ASSESSING THE CONVERGENCE OF SELF-REPORT AND INFORMANT MEASURES FOR ADULTS WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Rachel K. Sandercock: Assessing the Convergence of Self-Report and Informant Measures for
Adults with Autism Spectrum Disorder
(Under the direction of Laura G. Klinger)

Self-report measures are widely used for research and clinical assessment of adults with
ASD, though there has been little research examining the convergence of self- and informant-
report in this population. The present study examined agreement between reporters on measures
of symptom severity, daily living skills, and quality of life, as well as predictive value of each
reporter for independent living and employment outcomes. Results indicated no significant
differences between caregiver and self-report ratings of symptom severity, though there were
significant differences between reporters on ratings of daily living skills and quality of life.
Despite discrepancies, caregiver and self-report scores were significantly positively correlated on
all measures. Additionally, combining caregiver-report and self-report measures provided
significantly higher predictive value of objective outcomes than did measures from a single
reporter. These results indicate that self-report is valid for this population, but emphasizes the
importance of a multi-informant approach in assessment and treatment planning.

ACKNOWLEDGEMENTS

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LIST OF ABBREVIATIONS

ASD   Autism Spectrum Disorder

ADOS-2   Autism Diagnostic Observation Schedule, Second Edition

AQ   Autism Quotient

SRS-2   Social Responsiveness Scale, Second Edition

SRS-A   Social Responsiveness Scale, Second Edition: Adult Form

ADI-R   Autism Diagnostic Interview, Revised

ASBQ   Adults Social Behavior Questionnaire

W-ADL   Waisman Activities of Daily Living Scale

QoL-Q   Quality of Life Questionnaire

SCI   SRS-A Social Communication Index

RRB   SRS-A Restricted and Repetitive Behaviors Index

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social interaction and communication, stereotyped or repetitive behaviors and interests, sensory issues, and, in some cases, cognitive delays (American Psychiatric Association, 2013). Because symptoms must be present from infancy or early childhood, ASD is often thought of as a childhood disorder; consequently, a vast amount of research has been conducted with children with ASD, providing professionals with the necessary insight to tailor services and interventions to fit the needs of children from early intervention services through elementary school (e.g., Bradshaw, Steiner, Gengoux, & Koegel, 2015; Corsello, 2005; Wong et al., 2015). A growing number of interventions have also been designed to target adolescence (e.g., Luxford, Hadwin, & Kovshoff, 2016; McMahon, Vismara, & Solomon, 2013). By stark contrast, very little is known about the disorder in adulthood, though behavioral problems of ASD generally persist across the lifespan (Howlin, Goode, Hutton, & Rutter, 2004). Research on this population suggests that the positive symptoms of ASD – such as repetitive behaviors or emotional outbursts – tend to decline with age, and the negative symptoms – such as social and communicative deficits – instead become more pronounced (Seltzer et al., 2003; Taylor & Seltzer, 2010). Beyond this basic profile, however, there is very little research to improve our understanding of adults with ASD.

The need to fill this gap in knowledge is now more pressing than ever. Upwards of 500,000 children with ASD are projected to enter adulthood over the next ten years (Autism Speaks, 2013). Specifically, according to the Centers for Disease Control, the national

prevalence of ASD has risen from 1 in 150 8-year-olds in 2002 to 1 in 68 8-year-olds in 2010representing a 121% increase (Christensen et al., 2016). Based on these estimates, we will likewise see a 121% increase in the demand for adult services in the coming decade. However, despite the growing number of evidence-based interventions for children with ASD, there are few systematic studies of effective treatments or services for adults (Howlin & Moss, 2012; Taylor & Seltzer, 2010). This is particularly problematic given that adult outcomes are typically poor. A large proportion of individuals with ASD continue to need significant supports throughout adulthood, with the majority living with family and many (42-58%) remaining unemployed (Klinger, Klinger, Mussey, Thomas, & Powell, 2015). Additionally, the lifetime cost of care for an individual with ASD is estimated to be upwards of $1.4 million, and $2.4 million for an individual with ASD and a comorbid intellectual disability. Due to the costs of housing, disability, and lost productivity from unemployment, the majority of these expenses are associated with adulthood (Buescher, Cidav, Knapp, & Mandell, 2014; Mandell & Knapp, 2012). In order to address these issues, appropriate assessment tools are needed. Assessment is key to establishing a more comprehensive understanding of ASD in adulthood. Furthermore, it is crucial to have measures that can adequately capture the unique symptomatology of adults to facilitate diagnosis and treatment planning, and to measure treatment effectiveness. Thus, better understanding how to meet the growing need for psychological assessment in this population and promote more positive outcomes is a public health imperative. The purpose of this research is to examine the convergence and predictive value of adult self-report and caregiver measures of symptom severity, daily living skills, and quality of life, and to identify the extent to which greater social impairment relates to larger discrepancies between caregiver- and self-report in other domains. Insight into where adults with ASD and caregivers are most likely to agree and

where they are most likely to disagree can help to shape future assessment protocols, and can guide decisions regarding if and when multiple informants should be consulted in making diagnoses and treatment recommendations.

Issues in the Assessment of Adults with ASD

Unlike assessments with children, adult assessments for the purposes of diagnosis and treatment planning often involve self-report. Particularly for intellectually capable adults, clinicians often need to rely on self-report as they do with other adult populations without an intellectual disability. However, several issues arise in the effort to accurately assess adults with ASD, including the unique symptom profile of adults, potential biases in caregiver-report, and the effects of impaired social insight on self-report.

Measures of Symptomatology of ASD in Adulthood. There is a fundamental lack of tools designed to capture the developmental phase of adulthood in those with ASD. When Leo Kanner first described what is now understood more broadly as ASD, he introduced the label "early infantile autism" (Kanner, 1943). From that point, ASD has often been thought of as a disorder of childhood. As such, the majority of currently available measures were developed to target the symptoms of ASD in children. However, ASD is a life-long developmental disability. Measures used for both research and clinical purposes must be able to reliably capture the aspects of ASD that change over the lifespan and the differential presentation of the disorder in adults. Clinical presentation of ASD is often more complex in adulthood, particularly when developmental history is unavailable (Bastiaansen et al., 2011).

The symptoms of ASD in adulthood may differ from those in childhood, as maturation and developmental change interact with the manifestation of core symptoms and affect the acquisition of skills (Burack, Charman, Yirmiya, & Zelazo, 2001). As reflected in the current

Diagnostic and Statistical Manual of Mental Disorders criteria (DSM-5; American Psychiatric Association, 2013), ASD is fundamentally defined by two core clusters of symptoms: the absence of typical social and communicative behaviors, and the presence of abnormal restricted, repetitive patterns of behavior. It is likely that these two types of symptoms are characterized by different developmental trajectories. In line with this hypothesis, Seltzer and colleagues (2003) found that, in a sample of 405 individuals with ASD, adults were more impaired than adolescents in their ability to communicate nonverbally, in their ability to engage in reciprocal conversations, and in their overall level of language. By contrast, adults were less symptomatic than adolescents with respect to restricted, repetitive behaviors and interests, and were less likely to engage in inappropriate verbalizations.

It is also important to note that autism presents across a wide spectrum of severity and cognitive ability. DSM-5 criteria (American Psychiatric Association, 2013) considers ASD on two separate continuums of intellectual functioning and symptom severity. For some, high intelligence may help to compensate for limitations. However, neither verbal nor performance IQ can be utilized as a consistent prognostic indicator of independent living outcomes, as outcomes vary even amongst those with average or above average IQs: while a minority of adults with ASD achieve relatively high levels of independence, including employment, many remain dependent on their families or other support services (Howlin et al., 2004; Klinger et al., 2015). The symptoms of ASD can also range from mild to severe, influencing not only daily functioning, but also access to appropriate services; thus, a person with high IQ may be more impaired by significant ASD symptoms, whereas someone with a below average IQ or a comorbid intellectual disability may demonstrate relatively mild ASD symptoms (and vice versa). Though individuals on the higher functioning end of the symptom severity spectrum may

require fewer supports than those with more significant ASD-related impairments, subtle symptoms can often go undetected, resulting in a lack of diagnosis and services all together (Bastiaansen et al., 2011; Kan, Buitelaar, & van der Gaag, 2008). Because of these broad spectrums of intellectual functioning and symptom severity, it is important to have access to measures that will reliably capture the full range of the presentation of ASD in adulthood.

Because very few measures have been designed specifically for use with adults with ASD, researchers and clinicians must often use measures originally intended for use with children or intellectually disabled populations. For example, the *Vineland Adaptive Behavior Scales* (Cicchetti, Carter, & Gray, 2013), which were developed to assess the personal and social skills necessary for independent living, are commonly used to assess functioning level and to determine service needs for individuals with ASD. Though the Vineland may be used with individuals from birth to age 90, it was originally designed for children up to age 21 and is primarily intended for individuals with mild to severe ID. As a result, many of the items are inappropriate for adults and higher functioning individuals, which may then provide an incomplete or misleading picture of current functioning (Howlin, Savage, Moss, Tempier, & Rutter, 2014).

Recently, there have been efforts to develop measures specifically for adults with ASD. In particular, Module 4 of the *Autism Diagnostic Observation Schedule, Second Edition* (ADOS-2; Rutter, Dilavore, Risi, Gotham, & Bishop, 2012) is designed for verbally fluent adolescents and adults. The ADOS-2 is a semi-structured, observation-based assessment of social interaction, communication, play, and imaginative use of materials; The ADOS-2, in combination with clinical judgment, is widely considered the "gold standard" method of diagnosis for ASD (Falkmer, Anderson, Falkmer, & Horlin, 2013; Reaven, Hepburn, & Ross, 2008). Though the

psychometric properties of Module 4 have not been as widely validated as those of the modules designed for younger and less verbal individuals, findings suggest that Module 4 demonstrates acceptable sensitivity and specificity for use with adults (Bastiaansen et al., 2011; Pugliese et al., 2015). However, the ADOS-2 is not a self- or caregiver-report measure and requires implementation and scoring by a skilled clinician.

Unlike other types of psychopathology, for which self-report measures are central to diagnostic practices, self-report has not traditionally been involved in the assessment of ASD. Despite growing interest in remedying this gap, only two self-report measures are routinely used to assess diagnostic symptoms in adults with ASD: the *Autism-Spectrum Quotient* (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) and the *Social Responsiveness Scale* (SRS-2; Constantino, 2012). The AQ is comprised of 50 questions designed to provide a continuous measure of autistic traits in those without intellectual disability that can be used to determine where an individual falls on the ASD continuum. In the measure's initial validation study, Baron-Cohen et al. (2001) reported that 80% of individuals with an independent diagnosis of ASD scored above the proposed cut-off score of 32, whereas only 2% of controls selected randomly from the general population scored about that cut-off. Follow-up studies of the diagnostic validity of the AQ report more variable results. Analysis of the AQ among a Dutch sample found that the measure failed to differentiate between individuals diagnosed with mild ASD and those without ASD (Ketelaars et al., 2008). More recently, Bishop and Seltzer (2012) found that, in a sample of 65 intellectually heterogeneous adults independently diagnosed with ASD, only 11 (17%) scored above the proposed diagnostic cut-off and 24 (27%) exceeded the screening cut-off; Even when analyses were restricted to the 39 adults with average to above average IQ, only 44% met the screening cut-off. These findings indicate that the AQ may not be

a reliable self-report measure across the autism spectrum. Additionally, the AQ does not provide an informant version with which to compare self-report responses.

The *Social Responsiveness Scale, Second Edition* (SRS-2; Constantino, 2012) is the most frequently used self-report measure for the assessment of ASD. The SRS-2 is a 65-item rating scale measuring deficits in social behavior associated with ASD across the full range of severity, including sub-threshold levels. The current version of the SRS-2 has four rating forms across three age ranges: the Preschool Form (ages 2-4), the School-Age Form (ages 4-18), and the Adult form (ages 19-89). The Adult Form (SRS-A) can be completed by parents, spouses, friends, and relatives. An Adult Self-Report Form is also available. The initial validation study of the SRS-A reported high interrater reliability between self-report and informant-report for a variety of different raters, including mothers, fathers, spouses, non-parental relatives, and others (e.g., friends); the interrater reliability between self- and informant-report ranged from $r = .61$ (for others) to $r = .78$ (for mothers). In the standardization sample, sensitivity and specificity analyses were conducted for the School-Age Form only; these analyses resulted in a sensitivity value of .92 and a specificity value of .92. Follow-up studies have examined sensitivity and specificity for the Adult Form of the SRS-2 and have suggested that it may not discriminate as well as the School-Age form. Mandell and colleagues (2012) found a specificity value of .60 and sensitivity of .86 for the adult version, while a study with a German sample found a sensitivity of .85 and a specificity of .83. Takei and colleagues (2014) found more positive results, reporting that the SRS-A demonstrates high internal consistency ($\alpha = .96$) and moderate convergent validity with other measures ($r = .34$ to .62), and capably discriminated adults with ASD from those with non-ASD psychiatric disorders.

Recently, Horwitz and colleagues (2016) have made efforts to develop and validate a new measure of autistic traits in adults that provides the opportunity for both self- and other-report: the *Adults Social Behavior Questionnaire* (ASBQ). The authors report cross-informant correlations on par with those for other emotional and behavioral problems in adults [Achenbach, Krukowski, Dumenci, & Ivanova (2005) report average cross-informant correlations ranging from $r = .38$ to $r = .57$ in other populations]. Because this measure was developed so recently and only preliminary data regarding its psychometric properties have been published, however, the ASBQ is not yet widely used in clinical or research practice.

Caregiver Biases. Because symptoms of ASD must be present from childhood, many assessments rely on caregiver recollection of developmental milestones and early indicators of impairment. Indeed, the DSM-5 (American Psychiatric Association, 2013) specifies that a lifetime history of clinically significant ASD symptoms is sufficient to yield a diagnosis, even if current symptoms are below-threshold. The *Autism Diagnostic Interview, Revised* (ADI-R; Rutter, Le Couteur, & Lord, 2003), for example, aims to identify present level of impairment in addition to a "lifetime" rating of the most severe degree of impairment earlier or ever in the individual's life. Several studies of the ADI-R have shown that caregivers report a reduction in current ASD-related symptoms relative to early symptoms, reported retrospectively (Boelte & Poustka, 2000; Piven, Harper, Palmer, & Arndt, 1996; Seltzer et al., 2003). However, it is unclear to what extent parental bias, such as over- or underestimating current symptoms in comparison to childhood impairment, influences these findings. Additionally, though the ADI-R is intended for use across the lifespan, it is most commonly used with parents of young children who are asked to recall behaviors that occurred recently rather than with parents of adults, who are asked to recall behaviors that occurred several years or even decades ago (Seltzer et al.,

2003). Dependence on parent recollection also raises issues of how to best assess adults with ASD when no parent or caregiver is available, particularly given the lack of measures available for non-parent reporters.

  Effects of Impaired Insight on Self-Report. Reliance on self-report measures may be problematic, given that such measures require significant insight into one's own impairments. The hallmark symptoms of ASD are poor insight into social and communicative difficulties, which may hinder this population's ability to accurately report their own symptoms (Berthoz & Hill, 2005; Bishop & Seltzer, 2012; Mitchell & O'Keefe, 2008; Shalom et al., 2006). Though some contend that higher functioning individuals are capable of accurately reflecting on inner experiences (Spek, Scholte, & Van Berckelaer-Onnes, 2010), research with adolescent samples indicates that there is little convergence between self-report and parent interviews: individuals with ASD report fewer autistic traits and less anxiety in comparison to parent and clinical reports while reporting a greater level of empathic abilities (Johnson, Filliter, & Murphy, 2009; Mazefsky, Kao, & Oswald, 2011; White, Schry, & Maddox, 2012).

  However, self-report measures are very appealing for both research and clinical purposes, as they are typically inexpensive and easy to administer, and information from a parent/caregiver informant is more often unavailable for adults (Anderson, Bush, & Berry, 1986; Volkmar, Booth, McPartland, & Wiesner, 2014). Additionally, the fastest growing subgroup within the ASD population is individuals without a comorbid intellectual disability (Christensen et al., 2016), for whom self-report measures may be seemingly most appropriate. Without greater knowledge on the utility of self-report for adults with ASD, it is impossible to know if research relying on this method of data collection accurately reflects the target population. Moreover, if adults tend to report fewer ASD symptoms and higher levels of adaptive behavior, self-report may provide a

conservative estimate of an individual's true level of impairment, making treatment planning and implementation more difficult. Further, the possibility of under-reporting symptom severity and daily skills challenges can result in an individual failing to document clear need for adult service delivery services.

