THE RELATION BETWEEN EMPLOYMENT AND DEPRESSION IN ADULTS WITH AUTISM SPECTRUM DISORDER

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ABSTRACT
Molly Schweers: The Relation between Employment and Depression in Adults with Autism Spectrum Disorder
(Under the direction of Mark R. Klinger)

Many studies have investigated the symptoms, etiology, and intervention strategies for children with autism spectrum disorder (ASD). However, little research has addressed outcomes of adults with ASD. Additionally, research on co-occurring disorders such as depression is also very limited. This study looked at predictors of depression in adults with ASD, specifically employment and ASD symptom severity. This study measured co-morbid disorders including depression, long term outcomes, and ASD symptom severity in 97 adults with ASD diagnosed at the TEACCH Autism Program between 1965 and 2000 reported by caregivers of the adults. In addition to the data collected from adulthood, childhood assessment data were used including intelligence, ASD symptom severity, and adaptive functioning. Employment, childhood intelligence, and ASD symptom severity were predicted to be related to the presence of depression in adults with ASD. The results showed employment factors were most significantly related to depression in adults. Vocational index, number of hours worked per week, and current job status were strong predictors of depression. Specifically, individuals who had previously held a job but were not currently employed were more likely to score higher on the ADAMS Depression scale than individuals who never had a job or who were currently employed. Activities of daily living were also related to current depression. These findings show the importance of focusing interventions on integrating supported employment and depression interventions to help decrease depressive symptoms and increase employment outcomes.
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CHAPTER 1: AUTISM SPECTRUM DISORDER AND DEPRESSION

Introduction

In recent years autism spectrum disorder (ASD) has become a more common and widespread disorder in terms of public knowledge and research. Although the onset of ASD is in the early developmental period, ASD is a lifelong disorder. Many people look at ASD as a childhood disorder, but the symptoms do not inevitably go away as individuals grow up. In the last 20 years, there has been an increasing rate of ASD among children and adolescents. A significant increase in adults with ASD is taking place because all of these children who were diagnosed years ago are reaching adulthood. Because it has been thought to be a childhood disorder, the vast majority of the research on ASD has focused on children and adolescents. Very little research has been done on the outcomes of adults with ASD, so treatment and interventions are relatively unstudied. There is substantial need for research on the long term outcomes to have a better understanding of what happens as individuals with ASD reach adulthood. Not only is there limited research on the outcomes of adults, but research is also lacking on the affective and emotional well-being of adults with ASD. The purpose of this study is to examine depression in adults with ASD to determine the psychosocial factors that predict depression in ASD. I will examine both childhood and adulthood predictors of depression in adults with ASD. This study is especially focused on the relation of employment to depression.

Autism Spectrum Disorder

According to the Center for Disease Control and Prevention (CDC, 2014), the prevalence of ASD is every 1 in 68 children that have been diagnosed. The prevalence rates have increased...
considerably over the past 14 years. Across Asia, Europe, and North America, studies have shown that individuals with ASD represent about 1% of the population (CDC, 2013), yet more recent studies estimate higher, such as one by Kim et al. (2013) which estimates a prevalence rate of 3% of the general population in South Korea. According to the CDC, “ASD prevalence estimates also varied widely by sex and by racial/ethnic group” (2012). This shows that ASD takes place across all racial, ethnic, and socioeconomic populations rather than one specific group. Currently, there are about four to five times more males diagnosed with ASD than females, with 1 in 42 boys and 1 in 189 girls diagnosed (CDC, 2014).

Originally thought to be due to environmental or parenting factors, ASD is now known to be caused by physiological factors. The exact cause of the disorder is still unknown, but there are many identified factors that have an influence. Structural abnormalities of the brain, genetic factors, and medical conditions are all contributing factors, according to Smith and Philpen (2005). Although all of these factors influence ASD, none of them occur solely with the ASD population and can be seen as a unique cause.

According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), autism is a neuro-developmental disorder with impairments in social communication and interaction as well as repetitive and restricted behaviors, interests, or activities (APA, 2013). The social impairments can range from reciprocation of social-emotional interaction, verbal and nonverbal communication, and overall comprehension of relationships. These deficits typically appear across several contexts within a person’s life. The restricted, repetitive behaviors can manifest in movements, schedules, interests, or sensory qualities. Ornitz (1989, p. 174) proposed a neurophysiological model for infants with autism and suggested the “disturbances of social relating, communication, language, and the bizarre responses to the environment are
consequences of a dysmodulation of sensory input”. This means that the stimuli that the individual is trying to process becomes altered resulting in a distortion of the sensory information received in the brain. Additionally, intellectual or language impairments often co-occur with ASD. The rate of individuals diagnosed with ASD who have comorbid intellectual disability (ID) ranges from 30% to 55% (Baird et al., 2006; CDCP, 2007; Chakrabarti and Fombonne, 2005; Joseph, 2011). The onset of ASD is typically in the developmental period ranging from birth to eighteen, but is most commonly diagnosed around ages three or four years. Other related symptoms can occur such as sleep disturbances, eating disturbances, and self-injurious behaviors including head banging or slapping, hair pulling, and finger or hand biting (Klinger, Dawson, & Renner, 2003). Due to the fact that autism is defined as occurring along a spectrum, the severity and specific symptoms differ greatly from person to person, resulting in the vague and ambiguous nature of the disorder.

The various social and communication impairments involved with ASD lead us to the question of the life outcomes for individuals with ASD. Employment has been recognized as an important factor in determining quality of life for adults who are typically developing, as well as adults with ASD. However, one of the main difficulties is that social impairments in adults with ASD can interfere with maintaining steady employment. A study done on psychosocial outcomes of adults with ASD found that “most individuals had gained or were working towards some form of vocational qualification, but stable employment proved to be an area of difficulty for this group” (Whitehouse, Watt, Line, & Bishop, 2009). Shattuck, Narendorf, Cooper, Sterzing, Wagner, and Taylor (2012) found that about 55% of adults with ASD were involved in any paid employment, with or without supports. However, Taylor and Seltzer (2012) found that only 7% of individuals sampled were competitively employed in the community without
supports. Similar studies found low rates of competitive employment in adults with ASD, ranging from 4% to 17% (Ballaban-Gil, Rapin, Tuchman, and Shinnar, 1996; Eaves and Ho 2008; Howlin, Goode, and Hutton, 2004; Taylor and Seltzer, 2011). There are many factors that contribute to this vocational instability, but symptoms of ASD such as, “insistence on sameness, difficulty with change in routine, or restricted interests, as well as maladaptive behaviors such as aggression or uncooperative behavior, interfere with day-to-day functioning and thus limit the possible vocational and educational activities available” (Taylor & Mailick, 2014). Additionally, Taylor and Mailick found that there was little improvement in academic and vocational activities over time, specifically showing that “less than one-fourth of adults were improving to any degree, and less than 5% had improvements deemed to be substantial” (2014). As individuals with ASD are growing older, the need for available vocational activities is increasing, especially in respect to addressing the social impairments that interfere with the level of functioning needed to maintain employment.

