
Discrepancy between parent report and clinician observation of symptoms in children with autism spectrum disorders

Maria Lemler

Case Western Reserve University

Follow this and additional works at: <https://commons.case.edu/discussions>

Recommended Citation

Lemler, Maria () "Discrepancy between parent report and clinician observation of symptoms in children with autism spectrum disorders," *Discussions*: Vol. 8: Iss. 2, Article 5.

DOI: <https://doi.org/10.28953/2997-2582.1145>

Available at: <https://commons.case.edu/discussions/vol8/iss2/5>

This Article is brought to you for free and open access by the Undergraduate Research Office at Scholarly Commons @ Case Western Reserve University. It has been accepted for inclusion in Discussions by an authorized editor of Scholarly Commons @ Case Western Reserve University. For more information, please contact digitalcommons@case.edu.

Discrepancy between parent report and clinician observation of symptoms in children with autism spectrum disorders



Maria Lemler

Maria Lemler is a graduate of Case Western Reserve University who majored in Cognitive Science with a minor in Public Policy. At CWRU she enjoyed spending her time outside of class as an executive member of Habitat for Humanity, the creator of Words Matter, and cofounder of Autism Speaks U. Maria is now studying at Vanderbilt University's Peabody College earning her Master's in Early Childhood Special Education. She intends to become a developmental specialist for children with autism spectrum disorders (ASD) and work on systematic efforts toward bettering educational services for people with ASD and their families.

-Acknowledgements-

I would like to thank Dr. Anastasia Dimitropoulos, adviser for this project and head of the Neurodevelopment Research Lab at Case Western Reserve University. This research was funded through the NIH (RO3HD058766-01) and the Prader-Willi Syndrome Association of America (PWSA).

ABSTRACT

The Center for Disease Control and Prevention defines Autism Spectrum Disorders (ASD) as pervasive developmental disabilities in which individuals have language impairment, social impairment and stereotyped behaviors. At this time there are no required assessments for a diagnosis. Diagnosis is often made with almost exclusive reliance on parent report of symptoms. The purpose of this research is to examine the consistencies between parent report and clinician observation of symptoms using the commonly used measures to diagnose ASD (ADOS & ADI-R). Previous research has shown diagnosis is more reliable and valid when using both ADOS (clinician observation) and ADI-R (parent interview). It is hypothesized that parents will score their children as less affected in the domains of social deficits and communication and more affected on restricted interests and stereotypies than clinicians. This discrepancy is expected based on the unique relationship between parents and their children and the resulting difference in social interactions and communication parents have with their children compared to an individual with whom the children are less familiar. This research included 12 individuals diagnosed with an ASD who ranged between the ages of 9 to 22 years old (mean age = 15.8). Results from the present study indicate a discrepancy between parent and clinician report on percent agreement on comparable items from the ADI-R and the ADOS. Such findings are crucial as they can help determine how different sources should be considered during the process of diagnosis and creating treatment plans for individuals with ASD.

INTRODUCTION

Parents and professionals provide crucial information during the diagnostic and treatment planning processes for individuals with special needs. Parents typically spend the most time with their child and are the main informants regarding their child's behaviors and needs. Parents provide valuable information about social behavior, obsessions, compulsions, self-injury, sensory needs, and other atypical behaviors. These observations however can lack objectivity, which becomes especially relevant when the child is being formally assessed for a developmental disability. Autism Spectrum Disorders are a group of pervasive developmental disorders characterized by difficulties in nonverbal and verbal communication, social interaction, and repetitive behaviors or restricted interests (Rice 2010). The Center for Disease Control reports that 1 out of every 110 children in the United States has an ASD (Rice, 2010). Some disabilities,

including ASD, do not have a known genetic foundation or physical features and therefore diagnosis relies heavily on the identification by parents and professionals of atypical behaviors. Sources of data need to be examined for the best quality of assessment for ASD, this is now particularly important as the number of children being diagnosed with ASD is rising.

According to the American Psychiatric Association in the Diagnostic and Statistical Manual IV (DSM IV) in order to be given a diagnosis of ASD, a child must have impairments in all three areas and symptoms must appear in the first three years of life (American Psychiatric Association, 2000). Many people with ASD have language delay but are able to learn spoken language with therapy, or sign language; others are nonverbal. Poor eye contact, disinterest or discomfort in social situations and lack of theory of mind are social challenges faced by individuals with ASD. This disorder is pervasive in that it impacts children in many ability areas, and individuals are often unable to live independently as adults. With a proper diagnosis at the earliest signs, children can receive the most effective services and parents can become educated on the disorder. Because ASD is such a prevalent disorder and symptoms of it are detectable when a child is young, investigating parents' abilities to report behavior is important.

