondary education and register with the disability support office at their university may still experience difficulties, as many of the traditional accommodations that are provided through the disability office may not fully meet the needs of students with ASD (Cai & Richdale, 2016).

Individuals with ASD are also likely to have a number of impairments in their ability to engage in adaptive behavior skills. Hees, Moyson, and Roeyers (2015) conducted a qualitative study to explore challenges faced by college students with ASD. They found five major themes identified as primary concerns for college students including "struggling with new situations and unexpected changes, exhausting but necessary social contacts, processing information and time management, doubts about disclosure, and mental health issues" (Hees et al., 2015, p. 1678).

In one of the more promising outcome studies, the authors found that half of their sample of 16 adults had attended college or other postsecondary educational institution (community college, vo-tech, etc.) (Szatmari, Bartolucci, Bremmer, Bond, & Rich, 1989). Although the number of adults with ASD who attend postsecondary education is increasing, there continues to be a gap between students with ASD and the non-autistic population. Additional research in this area is needed to understand and assess the efficacy of educational support services for this population.

Employment and Job Satisfaction

Employment outcomes for individuals with ASD are particularly discouraging. According to a study examining employment outcomes for adults with ASD, 56%

of their sample reported being employed at some point; however, most reported volunteer or part-time work (Eaves & Ho, 2008). According to Billsted et al. (2011) a large majority of individuals who took part in their study reported having minimal occupational activities. Howlin, Goode, Hutton, and Rutter (2004) found that one-third of their sample of adults with ASD reported being employed; however, type of employment was not assessed. This estimate is slightly higher than other reports of employment for individuals with ASD. Overall, research regarding adult outcomes demonstrates that individuals with ASD often have low levels of employment despite experiencing increases in adaptive functioning and social skills (Farley & McMahon, 2014). Additionally, parents and caretakers of adults with ASD identified a lack of occupational or employment opportunities as a major concern for their families (Billstedt et al., 2011). Many parents reported a complete lack of support in the area of employment and worried about their children being able to engage in meaningful daily activities.

Surprisingly, for individuals with average or above average intellectual ability and high adaptive skills, employment rates are not much higher than those with below normal IQ (Geller & Greenbert, 2010). Kapp et al., (2011) suggest that low employment may be related to problems with social interaction and communication, sensory issues, and low self-awareness. They also attribute poor employment rates to lack of proper community support and work programs as well as general misconceptions regarding ASD by employers (Kapp et al., 2011). For example, for individuals with ASD, issues associated with employment begin during the hiring process. Factors such as interview etiquette, proper attire, and the ability to quickly process complex information may

leave individuals with ASD at a clear disadvantage compared to other job candidates (Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015). Although there is evidence that job placement and job support programs are effective within in this population, there are relatively few support services available for higher functioning individuals (Levy & Perry, 2011).

Individuals with autism, who do find employment, often have high rates of early termination or frequent job changes (Eaves & Ho, 2008; Levy & Perry 2011; Howlin, 2000). Employment is typically part-time and adults with ASD may also find themselves working in occupations that they are overqualified for based on their educational background and technical skills (Nicholas et al., 2015). This cycle may contribute to poor occupational outcomes because individuals with ASD will likely have difficulty building their resumes due to lack of consistent employment and evidence of progress.

Moreover, once employed, adults with ASD do not always have occupational support to help navigate problems that occur in the workplace. According to Nicholas et al. (2015), "supported employment" allows an individual with disabilities to maintain a paid position that is integrated in a typical work setting. The authors found that that individuals who participated in supported employment were more likely to be employed, stay employed longer, have diverse job experiences, and earn higher salaries than individuals who did not have employment support in place. Various types of supported employment programs exist to aid individuals with disabilities; most include aspects of job training, job matching, and advocating for appropriate accommodations (Nicholas et al., 2015, Stodden & Mruzek, 2010).

Employment satisfaction has been linked to self-esteem and quality of life. Migliore and Butterworth (2008) found a connection between challenging occupational skills and increased adaptive skills. They suggest that individuals who engage in competitive employment may experience a boost in self-confidence. In contrast, Levy and Perry (2011) found that adults with ASD who completed higher education still reported lower than average employment rates and job satisfaction. In their sample, only 24% of participants were able to find employment after completing "mainstream" education programs. Together, these findings would seem particularly salient for individuals with ASD, given research that suggests that individuals with ASD are often employed in positions that require only minimal skills. Additionally, this disparity between ability and job requirements may leave some adults with ASD feeling ineffective and depressed.

Social Impairment, Relationships, and Loneliness

Social and communication deficits are a hallmark of ASDs. Adults with ASD may have difficulty applying appropriate context to communication and often struggle to interpret the meaning of certain aspects of language (Kapp et al., 2011). Some individuals with autism avoid social interaction due to the difficulty they have engaging in communication. In turn, this lack of social skills likely leads to difficulties in development of significant relationships. Furthermore, high functioning individuals with ASD might have greater awareness of their social isolation, which may put them at higher risk of developing mental health disorders (Mazurek, 2014). Because social impairment is a defining characteristic of ASD, adults with ASD often have difficulty making and maintaining relationships. In fact, research supports this conjecture, as

individuals with ASD are reported to have fewer social contacts when compared to individuals with other types of disabilities (Shattuck et al., 2011).

The challenges that individuals with autism experience with complex social situations and communication may also be the result of difficulties integrating external input. Although some individuals with ASD are able to process a large amount of information at once, they experience difficulty in translating that information in a meaningful way. For example, adults may not understand the nuance of sarcasm or may rigidly apply communication rules across settings where it may not be appropriate, such as dressing casually for a job interview (Kapp et al., 2011). Additionally, while adults with ASD may possess language skills to adequately engage in social interactions, they often lack the ability to communicate in a logical manner. For example, an individual with ASD may share lengthy details while story telling that may interfere with the intended message. As a result, individuals with ASD may have difficulty developing and sustaining relationships, particularly intimate relationships that are not centered on a specific shared interest or activity.

Romantic relationships and friendships. In one study, only one third of a sample of adults with ASD reported having a romantic relationship during their adulthood, indicating that the number of intimate relationships within the ASD population is lower than in the general population. Although some participants reported having marriages and children, most of the adults who participated in the study reported having very limited social connections, reporting less than one social interaction per month outside their family units (Volkmar et al., 2014). This finding is, no doubt, related to what we already know about the difficulties with social interaction faced by

individuals with ASD. It may also be related to the fact that students with disabilities are often not offered the same sex education that typically developing students receive (Koegal, Detar, Fox, & Koegal, 2014). As a result, adults with ASD may experience more anxiety and appear less interested in romantic relationships. In fact, research has shown that adolescents and adults with ASD often do express interest in intimate relationships (Koegal et al., 2014). It certainly makes sense that individuals who have lower sexual confidence and fewer sexual experiences might be more hesitant to engage in intimate relationships. This conjecture also seems to be supported by research in that adults with ASD typically report fewer intimate relationships and marriages (Eaves & Ho, 2008; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). Given that accurate knowledge about sex and healthy sexual functioning go hand in hand, it seems important to examine how and whether individuals with ASD are exposed to sex education to further understand how this influences their intimate relationship development.

Social isolation and loneliness. Given the interpersonal challenges that individuals with autism experience, it is no surprise that social isolation is a common characteristic of adults and children diagnosed with this disorder. To illustrate, it is estimated that adults with autism are three to fourteen times more likely to experience social isolation compared to other populations, including individuals with DD or other disabilities (Orsmond et al., 2013). Very few studies were found that examined individuals' satisfaction regarding friendships, so it is difficult to ascertain whether friendship quality or quantity has a greater impact on loneliness for adults with autism. There is, however, some indication that social interaction may decrease as individuals

with autism age. This may be a function of increasing awareness, or, due to factors that have not yet been explored. Because language development in childhood is highly correlated with social functioning in adults with autism (Howlin et al., 2000), individuals with significant language delays may have increased difficulty with establishing relationships and, therefore, are at greater risk for loneliness (Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Mazurek, 2014). To illustrate, adolescents with autism are less likely to socialize with friends outside of organized group activities or through school. According to Shattuck, Orsmond, Wagner, Cooper, and Sirigu (2011). 43% of their sample of adolescents from the NLTS-2 did not have contact with friends outside of school, and over half of the sample reported that they did not receive invitations to events or phone calls from their peers.

