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September 9, 2010

Dear Interested Parties:

I am pleased to release a report by John Mantovani, M.D. discussing the results of a pilot project to test the clinical efficacy of using telehealth for the diagnostic evaluation and assessment for intervention. In late 2009, I requested Dr. Mantovani to conduct this pilot to help in our efforts to increase access to diagnostic and treatment services by children who experience ASD and their families. Dr. Mantovani was appointed by Governor Nixon to the Missouri Commission on Autism Spectrum Disorders (ASD) in 2008 and has extensive experience in providing diagnostic services to children with ASD.

The Division of Developmental Disabilities was awarded a Real Choice Systems Transformation grant from the Centers for Medicare and Medicaid Services (CMS) in late 2005. This five year grant has enabled the Division to initiate a number of strategies to improve access to community-based services and to enhance quality. One of the goals of systems transformation has been to use information technology both to improve access and to enhance quality. Providing services via telehealth technology is a key strategy consistently recommended by stakeholders throughout the DD Systems Transformation initiative these past five years.

During the past decades, Missouri has taken many progressive steps to address the increasing prevalence of Autism Spectrum Disorders (ASD) in young children. The Centers for Disease Control now estimates the prevalence of ASD to be 1 in 110, up from 1 in 150 just 3years ago. Appropriations to fund services for children with autism in Missouri began in the 1970s. In 1991, the first regional Parent Advisory Council (PAC) was formed and the five regional PACs continue to fulfill a critical role in the service system for children with ASD. A Senate Interim Committee on Autism was created in 2001 and discussions by this body became the basis for the Missouri Autism Research and Response Agenda (MARRA). A Blue Ribbon Panel appointed by President Pro Temp Michael Gibbons in 2007 held hearings throughout the state and issued a report containing 36 recommendations to the Governor in late 2007. Many of those recommendations have been implemented through legislations and through policy initiative undertaken by agencies themselves. Senate Bill 768, signed into law in 2008, established a Governor-appointed Commission for Autism Spectrum Disorders and established an Office for Autism within the Division of Developmental Disabilities. A home and community-based Medicaid waiver for children with ASD was approved by CMS in 2009 and currently serves 150 children. Legislation passed

in 2010, to be effective January of 2011, requires private insurance to cover applied behavioral analysis for children through age 18 and establishes standards for professionals providing services to children with autism. The Missouri Guidelines Initiative, a partnership of 42 professionals, was assembled in late 2008 and worked throughout the next 18 months to develop best practices for screening, diagnosis, and assessment of ASD. The Missouri Guidelines were just released under a proclamation by Governor Jay Nixon in April of this year.

While the causes of ASD are unknown, effective treatment is available and there are now more resources through public funds and private insurance to meet the need than ever before. It is clear that increased access to physicians and other diagnosticians is a critical issue in Missouri, and many families are traveling hundreds of miles at significant personal and emotional cost just to have their child's condition diagnosed. Support from the CMS Transformation Grant enabled this pilot which provides us with much information to help us move the system forward for children with ASD and their families.

Sincerely,

Bernard Simons, Director
Division of Developmental Disabilities

BS:RR:mls

Enclosure

This report was produced under grant CFDA 93.779 from the US Department of Health and Human Services, Centers for Medicare and Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal Government.

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CHILDREN'S HOSPITAL

MEDICAL DIRECTOR, CHILDREN'S HOSPITAL
MEDICAL DIRECTOR, CHILD DEVELOPMENT CENTER
DIVISION CHIEF, CHILD NEUROLOGY

John F. Mantovani, MD

Missouri Department of Mental Health Project
The Use of Telehealth for Service Provision to Children with Autism Spectrum Disorders

Project Completion Document
August 20, 2010
John F. Mantovani, M.D.

Specific Performance Requirements

I. **DEVELOP AND IMPLEMENT A PILOT PROGRAM TO SERVE BETWEEN 5 AND 15 CHILDREN TO TEST THE CLINICAL EFFICACY OF USING TELEHEALTH FOR THE DIAGNOSTIC EVALUATION AND ASSESSEMENT FOR INTERVENTION PROCESS**

a. **Obtain the history and interact directly with the participating individuals**

The Pilot Project report submitted previously (July 30, 2010) includes a section on Description and Methodology which confirms that obtaining the history from parents and interacting directly with children are possible using the telehealth process.

b. **Provide an assessment/evaluation of diagnostic tools utilized during telehealth sessions**

c. **Review the publication developed by Missouri's Autism Guidelines Initiative (MAGI), Identifying Best Practice Guidelines for screening, diagnosis and assessment of ASD**

The Pilot Project report includes copies of the questionnaires and forms used to obtain the history during the telehealth sessions. These forms are based on the DSM-IV criteria and the Social Communication Questionnaire which are consistent with best practice standards for ASD diagnostic evaluation and are identical to those used in my clinical practice. This method of obtaining pre-evaluation information conforms to the history recommendations within the MAGI document (p. 57).

The specific observational and interactive diagnostic approach is adapted from the ADOS Modules 1 & 2 in which observations of the child's spontaneous interest in provided play materials and interactions of the child with the parent during the session are observed closely and also conform to the recommendations of the MAGI document (p. 57).

Specific materials used included (1) 2 picture books, (2) a 6 piece animal puzzle, (3) soap bubbles, (4) a toy cell phone, (5) 2 small plastic cars and a plastic dump truck, (6) 2 toy dinosaurs, (7) an Elmo jack-in-the-box (8) a ball, (9) a Winnie-the-Pooh doll (10) a baby doll with bottle and small cloth to serve as a cover (11) a small Dora the Explorer doll-house with a Dora figure and small table and chair. Either this type of adapted approach or incorporation of the ADOS Modules into the examination is recommended to permit structured observation of the child.

The types of observations used during the pilot project are those based on current best practice standards used in my clinical practice. This approach included evaluation of the child's developmental status with regard to:

(1) SOCIAL INTERACTION (a) social approach & response: by reaction to name call, greeting and waiving to the examiner and to a stuffed animal held by the examiner on the video-screen, greeting of the aide in the examining room, (b) shared interests: by observing the child's response to pictures in a book, soap-bubble play, puzzle play, parent taking one of the cars and pushing it back and forth to see if the child imitated or participated in the activity (c) joint attention: by observing the child and parent look at the book, play with the puzzle, play catch, and the child's visual response to the parent pointing to an object across the table, (d) shared enjoyment by observing the child and parent playing ball, working with the puzzle, looking at the book, and the child's reaction to parent's smile, and/or parent's tickling or gently stroking the child's arm

(2) COMMUNICATION (a) quality/quantity, content and use of verbalizations: by observing the child's spontaneous and reactive verbal interaction with the mother and with the examiner via video screen during the book, ball, soap bubble, puzzle, and imaginative play activities, (b) use of nonverbal communication: by observing the child's use of gesture, waiving/pointing and how the child indicated his/her desire for or interest in items out of reach, (c) play skills: by observing the child's initial interest in the toys in the toy box, his/her style of spontaneous and/or interactive play with the parents using the cars, the dump truck, the dinosaurs, the Dora doll-house and the child's approach to feeding and putting the doll-baby "night-night"

(3) INTERESTS/REPETITIVE BEHAVIORS (a) use of toys and objects: as noted above, observations with multiple toys and play objects (b) problem behaviors: by observing the child's tolerance of the examining room environment, observed interactions with the parent, and his/her ability/willingness to follow the sequence of changing activities during the examination, (c) preoccupations or repetitive behaviors: by observing for verbal or behavioral perseverations,

stereotypical mannerisms, and his/her ability to tolerate task and interactive changes during the examination

