

Award Number: W81XWH-08-1-0233

TITLE: Reliability and Validity of Autism Assessments and
Diagnosis Using Telemedicine?

PRINCIPAL INVESTIGATOR: R. Matthew Reese, PhD

T. Rene Jamison, PhD-Project Coordinator
Maura Wendland, PhD
Matthew Braun, MA, CCC-SLP
Joshua Turek, BA-Graduate Research Assistant

CONTRACTING ORGANIZATION:

University of Kansas Medical Center **Research Institute**
Kansas City, Kansas 66160

REPORT DATE: September, 2009

TYPE OF REPORT: Final Report

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT:

Approved for public release; distribution unlimited

The views, opinions and/or findings contained in this report
are those of the author(s) and should not be construed as an official
Department of the Army position, policy or decision unless so
designated by other documentation.

REPORT DOCUMENTATION PAGE			Form Approved OMB No. 0704-0188		
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.					
1. REPORT DATE (DD-MM-YYYY) 01-09-2009		2. REPORT TYPE Final		3. DATES COVERED (From - To) 1 July 2008 - 31 Aug 2009	
4. TITLE AND SUBTITLE The Reliability and Validity of Autism Assessments		5a. CONTRACT NUMBER			
		5b. GRANT NUMBER W81XWH-08-1-0233			
		5c. PROGRAM ELEMENT NUMBER			
6. AUTHOR(S) PRINCIPAL INVESTIGATOR: R. Matthew Reese, PhD T.Rene Jamison, PhD-Project Coordinator Maura Wendland, PhD Matthew Braun, MA, CCC-SLP Joshua Turek, BA-Graduate Research Assistant		5d. PROJECT NUMBER			
		5e. TASK NUMBER			
		5f. WORK UNIT NUMBER			
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of Kansas Medical Center Research Institute Kansas City, Kansas 66160		8. PERFORMING ORGANIZATION REPORT NUMBER			
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSOR/MONITOR'S ACRONYM(S)			
		11. SPONSOR/MONITOR'S REPORT NUMBER(S)			
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT Telemedicine is increasingly utilized as a means to provide health care to underserved areas, including rural and urban areas without providers. The current research explores the accuracy of diagnosis, parent satisfaction and the use of two “gold standard” measures, the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R) in their use in the assessment and diagnosis of children via telemedicine. Participants were children ages 3-5 with a previous diagnosis of an autism spectrum disorder (n=11), or developmental delays acting as control subjects (n=10). Participants were randomly assigned to interact with a lead psychologist through telemedicine or in person. One pair of clinicians observed in the room with families (Live) while one pair of clinicians simultaneously observed via telemedicine (Telemedicine). Each pair of clinicians provided scores on the ADOS and the ADI, as well as an overall diagnosis for the child. Inter rater agreement was computed for each pair of clinicians (item by item) and then compared to the inter rater agreement (item by item) of the other pair of clinicians with results indicating clinicians are able to score autism measures equally well in person or via telemedicine. Family satisfaction indicated families were highly satisfied in both conditions.					
15. SUBJECT TERMS Autism, autism spectrum disorders, telemedicine, ADOS, ADI					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT UU	18. NUMBER OF PAGES 20	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT U	b. ABSTRACT U	c. THIS PAGE U			19b. TELEPHONE NUMBER (include area code)

Table of Contents

	<u>Page</u>
Introduction.....	5
Body.....	5
Key Research Accomplishments.....	12
Reportable Outcomes.....	12
Conclusion.....	13
References.....	16
Appendices.....	16

Introduction

Children with autism are being diagnosed at increasing numbers (Center for Disease Control suggests 1 in 150). This has placed a demand to conduct an appropriate diagnostic work-up which may be difficult in rural, underserved areas. A potential solution used in other areas of medicine for specialty care has been telemedicine. We explored the use of telemedicine in the diagnosis of autism to determine if autism could be accurately diagnosed, families were satisfied with the diagnostic process, and gold standards for the assessment of autism (Autism Diagnostic Observation Schedule and Autism Diagnostic Interview-Revised) were equally reliable in a telemedicine versus a live condition. Twenty-one children between the ages of three and five were recruited. Half of the children had an existing diagnosis of autism and half developmental delay. These children were randomly assigned to either a telemedicine or live assessment condition. Results indicated that clinicians were equally accurate in their diagnosis, families were satisfied, and reliability measures on gold standards were no different in the live versus the telemedicine condition. Future research includes a prospective study comparing telemedicine to live assessments with more and a broader range of subjects.

