Assessing the Validity of the Social Communication Questionnaire in Adults with Autism Spectrum Disorders and Intellectual Disability

THESIS

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Abstract

Assessing autism spectrum disorders in adults is a challenging task, as ASD symptoms change over time and early developmental history may be unavailable for many adults. This study assessed the diagnostic validity of the Current version of the Social Communication Questionnaire (SCQ), an autism rating scale, in a sample of adults with intellectual disability (ID). Participants included 52 individuals, aged 19 to 40 years (mean age = 28.6 years, SD = 6.0), who were recruited from agencies serving individuals with ID, a large university center for intellectual and developmental disabilities, and the Autism Society of Ohio. Parents and/or support staff completed the SCQ Current and SCQ Lifetime (when applicable) versions and measures of participants' behavior and adaptive functioning. The SCQ Current version, as rated by support staff, yielded a sensitivity of .60 and a specificity of .81 at the cutoff score of 15 proposed by the authors. However, the optimal cutoff score in this sample was 12, which yielded a sensitivity of .80 and specificity of .65. Analyses were repeated in a subset of participants in the ID-only group with high and low level of behavioral problems, and comparable sensitivity and specificity values were found. Behavior problems did not appear to affect the discriminative validity of the SCQ Current in this sample. Although the SCQ Current version was not specifically designed to screen for ASDs in adults, it may be a useful tool for screening individuals whose early developmental history is unavailable. A lower

cutoff score than the authors originally proposed is recommended for use in adults, which is consistent with research indicating that autism symptoms improve with age.

This document is dedicated to my family, my friends, and Andrew.

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Fields of Study

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Chapter 1: Introduction

The first cases of autism were described independently by Leo Kanner as "infantile autism syndrome" (Kanner, 1943) and Hans Asperger as "autistic psychopathy" (Asperger, 1944). The central features of the disorder include impairments in three areas of functioning: reciprocal social interaction, communication, and restricted interests/ repetitive behavior. While the core features are present in some form in all autism spectrum disorders (ASDs), the presentation varies widely depending on level of adaptive functioning and IQ. Consequently, a conceptualization of autism as occurring on a spectrum has been accepted by many in the research community, with the most common diagnoses being Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-[NOS]).

Autistic Disorder, sometimes referred to as "classic autism," involves the most stringent criteria for impairments in the three core domains of social and communicative functioning and repetitive/stereotyped interests. According to the *Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision* (DSM-IV-TR), a diagnosis of Autistic Disorder requires meeting criteria in three areas of functioning: 1) qualitative impairment in social interaction; 2) qualitative impairment in communication; and 3) restricted repetitive and stereotyped patterns of behavior, interests and activities

(American Psychiatric Association, 2000). Despite having the most stringent diagnostic criteria, individuals with Autistic Disorder exhibit a range of intellectual and adaptive functioning.

PDD-NOS, also described as "atypical autism," is diagnosed when not all of the criteria for Autistic Disorder are met. A diagnosis of PDD-NOS must include significant impairment in social interaction, but the criteria for impairment in communication or restrictive, repetitive and stereotyped patterns of behavior may be sub-threshold. Asperger's Disorder is an autism spectrum disorder that involves social deficits, but no cognitive or language delays, although communication is often perceived as odd, overly rule-focused or literal. The DSM-IV-TR criteria for a diagnosis of Asperger's Disorder include: 1) qualitative impairment in social interaction, 2) restricted repetitive and stereotyped patters of behavior, interest and activities, 3) clinically significant impairment in social, occupational, or other important areas of functioning, with 4) no clinically significant general delay in language, and 5) no clinically significant delay in cognitive developmental or adaptive behavior (APA, 2000). While the core feature of profound impairments in reciprocal social interaction is a common thread in Autism Spectrum Disorders, Autistic Disorder, PDD-NOS and Asperger's Disorder clearly present with a diverse group of symptoms.

Obtaining accurate prevalence estimates of ASDs is a challenging task, as the rates may vary according to how broadly the disorder is defined and by the sophistication of the

diagnostic tools. The prevalence of ASDs appears to be increasing, with earlier studies reporting rates of 4-6/10,000 (i.e. Wing et al., 1976) and studies with an expanded diagnostic concept of autism reporting higher rates of 21/10,000 (i.e. Wing & Gould, 1979). Fombonne (2003) reported an increase in autism rates in a meta-analysis of ASD prevalence studies from 13 countries, conducted from 1966 to 2001. Using conservative diagnostic criteria for autism (PDD-NOS and Asperger's Disorder excluded), Fombonne (2003) reported a median rate of 4.4/10,000 from studies conducted from 1966-1991 and a median rate of 12.7/10,000 from 1992-2001. Based on less precise studies of "atypical autism," Fombonne estimated the prevalence of PDD-NOS as 15/10,000 and of Asperger's Disorder as 2.5/10,000 (2003). According to the most recent study from the Center for Disease Control and Prevention (CDC), the prevalence of autism spectrum disorders in 2002 among children sampled across the United States was 6.6/1,000 (Center for Disease Control and Prevention, 2007).

There has been much debate about the cause of this apparent rise in prevalence, with possible factors including widening definitions, less stringent diagnostic criteria, increased public awareness, and earlier diagnosis of ASDs. A recent California study reported an increase in autism incidence in children from 6.2 per 10,000 births in 1990 to 42.5 per 10,000 births in 2001 (Hertz-Picciotto & Delwiche, 2009). Hertz-Picciotto and Delwiche reported that the above factors could only account for a small portion of this significant increase in prevalence of ASDs in their sample, arguing for a true increase in rates with substantial environmental contributions (2009). However, it remains unclear

whether the apparent increase in the prevalence of autistic disorders is a true increase and/or a result of these other factors, such as expanding diagnostic criteria, increased sophistication of diagnosis and assessment tools, or increased awareness of ASDs (Fombonne, 2003; Gilberg & Wing, 1999; Rutter, 2005).

ASDs in Adults

While the prevalence of ASDs in children is well-studied, there remains a gap in the research in identifying adults with autism, many of whom were diagnosed with other disorders before the increased awareness of ASDs. A community prevalence study of adults with autism and intellectual disability in Britain reported a rate of 7.7/10,000, which consisted of 30% of the intellectually disabled population (Morgan et al., 2002). Using a brief screening measure, the Autism Spectrum Disorder in Adults Screening Questionnaire (ASDASQ), a Scandinavian study reported a rate of 1.4% of adult psychiatric outpatients, who had not previously been diagnosed with ASDs (Nylander & Gillberg, 2001). The authors suggest that many adults with Asperger's Disorder or High-Functioning Autism (HFA) may not have been diagnosed due to sub-threshold presentation of impairments associated with the disorder (Nylander & Gillberg, 2001). Nylander and Gillberg (2001) also note that individuals with a psychiatric diagnosis may not have been diagnosed with ASDs earlier because of diagnostic overshadowing, which occurs when one diagnosis, such as intellectual disability, is used to explain symptoms that may be caused by another, distinct diagnosis, such as a mood disorder (Reiss,

Levitan, & Szyszko, 1982). In this sample, the authors note that psychiatric diagnoses may have overshadowed diagnoses of ASDs (Nylander & Gillberg, 2001).

A recent study reported an ASD prevalence rate of 1% of adults living in the general English population (Brugha et al., 2009). While many studies have relied on parental or self-report of ASD diagnoses, this study used standardized measures to assess the presence of ASDs. Participants were initially assessed with a self-report ASD screening measure, the Autism Quotient (AQ) (Baron-Cohen et al., 2001), and later assessed by trained clinicians using the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000). It is important to note that the researchers administered the ADOS, which focuses on current, observable behaviors, rather than diagnostic interviews that rely on early developmental history. The researchers argued that the similar prevalence rate found in this adult sample and prevalence rates reported in children suggest that there has not been a true increase in rates of autism; rather many adults with ASDs were not previously identified with the disorder (Brugha et al., 2009).

Matson and Neal, in their review of diagnosis of ASDs in adults, noted that many adults may not have been diagnosed with autism due to diagnostic substitution (2009). For example, Bishop and colleagues reported that a sample of 38 adults who met criteria for autism had initially been diagnosed with developmental language disorder (2008). Matson and Neal (2009) also argued that continued assessment throughout the lifespan is essential for maintaining appropriate support and treatment, as substantial life events and

changes can significantly affect symptom presentation (Seltzer, Krauss, Orsmond, & Vestal, 2001). These studies highlight the need to identify adults with ASDs, who may not have received an accurate diagnosis in the past.

While the overwhelming majority of research focuses on the presentation and treatment of ASDs in children, there is an increasing recognition of the importance of lifespan issues affecting individuals with ASDs (Orsmond, Krauss, Seltzer, 2004; Schroeder, LeBlanc, & Mayo, 1996). Studies on the behavioral correlates of ASD in adolescents and adults have shown a different pattern than behavioral correlates of ASD in children, including a decrease in repetitive and stereotyped behaviors and maladaptive behaviors (Esbenson et al., 2008; Seltzer et al., 2004; Shattuck et al., 2007). Taylor and Seltzer (2010) recently examined the *rates* of change in autism symptoms and maladaptive behaviors after graduation from high school in a longitudinal study. They reported that while autism symptoms and internalizing behaviors improved with age, the rates of change slowed significantly after participants transitioned from high school to day or vocational activities, especially in individuals without intellectual disabilities (Taylor & Seltzer, 2010a).

Despite improvements in ASD symptoms, research has suggested that children with autism often show poor outcomes in adulthood, including limited employment opportunities, independent living skills, and peer relationships (Billstedt, Gilberg, & Gilberg, 2006; Howlin et al., 2004). Unfortunately, adults with diagnoses of ASDs face

difficulty in receiving appropriate support and treatment once they have graduated from high school, and research indicates low rates of community employment and high rates of participation in sheltered workshops and day activity centers (Taylor & Seltzer, 2010b). However, research suggests that intervention and support for individuals with ASD starting in adult life can yield positive outcomes, such as increased self-care skills and social support networks (Jorden & Powell, 1996; Van Bourgondien et al., 2003).

Diagnosing ASDs in adults is a crucial component of understanding the etiology, development, and course of this disorder. It is also important to identify ASDs in adults, in order to obtain accurate diagnoses that may have been overlooked in the past and to implement appropriate treatments and allocate resources to address the continual challenges faced by adults with ASDs. However, the issue of diagnosing ASDs in adults presents several challenges, such as difficulty obtaining early developmental history information and changing ASD symptom presentation across the lifespan.

Diagnostic Instruments

The increased awareness of ASDs has contributed to the development of more sophisticated measures to identify the disorder so that early intervention services can be implemented. Lord and Corsello noted several challenges associated with ASD assessment, including defining comparison groups, generating appropriate norms, and disentangling confounding factors, such as language impairment and intellectual and

adaptive functioning levels, from diagnosis (2005). However, they cite several diagnostic scales that, despite flaws, address many of these challenges quite effectively (Lord & Corsello, 2005). Among the most widely used diagnostic instruments that have been validated with both children and adult populations are the Autism Diagnostic Interview – Revised (ADI-R) (Le Couteur et al., 1989; Lord, 1997; Lord, Rutter & Le Couteur, 1994), the Autism Diagnostic Observation Schedule (ADOS) (DiLavore, Lord & Rutter, 1995; Lord et al, 1989; Lord et al., 2000), and the Childhood Autism Rating Scale (CARS) (Schopler, Richter, DeVellis, & Daly, 1980; Schopler, Reichler, & Renner, 1986).

The ADI-R, a clinician-rated measure based on DSM-IV criteria for ASDs, consists of an extensive semi-structured interview with primary caregivers (Le Couteur *et al.*, 1989; Lord, 1997; Lord, Rutter & Le Couteur, 1994). Studies have reported good psychometric properties overall, with some difficulty in discriminating between autistic disorder and PDD-NOS and between ASDs and nonverbal children with intellectual disabilities (Cox et al., 1999; Fombonne, 1992; Lecavalier, et al., 2006; Lord, Rutter & Le Couteur, 1994).

The ADOS and its revised version, the Autism Diagnostic Observation Schedule – Generic (ADOS-G), were also developed based on DSM-IV criteria for autism, in order to allow standardized observation of current communication and social functioning (DiLavore, Lord & Rutter, 1995; Lord et al, 1989; Lord et al., 2000). De Bilt et al. (2004) reported good convergent validity of the ADI-R and ADOS-G with the DSM-IV-

TR classifications of Autistic Disorder (AD) and PDD, and fair agreement between the ADI-R and the ADOS-G.

The Childhood Autism Rating Scales (CARS), which also relies on direct observation by trained clinicians, consists of fifteen scales which measure the core features of ASDs, as well as associated features such as emotional expression, sensory responsiveness, activity level, and intellectual ability (Schopler, Richter, DeVellis, & Daly, 1980; Schopler, Reichler, & Renner, 1986). This measure has exhibited sound psychometric properties (DiLalla & Rogers, 1994; Perry et al., 2005; Saemundsen, Magnusson, Smari, et al., 2003; Stella, Mundy, & Tuchman, 1999) and has also been validated with adolescent and adult populations (Mesibov et al., 1989). The ADI-R, ADOS-G, and CARS provide a thorough assessment of ASDs, but they are time-consuming and costly.

Due to the increasing prevalence of ASDs and the large amount of resources needed for clinician-rated diagnostic tools, caregiver-rated screening measures have been developed as less costly and time-consuming methods to identify ASDs. While these screening measures are not designed to provide a diagnosis, they do provide an efficient method for screening large groups of individuals who may need further assessment (i.e. preschoolers and or adults receiving care for psychiatric disorders). Several screening measures have been developed over the past two decades, such as the Gilliam Autism Rating Scale (GARS) (Gilliam, 1995), the Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers, Gillberg, & Wing, 1999), and the Social Responsiveness Scale (SRS) (Constantino &

Gruber, 2005; Constantino et al., 2000). Reviews of previous research on these scales suggest that the SRS and ASSQ have promise as screening instruments, while the GARS has exhibited poor sensitivity (see Norris & Lecavalier, 2010).