It is, of course, no surprise that chronic loneliness is associated with negative mental health outcomes such as depression, anxiety, paranoia, aggression, low self-esteem, and overall life satisfaction (Heinrich & Gullone, 2006; Jobe & Williams-White, 2007). According to self-reported autism symptomatology as measured by the AQ, individuals who reported higher severity of autism symptoms typically have shorter friendships and higher levels of loneliness. One study indicated that children with ASD or HFASD were more likely to report lower satisfaction with their relationships, lower perceived quality of relationships, and higher levels of loneliness than their peers (Whitehouse, Durkin, Jaquet, & Ziatas, 2009). It should be noted that this comparison of social interaction was based on expectations established from typically developing populations. This speaks directly to the need to understand how

individuals with autism perceive their social connections and how their social needs influence their behavior.

Social Support

Social support is an important factor in mental health due to its association with stress buffering (Lakey & Orehek, 2011). Stress buffering occurs when people are protected from the negative effects of stress through social support. Hefner and Eisenberg (2009) examined how social support plays a role in mental health for college students. They found that functional social support, or quality of social support, was highly correlated with improved mental health. Although both functional and structural social support impacted mental health for college students, functional support was the strongest and most persistent predictor of mental health (Hefner & Eisenberg, 2009). This finding is significant because much of the research regarding relationships for individuals with autism focuses on the number of friendships and frequency of social contact. Because perceived social isolation has been shown to be prevalent among individuals with autism and functional support appears directly related to psychological outcomes, examining the potential impact of perceived support on QoL for this population seems warranted (Campos, Ullman, Aguilera, & Dunkel, 2014).

Living Status

Independent living skills encompasses activities that individuals engage in that allow them to function on a daily basis. Some examples of independent living skills include bathing and dressing, toileting, meal preparation, housekeeping, and general hygiene (Matson, Dempsey, & Fodstad, 2009). Often, independent living skills are closely tied to adaptive behaviors. Although individuals with autism are able to make

advances in many areas, research shows that they often lag behind peers in terms of independent living. For example, adults with autism have the highest impairment in adaptive functioning skills when compared to adults with other types of developmental disabilities (Matson et al., 2009). Hustyi et al. (2015) compared a sample of young adults diagnosed with Fragile X Syndrome with a sample of young adults with Fragile X Syndrome and autism. They found that adults who reported higher levels of autism symptomatology also demonstrated greater impairment in their independent living skills. Even when controlling for other factors such as IQ, individuals who also had a diagnosis of autism consistently demonstrated fewer independent living skills. Clearly, individuals who lack daily living skills are less likely to be able to support themselves enough to live in independent housing.

As mentioned previously, adults with HFASD are more likely to be living in dependent living situations and often rely on family members as their primary source of support. According to Cederlund et al. (2008) individuals diagnosed with Asperger's Syndrome may have more positive outcomes compared to individuals diagnosed with autism disorder. In their study, they found that 64% of the 70 adult males in their study with Asperger's syndrome were living independently compared to only 8% of adult males diagnosed with autism (Cederlund et al., 2008). Despite higher verbal skills and IQ, the authors concluded that adults with Asperger's still experienced generally poor psychosocial outcomes. Additionally, when individuals with autism are compared to adults with other developmental disabilities, they have much lower rates of independent living (Levy & Perry, 2011). Even when studies control for demographic information and autism severity, adults with autism are less likely than adults with other types of

disabilities to have ever lived independently after completing high school (Anderson, Shattuck, Cooper, Roux & Wagner, 2014). In fact, there is some evidence that suggests that young adults with autism may be most vulnerable during the transition period following high school.

This transitional period has been the subject of several studies regarding the importance of transition planning, particularly for students with autism. Of note, the results of one study in this area revealed that adults with autism have lower rates of independent living when compared to adults with mental retardation (MR), especially in the two years following high school (Anderson et al., 2014). This outcome may be due to the fact that more attention is given to individuals with diagnoses of MR regarding the transition out of high school due to the severity of their deficits. Additionally, autism did not become a protected disability category until 1990 when education legislation changed from the Education for All Handicapped Children Act to the Individuals with Disabilities Education Act (Katsiyannis, Yell, & Bradley, 2001). Prior to this time, students with autism were not guaranteed equal access to education under federal law even though the original EAHCA legislation was passed in 1975. Prior research has demonstrated that students with autism often have worse postsecondary outcomes compared to non-autistic peers. Perhaps the lack of awareness as demonstrated by the late inclusion of autism to IDEA is reflective of the field's inexperience in successfully supporting individuals with autism.

Similar research conducted by Volkmar et al. (2014) revealed that almost 60% of their sample of adults with autism reported living with their families. The authors noted that even high achieving individuals who appeared to have near normal

functioning were found to live with their family at higher rates than expected given their adaptive abilities. While more recent trends point to an increase in the number of adults returning to live with their parents after completing postsecondary education (Anderson, et al., 2014), moving away from home has been historically considered a hallmark of the transition from adolescence to adulthood. However, the question remains whether quality of life for adults with autism is diminished by their living status, given the large number of adults with autism who report living with family members after leaving high school. Further investigation regarding the role of independent living for adults with autism appears necessary.

Quality of Life

Felce and Perry (1995) examined several commonly used measures of quality of life used specifically in disability populations to determine the core factors that are likely to influence QoL. They found that nearly all measures included the study had overlap in the areas of involvement in activities, autonomy, social/community integration, personal development, and social interaction. Furthermore, Felce and Perry suggested that QoL measures should always reflect personal preferences and individual factors. There is also evidence in the available literature that emotional well being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights should be considered in the definition of QoL for individuals with disabilities (Selzter & Krauss, 2001). In their study, Selzter and Krauss included consideration of perceived needs and values of individuals with mental retardation and developmental disability when measuring QoL. Interestingly, their results suggest that perceptions of quality of life do not rely on the imposition of

values from the dominant culture. This finding seems important for the autism population in particular because research has demonstrated that individuals may have different preferences related to their social interactions, interests and activities.

As defined by the World Health Organization, quality of life or QoL is "an individual's perceptions of their position in life in the context of culture and value systems in which they live and in relationship to their goals, expectations, standard and concerns" (WHOQOL Group, 1998, p. 551). This definition is important because it acknowledges the subjective nature of QoL. This is particularly salient for individuals with autism because their standards and expectations may differ from typically developing individuals. Travenor, Barron, Rodgers, and McConachie (2013) found that many adolescents with autism prefer spending time alone and as a result report fewer relationships. Many previous studies that have examined QoL for individuals with autism have focused on either one or two domains or objective ratings, such as employment or number of friends. Few studies have measured more subjective ratings of relationship satisfaction or work satisfaction. Most of the published research regarding QoL for individuals with autism includes some type of measurement of relationships, typically quantity of social interaction. However, quantity of social interactions may not fully capture the complex nature of social relationships for adults with autism. It may be more helpful to examine how quality and satisfaction with relationships impacts overall QoL.

It has been suggested that a comprehensive QoL measure should include ratings of physical health, social well-being, emotional functioning, independent living skills, and material well-being (employment, income, transportation) (Claes et al., 2010; Felce

& Perry, 1995; Travenor, et al., 2013). Quality of life is also made up of aspects of personality as well as environmental factors (Claes et al., 2010). In particular, the idea of person-environment fit may have important implications in the area of autism research. As mentioned previously, person-environment fit takes into consideration individual preferences and culture. For individuals with autism, "traditional" aspects of life satisfaction may not fully apply. Some research has argued that individuals with autism are unable to complete self-reports of quality of life due to their lack of emotional recognition (Gerber et al., 2008). However, Shipman et al. (2011) found that children's ratings of their own QoL were valid and reliable, which suggests that adult ratings of subjective QoL would also be valid. Furthermore, although research suggests that adults with autism may have limited introspective abilities, there is no evidence that this capacity is absent or inaccurate. For example, we would not deny adults diagnosed with depression the ability to self-report their symptoms, although it could be argued that their cognitive state is influenced by the severity of their depression. In the same manner, we should not deny adults with autism the opportunity to report their experience because their self-awareness may be limited by their theory of mind. On the contrary, it is vital to understand an individual's perspective in order to create support systems and treatment interventions that are individually tailored, culturally sensitive, and grounded in best practices.