Body

Children with autism are being screened and diagnosed at alarming rates. Current data from the Center for Disease Control indicates that 1 of 150 children have autism. These rates have placed an increased demand on providers to conduct an appropriate diagnostic workup. The need for providers who can conduct an assessment for autism is particularly evident in rural communities. One possible solution to this problem is the use of telemedicine. Telemedicine is defined as the use of real-time video conferencing for clinical purposes. Telemedicine allows children and their families in rural communities access to services without time consuming and costly travel. Telepsychiatry has been found to reduce costs for patients related to travel (Hyler & Gangure, 2003). The estimated savings for general telemedicine including travel expenses, work hours lost and hospital visits avoided was as high as \$224 per visit (Young & Ireson, 2003). Telemedicine has been suggested for specialty care consultation for children with special health care needs (Karp, et al. 1999). This study found that most telemedicine involved pediatric allergy (35%), pulmonology (29%), neurology (19%) and genetics (16%). Both physicians and family members were generally positive about telemedicine as a way of improving collaboration

In the January 2004 issue of *Pediatrics*, Marcin et al. presented evidence that Children with Special Healthcare Needs including autism could be provided with medical care in underserved rural communities for their specially needs using telemedicine and that families were satisfied with these services.

Nesbitt et al. (2006) developed guidelines for effective telemedicine technologies and delivering empirically supported services for children with autism living in rural

communities using telemedicine technology. This project highlighted the need for effective strategies to deliver services for those with autism, when families live in underserved areas and suggested research is needed to evaluate clinical services delivered over telemedicine.

Practice parameters for screening and diagnosis of autism from the American Academy of Neurology indicate that adequate diagnosis includes a parent interview for autism such as the Autism Diagnostic Interview (ADI) and a structured observation of the child using validated instruments such as the Autism Diagnostic Observation Schedule (ADOS). The ADI and ADOS are currently gold standards that are used to diagnose autism. These measures along with a medical history, review of records, and clinic observations are used in an autism assessment to determine if the child meets the DSM-IV criteria for autism.

The proposed research questions included: Is there a difference in reliability of the ADI and ADOS when observers are watching live versus over telemedicine?, Is there a difference in diagnostic impressions regarding autism when observers are evaluating live versus telemedicine?, and is there a difference in satisfaction between onsite and telemedicine evaluations of autism?.

Statement of Work (SOW)

Goal 1-Recruitment of children

May 2008-July 2008:

Project Coordinator, Rene Jamison, PhD. and Project Director, Ronald Matthew Reese, PhD. will revise the Human Subjects Protocol for the study and resubmit to the Human Research Committee (HRC).

Human Research Committee approval was granted on June 4, 2008.

May 2008-March 2009:

Between May 2008 and March 2009, Dr. Jamison will meet with Dr. Reese to identify subjects who might be recruited for the study. The subjects will be identified from the clinics where the study will take place. After HSC approval, Dr. Jamison and the research assistant will call potential candidates, obtain consent, and schedule them into the study. Two-three subjects will be recruited per month.

In order to ensure participants met the inclusion criteria (either diagnosis of an autism spectrum disorder or developmental delay), participants were only recruited if evaluated at our clinic. Therefore recruitment efforts focused on reviewing patient charts from the past year, identifying children who were between the ages of 3-5 years old and living in the Kansas City or surrounding area. Recruitment efforts also focused on newly diagnosed patients by providing clinicians as well as families information about opportunities for study participation. In August of 2008 a recruitment flyer was developed and distributed in clinic areas and distributed at community events

participated in by our center. Dr. Jamison (Project Director) and Josh Turek (research assistant) reviewed patient reports from the birth to five year old clinics to identify potential participants for the study. Josh Turek contacted potential participants and scheduled participants for their study visit. To date, a total of 21 participants have been recruited and completed their study visit. Eleven of these participants were previously diagnosed with an autism spectrum disorder, while 10 were previously diagnosed with developmental delays. Some of the children appeared to change diagnosis since their first diagnostic visit. All of the children had been referred because of red flags for autism so it is understandable the diagnosis may have changed in some cases. The pilot data will give us information for a prospective study with sufficient power to determine if there is a difference between telemedicine and live visits. Also the fact that children were already diagnosed may have affected parents' perception of the telemedicine diagnostic process.