RESULTS OF THE PILOT STUDY

The Project: Conclusions

Based on this small pilot study of 5 patients, the use of telehealth for evaluation of children with ASD and related conditions appears to be a reliable method for diagnosis which is consistent with the approach recommended in the MAGI Document, Missouri Best Practice Guidelines. The reliable use of telehealth for diagnosis is dependent on the following

1. An examiner with appropriate professional qualifications including a Missouri state license as a physician, psychologist or other health or mental health professional and advanced training and clinical experience in the diagnosis and treatment of ASDs and other neurodevelopmental disorders as well as adequate experience with the Tier 1 diagnosis of children with ASD

2. Reliable, secure and confidential video access and adequate support from information technology staff availability on both ends of the connection

3. Accessible locations and physical facilities for the provider and the child/family

4. Availability of completed pre-evaluation information in the form of parental questionnaires and prior testing and observational information from relevant care-takers & professionals

5. Reliable and supportive staff support at the patient site to facilitate the process

6. A range of age appropriate toys and other items at the patient site to facilitate the evaluation

7. Parents who can understand the examiner and are able to work with their child under the direction of the examiner

8. Adequate professional reimbursement and financial support for the required staff and locations to encourage utilization and to maintain a high quality program

9. The possibility of using telehealth for a Tier 2 diagnostic process (ie. two examiners who observe and interact with the child and family either simultaneously or in tandem) would be expected to be similarly reliable. This approach is currently being used by Dr. Matt Reese and colleagues at the Kansas University Center for Child

Health and Development where a physician and psychologist work side-by-side during the telehealth evaluations.

The Project: Limitations

1. This pilot project focused on Tier 1 diagnosis only and compared two Tier 1 diagnostic evaluations by experienced child neurologists who work together in a clinical private practice and tend to view developmental disorders from similar perspectives. Inter-observer variability may be greater between other providers, particularly those with different levels of experience or those from different professional disciplines.

2. This project focused on young children between 2 and 4 years of age referred for possible ASD by primary care physicians. The reliability of the process may be different for older patients or those referred from different sources.

3. Diagnostic reliability appears to be directly related to the severity of the symptomotology when using telehealth. Although a considerable number of young children can be diagnosed with this telehealth methodology, there will be children that cannot be adequately diagnosed using this Tier 1 approach via telehealth. Tier 2 or 3 processes will be necessary in such cases.

4. There were issues during the examinations relating to inconsistent visibility of the child at times and too great a distance of the child from the videoscreen which inhibited direct interaction. Some of the children ran around the room and were out of the camera's view at times. This could be improved by the use of some type of barrier/small wall, etc to form a "corral" to contain the child. Additionally, the ability to interact with the child via the equipment could be improved by lowering the video-screen in the room to either eye-level with the mother's seated position or the child's eye level to enable the child to get as close to the screen as possible in order to enhance the opportunities for direct interaction with the examiner.

5. The use of a telemedicine approach for older children and adolescents was not evaluated in this study but would appear to be dependent on the same factors noted above

6. Assessment (the more time-intensive and detailed processes of evaluation to specify individual strengths and weaknesses across multiple developmental domains) was not evaluated by this pilot project. Such in-depth testing will be more challenging via a telehealth approach. The potential for using telehealth developmental assessment requires further evaluation.

d. Provide analysis of other best practice guidelines in the context of this project

Best practice guidelines include the California Document published in 2003 on which the initial MAGI project was based and the American Academy of Neurology & Child Neurology Society Practice Parameter from 2000 (Filipek PA, Accardo PJ, Ashwal S et al Neurology 55:468-479). Despite being current at the time they were written, both are significantly out-dated at present and have been replaced by the MO Document. An up-dated summary "Identification and Evaluation of Children with ASD" was published by the American Academy of Pediatrics in 2007 (Johnson CP & Myers SM Pediatrics 120: 1183-1215) but is a state of the art type review and does not provide specific recommendations for diagnosis or assessment.

II. DEVELOP AND IMPLEMENT A TRAINING PROGRAM TO EDUCATE PHYSICIANS AND PRACTIONERS

Introduction: Although many ASD experts agree that an evidence-based approach to screening, diagnosis and assessment of ASD is needed, many full-time medical faculty and clinical practitioners either believe that their current approach is working well or that ASD is too small a part of their practice to invest the necessary time to learn a new approach. The challenge of encouraging the adoption of the MAGI Document into daily practice is considerable. Although I can outline the major components that are required, the creation of an effective training program to educate physicians on the use of the Guidelines and/or telehealth will require an on-going state-wide effort to engage stake-holders and convince thought leaders of its value.

(a) The Missouri Autism Guidelines initiative (MAGI) Document

Components of a training program include

1. **Awareness:** Provision of the Guidelines Document and Clinicians' Overview Booklet to Missouri primary care and specialty physicians—this has begun in partnership with the Missouri state chapters of the American Academy of Pediatrics, American Academy of Family Physicians, and MO Osteopathic Family Physicians, as well as the Mercy Medical Group Pediatric and Family Medicine practitioners in St. Louis. These physicians were sent copies of the book with a personalized cover letter.
    - This month a link between the MAGI web-site and the state chapter American Academy of Pediatrics will be established with a brief article to call attention to the project
    - Further efforts should include sending copies of the book to the Chairman of the Department of Pediatrics and Chairman of Departments of Family Medicine (where one exists), and the Division Directors of Child Neurology, Child Psychiatry and Developmental/Behavioral Pediatrics (where one exists) at the Schools of Medicine of University of Missouri—Columbia, St. Louis University, Washington University and the University of Missouri—Kansas City and the Kirksville School of Osteopathic Medicine.

- Additionally, the Touchpoints organization has hand-delivered approximately MAGI documents to approximately 400 physicians state-wide during personal office meetings in the context of discussions relating to their service offerings and over 200 copies have been ordered directly by practicing physicians in Missouri.

- Presentations and wide distribution of the MAGI Document and summary publications to educators, service providers and families also serves to raise awareness among practitioners. The hope is to have parents and others ask their children's physicians about the Document and the practitioners' utilization of its guidelines in their practices.

2. **Introduction** of the document into the curriculum of medical schools and selected residency and post-residency education programs—this requires acceptance by the Chairmen of Pediatrics and Family Medicine Departments and/or the Training Directors or Section Chiefs of Child Neurology, Developmental Pediatrics and Child Psychiatry training programs of Missouri Schools of Medicine and Osteopathy (St. Louis University [SLUSM], University of Missouri-Columbia [UMC], University of Missouri-Kansas City [UMKC], Washington University [WUMS] and Kirksville School of Osteopathic Medicine [KSOM].
   - The MAGI process included the Director of Developmental & Behavioral Pediatrics at UMKC (Michele Kilo. M.D.), and Autism Program Directors from SLUSM (Rolanda Maxim, M.D.) and UM-C (Janet Farmer Ph.D. & Judith Miles, M.D, Ph.D.) but none of the clinical leadership from WUMS or KSOM.
   - RECOMMENDATION: Contact Drs. Kilo, Maxim and Farmer to determine the extent to which the Guidelines have been incorporated into their training programs (this is in process at the present time)
   - RECOMMENDATION: Contact the Residency Training Director of Child Neurology (Bradley Schlaegger, M.D., Ph.D.) and Chief of Child Psychiatry (John Constantino. M.D.) at WUMS; the Residency Training Director of Child Neurology (Thomas Geller, M.D.) at SLUSM; identify and the Chairs of Pediatrics and Family Medicine at KSOM to inform them about the MAGI Process and ask them to consider introducing the book into their training programs—this can be coordinated by Lee Falk