**Depression**

The incidence of depression is extremely high throughout the world. According to a recent CDC (2010) study looking at surveillance from 2006 to 2008, 9% of adults currently met criteria for depression including 3% for major depression out of 235,067 in the United States. Specifically, in a twelve-month period the DSM-5 (2013) noted that the prevalence of major depressive disorder was 7% in the United States. The CDC (2010) reported that the prevalence of major depression was higher in women compared to men (4% versus 3%). Additionally, major depression was significantly higher in minorities such as African-Americans (4%), Hispanics (4%), and other races (4%) than in non-Hispanic whites (3%; CDC, 2010). The CDC (2010) also reported that those with a lower level of education, such as individuals with less than
a high school diploma (7%) and individuals who graduated high school (4%), tended to be more likely to report depression than individuals with some college education (3%). Individuals who were unable to work (22%) or were unemployed (10%) were significantly more likely to report depression compared to those who were employed (2%) or retired (2%; CDC, 2010). These data suggest that depression rates tend to be strongly related to employment, level of education, and gender. In a more generalized perspective, these categories reflect the probable occurrence of depression in individuals from socioeconomic status and with lower intelligence. A study done on depression and socioeconomic status in students found that students coming from less advantaged backgrounds were at a higher risk for depression (Ibrahim, Kelly, & Glazebrook, 2013). Additionally, 5% of individuals with ID are affected by depression at any given time and the rates are likely to increase over time (Cooper, Smiley, Morrison, Williamson, and Allan, 2007; Langlois and Martin, 2008; Richards, Maughan, Hardy, Hall, Strydom, and Wadsworth, 2001). Perez-Achiaga, Nelson, and Hassiotis (2009) discussed the misrepresentation, over and under, of individuals with ID and other mental disorders due to the lack of valid instruments for testing. It would seem that depression is more prevalent in lower socioeconomic status, as well as individuals with lower intelligence levels.

The increased rates of depression have reinforced the need for researchers to continue to search for specific information and gain a better understanding of the etiology. Earlier studies, such as one by Sullivan, Neale, and Kendler (2000) discussed depression as a complex disorder where both genetic and environmental factors have an effect on depression, and showed this interaction through the results of adoption and twin studies. The results made it clear that the ways the genes and environment interact are what likely causes the depression, rather than simply one or the other. In a recent study by Saveanu and Nemeroff (2012), gene-environment
interaction was discussed further by explaining that “even though early life stress increases risk of depression, there are important differences in the way individuals respond to the same stressful event, and these differences may be explained in part by genetic factors” (p. 60).

Another important aspect of the etiology of depression involves lower levels of serotonin, norepinephrine, and dopamine influencing mood, including feelings of well-being, happiness, and pleasure (Saveanu et al., 2012). Furthermore, inflammation due to high levels of cortisol hormones caused by stress can contribute to depression (Saveanu et al., 2012). As explained before, depression is a complex disorder that has several different interrelated factors influencing the development collectively.

Because the nature of depression is so complex and indistinct, the development and course of the disorder is also ambiguous. Although the onset of depression can happen at any age, the DSM-5 expresses that the probability of onset for Major Depressive Disorder (MDD) increases during puberty, typically peaking in the 20s (APA, 2013). While this information is found in the DSM-5 under the section for MDD, the course for subthreshold depression (SD) is very similar to that of MDD. A study on subthreshold and threshold depression discussed how depression is on a spectrum, and that lower levels of depression also hold a lot of significance in understanding prognosis of the wide-ranging depressive spectrum (Angst & Merikangas, 1997). Throughout the spectrum of depression, the general course is similar, but there are certain differences that can be identified. A literature review about childhood and adolescent SD described that “there are also indications of an age-shift, with SD being more common than MDD in early adolescence but less common later on. This may support the view of SD as a precursor for MDD, indicating that threshold depression may develop if intervention is not applied” (Wesselhoeft, Sorensen, Heiervang, & Bilenberg, 2013, p. 19).
Remission and recovery are also examples of how the course of depression can vary. For some, remission can occur where individuals may go two months or more without symptoms, while some may go years. Others rarely experience remission and have chronic symptoms. According to the DSM-5, “the risk of recurrence becomes progressively lower over time as the duration of remission increases” (APA, 2013, p. 165). Because depression has such a broad spectrum, the course of depression is also rather variable, so there are numerous other differences making it very difficult to predict the prognosis from individual to individual.

**Depression in Persons with ASD**

Research on depression rates in individuals with ASD have been extremely variable with estimates ranging anywhere from 4% to 58% (Lainhart, 1999). Mazefsky, Conner, and Oswald explained, “This variability in ranges is not unexpected due to differences across studies in age ranges, level of intellectual ability, recruitment methods, focus on current vs. lifetime symptoms, and method of determining comorbidity status” (2010, p. 120). One specific example showed that adolescents with ASD had a long-term depression prevalence rate of 32% (Mazefsky et al., 2010). Although a specific rate has not been established, many studies have been reviewed to show that depression is a common occurrence in individuals with ASD, which reinforces the need for additional research on this comorbid disorder.

Although research in adults with comorbid depression and ASD is lacking, there are a number of studies that have been done on depression in children and adolescents with ASD. Some of these highlight the factors that influence the relationship between ASD and depression. A study by Mayes, Calhoun, Murray, Ahuja, and Smith (2011) found that in children with ASD, depression ratings were higher in the high-functioning children compared to low-functioning children. A possible explanation for this could be that the high functioning children are more
aware of their differences than lower functioning children. Further supporting this notion, Pouw, Rieffe, Stockmann, and Gadow (2013) mentioned that depression in children with ASD may be related to being bullied or having low quality friendships. This shows that those with ASD who are aware of their differences may have a higher chance of developing depression. A review by Ghaziuddin, Ghaziuddin, and Greden (2002) strengthens this argument by suggesting, “higher-functioning people, because of their vulnerability to lower self-worth, may be more predisposed to depression” (p. 303). However, evidence to support this is missing, underlining the need for more research on the subject.