Physicians regularly check all pediatric patients for meeting developmental milestones by looking for abilities like eye contact, responding to their name, and language use. When a child is suspected of having an ASD, the child's pediatrician evaluates the child personally or refers them to a child psychologist. If the child is not developing typically, a developmental psychologist or pediatrician specializing in development will make a formal diagnosis based on the specific behaviors of the child using the DSM IV criteria for ASD. No test, survey or interview is required for diagnosis.. There are several standardized surveys and assessments that can be used when diagnosing and evaluating a person with an ASD. The results from these assessments are also used later when developing an Individualized Education Plan (IEP) for the child's education. The most commonly used assessments for a child with an ASD are the Autism Diagnostic Interview-Revised (ADI-R) (Rutter, Le Couteur & Lord, 2005), The Child Behavior Checklist (CBCL) (Achenbach, 2000), and the Social Communication Questionnaire (SCQ) (Rutter, Bailey & Lord, 2003). All three assessments are based on? parent interviews but content differs on each. Because there is no policy requiring the use of certain assessments, there are inconsistencies for individual children and for people with ASD as a group in the information that is provided for

their health care, schooling and therapeutic providers. It is rare that children have a standardized clinical assessment and observation paired with a comprehensive parent interview. Because ASD is a disorder in which individuals have a variety of needs and symptoms, a detailed assessment is of the utmost importance. Over the last decade clinicians have been investigating the reliability and validity of commonly used diagnostic measures and behavioral assessments. The currently regarded "gold standard" for diagnosing a child with an ASD is the Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore & Risi, 2006), which is performed by specially trained objective professionals in a semi-structured environment (Bishop, 2002). This test uses direct observation from the tester in a standardized format of play in which they observe interaction, communication and any atypical repetitive behaviors (Sikora, 2008). Research has been performed to identify the reliability and validity of parent questionnaires and surveys (Lord, 2006; Sikora, 2008;). However, research is lacking in investigating any potential discrepancy between parent-report and objective clinician findings using standardized measures and the possible causes of such discrepancies. Parents often think their children are more or less capable than they may in fact be as they aren't with their children in school or therapy settings. In contrast, clinicians only see the children in clinical settings which limits the behaviors they may observe. It is likely that a discrepancy exists given these differences.

Research suggests that standardized parent questionnaires alongside objective clinical assessment lead to the most stable diagnosis in ASD (Risi, 2006; Lord, 2006; Sikora, 2008). Risi, Lord, Gotham, Corsello, Chrysler, Szatmari et. al investigated multiple sources used in diagnosis of autism using the ADI-R and the ADOS (2006). Their data suggest that both the ADI-R and the ADOS should be used, but this study does not investigate the domains of autism and settles on using both instead of examining the reasoning behind possible discrepancies (Risi et. al, 2006). Bender, Auciello, Morrison, MacAllister and Zaroff (2008) found the same to be true for children with epilepsy. In a study using both the ADOS and ADI-R to examine the stability of the diagnoses of ASD at age two and age nine, Lord et. al found that clinicians were the group that had the higher percentage of agreement in accurate diagnosis as compared to parents (2006). De Bildt, Sytema, Ketelaars, Kraijer and Volkmar compared parent and clinician agreement. De Bildt et. al (2003) used the ADI-R, ADOS, Autism Behavior Checklist (ABC) (parent report), and the Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS) (clinician observation). The partici-

pants all had intellectual disability and the authors were assessing the developmental disorder component of the participants' disabilities. De Bildt et. al (2003) found that the two parent report measures had good agreement with each other. Clinician observation measures also had good agreement with each other, but the parent report with the clinician observation had poor agreement. De Bildt et. al (2003) did not further investigate the discrepancy between clinicians and parents however, and only noted that it might be the facility and environment that may create these differences. The results from these studies suggest that parents and clinicians are reporting different behaviors.

The ADI-R and ADOS are very expensive diagnostic measures, as they require trained professionals, are expensive, and require large amounts of time compared with other diagnostic measures. In an effort to determine if diagnosis can become less expensive and time consuming, newer diagnostic tools have been developed. One such measure is a shortened version of the ADI-R, the developmental, diagnostic and dimensional interview (3Di) designed by Santosh, Mandy, Puura, Kaartinen, Warrington and Skuse (2009). Santosh et. al's (2009) found their 3Di had a strong agreement with the ADI-R. This is an important study that compares two parent-report diagnostic measures but includes no clinician evaluation thus providing no comparison to clinician observation.

