THE RELATION OF SOCIAL ACTIVITY TO INTERNALIZING DISORDER IN ADULTS WITH AUTISM

Katherine Clary

A thesis submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Science in the Department of Allied Health Sciences in the School of Medicine (Clinical Rehabilitation and Mental Health Counseling).

Chapel Hill
2016

Approved by:
Mark R. Klinger
Laura G. Klinger
Dara Chan
ABSTRACT

Katherine Clary: The Relation of Social Activity to Internalizing Disorders in Adults with Autism
(Under the direction of Mark R. Klinger)

Persons with autism spectrum disorder (ASD) have high rates of comorbid anxiety and depression. The purpose of this study was to test whether increased social activities is associated with reduced anxiety and depression symptoms and higher Quality of Life in adults with ASD. A survey was conducted of 189 caregivers of adults with autism who were diagnosed as children. The survey included measures of mental health diagnoses including anxiety or depression, internalizing symptom severity using the Anxiety, Depression and Mood Scale (ADAMS), and a number of questions about social activities. These social activities questions were combined to create a social activity index and a friends activity index. It was predicted that internalizing symptoms and Quality of Life would be affected by the number and kind of social activities in which the individual was involved and by the level of functioning of the individual. Results showed that friends based activities were related to functioning level and that social activities increased the sense of belonging, life satisfaction, and empowerment on a Quality of Life measure. Effects of specific social activities on symptoms of anxiety and depression were also discussed.
# TABLE OF CONTENTS

LIST OF TABLES .................................................................................................................... vi

LIST OF ABBREVIATIONS ..................................................................................................... vii

INTRODUCTION .................................................................................................................... 1

Importance of Social Interactions and Friendships .............................................................. 1

Friendships and Social Activity in Individuals with ASD ..................................................... 3

Presence of Anxiety and Depression in Individuals with ASD ............................................ 7

The Present Study .................................................................................................................. 8

METHODOLOGY .................................................................................................................. 10

Participants ............................................................................................................................ 10

Measures ............................................................................................................................... 12

Procedure .............................................................................................................................. 15

Analysis ................................................................................................................................. 15

RESULTS ............................................................................................................................... 17

Relation of ASD Characteristics to Social Activity ......................................................... 18

Relation of Internalizing Symptoms to Social Activity .................................................... 19

Relation of Quality of Life to Social Activity .................................................................... 20

DISCUSSION ........................................................................................................................ 22

Limitations of Present Study ............................................................................................... 27
Implications for Further Research.................................................................................. 28
Implication for Rehabilitation Counselors .................................................................. 30
Conclusions .................................................................................................................... 34

APPENDIX 1: TABLES OF DATA FINDINGS.................................................................. 35
APPENDIX 2: TEACCH AUTISM IN ADULTHOOD SURVEY .......................................... 39
REFERENCES ...................................................................................................................... 59
LIST OF TABLES

Table 1  Frequency of Social Activity and Contact with Friends ..................................................33

Table 2  Sample Means and Standard Deviations ........................................................................34

Table 3  Pearson’s Correlations between Social Activity and
        ASD Characteristics ........................................................................................................35

Table 4  Pearson’s Correlations between Social Activity, Quality
        of Life, and Internalizing Symptoms .............................................................................36
# LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADAMS</td>
<td>Anxiety, Depression, and Mood Scale</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>CARS</td>
<td>Childhood Autism Rating Scale</td>
</tr>
<tr>
<td>QOL-Q</td>
<td>Quality of Life Questionnaire</td>
</tr>
<tr>
<td>RRB</td>
<td>Repetitive and Restrictive Behavior</td>
</tr>
<tr>
<td>SCI</td>
<td>Social Communication Inventory</td>
</tr>
<tr>
<td>SRS-2</td>
<td>Social Responsiveness Scale-2</td>
</tr>
<tr>
<td>W-ADL</td>
<td>Waisman Activities of Daily Living Questionnaire</td>
</tr>
</tbody>
</table>
CHAPTER 1: INTRODUCTION

Autism Spectrum Disorder (ASD) is characterized by difficulties in many areas of life, including communication skills, social interactions, restricted behaviors and interests, activities of daily living, and mental health (Autism Speaks, 2015). In just over twenty years, the incidence of ASD has gone from 1 in every 1,000 births to 1 in 68 births. As this population ages, it will be important to learn how to best accommodate the surrounding environment to result in the most independence, empowerment, and fulfillment in the lives of adults with ASD.

Because ASD is a spectrum disorder, it manifests differently in each individual. While some adults live independently, work, and fully incorporate themselves into society, others rely on family or other caregivers to assist with most activities of daily living for their entire life, thus limiting their ability to engage in social activities. In addition to the social communication and repetitive behavior deficits typical of ASD, persons with ASD also experience many co-morbid disorders including anxiety, depression, attention disorders, and seizures (Bellini, 2004), potentially further limiting their ability to participate in social activities. This study will examine the relationship between social activity and the presence of internalizing symptoms such as anxiety and depression in adults with ASD.

Importance of Social Interactions and Friendships

When considering the neurotypical population, we find that social interactions and friendships serve many purposes as we move into adulthood. Woodhead, Faulkner, and Littleton
(1999) explored several of the purposes friendships have for adolescents. They described three main roles of friendships: companionship, belonging, and identity formation. As teenagers move from relying on their parents, they seek to find a social network in which to surround themselves. As they age, they have fewer interactions with parents and seek companionship and belonging with peers who become friends (Woodhead, Faulkner, & Littleton, 1999). Adolescents typically have more than one peer that they would consider a “best friend” (Woodhead, Faulkner, & Littleton, 1999). The researchers reasoned that this helps protect an individual against isolation given any number of situations that could befall a best friend pairing.

Shulman (1993) reviewed studies of friendships in adolescence. The studies showed that adolescents value self-disclosure, openness, and affection in their friendships. An ideal friendship was described as one in which all parties work together in a mutually beneficial way (Shulman, 1993). Another important facet of friendship involves the ability to work through conflict, and maintain friendships through challenging times.

Friendships evolve and values shift over time. Nelson, Thorne, and Shapiro (2011) studied the values held by same-sex friends in college. They found two different kinds of friendships: matched and contrasting personalities. In friendships that were matched, commonalities between the two were celebrated. Friendships based on differing personalities, called contrasting friendships, typically involved finding ways to incorporate and celebrate differences within the friendship. The authors cited many studies that claimed that people most often choose friends and romantic partners with whom they shared similar personalities. These similar traits serve as reinforcement within the relationship. Studies were also cited in which researchers found that friendships between very differing personalities worked when these different personalities complemented each other (Nelson, Thorne & Shapiro, 2011).
Peer interactions and friendships serve a long-term purpose. A study by Bulkowski, Hoza, and Boivin (1993) found that problems in emotions and behaviors in adulthood could be linked to poor peer relationships in early adolescence. The research found that over the course of a child’s development, the importance of friendship shifted from popularity in childhood to reciprocal friendship in adolescence. They found that younger children depended on being accepted (rated as “liked” by others) whereas teenagers were more concerned about the intimacy of a friendship. However, the literature shows that both popularity and intimacy are essential components of an individual’s development into a well-adjusted adult.