In our clinical experiences, this situation is not uncommon. Take, for example, a man with ASD in his late 30s with an average IQ. He was having difficulty keeping a job and had no lasting social connections outside of his family. He lived alone in an apartment, but his parents, who lived a few hours away, were actively involved in organizing many aspects of his life. He routinely had problems interacting with coworkers, as he often interrupted others, discussed inappropriate topics at work, and was argumentative with superiors. Most recently, a significant problem arose at work because he developed a romantic interest in a coworker but did not know how to approach her in a socially appropriate way, and instead began following her around. Her complaint about his behavior resulted in him being referred for supported employment services through Vocational Rehabilitation. However, because his parents did not live nearby and because he was cognitively able to complete measures independently, his assessment for eligibility for these services relied exclusively on self-report measures. On measures of symptom severity, he reported essentially no difficulties with social interaction or communication and did not indicate any issues in how others perceived him. His self-reported level of impairment fell well below the threshold needed for his insurance company to cover any services; fortunately, his clinician advocated for his true need for employment supports and involved his parents in providing additional information on his level of impairment. As evidenced by this case, understanding the extent to which self-report measures are reliable and valid tools for adults with ASD is essential

not only to effective research, but to the provision of appropriate clinical assessment and services, as well.

Areas of Assessment in ASD

Three areas of assessment are particularly relevant to assessment of service needs and treatment effectiveness: symptom severity, daily living skills, and quality of life. These areas are essential to better understanding and improving outcomes for adults with ASD.

Symptom Severity. Accurate assessment of symptom severity is necessary for establishing diagnoses, as well as for identifying areas of greatest impairment as a target for treatment planning. Because adults with ASD may have a limited awareness of their social and communicative impairments (Mitchell & O'Keefe, 2008), comparing adult self-report against the report of others may lend insight to the utility of a multi-informant approach in this population. Though multiple informants are recommended in the assessment of psychopathology in children and adolescents, as well as for adults with developmental and personality disorders (Barkley, Knouse, & Murphy, 2011), there has been very little research on this methodology for individuals with ASD. Overall, there is a striking absence of studies that directly compare informant- and self-report for adults with ASD. Outside of the preliminary validation analyses of the SRS-2 (Constantino, 2012) and the ABSQ (Horwitz et al., 2016), no studies to date have examined self and informant/caregiver convergence in reporting the severity of symptoms associated with ASD (i.e., impairments in social communication, and restricted interests and repetitive behaviors). Despite the acceptable levels of interrater agreement reported on these measures, there were still considerable discrepancies between reporters across domains, further emphasizing the importance of seeking information from multiple informants.

Daily Living Skills. While cognitive ability has been consistently found to be the best indicator of adult outcome (Eaves & Ho, 2008; Farley et al., 2009), there is still a great deal of variability in outcomes amongst individuals with ASD with average or above average IQs. For example, Howlin et al. (2004) found that just 32% of adults with nonverbal IQs over 70 had "good" or "very good" outcomes, as evidenced by their functioning in the areas of friendship, employment, and independent living. Poor adaptive behaviors, such as daily living skills, are a possible explanation for why adults with ASD often experience worse outcomes than would be expected based on cognitive ability alone, as even those with average to above average intellectual ability often demonstrate very poor adaptive behaviors (Duncan & Bishop, 2013; Klinger et al., 2015). Research suggests that children and adolescents with ASD have fewer daily living skills than both typically developing children and children with other developmental disorders. Furthermore, daily living skills may decline with age for individuals with ASD because they are not acquiring skills at the same rate as typical peers (Klin et al., 2007). The developmental trajectory has also been characterized by a pattern of initial increase in adaptive behavior skills in early childhood followed by a plateau during adolescence across all levels of cognitive functioning (A. T. Meyer, Powell, Buttera, Klinger, & Klinger, in press). Difficulties with everyday activities such as hygiene, cooking, or money management make it significantly harder for an individual with ASD to ever achieve independence in adulthood (Duncan & Bishop, 2013). Because daily living skills are relatively concrete concepts, they have the potential to be easily targeted through supports and intervention (Hume, Loftin, & Lantz, 2009). However, due to social insight difficulties described above, it is possible that adults with ASD may self-report more daily living skills than they actually perform, making it difficult to both

demonstrate a "medical necessity" for services and to appropriately tailor services to their individual needs and a key opportunity to improve outcomes may be lost.

Consider again the previous clinical example: the same man who demonstrated limited insight into his level of symptom severity similarly reported no issues in completing daily living tasks independently. He indicated that he was able to manage his finances, shop for food and prepare meals, and complete household chores independently. This differed considerably from what was reported by his parents, who noted that while he was *able* to complete all of these tasks, he did not actually do them consistently. Despite living several hours away, they were required to maintain a significant level of involvement in monitoring and managing many aspects of his day-to-day life. Consequently, understanding the extent to which adults with ASD are able to accurately report their own adaptive behaviors and daily living skills will provide important information to researchers and clinicians seeking to understand and improve adult outcomes.

Despite the extensive use of measures assessing adaptive daily living skills in public health practice, there has been very little research on the reliability and validity of these measures for the purpose of self-report in adulthood—particularly for those with developmental disabilities. While the *Vineland Adaptive Behavior Scales* (Cicchetti et al., 2013) is one of the most widely used measures to assess functioning across the domains of communication, daily living skills, and socialization and has been normed for use in an ASD population, the measure does not offer a self-report format. Recently, the *Waisman Activities of Daily Living Scale* (W-ADL; Maenner et al., 2013) was developed in an effort to provide a briefer survey measure of adaptive functioning. The psychometric properties of the W-ADL have been studies for individuals with a range of disabilities, including ASD, Down syndrome, fragile X, and

intellectual disabilities. The W-ADL demonstrates high internal consistency for all of these groups (α = .88 to .94), and moderate inter-item correlations (r = .2 to .6). To our knowledge, however, no studies have examined the convergence of self- and other-report of adaptive behavior skills in adults with ASD.

      Quality of Life. Improved quality of life is increasingly a primary goal of interventions and services for adults with ASD (Gerber et al., 2011), making accurate assessment of this construct critical for both research and clinical practice. Measuring the validity of self-report is quite complex when it comes to quality of life, however. When quality of life is evaluated, one must take into account an individual's subjective feelings about his or her life, as well as objective information about psychosocial factors, such as the individual's living situation, occupation, and personal relationships. (Eriksson & Lindström, 2007; Helles, Gillberg, Gillberg, & Billstedt, 2015). Effectively assessing each of these aspects of quality of life for individuals with any type of psychiatric disorder raises several methodological issues, notably: (1) the problematic validity and reliability of adult self-report due to affective, cognitive, and reality distortion of symptoms; (2) intrinsic difficulties in assessing quality of life in people suffering from these disorders; and (3) low life expectations that may paradoxically lead individuals to rate their quality of life as high (Albrecht & Devlieger, 1999; Katschnig, 2000; Welham, Haire, Mercer, & Stedman, 2001). Additionally, responses to quality of life measures may be biased by an individual's cognitive and emotional functioning, motivation (or lack thereof) for life improvement, and current medications (Jenkins, 1992). Indeed, these factors—in addition to the inherently subjective nature of quality of life ratings—tend to result in large discrepancies between the target individual and an informant. As with other intrinsic or internalizing constructs, it is difficult to determine which report is "correct."

Ratings by adolescents with ASD on subjective measures of quality of life, such as the *World Health Organization Quality of Life* assessment (World Health Organization, 1995) and *Pediatric Quality of Life Inventory* (Varni, Seid, & Rode, 1999), demonstrate significant discrepancies between self-reports and parental proxy-reports, with self-reported quality of life being generally more favorable than parental-proxy reports (Ikeda, Hinckson, & Krägeloh, 2014; Shipman, Sheldrick, & Perrin, 2011). By contrast, recent research found that adults with ASD rated their own quality of life similarly to maternal and maternal-proxy report. However, some differences across reporters were noted: subjective factors such as perceived stress and having been frequently bullied were most predictive of quality of life based on self-report, while level of independence and physical health were significantly associated with maternal reports of quality of life (Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2015). Quality of life measures offer an opportunity to assess the extent to which adults with ASD are satisfied with the physical, psychological, and social aspects of their lives, and have the potential to provide a fuller picture of an individual's current functioning level (Renty & Roeyers, 2006). The *Quality of Life Questionnaire* (QoL-Q; Schalock, Hoffman, & Keith, 1993) was developed to assess the quality of life of individuals with intellectual or developmental disabilities across the domains of Life Satisfaction, Competence/Productivity, Empowerment/Independence, and Social Belonging. The QoL-Q is designed to accommodate both self-report and caregiver or staff report. The internal consistency of the subscales is relatively high (α = .66 to .83, total α = .83.). Though no studies have been conducted comparing self- and informant-report on the Qol-Q for individuals with ASD, specifically, research comparing staff and client ratings in other populations has found consistently low cross-informant correlations on all subscales (r = .07 to .31). These low

levels of agreement further emphasize the complexity of measuring quality of life and the inherent subjectivity underlying rater responses.

The Use of Self-Report Measures in Non-ASD Populations

  Symptom Severity. Though self-report methods of assessment have been widely studied in child and adolescent populations, there are surprisingly few studies of self-report assessment or cross-informant agreement for adult psychopathology, even outside of ASD (Achenbach, 2006; Mazefsky et al., 2011). A meta-analysis of the cross-informant studies that do exist found that the correlations between self-report and collateral report averaged just .45 for both internalizing and externalizing problems (Achenbach et al., 2005). These findings demonstrate that the information obtained from informants may often differ notably from the information provided by the target individuals themselves, supporting conclusions that diagnoses based solely on self-report tend to agree poorly with diagnoses based on multiple data sources (G. Meyer et al., 2001). Effects of trait visibility may influence agreement, as easily observable traits and symptoms tend to yield better interrater correlations than do more internal traits. Poor self-awareness (e.g., unawareness of negative affect during social interactions) also has the potential to skew responses, as do personal characteristics and biases of informants (Ferdinand, Van Der Ende, & Verhulst, 2006; South, Oltmanns, Johnson, & Turkheimer, 2011). The discrepancies in scores obtained from multiple informants can have significant clinical utility, however: if a specific behavior or impairment is only reported by one informant, this may lend insight into the contexts in which symptoms are most challenging, while agreement across all informants on a particular domain may indicate higher levels of severity and consistency across contexts.

  For externalizing disorders such as ADHD, Achenbach and colleagues (2005) report a mean cross-informant correlation of .44. Overall reporting of externalizing symptoms of ADHD

tended to be more convergent than reporting of internalizing symptoms of ADHD. Both

adolescents and adults with ADHD have been shown to under-report their inattention and

impulsivity symptoms in comparison to objectively measured behavior frequencies (Kooij et al.,

2008; Smith, Pelham, Gnagy, Molina, & Evans, 2000; Young, 2004; Zucker, Morris, Ingram,

Morris, & Bakeman, 2002), though self-report measures largely demonstrate significant

correlations with informant ratings overall (Magnússon et al., 2006; Murphy & Schachar, 2000).

In particular, adolescent self-report of social competence departs significantly from parent

ratings, with cross-informant correlation averaging just .21 (Renk & Phares, 2004).There is less

agreement, however, on the extent to which individuals with ADHD accurately report more

visible symptoms: while there is evidence that adults are relatively reliable in reporting negative

social behaviors (Smith et al., 2000; Young, 2004). Notably, cross-informant correlations for

substance abuse averaged .68 (Achenbach et al., 2005), supporting findings that agreement may

generally be higher when addressing more observable, less intrinsic constructs (Halfens, Alphen,

Hasman, & Philipsen, 1999). Similarly, we may expect to see higher cross-informant correlation

for more observable symptoms of ASD, such as repetitive behaviors or restricted interests, while

there may be less agreement about internal processes, such as social awareness or emotional

insight.

Self-report measures are also widely used in the assessment of internalizing disorders,

such as depression and anxiety. While past research indicates that depressed individuals may

over-report poor social adjustment and negative life events (Morgado, Smith, Lecrubier, &

Widlöcher, 1991), other studies have found significant correlations between responses from

depressed patients, familiar informants, and clinical interviewers on measures of symptom

severity (Sanchez-Villegas et al., 2008; Stuart et al., 2014) and social adjustment (Weissman &

Bothwell, 1976). Several studies have also demonstrated that neither past nor current depression has a significant impact on the self-report of personality traits (Bagby et al., 1998; Shea et al., 1996; Surtees & Wainwright, 1996). Similarly, individuals with schizophrenia have been shown to accurately report personality characteristics, as well as many internalizing and externalizing symptoms. Like adults with ASD, individuals with schizophrenia typically have poor social insight. Though it appears that schizophrenia patients with poor insight are able to accurately report their degree of social avoidance and withdrawal, individuals with poor insight tend to present themselves as more extraverted than they actually are and are likely to be more certain of their perceptions than is warranted (Bell, Fiszdon, Richardson, Lysaker, & Bryson,2007).

Daily Living Skills. Little research has been conducted on self-report of daily living skills outside of ASD, as such abilities tend to be less of an issue in other clinical populations (Klin et al., 2007). A study with a sample of 48 adults with intellectual disabilities found that, when comparing self-report to standard Vineland interviews with program counselors, responses on domains measuring adaptive skills were highly consistent (Voelker et al., 1990). For those with severe mental illnesses, such as schizophrenia, skills that are essential to an individual's ability to function in the community are considered an essential part of functional outcome. It can be difficult to use self-report measures with these individuals, however, as the core features of their psychopathology may distort their ability to accurately rate their own functioning. Furthermore, ratings based on self-report or interview methods may not directly relate to capabilities in the domains of daily living in the outside world. Performance-based measures— which are often used in geriatric populations and with individuals with dementia—may be one way to more accurately assess daily living skills for adults with severe psychiatric disorders (Patterson, Goldman, McKibbin, Hughs, & Jeste, 2001).

Quality of Life. As with individuals with ASD, measuring quality of life in other

populations is complex: the same methodological issues arise in regards to the influence of low

life expectations or fundamental differences in the intrinsic values of the individual versus an

informant (Katschnig, 2000; Welham et al., 2001). For example, a study of self-report and proxy

assessments of quality of life for patients with schizophrenia found that proxies tend to rate

patients' quality of life lower than the patients themselves (Becchi, Rucci, Placentino, Neri, & de

Girolamo, 2004). Additionally, a study of self-report on quality of life in patients with

depression, bipolar disorder, or schizophrenia found no significant intraclass correlations

between global scores on a quality of life index and objective quality of life indicators; in other

words, participants' overall self-reported quality of life scores did not significantly relate to their

scores on measures of health, socioeconomic status, or social involvement (Atkinson, Zibin, &

Chuang, 1997).

Present Study

Taken together, the previously outlined literature highlights how little research has been

conducted on the use of self-report measures for adults with ASD. Research in other populations

indicates that self- and informant-report of symptom severity is typically only modestly

correlated, lending support to the value of multiple reporters in these populations and for

individuals with ASD. As social impairment is characteristic of both schizophrenia and ASD,

findings on self-report abilities in individuals with schizophrenia may be most useful in forming

predictions about the extent to which individuals with ASD have insight into their own

impairments. While individuals with schizophrenia demonstrate some level of insight into their

own symptoms, including levels of social avoidance and withdrawal, because lack of social

awareness is a more central component of the ASD diagnosis, individuals with ASD may have

greater difficulty reflecting on their own levels of impairment—particularly those related to social understanding and interaction. Research across populations also demonstrates that agreement between reporters is typically higher for more observable symptoms. As such, reported number of adaptive behaviors is likely to be reasonably aligned between individuals with ASD and informants. Measuring quality of life, however, is fraught with complications. Across psychological disorders, informants tend to report consistently lower quality of life than the target individuals, even when ratings are significantly correlated; this is likely to be the case for adults with ASD, as well. Disparities in quality of life ratings also raise questions about whose reports should be prioritized. Because quality of life is so inherently subjective and relies on the value system of the individual reporter, it seems that greatest credence should be given to self-report rating, while still keeping in mind possible biases induced by presenting symptoms. It is also important to examine the extent to which each informant's report maps onto objective outcomes, such as employment or independent living status. By understanding which informant's or combination of informants' reports are most predictive of true-life factors, we will be able to better shape best practice for ensuring comprehensive and accurate assessments.