3. **Inclusion** of the MAGI Document as a textbook during pediatric educational programs for pediatric and family medicine residents and during fellowship training in developmental pediatrics, child neurology and child psychiatry—based on acceptance of the book as a standard reference by the teaching faculties of Missouri Medical Schools

4. **Adoption** of the MAGI Document into the clinical practices of clinically active physicians past training and/or in practice, awareness of the MAGI Document will require lectures in academic and community physician CME programs to extend awareness of the document into practice
    - A number of such lectures have already been given including those by myself and Dr. Kanne at the Thompson Center Autism Intervention Conference (March, 2010) and another planned for me at the upcoming MO Council of Administrators of Special Education (MOCASE) annual meeting next month.
    - Additional lectures already presented or planned include those to the Truman Center Family Medicine Conference, The Mo Academy of Family Physicians Annual Scientific Assembly, University of MO Common Childhood Problems CME Conference, and the Mo Psychological Association Medicine Conference
    - RECOMMENDATION: Contact MAGI members who have not done so and request that they work to arrange to participate in a CME course or lecture at their medical centers (Dr. Burris [St. Luke's Hospital, St. Louis]; Dr. Kilo [UMKC Hospital, Kansas City]; Dr Mantovani [St. John's Children's Hospital, St. Louis]; Dr. Maxim [SLUMS, St. Louis]; Dr. Miles [UM-C Children's Hospital, Columbia]; Dr. Mothersead [St. John's Hospital, Springfield]; Dr Preuschoff {AAP State Chapter Conference and/or local hospital]; Dr. Watson [St Francis Hospital, Maryville]— Focus these sessions on the sections of the book most useful for practitioners with different responsibilities—ie. the screening section for primary care physicians and the diagnostic/assessment sections for specialists can be coordinated by Lee Falk including provision of prepared slides as we have done for some previous lectures

(b/c) The efficacy of telehealth as a healthcare delivery system and the positive outcomes for children and families accessing healthcare via telehealth

Physician education regarding the value and potential of telehealth methodology for healthcare delivery is a large and multi-dimensional project that has local, regional and national components. The process will require opportunities to engage medical educators, administrators and health care systems in the process.

1. **LOCAL:** The program to gain local acceptance begins with presentations to groups of physicians and other stake-holders to explain the process, summarize the results of the DMH Pilot Project showing excellent reliability and patient acceptance, and share the results of other's experience with telehealth such as the Kansas University Medical School Child Health & Development Center's on-going use for telehealth diagnosis of ASD in collaboration with Kansas school districts and the pilot project going on at the Kennedy-Krieger Institute at Johns Hopkins School of Medicine. I

will share this information in presentations to groups at St John's Mercy Children's Hospital, Mercy Medical Group, the MOCASE conference and anywhere else I am invited to speak on the topic of the Guidelines or ASD in general.

2. **REGIONAL**: Exploration of the role for telehealth within the DMH Regional Systems in discussion and collaboration with Mr. Bernie Simons and others in the Division of Developmental Disabilities. Discussion of the methodology for selection and scheduling of patients as well as professional and support staffing for such a process has already begun and will be continued.

I have also initiated a series of discussions regarding the potential use of telehealth as a component of a regionally distributed system within the Mercy Healthcare System (MHS) based at the St. John's Mercy Child Development Center to provide diagnostic and support services for children with developmental disabilities. These services would be available to Mercy Healthcare settings in outstate Missouri, Northern Arkansas and eastern Oklahoma and would be coordinated through a MHS system of telehealth. These discussions have included the MHS administrative and clinical leadership and are currently being incorporated into strategic planning for the system.

3. **NATIONAL**: Opportunities for presentations to national groups of physicians may also be possible in the future. Specifically organizations like the American Academy for Cerebral Palsy and Developmental Medicine, the American Academy of Pediatrics and the American Telemedicine Association solicit abstracts and instructional course applications for presentations to their annual meetings. These meetings occur in September and October of each year and depending on the data we have collected, may be appropriate venues for presentations on this topic.

   In my opinion additional evaluations using the telehealth methodology would be necessary before a national meeting is likely to be interested in the data but such a process in collaboration with other centers and clinicians could be discussed and perhaps organized to extend our preliminary observations on the value and acceptability of this approach. Additional funding would be required for such a process (see below regarding grant proposals)

III. PRACTITIONER ASSESSMENT OF THE CURRENT NETWORK OF TELEHEALTH ACCESS POINTS ACROSS MISSOURI BASED ON CURRENT ASD PREVALENCE ESTIMATES FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION

The Regional Office distribution and the availability of the polycom video-conferencing

equipment with a secure network connection provide a good platform for telehealth diagnostic and treatment services. A current estimate of children and adolescents under the age of 18 based on Missouri Kids Count and the most recent CDC prevalence data (.7—1.2%) gives the following estimates of the childhood ASD population within each Regional Office service area.

Albany Regional Office	325-460 children
Central Missouri Regional Office	735-1050 children
Hannibal Regional Office	325-460 children
Joplin Regional Office	625-900 children
Kansas City Regional Office	2125-3030 children
Kirksville Regional Office	200-280 children
Poplar Bluff Regional Office	325-465 children
Rolla Regional Office	715-1020 children
St. Louis City/St Charles Regional Office	1250-1790 children
St. Louis County	1980-2825 children
Sikeston Regional Office	370-530
Springfield Regional Office	960-1375 children
TOTAL ESTIMATE	10,000-14,000

Accurate assessment of presently diagnosed individuals with ASD is problematic for a number of reasons. The diagnosis of ASD can be determined by different providers and entities and include those served in both the private and public sectors. Statistics from the federal IDEA and MO Regional Center registrations indicate that the number recognized is likely to be in the range of approximately 6000-7000, but the true number of MO children who currently carry a diagnosis of an ASD from any source is unknown.

The capacity for the Developmental Disabilities Service Delivery System to meet the needs of children with ASD depends on which services are discussed for which children. Diagnostic services would appear to be the most easily provided for children without access to providers for diagnosis if adequate DMH staff and diagnostician access can be provided. Telehealth makes the most sense for those with inadequate access to care due to distance, transportation limitations or other socio-demographic factors. Identifying the counties with the poorest access and working with those Regional offices to establish a process of intake and then telehealth diagnosis from a Regional Office in St. Louis would certainly be possible if the conditions for a successful program as outlined in the Pilot Project Report can be met.

It also seems reasonable to explore a potential collaboration with the MU Telehealth Network (MTN) in terms of state-wide access to ASD services. A discussion regarding collaboration and/or grant-seeking activities to expand their current ASD services which are limited to follow-up care through the Thompson Center ASD Clinic could be explored.

IV. ADDITONAL ISSSUES

- Feasibility of telehealth use by practitioners

Small numbers of medical practitioners are using or expressing interest in the potential of telehealth at this time. Although It clearly is an area with tremendous potential telemedicine has not yet reached its tipping point of acceptance for most regions of the United States. Where it is being used however practitioner and patient acceptance is consistently favorable. I believe that increasing the use of telemedicine by practitioners is both feasible and desirable.