The effects of friendships continue into adulthood. We can see ramifications of this in adult mental health and depression. In a study by Kawachi and Berkman (2001), being involved socially was psychologically beneficial to adults, showing similar benefits as seen in adolescents. Among the benefits studied, the researchers found improved sense of purpose, belonging, and self-worth. Kawachi and Berkman interpreted this research within a stress-buffering model. The study posited that having a support system can help keep an adult from responding to a stress-inducing event negatively. Knowing that support is available and receiving social support can help individuals recognize more positive views of various situations. This can help create responses that lend toward being more positive and can help maintain mental health.

**Friendships and Social Activity in Individuals with ASD**

Orsmond, Shattuck, Cooper, Sterzing, and Anderson (2013) studied reciprocal friendships in adolescents and young adults with ASD and their typically functioning peers. In comparison to young adults with other developmental disabilities, many individuals with ASD reported never spending time with friends (39%), not having friends who called (47%), and never being included in social activities (48%). These rates were much higher than for
individuals with other developmental disabilities. In terms of social isolation, the group with ASD was 3 to 14 times more likely to have no involvement with activities other than groups with other individuals with developmental disabilities (Orsmond et al. 2013).

Kuo, Orsmond, Cohn, and Coster (2011) conducted a study looking at the content of friendships for adolescents with ASD, both from the perspective of the adolescent and a parent. Nearly all teens (96%) claimed to have at least one friend, but there was a 10% discrepancy in the percentage of parents who said their child had at least one friend (86%). The amount of agreement between parent and teen about who was the teen’s best friend was only 60%. They found that the 26% of the sample who disagreed with their parents had a higher severity of symptoms than the teens who agreed with parents (Kuo et al. 2011). This seems to indicate that individuals with ASD may have differing criteria for what makes someone a friend than those around them. This study also showed the possibility that symptom severity may be a hindrance to establishing meaningful friendships. Most of the friends that were reported were of the same gender as and a year younger than the teen with ASD. However, the researchers also found that as the teen got older, both the number of friends and the number of same gender friends diminished (Kuo, Orsmond, Cohn & Coster, 2011). The reports from teens and from their parents were similar in this regard. Additionally, parents included information that 56% of their children’s friends also had some sort of disability (Kuo, Orsmond, Cohn & Coster, 2011).

Finally, Kuo et al. (2011) found that teens with ASD who had more friends considered their friendship with their best friend to be closer. Also, friendships with girls were more likely to be ranked as close and helpful. Less conflict was reported with school friends than was reported with childhood friends and friends who were siblings. When spending time with their friends, teens with ASD reported very similar activities to most other teenagers. The adolescents
with ASD played video games, engaged in physical activity (swimming, running, etc.), had conversations with, ate with, and watched television with their friends.

Social impairment is one of the key diagnostic features of ASD. Some central social impairments of people with ASD are an inability to make eye contact, a hard time initiating and maintaining social contact, and learning how to celebrate the accomplishments of others (Ormond, Krauss & Seltzer, 2004). Other difficulties include reading emotional expression, understanding social cues, and an inability to read humor, clichés, or sarcasm used in conversation. In addition to difficulty instigating contact with others, individuals with ASD are often overlooked for social interactions by others.

Ormond, Krauss, and Seltzer (2004) reviewed literature in which they found that individuals with ASD often have a hard time finding a typical relationship in the same way their peers are able. They cited Bauminger and Kasari’s study (2000) that found that children and adolescents with ASD who claim to have friends still report feelings of loneliness, or often cannot find a way to describe the abstract concept of friendship. Other studies have found that though social interactions remain complicated, most adults with autism have developed social skills and interests during adolescence, particularly with other adults such as parents and teachers (Mesibov, 1983; Mesibov & Handlan, 1997; Rutter, 1970; Volkmar & Klin, 1995; Travis &Sigman, 1998; Volkmar, 1987).

Ormond, Krauss and Seltzer (2004) examined environmental factors that were related to social contacts. In particular, two factors were examined, family involvement and services received. For instance, many adults and adolescents who have ASD live with their families for much longer than their typically functioning counterparts. Therefore, many of their social activities are strongly influenced by their parents’ choices. What Ormond and colleagues found
was that adults with ASD were often involved in a “spillover” of the interactions of their caregivers, particularly their mothers. That is, adults with ASD often do not have a social network of their own but instead are only involved in the social network of their caregivers. For instance, an adult with ASD may go with his/her mother to church groups, grocery shopping, dinner with her friends, or line dancing. These could be the primary social interactions this adult has.

Additionally, an adult with ASD’s social circumstance may be strongly influenced by the community programs. If an individual goes to a community recreation facility, skills-training program, or other teaching facility, that involvement will strongly affect the social interactions of the adult. An individual’s social contacts may be largely defined by their parent’s interactions and their community programs. This study showed that over half of the participants did not report having any reciprocal, mutually-benefitting peer relationship outside of their home (Orsmond, Krauss, & Seltzer, 2004). A quarter of the participants met the requirements for having peer relationships inside a predetermined setting (such as at a community program), and a fifth of the participants had other peer relationships outside of the home or community setting (Orsmond, Krauss, & Seltzer, 2004). Only 23% of the participants of this study went to a social gathering with a relative at least once a week.

Orsmond and colleagues (2004) also examined the predictors of successful peer relationships. They found that adolescents and those who experienced less social impairment were more likely to be involved in peer relationships. While age of the individual showed a relationship with likelihood of peer relationship, age did not play a part in the likelihood of social activity. However, there were several factors that did influence social participation. These
factors included: higher levels of independence, better social skills, and a higher level of social activity by the participant’s mother (Orsmond, Krauss, & Seltzer, 2004).

An additional and surprising factor was that higher rates of internalizing behavior led to increased social participation than those who showed more externalizing behaviors. Internalizing behaviors are behaviors involving the individual only, such as self-injurious behaviors like hitting self, biting self, etc. or emotional experiences such as anxiety or depression, compared to external behaviors such as aggression toward others, property destruction, etc (Heyvaert, Saenen, Campbell, Maes, Onghenal, 2014). Three quarters of Orsmond’s (2004) sample engaged in recreational activities that did not require the participant to engage socially. The results from this study left researchers questioning the motivations of individuals with ASD for social interaction in relation to reports of loneliness.

**Presence of Anxiety and Depression in Individuals with ASD.**

Anxiety and depression are both classes of internalizing disorders. There are multiple kinds of anxiety disorders and depressive disorders. These include Generalized Anxiety Disorder, Obsessive Compulsive Disorder, Disruptive Mood Dysregulation Disorder, and Major Depressive Disorder, among others. Tantam (2000) reviewed the literature and reached the conclusion that anxiety and depression can manifest as a result of the rejection and isolation individuals with ASD feel because of their own social impairments. This study showed that adolescents with high functioning autism experienced significantly more anxiety than their counterparts who were typically functioning, and around half of the sample experienced clinically significant social anxiety (Bellini, 2004).