One important distinction to be made in terms of ASD and depression is how the symptoms are presented in high and low functioning individuals. Ghaziuddin et al. (2002) noted that because a diagnosis of depression relies highly on communication skills, individuals with ASD who have higher verbal skills are able to communicate their depressive symptoms better than individuals with lower-functioning ASD. Although studies hypothesize that higher functioning individuals with ASD are more likely to be depressed, Ghaziuddin and colleagues made a valid suggestion that the vegetative signs of depression are more representative of an individual with lower functioning ASD for assessments of depression than an indication of depressed mood. In order to provide accurate information on the presence of depression between high and low functioning individuals with ASD, understanding how the symptoms of depression are presented is crucial.

A few other likely causes in the relationship between ASD and depression include negative life events, genetic factors, and possibly gender. Children with ASD who have depression tend to have undergone more negative experiences than typically developing children (Ghaziuddin et al., 2002). Genetic factors may also have an effect on depression in persons with
ASD, though no specific relation has been identified (Ghaziuddin et al., 2002). More information on the effect of gender is also needed. However, Solomon, Miller, Taylor, Henshaw, and Carter (2012) found that compared to typically developing girls and boys with ASD, girls with ASD were more likely to internalize psychopathology with 26% in the clinical range of the Children’s Depression Inventory (CDI). Higher rates of depression in girls with ASD are consistent with the higher rates of depression in typically developing females.

Another important implication of depression in individuals with ASD relates to how the two interact in terms of the course of the disorders. Studies have shown that depression can actually worsen the outcomes of individuals with ASD. Ghaziuddin et al. (2002) explained that an individual’s placement in the community can be affected by the increased social withdrawal and aggressive behavior related to depression. Understanding the comorbidity of these two would be incredibly beneficial to help develop interventions that may avoid worsening symptoms with depression, and work on improvement.

Additionally, the lack of social connection in individuals with autism may increase rates of depression. Mazurek (2014) found that reports of loneliness showed higher rates of depression and anxiety and lower rates of self-esteem and overall satisfaction with life. This suggests that loneliness can be linked with negative emotional outcomes for individuals with ASD. Conversely, this tells us that more social connection and community inclusion could lead to lower rates of depression. In respect to employment and quality of life, Garcia-Villamisar, Wehman, and Navarro (2002) found that supported employment helped to increase quality of life ratings in individuals with ASD from 1996 to 2000. Additionally, a study done using the Structured Teaching model showed an increase in indirect measures of quality of life due to significant progress of behavioral and adjustment impairments related to vocational skills.
(Persson, 2000). Another study found that an increase in emotional lability and irritable or aggressive behaviors were associated with a lower socioeconomic status (Mayes & Calhoun, 2011). Something to note is that this study used children as participants; no study on the effect of socioeconomic status on depression in adults with ASD has been done. Some degree of research has been done related to employment, socioeconomic status and quality of life in individuals with ASD, but it still remains fairly limited.

The amount of information available on depression in children and adolescents with ASD is limited, yet the amount for adults is even more limited. An article by Piven and Rabins (2011) about long-term outcomes of adults with ASD estimated that with the growing population there will be 700,000 individuals with ASD in the next 20 years who are 65 years or older. Not only will we be unprepared for long-term care with this influx of adults with ASD without any comorbid disorders, but we will be even more unprepared for high numbers of persons with ASD who are depressed. There will be a high demand for services for adults with ASD in the next few years, and without knowledge on long-term outcomes of ASD, especially with depression, we will not be able to provide sufficient care. Piven and Rabins suggested the possibility that “different interventions might be effective at different ages” (p. 2151). A study on long-term outcomes of adults with ASD and quality of life showed that individuals with ASD are still very dependent on caregivers, and outcomes for social and occupational facets are poor (Billstedt, Gillberg, & Gillberg, 2011). Some of the main goals of this study are to better understand the scope of depression in adults ASD and the predictors of depression. This will help us understand what service programs are needed in the future to increase the quality of life in this population. By understanding better the relationship between depression and ASD we can attempt to achieve these goals.
Hypotheses

The purpose of this paper is to examine factors related to depression in adults with ASD in order to determine whether current factors relate to depression more than childhood factors. Using data from the TEACCH Adult Outcome survey, my hypotheses include:

1. Both childhood and current ASD related functioning will be related to depression in adults with ASD. Children with high-functioning ASD will be more likely to become depressed in adulthood than children with low-functioning ASD.

2. Current participation factors, including employment and social participation will be strongly related with depression in adults with ASD with those who are employed and socially active showing lower rates of depression.
CHAPTER 2: ADULT OUTCOMES STUDY

Methods

Participations

Participants were 97 adults diagnosed with an ASD at the TEACCH Autism Program between 1965 and 2000 reported by the caregivers. The adults range from 22 to 64 years in age. Because the DSM-5 has recently changed the diagnosis from autistic disorder to ASD, individuals were diagnosed with autistic disorder, Asperger’s syndrome, or pervasive developmental disorder-not otherwise specified. These are included within the spectrum, and therefore were included in the eligibility. These individuals were tested on intelligence, symptom severity, and adaptive behavior skills during these assessments. The participants involved represented a full range of severity on all measurements. Almost 60% of these individuals had a co-morbid ID diagnosis, which was closer to the projected childhood rates from 1965 through 2000 (75%) than to current rates (30-40%; CDC, 2014). The caregivers who reported the information concerning the adults included 67 moms, 22 dads, 1 sibling, 1 legal guardian, and 6 in the “other” category, including an aunt, grandmother, both mother and father, both mother and legal guardian, and psychiatrist. Most of the individuals recruited still remained in North Carolina.

Recruitment of participants occurred mainly through searching clinical records for past clients. Once eligible clients were found, information including assessments and address at time of intake were used to find current addresses for the families of the adult. Recruitment efforts were made through all of the TEACCH locations, including Chapel Hill, Asheville, Greenville,
Wilmington, Greensboro, Charlotte, and Fayetteville. However, higher priority was placed on recruitment of individuals from the oldest TEACCH locations, Chapel Hill, Asheville, and Greenville, due to the likelihood that these individuals would be older and would have had multiple childhood assessments.

There were several stages involved in the process of recruitment, starting with collecting information from a microfiche database, as well as intake forms that consisted of childhood assessments to determine eligibility. After identifying eligible individuals based on diagnoses, age, and assessment scores; information regarding the parents’ names and addresses at the time of the initial assessment was found. Using Intelius software, we searched the names and addresses of the parents to verify the most current address. Once the address was verified, a recruitment letter was sent to the family. A follow up phone call was made to the family if there was no response to the recruitment letter. Once a caregiver of an adult was recruited for participation, the survey was sent through email or mail for the individual to fill out. Approximately 13% of individuals contacted were successfully recruited into the study.

