

THE RELATIONSHIP OF EMPLOYMENT AND SOCIAL DEFICITS IN ADULTS WITH  
AUTISM SPECTRUM DISORDER

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## **ABSTRACT**

Shaun P. Thomas: The Relationship of Employment and Social Deficits in Adults with Autism Spectrum Disorder

(Under the direction of Mark R. Klinger)

Deficits in social interaction and social communication are life-long in individuals with Autism Spectrum Disorder (ASD). These social deficits contribute to the difficulty many adults have finding and maintaining employment. Employment for every adult has benefits of pay and independence, but the benefits of the social interaction provided in a work environment may be especially important for adults with ASD. For other populations, employment is associated with improved social behaviors. The purpose of this study is to determine if the positive relationship between employment and social skills holds true for adults with ASD. Additionally, this study investigates the effect of comorbid diagnoses, especially ID and Anxiety disorders, on employment and social skills. There are few interventions designed for adults with ASD; if employment is demonstrated to have a positive effect on the social deficits of these adults, focus can be placed on successfully integrating adults with ASD into employment settings.

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## LIST OF ABBREVIATIONS

ADAMS	Anxiety, Depression, and Mood Scale
ASD	Autism Spectrum Disorder
CARS	Childhood Autism Rating Scale
QOL-Q	Quality of Life Questionnaire
RRB	Repetitive and Restrictive Behaviors
SCI	Social Communication Inventory
SRS-2	Social Responsiveness Scale-2
W-ADL	Waisman Activities of Daily Living Questionnaire



## **CHAPTER 1: INTRODUCTION**

Our understanding of children and school-age individuals with Autism Spectrum Disorder (ASD) has increased rapidly since the disorder was first discussed. However, we know little about how the symptoms of ASD change and impact individuals throughout their adult life. We do know that the general life outcomes tend to be poor (Henninger & Lounds-Taylor, 2013); most adults do not live independently, and adults with ASD have a particularly difficult time finding and keeping employment compared to both typical adults and adults with a range of other disabilities (Roux et al., 2013; Shattuck et al., 2012; Shogren & Plotner, 2012; Taylor & Seltzer, 2010). Although social and communication deficits are two of the hallmark symptoms of ASD, the relationship between these deficits and the difficulties that many adults with ASD have achieving gainful employment has not been thoroughly investigated. Interventions for young adults with ASD seeking competitive employment often include a component of developing appropriate social skills for the work environment (Burt, Fuller, & Lewis 1991; Lee & Carter, 2012; Wehman et al., 2013), but we do not know if these social skills are reinforced in the work environment and generalized to other situations. The purpose of this study is to investigate whether employment is linked to better social and communication skills in adults with ASD.

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder characterized by two categories of symptoms: deficits in social interaction and social communication, and repetitive behaviors and restricted interests (American Psychiatric Association [APA], 2013). The ASD literature distinguishes between high functioning and low functioning individuals with ASD; high functioning individuals have average or above average IQ, while low functioning

individuals have below average IQ. The extent of ASD symptoms can range from mild to severe in both groups. First classified in 1943 by Leo Kanner, our understanding of ASD has undergone many changes in the past 70 years, leading to changes in prevalence rates and diagnosis. The disorder has been diagnosed with increased frequency, a trend that is still continuing. In 2000, the rate of diagnosis of ASD was 1 in 150 children, and that figure increased to 1 in 68 children in 2014 (Center for Disease Control and Prevention [CDC], 2014). Males are close to five times as likely as females to be diagnosed with ASD, with prevalence rates of 1 in 42 for males and 1 in 189 for females (CDC, 2014). The trend of increasing prevalence of ASD is occurring at the same time as downward trends in diagnosis of Intellectual Disabilities (ID) and Learning Disabilities (LD), suggesting that part of the reason for the increased diagnosis of ASD is that it is replacing these diagnoses in some cases (Shattuck, 2006). This, along with increased understanding of the disorder and more widespread awareness, may partially contribute to this dramatic and continued increase in prevalence rate. There has also been an increasing amount of attention paid to comorbid mood disorders in individuals with ASD in recent years, of which ADHD, anxiety, and depression are the most common (Simonoff et al., 2008). There is no known cause of autism, but there are possible genetic and environmental links and extensive research is being done in both of these fields to investigate what contributes to a diagnosis of ASD.

A great deal of research has been conducted on ASD in childhood, including studies on possible genetic causes, risk factors, treatments, and symptom course. This is, in part, because it has been demonstrated that the earlier intervention begins the better the prognosis is. A review of early interventions finds that many are initiated around age three, with the earliest beginning at 18 months. The majority of these interventions found some improvement in symptoms after the

intervention (Rogers & Vismara, 2008). One particularly intense intervention, beginning between 18 and 30 months of age, found that children in the intervention group improved one standard deviation in IQ score and had significantly greater improvements in adaptive behavior and autism symptoms compared to the control group who did not receive this intervention (Dawson et al., 2009).

Deficits in social interaction and social communication are among the first visible symptoms in children with ASD (Osterling & Dawson, 1994). Jones and Klin (2013) found that infants who later developed ASD looked at others' faces less than children that did not develop ASD, and the rate of looking at faces declined in the group who developed ASD from two to six months of age. They hypothesized that this causes the infants to miss out on many of the social cues that other children receive and therefore not learn about the world as well as typically developing children during this time period. In addition to missing important social cues in early childhood, individuals with ASD often have atypical language development and learn new words and meanings in a more constricted fashion than typically developing children (Tager-Flusberg, 2000). These factors contribute to the inherent difficulties in the social domain experienced by individuals with ASD.

Research is limited on how individuals with ASD, and their symptoms, progress across the lifespan. An analysis of the few outcome studies in the literature came to the conclusion that adults with ASD have much poorer outcomes than the general population (Henninger & Taylor, 2013). This may be a result of limited understanding of ASD in adults by the general population and service delivery systems that are not designed for these adults. Low adaptive behavior has a negative effect on lifestyle outcome in adults with ASD (Felce, Perry, Lowe, & Jones, 2010), and it may be found that employment has a significant effect on the level of adaptive behaviors in

mid- to late-adulthood. Very few of the services currently available for adults, such as Vocational Rehabilitation (VR), are designed to work with individuals with ASD (Hendricks, 2009). Due to the increasing diagnosis rate, the majority of individuals who now have a diagnosis of ASD are under 18 years old and will soon be entering our service systems for adults with disabilities. This means it is a critical time to examine how adults with ASD are navigating the system of available services, so we can redesign our service delivery system to be prepared for the upcoming influx of adults with ASD into our society. It is important to serve these soon-to-be adults in the best possible way to maintain the trend of decreasing symptom severity seen from childhood into adolescence.

### **ASD, Social Interaction, and Social Communication**

Much of the literature on ASD includes social skills and communication as part of the adaptive behavioral symptoms of ASD. Adaptive behaviors are a group of behaviors that enable an individual to live independently, safely, and successfully in the context of their culture on a daily basis, and in the ASD literature they are usually measured using the Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla & Cicchetti, 1984). In general, individuals with ASD score lower on measures of adaptive behavior than their typically developing peers, but higher than individuals with ID (Jacobson & Ackerman, 1991). Youth with ASD also exhibit adaptive behaviors lower than their cognitive ability level, with this discrepancy increasing as they age (Jonsdottir et al., 2006). The severity of the ASD diagnosis as early as age five can be a predictor of the trajectory of social and communication skills in adulthood (Baghdadli et al., 2011), and a comorbid diagnosis of ID correlates with much lower adaptive behavior scores through adulthood (Nordin & Gillberg, 1998). When compared to individuals with Specific Language Impairments (SLI), young adults with ASD showed significantly fewer greeting behaviors and

social responses, more limited initiations, and were less likely to enjoy being around others (Howlin, Mawhood, & Rutter, 2006).

Social interaction and social communication deficits appear to decrease from childhood to adolescence and into adulthood. In a study conducted by Seltzer et al. (2003), criteria of over 400 individuals diagnosed with ASD in childhood were compared with diagnostic criteria of those same individuals in adolescence and adulthood. In the domain of communication, only 65% of adolescents and 73% of adults scored above cutoff levels to be diagnosed with ASD. All of these adolescents and adults were above the cutoff level when measured on the same domain in childhood. The results for reciprocal social interaction were not as drastic, but were still significant; 82% of adolescents were above the cutoff levels to be diagnosed with ASD, while 92% of adults were above the cutoff. Furthermore, it has been shown that while receiving any form of treatment, over 90% of individuals demonstrate an increase in social ability between childhood and adolescence (Mazurek, Kahn, & Meyers, 2012), with higher functioning individuals showing increases at a higher rate than low functioning individuals (McGovern & Sigman, 2005).

Adaptive behavior scores generally improve through adolescence and young adulthood. However, the rate of improvement decelerates following high school exit. Taylor and Seltzer (2010) conducted a study that followed youths with ASD for ten years beginning before the age of 16. They found that during this time period the severity of symptoms of ASD decreased, and that there was a distinct difference in the rate of symptom improvement between the high school years and the years following high school exit. The rate of decreasing symptom severity was continuous and steady during the high school years, but after high school exit the rate of improvement slowed. High school exit was more detrimental to individuals with high

functioning ASD; their symptom improvement slowed even more than that of lower functioning individuals at the same time. This study did not examine the effect of employment on this change in symptom severity. However, because many adolescents and young adults with ASD do not gain employment immediately following high school (Roux. et al, 2013; Shattuck et al., 2012; Taylor & Seltzer, 2009), it can be hypothesized that employment may offset the slowing of symptom improvement currently observed and continue improvement on the same trajectory seen while in high school. Therefore, this thesis proposes to look at how employment affects the symptom severity of social interaction and social communication in individuals with ASD.

### **ASD and Comorbid Conditions**

This section will discuss co-occurring diagnoses that could have an effect on socialization and employment in adults with a comorbid disorder, specifically focusing on ID and Anxiety disorders. For 20 years following the classification of ASD by Kanner (1943), researchers did not consider co-occurring psychopathology in ID, because ASD and ID were considered to be separate, non-overlapping disorders (Matson & Williams, 2014). This has led to a continuously developing classification of the comorbidity of the two disorders. As a result, ID is reported to be comorbid with ASD at rates that vary according to the time the study was conducted and the methodology of the study. Earlier studies, including Fombonne (2003) and LaMalfa, Lassi, Bertelli, Savini, and Placidi (2004) concluded that 60-70% of individuals with ASD had a comorbid ID. Fombonne (2003) based his estimate on a review of studies conducted from 1966-2001. More recent data released by the CDC states that 46% of individuals diagnosed with ASD have average or above average IQ, which suggests a decrease in the percentage of comorbid ID (CDC, 2014). It is worth noting that the population sampled in the current study are in the former

of the two prevalence rates, and 60-70% of individuals in the current sample can be expected to have a comorbid ID diagnosis.