Physicians are interested in telemedicine for several reasons including extending their access to patients challenged geographically or otherwise, providing services in situations where provider expertise is limited or scarce, and improving efficiencies of care by reducing physician travel time. Barriers to increased practitioner use include (1) physician lack of familiarity with the process, (2) lack of technical facility or comfort with the technical aspects of telemedicine, (3) generic reluctance to adopt new technology or approaches to care and (4) reimbursement concerns.

Increasing physician interest can occur through CME presentations and professional activities noted above in the section on encouraging adoption of the MAGI Document. Increasing physician comfort will require hands-on experience in training or through CME courses. In reality the technical aspects are managed by information technology professionals and working through telemedicine is no more technically challenging than operating a television remote control device. But practitioners need to have a reason to try it and be encouraged to do so. Although logistically difficult, an additional incentive for adoption could include discussion of a reimbursement incentive for diagnostic utilization of the MAGI Document guidelines which could be explored in discussion with MOHealthNet and third party payers.

Reimbursement concerns will need to be dealt with locally and regionally since third-party payers vary significantly with regard to coverage for professional services. As noted in the March 15 Project Report, the MO HealthNet Program has been reimbursing for telehealth services by physicians, nurse practitioners, and psychologists since August 30, 2008. An additional modifier code (GT) is added to the usual CPT code for the provider but reimbursement is the same as for an office consultation. A small additional fee ($14.60) is also provided for the originating site facility fee (HCPS code Q3014).

- Ensuring Medicaid reimbursement is utilized to its full potential for covered services

Given that MO HealthNet has already approved coverage for these services, the primary issues will be timely filing and proper coding for the professional services provided and the originating site facility fee. Additionally professional providers will need to be MO HealthNet providers which may provide some difficulties in terms of provider capacity. Nonetheless these issues should not present any new challenges to the operational system currently be used for billing MO HealthNet for services being provided at the present time.

- Outreach and provision of services to non-Medicaid eligible consumers

The issues with regard to uninsured individuals are particularly difficult since access to care is often constrained by financial and demographic factors, lack of access to primary care physicians and limited involvement in the health care system. Collaboration between a diagnostic program, either within the Regional Offices or other facility and school districts would be one potential way of minimizing the impact on children of being uninsured. Such a collaborative program exists in Kansas and is coordinated by the KU Child Health and Development Center in Kansas City. Their program could serve as a model for accessing diagnostic services in a separate pathway from the healthcare system.

The use of telehealth for the care of insured individuals is also complex. As noted above insurance coverage for telemedicine services is quite variable and will require a prospective carrier-by-carrier evaluation to determine the specifics regarding coverage. Additionally, providers will need to be participants in the relevant insurance-carrier network and facilities will need to be identified, staffed, and supported.

Additionally the availability of a tele-network is a major barrier. Utilization of currently available networks or creating new ones each present logistical and economic challenges. Although many hospitals and medical centers have the capacity for telehealth connections, these are most often used for distance-learning educational lectures/conferences rather than clinical activities. The MTN telehealth system operates many sites around the state, but these are limited to University of Missouri Health System providers. For new systems, investment in the technology is considerable. Practically, issues of scheduling, staffing and HIPPA compliant confidentiality of the network are also more complex and would require more start-up time, organizational commitment and economic investment. Independent telemedicine networks such as we are discussing within the Mercy Health System may offer some opportunities but these will also be limited by proprietary interests, insurance carrier reimbursement, provider participation and reimbursement challenges.

- Other potential funding opportunities/grant proposals

Given the existing system within the Regional Offices and the national interest around ASD, a more comprehensive project to evaluate the value of telehealth for both diagnosis and management of children with ASD should be a natural for a grant or philanthropic support. I do not have any specific funding opportunities in mind but the Human Resources and Services Administration (HRSA)—particularly in its emphasis on rural health services, the Missouri Foundation for Health, Autism Speaks, and the Thompson Foundation are possible sources of support.

The process might begin with organizing a small group of clinicians, ASD researchers, family members, and other stake-holders to explore and discuss the potential for such a project. Collaboration between several programs would be desirable. I would be interested in participating in this effort if the Division would like to explore it further.

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John F. Mantovani, MD

Missouri Department of Mental Health Project
The Use of Telehealth for Service Provision to Children with Autism Spectrum Disorders

Pilot Project Completion Document
July 30, 2010
John F. Mantovani, M.D.

Primary Goals of the Project

I. To test the clinical efficacy of using telehealth for the diagnostic evaluation and assessment for intervention processes by demonstrating that telehealth is a clinically appropriate method of delivering such services to children with autism spectrum disorders (ASD) the project sought to

- Demonstrate the feasibility of obtaining an adequate history and directly interacting with the participating individuals for diagnostic purposes
- Provide an assessment/evaluation of diagnostic tools utilized during the telehealth sessions
- Review the published guidelines in the Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment of ASD in the context of this project
- Provide analysis of other best practice guidelines in the context of this project

The Project: Description and Methodology

1. Sites for the evaluations were identified within MO Department of Mental Health Facilities at the St. Louis County North Service Center Regional Office in Florissant, Missouri and the St. Louis Tri-County Regional office in Downtown St. Louis.

2. Volunteers were requested from the North County site, and two individuals agreed to provide the on-site support and facilitation role for the children and families

3. The Polycom video-conferencing System equipment available at these sites was evaluated and found to be adequate for the diagnostic sessions. On-site technical support staff was available at each of the sites before and during the sessions to coordinate the tele-networking connections for the evaluations.

4. A process for identifying patient volunteers was established for the Pilot Program in collaboration with Dr. Denis Altman, a board-certified child neurologist and my partner in clinical practice at St. Louis Child Neurology Services, P.C., in St. Louis County.

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5. Children between the ages of 2 ½ years and 5 years old who had been evaluated and by Dr. Altman between January 1 and July 1, 2010 and diagnosed with either an ASD or a developmental impairments without ASD and who were unknown to me were identified by our office manager, Stephanie Vazquez. 21 families with children in the target age group were identified and contacted by telephone. 12 expressed interest in participating and were sent a letter describing the purpose of the project and the process for participation. 6 families agreed to participate (5 actually did so), and Mrs. Vazquez coordinated scheduling and other details prior to the evaluations. I had no direct contact with the family or child before the evaluation, and the results of Dr. Altman's previous diagnostic evaluation were unknown to me until after the entire project was completed .

6. The evaluations were completed on Monday or Friday afternoons between 1:00 and 3:00pm to minimize the technical interference from concurrent computer use and other Regional Office activities.

7. A parent satisfaction questionnaire modeled on the one used by the Center for Child Health and Development (CCHD) at Kansas University Medical Center was developed to assess parent satisfaction with the process of evaluation and communication for the pilot study.

8. Age-appropriate toys and other play items typically used for the Autism Diagnostic Observation Schedule (ADOS) Module 1 testing activities were obtained and provided for the North County site to be used during the examination.

9. This project was structured as a Tier 1 diagnostic approach as described in the Missouri Best Practice Guidelines document; one that relies on a single professional to make the diagnosis of an ASD (pp.47-49).

