Preliminary Evidence for the Integrated Systems Using Telemedicine

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Abstract

Background: Autism affects as many as 1 in 68 children in the United States. Early identification and access to intervention services promote improved outcomes for children with autism and other developmental delays. Children living in rural and underserved areas have limited access to such services and are diagnosed later than those living more suburban and urban areas. Our Integrated Systems Using Telemedicine (ISUT) Model uses a cost-effective method for families to access diagnostic and other specialty care through telemedicine. This model links families, trained early intervention providers and educators, and university-based medical professionals. Materials and Methods: We trained autism diagnostic teams throughout the state who completed diagnostic measures and connected to university medical center teams for final diagnosis of autism and coexisting conditions. We gathered preliminary data to measure the impact of the ISUT model on access to services, potential cost savings for families, and parent satisfaction with the model. Results: Preliminary data indicate that our ISUT model provided families in rural and underserved areas improved access to diagnostic services as well as cost savings for travel. Our satisfaction data indicate that parents are equally satisfied with services received through the ISUT and through the University-Based Medical Center Team Model. Conclusions: The ISUT model provides a unique collaboration among the family, educational system, autism experts in the community, and the university medical center autism team while providing a cost-effective means for families to access specialty care while promoting coordination of care within the community.

Key words: *autism, diagnosis, telemedicine, rural health, pediatrics, parent satisfaction*

Introduction

Early identification and intervention promote improved outcomes (including functional brain changes for some individuals) for children with autism and other developmental delays.[1–3] However, children living in rural and underserved areas are diagnosed at a later age (on average, 0.4 years later) compared with those living in urban or suburban areas[4,5] and have decreased access to healthcare services.[5] Such delays in diagnosis may also result in postponed access to early intervention services that are critical for improvement and successful outcomes. Sudhinaraset and Kuo[6] noted that autism symptoms are recognizable in the first year of life and that reliable autism diagnosis is possible by 2 years of age. Even with improvements in earlier identification, the median age for autism diagnosis remains between 3.1 and 5.7 years,[5,7,8] with children in rural and lower socioeconomic regions being diagnosed later than those in urban and suburban areas.[5] Healthcare provider shortages in rural and underserved areas result in decreased access to health and related care services,[9] which may include primary care coverage, pediatric and subspecialty care, mental and behavioral health supports, vision, and dental care. As a result, families from rural areas with concerns about their child's development often travel long distances for an evaluation, resulting in additional travel-related costs as well as recommendations from healthcare providers who are not familiar with resources in the families' communities.

One option for families to access services in rural areas is telemedicine. Nesbitt et al.[10] developed guidelines for delivering empirically supported services for children with autism in rural communities through the use of interactive televideo (ITV) technologies. This project highlighted the need for quality services for those with autism living in underserved areas. The project also indicated a need for research to evaluate the effectiveness of such clinical services delivered over ITV. Reese et al.[11] found ITV to be an effective method for accurately diagnosing autism and that families are equally satisfied with this method of service delivery when compared with a more traditional university-based medical center team (UBMCT). Marcin et al.[12] also proposed the use of telemedicine to provide services to children with special healthcare needs (including autism) in underserved rural communities and found families and clinicians were satisfied with such services (rating their experiences as excellent or very good).

Early intervention providers and/or educators are often the first to notice symptoms of autism. Several states have developed models to improve the expertise of educators in recognizing symptoms of

autism and in providing support to children identified under the Individuals with Disabilities Education Act with an exceptionality of autism. Existing literature[13–15] addresses these various components related to the broader issue of improving access to autism services in rural areas. However, to our knowledge, none of this existing research takes a comprehensive approach that includes access to diagnostic and treatment services as well as an integral link between the medical and educational systems to build capacity of rural-based providers.

For example, Warren et al.[13] developed a model to improve timely autism spectrum disorder (ASD) diagnostic services. Findings indicate significant agreement between the pediatricians' diagnostic decisions and independent evaluations of the same children by clinical specialists at a university-based center. Although this model may potentially increase community pediatricians' capacity to identify children with ASD and provide more timely initiation of early intervention services, this model does not provide a link between the medical and the educational systems.