White, Oswald, Ollendick, and Scahill (2009) studied the appearance of anxiety in individuals with autism, starting in childhood. In their review of 40 articles, the researchers
found that between 11% and 84% of children with ASD had anxiety that impaired their functioning on some level, and that just over half of individuals (55%) met criteria for at least one anxiety disorder. White and colleagues (2009) suggested that as children become adolescents, they become more acutely aware of their social differences from their counterparts, which could in turn lead to more anxiety. A study by LaGreca and Lopez (1998), reasoned that social anxiety may be caused by social impairments because individuals have had bad experiences interacting with others.

The Present Study

The present study examined the relationship between social activity (including activity with friends) and anxiety and depression and Quality of Life in adults with ASD. One purpose of this study was simply to describe what the social activities of adults with ASD are like. Related to this, this study examined how characteristics associated with ASD, including repetitive behavior and social symptoms and intellectual functioning are related to social activity. This will help better understand which adults with ASD are more socially active and which are less. Finally, past research has shown that anxiety and depression are commonly co-morbid diagnoses in individuals with ASD that may be related to social activity. This study examined this relation which may be bi-directional. That is, anxiety and depression may cause an individual to be less socially active, and being less socially active may increase anxiety and depression symptoms. Finally, the relation between social activity and Quality of Life was examined.

This study was part of a larger study conducted at the TEACCH Autism Program at the University of North Carolina at Chapel Hill. This larger study investigated the outcomes of adults with ASD who were diagnosed with autism by TEACCH as children and childhood and
predictors of these outcomes. The major goal of this larger study and the present study was to describe the lives of adults with ASD in society today.

Research Goals

The goal of this study is learn more about social activities in adults with ASD. This study looked at what social activities adults with ASD were involved in and how they were related to other constructs:

1. How often are adults with ASD participating in social activities, and in what kind of social activities are adults involved?
2. What is the relation of characteristics of ASD (symptom severity, IQ scores, daily living skills) to number and types of social activities?
3. What is the relation of social activities to internalizing mental health symptoms?
4. What is the relation of social activities to Quality of Life?
CHAPTER 2: METHODS

Participants

Participants were 189 caregivers of individuals diagnosed with an ASD by clinicians at the UNC TEACCH Autism Program between 1969 and 2000. TEACCH began in 1965, was funded by the state of North Carolina in 1972 (UNC School of Medicine 2014), and currently has seven regional outpatient clinics throughout North Carolina. The participants recruited for this study were age 21 years or older and received an ASD diagnosis by TEACCH during childhood. A power analysis using the G Power Software showed that, with a sample size of 189 participants, this study had 99% power to detect medium effect size relations ($r = .3$) between social activities and ASD and mental health symptoms.

Participants for this study were recruited from a clinical database of over 7,000 individuals who were seen at the UNC TEACCH Autism Program between 1965 and 2000. Names of individuals were obtained from clinical records at TEACCH. Once an individual was deemed eligible from his/her clinical records, an online software was used to locate the most recent registered address for either the individual, a family member, or another primary contact. If available, a phone number associated with the address was also noted. After an address was found, a letter about the study was sent to the address. If the participant did not respond to this first contact, a phone call was made to follow up in two weeks. Participants received $20 for completion of the survey to compensate for their time.
From the records representing 7,000 individuals, the recruitment pool for the study was approximately 3,200. The sample used for this study came from the sample recruited for a larger study conducted by TEACCH about adult outcomes for individuals with ASD. In order to study outcomes in adulthood, it was important to have a mean age as close to 30 as possible, so recruitment efforts centered on the oldest established centers first, and then moved chronologically to the more recently opened regional centers.

There was an attempt to find contact information for 3,226 individuals, 1,710 were attempted contact by mail. Of that total, 529 made contact by phone, 270 never responded to a voicemail message, 727 did not have a correct phone number to make contact, and 184 letters were returned. Of the 529 for which contact was made, 408 were enrolled. This breaks down to 408 caregivers and 44 adults. Of the 408 who were enrolled, 316 surveys were competed, which breaks down to 284 caregivers and 32 adults, representing 293 unique individuals. The sample used for this study represents the first 189 individuals from the 284 caregivers who completed the study.

The sample for the present study was 80% male, close to the 4.5 ratio of males to females seen in ASD. The sample was 78% identified at Caucasian, 19% identified at African American, and the remaining 3% identified as other races. These race percentages represent the population of North Carolina from the 1970s to the 1990s. The information regarding mean age at the time of the study, childhood IQ scores and Childhood Autism Rating Scale scores at first diagnosis by TEACCH are seen in Table 1.

Measures

TEACCH Autism in Adulthood Survey. This 87 question survey focuses on measuring a wide variety of aspects of contemporary lives of adults with autism including communication
skills, employment, activities of daily living, social interactions, benefits, services needed and used, and family financial situation. This thesis will use the questions about the adult’s social activities, mental health diagnoses, and conversation ability. This survey is included as Appendix 2. Included in the survey, on question 12, was a measure of current conversation ability. Conversation ability was coded as a proxy for IQ level. Table 2 shows the mean and standard deviation for this section of the survey. Conversation ability was measured on a scale from 1 (does not carry on a conversation at all)—4 (has little trouble).

Anxiety, Depression and Mood Scales (ADAMS). The ADAMS was developed to measure depression and anxiety in individuals with intellectual disability (Esbensen, Rojahn, Aman, & Ruedrich, 2003). There are 55 items on the ADAMS covering 5 areas, including depression and generalized anxiety. After conducting tests for interrater reliability, Esbensen and colleagues also tested the validity of the scale using 129 participants. These tests led to conclusions that the ADAMS was both valid and reliable. The internal consistency ranged from .75-.83 with a mean of .80, interrater reliability had a mean correlation of .48, and test-retest reliability of .78. The study by Esbensen and colleagues (2003) measured means and standard deviations for each subscale of the ADAMS grouped by disability. For those diagnosed with ASD, the mean for the Generalized Anxiety subscale was 5.12 with a standard deviation of 3.34. The depression subscale had a mean of 3.85 for individuals with ASD and a standard deviation of 2.67.

Social Responsiveness Scale: Second Edition (SRS-2). The second edition of the SRS-2 was designed to identify the social deficits specific to ASD and detect the severity of these deficits. A caregiver or another adult with a close relationship to the individual with ASD completed the scale. The SRS-2 is appropriate for individuals 2.5 years of age through
adulthood (Constantino, 2015). The 65 items on the SRS-2 are rated from 1 to 4, with 1 meaning the statement is untrue and 4 meaning the statement is mostly true of the individual. Statements on the SRS-2 assess the individual’s ability to read expressions, social cues, personal space, conversational volume, rigidity, and comfort level in social interactions. The internal consistency for all forms of the SRS-2 range from .92-.95. SRS-2 raw scores are then converted into T-scores for interpretation. T-scores indicating typical limits of social impairment are 59 or less, T-scores ranging from 60-75 are considered mild –moderate impairment and show clinically significant impairment, and severe impairment scores are T scores of 76 and above. T-scores of 60 or higher indicate a potential diagnosis of ASD (Aldridge, 2012).