In contrast, a study that used both parent and clinician assessment investigated the validity of the Children's Social Behavior Questionnaire (CSBQ)(Rutter, Bailey, Lord, 2008), a parent questionnaire for children with intellectual disability (de Bildt, 2009). In comparison to the ADOS and ADI-R, de Bildt et. al found much higher correlations of the various subscales with the CSBQ and the ADI-R than with the ADOS (2009). The authors attribute this to the ADOS test requiring a short amount of time so that only a limited number of behaviors may be observed. Other research performed by Bishop and Norbury (2002) compared the Social Communication Questionnaire (SCQ), another questionnaire for parents, with the ADOS and the ADI-R and had similar results; a good agreement between the SCQ and the ADI-R but poor agreement between both of those and the ADOS (Bishop, 2002). The authors also noted that categorization on the ADI-R is much more closely related to the diagnostic information from school records than the ADOS and stated that the ADI-R is unlikely to be informed by the school staff and is strictly a parent report (Bishop, 2002). However, this literature does not discuss the fact that the parents communicate with the school staff and unlike the objective clinician, the parents may be biased on that communication. As the literature lacks this

discussion, the ADI-R may be representing more than just home life and parents could be influenced by information from the school that the parent may not have observed first-hand.

Educators are providing different information than parents as they do not see the child at home and also do not have the same ASD specific training as clinicians who perform the ADOS. Comparing teacher and parent reports of communication skills in children with ASD, Bishop (2001) found significant differences in the parent versus teacher reports, $p < 0.05$ for speech scores, $p < 0.01$ for inappropriate initiation, stereotyped language, and social relationships, $p < 0.001$ for pragmatic composite scores. Teachers were more accurate in diagnosis than parents when compared with the official diagnosis on record. These results indicate that teachers significantly scored more accurately than parents (Bishop, 2001). Additionally, parental ratings of the child's social rapport had significant differences within the parent group unlike the professional ratings which were consistent (Bishop, 2001). The findings show that parents do not give the same responses as trained professionals, however the results may have been confounded since some of the teachers included mainstream general education teachers with no special education training.

In an effort to improve the reliability of ASD diagnoses, Tomanik, Pearson, Loveland, Lane and Shaw (2007) used the ADI-R, ADOS and the Vineland Adaptive Behavior Scales (VABS)(Sparrow 2005) to examine the importance of parent-report. VABS is a parent interview which includes questions about daily living skills, socialization and adaptive functioning (Tomanik et. al, 2007). Results indicated a concordance rate of diagnoses of ASD of 75% between the ADI-R and the ADOS and including the VABS the accuracy improved to 84% (Tomanik et. al, 2007). This study provides insight on the value of parent report, as the addition of VABS further improved the accuracy.

Wiggins and Robins (2007) also investigated the ADI-R, and ADOS in their use of diagnosis. They brought in 142 toddlers, 60 with no disorder, 42 with Autistic Disorder, and 30 with another spectrum disorder to see the validity of diagnosis. Using a double-blind study Wiggins and Robins had clinicians perform the ADI-R, ADOS, and the Child Autism Rating Scale (CARS), which is an observation measure, on the participants (2007). They found disagreement between the parent report of ADI-R with the CARS and ADOS, and when controlling for diagnosis of Autism alone rather than including other ASD diagnoses, they found that the ADI-R under-diagnosed according to the diagnoses that the toddlers came in with. When they removed the behavior domain there was much greater

agreement between the measures, which shows that the behavior domain may need further analysis (Wiggins & Robins, 2007).

Stone, Hoffman, Lewis and Ousley have investigated parent report and clinician observation in their research on early recognition of autism (1994). Stone et. al used the Childhood Autism Rating Scale (CARS) and the Parent Interview for Autism (PIQ) as the parent assessments and evaluated the child directly using either the Bayley Scales of Infant Development or the Merrill Palmer Scale of Mental Tests, and a motor imitation task (1994). They directly compared the parent reports with the clinician reports of behaviors in the domain of Rutter's criteria for a clinical diagnosis and compared the agreement on items within each domain for children under the age of four (Rutter, 1987). They found that agreement was strongest for the absence of behaviors rather than the presence, and only three of the twenty six participants had an acceptable level of agreement between clinicians and parents on the items of abnormal social play, stereotyped body movements, and restricted interests (Stone et. al, 1994). Low agreement was found on the items of impaired imitation, lack of awareness of others, impaired peer friendships, no mode of communication, abnormal nonverbal communication, absence of imaginative play, and preoccupation with parts of objects (Stone et. al, 1994). Their study is incredibly relevant to diagnosis, but because the age range is limited, information is lacking on whether the parent's knowledge of the child's behaviors at different ages can affect their assessment on current behaviors. Additionally, since this study no one has performed a comparative analysis of these using updated measures such as the ADI-R and ADOS.