Screening measures are often evaluated based on their discriminative validity, which includes sensitivity, specificity, positive predictive value, and negative predictive value. Sensitivity refers to the proportion of individuals who are correctly identified by a screening measure as having a specific condition, and specificity refers to the proportion of individuals who are correctly identified by the measure as *not* having that condition. Glascoe (2005) argues that the sensitivity of screening measures should be 70-80% and specificity should be 80%, in order to minimize over-referrals to clinicians. However, some researchers argue that sensitivity should be given more weight, as it is more important to identify those who need further assessment (i.e. Norris & Lecavalier, 2010). Positive predictive value refers to the probability that an individual actually has the condition when a positive test result occurs. Negative predictive value refers to the probability that an individual does not have the condition when a negative test result occurs. Positive predictive value and negative predictive value should be interpreted with caution, as they are inherently dependent on the prevalence of a disorder.

The Social Communication Questionnaire (SCQ) is a widely used and studied screening measure that was developed with a sample of both children and adults (Berument et al., 1999; Rutter, 2003). The SCQ (originally the Autism Screening Questionnaire [ASQ]), is based on the ADI and consists of 40 questions that focus on behavioral impairments in

the areas of reciprocal social interaction, language and communication, and repetitive and stereotyped patterns of behavior (Berument et al., 1999). The SCQ includes two versions: the SCQ Lifetime, which measures ASD symptoms that have ever been present, with a focus on ages 4-5 years, and the SCQ Current, which measures current ASD symptoms. The SCQ Lifetime was designed to screen for individuals older than six years old who may need further assessment for an ASD. When children are below this age, the SCQ Current can be used to screen for ASDs. The SCQ Current can also be used to compare overall levels or severity of ASD symptoms across different samples and to assess current ASD symptoms and change over time in older children, adolescents, and adults.

The first published study of the SCQ examined the diagnostic validity, the factor structure and the convergent validity with the ADI-R in a British sample of 160 individuals, aged 4 to 40 years, with a diagnosis of ASD and 40 individuals without a diagnosis of ASD. Correlations between the SCQ and ADI were conducted and receiver operating characteristics and *t*-tests were carried out to assess the discriminative validity of the SCQ. Berument and colleagues (1999) reported that correlation coefficients between the SCQ and ADI total scores, as well as the SCQ and ADI domains were significant (SCQ Total and ADI total, $r = 0.71$). The authors reported that an optimal cutoff score of 15 produced a sensitivity of 0.85 and a specificity of 0.75 for differentiating between individuals with and without a diagnosis of ASD and sensitivity of 0.96 and specificity of 0.67 for differentiating ASD from intellectual disability

(Berument et al., 1999). The authors note that parents rating their children had recently been administered the ADI or ADI-R, and were thus informed about autism symptoms before completing the SCQ.

There have been several independent studies examining the psychometric properties of the SCQ in individuals ranging from 2 to 16 years of age. Bishop and Norbury (2002) examined the agreement between the SCQ and two clinician-rated diagnostic instruments, the ADI-R and the ADOS-G, in a sample of children aged 6-9 who were diagnosed with ASDs or pragmatic language impairment. The authors reported good agreement in diagnostic categorization between total SCQ and the ADI-R scores, but poor item-by-item agreement (Bishop & Norbury, 2002). Howlin and Karpf (2004) examined the validity of the SCQ in a British sample of individuals (mean age = 16.7 years) with Cohen syndrome, a rare autosomal recessive disorder that presents with behavioral profiles similar to ASDs, such as social and communication deficits and repetitive/stereotyped behaviors (Chandler et al., 2003; Howlin, 2001). They reported good agreement between the SCQ and ADI-R total scores ($r = 0.85$) and fair agreement between the SCQ and the ADOS ($r = 0.55$). Sensitivity of the SCQ remained high when compared to the ADI-R and the ADOS in combination, but specificity dropped considerably (Howlin & Karpf, 2004).

Eaves and colleagues examined the sensitivity and specificity of the SCQ in a sample of 151 children (mean age = 5 years) who were enrolled in either a preschool or autism

clinic (2006). The investigators reported an overall sensitivity of 0.71 in both settings and a specificity of 0.62 for the preschool clinic and 0.53 for the autism clinic (Eaves et al., 2006). Chandler and colleagues reported a sensitivity of 0.88 and specificity of 0.72 in differentiating between ASD and non-ASD cases and a sensitivity of .90 and specificity of .86 in differentiating between autism and non-autism cases in a cohort of 9-to-10-year-old children (2007).

Witwer and Lecavalier (2007) examined the diagnostic validity of the SCQ and the Developmental Behaviour Checklist – Autism Screening Algorithm (DBC-ASA) (Brereton et al., 2002) and associations with participant characteristics in a sample of 49 children with intellectual disability. Their results indicated that the SCQ (sensitivity = 0.92; specificity = 0.62) performed better than the DBC, (sensitivity = 0.94; specificity = 0.46) at the established cut-off scores of each instrument. They also reported that behavior problems significantly affected the diagnostic validity of the DBC, but behavior problems did not appear to have an impact on the diagnostic validity of the SCQ (Witwer & Lecavalier, 2007).

Studies of the SCQ in younger children have found that the established cutoff of 15 produces much lower sensitivity and specificity than the initial report, but the discriminative validity improves by lowering the cutoff score (Allen et al., 2007; Snow & Lecavalier, 2008; Wiggens et al., 2007). In a sample of 590 children and adolescents, aged 2-16 years, Corsello and colleagues (2007) replicated the methods used in the initial

psychometric study and found lower sensitivity (0.71) and specificity (0.71) than Berument et al (1999). They also reported lower sensitivity for younger children (aged < 5 years, 5-7 years) than older children (aged 8-10 years, > 11 years). Consistent with previous studies, lowering the cutoff score improved sensitivity, but did not improve specificity (Corsello et al., 2007).

Charman and colleagues (2007) conducted a study to compare the SCQ to the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005) and the Children's Communication Checklist (CCC) (Bishop, 1998) in a sample of 9-13 year-olds in a special needs preschool with either a diagnosis of autism or no diagnosis of autism. They reported that the SCQ performed better than the other two measures on both sensitivity and specificity (SCQ: sens = .86, spec = .78; SRS: sens = .78, spec = .67; CCC: sens = .93. spec = .46). However, they noted that behavior problems reduced the specificity of all screening instruments. When the sample was divided into individuals with high scores on the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997; Goodman, 2000), the sensitivity of the SCQ did not change, but the specificity decreased to .57 (Charman et al., 2007).

In 2005, Towbin and colleagues examined the SCQ and two other ASD symptom measures, the Children's Communication Checklist (CCC-2) and the Social Reciprocity Scale (SRS) as ASD screening measures for children in a mood and anxiety disorders research clinic setting. The study reported that 13% of subjects who presented to the

clinic scored in the "likely ASD range" on the SCQ (Total Score ≥ 15), 61% scored in the likely ASD range on the SRS, and 56% scored in the likely ASD range on the CCC-2 (Towbin et al., 2005). Towbin and colleagues (2005) posit these findings may suggest that these screening measures, especially the SRS and the CCC-2, may have high sensitivity at the expense of low specificity. Alternatively, they suggest that these findings may indicate that individuals with ASD characteristics who present in clinical settings may not be assessed for ASD when needed. Indeed, these findings correspond with previous research indicating that many individuals with signs of mild-moderate ASDs present in clinical or research practice (Harpaz-Rotem & Rosenheck, 2004) but receive either no psychiatric diagnoses or non-ASD diagnoses (Fombonne et al., 2004).

While the psychometric studies of the SCQ in children and adolescents provide strong evidence that this screening measure is useful and valid, no independent studies on the validity of the SCQ among adults with ASDs were found. However, there are several aspects of this measure that bode well for the overall psychometric properties with an adult population. The initial validation sample included adults up to age 40, and previous studies have shown stronger discriminative validity with older children and adolescents (Corsello et al., 2007). Additionally, the focus of the SCQ on current, observable behavior could facilitate the use of this measure with adults (Berument et al., 1999). While the SCQ Current version has not been used to screen for the presence of ASDs in an adult population, this version was examined in the present study in order to assess its

usefulness in screening for ASDs in adults with intellectual disability, whose developmental histories are often unavailable or difficult to obtain.

Adaptive Behavior

The adaptive functioning of individuals with ASDs is an important aspect of understanding both diagnosis and profiles of challenging behavior. The Adaptive Behavior Assessment System (ABAS) (Harrison & Oakland, 2000) and the Adaptive Behavior Assessment System – Second Edition (ABAS-II) (Harrison & Oakland, 2003) have exhibited sound psychometric properties with children and adults with ID. The ABAS-II was revised in 2003, in order to meet the 2002 guidelines for the ten domains of adaptive behavior specified by the American Association of Intellectual and Developmental Disabilities (AAIDD) and the DSM-IV-TR (APA, 2000). The General Adaptive Composite (GAC) represents an overall, global estimate of adaptive functioning, which consists of three adaptive domains - Conceptual, Social, and Practical. Each of the three domains can be further divided into ten adaptive skill areas: Conceptual - Communication, Functional Academics, and Self-Direction; Social - Leisure and Social; and Practical - Self-Care, Home Living, Community Use, Health and Safety, and Work (specifically for the adult form).

The measure consists of five rating forms to assess these domains for parents/primary caregivers (ages 0-5), parents (ages 5-21), teachers/daycare providers (ages 2-5), teachers

(ages 5-21), and adults (ages 16-89). The ABAS-II includes norms for individuals from birth to 89 years, and the standardization sample for the Parent, Teacher, and Adult Forms combined consisted of 5,270 individuals. The sample for the ABAS-II Adult form, which can either be completed using self-report or ratings by others, consisted of 1,910 individuals, with about half using self-report (Harrison & Oakland, 2003).
The data from the standardization sample suggests sound psychometric properties for this measure (Harrison & Oakland, 2003). Correlations among the skill areas were moderate (0.40-0.70), and there was a high degree of internal consistency, with the average internal consistency coefficient for the standardization sample's General Adaptive Composite (GAC) ranging from 0.97-0.99 (Rust & Wallace, 2004). The test-retest reliabilities for teacher, parent and adult forms were mostly at or above 0.90 (Harrison & Oakland, 2003). A number of studies reported in the manual show high concurrent validity between the Adaptive Behavior Composite on the Vineland Adaptive Behavior Scales (VABS) (Sparrow et al., 1984) and the GAC (Harrison & Oakland, 2003).

The ABAS-II also includes norms for small samples of individuals with ASDs. Children diagnosed with PDD-NOS exhibited global deficits in adaptive functioning, particularly in the communication domain. Children diagnosed with Autistic Disorder also exhibited global adaptive functioning deficits, with the greatest deficits in Communication, Health and Safety, Leisure, and Social Skill areas (Harrison & Oakland, 2003). Due to the number of studies demonstrating sound validity and reliability and the flexible manner in

which the adaptive functioning of adults can be measured in the ABAS-II, this measure was used in the current study to assess the adaptive functioning of participants.

Behavioral Associations

For screening measures of ASDs to effectively differentiate individuals with ASDs from individuals without ASDs, they must be sensitive to differences in behavioral profiles. Research among both children and adults is inconclusive concerning whether or not challenging behavior is more prevalent in individuals with intellectual disability and ASD than individuals with intellectual disability and no diagnosis of ASD (Aman, Lam, & Collier-Crespin, 2003; Lecavalier, 2006; Tonge and Einfeld, 2003). For example, McClintock, Hall, and Oliver (2003) reported that maladaptive behaviors, such as aggression, disruptive behavior, and self-injury, are more prevalent among children and adults with autism (2003). However, Tyrer and colleagues reported no differences in challenging behavior between individuals with autism and individuals without autism when pertinent characteristics, such as level of intellectual disability, were taken into account (Tyrer et al., 2006).

Bodfish and colleagues also found no significant differences on severity of aggression between individuals with ID and autism and individuals with ID and no diagnosis of autism (2000). The researchers reported that both groups exhibited significant patterns of repetitive behavior, but they found a higher rate of compulsions, stereotypy, and self-

injurious behavior among participants with autism. They also reported that the severity of repetitive behavior was predictive of the severity of autistic symptoms (Bodfish et al., 2000).

One of the most widely used measures of challenging behavior is the Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985a). The ABC is a factor-analytically derived scale that assesses behavioral problems and measures treatment effects in individuals with intellectual disabilities across five domains: (1) Irritability, Agitation, and Crying, (2) Lethargy, Withdrawal, (3) Stereotypic Behavior, (4) Hyperactivity, Noncompliance, and (5) Inappropriate Speech (Aman, Singh, Stewart, & Field, 1985a). Initial psychometric studies (Aman, Singh, Stewart, & Field, 1985b) and subsequent studies with children, adolescents and adults report sound psychometric properties for this measure, with good to excellent test-retest reliability and internal consistency, and robust support for the original five-factor structure (Aman, 1995; Aman, Singh, Turbott, 1987; Newton & Sturmey, 1988).

While the original ABC was developed with individuals residing mostly in developmental centers (Aman, Singh, Stewart, & Field, 1985a), a revised version, the Aberrant Behavior Checklist-Community (ABC-C) was developed in a community sample of children (Marshburn & Aman, 1992) and adults residing in supported living homes in the community to adapt to changing trends in de-institutionalization of individuals with I/DD (Aman, Burrow, & Wolford, 1995). Studies of the ABC-C have

also reported sound psychometric properties, with the validity of the original factor structure and subscale scoring system remaining sound for the community sample (Aman, Burrow, & Wolford, 1995).

While the current study did not examine the effect of co-occurring psychiatric diagnoses on behavioral profiles of individuals with ASD, it is important that behavioral measures, such as the ABC-C, reliably characterize challenging behavior in individuals with dual diagnoses, as individuals with ID and/or ASDs may be particularly susceptible to psychiatric disorders (Bradley et al., 2004; Ghaziuddin, Ghaziuddin, & Greden, 2002; Gillberg & Billstedt, 2000; Morgan, Roy, & Chance, 2003). There have been several studies examining the psychometric properties of the ABC and the ABC-C in both children and adults with ID and/or ASDs with co-occurring psychiatric diagnoses. Rojahn and Heisel (1991) examined the factor structure, internal consistency, and criterion validity of ABC in a sample of 204 children and adolescents with ID and co-occurring psychiatric diagnoses in a child psychiatry unit. Given the robust psychometric properties of the ABC that the researchers reported in this sample, the measure was recommend for use in populations with dual diagnoses.