**Waisman Scale of Activities of Daily Living (W-ADL).** The Waisman Activities of Daily Living Scale (Maenner et al., 2013) measures the ability of individuals with intellectual/developmental disabilities in adolescence and adulthood to complete activities of daily living. This measure lists 17 activities that are rated from 1 (does not do at all) to 3 (does independently). This measure has been used with several groups with developmental disabilities, including ASD. The Waisman was proved to be both valid and reliable, with an alpha internal consistency coefficient of .88-.92.

**IQ Test.** Children who were tested at TEACCH from 1965-2000 typically completed an IQ test during their childhood assessment. There was not one uniform IQ test used; instead, most of the participants in the study received either a Stanford-Binet, Bayley Scales of Infant Development, Leiter, or Merrill-Palmer. Each of these tests was appropriate based on the developmental level of the child at the time. Standardized scores from these tests were used for analyses. When standardized scores were not available, they were computed as a ratio of mental age divided by chronological age times 100.
**Childhood Autism Rating Scale (CARS).** Designed at TEACCH in 1966, the CARS is completed by clinician after observing the first diagnostic testing session with a child. The CARS is comprised of 15 subscales that are rated with a score from 1-4. The score assigned is representative of how closely the child’s response matches with a typical response. The more closely aligned the response to that of typical development, the lower the score. The subscales on the test measure important areas impacted by ASD such as verbal communication, nonverbal communication, imitation, resistance to change in the environment, and relationships. For the distribution of 537 participants in the study by Schopler et al., (1980), scores of 30 or higher indicated a diagnosis of ASD. The CARS has an alpha of .94 and an inter-rater reliability score of $r = .71$ (Schopler, Reichler & Renner, 1980).

**Quality of Life Questionnaire.** The Quality of Life Questionnaire (QOL-Q) is a measure made of up four subscales including Life Satisfaction, Competence, Belonging, and Empowerment (Schalock & Keith, 1993). This questionnaire evaluates the Quality of Life of individuals with Intellectual Disabilities, and can be completed by the individual, caregiver, or other staff with knowledge of the individual (Rapley, 1998; Lachapelle, 2005). Completion of the questionnaire by someone other than the individual is done as if the respondent was the individual.

**Vineland Adaptive Behavior Scale (VABS).** The VABS is a tool used to measure adaptive behavior in individuals (Carter et. al, 1998). There are four scales on the VABS including Communication, Socialization, Activities of Daily Living, and Motor Skills. There is also a Maladaptive Behavior component to the Vineland. The composite, total score across domains was used. This measure was conducted as a caregiver interview during childhood. Reliability of the Vineland ranges from .93-.99 (Carter et al., 1998).
Procedure

The current study was part of a larger study conducted by the TEACCH Autism Program at the University of North Carolina at Chapel Hill. This survey was a caregiver report detailing living situation, social involvement, work history, benefits, family financial history, and physical and mental health of the adult with ASD. After contact was made through recruitment efforts, a potential participant was screened over the phone for eligibility, and then enrolled. Once a participant was enrolled, a survey was distributed either electronically or as a hard copy mailed to the participant, whichever the participant preferred. The paper surveys included a pre-paid return envelope. Of the 189 participants, 102 (54%) completed the survey online while the remaining 87 (46%) completed the survey on paper. The order of the questionnaires in the survey was the Autism in Adulthood Survey, Adult Health Survey, W-ADL, ADAMS, SRS-2, and The Quality of Life Scale (Schalock & Keith, 1993).

Analysis

The first goal of this study was to address the types of social activities in which adults with ASD are involved and how often they are participating in social activities. To address this goal, first, I computed the simple frequencies of the social activity questions listed in question 30 of Appendix A.

The second research question asked by this study regarded the relation of characteristics of ASD (symptom severity, childhood IQ scores, daily living skills) to number and type of social activities. To answer this question, correlational analyses were conducted to find the relationship between ASD characteristics and social activity. Results showed that there are activities in which individuals have participated, regardless of IQ level. However there were some activities that were significantly impacted by IQ level.
The third research question involved the relation of social activities to internalizing mental health diagnoses and their symptoms. Analyses were conducted to look at the relation between being involved in social activities and internalizing symptoms. The scores of the ADAMS Depression and ADAMS Generalized Anxiety scales were correlated with the number of total activities and the number of activities with friends.

Finally, analyses were conducted to look at the relation between being involved in social activities and Quality of Life. To do this, the total QoL score and three component scores (Life Satisfaction, Empowerment, and Belonging) were correlated with the number of total activities and the number of activities with friends.


CHAPTER 3: RESULTS

Table 1 shows the percent of individuals with ASD who participated in each social activity. Going to religious services was the most common activity in which participants took part with half of the participants (50%) having been to a religious service in the last year. The second most common activity was getting together with friends outside of organized activities (41%). The third most common activity was volunteer activities (40%), with attendance at social skills groups as the fourth most common (37%). Having been invited to a friend’s social event was the fifth most common activity (35%). Taking lessons such as art or music had the fewest participants with 19% involvement in the last year. Of the sample, seven individuals (4%) reported being involved in all activities, while 28 (15%) reported being involved in none of the activities. The most frequently reported number of activities was two out of the seven listed, and on average individuals were involved in 2.21 activities in the last year. For data analysis purposes, the listed social activities were combined into a measure called All Activities. The All Activities variable was created by combining the six social activity questions seen in Table 1 (attending religious services, volunteering, attending social skills groups, and taking lessons, getting together outside of social events, being invited to friends’ parties). A measure called Activities with Friends was created by combining the activities that were friend based (getting together outside of social events, being invited to friends’ parties) and question number 33 which
asked how often friends called. For both combined variables, any affirmative response was considered an answer of “yes”. For instance, when asked how often friends called, there are six options participants could choose. Any option other than “never” was coded as “yes”. That way all the activities were counted as a “yes” or “no” answer.

Table 2 shows the number of phone calls or texts from friends in the last month. Over half of the participants had not received any phone calls (57%). The percentages of participants who had received calls less than once a month, two to three times per month, two to three times a week, and daily are similar. Very few participants were reported to have received calls once a month or once a week (Figure 1).

**Relation of ASD Characteristics to Social Activity**

Table 3 presents the correlations between ASD characteristics and measures of social activity. Conversation ability was used as a proxy measure of current intellectual functioning. Conversation ability was related with participation in All Activities ($r(187)= +.34, p < .001$) and was strongly related to participation in Activities with Friends ($r(186)= +.62, p < .001$). These findings show that ability to converse with others likely impacts the activities in which participants are involved, especially interactions with friends. Those individuals with better conversation ability were more likely to have reciprocal friendships than those on the lower intellectual functioning end of the spectrum.

Interestingly, while current functioning level was related to activities, childhood IQ was more weakly related. Childhood IQ was not related to participation in All Activities ($r(164)= +.11, p = .17$) but was related to Activities with Friends ($r(164)= +.38, p < .01$). These results show that Childhood IQ may prove as a predictor for current functioning level which is related to
the activities in which individuals are involved with friends. However, Childhood IQ was more weakly related to these activities.