Stone et. al's (1994) research shows the discrepancy between parent report and clinician observation but more research is needed. Some research indicates that parents can be a reliable source of information regarding their child's development (Glascoe, 2003). Little research has indicated whether clinician report is more accurate than the parent's or if it is offering information that the parent cannot provide. The research of Lord et. al (2006), Bender et. al (2008), Sakora et. al (2008) and Tomanik et. al (2007), lends itself to the study of parent versus clinician assessment. Using the ADI-R and the ADOS these clinicians have found discrepancies between the different kinds of tests and further investigation should follow up by comparing the differences in the subtests and if the results are different because of the reporters or because of the tests. The subtests are categorized based on the DSM IV criteria for diagnosis, and questions are coded and in-

cluded on the subtests in each assessment. The assessments include subtests on social skills, restricted interests, behavior, and communication. This may be valuable information for the healthcare provider, educator, and therapeutic intervention service providers who will need specific details on a child's diagnosis. It could provide information to help them determine if they should rely more heavily on a specific test or reporter or give them equal weight in the diagnostic process.

Research indicates that using both the ADI-R and the ADOS gives the most accurate results (Risi et. al, 2006; Lord, 2006). Because both have been shown to be reliable and valid, further investigation should be done using the subtests to isolate current behaviors, past behaviors, adaptive behavior, communication skill, imaginative play, and other components of the child's activities to determine whether parents or objective clinicians have a more accurate rating of the activities. The purpose of this study is to investigate if parent and clinician report differ on the sub-scores of communication abilities, stereotyped behavior and restricted interests for children with ASD. It is hypothesized that parents will over report symptoms in the social domain, and under-report symptoms in the domains of interests and communication compared to the clinician. This should also be done to investigate if there is a deficit in the DSM IV criteria that parents and clinicians do not report the comparable scores. This may lead to the inclusion of not only the ADOS and the ADI-R in an official diagnosis but other assessments that may be aimed towards one particular deficit area. By doing this more specific analysis, future research can lead to finding why there may be discrepancies. If results indicate a discrepancy, programs can be created to help parents learn how to observe and analyze their child's behavior and clinicians to gather full information from their assessments.

METHODS

Twelve participants who had previously received diagnosis of autism spectrum disorder including Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS), Autism, or Asperger's syndrome and their parents participated in the study. Participants' parents provided verification of diagnosis from a physician or psychologist. The parents acted as informants and are the persons who are most familiar with the person with daily behaviors of ASD

INCLUSION/EXCLUSION CRITERIA

All participants were individuals with ASD, PDD-NOS, or Asperger's Syndrome who have an IQ of less

than 100. Those with additional diagnosis of genetic neurodevelopmental disabilities or major mental or psychological disorders were excluded from this study. Eligibility was determined by the most recent IQ test results provided to the study, and their ability to communicate verbally being present. Participants were between the ages of 7 and 40 years old, have a parent or guardian as an informant that is familiar with their behavior, have an IQ of 100 or below, are verbal and use English as their primary language. The age range for this study was 9 to 22 years old (mean age = 15.8) and Participants also had Performance IQ's that ranged from 45 to 117 with a mean of 86. All of the participants lived with the person acting as the informant.

Participants were recruited through the Autism Society of Greater Cleveland, "Walk Now" for Autism Speaks and Northeast Ohio schools and camps for children with ASD. Participants and informants signed the Consent and Assent forms before beginning any part of the study. They were compensated for their participation, travel, and parking when they traveled to Case Western Reserve University's Neurodevelopment Research Lab in Cleveland.

PROCEDURE

Measures

The Autism Diagnostic Observation Schedule (ADOS) is the "gold standard" for assessing individuals with PDD-NOS and ASD for toddlers through adults (Lord, Rutter, DiLavore, Risi, 2006). It is a 30 to 45 minute standardized observation measure designed to assess autistic behaviors. Scoring yields cutoffs for fitting diagnosis of categories of ASD and for fitting diagnostic criteria for each domain. The ADOS involves the participant and a trained clinician and consists of four modules, which are divided based on developmental and language level. The developmental and language level of each participant was matched to the proper module, and only that module was administered to that participant. In this study Modules 2, 3 and 4 were administered given the verbal level of participants recruited. During the ADOS the clinician presented many opportunities for the participant to exhibit behaviors of interest in the diagnosis of ASD through "standard presses" for communication and social communication (Lord, 2006). These presses are used in the different portions of the test, and are similar to psychoeducational or developmental tests such as the Psychoeducational Profile by Shopler and Reichler (1980). The ADOS uses structured activities and materials that provide standard contexts for social interaction, communication, and any atypical behaviors. The presses refer to the "immediate environment that has direct implications for the subjects behavior" (Lord,

1989). The environment includes the toys, tools, and the clinician who attempts to interact during play with the child. The ADOS domain for language and communication, variable ADOS Communication, includes: overall level of non-echoed language, speech abnormalities associated with ASD (intonation, volume, rhythm, rate), immediate echolalia, stereotyped/idiosyncratic use of words or phrases, offering information, asking for information, reporting events, conversation, and descriptive, conventional, instrumental or informational gestures. The domain for reciprocal social interaction, variable ADOS Social, includes; unusual eye contact, facial expressions directed to others, language production and linked nonverbal communication, shared enjoyment in interaction, empathy/comments on others emotions, insight, quality of social overtures, quality of social response, amount of reciprocal social communication, and overall quality of rapport. The domain for stereotyped behaviors and restricted interests, variable ADOS Behaviors, includes; unusual sensory interest in play material/person, hand and finger and other complex mannerisms, self-injurious behavior, excessive interest in or references to unusual or highly specific topics or objects or repetitive behaviors, and compulsions or rituals.