Goal 2: Testing of Children

June 2008-March 2009:

Researchers Dr. Maura Wendland, Matthew Braun, SLP, Dr. Jamison, and Dr. Reese will evaluate subjects using the ADOS, ADI-R, and medical interview. Two of these research personnel will be with the parents and child in the same room and two will evaluate through telemedicine. For half the families the assessment will be directed by the research personnel who are in the room and half will be evaluated with the research personnel directing the assessment over telemedicine. All research personnel have been trained in the ADOS, ADI, and the diagnostic criteria for autism. Research personnel will be randomly assigned to live versus telemedicine conditions and will not have seen the subjects in the study.

All members of the research were fluent in the administration and scoring of both the ADOS and ADI-R measures. Four of the five research team members had completed ADOS clinical user training and the PI has also completed the ADOS research training prior to beginning the study. All members of the research team completed practice scoring tapes, with independent scoring followed by group discussions to help work towards reliability on ADOS scoring. The team completed a total of 5 practice scoring sessions, with 2 of 3 consecutive sessions at 72% or more interobserver agreement. Participants were randomly assigned to condition (telemedicine or live), with half of the participants in the autism group in each condition (5 live, 5 telemedicine) and half of the participants in the developmental delay group in each condition (5 live, 5 telemedicine). In the telemedicine condition, the PI, Dr. Reese, directed families to complete ADOS activities with their child over interactive television and completed the ADI-R interview over interactive television. In the live condition, the PI, Dr. Reese, directed families to complete ADOS activities with their child while in the same room with the family and completed the ADI-R interview in the room as well. Clinicians were randomly assigned to create pairs, with two clinicians in each setting (telemedicine or live) for each participant. In order to limit administration variability, Dr. Reese directed all families, regardless of condition. Assessments were independently scored by the four clinicians. Dr. Reese, in addition to directing the assessment, was also responsible for scoring the

assessments as part of the four person team. Following ADOS activities and ADI-R interview, caregivers completed a brief satisfaction survey and was provided compensation for their participation (\$30.00 gift card to target). Brief feedback was also provided for the caregivers, including comments on the child's strengths, areas to develop and future treatment directions for the child and family.

Goal 3: Scoring of Tests and Assigning a Diagnosis

June 2008-March 2009

All four researchers will independently score the ADOS and ADI and will assign a DSM-IV Diagnosis. Subjects will be assigned a number by Dr. Jamison and the research assistant so that they cannot be identified. Protocols and diagnostic sheets will be kept in a locked cabinet and supervised by Dr. Jamison. Identifiers will be kept in a separate locked cabinet. Dr. Jamison and the research assistant will be responsible for entering data for each subject on a spreadsheet.

Each ADOS and ADI was independently scored by 4 of 5 researchers. Upon completion, the research assistant entered the data into a SPSS database developed in December 2008. All research participants and their families were assigned a number (1-21). A master list was created and kept in a separate file that contained participant identifying information along with their participant ID number. A file was created for each participant containing unidentifiable raw data, with the completed ADOS protocols, completed ADI protocols, and completed family satisfaction survey and feedback forms maintained in each file. Signed consents were kept in a separate file with no subject number attached. All participant folders were maintained in a locked file cabinet in an office with a secure, keyless entry for participant security.

Study information for all participants was entered into an SPSS data base developed by Dr. Jamison and Josh Turek. Additional consultation was provided by Kandace Fleming regarding data base development and the creation of appropriate variables for future analysis. Data was entered in a timely manner, typically within a week of completion of assessments.

Goal 4: Measuring Parent Satisfaction

May 2008-June 2008

Dr. Jamison and Dr. Reese will develop parent satisfaction evaluation from existing telemedicine forms.

A satisfaction survey was revised based on existing telemedicine satisfaction forms in July of 2008. Family satisfaction was measured using a 7 point Likert-type scale, ranging from 1 (Strongly Disagree) to 7 (Strongly Agree). See addendum 1. Items 4, 5, 8-10 were reverse scored, with 1 indicating positive feelings and 7 indicating negative feelings. Questions 1-7 were completed by all participants while questions 8-13 were only completed by participants in the telemedicine condition.

June 2008-March 2009

Dr. Jamison and the research assistant will administer the parent satisfaction form, file forms, and enter data.

Satisfaction forms were collected and entered into the database for all participants, with study visits from January 2009 to September 2009. All 21 caregivers of participants completed a satisfaction survey following study measures. Partial data is missing from two participants, each failing to answer two questions, which seemed to be a random error. In general, families in both the Live and Telemedicine conditions rated their satisfaction with the experience as high (see summary of results below).

Goal 5: Data Analysis, Write Up, and Presentation

April 2009-May 2009

Dr. Jamison and Dr. Reese will analyze the data to determine if there are significant differences between the ADOS and ADI reliability scores, diagnostic impressions, and parent satisfaction when the assessments are completed live as compared to telemedicine. This data will be presented at autism and telemedicine conferences and written up for publication.