Critically, the limited research on adult self-report in ASD that *is* available tends to focus solely on correlational analyses without addressing the extent of discrepancies between self- and informant-reports; In other words, ratings provided by all reporters may be highly related on every item, but consistently higher or lower than one another. There is a fundamental knowledge gap regarding the domains in which self-report responses for adults with ASD are most likely to differ from informant-report and for which domains these discrepancies are largest. Given the rapidly increasing number of adults with ASD – particularly those with average to above average IQs – addressing this gap is essential to advancing both research and clinical services in this

population. The aim of the present study is to examine the level of agreement between self- and caregiver-report of (1) symptom severity (as measured by the SRS-A; Constantino, 2012) for adults with ASD, and the extent to which more impaired social insight relates to the level of agreement between self- and caregiver-report of the adult's (2) daily living skills (as measured by the W-ADL; Maenner et al., 2013), and (3) quality of life (as measured by the QoL-Q; Schalock, Hoffman, & Keith, 1993). These findings will serve to elucidate the unique information provided by both adults with ASD and their caregivers, thus emphasizing the utility of multiple informants in the assessment of ASD for the purposes of diagnosis and treatment planning.

Hypotheses:

1. Self-report and caregiver responses will be significantly discrepant on measures of symptom severity, independent living skills, and quality of life. Specifically:

   a. Caregivers will report consistently higher levels of symptom severity on the *Social Responsiveness Scale*, compared to adults with ASD self-report.

   b. Caregivers will consistently endorse fewer independent daily living activities performed by the adults with ASD on the *Waisman Activities of Daily Living Scale*, compared adults with ASD self-report.

   c. Caregivers will report consistently lower quality of life ratings on the *Quality of Life Questionnaire* compared to adults with ASD self-report.

2. Despite consistent discrepancies, there will be significant positive correlations between self-report and caregiver responses, on the:

   a. The *Social Responsiveness Scale*,

   b. The *Waisman Activities of Daily Living Scale,*

c. The *Quality of Life Questionnaire,*

and these correlations will not be significantly different from cross-informant correlations reported in meta-analyses of other adult populations (Achenbach et al., 2005).

3. Caregiver report will be most predictive of objective outcome measures of employment and independent living outcomes, above and beyond the predictive value-added of self-report on the *Social Responsiveness Scale*, the *Waisman Activities of Daily Living Scale*, and the *Quality of Life Questionnaire.*

Exploratory Hypothesis:

1. Caregiver *t*-scores on the *Social Responsiveness Scale*'s Social Communication Index (SCI) will be significantly associated with the size of discrepancies between self-report and caregiver scores on the *Waisman Activities of Daily Living Scale* and the *Quality of Life Questionnaire*. It is expected that individuals who are reported by caregivers to have greater impairment in social insight (as indicated by higher SCI scores) will be less perceptive of their own characteristics and will thus report more daily living skills and higher quality of life than their caregivers, resulting in larger discrepancy scores.

METHOD

Experimental Design

This study utilized a quasi-experimental design with data collected from a sample of adults with ASD and their matched caregivers. Reporter group (self or caregiver) served as a within-subjects variable, with responses on three measures assessing the adult with ASD's functioning (social impairment, quality of life, and daily living skills) serving as dependent variables. Analyses were conducted to address discrepancies between adult and caregiver responses, correlations between adult and caregiver responses, predictive value of adult and caregiver responses on objective outcome measures, and the extent to which social impairment is predictive of discrepancies between adult and caregiver responses.

Participants

Forty pairs of adults with ASD (32 males; age range: 23.83 - 47.84; $M = 33.18$ years) and their caregivers (29 mothers, 9 fathers, 2 other relative informants) participated in this study (see Table 1 for full sample characterization). Participants were identified as part of a longitudinal study examining caregiver-reported outcomes for middle-aged adults with ASD and were originally recruited from a clinical database of 3,226 individuals who were seen at a TEACCH clinic between 1969 and 2000, who were at least 30 years old at the time of the search, and had at least one clinical evaluation before the age of 17. This pool was examined for individuals who met additional criteria of a Childhood Autism Rating Scale (Schopler, Reichler, and Rochen Renner 1988) score of 27 or higher and had a confirmed ASD diagnosis in archival clinical records. Using a specialized online search program, we located current addresses and phone

numbers for these clients. Recruitment letters were mailed to these families, with follow-up recruitment phone calls occurring approximately two weeks after the initial letter was sent. Using these recruitment methods in the larger longitudinal study, we successfully contacted 529 families. Of the 485 individuals who met eligibility criteria after screening, 364 caregivers elected to enroll in the study. Two hundred eighty-four surveys were completed (78% completion rate). While this longitudinal study targeted only caregiver participation, 21 paired samples of caregivers and adults with ASD elected to complete the survey, with the adults with ASD using a version adapted for self-report.

To recruit additional pairs for the current study, the age cut-off was lowered from 30 to 23 in order to broaden the potential recruitment pool. Because the adults with ASD recruited were required to complete self-report measures with limited assistance, we only contacted individuals without a comorbid intellectual disability in their records and with a childhood IQ of 85 or higher. In addition to recruiting new participant pairs through the methods utilized in the original longitudinal study (i.e., recruitment letters and phone calls to families in the TEACCH database), caregivers who participated in the longitudinal study at least two years ago were re-contacted if the respective adult met our new inclusion criteria, and were offered the option to complete a new survey along with the addition of the adult self-report. Twenty-four additional pairs were recruited through these methods, with a completion rate of 79% (19 pairs), for a total of 40 pairs overall.

Measures

TEACCH Autism in Adulthood Survey. This 87-question survey was designed as part of the larger longitudinal study and aimed to collect information about the current life characteristics of adults with ASD. The present study utilized responses to survey questions

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regarding current living situation and employment status of the adult with ASD. Two versions of this survey were created, one for caregiver-report and one for self-report. These are included as Appendices A and B, respectively.

  Social Responsiveness Scale, Second Edition: Adult Form (SRS-A; Constantino, 2012)**.** The SRS-A is a 65-item measure that assesses the severity of social communication and restricted and repetitive behavior symptoms in ASD over five domains: social awareness, social information processing, capacity for reciprocal social responses, social anxiety/avoidance, and characteristic autism preoccupation rates. In addition to a total standard score, the SRS-A provides a Social Communication Index (SCI) and Restricted and Repetitive Behaviors Index (RRB) to reflect the two categories of DSM 5-compatible symptoms. The caregiver completed the informant version of the SRS-A; the individual with ASD completed the self-report version of the SRS-A. Questions are identical between versions with the exception of pronoun usage and perspective of the question framing (e.g., "I am able to communicate my feelings to others" in the self-report version vs. "Is able to communicate his or her feelings to others" in the informant version). For both versions, all items on the SRS-A are rated from 1 to 4, where 1 indicates that the statement is *not true* and 4 indicates that the statement is *almost always true* of the individual. Both the informant and self-report versions have strong psychometric properties, with high internal consistency values across all forms (α = .94 to .96). The interrater reliability between self- and other-report on the SRS-A averaged r = .66 across a variety of informants (e.g., parents, spouses, etc.). The SRS-A manual states that "in the vast majority of cases, the scores [between multiple reporters] will be well within 10 *t*-score points of one another, very often within 5 *t*-score points." *T*-scores of 59 and below on the SRS-A are classified as "within normal limits" and are generally not associated with clinically significant autism spectrum disorders. *T*-scores of

60 and above indicate clinically significant deficiencies in reciprocal social behavior across three ranges of impairment: *t*-scores of 60 to 65 fall in the "mild range" and indicate deficiencies in reciprocal social behavior that may lead to mild to moderate interference with everyday social interactions; *t*-scores of 66 to 75 fall in the "moderate range" and indicate deficiencies in reciprocal social behavior that lead to substantial interference with social interactions, and such scores are typical for individuals with an ASD of moderate severity; *t*-scores of 76 or higher indicate deficiencies in reciprocal social behavior that lead to severe and enduring interference with everyday interactions, and such scores are strongly associated with clinical diagnosis of ASD. The caregiver report and self-report versions of the SRS-A are included as Appendices C and D.

Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013). The W-ADL measures the ability of individuals with intellectual/developmental disabilities in adolescence and adulthood to complete activities of daily living, such as household chores and self-care routines. This measure lists 17 activities that are rated on a 3-point scale (0 = ''does not do at all'', 1 = ''does with help'', 2 = ''independent''). It has been validated for use as a caregiver report with individuals with Down Syndrome, Fragile X Syndrome, ASD, and intellectual disabilities. For caregivers, the W-ADL demonstrates high internal consistency (α = .88 to .92), and is reliable over time. No studies have examined the W-ADL as a self-report measure. The W-ADL is included as Appendix E.

Quality of Life Questionnaire (QoL-Q; Schalock & Keith, 1993). The QoL-Q is a 40-question measure that was developed to assess the quality of life of individuals with intellectual or developmental disabilities. It is intended for both self-report and caregiver or staff report. The QoL-Q contains questions across four subscales: Life Satisfaction, Competence/Productivity,

Empowerment/Independence, and Social Belonging. Each subscale contains 10 questions, each with a 1-point, 2-point, and 3-point response wherein a higher score indicates a higher quality of life rating. Eight out of the 10 questions on the Competence/Productivity can only be complete if the individual being rated is currently employed. The internal consistency of the subscales is relatively high (α = .66 to .83, total α = .83.). Though no studies have been conducted comparing self- and informant-report on the Qol-Q for in an intellectually high functioning sample or for individuals with ASD, specifically, research comparing staff and client ratings in other populations has found consistently low cross-informant correlations on all subscales (r = .07 to .31). The QOL-Q is included as Appendix F.

Procedure

The current study is part of a larger study conducted by the TEACCH Autism Program at the University of North Carolina at Chapel Hill (Laura Klinger, PI, of a study funded by Autism Speaks) and has been approved by the Institutional Review Board. After contact was made through recruitment efforts, potential participants were screened over the phone for eligibility. Once eligibility was established and the participants (both adult and caregiver) verbally indicated their desire to participate, they were enrolled. After participants were enrolled, the measures were distributed either electronically or as a hard copy mailed to the participants, based on their individual preferences. The electronic version of the survey was presented via Qualtrics survey software and was distributed to participants by an email containing a unique link to the survey that is associated with the participant's ID number. The paper and pencil version of the survey was distributed by mail, and each packet included a postage-paid envelope for returning the completed survey. If the surveys were not completed or returned within two weeks of receipt, a follow-up occurred via phone call. Participants who returned incomplete surveys or whose

surveys contain unclear answers were also contacted by phone to ensure accurate and complete data collection. All caregivers completed the TEACCH Autism in Adulthood Survey, the W-ADL (Maenner \et al., 2013), the SRS-2 (Constantino, 2012), and the QoL-Q (Schalock et al., 1993); adults with ASD completed the self-report versions of the same measures. The entire battery was estimated between 40 minutes and 1 hour to complete, and each participant received $20 for taking part in this study.

Statistical Analyses. The primary dependent variables are participant responses to the included measures. G*Power3 was used to determine the appropriate sample size. Assuming an alpha of .05, 40 individuals per group provides a power of 87% to detect medium-sized ($d = .5$) mean differences in responses between caregivers and adults with ASD on the SRS-2 and W-ADL, a power of 83% to detect small ($d = .3$) mean differences in responses between caregivers and adults with ASD on the QoL-Q, and a power of >99% to detect large ($d = .8$) mean differences in responses between caregivers and adults with ASD on these measures. Paired samples t-tests were used to test the hypothesis that self-report and caregiver responses were significantly discrepant on the SRS-2, W-ADL, and QoL-Q; Specifically, it was predicted that adults with ASD would self-report lower levels of social impairment, higher numbers of daily living skills, and higher quality of life in comparison to caregiver report. Paired samples t-tests were also used to test for group differences based on living situation (i.e., adult with ASD living with the participating caregiver or outside of the home).

Next, correlational analyses were conducted to assess the extent to which caregiver responses are related to those of the adults with ASD on the SRS-2, W-ADL, and QoL-Q. It was hypothesized that there would be significant, positive correlations between self-report and caregiver responses on all three measures. This was hypothesized to be true regardless of

whether there are mean differences in self-report and caregiver ratings. Using an alpha of .05, 40 pairs of self-report and caregiver ratings provided 62% power to detect a correlation of $r = .3$ and 97% power to detect a correlation of $r = .5$. Follow-up analyses were conducted to test the hypothesis that correlation between caregiver and adult responses would not differ significantly from the expected correlation demonstrated in other populations. Specifically, we tested that the correlation between self-report and caregiver responses would not be significantly different the average .45 correlation established by Achenbach and colleagues (2005) in a meta-analysis of studies examining reporter agreement in other types of adult psychopathology.

We then used hierarchical logistic regression to analyze the extent to which each reporter's responses on the included measures were predictive of objective employment and independent living outcomes. Covariates were added simultaneously and then individually to calculate the relative value-added predictive power of multiple informants versus caregiver- or self-report alone on all measures together, as well as each individual measure. A sample size of 40 provides over 80% power to detect medium effect sizes in this analysis.

Finally, it was hypothesized that caregiver scores on the SRS-2 Social Cognition Index (SCI) would be strongly associated with the size of discrepancies between self-report and caregiver responses on the W-ADL and QoL-Q. To test this hypothesis, we conducted correlational analyses between discrepancy scores and caregiver scores on the SCI. Discrepancy scores were first calculated by subtracting self-report scores on the W-ADL and QoL-Q from caregiver scores on the same measures; a positive score indicated that the caregiver reported more daily living skills and higher quality of life than the adult, while a negative score indicated that the adult reported more daily living skills and higher quality of life than the caregiver. We expected to find a significant, negative correlation between caregiver SCI scores and discrepancy

scores. The reported power for this analysis is somewhat underpowered with 62% power to

detect the expected medium-sized effect and 97% power to detect a large effect. Because this test

is underpowered for the expected effect size, it is considered exploratory.

RESULTS

All data were analyzed using IBM SPSS Statistics. Data were scored and double entered by two trained research staff to ensure accuracy of the data. Once data entry was complete, descriptive analyses such as central tendency and frequency were conducted to investigate distributional assumptions. Box plots and histograms were performed on all continuous variables of interest to investigate distributional properties and check for outliers. Based on the distributional properties of the data, all participants were included in subsequent analyses. Due to incomplete measures, data for two pairs on the SRS-A total score, three pairs on the QoL-Q total score, and two pairs on the W-ADL total score could not be included in analyses; analyses on most individual subscales were still able to be conducted for all 40 pairs. All analyses were conducted with a two-tailed alpha of $p < .05$.

Given concerns that there may be fundamental differences in reporter agreement based on level and frequency of contact between caregivers and adults with ASD, independent samples t-tests were conducted to test whether there were any differences in discrepancy size between reporters on the included measures for adults living with the participating caregiver ($n = 23$) versus adults away from the caregiver ($n = 17$). Living situation was considered a proxy measure for caregiver frequency of contact. There were no significant differences between caregiver contact groups on the size of the discrepancy between caregiver and self-report scores on the SRS-A ($p = .60$), W-ADL ($p = .72$), or QoL-Q ($p = .85$). There was also no significant difference in age between groups ($p = .96$). Therefore, caregiver frequency of contact was not included in further analyses.

Hypothesis 1: **Discrepancies Between Caregiver-Report and Self-Report**

Paired samples *t*-tests were conducted to test the hypothesis that caregiver responses on the included measures would differ significantly from self-report responses (see Table 2 for all comparison statistics). Effect size data are provided using Cohen's guidelines: for paired samples *t*-tests, a Cohen's *d* of .2 is a small effect, .5 is a moderate effect, and .8 is a large effect. Dependent variables included caregiver and self-report scores on the: (1) the SRS-A, (2) the W-ADL, and (3) the QoL-Q. It was hypothesized that caregivers would report higher symptom severity across all domains on the SRS-A, fewer daily living skills on the W-ADL, and lower quality of life on the QoL-Q than adults with ASD reported about themselves.

On the SRS-A, there was no significant difference between the mean caregiver-report t-score of 61.97 (*SD* = 12.25) and the mean self-report t-score of 60.26 [*SD* = 9.49; *t*(37) = -.95, *p* = .25, *d* = .15]. There were also no significant differences between reporters on the SCI [*t*(37) = -1.52, *p* = .35, *d* = .16 or the RRB scales [*t*(39) = -.804, *p* = .43, *d* = .13]. The SRS-A manual indicates that most informants' scores will be less than 10 *t*-score points apart. Despite the non-significant difference and the small effect size of the difference between caregiver and self-report *t*-scores on the SRS, the *t*-scores for 14 pairs (35%) differed by 10 or more points. For seven pairs (17.5%), caregivers reported higher symptom severity than the adult with ASD reported. Additionally, scores were examined to determine if clinical classifications differed between self and caregiver reports. Different clinical classification (i.e., "within normal limits," "mild," "moderate," or "severe") on the SRS-A were found for 19 pairs (47.5%); caregiver scores placed the adult with ASD in a more elevated severity range than did self-report scores for 17 individuals (42.5%). For 9 (22.5%) pairs, caregiver scores placed the adult with ASD in an

elevated clinical range on the SRS-A while self-report scored classified the adult's symptoms as sub-threshold (i.e., "within normal limits).

