USABILITY AND RELIABILITY OF REMOTE AUTISM DIAGNOSTIC OBSERVATION SCHEDULE (ADOS) MODULE 4 ADMINISTRATION

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University of Pittsburgh, 2012

Autism Spectrum Disorder (ASD) is characterized by impairments in social interaction, impairments in communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities. The Autism Diagnostic Observation Schedule (ADOS) Module 4 is a semi-structured diagnostic assessment tool designed for verbally fluent adolescents and adults with possible ASD. Due to a lack of available clinical expertise, it can be difficult for adults to receive an accurate ASD diagnostic assessment, especially those residing in rural areas. An ADOS teleassessment system was developed using the Versatile and Integrated System for Telerehabilitation (VISYTER). VISYTER consists of computer stations at the client site and clinician site, and a web portal server for managing and coordinating all elements of the assessment process. Clinician usability and fidelity to standard, face-to-face administration, was assessed. After improvements to the system were made, a study was conducted to determine the reliability of the ADOS module 4 administrations delivered remotely. Twenty-three adults with an ASD diagnosis participated in a within-subject crossover design study in which both a remote and face-to-face ADOS were administered. Weighted kappa was calculated for all 31 ADOS items. There was substantial agreement on 11 items and almost perfect or perfect agreement on 10 items. Intraclass correlations (ICCs) were calculated for algorithm subtotals. ICCs were greater than .75 for three out of four subtotals. There was substantial agreement on ADOS

classification (i.e., diagnosis) between assessments delivered face-to-face versus assessments delivered remotely, P_o=83%; κ =.772, ICC=.92. Non-agreement may have been due to outside factors or practice effect despite a washout period. Finally, usability and satisfaction of the remote assessment system was evaluated from the participants' perspectives. Participant satisfaction with the remote ADOS delivery system was high. The results of these studies demonstrate that an ASD assessment designed to be delivered face-to-face can be reliably administered remotely using an integrated web-based system.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

PREFACE

This research was supported by grants from the National Institute on Disability and Rehabilitation Research (NIDRR) grant number H133E090002 Rehabilitation Engineering Research Center (RERC) on Telerehabilitation (TR); from the Pennsylvania Department of Public Welfare (DPW) and Bureau of Autism Services (BAS) Western Pennsylvania Autism Service, Education, Research, and Training (ASERT) Regional Center; and by the National Institutes of Health through grant numbers UL1 RR024153 and UL1TR000005.

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1.0 CHAPTER 1: INTRODUCTION

Autism spectrum disorders (ASD) includes pervasive developmental disorders (PDDs) that are characterized by impairments in social interaction, impairments in communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2000, p. 75). For 2008, the Autism and Developmental Disabilities Monitoring (ADDM) Network estimated the prevalence of ASD at 11.3 per 1,000 (one in 88) children aged 8 years. This is an increase in prevalence from previous reports (Centers for Disease Control and Prevention, 2012). The United States Centers for Disease Control and Prevention (CDC) considered ASD an urgent public health concern (CDC, 2009).

Symptoms of ASD emerge in infancy or childhood, and while intensive therapy may decrease severity, there is no cure. Autism spectrum disorder is not a terminal disorder; children with ASD grow up to be adults with ASD who face challenges in many areas of daily functioning. Chapter 2 will provide an overview of the impairments often experienced by adults with autism spectrum disorders.

In addition, chapter 2 will cover topics relevant to the diagnosis of ASD in adults. Because research and clinical interest in ASD has only become prevalent in recent years, it is possible that adults with ASD are currently undiagnosed (especially high-functioning adults) or misdiagnosed (with emotional or psychiatric disorders) (Akande, Xenitidis, Mullender, Robertson, & Gorman, 2004; Dossetor, 2007; Matson, 2007; Palucka, Bradley, & Lunsky, 2008).

Identification and diagnosis of ASD in adults is important for a variety of reasons, including implications for treatment, public policy (planning for needs and development of services), granting access to resources to qualified recipients, and individual attitudes towards and adjustment to disability.

An ASD diagnosis is made on the basis of behavioral observations combined with evidence from a detailed developmental history (Barbaro & Dissanayke, 2009). Identifying ASD in adults can be challenging if a diagnosis has not been made in childhood because information regarding developmental history is often unavailable. Caregiver reports may be flawed due to incorrect memory recall, recall bias, and distortion of events. Furthermore, responses can be influenced by a variety of reliability-reducing factors, including alertness in recognizing behaviors, socioeconomic status, personality, intelligence, and mental health (Barbaro & Dissanayke, 2009).

While there are many ASD assessment and diagnostic tools, few are designed for use with adults. The Autism Diagnostic Observation Schedule (ADOS) is a standardized assessment designed to obtain behavioral information and is part of the gold standard in ASD diagnosis (Le Couter, Handen, Hammal, & McConachie, 2008; Gray, Tonge, & Sweeney, 2008). It is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials. The ADOS Module 4 is designed specifically for verbally fluent adolescents and adults. The ADOS must be administered by an experienced and highly trained clinician (Lord, Rutter, DiLavore, & Risi, 2008). Training to reliably conduct the ADOS requires a week-long workshop, experience with using the instrument across many patients, and demonstration of one's ability to accurately administer the tool via review of one or more taped administrations by an ADOS trainer. It is highly unlikely that the number and distribution of

trained ADOS administrators is equal to the need and location of individuals with ASD identified in the censuses. Given the number of adults with ASD in need and the lack of trained clinicians, assessment services are not available at the level required.

Over the past 30 years, technologists and clinicians have investigated the use of advanced telecommunications and information technologies as a way of bridging the gap between individuals with specialized medical needs living in remote areas and the source of specialty care that is often distal (Bashshur, 2002; Kinsella, 1998; Scalvini, Vitacca, Paletta, Giordano, & Balbi, 2004). Telemedicine is a broad term that encompasses a variety of remotely delivered healthcare services, including telerehabilitation and teleassessment. Telemedicine may present opportunities for offering critical services in new ways to underserved populations. One possible solution to lack of access to trained clinicians is the use of technology for remote assessment. Teleassessment is a sub-specialty within telemedicine that uses text, audio, visual, virtual reality, web-based, integrated, and tailored systems to create interactions that are comparable to face-to-face interactions. Teleassessment has potential to reduce service delivery costs associated with travel and time. Chapter 3 will discuss teleassessment background, current uses, and strengths and potential limitations.

We have developed an ADOS Module 4 remote assessment system that integrates videoconferencing, presentation of stimuli, scoring, data storage, and report generation into an integrated and intuitive web portal environment. The development of this system will be described in chapter 3. In addition, a formative remote usability assessment study of the ADOS teleassessment system was conducted with the goal of determining if and how much the remote administration broke standard, face-to-face administration procedure. Results and discussion of this study will also be presented in chapter 3.

Chapter 4 will detail the reliability and usability of the remote ADOS Module 4 administration system. Researchers hypothesized that the integrated internet-based teleassessment system is as effective as face-to-face assessment. In a within-subjects crossover design, the results of ADOSs administered face-to-face were compared to the results of ADOSs administered remotely. Participants were asked about the usability of the system, including quality of sound, picture, and their comfort level with the remote administrations system. Results on the reliability of ADOS individual items and the reliability of ADOS domain scores and classifications will be reported, in addition to feedback from participants regarding usability. The discussion section will include notes on the limitations of and future directions for remote ADOS assessment research. Figure 1 provides a visual overview of the background, problem, and research methodology.

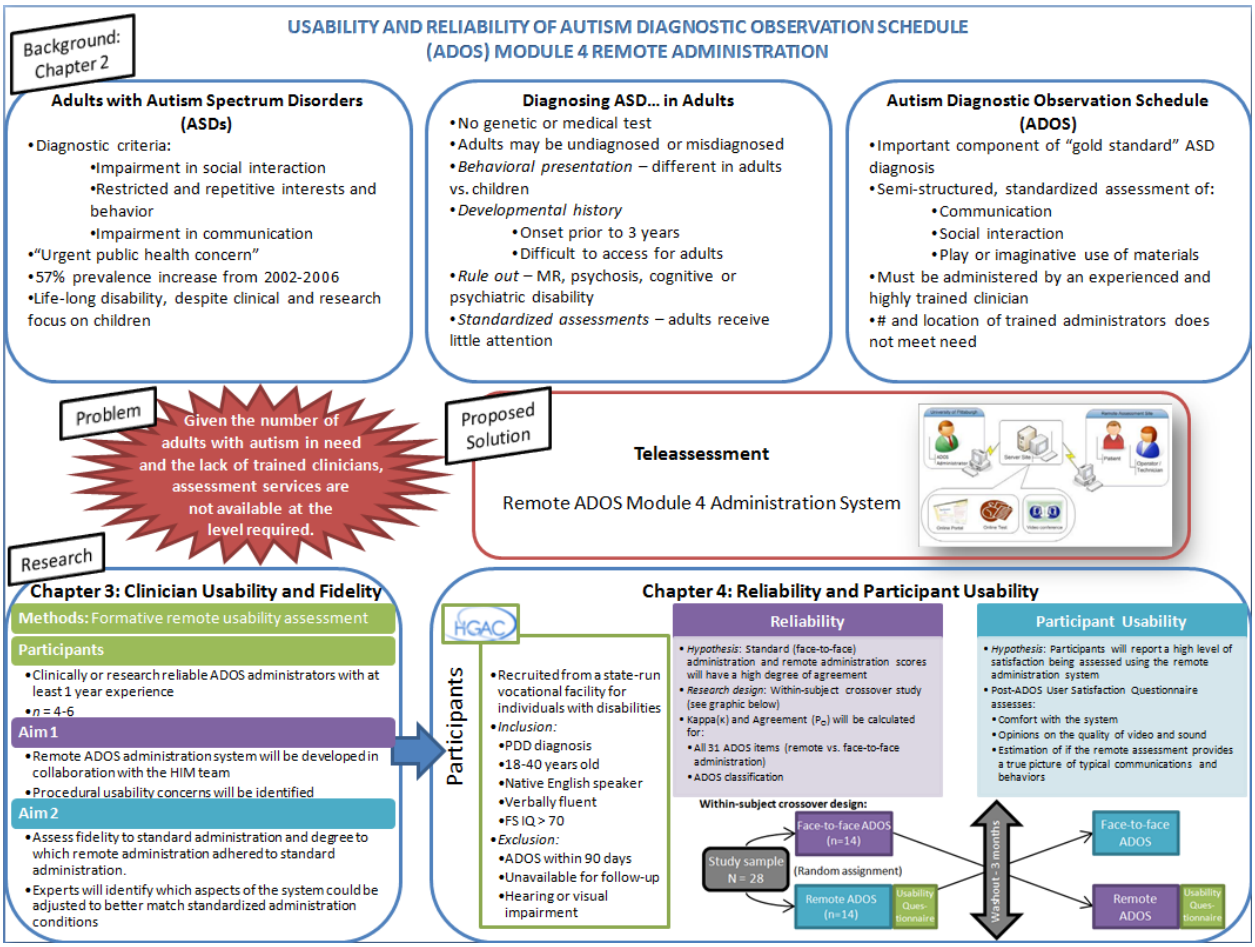


Figure 1. Overview: Usability and Reliability of Autism Diagnostic Observation Schedule (ADOS) Module 4 Remote Administration.

Finally, Chapter 5 provides a summary of all study objectives and results as well as implications for future research in adult ASD assessment and teleassessment.

2.0 CHAPTER 2: ADULTS WITH AUTISM SPECTRUM DISORDER: POPULATION CHARACTERISTICS, ASSESSMENT AND DIAGNOSIS

Pervasive Developmental Disorders (PDDs) include Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Autistic Disorder, Asperger's Disorder, CDD, and PDD-NOS are soon to be subsumed under the single diagnostic term, Autism Spectrum Disorder (ASD) diagnoses (American Psychiatric Association, 2012). The spectrum represents a continuum of disorders, from mild to severe functional impairments.

The current American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) identifies the following three primary diagnostic criteria for Autistic Disorder:

1. Qualitative impairment in social interaction
2. Qualitative impairments in communication
3. Restricted repetitive and stereotyped patterns of behavior, interest, and activities (2000, p. 75). (See APPENDIX A for complete DSM-IV-TR Autistic Disorder diagnostic criteria.)

According to the DSM, autism is typically associated with a diagnosis of mild to profound mental retardation. In a review of epidemiological surveys, Fombonne (1999) found that nearly 80% of individuals with autism had at least mild intellectual impairments.

Like Autistic Disorder, the diagnostic criteria for Asperger's Disorder also includes qualitative impairment in social interaction and restricted repetitive and stereotyped patterns of behavior, interest, and activities. The primary difference between the two diagnoses is that Asperger's Disorder does not require impairment in communication. In fact, Asperger's diagnostic criteria states, "There is no clinically significant general delay in language" (2000, p. 84). However, there may be abnormalities in language use, including variations in pitch/fundamental frequency, loudness/intensity, duration, pause/silence, intonation, rate, stress, and rhythm, (i.e., prosody) (McCann, Peppe, Gibbon, O'Hare, & Rutherford, 2007). Also unlike Autistic Disorder, mental retardation is rarely observed in Asperger's (APA, 2000). (See APPENDIX B for complete DSM-IV-TR Asperger's Disorder diagnostic criteria.)

Childhood Disintegrative Disorder (CDD) is very rare and much less common than Autistic Disorder. The diagnostic criteria includes "Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, plan and adaptive behavior," and "Clinically significant loss of previously acquired skills" (APA, 2000, p. 79). CDD is usually associated with sever mental retardation.

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is a catch-all diagnosis used when "there is a severe and pervasive impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder" (APA, 2000, p. 84).

The APA website has posted proposed revisions to the DSM-IV-TR for the DSM 5, which will be released in May 2013. Revisions include a new category called "Autism Spectrum

Disorder." This category is proposed to include Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and PDD-NOS, thus eliminating Asperger's and PDD-NOS as distinct diagnoses. Recommendations for severity will be based on the amount of support needed (APA, 2012).

To further complicate matters, the Autism Diagnostic Observation Schedule Module 4, the gold standard ASD assessment that will be reviewed in this chapter, results in a diagnostic classification of autism, autism spectrum disorder (which includes Asperger's disorder, PDD-NOS, and atypical autism), or non-spectrum. (See Figure 2 for clarification of terminology.)

For the purposes of this paper, the population will include adolescents adults diagnosed with autism, Asperger's disorder, and PDD-NOS. The focus will be on individuals on the "high-functioning" end of those on the spectrum, or individual without intellectual disabilities. This population will hereafter be referred to as autism spectrum disorder (ASD).

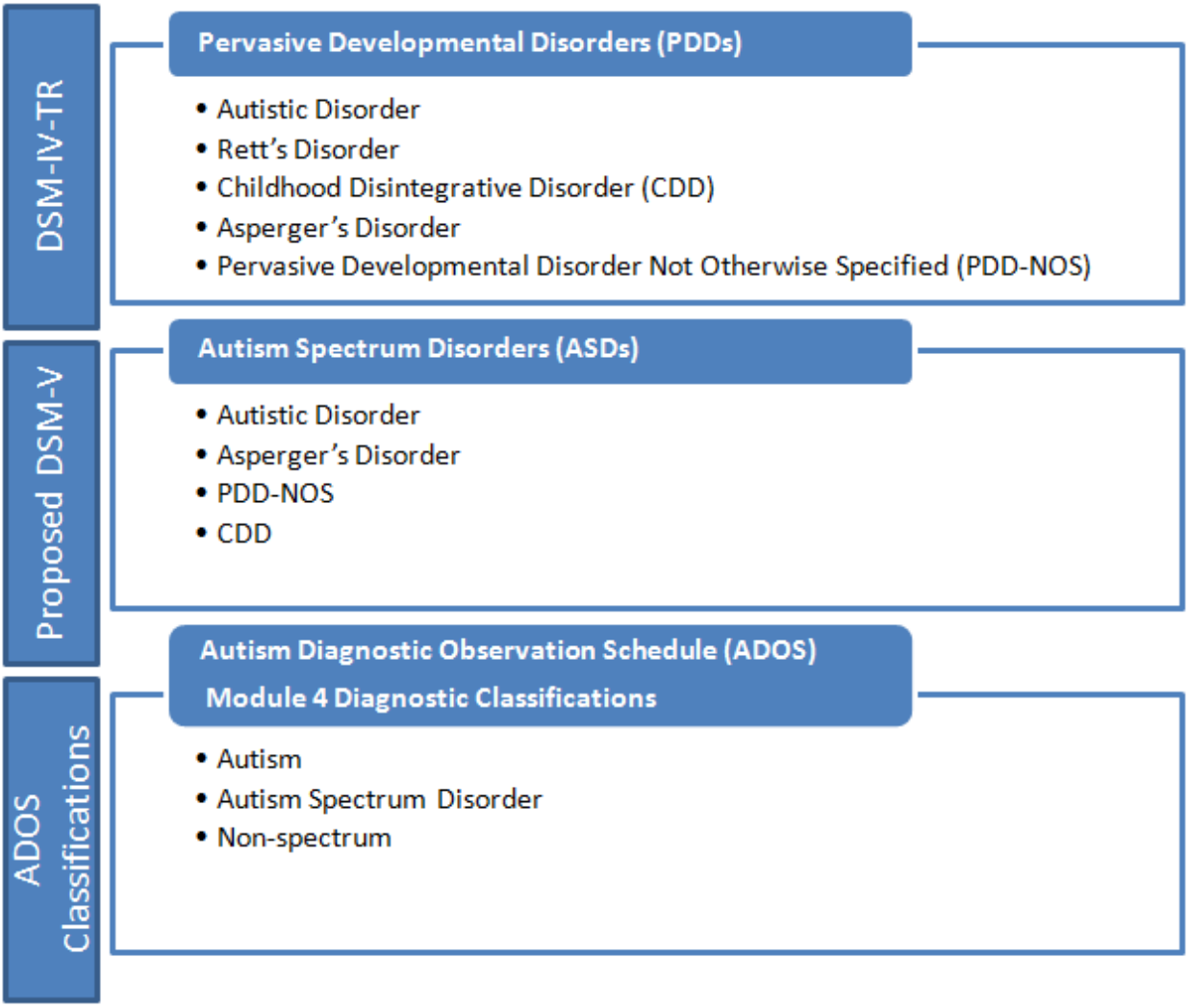


Figure 2. Pervasive developmental disorders, autism spectrum disorders, and ADOS Module 4 classifications.

While there is a plethora of published research exploring the characteristics of children with ASD, research on adults is limited. The following review will examine the behavioral characteristics of the diagnostic features and associated disorders of adolescents and adults with ASD, including impairment in social interaction, impairment in communication, restricted and repetitive interests, impairment in symbolic or imaginative use of materials, sensory processing issues, behavioral symptoms, and abnormalities of mood or affect. In addition, this review will address diagnostic issues pertinent to adults who may be on the autism spectrum. An ASD

diagnosis is made on the basis of a behavioral observation and a developmental history, which can be difficult to obtain in adults. The Autism Diagnostic Observation Schedule (ADOS) Module 4 is a standardized behavioral assessment designed for verbally fluent adolescents and adults. Adults with ASD meet the ASD diagnostic criteria in ways that are different than young children, and because so much research in ASD is geared towards children, they are an underserved population. Accurately identifying and evaluating the ASD diagnostic criteria in adults, including use of standardized assessments, is crucial for diagnostic purposes, which then has implications for access to appropriate treatment.

2.2 METHODS

The databases PsychInfo, Academic Search Premier, CINAHL, Expanded Academic ASAP, Medline, and HAPI were searched using terms that included: autism, Asperger's syndrome, pervasive developmental disorders, autism spectrum disorders, social skills, communication, symbolism/abstraction/imagination, self-stimulation/stereotyped behavior/interests, sensory processing, self-injurious behavior, aggressive behavior, attention, attention deficit disorder with hyperactivity, impulsiveness, emotional states, anxiety, depression, diagnosis, differential diagnosis, Autism Diagnostic Observation Schedule, interrater reliability, measurement, statistical reliability, statistical validity, test reliability, and test validity.

Prominent journals, including *Focus on Autism and other Developmental Disabilities*, *Journal of Autism and Developmental Disorders*, *Autism*, and *Journal of Child Psychology and Psychiatry* were browsed for relevant articles. The reference sections of all important articles were searched for further resources and also for prominent authors and researchers in the field.

In addition, literature was gathered from articles and lists of references provided at ADOS clinical and research trainings.

Articles were included in the literature review if they were peer-reviewed, English language, and preference was given to articles published in 2010 or later. In part 1 of this chapter, which addresses the signs and symptoms of ASD in adults, 37 articles were reviewed. Literature focusing on adolescents and adults was preferred, but inclusion of child-focused research was included when it was all that was available. It is noted when research on children is generalized to an adolescent/adult population.

2.3 ADULTS WITH HIGH-FUNCTIONING AUTISM: AN OVERVIEW OF CHARACTERISTICS

2.3.1 Impairment in social interaction

ASD is primarily a social disorder. Despite average intelligence, individuals with ASD do not translate their potential into real-life adaptive skills (Saulnier & Klin, 2007). Unlike individuals with profound autism, those with ASD often desire social interaction, but they do not know how to achieve it (Myles & Simpson, 2002). According to the DSM-IV-TR, impairment in social interaction manifests as impairment in use of nonverbal behavior (eye contact, facial expressions, body language, and gestures), lack of development of peer relationships, failure to seek shared enjoyment, and lack of social or emotional reciprocity (APA, 2000, p. 75, 84).

Impairment in non-verbal behavior includes both receptive and expressive skills. Individuals with ASD struggle with spontaneously inferring the meaning of facial expressions,

matching events with facial expressions, interpreting subtle social prompts, and performing within social norms regarding eye contact, proximity to others, gestures, and posture (Koning & McGill-Evans, 2001; Myles & Simpson, 2002).

It is unsurprising that the combination of the desire to be social and the inability to comprehend complex and subtle social rules leads to a great deal of stress and anxiety for this population. Because these individuals are limited in their ability to express their emotions through the typical means (e.g. voice inflection, posture), situations can escalate to an explosion before others realize the individual was feeling anger or excitement (Myles & Simpson, 2002). Simultaneously not being able to understand social demands or express frustration and anxiety in an effective way results in difficulty initiating and maintaining relationships.

Individuals with ASD have difficulty with Theory of Mind (ToM). ToM is defined as understanding that others have feelings and thoughts different from your own, and that people's thoughts and beliefs guide their behavior even when those beliefs are false (Peterson, Garnett, Kelly, & Attwood, 2009). Myles & Simpson (2002) identified three areas where theory of mind is especially difficult for those with ASD: (1) understanding the intentions of others, (2) understanding how their behavior affects others, and (3) participating in reciprocal skills, such as turn-taking.

In an interesting study, Klin (2000) showed a silent cartoon with geometric shapes enacting a social plot to three groups of adolescents and adults: (1) high-functioning autism, (2) Asperger's, and (3) a neurologically typical group. In both clinical groups, one third of their attributions were irrelevant to the cartoon, they missed three-fourths of the social elements in the cartoon, and they used significantly fewer ToM cognitive (e.g., knowledge, desire, belief) and affective mental state terms (e.g., jealousy, embarrassment – emotions that can only exist within

a ToM framework). Even when provided with explicit verbal information regarding the nature of the cartoon, the clinical groups were still unable to significantly improve their performance. According to Klin, these results suggest that:

> When coming face to face with a complex social situation—say, a high school cafeteria—they might be able to identify only a small number of important clues required for creating the social context of that setting. Failing to do so might place them at great disadvantage when having to predict other people's intentions and the select responses that will be appropriate to the social demands of that situation (p. 840-841).

2.3.2 Impairment in communication

In ASD, there is not an absence or significant delay in language development, but there may be impairment in ability to initiate or sustain conversations, stereotyped or repetitive use of language, preoccupation with certain topics, and verbosity (APA, 2000, p. 75, 81).

Several studies have provided evidence that speech and prosody is abnormal in individuals with ASD. Prosody includes aspects of language that modulate and enhance its meaning. Shriberg et al. (2001) identified three prosody sub-domains: (1) grammatical prosody – cues that indicate part of speech and question or statement; (2) pragmatic prosody – used to add social information beyond that conveyed by the syntax of the sentence; and (3) affective prosody – personal speech style, changes in speech style depending on communication partner, (e.g., boss versus child), and expression of general emotional state (p. 1098). In observational reports, individuals with ASD have been noted to speak in a monotone or robot-like voice, lack use of pitch and control of volume, have deficiencies in vocal quality, and use atypical stress patterns. These verbal behaviors tend to be persistent and show little change over time (Kanner, 1971).

Schriberg et al., (2001), conducted a study in which they reported speech and prosody-voice profiles for 30 adolescent and adult males with high-functioning autism or Asperger's. They found few significant differences between the high-functioning autism and Asperger's groups, but many differences between the ASD groups and a neurotypical age-matched control group. The clinical groups demonstrated a high prevalence of speech-sound distortions, inappropriate or nonfluent phrasing, inappropriate stress (typically involving the placement of stress cues within the utterance), louder speech, higher pitch speech, and more nasal speech.

In another study, McCann, Peppe, Gibbon, O'Hare, and Ruthford (2007) examined the nature and relationship of expressive and receptive language, phonology, pragmatics, and non-verbal ability in children (mean age = 9.45 years) with ASD. They found that the majority of children had deficits in at least one aspect of language and that expressive language was the most severely impaired. All participants had difficulty with at least one aspect of prosody. Other studies have supported and expanded on these findings (Paul et al., 2005; Peppe, McCann, Gibbon, O'Hare, & Rutherford, 2006; Peppe, McCann, Gibbon, O'Hare, & Rutherford, 2007).

2.3.3 Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities

According to the DSM-IV-TR, restricted, repetitive, and stereotyped patterns of behavior, interests, and activities are manifested in ASD as abnormally intense or focused preoccupation with stereotyped and restricted patterns of interest, inflexible adherence to rules or routines, stereotyped and repetitive motor mannerisms, and preoccupations with parts of objects (APA, 2000, p. 75, 84).

Individuals with ASD often have a restricted range of interests (Myles & Simpson, 2002). The special interest, (also known as passions, or obsessions) may be in areas as diverse as

geology, astronomy, mechanics, numbers, or fabrics (Myles & Simpson, 2002). Interests are not completely random. Individuals with ASD are significantly more interested in areas of folk physics (an interest in how things work) than in folk psychology (an interest in how people work) (Baron-Cohen & Wheelwright, 1999). This is not surprising given the previously discussed difficulty those with ASD have comprehending social phenomena. Special interest topics may be similar to those enjoyed by neurotypical peers, but individuals with ASD will often choose one topic to the exclusion of all others, or develop a depth of knowledge in a particular area that is atypical (Myles & Simpson, 2002).

There are several hypothesized reasons for these obsessive interests, including having something to talk about, facilitating or avoiding social interactions, demonstrating intelligence, or providing a fun, intensely enjoyable activity, a way to relax, or a way to create order and consistency, security, and comfort (Barnhill, 2001, p. 262; Bashe & Kirby, 2001). Because individuals with ASD do not gain much enjoyment from the social aspects of life, they may find pleasure in their special interests (Bashe & Kirby, 2001).

Inflexible adherence to rules or routines may be due to a deficit in cognitive shifting. Individuals with ASD are often mentally inflexible; they have difficulty generating strategies to adapt to a variety of social contingencies. Therefore, they prefer circumstances that are controlled and consistent. Even small changes in their environment can be overly distressing (Berger, Aerts, van Spaendonck, Cools, & Teunisse, 2003). Green et al. (2006) conducted a study in which they asked parents of individuals with autism, Asperger syndrome, and Down syndrome to complete the Behavioral Flexibility Rating Scale (BFRS). Reports were obtained on 724 children and adolescents, from under five years old to older than 19. The BFRS covered five areas: 1) a preferred item is unavailable, 2) a desired event or activity is interrupted,

canceled, or delayed, 3) an unexpected sensory stimulation occurs, 4) a task is failed, and5) a task is left unfinished (p. 231). Results showed that individuals with Asperger syndrome were rated as having the least behavioral flexibility. They were less flexible than individuals with autism. Individuals with autism were found to be less flexible than individuals with Down syndrome (Green et al., 2006).

A preoccupation with parts of objects is often conceptualized as a lack of central coherence. Central coherence is defined as "the natural drive to integrate information into context, gestalt, and meaning" (Berger, Aerts, van Spaendonck, Cools, & Teunisse, 2003, p. 503). It makes sense that if individuals with ASD have difficulty "seeing the forest for the trees," they will be more likely to focus on the details or parts of objects.

Stereotyped and repetitive motor mannerisms are often referred to as self-stimulatory behaviors, or stims. Some evidence suggests that repetitive motor movements are most severe early in life, and may decrease in intensity with age (South, Ozonoff, & McMahon, 2005).

Cuccaro et al., (2007) conducted a study in which they compared 33 IQ, sex, and age matched pairs of individuals with Asperger's disorder and high-functioning autism on measures of repetitive behavior. The mean age of participants was 11 years old. Results showed no significant differences between the groups in intensity or frequency of restricted behavior on six scales: stereotyped behaviors (e.g., body, head, hand, locomotion, object, sensory), self-injurious behavior (e.g., body, surface, bites, rubs, skin), compulsive behavior (e.g. arrange, complete, wash, check, count, hoard, repeat, touch), ritualistic behavior (e.g., eat, sleep, self care, travel, social), sameness behavior (e.g., places, interrupt, activities, routine), and restricted interest behavior, (e.g., subject, object, parts, movement) (Cuccaro et al., 2007). This research demonstrates the types of repetitive behaviors that are common in ASD.

2.3.4 Symbolic or imaginative use of materials

The characteristic lack of symbolic play in children with ASD has been often noted but rarely researched. This lack becomes a dearth of research when addressing abstract thinking and imagination in adults.

Children with autism have been shown to be less likely to use representation play (e.g., pick up a block and say, "this is my car, vroom vroom!") (Charman & Baron-Cohen, 1997). Hobson, Lee, and Hobson (2009) conducted an experiment in which they hypothesized that the play of children with ASD would demonstrate limitations in playful pretending, including creating new meanings and using symbolism. They found that, indeed, the play of children with autism was distinctive because it lacked playful pretend – awareness of self as creating meanings, investment in symbolic meanings, creativity, and fun (p. 18).

Ropar and Peebles (2007) conducted an interesting study in which they investigated preferences of children with autism to sort books that could be categorized based on either concrete (size, color) or abstract (category membership: sports/games) features. Participants with autism were significantly more likely than a control group to sort books based on a concrete criteria (Ropar & Peebles, 2007). It is likely that this deficit of symbolic or imaginative use of materials continues into adolescence and adulthood.