Billstedt et al. (2011) examined several aspects of quality of life in 120 adults diagnosed with autism in childhood. The authors found that most of the adults that participated in their study lived with parents/caregivers and were unemployed. Despite these findings, they found that QoL was actually higher than anticipated based on

previous studies. Other research has produced similar results. For example, adults who participated in a yearlong leisure program demonstrated higher overall QoL, lower stress, and increased life satisfaction. Additional individual factors were not targeted for this study indicating that it is possible to improve QoL for individuals with autism despite their current living, employment, and educational status (Turygin & Matson, 2014).

According to Renty and Roeyer (2006), perceived support was significantly related to QoL. They defined perceived support as "a perception that one's network is ready to provide support and aid if needed" (p. 519). They also found that received support, "transfer of advice, aid and affect through interpersonal networks" was not significantly related to QoL (p. 519). This seems to indicate that studies that only measured quantity of social support may be missing a key aspect of QoL, especially for individuals with autism. According to a study of Japanese adults with HFASD, individuals with HFASD had worse psychological and social outcomes than "healthy" adults on a measure of QoL (Kamino, Inada, & Koyama, 2013). Furthermore, this study found that ratings of QoL differed between individuals self-report and the ratings of their caregivers or family members. van Heijst and Guerts (2015) also found significant differences in parental and self-reported QoL for a group of children with ASD. Interestingly, parents typically reported lower QoL compared to their children's self-report. Other studies have also replicated this finding (Travenor et al., 2013; White-Koning, 2008). This seems to suggest that although individuals may appear to function well (having frequent social interaction, steady employment, etc.), they might not

perceive themselves as functioning well or vice-versa. This again highlights the importance of incorporating self-report measures of QoL for the autism population.

Purpose of current study

Clearly there is a lack of research regarding the impact of autism in adulthood. Most of what we know about how autism affects individuals as they age is based on information collected during childhood. Rarely has any data been collected from adults diagnosed with ASD who are able to independently complete measures about their personal lives. Thus, the purpose of this study is to (a) explore factors that may impact the quality of life for adults with autism, and (b) based on those results, offer recommendations or interventions designed to improve the quality of life for ASD individuals. As such, the following hypotheses were proposed:

1. Level of education, living status, job satisfaction, and perceived social support will significantly predict quality of life for individuals with autism.
2. The association between education, living status, job satisfaction, social support, and quality of life will be mediated by level of autism symptoms.

Chapter 3: Method

Participants

Participants for this study were recruited through advertisements placed on social media sites designed for individuals with autism. Information regarding the study as well as a link to the informed consent was posted on Facebook groups for adults with autism. The study was also posted on the Autism Research Center (ARC) website and others. In order for individuals to take part in this study, they had to be over the age of 18 and be diagnosed with autism. The University of Oklahoma Institutional Review Board approved the current study (OU IRB #6764).

A total of 203 individuals agreed to take part in the study and identified as being formally diagnosed with autism. Due to significant missing data, 30 participants had to be excluded from analysis, leaving a total of 173 cases.

Participants were asked to report their gender, race/ethnicity, age, level of education, and employment status. Participants ranged in age from 18 to 64 years of age, mean age = 29.45 [*SD* = 9.56]. Participants were also asked to report their age at the time of their diagnosis. Six participants (2.9%) were not sure of their age at the time of diagnosis; however, ages for the remaining participants (*n* = 168; 97.1%) ranged from 1 to 63 years of age, mean age = 22.42 [*SD* = 11.71]. Individuals were asked to self-report their gender identity, which resulted in 49.7% identifying as female (*n* = 86), 27.7% as male (*n* = 48), 19.1% as Other (*n* = 33). Six participants (3.5%) did not respond to this item. Participants were also asked to self-identify their race or ethnicity, which resulted in the following categories: White/Caucasian (70.5%; *n* = 122), British (8.7%; *n* = 15), Mixed Race/Bi-Racial (6.9%; *n* = 12), Jewish (2.9%; *n* = 5), Asian

(2.3%; *n* = 4), African American (1.7%; *n* = 3), Native American (1.2%; *n* = 2), Hispanic (0.6%; *n* = 1), and Other (5.2%; *n* = 9).

The reported education levels of the participants were collapsed into the following categories: High school (15%; *n* = 26), College (54.9%; *n* = 95), Graduate college (20.2%; *n* = 35), and Other (9.3%; *n* = 16). One participant did not complete this item (0.6%, *n* = 1). Participants' current employment status was: Full Time (21.9%; *n* = 38), Part Time (16.1%; *n* = 28), Student (21.4%; *n* = 37), Out of work and looking for work (8.7%; *n* = 15), Out of work and not looking (5.2%; *n* = 9), Homemaker (2.9%; *n* = 5), Retired (0.6%; *n* = 1), Unable to work (16.8%; *n* = 29), and Never employed (6.4%; *n* = 11). Participants were asked to indicate their current living status. Overall, 36.4% reported living with their parents or caregivers (*n* = 63), 59.5% of the sample indicated living independently (either with a partner/spouse or roommate or alone) (*n* = 103), and 3.5% reported some other type of living situation (*n* = 6). One individual did not respond to this item (0.6%, *n* = 1). Participants were also asked to identify the primary source of their social support. Individuals were given four options and asked to choose all sources of support that applied to them. Overall, 48% (*n* = 83) of participants identified family members as their primary source of social support, followed by 41.6% (*n* = 72) reporting a partner/significant other, 39.3% (*n* = 68) indicated peer support online, and 21.3% (*n* = 37) indicated in-person peer support. Because participants were able to endorse multiple categories regarding the source of social support, combined percentages exceeded 100. Over half of the present sample reported living in the United States (64.7%) while the rest reported living outside the United States (35.3%).

As to the demographic item that asked about additional psychological diagnoses, two participants (1.2%) did not respond; however, of the remaining 171 participants who did respond, 33.5% (n = 58) denied having a diagnosis. A majority of the participants, 65.3% (n = 113) indicated having an additional psychological disorder. Of the participants who did endorse having a psychological diagnosis, 72 (41.6%) participants reported having two or more diagnoses. The most common psychological diagnosis was depression (41.0%, n = 71), followed by anxiety (32.9%, n = 57), attention deficit/hyperactivity disorder (16.8%, n = 29), post-traumatic stress disorder (13.3%, n = 23), and obsessive-compulsive disorder (9.2%, n = 16). Other diagnoses that were reported include personality disorders, eating disorders, bipolar disorder, gender dysphoria, and learning disorders (27.2%, n = 47). Again, combined percentages exceeded 100%, as individuals were able to list any or all of their additional diagnoses.

Finally, participants were asked to indicate their relationship status and individual earned income. The results were: Partnered in a significant relationship (22.5%, n = 39), Single (48%, n = 83), Widowed (1.2%, n = 2), Married (17.3%, n = 30), Dating (5.8%, n = 10), and Other (4.6%, n = 8). One individual (0.6%) did not respond to this item. In terms of income, the results were as follows: $0 – 9,999 (57.2%, n = 99), $10,000-20,000 (17.8%, n = 31), $21,000-30,000 (9.8%, n = 17), $31,000 – 40,000 (2.9%, n = 5), $41,000 – 50,000 (3.5%, n = 6), $51,000 – 60,000 (.6%, n = 1), $61.000 - 70,000 (1.7%, n = 3), $71, 000 – 80,000 (.6%, n = 1), $81,000 – 90,000 (1.2%, n = 2), and 91,000 and above (3.5%, n = 6). Two individuals did not respond to this item (1.2%).