On the W-ADL, there was a statistically significant difference with a small-to-moderate effect size between caregiver-report and self-report of the adult with ASD's number of daily living skills [$t(37) = 2.36$, $p = .023$, $d = .38$). Caregivers reported that adults with ASD demonstrated significantly fewer ($M = 28.87$, $SD = 4.39$) daily living skills than adults with ASD reported ($M = 30.00$, $SD = 3.81$).

Analyses of total scores on the QoL-Q were conducted using scores across the three subdomains of Satisfaction, Belongingness, and Empowerment; analyses excluded the Competence subdomain, as it can only be completed if one is employed. A 3x2 ANOVA indicated an overall effect of reporter moderated by an interaction of scale type [$F(2,72) = 3.40$, $p = .04$]. Follow-up t-tests revealed a significant difference with a moderate effect size between caregiver- and self-report scores on the Satisfaction subdomain of the QoL-Q [$t(39) = 2.96$, $p = .002$, $d = .55$], with caregivers reporting significantly lower satisfaction ratings for the adults with ASD ($M = 20.55$, $SD = 3.49$) than adults with ASD reported for themselves ($M = 22.43$, $SD = 4.07$). There were no significant differences between reporters on the Belongingness [$t(36) = 1.14$, $p = .93$, $d = .02$] or Empowerment [$t(39) = 1.28$, $p = .45$, $d = .12$] subdomains.

Hypothesis 2: **Correlation Between Caregiver-Report and Self-Report**

We hypothesized that there would be significant positive correlations between caregiver and self-report scores for all measures even when discrepancies existed. We also hypothesized that these correlations would not differ significantly from the $r = .45$ average inter-rater reliability observed in other populations, as calculated through a meta-analytical approach (Achenbach et al., 2005). There was a significant positive correlation between caregiver- and

self-report *t*-scores on the SRS-A total ($r = .50$, $p = .001$; see Figure 1). This correlation did not differ significantly from the expected average of $r = .45$ ($Z = .39$, p's $= .45$) or from the average cross-informant agreement reported in the SRS-A manual ($Z = -1.48$, $p = .14$). There was also a significant positive correlation between caregiver- and self-report scores on the W-ADL ($r = .75$, $p < .001$; see Figure 2), and the correlation was significantly higher than the expected average of $r = .45$ ($Z = 2.89$, $p = .004$). For the QoL-Q total scores across the three included subdomains, there was a significant positive correlation between caregiver- and self-report total scores ($r = .78$, $p < .001$; see Figure 3. This correlation were significantly higher than the expected average of $r = .45$ ($Z = 3.28$, $p = .001$).

Although there was no overall difference in reporter discrepancies based on caregiver contact, it is possible that caregiver frequency of contact could influence the strength of the relation between caregiver and self-reports. Therefore, follow-up analyses were conducted to probe for potential interaction effects of caregiver contact. Two-way ANOVAs were used to examine the effect of caregiver frequency of contact (living at home; living away from home) and caregiver SRS-A, W-ADL, and QoL-Q scores on self-report scores. Effect size data is provided using Cohen's guidelines (i.e., partial eta squared [$\eta p2$] of .01 is a small effect, .06 is a moderate effect, and .14 is a large effect). There was a statistically significant interaction with a moderate-to-large effect size between the influence of caregiver contact and caregiver SRS-A scores [$F_{(1, 34)} = 4.38$, $p = .04$, $\eta p2 = .11$]: for adults away from caregivers, SRS-A self-report scores were less correlated with caregiver SRS-A scores than for adults living with the participating caregiver. There was not a significant interaction between caregiver contact and caregiver W-ADL scores [$F_{(1, 35)} = .11$, $p = .75$) or between caregiver contact and caregiver QoL-Q scores [$F_{(1, 33)} = .16$, $p = .69$).

Hypothesis 3: **Relationship to Employment and Independent Living Outcomes**

Next, we used hierarchical logistic regression to analyze the predictive value-added of each reporter for correctly predicting objective living and employment outcomes. For these analyses, living situation was used to identify level of daily living supports needed and was classified as either independent (i.e., living along or with a spouse/roommate without supports) or supported (i.e., living with a caregiver or in a supervised setting, such as a group home). Employment outcome was classified as either currently employed or unemployed. We first entered self-report SRS-A, W-ADL and QoL-Q scores in block one, followed by caregiver SRS-A, W-ADL, and QoL-Q scores in block two. In this model, the addition of caregiver report significantly increased predictive power ($\chi^2 = 8.99$, $p = .03$) and classification accuracy of employment status increased from 77.8 percent to 88.9 percent. The addition of caregiver report did not significantly increase predictive power of current living situation (supported vs. unsupported; $\chi^2 = 4.72$, $p = .19$; classification increase from 77.8 to 80.6%). When done in reverse, with caregiver scores entered in block one and self-report scores entered in block two, the addition of self-report scores significantly increased the predictive power of employment status ($\chi^2 = 12.19$, $p = .007$). Classification accuracy increased from 75.0 percent in block one to 88.9 percent in step two. The addition of self-report scores also significantly increased predictive power of living situation ($\chi^2 = 8.50$, $p = .04$), and classification accuracy increased from 75 percent in block one to 80.6 percent in block two.

We then used hierarchical logistic regression to examine the relative value-added of each reporter for each individual measure to identify if overall effects were related to specific measures. On the SRS-A, the addition of caregiver-report on top of self-report did not significantly increase predictive power for either living situation ($\chi^2 = 1.47$, $p = .69$;

classification increase from 71.1% to 76.3%) or employment status ($\chi^2 = .10$, $p = .75$; classification increase from 63.2% to 68.4%). Similarly, adding self-report scores on the SRS-A on top of caregiver scores did not significantly increase the predictive power of the model for either outcome ($\chi^2 = 3.10$, $p = .08$; $\chi^2 = 2.08$, $p = .15$; classification increase from 68.4% to 76.3%).

We next examined the relative value-added for each reporter's measure of daily living skills in predicting living situation and employment. We entered self-report W-ADL scores in block one, followed by caregiver W-ADL scores in block two. In this model, the addition of caregiver-report on top of self-report did not significantly increase predictive power of living situation ($\chi^2 = .03$, $p = .87$), though classification accuracy increased from 69.2 percent to 74.4 percent. Likewise, the addition of self-report on top of caregiver-report did not significantly increase predictive power of living situation ($\chi^2 = 1.93$, $p = .16$), though classification accuracy once again increased from 69.2 percent to 74.4 percent. However, the addition of caregiver report significantly increased predictive power ($\chi^2 = 5.47$, $p = .019$) and classification accuracy of employment status increased from 69.2 percent to 82.1 percent. When done in reverse, with caregiver W-ADL scores entered in block one and self-report scores entered in block 2, the addition of self-report scores did not increase the predictive power of the model ($\chi^2 = .13$, $p = .72$). Classification accuracy remained stable at 82.1 percent from the addition of caregiver W-ADL scores in block one to the addition of self-report scores in block two.

The addition of caregiver-report or self-report on top of either report independently did not significantly increase predictive power of the QoL-Q for either living situation of employment status (χ^2's $= .21 - 2.53$, p's $= .11 - .86$). Specifically, adding caregiver-report on top of self-report did not change classification accuracy of living situation from 69.4 percent.

Done in reverse, the addition of self-report on top of caregiver report changed classification accuracy of living situation from 67.6 percent to 64.9 percent, which did not represent a significant change. For employment status, adding caregiver-report onto self-report changed classification accuracy from 67.6 percent to 75.7 percent, which did not represent a significant change. Last, adding self-report onto caregiver-report changed classification accuracy from 73.0 percent to 75.7 percent, which also did not represent a significant change.

Exploratory Hypothesis: **Correlation Between SCI and Discrepancy Size**

Finally, we conducted correlational analyses to investigate the exploratory hypothesis that Caregiver scores on the SRS-A's Social Communication Index (SCI) would be significantly negatively associated with the discrepancies between self-report and caregiver scores on the W-ADL and Qol-Q. A positive discrepancy score indicated that the caregiver reported higher numbers of daily living skills and higher quality of life than the adult reported about him or herself, while a negative score indicated that caregivers reported lower numbers of daily living skills and lower quality of life than the adult. Caregiver scores on the SCI were significantly negatively correlated with the discrepancy size between caregiver and self-report scores on the W-ADL ($r = -.35, p = .03$), indicating that higher caregiver-reported levels of social communication difficulties were associated with caregivers reporting fewer daily living skills than the adult with ASD. Self-report scores on the SCI were not significantly correlated with discrepancy size on the W-ADL ($r = .17, p = .32$). Caregiver scores on the SCI were also significantly negatively correlated with the discrepancy size between caregiver and self-report scores on the QoL-Q ($r = -.56, p = < .01$), indicating that higher caregiver-reported levels of social communication difficulties were associated with caregivers reporting lower quality of life

than the adult with ASD. Self-report scores on the SCI were not significantly correlated with

discrepancy size on the QoL-Q ($r = -.19, p = .27$).

DISCUSSION

Overall, results indicated that there were high relationships between caregiver and self-report responses on measures of symptom severity, daily living skills, and quality of life. However, discrepancies between reporters on level of reported symptom severity impacted clinical utility despite the lack of statistically significant differences. Additionally, the combination of self-report and caregiver-report on all measures better predicted employment outcomes than did an individual reporter. In particular, caregiver report of daily living skills was valuable in determining the likelihood that an adult was currently employed. Taken together, these findings suggest that, while self-report is valid for this subset of adults with ASD, a multi-informant approach should be best clinical practice for assessment in this population.

Specifically, the present study investigated whether self-report and caregiver measures of symptom severity, adaptive daily living skills, and quality of life were: (1) significantly discrepant from one another, (2) significantly positively correlated even if discrepancies existed, and (3) differentially predictive of employment and independent living outcomes. Exploratory analyses examined whether higher caregiver-reported symptom severity in the area of social communication was associated with more disagreement between caregiver-report and self-report on measures of daily living skills and quality of life.

A primary aim of this study was to elucidate the extent to which self-report on ASD symptoms can be reliably used for adults with ASD of average to above average intellectual functioning. In assessing symptom severity, our findings indicate that adults with ASD and their caregivers are consistent in their report of ASD symptoms. Caregiver and self-report responses

also demonstrated positive significant correlation with one another. The correlation of $r = .50$ found in the present study was not significantly different from the average cross-informant correlation of $r = .66$ reported in the original standardization study of the SRS-A ($Z = 1.46$, $p = .07$; Constantino & Gruber, 2007). Further, neither self-report nor caregiver report of symptom severity proved more useful in predicting objective measures such as employment or need for daily supports. Although ASD symptom severity scores were, on average, remarkably consistent across reporters, discrepant reports resulted in different clinical classifications for 47.5% of the sample. Further, for 22.5% of pairs, caregiver scores placed the adult with ASD within the clinical range while self-report scores resulted in a sub-threshold classification.

Taken together, the present study indicates that, overall, adults with ASD of average to above average intellectual functioning can serve as reliable and accurate reporters of their own symptoms. These findings contrast with previous research suggesting that poor social insight limits the validity of self-report for this particular population (e.g., Berthoz & Hill, 2005; Bishop & Seltzer, 2012). Exploratory analyses did suggest that higher levels of caregiver-reported difficulties with social communication were associated with adults with ASD reporting more daily living skills and higher quality of life than their caregivers reported about them. While this finding may suggest that higher impairments in social insight in this population may lead to greater difficulties in accurately reporting daily living skills and quality of life, it may also driven by the fact that caregivers who reported higher levels of symptom severity were more likely to report more elevated difficulties in other areas, as well. Knowing that self-report in this population is likely to provide valuable information about symptom severity will allow self-report measures to become incorporated into comprehensive assessment methods. Recognizing the utility of self-report in this capacity can help to shape treatment planning, as well as provide a

means of measuring intervention effectiveness in research contexts. However, the fact that clinical classifications were not always consistent across reporters suggest that including a caregiver is still important in clinical contexts and a multi-informant approach is likely to provide the most comprehensive information. These findings also suggest that it may be useful to establish different clinical cut-off scores for self-report measures than for informant-report measures in order to ensure that adults with significant levels of impairment are not being incorrectly disqualified from services.

Accurately assessing daily living skills is also a key part of shaping treatment planning and supporting increased independence for adults with ASD. In the present study, we found that, despite a significant positive correlation between scores, there was a significant discrepancy between caregiver and self-report scores on the W-ADL. Specifically, caregivers reported that the adults with ASD demonstrated fewer daily living skills on average than adults reported about themselves. This discrepancy may be driven in part by the framing of the W-ADL items, which ask about what skills the adult *can do* as well as what skills the adult *does.* This difference between what someone "can do" vs. what someone "actually does" may contribute to divergence in reporting between adults with ASD and caregivers. An outside reporter may be better able to objectively monitor what skills are actually conducted on a regular basis. Interestingly, however, the correlation between caregiver and self-report scores on the W-ADL was significantly higher than the average correlation observed in other populations, supporting research indicating that cross-informant agreement is typically higher for more visible or objective constructs (Achenbach et al., 2005; G. Meyer et al., 2001)

Notably, caregiver-report on the W-ADL was the only measure found to significantly increase predictive accuracy of current employment status of the adult with ASD. This finding is

in line with longitudinal data showing that better daily living skills was one of the keys to successfully finding and maintaining employment for adults with ASD (Klinger et al., 2015). Because the addition of caregiver-reported daily living skills resulted in increased prediction of an objective outcome measure compared to self-report scores alone, caregiver-report may be more accurate in comprehensively assessing independence in completing daily living skills. Having accurate information on the W-ADL is essential in both clinical and research contexts, as adaptive behaviors and daily living skills have been consistently shown to be one of the best measures of long-term outcomes. For example, a study of adult outcomes for people with ASD and cognitive functioning in the average range found that adaptive behavior measures – particularly in the daily living skills domain – were most closely correlated with outcomes in independent living, working, and social functioning (Farley et al., 2009). These findings also support research indicating that IQ scores alone are not always reliable prognostic indicators (Howlin et al., 2004, 2014; Klinger et al., 2015), as individuals with high IQ scores but low daily living skills had poorer independent living outcomes than individuals with relatively low IQs who were able to care for themselves with little assistance. Because our data showed that caregiver-report on the W-ADL provided additional information that was not gathered in the self-report assessment alone, daily living skills may be the area in which it is most essential to involve informant report.

With regards to assessment of quality of life, overall, caregivers reported significantly lower quality of life – particularly in the Satisfaction domain – on the QoL-Q than adults with ASD reported about themselves, despite a significant positive correlation between reporters. The finding that self-reported quality of life was higher than caregiver ratings is consistent with research in other populations (Ikeda et al., 2014; Shipman et al., 2011), though correlation

between reporters in our sample was actually higher than would be expected based on such research. Improving quality of life is a primary consideration in interventions and services for adults with ASD (Gerber et al., 2011); as such, an individual's subjective feelings about one's own life must be taken into account and, in many cases, may be given higher priority than an informant's report. However, it is also important to consider the objective factors that influence quality of life, such as independence and success in work or social contexts. Klinger and colleagues (2015) found that higher daily living skills predicted employment and that employment was significantly associated with higher quality of in regards to satisfaction, sense of belonging, and empowerment. Because neither self-report nor caregiver report of quality of life proved more useful in predicting employment status, results of the current study do not provide evidence that one reporter is more accurate than another.

While a multi-informant approach has been a standard recommendation in the assessment of psychopathology in children, as well as adults with developmental or personality disorders (Barkley et al., 2011), this approach has not been well-studied for individuals with ASD. Inclusion of a caregiver or other informant in the assessment of daily living skills is particularly essential, as our data showed that caregivers added significant information that was not provided by adults with ASD themselves. Because we know that daily living skills influence employment outcomes, which in turn have a significant impact on overall quality of life, improving daily living skills should be a primary target of interventions with adults (Duncan & Bishop, 2013; Hume et al., 2009; Klinger et al., 2015). As such, it is imperative to have an accurate picture of what an adult's daily living skills truly look like.