Scoring for most tasks in the ADOS are on a three-point scale. Beginning with 0= *within normal limits*, to 1= *infrequent or possible abnormality*, to 2 = *definite abnormality* (Lord, 1989). The same aspect of a behavior cannot be coded as abnormal more than once but different aspects of that behavior can be coded more than once (Lord, 1989). An algorithm based on the tasks and items was used to determine the number of participants who meet diagnostic criteria in each domain. Lord et. al (1989) found the discriminant validity of the algorithm as quite good for social and communication criteria. Using intraclass correlations, Lord et. al (1989) assessed the interrater reliability of the algorithm and found no changes in classification with different clinicians as raters. The ADOS was also videotaped and another trained clinician watched the video and scored for reliability.

The Autism Diagnostic Interview-Revised (ADI-R) is a diagnostic measure used for individuals of all ages and administered in interview format to informant (Rutter, Le Couteur, Lord, 2005). The informant is asked questions about the participant's family and education, diagnosis, and medications, informant's concerns and introductory questions that help to create a general picture of the participant's behavior, early development and key developmental milestones, language history, communication and language functioning, social development and play, interests and behaviors, and general behaviors of clinical impor-

Table 1. Items compared from ADI-R and ADOS

ADI-R	ADOS
Range of Facial Expressions Used to Communicate	Facial Expressions directed at others
Quality of social Overtures	Quality of Social Overtures
Appropriateness of social responses	Quality of Social Response
Conventional/instrumental gestures	Descriptive, conventional, instrumental, or informational gestures
Social verbalization/chat	Amount of reciprocal social communication
Reciprocal conversation	Conversation
Neologisms/idiosyncratic language	Stereotyped/idiosyncratic use of words or phrases
Unusual preoccupations	Excessive interest in unusual or highly specific topics or objects
Circumscribed interests	Excessive interest in unusual or highly specific topics or objects
Hand and finger mannerisms	Hand and finger and other complex mannerisms
Unusual sensory interests	Unusual sensory interest in play material/person
Seeking to Share Enjoyment with Others	Shared Enjoyment in Interaction
Compulsions/Rituals	Compulsions/Rituals

tance (aggression, self-injury, epileptic features). The ADI-R is divided into three domains when interpreting results. These domains correspond to ASD diagnostic criteria in the DSM IV: Qualitative abnormalities in reciprocal social interaction (“A”), Qualitative abnormalities in communication (“B”), and restricted, repetitive, and stereotyped patterns of behavior (“C”), and if these signs of ASD were evident before the age of 36 months (“D”)(Rutter, 2005). The interviewer obtains specific and detailed responses from the informant. There are nine codes for responses from the informant. These codes begin at one with behaviors not being present, progress to abnormal behaviors being present at varying degrees, and the question being non-applicable. The algorithm for scoring conversion was created based on the maximum likelihood of ASD according to clinical consensus that participants would score above the cutoff. The Current Behavior Algorithm is used in scoring so as to get a direct comparison between the current be-

havior that is observed in the ADOS. The Current Behavior Algorithm does not have cutoffs, but can be compared with ADOS scores on items endorsed and when scores are normalized with the ADI-R using z-scores (Noterdaeme et. al, 2002).

The ADI-R variable ADI-R Social includes failure to use nonverbal behaviors to regulate social interaction, failure to develop peer relationships, lack of shared enjoyment, and lack of socioemotional reciprocity in the domain of qualitative abnormalities in reciprocal social interaction. Included in the domain of qualitative abnormalities in communication, variable ADI-R communication is; lack of, or delay in, spoken language and failure to compensate through gesture, relative failure to initiate or sustain conversational interchange, stereotypes, repetitive idiosyncratic speech, and lack of varied spontaneous make-believe or social initiative play. Included in domain of restricted, repetitive and stereotyped patterns of behavior, variable ADI-R Behavior

is; encompassing preoccupation or circumscribed pattern of interest, apparently compulsive adherence to non-functional routines or rituals, stereotyped and repetitive motor mannerisms, and preoccupations with part of objects or non-functional elements of material.

The ADOS and ADI-R do not use the same metrics in their scoring, but have been reliably converted and compared (Lord et. al, 2006; Bender et. al, 2008; Sakora et. al, 2008; Tomanik et. al, 2007; Noterdaeme et. al CITE). The domains correspond with one another and the scores can be compared directly after the conversion. In this study z-scores were created to directly compare the ADI-R and the ADOS. Many of the items on the ADI-R and the ADOS are also directly comparable and can be used to examine percent agreement.