Measures

Level of education and living status. Two items were included in the demographic questionnaire to assess for participants' reported level of education and current living status. Participants were asked to select the most appropriate choice for their highest level of education completed from the following options: high school graduate, GED, some college, associates degree, college degree, some graduate college, master's degree, doctoral degree, or other. Participants were then asked to select the most appropriate choice for their living situation from the following options: with parents/primary care givers, with partner/spouse, with children/dependents, Independently- no roommates, Independently- with roommates, group home, assisted living facility, or other.

Autism-spectrum symptoms. Very few subjective measures of autism symptoms exist and even fewer measures have been a central part of outcome research within the field of autism. Given the shift from a categorical diagnosis of what is now a part of the autism spectrum, it is important to find ways to account for differences in symptom severity for individuals on the autism spectrum. Baron-Cohen et al., (2001) designed a self-administered scale intended to measure the severity of symptoms associated with autism in a population of individuals with normal IQ. The standard version of the Autism-Spectrum Quotient (AQ) is made up of 50 items that assess areas of social function, attention, communication, and imagination (Baron-Cohen et al., 2001). The authors examined the face validity of the measure by administering the AQ to individuals diagnosed with autism. They found that approximately 80% of the sample of individuals with normal IQ scored above the critical cutoff value of 32. Conversely,

only 2% of individuals without autism who completed the measure scored above the cutoff value (Baron-Cohen et al., 2001). Further, they found that the AQ demonstrated good test-retest reliability. Scores obtained from administrations of the AQ given two weeks apart did not differ significantly, t (16) = 0.3, p = .75. A comparison of parental scores and individual scores on the AQ did not reveal significant differences between parental report and self-report. The mean difference was 2.8 *(SD* = -0.6*),* with parents reporting higher mean scores than their children. Cronbach's alpha was found to be moderate to high for all subcategories of the AQ, with coefficients ranging from .63 to .77 (Baron-Cohen et al., 2001). To clarify, the AQ in itself is not a diagnostic tool; however, there is evidence that it is helpful in identifying characteristics typical of autism for individuals with normal IQ.

Items that make up the AQ are divided into five categories including Social Skills, Communication, Imagination, Attention to Detail, and Attention Switching (Hoekstra at al., 2011). The Autism-Spectrum Quotient-Short (AQ-S) is a brief, 28-item, version of the 50-item AQ designed for use in studies where the original version may be too long (Kuenssberg, Murray, Booth, & McKenzie, 2014). Development of the AQ-S included exploratory factor analyses as well as confirmatory factor analyses to reduce the overall number of items on the original AQ. Items that were found to have similar content or phrasing were removed from the item pool and further analysis was conducted to determine the best fitting model for the remaining items. The resulting five-factor structure of the AQ-S includes social skills, routine, switching, imagination, and numbers/patterns (Hoekstra et al., 2011). Pearson correlations between scores on the AQ and the AQ-S were found to be significant in all samples in the study (r between

.93 and .95). Cronbach's alpha was shown to be good (alpha between .77 and .86) (Hoekstra et al., 2011). Therefore the AQ-S appears to be a reliable and valid measure of autistic characteristics and will be used in this study.

Each item on the AQ-S has four response options including definitely agree, slightly agree, slightly disagree, and definitely disagree. The five areas of the AQ-S is assessed with items that are scored one point if a respondent marks the autistic like behavior either definitely agree or slightly agree (Baron-Cohen et al., 2011). The item scores are then added together with higher total scores indicating more autistic-like behaviors. The highest possible score that could be obtained on the AQ-Short was 28. Sample items include: "I prefer to do things with others rather than on my own; When I am reading a story I can easily imagine what the characters might look like; I tend to have very strong interests which I get upset about if I can't pursue" (Baron-Cohen et al, 2001). In this study, the AQ-Short demonstrated good inter-item reliability (28 items, α = .80).

Employment. The Global Job Satisfaction (GJS) survey, originally developed by Quinn and Shepard (1974), and revised by Pond and Geyer (1991) was utilized to measure participants' job satisfaction. The GJS is a six-item questionnaire designed to measure an employee's affective reaction to their job. According to Pond and Geyer (1991), Cronbach's alpha was .89, and studies have shown the measure to display good validity. Moreover, scores on the GJS were correlated with satisfaction regarding supervision, pay, customer contact, co-workers, and facets of the job itself. Individuals respond to items on a Likert-type scale, where 1 = not at all and 6 = a great deal, with higher scores indicating higher satisfaction with their current employment. The highest

possible score that could be obtained on the GJS was 30. A sample item from the GJS is "How does this job compare to your ideal job?" For participants not currently employed, they were asked to respond to items based on their most recent employment experience. Participants who have never been employed did not complete this measure. In the current study, the GJS scale demonstrated excellent internal consistency reliability (6 items, $\alpha = .94$).

Social Support. In order to measure participants' social support, the Revised UCLA Loneliness Scale was used. This scale, developed by Russell, Peplau, and Ferguson (1978), was created to measure the impact of relationships on various outcome factors including alcoholism, delinquent behavior, and suicide. As mentioned above, social relationships may have a buffering effect on the impact of stress and other psychosocial problems commonly experienced by individuals with and without autism. The Revised UCLA Loneliness Scale is made up of 20 items that ask participants to indicate how often they feel the way described in 20 statements from the following options: Never, rarely, sometimes, and often. Items on this scale were reversed scored so that higher scores indicated higher social support and less loneliness. The highest possible score that could be obtained on this scale was 80. Sample items from the UCLA Loneliness Scale include "I feel in tune with people around me", and "There are people I can talk to." The Loneliness Scale has been shown to have high internal consistency (alpha = .94) and concurrent validity with measures of emotional states known to be associated with loneliness (Russell et al., 1978). For the current study, the UCLA Loneliness Scale was shown to have high inter-item reliability (20 items, $\alpha = .91$)

Quality of life. The WHOQOL-BREF (WHOQOL Group, 1998) is a rating instrument designed to measure an individual's overall perception of quality of life. The WHOQOL-BREF is made up of 26 items that result in four domain scores: Physical Health, Psychological, Social Relationships, and Environment. The measure also includes two items that measure overall quality of life and general health. For the purpose of this study, each of the four domain scores was combined to give an overall rating of an individual's quality of life. Individuals respond to items on a five-point Likert scale (1 = not at all, 5 = an extreme amount), with a higher total score reflecting higher overall quality of life. The highest possible score that could be obtained on the WHOQOL-BREF was 125. Sample items from the WHOQOL-BREF include "To what extent do you feel your life to be meaningful", and "How much do you enjoy life?" One of the many strengths of this measure is that it relies on the individual's "perception of their position in life in the context of culture and value systems in which they live and in relationship to their goals, expectations, standards, and concerns" (WHOQOL Group, 1998, p. 551). According to Trompenaars et al. (2005), the WHOQOL-BREF displays good validity and reliability. The authors reported that internal consistency for the four domains ranged from .66-.80. They also found the WHOQOL-BREF to demonstrate good content and contrast validity. Additionally, their research indicated that items on the WHOQOL-BREF were significantly correlated with self-report inventories of common psychiatric complaints (e.g., SCL-90) and perceived social support (e.g., PSSS). The quality of life measure for the current study was shown to have high internal consistency reliability (26 items, $\alpha = .91$).

Procedure

Online support groups were contacted and requested to distribute information regarding the study to individuals involved in the respective online communities. Facebook support group administrators gave permission for the researcher to post information regarding the current study on their respective support group websites. Organizations involved in autism research were contacted to post information regarding the current study on their research participation websites including Autism Advocacy, Texas Autism Research and Resource Center, Autism NOW, the Organization for Autism Research, and the Arc. In addition, participants from the University of Oklahoma were contacted via email and given a link to the study website. Participants and members of the community were asked to share a link to the survey with any individual they believed might be interested in taking part in the study.

Participants who self-identified as having autism were asked to complete a survey that contained items from the AQ-Short, Global Job Satisfaction survey, UCLA Loneliness Scale, and the WHOQOL-BREF. Participants were also asked to complete a short demographic questionnaire. Data collected from the surveys was stored on Qualtrics, a secure website managed by the University of Oklahoma. Participants completed the demographic questionnaire first, followed by the WHOQOL-BREF. The remaining surveys were presented in a randomized order. In order to ensure the anonymity of the participants, no personally identifiable information was collected.