Despite the demonstrated value of involving multiple informants in assessing adults with ASD, this study also shows that self-report should be considered an important consideration for

individuals with average or above intellectual ability. As self-report has not traditionally been part of assessments for ASD, there has been consequently very little research addressing the appropriateness of self-report measures in this population. This lack of research had impacted not only the provision of clinical services, but also the progress of research on adults with ASD. Particularly for the field of intervention research, it is impossible to move forward without knowing if self-report assessments can adequately capture the unique symptomatology of ASD in adulthood or measure treatment effectiveness. The present study demonstrates that, while a multi-informant approach is ideal, adults with ASD are capable of reporting on many aspects of their own lives. The fact that there was not a significant discrepancy between reporters on the SRS-A and that self-report on this measure was significantly predictive of employment outcomes indicates that adults with ASD are able to accurately report on their levels of symptom severity and ASD-related impairment. While there were significant discrepancies between reporters on both the W-ADL and QoL-Q, correlation between reporters was still on par with (or better than) interrater agreement in other populations. The combination of self-report on the SRS-A, W-ADL, and QoL-Q together was also predictive of employment outcomes, indicating that self-report accurately maps onto objective constructs. By identifying areas in which caregivers and adults with ASD are most likely to disagree, and the areas in which caregiver-report adds significant information that may not have been gathered from self-report alone, such as daily living skills, we can better guide decisions about if and when multiple informants should be consulted in making diagnoses and treatment plans. We can also use this information the help shape future assessment protocols and practices so that the field of intervention research for adults with ASD can continue to progress.

Limitations and Future Directions

Although this study makes significant strides in improving our understanding of self-report adults with ASD, there are still several limitations. Firstly, while this study was sufficiently powered to conduct the present analyses, the sample size was still relatively small. Future research examining a larger sample is recommended. Additionally, the full sample was recruited from a pool of adults who were diagnosed as children at the TEACCH Autism Program. Individuals who received diagnoses as children are often different from those who did not receive diagnoses until later in life, as more substantial symptoms often result in earlier diagnoses. Consequently, our findings may not be representative of self-report capabilities across the full autism spectrum. However, finding that adult self-report of ASD symptoms is consistent with caregiver report doesn't support these sample concerns.

Future directions for this study include expanding participant range of age and intellectual functioning. A large proportion of adult assessments for ASD are conducted around the transition age (i.e., late teens to early twenties); the average age in our sample (33.17 years) was older than that time period, and the results presented here may be less applicable to transition-aged adolescents and young adults. Additionally, because our sample was recruited from childhood records, IQ cutoffs for inclusion were also based on reported childhood IQ; thus, it is difficult to characterize the current cognitive functioning of adults in our sample. Given that there may be larger discrepancies in scores for individuals with lower IQs, future studies would benefit from having access to current IQ scores and should aim to include individuals from a wider range of intellectual functioning.

Finally, analyses involving the W-ADL should also be interpreted with caution, as the measure contains only 17 items and the range of scores is 1 to 34. Given the limited range of

possible scores, correlation between reporters was likely inflated as both members of adult-caregiver pairs hit ceiling in many instances. Future research including a standardized measure of adaptive behavior/independent living skills is needed to confirm the findings in this study. Follow-up analyses of the present sample could also include examining the extent to which reporters differ specifically on what adults *can do* vs. what they *actually do*.

The overarching goal of this research was to provide a greater understanding of what information different reporters provide on existing measures, as well as how particular measures map onto outcomes in order to help to shape assessment practices and treatment planning. Moving forward, this research aims to help shape future measures as they are being developed so that clinicians and researchers are able to ascertain the most accurate picture of how an individual is functioning in the areas of symptom severity, daily living skills, and quality of life. For example, this may mean having different cut-off scores for self-report than for informant report for areas in which we know the reporters differ (such a daily living skills), and next steps include investigating if and how such cut-off scores should be established. In a research context, having access to valid self-report measures is also essential to move forward with treatment/intervention studies in this population, as such measures are essential reliably capturing changes from pre- to post-intervention. The present study may serve as a first step in demonstrating the validity of self-report in this population, allowing intervention research to move forward using self-report as a meaningful assessment tool.

Summary

Overall, this study promotes a multi-informant approach as best clinical practice for assessing various aspect of ASD, including symptom severity, daily living skills, and quality of life. While results indicated remarkable consistency across reporters for assessing autism

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symptomatology, when differences occurred they resulted in different clinical classifications for 47.5% of the sample. Thus, a multi-informant approach is recommended for assessments conducted to either diagnose ASD or to evaluate symptom severity. Further, a multi-informant approach is supported by findings that both caregiver- and self-report of daily living skills improved the prediction of employment outcomes. Thus, when evaluations are being conducted to recommend adult independent living and employment support services, results suggest that it is important to include both self- and caregiver-reports. Overall, when it comes to qualification for services and shaping treatment plans, the inclusion of both caregiver- and self-report may ensure a more comprehensive picture of current functioning across domains.

Table 1. *Demographics for the total sample (n = 40).*

Sex (%male)	80% (*n* = 32)
Mean Age (*SD*; range)	33.17 (5.54; 23.83 – 47.84)
% Caucasian	87.5% (*n* = 35)
Employment Status (% employed)	57.5% (*n* = 23)
Living Situation	
With Family	57.5% (*n* = 23)
Independently	30% (*n* = 12)
Supervised Housing	12.5% (*n* = 5)
Caregiver (% mothers)	72.5% (*n* = 29)

Table 2. *Differences between self-report and caregiver-report on included measures.*

	Adult: *Mean (SD)*	Caregiver: *Mean (SD)*	Test Statistic (df)	Significance (two-tailed)
SRS-A Total (*t*-scores)	60.26 (9.49)	61.97 (12.25)	*t*(37) = -.95	*p* = .35
SCI	59.92 (9.01)	60.97 (12.27)	*t* (37)= -1.17	*p* = .25
RRB	63.20 (12.06)	65.03 (12.78)	*t*(39) = -.80	*p* = .43
QoL-Q Total (3 domains)	67.57 (7.67)	65.08 (8.87)	*F*(2, 72) = 3.40	*p* = .04*
Satisfaction	22.43 (3.49)	20.55 (4.08)	*t*(39) = 2.96	*p* = .002*
Belongingness	19.89 (3.78)	19.95 (4.37)	*t*(36) = 1.14	*p* = .93
Empowerment	25.13 (3.60)	24.78 (3.79)	*t*(39) = 1.28	*p* = .45
W-ADL Total	30.00 (3.81)	28.87 (4.39)	*t*(37) = 2.36	*p* = .02*

*$p \le .05$

Figure 1. *Correlation between caregiver and self-report total scores (t-scores) on the SRS-A. Higher scores indicate greater symptom severity. A t-score of 59 and below is classified as "within normal limits," 60 to 65 as "mild range" 66 to 75 as "moderate range," and 76 or higher as "severe range." Reference line (red) represents r = 1.00.*
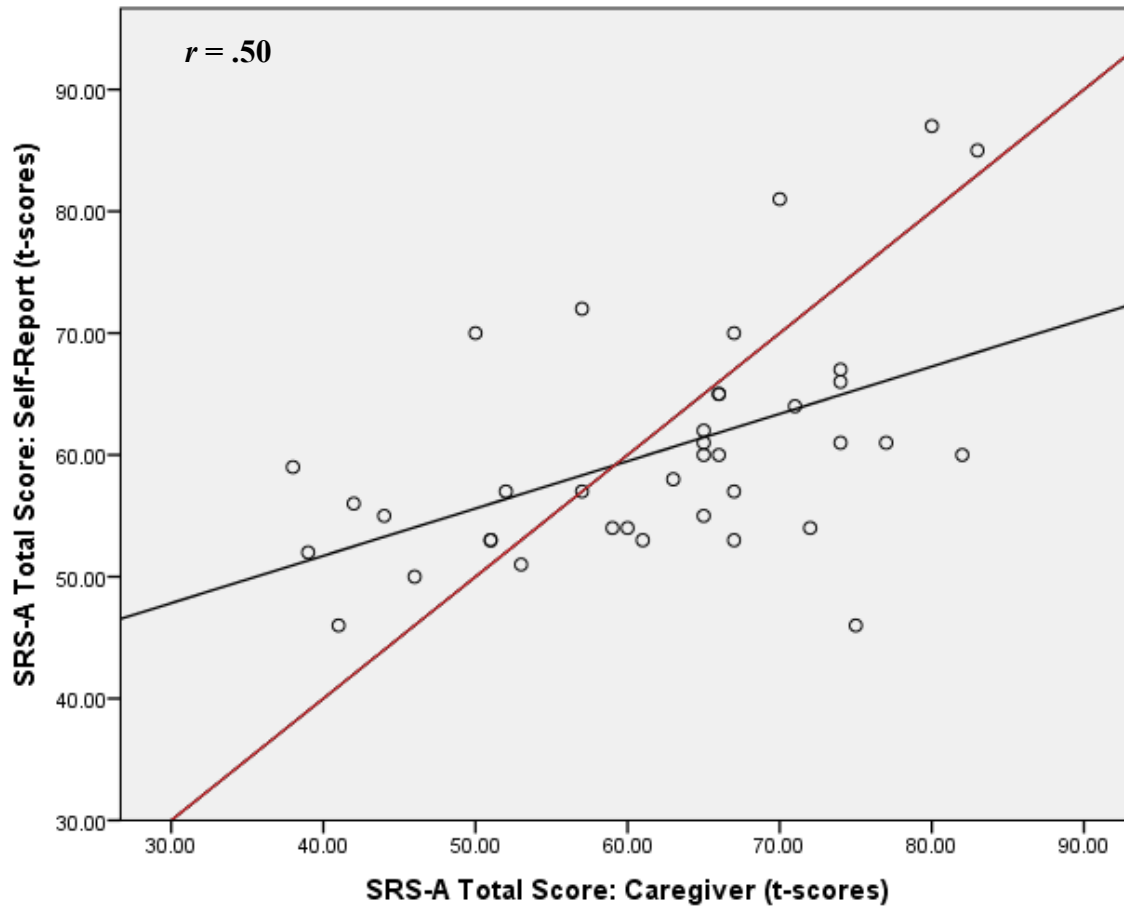
Figure 2. *Correlation between caregiver and self-report total scores on the W-ADL. Scores range from 0 to 34. Higher scores indicate a greater number of daily living skills used independently. Reference line (red) represents r = 1.00.*
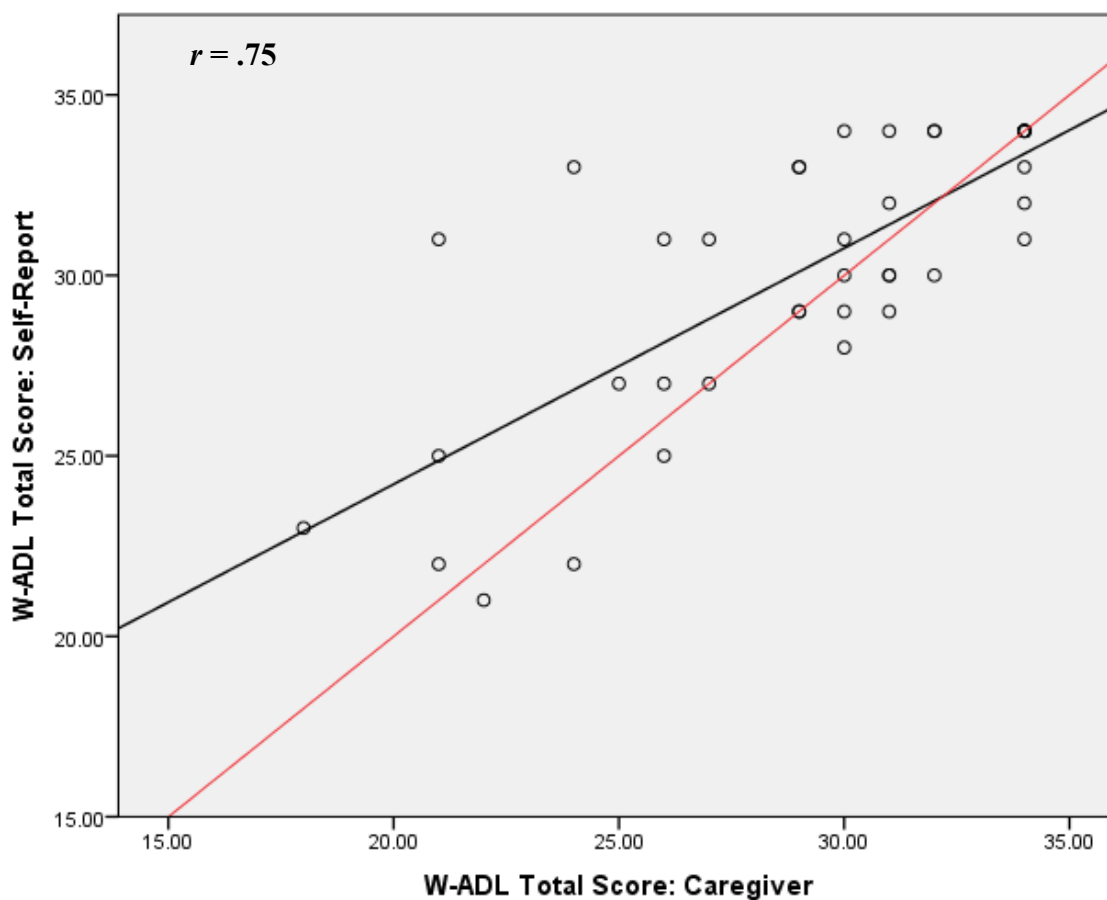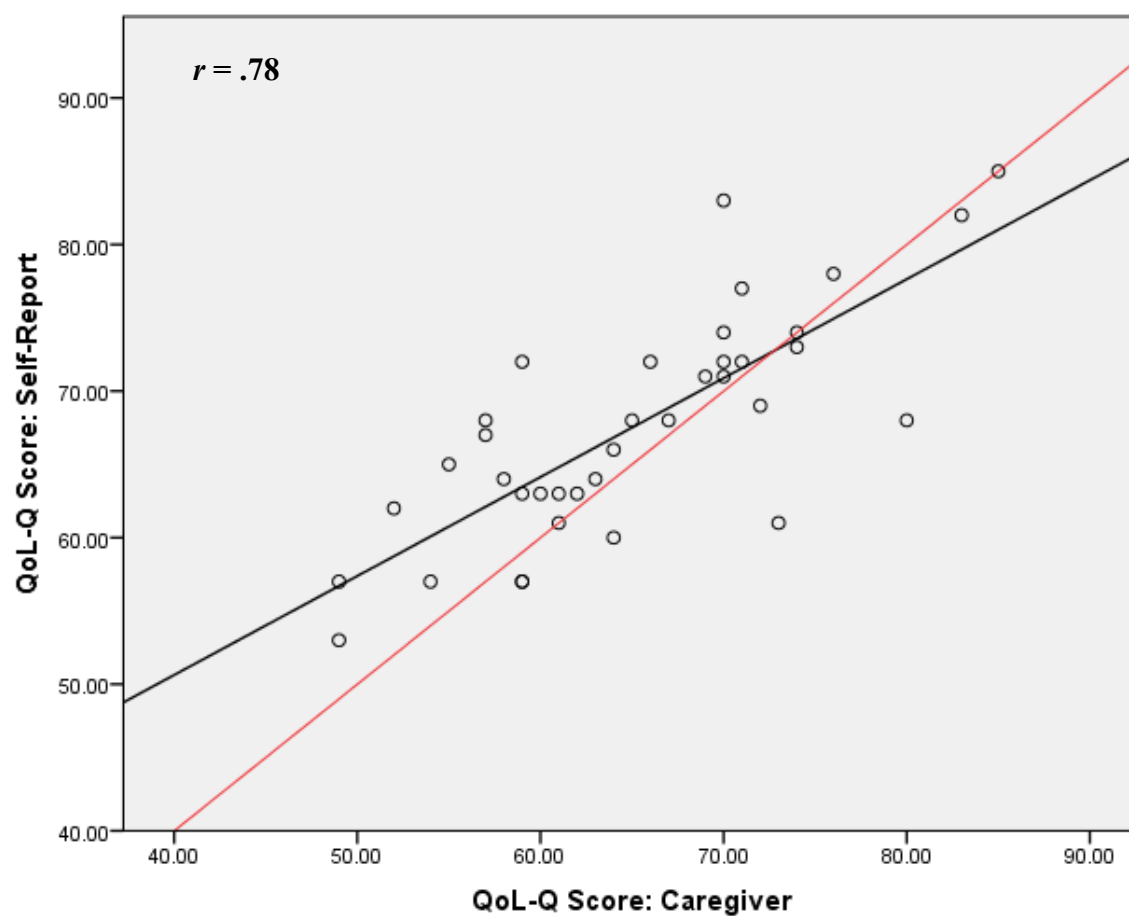
Figure 3. *Correlation between caregiver and self-report scores on the QoL-Q across three subdomains: Satisfaction, Belongingness, and Empowerment. Higher scores indicate higher quality of life. Reference line (red) represents r = 1.00.*

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TEACCH AUTISM IN ADULTHOOD SURVEY: CAREGIVER VERSION

THE UNIVERSITY of NORTH CAROLINA

TEACCH Autism Program
Services Across the Lifespan

TEACCH
Autism in Adulthood Survey

The following survey will ask about the educational background, work experience, social life and service usage of the adult with Autism Spectrum Disorder (ASD) including diagnoses of autism, Asperger syndrome, and pervasive developmental disorder who you know. <u>*Please answer every question*</u>. *Thank you!*

1. **Today's date (e.g., mm/dd/yyyy):** _____

2. **Your relationship to the adult with autism spectrum disorder (ASD):**
☐Mother ☐Father ☐Sibling ☐Spouse ☐Friend ☐Legal Guardian ☐Residential caregiver

☐Other _____

For the following questions, <u>please answer every question thinking about the adult with autism</u>.