Chung and colleagues (1995) reported that the ABC was useful in describing challenging behavior in adults, ranging from 17 to 69 years old (mean age = 35.7), with ID and psychiatric diagnoses. Katz, Berry, and Singh (1997) investigated the ABC-C in four groups of older individuals, with a mean age of 79.35 years with either: 1) dual diagnosis

of intellectual disability and psychiatric diagnosis, 2) psychiatric diagnosis only, 3) intellectual disability only, or 4) no psychiatric diagnosis or intellectual disability. The investigators reported that this measure was an appropriate assessment of problem behaviors in older adults with dual diagnoses.

Helverschou, Bakken, & Martinsen (2009) note that it may be particularly challenging to differentiate symptoms of autism spectrum disorders from psychiatric symptoms due to an overlap of symptoms, atypical presentation of symptoms, and lack of insight and communication difficulties in this population. In 2008, Helverschou, Bakken, Martinsen used the ABC-C to assess behavior problems in individuals with autism and psychiatric diagnoses, lending support for its validity as a measure of challenging behavior in individuals with ASDs and psychiatric diagnoses.

The ABC has been utilized in numerous treatment studies as a measure of response to psychotropic medication treatment in children with ASDs (Aman, 2005). The ABC has also been used to measure maladaptive behavior in children and adults with ASDs. Gabriels and colleagues (2005) examined the relationship among repetitive behaviors and other clinical behaviors, such as levels of cognitive and adaptive functioning and behavioral problems. They reported that nonverbal cognitive ability, adaptive functioning, and the Hyperactivity scale of the ABC were correlated with repetitive behavior (Gabriels et al., 2005). Research on the ABC and ABC-C supports the use of this measure with individuals with diagnoses of autism spectrum disorders, intellectual

disability and psychiatric diagnoses. In order to accurately differentiate between adults with ASDs and adults without ASDs, it is also important that screening measures, such as the SCQ, be sensitive to the presentation of challenging behavior and co-occurring psychiatric diagnoses among these populations.

Hypotheses

The aim of the current study was to examine the psychometric properties of the Social Communication Questionnaire (SCQ) in a sample of adults with a prior diagnosis of 1) intellectual disability (ID) and an autism spectrum disorder (ASD), 2) intellectual disability (ID) presenting with high levels of behavior problems, and 3) intellectual disability (ID) presenting with low levels of behavior problems. Based on previous research indicating a decrease in the specificity of the SCQ in children who presented with challenging behavior (Charman et al., 2007), it is hypothesized that the specificity of the SCQ will also decrease when used to screen adults with ID and no diagnosis of an ASD, who present with high scores on the ABC-C Irritability Subscale.

The effects of participant characteristics on SCQ Current total scores were examined, as well as the relationship among SCQ Current total scores and ABC-C and ABAS-II subscales.

Chapter 2: Method

Participants

Participants were 52 adults aged 19 to 40 years old (mean age = 28.6 years, SD = 6.0 years) with a previous diagnosis of intellectual disability by psychologists or psychiatrists with experience in the ID field. All participants received residential, vocational, or community services for individuals with intellectual and developmental disabilities (IDD) through county agencies. Participants in the ASD group included 20 individuals with a mean age of 26.8 (SD = 5.6), and participants in the ID-only group included 32 individuals with a mean age of 29.7 (SD = 6.1). Participants were rated by support staff and/or parents, and analyses were conducted separately between parent and staff raters.

Participant Characteristics as Rated by Staff

The ASD group rated by staff consisted of 15 individuals (10 males and 5 females) with a mean age of 25.9 years (SD = 4.5 years). Participants were diagnosed with the following ASD types, based on prior diagnoses as assessed by psychologists and psychiatrists: 40% autistic disorder (*n* = 6), 40% PDD-NOS (*n* = 6), and 20% Asperger's Disorder (*n* = 3).

Participants included the following ethnic groups: 93.3% Caucasian (*n* = 14) and 6.7% African-American (*n* = 1). Participants resided in the following living situations: 66.7% supported living homes with 24-hour support (*n* = 10) and 33.3% with their families (*n* = 5). Participants were involved in the following day programs: 33.3% sheltered vocational workshops (*n* = 5); 33.3% day habilitation program (*n* = 5), 20% school (*n* = 3), and 13.3% supported community employment (*n* = 2). Participants were classified as functioning in the following ranges of intellectual disability: 6.7% severe (*n* = 1); 53.3% moderate (*n* = 8); 26.7 % mild (*n* = 4); and 13.3% borderline (*n* = 2). Verbal language was present in 60.0% of the participants (n = 9) (See Table 1).

The ID-only group rated by staff consisted of 31 individuals (22 males and 9 females) with a mean age of 29.8 years (SD = 6.1 years). Participants included the following ethnic groups: 80.6% Caucasian (*n* = 25) and 19.4% African-American (*n* = 6). Participants resided in the following living situations: 87.1% supported living homes with 24-hour support (*n* = 27), 6.5% supported living homes with less than 24-hour support (*n* = 2), and 6.5% with their families (*n* = 2). Participants were involved in the following day programs: 70.9% sheltered vocational workshop programs (*n* = 22), 19.4% day habilitation programs (*n* = 6), 6.5% supported community employment (*n* = 2), and 3.2% no day program (*n* = 1). Participants were classified as functioning in the following ranges of intellectual disability: 48.4% moderate (*n* = 15); 45.1% mild (*n* = 14); and 6.5% severe (*n* = 2). Verbal language was present in 83.9% of the participants (*n* = 26) (See Table 1).

Characteristics of the ASD and ID-only groups, as rated by staff, were compared. An independent samples *t*-test indicated that participants in the ASD group were significantly older than participants in the ID-only group (t = -.25, p = .019). Chi-square tests indicated no significant differences in gender ($\chi 2$ = .09, p = .766) or in presence of verbal language between the groups ($\chi 2$ = 3.12, p = .075) (See Table 1).

Fisher's exact tests were conducted to compare ethnicity, levels of intellectual disability, type of living situation, and type of vocational/day program because several cells had values less than the expected count of 5. No significant differences were found between the groups in ethnicity (p = .399). Because Fisher's exact test can only be conducted for 2 x 2 tables, the other groups were collapsed into two levels: level of intellectual disability (borderline-mild vs. moderate-severe), type of living situation (supported living vs. living with family), and type of vocational/day program (vocational: community and supported employment/sheltered vocational workshop vs. non-vocational: day habilitation program/school/none). No significant differences were found between the groups on level of intellectual disability (p = .497). The proportion of participants in the ASD group residing in supported living homes (66.7%) and with their families (33%) was significantly different (p = .029) than the proportion of participants in the ID-only group residing in supported living homes (93.5%) and with their families (6.5%). The proportion of participants in the ASD group who participated in vocational programs (46.7%) and non-vocational programs (53.3%) was also significantly different (p = .050)

than the proportion of participants in the ID-only group who participated in vocational programs (77.4%) and non-vocational programs (22.6%) (See Table 1).

The presence of psychiatric disorders, based on record review indicating a prior diagnosis by a psychologist or psychiatrist, was assessed across these broad categories: Anxiety Disorders (OCD, PTSD, GAD); Mood Disorders (Major Depressive Disorder, Bipolar Disorder, Dysthymia); Psychotic Disorders (Schizophrenia, Psychotic Disorder – Not Otherwise Specified); Externalizing Disorders (ADHD, Intermittent Explosive Disorder, Conduct Disorder); Personality Disorders (Antisocial Personality Disorder and Borderline Personality Disorder); and None. The proportion of individuals in the ID-only group (16.1%) with no psychiatric diagnoses ($n = 5$) was significantly lower ($\chi 2 = 4.89$, $p = .027$) than the proportion of individuals in the ASD group (53%) with no psychiatric diagnoses ($n = 7$). Significantly more individuals in the ID-only group were diagnosed with mood disorders (74%, $n = 23$) than in the ASD group (33%, $n = 5$) ($\chi 2 = 6.08$, $p = .014$). No significant differences were found between the groups on Anxiety, Psychotic, or Personality Disorders, although it is noteworthy that 58% of individuals in the ID-only group were diagnosed with Externalizing Disorders ($n = 18$), while no individuals in the ASD group received this diagnosis (See Table 1).

Participant Characteristics as Rated by Parents

The ASD-group rated by parents consisted of 12 individuals (9 males, 3 females) with a mean age of 25.3 years (SD = 6.4 years). Half of the participants rated had diagnoses of autistic disorder and half had diagnoses of PDD-NOS. The sample was composed of the following ethnic groups: 91.7% Caucasian (*n* = 11) and 8.3% African American (*n* = 1). 58.3% of participants (*n* = 7) resided with their families, and 41.7% of participants resided in supported living homes with 24-hour support (*n* = 5). Participants were involved in the following types of vocational/day programs: 33.3% day habilitation programs (*n* = 4), 25% school (*n* = 3), 25% supported community employment (*n* = 3), 8.3% sheltered vocational workshops (*n* = 1), and 8.3% competitive community employment (*n* = 1). Participants were classified as functioning in the following ranges of intellectual disability: 16.7 % severe (*n* = 2); 41.7% moderate (*n* = 5); 33.3% mild (*n* = 4); and 8.3% borderline (*n* = 1). Verbal language was present in 41.7% of the participants (n = 5) (See Table 2).

The ID-only group rated by parents consisted of 3 individuals (1 male, 2 females) with a mean age of 27.7 years (SD = 2.1 years). The ethnicity of this group was 100% Caucasian and all lived with their families (*n* = 3). One participant each from this group was classified into the diagnostic categories of mild, moderate, and severe intellectual disability. One participant each from this group participated in a supported community

employment program, sheltered vocational workshop program, and day habilitation program. Verbal language was present in 66.7% of the participants (*n* = 2) (See Table 2).

Staff Raters

Staff raters in the ASD group included 15 individuals, with a mean age of 39.4 years (SD = 13.9 years). They worked with participants in the following capacity: 60% residential support provider (*n* = 9), 20% teacher (*n* = 3), 13.3% vocational/day support provider (*n* = 2), and 6.7% behavior support specialist (*n* = 1). The majority of the raters (73.3%) in the group were female (*n* = 11) and had completed undergraduate or graduate degrees (60%, *n* = 9). Staff raters had worked in the field of intellectual and developmental disabilities for a mean of 14.5 years (SD = 8.9 years), and they had worked with the participant for whom they provided ratings for a mean of 5.4 years (SD = 5.4 years) (See Table 3).

Staff raters in the ID-only group included 21 individuals with a mean age of 37.8 years (SD = 8.6). They worked with participants in the following capacity: 81% residential support provider (*n* = 17), 14.3 % vocational/day support provider (*n* = 3), and 6.7% behavior support specialist (5%, *n* = 1). The majority of the raters (61.9%) in this group were female (*n* = 13), and had completed undergraduate or graduate degrees (61.9%, *n* = 13). Staff raters had worked in the field of intellectual and developmental disabilities for

a mean of 8.8 years (SD = 6.6 years), and they had worked with the participant for whom they provided ratings for a mean of 4 years (SD = 4.9 years) (See Table 3).

No significant differences were found between staff raters in ASD and ID-only group in mean age or years of experience with the individual for whom they provided ratings. Raters in the ASD-group had worked in the ID field for an average of 5.7 years longer than raters in the ID-only group, indicating a trend toward significant differences (p = .067). Chi-square tests indicated no significant differences between groups on level of education ($\chi 2$ = .01, p = .908), and Fisher's exact tests indicated no significant differences on gender (p = .721). When rater types were compressed into two groups (residential vs. non-residential) in order to conduct Fisher's exact test analyses, there were no significant differences in the proportion of residential vs. non-residential staff between groups (p = .260) (See Table 3).

Parent Raters

Parent raters in the ASD group included 11 mothers and 1 father, with a mean age of 54.8 years (SD = 6.6 years). The majority of parent raters in the ASD group (75%) had completed undergraduate or graduate degrees (n = 9) (See Table 4).

Parent raters of individuals in the ID-only group included 3 mothers with a mean age of 58.7 years (SD = 5.5 years). The majority of parent raters in the ID-only group (66.7%) had completed undergraduate or graduate degrees (*n* = 2) (See Table 4).

Instruments

The *Aberrant Behavior Checklist-Community (ABC-C)* (Aman, Burrow, & Wolford, 1995) is a 58-item assessment designed to be rated by a parent, primary caregiver or support staff. The items assess behavior in five subscales: (1) Irritability, Agitation, and Crying – 15 items, (2) Lethargy/ Withdrawal – 16 items, (3) Stereotypic Behavior – 7 items, (4) Hyperactivity, Noncompliance – 16 items, and (5) Inappropriate Speech – 4 items. Items are rated on a 4-point scale, ranging from (0) = not at all a problem to (3) = the problem is severe in degree. Individuals in the ID-only group who scored 15 or higher on the Irritability subscale were assigned to the ID-only High Irritability Group and individuals who scored below 15 on the Irritability subscale were assigned to the ID-only Low Irritability Group. This method was based on previous research, which used this classification scheme with the ABC-C Irritability subscale to differentiate high and low behavior problem groups in a psychotropic drug treatment effect study with individuals with ASDs (McCracken et al., 2002; Owley et al., 2001). Participants with ASD and ID-only will also be compared on the ABC-C subscales of Lethargy/Withdrawal, Stereotypic Behavior, Hyperactivity/Noncompliance, and Inappropriate Speech.