2.3.5 Sensory processing

Individuals with ASD often have sensory profiles that differ from those of neurotypical individuals. Specifically, they may differ when interpreting information from the seven different sensory systems: tactile (touch), vestibular (balance), proprioception (body awareness), visual

(sight), auditory (hearing), gustatory (taste), and olfactory (smell) (Dunn, Saiter, & Rinner, 2002). Table 1 concisely describes the potential sensory profiles of individuals with ASD.

Table 1. Characteristics of Specific Sensory Processing Patterns and Common Characteristics of Individuals with Autism Spectrum Disorder

	Low Registration	**Sensation Seeking**	**Sensory Sensitivity**	**Sensation Avoiding**
Neurological thresholds (The amount of stimuli needed to notice or react)	High	High	Low	Low
Behavioral response/self-regulation strategy	Passive	Active	Passive	Active
Functional characteristics of this pattern of sensory processing	High ability to focus on something Unaffected by varying emotions	High ability to generate ideas and responses Notices and enjoys all the activity in the environment	High ability to notice what is going on in the environment Particular about task completion parameters	High ability to design & implement structure Enjoys routines
Potentially interfering characteristics of this pattern of sensory processing	Appears to be uninterested or withdrawn May have a dull affect or seem self-absorbed May seem "overly tired" or apathetic	Always active, continuously engaging Fidgety and excitable	Distractible in busy, complex settings May seem like a "complainer"	Resistant to change Reliant on rituals to participate
Common characteristic of individuals with Asperger syndrome	Does not notice facial expressions or gestures of others Limited capacities for self-monitoring	Demonstrates repetitive patterns of behavior Intense pursuit of interests and activities Verbosity	Marked distress with change Strong dislike for certain fabrics Aversion to daily life activities with	Lack of spontaneous seeking to share enjoyment Limited participation in social play or games

	May be motorically "clumsy"	Symptoms of overactivity and inattention	strong tactile sensory input Hypersensitive to environmental noise	May create "rituals" or rigid social approaches Self-isolation

Note. Adapted from "Asperger Syndrome and Sensory Processing: A Conceptual Model and Guidance for Intervention Planning," by W. Dunn, J. Saiter, and L. Rinner, 2002, *Focus on Autism and Other Developmental Disabilities, 17* (3), p. 175.

Especially in the bottom two rows, it is clear that many of the signs and symptoms of ASD are potentially attributable to sensory processing issues. For example, someone with a high neurological threshold and an active behavioral response will display symptoms that are often misattributed to behavioral or attitudinal problems. "Always active, continuously engaged; Fidgety and excitable" are also diagnostic criteria of Attention Deficit/Hyperactivity Disorder.

It is important to understand that individuals may not necessarily have only one consistent sensory processing pattern. They may have different patterns for different locations, times of day, or sensory systems. For instance, someone might avoid all tactile stimulation but seek out or have moderate responses to visual or auditory input (Dunn, Saiter, & Rinner, 2002). In a recent study, Crane, Goddard, and Pring (2009) found that 94.4% of adults with ASD reported extreme levels of sensory processing, but within-group variance was very high, indicating that individuals with ASD can experience very different, yet equally severe, sensory processing abnormalities.

2.3.6 Behavioral symptoms

Myles and Simpson (2002) hypothesized that children and youth with Asperger's have behavioral problems due to their difficulty functioning in a world they perceive as utterly

unpredictable and unaccommodating. In a 2000 study, Barnhill et al. surveyed parents of children with Asperger's, and found that they had great concern over conduct problems, aggression, and hyperactive behaviors. The following discussion will focus on five behavioral symptoms of ASD identified by the DSM-IV-TR: attention deficit/hyperactivity, short attention span, impulsivity, aggressiveness, and self-injurious behavior.

2.3.6.1 Attention deficit/hyperactivity

Attention Deficit/Hyperactivity Disorder (ADHD) and ASD are developmental disabilities associated with executive function deficits. According to the current version of the DSM, technically ADHD cannot be diagnosed during the course of a PDD (APA, 2000, p. 93). However, there is considerable debate over whether the two disorders are related, and whether they can be co-morbid. (The DSM-V will eliminate this diagnostic problem.)

Most individuals with ASD do present with ADHD-like symptoms in their childhood and middle school years (Ghaziuddin, 2002; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998), and it can be difficult to differentiate between Asperger's symptoms and ADHD symptoms. For instance, social oddities and intrusiveness can be misinterpreted as inattention and hyperactivity (Ghaziuddin, 2002). Some studies have shown that attention deficits are prominent, if not universal in disorders on the autism spectrum. Sinzig, Walter, and Doepfner (2009) evaluated ADHD symptoms in 83 children with ASD and found that 53% fulfilled DSM-IV criteria for ADHD. Raymaekers, Antrop, van der Meere, Wiersema, & Roeyers (2007) found no difference between groups of children with high-functioning autism and children with ADHD for state regulation and response inhibition. In fact, there may be a subgroup of individuals with ASD that are better defined as having a duel diagnosis of ASD and ADHD than simply being on the autism spectrum (Gillberg & Billstedt, 2000).

2.3.6.2 Violence and aggression

There is currently not enough information to make a general statement about whether or not having a diagnosis of ASD increases one's propensity for aggression, crime, and violence. Lecavalier, (2006) found that up to 20% of children with autism have symptoms of irritability and aggression including aggression, severe tantrums, and deliberate self-injurious behavior. When individuals with ASD do commit crimes, they usually have some similar characteristics: (1) the criminal or violent acts are an extension of their restricted and repetitive interests, (e.g., a fixation on weapons leads one to experiment with guns), (2) unlike most individuals or individuals with conduct disorder, when someone with Asperger's commits a crime, he or she is unlikely to attempt to hide or cover-up his or her actions or motivations, and (3), violence and crime might not have anything to do with ASD but with an unrelated undiagnosed psychiatric disorder, (e.g., a major depressive disorder could be the cause of an attempt to hurt oneself or others) (Ghaziuddin, 2002).

2.3.6.3 Self-injurious behavior

Lecavalier (2006) found that rates for specific self-injurious behaviors rated as moderate or severe problems ranged from 5% to 16% in young people with pervasive developmental disorders. Self-injurious behavior seems to be linked more with profound mental retardation, and is unlikely to be present ASD. Gal, Dyck, and Passmore (2009) argued that self-injurious behavior is a more severe form of stereotyped movements. Therefore, it is more likely adults with ASD will engage in stims as opposed to self-injurious behavior.

2.3.7 Abnormalities in mood or affect

Studies have suggested that individuals with ASD experience psychiatric disorders, especially anxiety and depression, at higher levels than individuals in the general population (Gillott, Furniss, & Walter, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). The development of social anxiety is not surprising given the deficit in social skills that is characteristic of ASD. Many symptoms of ASD and depression overlap, which can make it difficult to identify and diagnose. These problems have a significant impact on adults with ASD overall ability to function.

2.3.7.1 Anxiety

Because the social world can be incomprehensible and unpredictable, yet something they want to be a part of, individuals with ASD experience a considerable amount of anxiety, especially social anxiety. In a 2006 study, Farrugia and Hudson found that adolescents with Asperger's disorder experienced comparable amounts of anxiety with a group of adolescents diagnosed with anxiety disorder, and both groups experienced significantly more anxiety than a non-clinical group. The high levels of anxiety were reported by both the individuals with Asperger's and their parents. Possible explanations for this high level of anxiety include reactions to having to deal with the core symptoms of Asperger's, peer relationship problems, and negative peer interactions (Farrugia & Hudson, 2006). Several other studies have demonstrated the same relationship between anxiety and ASD (Bellini, 2006; Gillott & Standen, 2007; Kuusikko et al., 2008).

Because restricted and repetitive interests are one of the core features and diagnostic criteria for ASD, it is often difficult to determine where to draw the line between ASD and Obsessive Compulsive Disorder (OCD). However, with ASD, the obsessions are pleasurable

and desirable, whereas with OCD, the thoughts and compulsions are unwanted. Occasionally, ASD and OCD do occur together. It is important for clinicians and practitioners to recognize the addition of OCD because of its implications for treatment (Ghaziuddin, 2002).

2.3.7.2 Depression

Both major depressive disorder and bipolar disorder are associated with ASD, with a prevalence level as high as 34% (Ghaziuddin, 2002; Munesue et al., 2008; Stewart et al., 2006). Many individuals with ASD present with depressive symptoms once they reach puberty (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Hedley and Young (2006) found a relationship between psychosocial factors, i.e., perceived group membership, and depressive symptoms. Barnhill and Myles (2001) found individuals with ASD experienced learned helplessness, blamed themselves for negative events, and viewed the causes of negative events as consistent and generalizable.

Long, Wood, and Holmes (2000) presented a case report where they described the presentation, differential diagnosis, and treatment of a young woman with autism and depression. Interestingly, the authors noted some behavioral factors that were not typically associated with depression, but in this individual were felt to be reflective of the individual's depressive disorder. Atypical symptom presentation may make it difficult to accurately identify depression in individuals with ASD. In addition, individuals with ASD may have language impairments that prevent them from verbalizing their feelings, or may have difficulty identifying and describing the complex emotions associated with depression. Stewart et al. (2006) reported that the key features of depression in individuals with ASD were reported by third-party accounts or were shown in behavior rather than by self-report.

2.4 DIAGNOSING ASD IN ADULTS

ASD diagnosis is based on a clinical diagnostic interview, analysis of behavioral presentation, and detailed developmental history. While there are many assessment and diagnostic tools, very few are designed for use with adolescents and adults. However, the Autism Diagnostic Observation Schedule (ADOS), considered an essential part of the "gold standard" diagnosis, does have a module specifically designed for verbally fluent adolescents and adults. Reliability and validity of this instrument will be discussed. There are specific difficulties and challenges associated with diagnosing adults with ASD. The ADOS Module 4 is a good candidate to be considered an essential component of the ASD assessment process.

2.4.1 Diagnosing and assessing ASD

The biological basis and underlying neuropathology for ASD is relatively unknown. Therefore, a diagnostic medical examination – a brain scan or blood test – does not exist. ASD diagnosis is primarily made on the basis of behavioral observations combined with evidence from a detailed developmental history (Barbaro & Dissanayke, 2009). Clinical judgment by experienced clinicians is typically the method of diagnosis. Clinicians base their clinical judgments on the DSM-IV-TR criteria for Autistic Disorder, Asperger's Disorder, PDD-NOS or CDD, as it is frequently used and widely accepted as the preeminent diagnostic criteria (Ventola et al., 2006).

2.4.1.1 Behavioral presentation

In line with the DSM-IV-TR diagnostic criteria (see Appendices A and B), key behaviors that differentiate children with ASD from typically developing children are in the areas of

socialization and communication. Socialization behaviors include avoiding eye contact, not orienting to name call, absence of showing objects, absence of pointing, ignoring people, preference for being alone, and poor social interaction. Communication behaviors include lacks or absences in verbal communication, appropriate facial expressions, social smiles (i.e., smiling in response to a purely social overture from another person), gestures, and imitation of others (Barbaro & Dissanayke, 2009). Repetitive motor actions are also observed, but are often associated with intellectual disability, and must be observed in addition to social and communication deficits for a diagnosis of autism (Osterling, Dawson, & Munson, 2002).

Billstedt, Gillberg, and Gillberg (2007) conducted a study in which they looked at the long-term outcomes of individuals who were diagnosed with "autistic disorder/infantile autism [n = 71]… or autistic-like conditions/atypical autism [n = 34]" in childhood (p. 1103). At follow-up, participants were diagnosed with autism (n = 89) or atypical autism (n = 15), and one participant no longer met diagnostic criteria for an ASD. They used a structured interview, the Diagnostic Interview for Social and Communication Disorders (DISCO), to evaluate symptoms and symptom patterns in adults 17 to 40-years-old. Following are the abnormal social interaction, communication, and behavior symptoms that were present in at least 75% of the study group:

- No interaction or inappropriate quality of interaction
- One-sided social approaches or no approach at all
- No interaction with age peers/interacts only if led by other
- No or inappropriate conventions of peer interaction
- Lack of or inappropriate emotional response to age peers
- No or inappropriate sharing of interest and enjoyment

- No adequate giving of comfort to others
- Avoidance of age peers
- Behaviors indicating no awareness of others' feelings
- Little, if any reciprocity in verbal communication
- Lack of awareness of suitability of clothing (Billstedt, Gillberg, & Gillberg, 2007, p. 1105)

Complicating the interpretation of the behavioral presentation, it is important to remember individuals with ASD represent an extremely heterogeneous population. While individuals with ASD will demonstrate similar patterns of behavior or deficits, the ways in which patterns manifest differs both across individuals and within an individual over time. No single behavior is abnormal or absent in every individual with ASD throughout the lifespan (Lord & Risi, 1998).

2.4.1.2 Developmental history

According to the DSM, for a diagnosis of autism, age of onset must be prior to three years (APA, 2000). Many children show symptoms between the ages of one and two, and some even show abnormalities before 12 months (Barbaro & Dissanayake, 2009). There is no age of onset specified by the DSM for Asperger's disorder. However, pervasive development disorders are "usually evident in the first years of life," despite the fact that the "disorders sometimes are not diagnosed until adulthood" (APA, 2000, p. 69, 39). For this reason, retrospective reports from parents and caregivers are often solicited as a source of diagnostic information.

As in all retrospective research, caregiver reports may be flawed due to incorrect memory recall, recall bias, and distortion of events. Furthermore, responses can be influenced by a

variety of reliability-reducing factors, including alertness in recognizing behaviors, socioeconomic status, personality, intelligence, and mental health (Barbaro & Dissanayake, 2009). For adults, toddlerhood was a long time ago. The older an individual is, the less likely it is that a reliable developmental history will be obtained. The individuals who are in the best position to provide information (e.g., preschool teachers, daycare caregivers), may no longer be accessible. The memories of those who are available are likely imperfect and influenced by years of interceding events.

2.4.1.3 Differential diagnosis

ASD shares common symptoms with a variety of disorders and diagnoses, including anorexia nervosa, Tourette syndrome, ADHD, cerebral palsy, muscular dystrophy, Leber's congenital amaurosis, Fragile X syndrome, Down syndrome, and Rett syndrome (Fombonne, 1999; Moss & Howlin, 2009). These diagnoses may occur co-morbidly, or a true ASD may be misdiagnosed. Accurate diagnosis is important for treatment implications. The following section will review common differential diagnoses to be considered when assessing ASD.

Genetic syndromes and intellectual disability

Moss and Howlin (2009) conducted a systematic review in which they examined the association of ASD and ASD characteristics with Fragile X, Rett's, Tuberous Sclerosis Complex, Down, Angelman, CHARGE, and Phenylketonuria syndromes. They found that the estimated prevalence of ASD was inversely correlated with higher levels of Intellectual Disability (ID). (In this discussion, ID and Mental Retardation (MR) will be used interchangeably.) For instance, in Angleman syndrome, where the associated degree of ID is severe to profound, the estimated prevalence of ASD is 50-80%; conversely, in Phenylketonuria, where the associated degree of

ID is normal to severe, the estimated prevalence of ASD is just 5% (Moss & Howlin, 2009). In lower-functioning individuals, it is important to check for the existence of genetic syndromes before diagnosing ASD. This is important for treatment because while behaviors are similar, the underlying mechanisms may be different depending on diagnosis. For example, lack of eye contact in Fragile X Syndrome is considered to be a response to hypersensitivity to sensory stimuli, hyper-arousal, and social anxiety, while in ASD it is often considered a result of impairment in social skills (Moss & Howlin, 2009).

In general, a diagnosis of ID can make ASD diagnosis difficult (Moss & Howlin, 2009). As previously discussed, some behaviors, such as self-injury and stereotypic movements, are common in both ID and lower-functioning ASD (Osterling, Dawson, & Munson, 2002). In individuals with ASD, diagnostic confusion is more likely due to schizophrenia symptoms, ADHD, anxiety, or depression as opposed to mental retardation. These conditions will be discussed next.

Schizophrenia and psychosis

Several symptoms of ASD overlap with the negative symptoms of schizophrenia, including: social dysfunction, qualitative impairment in social interaction and communication, and repetitive and stereotyped behaviors. However, the core positive symptoms of schizophrenia, delusions and hallucinations, are absent in ASD. According to Palucka, Bradley, & Lunsky (2008), “It is particularly important in autism to evaluate any such ‘positive’ symptoms against baseline of premorbid behaviors and thought patterns as persons with autism often have idiosyncratic perceptions and meaning attached to their experiences which may appear bizarre to others unless this historical and current meaning is understood” (p. 55).

There are many published case studies of individuals with PDDs misdiagnosed with schizophrenia. In fact, only in 1971 was the diagnosis of autism clearly distinguished from schizophrenia (Volkmar & Cohen, 1991). Akande et al. (2004) described the case of "Mr. D," which highlighted the similarities in clinical and neurodevelopmental course between schizophrenia and ASD, and the difficulties of making a diagnosis of autism in an adult. Palucka, Bradley, & Lunsky (2008) discussed the case of an adult whose initial diagnostic formulation did not rule out developmental disorders and of whom an extensive early developmental history was never taken. Dossetor (2007) discussed four case studies in which features that were mistaken for psychotic phenomena were identified as symptoms of PDDs, and successfully treated. Examples from these case studies of symptoms that may be shared by schizophrenia and ASD include: withdrawn behavior, episodes of aggression, talking to oneself, neglecting person hygiene, and needing prompting to attend to daily activities.

Attention deficit/hyperactivity disorder (ADHD)

The DSM currently does not allow for diagnosis of ADHD if the symptoms occur in the context of a PDD (APA, 2000, p. 93). However, as with ASD, ADHD involves difficulties with social interaction, communication, and restricted interests. Koyama, Tachimori, Osada, & Kurita (2006) conducted a study in which they compared children with high-functioning PDD-NOS to children with ADHD on an intelligence test and a standardized autism assessment (Childhood Autism Rating Scale-Tokyo Version; CARS-TV). They found that the distinguishing variables were relationships with people, nonverbal communication, and general impressions, on which children with PDD-NOS scored more abnormally; and near receptor responsiveness and activity level, on which children with ADHD scored more abnormally.

Based on semi-structured interviews of parents of children, adolescents, and young adults (ages 6 to 25 years old) with ASD, ADHD, and anxiety, Hartley and Sikora (2009) found criteria within the domains of communication and social relatedness were largely able to discriminate the ASD group from ADHD and anxiety. Positive endorsement of abnormal non-verbal behavior, failure to develop peer relations, stereotyped/repetitive/idiosyncratic language, and a lack of make-believe/imaginative play were significantly higher in the ASD group than in the ADHD group.

Anxiety

ASD also overlaps with anxiety disorders (Weisbrot, Gadow, DeVincent, & Pomeroy, 2005). As with ASD, individuals with anxiety may demonstrate preoccupations with topics, rigid routines, repetitive activities and behaviors, and social withdrawal (Gillott, Furniss, & Walter, 2001). In the previously mentioned Hartly and Sikora (2009) study, positive endorsement of abnormal non-verbal behavior, lack of seeking to share, delay/lack of speech, impaired conversational ability, stereotyped/repetitive/idiosyncratic language, and lack of make-believe/imaginative play were significantly higher in the ASD group than in the anxiety group.

Depression

Symptoms of ASD that overlap with depression include flat affect, abnormal speech patterns (e.g., flat intonation in speech), minimal facial expressions, irritability, and social isolation/withdrawal (Cooper & Hanstock, 2009; Stewart et al., 2006). In a case study, Cooper and Hanstock (2009) discussed an 11-year-old female who had been diagnosed with depression and bipolar disorder. The client presented with lack of speech/unwillingness to engage in conversation, social problems, lack of facial animation, sleep difficulties, and unpredictable

moods. Through a thorough history and assessment that included a clinical history, clinical questionnaires, ADI-R, ADOS, Wechsler Intelligence Scale for Children (WISC), and school observation, the client was diagnosed with ASD, appropriately treated, and subsequently demonstrated significant improvement.

There are characteristics of other diagnostic categories that are related to socialization and communication. For example, personality disorders and other disorders that exhibit lack of empathy for the experiences of others, (e.g., oppositional defiant disorder and conduct disorder) have some overlap with the signs and symptoms of ASD. For one example of this overlap, Hurst, Nelson-Gray, Mitchell, and Kwapil conducted a survey study in 2006 that examined the relationship between Asperger's disorder and schizotypal personality disorder (SPD). The authors described these as mutually exclusive but similar diagnoses. They identified similarities in the social impairments experienced by those with Asperger's disorder and the interpersonal problems experienced by those with SPD; and the communication deficits experienced by those with Asperger's disorder and the disorganized features of those with SPD (Hurst et al., 2006). In addition, there is a lack of stereotyped interests and rituals in SPD in contrast to ASD.

2.4.1.4 Standardized assessments

One way to increase diagnostic accuracy may be the use of standardized assessments. There are many screening tools available. Table 2 provides a summary of the most popular assessments.

Table 2. Summary of Autism Spectrum Disorder Assessments

Assessment	Authors	Description	Ages
AAA Adult Asperger Assessment	Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005	Electronic, data-based, and computer-scorable; linked with two screening instruments (the AQ and the Empathy Quotient [EQ]); employs a more stringent set of diagnostic criteria than DSM-IV to avoid false positives	Adults

Table 2 (continued).

AAPEP	Adult-Adolescent Psychoeducational Profile	Mesibov, Schopler, Schaffer, & Landrus, 1988	Provides an evaluation of current and potential skills in individuals with autism who have moderately to severely impaired intellectual functioning, to identify instructional priorities	Older than 12 years
ABC	Autism Behavior Checklist	Krug, Arick, & Almond, 1980	Intended to be completed by teachers as initial step in educational planning; emphasizes observable features associated with ASD	School-age children, 3 years of age and older
ADI-R	Autism Diagnostic Interview-Revised	Rutter, Le Couteur, & Lord, 2003	Diagnostic tool; semi-structured parent interview to identify autism and PDD; focuses on current behavior and queries if behaviors were ever observed	Children and adults with mental ages above 2 years 0 months
ADOS	Autism Diagnostic Observation Schedule	Lord, Rutter, DiLavore, & Risi, 2008	Diagnostic tool; standardized protocol for observation of social and communicative behavior	Toddler to adults; no speech to fluent
ASDASQ	Autism Spectrum Disorder in Adults Screening Questionnaire	Nylander & Gillberg, 2001	Nine symptom/impairment-oriented questions concerning diagnostic issues, plus one item relating to previous contact with child and adolescent psychiatric services; useful as a screening instrument for ASD in psychiatric populations	Adults
ASD-DC	Autism Spectrum Disorders-Diagnostic for Children	Matson, Gonzalez, & Wilkins, 2009	Informant-based measure developed to assess symptoms associated with Autistic Disorder, PDD-NOS, and Asperger's Disorder	3-16 years
ASDS	Asperger Syndrome Diagnostic Scale	Myles, Bock, & Simpson, 2001	Norm-referenced rating scale to identify students with AS, develop goals, document progress; can be used for research	5-18 years
ASSQ	Autism Spectrum Screening Questionnaire	Ehlers, Gillberg, & Wing, 1999	Screening instrument to determine if more comprehensive assessment needed; created for use in epidemiological study; not normed; designed for individuals without MR	6-17 years
AQ	Autism-spectrum Quotient	Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001	Self-report screening questionnaire; 50 items, score on 5 domains of behavior: social skill, attention switching, attention to detail, communication, and imagination	Adults with normal intelligence

Table 2 (continued).

CARS-2	Childhood Autism Rating Scales Second Edition	Schopler, Van Bourgondien, Wellman, & Love, 2010	One of the earliest screening tools specifically for autism; distinguished children with autism from those without and provides indication of severity; consists of 15 independent scales such as verbal communication and imitation	Children 2 years and older
CAST	Childhood Asperger Syndrome Test	Scott, Baron-Cohen, Bolton, & Brayne, 2002	Designed to screen children and youth for AS	4-11 years
DISCO	Diagnostic Interview for Social and Communication Disorders	Wing, Leekman, Jibby, Gould, & Larcomb, 2002	Schedule for the diagnosis of autistic spectrum and related disorders and assessment of individual needs; enables information to be recorded systematically for a wide range of behaviors and developmental skills	All ages
GADS	Gilliam Asperger's Disorder Scale	Gilliam, 2001	Norm-referenced rating scale to identify students with AS, develop goals, document progress; can be used for research	3-22 years
GARS	Gilliam Autism Rating Scale	Gilliam, 1995	Checklist for use by parents, teachers, and other professionals to identify and estimate severity of symptoms of autism	3-22 years
KADI	Krug Asperger Disorder Index	Krug & Arick, 2003	Norm-referenced rating scale to identify students with AS and develop goals; can be used for research	Elementary form for ages 6-11 and secondary form for ages 12-21
M-CHAT	Modified-Checklist for Autism in Toddlers	Robins, Fein, Barton, & Green, 2001	Parent report/clinical observation; Modified the CHAT by adding items for children 18-24 months and to adapt for use in US	18-30 months of age identified at risk for developmental disorders
PDDBI™-SV	PDD Behavior Inventory™: Screening Version	Cohen, Schmidt-Lackner, Romanczyk, & Sudhalter, 2003	Purpose is to screen for pervasive developmental disorders in children; parent report, individual or group; takes 5-10 minutes to administer	1.6-12.5 years
RAADS	Ritvo Autism and Asperger's Diagnostic Scale	Rivto, Rivto, Guthrie, Yuwiler, Rivto, & Weisbender, 2008	Empirically based 78 question self-rating scale based on the DSM-IV-TR and ICD-10 criteria developed to assist clinicians' diagnosis of adults with autism and Asperger's Disorder	Adults

Table 2 (continued).

SCQ	Social Communication Questionnaire	Rutter, Bailey, & Lord, 2003	Screening questionnaire based on the original ADI; provides indication of ASD symptoms	Child needs to be above 4 years of age with mental age > 2 years
SRS-2	Social Responsiveness Scale Second Edition	Constantino, 2005	Identifies the presence and severity of social impairment within the autism spectrum and differentiates it from that which occurs in other disorders.	2.5 years through adulthood
STAT	Screening Tool for Autism in Two-year-olds	Stone, Coonrod, and Ousley, 2000	Attempt at very early identification of autism	Targeted 2-3 year old children

Note. Adapted from *Students with Autism Spectrum Disorders*, by L. J. Heflin and D. F. Alaimo, 2007, pp. 24-32.

According to Matson (2007), a dominant theme in diagnostic tools for identifying ASD is that adults receive little attention. "For many reasons," the author states, "not the least of which is the general lack of national screening for ASD, some people with these disorders go undetected into the teenage years or are misdiagnosed in adulthood" (2007, p. 110). The few diagnostic tools that have been developed for adults are summarized next.

One of the most commonly used and easily accessible adult autism assessment is the Autism-spectrum quotient (AQ). The AQ can be found online and consists of 50 statements; the individual indicates how strongly they agree or disagree with the statements. Ketelaars et al. (2008) conducted a study in which they compared AQ scores of adults who were (1) referred to an autism diagnostic clinic and diagnosed with an ASD (n=15), (2) adults who were referred to an autism diagnostic clinic and not diagnosed with an ASD (n=21), and (3) adults who were referred to a general outpatient psychiatric clinic (n=369). Generally, they found there were no significant differences between the three groups on the sub-domain and total scores. Only for the communication domain, the ASD group had higher scores relative to the general outpatient group.

Ritvo et al. (2008) examined the Ritvo Autism and Asperger's Diagnostic Scale (RAADS), a scale designed to assist clinicians in identifying autistic disorder and Asperger's disorder in adults. The self-rating diagnostic scale's initial results indicated that it is sensitive and specific and can be administered and scored in less than one hour. The authors caution that the scale was standardized on just 17 individuals with autism, 20 individuals with Asperger's, and 57 comparison participants, and that further studies are needed to determine reliability and validity.

The Asperger Syndrome Diagnostic Scale (ASDS) was developed for individuals 5 to 18-years-old, so it is appropriate for adolescents and young adults. Goldstein (2002) reviewed the instrument to determine its reliability, validity, and clinical utility. The author detailed several limitations, including positive and negative predictive power, subscale validity, characteristics of the normative sample, and rating scale properties. The author urges caution in incorporating this scale into a diagnostic protocol.

Finally, Baron-Cohen, Wheelwright, Robinson, and Woodbury-Smith (2005) presented a new diagnostic method called the Adult Asperger Assessment (AAA). This is not a singular diagnostic assessment, but rather a system for diagnosis. It consists of four sections each describing a group of symptoms as listed in the DSM-IV and an additional section describing prerequisites. Completion of the AQ and the Empathy Quotient (EQ; a 60 question self-assessment assessing empathy) is also incorporated. The authors knowingly undertook a conservative design to err on the side of under-diagnosis. Sensitivity and specificity studies have not been conducted.

The Autism Diagnostic Interview – Revised (Rutter, Le Couteur, & Lord, 2003) is "an extended interview designed to elicit a full range of information needed to produce a diagnosis of

autism and to assist in the assessment of related disorders." The individual who is being assessed must have a developmental level of at least two years. The interview takes approximately 1.5 to 2.5 hours to administer. There must be an informant who knew the individual well during the 4-5 year age period and beyond. The ADI-R includes the following sections: background questions, introductory questions, early development, language and communication functioning, social development and play, favorite activities/toys, interests and behaviors, and general behaviors (e.g., gait, aggression, self-injury). Reliability and validity studies have been conducted and have shown positive results, but upon close examination the participants in these studies have been representative of a very young population:

- 20 children between the ages of 36-59 months,
- 30 children with a mean age of 47 months for the autism group and 45 months for the nonautistic group,
- 22 participants ranging in age from 5 to 29 years,
- 53 children ranging in age from 2.2 to 5.7 years,
- 33 participants from 4.3 to 16.9 years,
- 50 children,
- 53 male participants with mean ages of 21 years for the autism group, 14 for the Asperger group and 14 for the conduct disorder group ((Rutter, Le Couteur, & Lord, 2003, pp. 40-41).

2.4.2 Autism Diagnostic Observation Schedule (ADOS)

The ADI-R and ADOS, along with clinical judgment, is considered the current gold standard in diagnosing ASD (Barbaro & Dissanayke, 2009; Gray, Tonge & Sweeney, 2008; Reaven, Hepburn, & Ross, 2008; Risi et al., 2006).

2.4.2.1 Description of the instrument

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials for individuals who have been referred because of possible autism or other pervasive developmental disorders. The ADOS consists of standard activities that allow the examiner to observe behaviors that have been identified as important to the diagnosis of ASD at different developmental levels and chronological ages. The ADOS incorporates the use of planned social occasions in which a behavior of a particular type is likely to appear. Structured activities and materials provide standard contexts in which social interactions, communication, and other behaviors relevant to ASD are observed (Lord, Rutter, DiLavore, & Risi, 2008).