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

4. **Adult's Gender:**
○ Male
○ Female

5. **Adult's Ethnicity:**
○ Hispanic or Latino
○ Not Hispanic or Latino

6. **Adult's Race** (*check all that apply*):
☐American Indian or Alaska Native
☐Asian
☐Black or African-American
☐Native Hawaiian or Other Pacific Islander
☐White
☐Unknown

7. **Has the adult ever been diagnosed with any of the following?** (*check all that apply*):
☐Autism Spectrum Disorder (autism, Asperger's, PDD-NOS)
☐Epilepsy and/or seizures
☐Intellectual Disability (formerly called Mental Retardation), please specify: ☐mild ☐moderate ☐severe/profound
☐Fragile X Syndrome
☐Attention Deficit Disorder (ADHD)
☐Anxiety (OCD, phobias, panic attacks, generalized)
☐Depression
☐Learning Disability (please specify): _____
☐Cerebral Palsy
☐Tourette's/Tic Disorder
☐Other Psychiatric Disorders (specify): _____

8. **Mother's highest level of education**
○ Some high school
○ High school degree
○ Vocation training
○ Some college but not degree
○ 4 year college
○ Graduate degree (e.g., J.D., M.A., Ph.D., M.D.)
○ Don't know

9. **Father's highest level of education**
○ Some high school
○ High school degree
○ Vocation training
○ Some college but not degree
○ 4 year college
○ Graduate degree (e.g., J.D., M.A., Ph.D., M.D.)
○ Don't know

10. **How many siblings does the adult with autism have?**
○ 0
○ 1
○ 2
○ 3
○ 4
○ 5 or more

11. **Do any of these siblings have an autism spectrum diagnosis (autism, Asperger's syndrome, PDD)?** ○Yes ○No

ID #

LANGUAGE ABILITIES

12. How clearly does he/she speak? Would you say he/she...
- ○ has no trouble speaking clearly
- ○ has a little trouble speaking clearly
- ○ has a lot of trouble speaking clearly
- ○ doesn't speak at all
- ○ don't know

13. How well does he/she communicate by any means (e.g., verbal communication, sign language, adaptive technology, etc.)? Would you say he/she...
- ○ has no trouble communicating
- ○ has a little trouble communicating
- ○ has a lot of trouble communicating
- ○ doesn't communicate at all
- ○ don't know

14. How well does he/she carry on a conversation? Would you say he/she...
- ○ has no trouble carrying on a conversation
- ○ has a little trouble carrying on a conversation
- ○ has a lot of trouble carrying on a conversation
- ○ doesn't carry on a conversation at all
- ○ don't know

15. How well does he/she understand what people say to him/her? Would you say he/she...
- ○ has no trouble understanding others
- ○ has a little trouble understanding others
- ○ has a lot of trouble understanding others
- ○ doesn't understand others at all
- ○ don't know

EDUCATION

16. When he/she left high school, did he/she...
- ○ receive a regular diploma
- ○ receive an occupational diploma
- ○ receive a certificate of completion
- ○ take a test and receive a GED without completing all classes
- ○ drop out or stop going
- ○ get suspended or expelled
- ○ did not attend high school
- ○ other _____

17. Since high school, has he/she.... *(check all that apply)*
- ☐ attended a 2 year or community college
- ☐ graduated with a diploma, certificate, or license from a 2 year or community college
- ☐ attended a vocational, business, or technical school after high school
- ☐ graduated with a diploma, certificate, or license from a vocational, business, or technical school
- ☐ attended a 4 year college
- ☐ graduated with a diploma, certificate, or license from a 4 year college
- ☐ attended a graduate program (e.g., master's or doctoral program)
- ☐ graduated with an advanced degree (e.g., master's or doctoral degree)

18. Is he/she currently enrolled in college?
- ○ No
- ○ Yes, Part-time (less than 10 class hours per week)
- ○ Yes, Full time (10 or more class hours per week)

LIVING SITUATION

19. Where does he/she currently live?
- ○ Independently (alone)
- ○ Independently (with spouse or roommate)
- ○ Supervised housing
- ○ With parent(s)
- ○ With another relative/guardian other than a spouse or parent
- ○ Community group home
- ○ Intermediate Care Facility for Individuals with Mental Retardation/Intellectual Disability (ICF-MR/IID home)
- ○ "Family Care" home
- ○ Correctional facility
- ○ Transient, homeless, on the street, in their car
- ○ Other, specify _____
- ○ Don't know

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

	Daily	2-3 Times/Week	1 Time/Week	1-2 Times/Month	< 1 Time/Month
Email/Text	○	○	○	○	○
Phone Call	○	○	○	○	○
In-Person Visit	○	○	○	○	○

21. Has he/she lived anywhere other than current residence since high school? ○Yes ○No

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

_____
_____
_____

23. Did he/she live in any of these places in the last 2 years? (Excluding camps and vacations) ○Yes ○No

If yes, which one(s)?

_____
_____
_____

24. What is his/her current marital status?
- ○ Single, never married
- ○ Domestic partner (same sex or opposite sex)
- ○ Engaged
- ○ Married
- ○ Divorced
- ○ Separated
- ○ Widowed
- ○ Don't know

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

○Yes ○No

26. Does the adult with autism have children? ○Yes ○No

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

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

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28. How much unpaid supervision (including from parents) does he/she receive in his/her living situation?
- ○ None
- ○ Several hours a week
- ○ Several hours a day
- ○ All day, but not overnight
- ○ 24 hours per day

29. How much paid supervision does he/she receive in his/her living situation?
- ○ None
- ○ Several hours a week
- ○ Several hours a day
- ○ All day, but not overnight
- ○ 24 hours per day

RECREATIONAL ACTIVITES AND SOCIAL LIFE

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

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

31. Do any of these activities include only people with special needs? ○Yes ○No

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

	Yes	No
Work, homework, or school assignments	○	○
Playing games	○	○
Internet	○	○
Recreation and hobbies	○	○

33. How often have friends called or texted him/her on the phone in the last 12 months?
- ○ Never
- ○ Less than once a month
- ○ Once a month
- ○ 2 – 3 times a month
- ○ Once a week
- ○ 2 – 3 times a week
- ○ Daily

34. How frequently has he/she used email, instant messaging, Skype, texting, Facebook messaging or take part in chat rooms in the last 12 months?
- ○ Never
- ○ Less than once a month
- ○ Once a month
- ○ 2 – 3 times a month
- ○ Once a week
- ○ 2 – 3 times a week
- ○ Daily

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

36. Does/Is he/she...

	Yes	No
Have a driver's license?	○	○
Drive independently on a regular basis?	○	○
Receive money that he/she can decide how to spend?	○	○
Have a Savings account?	○	○
Have a Checking account where he/she writes checks or uses a debit card?	○	○
Have a Credit card or charge account in his/her name?	○	○
Registered to vote?	○	○

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

	Yes	No
Arrested	○	○
On probation or parole	○	○
Arrested in the last 2 years	○	○
Stopped and questioned by the police in the last 2 years	○	○

SERVICES USED

38. Has the adult received any of the following services:

	Used since high school?		Used in the last 2 years?	
	Yes	No	Yes	No
Help in finding a job, training in job skills or vocational education, other than from an employer	○	○	○	○
Job coaching	○	○	○	○
Financial aid, like paying for college classes or training	○	○	○	○
Educational assistance or tutoring (e.g., college disability services)	○	○	○	○
Instruction or help with independent living skills (e.g., managing money, cooking), NOT including instruction from family members or friends	○	○	○	○
Psychological or mental health services or counseling	○	○	○	○
Social work services	○	○	○	○
Physical therapy	○	○	○	○
Assistive technology services or devices (e.g., special calculator, reading machine, or augmentative & alternative communication device (AAC))	○	○	○	○

38. Has the adult received any of the following services: *(CONTINUED)*

	Used since high school?		Used in the last 2 years?	
	Yes	No	Yes	No
Transportation assistance because of disability	○	○	○	○
Medical services for diagnosis or evaluation related to his/her disability	○	○	○	○
Speech or language therapy, or communication services	○	○	○	○
Audiology services for hearing problem	○	○	○	○
Respite care	○	○	○	○
Housing assistance or residential services or help with a supervised living arrangement (e.g., a group home)	○	○	○	○
Personal assistant/or in-the-home aid	○	○	○	○
Nursing care	○	○	○	○

39. Overall, how satisfied have you been with all services he/she has received?
- ○ Very dissatisfied
- ○ Dissatisfied
- ○ Somewhat Dissatisfied
- ○ Neutral
- ○ Somewhat Satisfied
- ○ Satisfied
- ○ Very Satisfied

40. Have any of the following been a problem in getting or dealing with services during the last 12 months?
(check all that apply)
- ☐ Cost of services
- ☐ Services not available or too far away
- ☐ Poor service quality
- ☐ Language problems (includes sign language or interpreter)
- ☐ Transportation
- ☐ Adult is not eligible for the service
- ☐ Not sure where to find services needed

41. Do you think he/she needs any services besides the one he/she receives now? ○Yes ○No

42. What services do you think he/she needs?

_____

_____

_____

43. Has anyone (i.e., you, family member, professional, or the adult with autism) ever tried to get the service(s) listed in question 42? ○Yes ○No

44. Is he/she on a waiting list for the services listed in question 42? ○Yes ○No

JOB AND WORK EXPERIENCE

45. At any time since high school did he/she work for pay other than work around the house? If no, please skip to **question 66.** ☐Yes ☐No, (please skip to question 66)

46. What is the longest time he/she has worked at a particular job since leaving high school?
- ○ A few days
- ○ A few months
- ○ 1 -2 years
- ○ 3 – 5 years
- ○ 5 or more years

47. Has he/she had a paid job in the last 2 years? ○Yes ○No

48. Does he/she have a paid job now? ○Yes ○No

49. Does he/she have more than one paid job right now? ○Yes ○No

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

50. For the current or most recent job where he/she works (the job with the most hours), about how much is/was he/she paid?
- ○ Below minimum wage
- ○ Minimum wage
- ○ Above minimum wage

51. Did he/she receive benefits from this job?
(check all that apply)
- ☐Health Insurance
- ☐Vacation/sick leave
- ☐Retirement account
- ☐None

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

_____

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

_____

_____

54. About how long was this job held?
- ○ Less than a week
- ○ Less than a year
- ○ 1 to 2 years
- ○ 3 to 4 years
- ○ 5 or more years

55. Across all current jobs (or most recent job if not currently employed), about how many hours a week does he/she usually work?
- ○ Less than 5 hours per week
- ○ 5 to 9 hours per week
- ○ 10 to 19 hours per week
- ○ 20 to 29 hours per week
- ○ 30 to 39 hours per week
- ○ 40 hours per week
- ○ More than 40 hours per week

56. If currently working less than 40 hours per week, would he/she rather work more hours?
- ○ Yes
- ○ No
- ○ Working 40 hours per week or more

57. How satisfied is the adult with his/her current job?
- ○ Very Dissatisfied
- ○ Dissatisfied
- ○ Somewhat Dissatisfied
- ○ Neutral
- ○ Somewhat Satisfied
- ○ Satisfied
- ○ Very Satisfied
- ○ N/A – not currently employed

58. Did he/she find their current or most recent job himself/herself or did he/she have help?
- ○ Found the job on their own
- ○ Found the job with help from an agency (e.g., a job coach or vocational rehab)
- ○ Found the job with help from a family member
- ○ Other _____
- ○ N/A – not employed

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

60. If the adult has received help finding the current (or most recent) job, how useful were these services?
- ○ Not useful at all (i.e., did not provide any additional advantage for getting a job)
- ○ Slightly useful (i.e., helped a little when getting a job)
- ○ Useful (i.e., helped a good deal with getting a job)
- ○ Very useful (i.e., made the difference between getting a job and not getting one)
- ○ N/A – no services used

61. Thinking about all current jobs (or most recent job if not currently employed), has he/she applied for any accommodations or supports to help maintain employment? ○Yes ○No

62. Thinking about all current jobs (or most recent job if not currently employed), has he/she received any accommodations or supports to help maintain employment? ○Yes ○No

63. If the adult has received accommodations or supports to help maintain the current or most recent employment, how useful were these services?
- ○ Not useful at all (i.e., did not provide any additional advantage keeping job)
- ○ Slightly useful (i.e., helped a little for keeping job)
- ○ Useful (i.e., helped a good deal for keeping job)
- ○ Very useful (i.e., made the difference between keeping or losing a job)

64. Do you think he/she needs any additional career counseling, job training or job assistance? ○Yes ○No

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

_____

_____

_____

INDEPENDENT LIVING SERVICES

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

	Yes	No
Using transportation	○	○
Home care skills, such as cooking and cleaning	○	○
Financial issues, such as managing his/her money	○	○
Self-care skills such as brushing his/her teeth	○	○
Relationship skills, such as getting along with others	○	○
Self advocacy skills (e.g., talking to others about autism diagnosis)	○	○

67. Is he/she getting any of these services now? ☐ Yes ☐No

68. How useful do you think this training or help with independent living skills has been?
- ○ Not useful at all
- ○ Somewhat useful
- ○ Useful
- ○ Very useful
- ○ Not applicable, did not receive independent skills training

69. Do you think he/she needs additional training or help with independent living skills now?
- ○Yes ○No

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

_____

_____

_____

71. Has anyone (i.e., you, family member, professional, or the adult with autism) ever tried to get the service(s) listed in question 70? ○Yes ○No

72. Is he/she on a waiting list for this/these services? ○Yes ○No

APPENDIX B

TEACCH AUTISM IN ADULTHOOD SURVEY: SELF-REPORT VERSION

THE UNIVERSITY of NORTH CAROLINA

TEACCH
Autism Program
Services Across the Lifespan

TEACCH
Autism in Adulthood Survey

The following survey will ask about your educational background, work experience, social life and service usage as an adult with Autism Spectrum Disorder (ASD) including diagnoses of autism, Asperger syndrome, and pervasive developmental disorder. Please answer every question. Thank you!