A preliminary analysis of the data was conducted in May of 2009 for presentation at our annual LEND trainee research forum, with data presented by Josh Turek, research assistant. Final data analysis was conducted in September of 2009 by the research team and statistical consultant. We evaluated the following hypotheses:

1. We expected that the ADOS and ADI will be as reliable, based on inter-rater agreement at the item level, when scored live versus telemedicine.
2. Families will be equally satisfied (according to satisfaction survey) with their evaluation experience, regardless of evaluation setting (live versus telemedicine).
3. Clinicians will be equally reliable identifying the diagnosis regardless of condition (live versus telemedicine).

In order to determine if percent agreement for the ADOS items were as high in the telemedicine condition as they were in the live condition, the individual item ratings for each of the four raters were compared in sets. The scores for the two live raters and two telemedicine raters were compared. If the item score for the two raters was identical, then an agreement was scored. If the scores were not identical, then a disagreement was scored. Similar scores were calculated for both the two telemedicine raters and two live raters. These agreement/disagreement scores were then summarized across the 21 clients to yield a percent agreement score for each condition by item. Occasionally an item was missing for an individual child, so percentages are not necessarily consistent across items. Percent agreement scores for each of the ADOS items are presented in Table 1 for each condition. A difference score was calculated for each item in order to summarize the magnitude of the discrepancy between agreement percentages and the direction of the higher score across items. For 14 items, percent agreement was higher in the Live condition, although many of the

differences were quite small. For 13 items, percent agreement was higher in the Telemedicine condition. For two of the items there was no difference in percent of agreement. The magnitude of the difference was similar across conditions. For items where agreement was higher in the Live condition, the difference was 13 percentage points higher on average. For items in which Telemedicine yielded higher agreement, telemedicine was 11 percentage points higher on average. Contingency tables with a dichotomous variable for Live/Telemedicine and a second variable coded as agreement/disagreement were evaluated for each of the ADOS items. The Chi Square calculated was significant at the $p=.05$ level for only two items (ADOS A7 and ADOS E1). Controlling the Type I error rate for the number of tests, only the ADOS A7 Chi Square would be considered to be significant ($X^2(1) = 13.10$, $p < .001$). Item A7 is related to socially directed pointing, with results suggesting raters agreed more often in the Live condition (inter-rater agreement for Live = 86% versus Telemedicine = 30%).

Table 2 provides the percent agreement values for the ADI items by condition as well as the difference between conditions. The differences in agreement between Live and Telemedicine were generally smaller for the ADI items than for the ADOS items. For 10 of the ADI items, percent agreement was higher in the live condition than in the telemedicine condition (the average difference was 7% for these items). For 18 of the ADI items, the percent agreement was higher in the Telemedicine condition than in the Live condition (11% higher on average). For 8 of the ADI items there was no difference in percent agreement. The Chi Square Tests indicated that only one of the items was significantly different in agreement across Live and Telemedicine, item 71 ($X^2(1) = 5.56$, $p = .018$). Item 71 is related to unusual sensory interests, with results suggesting raters agreed more often in the Telemedicine condition.

In order to determine if families who were evaluated in the Telemedicine setting were equally as satisfied with the evaluation as families who were evaluated in the Live setting, parent's responses to seven items about the quality of the evaluation experience were examined. Parents responded to each of the seven items using a Likert scale which ranged from 1 (Strongly Disagree) to 7 (Strongly Agree). Two of the items were reversed scored so that high scores would indicate high satisfaction with the evaluation for all items. Mean scores were calculated for each family averaging scores across the seven possible items. If a family answered at least 6 of the 7 items, a mean across all available items was calculated. If a family answered less than 6 items, then the family was missing a mean satisfaction score. Independent Samples t-tests were calculated for each of the items and the mean across all seven items to determine if the mean satisfaction was significantly different based on condition. Table 3 presents the means, standard deviations, t-test summary, and effect size (Cohen's d) for each question individually and for the mean satisfaction across all seven items. None of the probability values for the t-tests would indicate that there are significant differences in mean satisfaction between the Live and Telemedicine families as all of the p-values were greater than .15. Because of the relatively small sample sizes within each condition, effect sizes are also important to consider when drawing conclusions about these data. Two of the effect sizes for the satisfaction data are moderate suggesting