**Measures**

**Adult Survey Measures**

*TEACCH Adult Outcome Survey*. The survey was created by TEACCH to evaluate outcomes in adulthood. The 88-item survey measures various aspects of adult outcomes including language abilities, educational outcomes, living situation, hobbies and social activities, services used, employment outcomes, government benefits, and impact on the family.

*Anxiety, Depression, and Mood Scale* (ADAMS; Esbensen, Rojahn, Aman, & Reudrich, 2003). This scale assesses co-occurring psychiatric disorders for individuals with ID, which was helpful due to the large percentage of participants with ID. It is also useful for individuals who
have a difficult time communicating their symptoms. Manic/hyperactive behaviors, depressed mood, social avoidance, general anxiety, and obsessive/compulsive behaviors are all measured and scored separately. This 28-item scale uses Likert scale responses for each item ranging from 0 to 3, with 0 being not a problem and 3 representing a severe problem. The totals are then added up for each separate category, and the sums represent the severity for each category. The mean item-total correlation for Depressed Mood was .70 (SD=.07, range from .65 to .78), which is one way of measuring the reliability. Internal consistency, measured with Cronbach’s alpha, has a mean alpha coefficient of .80 for all subscales. The retest and interrater reliability for all scales were calculated using intraclass correlation coefficients (ICC) with a one-way random effects model. The retest reliability of all subscales was .81, which is considered exceptional, and the interrater reliability was .43, which was considered adequate.

Social Responsiveness Scale—Adult Version (SRS-A; Constantino & Todd, 2005; Constantino et al., 2003). The SRS was used to assess ASD symptom severity. This questionnaire has 65 items to measure the characteristics of the autism spectrum in adulthood. Each item is rated on a Likert scale ranging from 0-3. It is appropriate for both self-report and informed others. The higher the participant’s score, the more severe the impairments are. Scores range from 0 to 195. This assessment takes 15-20 minutes to complete. The test-retest reliability of the SRS was previously found to be 0.88 in clinical subjects, and the inter-rater reliability for the SRS ranged from 0.75 to 0.91 when compared to the Autism Diagnostic Interview-Revised (ADI-R). The SRS is a valid measure of symptom severity of ASD based on the strong correlations with the ADI-R.

Waisman Activities of Daily Living (W-ADL; Maenner, Smith, Hong, Makuch, Greenberg, & Mailick, 2013). The scale has 17 items measuring various activities involved in
daily functioning for individuals with developmental disabilities. The items are rated on a 0 to 2 scale measuring independence for each activity (0—does not do, 1—does with help, 2—does on own/independently). A few examples of activities include dressing, grooming, eating from a plate, etc. The W-ADL is considered to be highly reliable over time with weighted kappas between 0.92 and 0.93. Inter-rater reliability is also high with a weighted kappa of 0.88. The W-ADL shows high internal consistency with Cronbach’s alphas ranging from 0.88 to 0.94, with inter-item correlations ranging from 0.2 to 0.6. Additionally, the W-ADL scores were strongly correlated with the Vineland Screener Composite showing criterion validity ($r = 0.78$).

*Quality of Life Questionnaire* (QOL-Q; Schalock & Keith, 1993; Kober & Eggleton, 2002). The scale includes 40 items that measures various aspects of the quality of life of individuals with developmental disabilities including productivity, social interaction/community integration, satisfaction, and independence. It can be given as self-report or caregiver report. A Cronbach alpha coefficient of .81 showed that the overall reliability was very good. The questionnaire is considered valid based on highly congruent (above .94) coefficients of congruence in a factor analysis done across different populations.

**Childhood Clinician Ratings and In-Person Interviews**

*Child Autism Rating Scale* (CARS; Schopler, Reichler, DeVellis & Daly, 1980; Mesibov, Schopler, Schaffer, & Michal, 1989). The CARS is a rating scale used to diagnose autism. The scale ranges from 1 (normal) to 4 (severely abnormal). The scale includes 15 questions rating the children’s behavior to determine distinctions between children with ASD and children who have other developmental disabilities. Any score above 27 on the CARS is considered diagnosable for ASD. The data used for this study were collected during childhood at the time of diagnosis, and were collected in the TEACCH database. The CARS is indicated to be a highly
reliable measure with an alpha of .94 showing high internal consistency and interrater reliability of .71. A correlation of $r = .84$, $p < .001$, shows that the scale has high validity based on clinician’s perceptions of ASD.

Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla, & Cicchetti, 1984). The VABS is a scale used to assess different behaviors that are intended to measure personal and social functioning based on caregiver report. The items are to be rated from 0 to 2 (0-never performed, 1-sometimes or partly performed, 2-behavior is usually or habitually performed, N-child had never had opportunity to perform the activity, DK-caregiver does not know if child has performed the activity), indicating lower standard scores relating to more severe impairments. The VABS is considered to have high split-half reliability with correlations ranging from 0.92 to 0.96. The criterion-related validity between the composite score and social quotient is considered adequate based on a correlation of 0.55.

Procedures

Individuals who decided to participate provided informed consent. Once consent was given, the participant chose whether to complete the questionnaires online or using paper questionnaires. If the online option was chosen, a link was provided for the participant. If the participant chose the paper option, a packet was sent by mail including all of the questionnaires, as well as a pre-stamped return envelope. Each survey included a set of questionnaires used for the long-term outcome study for adults with ASD from TEACCH. The packet included the Adult Outcome Survey created by TEACCH, a health survey created by TEACCH, Anxiety Depression and Mood Scale, Waisman Activities of Daily Living, Social Responsiveness Scale – Adult Form, and the Quality of Life Questionnaire measuring global outcomes. Each survey packet, including both online and paper copies, was in that particular order, which was important.
to maintain consistency to avoid any change in the way participants would answer questions based on the order of the questionnaires. Although each of these questionnaires was included in the packet for the TEACCH study, this specific Master’s thesis only used the questionnaires described in the Measures section above. Once the participant was finished with the survey they clicked submit if the online option was chosen or sent the packet back by mail in a self-addressed return envelope if the paper option was chosen. For both methods, we re-contacted the participant if any items were incomplete. Once we received the questionnaire, participants were compensated $20 for their time.