Procedure

Participants and informants came to the Neurodevelopment Research Lab at Case Western Reserve University on the day of their appointment. The procedures were explained to them and informed consent was obtained. Then the participant was administered the ADOS. Later, a trained professional or research assistant interviewed the informant by administering the ADI-R. Once both assessments were completed the participants were compensated for their time.

Analyses and Results

The three domains from the ADI-R were compared with matching domains from the ADOS. Z-scores were created for each domain for ADOS Communication and ADI-R Communication, ADOS Interests and ADI-R Interests, ADOS Social and ADI-R Social and were compared. A paired t-test showed no significant differences on these items. Correlations showed no significant relationships between the items for the domains.

Twelve items from the ADOS and ADI-R were directly comparable. These items were coded for endorsement, if the behavior was marked as present (a response of 1, 2, or 3 on the ADI-R or the ADOS) the item was coded as "1," if not present (a response of 0 on the ADI-R or the ADOS) the item was coded as "0." Table 1 shows the items that could be directly compared were: Range of facial expressions used to communicate, Quality of social overtures, Appropriateness of social response, Conventional or instrumental gestures, Social verbalization or chat, Reciprocal Conversation, Neologisms or idiosyncratic language, Unusual preoccupations or circumscribed interests, Compulsions and rituals, Hand and finger mannerisms, Unusual sensory interests, and Seeking to share enjoyment with others.

Table 2. Percent agreement on items

	Agreement	Both	Neither	Agreed
Communication Domain				
Conversation	91.7%	10	1	11
Quality of Social Response	75.0%	7	2	9
Gesture	75.0%	3	6	9
Restricted Interests and Stereotypies Domain				
Enjoyment Interaction	66.7%	3	5	8
Hand & Finger Mannerisms	58.3%	1	6	7
Facial Expressions Directed at Others	58.3%	3	4	7
Stereotyped & Idiosyncratic Use of Words or Phrases	58.3%	0	7	7
Social Domain				
Chat (8 participants inc.)	50.0%	0	4	4
Compulsions (11 participants inc.)	45.5%	0	5	5
Unusual Sensory Interests	41.7%	1	4	5
Excessive/Unusual Interests or Preoccupations	33.3%	4	0	4
Quality of Social Overture	25.0%	2	1	3

Table 3. Percent endorsement on ADI-R and ADOS

		Assessment Cases Endorsed	
Communication Domain			
Chat	ADI-R	8.3%	
	ADOS*	58.3%	
Stereotypies & Restricted Interests Domain			
Compulsions	ADI-R*	63.3%	
	ADOS	0.0%	
Unusual Sensory Interests	ADI-R*	50.0%	
	ADOS	25.0%	
Excessive/Unusual Interests or Preoccupations	ADI-R*	83.0%	
	ADOS	50.0%	
Social Domain			
Quality of Social Overture	ADI-R	33.3%	
	ADOS*	83.3%	

*indicates assessment was more often endorsed for the item

Percent agreement between parent responses on ADI-R items and the comparable items on the ADI-R was calculated using the codes for endorsement. Only 3 items (Conversation 91.7%, Quality of social response 75%, Gesture 75%) showed an agreement of 75% or more of the participants. In contrast, 5 items showed agreement 50% or less of the time, these were Chat at 50%, Compulsions 45.5%, Unusual sensory interests 41.7%, Excessive/unusual interests or preoccupations 33.3%, and Quality of social overture 25% (Table 2). The five items fall in all three domains of ASD. The item in the communication domain, Chat, and the item in the social domain, Quality of social overture, showed more endorsement, meaning the behavior was more often present by the clinician on the ADOS. In the domain of restricted interest and stereotypies parents consistently endorsed the items, Unusual sensory interests, Excessive or unusual interests or preoccupations, and Compulsions more often (See Appendix: Table 3).

Discussion

At this time the ADOS and the ADI-R are the most comprehensive diagnostic assessments for ASD. Presently they are not required for an official diagnosis of ASD and are not consistently used by clinicians in the process of diagnosis. Given that they are not both required for diagnosis, schools, therapeutic services and other intervention services are receiving only partial information, most often just parent report information, like that of the ADI-R. One study (Pilowsky, Yirmiya, Shulman, & Dover, 1998) report-

ed that the Childhood Autism Rating Scale (Cars: Schopler, Reichler, De Vellis, & Daly 1980; Schopler, Reichler, & Renner, 1998) and the ADI-R disagree and this could be due to the source of information and time and place limits on both measures.

Results indicate that there is a difference between parent and clinician reports of symptoms in children with ASD. As hypothesized, parents reported their child as having more behaviors in the domain of restricted interests and stereotypies and clinicians reported more behaviors in the social and communication domains. These results suggest that parents and clinicians are both missing information when they report symptoms. Clinicians are not seeing all the restricted interests and behaviors while parents are not seeing the social and communication challenges.