that further examination of satisfaction with a larger sample is warranted. Item 7 which asks families to rate their overall satisfaction with the evaluation visit was uniformly rated as highly as possible by the telemedicine families yielding a mean of 7.0. The overall rating was also high for the Live families, but the effect size was moderate suggesting a potentially meaningful difference in satisfaction favoring the Telemedicine families. Conversely, the effect size for average satisfaction across all seven items was also moderate suggesting that average satisfaction in the Live condition was higher than satisfaction in the Telemedicine condition. This discrepancy in finding may indicate that there is really not a meaningful difference in satisfaction across condition or it may be that with larger sample sizes the potential differences would be clarified. A larger study is being planned to further examine satisfaction with evaluation across Live and Telemedicine conditions. Given an effect size (d) of .6 as observed in this study, one would need to have a sample of 45 per group or 90 total to detect a significant difference between groups at .80 power.

In order to determine if clinicians were equally reliable identifying diagnosis regardless of condition (Live vs. Telemedicine), each of the four raters who were observing the evaluation (2 Live and 2 Telemedicine) were asked to indicate whether the observed child should have a diagnosis of DD or ASD based on their professional observations during the session and scores from the autism assessments. These predicted diagnoses were then compared to the actual previous diagnosis given to the family. The Live and Telemedicine clinicians were extremely consistent in their assignment of diagnoses and only differed on the rating for a single child when one of the Live coders differed in assigned diagnosis from the other Live coder and the two Telemedicine coders. Thus, the percentage agreement with previous diagnosis was not significantly different across condition with 83% of the diagnosis ratings made by Live raters and 86% of the diagnosis ratings made over Telemedicine agreeing with previous diagnosis. It is possible that the correct diagnosis for some of the children was different from their previous diagnosis and thus the agreement between previous diagnosis and diagnosis during the evaluation is not closer to 100%.

The data will be presented at the Kansas Center for Autism Research and Training (K-CART) autism conference in November in Wichita, Kansas. We are currently writing a manuscript and plan to submit the manuscript by the end of December to the Journal of Autism and Developmental Disabilities, Focus on Autism and Developmental Disorders, Autism, or Journal of the Association of Intellectual and Developmental Disabilities.

Goal 6: Grant Development

May 2009-August 2009

Telemedicine grants will be developed using the innovative grant as pilot data.

We submitted an R40 grant to the Maternal Child and Health Bureau (MCHB) in response to their Intervention in Autism competition and proposed to compare telemedicine, with outreach and hospital based clinics in terms of cost effectiveness

and access to empirically based treatments after the visit. We used preliminary data from this DOD grant (telemedicine data) as pilot data in an attempt to secure funding for this future project. The grant made it to the review panel and was scored. The reviewers were impressed with the pilot data but criticized the grant for the lack of random assignment to conditions although were using a co-variable to control for differences between conditions. We will resubmit to a similar, revised proposal to MCHB, NIH and/or Autism Speaks.

We now have pilot data for a larger prospective study with sufficient power to determine if there are differences in inter-rater agreement on the autism tools when scored live versus over telemedicine. These data were accepted for a presentation at the K-CART conference and also discussed at the Kansas Children's Cabinet meeting for financial support. The Children's Cabinet awarded \$50,000 to help us serve families who had children suspected of autism and live in rural communities and continue our research on family satisfaction with telemedicine services in autism. Our colleagues also received a NIDRR grant to examine telemedicine as an approach for parent training to treat children with autism.

We continue to collaborate with the Department of Telemedicine at The University of Kansas Medical Center which is one of the top telemedicine departments in the nation and has received national awards

Key Research Accomplishments

- Paper presentation at Association of University Centers on Disability national meeting in November 2009 in Washington, D.C.
- Preliminary data presented at the Kansas Children's Cabinet meeting and at our annual LEND trainee research forum.
- Data to be presented at the KCART autism conference in November 2009.
- Preliminary data utilized in development of a MCHB Intervention in Autism competition grant application.
- There have been no published studies examining the use of telemedicine to assess and treat autism
- We are currently writing a manuscript and plan to submit the manuscript by the end of December to the Journal of Autism and Developmental Disabilities, Focus on Autism and Developmental Disorders, Autism, or Journal of the Association of Intellectual and Developmental Disabilities.
- Members of this research team submitted a grant to Autism Speaks continuing research in telemedicine, focusing on intervention for families with children with autism (The Delivery of Parent-Child Interaction Therapy over Interactive Television: Outcomes for Families of Children with Autism).