Chapter 4: Results

Data Analysis

Descriptive statistics for the current sample as well as for each independent measure was calculated, the results are listed in table 1. In order to test the first hypothesis, that level of education, social support, living status, and job satisfaction will predict quality of life, a hierarchal multiple regression analysis was conducted. Demographic variables were entered into a correlation with each of the predictor variables and the outcome variable to determine whether any significant relationships existed. Variables that were significantly correlation with the predictor and outcome variables were then entered into the hierarchal multiple regression analysis in step one in order to control for their effect on the outcome variable. All of the predictor variables were then entered into the second step of the analysis to determine their predictive value on the outcome, quality of life.

In order to test the second hypothesis, that the association between education, living status, job satisfaction, social support, and quality of life will be mediated by level of autism symptoms, the PROCESS macro was utilized in SPSS.

Associations among variables. Preliminary analyses were performed on the data to ensure there were no violations of the assumptions of normality, linearity, and homoscedasticity. As might be expected given the population, participants tended to display higher scores on the AQ-Short, which resulted in a significantly negatively skewed distribution. The dependent variable, quality of life, was significantly and negatively correlated with the AQ-Short, $r = -.19$, $n = 150$, $p = .02$. It was significantly and positively correlated with all other variables including level of education, $r = .21$, n

= 161, p = .01, job satisfaction, r = .43, n = 129, p < .001, and social support, r = .57, n = 156, p < .001 (See Table 2).

Pearson's correlations were then utilized to examine the relationships among the variables of interest. Age was significantly positively correlated with Education, r = .29, n = 172, p < .001, Living Status, r = .47, n = 172, p < .001, and significantly negatively correlated with Social Support, r = -.18, n = 167, p < .03. Age at Diagnosis was significantly and negatively correlated with perceived Social Support, r = -.20, n = 162, p < .02, and significantly and positively correlated with Living Status, r = .36, n = 167, p < .001 and Level of Education, r = .19, n = 167, p < .02. The Additional Diagnoses demographic variable was significantly and positively correlated with Education and QoL, r = .20, n = 170, p < .01 and r = .31, n = 160, p < .001, indicating that individuals with no additional diagnoses were better educated and reported higher quality of life compared to individuals with one or more additional diagnoses. Significant positive correlations also occurred between Individual Income and Education, r = .37, n = 170, p < .001, Living status, r = .46, n = 170, p < .001, and QoL, r = .18, n = 160, p < .03 (See Table 3).

In order to determine if there were group differences among the predictor and criterion variables, several one-way ANOVAs were conducted. Results indicated significant gender differences for Job Satisfaction, F (2, 135) = 3.39, p < 004. Post-hoc analysis revealed that both females (M = 19.50, SD = 7.28) and males (M = 18.93, SD = 7.50) reported significantly higher job satisfaction than participants endorsing gender-other (M = 14.76, SD = 6.34).

Primary Analyses

Hierarchal multiple regression. In order to test the first hypothesis, that level of education, living status, job satisfaction, and perceived social support will significantly predict quality of life for individuals with autism, a hierarchical multiple regression was conducted. The variables Living Status and Gender were both dummy-coded into three categories prior to being entered in the regression model. Preliminary examination of the relationships among all variables indicated the need to control for the following demographic variables: Gender, Age, Age at Diagnosis, Additional Diagnoses, and Income. Thus, these variables were entered into Block 1 to control for their effects. Education, Living Status, Job Satisfaction, and Social Support were entered into Block 2. Results from this analysis revealed that the full model was significant and accounted for 50% of the variance in QoL, $F(5, 107) = 9.68$, $p < .001$. In step 1, Gender, Age, Age at Diagnosis, Additional Diagnoses, and Income accounted for 10.9% of the variance in QoL, $F(6, 112) = 2.27$, $p = .04$. When Education, Living Status, Job Satisfaction, and Social Support were all entered together in step 2, they accounted for an additional 39.0% of the variance in QoL, R^2 change = .39, F change (5, 107) = 16.67, $p < .001$ (See Table 4). The effect size for this analysis ($R = .71$) was found to exceed Cohen's (1988) convention for a large effect ($R = .5$).

Mediation by autism symptoms. In order to determine the predictive value of level of autism symptoms on quality of life, a second hierarchical regression was conducted to determine whether autism symptoms contributed predictive significance to the overall model. Based on the preliminary analysis, Gender, Age, Age at Diagnosis, Additional Diagnoses, and Income were entered in step one due to their significant correlation with the independent variables and/or dependent variable. Level of reported

Autism Symptoms was entered in step two. Education, Living Status, Job Satisfaction, and Social Support were entered together in the final step. The results revealed that the full model was significant and accounted for 50.0% of the variance in QoL, $F(5, 96) = 7.94$, $p < .001$. In step 1, Gender, Age, Age at Diagnosis, Additional Diagnoses, and Income accounted for 10.6% of the variance in QoL, $F(6, 102) = 2.02$, $p = .07$, which was not significant. The model at step two was not significant, with Autism Symptoms only contributing 1.3% of additional variance to QoL, $F(1, 101) = 1.95$, $p = .07$. At step 3, Education, Living Status, Job Satisfaction, and Social Support accounted for an additional 38% of the variance in QoL, R^2 change = .38, F change $(5, 96) = 14.50$ $p < .001$ (See Table 5). The effect size for this analysis ($R = .71$) was found to exceed Cohen's (1988) convention for a large effect ($R = .5$).

In order to test the mediation hypothesis, a series of multiple regression analyses were conducted to determine whether a mediation hypothesis was supported. In order to confirm a mediating variable and its significance in the model, each independent variable must significantly predict the dependent variable, the independent variables must also significantly predict the mediator variable, and finally, the initial independent variable loses significance when the mediator is included in the model. Based on the primary analysis, we know that each independent variable, level of education, independent living, job satisfaction, and social support, significantly predicted the dependent variable, quality of life. Based on these results, each independent variable was included in the second step of the mediation analysis.

Results indicated that education and job satisfaction were not significant predictors of autism symptoms, $b = -.21$, $SE = .41$, $p = .60$ and $b = .08$, $SE = .05$, $p = .13$

respectively. Living status was not a significant predictor of autism symptoms, $b = .04$, $SE = .74$, $p = .95$, and $b = .73$, $SE = .72$, $p = .31$. These results do not support the mediation hypothesis; therefore, no further analysis was conducted utilizing those variables. Perceived social support was shown to be a significant predictor of autism symptoms, $b = -.14$, $SE = .03$, $p < .001$. Autism symptoms was also a significant predictor of social support, $b = .98$, $SE = .20$, $p < .001$. While these results support a mediating effect for the mediator, perceived social support remained a significant predictor of QoL when level of autism symptoms was included in the model ($b = .85$, $SE = .12$, $p < .001$). These results indicate that autism symptoms do not mediate the effect of education, job satisfaction, living status, or social support on quality of life.

Chapter 5: Discussion

The purpose of the current study was to contribute to the limited research base examining variables impacting quality of life for adults with autism. There is some evidence (Eaves & Ho, 2008; Farley & McMahon, 2014; Howlin et al., 2000; Kamio et al., 2013; Kapp et al., 2011; Levy & Perry, 2011) that adults with autism continue to experience different outcomes when compared to individuals without autism and individuals with other types of neurodevelopmental disabilities. Based on adult outcome research, it seems that employment, social relationships, education, and independent living are the most common indicators of positive outcomes. It could be argued however, that these "pillars" of adulthood are based on a neurotypical, or "normally developing" frame of reference. Literature in the field of autism has repeatedly revealed that individuals with autism have low levels of quality of life and psychological well being. In order to develop appropriate support services and interventions for adults with autism, we must first understand how these factors, and potentially others, impact their quality of life.