The Project: Results

1. Telehealth evaluations were conducted in 4 separate sessions. The patients and families were located at the Florissant site where a volunteer Regional Office staff member served as an on-site facilitator in the room with the patient and parent(s). I performed the interviews and observational evaluations via tele-connection from the Tri-County Office in the Wainwright Building in downtown St. Louis. The evaluations were completed in 30 to 60 minutes.
    a. 5 children were evaluated (1 family did not keep the scheduled the appointment)
    b. The diagnostic process included two major components: a detailed history and a period of direct observation and interaction with the child based on the Missouri Guidelines for Screening, Diagnosis and Assessment of ASD Document (p. 57)

c. At the time of the evaluation I reviewed a parent-completed a Pre- history form similar to the one we routinely use in our clinical practice (Attached), parents' completed Gilliam Autism Rating Scales for their child, and an ASD-specific series of developmental questions based on DSM-IV criteria which I have developed for my clinical practice (Attached). These had been mailed to the parents and returned prior to the evaluation
d. The interview used a semi-structured format based on the history questionnaire and the Autism Checklist used in my clinical practice which is adapted from the Autism Diagnostic Interview (Revised)
e. The observational and interactive aspects of the session were adapted from the ADOS Module 1 and 2 processes. The parent followed my directions for the interactive aspects by playing with their child using the items provided at the North County site

2. DIAGNOSTIC RELIABILITY
   a. The children ranged in age from 29 months to 51 months of age
   b. The case-by-case results are summarized in Appendix 1
   c. 3 of 5 children were diagnosed with ASD (1 severe and 2 mild) and 2 of 5 children were diagnosed with other developmental conditions
   d. My diagnosis using the telemedicine process correlated with Dr. Altman's diagnosis in 100% of cases; two of the 5 cases were borderline diagnoses—1 judged to be within the ASD category; the other not. Our final diagnoses were the same for these more subtle and complex cases as well as for the more straightforward ones.

3. PARENT SATISFACTION
   a. The parent satisfaction surveys indicated an excellent (4) or good (1) degree of satisfaction with the process and confidence in the diagnosis. The results of the parent questionnaire are summarized in Appendix 2.

4. TECHNICAL ASPECTS
   a. The teleconnection process coordinated by the Information Technology Staff at the Wainwright and the North County Service locations produced generally reliable visual and auditory communication between the sites and the parent satisfaction surveys indicate a high degree of satisfaction with the process.
   b. One of my four sessions had significant visual interference on my end which compromised my ability to see details of the child's activities to a modest degree but not enough to impact the diagnostic formulation. The interference was felt by IT staff to relate to concomitant use of the computer network within the Wainwright Office Building.

The Project: Conclusions

Based on this small pilot study, the use of telehealth for evaluation of children with ASD and related conditions appears to be a reliable method for diagnosis which is consistent with the approach recommended in the Missouri Best Practicce Guidelines document. The reliable use of telehealth for diagnosis is dependent on the following

1. An examiner with appropriate professional qualifications and adequate experience with childhood developmental disabilities and the Tier 1 diagnosis of children with ASD

2. Reliable, secure and confidential video access and adequate support from information technology staff on both ends of the connection

3. Accessible locations and physical facilities for the provider and the child/family

4. Availability of completed pre-evaluation information in the form of parental questionnaires and prior testing and observational information from relevant care-takers and others as possible

5. Reliable and supportive staff support at the patient site to facilitate the process

6. A range of age appropriate toys and other items at the patient site to facilitate the evaluation

7. Parents who can understand the examiner and are able to work with their child under the direction of the examiner

8. Adequate professional reimbursement and financial support for the required staff and locations to encourage utilization and to maintain a high quality program

9. The possibility of using telehealth for a Tier 2 diagnostic process (ie. two examiners who observe and interact with the child and family either simultaneously or in tandem) would be expected to be similarly reliable. This approach is currently being used by Dr. Matt Reese and colleagues at the Kansas University Center for Child Health and Development where a physician and psychologist work side-by-side during the telehealth evaluations.

The Project: Caveats

1. This pilot project focused on Tier 1 diagnosis only and compared two Tier 1 diagnostic evaluations by experienced child neurologists who work together in a clinical private practice and tend to view developmental disorders from similar perspectives. Inter-observer variability may be greater between other providers, particularly those with different levels of experience or those from different professional disciplines.

2. This project focused on young children between 2 and 4 years of age referred for possible ASD by primary care physicians. The reliability of the process may be different for older patients or those referred from different sources.

3. Diagnostic reliability and inter-observer reliability bear a relationship to the severity of the ASD symptomotology and to co-morbidities. Although a considerable number of young children should be diagnosable with this telehealth methodology, there will be some who cannot be adequately diagnosed using a Tier 1 approach via telehealth. Tier 2 or 3 processes will be necessary in such cases.

4. There were occasional issues relating to inconsistent visibility of the child and too great a distance between the child and the videoscreen which inhibited direct interaction. Some of the children were highly active and ran out of the camera's view at times. This could be improved by the use of some type of barrier/small wall, etc to form a "corral" to contain the child. Additionally, the ability to interact with the child via the equipment could be improved by lowering the video-screen in the room to either eye-level with the mother's seated position or the child's eye level to enable the child to get as close to the screen as possible in order to enhance the opportunities for direct interaction with the examiner. Finally, the factors which may have interfered with the clarity of viewing during one session require further evaluation.

5. The use of a telemedicine approach for older children and adolescents was not evaluated in this study but is likely to be dependent on the same factors noted above

6. The assessment process outlined in the ASD Guidelines (pp79-93) is more time-intensive and requires an even more detailed level evaluation in multiple developmental domains. Assessment was not evaluated by this pilot project and is likely to be more challenging via a telehealth approach. The potential for using telehealth for detailed developmental assessment requires further evaluation.

(APPENDIX 1)
DIAGNOSTIC RESULTS SUMMARY
Comparison of Diagnoses DA and JM

	DA (treating MD) Diagnosis (Office diagnosis date)	JM Diagnosis (Telehealth Diagnosis 6/21—7/26/10)
Patient 1 (CL) (3/15/10)	Developmental coordination disorder ADHD (combined type) Sensory integration disorder	Developmental coordination disorder ADHD (combined type) Sensory integration disorder
Patent 2 (JM) (5/13/10)	Global developmental delay Borderline/mild ASD	Global developmental delay Borderline/mild ASD Developmental language disorder
Patient 3 (HB) (4/6/10)	ASD---mild-moderate	ASD---mild ADHD---moderately severe
Patient 4 (BR) (6/7/10)	ASD—severe Epilepsy	ASD—severe Epilepsy
Patient 5 (BA) (1/19/10)	Developmental language disorder Developmental speech apraxia Mentioned PDD (NOS)—not dxed	Developmental language disorder Developmental speech apraxia Not dxed ASD—noted borderline ASD characteristics

APPENDIX 2

RESULTS OF PARENT QUESTIONNAIRE (n=5)

Missouri Department of Mental Health Project
The Use of Telehealth for Service Provision to Children with Developmental Delays

PARENT QUESTIONNAIRE

Thank you for participating in this project. Your feedback regarding this process will be very helpful in helping us assess the potential of this approach for other Missouri children and families.