The *Adaptive Behavior Assessment System – Second Edition (ABAS-II)*: Adult Form, Ages 16-89 (Harrison & Oakland, 2003) can be completed by self-report or by a primary caregiver. To maintain consistency, only the caregiver-rated form was administered in this study. The ABAS-II is designed to assess adaptive functioning in the domains of Conceptual, Social, and Practical skills. Each of the three domains can be further divided into ten adaptive skill areas: Conceptual - Communication, Functional Academics, and Self-Direction; Social - Leisure and Social; and Practical - Self-Care, Home Living, Community Use, Health and Safety, and Work. The scaled scores for Self-Care, Leisure, Social, and Communication skill areas were examined to assess differences among the groups in specific aspects of adaptive functioning.

The *Social Communication Questionnaire (SCQ)* (Berument et al., 1999; Rutter, Bailey, & Lord, 2003) is a 40-item caregiver-rated screening measure that focuses on behavioral impairments in the areas of reciprocal social interaction; language and communication; and repetitive and stereotyped patterns of behavior. The SCQ is scored with "1" given for the presence of abnormal behavior and "0" given for the absence of abnormal behavior. There are separate algorithms for different communication abilities, with a maximum score of 39 for individuals who possess spoken language (the first question is used to assess the presence of absence of language) and a maximum of 34 for individuals who lack spoken language. Participants were compared on total SCQ Current scores and total SCQ Lifetime scores (if applicable).

An autism spectrum disorders diagnostic checklist was adapted from the *Diagnostic and Statistical Manual (DSM-IV-TR)* (APA, 2004) by the researchers into non-clinical language and administered as a brief questionnaire. Agreement between this diagnostic checklist as completed by raters and prior diagnosis of an ASD by a psychologist or psychiatrist was examined.

A *Rater Demographic Questionnaire* was completed by staff and parent raters, which included the rater's age, gender, ethnicity, education level, length of experience working in ID field (if applicable), and length of experience working with participant (if applicable).

Procedure

This project was approved by The Ohio State University Institutional Review Board. Participants were recruited from community agencies serving individuals with intellectual and developmental disabilities, a large mid-Western university center for intellectual and developmental disabilities, and local autism support groups. Inclusion criteria included adults, aged 18 to 40 years, with a prior diagnosis of intellectual disability by a psychologist with experience in the intellectual disability field. The presence of intellectual disability is determined by measures of adaptive functioning and scores on standardized intelligence measures, such as the Weschler Adult Intelligence Scales, 3rd Edition (WAIS-III) (Weschler, 1997), the Stanford Binet Intelligence Scales,

Fifth Edition (SB5) (Roid, G. H., 2003) and the Leiter International Performance Scale-Revised (Leiter-R) (Roid & Miller, 1997). Levels of ID in the sample ranged from severe to borderline intellectual functioning corresponding to the following IQ scores: severe (IQ = 20 – 40); moderate (IQ = 35 – 55); mild (IQ = 50 - 75); and borderline (IQ = 70 – 84). While borderline intellectual functioning is not included as a diagnosis in the DSM-IV-TR (APA, 2000), it is often used by clinicians to describe individuals who have intellectual and adaptive deficits and may require daily living support. Individuals with diagnoses of Down Syndrome, Fragile X Syndrome, Prader-Willi Syndrome, Angelman Syndrome, Turner Syndrome, and Williams Syndrome were excluded due to specific behavioral profiles that could complicate the diagnosis of autism or affect behavioral measures.

The public guardian agency, Advocacy and Protective Services, Inc. (APSI) was contacted directly to provide information about the study aims and researcher contact information. APSI guardians identified individuals who qualified for the study, and provided consent for their participation (Consent Form 1) and authorization to review agency files with personal health information (Consent Form 2). After APSI guardians had provided consent, participants with intellectual disability provided assent to participate (Consent Form 3). APSI guardians also identified residential or vocational service agencies of their charges and provided contact information of service providers who might be willing to participate in the study by completing questionnaires about their clients. Raters provided separate consent to participate in the study (Consent Form 4).

The Franklin Country Board of Developmental Disabilities (FCBDD) and the Muskingum County Board of Developmental Disabilities (MCBDD) were contacted to obtain permission present study information at board-operated vocational and supported living programs. Interested ID participants with self-guardianship completed consent forms and provided authorization to use personal health information (Consent Form 5). Legal guardians of ID participants without self-guardianship were sent fliers to determine interest in the study.

The Autism Society of Ohio (ASO) and the Autism Society of America – Central Ohio Chapter were contacted to provide information about the study aims and researcher contact information. The researchers presented study information at several ASA – Central Ohio Chapter meetings, and ASO members agreed to post study information and researcher contact information on their website. Parents who served as guardians of their sons or daughters provided consent for their participation (Consent Form 6) and authorization to use personal health information (Consent Form 2).

The researchers mailed consent/assent forms and study questionnaires to interested participants with a stamped, addressed envelope in which to return the materials. Participants with intellectual disability received a $5.00 gift card to a restaurant or a movie theater for agreeing to participate in the study, by signing consent or assent forms, and nominating up to three staff members who might be willing to complete questionnaires about them. Raters who completed questionnaires received a $15.00 gift

card to a department store or grocery store for completing questionnaires about a participant. Staff raters could complete questionnaires for up to three individuals with whom they have worked for at least 6 months, and they received a $15.00 gift card for each individual rated.

Parent and staff raters completed the SCQ and other measures about the ID participants' behavior and adaptive functioning. Parents completed both the SCQ Lifetime and SCQ Current versions, while support professionals completed only the SCQ Current version, due to lack of knowledge of participant behavior during early development. When possible, both a parent and support professional/caregiver each completed ratings for the same ID participant. In addition to the SCQ, all raters completed the Aberrant Behavior Checklist-Community (ABC-C; Aman et al., 1995), four subscales of the Adaptive Behavior Assessment System, (ABAS-II; Harrison & Oakland, 2003), an autism diagnostic checklist adapted from DSM-IV (APA, 2000) (Questionnaire 1), and a short demographic questionnaire about their education and experience with the ID participant (Questionnaire 2).

Statistical Analyses

Paired-sample correlations were conducted between parent SCQ Current total scores and staff SCQ current scores (n = 9), in order to determine if parent and staff ratings were comparable and could be used in the same overall analysis. Parent and staff scores did

not correlate significantly (r = .08, p = .834). Consequently, analyses were computed separately for staff and parent raters.

SCQ Current total scores were compared between the ASD group and the ID-only group, as rated by staff, using an independent samples *t*-test. The discriminative validity of the SCQ Current version, as rated by staff, was assessed by examining the sensitivity, specificity, positive predictive value, and negative predictive value, calculated with DAG_STAT (Mackinnon, 2000). Sensitivity refers to the percent of individuals with autism spectrum disorders who were correctly identified as having ASDs by the screening measure (true positive rate), while sensitivity refers to the percent of individuals without ASDs who were correctly identified as not having ASDs by the screening measure (true negative rate). Positive predictive value refers to the probability that an individual was actually diagnosed with an autism spectrum disorder when a positive test result occurred (i.e. the individual scored above the cut-off). Negative predictive value refers to the probability that an individual was not diagnosed with an autism spectrum disorder when a negative test result occurred.

Receiving Operating Characteristic (ROC) analyses were conducted to identify optimal cutoff scores of the SCQ Current in the ASD group and ID-only group. The ROC curve is a graphical representation of the trade-off between the true positive rate (sensitivity) on the vertical axis and the false positive rate (1 – specificity) on the horizontal axis at every possible cut-off score. The area under the ROC curve (AUC) can be calculated to

determine the expected performance of the test measure. AUC values range from .5 (indicating a test that performs no better than chance with equal true positive and false positive rates) to 1.0 (indicating a perfect test with all true positives and no false positives) (Hanley & McNeil, 1982).

The relationships between participant characteristics, such as age, gender and level of intellectual disability, and SCQ Current total scores were examined separately in the ASD and ID-only groups. The association between SCQ Current scores and participant age were examined using Pearson correlations, and associations between SCQ Current scores and level of intellectual disability, including (1) severe, (2) moderate, (3) mild, and (4) borderline were examined using Spearman's *rho* (ρ). The relationship between SCQ Current scores and gender and between SCQ Current scores and presence of verbal language were examined with independent samples *t*-tests.

Associations between SCQ Current scores and ABC-C subscales were examined separately in the ASD and ID-only groups, using Pearson Correlations, as well as between SCQ Current scores and ABAS-II scores.

Differences between the ASD and ID-only groups among ABC-C subscales and ABAS-II scaled scores, as rated by staff, were calculated using a one-way ANOVA.

An interrater reliability analysis using the Kappa statistic was performed to determine agreement between prior diagnosis of an autism spectrum disorder by a psychologist or psychiatrist and classification based on the adapted DSM-IV-TR (APA, 2000) diagnostic checklist as completed by raters.

The ID-only group was divided into two subgroups based on ABC-C Irritability subscale scores, including an ID-only High Irritability group (ABC-C $\geq$ 15) and an ID-only Low Irritability group (ABC-C < 15). Mean SCQ Current total scores, as rated by staff, were compared between the ASD group and the ID-only High Irritability subgroup, and between the ASD group and the ID-only Low Irritability subgroup, using independent samples *t*-tests. ROC analyses, sensitivity, specificity, PPV, and NPV of the SCQ Current were calculated separately for the ID-only High and Low Irritability subgroups.

Differences between the ASD and ID-only High Irritability subgroup, and between the ASD and ID-only Low Irritability subgroup, among ABC-C subscales and ABAS-II scores, as rated by staff, were calculated using a one-way ANOVA.

ROC analyses, sensitivity, specificity, PPV, and NPV of the SCQ Current and Lifetime versions, as rated by parents, were not calculated, as there were too few participants in the ID-only group (n = 3) to produce meaningful comparisons. Paired-samples *t*-tests and Pearson correlations were conducted to determine the relationship between SCQ Current scores and SCQ Lifetime scores in the ASD group, as rated by parents.

Chapter 3: Results

ASD vs. ID-only Total Group as Rated by Staff

SCQ Current Scores differed significantly between the ASD and ID-only group (t = 3.89, p = .001, df = 45), and demonstrated a large effect size (Cohen's d) = 1.27. The mean SCQ Current total score in the ASD group was 17.8 (SD = 6.7), and the mean score in the ID-only group was 10.2 (SD = 5.6) (See Table 5).

The ROC analysis of SCQ Current total scores in the total sample, as rated by staff, yielded an AUC of .72 (p = .003; 95% CI = .60 - .84) (See Figure 1). When more weight was assigned to sensitivity, the optimal cutoff score in this sample was 12, which yielded a sensitivity of .80 (95% CI = .52 - .96), a specificity of .65 (95% CI = .45 - .81), a positive predictive value (PPV) of .52 (95% CI = .31 - .73), and a negative predictive value (NPV) of .87 (95% CI = .66 - .97). A cutoff of 12 in this sample resulted in 12 of the 15 ASD participants (80%) being correctly classified. In the ID-only sample, 20 of the 31 participants (64.5%) were correctly classified (See Table 7).

The authors' proposed cutoff score of 15 (Berument et al. 1999; Rutter, Bailey, & Lord, 2003) yielded a sensitivity of .60 (95% CI = .32 - .84), a specificity of .81 (95% CI = .63

- .93), a positive predictive value (PPV) of .60 (95% CI = .32 - .84), and a negative predictive value (NPV) of .81 (95% CI = .63 - .93). At this cutoff score, 9 of the 15 participants with ASD (60%) were correctly classified, and 25 of the 31 of the ID-only participants (80.6%) were correctly classified. Table 7 presents the corresponding values for different cut-off scores.

In the ASD group, level of ID and SCQ Current total scores were correlated significantly, with more severe levels of ID associated with higher SCQ Total scores (ρ = .52, p = .046). In order to further examine this relationship, an independent samples t-test was performed between SCQ Current scores of participants with borderline-mild ID (n = 6, mean = 15.2, SD = 5.0) and moderate-severe ID (n = 9, mean = 19.3, SD = 7.7). No significant differences in SCQ Current scores were found between these groups (t = -1.15, p = .321). Participant age (r =-.39, p = .150) was not significantly correlated with SCQ Current scores. Mean scores on the SCQ Current did not differ significantly (t = .22, p = .831) between males (n = 10, mean = 18.0, SD = 6.1) and females (n = 5, mean = 17.0, SD = 9.1) in the ASD group. Individuals with verbal language (n = 9, mean = 15.1, SD = 16.4) did not differ significantly than individuals without verbal language (n = 6, mean = 21.5, SD = 6.3) on SCQ Current total scores (t = -1.92, p = .081).

In the ID-only group, males scored significantly higher on the SCQ Current (n = 22, mean = 11.6, SD = 5.6) than females (n = 9, mean = 6.7, SD = 3.9) (t = 2.39, p = .011). Participant age (r = -.09, p = .629) and level of ID (ρ = .17, p = .351) were not correlated

significantly with SCQ Current scores in this group. No significant differences in SCQ Current scores (t = -1.41, p = .225) were found between participants who possessed verbal language (n = 26, mean = 9.3, SD = 4.6) and participants who did not (n = 5, mean = 14.8, SD = 8.6).

In the ASD group, SCQ Current scores were correlated significantly with the ABC-C subscales of Lethargy (r = .66, p = .005) and Stereotypy (r = .74, p = .001), indicating that higher scores on these subscales were strongly associated with higher SCQ Current scores. SCQ Current scores were negatively correlated with ABAS-II Communication (r = -.56, p = .023), Leisure (r = -.64, p = .007), and Social (r = -.55, p = .028) scaled scores, indicating that lower scores on these adaptive skills areas predicted higher SCQ Total scores (See Table 12) (See Table 12).

In the ID-only group, SCQ Current scores were correlated significantly with ABC-C subscales of Irritability (r = .36, p = .047), Lethargy (r = .79, p = .000), Stereotypy r = .42, p = .017), and Inappropriate Speech (r = .45, p = .011). As in the ASD group, higher scores on the ABC-C subscales were associated with higher SCQ Current total scores. SCQ Current scores were significantly correlated with all ABAS-II scaled scores, also indicating that lower scores on these adaptive skills areas predicted higher SCQ Total scores in this group (See Table 12).

There were no significant differences between the ASD and ID-only groups among ABC-C subscales or ABAS-II scaled scores (See Table 5).