The effect of a comorbid ID can be significant; as the severity of ID increases, the severity of the ASD symptoms and challenging behavior also increases (O'Brien & Pearson, 2004), and individuals with a comorbid diagnosis tend not to grow out of their challenging behaviors as they age (Murphy, Healy, & Leader, 2009). Another area that is affected in individuals with ASD and a comorbid severe or profound ID is behavioral feeding problems (Fodstad & Matson, 2008). This includes food selectivity and feeding refusal. Individuals with ID and ASD may also be diagnosed with comorbid psychiatric disorders. When this is the case, the symptoms of a comorbid psychiatric disorder tends to persist over time (Sabaratnam, Murthy, Wijeratne, Buckingham, & Payne, 2003).

Individuals with ASD who do not have an ID have a higher likelihood of having a comorbid Psychiatric diagnosis. Simonoff et al. (2008) found that 70% of the children and adolescents in their study (N=112) had at least one comorbid mental health disorder, and 41% had two or more comorbid conditions. The most common comorbid condition was Social Anxiety Disorder (29%), followed by Attention Deficit Hyperactivity Disorder (ADHD; 28%) and Oppositional Defiant Disorder (28%). A recent meta-analysis conducted by van Steensel, Bogels, and Perrin (2011) looking specifically at anxiety found that 40% of individuals with ASD have at least one comorbid anxiety disorder, the most frequent being specific phobia (30%), followed by OCD (17%) and Social Anxiety Disorder (16.6%). A comorbid anxiety disorder can have a complex effect on the behavior and wellbeing of an individual with ASD. One study in youth with ASD and a comorbid anxiety disorder showed increased self-injurious behavior and depressive symptoms at the same time as increased functional communication and ability to

initiate and support a relationship compared to individuals with ASD alone (Kerns et al., 2015).

A study more broadly investigating any comorbid psychiatric disorder in a sample of adults with ASD with and without a comorbid disorder found that adults with a comorbid disorder had higher rates of psychosocial challenges, more dysfunction related to their diagnosis, and more likely to receive counseling and psychopharmacology than those without (Joshi et al., 2012). From this one could infer that the difficulties beginning in childhood in individuals with a comorbid psychiatric diagnosis continue into adulthood.

The relationship between anxiety, ASD, and IQ is complex. One issue is the number of variables involved: ASD symptom severity, IQ level, anxiety level, and social integration. The more severe the ASD symptom severity, the lower the likelihood of an individual having a comorbid anxiety disorder (Eussen et al., 2013). In terms of intelligence, the higher an individual's IQ, the higher the likelihood of a comorbid anxiety disorder (Eussen et al., 2013). The relationship of social integration and anxiety level is less clear, and may depend on the interaction of IQ and symptom severity. Generally, one would think of friendships as a protective factor against anxiety, and they act as such in the general population (Mazurek & Kanne, 2010). However, individuals who are more likely to have friends, i.e. those with higher intelligence and lower ASD symptoms, are the same individuals who are more likely to have high levels of social anxiety (Kuusiko, 2008). It is not clear whether the friendships of these individuals is a protective factor of anxiety, or whether the increased insight into the nature of these friendships and awareness of social norms that individuals with ASD have difficulty conforming to mitigates this protection. On a related note of depression, in individuals with ASD and high IQ is a predictor of low self-perceived social competence, and in turn individuals who had lower self-confidence had higher rates of depression (Vickerstaff et al., 2007).



Employment provides the opportunity for an increased amount of social interactions, and as such it may also increase the likelihood that an individual develop anxiety, especially if that individual has average to above average intelligence. However, the sense of accomplishment and fulfillment stemming from employment may offset these difficulties. In one study, young adults with autism who received social and vocational skills training self-reported a significant reduction in depression and anxiety symptomology (Hillier, Fish, Siegel, Beversdorf, 2011). Measures of peer relationships post-intervention were also improved, although not significantly. Research in the field of comorbid ASD and anxiety in adults is relatively limited, and the way that employment affects individuals in this population is not yet clear. This complex relationship would need to be carefully assessed while an individual is beginning a new job or transitioning from high school into an employment setting.

### **ASD Through the Lifespan**

ASD can be diagnosed as early as 15 months old, but the disorder has lasting effects on the life of individuals with ASD (Kanner, 1971; Rumsey et al., 1985). The diagnosis of ASD appears to be stable throughout childhood (Eaves & Ho, 1996) and into early adolescence (McGovern & Sigman, 2005). However, when looking specifically at certain symptoms of ASD, McGovern and Sigman found that parents saw improvements in the domains of social interactions, repetitive/stereotyped behaviors, adaptive behaviors, and emotional responsiveness to others' distress in adolescence when compared to those same symptoms in middle childhood. A comprehensive review of the literature by Seltzer and colleagues (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004) concluded that there is modest improvement evident in symptom severity from childhood to adolescence to adulthood. Unfortunately, these improvements seldom bring an individual with ASD into functioning within the normal range of behavior.

Moving into adolescence, individuals with ASD are significantly more likely to never see friends outside of school, to never get called by friends, and never to be invited to social activities when compared to adolescents from other groups (Shattuck, Orsmund, Wagner, & Cooper, 2011). Additionally, Orsmund, Krauss, and Seltzer (2004) found that only 8% of adolescents and adults with ASD had at least one age-appropriate and significant friendship, and almost half had no peer relationships within or outside of prearranged settings. They found that the strongest correlate to a lack of peer relationships was impaired social skills.

Adults with ASD have poorer life outcomes than the general population in terms of education, employment, independence, and social life (Billstedt et al., 2005; Henniger & Lounds-Taylor, 2013). In fifteen studies of outcomes for adults with ASD between 1967 and 2011, most of the studies found that very few adults had good outcomes, with the majority having poor outcomes (Henninger & Lounds-Taylor, 2013). Only one study reported that the majority of individuals with ASD in their study had good or very good outcomes, across a variety of definitions of a good outcome. This study defined outcomes in terms of person-environment fit and the existence of an autism-friendly environment (Billstedt, Gillberg, & Gillberg, 2011). This resulted in a comparison of individuals with ASD to each other rather than to typical adults, the latter being the norm for the remainder of the studies. In terms of general life outcome, it has also been demonstrated that individuals with ASD and a comorbid ID diagnosis have consistently worse outcomes than individuals with high functioning ASD (Ebensen, Bishop, Seltzer, Greenberg, & Taylor, 2009; Farley et al., 2009).

### **ASD and Employment**

An area that many individuals with disabilities struggle with after exiting high school is finding successful employment, and individuals with ASD are no exception. The symptoms of

ASD make it difficult to be successful in the typical work setting. A consistent schedule and a well-defined list of tasks are ideal for an individual with ASD, but employers unfamiliar with ASD may not know how to provide these in the work setting (Wehman et al., 2013). Moreover, the social deficits specific to ASD can make holding a job very difficult. These social deficits impair individuals with ASD when it comes to their mastery of soft skills, which are skills that are very important in a working environment but do not deal specifically with the assignments people are hired to complete. Soft skills include oral communication skills and interpersonal and teamwork skills (Duncan & Dunifon, 2012). Individuals with ASD are consistently poor at these types of skills, which can result in an employer becoming annoyed and frustrated with their employee, or a co-worker becoming uncomfortable or offended. These deficits have a tangible effect on employment outcome; Roux and colleagues (Roux et al., 2013) found that greater conversational impairment in young adults with ASD is associated with lower odds of having a paid job.

Individuals with ASD have worse employment outcomes than the general population, and poor outcomes when compared to most other disability groups. Using data from the National Longitudinal Transition Study-2 (NLTS-2), Roux et al. (2013) found that only 53% of young adults with ASD have had at least one job since high school. This is worse than the 62% of individuals with ID who have had at least one job, and the more than 80% of individuals with Learning Disabilities (LD), Emotional Disturbance (ED), or SLI who have held at least one job since high school. This figure is in fact optimistically misleading; the percentage of individuals with ASD that were employed at the time of the study was only 33%. Even when employed, young adults with ASD are less likely to work full time, have held fewer jobs, and earn less per hour in these jobs than individuals with LD, ED, and SLI (Roux et al., 2013).

Problems with employment may stem from difficulty transitioning out of high school and into post-secondary education or employment. Compared to adolescents with other disabilities, individuals with ASD were less likely to attend Individualized Education Program (IEP) meetings for transition planning, and when they did attend they were less likely to take an active role in planning that transition, or to provide any input at all (Shogren & Plotner, 2012). The same study found that a much lower percentage of individuals with ASD have the goal of achieving competitive employment following graduation compared to individuals with ID. Many individuals with ASD may have a goal of attending a 2-4 year college. When they do not end up attending any post-secondary institution, they find themselves in an especially difficult position when it comes to attaining employment. This is because they are likely to be on a high school curriculum that focuses more on academics and preparing students for college than on activities and internship opportunities designed to prepare students for the competitive work environment.

The time directly following exit of high school is especially difficult for individuals with ASD in relation to employment. One study of 66 young adults with ASD who had recently exited high school found that 56% of those individuals were employed in adult-day programs and only 18% were employed either competitively or with supported employment. Of the remainder, 13% attend a post-secondary institution and 12% were involved in no activities at all (Taylor & Seltzer, 2011). This should be interpreted within the context of the small sample size. However, a larger scale study (n=680) found that in six years following high school, only 55% of individuals with ASD had been involved in any kind of paid employment, while 35% of individuals had attended a post-secondary institution (Shattuck et al., 2012). Out of those who had left high school in the past two years, more than 50% had no participation in either employment or education. There seems to be improvement as time passes from high school exit;

the odds of participating in college, paid work, or both were significantly higher for those who had been out of high school for four or more years than the odds of participation for individuals who had been out of high school for less than three years (Shattuck et al., 2012).

This improvement over time does appear to have limits. In a longitudinal study of vocation, Taylor and Mailick (2013) found that only 25% of adults showed any improvement in vocational activities over a 10 year period. Only 5% had substantial changes, and 13% had declines in their vocational activities. This can be compared to the well-established pattern of typical adults improving their occupational positions as they grow older (Mare, Winship, & Kubitschek, 1984). Though many adults with disabilities have difficulties finding a job, the current Vocational Rehabilitation (VR) system is particularly unsuited for adults with ASD. Adults with ASD are more likely to be denied services than those with other disabilities, because in many cases the disorder is considered too severe to result in successful case closure (Lawer, Brusilovskiy, Salzer, & Mandell, 2009). Surprisingly, the same study found that adults with ASD, along with adults with ID, are the most likely groups to have competitive employment at time of case closure. However, they are likely to work fewer hours and earn lower wages than other groups served by VR (Cimera & Cowan, 2009).