These results can be due to a number of differences in relationships clinicians have with the child with ASD and parents have with their child, and further research should investigate these differences and their causes. One of the causes of the discrepancy is that parents don't see their child in school or group therapy sessions so they may think their child is more social. One Explanation for parents saying their child has stronger communication may be that parents often learn their children's idioms, i.e. "wa wa" meaning water, and can understand their child's speech best because they are present for every step of development.

The discrepancy between parent report on the ADI-R and clinician observation on the ADOS in the domains of Communication, Social and Interests will help clinicians in diagnosis, school and therapy settings, and describe parent perspective versus that of an objective clinician. By investigating the domains, on the ADI-R and the ADOS, crucial detail is provided on the child with ASD's abilities, symptoms, and needs. In the future, the study could be expanded with more participants, which could provide for more generalizable data. A limitation is that even though we are able to convert the data from the ADI-R to the ADOS metrics they aren't on the exact scale as the original scores.

Further research could study specific tasks or questions within those domains, i.e. social reciprocity, with parents and clinicians. This research creates a greater body of literature on parent knowledge and clinician evaluation abilities. Future research could also compare ages, spectrum diagnosis and level of functioning of the children and the agreement on these domains between the ADI-R and the ADOS. It is expected that with increasing age agreement will also increase. This could be due to the parents having knowledge of their child's diagnosis and having spoken with experts in the school system or intervention services. In regard to the level of functioning, if a parent has been told over the years that their child is "low" or "high-functioning" this information may impact how they analyze their child's behavior in response to the questions in the ADI-R. Clinicians who administer assessments themselves may not be impacted by previous assessments but may also spend a limited amount of time with the child as compared to the parents.

By investigating the three criteria of ASD and determining where a discrepancy between parent and clinical report lies, policy could be created regarding which tests should be required in order to gain the most comprehensive assessment of the needs of a child with ASD. [transition word] Future policy and programs could be created to educate parents on how to better understand and analyze their child's behavior. Also, physicians and psychologists who perform the diagnosis could hold greater value in certain information that the parents provide. As so much development occurs during the ages that children with ASD begin showing symptoms and are diagnosed, early intervention is crucial. This research could be the basis for future policy which would require both the ADOS and the ADI-R for a diagnosis and children receiving early intervention services, already provided by the state, that are most appropriate for their individual needs and they could receive specific intervention based on a comprehensive diagnosis when they need it the most.

REFERENCES

- 3, By Age. "NIMH • Autism Spectrum Disorders (Pervasive Developmental Disorders)." NIMH • Home. 24 Aug. 2010. Web. 25 Sept. 2010. <<http://www.nimh.nih.gov/health/publications/autism/complete-index.shtml#pub3>>.
- Achenbach, T. M., & Ruffle, T. M. (2000). The child behavior checklist and related forms for assessing behavioral/emotional problems and competencies. *Pediatrics in Review / American Academy of Pediatrics*, 21(8), 265-271.
- Allison Bender, H., Auciello, D., Morrison, C. E., MacAllister, W. S., & Zaroff, C. M. (2008). Comparing the convergent validity and clinical utility of the behavior assessment system for children-parent rating scales and child behavior checklist in children with epilepsy. *Epilepsy & Behavior: E&B*, 13(1), 237-242. doi:10.1016/j.yebeh.2008.03.007
- Altman, D. (1981). Statistics and ethics in medical research. VIII-Improving the quality of statistics in medical journals. *British medical journal (Clinical research ed.)*, 282(6257), 44-47. doi:10.1136/bmj.282.6257.44
- American Psychiatric Association, Diagnostic and statistical manual of mental disorders (Revised 4th ed.). Washington D.C.
- Bishop, D. V., & Baird, G. (2001). Parent and teacher report of pragmatic aspects of communication: Use of the children's communication checklist in a clinical setting. *Developmental Medicine and Child Neurology*, 43(12), 809-818.
- Bishop, D. V., & Norbury, C. F. (2002). Exploring the borderlands of autistic disorder and specific language impairment: A study using standardised diagnostic instruments. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 43(7), 917-929.
- "CDC - Autism Spectrum Disorder (ASDs) - NCBDDD." Centers for Disease Control and Prevention. 24 June 2010. Web. 26 Sept. 2010. <<http://www.cdc.gov/ncbddd/autism/index.html>>.
- Charman, T., Taylor, E., Drew, A., Cockerill, H., Brown, J., & Baird, G. (2005). Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. *Journal of Child Psychology and Psychiatry*, 46(5), 500-513. doi:10.1111/j.1469-7610.2004.00377.x
- Cicchetti, D. V. (2001). The precision of reliability and validity estimates re-visited: Distinguishing between clinical and statistical significance of sample size requirements. *Journal of Clinical and Experimental Neuropsychology*, 23, 695-700. doi: 10.1076/jcen.23.5.695.1249.
- Cicchetti, D. V., & Sparrow, S. S. (1981). Developing criteria for establishing interrater reliability of specific