Symptom severity was also measured through the SRS-2. A significant relation was found to be significant between SCI and All Activities ($r(182) = -.38, p < .01$), SCI and Activities with Friends ($r(181) = -.51, p < .01$), RRB and All Activities ($r(182) = -.23, p = .002$) and RRB and Activities with Friends ($r(181) = -.32, p < .01$). These results indicate that the severity of ASD characteristics had a significant effect on participation in number of activities and participation in number of activities involving friends.

Daily living skills and the relation with social activities were also measured. Significant relations were found between scores on the Waisman ADL scale and All Activities ($r(187) = +.34, p < .01$) and Activities with Friends ($r(186) = +.56, p < .01$). Similarly, Childhood Vineland scores were significantly related to Activities with Friends ($r(162) = +.30, p < .01$). However, Childhood Vineland scores were not significantly related to All Activities ($r(163) = +.09, p = .26$). These results show that current daily living skills affects number of activities in which individuals are involved as well as number of activities in which individuals are involved with friends. Meanwhile, Childhood Vineland results showed a relationship with number of activities in which individuals were involved with friends as adults, but did not result in a relationship with number of activities in which individuals were involved as adults.

**Relation of Internalizing Symptoms to Social Activity**

Table 4 shows the relation between social activity and internalizing symptoms. Results showed that involvement in activities is not related to symptoms of anxiety and depression. The number of All Activities did not relate with symptoms of anxiety ($r(186) = +.06, p = .41$) or with symptoms of depression ($r(186) = +.04, p = .61$), Activities with Friends also showed no relation
with symptoms of depression ($r(185) = -0.02, p = .77$) and symptoms of anxiety ($r(185) = -0.01, p = .94$). Analyses were also conducted to measure the relation of social activity to symptoms of anxiety and depression for those who were higher functioning compared to those who were lower functioning. Again, no significance was found for either group. These results are interesting and imply that the number of activities in which individuals with ASD participate or the number of activities with friends does not affect symptoms of anxiety and depression.

However those who volunteered reported more depression symptoms on the ADAMS (M=2.91) than those who did not volunteer (M=2.04) though this difference was smaller and only marginally significant ($t(186) = 1.87, p = .06$). Those who attended religious services (M=3.55) and social skills groups (M=3.88) also did not report differing rates of anxiety than those who did not attend religious services (M=4.55; $t(186)=1.80, p=.074$) or social skills groups (M=4.15; $t(186)= .46, p=.647$) though this difference approached significance for religious services. The report of depression symptoms for those who attended religious services (M=2.17) or social skills groups (M=2.13) on the ADAMS was not significant compared to those who did not go to religious services (M= 2.59; $t(186)= .91, p=.366$) or social skills groups (M= 2.52; $t(186)=.81, p=.421$).

**Relation of Quality of Life to Social Activity**

Table 4 shows the relation between Social Activity and Quality of Life. The total number of All Activities that an individual was involved in was related to Total QoL and each of its components. However, the correlation with the Belonging component of QoL was especially strong ($r(185)= +.59, p < .001$) demonstrating that being involved in activities may be especially important for increasing one’s sense of Belonging in the community. The number of Activities with Friends was also strongly related to aspects of QoL including Empowerment, Belonging,
and Total QoL. The relation between Activities with Friends and Empowerment was especially strong ($r(183) = +.62, p < .001$). Interestingly, there was not a significant relation between Activities with Friends and Life Satisfaction ($r(185) = +.08, p = .26$) suggesting that being involved with friends may not be important to how happy adults with ASD are with their lives.

In addition to studying the relation between QoL and number of social activities, the relation between QoL and specific activities was also examined. The resulting relation of three activities to QoL in particular stood out. Those who participated in volunteering ($M= 20.46$), religious services attendance ($M=20.92$), and social skills groups ($20.09$) had significantly higher feelings of Belongingness than those who did not volunteer ($M= 18.20; t (185)= 3.67, p<.001$), attend religious services ($M=17.29; t (185)= 6.47, p < .001$), or social skills groups ($18.53; t (185)= 2.45, p=.015$). Those who attended religious services ($M=22.94$) also had significantly higher Life Satisfaction than those that did not ($M=21.07; t (186)= 3.21, p=.002$. Finally, those who attended social skills groups reported significantly higher Life Satisfaction ($M=22.97$) than those who did not ($M=21.46 t (186)= 2.48, p=.014$), and lower Empowerment ($M=18.84$) than those who did not attend social skills groups ($M=20.50; t (184)=2.21, p=.03$).
CHAPTER 4: DISCUSSION

This study was one of the first studies to look at social activities in a large sample of adults with ASD who were diagnosed during childhood. This study found that adults with ASD often have limited social interactions. Difficulty with social interactions and friendships is a theme that has been seen in prior research. The study conducted by Orsmond et al., (2013) found that adolescents and young adults with ASD had very limited interactions with friends. The information from that study used another large set of data similar to the present study. The questions asked by the 2013 study were also used in the TEACCH ASD in Adulthood survey in order to be able to do a direct comparison with results from adolescence and young adulthood to middle adulthood. Orsmond and colleagues found that 39% of their sample reported never spending time with friends, the current sample reported that 59% never spent time with friends. The sample in adolescence/young adulthood that reported never being called by friends was 47%, while the sample in middle adulthood reported never being called by friends at 57%. In the 2013 study, 48% of the sample reported never being included in social activities, while for the current sample, 65% reported never being invited to friends’ activities.

Lack of participation in social activities is a common issue seen in this population for years. Amado and Simon (2001) suggested that despite living and working in the community, many individuals with developmental disabilities tend to feel socially isolated and to be without friends. This can start as early as the preschool years, when many parents of children with
disabilities hope to enroll their children in the local church preschool. However, these parents may be turned away because the preschools are not equipped to properly serve the needs of the child (Amado & Simon, 2001). As children grow, the difficulties shift from classrooms that are not properly equipped to a lack of structure to the typical day once a student graduates from high school. Not only is a structured day lacking, individuals who are leaving the school system for the first time also have to contend with a lack of employment and social opportunities.

Of the sample for this study, 15% of the participants were not involved in any social activities in the last year. Sixty four percent of the sample were involved in two or less of the activities listed. The most commonly reported activity was attendance in religious services, while the least reported activity was taking some sort of lesson (art, music, language, etc). Volunteering (40%), participation in social skills groups (37%), getting together with friends outside of organized activities (41%) and being invited to friends’ social activities (35%) were reported with similar frequency. However, while large percentages of the sample reported lack of activities with friends, 85% of the sample reported being involved in some sort of social activity in the last year, showing that there are outlets and ways for everyone to be involved.

The relation between characteristics of the individual with ASD and their social activities was examined next. These results showed that current cognitive functioning was strongly related to activities with friends, but not number of social activities overall. So while even individuals with cognitive difficulties can be active socially, these findings suggest maintaining friendships requires a certain level of cognitive functioning including the ability to communicate well with others and to understand others’ thought and feelings.