In summation, adults with ASD are frequently denied services because of the perceived severity of the disorder. When they are entered into the service system, they find employment at comparable rates to individuals with ID, but earn less and work less than other groups at the time of case closure. While it is promising that adults with ASD are able to find employment through VR, it appears they are being underserved by the system in terms of finding the best possible employment opportunity. Hendricks (2009) determined that the current VR system is inadequate for adults with ASD, and many more adults with ASD want to work and enter the work system

than are currently employed. Hendricks also discussed strategies being implemented by successful programs, including job placement, supervisor and co-worker training, on-the-job training, work place modifications, and long-term support. Using these strategies, finding consistent employment is possible. For example, after serving over 100 clients with ASD, the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) supported employment program found their clients had a job retention rate of 89%, with these individuals working an average of 28.6 hours a week (Keel, Mesibov, & Woods, 1997). Another successful program, NAS Prospects, found that 68% of clients found employment during an 8 year period (Howlin, Alcock, & Burkin 2005). These programs demonstrate that while our current system is under serving adults with ASD looking for employment, there are successful models available.

### **The Present Study**

The TEACCH Autism Program was founded in North Carolina in 1971, and since then thousands of individuals with ASD in North Carolina have been diagnosed or treated at one of the TEACCH centers. Diagnostic information on these individuals has been saved, resulting in more than 7,000 records of individuals and their diagnostic information between the years 1967 and 2000. The goal of this study is to examine the relationships between childhood and adult ASD characteristics and employment outcomes.

The purpose of this study is to investigate whether employment is related to better social and communication skills in adults with ASD. In other populations, such as those with Severe Mental Illness, employment has been shown to increase social functioning in all aspects of life (Burns et al., 2008). This is significant because the social deficits experienced by those with ASD and those with schizophrenia are in many ways comparable (Sasson et al., 2007). A work

environment gives adults with ASD a chance to interact with others, which may be very important to maintaining and improving social interaction and social communication. If employment is related to social interaction and communication, then employment may replace or augment specific social interventions for adults, and more effort should be directed towards successfully integrating adults with ASD into the workforce.

*Hypotheses:*

1. Individuals with ASD who have been employed since high school will have better scores on measures of ASD symptoms, especially ASD social symptoms, than individuals who have never been employed.
2. Length of time spent employed and independence in employment will have a positive relation to the severity of ASD symptoms and characteristics.
3. Childhood measures of symptom severity will be related to employment history as an adult.
4. Employment may negatively impact mental health symptoms of depression and anxiety.

## **CHAPTER 2: METHODOLOGY**

### **Participants**

Participants were 97 men and women seen and diagnosed by the TEACCH Autism Program between 1965 and 2000, who are currently between the ages of 20 and 64. A statistical power analysis determined that with 97 participants the study has 87% power to detect a correlation of  $r = .3$  with an  $\alpha = .05$ . TEACCH has seven regional centers in North Carolina, and any individual who is an adult and has been seen at one of these sites and received an ASD diagnosis during childhood was eligible to participate in the study.

Several recruitment methods were used. Efforts were made to recruit individuals from the longest standing TEACCH centers of Chapel Hill, Asheville, and Wilmington. This was done for several reasons. First, because these were the oldest centers individuals recruited from these centers were likely to be older, and one aim of this study was to sample an older population than existing studies in the literature. Second, these individuals were likely to have multiple childhood assessments completed, giving more data points for childhood assessments. Third, these three centers span the state of North Carolina, and moreover, when there were fewer centers families tended to travel further from home for services. Thus, these three centers should be able to provide a representative sample of the entire state. While the earliest three centers were the recruitment target, individuals seen at the other TEACCH centers were also recruited.

In order to recruit these individuals, several steps were taken. First, information about the individuals with ASD was collected from a database of forms containing a brief summary of assessments completed during childhood. Second, information regarding the names and



addresses of the parents of these individuals with ASD were retrieved from a more complete clinical records database. Third, the addresses and phone numbers found in the clinical records were verified using Intelius software, and a recruitment letter was sent to the most current address available. Finally, if the parents did not call in regard to the letter they received they were called by the research team to follow up on the recruitment letter.

Secondary to the above method of participant recruitment, several other forms of recruitment were utilized. Information about the study was posted both on the TEACCH website and printed in quarterly newsletters. Recruitment flyers were distributed to each of the regional TEACCH centers, to be displayed at those offices. Emails with information regarding the study were distributed to the directors of the regional centers, and then distributed to their respective listservs in order to spread awareness of the study. In addition, members of the research team spoke during support groups for parents of adults with ASD in order to give information and flyers to interested and eligible participants. Finally, flyers were sent to the Autism Society of North Carolina (ASNC) to be distributed to their clients. Individuals responding from ASNC recruitment were screened to ensure they met criteria to participate in the study.

## **Measures**

**TEACCH Autism in Adulthood Survey.** This survey was designed to get information about the current lifestyle of adults with ASD. The total survey was 87 questions, and 12 of these specifically asked about employment and employment history such as: number of jobs held, length of time worked at jobs, number of hours worked, wages, supports received on the job, supports present in the community that facilitate getting a job, and whether these supports were sought after or used. This survey also collected information about the demographics of the participants. A copy of the electronic version of this survey is included as Appendix 4.

**Social Responsiveness Scale-2 (SRS-2; Constantino, 2012).** The SRS-2 is a 65-item measure that is designed to capture the severity of social communication symptoms in ASD over five domains: social awareness, social information processing, capacity for reciprocal social responses, social anxiety/avoidance, and characteristic autism preoccupation rates. It has strong psychometric properties across all four versions of the survey: preschool (2-4 years), school-age (4-18 years), adult (19 years and older) and adult self-report. Alpha internal consistency values across all forms fall in the range of .92 to .95. The interrater agreement of the adult measures is  $r = .88$  for mothers,  $r = .87$  for fathers,  $r = .86$  for a relative,  $r = .86$  for others (e.g. a friend) and  $r = .66$  for self-report. This measure was included with the survey packet distributed to caregivers, and this study used the adult version of the measure.

**Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013).** The W-ADL is a free scale designed for use with individuals with a Developmental Disability as a measure of the level of independence in a number of activities of daily living. It is designed to be completed by a caregiver of an individual or someone who knows the individual well. It has been validated in studies involving individuals with Down Syndrome ( $n = 169$ ), Fragile X Syndrome ( $n = 147$ ), ASD ( $n = 406$ ), and ID ( $n = 292$ ). The W-ADL has an alpha internal consistency coefficient of .88-.92, and is reliable over time and between respondents. This measure was included with the survey packet distributed to caregivers.

**Anxiety, Depression, and Mood Scale (ADAMS; Esbensen, Rojahn, Aman, & Ruedrich, 2003).** The ADAMS is a 28 item scale designed to measure the level of 5 subscales related to anxiety, depression, and mood in individuals with ID. These subscales include manic/hyperactive behavior, depressed mood, social avoidance, general anxiety, and compulsory behavior. The ADAMS has an alpha internal consistency coefficient ranging from .75 to .83 on

the 5 subscales, with a mean of .80. The ADAMS has an interrater reliability of .50, which is fair, and a test-retest correlation of .78 (average of subscale scores). This measure was included with the survey packet distributed to caregivers.

**Quality of Life Questionnaire (QOL-Q; Schalock & Keith, 1993).** The QOL-Q was developed to assess the quality of life of individuals with an Intellectual Disability. It is intended for both self-report and caregiver or staff report. The QOL-Q has several subscales: satisfaction, competence/productivity, empowerment/independence, and social belonging/community integration. The alpha reliability coefficients of the subscales range from .66-.83, with a total alpha reliability coefficient of .83. This measure was included with the survey packet distributed to caregivers.

**Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis & Daly, 1980).** The CARS is an autism diagnostic tool made up of 15 scales, all rated from 1 to 4; 4 meaning that for that particular rating the individual acted in a way that is most stereotypical of ASD. These scales capture what the authors believe to be the major domains of ASD, including verbal communication, nonverbal communication, and impairment in human relationships. This scale is designed to be answered by a clinician after a complete diagnostic assessment of child or adult. The CARS has strong psychometric properties when tested over 537 children; the alpha internal consistency coefficient is .94, and the average interrater reliability is  $r = .71$ . CARS scores from the first assessment in childhood was used for the adults in this study.

**Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla & Cicchetti, 1984).** The VABS was designed to assess the level of adaptive behavior functioning in children with a developmental disability. Since its original publication as the Vineland Social Maturity Scale, it has seen two revisions: the VABS (1984) and the Vineland-II (2005). The childhood assessments

of the individuals in the current study include either the Vineland Social Maturity Scale or the VABS. Both assessments have been validated in multiple populations and have strong psychometric properties. Vineland score from the first assessment in childhood was used for the adults in this study.

## **Procedure**

This study was part of a larger study that included a number of other measures. These surveys were completed by caregivers of adults with ASD. Surveys were completed either electronically (n = 71) or as a paper survey (n = 26) mailed to each participant. The electronic version of the survey was presented by Qualtrics survey software and was distributed to participants by an email that contained a unique link to the survey that was linked to the participant's ID number. Completed surveys were automatically saved on the Qualtrics server. The paper and pencil version of the survey was distributed by mail, and each packet included a postage-paid envelope for returning the completed surveys. Most participants completed the surveys within two weeks of receiving them. If the surveys were not completed or returned in that time a follow-up was done by phone call. Participants who returned incomplete surveys or whose surveys contained unclear answers were also followed up by a phone call to ensure accurate and complete data collection. The entire packet of surveys generally took between 1 and 2 hours to complete, and participants received \$20 for taking part in this study.

### **CHAPTER 3: RESULTS**

Analyses were conducted on a final sample of 97 adults with ASD with an average age of 33.8 years. Demographics of the study can be found on Table 1. About 81% of adults were male. Of the sample, 83% identified as White, 15% as African-American, 2% as Asian, and 1% as American Indian; ethnically, 2% of the sample identified as Hispanic. The surveys were completed by individuals with a number of relationships to the adult with ASD: 69% were completed by the mother of the individual with ASD, 23% by the father, 1% by a sibling, 1% by a legal guardian, and 6% by a person with another relationship. Comorbid diagnoses were reported: 56% reported a diagnosis of an Intellectual Disability – of those who identified the severity, 38% had a mild ID, 38% had a moderate ID, and 25% had a severe/profound ID. In comorbid psychiatric diagnoses, 27% reported an anxiety disorder, 11% reported depression, and 4% reported bipolar disorder. It is important to note that there was no process of validation for reported diagnoses of ID and psychiatric diagnoses, nor any indication whether these diagnoses were current or past. While analyses were conducted using these responses as variables, those analyses should be interpreted with caution.

Employment rates in the sample were as follows: 44% of adults were employed at the time of the study, 20% had been employed at least once since high school but were not currently employed, and 37% had never been employed. Of those who were employed at the time of the study (44%), 29% were employed competitively or in supported employment programs, and 13% were employed in adult day programs (see Figure 1). Two percent of adults were enrolled in college at the time of the study, 27% volunteered with no other vocational activities, and 27%

participated in no vocational, educational, or volunteer activities. Sample means for other measures analyzed in this study can be found on Table 2.

### **Employment and ASD Characteristics**

First, the relation of employment to ASD characteristics was examined. The ASD characteristics discussed in this and the following sections include childhood and adulthood measures of ASD symptom severity, intellectual functioning, and activities of daily living skills. Symptom severity in adulthood was measured by SCI and RRB scales of the SRS-2, and childhood symptom severity was measured by CARS scores. Intellectual functioning was measured using current conversational ability as a proxy for adult level of intelligence, and childhood IQ. Activities of daily living skills were measured using adult W-ADL scores and childhood Vineland scores.