Results

Descriptive Results

The mean age of the adults with ASD was 33 years old, ranging from 22 to 64. Of the 97 adults 81% were male, and 19% female, which was representative of the expected 4.5:1 ratio of male to female in this population. In terms of race, 84% were white, 16% were African-American, 2% were Asian, and 1% was American Indian or Alaska Native, with 2% of individuals identified as Hispanic or Latino. Additionally, 58% of the adults had a comorbid diagnosis of ID, slightly higher than the rate of ID in the general population of individuals with ASD (CDC, 2014). However, this rate is lower to the 70-75% rate of ID reported when the participants were originally diagnosed (APA, 1980, 1994). The percentage of individuals with a comorbid seizure disorder or epilepsy was 29% in this sample. This is very similar to 20-40% typically seen in the population with ASD (Malow, 2006; Tuchman & Rosanoff, 2011). Overall, this sample appears to be fairly representative of the general population of individuals with ASD diagnosed between 1965 and 1999.
**Childhood scores.** The child data can be found in Table 1 including scores for the CARS, childhood IQ, and Vineland Adaptive Behavior Scales. The mean score for the CARS was a 34.02, ranging from 15 to 58, showing a majority of the individuals’ scores (81%) were indicative of being diagnosable for ASD. The childhood IQ mean score was 62.53, ranging from 17 to 112. This shows that the mean score for IQ during childhood was below average intelligence. The mean standard score for the Vineland was 52.8, ranging from 16 to 137, which indicates substantial delays in adaptive skills that are even greater than the delays in intellectual functioning, a common pattern in ASD.

**Adult Scores.** Because the childhood measures were obtained through interviews and in-person testing, attempting to use the same assessment for each measure was not plausible. As a result, different assessments were used to measure similar constructs in survey form. Although the childhood and adult measures were not unquestionably related, the measures used for each construct were selected because they were most similar to the measures used in childhood. The adult data can also be found in Table 1. The SRS-A measures ASD symptom severity and is an adult measure similar to the CARS scores. The mean score for the SRS-A was 62.48, ranging from 4 to 138, showing that a majority of the adults were in the mild to moderate range of ASD symptom severity. SRS-A was not correlated with child CARS score, $r(67) = -0.15$, $p = .90$. The adult measure that best related to childhood intelligence was the Conversation measure. The question used to measure this variable was “How well does he/she carry on a conversation?” and was used in this study as a proxy measure of current intellectual functioning. A majority of the adults with ASD (60%) had a lot of trouble communicating or were not able to communicate at all. Conversation ability was strongly correlated with child IQ, $r(65) = +0.60$, $p < .01$. The score similar to the Vineland measuring adult daily living skills was the W-ADL, which showed
a mean score of 21.78, ranging from 3 to 34, which is lower than the mean score in the original sample of individuals with ID (28.3; Maenner et al., 2013). W-ADL was correlated with child Vineland, $r(60) = +0.48, p < .01$. Unrelated to the childhood data, the mean total score for the Quality of Life measure was 77.59, ranging from 53 to 115, suggesting that a majority of the adults were considered to have relatively low quality of life.

**Depression**

For this study, depression was measured in two different ways. One involved the measurement of whether the adult had ever had a depression diagnosis. The other measure was the score from the depression subscale in the ADAMS. In this sample, 11% of the adults were previously diagnosed with depression. As noted previously, the range in prevalence of comorbid depression and ASD is extremely variable. However, the percentage found in this study is within the expected range found in several related studies. The mean depression score in the ADAMS was 2.8, ranging from 0 to 20, indicating a relatively low level of current depression as reported by the caregiver. The relationship between the depression diagnosis and ADAMS Depression score was examined, first using a correlation analysis. The two measures for depression were found to be significantly correlated ($r(92) = .45, p < .01$), suggesting that the ADAMS Depression score and depression diagnosis measure similar constructs.

**Employment Statistics**

The percentage of individuals who were reported as having ever been employed was 64%, with 49% having a job in the last 2 years and 44% being currently employed. This shows that a large number of the adults had a job at one point since high school, but less than half of the adults were currently employed at the time of the study. The average number of hours worked per week for the adults was between 10 and 19 hours. The mean longest individuals held a job
was more than a few months and less than 1-2 years. Additionally, the vocational index score mean was 3.8 showing that factors related to employment such as levels of support, number of hours worked per week, and setting were relatively poor for this sample.

**Relational Analyses**

Correlation analyses were done to first examine the relation between the ADAMS depression score and measures of three kinds of functioning: intellectual, adaptive behavior, and ASD symptom severity. These results are found in Table 2. The ADAMS depression scale was not significantly correlated with either childhood intelligence ($r(62) = .14, p = .28$) and conversation ($r(92) = -.07, p = .53$). Additionally, the measures of ASD symptom severity were not significantly correlated with the ADAMS depression scale. However, the CARS score had a small correlation with the ADAMS depression scale that was trending toward significant ($r(67) = -.19, p = .11$) and may become significant with a larger sample. Finally, adult adaptive behavior (W-ADL) was related to ADAMS Depression score ($r(91) = -.25, p = .01$). However, the childhood measure of adaptive behavior (Vineland) was not related to ADAMS Depression score ($r(59) = -.16, p = .22$). One interesting pattern is that correlations were stronger, though non-significant, in childhood measures than adult measures for both symptom severity and intellectual functioning. Conversely, adaptive behavior in adulthood was more strongly related to depression compared to the childhood measure. For most measures of functioning (childhood IQ, conversation, CARS, SRS-A, Vineland), there were no significance correlations with the ADAMS depression scale. Based on these findings, neither childhood nor adult intelligence and symptom severity were predictors of depression in adults with ASD, but adult activities of daily living was significantly related to adult depression.
Next, relations between the ADAMS depression score and measures of participation in vocational and social domains were examined. These correlations are found in Table 3. Measures related to employment were found to be related to ADAMS Depression scores. The ADAMS Depression score was significantly correlated with vocational index \((r(91) = -0.23, p = 0.03)\) indicating that those with higher Vocational Index scores were less depressed on the ADAMS. Similarly, the more hours worked per week, the lower the depression score \((r(56) = -0.34, p = 0.009)\). However, the longest length of time that a job was held was not related to ADAMS Depression score \((r(92) = -0.16, p = 0.14)\). Finally, the relation between the amount of contact with friends and ADAMS Depression score showed these variables were unrelated \((r(92) = +0.01, p = 0.94)\).