The ADOS consists of four modules, each of which can be administered in 30-45 minutes. Each module has its own protocol, which contains a schedule of activities designed for use with children or adults at a particular developmental and language level, ranging from no expressive or receptive language to verbally fluent adults. Only one module is administered to an individual at a given point in time. The modules are labeled 1 to 4 and contain an number of activities, or presses. The examiner selects the module that is most appropriate for a particular child or adult on the basis of his/her expressive language skills and chronological age. See Table 3 for the suggested guidelines for selecting the most appropriate ADOS module. The four

ADOS modules provide social-communicative sequences that combine a series of unstructured and structured situations. Each situation provides a different combination of presses for particular social behaviors. (Lord, Rutter, DiLavore, & Risi, 2008).

Table 3. Suggested Guidelines for Selecting the Most Appropriate ADOS Module

ADOS Module	**Expressive Language Level**	
	Minimum	Maximum
1	No speech	Simple phrases
2	Flexible three-word phrases (i.e., regular, spontaneous, meaningful use of three-word utterances, including a verb)	Verbally fluent (i.e., producing a range of flexible sentence types, providing language beyond the immediate context, and describing logical connections within a sentence)
3	Verbally fluent (child/younger adolescent)	--
4	Verbally fluent (adolescent/adult)	--

Note. Adapted from Autism Diagnostic Observation Schedule: ADOS Manual, by C. Lord, M. Rutter, P. C. DiLavore, and S. Risi, 2008, p. 5.

Notes are taken during administration of each ADOS module. Overall ratings are completed immediately after administration, even if the session is videotaped. These ratings can then be used to formulate a diagnosis through the use of the diagnostic algorithm provided for each module. Thus, the ADOS provides a 30- to 45-minute observation period during which the examiner presents numerous opportunities for the individual being assessed to exhibit behaviors of interest in the diagnosis of ASD through standard “presses” for communication and social interaction.

According to the ADOS authors:

> Because the focus of the ADOS is on observation of social behavior and communication, the goal of the activities is to provide interesting, standard contexts in which interactions occur. Standardization lies in the hierarchy of behaviors employed by the examiner and the kinds of behaviors taken into account in each activity during the overall ratings. The activities serve to structure the interaction; they are not ends in themselves. The object of the ADOS activities is not to test specific cognitive abilities or other skills, but to present tasks that are sufficiently intriguing so that the child or adult being assessed will want to participate in social interchanges. In allowing opportunities for observation, what the examiner *doesn't* do (such as deliberately waiting to see if the participant will initiate and interaction or try to maintain it) is often as important as what he or she does (Lord, Rutter, DiLavore, & Risi, 2008, p. 2).

The ADOS does not include information about onset or early history. To receive a DSM-IV-TR or International Classification of Diseases-10 (ICD) diagnosis of autism, an individual must show evidence of restricted or repetitive behaviors and abnormalities before age 36 months. If the participant is not under age 3 years, then there is a need for additional historical information from teacher or parent report (such as in the ADI-R), and, in some cases, from more extensive observation (Lord, Rutter, DiLavore, & Risi, 2008).

It is important to distinguish between an ASD classification and an overall diagnosis. An overall diagnosis requires abnormalities in restricted, repetitive behaviors and early onset. Clinicians are encouraged to use all information, including ADOS scores and results of other assessments, such as the ADI-R, in final decisions (Lord, Rutter, DiLavore, & Risi, 2008).

In 2012, the ADOS-2 was released. The ADOS-2 offers revised algorithms and a new Comparison Score for Modules 1 through 3, a new Toddler Module, and updated protocols with clearer administration and coding guidelines for all modules. Modules 1 through 4 retain the same basic activities and codes, though some codes have been expanded and several new codes have been added. Modules 1 through 3 algorithms have been revised to achieve more accurate and useful results. Modules 1 through 3 also now have a new Comparison Score that allows the

administrator to compare the child's overall level of autism spectrum-related symptoms to that of children diagnosed with ASD who are the same age and have similar language skills (Western Psychological Services (WPS), n.d.).

2.4.2.2 Learning to administer the ADOS

The ADOS must be administered by an experienced and highly trained clinician. Training to administer the ADOS requires time, money, and commitment to practice. There are four steps to obtain essential competence:

1. Have prior education, training, and experience working with individuals with ASD, and experience with typical development and non-autism spectrum developmental disabilities
2. Take a Western Psychological Services (WPS) in-person clinical training workshop (2 days) or use the WPS Training Video/DVD and accompanying materials
3. Practice using the ADOS on cases that are not part of formal evaluations, become familiar with the assessment activities, and develop complete confidence in one's ability to apply the coding categories accurately.
4. Take a research training workshop (2.5 days) followed by exercises that establish coding accuracy to a specific criterion, if the user is to be involved in formal research (Western Psychological Services, n.d.; Lord, Rutter, DiLavoire, & Risi, 2008).

Trainings are offered twice a year at Weill Cornell Medical College (Weill Cornell Medical College, n.d.). There are a limited number of spots and admission into trainings can be competitive. Cost of training is significant, and increasing. In 2010, the cost for clinical training

was $400 and the cost for research training was $1,800. In 2012, the cost for research training increased to $2,750. This does not include the cost of the ADOS kit itself, which currently costs $1,995. It is apparent that training opportunities are relatively limited and potentially difficult to access, especially for small facilities in rural areas.

Examiners are encouraged to work in a team to practice consensus coding and check for reliability. According to the ADOS manual, "The ADOS is not an instrument that can be used appropriately without extensive practice. Even clinicians with substantial practice using the ADOS should arrange to jointly administer the schedule with other clinicians several times a year… in order to avoid 'drift' in scoring, particularly with more able participants" (Lord, Rutter, DiLavore, & Risi, 2008, p. 7).

2.4.2.3 ADOS research

Reliability: Domain scores and classifications

Reliability of individual items is described in detail in the ADOS manual (Lord, Rutter, DiLavore, & Risi, 2008). Lord et al. (2000) conducted psychometric analysis on the ADOS with a sample of 223 children and adults with ASD. Participants were roughly evenly divided between diagnoses of autism, PDD-NOS, and non-spectrum.

For reliability of domain scores and classification, intraclass correlations were computed across pairs of raters for algorithm subtotals and totals for each module separately and for the four modules combined. For the "Social Interaction" domain, intraclass correlations ranged from .88 to .97 for separate modules. Intraclass correlations for the "Communication" domain ranged from .74 to .90. For the "Communication-Social Interaction" total used in the algorithm, intraclass correlations ranged from .84 to .98. Intraclass correlations for the "Stereotyped

Behaviors and Restricted Interests" domain were somewhat lower, ranging from .75 to .90. Intraclass correlations for data pooled across modules are presented in Table 4 (Lord et al., 2000).

Table 4. Intraclass Correlations for Interrater and Test-Retest Reliability

	n	Social Interaction	Communication	Communication -Social Interaction Total	Stereotyped Behaviors and Restricted Interests
Interrater (all)	97	.93	.84	.92	.82
Live-Live	62	.92	.80	.90	.86
Live-Video	35	.92	.82	.91	.72
Test-Retest	27	.78	.73	.82	.59

Note. Adapted from Autism Diagnostic Observation Schedule: ADOS Manual, by C. Lord, M. Rutter, P. C. DiLavore, and S. Risi, 2008, p. 115.

Interrater agreement in diagnostic classification for autism versus nonspectrum comparisons based on the ADOS algorithm was 100% for Modules 1 and 3, 91% for Module 2, and 90% for Module 4. When PDD-NOS participants were included, agreement fell to 93% for Module 1, 87% for Module 2, 81% for Module 3, and 84% for Module 4.

The number of test-retest participants was very small, only 27. Test-retest also had the lowest reliability, ICC = .78. This is likely due to differences in participants from one test to the next. Children were included in the test-retest population, and generally children are learning and developing very quickly; a few months can have a substantial impact on behaviors, signs, and symptoms of ASD. It would be interesting to know if the test-retest reliability is higher using a more developmentally stable population (i.e., adults).

Validity

Validity of individual items is described in detail in the ADOS manual (Lord, Rutter, DiLavore, & Risi, 2008). In the Lord et al, (2000) psychometric analysis study, internal consistency was assessed using Cronbach's alpha. Cronbach's alphas were consistently highest for the "Social" domain (.86-.91 for each module), slightly lower for "Communication" (.74-.84) and lower for "Stereotyped Behaviors and Restricted Interests" (.63-.65 for modules 2 and 1; .47-.56 for modules 4 and 3, respectively) although still indicating good agreement. For the "Social-Communication" totals, Cronbach's alphas were very high (.91-.94) for all modules (Lord et al., 2000).

Receiver Operating Characteristic (ROC) curves were used to provide information concerning where to set cutoffs to indicate different diagnoses for each domain and for each total in each module (Lord et al., 2000). Table 5 depicts the distribution of participants according to the final ADOS algorithm classification and clinical diagnosis. Table 6 summarizes sensitivities and specificities.

Table 5. Distribution of Participants by ADOS Diagnosis and Overall Clinical Diagnosis

	ADOS Diagnosis		
Clinical classification	Autism	ASD	Other
Module 1			
Lower autism	20	0	0
Autism	19	1	0
PDD-NOS	11	5	1
Non-spectrum	0	1	16
Module 2			
Autism	20	1	0
PDD-NOS	8	8	2
Non-spectrum	1	1	14
Module 3			
Autism	21	0	0
PDD-NOS	12	4	4
Non-spectrum	0	1	17
Module 4			

Autism	13	1	1
PDD-NOS	6	6	2
Non-spectrum	1	0	14

Note. Adapted from Autism Diagnostic Observation Schedule: ADOS Manual, by C. Lord, M. Rutter, P. C. DiLavore, and S. Risi, 2008, p. 120.

Table 6. Sensitivities and Specificities for Different Comparisons across Modules

	Module 1 (n = 54)	**Module 2** (n = 55)	**Module 3** (n = 59)	**Module 4** (n = 45)
Autism and PDD v. Non-spectrum				
Sensitivity	97	95	90	90
Specificity	94	87	94	93
Autism v. PDD and Non-spectrum				
Sensitivity	100	95	100	87
Specificity	79	73	68	76
PDD v. Non-spectrum				
Sensitivity	94	89	80	86
Specificity	94	88	94	93
Autism v. Non-spectrum				
Sensitivity	100	95	100	93
Specificity	100	94	100	93

Note. Adapted from Autism Diagnostic Observation Schedule: ADOS Manual, by C. Lord, M. Rutter, P. C. DiLavore, and S. Risi, 2008, p. 121.

In a 2006 study, Ventola et al. compared four diagnostic measures, (1) ADOS, (2) ADI-R, (3) CARS, and (4) clinical judgment using DSM-IV criteria. Participants were 45 children with an average age of 22 months (range = 16-30 months). Results demonstrated agreement between the ADOS, CARS, and clinical judgment, but not with the ADI-R. (Children were not classified as having autism by the ADI-R due to a lack of repetitive behaviors and stereotyped interest.) The ADOS also showed very good sensitivity in identifying ASD in toddlers, (sensitivity = .972, specificity = .667, positive predictive value = .921).

In a similar study, Mazefsky and Oswald (2006) explored the diagnostic utility and discriminative ability of the ADOS, ADI-R, and GARS. Participants included 78 children between the ages of 22 months and 8 years. Results showed that the ADOS and ADI-R algorithm diagnoses led to fairly high rates of agreement with team diagnoses, with

inconsistencies consisting mostly of false positives. The GARS was not very effective at discriminating between children with various team diagnoses and consistently underestimated the likelihood of autism.

In 2007, Gotham, Risi, Pickles, and Lord published a study in which they revised the algorithms for modules 1, 2, and 3 in order to improve diagnostic validity. The dataset consisted of 912 cases with clinical diagnoses of autism (56% of entire sample), 439 with non-autism ASD (27%), and 279 with non-ASD developmental delays (27%). Children were divided by language level and age to yield more homogeneous cells. Items were chosen that best differentiated between diagnoses and were arranged into domains on the basis of multi-factor item-response analysis. Reflecting recent research, the revised algorithm now consists of two new domains, "Social Affect" and "Restricted, Repetitive Behaviors (RRB)," combined to one score to which threshold are applied, resulting in generally improved predictive value.

In another study, (Gray, Tonge, & Sweeny, 2008) the validity of the ADI-R and the ADOS in the assessment of preschool children with developmental delays was examined. Participants were 209 children aged 20-55 months; 120 children were diagnosed with autism. Results showed the ADOS performed better than the ADI-R in comparison to consensus clinical diagnosis.

Lord et al.'s (2000) ADOS psychometric analysis study consisted of 16 participants with autism, 14 participants with PDD-NOS, and 15 non-spectrum participants (total N = 45). Participants ranged in age from 10 to 40 years. For Module 4, the use of the three-threshold model yielded the highest sensitivity and specificity for the discrimination of autism and ASD from non-spectrum disorders (sensitivity = 90%, specificity = 93%). However, the use of the three-threshold model added little to the ability of the ADOS to differentiate autism and ASD

from other disorders when using the "Communication-Social Interaction" total (sensitivity = 87%, specificity = 76%) or the "Social Interaction" domain alone (sensitivity = 100%, specificity = 93%). Adding a cut-off for the "Stereotyped Behaviors and Restricted Interests" domain increased specificity to 93% for the discrimination of autism from all other groups, but decreased sensitivity to 46% (Lord, Rutter, DiLavore, & Risi, 2008).

Few studies examine the validity of the ADOS Module 4. de Bildt et al. (2004) attempted to describe the interrelationship between ADI-R and ADOS in children and adolescents with mental retardation (MR), and to study the criterion-related validity between a clinical DSM-IV-TR classification and the ADOS and ADI-R in participants with MR. Participants were 184 children and adolescents, (ages 5 to 20 years old), with mild to profound MR. The authors found that the combination of ADI-R and ADOS identified ASD most appropriately. Both instruments seemed to be of great value in the diagnostic process of PDD in children and adolescents with MR.

2.5 SUMMARY AND CONCLUSIONS

Adolescents and adults with ASD do not meet the criteria for mental retardation, but do experience profound impairments in social interaction and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. Impairments in communication are also common, although they manifest as abnormalities in speech and prosody as opposed to an absence or significant delay in language. Individuals with ASD are also likely to experience sensory processing abnormalities, a lack of symbolic or imaginative use of materials, symptoms of Attention Deficit/Hyperactivity Disorder, anxiety, and depression.

It is crucial to note that ASD is an extremely heterogeneous population. Every individual with ASD is different, not everyone will demonstrate all of the above signs and symptoms in the specific ways described.

Diagnosis of an ASD is typically done in early childhood, through a combination of clinical judgment, behavioral presentation, and developmental history. It is not always an obvious diagnosis; genetic syndromes, mental retardation, schizophrenia, ADHD, anxiety, and depression can all display symptoms that overlap with those of an ASD, thus delaying the correct diagnosis and treatment. Many standardized assessments have been created recently in order to increase diagnostic validity. The Autism Diagnostic Observation Schedule (ADOS), a semi-structured, standardized assessment of communication, social interaction, and imaginative use of materials, in combination with an ADI-R, has been deemed the "gold standard" in ASD diagnosis.

Unlike many other diagnostic instruments, the ADOS Module 4 is appropriate for adolescents and adults who are verbally fluent. The ADOS had been demonstrated to be reliable and valid in a variety of clinical populations, however there is very little research regarding the validity of the ADOS in adults. Diagnosing ASD in adults who have been un- or misdiagnosed throughout their lives is a challenge. Application of this gold standard is necessary for diagnostic accuracy, but access to this assessment is limited by the relatively few number of trained ADOS Module 4 administrators compared to the number of adults with possible ASD in need.

3.0 CHAPTER 3: DEVELOPMENT, USABILITY, AND FIDELITY ASSESSMENT OF A REMOTE ADOS MODULE 4 ADMINISTRATION SYSTEM

Telehealth is a broad term that includes telerehabilitation. Telerehabilitation is defined as the application of telecommunication technology for supporting rehabilitation services (Russell, 2007). Telerehabilitation (TR) is experiencing rapid growth and is fast becoming a significant segment of telemedicine and e-health (Parmanto & Saptono, 2008). The underlying assumption of telerehabilitation is that the barriers imposed by distance can be minimized by facilitating remote access to professional expertise (Bashshur, 2002; Winters, 2002). Importantly, telerehabilitation technologies must be tailored to the specific clinical activities, which include teleeducation, teleconsultation, and telesupport, teleevaluation, and teleassessment (Winters, 2002).

In the following discussion, teleassessment will be defined and examples and non-examples provided. Remote assessment is not new, with current practice using mainly a single mode of telecommunication (typically videoconference) over a dedicated line. An overview of studies examining the reliability of remote assessment of cognitive functioning, psychiatric symptoms, and speech/language disorders will be provided. Advantages and disadvantages of teleassessment will be summarized.

This research focused on clinical usability and fidelity of a remote administration of a standardized ASD assessment. Researchers worked in conjunction with a Health Information

Management (HIM) development team that was responsible for technical development of the teleassessment system. The instruments used in this research will be described in detail, including the adult ASD assessment, the Autism Diagnostic Observation Schedule (ADOS) Module 4; and the system that will be used to deliver the ADOS Module 4 remotely, the Versatile and Integrated System for Telerehabilitation (VISYTER).

There were two specific aims of this study. Aim 1 was to identify procedural and technical usability concerns to provide formative feedback to improve the remote ADOS administration system. Aim 2 was to assess fidelity to standard administration and evaluate the degree to which the adapted version adhered to standard administration conditions. Results identified which aspects of the system could be adjusted to better match standardized administration conditions and were incorporated into system enhancement. Outputs of this research are two manuals: Technical Guidelines and Administration Guidelines for ADOS remote administration (See appendices C and D).

3.1 TELEASSESSMENT

3.1.1 Methods

The Ovid MEDLINE, Health and Psychosocial Instruments (HAPI), and PsycINFO databases were searched using terms including telehealth, telemedicine, telerehabilitation, assessment, and reliability, resulting in 62 articles. Prominent journals, including *Telemedicine and e-Health* and *Journal of Telemedicine and Telecare*, were browsed using the search terms for relevant articles. The reference sections of all important articles were searched for further resources and also for

prominent authors and researchers in the field. In addition, the Telerehabilitation Bibliography (Spring 2007) provided to the American Telemedicine Association (ATA) Telerehabilitation Special Interest Group as a member service was browsed for articles pertinent to remote assessment.

Included literature is English language, peer-reviewed, and published within the last 10 years. Excluded literature examined remote assessment in strictly medical (e.g., diagnosing stroke) or physical (e.g., physical therapy) capacities.

3.1.2 Teleassessment background: Telehealth and telemedicine

Telehealth is a generic term used for designation of fields including telemedicine, telerehabilitation (Seelman & Hartman, 2009), and teleassessment. Telemedicine is defined as:

> The delivery of healthcare services, where distance is a critical factor, by all healthcare professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of healthcare providers, all in the interest of advancing the health of individuals and communities" (Scalvini, Vitacca, Paletta, Giordano, & Balbi, 2004, p. 226).

As long as technology has existed, so has the attempt to administer health services remotely. In the 1880s, soon after the invention of the telephone, doctors experimented with the use of telecommunication technologies in managing medical practices (Scalvini, et al., 2004).

Modern telemedicine, beginning in the late 1960s and early 1970s, can be divided into the three major periods or eras, each characterized by a significant advance in technology. First was the telecommunications era, which depended on broadcast and television technologies. Technologies were complex, cumbersome, unreliable, and it was difficult to integrate audio and video. Next was the digital era, which emerged in the late 1980s. The Integrated Service Digital

Network (ISDN) technology, which allows simultaneous transmission of voice, video, and biometrics data, was the foundation of this era. Finally, we have recently entered the internet era. The internet allows open access to a global-communication environment and is relatively inexpensive, ubiquitous, and accessible (Bashshur, 2002).

Telemedicine can be classified on the basis of the mode of operation or the basis of application (Scalvini et al., 2004). The mode of operation is either store-and-forward or real-time. Store-and-forward mode uses still digital images of a patient for the purpose of rendering a medical opinion or diagnosis, and includes the asynchronous transmission of clinical data. (Common types of store-and-forward services include teleradiology, telepathology, and teledermatology.) Real-time mode involves a live interaction between a patient and a physician when they do not share a physical location.

When classifying telemedicine on the basis of application, it may be useful to consider Parmanto and Saptono's (2008) map of telemedicine services on an intensity-duration quadrant model (Figure 3). The intensity continuum depicts the amount of information exchanged, typically measured by the size of the files or speed/resolution of video required. The duration continuum depicts the length of the interaction, from a brief, singular encounter to long-term or lifespan services. Some applications of telemedicine are high intensity but short duration. These applications, such as teleradiology and telepathology, are considered traditional telemedicine applications. In the opposite quadrant, low intensity and long duration services require low-intensity interactions between a client and clinician, but are conducted over a long period of time, such as telemonitoring or telehomecare.

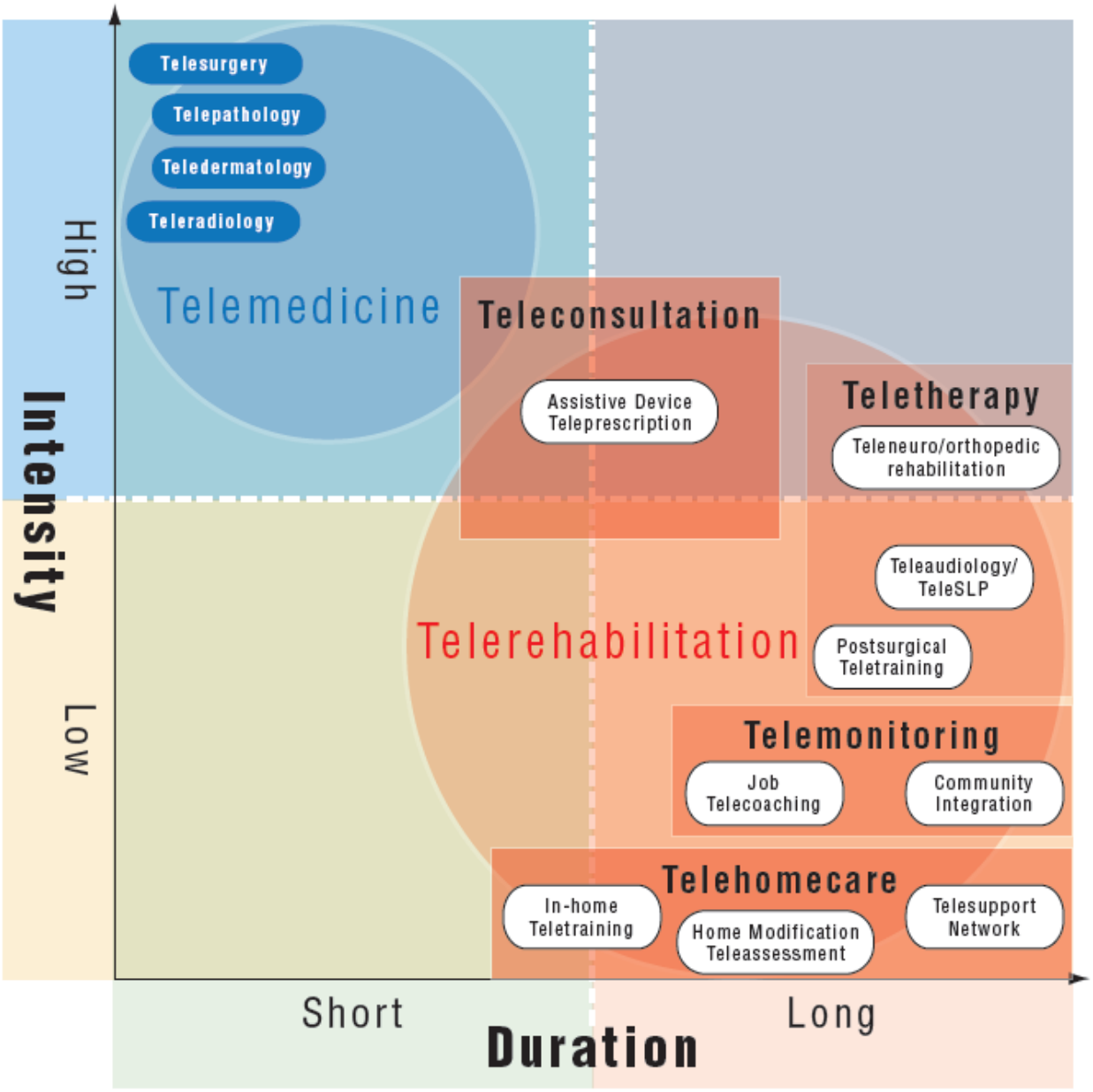


Figure 3. Map of telemedicine services in intensity-duration quadrant model. From "Telerehabilitation: State-of-the-Art from an Informatics Perspective," by B. Parmanto and A. Saptono, 2008, *International Journal of Telerehabilitation, 1* (1), p. 77.

Telerehabilitation represents a relatively new field in telemedicine. It emerged in 1997 when the National Institute on Disability and Rehabilitation Research (US Department of Education) created a new Rehabilitation Engineering Research Center (RERC) in the

Telerehabilitation. Telerehabilitation emphasizes "the delivery of conventional clinical services, with a special focus on research that will yield access to service in underserved (e.g., rural) geographic areas" (Winters, 2002, pp. 288-289). Russell (2007) simply defined telerehabilitation as the application of telecommunication technology for supporting rehabilitation services. In 2010, the American Telemedicine Association (ATA) defined telerehabilitation as the "delivery of rehabilitation services via information and telecommunication technologies, i.e., assessment, monitoring, intervention, supervision, education, consultation, and counseling." Telerehabilitation services may include, but are not limited to: consultations, homecare, monitoring, therapy, and direct patient care delivered to locations including home, community, health care facilities, and work settings (Seelman & Hartman, 2009). Rehabilitation interactions between the healthcare provider or therapist and client vary depending on service, but are generally low-intensity and conducted over a longer period of time, putting them in the lower right quadrant of Parmanto and Saptono's (2008) intensity-duration quadrant model, (see Figure 3).

Teleassessment, like telerehabilitation, may be considered a subspecialty of telemedicine, (see Figure 4). According to the Executive Summary of the NIH-sponsored Report of the Task Force on Medical Rehabilitation Research, two of the three overriding needs deemed critically important to the rehabilitation field's progress concern the process of assessment: (1) develop meaningful quantitative measures of impairments, disabilities, and handicaps, and of the outcome of rehabilitation interventions, and (2) develop standards and guidelines for the design and application of evaluative tools (Cole & Edgarton, 1990). Telepsychiatry is the application of videoconferencing technology for mental health care. Diagnostic assessment and cognitive and

mental status assessment have long been considered an important application of telepsychiatry (Frueh et al., 2000) and telerehabilitation (ATA, 2010).

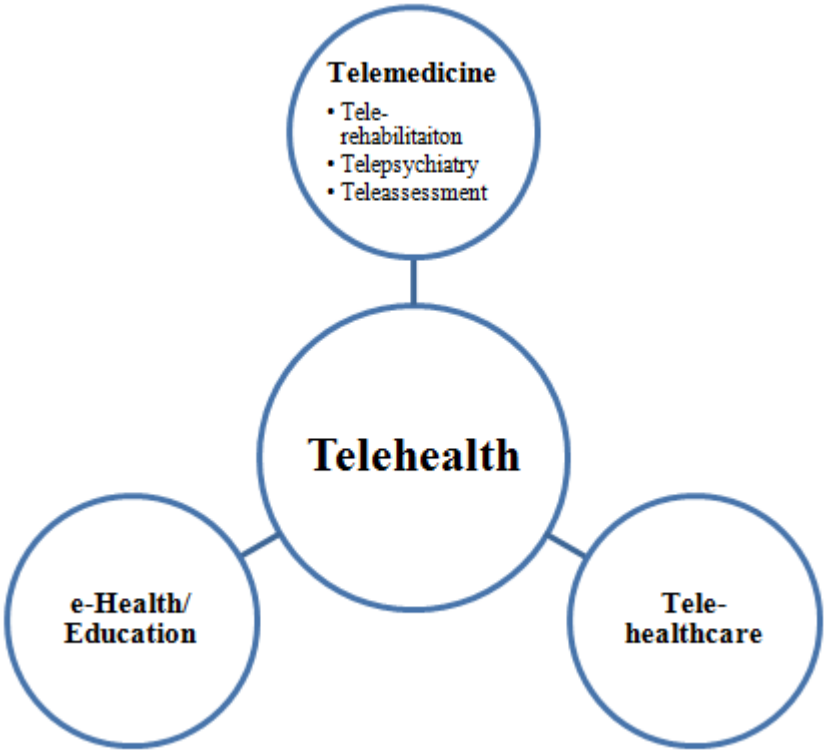


Figure 4. Telehealth includes telemedicine, telehealthcare, and e-health/education; telemedicine includes telepsychiatry, telerehabilitation, and teleassessment.

Assessment is a conceptually broad term referring to the processes and tools used in the measurement of human subjects. Assessment, or psychological measurement, is concerned with the abstract aspects of human behavior, (e.g., intelligence, personality), which are inferred from objective, observable behaviors (Bolton & Brookings, 2001). Teleassessment, therefore, may be defined as: The remote administration of systematic procedures for observing and describing behaviors with the aid of numerical scales or fixed categories, through use of interactive videoconferencing between a client (and usually a technician) at a local site and a remotely located assessment expert.

Referring back to Parmanto and Saptono's intensity-duration quadrant model (Figure 3), teleassessment is most similar to teleconsultation. Teleconsultation is defined as a standard "face-to-face" telemedicine model using interactive videoconferencing between a local provider and client a remote rehabilitation expert to gain access to specialized expertise. Teleassessment is likely to be relatively high intensity, as significant amounts of visual and audio data must be conveyed in real-time; and medium duration, as some assessments (e.g., Mini-Mental State Examination), can be completed in 5-10 minutes, while others, (e.g., neuropsychological battery) occur over the course of one or several days.