To investigate the relationship between employment and ASD characteristics, first an ANOVA was conducted using the variables of being currently employed, being previously employed but not currently employed, and never being employed as the independent variable on these ASD related characteristics. These results can be found on Table 3. Looking at symptom severity, the SCI and RRB scales of the SRS-2 were not significantly related to employment status. However, the childhood CARS score showed a negative relation to employment status ( $F(2,83) = 4.76, p < .05$ ). Individuals who were currently or previously employed did not differ significantly in childhood CARS scores from one another, but both groups differed significantly from individuals who had never been employed. That is, individuals whose score on the CARS in childhood reflected more severe ASD symptoms were less likely to be ever be employed as adults.

In the domain of intellectual functioning, both current conversational ability ( $F(2,93) = 14.0, p < .001$ ) and childhood IQ ( $F(2,63) = 5.39, p < .01$ ) were positively related to employment status. Using Tukey's post-hoc comparisons on the variable of conversational ability, individuals who were currently or previously employed did not differ significantly from one another, but both groups did differ significantly from individuals who had never been employed. The same relationship holds true for childhood IQ score. In intellectual ability, individuals who are currently employed or have been employed previously look quite similar to one another both in childhood and as adults, but different from individuals who have never been employed.

In measures of daily living skills, both W-ADL ( $F(2,93) = 29.9, p < .001$ ) and childhood Vineland ( $F(2,60) = 5.83, p < .01$ ) were positively related to employment status. Using a Tukey's post-hoc comparison on the variable of W-ADL, individuals who were currently, previously, or never employed all differed significantly from one another, with those currently employed scoring highest on the measure. On the childhood Vineland scores, individuals who were currently employed scored significantly higher than individuals who had never been employed. Individuals who had been employed previously but were currently unemployed did not differ significantly from those who were currently employed or those who were unemployed. In both intellectual ability and activities of daily living, current level of functioning (conversational ability and W-ADL) were more strongly related to employment history than childhood measures (childhood IQ and childhood Vineland).

Next the relation of ASD characteristics to several continuous measures of employment was examined. These employment variables included the Vocational Index, length of time the longest-held job was kept (referred to as length of employment), and hours worked per week. The Vocational Index, developed by Seltzer and Taylor (2012), was used to add precision to the

measure of employment. Using the Vocational Index, the employment status of individuals was ranked based on several factors including independence in employment setting, hours worked per week, post-secondary activities, and volunteering and other activities. Scores range from 1 meaning no employment, volunteering, or postsecondary activities to 9 meaning either employment or post-secondary degree-seeking activities in the community without supports for 10 or more hours per week. The full Vocational Index scoring matrix is included as Appendix 3. Hours worked per week was only available for those who had been employed at some point, so these analyses were conducted on a subset of participants for this variable.

The results of these correlation analyses can be found in Table 4. On measures of symptom severity, the RRB scale of the SRS-2 was not correlated with any of the employment variables. The SCI scale was negatively correlated with a medium effect size to the Vocational Index ( $r(91) = -.30, p < .01$ ). That is, those with more severe social symptoms had less independence in vocational activities, or individuals who were less independent in vocational activities had more severe social symptoms. Length of time employed or hours worked per week was not related to these social symptoms. Childhood CARS score was negatively correlated with a medium effect size to the Vocational Index ( $r(84) = -.31, p < .01$ ) and length of time employed ( $r(85) = -.26, p < .01$ ) but not hours worked per week. Individuals who scored higher on the CARS, indicating higher levels of symptom severity, were less independently employed and had held a job for a shorter length of time. Severity of ASD symptoms as measured by childhood CARS was not related hours worked per week.

Our proxy measure of intellectual functioning in adulthood, conversational ability, was strongly correlated with a medium to large effect size with both Vocational Index ( $r(94) = +.45, p < .001$ ) and length of time employed ( $r(95) = +.39, p < .001$ ), but not hours worked per week.



Childhood IQ score was also strongly correlated with a medium effect size to Vocational Index ( $r(78) = +.39, p < .001$ ) and length of time employed ( $r(79) = +.35, p < .01$ ), but not hours worked per week. A higher level of intellectual functioning in both childhood and adulthood was related to more independence in employment and longer employment, but as with measures of symptom severity, intellectual functioning was not related to hours worked per week.

The adulthood measure of daily living skills, the W-ADL, was positively correlated with a large effect size to Vocational Index ( $r(92) = +.66, p < .001$ ) and length of time employed ( $r(93) = +.69, p < .001$ ), and with a medium effect size with hours worked per week ( $r(57) = +.38, p < .01$ ). Adults who were more independent in activities of daily living were more likely to score well on all measures of employment. Alternately, individuals who scored well on measures of employment were more likely to have higher levels of independence in activities of daily living skills. Childhood Vineland was positively correlated with a large effect size to Vocational Index ( $r(61) = +.50, p < .001$ ) and with a medium effect size to length of time employed ( $r(61) = +.41, p < .05$ ) but not the hours worked per week. Out of all measures of symptom severity, the only variable that was related to hours worked per week was level of independence in activities of daily living skills.

### **Employment and Quality of Life Outcomes**

The second set of analyses related employment to several quality of life measures. The measures used for these outcomes were the QOL-Q, the ADAM Depression Scale (ADAMS-D), the ADAMS Anxiety Scale (ADAMS-A), and frequency of social contacts with friends. First, an ANOVA was conducted using the employment status variable of currently employed, previously employed but currently unemployed, and never employed as independent variables on quality of life outcomes. The results of these analyses can be found in Table 5. Frequency of contact by

friends was first examined. This variable was examined using a question from the Autism in Adulthood survey asking how often the adult with ASD had been called or texted by friends in the past 12 months. The response options ranged from 1 meaning never to 7 meaning daily. The full question and response options can be found in the Autism in Adulthood survey in Appendix 4.

This measure of contact with friends was related to employment history ( $F(2, 93) = 6.64, p < .01$ ). Those who were currently employed had significantly more contact with friends (Mean = 3.3, between Once a Month and 2-3 Times per Month) than those never employed (Mean = 1.6, between Never and Less than Once a Month), with those who were previously employed falling in the middle (Mean = 2.4, between Less than Once a Month and Once a Month).

No relationship was found with the ADAMS-Anxiety with all three groups showing similar current anxiety levels. However, ADAMS-Depression was related to employment status ( $F(2,90) = 7.63, p < .01$ ). On the ADAMS-D, the mean score of individuals who were previously employed but currently not employed was significantly higher than both individuals who were currently employed ( $t(57) = 3.70, p < .001$ ) and individuals who had never been employed ( $t(51) = 2.22, p < .05$ ). This is an interesting pattern that seems to suggest that previously but not currently being employed is linked to greater depression in these adults with ASD. Finally, the relation of employment status to QOL-Q was examined. Employment status was strongly related to QOL-Q, ( $F(2, 89) = 33.9, p < .001$ ). Individuals who were currently employed scored significantly higher on this measure than individuals who had been previously employed and individuals who had never been employed. Individuals who were currently unemployed, whether or not they had been employed previously, had similar scores on the QOL-Q. Of the quality of

life measures here discussed, the QOL-Q shows the most drastic difference between individuals who are currently employed from those who are not.

Next, the relation of the same continuous employment variables (Vocational Index, length of time employed, and hours worked per week) and quality of life outcomes was examined. Results of these analyses are found in Table 6. First, frequency of contacts from friends was correlated with a large effect size with Vocational Index ( $r(93) = +.52, p < .001$ ) and with a medium effect size to length of time employed ( $r(95) = +.29, p < .01$ ), but was not correlated with hours worked per week. In other words, individuals who were more independently employed, and had worked for a longer period of time at one job, received more phone calls and texts from friends. Or, individuals who received more contact from friends were likely to be employed more independently and for greater lengths of time. The ADAMS-Depression scale was negatively correlated with a medium effect size with both the Vocational Index ( $r(91) = -.22, p < .05$ ) and hours worked per week ( $r(56) = -.34, p < .01$ ), but was not related to length of employment. Individuals who were more independently employed and working more hours during the week indicated a lower level of depressive symptoms. The ADAMS-Anxiety scale was only correlated with hour worked per week ( $r(57) = -.27, p < .05$ ), meaning that individuals who were working more hours per week indicated a lower level of anxiety symptoms.

Finally, the QOL-Q was positively correlated with a large effect size with Vocational Index ( $r(91) = +.67, p < .001$ ) and length of time employed ( $r(91) = +.55, p < .001$ ), but not to hours worked per week. Over all the quality of life variables, individuals with a higher frequency of social contacts and higher score on the QOL-Q measure were more independently employed and had held employment for a longer period of time. The mood variables of depression and

anxiety were less related to independence and length of employment, but highly related to the number of hours an individual was working each week.

## **CHAPTER 4: DISCUSSION**

This sample of 97 adults with ASD appears to be a good representation of the population of adults with ASD eligible for this study. Eighty-one percent of participants were male, consistent with current rates of diagnosis of ASD (CDC, 2014). The rate of co-occurring ID in this study (56%) is close to what one would expect to find in an older sample of adults with ASD. At the time many of these adults were diagnosed, the rate of co-occurring ID was estimated to be between 60-70% (Fombonne, 2003). The rate of reported anxiety disorders in this sample (27%) is slightly lower than found in a meta-analysis by van Steensel, Bogen, and Perrin (2011; 40%). However, the oldest mean age in the studies they sampled was 16.8, suggesting that the age difference could be a contributing factor to the differing rates of an anxiety disorder.

Employment rates in this study were similar to those found in other studies. Sixty-four percent of adults in this study had been employed at some time since high school, which is comparable to the 55% of adults employed in the six years following high school found by Shattuck et. al (2012). Shattuck et al. found that employment rates improved as time following high school exit increased, and the findings of this study are consistent with that finding continuing into adulthood. The adults with ASD in this study were older, and have had more time since high school to attain employment. Nevertheless, there were substantial employment challenges for the adults with ASD in this study. Only 44% of adults were currently employed, and of those who were employed most were employed between 10 and 29 hours per week with only 6% employed full time. Using the measure of the Vocational Index, only 10% of

individuals scored a nine, indicating they were competitively employed without any supports for 10 or more hours per week. Almost half of individuals (47%) who had ever been employed had never been employed for more than 2 years. Only 29% of individuals employed earned higher than minimum wage, while 44% earned minimum wage and the remainder earned less than minimum wage. In a sample with a mean age of 34, these employment results demonstrate a need for continued improvement of the service system currently in place for adults with ASD, both in assisting adults in securing employment and providing continued support after a job is secured.