Characteristics that did show significant relation to social activities were social impairments measured by the SRS-2. ASD symptom severity was also significantly correlated
with involvement in number of activities as well as activities with friends. Those who scored as more impaired by their ASD (especially social impairments) were less involved in all activities, and less involved in activities with friends. There could be a host of reasons as to why these results were so strong. Those who had more social impairments may have been less interested in pursuing social activities. However, if they had more severe social impairments in childhood, then they also may have been given fewer opportunities to participate socially and develop social skills, leading to fewer activities as adults.

In addition to social impairment, individuals who scored high on the repetitive behaviors section of the SRS-2 had significantly fewer social activities and friend-related activities. Speculation for the significance in this relationship can include that repetitive behaviors exhibited by this population may get in the way of individual’s ability to successfully engage in social activities. In addition, the way other people perceive their restricted and repetitive behaviors may make individuals surrounding them less likely to engage in social interactions with this population.

Finally, the relation between being involved in activities, including activities with friends, had no effect on internalizing symptoms or vice versa. Symptoms of anxiety and depression were neither increased nor decreased by participating in social events, and participating in activities with friends. However, strong relationships were found regarding quality of life. Participating in social activities was shown to have a strong impact on feelings of satisfaction, belonging and overall quality of life. In fact, the results showed that individuals across the entire spectrum of functioning who participated in social events gained benefits from their participation. Across the board, quality of life was improved by being involved in activities in the community and contact with friends.
These results lead to the conclusion that social activity is beneficial, and is something that should be encouraged for adults with ASD. Social activity can take on many forms, from art or music lessons to interaction on the internet or a conversation over the phone. The results of this study showed that being more involved in activities improved the sense of belonging and life satisfaction of all adults with ASD, regardless of cognitive functioning. All individuals can participate in social activities and this will improve their quality of life. It is likely that everyone can find a place to belong and to thrive.

Using conversation ability as a proxy for IQ means that for the purposes of this study, having a higher conversation ability would put an individual in the category of having higher cognitive functioning. Thus, for the relationship between activities with friends and higher level of cognitive function, the connection can be made that the individuals who have more activities with friends are also the individuals who are better able to communicate conversationally with others. Overall, this finding is not surprising, but it is important to note having more friend-related activities was related to a greater sense of empowerment and belonging. So individuals who are more cognitively challenged may have difficulty forming friendships and gaining the benefits that come from having friends. If this is the case, finding activities that resonate with the individual and their interests may be especially important.

While some of these results were expected, there were also some surprises. For instance, volunteering was associated with higher levels of anxiety, but church attendance & social skill group activities were not was surprising. However, this difference may be attributed to the setting structure of these activities. Social skills groups tend to be predictable, structured activities. The members of the group know what to expect each week, and are probably not surprised by what happens during the session. Religious services are very similar, highly
structured events. Each service tends to follow a structure. An order of service is usually provided before the service starts so that those attending can follow along. Likewise, the same people usually attend both activities weekly. However, volunteering is different in that the volunteer activities likely may be less predictable, the same people may not necessarily be around all the time, and what happens during volunteering may often be unpredictable. This may lead to a sense of anxiety associated with volunteering.

While some individuals may experience some anxiety before engaging in a particular social activity, the anxiety should be examined. If an individual is experiencing anxiety when participating, then it may be important to assess whether the social benefits outweigh the increased anxiety. However, if the anxiety seems to be related to excitement, and the reward of getting to participate in an exciting social outlet is greater than the anxiety, then the individual may have found a good fit.

It is important to note the strong relation between being involved in activities to the Belongingness scale from the Quality of Life measure. In the field of rehabilitation counseling, increasing quality of life for clients is a desired goal, specifically in helping individuals live fulfilling, productive lives where they feel a sense of satisfaction with their life and a sense of belonging to the community. These results suggest that it is extremely valuable and important to get adults with ASD to be socially active. This study found those who were more socially active were both more satisfied with their lives and had a greater sense of belonging to their community. This means it is crucial to provide coping skills training, one-on-one community guides, social stories, schedules, and one-on-one or group outpatient therapy, among other possibilities that will help adults with ASD be successful becoming active socially in their communities.
As rehabilitation counselors, working on coping skills for anxiety, helping clients produce schedules, and providing appropriate assistive technology can help clients work through potential anxiety brought on by social activities. Results that show involvement in social activity increases Quality of Life for individuals with ASD calls for focus on increasing participation in social events and preparing clients for social activities.

**Limitations of Present Study**

This study had many strengths, and found strong relationships between different characteristics of the lives of adults with ASD. However, there were some notable limitations to this study as well. First, the topic of the study was decided upon after the survey was finalized. Therefore, the survey was not designed solely for the purpose of investigating the social interactions of individuals with ASD. Instead, it was aimed to gather a full picture of the lives of adults with ASD. The list of social activities provided was not exhaustive list of activities in which individuals could be involved. There also was not a section in which caregivers and individuals could include other activities in which they might participate. This may have affected the percentage of individuals who reported involvement in no activities. Inclusion of more complete social activity questions in future research is important.

Secondly, this study considered the relationship between social activity and internalizing symptoms. The analyses conducted were not conducted to study the relationship between social activity and the presence of diagnoses of anxiety and depression. This means that conclusions cannot be drawn about the relationship to internalizing diagnoses. The ADAMS is a caregiver reported measure created for individuals with Intellectual Disability who are unable to report their own experience of anxiety and depression. It is not clear how effective the ADAMS
is as a measure for those who are higher functioning. Because of this, social activities may really have been related but undetected to internalizing problems in this study.

Additionally, this study was conducted using quantitative measures. Qualitative testimony from either caregivers or individuals themselves about the impact of social activity on their lives was not included but would be important for future research. Another question that could be asked is if there is a desire to include more social activity in the lives of the study participants. Other qualitative questions that could be considered include participants’ perception as to why engaging in social activity can be difficult. Having this knowledge could help erase some of the speculation that researchers make about the relationship, and can instead help to provide answers to the questions that researchers seek to answer.

**Implications for Further Research**

This study aimed to examine the relation between social activity and the presence of anxiety and depression in adults with ASD and quality of life. Results found no relation between social activity and anxiety or depression but a positive relation between social activity and quality of life. There is need for further research on this topic. For example, these results call for further research into predictors of anxiety and interventions that will alleviate client anxiety. For families who are concerned about involving their loved ones in activities that may be stressful or anxiety producing, knowing the types of activities that are widely regarded as beneficial to quality of life could be immensely helpful. One way to gauge individual interest in various activities would be to develop surveys of various social activities and measure participant reactions. If a school or day program has service dogs that frequently visit, participants who enjoy the visit with the service dogs might enjoy volunteering at an animal shelter. Likewise, if participants enjoy interacting with children through reading or other
activities, they may enjoy reading with children at a preschool. Studies could be done to examine the effectiveness of an interest inventory of social activities.