The results of this study indicate that, as predicted, level of education, job satisfaction, perceived social support, and living status significantly predicted quality of life for individuals with autism. Of note is the significant impact of job satisfaction and perceived social support. This finding has important implications for the development of intervention services aimed at improving quality of life for adults with autism. Social support and job satisfaction are both variables that are amenable to change. On the other hand, an individual's reported autism symptoms are qualities that are less likely to change, even with the use of specific intervention techniques. The fact that autism

symptoms did not contribute significant predictive value to the overall model is a promising finding. This seems to indicate that despite the extent of autism symptoms, social support and job satisfaction still appear to positively impact quality of life. The current study seems to be consistent with prior research that has demonstrated low employment rates for adults with autism despite having appropriate qualifications and higher education (Howlin et al., 2004; Farley & McMahon, 2014; Geller & Greenbert, 2010; Kapp et al., 2011; Nicholas et al., 2015). Although 75.1% (n = 130) of participants attended college or graduate college, only 21.9% (n = 38) indicated being employed full time. Further, 37.6% (n = 65) indicated being a student or being employed part time. Although it is unclear based on the current study whether individuals obtained jobs commensurate with their abilities, there seems to be a disparity among employment outcomes for adults with autism. Moreover, 56.6% of the participants reported yearly individual incomes less than $10,000. This result contributes to the troubling base of research that suggest individuals with autism have worse employment outcomes compared to adults without autism. Developing interventions that target increasing employment such as interview training, job search support, resume critiques, etc. is likely to improve quality of life for adults with autism. Adults with autism would likely benefit from access to services such as pay negotiation strategies. Professionals working with adults with autism may consider implementing tools to measure job satisfaction as a quick way to determine the need for additional employment support services.

Creating opportunities for growth regarding perceived social support is another important area of focus for adults with autism. Based on the results of the current study,

an individual's perceived social level of social support is a significant predictor of overall quality of life. Given the social communication difficulties that many adults with autism experience, it may be useful to implement social skills interventions for children and adolescents with autism. Prior research has demonstrated that as individuals with autism age, social interaction outside of school or organized activities decreases significantly (Shattuck et al., 2011). It may be important for providers who work with adolescents and young adults with autism to understand the impact of social support on quality of life and develop tools and approaches that focus on increasing communication and social skills training. Often, individuals build confidence in social interactions through experience, therefore, individuals with autism would likely benefit from participating in programs or interventions designed to increase social confidence. Perhaps another necessary intervention is assisting adults with autism to identify sources of social support based on individual needs and preferences.

Another potential area of intervention is education. Although its predictive contribution was smaller, it still appears to be an important factor for adults with autism. A unique finding in the current study is that most of the participants reported attending college. This reflects trends in more current research that suggests that individuals with autism are able to meet the demands of postsecondary academic programs (Cai & Richdale, 2016). Moreover, the finding that perceived social support was higher for participants who reported attending college and graduate school compared to participants who completed high school, suggests that the transition to high school may be an important time for implementing programs and interventions designed to assist individuals in preparation for secondary and post-secondary expectations and

responsibilities. Based on previous research, participation in higher education involves reliance on complex social skills, organizational and planning abilities, and the ability to navigate support services independently (Shrogren & Plotner, 2012; Stodden & Mruzerk, 2010).

The current study appears consistent with prior research that has demonstrated increased psychological diagnoses in individuals with autism (Eaves & Ho, 2008; Farley & McMahon, 2014; Levy & Perry, 2011). The present study revealed that over half, 65.3% (n = 113), of participants identified as having an additional psychological diagnosis, and many of these individuals reported having two or more diagnoses (41.6%, n = 72). In terms of intervention strategies, adults with autism may benefit from gaining access to comprehensive mental health services. According to the CDC, depression affects approximately 7.9% of adults living in the United States (CDC, 2014). Results from the current study showed that 41% (n = 71) of participants had a diagnosis of depression. This number is significantly higher than would be expected based on rates of depression in the general population.

The demographic makeup of participants in the current study was rather unique compared to the general body of autism research. The mean age of diagnosis reported by study participants was 22.9 years of age, which is significantly higher than the national average of six years of age. Also, nearly half of the sample was female, whereas the CDC reports males being more commonly diagnosed as 3:1. Recruitment methods likely contributed to the higher age of initial diagnosis as information regarding participation was posted on social media websites aimed at promoting autism advocacy. However, it is interesting that despite being diagnosed later in life than the

average individual with autism, employment and income rates were lower than expected, particularly given the high level of educational attainment reported in the sample. Clearly more information is needed regarding the needs of adults with autism, as there is such wide variability in outcomes.

Although it was not specifically within the scope of the research questions to examine factors related to gender identity for adults with autism, it was interesting that 33% of the sample indicated nonbinary gender identity. This appears to be an area in need of further exploration in order to better understand factors that contribute to gender identity development for individuals with autism.

The second hypothesis, that level of autism symptoms would mediate the impact of education, independent living status, job satisfaction, and social support on quality of life was not supported. This finding is somewhat surprising as it would seem that individuals with higher levels of autism symptoms would experience a greater amount of distress that would in turn decrease their overall quality of life. However, this is a promising finding in terms of developing evidence-based interventions. It should be noted that individuals who took part in this survey might possess higher levels of adaptive skills as recruitment material was primarily posted on websites or Facebook groups that support autism advocacy. Many groups that circulated recruitment information were designed as online support communities. On the other hand, it could be argued that many adults with autism have developed coping strategies to manage disruptive behavioral symptoms. Again, this seems to indicate that efforts should be exerted to explore external factors and incorporate practices that aim to build support networks to assist adults with autism in reaching their full potential.

An additional note regarding the current study involves feedback that several participants provided regarding the autism community. Although only a handful of participants responded via email to offer statements, it seemed the overarching theme connecting the community is the desire to move past the stigma of autism as a disability. The information provided by participants was a useful reminder of the importance of utilizing "people-first" language wherein the focus is on the person rather than what makes them different. In addition, several individuals who are active in the advocacy community promote the concept of neurodiversity and the importance of embracing differences as unique and valuable strengths.

Limitations

The purpose of this study was to contribute to the body of knowledge regarding outcomes for adults with autism; however, there were several limitations to the research that should be noted. First, the participants included in this study appear to have unique demographic characteristics compared to other research regarding outcomes for adults with autism. Half of the participants in this study identified as female, which is much higher than typical representations of females in autism research. It is possible that due to the method of sampling, the participant pool was skewed. Participants were also homogenous in their ethnic make up. Most of the participants that took part in this study identified as White/Caucasian. This makes generalizing results and recommendations to populations in different cultures more difficult. Although it can be estimated that beneficial support services may be similar, it is important to understand the role of culture in developing effective treatment modalities. Another general consideration is that participants were recruited primarily through online support communities via

Facebook. This poses some challenges, as individuals who are involved in online communities are likely to have higher levels of adaptive behaviors. Another major limitation is the number of participants who reported having an additional psychological disorder. Nearly 60% of the participants reported being diagnosed with disorders such as depression, anxiety, PTSD, ADHD, and OCD. This is problematic in that it is more difficult to ascertain whether additional psychological diagnoses had an impact on QoL. It should be noted, however, that this representation of co-morbid psychological disorders among individuals diagnosed with autism is comparable to other research in this area.

Future Research

As the idea of neurodiversity continues to gain momentum, the need for inclusive practices in education, employment, housing, and community activities will continue to grow. Future research should focus on the efficacy of implementing support services specifically for individuals with autism. Relatively little is known about the outcome of various support programs. In terms of employment, there seems to be evidence that although many adults with autism are capable of gaining employment, a much higher percentage of individuals report being unemployed or dissatisfied with their current employment situation. A few studies have demonstrated some promising results in implementing employment assistance programs. Again, it is important to understand further what aspects of these programs are most helpful to individuals with autism. It would be interesting to examine how self-reported QoL changes over time for individuals with autism as well as for those without autism. This may lead to even more specific services that would benefit the well being of those with autism.

Given that some of the variables influencing outcomes with this population likely work in tandem, future studies should focus on research designs conducive to examining interaction effects. One of the purposes of this study was to give adults with autism their own voice in research. As advocacy efforts grow, it is important to understand autism as an area of diversity, and research should continue to strive to incorporate the individual perspectives of this population. Qualitative research designs would be ideal for this purpose.