The results relating ASD characteristics to employment are important for describing who within the ASD population is most likely to be employed. As predicted in the first hypothesis, employment was related to a variety of these ASD related characteristics including ASD symptom severity, intellectual functioning, and adaptive functioning. On the adult measure of symptom severity, the SRS-2, the SCI subscale was correlated with the Vocational Index while the RRB subscale was not correlated with any employment variables. Symptom severity in childhood as measured by the CARS was negatively correlated with both Vocational Index and length of employment. When looking at the results of the ANOVA as employment status relates to measures of ASD symptom severity, the childhood CARS score of those who were currently employed and currently unemployed but previously employed were not significantly different from each other, but were both significantly different than scores on those measures of individuals who had never been employed. This suggests that either CARS score can be a moderate predictor of future employment variables, or there is a third variable accounting for the difference in these scores. This also suggests that these groups of individuals have similar abilities at least in childhood, but those who are currently employed may receive more support in

their employment that helps them to keep their jobs. This is an important group difference, especially since individuals who were currently employed score significantly higher on the QOL-Q than individuals who have been employed previously but were currently unemployed.

In the measures of intellectual functioning, current conversational ability was correlated with both Vocational Index and length of time employed. Childhood IQ scores had similar effect sizes with Vocational Index and length of employment. It is important to note that while childhood IQ could have an effect on employment variables in adulthood, it is very unlikely that employment would affect the level of intellectual functioning of an adult. Looking at the results of the ANOVA of employment status and intellectual functioning, both childhood and adult intellectual functioning is similar in groups of adults who are currently or formerly employed, while both these groups are significantly different in intellectual functioning than individuals who have never achieved employment. This is a similar finding to ASD symptom severity and its relationship to employment status.

In measures of activities of daily living, current W-ADL score was positively correlated with Vocational Index, length of time employed, and hours worked per week. Notably, level of independence in daily living skills in adulthood is the only measure of ASD characteristics correlated to number of hours worked per week. Childhood Vineland was correlated both with Vocational Index and length of time employed. Looking at an ANOVA of activities of daily living and employment status, a slightly different pattern emerges than in symptom severity and intellectual functioning. Adults who are currently, formerly, or never employed all score significantly differently on the W-ADL. Looking at childhood Vineland scores, individuals who are currently employed score higher than individuals who have never been employed, with individuals who have been employed previously fall in the middle.

The variation in adulthood activities of daily living skills would seem to suggest that of the adulthood measures, these skills are most sensitive to the impact of employment. It is not surprising that individuals who are currently employed are most independent in these skills. In order to go to work and hold a job, an individual must show up clean and well groomed every day, and be self-sufficient in all areas of work including during breaks and meal times. After losing a job, it is no longer necessary for an individual to use these skills daily, and they may no longer be maintained to the same degree as if they were currently employed. On the other hand, it could be that individuals who have been previously employed had enough independence in daily living skills to gain employment, but these skills were still impaired to a degree that interfered with the ability to maintain their employment. Whichever direction the relationship is, employment appears to give individuals a chance to improve and maintain daily living skills. These skills are already observed to be improving throughout adolescence while attending high school, and an employment setting gives an individual another opportunity to utilize and practice these skills.

Daily living skills ability in adulthood is more highly correlated with measures of employment than childhood. This may suggest that low levels of daily living skills as children does not mean that an individual is fated to be unemployed as an adult. If interventions are utilized that improve these skills in children with ASD, the chance that these individuals become employed in the future may be increased. This raises the issue of the importance of integrating daily living skills into the treatment of young people with ASD in order to increase likelihood of employment in the future, as well as support in maintaining and increasing those skills after they have attained employment.



Addressing the second hypothesis, it is seen that ASD characteristics in adulthood are indeed correlated with the Vocational Index and length of time employed. Unfortunately, it is impossible to know the directionality of these correlation relationships. Individuals who are less impaired in these categories of ASD characteristics may be more likely to find and keep employment, or individuals who find employment may be higher functioning in these measures due to daily practice and application of those skills. This is less true for intellectual functioning, which as mentioned previously is not likely to be impacted by employment. In adulthood, daily living skills were the most strongly correlated with employment variables, followed by intellectual functioning and lastly social deficits. This gives focus to areas of intervention in adults with ASD. Adulthood IQ is relatively stable, and restrictive and repetitive behaviors are not related to employment variables. As a result, programs that prepare adults with ASD for employment should focus on social skills and level of independence in daily living skills. At the same time, gaining employment provides an individual with the opportunity to improve and become increasingly independent in social skills and activities of daily living throughout adulthood.

Addressing the third hypothesis, childhood ASD characteristics are related to employment outcomes in adulthood. Of these childhood measures, the Vineland was most strongly correlated with measures of employment in adulthood. Adaptive behavior scores tend to increase through childhood and adolescence. This is an encouraging finding in that it means that the childhood measure most strongly correlated with employment in adulthood also measures a skill set that is subject to improvement as individuals grow older.

In quality of life outcomes, Vocational Index score and the length of time a job has been held were both very strongly positively correlated with the QOL-Q and the number of social

contacts an individual with ASD receives. Importantly, the QOL-Q and frequency of social contacts were not related to the hour worked per week. This suggests quite strongly that it is not necessary for an individual with ASD to be working 40 hours each week in order to experience the positive impact of employment on their quality of life. The fact that an individual with ASD has a job, has independence in that job, and has held that job for some length of time are far more important than how many hours a week an individual works.

Looking at the fourth hypothesis, the results of the data analyses show a different pattern than was predicted. Individuals in this study who were more independently employed did not have higher anxiety than those who scored lower on the Vocational Index, both as measured by symptom severity (ADAMS-A) and presence of an anxiety diagnosis. Because of the concerns discussed previously about the possibility of employment as a stressor increasing anxiety in individuals with ASD, this is an important result. If this conclusion holds true, it indicates that improving the employment status of adults with ASD likely will not increase anxiety. This could be the result of offsetting effects: successful employment gives adults with ASD more social practice and life experiences, while at the same time introducing them to more social situations that could be anxiety-provoking. In addition to no significant changes in anxiety, higher scores on the vocational index were correlated with lower depression scores on the ADAMS, consistent with the results found by Hillier et al. (2011) in their younger sample. Once again, it is impossible to determine the directionality of these relationships, but these results suggest employment may be a protective factor against some of the symptoms of depression, while at the same time employment is not a risk factor for increased anxiety. In short, employment may relate to improvements in mental health in adulthood rather than being detrimental. This is important

because it suggests that helping individuals with ASD achieve employment could be a successful intervention to prevent mental health difficulties.

One result that supports this finding is that levels of depression on the ADAMS-D were highest among individuals who have been previously employed but were currently unemployed, significantly higher than both individuals who are currently employed and those who have never been employed. This result is consistent with the notion that individuals with ASD who lose their jobs may be at the highest risk for experiencing depression symptoms. It would appear that the benefits of attaining and holding employment are lost when an individual with ASD loses a job. This underscores the importance of ongoing vocational support for adults with ASD who have attained employment.

### **Limitations and Future Directions**

There are several limitations of this study. First, there was not an accurate measure of current intellectual ability, only a self-reported diagnosis of intellectual disability and a proxy of current intellectual functioning using conversational ability. This makes it difficult to ascertain exactly how much intellectual functioning may underlie the effects reported here. Second, while this study has the advantage of access to assessments during childhood, the single time point in adulthood does not allow for determination of the direction of the relationship between employment and social skills. For example, employment could improve social skills, or better social skills could make it more likely that an individual attains employment. Longitudinal data collection in adulthood would help resolve these issues of directionality.

Third, there was not a full assessment of anxiety or depression included in the survey, only the brief screening scales of the ADAMS. In order to determine more accurately the level of internalizing symptoms experienced by adults with ASD, a more complete mental health

assessment may be needed. Fourth, when asking about diagnosis of other developmental and psychiatric disorders, the survey asked if the individual with ASD had ever been diagnosed with each disorder or disability, rather than if the individual with ASD was currently diagnosed with each disorder or disability. For example, an adult with ASD may have had depression in early adulthood, but has received treatment and no longer experiences any symptoms of depression. This study does not have the power to discriminate between this individual and an individual who has a current diagnosis of depression.

Future directions should include a study that measures the social skills of individuals before they attain employment and after they have been employed for some amount of time to test whether employment directly improves social skills. Additionally, a study that teases apart the importance of social skills and adaptive behaviors at the workplace would be an important indicator of how to coordinate services to be more effective for the individuals with ASD.

### **Implications of Research**

The goal of this study was to investigate the relationship between social deficits of ASD and success in a number of aspects of employment. The findings indicated that social ability was indeed related to aspects of employment. Additionally, the repetitive behaviors and restricted interests of individuals with ASD had no relationship to employment variables, suggesting that the symptoms of ASD that are important to employment are the social aspects of the disorder, not the repetitive behaviors and restricted interests. Another important finding was the impact of adaptive behaviors on employment. This relationship was seen both in childhood Vineland scores and in adulthood with the W-ADL measure. This gives clinicians two concrete areas to focus on in preparing individuals for success in employment – social skills and independence in daily living skills.

Employment was strongly related to quality of life outcomes, including mental health outcomes, and this relationship was stronger the longer an individual held a job and the more independently they worked. Importantly, the number of hours worked per week was not related to these outcomes. This underscores the importance of providing ongoing support so that adults with ASD can maintain employment and become increasingly independent in their work role, even if the job is part time for only a few hours per week. Another finding that calls for ongoing support in retaining employment is that individuals who look similar in other characteristics of ASD look different in quality of life measures based on being currently employed, with individuals who are currently employed reporting a higher quality of life. The positive effects of having employment on many other aspects of life seem to hold true for individuals with any combination of the characteristics of ASD. As more and more adolescents with ASD become adults, emphasis should be placed on working for a smooth transition into employment during the critical period following high school exit, and then providing ongoing support in maintaining employment status by building social skills and increasing independence in daily living skills.

## APPENDIX 1: TABLES OF DATA FINDINGS

Table 1

### *Study Participant Descriptives*

Demographics (%)	
Male	81%
Caucasian	83
African American	15
Asian	2
American Indian	1
Hispanic	2
Comorbid Diagnoses* (%)	
Intellectual Disability	56%
Learning Disability	16
Anxiety Disorder	27
Depression	11
Bipolar Disorder	4
Mean Age (SD)	33.8 (8.2)

*Note.* \* Reported by caregivers to have ever been diagnosed with...

Table 2

*Sample Means and Standard Deviations*

	Mean	Standard Deviation	N
<u>ASD Characteristics</u>			
SRS	62.5	23.4	94
SRS-SCI	52.6	18.3	94
SRS-RRB	9.8	6.2	96
Childhood CARS	34.0	6.7	87
<u>Intellectual ability</u>			
Conversational Ability	3.7	1.0	97
Childhood IQ	62.5	25.4	79
<u>Daily Living Skills</u>			
W-ADL	21.8	7.0	95
Childhood Vineland	52.8	18.7	64
<u>Quality of Life Outcomes</u>			
Frequency of Social Contacts	2.5	2.2	97
ADAMS-D	2.8	3.4	94
ADAMS-A	4.9	4.1	94
QOL-Q	77.6	14.0	93
<u>Employment Variables</u>			
Vocational Index	3.8	2.9	96
Length of Employment – longest held job	3.2	1.5	60
Hours worked per week	3.4	1.6	60

*Note.* Mean length of employment between 1-2 and 3-5 years, mean hours worked per week between 10-19 and 20-29 hours.