Reportable Outcomes

- Overall levels of consumer satisfaction indicate high satisfaction with telemedicine as a service delivery model and we have expanded our clinics based on our data
- Differences between the clinicians scoring via telemedicine versus live were non-significant, indicating telemedicine as a viable option for use of autism tools and diagnosis for families with minimal access to specialty services in their region.
- The differences in diagnostic conclusion reached were non-significant, indicating reliability between conditions.

Conclusion

While current data indicates approximately 1 of 150 children have autism, these rates have placed an increased demand on providers to conduct an appropriate diagnostic assessment. The need for providers who can conduct an assessment for autism is particularly evident in rural communities. Advances in technology have aided the possible solution to this problem in the use of interactive television, telemedicine, as a means to provide services to families near their home community. In order to ensure accurate diagnosis and evaluation procedures, it is important to evaluate the “gold standard” tools used to aid diagnosis of autism for use with this new technology. The current pilot study evaluated the ADOS and ADI-R for use in telemedicine to begin evaluating the accuracy and feasibility of using telemedicine as a viable means to diagnose autism spectrum disorders. The main research questions included: Is there a difference in reliability of the ADI and ADOS when observers are watching live versus over telemedicine?, Is there a difference in diagnostic impressions regarding autism when observers are evaluating live versus telemedicine?, and is there a difference in satisfaction between onsite and telemedicine evaluations of autism?.

In general, results from this pilot study are favorable in that there was little difference in the reliability, utilizing percent agreement, when the autism measures were scored live or over telemedicine. For the ADOS, a significant difference in mean percent agreement between conditions was only found for one item (A7), which was related to socially directed pointing. All other items were similar in agreement between the pairs of researchers, regardless of condition. These findings suggest clinicians were able to score the play based autism measure, ADOS, equally well when viewing the child live or over telemedicine, providing beginning evidence this tool can be effective when used over telemedicine. Similar results were found for the ADI-R, which is the parent interview used to evaluate characteristics of an autism spectrum disorder over the child’s development. Again, only one item on the ADI-R (unusual sensory differences) showed a significant difference in mean percent agreement between conditions, which was related to unusual sensory differences. These data also provide preliminary evidence that the ADI-R can also be used over telemedicine equally well as in a traditional clinic setting (live). Although we found little difference in percent agreement between conditions, it is important to note that overall percent agreement (regardless of condition) was variable and did not consistently meet the goal of 85% agreement for most items. Clinicians did reach this criterion during training; however criterion was only

reached one time during training, with percent agreement consistently between 67% and 72% prior to beginning the study.

In addition to the autism tools, identification of diagnosis was also evaluated. Clinicians agreed almost 100% of the time on the diagnosis of the child, regardless of the condition. Accuracy of diagnosis was defined if the diagnosis following the assessment matched the previous diagnosis the child received. Accuracy was 83% and 86% for live and telemedicine respectively, with clinicians correctly identifying the diagnosis in 19 of the 21 cases. It is important to note that clinicians agreed 100% of the diagnosis of the child in both of the cases where the diagnosis did not match the previous diagnosis. Although inclusion criteria attempted to include children with an appropriate diagnosis, it is possible that the child's diagnosis had changed from the initial visit and the study visit, suggesting the research was 100% accurate in identification of diagnosis. All of the children had been referred because of red flags for autism so it is understandable the diagnosis may have changed in some cases.

Lastly, we hoped families would be equally satisfied with their diagnostic experience regardless of being conducted live or over telemedicine. Results from the satisfaction survey showed high levels of satisfaction for all families with no significant differences in satisfaction between conditions. Although a moderate effect size was noted in favor of the live setting for satisfaction across all 7 items of the survey, this may not be a clinically meaningful difference with ratings of 6.57 and 6.23 out of 7 in the live and telemedicine conditions respectively suggesting families were highly satisfied with their experience, regardless of setting.

The pilot data will give us information for a prospective study with sufficient power to determine if there is a difference between telemedicine and live visits. Also the fact that children were already diagnosed may have affected parents' perception of the telemedicine diagnostic process.

Results from this pilot study provide preliminary evidence that autism diagnostic assessments can be conducted equally well over telemedicine as compared to the traditional clinic setting (live). Clinicians were able to score measures as well for almost all items and families reported high levels of satisfaction in both conditions. With the increasing demand for trained professionals to conduct diagnostic assessments for autism, the use of telemedicine provides a viable option for families in rural areas that may not have access to specialty care and offers a considerable cost savings to these families as well. Families often travel long distances for similar evaluations resulting in travel expenses (gas, hotel, food) as well as lost work time. Telemedicine provides families with a more cost effective means to access needed medical care.