Taking interventions that may work in a clinic or home setting into the community is also essential for social involvement for individuals with ASD. However, knowing what interventions work and how to generalize them effectively is necessary to increase comfort and familiarity for individuals and their social activities. One example of an intervention to study is taking an activity that is enjoyed but may produce anxiety, like volunteering, and creating a schedule or talking individuals through the expectations of the day. This way, participants may learn what to expect, even if these expectations change from event to event. Similarly, if participants enjoy creating art but do not seem to enjoy art classes, they could obtain a calendar of the scheduled art classes and know ahead of time what the focus of each week’s class will be. Research should be conducted measuring levels of anxiety or enjoyment at various social activities with the added implementation of these preparatory interventions.

Further studies can be conducted to see the relationship social activities have with one another. For instance, does participation in social groups lead to more invitations to spend time with friends? Drawing connections between the effects different social interactions have with one another can lead to further encouragement to seek out ways to be involved socially in the surrounding community. Studies can also be conducted to measure the relationship between social involvement of the child and the effect it has on the social involvement of the caregiver, as well as measuring the caregiver’s quality of life. It could be hypothesized that the more socially involved the child, the more involved the parent feels they can be. Also, parents of children with higher quality of life could be hypothesized also to have a higher quality of life. Overall, social
activity shows important benefits for individuals with ASD, and activities should be based on the individual, their desires, and their comfort level.

For the purposes of this study, the survey responses asked about activities completed with friends, but did not ask any questions about who the individuals with ASD considered to be friends. As Orsmond and colleagues found (2013), adults with ASD and their caregivers may have discrepancies in whom they categorize as friends. This study looked only at the survey responses provided by the caregiver and did not include the survey responses from the adults with ASD. Future studies should compare the responses given by the individual and their caregiver about contact and activity with friends. Follow up questions can include asking more information about the individual’s friends to measure whether the adults view their friendships differently from their caregivers.

**Implications for Rehabilitation Counselors**

Many current interventions and programs for individuals with ASD include honing social skills, reading emotions, expressing emotions, and coming up with rules for appropriate social behavior. Seemingly, these goals are to help individuals with ASD to have more meaningful social interactions. This study was conducted to discover if participating in social interactions and social activities improved the quality of life of adults with ASD, or if being involved in more social interactions would worsen symptoms of anxiety and depression in this group. Social activities were not related to depression and anxiety, and social activities were strongly correlated with higher quality of life. This lends itself to considerations that involvement in social activity and interaction with friends is beneficial to individuals with ASD in many aspects of their lives and is something to value, encourage, and include.
In addition to encouraging families to explore options for social activity for their loved one, rehabilitation counselors can work with families to find activities that are interesting to the individual. Encouraging participation in activities that are of interest to the individual may allow them some added independence in addition to the benefits noted from this study. Having the opportunity to engage their loved one in social activities is likely to have a multifaceted benefits. The adult with ASD will have the opportunity to engage with others outside of the home, and experience a greater quality of life, and the caregiver may have more positive interactions with their child.

Rehabilitation counselors are often looking for modifications and accommodations to help clients live the most independent and empowered lives that they can. Some clients with ASD may be able to work part-time or full-time positions while others may not. Some clients will be able to volunteer and find fulfillment through those activities, while others may experience fulfillment through social groups and community outings. While some clients may be able to drive, others may need to rely on family members or community guides to provide transportation to outings. Accommodations can take many forms, including physical modifications, addition of a community guide/helper, or other accommodations to help clients be successful in their particular social activities.

One of the first things rehabilitation counselors can do is look for social activities that are routine-based and predictable. Finding activities that follow a consistent routine and pattern that the individual can predict may alleviate anxiety for individuals who find themselves anxious around transitions and unexpected occurrences. However, this should not result in limitations for the individual. For instance, if an individual is expressing interest in an activity that is not predictable, like volunteering at a church nursery, the counselor and support system can take
time prior to participating in the activity to talk about the different things that can happen, and help the individual develop rules and a plan for how to respond. For instance, they can discuss the fact that a child might start crying. Rules for how to react may include, checking to see if the child is hungry, if they have gotten hurt, or if they need a diaper change. If the individual is prepared with tools/rules to be successful, then the possibility of unforeseen occurrences may seem less overwhelming. Another preparation strategy is using role play to practice responses to certain situations. These role plays could include a supervisor/teacher/volunteer asking the individual to change tasks, to clean up in the middle of a project, someone interrupting or changing the subject, conflict with another participant, or correction to the job the individual is completing. As previously mentioned, rehabilitation counselors can also recommend relaxation techniques to assist clients in these sometimes stressful moments.

This method of preparation can be used in other ways. When discussing participation in any activity, an individual’s support system can spend time leading up to participating discussing what to expect in general. These discussions can include how many people may be around, what sorts of tasks may be expected of the individual, how long the event may last, and what kind of environmental conditions may surround the individual during the event. If a community guide is going to be present at the social event, then they can help the individual engage in relaxation techniques when they start to feel overwhelmed. If there is no community guide present, then one of the rules discussed with the counselor may be relaxation techniques that the individual can walk through individually. Counting to ten, progressive muscle relaxation, and learning to separate themselves from the upsetting situation are all healthy coping skills that can be done anywhere and can be tools used to help individuals be successful.
The presence of a community guide can also be beneficial when considering the relationship with social behaviors. Community guides can help the individual engage with other people who are present at the social activity, and help provide a bridge for communication if necessary. Community guides typically know a great deal about the individual, and can interpret a lot of their behaviors. For instance, if the guide is able to tell that the individual is becoming anxious or may need to step outside, they can help the individual step away for a moment before returning back to the group.

If an individual enjoys being with animals, but is not able to steadily hold onto a dog leash, the community guide may be able to hold the leash, but allow the individual the experience of walking the dog. Along the same lines, the community guide may know what steps of feeding animals the individual is able to do well, and can help break down the potentially difficult task so that the individual is able to participate.

Another consideration for Rehabilitation Counselors would be sensory processing accommodations for their clients. If clients are interested in social activities, but have certain sensory sensitivities, then Rehabilitation Counselors could look into accommodations that would work with the individual’s sensory processing needs to allow them to participate in the activities they find themselves excited about. For example, if individuals are really interested in spending time at the park, but find that the extra noise is painful, then purchasing ear phones or ear plugs to block out some of the extra noise may be helpful. Another sensitivity for adults with ASD who enjoy the park could be the feeling of sand on their skin. Blocking sand from touching the skin would be difficult to completely erase, but encouraging clients to wear long pants, long sleeved shirt, with socks to the ankle and sneakers would help minimize that particular sensory sensitivity.
Conclusions

The relationship between social activity and quality of life for individuals with ASD has important long term implications. Having a sense of empowerment and belonging are enduring qualities that will last for a lifetime. Another added benefit is the community that is created by social involvement. As participants spend more time with others, they build a community of friends and a support system that may endure through the years. The community built through increased social interaction from the individual may also extend to the family. Families who were initially hesitant to encourage their loved one to participate in social activity for fear of stigma may find that they are creating their own community of individuals who will support them and not judge them.