Specifically, the results of the current study revealed that approximately 33% of the participants indicated non-binary gender identity. This is a rather unique finding and warrants further exploration. Perhaps social and communication differences contribute to varying gender expression. There is also some evidence that children with autism do not receive appropriate sexual education during their development. Clearly there are several unanswered questions related to gender and autism that should be the focus of future research.

Conclusions and Implications for Intervention

This study demonstrated several important findings regarding quality of life for individuals with autism. First, consistent with previous research on predictors of quality of life, level of education, living status, job satisfaction, and perceived social support, all significantly predicted quality of life for the participants diagnosed with autism. This is important information for individuals and practitioners interested in designing programs or interventions for adults with autism. Clearly, interventions aimed at building social support and increasing job satisfaction are likely to have a significant impact on quality of life and, as a result, overall well-being for individuals with autism.

Social support was shown to play a significant role in predicting quality of life for adults with autism; however, one of the most common features of autism is deficits in social communication and interactions. Development of appropriate interventions aimed at increasing social support must be creative and based on individual needs and expectations. Interventions that target increasing opportunities for social interaction may be useful to increase confidence and self-efficacy. Social skills training may be another useful intervention to build greater social support. It is also vital that communities respond to individuals with autism in the most inclusive way possible. Providers should also work to advocate for greater awareness and understanding of autism and to create opportunities in the community that welcome individuals with autism.

Employment assistance programs could allow adults with autism to experience higher levels of job satisfaction. Interventions focused on improving interview skills, resume building, and job searching might increase positive employment outcomes for adults with autism. Additionally, greater support in navigating complex social interactions at work or assistance in negotiating salary or pay raises may also increase job satisfaction for adults with autism. Education and training should be provided to managers and supervisors to increase awareness and knowledge regarding autism.

Additional interventions that target educational outcomes and living status may also prove beneficial for adults with autism. For example, colleges and universities should examine the potential role of transition programs designed specifically for students with autism. Programs that target areas such as self-care, practical life skills, social skills training, time management, etc. are likely to enhance students' opportunity

to succeed in postsecondary opportunities. Based on the current study, a majority of the participants completed at least some college education, however, their employment and income outcomes were lower than expected based on their educational background. This seems to indicate the importance of adequate support services in postsecondary institutions. Goal setting and attainment skills could also impact independent living and education outcomes. It appears that individuals with autism lack behind their peers in terms of transitional goal setting. Having instruction and opportunity to participate in and engage in goal setting and acquisition may also contribute to improved outcomes.

The current study also revealed that a large number of adults with autism report having one or more additional psychological diagnoses, particularly depression and anxiety. Interventions and support services that assist individuals with autism to develop coping skills and greater awareness of symptoms of depression and anxiety would likely be a vital step in impacting overall quality of life.

A secondary goal of this study was to demonstrate the importance of including individual perspectives in research. Understanding the needs of people with autism is something that can only be done through thoughtful and purposeful collaboration with individuals and families living in the community. Also, given the drastic increase in the number of individuals being diagnosed with autism, it will, no doubt, be important to develop seamless, comprehensive educational and support programs spanning the early childhood, elementary, middle school, high school, and post-secondary years. Finally, promoting more inclusivity and respect for neurodiversity throughout research, education, and treatment is paramount in order to maximize the talents and skills of individuals with autism.

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Appendix A: Tables

Table 1

Mean and Standard Deviation for Study Measures and Demographic Variables

Variable	N	Mean	Std. Dev
AQ	158	20.68	4.42
Education	172	2.37	0.84
Job Satisfaction	138	18.52	7.43
Social Support	167	45.28	11.33
QoL	162	79.33	17.07
Age	173	29.56	9.56
Age at Diagnosis	168	22.42	11.71

Table 2

Correlations Among Independent Variables and Dependent Variable

Variables	1	2	3	4	5
1. QoL	-				
2. AQ	-.19*	-			
3. Education	.21**	-.03	-		
4. Job Satisfaction	.43**	.11	.158	-	
5. Social Support	.57**	-.38**	.05	.306**	-

** *Correlation is significant at the .01 level*

* *Correlation is significant at the .05 level*

Table 3

Correlations Among Variables of Interest

Variables	M (SD)	1	2	3	4	5	6	7	8	9	10
1. Age	29.5 (9.96)	-									
2. Age at Dx	22.4 (11.71)	.70**	-								
3. Add't Dx	1.34 (.48)	0.1	0.08	-							
4. Income	2.23 (2.30)	.36**	.23**	0.13	-						
5. Education	2.90 (.84)	.36**	.19*	.20**	.37**	-					
6. Ind. Living	2.56 (.56)	.53**	.36**	0.01	.46**	.29**	-				
7. Job Satisfaction	18.52 (7.43)	-0.07	-0.03	0.11	.22**	0.16	-0.004	-			
8. Social Support	45.28 (11.33)	-.18*	-.20**	0.12	0.04	0.06	-0.13	.30**	-		
9. AQ	0.79 (.27)	0.03	-0.14	0.14	-0.04	-0.04	-0.18	-0.13	.37**	-	
10. QoL	79.33 (17.07)	-0.04	-0.00	.31**	.21**	.24**	-0.11	.44**	.57**	.20*	-

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Table 4

Summary of First Hierarchical Regression Analysis Predicting Quality of Life

	Model 1			Model 2		
	B	SE β	β	*B*	SE β	β
Age	-.16	.25	-.10	-.08	.21	.21
Male vs. other	-.52	4.59	-.0.02	.74	3.63	.02
Female vs. other	2.24	5.28	.07	.82	4.14	.02
Age at Dx	.03	.172	.19	.17	.14	.12
Additional Dx	8.67	3.34	.25**	5.28	2.52	.15*
Income	1.91	.60	.19*	1.10	.49	.17*
Level of Education				4.19	1.60	.20**
Living w/Parents vs. other				2.73	6.20	.07
Independent vs. other				-6.44	6.17	-.18
Job Satisfaction				.57	.17	.25**
Social Support				.65	.12	.43**
R^2		.11*			.50**	
F for Change in R^2		2.27			9.68	

*$p < .05$; **$p < .001$

Table 5

Summary of Hierarchal Regression Analysis to Test Mediation with Autism Symptoms

	Model 1			Model 2			Model 3		
	B	SE β	β	*B*	SE β	β	*B*	SE β	β
Age	-.14	.28	-.08	-.15	.28	-.09	.01	.23	.00
Male	.11	5.08	.003	.812	5.12	.023	1.4	4.10	.04
Female	2.31	6.09	.067	3.51	6.19	.10	2.22	4.83	.06
Age at Dx	.06	.18	.04*	.10	.18	07*	.16	.14	.12
Additional Dx	8.92	3.42	.25	8.32	3.47	.24	5.08	2.72	.14
Income	1.14	.62	.18	1.10	.62	.17	1.15	.53	.18*
Autism Symptoms				-.49	.41	-.12	-.04	.35	-.01
Level of Education							4.19	1.73	.20*
Living w/Parents							2.65	6.52	.07
Independent							-7.18	6.43	-.194
Job Satisfaction							.60	.19	.27**
Social Support							.63	.13	41**
R^2		.11			.12			.50**	
F for Change in R^2		2.02			1.95			7.94**	

*$p < .05$; **$p < .001$

Appendix B: Measures

Demographic Survey

1. Have you been formally diagnosed with an Autism Spectrum Disorder? (i.e. diagnosis from a psychologist, psychiatrist, or physician?

- ❍ Yes
- ❍ No

2. Age?

3. Gender?

4. Race or ethnicity?

5. Where do you live?

- ❍ United States (Please specify what state) _____
- ❍ Outside of the United States (Please specify what country) _____

6. What is your highest level of education completed?

- ❍ High School graduate
- ❍ GED
- ❍ Some College
- ❍ Associates degree
- ❍ College degree
- ❍ Some graduate college
- ❍ Master's degree
- ❍ Doctoral Degree
- ❍ Other (Please specify) _____

7. What is your Current employment status?

- ❍ Full time
- ❍ Part time
- ❍ Student
- ❍ Out of work and looking for work
- ❍ Out of work but not currently looking for work
- ❍ A homemaker
- ❍ Military
- ❍ Retired
- ❍ Unable to work
- ❍ I have never been employed

8. What was your age at the time of your diagnosis?

9. Are you currently diagnosed with any other psychological condition? Please specify if possible.

- ❍ Yes _____
- ❍ No

10. What is your primary source of social support? Select all that apply.

- ❑ Family
- ❑ Peer support in person
- ❑ Peer support online
- ❑ Partner/Significant other

11.What is your current living situation? Select all that apply.