Agreement between diagnosis of an ASD by a psychologist or psychiatrist and the adapted DSM-IV-TR (APA, 2000) ASD diagnostic checklist was computed using Cohen's Kappa. Interrater reliability was found to be Kappa = .49 (p = .001), 95% CI (.22 - 0.76), which indicates significant, but moderate interrater agreement (Landis & Koch, 1977). In the ASD group, 9 of the 15 participants (60%) were classified as meeting criteria on the DSM-IV ASD Checklist by staff raters. In the ID-only group, 27 of the 31 participants (87%) were classified as not meeting criteria for ASD.

ASD vs. ID-only High Irritability and ID-only Low Irritability Groups as Rated by Staff

SCQ Current Scores differed significantly (t = 2.90, p = .008, df = 24) between the ASD group (mean = 17.8, SD = 6.7) and the ID-only High Irritability group (mean = 11.7, SD = 4.0), and there was a large effect size (Cohen's d) of 1.06 (See Table 8). SCQ Current scores also differed significantly (t = 3.87, p = .001, df = 35) between the ASD group and the ID-only Low Irritability group (mean = 9.4, SD = 6.2), with a large effect size (Cohen's d) of 1.31 (See Table 10).

The ROC analysis of SCQ Current total scores in the ID-only High Irritability group yielded an AUC of .73 (p = .007; 95% CI = .58 - .87) (See Figure 2). The optimal cutoff

score in this sample was also 12, which yielded a sensitivity of .80 (95% CI = .52 - .96), a specificity of .60 (95% CI = .26 - .88), a positive predictive value (PPV) of .75 (95% CI = .48 - .93), and a negative predictive value (NPV) of .67 (95% CI = .30 - .93) (See Table 9).

At the author's proposed cutoff score of 15, sensitivity was .60 (95% CI = .32 - .84), specificity was .70 (95% CI = .35 - .93), PPV was .75 (95% CI = .43 - .95), and NPV was .54 (95% CI = .25 - .81). See Table 9 for corresponding values of the ID-only High Irritability group at different cutoff scores.

The ROC analysis of SCQ Current total scores in the ID-only Low Irritability group yielded an AUC of .72 (p = .004; 95% CI = .59 - .86) (See Figure 3). The optimal cutoff score in this sample was 10, which yielded a sensitivity of .93 (95% CI = .68 - .99), a specificity of .62 (95% CI = .38 - .82), PPV of .64 (95% CI = .41 - .83), and NPV of .93 (95% CI = .66 - .99) (See Table 11).

At the author's proposed cutoff score of 15, sensitivity was .60 (95% CI = .32 - .84), specificity was .86 (95% CI = .64 - .97), PPV was .75 (95% CI = .43 - .95), and NPV was .75 (95% CI = .53 - .90). See Table 11 for corresponding values of the ID-only Low Irritability group at different cut-off scores.

ABC-C subscale scores and ABAS-II scores were compared between the ASD group and the ID-only High Irritability group. Participants in the ID-only High Irritability group

(mean = 27.8, SD = 7.9) scored significantly higher (F = .01, p = .005, effect size (Cohen's d) = -1.25) on the ABC-C Hyperactivity subscale than participants in the ASD group (mean = 14.0, SD = 12.7). There were no significant differences between the groups on ABAS-II scores (See Table 8).

Participants in the ASD group scored significantly higher (mean = 6.5, SD = 5.7) on the ABC-C Stereotypy subscale (F = 9.03, p = .005, effect size (Cohen's d) = 1.01) than the ID-only Low Irritability group (mean = 2.1, SD = 3.1). ASD participants also scored significantly higher (mean = 3.9, SD = 4.0) on the ABC-C Inappropriate Speech subscale (F = 5.28, p = .028, effect size (Cohen's d) = .79) than the ID-only Low Irritability group (mean = 1.5, SD = 2.1). There were no significant differences between the groups on ABAS-II scores (See Table 10).

SCQ Lifetime and Current Scores as Rated by Parents

Parent ratings of SCQ Lifetime scores (mean = 23.3, SD = 8.4) were significantly higher (t = 5.16, p < .001, df = 11) than SCQ Current scores (mean = 16.8, SD = 7.9). There was a significant correlation between SCQ Lifetime and SCQ Current scores as rated by parents (r = .83, p < .001).

Chapter 4: Discussion

Previous research on autism screening measures has focused largely on identifying ASDs in children, as early intervention can have significant positive effects on outcomes (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Rogers, 1998). However, greater attention has recently been given to the concerns of adults with autism and their families. Adults with autism present with different behavioral profiles than children with the disorder, showing improvements in autism symptoms and decreases in maladaptive behavior over time (Seltzer et al., 2004; Shattuck et al., 2007). These changes in symptom presentation pose considerable challenges to assessing ASDs in adults who do not exhibit many of the same behaviors necessary for ASD diagnosis in children. This factor, combined with the lack of public awareness of ASDs and less sophisticated diagnostic tools two decades ago, suggest that there are quite a few undiagnosed adults with autism spectrum disorders.

To our knowledge, this study is the first to examine the SCQ Current as a screening measure in an adult population. Based on established research norms, only the SCQ Lifetime version has been used to screen individuals past the age of six years old for ASDs, as it includes developmental history, which is a key component in the diagnosis of ASDs. The SCQ Current was designed to be used for diagnostic screenings in children

below the age of six or as a measure of symptom change, treatment response, or comparison of severity of symptoms (Rutter, Bailey, & Lord, 2003). However, the SCQ Current, which relies on current observable behaviors, could have potential as a diagnostic screening measure for adults with higher risks for ASDs whose developmental histories are unavailable or difficult to obtain (i.e. individuals with ID who receive services from local agencies serving persons with developmental disabilities or guardianship through public agencies),

The SCQ Current exhibited fair to good diagnostic validity in a sample of adults with intellectual disability, with an AUC score of .72 (p = .003; 95% CI = .60 - .84). The optimal cutoff score in this sample was 12, which yielded a sensitivity of .80 (95% CI =.52 - .96) and a specificity of .52 (95% CI = .31 - .73). Sensitivity was given more weight than specificity in determining this cutoff score, as the purpose of screening for ASDs in adults is to identify high-risk individuals (i.e. with intellectual disabilities) who may not have been diagnosed with these disorders in the past, and therefore may not currently be receiving appropriate support.

Contrary to the hypothesis, behavioral problems did not appear to affect the specificity of the SCQ Current. The AUC scores in the ID-only High Irritability (AUC = .73, p = .007; 95% CI = .58 - .87) and ID-only Low Irritability subgroups (AUC = .72; p = .004; 95% CI = .59 - .86) were virtually identical to the AUC score of the overall sample (AUC = .72; p = .003; 95% CI = .60 - .84). The values and confidence intervals for sensitivity,

specificity, PPV, and NPV among the ID-only total sample, the ID-only High Irritability subgroup, and the ID-only Low Irritability subgroups overlapped considerably, indicating that there were no meaningful differences among these groups in discriminative validity. However, it is difficult to make strong conclusions based on these findings because the sample size for the High Irritability group was quite small (n = 10).

The relationships among SCQ Current scores and ABC-C and ABAS-II scores in the ASD-group were consistent with the core symptoms of ASDs. For example, higher scores on ABC-C subscales associated with autism symptoms (Lethargy/Social Withdrawal and Stereotypy) were associated with higher scores on SCQ Current scores, with moderate to high correlation coefficients. Lower scores on the ABAS-II Communication, Leisure, and Social skill areas (indicating deficits in these areas consistent with core autism features) were correlated with higher SCQ Current scores in the ASD group, as well.

In the ID-only group, higher ABC-C subscale scores on Irritability, Lethargy/Social Withdrawal, Stereotypy, and Speech predicted higher SCQ Current scores, and lower scores on all ABAS-II areas were correlated with higher SCQ Current scores. It is noteworthy that higher ABC-C Irritability scores were associated with higher SCQ Current scores in the ID-only group, but not in the ASD group. These findings suggest that higher behavioral problems and lower adaptive functioning increase SCQ Current scores in general.

Correlations among SCQ Current scores and ASD participant characteristics indicated a small, but significant, relationship between the measure and level of intellectual disability. However, when intellectual disability was collapsed into two groups (due to small cell counts) and mean SCQ Current scores were compared, there did not appear to be significant differences between more severe and milder forms of ID. In the ID-only group, males scored significantly higher than females on the SCQ Current, which may be a result of two male ID-only participants who both scored above 20 on the SCQ Current.

The decrease in SCQ scores between the Lifetime and Current versions, as rated by parents, is consistent with previous research indicating a decrease in severity of ASD symptoms across time (Esbenson et al., 2008; Seltzer et al., 2004; Shattuck et al., 2007; Taylor & Seltzer, 2010a).

Agreement between ASD diagnoses made by psychologists and psychiatrists and classification on the adaptive DSM-IV checklist (APA, 2000) completed by raters was statistically significant but only moderate in strength (Landis & Koch, 1977). It is not surprising that agreement between these two raters would not be particularly strong, given the different contexts in which these classifications were obtained.

The lack of significant differences between the ASD and ID-only groups among the ABC-C subscales of Lethargy/Social Withdrawal, Stereotypy, or Inappropriate Speech or among ABAS-II Communication, Leisure, or Social scaled scores was surprising,

especially in light of the strong correlations between SCQ Current total scores and these measures. This finding is likely due to limitations of the study, which are discussed below.

Limitations and Future Directions

Significant limitations of the study include small sample size and lack of standardized IQ measures and ASD diagnoses. It was not feasible to match participants on important characteristics, such as age, gender, level of intellectual functioning, and verbal language due to small sample size, which limited the ability to control for factors that have been shown to impact the performance of the SCQ (i.e. Charman et al., 2007). The lack of standardized IQ scores is also problematic in determining how comparable the groups are on intellectual functioning. However, it should be noted that half of the total ASD participants (n = 20) and 83.4% of the total ID-only participants (n = 32) had been assessed by an experienced psychologist in the ID field using standardized IQ measures, as these measures are required for individuals to receive services for intellectual and developmental disabilities. Additionally, there were no significant differences between the ASD and ID-only groups in ABAS-II Self-Care scaled scores (see Table 5), which have been shown to correlate well with measures of IQ (Harrison & Oakland, 2003).

The lack of standardized assessment of ASDs in this study raises a significant issue, as some participants without a diagnosis of an ASD may indeed have the disorder, but not

have been assessed for it yet. For example, five participants without diagnoses of ASDs scored above 15 on the SCQ Current (two of those had scores of 21 and 25). Some of these individuals may actually meet criteria for an autism spectrum disorder, and their inclusion in the ID-only group may have falsely lowered the specificity of the SCQ in this sample. The presence of participants in the ID-only group who may meet criteria for an ASD may have impacted several findings in the study, including differences between groups among subscales of the ABC-C and ABAS-II. If standardized measures of ASD diagnoses had been used in the study, the SCQ Current would likely have performed much better as a diagnostic screening measure in this sample.

There were also several significant differences between the ASD and ID-only groups on characteristics, such as age, type of living situation, type of vocational/day programs, and psychiatric diagnoses which may have impacted the results. These differences could be related to several factors. For example, many older participants may, in fact, have ASDs, but not have been diagnosed due to lack of awareness when they were children. Significantly more individuals with autism lived at home with their families and significantly less participated in vocational programs, which is consistent with research suggesting a gap in community services for adults with ASDs (Taylor & Seltzer, 2010b).

Another limitation to the study involved the difficulty in recruiting parent raters of adults with ID-only, which resulted in more parent volunteers for rating ASD individuals than for ID-only adults. The small number of parents who provided ratings of ID-only

participants (n = 3) did not allow for statistical comparisons to be made between these groups. The discrepancy between number of ASD and ID-only parent raters may be related to recruitment methods, in which the researchers contacted local autism support groups, which consist mainly of parents and family members of individuals with ASDs. While the researchers did present study information to a parent support group of individuals with general intellectual and developmental disabilities, there were few other parent or advocacy organizations for individuals with ID who do not have diagnoses of specific genetic disorders. Also, parents of individuals with ASDs appeared more willing to participate in research, often reporting that they were very interested in learning more about issues relating to adults with ASDs.

However, the discrepancy between number of ASD and ID-only parent raters may also be a reflection of the overall difficulty in obtaining developmental history of adults with ID. Many guardians and residential providers of ID-only participants were unaware of how to contact their parents or families voluntarily had little contact with the participants with ID. This problem is consistent with the difficulty that many professionals face when trying to obtain developmental history, and it reflects the need for screening tools to assess current, observable behaviors to determine if further ASD diagnostic testing is needed.

The SCQ Current appears to have promise as a screening instrument for adults with intellectual disability, although lowering the cutoff score may be optimal for this purpose.

Assessment of ASDs in adults is clearly an important issue that continues to impact individuals and their families across the lifespan. Future research on the SCQ Current should include standardized measures of intellectual functioning and more thorough diagnostic testing by trained psychologists, using “gold standard” instruments, such as the ADI-R, the ADOS-G, and expert clinical judgment.