Teleassessment is not to be confused with other technology-based assessment tools. Specifically, teleassessment neither is web-based psychological assessment nor is it computerized versions of neuropsychological tests. Web-based psychological assessment involves taking (typically) brief questionnaires and rating scales designed for evaluation of personality and clinical constructs that are traditionally administered via paper and pencil and making them into a form available on an internet page. The respondent views and completes the form from a computer with internet access, and the data are then automatically scored and presented to the test-taker or transferred to the test administrator (Buchanan, 2002). The number of available online psychological assessments is large and increasing. The sites vary considerably in content, quality, and function[1]. Buchanan (2002) pointed out several potential problems for web-based assessment, including the possibility of interactions between the construct being tested and medium used to test it, the fact that online respondents tend to report higher levels of negative affect than paper-and-pencil test-takers, and unaddressed professional

[1] For an example of a generally well-respected site, see the Authentic Happiness Positive Psychology website (http://www.authentichappiness.sas.upenn.edu/default.aspx); it offers a variety of web-based psychological assessments claiming to help individuals to gain personal insights.

and ethical issues (p. 151). Regardless of the potential advantages or disadvantages of online assessments, they are separate from teleassessment, primarily because they are always self-administered and sometimes self-interpreted. Unlike web-based psychological assessments, teleassessment is not possible without a real-time interaction between a trained clinician and a client. Teleassessment activities are typically more complex than administering questionnaires. Furthermore, teleassessment requires observation of behaviors that occur throughout the assessment and not just analysis of the results of administered activities.

Teleassessment is also not a computerized version of a test. Software programs that assist in administration and scoring of the complex tasks have been developed, (e.g., Wisconsin Card Sort Test). Clinicians have the option of administering the test on-screen or by entering the client's item responses from a previous administration. While a remote clinician may use a computerized version of a test during the course of a teleassessment, the two concepts are not equivalent. First, a computerized version of a test may be administered in person or remotely, as its main goal is to aid standardized administration and scoring. Computerized versions of tests are administration tools, a clinician must still be available to provide direction, observe performance, provide prompts, and interpret results.

3.1.3 Teleassessment of cognitive functioning

Administering tests of cognitive functioning remotely is one way to improve rural accesses to healthcare. Especially given the aging demographic in these locations, the need for convenient, reliable, and valid cognitive assessment in these areas is well established (Ciemins, Holloway, Coon, McClosky-Armstrong, & Min, 2009; McEachern, Kirk, Morgan, Crossley, & Henry,

2008). The reliability of remote assessment of the Standardized Mini-Mental State Examination (MMSE), a screening questionnaire, has been evaluated several times in recent literature.

Ciemins et al. (2009) attempted to determine the reliability of MMSE administrations via telehelath (i.e, remote administration), focusing on the auditory and visual test components. They enrolled 72 participants with Type II diabetes. The MMSE was administered one time through the Eastern Montana Telemedicine Network (EMTN), which was initiated in 1993 to improve access to medical and behavioral specialty services through the use of interactive videoconferencing. (No further information about the technology used is provided.) In an interesting design, the MMSE was administered only once, remotely, but the patient responses were recorded by both the remote administrator and a face-to-face collaborator. Results showed that 80% of individual items demonstrated remote to in-person agreement of $\geq$ 95%, and all items were $\geq$ 85.5% in agreement (Ciemins et al., 2009). However, due to the design, only the differences between remote and in-person scoring were documented; differences in performance (that would result in different scores) that were due to the administration method (remote vs. in-person), were lost.

McEachern et al. (2008) also examined whether MMSE scores were comparable when administered in-person and remotely. Participants in this study were elderly individuals referred to a memory clinic. Portable, high performance videoconferencing equipment was used to administer the remote assessments. The 768 kbps baseline speed provided a real-time connection that operated across a private IP network with security measures in place. The design was test-retest: after an initial assessment, patients were seen in follow-up at six and 12 weeks. Participants were randomly assigned to receive either the six or 12 week follow-up assessment remotely. Results showed that MMSE scores did not differ significantly between remote

assessment (22.34 ± 6.35) and in-person (22.70 ± 6.51). In a similarly designed study, Loh et al. (2004) found that the correlation between face-to-face and remote MMSE scores was 0.90.

Gualtieri and Johnson (2006) developed CNS Vital Signs (CNSVS), a battery of computerized neuropsychological tests. CNSVS is composed of well-established tests including verbal and visual memory, finger tapping, symbol digit coding, the Stroop Test, a test of shifting attention, and the continuous performance test. In a concurrent validity study, the performance of participants on CNSVS to their performance on conventional neuropsychological tests and on another computerized neurocognitive test was compared. No information was provided on the technology used to administer CNSVS. Participants were 144 individuals with various neuropsychiatric disorders and 36 neuro-typical individuals. Researchers found that when the tests in CNSVS were compared to conventional neuropsychological tests, moderate correlations were found in tests of memory, perceptual-motor speed (coding) and executive function. CNSVS tests were moderately well correlated with tests of psychomotor speed (finger tapping and coding) and executive function on the other computerized neurocognitive test.

Jacobsen, Sprenger, Andersson, & Krogstad (2003) evaluated the reliability of administering a broader neuropsychological assessment remotely. The researchers choose 12 measures covering eight cognitive domains: visuomotor speed, auditory attention, verbal memory, nonverbal memory, visual perception, verbal ability, attention, and information processing. Participants were 32 neuro-typical volunteers without any known history of neurological or psychiatric illness. In a cross-over design, the participants were tested over two sessions within the same day, one face-to-face and another via videophones. The videophones were a Tanberg 5000 located at the psychologist's office and a Polyspan View Station at the participant's location. A 384 kbit/sec transmission was required for sufficient resolution. For

most of the measures sampled, the in-person and remote scores were highly correlated (reliability coefficients ranging from 0.37 to 0.86 with a median value of 0.74) (Jacobsen et al., 2003).

Other studies have demonstrated similar findings with neuro-typical volunteers, participants with histories of alcohol abuse, and elderly nursing home residents. (Grob, Weintraub, Sayles, Raskin, & Ruskin, 2001; Hildebrand, Chow, Williams, Nelson & Wass, 2004; Kirkwood, Peck, & Bennie, 2000) In addition, Hildebrand et al. (2004) and Kirkwood et al. (2000) found that participants were comfortable with the technology and most participants expressed high overall satisfaction with the remote administration.

3.1.4 Teleassessment of psychiatric symptoms

Telepsychiatry is a growing field focused on the delivery of psychiatric services at a distance via telecommunications and information technology (Grob et al., 2001). Assessment is often a part of these services.

A commonly used assessment is the Brief Psychiatric Rating Scale (BPRS). Reliability of the BPRS administered remotely was assessed in three studies using three different methods. Grob et al., (2001) administered the BPRS to 27 elderly nursing home residents two times. Half of the participants received both assessments in-person (in-person group) and the other half received one assessment in person and on assessment remotely (remote group). The communication between the interviewer and the participants occurred through a VTEL desktop conferencing unity. The units were connected by ISDN lines and transmitted at a speed of 384 kb/sec. The researchers found intraclass correlations (ICCs) on the BPRS of 0.81 for the remote group and 0.49 for the in-person group; there was not a statistically significant difference in ICC for the remote group compared to the in-person group.

Jones, Johnston, Reboussin, & Vaughn (2001) also examined the reliability of telemedicine ratings compared with face-to-face ratings. Their participants were 30 geriatric patients recruited from an adult psychiatry unit. To administer the remote assessments, they used a commercially available videoconferencing product, "ProShare" version 2.0 (Intel Corporation). A single ISNDN line with a bandwidth of 126 kb/sec provided dial-up connection between the two computers. This system provided a video image that was approximately four square inches. In this study, the assessment was administered remotely by a telemedicine interviewer and scored by the telemedicine interviewer and by two observers, one located with the participant (face-to-face observer) and one located with the administrator (remote observer). The ICC between the telemedicine interviewer and the face-to-face observer was 0.83. The ICC between the telemedicine observer and the face-to-face observer was 0.89.

Depression has also been evaluated at a distance. The reliability of remote administration of the Geriatric Depression Scale (GDS) was evaluated in two studies. Psychiatric assessment was found to be as reliable when interviews were conducted remotely as when they were conducted in person; ICCs were never below 0.78 (Grob et al., 2001; Loh et al., 2004). These results are especially impressive because the participants were elderly individuals who are often not as comfortable with technology as younger individuals.

3.1.5 Teleassessment of speech/language disorders

A number of studies have used videoconferencing to assess speech and language skills. Research articles included in this analysis included 11-44 participants with cognitive-communication, language, and/or speech impairments of varying degrees. Results have been encouraging; no studies have found significant differences between the face-to-face and remote

administration conditions of a variety of speech-language assessments (Brennan, Georgeadis, Baron, & Barker, 2004; Georgeadis, Brennan, Barker, & Baron, 2004; Hill et al., 2006; Hill, Theodoros, Russell, & Ward, 2009a; Hill, Theodoros, Russell, & Ward, 2009b; Theodoros, Hill, Russell, Ward, & Wootton, 2008).

Several of these studies also evaluated user satisfaction with the remote assessment system. Generally, results indicated high levels of satisfaction with the remote assessment. In Hill et al.'s (2009a) study, all of the participants indicated they would be "happy to participate in an internet session again," that it would be "more convenient to access services via the internet," and that they were "confident with the results from the session." In Hill et al.'s (2009b) study, all of the participants were "comfortable" or "very happy" with the remote assessment session, and all of the participants rated their overall satisfaction as "more than satisfied" or "very satisfied." Similarly, Theodoros et al. (2008) found that all participants were at least "satisfied" with the remote administration, while 67% were "more than satisfied" or "very satisfied." Finally, the participants in Georgeadis et al.'s (2004) study expressed a high level of acceptance of the remote assessment. Interestingly, participants with traumatic brain injuries (TBI) responded less favorably then participants with left- or right-hemisphere cerebrovascular accident (LCVA/RCVA). (TBI sample comment: "It was harder to pay attention. It was really easy just to look away from the computer and not listen. A couple of times I was looking at something else and didn't hear half the story." LCVA sample comment: "I felt more comfortable without the clinician next to me." RCVA sample comment: "It could be convenient for some who are not able to get to the therapist." [Georgeadis et al., 2004, pp. 651-652]).

3.1.6 Strengths and potential limitations of teleassessment

3.1.6.1 Strengths

Improved access

There are several advantages to teleassessment, the primary being that it improves access to needed health services by reducing time and distance. According to Miller, Elliott, Long, Mazenac, & Moder (2006) "The growth in telehealth technology has provided an opportunity for isolated healthcare practitioners in rural communities to have the advice and consultation of specialists in the field and provide a more detailed and specialized contribution to the delivery of healthcare for adults with developmental disabilities" (p. 137). Bashshur (2002) echoed this conclusion with the following observation:

> By virtue of its distributive capacity, telemedicine can obviate or reduce most travel distance, travel time, and some appointment delay to care. In theory, other things being equal, access to both specialty and primary care would be available regardless of the relative location of the patient. Thus, the need among patients to travel for specialty care, *especially diagnosis* [emphasis added], would diminish (p. 7).

Improved quality

Telemedicine may promote coordination and continuity of care because it allows for ready availability of comprehensive information on clients regardless of site of care (Bashshur, 2002). Clinicians working with a client all have access to them most recent progress reports, status updates, and assessment outcomes, regardless of physical location.

In some situations, telemedicine may not only be equal to face-to-face assessment, but superior, especially if it results in more accurate or timely diagnosis and intervention implementation. Changes in routine such as traveling long distances to an unfamiliar environment, sitting in a waiting room, and interacting with a variety of strangers, can be

stressful, especially for individuals with developmental disabilities. Excessive amounts of stress and anxiety can result in the clinician not receiving an accurate impression of how a client thinks, acts, and responds on a day-to-day basis. It is possible that by increasing ease of access to assessment services, clinicians may get a more accurate impression of the client being assessed.

Telemedicine services can be designed and implemented with the users in mind. Demographic (e.g., age, education, technology experience) as well as disability (e.g., deficits in language, cognition, motor function, vision, voice) factors can be taken into account when developing telemedicine services, thus improving access to a wider range of telerehabilitation services (Brennan & Barker, 2008). Clients should perceive that the system has been set up to serve their interests.

Reduced health-care costs/cost containment

The introduction of telehealth technology offers access and availability of expertise at minimal costs (Miller et al., 2006). Teleassessment can help contain cost inflation by providing assessments to remote patients in their home communities. The cost at a local facility is likely to be less than that at urban care centers. Remote assessment may also reduce "over treatment" or replication of services as a result of access to extensive information about patients in electronic form (Bashshur, 2002).

In a 2003 study, Hassal, Wootton, and Guilfoyle calculated the costs of conducting assessments via videoconferencing versus face-to-face with residents of a rural facility for elderly people. Over the course of at three-month pilot study, they calculated that the cost of a videoconference assessment would be $84.93, compared to $90.25 for a face-to-face assessment.

They also found that the more the workload increased, the greater the financial viability of this approach of service delivery.

Cost savings are often shared. According to Seelman and Hartman (2009), "Patients have reductions in waiting time, time away from work and travel time. Third party payers reduce reimbursement for travel and provide more timely and appropriate treatment that averts costly complications. Providers' costs are reduced through efficiencies in the care process" (p. 51).

3.1.6.2 Potential limitations

Reliability and validity

The most important question to ask of teleassessment is whether or not it is valid. If a remote assessment does not evaluate the same constructs as face-to-face assessment, than it is useless despite any other potential benefits. Researchers have pointed out there is the possibility of an interaction between the construct being tested and the medium used to test it (Buchanan, 2002). Scientifically rigorous reliability and validity studies must be carried out on remote assessment tools before they are determined to be valid and used in a clinical population.

Further affecting reliability, individuals who are not comfortable with technology may respond differently to measures administered remotely versus administered face-to-face. "Technophobia" may limit the appropriateness of teleassessment, especially in populations that are characteristically unfamiliar or uncomfortable with technology, (e.g., the elderly).

Training clinicians

Many clinicians may not be at ease with technology. Guilfoyle, Wootton, Hassall, Offer, Warren, and Smith (2003) conducted a study in which they examined the reliability of allied health assessments delivered by videoconference to a residential facility for elderly people. Despite the fact that care plans formulated via videoconferencing were highly similar to those formulated in face-to-face assessment, the therapists' mean ratings for the efficiency and suitability of videoconferencing for assessment were significantly lower than for face-to-face, and their ratings for the adequacy of their care plans was significantly lower for videoconferencing. (However, studies have demonstrated generally high rates of patients' and clinicians' satisfaction with telepsychiatry; Frueh et al., 2000.)

Grosch, Gottlieb, and Cullum (2011) wrote that there is a general ethical principle that clinicians only practice within their areas of expertise. Clinicians who plan to practice teleassessment have a requirement to develop expertise not only in their specific areas of practice, but also in factors related to teleassessment, such as information technology and computer security. This training may someday be regularly incorporated into graduate training.

Privacy and confidentiality

Privacy and confidentiality are important ethical issues in the field of rehabilitation. Teleassessment provides different privacy concerns from those in face-to-face assessment. In face-to-face assessment, a physical document is created that must be stored and shared according professional ethical guidelines. In remote assessment, there is an electronic document, and also often a recording captured by the video system that links the clinician with the remote client. Digital versions of sessions may provide opportunities for therapeutic interventions, education, and research, but are also a challenge in terms of confidentiality and privacy. Parmanto and

Saptono, (2008), in a discussion of telerehabilitation from an informatics perspective, simply stated that "it is important that TR [telerehabilitaiton] systems be developed in such a way that all users feel as comfortable and secure using them as they do when seeing a clinician in person" (p. 80). Some clients will understandably have concerns regarding confidentiality. Full explanations of the technology and procedures may ease some anxieties (Frueh et al., 2000).

Cost and reimbursement

Cost and reimbursement issues are among the most frequently addressed in the literature (Seelman & Hartman, 2009). As previously discussed, teleassessment has potential to reduce costs, but the evidence is limited. However reduced the costs, many clients still will be unable to afford teleassessment without health insurance reimbursement. In line with the main advantage of teleassessment, the primary reason telemedicine is reimbursed is to make services available where there is no local provider (Schmeida, McNeal, & Mossberger, 2007). As of 2007, telemedicine reimbursement, in varying degrees, was provided by public payers, Medicare and Medicaid, private payers (fee for service), Managed Care (both public and private), and special payers such as government and worksite (Waters, 2007). Telemedicine is currently most accepted in the fields of home health, psychiatry, and neurology, (Hersh, Hickam, Servrance, Dana, Krages, & Helfand, 2006). As of 2007, seven states reimbursed telepsychology and four reimbursed for other telerehabilitation services including speech/language therapy, physical therapy, and occupational therapy (Schmeida, McNeal, & Mossberger, 2007).

Legal and ethical considerations

To reduce liability issues, it is necessary to review the nature of the telehealth medium of clinical service with the client, client's family, and involved professionals. Informed consent,

confidentiality, and privacy issues must be understood and reviewed. Compliance with all state and federal regulations and requirements must be made. Risk assessment for liability must be reviewed (Miller et al., 2006).

Licensure and certification portability

Licensure and certification issues, especially across state and national borders, are sure to be prominent issues as telerehabilitation applications continue to grow. If the clinician's practice and the client's residence are not in the same state, issues related to licensure, malpractice insurance coverage, and billing may generate confusion. States and insurance companies all have different rules and standards governing telehealth, and these are likely to change rapidly over the coming years. When developing administrative procedures, it will be especially important for program designers to consider these cross-state assessment situations (Frueh et al., 2000).

3.1.7 Summary and conclusions

Teleassessment is the remote administration of systematic procedures for observing and describing behaviors with the aid of numerical scales or fixed categories, through use of interactive videoconferencing between a client at a local site and a remotely located assessment expert. Use of teleassessment in the administration of tests of cognitive function, psychological symptoms, and speech/language pathology have shown generally high levels of reliability. Its primary strength is that it improves access to services for underserved and rural clients, and it also has the potential to improve the quality of services. Reliability and validity of remotely

administered assessments must be established and general policy issues resolved before teleassessment is widely implemented.

Future directions of teleassessment involve making improvements over current practice of using mainly a single mode of telecommunication over a dedicated line. In comparison, a multimodal integrated environment approach will allow for richer interactions that are closer to face-to-face exchanges. New technology allows for the development of an integrated portal that combines videoconferencing, stimuli presentation, and other services. The availability of open-source technologies on the internet provides a rich integrated environment for low-cost development. As a result, an integrated telerehabilitation portal is significantly less expensive than the proprietary videoconferencing currently used in teleassessment. An easy to use and low-cost integrated system can potentially be deployed to larger numbers of users. The use of the familiar internet as the user interface for the integrated portal will also make it more intuitive and easier for clinicians and clients. The development and capacities of such an integrated telerehabilitation system will be discussed next, after a description of the adult ASD assessment that will use the system to be administered remotely.

3.2 INSTRUMENTATION

3.2.1 Autism Diagnostic Observation Schedule (ADOS) Module 4

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials for individuals who have been referred because of possible autism or other pervasive developmental

disorders (Lord et al., 2008, p. 1). The ADOS consists of standard activities that allow the examiner to observe behaviors that have been identified as important to the diagnosis of ASD at different developmental levels and chronological ages. Structured activities and materials provide standard contexts in which social interactions, communication, and other behaviors relevant to ASD are observed (Lord et al., 2008).

The ADOS consists of four modules. Module 4 was designed for adolescents and adults who are verbally fluent, (i.e., producing a range of flexible sentence types, providing language beyond the immediate context, and describing logical connections within a sentence). Module 4 consists of the following 10-15 activities, (activities marked with an asterisk are optional): Construction Task*, Telling a Story From a Book, Description of a Picture*, Conversation and Reporting, Current Work or School*, Social Difficulties and Annoyance, Emotions, Demonstration Task, Cartoons*, Break, Daily Living*, Friends and Marriage, Loneliness, Plans and Hopes, and Creating a Story.

The activities focus on social, communicative, and language behaviors important in the diagnosis of ASD. They combine unstructured conversation with a variety of presses (i.e., cues) for particular kinds of social and communicative behavior. The general format of the administration is meant to create an interaction that appears natural, during which pre-planned occasions for certain behaviors arise (Lord, et al., 2008, p. 79).

After the 45 to 60 minute assessment, overall ratings are assigned based on the participant's behavior throughout the entire evaluation. Coded items fall into five areas: (A) Language and Communication, (B) Reciprocal Social Interaction, (C) Imagination, (D) Stereotyped Behaviors and Restricted Interests, and (E) Other Abnormal Behaviors (Lord et al., 2008, p. 92). For an overview of coded items, see Table 7.

Table 7. Autism Diagnostic Observation Schedule Module 4 Coded Items

Grouping	Coded Items (Items to be Rated)
Language and Communication	1. Overall Level of Non-Echoed Language 2. Speech Abnormalities Associated With Autism 3. Immediate Echolalia 4. Stereotyped/Idiosyncratic Use of Words or Phrases* 5. Offers Information 6. Asks for Information 7. Reporting of Events 8. Conversation* 9. Descriptive, Conventional, Instrumental, or Informational Gestures* 10. Emphatic or Emotional Gestures* *Communication Total**
Reciprocal Social Interaction	1. Unusual Eye Contact* 2. Facial Expressions Directed to Others* 3. Language Production and Linked Nonverbal Communication 4. Shared Enjoyment in Interaction 5. Communication of Own Affect* 6. Empathy/Comments on Other's Emotions 7. Insight 8. Responsibility* 9. Quality of Social Overtures* 10. Quality of Social Response* 11. Amount of Reciprocal Social Communication* 12. Overall Quality of Rapport *Social Interaction Total** *Communication + Social Interaction Total**
Imagination	1. Imagination/Creativity*
Stereotyped Behaviors and Restricted Interests	2. Unusual Sensory Interest in Play Material/Person* 3. Hand and Finger and Other Complex Mannerisms* 4. Self-Injurious Behavior 5. Excessive Interest in or References to Unusual or Highly Specific Topics or Objects or Repetitive Behaviors* 6. Compulsions or Rituals* *Stereotyped Behaviors and Restricted Interests Total**
Other Abnormal Behaviors	1. Overactivity/Agitation 2. Tantrums, Aggression, Negative or Disruptive Behavior 3. Anxiety
	*Diagnostic Classification**

Note. Asterisk (*) indicates item is on the algorithm; *italics* indicates item is a total score. Adapted from *Autism Diagnostic Observation Schedule: ADOS Manual*, by C. Lord, M. Rutter, P. C. DiLavore, and S. Risi, 2008, pp.92-100.

Items receive a code of 0, 1, 2, 3, 7, or 8. Codes 0 to 3 indicate presence and severity of abnormality associated with ASD, and codes 7 and 8 indicate other abnormalities or inability to score. Under each item is a list of the codes that can be assigned for that item, along with general principles and specific examples that would earn that code. There are also general coding conventions, detailed in Table 8.

Table 8. Autism Diagnostic Observation Schedule Coding Conventions

Code	Rating Description
0	Behavior shows no evidence of abnormality as specified.
1	Behavior is mildly abnormal or slightly unusual, but not necessarily grossly abnormal.
2	Behavior is definitely abnormal in the way specified. The severity for coding abnormality at this level varies according to the item.
3	Behavior is markedly abnormal in a way that interferes with the interview, or when the behavior is so limited that judgments about quality are impossible.
7	There is an abnormal behavior of a type that is not encompassed by the other ratings (i.e., it differs from normality on a dimension other than those specified).
8	Behavior in question did not occur and/or the rating is inapplicable.

Note. Adapted from *Autism Diagnostic Observation Schedule: ADOS Manual*, by C. Lord, M. Rutter, P. C. DiLavore, and S. Risi, 2008, p. 6.

The diagnostic algorithms are sets of rules that allow classification of participants as having the social and communicative deficits of autism or autism spectrum disorder (including atypical autism, PDD-NOS, and Asperger's). For the algorithm, scores of 3 on the protocol are converted to 2, and all scores other than 0-3 are converted to 0. Diagnostic classification is made on the basis of exceeding the threshold on each of two domains – "Social Interaction" and "Communication" – and exceeding a threshold for a combined "Communication + Social Interaction" total. Because the administration is completed in less than one hour, the ADOS does not offer an adequate opportunity to measure restricted and repetitive behaviors. Behaviors

are coded if they occur, but it is also possible that an individual who regularly expresses restricted and repetitive behaviors will not do so during the relatively brief administration. Thus, an ADOS classification provides algorithms based only on observation of social behaviors and communication (Lord et al., 2008).

3.2.2 Versatile and Integrated System for Telerehabilitation (VISYTER)

The Rehabilitation Engineering Research Center on Telerehabilitation (RERC-TR) developed the Versatile and Integrated System for Telerehabilitation (VISYTER). VISYTER is "a platform for building TR applications that takes into account the diverse settings and requirements of various rehabilitation services" (Parmanto et al, 2010, p. 939). The architecture of VISYTER combines three unique concepts to deliver telerehabilitation: a software application that can be installed easily, a set of off-the-shelf hardware to minimize cost, and a secure server system as the backbone of the service. VISYTER is an integrated system that provides both real-time and asynchronous communication channels to support the collaboration and delivery of rehabilitation service remotely.

At ADOS administrator and client sites, VISYTER runs on desktop computers. The two computer stations are connected by a broadband internet connection, with a minimum connection of 3 Mbps/768 kbps (downstream/upstream). This connection is expected to provide optimal performance at an affordable cost. Figure 5 illustrates this connectivity: one desktop computer station, located at the clinician site (e.g., University of Pittsburgh); one desktop computer station, located at the client site (e.g., rural clinic); and, a server for managing and coordinating all elements of the assessment process.

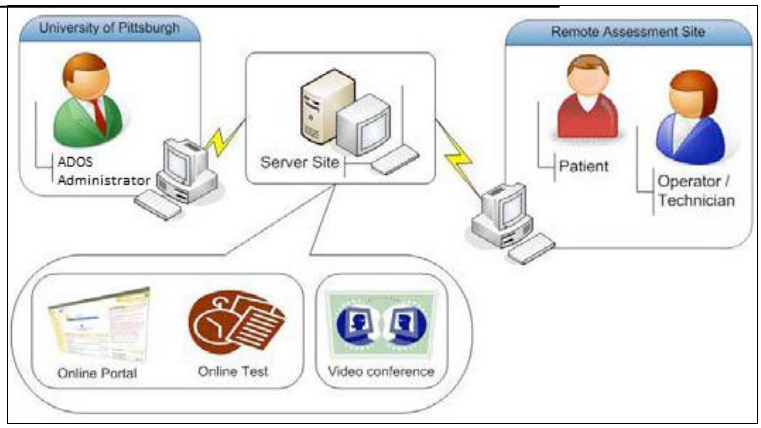


Figure 5. Components of an integrated Autism Diagnostic Observation Schedule Module 4 teleassessment system.

For this study, VISYTER was calibrated to deliver the ADOS remotely, i.e., VISYTER was configured to replicate standard face-to-face administration. The remote ADOS delivery system features videoconferencing, simulated eye contact, layout control, stimuli presentation, electronic scoring system, and session recording/archiving (Parmanto, Pulantara, Schutte, Saptono, McCue, in press).

3.2.2.1 Security

VISYTER is equipped with the highest level of security protection. In the design and implementation of VISYTER, strong layers of security and confidentiality measures have been included. The measures include firewalls for the secure servers and all computers that can access the database; encryption of all communication sessions between the administrator and participant sides; security and authentication at the operating system, database, and portal levels; and compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements for protecting health-related personal information.

VISYTER employs industry standard security policies, including an authentication system for all users, which also controls the user's access to specific clinic "rooms" or venues,

and encryption of all user authentication and the communications between the sites (video and voice) using a symmetric encryption key (Parmanto et al., 2010).

3.2.2.2 Videoconferencing

Videoconferencing is a key component of VISYTER and most telerehabilitation applications. VISYTER can handle high-quality full-screen video at 30 frames/s. Based on the speed of the Internet connection, the speed and quality of the video can be adjusted (Parmanto et al., 2010). The videoconferencing feature has the following capabilities: (1) Low-latency (i.e., minimal time delay) and high-resolution audio and video. (2) Two cameras on the client's side. The first camera is a static head on view that provides face-to-face interaction and simulates eye contact. The second (observational) camera captures the client's hand and finger and other complex mannerisms, gestures, and use of presented objects and materials. (3) Remote camera control of the observational camera. The remote camera control uses the Pan-tilt-zoom protocol, allowing the clinician to control the view of the client by panning right and left, tilting up and down, and zooming in and out (Parmanto et al., 2010). (4) Image capture, to take snapshots to be included in clinical reports (Parmanto et al., in press). See Figures 6, 7 and 8 for a view of the videoconference from the clinician and client perspectives.

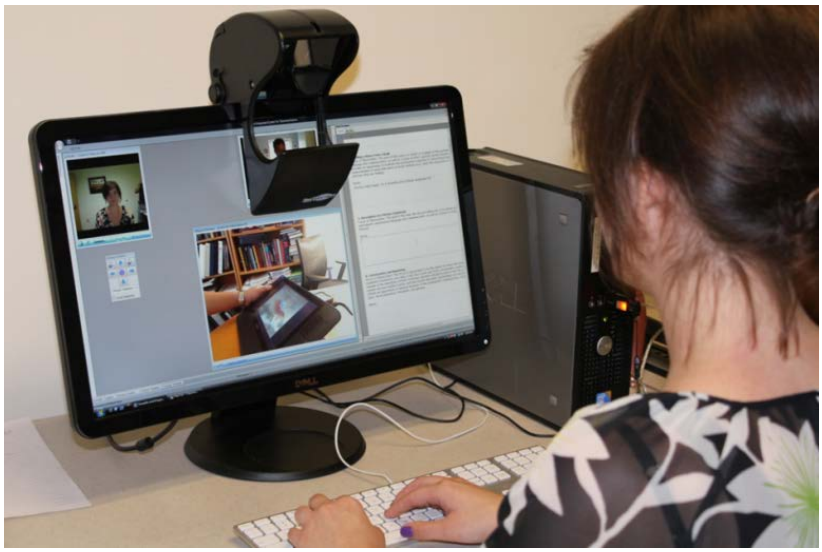


Figure 6. Remote Autism Diagnostic Observation Schedule (ADOS) administration from the clinician's perspective.

Figure 7. Screenshot of the Autism Diagnostic Observation Schedule Module 4 teleassessment system, clinician view.

Figure 8. Remote Autism Diagnostic Observation Schedule (ADOS) administration from the client's perspective.

3.2.2.3 Eye contact

Evaluating the quality and quantity of eye contact is an essential part of the ADOS administration. To achieve eye gaze perception at the client side, an inexpensive teleprompter was utilized on the clinician's site (Parmanto et al., 2010). (See Figure 6.)

3.2.2.4 Layout control

To minimize distraction and increase comfort on the client side, the display needs to be as simple and clutter-free as possible. However, the clinician needs access to both client video views and the ADOS protocol. A layout control system was developed that allows the clinician to control the screen layout on the client and clinician station (local and remote layout control) (Parmanto et al., in press).

3.2.2.5 Stimuli presentation

The ADOS has several visual stimuli that need to be seen by both the administrator and the client. For example, one of the first tasks is "Telling a Story from a Book," where the client is asked to tell a story from a children's picture book with no words. To make the remote administration as close to face-to-face as possible, the visual stimuli are placed on a tablet, rather than on the monitor, where they would compete with the image of the administrator. The administrator has the ability to upload stimuli from the clinician station and present it on the client's station. Just like with in-person administrations, both the clinician and the client have the ability to "turn the page" – the client can move forward or backwards by pressing large buttons on either side of the tablet. See Figure 8 where the book is displayed on the tablet.