Finally, the ADAMS Depression scores were compared for those with current jobs, those who previously held a job but were not currently employed, and those who had never worked. These results can be found in Figure 1. A one-way ANOVA was done to look at the main effect between these employment standings. There was a significant main effect for employment status on the ADAMS depression scale \((F(2, 90) = 7.63, p = 0.001)\). Additionally, the post-hoc test showed that there was a significant difference between those never employed and those previously employed \((p = 0.03)\) and between those previously employed and those currently employed \((p = 0.001)\). These findings indicate that depression scores are higher in individuals who have previously held a job but are currently unemployed than those currently employed or those never employed.

Next, independent samples t-tests were done to look at the effects of various employment factors on both ADAMS depression scores and ever having a depression diagnosis. However, no significant effects were found when the effect of having a depression diagnosis on the
employment factors of vocational index and number of hours worked per week were examined. These results can be found in Table 4.

Next, independent samples t-tests were done to investigate the relationship of the depression diagnosis to functioning. The results of these tests can be found in Table 4. While childhood IQ did not differ between those who had a depression diagnosis and those who did not, the depression diagnosis did have a significant effect on conversation ability with those who had a depression diagnosis having significantly better conversation abilities than those who did not have a depression diagnosis ($t(95) = 2.19, p = .03$). Although the W-ADL was the only functioning measure significantly correlated with the ADAMS Depression score, there was no significant effect in the independent samples t-test ($t(93) = -.85, p = .40$). Finally, childhood Vineland, CARS, and adult SRS-A also did not differ between those who were diagnosed with depression and those who were not.

Although there was no correlation between social participation and the ADAMS Depression score, a measure of social isolation was computed as those individuals who had no contacts with friends outside of structured group activities (church groups or social skills groups) in the past year. The relation of social isolation to ADAMS Depression score was examined. The results of the independent samples t-test demonstrated similar results, showing that there was not a significant difference in ADAMS Depression scores for those who were socially isolated compared to those who were not ($t(92) = -1.34, p = .19$).

Finally, a chi-square analysis was done to determine whether or not employment status was related to having a depression diagnosis. The chi-square test looked at employment status involving currently employed (14%), previously employed with no current job (21%), and never employed (3%). The results of the chi-square were not quite significant when examining
employment status and depression diagnosis ($X^2 = 4.61, p. = .10$). However, this interaction may become more significant with a larger sample size.

**Discussion**

The primary aims of this study were (1) to determine whether ASD related functioning throughout the lifespan was related to depression in adults with ASD and (2) to assess the strength of relation between factors of involvement such as employment and social contact with depression. The findings suggest that under some conditions functioning was related to depression in adults with ASD. For instance, intellectual functioning, both in childhood and adulthood, was not related to current depression symptoms. However, a proxy measure of adult intellectual functioning, conversation ability, was related to a previous diagnosis of depression; those with a depression diagnosis had better conversation abilities than those without. Furthermore, adaptive behavior functioning was related to current symptoms of depression, but not related to ever having a diagnosis of depression. Finally, neither child nor adult ASD symptom severity was related to having a depression diagnosis or current depression symptoms.

Most of the ASD functioning factors were unrelated to the ADAMS depression score. This included measures of intellectual functioning, symptom severity, and childhood adaptive behaviors. However, adult activities of daily living was significantly related to current depressive symptoms, in that individuals with higher scores on the ADAMS Depression scale were more likely to have lower scores on the W-ADL. This suggests that individuals with fewer adaptive behavior skills were more likely to show current depressive symptoms. Additionally, individuals with a depression diagnosis were significantly more likely to have better conversation abilities, indicating that individuals with higher adult intellectual functioning may have been better able to
discuss their emotions or may have been more aware of their distressing emotions and thus were referred for a mood assessment that resulted in a depression diagnosis.

As for the relation between depression and community outcomes, social contact was not found to have any significant relations with either current depressive symptoms or a depression diagnosis. However, employment measures were found to have strong correlations with current depressive symptoms measured by the ADAMS score. Specifically, higher depressive symptoms were linked to lower vocational index scores, current unemployment when previously employed, and fewer hours worked per week. This suggests that individuals more involved with employment have better quality of life due to an increase in feelings of productivity, self-worth, and independence.

The second measure of depression used in this study was whether or not individuals were ever diagnosed with depression. While currently being employed was not related to a diagnosis of depression throughout the lifespan, having a job at any time since high school was related. This suggests that the individuals most likely to be diagnosed with depression were those who had formerly held a job in the past but who were not currently employed. Upon further investigation, those who previously had a job but who were not currently employed were found to be more likely to have higher ADAMS depression scores than those currently employed or those who had never held a job. This suggests that individuals who have had past work experience, but are either unable to maintain employment or are no longer able to work have a higher likelihood of showing symptoms of depression. More research needs to be done on the relationship between a diagnosis of depression, as well as ADAMS depression scores throughout the lifespan and current versus past employment.
Examining the relationship of employment and depression even further, number of hours worked per week appeared to have the strongest relation to depression. Individuals who work more hours during the week scored lower on the ADAMS scale, suggesting that work may be decrease depressive symptoms or that people who are not depressed are able to work more. The measure of vocational index, which takes into account several different factors related to employment including hours worked per week, setting, and amount of independence (Taylor & Seltzer, 2012), was also related to current depression scores with more competitive, independent employment being linked to lower rates of depression.

As previously discussed, research on adults with ASD is very limited. Nevertheless, the findings in the current study can be related to other research. The current study found only a slight relationship between intellectual functioning and depression, specifically between conversation abilities in adulthood and depression diagnosis. However, the relationship to depression was marginal in comparison to what is often seen in research on children and adolescents with ASD. Those studies find that better intellectual functioning may be related to greater depression in children and adolescents (Ghaziuddin et al., 2002; Mayes et al., 2011; Puow et al., 2013). The results in the current study may be less robust due to several factors. First, the current study had a smaller percentage of high functioning individuals. This may have made it more difficult to examine depression in high functioning versus low functioning individuals. Another reason for the difference may be a shift from societal value in intelligence and academics in childhood to societal value in community participation and employment in adulthood. Finally, the difference may lie in the ADAMS as a measure of depression. Because it is designed to measure depression symptoms in individuals with ID, it relies on symptoms that are not necessarily verbal, which may make the lower functioning individuals in the study show
more depressive symptoms than other studies and therefore similar to higher functioning individuals.

The current study also found that social participation was minimally related to depression. Past studies have shown that lack of social participation and loneliness increase the risk of depression in adults with ASD (Mazurek, 2014). The difference in the current study may be due to the measures of social participation. While the amount of contact with others provides a great deal of information on social participation, it may not sufficiently measure social participation. For instance, most of the participants in this study lived at home, in group homes, or in intermediate care facilities. The important social contacts for these individuals may not be friends, but instead family, caregivers, and other residents. Social participation with these individuals is not reflected in the social participation measure. Additionally, the difference may lie in the smaller sample represented in the current study. The relation between social contact and depression was in the hypothesized direction, but the results were not quite significant. As data from more participants is collected, these results may become significant.