This study was a part of a groundbreaking study of adult outcomes of individuals diagnosed with ASD. Learning about the lives of individuals with ASD as they get older and potential predictors of success helps practitioners learn how to adjust interventions, accommodations, teaching strategies, and goals for treatment. This study of unique experiences of adults with ASD should help pave the way to improve outcomes for children who are diagnosed today. Rehabilitation counselors have training specific to individuals with disabilities, and helping them achieve their goals. Therefore, studies like this are imperative to the practice of rehabilitation counseling, as they help provide insight into what services may be necessary for the population with disabilities. As rehabilitation counselors, providing clients with the skills, tools, and opportunities to enhance independence, empowerment, and belonging in the community is the cornerstone of the profession, and the key to a job well done.
APPENDIX 1: TABLES OF DATA FINDINGS

Table 1: *Frequency of Social Activity and Contact with Friends*

<table>
<thead>
<tr>
<th>Social Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend Religious Services</td>
<td>50%</td>
</tr>
<tr>
<td>Hang out with Friends</td>
<td>41%</td>
</tr>
<tr>
<td>Volunteer</td>
<td>40%</td>
</tr>
<tr>
<td>Attend Social Groups</td>
<td>37%</td>
</tr>
<tr>
<td>Invited to Friends’ Parties</td>
<td>35%</td>
</tr>
<tr>
<td>Take Lessons</td>
<td>19%</td>
</tr>
<tr>
<td>Contact with Friends by Phone</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>57%</td>
</tr>
<tr>
<td>Less than Once a Month</td>
<td>9%</td>
</tr>
<tr>
<td>Once a Month</td>
<td>1%</td>
</tr>
<tr>
<td>2-3 Times a Month</td>
<td>10%</td>
</tr>
<tr>
<td>Once a Week</td>
<td>5%</td>
</tr>
<tr>
<td>2-3 Times a Week</td>
<td>8%</td>
</tr>
<tr>
<td>Daily</td>
<td>9%</td>
</tr>
</tbody>
</table>
Table 2: Sample Means and Standard Deviations

<table>
<thead>
<tr>
<th>Category</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ASD Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood CARS</td>
<td>33.6</td>
<td>6.0</td>
<td>171</td>
</tr>
<tr>
<td>SRS</td>
<td>90.3</td>
<td>32.2</td>
<td>184</td>
</tr>
<tr>
<td><strong>Intellectual ability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conversational Ability</td>
<td>2.6</td>
<td>1.1</td>
<td>189</td>
</tr>
<tr>
<td>Childhood IQ</td>
<td>64.0</td>
<td>27.7</td>
<td>166</td>
</tr>
<tr>
<td><strong>Daily Living Skills</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood Vineland</td>
<td>53.7</td>
<td>18.9</td>
<td>165</td>
</tr>
<tr>
<td>W-ADL</td>
<td>22.4</td>
<td>7.9</td>
<td>189</td>
</tr>
<tr>
<td><strong>Quality of Life Outcomes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Social Activities</td>
<td>2.2</td>
<td>1.6</td>
<td>189</td>
</tr>
<tr>
<td>ADAMS-Depression</td>
<td>2.4</td>
<td>3.2</td>
<td>188</td>
</tr>
<tr>
<td>ADAMS-Anxiety</td>
<td>4.1</td>
<td>3.8</td>
<td>188</td>
</tr>
<tr>
<td>QOL-Total</td>
<td>78.3</td>
<td>14.4</td>
<td>186</td>
</tr>
</tbody>
</table>
Table 3: Pearson’s Correlations between Social Activity and ASD Characteristics

<table>
<thead>
<tr>
<th>Social Activity</th>
<th>All Activities</th>
<th>Activities with Friends</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptom Severity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SRS SCI</td>
<td>-.38**</td>
<td>-.51**</td>
</tr>
<tr>
<td>N = 184</td>
<td>N = 183</td>
<td></td>
</tr>
<tr>
<td>SRS RRB</td>
<td>-.23**</td>
<td>-.32**</td>
</tr>
<tr>
<td>N = 184</td>
<td>N = 183</td>
<td></td>
</tr>
<tr>
<td>Childhood CARS</td>
<td>-.21**</td>
<td>-.40**</td>
</tr>
<tr>
<td>Score</td>
<td>N = 182</td>
<td>N = 181</td>
</tr>
<tr>
<td><strong>Intellectual Functioning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conversational Ability</td>
<td>+.34**</td>
<td>+.62**</td>
</tr>
<tr>
<td>N = 189</td>
<td>N = 188</td>
<td></td>
</tr>
<tr>
<td>Childhood IQ</td>
<td>+.11</td>
<td>+.38**</td>
</tr>
<tr>
<td>N = 166</td>
<td>N = 166</td>
<td></td>
</tr>
<tr>
<td><strong>Daily Living Skills</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waisman ADL</td>
<td>+.34**</td>
<td>+.56**</td>
</tr>
<tr>
<td>N = 189</td>
<td>N = 188</td>
<td></td>
</tr>
<tr>
<td>Childhood Vineland</td>
<td>+.09</td>
<td>+.30**</td>
</tr>
<tr>
<td>N = 165</td>
<td>N = 164</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* * = $p < .05$, ** = $p < .01$, *** = $p < .001$. Standard Deviations appear in parentheses below the means.
Table 4: *Pearson’s Correlations between Social Activity, Quality of Life, and Internalizing Symptoms*

<table>
<thead>
<tr>
<th>Quality of Life</th>
<th>Social Activities</th>
<th>Activities with Friends</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Activities</td>
<td>N = 188</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>+.26**</td>
<td>+.08</td>
</tr>
<tr>
<td>Empowerment</td>
<td>+.25**</td>
<td>+.62**</td>
</tr>
<tr>
<td>Belonging</td>
<td>+.59**</td>
<td>+.47**</td>
</tr>
<tr>
<td>Total</td>
<td>+.44**</td>
<td>+.51**</td>
</tr>
<tr>
<td></td>
<td>N =187</td>
<td>N =185</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Internalizing Symptoms</th>
<th>Social Activities</th>
<th>Activities with Friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADAMS- Depressed</td>
<td>+.04</td>
<td>-.02</td>
</tr>
<tr>
<td>ADAMS- Anxiety</td>
<td>+.06</td>
<td>-.01</td>
</tr>
</tbody>
</table>

Note. * = p < .05, ** = p < .01, *** = p < .001. Standard Deviations appear in parentheses below the means.
APPENDIX 2: 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</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>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</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>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>Have 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>Arrested?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<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 or Help</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using Transportation</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Home care skills, such as cooking and cleaning</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Financial issues, such as managing his/her money</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Self-care skills such as brushing his/her teeth</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Relationship skills, such as getting along with others</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>Self advocacy skills (e.g., talking to others about autism diagnosis)</td>
<td>☐</td>
<td>☒</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>Service</th>
<th>In the last 2 years</th>
<th>Currently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supplemental Security Income (SSI/SSDI)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Temporary Assistance to 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
REFERENCES