3.2.2.6 Scoring system

A scoring system was developed that is as close to in-person assessments as possible, except paperless. A web-based system that is integrated into VISYTER houses the ADOS protocol. During the assessment, the administrator can type notes directly into the ADOS protocol. After the assessment ends, a web-based version of the scoring form can be accessed and the clinician assigns scores for each of the 31 evaluation items. The system automatically calculates the final scores using the algorithms prescribed in the ADOS protocol (Parmanto et al., in press). See Figure 7, where the electronic scoring system is displayed on the right side of the clinician's screen.

3.2.2.7 Session recording/archiving

A secured session archive database was developed to allow clinicians to record entire ADOS administrations in a secure archive database server (Parmanto et al., in press). Clinicians can use the archived sessions for clinical, educational, and research purposes.

3.2.2.8 Materials

In addition to VISYTER, some additional materials are necessary for remote administration including wide-screen monitors, cameras, quiet keyboard, and, of course, ADOS materials. See Table 9 for a complete description of equipment necessary equipment and materials at the administrator and participant locations.

Table 9. Materials Needed for Remote Autism Diagnostic Observation Schedule Module 4 Assessment

	Material	Administrator Side	Participant Side
Hardware	Computer *Minimum configuration: Pentium Dual Core processor 2 GHz with 2 GB of RAM, and an NVIDIA GeForce 4 Series graphics card*	X	X
	Wide-screen monitor	X	X
	Quiet keyboard	X	
	USB Microphone – Phoenix Duet USB Speakerphone *ClearOne CHAT ® 60 or CHAT ® 160*	X	X
	Webcam 1 *Logitech HD C910*	X	X
	Webcam 2 *Logitech Orbit AF*		X
	Tele-prompter *SeeEye2Eye Webcam Teleprompter, Bodelin Technologies*	X	
	Tablet *Wacom Cintiq 12WX tablet*		X
	Sterilite 4 Drawer Storage Cart		X
Software	VISYTER	X	X

Internet connection *VISYTER requires a broadband connection, which is currently defined as a network with a speed of 768 Kbps or higher. To achieve an HD-quality videoconferencing, a network speed of greater than 10 Mbps duplex is required.*		X	X
ADOS Materials	Materials for "Break" *Items included in ADOS kit plus current newspaper (one step up from a tabloid), current magazine (something easy to read, such as People magazine), and batteries for small radio*		X
	Materials for "Demonstration Task" *Hand towel and soap (included in ADOS kit)*		X
	Materials for "Creating a Story" *6 items with a purpose, 6 items with no clear purpose (included in ADOS kit)*	X *5 randomly selected items*	X *Remaining 7 items*

3.2.2.9 Preliminary research

The University of Pittsburgh Departments of Rehabilitation Science and Technology (RST) and Health Information Management (HIM) have worked together on the development of an advanced telehealth system that is closely related to the proposed teleassessment system. The system development team was led by Dr. Parmanto (information scientist). The team has also worked on conducting preliminary research on delivering neuropsychological assessment batteries remotely using videoconferencing with various bandwidths, as well as providing neuropsychological assessment to remote rural areas in Pennsylvania. This effort is led by Dr. McCue and Dr. Michael Pramuka (neuropsychologists). The core components of the proposed ADOS teleassessment system was built on the prior success in developing an integrated portal system for telerehabilitation services.

Remote wheelchair assessment

An integrated multimodal telehealth system for remote wheelchair assessment and prescription has been developed at the University of Pittsburgh (Schein, Schmeler, Brienza, Saptono, &

Parmanto, 2008; Schein et al., 2011; Schein, Schmeler, Holm, Saptono, & Brienza, 2010). The integrated system has similar infrastructure and functionalities to the ADOS teleassessment system. The telehealth system is aimed at providing remote wheelchair assessment and prescription services to rural communities in western Pennsylvania. The system connects two rural rehabilitation clinics located in DuBois, PA and Coudersport, PA to the University of Pittsburgh Medical Center (UPMC). The rural clinics are located approximately 100 and 180 miles away from Pittsburgh, respectively.

The system primarily connects patient and local therapist at the rural clinics to an expert therapist at UPMC. The system is also capable of adding family, caregivers and assistive technology engineers into the communication. There is a strict requirement that the system have high clarity visual streaming to allow direct evaluation of patients by the remote therapists. Other requirements of the system include the need to communicate securely for privacy and confidentiality, and the need of archiving to review the sessions. In addition to high-quality synchronous communication, the system is also required to allow local therapists and experts at UPMC to share patient information and to browse wheelchair specifications over the system. All of these features are integrated into a web portal.

The integrated system consists of four types of infrastructure that can be used to serve as the backbone of various telehealth applications: (1) multimodal web-conferencing and document sharing, (2) database and archiving of multimodal data sets, (3) portal technology, and (4) electronic health records. The researchers used inexpensive DSL connections to link UPMC's Center for Assistive Technology (CAT) to the DuBois and Coudersport clinics. The connection speed is 3 Mbps/768 kbps (downstream/upstream).

The system has been used for delivering remote clinical services on a regular basis since November 2006.

Remote neuropsychological assessment

In a study on how telerehabilitation technology might be utilized by persons with cognitive disabilities, University of Pittsburgh researchers assessed the effect of high- and low-bandwidth videoconferencing on persons with known attention, perceptual processing, and language comprehension problems (McCue, Lang, Bates, & Germek, 2003). This was done through administration of a battery of psychometric instruments via video teleconferencing in face-to-face, low-bandwidth, and high-bandwidth conditions.

Results revealed that in a sample of 15 individuals with significant cognitive disability, there was a significant difference between face-to-face assessment and low- and high-bandwidth conditions on tests of understanding oral directions, repeating number series, and on tasks involving controlled fluency. These findings indicate that despite information processing limitations in this population and apparent fluctuations in audio and video quality, videoconferencing, including low-bandwidth applications, is an effective mechanism for communication.

While consideration should be given to the effects of low-bandwidth on communication, these findings supported the use of telerehabilitation as a potential means of support and rehabilitation intervention with individuals with cognitive disabilities.

3.3 FORMATIVE REMOTE USABILITY ASSESSMENT STUDY

A descriptive study known as a formative remote usability assessment study addressed two objectives. Aim 1 was to develop the remote ADOS administration system in collaboration with the Health Information Management team and identify procedural usability concerns so that improvements to the system could be made. Aim 2 was to assess fidelity to standard administration and the degree to which remote administration adhered to standard, face-to-face, administration. Experts identified which aspects of the system could be adjusted to better match standardized administration conditions.

3.3.1 Methods

The first phase of the usability inspection was aimed at identifying usability problems in the design. An experienced, research-reliable ADOS administrator (JS) participated, from the beginning, in the design and development of the ADOS teleassessment system. The ADOS administrator provided feedback to the technical development team led by Dr. Parmanto which was used to improve the system design and implementation. The result of this walkthrough inspection was an operational ADOS Module 4 teleassessment system.

In the next phase, experts assessed the face validity of the remote assessment system and identified which aspects of the system could be adjusted to better match standardized administration conditions. The methodology used was the "cognitive walkthrough" usability inspection (Nielsen & Mack, 1994). In its original form, cognitive walkthroughs involve one or a group of evaluators inspecting a user interface by viewing a set of tasks and evaluating understandability and ease of learning. In this study, experienced clinicians conducted a remote

ADOS administration with a volunteer mock participant to evaluate if the remote administration system replicated face-to-face administration conditions.

Clinicians received a 10-minute introduction to the system, including an introduction to telehealth and teleassessment, introduction to the ADOS Module 4 remote assessment system, how to begin a session, how to operate cameras, how to view the observation form, how to take notes, how to display visual stimuli, how to view the coding form, how to enter codes, and how to view the algorithm.

Clinicians then used the VISYTER-based remote ADOS administration system to administer a remote ADOS Module 4 assessment to volunteer mock participants. ADOSs were administered in a lab at the University of Pittsburgh, School of Health and Rehabilitation Sciences, Department of Rehabilitation Science and Technology. The clinician site and "client" site were located in different rooms.

After each ADOS activity, scoring items, and viewing the protocol, the clinician answered questions regarding ability to perform task, time and effort required to perform task compared to standard face-to-face administration, ability to hear and see (for administering activities), and degree to which deviation from standard face-to-face administration was required (for administering activities). At the end of the assessment, general questions regarding desired changes/additions to the system and differences from standard, face-to-face administration were asked. See APPENDIX C for the ADOS Remote Administration Usability Questionnaire in its entirety.

After completion of the ADOS administration the IBM Post-Study System Usability Questionnaire (Lewis, 1993) was used to structure an interview that focused on the clinicians' current needs, preferences, and goals to be achieved from using the system. The PSSUQ is a 19-

item questionnaire designed to assess overall user satisfaction with system usability. It provides an overall evaluation of the usability of a system. Psychometrics evaluation found the scale to be highly reliable, valid, and sensitive (Lewis, 1993). See APPENDIX D for the PSSUQ in its entirety.

3.3.2 Participants

Participants were clinically or research reliable ADOS administrators with at least one year experience administering the ADOS Module 4. Clinicians with extensive experience in face-to-face ADOS assessment were able to evaluate if the teleassessment system provided all the necessary requirements to allow them to assess clients remotely.

A nonprobability convenience sample in which consecutive sampling, (all participants who met the criteria were recruited as they became available), was used. Participants were recruited through the Autism Service, Education, Research, and Training (ASERT) collaborators network.

Participants received monetary compensation in the amount of $50 after completing the requirements of the study.

3.3.3 Results

IRB approval was obtained through the RERC-TR blanket usability IRB# H133E090002.

Five clinicians who were clinically or research reliable ADOS administrators with at least one year experience administering the ADOS Module 4 participated in the study.

3.3.3.1 Development and clinician usability

Participant feedback on the usability of the system was gathered in categories: feedback on the demographics information page, feedback on administering individual activities, feedback on scoring, and overall comments. Participant feedback included identification of typos on the scoring form; identification of a glitch in the system that wipes out notes if the administrator forgets to his "save" regularly; and the problem of visual stimuli not staying on the screen simultaneously with the administrator taking notes. All possible usability problems and suggestions were analyzed to create a list of modifications, sorted by the severity of the problem. This feedback was the basis for system improvements. See APPENDIX E for the full list of feedback gathered during this phase of the usability study.

The PSSUQ allowed participants to provide an overall evaluation of the system. Participants responded to the PSSUQ statements both (1) on a Likert scale ranging from 1 (strongly agree) to 7 (strongly disagree), and (2) in written comments. Scoring of the PSSUQ results in an overall score and three sub-scale scores. The subscales are System Usefulness (SYSUSE) (example item: "Overall, I am satisfied with how easy it is to use this system,") Information Quality (INFOQUAL), (example item: "The system gave error messages that clearly told me how to fix problems,") and Interface Quality (INTERQUAL), (example item: "The interface of this system was pleasant."). Lower score indicate greater satisfaction with the system. The most usable aspect of the system was Interface Quality (M = 1.60). The least usable aspect of the system was System Usefulness (M = 2.23) although the mean score was still very low. The Overall PSSUQ usability mean was 1.98. See Table 10 for descriptive statistics of the PSSUQ results.

Table 10. IBM Post-Study System Usability Questionnaire Results

	Minimum	Maximum	Mean	Standard Deviation
System Usefulness	1.29	4.00	2.23	1.11
Information Quality	1.20	3.60	2.00	1.07
Interface Quality	1.00	2.67	1.60	0.64
Overall	1.22	3.56	1.98	0.98

3.3.3.2 Fidelity to standard

Feedback was solicited on if, and how much administrators were forced to break standard face-to-face administration procedure to deliver the assessment remotely. Of the 14 ADOS activities administered, only 6 were noted by at least one subject to force breaking standard, face-to-face administration. These items were: Telling a Story from a Book, Description of a Picture, Demonstration Task, Cartoons, Break, and Creating a Story. Not surprisingly, the items that forced administrators to break standard administration were those that involved handling physical items. Most visual stimuli were on the tablet instead of in traditional book or paper form. Administrators had to change the wording of the administration by instead of referring to the "book," referring to the "book on the tablet."

When asked to rank to what degree, on a Likert scale from 1 (minimal break from standard administration) to 7 (maximum break), the mean ranking was 2.4, indicating that generally breaks in standardization were minimal.

The remotely administered ADOS is administered largely in the standard fashion. Technical guidelines for ADOS Module 4 remote administration were created, see APPENDIX F. These guidelines detail hardware and software requirements and administration preparation and set-up that allow for remote administration. Administration guidelines (complementary to those in the ADOS manual) were created to ensure standard remote administration, see APPENDIX G. Changes from traditional administration do not intend to change the meaning or

intent and do not affect standardization. They simply address differences in electronic stimuli versus face-to-face administration.

3.3.4 Discussion

The cognitive walkthroughs and ADOS usability questionnaires provided high-quality feedback and suggestions for improving the remote administration system.

The usability study identified major system deficits and elicited suggestions for making the system more usable. On the PSSUQ, all subscales and the overall rating were below 3, indicating that participants generally agreed with positive statements such as, "This system has all the functions and capabilities I expect it to have." The best score was in interface quality, indicating that the items that were used to interact with the system (e.g., keyboard, mouse, screens) were especially usable.

When examining an alternative administration method for a previously standardized assessment, it is important to evaluate whether or not the new administration has equal reliability and validity to the way the evaluation was originally standardized. Usability studies should include evaluating drift from standardization. In this study, the method of evaluating potential drift was a semi-structured interview with open- and close-ended question administered after each item. This proved to be an effective method as participants were regularly prompted to evaluate whether or not deviations from standardization existed and if so if they proposed a threat to validity. For the ADOS remote administration vs. traditional, face-to-face administration, departure from standardization was found to be negligible. Participants felt they had to break standard administration on fewer than half the activities administered, and when there were breaks, they were considered minimal. This method could be considered a starting

point for other researchers interested in evaluating whether or not remote administrations of standardized procedures are valid.

A variable affecting the usability of the system was familiarity, proficiency, and comfort with computer technology in general. While no formal measure of computer skills was administered, the researcher noted a relationship between the participant's comments about his/her computer skills and ratings of usability of the system.

3.4 CONCLUSIONS

Teleassessment is a new method of delivering services to rural and underserved populations. As research continues and policy changes are implemented, it has the potential to provide necessary and essential services by removing time and distance barriers. One service that is needed is assessment of ASD in adolescents and adults in rural and underserved areas. Development of a system for remote teleassessment requires ongoing collaboration between clinicians and the technical development team, including soliciting feedback from clinicians regarding usability and fidelity.

Clinicians trained in administering the ADOS Module 4 used the VISYTER-based ADOS Module 4 remote administration system and provided high-quality feedback that was used to improve the system. Clinicians found the system usable (especially the system interface quality), and to require minimal breaks from standard, face-to-face administration.

Before services are provided remotely, they must first be found to be reliable. The next chapter will discuss a reliability study that compares the results of an ADOS administered in the traditional, face-to-face way, to an ADOS administered remotely.

4.0 CHAPTER 4: RELIABILITY AND USABILITY OF A REMOTE ADOS MODULE 4 ADMINISTRATION SYSTEM

Autism Spectrum Disorder (ASD) is characterized by impairments in social interaction and communication and restrictive repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2000, p. 75). Symptoms of ASD emerge in infancy or childhood, and while intensive therapy may decrease severity, there is no cure; it is a lifelong disability. An ASD diagnosis is primarily made on the basis of behavioral observations combined with evidence from a detailed developmental history (Barbaro & Dissanayke, 2009). Identifying ASD in adults can be challenging if a diagnosis has not been made in childhood because information regarding developmental history is often unavailable. It is possible that adults with ASD are currently undiagnosed (especially high-functioning adults) or misdiagnosed (with emotional or psychiatric disorders) (Akande, 2004; Dossetor, 2007; Matson, 2007; Palucka, Bradley, & Lunsky, 2008). Accurately diagnosing ASD in adults is important for a variety of reasons, such as implications for treatment, public policy (planning for needs and development of services), and granting access to resources for qualified recipients.

While there are many ASD assessment and diagnostic tools, few are designed for use with adolescents and adults. The Autism Diagnostic Observation Schedule (ADOS), considered an essential part of the "gold standard" diagnosis (Barbaro & Dissanayke, 2009; Gray, Tonge & Sweeney, 2008; Le Couter, Handen, Hammal, & McConachie, 2008; Reaven, Hepburn, & Ross,

2008; Risi et al., 2006), does have a module specifically designed for verbally fluent adolescents and adults. The ADOS is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials (Lord, Rutter, DiLavore, & Risi, 2008).

Over the past 30 years, technologists and clinicians have investigated the use of advanced telecommunications and information technologies as a way of bridging the gap between individuals with specialized medical needs living in remote areas and the source of specialty care that is often distal (Bashshur, 2002; Kinsella, 1998; Scalvini, Vitacca, Paletta, Giordano, & Balbi, 2004). The ADOS is a critical part of ASD assessment in adults, but there is a lack of available clinical expertise to meet need (Boisvert, Lang, Andrianopoulos, & Boscardin, 2010), especially in poorly served areas. A possible solution is the use of technology for remote assessment. Boisvert, et al. (2010) found through a systematic review that telepractice has potential to be a viable means to address the need for improved access to services for individuals with ASD.

An ADOS Module 4 remote assessment system that integrates videoconferencing, presentation of stimuli, scoring, data storage, and report generation and sharing into an integrated and intuitive web portal environment was developed and technical and procedural usability assessed (Parmanto, Pulantara, Schutte, Saptono, & McCue, in press). The objective of this study was to establish the reliability of the Autism Diagnostic Observation Schedule (ADOS) Module 4 administration via teleassessment. Researchers hypothesized that standard (face-to-face) administration and remote administration scores would have a high degree of agreement.

4.1 MATERIALS AND METHODS

4.1.1 Instrumentation

4.1.1.1 Autism Diagnostic Observation Schedule (ADOS) Module 4

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials. The ADOS consists of standard activities that allow the examiner to observe behaviors that have been identified as important to the diagnosis of ASD at different developmental levels and chronological ages. Structured activities and materials provide standard contexts in which social interactions, communication, and other behaviors relevant to ASD are observed (Lord, Rutter, DiLavore, & Risi, 2008).

The ADOS consists of four modules. Module 4 was designed for adolescents and adults who are verbally fluent, (i.e., producing a range of flexible sentence types, providing language beyond the immediate context, and describing logical connections within a sentence). The Module 4 consists of ten standard activities and five optional activities. The activities focus on social, communicative, and language behaviors important in the diagnosis of ASD. They combine unstructured conversation with a variety of presses (i.e., cues) for particular kinds of social and communicative behavior. The ADOS Module 4 takes 45 minutes to one hour to administer. Notes are taken during administration of each ADOS module and overall ratings are completed immediately after administration. These ratings can then be used to formulate a diagnosis through the use of a diagnostic algorithm (Lord, Rutter, DiLavore, & Risi, 2008).

Dr. Lord approved this research (C. Lord, personal communication, January 4, 2010). The publisher, Western Psychological Services (WPS) has been contacted regarding requesting

permission to use the ADOS for research purposes (S. Weinberg, personal communication, November 2, 2012).

4.1.1.2 Versatile and Integrated System for Telerehabilitation (VISYTER)

The Rehabilitation Engineering Research Center on Telerehabilitation (RERC-TR) developed the Versatile and Integrated System for Telerehabilitation (VISYTER). VISYTER is "a platform for building TR applications that takes into account the diverse settings and requirements of various rehabilitation services" (Parmanto et al, 2010, p. 939). The architecture of VISYTER combines three unique concepts to deliver telerehabilitation: a software application that can be installed easily, a set of off-the-shelf hardware to minimize cost, and a secure server system as the backbone of the service.

At ADOS administrator and client sites, VISYTER runs on desktop computers. The two computer stations are connected by a broadband internet connection, with a minimum connection of 3 Mbps/768 kbps (downstream/upstream). This connection is expected to provide optimal performance at an affordable cost. Figure 5 illustrates this connectivity, with: one desktop computer station, located at the clinician site (e.g., University of Pittsburgh); one desktop computer station, located at the client site (e.g., rural clinic); and, a server for managing and coordinating all elements of the assessment process.

For this study, VISYTER was calibrated to deliver the ADOS remotely, i.e., VISYTER was configured to replicate standard face-to-face administration. The remote ADOS delivery system features: videoconferencing, simulated eye contact, layout control, stimuli presentation, electronic scoring system, and session recording/archiving (Parmanto, Pulantara, Schutte, Saptono, McCue, in press).

Security

VISYTER is equipped with the highest level of security protection. In the design and implementation of VISYTER, strong layers of security and confidentiality measures have been included. The measures include firewalls for the secure servers and all computers that can access the database; encryption of all communication sessions between the administrator and participant sides; security and authentication at the operating system, database, and portal levels; and compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements for protecting health-related personal information.

VISYTER employs industry standard security policies, including an authentication system for all users, which also controls the user's access to specific clinic "rooms" or venues, and encryption of all user authentication and the communications between the sites (video and voice) using a symmetric encryption key (Parmanto et al., 2010).

Videoconferencing

Videoconferencing is a key component of VISYTER and most telerehabilitation applications. VISYTER can handle high-quality full-screen video at 30 frames/s. Based on the speed of the Internet connection, the speed and quality of the video can be adjusted (Parmanto et al., 2010). The videoconferencing feature has the following capabilities: (1) Low-latency (i.e., minimal time delay) and high-resolution audio and video. (2) Two cameras on the client's side. The first camera is a static head on view that provides face-to-face interaction and simulates eye contact. The second (observational) camera captures the client's hand and finger and other complex mannerisms, gestures, and use of presented objects and materials. (3) Remote camera control of the observational camera. The remote camera control uses the Pan-tilt-zoom protocol, allowing the clinician to control the view of the client by panning right and left, tilting up and down, and

zooming in and out (Parmanto et al., 2010). (4) Image capture, to take snapshots to be included in clinical reports (Parmanto et al., in press). See Figures 6, 7, and 8 for views of the videoconference from the clinician and client perspectives.

Simulated eye contact

Evaluating the quality and quantity of eye contact is an essential part of the ADOS administration. To achieve eye gaze perception at the client side, an inexpensive teleprompter was utilized on the clinician's site (Parmanto et al., 2010). (See Figure 2.)

Layout control

To minimize distraction and increase comfort on the client side, the display needed to be as simple and clutter-free as possible. However, the clinician needs access to both client video views and the ADOS protocol. A layout control system was developed that allows the clinician to control the screen layout on the client and clinician station (local and remote layout control) (Parmanto et al., in press).

Stimuli presentation

The ADOS has several visual stimuli that need to be seen by both the administrator and the client. For example, one of the first tasks is "Telling a Story from a Book," where the client is asked to tell a story from a picture book with no words. To make the remote administration as close to face-to-face as possible, the visual stimuli are placed on a tablet, rather than on the monitor, where they would compete with the image of the administrator. The administrator has the ability to upload stimuli from the clinician station and present it on the client's station. Just like with in-person administrations, both the clinician and the client have the ability to "turn the

page" – the client can move forward or backwards by pressing large buttons on either side of the tablet. See Figure 3 where the book is displayed on the tablet.

Scoring system

A scoring system was developed that is as close to in-person assessments as possible, except paperless. A web-based system that is integrated into VISYTER houses the ADOS protocol. During the assessment, the administrator can type notes directly into the ADOS protocol. After the assessment ends, a web-based version of the scoring form can be accessed and the clinician assigns scores for each of the 31 evaluation items. The system automatically calculates the final scores using the algorithms prescribed in the ADOS protocol (Parmanto et al., in press). See Figure 2, where the electronic scoring system is displayed on the right side of the clinician's screen.

Session recording/archiving

A secured session archive database was developed to allow clinicians to record entire ADOS administrations in a secure archive database server (Parmanto et al., in press). Clinicians can use the archived sessions for clinical, educational, and research purposes. In this study, recordings of ADOS administrations were used to establish administrator reliability.

4.1.2 Participants

Participants were individuals with an ASD diagnosis recruited from a state-operated vocational rehabilitation and training facility for individuals with disabilities.

4.1.2.1 Inclusion and exclusion criteria

Criteria for inclusion were: a diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder in the individual's file; between the ages of 18 and 40 years; native English speaker; verbally fluent; and full scale IQ greater than or equal to 70.

Criteria for exclusion were: participation in an ADOS administration within the previous 90 days, being unavailable for follow-up (e.g., would graduate before the second ADOS could be administered), current participation in a social skills group (an intervention that could have an effect on the test-retest reliability), hearing impairment, visual impairment (other than mild visual difficulties corrected with glasses and/or contacts), non-ambulatory, motor problems more severe than very mild cerebral palsy, and having an identifiable syndrome (e.g., Down syndrome).

4.1.2.2 Sampling procedures

Counselors at the rehabilitation and vocational facility read a recruitment script to students with an ASD diagnosis. If the student was interested in participating, he or she provided contact information. The primary research coordinator (JS) then contacted interested students, read them a screening script, and received verbal consent to be screened before continuing. Individuals who consented were then screened. Individuals who after screening were found to meet the inclusion/exclusion criteria then provided consent to participant in the study by reading, discussing, and signing an informed consent form.

4.1.2.3 Sample size and power

Recruiting 28 participants, with an assumed dropout rate of 20%, yielded a final sample size of n=22. A sample size of 22 yields 80% power to detect a significant result for the intraclass correlation (ICC), tested against a null value of 0.5, assuming the true ICC is at least 0.8.

4.1.3 Research Design

IRB approval was obtained through the University of Pittsburgh (IRB# PR010100117).

The research design was a within-subjects crossover study. A crossover design has been used in previous studies involving remote psychometric assessments (Jacobsen, Sprenger, Andersson, & Krogstad, 2003; Kirkwood, Peck, & Bennie, 2000). Benefits of the crossover design include removing between-patient variation and requiring fewer participants.

Participants were randomly assigned to one of two experimental groups; one half of the participants were initially tested face-to-face, followed by a remotely administered test; the other half was tested in the opposite order. The two assessments were a minimum of 90 days apart. According to Dr. Lord, author of the ADOS, a 90-day break effectively serves as a washout period to reduce the learning effects on the performance in the second ADOS administration (C. Lord, personal communication, January 4, 2010). This is a longer break than is often used in a test-retest study design. In other studies, the washout period has consisted of an average of 72 days (Gualtieri & Johnson, 2006), an average of 1.21 months (Schweiger et al., 2003), two weeks (Beglinger et al., 2005), 10 minutes, one week, and one month (Falleti, Maruff, Collie, & Darby, 2006) and 1 month (Woods, Delis, Scott, Kramer, & Holdnack, 2006).

During the remote assessment, the participant was not alone in the evaluation room. A technician was on-site to facilitate administration.

After administering the ADOS activities, the examiner coded the participants' behavior throughout the entire evaluation on 31 items. Possible codes were 0, 1, 2, 3, 7, and 8. Per directions in the ADOS manual, scores of 3 were converted to 2, and all scores other than 0-3 were converted to 0. A score of 0 indicates no evidence of abnormality related to autism; 1, mildly abnormal or slightly unusual behavior; 2, definite or markedly abnormal behavior. The ratings are organized according to five main groupings: "A. Language and Communication," "B. Reciprocal Social Interaction," "C. Imagination," "D. Stereotyped Behaviors and Restricted Interests," and "E. Other Abnormal Behaviors" (Lord, Rutter, DiLavore, & Risi, 2008).

All assessments were administered and scored by the same ADOS Module 4 research reliable clinician (JS). Several steps were taken to ensure the administrator's second scoring was not influenced by the first interaction. First, the washout period of 90 days decreased likelihood of remembering the first administration. Second, all assessments were recorded using VISYTER. The video recordings of six randomly selected second administrations were scored by outside research reliable clinicians. The reliability of the original clinician as established by the outside clinician was established to be highly satisfactory: reliability on all items ranged from 81% to 87% with a mean of 84.5%; reliability on algorithm items ranged from 75% to 88% with a mean of 82%.

Upon completion of the remotely administered ADOS, participants completed a 7-item Post-ADOS User Satisfaction Questionnaire. (See APPENDIX H.) The Post-ADOS Assessment User Satisfaction Questionnaire consisted of the following statements: (1) I felt comfortable doing this assessment using the computer, (2) The quality and clarity of the video (picture) was acceptable, (3) The quality and clarity of the audio (sound) was acceptable, (4) Being assessed this way provides a true picture of how I typically behave and interact with

others, (5) There were things I was unable to do/say because of the computer system that I would have been able to do/say in person, (6) If I had to have assessments or tests in the future, I would be willing to do them over the computer, and (7) If this was your second administration, which administration did you prefer? For statements 1 through 6, participants responded on a Likert scale from 1 – strongly agree to 7 – strongly disagree. For the last question, participants choose: greatly prefer face-to-face, slightly prefer face-to-face, no preference, slightly prefer remote system, greatly prefer remote system, or NA – this was my first administration. Participants were also able to write in comments.

Participants were reimbursed for their time in the amount of $10 after completing the first ADOS and $20 after completing the second ADOS.

4.2 RESULTS

IBM SPSS Statistics software version 20.0 was used for data analysis.

4.2.1 Sample characteristics

A total of 46 individuals with an ASD diagnosis expressed interest in participating after being read the recruitment script. After screening for inclusion/exclusion criteria, 26 participants were enrolled in the study. Three dropped out because they were unavailable for the second ADOS (n=23).

Participants were between the ages of 19 and 30 (M 21.96, SD 2.88). Seventy percent of participants were male (n=16); 30% were female (n=7). Participant Full Scale IQs ranged from

70 to 110 (M 88.96, SD 10.09). Participants were almost exclusively Caucasian, with one African American participant.

4.2.2 Test-retest reliability

4.2.2.1 Reliability of individual items

Statistical procedures used to calculate reliability were derived from the procedures used when reliability for the ADOS was initially established. The kappa statistic (κ) is a measure of "true" agreement (agreement beyond that expected by chance) and is the standard measure for psychometric reliability (Cohen, 1960). Lord, Rutter, DiLavore, & Risi (2008) originally used a standard formula for weighted kappas (κ_w). When calculating a weighted kappa, disagreements involving distant values are weighted more heavily than disagreements involving more similar values (Sim & Wright, 2005). Two versions of the weighted kappa were calculated: one used weights that were based on the absolute distance (in number of rows or columns) between categories; the other used a set of weights that were based on the squared distance between categories. Kappas based on the absolute distance are more conservative, and are reported here. In the original research, mean weighted kappas ($M\kappa_w$) greater than .40 were considered to be adequate, and kappas greater than .60 were considered substantial (Lord, Rutter, DiLavore, & Risi, 2008.) Researchers generally agree that kappa of .61-.81 indicates substantial agreement, and .81-.99 indicates almost perfect agreement (Viera & Garrett, 2005).