The current findings related to employment are consistent with the literature in that community inclusion in the form of employment was related to lower risk of depression in adults with ASD (Garcia-Villamisar et al., 2002; Mayes & Calhoun, 2011; Persson, 2000). This relation brings up the question of directionality. One perspective could be that employment decreased depression symptoms because of the increased social contact and increased sense of purpose. Alternatively, depression could result in difficulty maintaining a job, which ultimately caused poorer outcomes for employment. Most likely, this relation is bidirectional, meaning both perspectives are probably true. While the current study is consistent with the literature on depression in adults with ASD and provides some insight into employment and depression, more
research should be done on the direction of these effects, as well as other related factors, in adulthood.

**Limitations**

One of the main limitations of this study is the difference between child and adulthood measures. The main reason for this difference is due to the nature of the measures, with childhood measures relying on in-person interviews and clinician ratings and adult measures relying on survey. Next, the sample size was relatively small compared to the amount of individuals diagnosed and seen at TEACCH. As previously discussed, including a larger sample size may have increased significance values for different analyses. Finally, the rates of depression within this sample were relatively low, making it difficult to detect robust relations and results within the sample.

**Implications**

Implications of this study stretch far beyond the domain of understanding depression in adults with ASD. Results showing a significant relationship between employment and depression are crucial in considering interventions for individuals with ASD and co-occurring depression. This information is important for rehabilitation counselors, job coaches, and other professionals who help individuals involved in the process of vocational rehabilitation because it puts more weight on the importance of meaningful and fulfilling employment for individuals with ASD. Similar to the general population, employment has been shown to improve quality of life in individuals with ASD, so more attention should be paid to interventions related to employment both as a means of boosting quality of life as well as mental health.

One of the main interventions available that would benefit individuals with comorbid ASD and depression would be supported employment. This type of intervention is an evidence-
based practice that allows the individual to be competitively employed, while still having the support and assistance essential to completing certain job tasks. One of the main goals of supported employment is helping the individual move towards independence in the work place. According to the National Alliance on Mental Illness (NAMI, 2003), 40-60% of individuals involved in supported employment become competitively employed. This rate of success in helping individuals become more independent in employment shows that supported employment could be a very beneficial intervention to decrease depression in individuals with ASD.

However, in the past supported employment options for individuals with ASD have been very limited due to its original focus on individuals with ID. In order to provide more individualized services to adults with ASD exploring employment options, TEACCH developed a supported employment program specific to individuals with ASD.

Within the TEACCH supported employment program are three different models: individual placement model, dispersed enclave model, and mobile crew model (Keel, Mesibov, & Woods, 1997). The models differ based on varying levels of independence of the individual needing services, with the individual placement model requiring more independence and the mobile crew model requiring the least. The individual placement model requires a job coach who helps to identify a job, provide training on the job, and eventually fade out of the job location to move the individual towards further independence. The dispersed enclave model involves one job coach at a job supervising and training several individuals with ASD. Finally, the mobile crew model involves a job coach training two to three individuals with ASD while providing a service in the community. This model is preferred for individuals who “are less independent and may have behavior difficulties” (Keel et al., 1997, p. 5). Having multiple levels of support for individuals is very helpful in an effort to create a more individualized program for
individuals with ASD, as well as to provide the opportunity to progress between these models. Additionally, long-term support is provided even after a job coach has ceased training on-the-job in order to ensure long-term success. The success of this supported employment program is attributed to this emphasis on long-term support due to the need for routines and predictability in the daily lives of individuals with ASD, regardless of independence level (Keel et al., 1997).

From when the TEACCH supported employment was developed in 1989 until 1997 when Keel, Mesibov, and Woods reviewed the program, there was an 89% retention rate for individuals within the program (1997). Additionally, the average number of hours worked per week was 28.6, with a majority of the individuals going through the individual placement model (72%; Keel et al., 1997). Although the success of this program is shown only for the first 100 individuals utilizing the services, over 500 individuals with ASD have gained employment through TEACCH supported employment since the supported employment program was developed in 1989 (TEACCH, 2015), which helps to show the continued success of the program. Based on the success rates of this program and the knowledge that employment is related to depression rates, more emphasis should be put on involving individuals in interventions such as supported employment.

The importance of these results is that finding fulfilling employment for individuals with ASD can decrease depressive symptoms and help to improve quality of life. In addition to supported employment, an intervention focusing on depressive symptoms may be beneficial. Because this relation between employment and depression may be bidirectional, focusing on one or the other may not be as effective as working on both simultaneously. Adding interventions focused on decreasing depressive symptoms to supported employment may be an additional opportunity to increase the chance of success for the individual and to increase employment...
outcomes. Incorporating depression interventions with supported employment may include several different approaches. One may involve a screening process through the job coach for depressive symptoms, ultimately leading to a referral for interventions to address depressive symptoms while the individual is also involved with supported employment. However, another approach to incorporating depression interventions involves the role of rehabilitation counselors in supported employment to provide an integrated treatment. Although job coaches have qualifications and training in supported employment, most are not qualified to provide interventions for depression. Starting from a foundation of vocational rehabilitation, rehabilitation counselors are a unique type of counselor trained to work towards community integration, employment skills, and mental health issues, providing a holistic perspective to treatment. Rehabilitation counselors may be the best possible interventionists for this integrated treatment for individuals with both depression and ASD based on the well-rounded training. Additionally, rehabilitation counselors may need further training on working with individuals with ASD to help increase knowledge and skills in working with this specific population.

Rehabilitation counselors providing integrated treatment may be more beneficial than providing each intervention simultaneously with different providers for many reasons. First, the individual will have one less service provider, making the process less complex. By integrating treatments, the individual will be able to decrease the number of services utilized, making the process of intervention more simplified. Next, the intervention will be much more efficient. Because one rehabilitation counselor would be working on both interventions, the training involved could incorporate both interventions at the same time. This might also decrease the amount of time in treatment compared to being in two separate interventions. Additionally, the rehabilitation counselor would be aware of what skills the individual is working on to ensure that
the interventions do not contradict one another. Finally, the rehabilitation counselor will be more understanding of the individual’s unique needs because the rehabilitation counselor will be involved in both interventions.