Table 3

*Impact of Employment at Any Time – Means and ANOVA with Tukey's Post-hoc*

	Employment Status			F	P
	Currently Employed	Previously employed, currently unemployed	Never employed		
<u>Symptom Severity</u>					
SRS-SCI	48.9 (18.9)	52.4 (13.0)	58.1 (19.2)	$F(2,92) = 2.43$	.09
SRS-RRB	9.3 (6.4)	9.1 (5.3)	11.3 (6.1)	$F(2,94) = 1.23$	.30
CARS	32.8a (7.3)	31.5a (5.1)	36.7b (5.8)	$F(2,83) = 4.76$	.01
<u>Intellectual Functioning</u>					
Conversational Ability	2.7a (1.0)	2.6a (1.0)	1.7b (.7)	$F(2,93) = 14.0$	< .001
Childhood IQ	69.5a (22.1)	74.5a (34.0)	50.7b (25.2)	$F(2,75) = 7.03$	.002
<u>Daily Living Skills</u>					
W-ADL	26.2a (4.9)	22.3b (6.2)	16.3c (5.8)	$F(2,93) = 29.9$	< .001
Childhood Vineland	61.7a (20.4)	53.3ab (12.0)	45.5b (15.2)	$F(2,60) = 5.80$	.005

*Note.* Standard Deviations are in parenthesis below the mean. Significantly different means are demarcated by an a, b, and c.



Table 4

*Pearson's Correlations between Employment and ASD Characteristics*

	Employment Status		
	Vocational Index	Length of Time Employed	Hours worked per week at current job
<u>Symptom Severity</u>			
SRS SCI	-.30** N = 93	-.19 N = 94	-.16 N = 60
SRS RRB	-.15 N = 95	-.11 N = 96	-.21 N = 60
Childhood CARS Score	-.31** N = 86	-.26** N = 87	+.03 N = 52
<u>Intellectual Functioning</u>			
Conversational Ability	+.45*** N = 96	+.39*** N = 97	-.03 N = 60
Childhood IQ	+.39*** N = 78	+.35** N = 79	.00 N = 47
<u>Daily Living Skills</u>			
Waisman ADL	+.66*** N = 94	+.63*** N = 95	+.38** N = 59
Childhood Vineland	+.50*** N = 63	+.41** N = 63	+.13 N = 36

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ , \*\*\* =  $p < .001$ . Standard Deviations appear in parentheses below the means.

Table 5

*Impact of Employment on Quality of Life Outcomes – Means and ANOVA with Tukey's Post-hoc*

	Employment Status			<i>F</i>	<i>P</i>
	Currently Employed	Previously employed, currently unemployed	Never employed		
Contact by Friends	3.3a (2.3)	2.4ab (2.1)	1.6b (1.6)	$F(2,93) = 6.64$	.002
ADAMS-D	1.7a (2.4)	5.2b (4.9)	2.8a (2.9)	$F(2,90) = 7.63$	.001
ADAMS-A	4.2 (4.0)	6.0 (4.5)	5.5 (4.8)	$F(2,90) = 1.62$	.21
QOL-Q	88.0a (12.2)	70.8b (10.6)	69.1b (8.4)	$F(2,89) = 33.4$	< .001

*Note.* Standard Deviations are in parenthesis below the mean. Significantly different means on each measure are demarcated by an a, b, and c.

Table 6

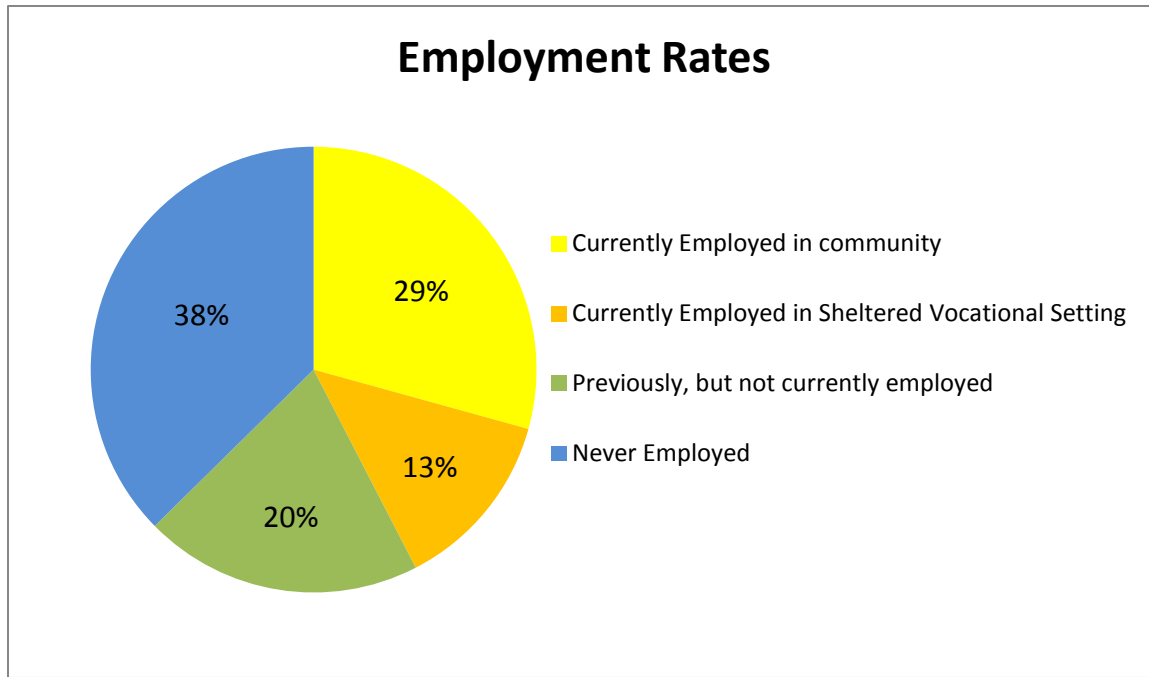
*Correlations Between Employment Variables and Quality of Life Measures*

	Quality of Life Measures			
	Social Contacts	ADAMS-D	ADAMS-A	QOL-Q
Vocational Index	+.52*** N = 96	-.22* N = 93	-.14 N = 93	+.67*** N = 93
Length of time Employed	+.29** N = 97	-.16 N = 94	-.13 N = 94	+.55*** N = 93
Hours worked per week at current job	+.06 N = 60	-.34** N = 58	-.27* N = 59	+.22 N = 58

*Note.* \* =  $p < .05$ , \*\* =  $p < .01$ , \*\*\* =  $p < .001$ .

## APPENDIX 2: FIGURES


Figure 1.



*Figure 1.* Employment Rates among adults with ASD. This figure gives a visual representation of current employment status of adults with ASD.

### APPENDIX 3: VOCATIONAL INDEX SCORING MATRIX

#### Vocational Index, from most to least independent

	Score	Category
Most Independent  	9	Employment in the community <i>without</i> supports greater than 10 h a week
	9	Postsecondary, <i>degree-seeking</i> educational program greater than 10 h a week
	8	Postsecondary, <i>degree-seeking</i> educational program or employment in the community <i>without</i> supports—total activities 10 h a week or less
	7	Employed in the community <i>with</i> supports greater than 10 h a week. No time spent in sheltered settings.
	6	Employed in the community <i>with</i> supports (no time spent in sheltered settings)—total activities 10 h a week or less
	5	Sheltered vocational setting and supported community employment—total activities greater than 10 h a week
	4	Sheltered vocational setting and volunteering in the community—total activities greater than 10 h a week
	4	Sheltered vocational setting (workshop or day activity center) with no community employment/volunteering—greater than 10 h a week.
	3	Sheltered vocational setting—total activities 10 h a week or less
	2	Volunteering with no other activities or postsecondary <i>non-degree seeking</i> education with no other activities
Least Independent	1	No vocational/educational activities

*Note.* The Vocational Index was developed by Taylor and Seltzer (2012)

## APPENDIX 4: TEACCH AUTISM IN ADULTHOOD SURVEY



The following survey will ask about the educational background, work experience, social life, and service usage of the adult with Autism Spectrum Disorder, including diagnoses of Autism, Asperger Syndrome, and pervasive developmental disorder who you know. Please answer every question. Thank you!

**1. Today's Date (mm/dd/yyyy):** \_\_\_\_\_

**2. Your relationship to the adult with autism spectrum disorder (ASD):**

- ☐ Self
- ☐ Mother
- ☐ Father
- ☐ Sibling
- ☐ Spouse
- ☐ Friend
- ☐ Legal Guardian
- ☐ Residential Caregiver
- ☐ Other \_\_\_\_\_

For the following questions, please answer every question thinking about the adult with autism.

**3. Adult's Date of Birth (mm/dd/yyyy):** \_\_\_\_\_

**4. Adult's Gender:**

- ☐ Male
- ☐ Female

**5 Adult's Ethnicity:**

- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino

**6. Adult's Race (check all that apply):**

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African-American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Unknown

**7. Has the adult ever been diagnosed with any of the following? (check all that apply):**

- ☐ Autism Spectrum Disorder (Autism, Aspergers, PDD-NOS)
- ☐ Epilepsy and/or seizures
- ☐ Intellectual Disability (formerly called Mental Retardation), please specify if Mild, Moderate, or Severe/Profound: \_\_\_\_\_
- ☐ Fragile X Syndrome
- ☐ Attention Deficit Disorder (ADHD)
- ☐ Anxiety (OCD, phobias, panic attacks, generalized)
- ☐ Depression
- ☐ Learning Disability (please specify): \_\_\_\_\_
- ☐ Cerebral Palsy
- ☐ Tourette's/Tic Disorder
- ☐ Other Psychiatric Disorders (specify): \_\_\_\_\_

**8. Mother's highest level of education:**

- ☐ Some high school
- ☐ High school degree
- ☐ Vocation training
- ☐ Some college but not degree
- ☐ 4 year college
- ☐ Graduate degree (e.g., J.D., M.A., Ph.D., M.D.)
- ☐ Don't know

**9. Father's highest level of education:**

- ☐ Some high school
- ☐ High school degree
- ☐ Vocation training
- ☐ Some college but not degree
- ☐ 4 year college
- ☐ Graduate degree (e.g., J.D., M.A., Ph.D., M.D.)
- ☐ Don't know

**10. How many siblings does the adult with autism have?**

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 or more



**11. Do any of these siblings have an autism spectrum diagnosis (Autism, Asperger's syndrome, PDD)?**

- ☐ Yes
- ☐ No

## **LANGUAGE ABILITIES**

**12. How clearly does he/she speak? Would you say he/she...**

- ☐ has no trouble speaking clearly
- ☐ has a little trouble speaking clearly
- ☐ has a lot of trouble speaking clearly
- ☐ doesn't speak at all
- ☐ don't know