- ❑ With parents/primary care givers
- ❑ With partner/spouse
- ❑ With children/dependents
- ❑ Independently, no roommates
- ❑ Independently, with roommates
- ❑ Group home
- ❑ Assisted living facility
- ❑ Other _____

12. What is your current relationship status?

- ❍ Partnered in a significant relationship
- ❍ Single
- ❍ Widowed
- ❍ Married
- ❍ Dating, monogamous
- ❍ Dating non-monogamous
- ❍ Other _____

13. What is your individual earned income?

- ❍ $0-9,999
- ❍ 10,000-20,000
- ❍ 21,000-30,000
- ❍ 31,000-40,000
- ❍ 41,000-50,000
- ❍ 51,000-60,000
- ❍ 61,000-70,000
- ❍ 71,000-80,000
- ❍ 81,000-90,000
- ❍ 91,000-100,000
- ❍ 100,000 and above

14. Do you have any dependents?(i.e. children, family member who is financially dependent)

- ❍ Yes
- ❍ No

Quality of Life

Please keep in mind your standards, hopes, pleasures, and concerns. We ask that you think about your life in the past two weeks.

	Very Poor	Poor	Neither poor nor good	Good	Very Good
How would you rate your quality of life?	❍	❍	❍	❍	❍

	Very Dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very Satisfied
How satisfied are you with your health?	❍	❍	❍	❍	❍

The following questions ask about how much you have experienced certain things in the last two weeks.

	None at all	A little	A moderate amount	A lot	A great deal
To what extent do you feel that physical pain prevents you from doing what you need to do?	❍	❍	❍	❍	❍
How much do you need any medical treatment to function in you daily life?	❍	❍	❍	❍	❍
How much do you enjoy life?	❍	❍	❍	❍	❍
To what extent do you feel your life to be meaningful?	❍	❍	❍	❍	❍

The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	Slightly	A moderate amount	Very Much	Extremely
How well are you able to concentrate?	❍	❍	❍	❍	❍
How safe do you feel in your daily life?	❍	❍	❍	❍	❍
How healthy is your physical environment?	❍	❍	❍	❍	❍

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	❍	❍	❍	❍	❍
Are you able to accept your bodily appearance?	❍	❍	❍	❍	❍
Have you enough money to meet your needs?	❍	❍	❍	❍	❍
How available to you is the information that you need in your day-to-day life?	❍	❍	❍	❍	❍
To what	❍	❍	❍	❍	❍

extent do you have the opportunity for leisure activities?					

	Very poor	Poor	Neither poor nor well	Well	Very Well
How well are you able to get around?	❍	❍	❍	❍	❍

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	❍	❍	❍	❍	❍
How satisfied are you with your ability to perform your daily living activities?	❍	❍	❍	❍	❍
How satisfied are you with your capacity for work?	❍	❍	❍	❍	❍
How satisfied are you with your personal relationships?	❍	❍	❍	❍	❍
How satisfied are you with your sex life?	❍	❍	❍	❍	❍
How satisfied are you with	❍	❍	❍	❍	❍

the support you get from your friends?					
How satisfied are you with the conditions of your living place?	❍	❍	❍	❍	❍
How satisfied are you with your access to health services?	❍	❍	❍	❍	❍
How satisfied are you with your mode of transportation?	❍	❍	❍	❍	❍

The following question refers to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	About half the time	Very often	Always
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	❍	❍	❍	❍	❍

AQ-Short

Below is a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it.

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
I prefer to do things with others rather than on my own.	❍	❍	❍	❍
I prefer to do things the same way over and over again.	❍	❍	❍	❍
If I try to imagine something, I find it very easy to create a picture in my mind.	❍	❍	❍	❍
I frequently get so strongly absorbed in one thing that I lose sight of other things.	❍	❍	❍	❍
I usually notice car license plates or similar strings of information.	❍	❍	❍	❍
When I'm reading a story, I can easily imagine what the characters might look like.	❍	❍	❍	❍
I am fascinated by dates.	❍	❍	❍	❍
In a social	❍	❍	❍	❍

group, I can easily keep track of several different people's conversations.				
I find social situations easy.	❍	❍	❍	❍
I would rather go to a library than a party.	❍	❍	❍	❍
I find making up stories easy.	❍	❍	❍	❍
I find myself drawn more strongly to people than to things.	❍	❍	❍	❍
I am fascinated by numbers.	❍	❍	❍	❍
When I'm reading a story, I find it difficult to figure out the characters' intentions.	❍	❍	❍	❍
I find it hard to make new friends.	❍	❍	❍	❍
I notice patterns in things all the time.	❍	❍	❍	❍
It does not upset me if my daily routine is disturbed.	❍	❍	❍	❍
I find it easy to do more than one thing at once.	❍	❍	❍	❍
I enjoy doing things spontaneously.	❍	❍	❍	❍

I find it easy to figure out what someone is thinking or feeling just by looking at their face.	❍	❍	❍	❍
If there is an interruption, I can switch back to what I was doing very quickly.	❍	❍	❍	❍
I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	❍	❍	❍	❍
I find it difficult to imagine what it would be like to be someone else.	❍	❍	❍	❍
I enjoy social occasions.	❍	❍	❍	❍
I find it difficult to figure out people's intentions.	❍	❍	❍	❍
New situations make me anxious.	❍	❍	❍	❍
I enjoy meeting new people.	❍	❍	❍	❍
I find it very easy to play games with children that involve	❍	❍	❍	❍

pretending.				

Global Job Satisfaction

Please answer the follow questions based on your current job. If you are not currently employed, please answer the questions based on your most recent employment experience.

	Definitely not take the job				Definitely take the job
If you had to decide all over again whether to take the job you now have, what would you decide?	❍	❍	❍	❍	❍

	Not recommend at all				Strongly Recommend
If a friend asked if they should apply for a job like yours with your employer, what would you recommend?	❍	❍	❍	❍	❍

	Very far from ideal				Very close to ideal
How does this job compare to your ideal job?	❍	❍	❍	❍	❍

	Not at all				A great deal
How does your job measure up to the sort of job you wanted when you took it?	❍	❍	❍	❍	❍

	Not satisfied				Completely satisfied
All things considered, how satisfied are you with your current job?	❍	❍	❍	❍	❍

	Not at all				A great deal
In general, how much do you like your job?	❍	❍	❍	❍	❍

Perceived Social Support

Please indicate how often each of the following statements is descriptive of you.

	Never	Rarely	Sometimes	Often
I feel in tune with the people around me	❍	❍	❍	❍
I lack companionship	❍	❍	❍	❍
There is no one I can turn to	❍	❍	❍	❍
I do not feel alone	❍	❍	❍	❍
I feel part of a group of friends	❍	❍	❍	❍
I have a lot in common with the people around me	❍	❍	❍	❍
I am no longer close to anyone	❍	❍	❍	❍
My interests and ideas are not shared by those around me	❍	❍	❍	❍
I am an outgoing person	❍	❍	❍	❍
There are people I feel close to	❍	❍	❍	❍
I feel left out	❍	❍	❍	❍
My social relationships are superficial	❍	❍	❍	❍
No one really knows me well	❍	❍	❍	❍
I feel isolated from others	❍	❍	❍	❍
I can find companionship when I want it	❍	❍	❍	❍
There are	❍	❍	❍	❍

people who really understand me				
I am unhappy being so withdrawn	❍	❍	❍	❍
People are around me but not with me	❍	❍	❍	❍
There are people I can talk to	❍	❍	❍	❍
There are people I can turn to	❍	❍	❍	❍