	Excellent	Good	Fair	Poor
1. My overall satisfaction with the video-conferencing experience was	**4**	**1**	0	0

Please rate the following by circling your opinion: 5=very much; 4=somewhat; 3=not much; 2=not at all; 1=don't know

2. During the evaluation I was nervous about the TV equipment	5 4 3 **2**	1-----all rated #2
3. During the evaluation my child seemed distracted by the TV	**5** 4 3 **2**	1-----4 rated #2; 1 rated #5
4. I had difficulty hearing the doctor	5 4 3 **2**	1-----all rated #2
5. I had difficulty seeing the doctor	5 4 3 **2**	1-----all rated #2
6. The delays in hearing or talking to the doctor were too long	5 4 3 **2**	1-----all rated #2
7. There were significant problems with the TV or connections	5 4 3 **2**	1-----all rated #2
8. I have confidence in the accuracy of this process for diagnosing my child	**5** **4** 3 2	1-----3 rated #5; 2 rated #4

Please add any comments you believe will help us evaluate the role of video-conferencing for the diagnosis or care of children and families with developmental delays-----One mother noted that her child seemed distracted by the television screen--running up to the screen trying to get my attention (I couldn't see this since he was out of camera range). Another mother suggested that a second visit might be helpful to see the child on another day (he didn't do as well as she thought he should have).

TELEHEALTH PROJECT FOR DIAGNOSTIC SERVICES PRE-HISTORY

Please complete and return these forms. There is one 3-page form and then a standardized questionnaire which are enclosed. Please complete and return these forms the week before your scheduled appointment for the telehealth project to:

Dr. John Mantovani 621 South New Ballas #5009 St. Louis, MO 63141

Child's Name:_____ **Age:**_____
First Last

Date of Birth: _____ **Date of this visit:**_____

Parents' Names:_____

Parents' main concerns regarding their child's development_____

_____

_____

_____

PAST MEDICAL HISTORY:

Pregnancy Birth/ Early Life (Give Details):

Is child adopted or a foster child? _____

Please describe any problems occuriring during the pregnancy, labor or newborn period that required special care or treatment_____

_____

_____

Later Life (Give Details)

Current medications_____

Significant illnesses or hospitalizations:_____

_____

Surgeries, injuries, ER visits: _____

_____

Medical testing, blood tests, CT or MRI Scans and other (give dates and results)_____

_____

Allergies:_____

Are immunizations up-to-date?:_____

Developmental History:

Approximate age child did the following:

Rolled over:	_____	**Walked:**	_____
Held toy:	_____	**Said first words:**	_____
Sat alone:	_____	**Used sentences:**	_____
Crawled:	_____	**Removed clothing:**	_____

Describe any feeding/ eating problems: _____

_____

Describe child's sleeping habits: _____

_____

Describe your child's temperament by using at least five adjectives (i.e.: quiet, restless, active, affectionate, withdrawn, whining): _____

_____

Does your child have any concerning behaviors such as rocking, head banging, breath holding, hair twirling, hand-flapping, etc.? Please describe: _____

_____

FAMILY HISTORY:

How old is mother? _____ **Father?** _____ **brothers/sister?** _____

How many times has mother been pregnant? _____

Any miscarriages? _____

Do you have a child with a serious illness or neurological disorder? _____

_____

Give details about family members with:

Seizures/ epilepsy:	_____	**Behavior disorders:**	_____
Mental retardation:	_____	**Psychiatric disorders:**	_____
Learning problems:	_____	**Autism:**	_____
Birth defects:	_____	**Vision/hearing problems:**	_____
Muscle problems:	_____	**Other family diseases:**	_____

ADDITIONAL QUESTIONS RELATING TO DEVELOPMENT

How does your child communicate what he/she wants (check all that apply)

_____ Verbally/using spontaneous words 1 or more words at a time

_____ Verbally/by repeating (echoing) back what he/she hears

_____ Verbally/by repeating (scripting) words/phrases from movies/videos, etc.

_____ Non-verbally/by using signs made with his/her hands (such as hand signing "more")

_____ Non-verbally by using pointing with his/her index finger toward objects

_____ Non-verbally by leading you to desired objects by your hand

_____ Non-verbally by crying or standing in front of the object until you guess correctly

How does your child interact with others (check all that apply)

_____ Usually looks people in the eye

_____ Usually responds to his/her name being called by looking right at you

_____ Usually initiates interaction to have you play with him/her

_____ Usually is interested in other children (wants to join in their activities)

_____ Usually plays back and forth games; taking turns with pushing cars, etc

_____ Usually prefers physical/roughhouse play to looking at books with you

_____ Usually shares your emotions (is happy when you are/ upset when you cry, etc)

What interests or habits does your child have (check all that apply)

_____ Back and forth games (reciprocal/turn-taking) play with cars, balls, book

_____ Turning things on and off (light switches, water faucets, etc)

_____ Spinning things or staring at things that go around like ceiling fans

_____ Running back and forth or bouncing up and down

_____ Walking on his/her toes or flapping his/her hands when excited

_____ Obsessive attachments to objects

_____ Poor tolerance of changes in usual routines (meals, bed-time, etc)

AUTISM CHECKLIST/Mantovani

PATIENT NAME_____ DATE_____

COMMUNICATION

Verbal

Spontaneous_____
Echolalia_____
Scripts _____
Regression _____

Non-verbal

Pointing/gesturing_____
Waiving_____
Hand-leading_____
Desires/needs_____

SLEEP

Location_____
Initiation_____
Roaming_____
Snoring _____

EATING

Setting _____
Preferences_____
Eating behaviors_____
Variety of foods_____

SOCIAL INTERACTION

Eye contact/facial expression_____
Response to name call_____
Initiation of contact/sharing interest_____
Response to greeting/waiving_____
Interest in & interaction w/ peers_____
Turn-taking; reciprocal interaction_____
Empathy/comforting responses_____

INTERESTS/MANNERSIMS/PLAY

Preferred toys_____
Manner of play (imitative, imaginative, interactive)_____
Spinning/sorting/mechanical interests_____
Interest in books, videos, other_____
Obsessive interests/carrying_____
Stereotypies/flapping/toe-walking_____
Opening/closing, spinning objects_____
Unusual visual behaviors_____
Easily upset by sounds/touch_____
Tolerance of change in routine_____

OTHER OBSERVATIONS

_____
_____
_____

MERCY
ST. JOHN'S MERCY
CHILDREN'S HOSPITAL

MEDICAL DIRECTOR, CHILDREN'S HOSPITAL
MEDICAL DIRECTOR, CHILD DEVELOPMENT CENTER
DIVISION CHIEF, CHILD NEUROLOGY

John F. Mantovani, MD

Missouri Department of Mental Health Project
The Use of Telehealth for Service Provision to Children with Autism Spectrum Disorders

LITERATURE REVIEW: THE USE OF TELEMEDICINE FOR DIAGNOSIS IN AUTISM SPECTRUM DISORDERS

Submitted February 8, 2010

By John F. Mantovani, M.D

INTRODUCTION

Telemedicine, often termed telehealth, has great potential for healthcare utilization and has been an area of interest for clinicians and researchers for more than 20 years. Interest in this technology and its opportunities has grown in parallel with the rapid growth of telecommunications, the internet and telehealth networks, and there have been a large number of publications relating to the use and/or potential of telemedicine for many adult health issues. A recent conference titled "Future of Telehealth: Essential Tools and Technologies for Clinical Research and Care" was held at the National Institutes of Health in June, 2009 and explored a range of issues including network development, technological aspects, public health and research opportunities (**Doarn CR et al 2009**).