1. Today's date (e.g., mm/dd/yyyy): _____

2. Your relationship to the adult with autism spectrum disorder (ASD): (if you are an adult with ASD completing this survey about yourself, select "self")

☐Mother ☐Father ☐Sibling ☐Spouse ☐Friend ☐Legal Guardian ☐Residential caregiver

☐Self ☐Other _____

3. Date of Birth (mm/dd/yyyy): _____ /_____ / _____

4. Gender:
○ Male
○ Female

5. Ethnicity:
○ Hispanic or Latino
○ Not Hispanic or Latino

6. Race (*check all that apply*):
☐American Indian or Alaska Native
☐Asian
☐Black or African-American
☐Native Hawaiian or Other Pacific Islander
☐White
☐Unknown

7. Have you ever been diagnosed with any of the following? (*check all that apply*):
☐Autism Spectrum Disorder (autism, Asperger's, PDD-NOS)
☐Epilepsy and/or seizures
☐Intellectual Disability (formerly called Mental Retardation), please specify:
    ☐mild ☐moderate ☐severe/profound
☐Fragile X Syndrome
☐Attention Deficit Disorder (ADHD)
☐Anxiety (OCD, phobias, panic attacks, generalized)
☐Depression
☐Learning Disability (please specify): _____
☐Cerebral Palsy
☐Tourette's/Tic Disorder
☐Other Psychiatric Disorders (specify): _____

8. Mother's highest level of education
○ Some high school
○ High school degree
○ Vocation training
○ Some college but not degree
○ 4 year college
○ Graduate degree (e.g., J.D., M.A., Ph.D., M.D.)
○ Don't know

9. Father's highest level of education
○ Some high school
○ High school degree
○ Vocation training
○ Some college but not degree
○ 4 year college
○ Graduate degree (e.g., J.D., M.A., Ph.D., M.D.)
○ Don't know

10. How many siblings do you have?
○ 0
○ 1
○ 2
○ 3
○ 4
○ 5 or more

11. Do any of these siblings have an autism spectrum diagnosis (autism, Asperger's syndrome, PDD)? ○Yes ○No

ID #

LANGUAGE ABILITIES

12. How clearly do you speak? Would you say you...
- ○ have no trouble speaking clearly
- ○ have a little trouble speaking clearly
- ○ have a lot of trouble speaking clearly
- ○ don't speak at all
- ○ don't know

13. How well do you communicate by any means (e.g., verbal communication, sign language, adaptive technology, etc.)? Would you say you...
- ○ have no trouble communicating
- ○ have a little trouble communicating
- ○ have a lot of trouble communicating
- ○ don't communicate at all
- ○ don't know

14. How well can you carry on a conversation? Would you say you...
- ○ have no trouble carrying on a conversation
- ○ have a little trouble carrying on a conversation
- ○ have a lot of trouble carrying on a conversation
- ○ can't carry on a conversation at all
- ○ don't know

15. How well can you understand what people say to you? Would you say you...
- ○ have no trouble understanding others
- ○ have a little trouble understanding others
- ○ have a lot of trouble understanding others
- ○ can't understand others at all
- ○ don't know

EDUCATION

16. When you left high school, did you...
- ○ receive a regular diploma
- ○ receive an occupational diploma
- ○ receive a certificate of completion
- ○ take a test and receive a GED without completing all classes
- ○ drop out or stop going
- ○ get suspended or expelled
- ○ I did not attend high school
- ○ other _____

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

18. Are you currently enrolled in college?
- ○ No
- ○ Yes, Part-time (less than 10 class hours per week)
- ○ Yes, Full time (10 or more class hours per week)

LIVING SITUATION

19. Where do you currently live?
- ○ Independently (alone)
- ○ Independently (with spouse or roommate)
- ○ Supervised housing
- ○ With parent(s)
- ○ With another relative/guardian other than a spouse or parent
- ○ Community group home
- ○ Intermediate Care Facility for Individuals with Mental Retardation/Intellectual Disability (ICF-MR/IID home)
- ○ "Family Care" home
- ○ Correctional facility
- ○ Transient, homeless, on the street, in their car
- ○ Other, specify _____
- ○ Don't know

20. How often do you use these forms of communication?

	Daily	2-3 Times/Week	1 Time/Week	1-2 Times/Month	< 1 Time/Month
Email/Text	○	○	○	○	○
Phone Call	○	○	○	○	○
In-Person Visit	○	○	○	○	○

21. Have you lived anywhere other than your current residence since high school? ○Yes ○No

22. Where else have you lived since high school (excluding camps and vacations)?

_____
_____
_____

23. Did you live in any of these places in the last 2 years? (Excluding camps and vacations) ○Yes ○No
If yes, which one(s)?

_____
_____
_____

24. What is your current marital status?
- ○ Single, never married
- ○ Domestic partner (same sex or opposite sex)
- ○ Engaged
- ○ Married
- ○ Divorced
- ○ Separated
- ○ Widowed
- ○ Don't know

25. Does your spouse or partner have a paid job? (If you do not have a current spouse or partner please skip this question)

○Yes ○No

26. Do you have children? ○Yes ○No

27. What types of activities do you need help with? *(check all that apply)*

☐ Financial management
☐ Cooking/meal planning
☐ Medication/health related needs
☐ Hygiene and self-care
☐ Cleaning and home maintenance
☐ Social and recreational activities
☐ Community activities
☐ Other _____
☐ I do not need help with any activities

28. How much unpaid supervision do you receive in your living situation?	**29. How much paid supervision do you receive in your living situation?**
○ None ○ Several hours a week ○ Several hours a day ○ All day, but not overnight ○ 24 hours per day	○ None ○ Several hours a week ○ Several hours a day ○ All day, but not overnight ○ 24 hours per day

RECREATIONAL ACTIVITES AND SOCIAL LIFE

30. During the past 12 months, have you (check all that apply):

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

31. Do any of these activities include only people with special needs? ○ Yes ○ No

32. Do you use a computer or other electronic device (e.g., a tablet or smartphone) or know how to use a computer for...

	Yes	No
Work, homework, or school assignments	○	○
Playing games	○	○
Internet	○	○
Recreation and hobbies	○	○

33. How often have friends called or texted you on the phone in the last 12 months?

○ Never
○ Less than once a month
○ Once a month
○ 2 – 3 times a month
○ Once a week
○ 2 – 3 times a week
○ Daily

34. How frequently have you used email, instant messaging, Skype, texting, Facebook messaging or taken part in chat rooms in the last 12 months?

○ Never
○ Less than once a month
○ Once a month
○ 2 – 3 times a month
○ Once a week
○ 2 – 3 times a week
○ Daily

35. About how many hours a week do you usually watch TV or videos? Hours per week: _____

36. Do/Are you...

	Yes	No
Have a driver's license?	O	O
Drive independently on a regular basis?	O	O
Receive money that you can decide how to spend?	O	O
Have a Savings account?	O	O
Have a Checking account where you write checks or use a debit card?	O	O
Have a Credit card or charge account in your name?	O	O
Registered to vote?	O	O

37. Have you ever been...?

	Yes	No
Arrested	O	O
On probation or parole	O	O
Arrested in the last 2 years	O	O
Stopped and questioned by the police in the last 2 years	O	O

SERVICES USED

38. Have you received any of the following services?

	Used since high school?		Used in the last 2 years?	
	Yes	No	Yes	No
Help in finding a job, training in job skills or vocational education, other than from an employer	O	O	O	O
Job coaching	O	O	O	O
Financial aid, like paying for college classes or training	O	O	O	O
Educational assistance or tutoring (e.g., college disability services)	O	O	O	O
Instruction or help with independent living skills (e.g., managing money, cooking), NOT including instruction from family members or friends	O	O	O	O
Psychological or mental health services or counseling	O	O	O	O
Social work services	O	O	O	O
Physical therapy	O	O	O	O
Assistive technology services or devices (e.g., special calculator, reading machine, or augmentative & alternative communication	O	O	O	O

38. Have you received any of the following services? *(CONTINUED)*

	Used since high school?		Used in the last 2 years?	
	Yes	**No**	**Yes**	**No**
Transportation assistance because of disability	○	○	○	○
Medical services for diagnosis or evaluation related to your disability	○	○	○	○
Speech or language therapy, or communication services	○	○	○	○
Audiology services for hearing problem	○	○	○	○
Respite care	○	○	○	○
Housing assistance or residential services or help with a supervised living arrangement (e.g., a group home)	○	○	○	○
Personal assistant/or in-the-home aid	○	○	○	○
Nursing care	○	○	○	○

39. Overall, how satisfied have you been with all services you have received?
- ○ Very dissatisfied
- ○ Dissatisfied
- ○ Somewhat Dissatisfied
- ○ Neutral
- ○ Somewhat Satisfied
- ○ Satisfied
- ○ Very Satisfied

40. Have any of the following been a problem in getting or dealing with services during the last 12 months?
(check all that apply)
- ☐ Cost of services
- ☐ Services not available or too far away
- ☐ Poor service quality
- ☐ Language problems (includes sign language or interpreter)
- ☐ Transportation
- ☐ Not eligible for the service
- ☐ Not sure where to find services needed

41. Do you think you need any services besides the ones you receive now? ○ Yes ○ No

42. What services do you think you need?

_____

_____

_____

43. Has anyone (i.e., you, family member, or professional) ever tried to get the service(s) listed in question 42?
○ Yes ○ No

44. Are you on a waiting list for the services listed in question 42? ○ Yes ○ No

JOB AND WORK EXPERIENCE

45. At any time since high school have you worked for pay other than work around the house? If no, please skip to **question 66.** ○Yes ○No, (please skip to question 66)

46. What is the longest time you have worked at a particular job since leaving high school?
- ○ A few days
- ○ A few months
- ○ 1 -2 years
- ○ 3 – 5 years
- ○ 5 or more years

47. Have you had a paid job in the last 2 years? ○Yes ○No

48. Do you have a paid job now? ○Yes ○No

49. Do you have more than one paid job right now? ○Yes ○No

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

50. For the current or most recent job where you work (the job with the most hours), about how much are/were you paid?
- ○ Below minimum wage
- ○ Minimum wage
- ○ Above minimum wage

51. Did you receive benefits from this job? *(check all that apply)*
- ☐Health Insurance
- ☐Vacation/sick leave
- ☐Retirement account
- ☐None

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

_____

53. Briefly describe your main duties at this job.

_____

_____

54. About how long was this job held?
- ○ Less than a week
- ○ Less than a year
- ○ 1 to 2 years
- ○ 3 to 4 years
- ○ 5 or more years

55. Across all current jobs (or most recent job if not currently employed), about how many hours a week do you usually work?
- ○ Less than 5 hours per week
- ○ 5 to 9 hours per week
- ○ 10 to 19 hours per week
- ○ 20 to 29 hours per week
- ○ 30 to 39 hours per week
- ○ 40 hours per week
- ○ More than 40 hours per week

56. If currently working less than 40 hours per week, would you rather work more hours?
- ○ Yes
- ○ No
- ○ Working 40 hours per week or more

57. How satisfied are you with your current job?
- ○ Very Dissatisfied
- ○ Dissatisfied
- ○ Somewhat Dissatisfied
- ○ Neutral
- ○ Somewhat Satisfied
- ○ Satisfied
- ○ Very Satisfied
- ○ N/A – not currently employed

58. Did you find your current or most recent job yourself or did you have help?
- ○ Found the job on my own
- ○ Found the job with help from an agency (e.g., a job coach or vocational rehab)
- ○ Found the job with help from a family member
- ○ Other _____
- ○ N/A – not employed

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

60. If you have received help <u>finding</u> the current (or most recent) job, how useful were these services?
- ○ Not useful at all (i.e., did not provide any additional advantage for getting a job)
- ○ Slightly useful (i.e., helped a little when getting a job)
- ○ Useful (i.e., helped a good deal with getting a job)
- ○ Very useful (i.e., made the difference between getting a job and not getting one)
- ○ N/A – no services used

61. Thinking about <u>all</u> current jobs (or most recent job if not currently employed), have you <u>applied</u> for any accommodations or supports to help maintain employment? ○Yes ○No

62. Thinking about <u>all</u> current jobs (or most recent job if not currently employed), have you <u>received</u> any accommodations or supports to help maintain employment? ○Yes ○No

63. If you have received accommodations or supports to help maintain the current or most recent employment, how useful were these services?
- ○ Not useful at all (i.e., did not provide any additional advantage keeping job)
- ○ Slightly useful (i.e., helped a little for keeping job)
- ○ Useful (i.e., helped a good deal for keeping job)
- ○ Very useful (i.e., made the difference between keeping or losing a job)

64. Do you think you need any additional career counseling, job training or job assistance? ○Yes ○No

65. What type of additional job supports do you think you need? (Please indicate below)

_____

_____

_____

INDEPENDENT LIVING SERVICES

66. Since high school, have you had training in or help with any of the following, not including training from family members or friends?

	Yes	No
Using transportation	○	○
Home care skills, such as cooking and cleaning	○	○
Financial issues, such as managing your money	○	○
Self-care skills such as brushing your teeth	○	○
Relationship skills, such as getting along with others	○	○
Self advocacy skills (e.g., talking to others about autism diagnosis)	○	○

67. Are you getting any of these services now? ○ Yes ○ No

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

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

69. Do you think you need additional training or help with independent living skills now?

○ Yes ○ No

70. What kinds of training or help with independent living skills do you think you need? *(Please describe below)*

_____

_____

_____

71. Has anyone (i.e., you, family member, or professional) ever tried to get the service(s) listed in question 70?
○ Yes ○ No

72. Are you on a waiting list for this/these services? ○ Yes ○ No

APPENDIX C

SOCIAL RESPONSIVENESS SCALE, 2ND EDITION: ADULT FORM, CAREGIVER VERSION

John N. Constantino, MD

Assessment ID _____

wps

SRS-2 AutoScore™ Form   **Adult**   ○ MALE   ○ FEMALE

INSTRUCTIONS

For each question, please darken the circle that best describes this individual's behavior over the past 6 months.

Rated individual's name _____ Age in years _____

Rater's name _____ Date of rating _____

Relationship to rated individual ☐ Mother ☐ Father ☐ Other relative
☐ Spouse ☐ Other

PLEASE PRESS HARD WHEN MARKING YOUR RESPONSES.

1 = NOT TRUE   2 = SOMETIMES TRUE   3 = OFTEN TRUE   4 = ALMOST ALWAYS TRUE

1. Seems much more uncomfortable in social situations than when alone. ① ② ③ ④
2. Expressions on his or her face don't match what he or she is saying. ① ② ③ ④
3. Seems self-confident when interacting with others. ① ② ③ ④
4. When under stress, he or she shows rigid or inflexible patterns of behavior that seem odd. ① ② ③ ④
5. Doesn't recognize when others are trying to take advantage of him or her. ① ② ③ ④
6. Would rather be alone than with others. ① ② ③ ④
7. Is aware of what others are thinking or feeling. ① ② ③ ④
8. Behaves in ways that seem strange or bizarre. ① ② ③ ④
9. Seems too dependent on others for help with meeting basic needs. ① ② ③ ④
10. Takes things too literally and doesn't get the real meaning of a conversation. ① ② ③ ④
11. Has good self-confidence. ① ② ③ ④
12. Is able to communicate his or her feelings to others. ① ② ③ ④
13. Is awkward in turn-taking interactions with others (for example, doesn't seem to understand the give-and-take of conversations). ① ② ③ ④
14. Is not well coordinated. ① ② ③ ④
15. Recognizes and appropriately responds to changes in other people's tone of voice and facial expressions. ① ② ③ ④
16. Avoids eye contact or has unusual eye contact. ① ② ③ ④
17. Recognizes when something is unfair. ① ② ③ ④
18. Has difficulty making friends, even when trying his or her best. ① ② ③ ④
19. Gets frustrated trying to get ideas across in conversations. ① ② ③ ④
20. Shows unusual sensory interests (for example, smelling his or her fingers frequently) or strange, repetitive ways of handling or manipulating small items within reach. ① ② ③ ④
21. Is able to imitate others' actions and demeanor when it is socially appropriate to do so. ① ② ③ ④
22. Interacts appropriately with other adults. ① ② ③ ④
23. Does not join group activities or social events unless forced to do so. ① ② ③ ④
24. Has more difficulty than others with changes in his or her routine. ① ② ③ ④
25. Doesn't seem to mind being out of step with or "not on the same wavelength" as others. ① ② ③ ④
26. Offers comfort to others when they are sad. ① ② ③ ④
27. Avoids starting social interactions with other adults. ① ② ③ ④
28. Thinks or talks about the same thing over and over. ① ② ③ ④
29. Is regarded by others as odd or weird. ① ② ③ ④
30. Becomes upset in a situation with lots of things going on. ① ② ③ ④
31. Can't get his or her mind off something once he or she starts thinking about it. ① ② ③ ④
32. Has good personal hygiene. ① ② ③ ④

Continue on back page

1 = NOT TRUE   2 = SOMETIMES TRUE   3 = OFTEN TRUE   4 = ALMOST ALWAYS TRUE

33. Is socially awkward, even when trying to be polite. .... ① ② ③ ④
34. Avoids people who want to be emotionally close to him or her. .... ① ② ③ ④
35. Has trouble keeping up with the flow of a normal conversation. .... ① ② ③ ④
36. Has difficulty relating to family members. .... ① ② ③ ④
37. Has difficulty relating to other adults. .... ① ② ③ ④
38. Responds appropriately to mood changes in others (for example, when a friend's mood changes from happy to sad). .... ① ② ③ ④
39. Has an unusually narrow range of interests. .... ① ② ③ ④
40. Is imaginative without losing touch with reality. .... ① ② ③ ④
41. Wanders aimlessly from one activity to another. .... ① ② ③ ④
42. Seems overly sensitive to sounds, textures, or smells. .... ① ② ③ ④
43. Enjoys and is competent with small talk (casual conversation with others). .... ① ② ③ ④
44. Doesn't understand how events relate to one another (cause and effect) the way other adults do. .... ① ② ③ ④
45. Generally gets interested in what others nearby are paying attention to. .... ① ② ③ ④
46. Has overly serious facial expressions. .... ① ② ③ ④
47. Laughs at inappropriate times. .... ① ② ③ ④
48. Has a sense of humor, understands jokes. .... ① ② ③ ④
49. Does extremely well at a few intellectual or computational tasks, but does not do as well at most other tasks. .... ① ② ③ ④
50. Has repetitive, odd behaviors. .... ① ② ③ ④
51. Has difficulty answering questions directly and ends up talking around the subject. ...... ① ② ③ ④
52. Knows when he or she is talking too loud or making too much noise. .... ① ② ③ ④
53. Talks to people with an unusual tone of voice (for example, talks like a robot or like he or she is giving a lecture). .... ① ② ③ ④
54. Seems to react to people as if they are objects. .... ① ② ③ ④
55. Knows when he or she is too close to someone or is invading someone's space. .... ① ② ③ ④
56. Walks in between two people who are talking. .... ① ② ③ ④
57. Isolative; tends not to leave his or her home. .... ① ② ③ ④
58. Concentrates too much on parts of things rather than seeing the whole picture. .... ① ② ③ ④
59. Is overly suspicious. .... ① ② ③ ④
60. Is emotionally distant, doesn't show his or her feelings. .... ① ② ③ ④
61. Is inflexible, has a hard time changing his or her mind. .... ① ② ③ ④
62. Gives unusual or illogical reasons for doing things. .... ① ② ③ ④
63. Touches or greets others in an unusual way. .... ① ② ③ ④
64. Is too tense in social settings. .... ① ② ③ ④
65. Stares or gazes off into space. .... ① ② ③ ④

APPENDIX D

SOCIAL RESPONSIVENESS SCALE – 2ND EDITION: ADULT FORM, SELF-REPORT VERSION

SRS-2 AutoScore™ Form **Adult** ○ MALE ○ FEMALE

John N. Constantino, MD

Assessment ID _____

Self-Report

INSTRUCTIONS

For each question, please darken the circle that best describes your behavior over the past 6 months.