There is some disagreement about the usefulness of the kappa statistic to assess intra-rater agreement. According to Sim and Wright (2005), there are three determinants of the magnitude of kappa. One is prevalence, kappa is dependent on prevalence and tends toward zero at both extremes of prevalence. However, some statisticians believe that the effects of bias and

prevalence on the magnitude of kappa are themselves informative and should not be adjusted and thereby discarded. The second determinant of magnitude is bias, or the degree to which the raters disagree on the proportion of positive (or negative) cases.

The third determinant is non-independent ratings. Non-independent ratings require that the participants be independent and ratings be independent. However, with all measures of intra-tester reliability, ratings on the first test may influence those given on the second test, which will threaten the assumption of independence. Therefore, there will always be some degree of dependence between ratings in an intra-rater study. Since raters are not independent, kappa is not technically a "chance-corrected measure of agreement," as is often claimed. To minimize dependence, a longer time interval between repeat ratings can be implemented. Sim and Wright (2005) recommend up to 14 days; for this study, the washout period was at least 90 days. Rating a more stable attribute will also minimize dependence. The behaviors of adults with ASD are generally stable. Finally, dependence can be minimized by different random ordering of participants on each rating occasion. For this study, there was a different order of participants in the first administration and in the second.

Alternatives to kappa were considered, such as the Pearson Product-Moment Correlation Coefficient, which is often calculated for reliability coefficients in test-retest studies. However, the Pearson product-moment correlation coefficient does not measure agreement, only trend. The Chi-square statistic is inappropriate for measuring agreement. It can yield a significant result even when there is marked disagreement. Therefore, despite its potential limitations, kappa was selected and chosen as the most appropriate statistic for this data.

There was perfect or almost perfect agreement on 10 items, substantial agreement on 11 items, and adequate agreement on two items. On five items, at least one of the variables in each

2-way table upon which measures of association are computed was constant, so κ could not be calculated. For these items, Agreement (P_o, the number of exact agreements divided by the number of possible agreements) was calculated. Four of these items had 100% agreement, and one item had 87% agreement. On only three items was $\kappa \leq .41$. (See Table 11.)

Table 11. Autism Diagnostic Observation Schedule Module 4: Percent Agreement with Kappas Indicating Reliability

Summary Rating	Percent Agreement	Weighted Kappa
A1. Overall Level of Non-Echoed Language	96	.646
A2. Speech Abnormalities Associated With Autism	100	1.000
A3. Immediate Echolalia	100	--
A4. Stereotyped/Idiosyncratic Use of Words or Phrases*	91	.880
A5. Offers Information	96	.777
A6. Asks for Information	65	.289
A7. Reporting of Events	100	--
A8. Conversation*	91	.777
A9. Descriptive, Conventional, Instrumental, or Informational Gestures*	87	.642
A10. Emphatic or Emotional Gestures*	87	.763
B1. Unusual Eye Contact*	100	1.000
B2. Facial Expressions Directed to Others*	78	.642
B3. Language Production and Linked Nonverbal Communication	87	.839
B4. Shared Enjoyment in Interaction	87	.697
B5. Communication of Own Affect	83	.731
B6. Empathy/Comments on Others' Emotions*	43	.230
B7. Insight	87	.806
B8. Responsibility*	91	.852
B9. Quality of Social Overtures*	91	.851
B10. Quality of Social Response*	91	.846
B11. Amount of Reciprocal Social Communication*	96	.862
B12. Overall Quality of Rapport	91	.826
C1. Imagination/Creativity*	78	.566
D1. Unusual Sensory Interest in Play Material/Person*	91	.617
D2. Hand and Finger and Other Complex Mannerisms*	78	.138
D3. Self-Injurious Behavior	100	--
D4. Excessive Interest in or References to Unusual or Highly Specific Topics or Objects or Repetitive Behaviors*	87	.517
D5. Compulsions or Rituals*	87	--
E1. Overactivity/Agitation	96	.646
E2. Tantrums, Aggression, Negative or Disruptive Behavior	100	--

E3. Anxiety		96	.646

Note. Asterisk (*) indicates algorithm item.

To determine if participants scored differently when the ADOS was administered remotely than when it was administered face-to-face, the Wilcoxon Signed-Rank Test was used. The Wilcoxon Signed-Rank Test is the nonparametric test equivalent to the dependent t-test. It is used when comparing two sets of scores from the same participants. As the Wilcoxon Signed-Ranks Test does not assume normality in the data it can be used when this assumption has been violated and the use of the dependent t-test is inappropriate. On 30/31 items, there was no significance when comparing face-to-face administration scores to remote administration scores. On one item, Asks for Information (a non-algorithm item), participants asked significantly more questions when the ADOS was administered remotely ($Z = -2.111$, $p = .035$). However, median Asks for Information rating was 2 both face-to-face and remotely, indicating this may be statistically, but not clinically, significant.

In addition, despite the washout period, there may have a practice effect on some items. For example, the Imagination/Creativity item weighs heavily on an activity that involves creating a story out of five random items. This is an item which might have had a practice effect, despite the washout period. At least one participant mentioned during the second administration that he had been waiting for the "Creating a Story" activity and had been thinking about what he might do with his five items. However, a Wilcoxon Signed Ranks Tests showed that there was not a practice effect on this item ($Z = -1.342$, $p = .180$). The only item on which there was a statistically significant difference between first and second administrations was again Asks for Information, where participants asked significantly more questions on the second ADOS versus the first ADOS ($Z = -2.111$, $p = .035$). Once more, the median Asks for Information rating was 2

for both first and second administration, indicating the difference may not be clinically significant.

4.2.2.2 Reliability of domain scores and classification

As in the original reliability report, intraclass correlation coefficients (ICC) were computed across pairs of administrations for algorithm subtotals and totals. A two-way mixed model was used because time was fixed and subjects was random. The ICC ranges between 0.00 and 1.00, with values closer to 1.00 representing stronger reliability. There are no standard values for acceptable reliability using the ICC. For this study, the general guideline will be implemented, in which values above .75 are indicative of good reliability (Portney & Watkins, 2009, p. 595). There was good reliability on the "Communication," "Social Interaction," and "Communication + Social Interaction Total" scores (ICC=.92 to .98). There was moderate agreement on the "Stereotyped Behaviors and Restricted Interest" score (ICC=.70). In Table 12, the current test-retest reliability (remote-face-to-face or face-to-face-remote) is detailed along with the test-retest reliability data published in the ADOS manual.

Table 12. Autism Diagnostic Observation Schedule Module 4: Intraclass Correlations for Test-Retest Reliability

	n	**Communication**	**Social Interaction**	**Communication + Social Interaction Total**	**Stereotyped Behaviors and Restricted Interests**
Original ADOS data – test-retest[a]	27	.73	.78	.82	.59
Face-to-Face vs. Remote Administration	23	.92	.98	.98	.70

Note. Adapted from "Autism Diagnostic Observational Schedule: ADOS Manual" by C. Lord, M. Rutter, P. C. DiLavore, & S. Risi, 2008, Los Angeles, CA: Western Psychological Services, p. 115.
[a]Intraclass correlations for data pooled across modules 1 through 4

The ADOS includes an algorithm for DSM-IV/ICD-10 (APA, 1994) ASD diagnosis. Participants are assigned an ADOS classification of "Autism," "Autism Spectrum," or "Non-

Spectrum." There was substantial agreement on ADOS classification between assessments delivered face-to-face versus assessments delivered remotely, P_o=83%; κ =.772, ICC=.92.

4.2.3 Usability

Twenty-three participants completed the Post-ADOS Assessment User Satisfaction Questionnaire. Participants responded to six statements on a Likert scale, from 1 (strongly agree) to 7 (strongly disagree). Lower numbers indicate greater satisfaction with the system, except on item 5, where higher numbers indicated greater satisfaction with the remote system. (See Table 13.)

Table 13. Post Remote ADOS Assessment User Satisfaction Questionnaire Results

Item	Mean	Median	Mode
1. Felt comfortable using computer	2.48	2.00	1
2. Quality of video was acceptable	1.96	1.00	1
3. Quality of audio was acceptable	2.00	1.00	1
4. True picture of how I typically behave	2.70	2.00	1
5. There were things I was unable to do/say	4.39	5.00	5
6. Willing to do assessments over the computer in future	2.26	1.00	1

Note: Lower numbers indicate greater satisfaction with the system, except on item 5.

The 14 participants who had the remote ADOS administered second were also asked which administration they preferred, face-to-face or remote. Two participants slightly preferred the remote system. Seven participants had no preference. Five participants slightly or greatly preferred the face-to-face administration.

4.3 DISCUSSION

There is a documented shortage of medical, psychiatric, and rehabilitation specialists in economically disadvantaged and rural areas (Gruen, Weeramanthri, Knight, & Bailie, 2003). Telemedicine and telerehabilitation have potential to increase access to and enhance continuity of services for individuals with disabilities, especially those living in remote areas. In addition, telemedicine and telerehabilitation boast potential time and cost-saving benefits (Cooper et al., 2001; Kairy, Lehoux, Vincent, & Visintin, 2009).

There is also an increase in the prevalence of ASD and therefore an increase in the need of specialists to assess, diagnose, and treat individuals with ASD, including adolescents and adults. Teleassessment – the remote administration of systematic procedures for observing and describing behaviors through use of interactive videoconferencing between a client at a local site and a remotely located assessment expert – is an exciting opportunity to ensure that adolescents and adults are able to access gold standard ASD assessment services, including the Autism Diagnostic Observation Schedule Module 4. Results of this study indicate clinical reliability at >80% for the remotely administered ADOS Module 4, which demonstrates the diagnostic accuracy of the remotely administered assessment, which is crucial for clinical purposes.

The reliability results generally supported the ability to conduct the ADOS via a telemedicine platform. Specifically, item B1 rates unusual eye contact, and had perfect agreement between remote and face-to-face assessments. Facilitating eye contact remotely was a challenge researches faced and solved with use of a teleprompter. Success was likely due to the fact that ADOS administrators are not evaluating the accuracy and directness of eye contact, but rather how gaze is being used with other communication to initiate, terminate, or regulate social interaction, (e.g., does the person “check in” with the evaluator when describing a picture?).

There were several problem noted that might be addressed in the future. There was low agreement on three out of 31 ADOS items ($\kappa \leq .41$): Asks for Information, Empathy/Comment on Others' Emotions, and Hand and Finger and Other Complex Mannerisms. There was adequate agreement on two items (κ .41-.61): Imagination/Creativity and Excessive Interest in or References to Unusual or Highly Specific Topics or Objects or Repetitive Behaviors.

There are several possible reasons for the low agreement. Several items are highly sensitive, and the participant labeling one additional emotion or asking one fewer question changes the score from a 0 to a 1 or a 1 to a 2. The test-retest study design allows for changes in performance from one ADOS administration to the next. Some participants did behave differently on the two ADOS administration days, likely due to outside factors (e.g., Having a good or bad day? Looking forward to going home for the weekend? Just received a bad grade on a test? etc.).

There was also limited agreement on two of the items from the Stereotyped Behaviors and Restricted Interests domain. For these items, the examiner is required to note behaviors that are often low-incidence for this population, e.g., a very brief or rare hand and finger mannerisms or complex mannerisms, or occasional references to unusual or highly specific topics or patterns of interest. Because these are often rare occurrences, it is very possible that the administrator would not observe the behavior during a one hour-long assessment, but may observe and code it in another assessment.

Participants indicated a high degree of satisfaction with the remote administration system. Seventy-five percent of participants indicated they felt comfortable using the system. Seventy-eight percent of participants indicated that being assessed this way provides a true picture of how they typically behave and interact with others. Eighty-three percent of participants indicated that

they would be willing to do future tests over the computer. The quality of the video was rated very highly. In addition, this population, adults with ASD, may be a good fit for telerehabilitation interventions. Individuals with ASD may be comfortable with and open to remote assessment and treatment. For example, Savin, Garry, Zuccaro, & Novins (2006) reported a case study in which a 13-year-old male "was able to express himself better during telepsychiatric consultation than he had during his previous face-to-face consultations" (p. 486).

4.3.1 Limitations

4.3.1.1 Limitations associated with methodology.

There were several limitations associated with the methodology, including limitations of the study design, population, and satisfaction survey.

A potential limitation of a crossover design is a learning effect where participants may rely on experiences obtained in the first session of study to implicitly improve their performance in the second session. Learning effects were minimized by having a 90 day washout period. This washout period was endorsed by the ADOS author Dr. Lord (C. Lord, personal communication, January 4, 2010) and is longer than the average washout period in most test-retest studies (Broglio, Ferrara, Macciocchi, Barumgartner, & Elliott, 2007; Gualtieri & Johnson, 2006; Schweiger, Doniger, Dwolatzky, Jaffe, & Simon, 2003; Woods et al., 2006). Also, equivalent alternative forms were used when available. Finally, learning effects were felt to have been less of a factor in an ADOS (as opposed to a neuropsychology battery) because the goal of the administration portion of the ADOS was to present opportunities for presentation of autistic symptoms. Scores were not based on performance on administered activities, but on overall impressions gathered from the interaction. Coded items such as Speech Abnormalities

Associated with Autism, Use of Descriptive and Emphatic Gestures, Facial Expressions, and Overall Quality of Rapport, were unlikely to be affected by practice. The fact that the goal of the ADOS is to present opportunities to observe the presentation of symptoms of ASD as opposed to measuring performance also mitigates the other typical issue with crossover designs, which is the issue of order effects.

The participants in this study were a homogeneous group; they were all students at a vocational training school, living independently on-campus and taking classes full-time. Therefore, this was a relatively high functioning group that was more likely to fall into the non-spectrum or autism spectrum classification on the ADOS, as opposed to the autism classification. Having a sample that was more evenly spread across the autism spectrum might lead to more generalizable results. However, the population of adults that is still seeking diagnosis in adulthood is likely to be more high-functioning and have less severe symptoms of ASD. In this way, this population was representative of the population who might come into a clinic seeking diagnostic clarity.

Participants were also homogeneous in race as they were almost exclusively Caucasian. Results may not be generalizable to individuals who are non-white. However, ASD diagnostic tools for adults of diverse cultural backgrounds are important, as racial minorities routinely experience either being misdiagnosed or diagnosed late with ASD. In addition, there may be cultural differences in the presentation of ASD (Mandell & Novak, 2005).

The Post-ADOS User Satisfaction Questionnaire was short (7 items) and was only completed after the remotely administered ADOS. The researchers noted that participants were often eager to return to lunch, class, etc., and occasionally seemed to rush through the questionnaire. Few participants left written comments. One participant may have misread the

scale and indicated 7 – strongly disagree, when he meant strongly agree. This was inferred because the participant indicated 7 – strongly disagree for all statements, including the statement where a 7 indicated the system was usable (e.g., "There were things I was unable to do/say because of the computer system that I would have been able to do/say in person." A longer, more detailed questionnaire or structured interview and questionnaires administered after both the in-person and remote ADOS administrations might have led to more comprehensive feedback about participants' satisfaction regarding remote assessment.

4.3.1.2 Limitations associated with remote administration.

There were also some limitations associated with the remote administration and the technology used to administer the ADOS remotely. It is necessary for the remote ADOS administrator to have a level of comfort and skill with technology to administer the ADOS remotely. As with all technology, with the remote ADOS administration system, there was an occasional need for troubleshooting (e.g., VISYTER settings need adjusted, computer internet connection secured, video and sound settings manipulated). ADOS administrators currently take steps to receive training and maintain reliability, and individuals conducting teleassessment should perhaps also receive training in factors specific to information technology.

There were differences between face-to-face and remote ADOS administration that may not have been captured by the item and algorithm scores. For example, when planning to administer the ADOS remotely, one optional ADOS activity was excluded from this study because it required the participant to physically hand a puzzle piece to the examiner, and this was impossible to translate to a remote administration. While this activity was optional and is often excluded when the ADOS is administered face-to-face, any information that might be gained from this activity is impossible to gather when the assessment is done remotely.

Also, some aspects of social interaction and rapport were difficult or impossible to assess using teleassessment. Occasionally the ADOS administrator had observations face-to-face that were impossible to make remotely. For example, the administrator noticed a participants' strong odor during a face-to-face ADOS that affected the quality of the rapport. A potential solution to this problem is to include the on-site technician's observations when scoring the ADOS.

Along the same lines, because of the remote administration, another person was brought into the ADOS administration – the on-site technician. While typically the on-site technician set up the computer and then had no involvement in the ADOS administration, occasionally the participant would engage the on-site technician in conversation during the ADOS, or direct answers from the administrator to the on-site technician. An on-site technician is a requirement in teleassessment because it is unethical to leave a client alone in a room in case of emergency, but it did alter the standard ADOS administration. In the future, studies might be conducted to evaluate the impact of the on-site technician, and describe ways in which the potential impact of the on-site technician might be minimized. For example, the on-site clinician could be stationed next door watching the video feed as well in case problems arose.

4.3.2 Future directions and conclusions

There has been limited research on the validity and reliability of assessment instruments via teleassessment. Given the shortage of specialists and the increasing prevalence of ASD, there is a clear need for further research on remote services for this population. A logical next step for this research is a validity study which estimates the diagnostic accuracy of a remotely administered ADOS Module 4 with adult participants who are diagnostically representative of those who might seek services from an adult ASD outpatient clinic.

Continuing on with reliability, it would make sense to consider the potential to conduct ADOS Module 3 via teleassessment. There are additional challenges presented in administering the Module 3 remotely due to "Joint Interactive Play" activity. Developing ways in which interactive play could be facilitated via teleassessment would be fascinating.

Another possibility is to examine the reliability of other types of ASD assessments delivered remotely. Currently the ADOS is the gold standard but with the increase in ASD, the revised diagnostic criteria that will be published in the Diagnostic and Statistical Manual of Mental Disorders 5 (to be published in May 2013), and the trend in interest in telemedicine, novel ways of assessing ASD using telemedicine are likely to emerge.

Teleassessment has potential to reduce service delivery costs associated with travel and time. Teleassessment can also increase the accuracy and timeliness of ASD diagnosis. The results of this study demonstrate that an ASD assessment designed to be delivered face-to-face can be reliably administered remotely using an integrated web-based system.

5.0 CHAPTER 5: SUMMARY AND CONCLUSIONS

The purpose of this study was to develop and evaluate the usability and reliability of a remotely administered Autism Diagnostic Observation Schedule (ADOS) Module 4, a gold-standard ASD assessment designed for verbally fluent adolescents and adults. The teleassessment system was designed to administer the ADOS in a way that was as close to standard, face-to-face administration as possible. The study objectives and how they were met are described below.

1. Systematically review the scientific literature to describe the population of adolescents and adults with autism spectrum disorder (ASD) who may be undiagnosed or misdiagnosed.
2. Systematically review the scientific literature to identify the gold standard for diagnosing adolescents and adults with ASD, including the Autism Diagnostic Observation Schedule (ADOS) Module 4.

These objectives were met in chapter 2, where the functional deficits of adults with ASD in the areas of social skills, communication, and restricted and repetitive behaviors and interests were discussed. Because ASD is a behavioral diagnosis, and diagnosis is typically made in childhood based on a developmental history and behavioral observations, diagnosing ASD in adults can be challenging. A literature review found a lack of standardized assessment instruments available for use with adults. The ADOS is a standardized behavioral assessment

that has a module designed for verbally fluent adolescents and adults. The ADOS is part of the gold standard in ASD diagnosis. However, there are currently not enough trained ADOS administrators to meet the needs of the population.

3. Systematically review the scientific literature to describe teleassessment, including its background, strengths, and potential limitations.
4. In collaboration with the Health Information Management team, develop the ADOS Module 4 remote administration system using the Versatile and Integrated System for Telerehabilitation (VISYTER) infrastructure.
5. Identify procedural usability concerns so that improvements to the remote ADOS administration system could be made.
6. Assess fidelity to standard administration and the degree to which remote administration adhered to standard, face-to-face, administration.
7. Develop Autism Diagnostic Observation Schedule (ADOS) Module 4 Remote Administration – Technical Guidelines
8. Develop Autism Diagnostic Observation Schedule (ADOS) Module 4 Remote Administration – Administration Guidelines

Chapter 3 began with a discussion of a review of the teleassessment literature. One outcome of this review was to define teleassessment as the remote administration of systematic procedures for observing and describing behaviors with the aid of numerical scales or fixed categories, through use of interactive videoconferencing between a client (and usually a technician) at a local site and a remotely located assessment expert. Teleassessment has potential for increasing the availability of services for individuals in underserved areas.

A descriptive study known as a formative remote usability assessment was conducted. This study addressed two aims. The first aim was to develop (in collaboration with the Health Information Management team) the remote ADOS administration system and to identify procedural usability concerns. Five participants (clinically or research reliable ADOS administrators with at least 1 year experience administering the ADOS Module 4) provided feedback that was the basis for system improvements. In general, results of the Post Study System Usability Questionnaire (PSSUQ) were positive, with clinicians indicating that the system usefulness, information quality, and interface quality were highly usable. The second aim was to assess the fidelity of standard face-to-face administration. The participants provided feedback on if, and how much, they were forced to break standard face-to-face administration procedure to deliver the ADOS remotely. Of the 14 ADOS activities administered, only 6 were noted by at least one participant to force breaking standard administration. When breaks in standardization were noted, participants stated that the breaks were minimal.

Outcomes of this research were the development of administration and technical manuals for remote administration of the ADOS Module 4.

9. Determine the reliability of the ADOS Module 4 administration via teleassessment.

The second study, in chapter 4, was a within-subjects crossover study designed to assess the reliability of the remote administration system. Twenty-three participants received an ADOS both face-to-face and remotely, and results were compared using the kappa statistic. There was perfect or almost perfect agreement on 10 items, substantial agreement on 11 items, and adequate agreement on two items. There was good reliability on the “Communication,” “Social

Interaction," and "Communication + Social Interaction Total" scores (ICC=.92 to .98). There was substantial agreement on ADOS classification between assessments delivered face-to-face versus assessments delivered remotely (P_o=83%; κ =.772, ICC=.92).

10. Evaluate the usability of the ADOS Module 4 administration via teleassessment, from the client's perspective.

The third study, in chapter 4, looked at the remote ADOS administration system from the participant's perspective. Twenty-three participants completed the Post-ADOS Assessment User Satisfaction Questionnaire. Participants indicated a high degree of satisfaction with the remote administration system. Seventy-five percent of participants indicated they felt comfortable using the system. Seventy-eight percent of participants indicated that being assessed this way provides a true picture of how they typically behave and interact with others. Eighty-three percent of participants indicated that they would be willing to do future tests over the computer.

11. Discuss the results of the studies and future implications.

There is an increase in the prevalence of ASD and therefore an increase in the need of specialists to assess, diagnose, and treat individuals with ASD, including adolescents and adults. Teleassessment has potential time and cost-saving benefits, in addition to the capacity to increase access to and enhance continuity of services for individuals with disabilities, especially those living in remote areas. The remote administration of the ADOS Module 4 is an exciting opportunity to for adolescents and adults to access gold standard ASD assessment services. The results of these studies supported the ability to conduct the ADOS via a telemedicine platform.

APPENDIX A

DSM-IV-TR DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER

A. A total of six (or more) items from (1), (2), and (3) with at least two from (1), and one each from (2) and (3):
   (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
      (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
      (b) Failure to develop peer relationship appropriate to developmental level
      (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
      (d) Lack of social or emotional reciprocity
   (2) Qualitative impairments in communication as manifested by at least one of the following:
      (a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
      (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
      (c) Stereotyped and repetitive use of language or idiosyncratic language
      (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
   (3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
      (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) Apparently inflexible adherence to specific, nonfunctional routines or rituals
(c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
(d) Persistent preoccupations with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
C. The disturbance is not better accounted for by Rett's Disorder or childhood Disintegrative Disorder (APA, 2000, p. 75).

APPENDIX B

DSM-IV-TR DIAGNOSTIC CRITERIA FOR ASPERGER'S DISORDER

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
    (1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
    (2) Failure to develop peer relationships appropriate to developmental level
    (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
    (4) Lack of social or emotional reciprocity
B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals
    (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    (4) Persistent preoccupation with parts of objects
C. The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.
D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia (APA, 2000, p. 84).

APPENDIX C

ADOS REMOTE ADMINISTRATION USABILITY QUESTIONNAIRE

Administering Activities - These 6 questions will be asked following administration of each individual ADOS activity.)

1. **Were you able to independently administer the activity?**
   - ☐ Yes
   - ☐ No

   Comments:

2. **Was the quality and clarity of the video acceptable?**
   - ☐ Yes
   - ☐ No

   Comments:

3. **Was the quality and clarity of the audio acceptable?**
   - ☐ Yes
   - ☐ No

   Comments:

4. **Were you forced to break standard face-to-face administration procedure?**
   - ☐ Yes
   - ☐ No

   If yes, how?

If yes, to what degree?

Minimal break from standard administration	1	2	3	4	5	6	7	Maximum break from standard administration

5. **This activity took _____ effort to complete versus standard, face-to-face administration.**
   - □ Much more
   - □ Somewhat more
   - □ The same
   - □ Somewhat less
   - □ Much less

6. **This activity required _____ time to complete versus standard, face-to-face administration.**
   - □ Much more
   - □ Somewhat more
   - □ The same
   - □ Somewhat less
   - □ Much less

Scoring Items

1. **Were you able to independently score all the items?**
   - □ Yes
   - □ No

   Comments:

2. **Scoring items required _____ effort to complete versus scoring items on by hand.**
   - □ Much more
   - □ Somewhat more
   - □ The same
   - □ Somewhat less
   - □ Much less

3. **Scoring items required _____ time to complete versus scoring items by hand.**
    - Much more
    - Somewhat more
    - The same
    - Somewhat less
    - Much less

Viewing Protocol

1. **Were you able to independently view the protocol?**
    - Yes
    - No

    Comments:

2. **Viewing the protocol required _____ effort to complete versus standard, face-to-face administration.**
    - Much more
    - Somewhat more
    - The same
    - Somewhat less
    - Much less

3. **Viewing the protocol required _____ time to complete versus standard, face-to-face administration.**
    - Much more
    - Somewhat more
    - The same
    - Somewhat less
    - Much less

Post-ADOS Administration

1. **What changes would make the system more usable?**

2. **What additions would make the system more usable?**

3. **In what ways is the remote assessment clinically different from face-to-face assessment?**

4. **What are potential confounds you would anticipate in clinical application?**

APPENDIX D

POST-STUDY SYSTEM USABILITY QUESTIONNAIRE (PSSUQ)

This questionnaire gives you an opportunity to tell us your reactions to the system you used. Your responses will help us understand what aspects of the system you are particularly concerned about and the aspects that satisfy you.

To as great a degree as possible, think about all the tasks that you have done with the system while you answer these questions.

Please read each statement and indicate how strongly you agree or disagree with the statement by circling a number on the scale. If a statement does not apply to you, circle N/A.

Please write comments to elaborate on your answers.

After you have completed this questionnaire, I'll go over your answers with you to make sure I understand all of your responses.

Thank you!

1. **Overall, I am satisfied with how easy it is to use this system.**

Strongly Agree	1	2	3	4	5	6	7 *Strongly Disagree*

Comments:

2. It was simple to use this system.

Strongly Agree	1	2	3	4	5	6	7 *Strongly Disagree*

Comments:

3. I could effectively complete the tasks and scenarios using this system.

Strongly Agree	1	2	3	4	5	6	7 *Strongly Disagree*

Comments:

4. I was able to complete the tasks and scenarios quickly using this system.

Strongly Agree	1	2	3	4	5	6	7 *Strongly Disagree*

Comments:

5. I was able to efficiently complete the tasks and scenarios using this system.

Strongly Agree	1	2	3	4	5	6	7 *Strongly Disagree*

Comments:

6. I felt comfortable using this system.

Strongly Agree	1	2	3	4	5	6	7 *Strongly Disagree*

Comments:

7. It was easy to learn to use this system.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

8. I believe I could become productive quickly using this system.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

9. The system gave error messages that clearly told me how to fix problems.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

10. Whenever I made a mistake using the system, I could recover easily and quickly.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

11. The information (such as on-line help, on-screen messages, and other documentation) provided with this system was clear.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

12. It was easy to find the information I needed.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

13. The information provided for the system was easy to understand.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

14. The information was effective in helping me complete the tasks and scenarios.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

15. The organization of information on the system screens was clear.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments

Note: *The interface includes those items that you use to interact with the system. For example, some components of the interface are the keyboard, the mouse, the screens (including their use of graphics and language).*

16. The interface of this system was pleasant.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

17. I liked using the interface of this system.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

18. This system has all the functions and capabilities I expect it to have.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

19. Overall, I am satisfied with this system.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

APPENDIX E

ADOS MODULE 4 ADMINISTRATOR USABILITY FEEDBACK

Bold indicates high priority feedback.

Demographics Info

- **System should calculate chronological age from date of birth and today's date.**

Telling a Story from a Book

- **Need option for other book – *Tuesday*.**

Demonstration Task

- Deviations from face-to-face necessary. Options:
    - Tech could show – draw pretend sink, water faucets, cup, toothbrush, toothpaste, etc.
    - Remote administrator could give an example, e.g., driving
    - Use screen (tablet) as sink; described "on left toothpaste and toothbrush, on right is cup…"
- Mock participant used a prop once, couldn't stop her. Would have to be the job of the on-site tech.

Cartoons

- Mock participant stood behind chair with hands on chair. Need to provide instructions/room set-up so that this doesn't happen.
- Couldn't tell if the mock participant was looking at the examiner or the cartoon because the cartoon was still on the screen. Need to make sure the cartoon is removed.

- Can't see face on close camera. Needs to be able to step back so can see if participant is making eye contact

Break

- Sometimes admin would show them things, could tech do this?
- Mock participant only took out magazines, include instructions to take out all materials?

Creating a Story

- Need camera on test administrator to move, OR
- Need a desk to put items on so they are all on screen**.**
- Keep five items for examiner – give participant more items to choose from.