However, there have been very few publications on the use of telemedicine in pediatrics. The first report from the American Academy of Pediatrics on telemedicine was published in 2004 and noted that "applications in pediatrics are sparse" (**Spooner SA et al, 2004**). That report listed a number of specific pediatric services that seemed well suited to telemedicine including radiology, pathology, dermatology, cardiology, emergency & transport services, child abuse, mental health, patient education, and school/home health. Although children's mental health services were considered an area of potential interest, psychiatric counseling was the only service described. The broader aspects of care for children with autism spectrum disorders (ASD) or other developmental disabilities were not included although prior publications had described the potential for telemedicine in the care of children with special health care needs (**Karp WB et al, 2000; Farmer JE & Muhlenbruck L, 2001**). Subsequently there have been a small number of articles describing the use of telemedicine for various aspects of special health care needs in children (**Cherry et al 2002; Marcin et al 2004; Cady R et al 2008; Clawson B et al 2008**). These reports have described its use in the care of chronic and complex conditions, but publications concerning the use of telehealth specifically for children with developmental disabilities remain scarce.

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314-251-5866 ph. ■ **314-251-5867** fax

Children with special health care needs (CHSHCN) are defined as those children who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (**McPherson M et al 1998**). This large group is currently estimated to be 1 in 7 children under age 18 years in the Unites States or approximately 10.2 million children nationwide which extrapolates to slightly more than 200,000 children in the state of Missouri (**U. S. Dept of Health & Human Services Administration, HRSA, Maternal & Child Bureau 2007**; **MO Kids Count, 2009**). Based on the recently published National Survey of parents with children classified as having special health care needs, children with ASD comprise 5.4% of the total group or approximately 12,400 children in Missouri (**Kogan et al, 2009**). This estimate for Missouri is also consistent with that reported in the last two Centers for Disease Control and Prevention reports citing prevalence for the St. Louis region at 7.3/1000 in the 2007 survey and 12.1/1000 in the 2009 survey (**ADDM 2007; ADDM 2009**). A range of 12,000-14,000 children with ASD in Missouri represents the best current estimate of statewide prevalence; it is this group which is the focus of possible telehealth use in this Department of Mental Health project.

METHODOLOGY

The following methods were used to identify published research and other credible sources of information regarding the use of telemedicine in the diagnosis or care of children with ASD and related conditions

- On-line PubMed and Google Scholar searches using the terms *telehealth* and *telemedicine* cross-referenced with *autism, ASD, autism spectrum disorders, childhood behavioral disorders, childhood developmental disabilities, childhood mental health conditions, childhood language disorders* to identify publications
- Subsequent review of all relevant references from the bibliography of identified publications
- Specific web-site review including
    - the American Telemedicine Association
    - The United States Department of Health and Human Services Office of Advancement on Telehealth
    - The University of Missouri Telehealth Network (MTN)
    - The Canadian Society of Telehealth
- E-mail or telephone communication with individuals and programs recommended by members of the Missouri Commission on ASD
- Personal contacts through my professional associations

CURRENT STATUS OF THE RESEARCH LITERATURE: ASD, Mental Health, Speech/Language disorders

Despite growing interest in using telemedicine for the overall CHSHCN group, very little research has been published on the utilization of telemedicine for developmental disabilities. Additionally, my literature and web searches identified a surprisingly small number of references on its use for any aspect of ASD and none on its use for ASD diagnosis. A search of PubMed, the U. S. National Library of Medicine (National Institutes of Health) database of more than 19 million citations from biomedical articles and life science journals identified only 9 articles referencing any aspect of *autism telemedicine or telehealth.* Of these 4 are broadly relevant. These include a case series of two children who received brief functional behavioral analyses via telemedicine at the University of Iowa (**Barretto A et al 2006**), a general commentary describing the growing interest in the use of telemedicine for diagnosis and treatment of ASD (**Terry M 2009**), and two technical articles describing a specific video-computer data-base system being marketed for remote video evaluation of challenging behaviors in ASD (**Oberleitner R et al 2004a, Oberleitner R et al 2004b**). A fifth article which is presently still in preparation has specific relevance and is discussed below (**Reese 2010**). For comparison a PubMed search on *autism treatment* identified over 5000 citations and *autism diagnosis* listed more than 7000 citations.

In broadening the search to include related conditions, I identified a number of reports on the use of telemedicine for diagnosis and treatment of children and adolescents with psychiatric conditions (termed telepsychiatry) and several involving the diagnosis and treatment of developmental speech/language disorders. Like ASD, childhood mental health conditions are diagnosed on the basis of DSM-IVTR diagnostic criteria and the diagnostic process follows a similar approach to that used for individuals with ASD. Specifically the diagnostic process of both utilizes parent questionnaires and interviews as well as interviews and/or direct observation of the child. A generally favorable experience with telepsychiatry in the pediatric age group has been reported in research publications from Washington state (**Myers KM et al 2004 & 2008; Sulzbacher S et al 2006**), California (**Hilty DM et al 2006**), Michigan (**Alessi NE 2003**), and Ontario (**Greenberg N et al 2006**) and at least one site in the United Kingdom (**Grealish et al 2005**). Collectively these and similar reports show positive results in terms of improved access to care providers, diagnostic reliability, and patient/family and provider satisfaction.

Similar results have been reported in small series for diagnosis and video-linked therapy for children with speech and language disorders (**Duffy JR et al 1997; McCullough A 2001; Sicotte et al 2003;**). Some of these studies reported challenges with regard to care at a distance including the critical need for readily-available technological support, continuing concerns relating to inadequate local resources for on-going treatment, and a lack of adequate reimbursement for teleservices in general.

CURRENT STATUS OF TELEMEDICINE USE IN ASD

Searching additional sources identified some additional information with respect to telemedicine and ASD including its current use for follow-up ASD patients at the MU Thompson Center in Columbia, MO.

The American Telemedicine Association (ATA) is a large international organization focusing exclusively on the clinical and technological aspects of telemedicine. I searched the ATA web-site and accessed the abstracts which have been selected for presentation at their annual meeting in May, 2010 (**www.americantelemed.org**). Of 178 total abstracts scheduled for presentation during the three day meeting, one deals with children with ASD. This report concerns home-based medication management by psychiatrists at University of California, Davis. Several other abstracts deal with the broader topics of behavioral or mental health projects but are focused on family education and support services.

The U. S. Human Resources and Services Administration (HRSA) Telehealth web-site was accessed (**hrsa.gov/telehealth**). There are no specific references to telemedicine and autism. The only HRSA links on autism concern funding for the Autism Intervention Research Network grants and projects which are not related to telehealth. Nonetheless, the HRSA web-site does contain a summary report on Telemental Health which encourages its use and recommends that "....more funding is needed to support research into the effectiveness of telemental health programs and to enable underserved areas of the country to benefit from this new tool for mental health service provision." (**Smith HA & Alison RA 2001**)

The MU Telehealth Network (MTN) web-site was accessed (www.telehealth.muhealth.org). The MTN is an extensive telehealth network initiated in 1994 with support from the HRSA Office of Rural Health Policy and established as a partnership among the University of Missouri, private telecommunication companies and local communities and hospitals. MTN currently has 175 sites in 58 Missouri counties and provides a variety of services including medical consultations in a range of 40 medical specialties and teleconferencing for medical educational purposes. According to the MTN web-site, the majority of telehealth consultations involve radiology, dermatology, mental health and cardiology. In the areas of CHSHCN, specialty clinics in pediatric genetics, health psychology and the MU Thompson Center for Autsim and Neurodevelopmental Disorders (MUTC) have active programs for follow-up of patients seen in their clinics (see below).