**13. How well does he/she communicate by any means (e.g., verbal communication, sign language, adaptive technology, etc.)? Would you say he/she...**

- ☐ has no trouble communicating
- ☐ has a little trouble communicating
- ☐ has a lot of trouble communicating
- ☐ doesn't communicate at all
- ☐ don't know

**14. How well does he/she carry on a conversation? Would you say he/she...**

- ☐ has no trouble carrying on a conversation
- ☐ has a little trouble carrying on a conversation
- ☐ has a lot of trouble carrying on a conversation
- ☐ doesn't carry on a conversation at all
- ☐ don't know

**15. How well does he/she understand what people say to him/her? Would you say he/she...**

- ☐ has no trouble understanding others
- ☐ has a little trouble understanding others
- ☐ has a lot of trouble understanding others
- ☐ doesn't understand others at all
- ☐ don't know

## **EDUCATION**

**16. When he/she left high school, did he/she...**

- ☐ receive a regular diploma
- ☐ receive an occupational diploma
- ☐ receive a certificate of completion
- ☐ take a test and receive a GED without completing all classes
- ☐ drop out or stop going
- ☐ get suspended or expelled
- ☐ did not attend high school
- ☐ other \_\_\_\_\_

**17. Since high school, has he/she... (Please select all that apply)**

- ☐ attended a 2 year or community college
- ☐ graduated with a diploma, certificate, or license from a 2 year or community college
- ☐ attended a vocational, business, or technical school after high school
- ☐ graduated with a diploma, certificate, or license from a vocational, business, or technical school
- ☐ attended a 4 year college
- ☐ graduated with a diploma, certificate, or license from a 4 year college
- ☐ attended a graduate program (e.g., master's or doctoral program)
- ☐ graduated with an advanced degree (e.g., master's or doctoral degree)

**18. Is he/she currently enrolled in college?**

- ☐ No
- ☐ Yes, Part-time (less than 10 class hours per week)
- ☐ Yes, Full time (10 or more class hours per week)

## LIVING SITUATION

### 19. Where does he/she currently live?

- ☐ Independently (alone)
- ☐ Independently (with spouse or roommate)
- ☐ Supervised apartment
- ☐ With parent(s)
- ☐ With another relative/guardian other than a spouse or parent
- ☐ Community group home
- ☐ Intermediate Care Facility for Individuals with Mental Retardation/Intellectual Disability (ICF-MR/IID home)
- ☐ "Family Care" home
- ☐ Correctional facility
- ☐ Transient, homeless, on the street, in their car
- ☐ Other, specify \_\_\_\_\_
- ☐ Don't know

### 20. If he/she does not live with you, about how often do you talk with him/her using these forms of communication?

	Daily	2-3 Times/Week	1 Time/Week	1-2 Times/Month	< 1 Time/Month
Email/Text	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phone Call	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In-Person Visit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 21. Has he/she lived anywhere other than current residence since high school?

- ☐ Yes
- ☐ No

### 22. Where else has he/she lived since high school (excluding camps and vacations)?

---

**23. Did he/she live in any of these places in the last 2 years (excluding camps and vacations)?**

- ☐ Yes (specify which ones) \_\_\_\_\_
- ☐ No

**24. What is his/her current marital status?**

- ☐ Single, never married
- ☐ Domestic partner (same sex or opposite sex)
- ☐ Engaged
- ☐ Married
- ☐ Divorced
- ☐ Separated
- ☐ Widowed
- ☐ Don't know

**25. Does his/her spouse or partner have a paid job? (If the adult with autism does not have a current spouse or partner please skip this question)**

- ☐ Yes
- ☐ No

**26. Does the adult with autism have children?**

- ☐ Yes
- ☐ No

**27. What types of activities does the adult with autism need help with? (check all that apply)**

- ☐ Financial Management
- ☐ Cooking/meal planning
- ☐ Medication/health related needs
- ☐ Hygiene and self-care
- ☐ Cleaning and home maintenance
- ☐ Social and recreational activities
- ☐ Community activities
- ☐ Other \_\_\_\_\_
- ☐ Does not need help with any activities

**28. How much unpaid supervision (including from parents) does he/she receive in his/her living situation?**

- ☐ None
- ☐ Several hours a week
- ☐ Several hours a day
- ☐ All day, but not overnight
- ☐ 24 hours per day

**29. How much paid supervision does he/she receive in his/her living situation?**

- ☐ None
- ☐ Several hours a week
- ☐ Several hours a day
- ☐ All day, but not overnight
- ☐ 24 hours per day

## RECREATIONAL ACTIVITIES AND SOCIAL LIFE

**30. During the past 12 months, has he/she (check all that apply):**

- ☐ Done any volunteer or community service activity
- ☐ Taken lessons (art, music, dance, foreign language, computers)
- ☐ Attended religious services
- ☐ Attended social skills groups
- ☐ Gotten together with friends outside of organized activities or groups
- ☐ Been invited to other friends' social activities (been invited to their home or to a party)

**31. Do any of these activities include only people with special needs?**

- ☐ Yes
- ☐ No

**32. Does he/she use a computer or other electronic device (e.g., a tablet or smartphone) or know how to use a computer for...?**

	Yes	No
Work, homework, or school assignments	<input type="radio"/>	<input type="radio"/>
Playing games	<input type="radio"/>	<input type="radio"/>
Internet	<input type="radio"/>	<input type="radio"/>
Recreation and hobbies	<input type="radio"/>	<input type="radio"/>

**33. How often have friends called or texted him/her on the phone in the last 12 months?**

- ☐ Never
- ☐ Less than once a month
- ☐ Once a month
- ☐ 2-3 times a month
- ☐ Once a week
- ☐ 2-3 times a week
- ☐ Daily

**34. How frequently has he/she used email, instant messaging, Skype, texting, Facebook messaging or taken part in chat rooms in the last 12 months?**

- ☐ Never
- ☐ Less than once a month
- ☐ Once a month
- ☐ 2-3 times a month
- ☐ Once a week
- ☐ 2-3 times a week
- ☐ Daily

**35. About how many hours a week does he/she usually watch TV or videos? Enter hours per week below:**

---

**36. Does/Is he/she...**

	Yes	No
Have a driver's license?	<input type="radio"/>	<input type="radio"/>
Drive independently on a regular basis?	<input type="radio"/>	<input type="radio"/>
Receive money that he/she can decide how to spend?	<input type="radio"/>	<input type="radio"/>
Have a savings account?	<input type="radio"/>	<input type="radio"/>
Have a checking account where he/she write checks or use a debit card?	<input type="radio"/>	<input type="radio"/>
Have a credit card or charge account in his/her name?	<input type="radio"/>	<input type="radio"/>
Registered to vote?	<input type="radio"/>	<input type="radio"/>

**37. Has he/she ever been...**

	Yes	No
Arrested?	<input type="radio"/>	<input type="radio"/>
On probation or parole?	<input type="radio"/>	<input type="radio"/>
Arrested in the last 2 years?	<input type="radio"/>	<input type="radio"/>
Stopped and questioned by the police in the last 2 years?	<input type="radio"/>	<input type="radio"/>



**38. Has the adult received any of the following services since high school? (check all that apply)**

	Yes	No
Help in finding a job, training in job skills or vocational education, other than from an employer	<input type="radio"/>	<input type="radio"/>
Job coaching	<input type="radio"/>	<input type="radio"/>
Financial Aid, like paying for college classes or training	<input type="radio"/>	<input type="radio"/>
Educational assistance or tutoring (e.g., college disability services)	<input type="radio"/>	<input type="radio"/>
Instruction or help with independent living skills (e.g., managing money, cooking), NOT including instruction from family members or friends	<input type="radio"/>	<input type="radio"/>
Psychological or mental health services or counseling	<input type="radio"/>	<input type="radio"/>
Social work services	<input type="radio"/>	<input type="radio"/>
Physical therapy	<input type="radio"/>	<input type="radio"/>
Assistive technology services or devices (e.g., special calculator, reading machine, or augmentative & alternative communication device (AAC))	<input type="radio"/>	<input type="radio"/>
Transportation assistance because of disability	<input type="radio"/>	<input type="radio"/>
Medical services for diagnosis or evaluation related to his/her disability	<input type="radio"/>	<input type="radio"/>
Speech or language therapy, or communication services	<input type="radio"/>	<input type="radio"/>
Audiology services for hearing problems	<input type="radio"/>	<input type="radio"/>
Respite care	<input type="radio"/>	<input type="radio"/>
Housing assistance or residential services or help with a supervised living arrangement (e.g., a group home)	<input type="radio"/>	<input type="radio"/>
Personal assistant or in-the-home aid	<input type="radio"/>	<input type="radio"/>
Nursing care	<input type="radio"/>	<input type="radio"/>

**38(2). Has the adult received any of the following services in the last two years? (check all that apply)**

	Yes	No
Help in finding a job, training in job skills or vocational education, other than from an employer	<input type="radio"/>	<input type="radio"/>
Job coaching	<input type="radio"/>	<input type="radio"/>
Financial Aid, like paying for college classes or training	<input type="radio"/>	<input type="radio"/>
Educational assistance or tutoring (e.g., college disability services)	<input type="radio"/>	<input type="radio"/>
Instruction or help with independent living skills (e.g., managing money, cooking), NOT including instruction from family members or friends	<input type="radio"/>	<input type="radio"/>
Psychological or mental health services or counseling	<input type="radio"/>	<input type="radio"/>
Social work services	<input type="radio"/>	<input type="radio"/>
Physical therapy	<input type="radio"/>	<input type="radio"/>
Assistive technology services or devices (e.g., special calculator, reading machine, or augmentative & alternative communication device (AAC))	<input type="radio"/>	<input type="radio"/>
Transportation assistance because of disability	<input type="radio"/>	<input type="radio"/>
Medical services for diagnosis or evaluation related to his/her disability	<input type="radio"/>	<input type="radio"/>
Speech or language therapy, or communication services	<input type="radio"/>	<input type="radio"/>
Audiology services for hearing problems	<input type="radio"/>	<input type="radio"/>
Respite care	<input type="radio"/>	<input type="radio"/>
Housing assistance or residential services or help with a supervised living arrangement (e.g., a group home)	<input type="radio"/>	<input type="radio"/>
Personal assistant or in-the-home aid	<input type="radio"/>	<input type="radio"/>
Nursing care	<input type="radio"/>	<input type="radio"/>

**39. Overall, how satisfied have you been with all services he/she has received?**

- ☐ Very Dissatisfied
- ☐ Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Neutral
- ☐ Somewhat Satisfied
- ☐ Satisfied
- ☐ Very Satisfied

**40. Have any of the following been a problem in getting or dealing with services during the last 12 months? (check all that apply)**

- ☐ Cost of services
- ☐ Services not available or too far away
- ☐ Poor service quality
- ☐ Language problems (includes sign language or interpreter)
- ☐ Transportation
- ☐ Not eligible for the service
- ☐ Not sure where to find services needed