**Conclusion**

As more individuals with ASD are becoming adults, a better understanding of specific outcomes is necessary to provide high quality services. Adults with ASD are frequently experiencing co-occurring mental health symptoms, specifically depression, which makes it difficult for service providers to make the most beneficial services available for this unique population. In order to provide these individualized services, professionals must first be aware of the factors related to depression in adults with ASD. Employment appears to have the strongest relation to depression, along with activities of daily living in adulthood and conversation ability. This highlights a need for integrated treatment in working with individuals towards gainful employment. Additionally, more research should be done to determine directionality of the relation between employment and depression. Further research should also be done to look into training rehabilitation counselors for working with individuals with ASD to provide the most integrated treatment possible.
APPENDIX 1: TABLES OF DATA FINDINGS

Table 1

_Sample Means and Standard Deviations_

<table>
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<th></th>
<th>Mean</th>
<th>Standard Deviation</th>
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*Note.* Mean number of hours worked per week is between 10-19 and 20-29 hours. Mean length of employment is between a few months and 1-2 years.
Table 2

*Pearson’s Correlations between Functioning and ADAMS Depression Score*

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<th>Significance (p value)</th>
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Table 3

*Pearson’s Correlations between Participation and ADAMS Depression Score*

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Table 4

Independent Samples t-Test with Depression Diagnosis

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<th>Mean Score (Not Depressed)</th>
<th>t</th>
<th>Significance (p value)</th>
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Table 5

Impact of Employment on ADAMS Depression Score

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<th>Employment Status</th>
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<tr>
<td>ADAMS-D</td>
<td>1.7 (2.4)</td>
<td>5.2 (4.9)</td>
<td>2.8 (2.9)</td>
<td></td>
<td>$F(2,90) = 7.63$</td>
<td>.001</td>
</tr>
</tbody>
</table>

*Note.* Standard Deviations are in parenthesis below the mean.
Comparing ADAMS Depression Scale means with Employment Status

- Never Employed: N = 34, Mean = 2.79
- Previously Employed: N = 19, Mean = 5.16
- Currently Employed: N = 40, Mean = 1.65
APPENDIX 3: 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?

<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>2-3 Times/Week</th>
<th>1 Time/Week</th>
<th>1-2 Times/Month</th>
<th>&lt; 1 Time/Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email/Text Phone Call</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>In-Person Visit</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

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...?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work, homework, or school assignments</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Playing games</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Internet</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Recreation and hobbies</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

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...

<table>
<thead>
<tr>
<th>Has a driver's license?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drive independently on a regular basis?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Receive money that he/she can decide how to spend?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Have a savings account?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Have a checking account where he/she write checks or use a debit card?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Have a credit card or charge account in his/her name?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Registered to vote?</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
37. Has he/she ever been...

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arrested?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>On probation or parole?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Arrested in the last 2 years?</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Stopped and questioned by the police in the last 2 years?</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
38. Has the adult received any of the following services since high school? (check all that apply)

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help in finding a job, training in job skills or vocational education, other than from an employer</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Job coaching</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Financial Aid, like paying for college classes or training</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Educational assistance or tutoring (e.g., college disability services)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Instruction or help with independent living skills (e.g., managing money, cooking), NOT including instruction from family members or friends</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Psychological or mental health services or counseling</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Social work services</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Assistive technology services or devices (e.g., special calculator, reading machine, or augmentative &amp; alternative communication device (AAC))</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Transportation assistance because of disability</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medical services for diagnosis or evaluation related to his/her disability</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Speech or language therapy, or communication services</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Audiology services for hearing problems</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Respite care</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Housing assistance or residential services or help with a supervised living arrangement (e.g., a group home)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Personal assistant or in-the-home aid</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Nursing care</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
38(2). Has the adult received any of the following services in the last two years? (check all that apply)

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

<table>
<thead>
<tr>
<th>Training/Help Provided</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using Transportation</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Home care skills, such as cooking and cleaning</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Financial issues, such as managing his/her money</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Self-care skills such as brushing his/her teeth</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Relationship skills, such as getting along with others</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Self advocacy skills (e.g., talking to others about autism diagnosis)</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

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...

<table>
<thead>
<tr>
<th></th>
<th>In the last 2 years</th>
<th>Currently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supplemental Security Income</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>(SSI/SSDI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporary Assistance to</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Needy Families (TANF)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food Stamps</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medicare</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medicaid</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Any form of health insurance</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
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)?

<table>
<thead>
<tr>
<th>Service</th>
<th>Ever used</th>
<th>In the last 2 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselor or psychologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician or medical professional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advocacy agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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
APPENDIX 4: ANXIETY DEPRESSION AND MOOD SCALE (ADAMS)

Please describe the individual’s behavior over the past 4 weeks.
- behavior has not occurred, or is not a problem
- behavior occurs occasionally, or is a mild problem
- behavior occurs quite often, or is a moderate problem
- behavior occurs a lot, or is a severe problem

<table>
<thead>
<tr>
<th></th>
<th>Not a Problem</th>
<th>Mild problem</th>
<th>Moderate problem</th>
<th>Severe problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nervous</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Problems initiating communication</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Does not relax or settle down</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Has periods of over-activity</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Sleeps more than normal</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Withdraws from other people</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Tense</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. Engages in ritualistic behaviors</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. Depressed Mood</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. Sad</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. Worried</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. Has difficulty staying on task or completing work</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13. Shy</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>14. Easily fatigued (not due to being overweight)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>15. Anxious</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16. Repeatedly checks items</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17. Easily distracted</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>18. Lacks energy</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>19. Avoids others, spends much of time alone</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>20. Easily upset if ritualistic behaviors are interrupted</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>21. Lacks emotional facial expressions</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>22. Has shown difficulty in starting routine tasks</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>23. Listless</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>24. Experiences panic attacks</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>25. Avoids eye contact</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
The next 8 items are additional behaviors that may be a problem for individuals with Intellectual Disabilities. Please answer in terms of the individual’s behavior over the past four weeks.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not a Problem</th>
<th>Mild Problem</th>
<th>Moderate Problem</th>
<th>Severe Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Attacks or threatens others</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>2. Deliberately damages property</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>3. Excessive drinking or excessive use of drugs</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>4. Experiences and/or expresses anger in ways that are inappropriate for the situation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>5. Acts without thinking</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>6. Repeatedly injures own body on purpose</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>7. Seriously thinks about killing himself/herself</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>8. Angry outbursts when frustrated or disappointed</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

### APPENDIX 5: VOCATIONAL INDEX SCORING MATRIX

Vocational Index, from most to least independent

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

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