Review of the 42 telemedicine-related abstracts listed on the MTN web-site identified only 1 with direct relevance to CHSHCN (**Farmer J, Muhlenbruck L 2001**). This is a survey of 11 individuals representing HRSA grant-receiving agencies from 7 states with known telemedicine programs involving children with special health care needs. The survey provides a detailed description of telehealth uses at that time which included physician evaluation with either direct or surrogate treatment recommendations to other providers, patient follow-up visits, professional education, patient consultations, and family

education or after care. The respondents' perceptions of current challenges to telehealth utilization were described and were followed by a cogent discussion of the opportunities and continuing challenges with respect to telehealth program development, implementation and evaluation for the care of CHSHCN.

The University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders (TC) Autism Clinic (www.thompsoncenter.missouri.edu) has utilized the MTN for follow-up contacts of selected patients with ASD—particularly those with on-going medication management issues. I discussed the current telehealth component of the TC ASD program with Paula Slusher, RN, MSN, CPNP, the pediatric nurse practitioner involved and Janet Farmer, PhD, the TC Director of Academic Programs in a telephone conference last month. They reported that telehealth follow-up appointments are provided for children who have been diagnosed with ASD and have significant barriers to returning to Columbia. Telehealth visits are incorporated into the regular clinic days for the physicians at the TC, and Ms. Slusher estimates that approximately 6-10 of the 25-30 follow-up contacts on a typical day are done via telehealth. Approximately nine sites, particularly from south central and southeastern Missouri are used most often for these contacts, and most of these sessions concern medication issues. This service is noted to be well-accepted by both the clients and the practitioners involved. To date no ASD diagnostic services have been provided via telehealth through the MUTC.

The Canadian Society of Telehealth (**cst-sct.org**) is a large, non-profit health association based in Kingston, Ontario which is devoted to all aspects of telehealth in Canada. The organization published an on-line literature review of abstracts from Canadian meetings and trade publications dealing with multiple aspects of telehealth in October 2009. I reviewed the document with a specific focus on the subsection devoted to the pediatric and geriatric age groups. Of 80 abstracts in this section, only one describes the use of telemedicine related to ASD. This summarizes the experience of a treatment consultation team from Toronto Sick Kids Child Development Center in the on-going management of children diagnosed with ASD and indicates a favorable experience. No abstracts regarding telemedicine use for ASD diagnosis were included.

A Google search found a link to the Autism Telehealth Summit in Boise Idaho which occurred in April 2009. The initial session was held at Boise State University, but the remainder of the conference was held at the headquarters of its sponsor, Caring Technologies, a telehealth technology company. This company is marketing the computerized, video-imaging system referenced above (**Oberleitner et al 2004a & 2004b**). This computerized system is reportedly designed to capture and record problem behaviors for later review—presumably to provide the basis for behavioral interventions via telemedicine. I was unable to locate any proceedings from that conference.

RESEARCH IN PROGRESS: KU Medical Center Project

Through MO Commission of ASD professional colleagues I identified an important on-going research project concerning the use of telemedicine for the diagnosis of ASD in young children. Dr Matt Reese and a team of investigators and clinicians are studying this application at the Center for Child Health and Development (CCHD) at the KU Medical Center in Kansas City, Kansas, and he has graciously provided me with a pre-submission copy of his group's research paper on this topic. To date, this appears to be the only controlled research on the reliability of using telemedicine for the diagnosis of children with ASD. The study, (**Reese et al, prepublication version**) is summarized below.

Introduction & Goals: The investigators recruited twenty-one children between the ages of two and five years who had been previously evaluated in the Autism Clinic at the CCHD and been given a diagnosis of ASD (10 children) or developmental delay without ASD (11 children). The goals of the study were to explore the diagnostic accuracy (measured as concordance with previous interdisciplinary diagnosis) and parent satisfaction (measured by a Family Satisfaction questionnaire) when assessments were conducted via telemedicine.

Methodology: After being recruited and consenting to participate in the study, 21 children and their family members were assigned randomly to either live or telemedicine evaluation on arrival at the clinic. A lead investigator and four evaluators comprised the research team. The evaluators were divided into two two-person teams which were involved in simultaneous observation of the children—one team in the room with the child/family and the other observing via telemedicine connection. A single lead investigator directed all families in the administration of Module 1 of the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised for evaluation. For half of the families in each group the lead investigator directed the diagnostic process from within the same room as the child and family, and for the other half he directed the process via telemedicine. One team of two examiners was in the room observing the diagnostic process, and the other two-person team was observing simultaneously via telemedicine. During the diagnostic assessment, each evaluator scored the diagnostic instruments separately and subsequently arrived at an independent diagnostic formulation of either ASD or non-ASD developmental delay.

Results: The statistical analysis of the ADOS/ADI-R scoring and the diagnostic correlations between team members and between teams evaluating live and by telemedicine is detailed in the article. The results are quite encouraging. Only a single item on both the ADOS (socially-directed pointing) and the ADI-R (unusual sensory differences) differed significantly in mean percent agreement between the live and telemedicine diagnostic teams in the study group. These differences did not adversely affect the diagnostic conclusions since **the live and telemedicine evaluators agreed 100% of the time on the diagnostic classification** of the child as either ASD or non-ASD developmental delay.

The percentage agreement with the previous diagnostic classification was also noteworthy. The study evaluators arrived at the same diagnosis as the prior clinic evaluation in 19 of 21 children—an 83% agreement by live evaluators and 86% agreement by telemedicine evaluators. This concordance data is consistent with research and clinical experience indicating that changes in diagnostic classification can occur over time in any group of young children with developmental variations and delays.

Analysis of the Parent Satisfaction Surveys indicated significant satisfaction. On a 7 question scale to rate parent satisfaction, a 1-7 Likert scale was used with 7 being the highest level of satisfaction. There were no significant differences between the live and telemedicine scores. Parents endorsed high scores with both the live (mean 6.57) and the telemedicine processes (mean 6.23).

Conclusions: Results from this study provide preliminary evidence that autism diagnostic assessments via telemedicine can be conducted with equal reliability and family satisfaction as compared to the traditional clinic setting.

Nonetheless there are important limitations of this study as noted by the study group which need to be considered in the evaluation of telemedicine technology for ASD diagnostic services. Possible limitations of study design relate to the study families' familiarity with the diagnostic process from their prior evaluation which may have altered the diagnostic process or influenced their satisfaction. There is also a possible issue with this study's reliance on the family to administer the ADOS Module 1 items since this approach is likely to be limited with older or higher functioning subjects who require more advanced Modules which utilize a more standardized assessment paradigm. Additional concerns for ASD diagnosis via telemedicine include possible limitations in seeing or hearing the child clearly during the assessment session due to variable room characteristics and/or limitations of the audio/video connections and the frequent challenges presented by achieving and maintaining optimal connections between telemedicine sites. Additional research and experience will be helpful in evaluating some of these concerns.

SUMMARY

Despite the lack of published research on telehealth and ASD, my impression from the literature, web searches and conversations with colleagues, families, and others involved in this field is that there is considerable interest in expanding telehealth services to individuals and families with ASD. Although limited, the existing research literature and current experience supports the value and reliability of this technology for children with a variety of special health care needs including psychiatric conditions, developmental language delays, and for follow-up care of ASD. Additionally, it seems very likely that there are other programs yet to be identified that are currently using telehealth for some aspect of care for ASD—particularly for follow-up care, medication management, family support and behavioral counseling.

Based on this review, the use of telemedicine technology for the diagnosis and assessment of young children with possible ASD deserves further evaluation. It has considerable potential to extend professional resources, improve access to care for families and significantly reduce travel costs. A teleheath network could be an important component of an organized and collaborative Missouri system of care for those with ASD and their families.

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