APPENDIX:

TABLES, FIGURES, QUESTIONNAIRES, AND CONSENT FORMS

TABLES

Table 1: Characteristics of Sample as Rated by Staff

	ASD (n = 15)	ID-Only (n = 31)	Test value	p
Mean Age in Years (SD)	25.9 (4.5)	29.8 (6.1)	t = -.25	.019
Male (%)	10 (66.7)	22 (71.0)	$\chi 2$ = .09	.766
Ethnicity				.399
Caucasian (%)	14 (93.3)	25 (80.6)		
African American (%)	1 (6.7)	6 (19.4)		
Language: (%) with verbal speech	9 (60.0)	26 (83.9)	$\chi 2$ = 3.12	.075
Level of ID				
Borderline (%)	2 (13.3)	0		
Mild (%)	4 (26.7)	14 (45.1)		
Moderate (%)	8 (53.3)	15(48.4)		
Severe (%)	1 (6.7)	2 (6.5)		
Borderline-Mild v. Moderate-Severe				.497
Living Situation				
24-hr residential support (%)	10 (66.7)	27 (87.1)		
< 24-hr residential support (%)	0	2 (6.5)		
With family	5 (33.3)	2 (6.5)		
Residential home vs. Family				.029
Vocational/day Program				
Supported Comm. Emp. (%)	2 (13.3)	2 (6.5)		
Sheltered Workshop (%)	5 (33.3)	22 (70.9)		
Day Habilitation (%)	5 (33.3)	6 (19.4)		
School (%)	3 (20)	0		
None	0	1 (3.2)		
Vocational vs. Non-vocational				.050

Continued

Table 1 continued

Psychiatric Diagnoses:				
Present				
None (%)	7 (46.7)	5 (16.1)	$\chi 2 = 4.89$	.027
Anxiety Disorders (%)	6 (40.0)	13 (41.9)	$\chi 2 = .02$	.901
Mood Disorders (%)	5 (33.3)	23 (74.2)	$\chi 2 = 6.08$	.014
Psychotic Disorders (%)	1 (6.7)	5 (16.1)		.990
Externalizing Disorders (%)	0	18 (58.1)		
Personality Disorders (%)	1 (6.7)	5 (16.1)		.647

Note. Anxiety Disorders - OCD, GAD, PTSD, Anxiety-NOS; Mood Disorders - Major Depressive Disorder, Bipolar Disorder, Dysthymia; Psychotic Disorders - Schizophrenia, Psychotic =Disorder-NOS; Externalizing Disorders - ADHD, Intermittent Explosive Disorder, Conduct Disorder; Personality Disorders – Antisocial Personality Disorder, Borderline Personality Disorder

Table 2: Characteristics of Sample as Rated by Parents

	ASD (n = 12)	ID-Only (n = 3)
Mean Age in Years (SD)	25.3 (6.4)	27.7 (2.1)
Male (%)	9 (75)	1 (33.3)
Ethnicity: n (%)		
Caucasian	11 (91.7)	3 (100%)
African-American	1 (8.3)	0
Language: (%) with verbal speech	5 (41.7)	2 (66.7)
Level of ID: n (%)		
Borderline	1 (8.3)	0
Mild	4 (33.3)	1 (33.3)
Moderate	5 (41.7)	1 (33.3)
Severe	2 (16.7)	1 (33.3)
Living Situation: n (%)		
24-hr residential support	5 (41.7)	0
With family	7 (58.3)	3 (100%)
Vocational Situation		
Competitive Comm. Emp. (%)	1 (8.3)	0
Supported Comm. Emp. (%)	3 (25)	1 (33.3)
Sheltered Workshop (%)	1 (8.3)	1 (33.3)
Day Habilitation (%)	4 (33.3)	1 (33.3)
School (%)	3 (25)	0
Psychiatric Diagnoses:		
Present		
None (%)	8 (66.7)	3 (100%)
Anxiety Disorders (%)	3 (25)	0
Mood Disorders (%)	2 (16.7)	0
Psychotic Disorders (%)	0	0
Externalizing Disorders (%)	0	0
Personality Disorders (%)	0	0

Note. Anxiety Disorders - OCD, GAD, PTSD, Anxiety-NOS; Mood Disorders - Major Depressive Disorder, Bipolar Disorder, Dysthymia; Psychotic Disorders - Schizophrenia, Psychotic =Disorder-NOS; Externalizing Disorders - ADHD, Intermittent Explosive Disorder, Conduct Disorder; Personality Disorders – Antisocial Personality Disorder, Borderline Personality Disorder

Table 3: Characteristics of Staff Raters

	ASD (n = 15)	ID-Only (n = 21)	Test value	p
Mean Age in Years (SD)	39.4 (13.9)	37.8 (8.6)	t = .40	.691
Female (%)	11 (73.3)	13 (61.9)		.721
Relationship to Participant				
Residential staff (%)	9 (60.0)	17 (81.0)		
Vocational/day staff (%)	2 (13.3)	3 (14.3)		
Teacher (%)	3 (20.0)	0		
Behavior Support Specialist (%)	1 (6.7)	1 (6.7)		
Residential vs. Non-residential				.260
College Education or higher (%)	9 (60.0)	13 (61.9)	$\chi 2$ = .01	.908
Mean years of experience in ID field (SD)	14.5 (8.9)	8.8 (6.6)	t = 1.92	.067
Mean years of experience with Participant (SD)	5.4 (5.4)	4 (4.9)	t = .89	.381

Table 4: Characteristics of Parent Raters

	ASD (n = 12)	ID-Only (n = 3)
Mean Age in Years (SD)	54.8 (6.6)	58.7 (5.5)
Female (%)	11 (91.6)	3 (100)
College Education or higher (%)	9 (75)	2 (66.7)

Table 5: Group Differences in Measures as Rated by Staff

	ASD (n = 15) Mean (SD)	ID-Only (n = 31) Mean (SD)	Test Value	Effect Size (Cohen's d)	p
SCQ Current	17.8 (6.7)	10.2 (5.6)	t = 3.89	1.27	.001
ABC-C Irritability	14.5 (11.8)	12.3 (9.1)	F = .55	.23	.462
ABC-C Lethargy	10.2 (9.8)	7.3 (7.4)	F = 1.26	.35	.267
ABC-C Stereotypy	6.5 (5.7)	3.6 (5.2)	F = 3.01	.54	.090
ABC-C Hyperactivity	14.0 (12.7)	15.7 (11.2)	F = .23	-.15	.638
ABC-C Inapprop. Speech	3.9 (4.0)	2.6 (2.9)	F = 1.43	.40	.238
ABAS-II Self-Care	3.8 (2.7)	4.2 (3.2)	F = .26	-.13	.612
ABAS-II Communication	3.9 (2.9)	5.1 (2.5)	F = 1.95	-.46	.169
ABAS-II Leisure	4.1 (2.8)	5.2 (2.5)	F = 1.91	-.42	.174
ABAS-II Social	3.2 (2.6)	4.1 (2.5)	F = 1.54	-.36	.221

Table 6: Means of Measures as Rated by Parents

	ASD (n = 12) Mean (SD)	ID-Only (n=3) Mean (SD)
SCQ Current	18.4 (7.9)	10.3 (4.6)
SCQ Lifetime	25.2 (7.8)	15.3 (6.8)
ABC-C Irritability	14.7 (11.6)	2.7 (4.6)
ABC-C Lethargy	15.5 (14.3)	1.3 (1.5)
ABC-C Hyperactivity	15.6 (13)	6.3 (4.5)
ABC-C Stereotypy	7.3 (5.0)	1.7 (1.5)
ABC-C Inapprop. Speech	4.8 (4.5)	1.7 (1.5)
ABAS-II Self-Care	3.2 (2.1)	3.7 (3.8)
ABAS-II Communication	3.5 (2.9)	2.3 (2.3)
ABAS-II Leisure	3.6 (2.1)	3.7 (2.1)
ABAS-II Social	3.0 (2.0)	3.7 (1.5)

Table 7: SCQ Current Sensitivity, Specificity, PPV, and NPV as Rated by Staff; Total Sample

Cutoff Score	Sens	Sens 95% C.I.	Spec	Spec 95% C.I.	PPV	PPV 95% C.I.	NPV	NPV 95% C.I.
15[a]	.60	.32 - .84	.81	.63 - .93	.60	.32 - .84	.81	.63 - .93
14	.67	.35 - .88	.74	.55 - .88	.56	.31 - .79	.82	.63 - .94
13	.67	.35 - .88	.74	.55 - .88	.56	.31 - .79	.82	.63 - .94
12[b]	.80	.52 - .96	.65	.45 - .81	.52	.31 - .73	.87	.66 - .97
11	.87	.60 - .98	.58	.39 - .76	.50	.30 - .71	.90	.68 - .99
10	.93	.68 - .99	.55	.36 - .73	.50	.31 - .69	.94	.73 - .99

Sens = Sensitivity; Spec = Specificity; 95% CI = 95% Confident Interval; PPV = Positive Predictive Value; NPV = Negative Predictive Value; [a]Cutoff proposed by Berument et al. (1999), [b]Optimal cutoff in current sample

Table 8: Group Differences in Measures as Rated by Staff:
ASD vs. ID-only High Irritability Group

	ASD (n = 15) Mean (SD)	ID-only High Irrit (n = 10) Mean (SD)	Test Value	Effect Size (Cohen's d)	p
SCQ Current	17.8 (6.7)	11.7 (3.9)	t = 2.90	1.06	.008
ABC-C Irritability	14.6 (11.8)	22.8 (6.6)	F = 4.02	-.81	.056
ABC-C Lethargy	10.2 (9.8)	9.1 (4.8)	F = .105	.13	.749
ABC-C Hyperactivity	14.0 (12.7)	27.8 (7.9)	F = 9.38	-1.25	.005
ABC-C Stereotypy	6.5 (5.7)	6.8 (7.2)	F = .01	-.05	.907
ABC-C Inapprop. Speech	3.9 (4.0)	5.0 (3.1)	F = .56	-.30	.460
ABAS-II Self-Care	3.8 (2.7)	3.6 (3.2)	F = .02	.07	.889
ABAS-II Communication	3.9 (2.9)	4.6 (2.9)	F = .33	-.24	.574
ABAS-II Leisure	4.1 (2.8)	4.6 (3.2)	F = .16	-.17	.694
ABAS-II Social	3.2 (2.6)	3.9 (3.3)	F = .37	-.24	.549

Note. High Irritability = ABC Irritability subscale score $\geq$ 15

Table 9: SCQ Current Sensitivity, Specificity, PPV, and NPV as Rated by Staff: ID-only High Irritability Group

Cutoff Score	Sens	Sens 95% C.I.	Spec	Spec 95% C.I.	PPV	PPV 95% C.I.	NPV	NPV 95% C.I.
15[a]	.60	.32 - .84	.70	.35 - .93	.75	.43 - .95	.54	.25 - .81
14	.67	.38 - .88	.70	.35 - .93	.77	.46 - .95	.58	.28 - .85
13	.67	.38 - .88	.70	.35 - .93	.77	.46 - .95	.58	.28 - .85
12[b]	.80	.52 - .96	.60	.26 - .88	.75	.48 - .93	.67	.30 - .93
11	.867	.60 - .98	.40	.12 - .74	.68	.43 - .87	.67	.22 - .96
10	.933	.68 - .99	.30	.07 - .65	.67	.43 - .85	.75	.19 - .99

Note. High Irritability = ABC Irritability subscale score $\geqq$ 15; Sens = Sensitivity; Spec = Specificity; 95% CI = 95% Confident Interval; PPV = Positive Predictive Value; NPV = Negative Predictive Value; [a]Cutoff proposed by Berument et al. (1999), [b]Optimal cutoff in current sample

Table 10: Group Differences in Measures as Rated by Staff:
ASD vs. ID-only Low Irritability Group

	ASD (n = 15) Mean (SD)	ID-only Low Irrit (n = 21) Mean (SD)	Test Value	Effect Size (Cohen's d)	p
SCQ Current	17.8 (6.7)	9.4 (6.2)	t = 3.87	1.31	.001
ABC-C Irritability	14.6 (11.8)	7.2 (4.7)	F = 6.69	.88	.014
ABC-C Lethargy	10.2 (9.8)	6.5 (8.3)	F = 1.55	.43	.222
ABC-C Hyperactivity	14.0 (12.7)	9.9 (7.2)	F = 1.51	.42	.227
ABC-C Stereotypy	6.5 (5.7)	2.1 (3.1)	F = 9.03	1.01	.005
ABC-C Inapprop. Speech	3.9 (4.0)	1.5 (2.1)	F = 5.28	.79	.028
ABAS-II Self-Care	3.8 (2.7)	4.5 (3.2)	F = .61	-.23	.442
ABAS-II Communication	3.9 (2.9)	5.3 (2.3)	F = 2.52	-.55	.121
ABAS-II Leisure	4.1 (2.8)	5.5 (2.1)	F = 3.09	-.58	.087
ABAS-II Social	3.2 (2.6)	4.3 (2.1)	F = 2.01	-.47	.165

Note. Low Irritability = ABC Irritability subscale score < 15

Table 11: SCQ Current Sensitivity, Specificity, PPV, and NPV as Rated by Staff: ID-only Low Irritability Group

Cutoff Score	Sens	Sens 95% C.I.	Spec	Spec 95% C.I.	PPV	PPV 95% C.I.	NPV	NPV 95% C.I.
15[a]	.60	.32 - .84	.86	.64 - .97	.75	.43 - .95	.75	.53 - .90
14	.67	.38 - .88	.76	.53 - .92	.67	.38 - .88	.76	.53 - .92
13	.67	.38 - .88	.76	.53 - .92	.67	.38 - .88	.76	.53 - .92
12[b]	.80	.52 - .96	.67	.43 - .85	.63	.38 - .84	.82	.57 - .96
11	.87	.60 - .98	.62	.38 - .82	.62	.38 - .82	.87	.60 - .98
10	.93	.68 - .99	.62	.38 - .82	.64	.41 - .83	.93	.66 - .99

Note. Low Irritability = ABC Irritability subscale score < 15; Sens = Sensitivity; Spec = Specificity; 95% CI = 95% Confident Interval; PPV = Positive Predictive Value; NPV = Negative Predictive Value; [a]Cutoff proposed by Berument et al. (1999), [b]Optimal cutoff in current sample

Table 12: Correlations Among SCQ Total Scores and Measures as Rated by Staff

	ASD Group		ID-only	
	Pearson Correlation SCQ Current (*r*)	*p*	Pearson Correlation SCQ Current (*r*)	*p*
ABC-C Irritability	.25	.351	.36	.047
ABC-C Lethargy	.66	.005	.79	.000
ABC-C Stereotypy	.74	.001	.42	.017
ABC-C Hyperactivity	.47	.070	.33	.071
ABC-C Inapp. Speech	.23	.383	.45	.011
ABAS-II Self-Care	-.39	.137	-.46	.009
ABAS-II Commun	-.56	.023	-.51	.003
ABAS-II Leisure	-.64	.007	-.39	.031
ABAS-II Social	-.55	.028	-.44	.013