Scoring

- **Quality of Social Overtures – 0, 2, and 3 only, 1 is missing (typo)**
- **Would be nice to be able to add notes in the scoring section**
- **Could automatically calculate ADOS algorithm based on the three thresholds**
- **Saved money – "our" should be "your" (typo)**

Overall Comments

- **You time out and have to re-sign-in by the end of the administration. Signing in causes the notes to disappear.**
- **Visual stimuli, during Telling a Story from a Book, Description of a Picture, and Cartoons, won't stay up at the same time as notes.**
- If you accidentally try to open the non-tablet presentation, it crashes. Can this button be removed/disabled?
- Difficulty with keyboard – might be a problem. Distracted because of taking notes and can't make eye contact. When face-to-face, the person can tell you're taking notes and that's why you're not looking. Online, the administrator is not looking, but the person being tested might not know why.
- **Teleprompter issues**
    - People wearing glasses may impede eye contact (although not always a problem, one mock participant and one ADOS administrator were wearing glasses – no problems reported.)
    - Shadowy, hard to see, teleprompter was dark – need to think about lighting.
    - Small head-on view, hard to get a gestalt of the whole person.
    - Eye contact difficult to gauge.
    - Had difficulty remembering to look at mock client. Could head-on view be bigger? Bigger teleprompter?

- One mock participant did not make any gestures. Because of technology or was that just the mock participant (i.e., she is an individual who doesn't make many gestures.)
- **Like to put notes in different places, e.g., keeping all gesture notes in one place. This would be adding to the current system and changing it… But could make a side notepad for personal checklist, optional, so not altering the system. Add comments/notepad function!**
- Color coding? Starring? Bolding? Would be nice features.
- Difficulty showing/minimizing ribbon.
- Set up so window automatically goes to top center for teleprompter.
- Hard to get the conversation during Description of a Picture.
- Current Work or School – Hard to watch hands and eyes together
- Will we be able to determine voice volume if both sides can control volume?
- How much can you type and see in boxes?
- Need to set up admin chair height to ensure potential for good eye contact
- Need familiarity – someone new and then wouldn't be good. Personal communication is missing – maybe an individual feeling; maybe young testers wouldn't miss it or have a problem

Responses to *General Questions*

1. *What changes would make the system more usable?*
    a. Note taking may be awkward at times as the participant may not know you are pausing to take notes.
    b. Teleprompter made gauging eye contact difficult at times.
    c. Problems w/ blue bar; losing the stimuli when typing; have window automatically center
    d. Ease of window placement on screen – need more familiarity
2. *What additions would make the system more usable?*
    a. Camera moving to show my items in creating a story.
    b. I thought it was very usable! Have cartoons, book, and picture remain open when also taking notes.
    c. Add a comment or notepad section
3. *In what ways is the remote assessment clinically different from face-to-face assessment?*
    a. Have to make effort to make eye contact with camera (would improve over time/use), note taking is different (would also improve over time)
    b. Manipulation of props/stimuli was a bit different
    c. Hard to get used to looking at person while typing or at their hands
    d. Having the personal connection with the individual
4. *What are potential confounds you would anticipate in clinical application?*

a. Eye contact may be less if the examinee is not comfortable with equipment – but this may improve as the examination goes on
b. Are people as comfortable using their hands on camera or engaging in conversation?
c. Flow of computer connection – unexpected interruptions

APPENDIX F

TECHNICAL GUIDELINES: AUTISM DIAGNOSTIC OBSERVATION SCHEDULE (ADOS) MODULE 4 REMOTE ADMINISTRATION

Introduction

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials for individuals who have been referred because of possible autism or other pervasive developmental disorders. The ADOS consists of four modules, designed for different developmental and language levels. Each module has its own protocol, which contains a schedule of activities designed for use with children or adults. Module 4 is intended for verbally fluent adolescents and adults. It depends primarily on interview questions and conversation, with some activities.

The ADOS Module 4 has been translated to be delivered remotely using teleassessment technologies, specifically, the Versatile and Integrated System for Telerehabilitation (VISYTER). This manual will detail system prerequisites, installing VISYTER, launching VISYTER, setting up VISYTER for the first time, and setting up an ADOS administration for the first time. Frequently asked questions (FAQs) are located at the end.

System Prerequisites

1. **Computer Requirements**
   VISYTER's video conferencing quality rapidly degrades when the computer approaches 100% CPU utilization. With this in mind, if you want to do two-way conferencing, you should use a computer with a minimum configuration of a Pentium IV 2.0 GHz dual processor, 1 GB of RAM, and an NVIDIA GeForce4 graphics card. Computers with this capacity should be at both the administrator and participant side.

   In addition, a Wacom Cintiq 12WX tablet is needed to display the ADOS visual stimuli. A tablet should be located at the participant side only. For the tablet installation guide

and hardware manual, go to:
http://www.wacom.com/~/media/Files/Manuals/Cintiq12WX_UserManual_Final.pdf .

2. **Network Requirements**
When using VISYTER, the host computer of a conference must use a static IP address. However, non-hosting computers can use dynamic (DHCP) IP addresses. Both computers, administrator side and participant side, should use a high-speed connection that supports multicasting or have access to a reflector service if within unicast network. At a minimum, the computers should use a high-speed internet service provider that has a download speed of 1 Mbps and an upload speed of 384 Kbps. However, the recommended set up is to use a local area network (LAN) that has download and upload speeds of greater than 10 Mbps with duplexing.

The easiest way to know whether the network meet this requirement is to run a couple test using popular bandwidth testing sites, such as: http://speedtest.net. For general, medium quality videoconferencing, VISYTER requires around 2Mbps download and 1Mbps upload speed.

3. **Audio/Video Requirements**
In order to conduct an ADOS Module 4 via VISYTER, you need to have a microphone and speaker connected to your computer. A USB speakerphone or similar unit with audio speakers and an echo-canceling microphone, such as the ClearOne CHAT® 60 or CHAT® 160, is recommended. You will need a microphone for both the administrator side and the participant side.

Additionally, you will need three webcams, one on the administrator side and two on the participant side. A wireless or USB-connected camera with at least 3 MP of resolution is required to use VISYTER. It is recommended that you have two Logitech HG C910 webcams, one on the administrator side and one on the participant side, and one Logitech QuickCam Orbit AF on the participant side. The Logitech QuickCam Orbit AF has additional features such as the ability to remotely control the camera.

A SeeEye2Eye Webcam Teleprompter allows for direct eye contact. The teleprompter is placed over the camera at only the administrator side. A set of mirrors beams the picture of the participant onto the optical grade beam-splitting glass, which sits in front of the camera lens. You see the reflected image, but the participant is not aware of you looking at anything but your camera. When you look directly at the participant's face and your webcam at the same time, the result is eye-to-eye contact.

4. Software Requirements

The following software should be installed on both computers (administrator and participant side):

- Operating System: Microsoft Window XP, Vista, or Server 2003
- Microsoft .NET Framework 3.5
  http://www.microsoft.com/downloads/details.aspx?displaylang=en&FamilyID=ab99342f-5d1a-413d-8319-81da479ab0d7
- Microsoft DirectX 9.0b or later
  http://www.microsoft.com/downloads/details.aspx?displaylang=en&FamilyID=2da43d38-db71-4c1b-bc6a-9b6652cd92a3
- Microsoft Windows Media Player 11 or later
  http://www.microsoft.com/windows/windowsmedia/player/11/default.aspx
- Webcam Driver
- Latest audio drivers
- VISYTER installer
  - Download the installer directly at:
    http://www.hari.pitt.edu/Portals/0/VISYTERSetup2_4NM.zip

5. **ADOS Requirements**
   The ADOS kit contains most of the items needed for Module 4 administration. The following items must be obtained separately prior to the first administration of the ADOS module 4.
   - Current newspaper (one step up from a tabloid) for "Break"
   - Current magazine (something easy to read, such as People magazine), for "Break"
   - Batteries for small radio
   - Other items that gradually wear out may also need replenished or replaced as necessary.

   In addition, for remote administration, a Sterilite 4 Drawer Storage Cart will be needed to store ADOS items on the participant's side.

Installing VISYTER

1. **Pre-Installation Process**
   Ensure that all of the above prerequisite software is installed. Also, VISYTER utilizes Windows Media Player's decoder to unscramble both the audio and video streams used in video conferencing. Ensure that this is the only decoder available for use and remove any open-source decoders that may have come preinstalled on the computer, as these decoders may interfere with your ability to use VISYTER properly.

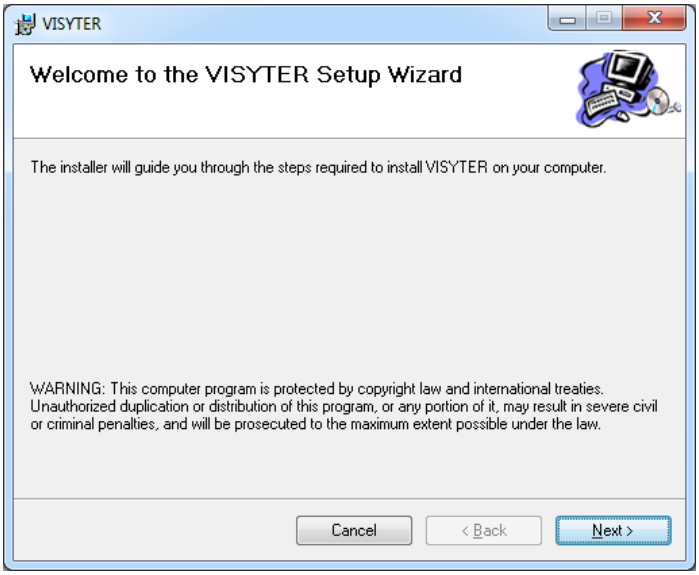
   If using the Logitech MP AF web cam, then remove the old driver and install the latest newest driver from the following link:
   http://www.logitech.com/pub/video/quickcam/qc1180.exe.

   Note: When prior to installing the new driver, unplug the USB camera from the computer. You will be prompted to install it during the installation process.

2. **Installing VISYTER**
   Unzip the contents of the .zip file you saved to your desktop.

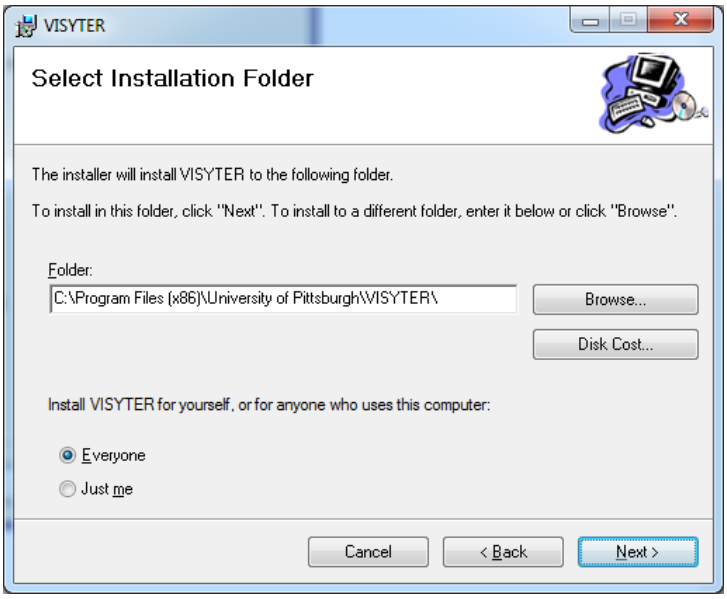
   Double-click the VISYTERSetup.msi installer package to run it.

Click *Next*.



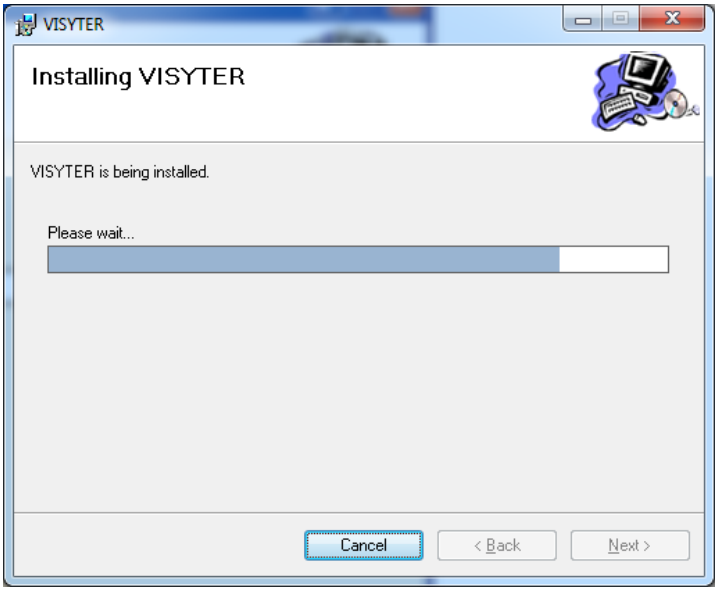
Read the License Agreement and check on *I Agree* radio button, then click *Next*.

Leave the install path to the default location, click *Just me*, and click *Next.*



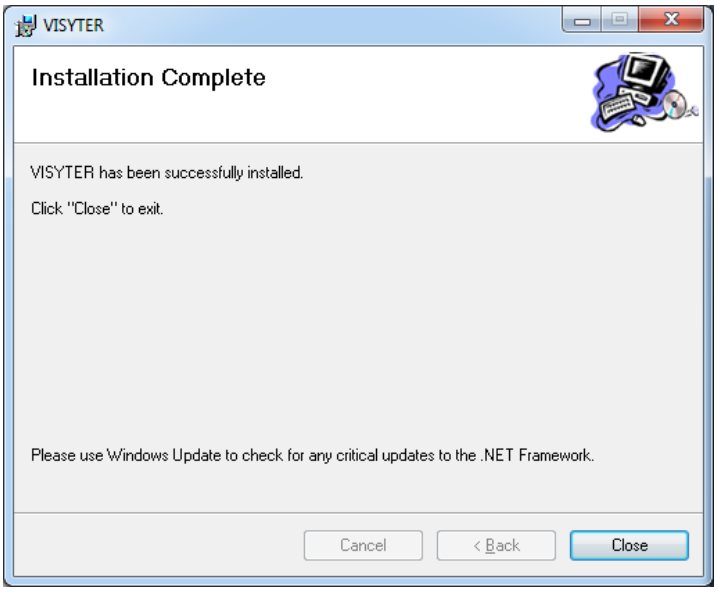
Note: VISYTER is designed for use by only one user at a time per computer

VISYTER will start installing.



Note: VISYTER may need permission to add into the local firewall. If this happens, the installation process might seem to have stopped. Usually, the installation window will cover a dialog box asking for permission to add into the local firewall. Please move the installation window to the side and click on the OK behind the window.

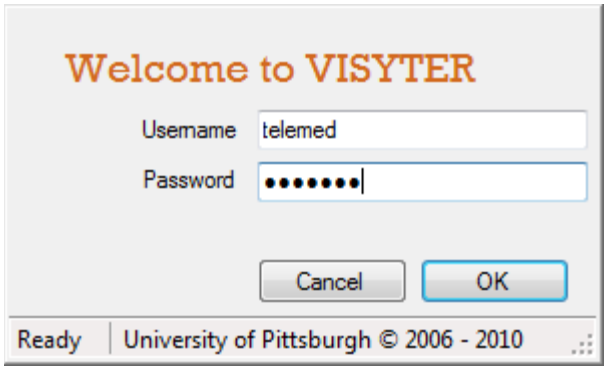
The installation is complete. Click *Close*.



Launch VISYTER

To run VISYTER, click on the VISYTER icon on the desktop.

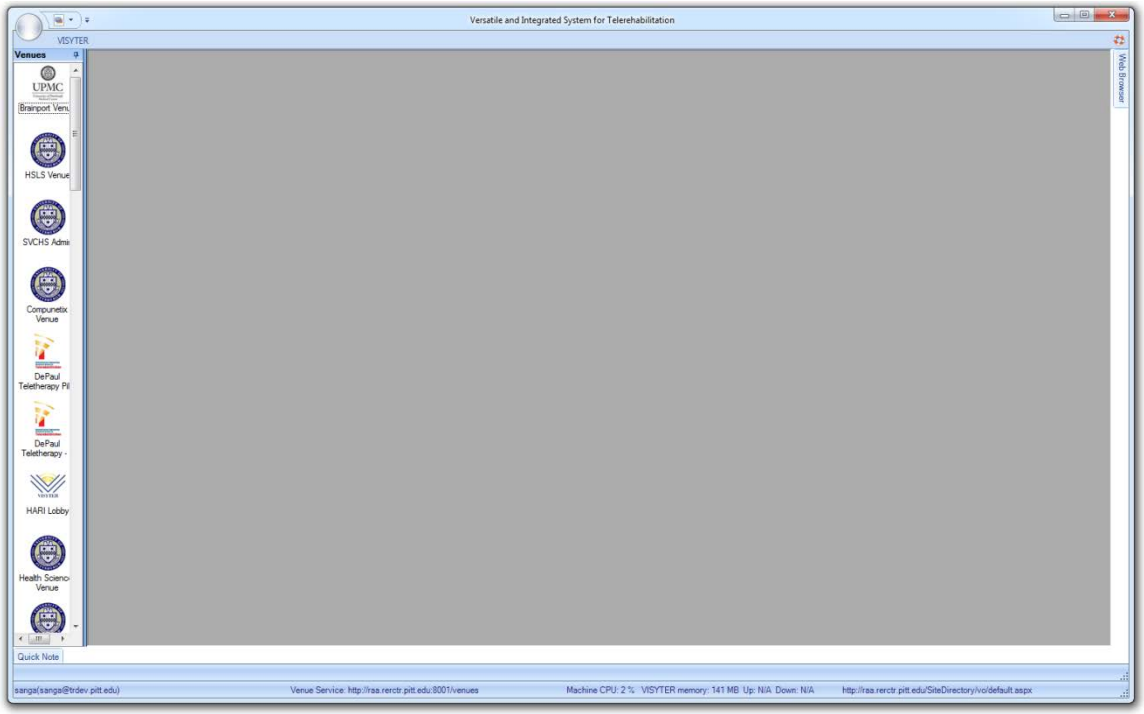
Enter your login/password to gain access to VISYTER.



The main window of VISYTER is below.

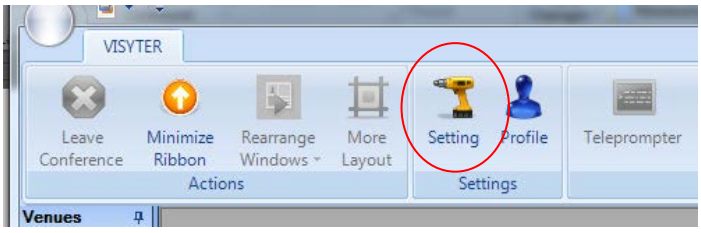
- The *Ribbon Menu* spans the top of the window. This is where clinicians can access all the features available in VISYTER in one click. By default, the ribbon menu is hidden. To activate the ribbon menu, click the 'VISYTER' text at the top left of the application.
- The *Venues Menu* is on the left side of the window. This is where the clinician can find their virtual rooms for video conferencing.

- The *Web Browser* is on the right side of the window. This browser points directly to clinician's collaboration portal. In addition, it also has 'My Site' tab that linked to clinician's personal online-workbench. By default, the web browser is hidden. Hover the mouse on top of the 'Web Browser' text to pull the browser.
- The *Video Placeholder* is in the middle part of the page. This is where the video for the video conferencing will appear.

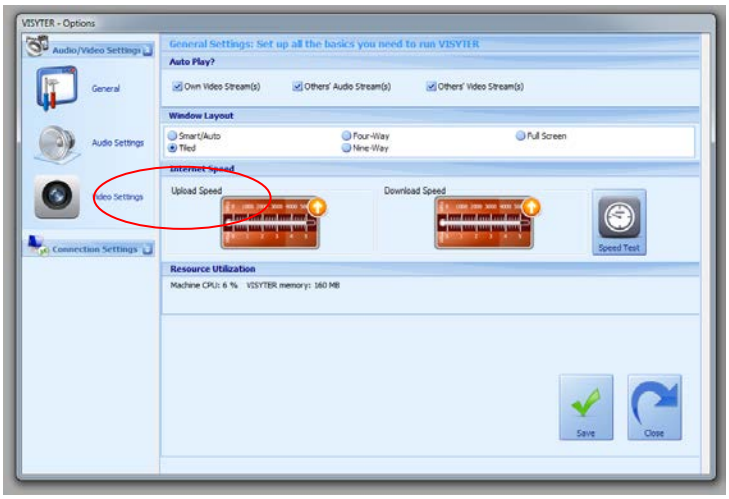


Setting up VISYTER for the First Time

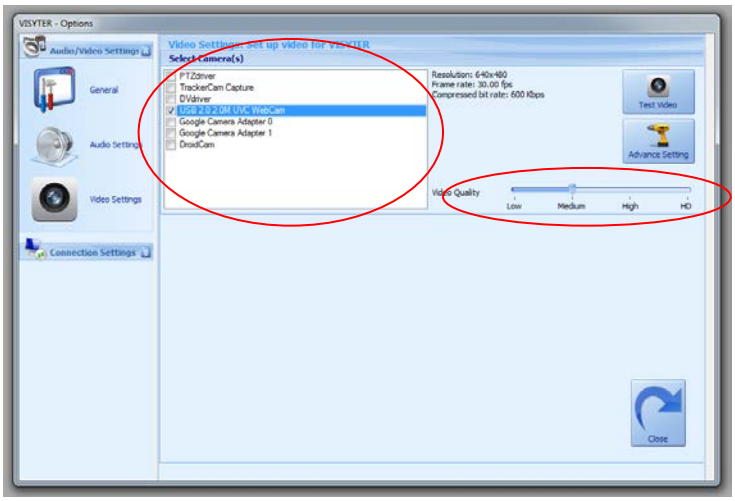
1. **Configure Your Video and Audio Settings**
   Click on *Setting* from the Ribbon Menu.



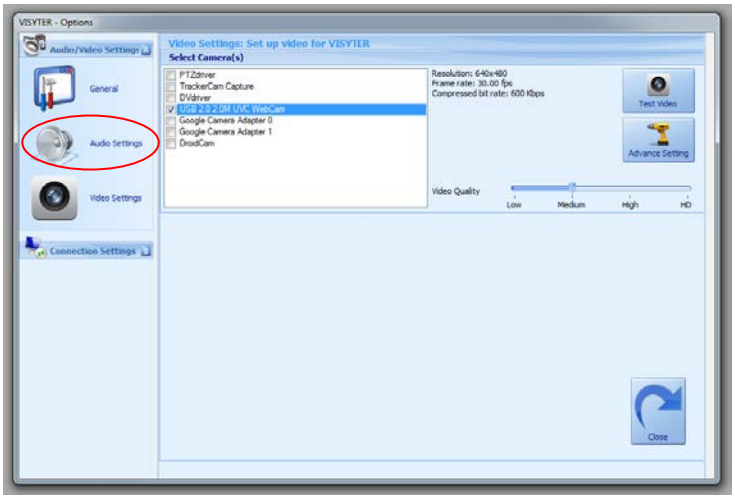
   The VISYTER Settings window will be shown in the middle of the screen. Click the *Video Settings* icon on the navigation bar at the left side of the window.



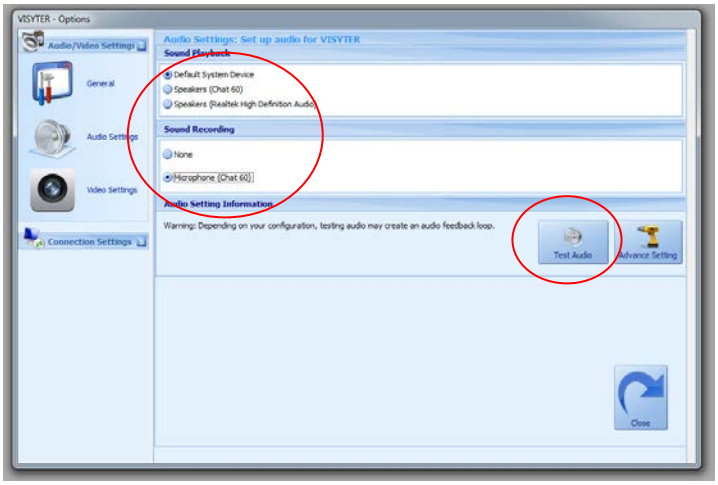
A list of available cameras will be displayed in the setup window. Select the appropriate camera. Multiple cameras may be used at the same time by checking the name of the cameras. The video stream quality from each camera can be controlled by the video quality slider to the right of the camera list.



Click on the ‘Audio Settings’ icon at the navigation bar to access VISYTER’s audio configuration.



A list of available sound playback and sound recording device will be displayed in the setup window. Select the appropriate device that will be used to record and playback the audio for the conference session.

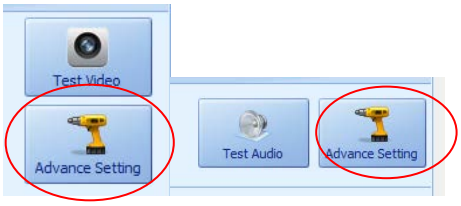


Note: When using ClearOne Chat 60 speakerphone for audio I/O:

- Always make sure that sound playback and sound recording are set to ClearOne Chat 60 speakerphone
- When testing the audio, try to make a test sound, if you heard any echo then there's other audio device beside Chat 60 that still active. Please disable all other audio device from the Microsoft Windows's Control Panel.

Further settings can be accessed via the 'advanced settings' button.

- The Advanced Settings... button at the Video Setting window can be used to control the quality of the video broadcasted to the conference.
- The Advanced Settings… button at the Audio Setting window can be used to control the quality of the audio broadcasted to the conference.

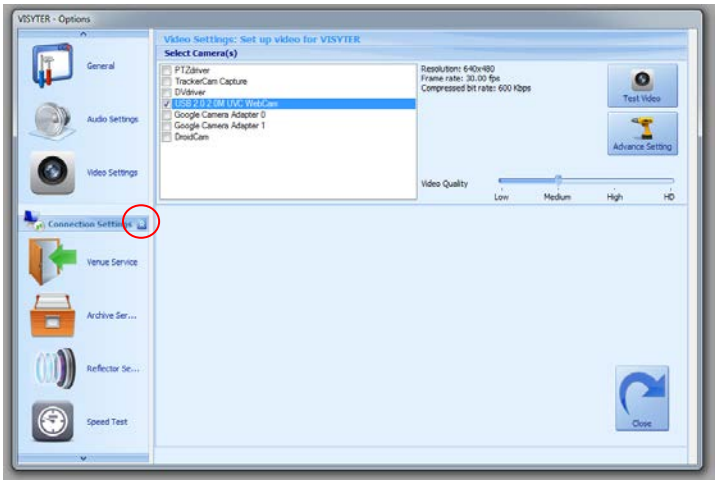


2. Server Configuration

Server configuration is for advance user only, and will allow user to customize the setting according to their need. Most of the server configuration is adjusted automatically.

The most important use of server configuration is to activate the 'Archiving Service'

To access the server configuration, expand the navigation bar on VISYTER Setting window by clicking the arrow sign next to "Connection Settings."

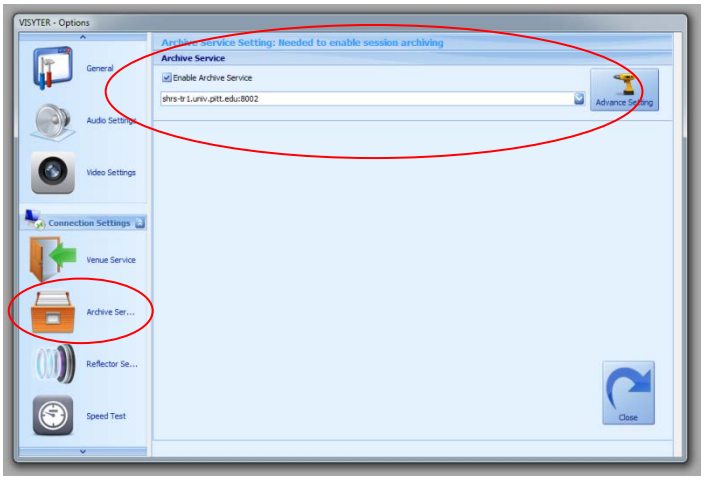


To record or play back the previously recorded session, the Archive Service needs to be activated.

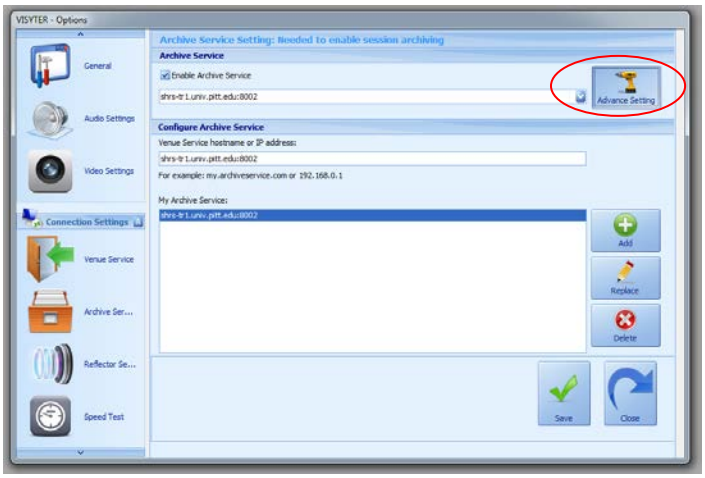
To access the Archive server configuration, click on the 'Archive Ser…' icon on the expanded navigation bar.

Ensure appropriate server address is listed under archive service and 'Enable Archive Service' checkbox is checked.[2]

[2] Note that every VISYTER installation package came with a default archive service that may differs from what described in this manual. Please contact administrator for further information



New archive server address can be added using the advance setting button. Clicking the advance setting button will display a list of available archive server.



Type the new archiving server address in *Archive Service host name or IP address*, then click *Add*, then click *Save.*

Remember to select the new server address from the drop down menu.

3. **Test Run**
   If all configurations are set-up properly, your approved list of venues will appear on the left side of the screen. We will use the 'VISYTER Venue' as our testing room. Afterwards, we will use specific venue (ex: Barber Institute Venue) for any other teleconsultation processes.

   Note: If VISYTER is unable to connect, then you may need to configure your firewall to allow certain ports through. Below is a list of ports that are required to be opened to allow a smooth connection for VISYTER.
   - Ports 5004 and 5005 are used for RTP/RTCP.

    - RTP/RTCP is used by the VISYTER to send video and audio in a multicast network
- Ports 7004 and 7005 are for the Reflector Service for VISYTER.
    - The Reflector Service is needed by clients who do not have Internet2 or multicast capability network.
- Port 8000, 8001,8002 are used to listen to the client's request for the Reflector Service, Venue Service or Archive Service.