- items: Applications to assessment of adaptive behavior. *American Journal of Mental Deficiency*, 86, 127-137.
- Cicchetti, D. V., Volkmar, F., Klin, A., & Showalter, D. (1995). Diagnosing autism using ICD 10 criteria: A comparison of neural networks and standard multivariate procedures. *Child Neuropsychology*, 1, 26-37. doi:10.1080/09297049508401340.
- de Bildt, A., Mulder, E. J., Hoekstra, P. J., van Lang, N. D., Minderaa, R. B., & Hartman, C. A. (2009). Validity of the children's social behavior questionnaire (CSBQ) in children with intellectual disability: Comparing the CSBQ with ADI-R, ADOS, and clinical DSM-IV-TR classification. *Journal of Autism and Developmental Disorders*, 39(10), 1464-1470. doi:10.1007/s10803-009-0764-x
- de Bildt, A., Sytema, S., Ketelaars, C., Kraijer, D., Mulder, E., Volkmar, F., Minderaa, R. (2004). Interrelationship between Autism Diagnostic Observation Schedule-Generic (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) classification in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders*, 34(2), 129-137.
- Dutra, L., Campbell, L., & Westen, D. (2004). Quantifying clinical judgment in the assessment of adolescent psychopathology: Reliability, validity, and factor structure of the child behavior checklist for clinician report. *Journal of Clinical Psychology*, 60(1), 65-85. doi:10.1002/jclp.10234
- Glascoe, F. P. (2003). Parents' evaluation of developmental status: How well do parents' concerns identify children with behavioral and emotional problems? *Clinical Pediatrics*, 42(2), 133-138.
- Lecavalier, L., Aman, M. G., Scahill, L., McDougle, C. J., McCracken, J. T., Vitiello, B., et al. (2006). Validity of the autism diagnostic interview-revised. *American Journal on Mental Retardation*, 111(3), 199-215. doi:10.1352/0895-8017(2006)111[199:VOTADI]2.0.CO;2
- Lord, C. (1989). Autism diagnostic observation schedule: a standardized observation of communicative and social behavior. *Journal of Autism and Developmental Disorders*, 19(2), 185-212.
- Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry*, 63(6), 694-701. Do
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (1999). ADOS. Autism diagnostic observation schedule. Manual. Los Angeles: WPS. i:10.1001/archpsyc.63.6.694
- Moss, J., Magiati, I., Charman, T., & Howlin, P. (2008). Stability of the autism diagnostic interview--revised from pre-school to elementary school age in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(6), 1081-1091. doi:10.1007/s10803-007-0487-9
- Pilowsky, T. (1998). The Autism Diagnostic Interview-Revised and the Childhood Autism Rating Scale: differences between diagnostic systems and comparison between genders. *Journal of Autism and Developmental Disorders*, 28(2), 143-151.
- Rutter, M., Le Couteur, A., & Lord, C. (2003). ADI-R. Autism diagnostic interview revised. Manual. Los Angeles: Western Psychological Services.
- Rutter, M., & Schopler, E. (1987). Autism and pervasive developmental disorders: Concepts and diagnostic issues. *Journal of Autism and Developmental Disorders*, 17, 159-186.
- Santosh, P. J., Mandy, W. P., Puura, K., Kaartinen, M., Warrington, R., & Skuse, D. H. (2009). The construction and validation of a short form of the developmental, diagnostic and dimensional interview. *European Child & Adolescent Psychiatry*, 18(8), 521-524. doi:10.1007/s00787-009-0004-0
- Schopler, E. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders*, 10(1), 91-103.
- Sikora, D. M., Hall, T. A., Hartley, S. L., Gerrard-Morris, A. E., & Cagle, S. (2008). Does parent report of behavior differ across ADOS-G classifications: Analysis of scores from the CBCL and GARS. *Journal of Autism and Developmental Disorders*, 38(3), 440-448. doi:10.1007/s10803-007-0407-z
- Snow, A. V., Lecavalier, L., & Houts, C. (2009). The structure of the autism diagnostic interview-revised: Diagnostic and phenotypic implications. *Journal of Child Psychology and Psychiatry*, 50(6), 734-742. doi:10.1111/j.1469-7610.2008.02018.x
- Tomanik, S. S., Pearson, D. A., Loveland, K. A., Lane, D. M., & Shaw, J. B. (2007). Improving the reliability of autism diagnoses: Examining the utility of adaptive behavior. *Journal of Autism and Developmental Disorders*, 37(5), 921-928. doi:10.1007/s10803-006-0227-6