FIGURES

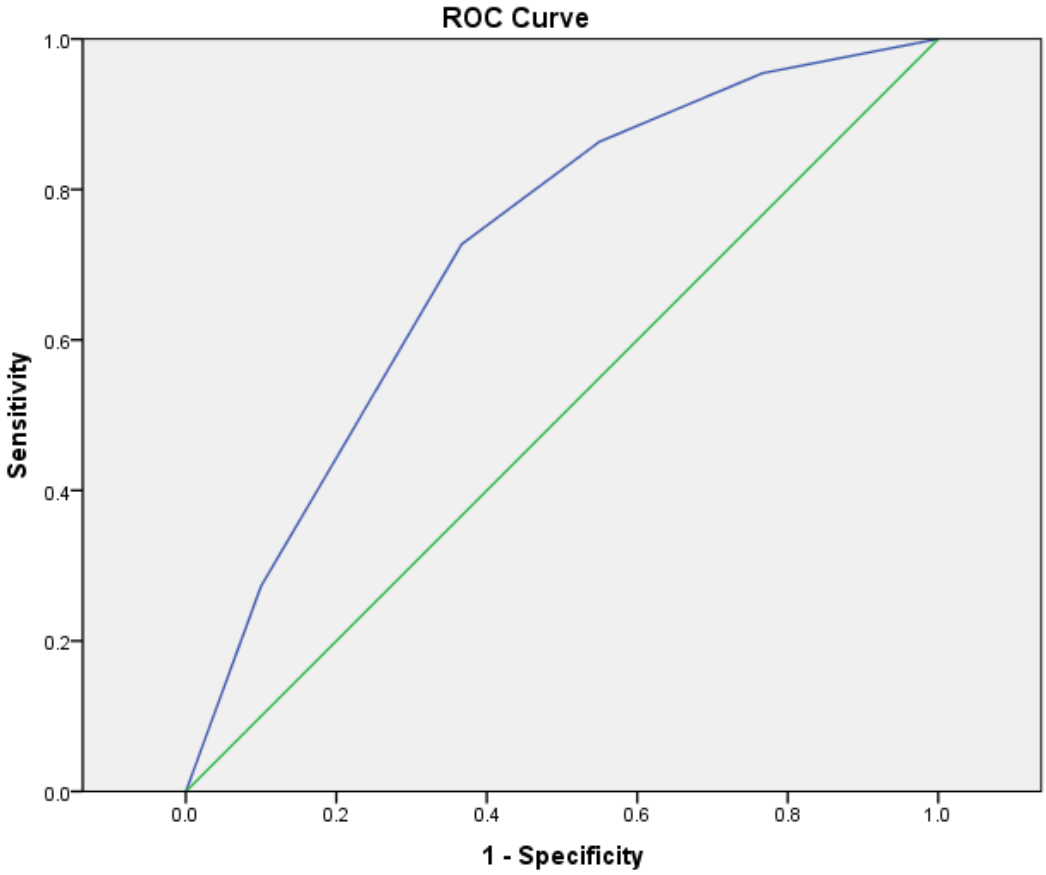

Figure 1: Receiver Operating Characteristic (ROC) Curve: Total Sample

AUC = .72 (*p* = .003; 95% CI = .60 - .84)

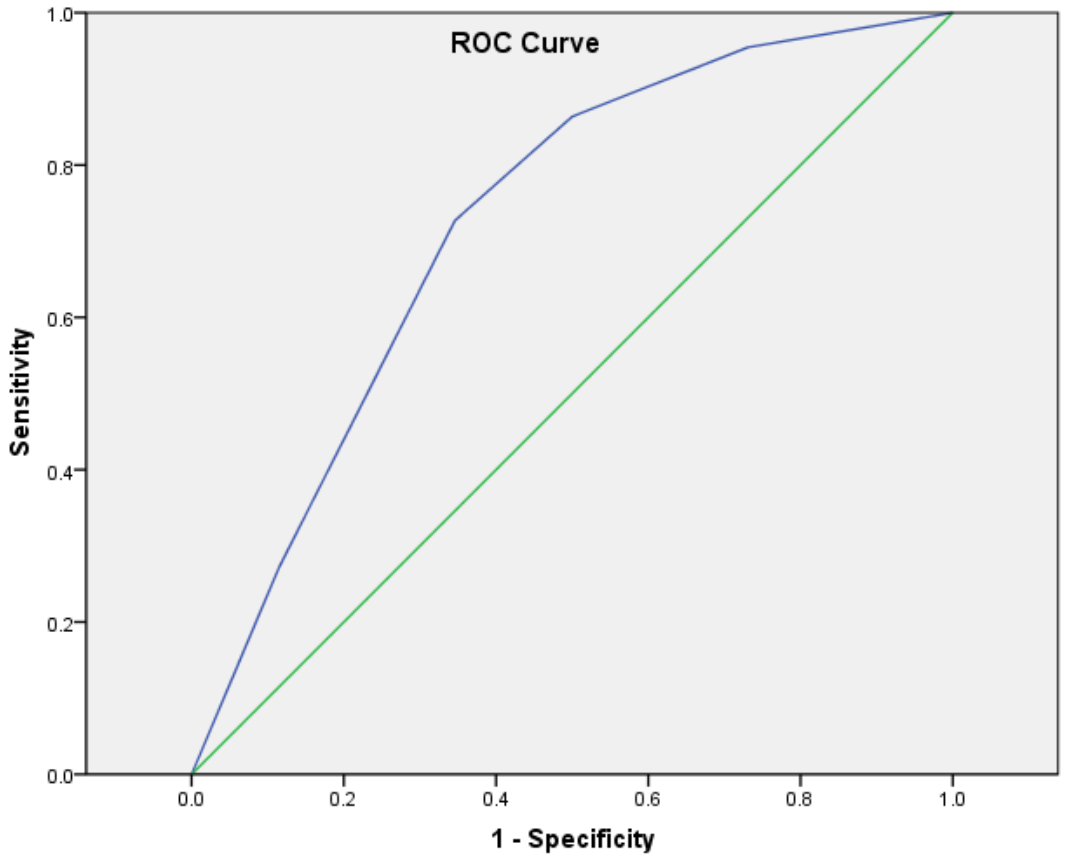

Figure 2: Receiver Operating Characteristic (ROC) Curve:
ID-only High Irritability Group

AUC = .73 (*p* = .007; 95% CI = .58 - .87)

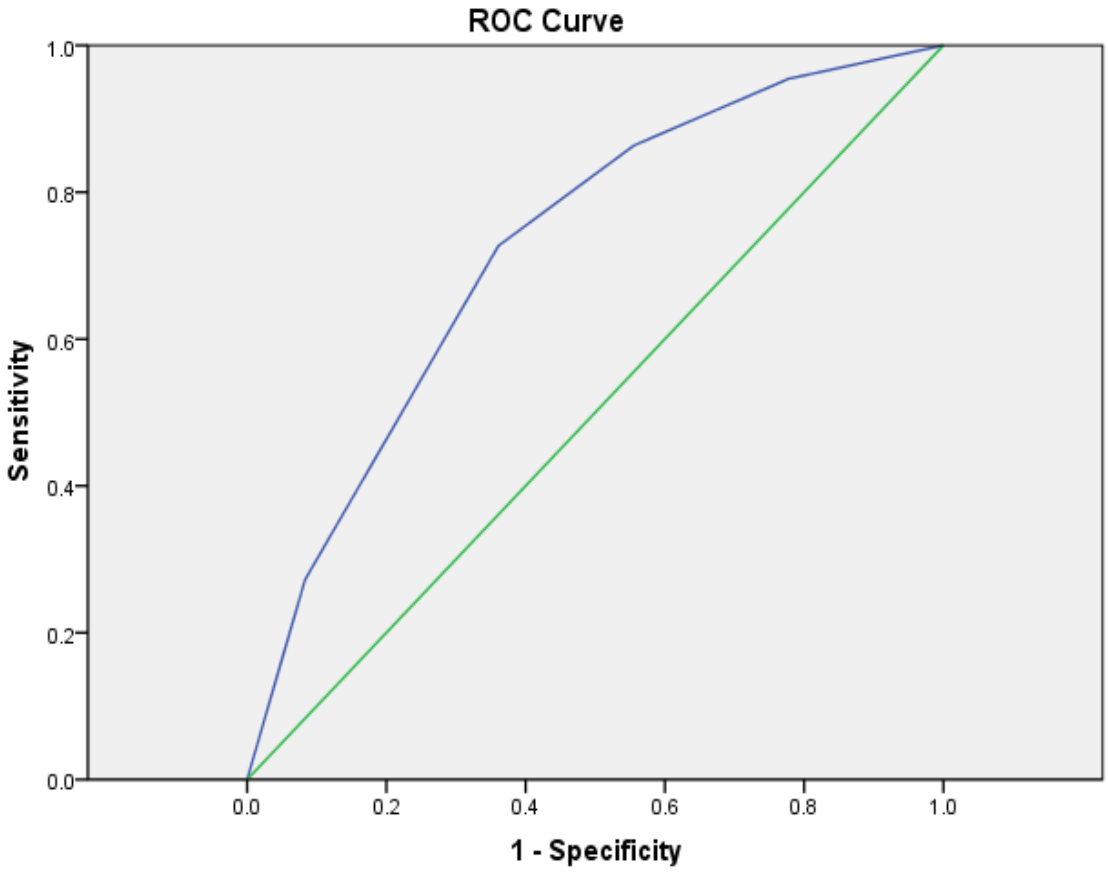

Figure 3: Receiver Operating Characteristic (ROC) Curve:
ID-only Low Irritability Group

AUC = .72 (*p* = .004; 95% CI = .59 - .86)

QUESTIONNAIRES

Questionnaire 1: Diagnostic Checklist

Participant Identification Code: _____
Date: _____

A. Please complete the following items concerning characteristics you have observed in the participant at least during the past 6 months. Circle "Yes," "No," or "Unknown" to each of the following questions.

Social Interaction

1) Does the individual use non-verbal cues, facial expression, body posture, and gestures when communicating with others?

Yes No Unknown

2) Does the individual have friendships comparable to other individuals the same age?

Yes No Unknown

3) Does the individual show enjoyment of interests or achievements with other people by showing or pointing out objects?

Yes No Unknown

4) Does the individual ask how other people are feeling or show concern when another person is hurt or upset?

Yes No Unknown

Communication

5) Does the individual lack spoken language?

Yes No Unknown

6) If the individual does lack spoken language, does he or she attempt to communication through gestures or sign language?

Yes No Unknown

7) Does the individual show the ability to initiate or continue conversations with other people, if able to speak?

Yes No Unknown

8) Does the individual exhibit repetitive or odd use of language, such as making up words or using words in the wrong context?

Yes No Unknown

9) Does the individual show spontaneous imaginative or social play appropriate to developmental level (if applicable)?

Yes No Unknown

Repetitive, Stereotyped Patterns of Behavior, Interests and Activities

10) Does the individual exhibit preoccupation with abnormal interests (e.g. collecting silverware) or normal interests with extreme intensity (e.g. consistently interrupting daily activities in order to engage in preferred interests)?

Yes No Unknown

11) Does the individual engage in apparently inflexible, non-functional routines?

Yes No Unknown

12) Does the individual show stereotyped and repetitive motor movements (e.g., hand or finger flapping or twisting, or whole-body movements, such as rocking back and forth)?

Yes No Unknown

13) Does the individual seem to be preoccupied with parts of objects?

Yes No Unknown

B. If known, did the participant display any abnormal or delayed functioning in the following areas before the age of 3 years?

1) Social interaction	Yes	No	Unknown
2) Language used in social communication	Yes	No	Unknown
3) Symbolic or imaginative play	Yes	No	Unknown

(Adapted from the DSM-IV-TR (APA, 2000))

Questionnaire 2: Rater Demographic Questionnaire

Participant Identification Code: _____
Date: _____

1. Your Age _____

2. Your Gender ¤ Female (0) ¤ Male (1) ¤

3. Relationship to Participant: _____

4. What is your highest level of education?
   - ¤ Attended High School (1)
   - ¤ Graduated High School (4)
   - ¤ Attended some College (2)
   - ¤ Graduated College (5)
   - ¤ Professional/Graduate School (3)
   - ¤ Other (6)

5. How long (in years and/or months) have you worked specifically with individuals with intellectual or developmental disabilities?

   _____
   _____
   _____

6. How long (in years and/or months) have you known or worked specifically with the current participant for whom you are completing these ratings?

   _____
   _____
   _____

CONSENT FORMS

Consent Form 1: The Ohio State University Consent to Participate in Research
Legal Guardian

Study Title:	**Assessing the Validity of the Social Communication Questionnaire in a Sample of Adults with Autism Spectrum Disorders and Intellectual Disability**
Researcher:	**Betsey A. Benson, PhD**
Sponsor:	

This is a guardian consent form for research participation. It contains important information about this study and what to expect if your charge decides to participate.

Your charge's participation is voluntary and will not affect his or her services in any way.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you permit your charge to participate, you will be asked to sign this form and will receive a copy of the form. Your charge must sign an assent form to participate in this study and he or she will receive a copy of the assent form.

Purpose: The purpose of this study is to examine a screening measure for autism spectrum disorders (ASDs) in an adult sample with intellectual disability. While the majority of research focuses on identifying young children with ASDs, there is little research on the rate of ASDs in adults. This screening measure may be useful in identifying ASDs in adults who were not diagnosed earlier and need appropriate treatment and support throughout their lives.

Procedures/Tasks: You and your charge will be asked to allow researchers access to your charge's records to gather demographic information and psychological and medical diagnostic information. You and your charge will be asked to nominate up to three support staff or caregivers who have worked with your client for at least six months to complete several short questionnaires concerning your charge's psychological symptoms, behavior profiles, and adaptive functioning.

Duration: It is expected that your participation, which includes review of consent and assent forms and nomination of support professionals who might be willing to complete these questionnaires, will take 15 to 20 minutes to complete.