**41. Do you think he/she needs any services besides the ones he/she receives now?**

- ☐ Yes
- ☐ No

**42. What service(s) do you think he/she needs?**

---

**43. Has anyone (i.e., you, family member, professional, or the adult with autism) ever tried to get the service(s) you listed in the previous question?**

- ☐ Yes
- ☐ No

**44. Is he/she on a waiting list for the services previously listed?**

- ☐ Yes
- ☐ No

## **JOB AND WORK EXPERIENCE**

**45. At any time since high school did he/she work for pay other than work around the house?**

- ☐ Yes
- ☐ No

**46. What is the longest time he/she has worked at a particular job since leaving high school?**

- ☐ A few days
- ☐ A few months
- ☐ 1 - 2 years
- ☐ 3 - 5 years
- ☐ 5 or more years

**47. Has he/she had a paid job in the last 2 years?**

- ☐ Yes
- ☐ No

**48. Does he/she have a paid job now?**

- ☐ Yes
- ☐ No

**49. Does he/she have more than one paid job right now?**

- ☐ Yes
- ☐ No

**INFORMATION ABOUT CURRENT OR MOST RECENT JOB (IF NOT CURRENTLY EMPLOYED)**

**50. For the current or most recent job where he/she worked (the job with the most hours), about how much is/was he/she paid?**

- ☐ Below minimum wage
- ☐ Minimum wage
- ☐ Above minimum wage

**51. Did he/she receive benefits from this job? (check all that apply)**

- ☐ Health Insurance
- ☐ Vacation/sick leave
- ☐ Retirement account
- ☐ None

**52. For the current or most recent job with the most hours, what is the job title?**

---

**53. Briefly describe his/her main duties at this job.**

---

**54. About how long was this job held?**

- ☐ Less than a week
- ☐ Less than a year
- ☐ 1 to 2 years
- ☐ 3 to 4 years
- ☐ 5 or more years

**55. Across all current jobs (or most recent job if not currently employed), about how many hours a week does he/she usually work?**

- ☐ Less than 5 hours per week
- ☐ 5 to 9 hours per week
- ☐ 10 to 19 hours per week
- ☐ 20 to 29 hours per week
- ☐ 30 to 39 hours per week
- ☐ 40 hours per week
- ☐ More than 40 hours per week

**56. If working part-time, is he/she working part time because he/she wants to, or would he/she rather work full-time?**

- ☐ Likes to work part-time
- ☐ Would rather work full-time
- ☐ Other, specify \_\_\_\_\_

**57. How satisfied is the adult with his/her current job situation?**

- ☐ Very Dissatisfied
- ☐ Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Neutral
- ☐ Somewhat Satisfied
- ☐ Satisfied
- ☐ Very Satisfied
- ☐ N/A - not currently employed

**58. Did he/she find their current or most recent job himself/herself or did he/she have help?**

- ☐ Found the job on his/her own
- ☐ Found the job with help from an agency (e.g., a job coach or vocational rehab)
- ☐ Found the job with help from a family member
- ☐ Other \_\_\_\_\_
- ☐ N/A - not employed

**59. About how long did he/she look for a job before finding the current one? (or most recent job if not currently employed)**

---

**60. If the adult has received help finding the current (or most recent job), how useful were these services?**

- ☐ Not useful at all (i.e., did not provide any additional advantage for getting a job)
- ☐ Slightly useful (i.e., helped a little when getting a job)
- ☐ Useful (i.e., helped a good deal with getting a job)
- ☐ Very useful (i.e., made the difference between getting a job and not getting one)
- ☐ N/A - no services used

**61. Thinking about all current jobs (or most recent job if not currently employed), has he/she applied for any accommodations or supports to help maintain employment?**

- ☐ Yes
- ☐ No

**62. Thinking about all current jobs (or most recent job if not currently employed), has he/she received any accommodations or supports to help maintain employment?**

- ☐ Yes
- ☐ No

**63. If the adult has received accommodations or supports to help maintain the current or most recent employment, how useful were these services?**

- ☐ Not useful at all (i.e., did not provide any additional advantages in keeping job)
- ☐ Slightly useful (i.e., helped a little for keeping job)
- ☐ Useful (i.e., helped a good deal for keeping job)
- ☐ Very useful (i.e., made the difference between keeping or losing a job)
- ☐ N/A - no accommodations or supports received

**64. Do you think he/she needs any additional career counseling, job training or job assistance?**

- ☐ Yes
- ☐ No

**65. What type of additional job supports do you think he/she needs? (Please indicate below)**

---

## **INDEPENDENT LIVING SERVICES**

**66. Since high school, has he/she had training in or help in any of the following, not including training from family members or friends?**

	Yes	No
Using Transportation	<input type="radio"/>	<input type="radio"/>
Home care skills, such as cooking and cleaning	<input type="radio"/>	<input type="radio"/>
Financial issues, such as managing his/her money	<input type="radio"/>	<input type="radio"/>
Self-care skills such as brushing his/her teeth	<input type="radio"/>	<input type="radio"/>
Relationship skills, such as getting along with others	<input type="radio"/>	<input type="radio"/>
Self advocacy skills (e.g., talking to others about autism diagnosis)	<input type="radio"/>	<input type="radio"/>

**67. Is he/she getting any of these services now?**

- ☐ Yes
- ☐ No

**68. How useful do you think this training or help with independent living skills has been?**

- ☐ Not useful at all
- ☐ Somewhat useful
- ☐ Useful
- ☐ Very useful
- ☐ Not applicable, did not receive independent skills training



**69. Do you think he/she needs additional training or help with independent living skills now?**

- ☐ Yes  
☐ No

**70. What kinds of training or help with independent living skills do you think he/she needs?**

---

**71. Has anyone (i.e., you, family member, professional, the adult with autism) ever tried to get the service(s) listed in the previous question?**

- ☐ Yes  
☐ No

**72. Is he/she on a waiting list for this/these service(s)?**

- ☐ Yes  
☐ No

## **GOVERNMENT BENEFITS**

**73. Has the adult with autism received any of the following...**

	In the last 2 years	Currently
Supplemental Security Income (SSI/SSDI)	<input type="checkbox"/>	<input type="checkbox"/>
Temporary Assistance to Needy Families (TANF)	<input type="checkbox"/>	<input type="checkbox"/>
Food Stamps	<input type="checkbox"/>	<input type="checkbox"/>
Medicare	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid	<input type="checkbox"/>	<input type="checkbox"/>
Any form of health insurance	<input type="checkbox"/>	<input type="checkbox"/>

**Please indicate whether you are the caregiver or guardian of the adult with autism or whether you are a residential facility caregiver.**

- ☐ I am a caregiver or guardian of the adult with autism
- ☐ I am a residential facility caregiver

**74. What is your gender?**

- ☐ Male
- ☐ Female

**75. Are you involved in making decisions about the adult with autism's life?**

- ☐ Yes
- ☐ No

**76. What type of decisions do you help with (check all that apply)?**

- ☐ Medical or health related
- ☐ Financial
- ☐ Living situations
- ☐ Legal
- ☐ Treatment or learning goals and objectives
- ☐ Work or day program planning
- ☐ Recreational

**77. How often do you meet/talk with others in order to help with the adult's care?**

- ☐ Everyday
- ☐ A few times a week
- ☐ Once a week
- ☐ Every few months
- ☐ Less often than every few months
- ☐ Don't know

**78. In your role helping the adult with autism, have you ever used any of the following support services (check all that apply)?**

	Ever used	In the last 2 years
Counselor or psychologist	<input type="checkbox"/>	<input type="checkbox"/>
Physician or medical professional	<input type="checkbox"/>	<input type="checkbox"/>
Support groups	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy agency	<input type="checkbox"/>	<input type="checkbox"/>
Church groups	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>

**79. For the last calendar year, what is your family income taking into account all sources of income (wages, interest, government assistance, child support etc.) before taxes.**

- ☐ Under \$15,000 per year
- ☐ \$15,001 - \$25,000
- ☐ \$25,001 - \$45,000
- ☐ \$45,001 - \$65,000
- ☐ \$65,001 - \$85,000
- ☐ \$85,001 - \$105,000
- ☐ \$105,001 - \$205,000
- ☐ Above \$205,000
- ☐ Don't know

## **IMPACT ON THE FAMILY**

The next questions are about the amount of money paid out-of-pocket during the past 12 months for his/her medical care. Please **DO NOT** include health insurance premiums or costs that were or will be reimbursed by insurance or another source. **DO** include out-of-pocket payments for all types of health-related needs such as, co-payments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, day program services, respite care, or any kind of therapy.

**80. During the past 12 months, how much would you estimate the family paid for care for the adult with autism?**

- ☐ More than \$5000
- ☐ \$1000 - \$5000
- ☐ \$500 - \$1000
- ☐ \$250 - \$500
- ☐ less than \$250
- ☐ Nothing, \$0.00
- ☐ Don't know

**81. Many families provide care at home such as managing diet, medications or therapy. In the past 12 months, how many hours per week do you or other family members spend providing this kind of care?**

- ☐ None
- ☐ less than 1 hour
- ☐ 1 to 5 hours
- ☐ 5 to 10 hours
- ☐ 10 to 20 hours
- ☐ 20 to 40 hours
- ☐ Around the clock care
- ☐ Don't know
- ☐ Not applicable

**82. In the past 12 months, how many hours per week do you or other family members spend arranging or coordinating the adult with autism's care (e.g., making appointments, making sure that care providers are exchanging information and following up on their health care needs)?**

- ☐ None
- ☐ less than 1 hour
- ☐ 1 to 5 hours
- ☐ 5 to 10 hours
- ☐ 10 to 20 hours
- ☐ 20 to 40 hours
- ☐ Around the clock care
- ☐ Don't know
- ☐ Not applicable

**83. Since the adult with autism left school, has the adult with autism's condition ever caused financial problems for your family?**

- ☐ Yes
- ☐ No
- ☐ Don't know

**84. Since the adult with autism left school, have you or other family members ever stopped working because of the adult with autism's condition?**

- ☐ Yes
- ☐ No
- ☐ Don't know

**85. Since the adult with autism left school, have you or other family members ever cut down on the hours you work because of the adult with autism's condition (do not include family members that have stopped working)?**

- ☐ Yes
- ☐ No
- ☐ Don't know

**86. Since the adult with autism left school, have you or other family members avoided changing jobs because of concerns about maintaining health insurance for the adult with autism?**

- ☐ Yes
- ☐ No
- ☐ Don't know

**87. Since the adult with autism left school has the amount of time you or other family members devoted to managing their care increased, decreased or remained the same?**

- ☐ Increased
- ☐ Decreased
- ☐ Remained the same
- ☐ Don't know

**88. Since the adult with autism left school, has financial strain of maintaining care for the adult with autism increased, decreased or remained the same for you or other family members?**

- ☐ Increased
- ☐ Decreased
- ☐ Remained the same
- ☐ Don't know

**THANK YOU FOR YOUR PARTICIPATION**

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