Setting up an ADOS Module 4

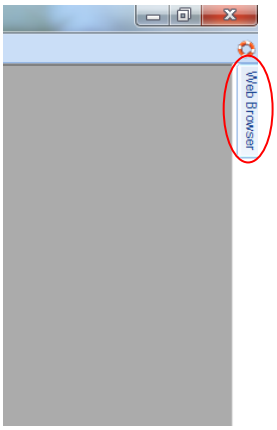
1. **Administrator Side**

   The administrator should set up the teleprompter over his/her camera. The head-on view of the participant should be moved to the top middle of the screen, so the administrator looks into the teleprompter to see the participant.

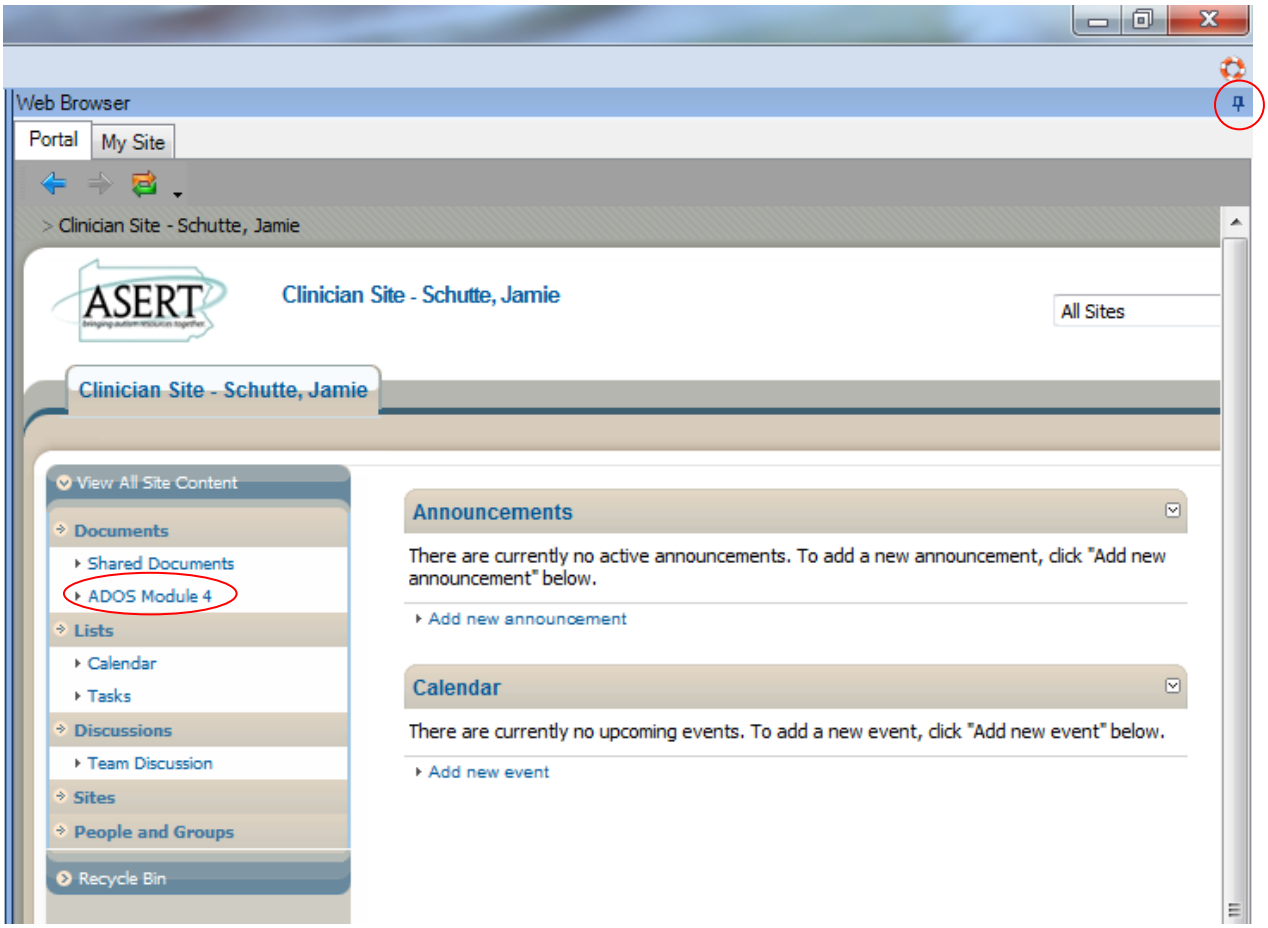
   The second camera view of the participant and the view of the administrator can be enlarged or made smaller and moved according to the administrator's preference. The administrator should test control of moving the second remote camera in all four directions and zooming in and out, and ensure that this camera is in an optimal position (typically, the same distance away from the participant as the computer monitor, to the right or left of the computer monitor).

   The three camera views should take up the left three quarters of the screen.

   The administrator can open the ADOS booklet by clicking on the "Web Browser" tab on the right. This tab can be secured by clicking on the pushpin icon in the top right corner. The ADOS booklet will occupy the right side of the screen.



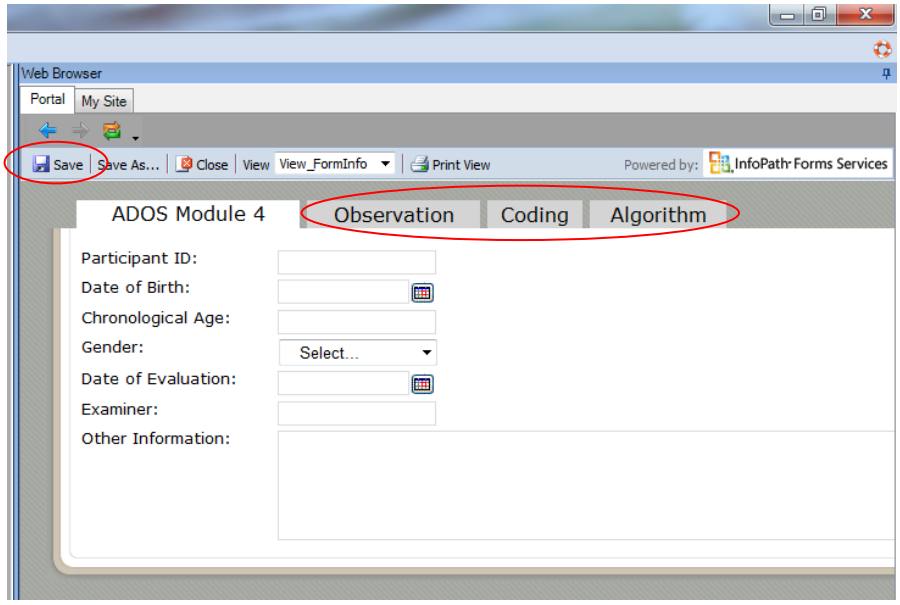
To open a new ADOS booklet, select *ADOS Module 4*, then *New*, then *ADOS Module 4*.



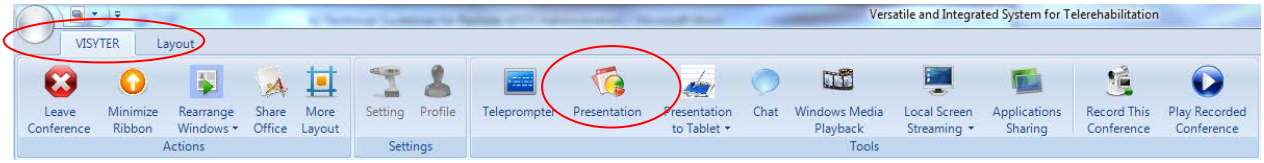
The administrator will be prompted to enter the participant ID, date of birth, chronological age, gender, date of evaluation, examiner and any other information.

The administrator should then click “Save,” and should regularly click “Save” throughout the evaluation.

In preparation for the administration, click on the *Observation* tab, where you will be typing notes during the administration.



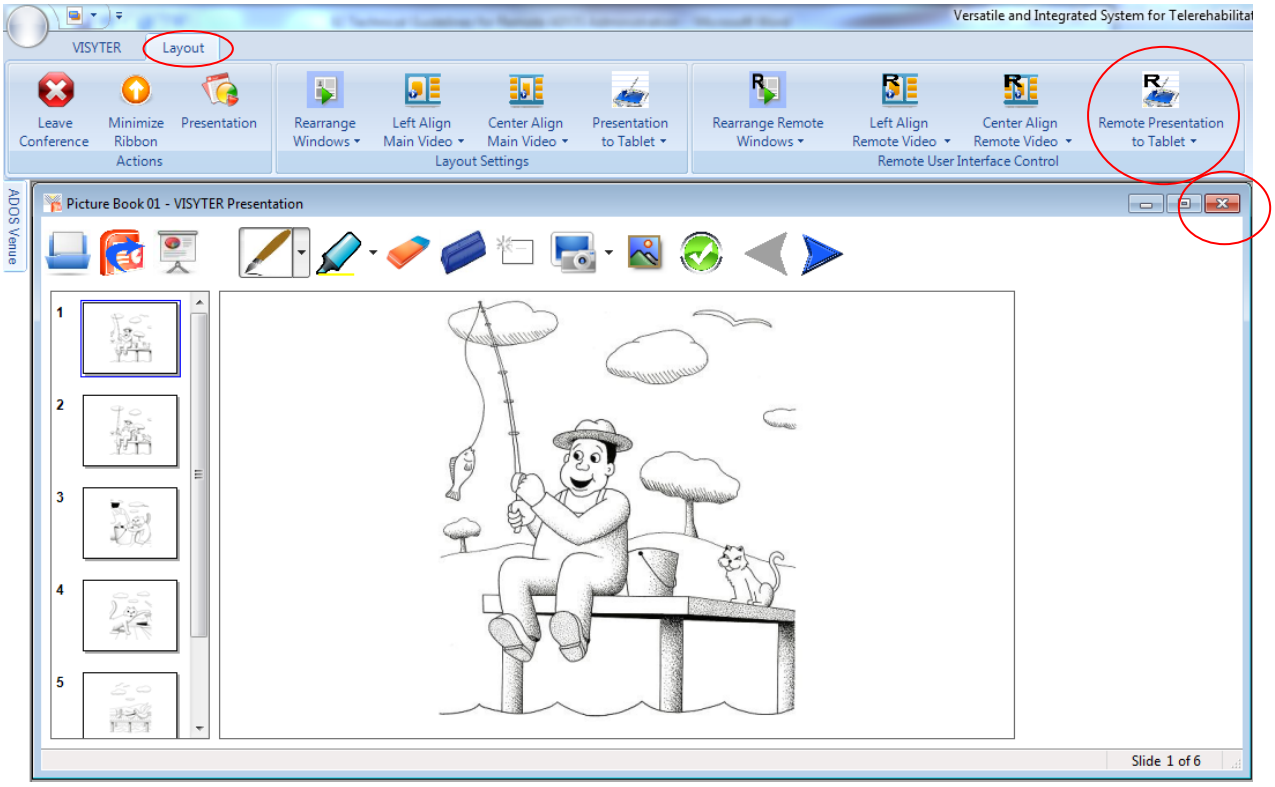
To open stimuli on the tablet, first obtain image files in .rtd format and save to your desktop. Then click on the *VISYTER* tab. Click on *Presentation*.



Click on the blue folder that will allow you to open a document. Select the .rtd document you wish to open (e.g., Cartoon – Fisherman.rtd).

Then click on the *Layout* tab. Click *Remote Presentation to Tablet*, and then click on the stimuli you wish to send to the tablet.

You can resize and move the visual stimuli in your window. To remove the stimuli from the tablet, simply click the *x* in the upper right hand corner.



The diagnostic algorithms are sets of rules that allow classification of participants as having the social and communicative deficits of autism or autism spectrum disorder (ASD). The examiner can access the coding form and the algorithm form by clicking on the appropriate tabs. After completion of the basic information under the "ADOS Module 4" tab and the scoring of the ADOS in the "Coding" tab, the information in the "Algorithm" tab will be automatically generated (excluding "Diagnosis").

2. Participant Side

The on-site technician should make sure the tablet is turned on and in the correct position, in front of the monitor. The mouse and keyboard should be moved out of the way, ideally out of sight.

The on-site technician should make the view of the examiner full-screen, so all other distractions are eliminated. The on-site technician can follow the administrator's guidelines to make sure all cameras are in place.

In addition, the on-site technician should make sure the 4-drawer storage cart is within eyesight and reach of the participant when he/she is seated at the computer.

Frequently Asked Questions (FAQ)

Can I use more than one camera with VISYTER?
Yes, VISYTER supports multiple cameras.

Can I run VISYTER on a laptop computer?
Yes, but the quality of video conferencing in VISYTER rapidly degrades when the system nears or hits 100% CPU utilization, so we recommend you monitor the CPU utilization and use high-end laptop hardware. In our observations, a laptop with a Pentium III 1.2 GHz processor with the NVIDIA Quadro2 Go Graphics Processing Unit (GPU) can do two-way conferencing, and a laptop with a Pentium IV 2.0 GHz processor with the NVIDIA GeForce4 Go GPU can do five-way conferencing. In both cases, the laptops are plugged into a power outlet to prevent the CPU from running at a lower speed to save power and the laptops use 100BaseT wired networking.

Does VISYTER work over a wireless network?
VISYTER includes enhancements that enable better transmission of slides and ink over wireless networks. However, these enhancements do not affect the quality of audio and video transmission over wireless networks. Generally, wireless networks do not have sufficient bandwidth and quality of service to support transmitting high-bitrate, high-quality audio and video streams.

Can I run VISYTER on Windows Server?
If the Windows Media codec that VISYTER requires is installed (which is included with Windows Media Player), you can run VISYTER on Windows Server. However, because we support running VISYTER on Windows XP, Vista and Windows 7, we have not done extensive testing of VISYTER running on Windows Server.

Does VISYTER require a server for receiving and sending streams?
VISYTER employs a peer-to-peer architecture. Because no server is involved, this architecture makes deployment easy, and it prevents network traffic bottlenecks and single points of failure.

Why does VISYTER use Windows Media codecs?
Video conferencing requires low latency and not all video codecs can do this. When we started designing VISYTER, we found that the Windows Media Video codecs, included with Windows Media Player, met all our latency and bandwidth requirements, worked well, and is free with your Windows license, which is the supported operating system. VISYTER uses the Windows Media 9 (or later) Series Audio and Video Codecs.

How are VISYTER multicast addresses selected?
The specific IP address chosen is determined by what venue is selected. One IP address is statically bound to each venue. When two VISYTER clients join the same venue, they are talking on the same multicast address and can see each other.
The Venue Server contains a database that maps friendly Venue names onto the IP addresses.

Which multicast addresses does VISYTER use?
VISYTER uses a range of 233.45.17.172-175:5004/5005 as well as a range of 'non-routed' multicast addresses in 234.*.*.*.

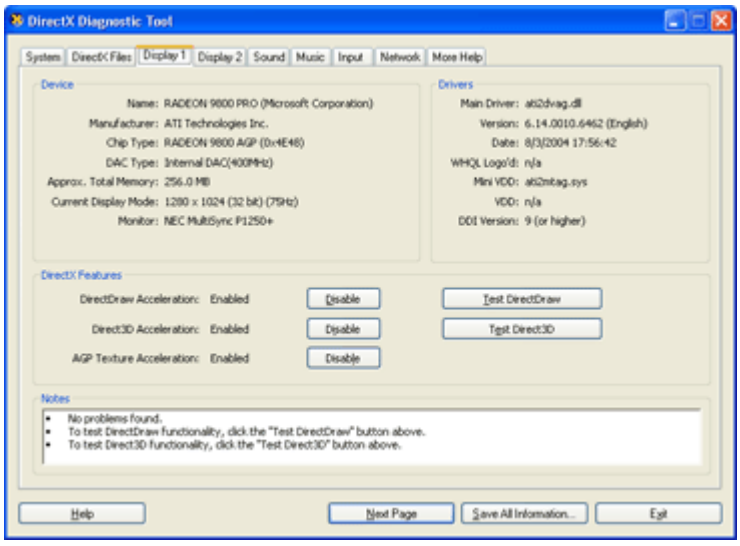
Are VISYTER video signals multicast?
Yes, VISYTER sends RTP and RTCP packets over multicast UDP/IP.

Is VISYTER compatible with my existing video conferencing system?
No, VISYTER uses the Windows Media codecs, which have been highly optimized for quality and efficiency on personal computers. Most commercial video conferencing systems today are based on the h.261 or h.263 video codecs, which provide relatively poorer quality and higher CPU utilization.
VISYTER transports its data over RTP (Real-Time Transport Protocol), described in RFC 3550 from the IETF.

How do I prevent video problems on my computer?
If you see video problems on your computer, such as several videos in the same window or not seeing your video on your computer while other participants can see your video, there may be a conflict with your graphics card. To determine if this is the problem, do the following:

Disable the DirectDraw Acceleration feature

1. On the Start menu, click *Run*
2. In the Open box, type *dxdiag*
3. Click the *Display 1* tab
4. Under *DirectX Features*, next *to DirectDraw Acceleration: Enabled*, click *Disable*



5. If you have a second monitor, click the *Display 2* tab, and then next to *DirectDraw Acceleration: Enabled*, click *Disable*.

I'm using Phoenix Duet in my computer, but why I still hear a loud echo?
You might be free from echo by using Duet, but how about the other sites/users in the conference? Even if one participant does not using any kind of echo canceling device, it will

propagates to the entire conference. Please make sure every participant is using an echo canceling speakerphone (e.g. Phoenix Duet) or a headset. For more information about how to setup a Phoenix Duet in Audio/Video Configuration section.

Important: Send I Wayan Pulantara your profile name and email address that you used for setting up the system.

You can contact us at:

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Active email: ans38@pitt.edu
Office phone: 412 383 5101
Cell phone: 412 708 3134

I Wayan Pulantara
iwp3@pitt.edu
Office phone: 412-383-5101
Cell phone: 412-799-3911

APPENDIX G

ADMINISTRATION GUIDELINES: AUTISM DIAGNOSTIC OBSERVATION SCHEDULE (ADOS) MODULE 4 REMOTE ADMINISTRATION

Introduction

The Autism Diagnostic Observation Schedule (ADOS) is a semi-structured, standardized assessment of communication, social interaction, and play or imaginative use of materials for individuals who have been referred because of possible autism or other pervasive developmental disorders. The ADOS consists of four modules, designed for different developmental and language levels. Each module has its own protocol, which contains a schedule of activities designed for use with children or adults. Module 4 is intended for verbally fluent adolescents and adults. It depends primarily on interview questions and conversation, with some activities (Lord, Rutter, DiLavore, & Risi, 2008).

The ADOS Module 4 has been translated to be delivered remotely using teleassessment technologies. Administration should be conducted as detailed in the *Autism Diagnostic Observation Schedule (ADOS) Manual* developed by Catherine Lord, PhD, Michael Rutter, MS, FRS, Pamela C. DiLavore, PhD, and Susan Risi, PhD (2008). These guidelines detail changes to the administration procedure necessitated by the remote delivery. These changes do not change the meaning or intent of the items. Care has been taken to not affect standardization.

Learning to Use the ADOS

Requirements for learning to use the ADOS include all requirements stated in the ADOS Manual (page 7). These include the need for examiners to have sufficient experience with typically developing individuals within the chronological age range of the child being evaluated with the ADOS, and experiences with individuals with ASD and with other developmental disorders that are not part of the autism spectrum. Examiners are also encouraged to work as a team and develop opportunities to practice ratings.

According to the Western Psychological Services (WPS) (the ADOS publisher), to obtain essential competence, ADOS users should (1) have prior education, training, and experience that includes extensive exposure to ASD, (2) Take a WPS in-person clinical training workshop or use the WPS Training Video/DVD and accompanying materials, (3) Practice using the ADOS on cases that are not part of formal evaluations and bring themselves to complete familiarity with the assessment activities and complete confidence that they can apply the coding categories accurately, and (4) If a user is to be involved in formal research directed at producing articles for publication in peer-review journals, he or she must additionally take a research training workshop followed by exercises that establish item coding accuracy to a specific criterion.

In addition, when the ADOS is administered remotely, it is necessary for the clinician to have a level of comfort and skill with technology and basic troubleshooting skills. Remote ADOS administrators should receive training in factors specific to information technology.

Despite the ADOS being administered remotely, the participant will never be alone in the evaluation room. An on-site technician will be available at all times. The on-site technicians should have some familiarity with the ADOS, but need not have participated in any formal training. He or she should also have a level of comfort with technology and computers, to be able to set up the computer for the assessment and troubleshoot before or during, if necessary. In addition, in case of emergency, the on-site technician should know who to contact, (e.g., local emergency services).

Module 4: Fluent Speech (Adolescent/Adult)

Introduction

Module 4 consists of 10-15 activities with 31 accompanying ratings. These activities combine unstructured conversation with a series of structured situations and interview questions that offer a variety of presses for particular kinds of social and communicative behavior. The general format of the schedule is to create an interaction that appears natural, during which pre-planned occasions for certain behaviors arise. The introduction in the ADOS Manual is an applicable introduction to the remote administration of the ADOS Module 4 as well (pages 79-81).

For a list of the activities and items needed, see the table below. Note that some ADOS administrative items will have to be split up between the administrator and the participant sites. Items at the participant site should be kept in a 4-drawer storage cart, like the Sterilite 4 Drawer Storage Cart pictured below.

Activities	Items Needed
1. Telling a Story From a Book	--
2. Description of a Picture *(Optional)*	--
3. Conversation and Reporting	--
4. Current Work or School *(Optional)*	--
5. Social Difficulties or Annoyance	--
6. Emotions	--
7. Demonstration Task	*Participant side*

	Hand towel and soap – in drawer #2*
8. Cartoons *(Optional)*	--
9. Break	*Participant Side* Shape puzzle, drawing paper, set of 8 markers, pin art, spin pen (top with a pen base), small radio, current newspaper and magazine, and materials from "make-believe play" – in drawer #3*
10. Daily Living *(Optional)*	--
11. Friends and Marriage	--
12. Loneliness	--
13. Plans and Dreams	--
14. Creating a Story	6 items with a purpose, 6 items with no clear purpose *Administrator Side* 5 randomly selected items *Participant Side* Remaining 7 items – in drawer #1*

*Sterilite 4 Drawer Storage Cart – Number drawers 1-4, from top to bottom.

Setup

In the ADOS Manual, it states, "The physical structure of the setting requires special attention. In order to provide encouragement for informal to-and-fro interactions and communication, it is preferable to avoid the confrontational nature of an arrangement in which the examiner and the participant are seated opposite one another across a table. An arrangement in which they are facing each other diagonally at the corner of the table or side by side at a round table may be more appropriate." Obviously, this set up is not possible when meeting remotely. However, many individuals are familiar with social videoconferencing (e.g., Skype, FaceTime for Mac), so there is unlikely to be a "confrontational" appearance of the interaction.

The administrator's office should be quiet and have a door that closes for privacy. The administrator should test the video and make sure there is nothing distracting in the background. The administrator can also select clothing for videoconferencing, including color choices like royal blue, burgundy, purple, and gray, that will contrast well with the background. Avoid wearing clothing with complicated or repetitive design, including stripes, checks, or dots.

The remote office should be neat and clean, and have as few distracters as possible. The room should be large enough to fit two adults comfortably. The room should have a door that closes for privacy. The on-site remote technician should be seated outside of the eyesight of both the participant and the administrator. Below is a potential layout for a 9' by 12' office space.

Instructions for Activities in Module 4

All instructions for activities in Module 4 are the same as are noted in the ADOS Manual (pages 81-86), except for the differences described below.

Construction Task (Optional)

This optional activity is not administered in the remote administration of the ADOS Module 4.

Telling a Story From A Book

Materials: The administrator will load the book onto the participant's tablet by selecting "Presentation" the blue file folder that indicates "Open," and selecting either of the two picture storybooks. After the book has opened, the administrator will select the Layout tab, and then "Remote Presentation to Tablet."

Instructions: The participant is presented with one of the books and told, "Have a look at this book on the tablet. Just like a real book, you can I can both turn the pages. You can turn the pages by clicking on the large buttons to the left and right of the screen. This book tells a story

in pictures. See, it starts out with… (*describe the first picture in the book*). Can you tell me the story as we go along? You go first, and then I'll take a turn."

When the book is over, the administrator can remove the book from the participant's tablet by clicking on the "x" in the upper right hand corner.

Description of a Picture (Optional)

Materials: The administrator will load the picture onto the participant's tablet by selecting "Presentation" the blue file folder that indicates "Open," and selecting either the American montage scene or the resort scene. After the picture has opened, the administrator will select the Layout tab, and then "Remote Presentation to Tablet."

Instructions: The participant is told, "Let's look at this picture on the tablet now. Can you tell me about it? What is happening in the picture?"

When the picture is over, the administrator can remove the book from the participant's tablet by clicking on the "x" in the upper right hand corner.

Conversation and Reporting

Current Work or School (Optional)

Social Difficulties and Annoyance

Emotions

Demonstration Task

Materials: Hand towel and soap

Instructions: The examiner says, "Now I want you to play a pretend game with me," and then sets up the imaginary scene with appropriate gestures. The examiner should look at the view of him or herself that the participant is seeing, to ensure that that his or her gestures are clearly visible to the participant. This may require making the gestures a little higher than one would in person. "Let us pretend this is the sink in the bathroom." Pretend to draw a sink and water taps. "This is the pretend toothbrush." Then pretend to draw the toothbrush. "And this is the pretend toothpaste." Again indicate the pretend object. These gestures should be slow and without extraneous movements. The examiner then says, "Now I want you to *teach* me how you brush your teeth. Can you show me and tell me? Start right at the beginning. You've come into the bathroom. What do you do now?"

Cartoons (Optional)

Materials: The administrator will load the cartoon onto the participant's tablet by selecting "Presentation" the blue file folder that indicates "Open," and selecting either the *Series A*

cartoons (a story involving a fisherman, a cat, and a pelican) or the *Series B* cartoons (a story about two monkeys and some coconuts). After the cartoon has opened, the administrator will select the Layout tab, and then "Remote Presentation to Tablet."

Instructions: The participant is told that, unlike the earlier task in which he/she narrated a story while looking at pictures, he/she will now be shown a very brief story in cartoons and then asked to retell it without looking at the pictures. The examiner will present the cartoon one slide at a time. As the examiner presents each set of cartoons, he/she should offer a brief statement describing the setting of the cartoons in very general terms and then ask the participant to look through the cartoons. Initially, the examiner should try not to give much information about the cartoons, but if the participant is confused about the nature of the story, the examiner can help clarify the events depicted.

After each set of cartoons has been presented, the examiner should remove the cartoon from the participant's tablet by clicking on the "x" in the upper right hand corner.

The participant should be asked to push his/her chair back from the table (so that the table is not within reach), stand up, and tell the story. It is particularly important for the participant to have nothing in his/her hands and to push his/her chair back from the table so that he/she will be able to gesture freely. If the participant is uncomfortable standing, he/she may be permitted to remain seated, but most people are much more animated telling stories if they cannot prop their arms and hands on a table. The administrator should adjust the camera to get the best view of the participant possible. It may be helpful to ask the on-site technician to move beside the desk, and ask the participant to tell him/her the story. If the participant does not gesture much while telling the stories shown in the cartoons, he/she should be asked to tell another one.

Break

Materials: Shape puzzle, drawing paper, set of 8 markers, pin art, spin pen (top with a pen base), small radio, current copies of a newspaper and a magazine, and materials from "Make-Believe Play."

Instructions: At an appropriate time, the examiner should say, "Let's take a break," and indicate that he/she needs some time to make notes in order to remember what he/she and the participant have done. The examiner should ask the participant to open up the drawer marked #3, and to bring all of the items out onto the desk. If the participant has difficulty finding or getting the items out, the on-site technician can assist. The examiner should refer to the specified "Break" materials, and express the hope that the participant can find something of interest among them. If the participant is unfamiliar with any of the materials, the on-site technician should demonstrate how they work (e.g., take the cap off the spin-pen, stick a toy in the pin art, etc.). Then the examiner should move to the side, so that he/she is sitting within view, but away from position he/she was previously in when engaging with the participant.

Once the participant is settled and everything possible has been offered (even if nothing is of interest), the examiner should work on his/her notes for at least 2 minutes (longer is fine if helpful to the participant or examiner). If the participant initiates an interaction, the examiner

should respond briefly and positively, but indicate that he/she has to finish more paperwork before he/she can talk. Later, after a few seconds, the examiner should look up, catch the participant's eye, and smile briefly in encouragement. The goal is to create an occasion for the participant to initiate an interaction. If this does not occur, the examiner can return to his/her notes or say, "I'll just be a few more minutes."

After several minutes, the examiner should return to original, interactive position. The examiner should say, "May I join you before we get back to work? What would you like to talk about?" If necessary, the examiner can look through the objects on the table, indicating interest in them, but continuing to allow the participant to take the lead.

Daily Living (Optional)

Friends and Marriage

Loneliness

Plans and Hopes

Creating a Story

Materials: 6 items with a definite purpose and 6 items with no clear purpose. The examiner should have 5 of these items, and the participant should have the remaining 7 in a bag in drawer #1.

Instructions: The examiner should tell the participant, "Now you and I are going to make up stories using some of the objects." The participant's task is to use five items to make up a story, newscast, or commercial. The examiner should hold up each of his or her five items to the camera, to give the participant a clear view of the objects. Then the examiner should tilt his/her camera down so that it faces the desk. The examiner should model making up a simple narrative in whatever format has been selected, primarily using items in ways for which they are not intended (e.g., using a toy parasol as a basket). The examiner's story should be simple enough so as not to inhibit the participant by seeming impossible to compete with. The examiner should attempt to provide a story that is geared to the developmental level of the participant. On object should be used as the "actor" in the story (e.g., "Mr. Flame woke up one morning," using a candlestick). Upon finishing the story, the examiner should move the camera up again so the participant can see his/her face.

The examiner should then gesture to the participant to choose a new group of items from those in the bag. The examiner can adjust the remote camera as necessary to get a good view of the participants' desk space.

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APPENDIX H

POST ADOS ASSESSMENT USER SATISFACTION QUESTIONNAIRE

Participant ID #: _____

Evaluation date: _____/_____/_____

Administration:

- ☐ First
- ☐ Second

1. I felt comfortable doing this assessment using the computer.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

2. The quality and clarity of the video (picture) was acceptable.

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

3. **The quality and clarity of the audio (sound) was acceptable.**

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

4. **Being assessed this way provides a true picture of how I typically behave and interact with others.**

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

5. **There were things I was unable to do/say because of the computer system that I would have been able to do/say in person.**

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

6. **If I had to have assessments or tests in the future, I would be willing to do them over the computer.**

Strongly Agree	1	2	3	4	5	6	7	*Strongly Disagree*

Comments:

7. If this was your second administration, which administration did you prefer?

- Greatly prefer face-to-face
- Slightly prefer face-to-face
- No preference
- Slightly prefer remote system
- Greatly prefer remote system

Other Comments:

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