You and your charge may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits: *Risks to you and your charge include the possibility of the confidentiality of protected health information (PHI) being breached.*

Confidentiality:

Efforts will be made to keep your charge's study-related information confidential. The researchers will collect information from his or her medical records in the location where they are stored. This information will then be entered into a study database at the Ohio State University Nisonger Center, where it will be kept on a secure, password protected desktop computer in a secure, locked room. After the study is complete, all links to your charge's identity will be destroyed.

However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

Your charge will be given a choice of a coupon worth $5.00 from a local restaurant, movie theater, or ice cream shop after the return of the consent form, the assent form, and the rater nomination to the researchers.

Participant Rights:

You and your charge may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you and your charge choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you or your charge may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study you may contact *Whitney Brooks, B.A.* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.
.
For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact *Whitney Brooks, B.A.* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Printed name of subject	**Signature of subject**
	AM/PM
	Date and time
Printed name of person authorized to consent for subject (when applicable)	**Signature of person authorized to consent for subject (when applicable)**
	AM/PM
Relationship to the subject	**Date and time**

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	**Signature of person obtaining consent**
	AM/PM
	Date and time

Consent Form 2: The Ohio State University
Authorization to Use Personal Health Information in Research

Title of the Study: Assessing the Validity of the Social Communication Questionnaire in a Sample of Adults with Autism Spectrum Disorders and Intellectual Disability

OSU Protocol Number: 2009B0260

Principal Investigator: Betsey A. Benson, Ph.D

Subject Name_____

Before researchers use or share any health information about you as part of this study, The Ohio State University is required to obtain your authorization. This helps explain to you how this information will be used or shared with others involved in the study.

- The Ohio State University and its hospitals, clinics, health-care providers and researchers are required to protect the privacy of your health information.
- You should have received a Notice of Privacy Practices when you received health care services here. If not, let us know and a copy will be given to you. Please carefully review this information. Ask if you have any questions or do not understand any parts of this notice.
- If you agree to take part in this study your health information will be used and shared with others involved in this study. Also, any new health information about you that comes from tests or other parts of this study will be shared with those involved in this study.
- Health information about you that will be used or shared with others involved in this study may include your research record and any health care records at the Ohio State University. For example, this may include your medical records, x-ray or laboratory results. Psychotherapy notes in your health records (if any) will not, however, be shared or used. Use of these notes requires a separate, signed authorization.

Please read the information carefully before signing this form. Please ask if you have any questions about this authorization, the University's Notice of Privacy Practices or the study before signing this form.

Initials/Date: _____

Those Who May Use, Share And Receive Your Information As Part Of This Study

- Researchers and staff at The Ohio State University will use, share and receive your personal health information for this research study. Other Ohio State University staff not involved in the study but who may become involved in your care for study-related treatment will have access to your information.
- Those who oversee the study will have access to your information, including:
    - Members and staff of the Ohio State University's Institutional Review Boards, including the Western Institutional Review Board
    - The Office for Responsible Research Practices
    - University data safety monitoring committees
    - The Ohio State University Research Foundation
- Your health information may also be shared with federal and state agencies that have oversight of the study or to whom access is required under the law. These may include:
    - The Food and Drug Administration
    - The Office for Human Research Protections
    - The National Institutes of Health
    - The Ohio Department of Human Services

These researchers, companies and/or organization(s) outside of The Ohio State University may also use, share and receive your health information in connection with this study:

- Health care facilities, research site(s), researchers, health care providers, or study monitors involved in this study: ***NONE***
- Private laboratories and other persons and organizations that analyze your health information in connection with this study: ***NONE***
- The research sponsor and companies owned or connected with the sponsor: ***NONE***
- Contract Research Organization(s): ***NONE***
- Independent data and safety monitoring boards and others who monitor the conduct of the study*:* ***NONE***

The information that is shared with those listed above may no longer be protected by federal privacy rules.

Initials/Date_____

Authorization Period

This authorization will not expire unless you change your mind and revoke it in writing. There is no set date at which your information will be destroyed or no longer used. This is because the information used and created during the study may be analyzed for many years, and it is not possible to know when this will be complete.

Signing the Authorization

- You have the right to refuse to sign this authorization. Your health care outside of the study, payment for your health care, and your health care benefits will not be affected if you choose not to sign this form.
- You will not be able to take part in this study and will not receive any study treatments if you do not sign this form.
- If you sign this authorization, you may change your mind at any time. Researchers may continue to use information collected up until the time that you formally changed your mind. If you change your mind, your authorization must be revoked in writing. To revoke your authorization, please write to:

  Dr. Betsey Benson (614-688-3214) or Whitney Brooks (614-247-6237 or 919-622-4892)

  215 McCampbell Hall

  1518 Dodd Dr.

  Columbus, OH 43210

- Signing this authorization also means that you will not be able to see or copy your study-related information until the study is completed. This includes any portion of your medical records that describes study treatment.

Contacts for Questions

- If you have any questions relating to your privacy rights, please contact *Sherry Feinstein (614- 247-7190)*
- If you have any questions relating to the research, please contact *Whitney Brooks (614-247-6237 or 919-622-4892) or Dr. Betsey Benson (614-688-3214)*

I have read (or someone has read to me) this form and have been able to ask questions. All of my questions about this form have been answered to my satisfaction. By signing below, I permit *Dr. Betsey Benson* and the others listed on this form to use and share my personal health information for this study. I will be given a copy of this signed form.

Signature_____
(Subject or Legally Authorized Representative)

Name _____
(Print name above)
(If legal representative, also print relationship to subject.)

Date_____ Time _____ AM / PM

Consent Form 3: The Ohio State University Assent to Participate in Research

Study Title:	**Assessing the Validity of the Social Communication Questionnaire in a Sample of Adults with Autism Spectrum Disorders and Intellectual Disability**
Researcher:	**Betsey A. Benson, PhD**
Sponsor:	

- **You are being asked to be in a research study. Studies are done to find better ways to treat people or to understand things better.**
- **This form will tell you about the study to help you decide whether or not you want to participate.**
- **You should ask any questions you have before making up your mind. You can think about it and discuss it with your family, friends, or guardian before you decide.**
- **It is okay to say "No" if you don't want to be in the study. If you say "Yes" you can change your mind and quit being in the study at any time without getting in trouble.**
- **If you decide you want to be in the study, your guardian or parent will also need to give permission for you to be in the study.**

1. What is this study about?

This study is about autism and behavior in adults with intellectual disability. The researchers want to learn about a questionnaire that might help identify people with autism.

2. What will I need to do if I am in this study?

You and your guardian will choose people who work with you in your home or at your job to answer some questions about your behavior. You and your guardian will allow the researchers to look at your records. These records have information about your medical or psychological diagnoses, intellectual functioning, and medications you are taking.

3. How long will I be in the study?

It will take about 15 to 20 minutes to review this form with your guardian and choose people who work with you to answer questions about you.

4. Can I stop being in the study?

You may stop being in the study at any time by contacting the researchers listed below.

5. What bad things might happen to me if I am in the study?

Your records contain private information. If someone other than the researchers got this information, they would know private information about you. The researchers will be very careful to keep your information safe and secure.

6. What good things might happen to me if I am in the study?

You will not get anything directly by being in the study. However, you may help people understand disabilities better.

7. Will I be given anything for being in this study?

You will be given a choice of a coupon worth $5.00 from a local restaurant or shop.

8. Who can I talk to about the study?

For questions about the study you may contact *Whitney Brooks* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

To discuss other study-related questions with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Signing the assent form

I have read (or someone has read to me) this form. I have had a chance to ask questions before making up my mind. I want to be in this research study.

		AM/PM
Signature or printed name of subject	**Date and time**	

Investigator/Research Staff

I have explained the research to the participant before requesting the signature above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining assent	**Signature of person obtaining assent**	
		AM/PM
	Date and time	

This form must be accompanied by an IRB approved parental permission form signed by a parent/guardian.

Consent Form 4: The Ohio State University Consent to Participate in Research Rater

Study Title:	**Assessing the Validity of the Social Communication Questionnaire in a Sample of Adults with Autism Spectrum Disorders and Intellectual Disability**
Researcher:	**Betsey A. Benson, PhD**
Sponsor:	

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose: The purpose of this study is to examine a screening measure for autism spectrum disorders (ASDs) in an adult sample with intellectual disability. While the majority of research focuses on identifying young children with ASDs, there is little research on the rate of ASDs in adults. This screening measure may be useful in identifying ASDs in adults who were not diagnosed earlier and need appropriate treatment and support throughout their lives.

Procedures/Tasks: If you agree to participate, you consent to complete one short demographic questionnaire about yourself and four questionnaires about the individual with intellectual disability who nominated you to participate. These questionnaires will include a screening measure for autism spectrum disorders, a behavior scale, an adaptive functioning scale, and a checklist assessing autism symptoms.

Duration: Completing the consent procedures and questionnaires will take about 30 to 60 minutes.

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits: *Risks of participation include the possibility of the confidentiality of your demographic information and your answers to questionnaires being breached.*

Confidentiality:

Efforts will be made to keep your study-related information confidential. The information that you provide will be entered into a study database at the Ohio State University Nisonger Center, where it will be kept on a secure, password protected desktop computer in a secure, locked room. After the study is complete, all links to your identity will be destroyed.

However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

You will receive a gift card for $15.00 for returning the signed consent form, regardless of whether or not all of the included measures are completed. If you provide ratings for multiple individuals, you will receive a $15.00 gift card per completed consent form.

By law, payments to subjects are considered taxable income.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study you may contact *Whitney Brooks* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

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For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact *Whitney Brooks* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Printed name of subject	**Signature of subject**
	AM/PM
	Date and time
Printed name of person authorized to consent for subject (when applicable)	**Signature of person authorized to consent for subject (when applicable)**
	AM/PM
Relationship to the subject	**Date and time**

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	**Signature of person obtaining consent**
	AM/PM
	Date and time

Consent Form 5: The Ohio State University Consent to Participate in Research

Study Title:	**Assessing the Validity of the Social Communication Questionnaire in an Adult Sample with Autism Spectrum Disorders and Intellectual Disability**
Researcher:	Betsey A. Benson, Ph.D.
Sponsor:	

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please look at the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:

This study is about autism and behavior in adults with intellectual disability. The researchers want to learn about a questionnaire that might help identify people with autism.

Procedures/Tasks:

You will choose people who work with you in your home or at your job to answer some questions about your behavior.

You will allow the researchers to look at your records. These records have information about your medical or psychological diagnoses, intellectual functioning, and medications you are taking.

Duration:

It will take about 15 to 20 minutes to review this form and choose people who work with you to answer questions about you.

You may leave the study at any time. If you decide to stop participating in the study, nothing bad will happen to you.

Risks and Benefits:

Your records contain private information. If someone other than the researchers got this information, they would know private information about you.

You will not get anything directly by being in the study. However, you may help people understand disabilities better.

Confidentiality:

Efforts will be made to keep your study-related information confidential. The researchers will be very careful to keep your information safe and secure.

However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

You will be given a choice of a coupon worth $5.00 from a local restaurant, movie theater, or ice cream shop.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:
For questions, concerns, or complaints about the study you may contact *Whitney Brooks* at 614-292-0086 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact *Whitney Brooks* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Printed name of subject	**Signature of subject**
	AM/PM
	Date and time
Printed name of person authorized to consent for subject (when applicable)	**Signature of person authorized to consent for subject (when applicable)**
	AM/PM
Relationship to the subject	**Date and time**

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	**Signature of person obtaining consent**
	AM/PM
	Date and time

Consent Form 6: The Ohio State University Consent to Participate in Research
Parent Legal Guardian

Study Title:	**Assessing the Validity of the Social Communication Questionnaire in a Sample of Adults with Autism Spectrum Disorders and Intellectual Disability**
Researcher:	**Betsey A. Benson, PhD**
Sponsor:	

This is a guardian consent form for research participation. It contains important information about this study and what to expect if your son or daughter decides to participate.

Your son or daughter's participation is voluntary and will not affect his or her services in any way.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you permit your son or daughter to participate, you will be asked to sign this form and will receive a copy of the form. Your son or daughter must sign an assent form to participate in this study and he or she will receive a copy of the assent form.

Purpose: The purpose of this study is to examine a screening measure for autism spectrum disorders (ASDs) in an adult sample with intellectual disability. While the majority of research focuses on identifying young children with ASDs, there is little research on the rate of ASDs in adults. This screening measure may be useful in identifying ASDs in adults who were not diagnosed earlier and need appropriate treatment and support throughout their lives.

Procedures/Tasks: You and your son or daughter will be asked to allow researchers access to his or her records to gather demographic information and psychological and medical diagnostic information. You and your son or daughter will be asked to nominate up to three supported living or employment professionals who have worked with your son or daughter for at least six months to complete several short questionnaires concerning your son or daughter's psychological symptoms, behavior profiles, and adaptive functioning.

Duration: It is expected that your participation, which includes review of consent and assent forms and nomination of support professionals who might be willing to complete these questionnaires, will take 15 to 20 minutes to complete.

You and your son or daughter may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits: *Risks to you and your son or daughter include the possibility of the confidentiality of protected health information (PHI) being breached.*

Confidentiality:

Efforts will be made to keep your study information confidential. The researchers will collect information from your son or daughter's records in the location where they are stored. This information will then be entered into a study database at the Ohio State University Nisonger Center, where it will be kept on a secure, password protected desktop computer in a secure, locked room. After the study is complete, all links to your son or daughter's identity will be destroyed.

However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

Your son or daughter will be given a choice of a coupon worth $5.00 from a local restaurant, movie theater, or ice cream shop after the return of the consent form, the assent form, and the rater nomination to the researchers.

Participant Rights:

You and your son or daughter may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you and your son or daughter choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you or your son or daughter may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study you may contact *Whitney Brooks* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact *Whitney Brooks* at 614-247-6237 or 919-622-4892, or *Betsey A. Benson, Ph.D* at 614-688-3214.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Printed name of subject	**Signature of subject**
	AM/PM
	Date and time
Printed name of person authorized to consent for subject (when applicable)	**Signature of person authorized to consent for subject (when applicable)**
	AM/PM
Relationship to the subject	**Date and time**

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	**Signature of person obtaining consent**
	AM/PM
	Date and time

References

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