Rated individual's name _____

Age in years _____ Date of rating _____

PLEASE PRESS HARD WHEN MARKING YOUR RESPONSES.

1 = NOT TRUE   2 = SOMETIMES TRUE   3 = OFTEN TRUE   4 = ALMOST ALWAYS TRUE

1. I am much more uncomfortable in social situations than when I am by myself. ① ② ③ ④
2. My facial expressions send the wrong message to others about how I actually feel. ① ② ③ ④
3. I feel self-confident when interacting with others. ① ② ③ ④
4. When under stress, I engage in rigid or inflexible patterns of behavior that seem odd to people. ① ② ③ ④
5. I do not recognize when others are trying to take advantage of me. ① ② ③ ④
6. I would rather be alone than with others. ① ② ③ ④
7. I am usually aware of how others are feeling. ① ② ③ ④
8. I behave in ways that seem strange or bizarre to others. ① ② ③ ④
9. I am overly dependent on others for help with meeting my everyday needs. ① ② ③ ④
10. I take things too literally, and because of that, I misinterpret the intended meaning of parts of a conversation. ① ② ③ ④
11. I have good self-confidence. ① ② ③ ④
12. I am able to communicate my feelings to others. ① ② ③ ④
13. I am awkward in turn-taking interactions with others (for example, I have a hard time keeping up with the give-and-take of a conversation). ① ② ③ ④
14. I am not well coordinated. ① ② ③ ④
15. When people change their tone or facial expression, I usually pick up on that and understand what it means. ① ② ③ ④
16. I avoid eye contact or am told that I have unusual eye contact. ① ② ③ ④
17. I recognize when something is unfair. ① ② ③ ④
18. I have difficulty making friends, even when trying my best. ① ② ③ ④
19. I get frustrated trying to get ideas across in conversations. ① ② ③ ④
20. I have sensory interests that others find unusual (for example, smelling or looking at things in a special way). ① ② ③ ④
21. I am able to imitate others' actions and expressions when it is socially appropriate to do so. ① ② ③ ④
22. I interact appropriately with other adults. ① ② ③ ④
23. I do not join group activities or social events unless prompted or strongly urged to do so. ① ② ③ ④
24. I have more difficulty than others with changes in my routine. ① ② ③ ④
25. I do not mind being out of step with or "not on the same wavelength" as others. ① ② ③ ④
26. I offer comfort to others when they are sad. ① ② ③ ④
27. I avoid starting social interactions with other adults. ① ② ③ ④
28. I think or talk about the same thing over and over. ① ② ③ ④
29. I am regarded by others as odd or weird. ① ② ③ ④
30. I become upset in situations with lots of things going on. ① ② ③ ④
31. I can't get my mind off something once I start thinking about it. ① ② ③ ④
32. I have good personal hygiene. ① ② ③ ④

Continue on back page

1 = NOT TRUE   2 = SOMETIMES TRUE   3 = OFTEN TRUE   4 = ALMOST ALWAYS TRUE

33. My behavior is socially awkward, even when I am trying to be polite. .... ① ② ③ ④

34. I avoid people who want to be emotionally close to me. .... ① ② ③ ④

35. I have trouble keeping up with the flow of a normal conversation. .... ① ② ③ ④

36. I have difficulty relating to family members. .... ① ② ③ ④

37. I have difficulty relating to adults outside of my family. .... ① ② ③ ④

38. I respond appropriately to mood changes in others (for example, when a friend's mood
changes from happy to sad). .... ① ② ③ ④

39. People think I am interested in too few topics, or that I get too carried away with those topics. .... ① ② ③ ④

40. I am imaginative. .... ① ② ③ ④

41. I sometimes seem to wander aimlessly from one activity to another. .... ① ② ③ ④

42. I am overly sensitive to certain sounds, textures, or smells. .... ① ② ③ ④

43. I enjoy small talk (casual conversation with others). .... ① ② ③ ④

44. I have more trouble than most people with understanding chains of causation (in other words,
how events are related to one another). .... ① ② ③ ④

45. When others around me are paying attention to something, I get interested in what they are
attending to. .... ① ② ③ ④

46. Others feel that I have overly serious facial expressions. .... ① ② ③ ④

47. I laugh at inappropriate times. .... ① ② ③ ④

48. I have a good sense of humor and can understand jokes. .... ① ② ③ ④

49. I do extremely well at certain kinds of intellectual tasks, but do not do as well at
most other tasks. .... ① ② ③ ④

50. I have repetitive behaviors that others consider odd. .... ① ② ③ ④

51. I have difficulty answering questions directly and end up talking around the subject. .... ① ② ③ ④

52. I get overly loud without realizing it. .... ① ② ③ ④

53. I tend to talk in a monotone voice (in other words, less inflection of voice than most people
demonstrate). .... ① ② ③ ④

54. I tend to think about people in the same way that I do objects. .... ① ② ③ ④

55. I get too close to others or invade their personal space without realizing it. .... ① ② ③ ④

56. I sometimes make the mistake of walking between two people who are trying to talk to one another. .... ① ② ③ ④

57. I tend to isolate myself. .... ① ② ③ ④

58. I concentrate too much on parts of things rather than seeing the whole picture. .... ① ② ③ ④

59. I am more suspicious than most people. .... ① ② ③ ④

60. Other people think I am emotionally distant and do not show my feelings. .... ① ② ③ ④

61. I tend to be inflexible. .... ① ② ③ ④

62. When I tell someone my reason for doing something, it strikes the person as unusual or illogical. .... ① ② ③ ④

63. My way of greeting another person is unusual. .... ① ② ③ ④

64. I am much more tense in social settings than when I am by myself. .... ① ② ③ ④

65. I find myself staring or gazing off into space. .... ① ② ③ ④

APPENDIX E

WAISMAN ACTIVITIES OF DAILY LIVING SCALE

Next we would like to know about the person's current level of independence in performing activities of daily living. For each activity please tell me the number which best describes their ability to do the task. For example, independent would mean that the person you know is able to do the task without any help or assistance.

Please Rate Person's Level of Independence in...

	0=does not do at all	1=does with help	2= independent/does on own
1. Making his/her own bed	○	○	○
2. Doing household tasks, including picking up around the house, putting things away, light house cleaning, etc.	○	○	○
3. Doing errands, including shopping in stores	○	○	○
4. Doing home repairs, including simple repairs around the house, non-technical in nature; for example, changing light bulbs or repairing a loose screw	○	○	○
5. Doing laundry, washing and drying	○	○	○
6. Washing/bathing	○	○	○
7. Grooming, brushing teeth, combing and/or brushing hair.	○	○	○
8. Dressing and undressing	○	○	○
9. Toileting	○	○	○
10. Preparing simple foods requiring no mixing or cooking, including sandwiches, cold cereal, etc.	○	○	○
11. Mixing and cooking simple foods, fry eggs, make pancakes, heat food in microwave, etc.	○	○	○
12. Preparing complete meal	○	○	○
13. Setting and clearing table	○	○	○
14. Drinking from a cup	○	○	○
15. Eating from a plate	○	○	○
16. Washing dishes (including using a dishwasher)	○	○	○
17. Banking and managing daily finances, including keeping track of cash, checking account, paying bills, etc. (Note: if he/she can do a portion but not all circle '1' with help)	○	○	○

ID #

APPENDIX F

AUQLITY OF LIFE QUESTIONNAIRE

INSTRUCTIONS

The QOL.Q may be administered to persons with mental retardation who have adequate receptive and expressive language. The examiner needs to be sensitive to the possibility that the respondent may not understand some of the items or the meaning of some of the words. If this happens, it is okay to paraphrase the item to improve understanding. If this happens frequently, or if the person is known not to have adequate receptive or expressive skills, it is acceptable to have two persons who know the individual well complete the Questionnaire.

Instructions for Respondents

Read the following instructions to the respondent:

I want you to think about where you live, work, and have fun, and the family, friends, and staff that you know. Together, let's answer some questions that express how you feel about these things. If you like, you can check the choices given for each item; if you like, I can check them for you after reading and discussing each of the three alternatives for each item. Please try to answer each of the items and we will take as much time as you need. There are no right or wrong answers. We want only to know how you feel about where you live, work, and have fun and the family, friends and staff that you know. Do you have any questions?

If the respondent consents, the examiner proceeds to administer the 40 items. When reading the items, pay close attention to the exact wording. You may paraphrase items and repeat them as often as necessary to ensure the respondent's understanding of the item content.

Instructions for Raters

Raters should know the person well and should complete the Questionnaire "as if they were the person" (that is, rate how the person is perceiving things).

Raters should complete the Questionnaire independently and without any discussion of the items or the individual.

Special Instructions for Employment Items

If the person is unemployed, do not ask Questions 13-20 and assign to each question the score "1".

Sheltered workshop programs should be considered as jobs when responding to the Questionnaire.

QUESTIONS	ANSWER ALTERNATIVES			RECORD SCORE HERE
	3 POINTS	2 POINTS	1 POINT	

SATISFACTION

QUESTIONS	3 POINTS	2 POINTS	1 POINT	RECORD SCORE HERE
1. Overall, would you say that life:	Brings out the best in you?	Treats you like everybody else?	Doesn't give you a chance?	_____
2. How much fun and enjoyment do you get out of life?	Lots	Some	Not much	_____
3. Compared to others, are you better off, about the same, or less well off?	Better	About the same	Worse	_____
4. Are most of the things that happen to you:	Rewarding	Acceptable	Disappointing	_____
5. How satisfied are you with your current home or living arrangement?	Very satisfied	Somewhat satisfied	Unsatisfied or very unsatisfied	_____
6. Do you have more or fewer problems than other people?	Fewer problems	The same number of problems as others	More problems than others	_____
7. How many times per month do you feel lonely?	Seldom, never more than once or twice	Occasionally, at least 5 or 6 times a month	Frequently, at least once or twice a week	_____
8. Do you ever feel out of place in social situations?	Seldom or never	Sometimes	Usually or always	_____
9. How successful do you think you are, compared to others?	Probably more successful than the average person	About as successful as the average person	Less successful than the average person	_____
10. What about your family members? Do they make you feel:	An important part of the family	Sometimes a part of the family	Like an outsider	_____

TOTAL SCALE SCORE — SATISFACTION

76

QUESTIONS	ANSWER ALTERNATIVES			RECORD SCORE HERE
	3 POINTS	2 POINTS	1 POINT	

COMPETENCE/PRODUCTIVITY

QUESTIONS	3 POINTS	2 POINTS	1 POINT	RECORD SCORE HERE
11. How well did your educational or training program prepare you for what you are doing now?	Very well	Somewhat	Not at all well	_____
12. Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?	Yes, definitely	Probably	I'm not sure, or definitely not	_____
Note: If a person is unemployed, do not ask Questions 13-20. Score items #13-20 "1".				
13. How good do you feel you are at your job?	Very good, and others tell me I am good	I'm good, but no one tells me	I'm having trouble on my job	_____
14. How do people treat you on your job?	The same as all other employees	Somewhat differently than other employees	Very differently	_____
15. How satisfied are you with the skills and experience you have gained or are gaining from your job?	Very satisfied	Somewhat satisfied	Not satisfied	_____
16. Are you learning skills that will help you get a different or better job? What are these skills?	Yes, definitely (one or more skills mentioned)	Am not sure, maybe (vague, general skills mentioned)	No, job provides no opportunity for learning new skills	_____
17. Do you feel you receive fair pay for your work?	Yes, definitely	Sometimes	No, I do not feel I am paid enough	_____
18. Does your job provide you with enough money to buy the things you want?	Yes, I can generally buy those reasonable things I want	I have to wait to buy some items or not buy them at all	No, I definitely do not earn enough to buy what I need	_____
19. How satisfied are you with the benefits you receive at the workplace?	Very satisfied	Somewhat satisfied	Not satisfied	_____
20. How closely supervised are you on your job?	Supervisor is present only when I need him or her	Supervisor is frequently present whether or not I need him or her	Supervisor is constantly on the job and looking over my work	_____

TOTAL SCALE SCORE — COMPETENCE/PRODUCTIVITY

QUESTIONS	ANSWER ALTERNATIVES			RECORD SCORE HERE
	3 POINTS	2 POINTS	1 POINT	

EMPOWERMENT/INDEPENDENCE

QUESTIONS	3 POINTS	2 POINTS	1 POINT	RECORD SCORE HERE
21. How did you decide to do the job or other daily activities you do now?	I chose it because of pay, benefits, or interests	Only thing available or that I could find	Someone else decided for me	_____
22. Who decides how you spend your money?	I do	I do, with assistance from others	Someone else decides	_____
23. How do you use health care facilities (doctor, dentist, etc.)?	Almost always on my own	Usually accompanied by someone, or someone else has made the appointment	Never on my own	_____
24. How much control do you have over things you do every day, like going to bed, eating, and what you do for fun?	Complete	Some	Little	_____
25. When can friends visit your home?	As often as I like or fairly often	Any day, as long as someone else approves or is there	Only on certain days	_____
26. Do you have a key to your home?	Yes, I have a key and use it as I wish	Yes, I have a key but it only unlocks certain areas	No	_____
27. May you have a pet if you want?	Yes, definitely	Probably yes, but would need to ask	No	_____
28. Do you have a guardian or conservator?	No, I am responsible for myself	Yes, limited guardian or conservator	Yes, I have a full guardian	_____
29. Are there people living with you who sometimes hurt you, pester you, scare you, or make you angry?	No	Yes, and those problems occur once a month or once a week	Yes, and those problems occur every day or more than once a day	_____
30. Overall, would you say that your life is:	Free	Somewhat planned for you	Cannot usually do what you want	_____

TOTAL SCALE SCORE — EMPOWERMENT/INDEPENDENCE

QUESTIONS	ANSWER ALTERNATIVES			RECORD SCORE HERE
	3 POINTS	2 POINTS	1 POINT	

SOCIAL BELONGING/ COMMUNITY INTEGRATION

QUESTIONS	3 POINTS	2 POINTS	1 POINT	RECORD SCORE HERE
31. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?	2-3	1 only	None	_____
32. How satisfied are you with the clubs or organizations (including church or other religious activities) to which you belong?	Very satisfied	Somewhat satisfied	Unsatisfied or very unsatisfied	_____
33. Do you worry about what people expect of you?	Sometimes, but not all the time	Seldom	Never or all the time	_____
34. How many times per week do you talk to (or associate with) your neighbors, either in the yard or in their home?	3-4 times per week	1-2 times per week	Never or all the time	_____
35. Do you have friends over to visit your home?	Fairly often	Sometimes	Rarely or never	_____
36. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?	3-4 per month	1-2 per month	Less than 1 per month	_____
37. Do you participate actively in those recreational activities?	Usually, most of the time	Frequently, about half the time	Seldom or never	_____
38. What about opportunities for dating or marriage?	I am married, or have the opportunity to date anyone I choose	I have limited opportunities to date or marry	I have no opportunity to date or marry	_____
39. How do your neighbors treat you?	Very good or good (invite you to activities, coffee, etc.)	Fair (say hello, visit, etc.)	Bad or very bad (avoid you, bother you, etc.)	_____
40. Overall, would you say that your life is:	Very worthwhile	Okay	Useless	_____

TOTAL SCALE SCORE — SOCIAL BELONGING/COMMUNITY INTEGRATION

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