While results from this pilot study are important and suggest telemedicine as a viable option for autism diagnostic evaluations, it is important to discuss some potential limitations to the use of the telemedicine technology for this purpose. The use of technology provides risk for equipment problems or connection problems that would not

occur in a traditional clinic setting. We did experience a few problems connecting to telemedicine sites, causing a few families additional wait time for technology problems to be resolved. Although in our study we were able to successfully connect and use the telemedicine equipment for all 21 participants, we did experience problems with the family being able to see the clinicians over telemedicine on one occasion. Although the clinicians were able to see and hear the family and appropriately score the measures, these types of problems using technology could contribute to difficulties establishing rapport with families, frustration with communication, or other differences that would not be experienced in the clinic setting. Limitations of telemedicine may also include difficulties or differences seeing or hearing behaviors in the child during the assessment. Although we only detected a significant difference in scores for one item related to pointing in this study, there is a potential for difficulties seeing or hearing because of audio equipment, angles of cameras, or placement of people in the room.

References

1. Hyler, S.E., Gangure, D.D. (2003). A review of the costs of telepsychiatry. Psychiatric Services, 54, 976-980.
2. Karp, W.B., Grigsby, K., McSwiggan-Hardin, M., Pursley-Crotteau, S., Adams, L.N., Bell, W., et al. (2000). Use of telemedicine for children with special health care needs. Pediatrics, 105, 843-847.
3. Mercin, J.P., Ellis, J., Mawis, R., Nagrampa, E., Nesbitt, T.S., & Diamond, R.J. (2004). Satisfaction and impact of providing specialty care through telemedicine to primary care. Pediatrics, 113, 1-6.
4. Nesbitt, T.S., Rogers, S.J., Rich, B.A., Anders, T.F., Yellowlees, P.M., Brown, J.R., Keast, P.R. (2006). Enhancing mental health services to children with autism in rural areas. Autism telehealth project, MIND Institute, UC Davis.
5. Young, T.L. & Iregon, C. (2003). Effectiveness of school-based telehealth care in urban and rural elementary schools. Pediatrics, 112, 1088-1094.

Appendices

1. Telemedicine Satisfaction Survey

Appendix 1. Telemedicine Satisfaction Survey

Telemedicine Consultation Evaluation – Revised							
	Strongly Disagree		Neutral			Strongly Agree	
1. I felt I could talk about anything with the clinicians	1	2	3	4	5	6	7
2. The clinicians cared about me as a person	1	2	3	4	5	6	7
3. The clinicians knew what they were doing	1	2	3	4	5	6	7
4. I was embarrassed or self-conscious during the session	1	2	3	4	5	6	7
5. I had difficulty hearing the clinicians	1	2	3	4	5	6	7
6. I had no trouble seeing the clinicians	1	2	3	4	5	6	7
7. Overall, I was very satisfied with today's visit	1	2	3	4	5	6	7

If your session was conducted by evaluators asking you questions and instructing you how to interact with your child over the TV, please answer the following questions.

	Strongly Disagree		Neutral			Strongly Agree	
8. During the evaluation, I was nervous about the TV equipment	1	2	3	4	5	6	7
9. During the evaluation, my child seemed distracted by the TV equipment	1	2	3	4	5	6	7
10. The delay in hearing or talking to the clinician was too long	1	2	3	4	5	6	7

- | | | | | | | | |
|--|---|---|---|---|---|---|---|
| 11. There were no significant glitches with the TV or connection | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. The care I received today was as good as my in-person visits | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. Telemedicine makes it easier to get medical care | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Supporting Data

Table 1. Mean percent agreement on ADOS items by condition.

	Live Percent Agree	TM Percent Agree	Difference TM - Live
ADOSa1: language level	71%	71%	No difference
ADOSa2: verbalizations	52%	65%	13 %
ADOSa3: intonation	67%	65%	- 2 %
ADOSa4: immediate echolalia	67%	65%	-2 %
ADOSa5: stereotyped language	71%	75%	4 %
ADOSa6: contact gestures	86%	80%	- 6 %
ADOSa7: pointing*	86%	30%	- 56 %*
ADOSa8: gestures	43%	65%	22 %
ADOSb1: eye contact	86%	90%	4 %
ADOSb2: social smile	71%	70%	- 1 %
ADOSb3: facial expressions	62%	80%	18 %
ADOSb4: gaze & social overture	62%	50%	- 12 %
ADOSb5: shared enjoyment	52%	70%	18 %
ADOSb6: response to name	67%	75%	8 %
ADOSb7: requesting	57%	50%	- 7 %
ADOSb8: giving	67%	55%	-12 %
ADOSb9: showing	67%	45%	-22%
ADOSb10: initiation of JA	71%	60%	-11%
ADOSb11: response to JA	91%	90%	- 1 %
ADOSb12: quality of overtures	62%	65%	3 %
ADOSc1: functional play	57%	70%	13%
ADOSc2: imagination/creativity	62%	50%	-12%
ADOSd1: unusual sensory	71%	90%	19 %
ADOSd2: hand/finger behaviors	81%	90%	9 %
ADOSd3: self injurious behavior	100%	100%	No difference
ADOSd4: repetitive/stereotyped	67%	80%	13 %
ADOSE1: overactivity	71%	40%	-31 %
ADOSE2: disruptive behaviors	76%	80%	4 %
ADOSE3: anxiety	91%	85%	- 6 %
Total agreement for ADOS	70%	69%	1%

JA = Joint attention, * denotes statistically significant difference between conditions.

Table 2. Mean percent agreement on ADI items by condition.

	Live Percent Agree	TM Percent Agree	Difference TM - Live
ADI50: eye gaze	86%	91%	5 %
ADI51: social smiling	86%	91%	5 %
ADI57: facial expressions	71%	91%	20 %
ADI49: imaginative play w/ peers	81%	86%	5 %
ADI62: interest in children	71%	81%	10 %
ADI63: response to children	86%	86%	No difference
ADI64: group play w/ peers	91%	85%	- 6%
ADI52: showing/directing	86%	100%	14 %
ADI53: offering to share	95%	91%	- 4%
ADI54: shared enjoyment	81%	86%	5 %
ADI31: contact gestures	81%	91%	10 %
ADI55: offering comfort	95%	95%	No difference
ADI56: quality of social overtures	71%	91%	20%
ADI58: inappropriate facial	86%	81%	-5%
ADI59: social response	76%	91%	15%
ADI42: pointing to express interest	76%	76%	No difference
ADI43: nodding	100%	91%	-9 %
ADI44: head shaking	95%	95%	No difference
ADI45: gestures	91%	86%	-5 %
ADI47: spontaneous imitation	81%	81%	No difference
ADI48: imaginative play	86%	91%	5 %
ADI61: imitative social play	71%	81%	10%
ADI34: social chat	76%	91%	15%
ADI35: reciprocal conversation	81%	76%	-5%
ADI33: stereotyped lang/echolalia	76%	86%	10%
ADI36: inappropriate questions	91%	91%	No difference
ADI37: pronominal reversal	76%	86%	10%
ADI38: neologisms/idiosyncratic	91%	86%	-5%
ADI67: unusual preoccupations	91%	76%	-15%
ADI68: circumscribed interests	86%	71%	-15%
ADI39: verbal rituals	86%	86%	No difference
ADI70: compulsions / rituals	95%	91%	-4%
ADI77: hand or finger mannerisms	91%	91%	No difference
ADI78: complex body movements	81%	86%	5 %
ADI69: interest in parts of objects	76%	91%	15%
ADI71: unusual sensory interests*	67%	95%	28%*
Total Agreement on all items	83%	87%	-4%

* denotes statistically significant difference between conditions.

Table 3. Mean satisfaction ratings by condition.

	Condition	N	Mean	Std. Deviation	t-test	Effect Size (d)
Evaluation1	Live	11	6.82	.41	t(19)=.89	.38
Comfort w/ talking to clinicians	ITV	10	6.30	1.89	p=.39	
Evaluation2	Live	11	6.73	.47	t(19)=.91	.39
Felt clinicians cared	ITV	10	6.20	1.87	p=.38	
Evaluation3	Live	11	6.91	.30	t(8.30)=.86	.41
Competent clinicians	ITV	9	6.33	2.00	p=.42	
Evaluation 4	Live	11	6.00	1.90	t(19)=.95	-.10
Felt embarrassed	ITV	10	6.20	1.93	p=.36	
Evaluation 5	Live	11	6.91	.30	t(19)=.70	.30
Difficulty hearing	ITV	10	6.70	.95	p=.50	
Evaluation 6	Live	11	5.82	2.40	t(19)=.81	.35
No trouble seeing	ITV	10	4.90	2.77	p=.43	
Evaluation7	Live	11	6.82	.41	t(10)= -1.49	-.62
Overall satisfaction	ITV	10	7.00	.00	p=.17	
Mean Satisfaction Items1-7	Live	11	6.57	.49	t(19)=1.16	.50
	ITV	10	6.23	.82	p=.26	

Evaluation questions #4 and #5 were reversed scored to create high scores = high satisfaction