Researchers in Europe trained professionals from a range of disciplines on the use of ASD measures and diagnostic criteria for diagnosis. They examined the professionals' reliability of ASD diagnoses with a professional diagnostic team.[14] Results indicated 92% agreement on "spectrum" or "not spectrum," high correlations on Autism Diagnostic Observation Schedule scores, and significantly less time on the wait list for access to community teams (13 weeks) compared with specialist teams (36 weeks). Although this model may also increase diagnostic capacity, it does not address the gap from the diagnostic evaluation to obtaining services through either behavioral therapists and/or educators.

Noland and Gabriels[15] discussed Colorado's model, which includes autism specialist teams (ASTs) in school districts that receive training to complete more comprehensive autism evaluations. ASTs gather initial data to determine if further evaluation is needed. The AST will complete an evaluation to determine eligibility under the exceptionality of educational autism under the Individuals with Disabilities Education Act and provides families with a referral to pursue a "medical" diagnosis and coexisting conditions if needed. However, there is no direct link to the medical system for an interface between the educational and medical professionals.

Our Integrated Systems Using Telemedicine (ISUT) Model uses ITV technology (telemedicine) to connect families, trained early intervention and educational teams, and medical/health-related experts in autism. The ISUT model increases the capacity of trained professionals across the state to evaluate children suspected of having an ASD and promotes collaboration among families, educational professionals, and medical professionals. Increasing capacity for diagnosis provides a platform for equity, early diagnosis and intervention, and positive outcomes for children and families. Providing services to families within their community (rather than traveling long distances for services) decreases burdens such as long wait times (for access to services) and costs related to travel and aids in linking families to local resources. Such change in the clinical practice of evaluating children with ASD would promote earlier detection and

access to intervention for individuals in rural and underserved areas. It would also work toward overcoming current inequities, resulting in significant improvement in the health and well-being of children with ASD and their families.

The purpose of this article is to describe the ISUT Model and its potential to address barriers to early identification of autism and access to services in rural and underserved communities. Such a model could result in less time from screening to diagnosis to intervention. We will provide preliminary data related to the number of families accessing services through this model, potential cost savings for families, and satisfaction data. We will also discuss how this model provides a direct link for interfacing between the medical and educational systems as well as future directions with respect to methods to formally evaluate this model.

Materials and Methods
TRAINING AUTISM TEAMS

Our State Department of Education developed autism intervention teams targeting rural, underserved areas. Teams include educational professionals who receive training in evidence-based interventions with little to no emphasis on screening and diagnostic measures. In collaboration with the State Department of Education, we developed a model to train existing autism intervention teams in screening and diagnostic procedures. We call these autism diagnostic teams (ADTs).

ADT TRAINING PROTOCOL

Initial training for ADT members occurs across a 2-day workshop and covers recognizing ASD symptoms, including instruction on differentiating characteristics from typical child development and delays in development without ASD. Training includes an introduction to gold standard autism measures (such as the Autism Diagnostic Observation Schedule, 2nd edition[16] and the Autism Diagnostic Interview–Revised[17]), and participants are strongly encouraged to complete formal training on these measures outside of the workshop. All teams have access to commercially available training materials, and teams receive ongoing coaching and collaboration through the state-funded technical assistance program for autism. Ongoing training and technical assistance for ADTs are funded through a $50,000 a year state Children's Cabinet grant.

THE ISUT MODEL

Figure 1 provides a visual representation of the ISUT model. Trained ADTs independently complete the autism measures to examine characteristics of autism, including observation, play-based assessments, and parent interview. The team then presents data to the parents and UBMCTs, who make the final diagnostic determination via telemedicine. The UBMCT also makes recommendations, as well as diagnosis of and recommendations for additional coexisting medical (e.g., constipation, sleep or eating disorders) or mental health conditions (e.g., attention-deficit hyperactivity disorder, depression, anxiety, self-injurious behavior, tics, seizures, etc.).

ADTs connect to the UBMCT via ITV at the area local mental health center, a local hospital, or the child's school, depending on where the
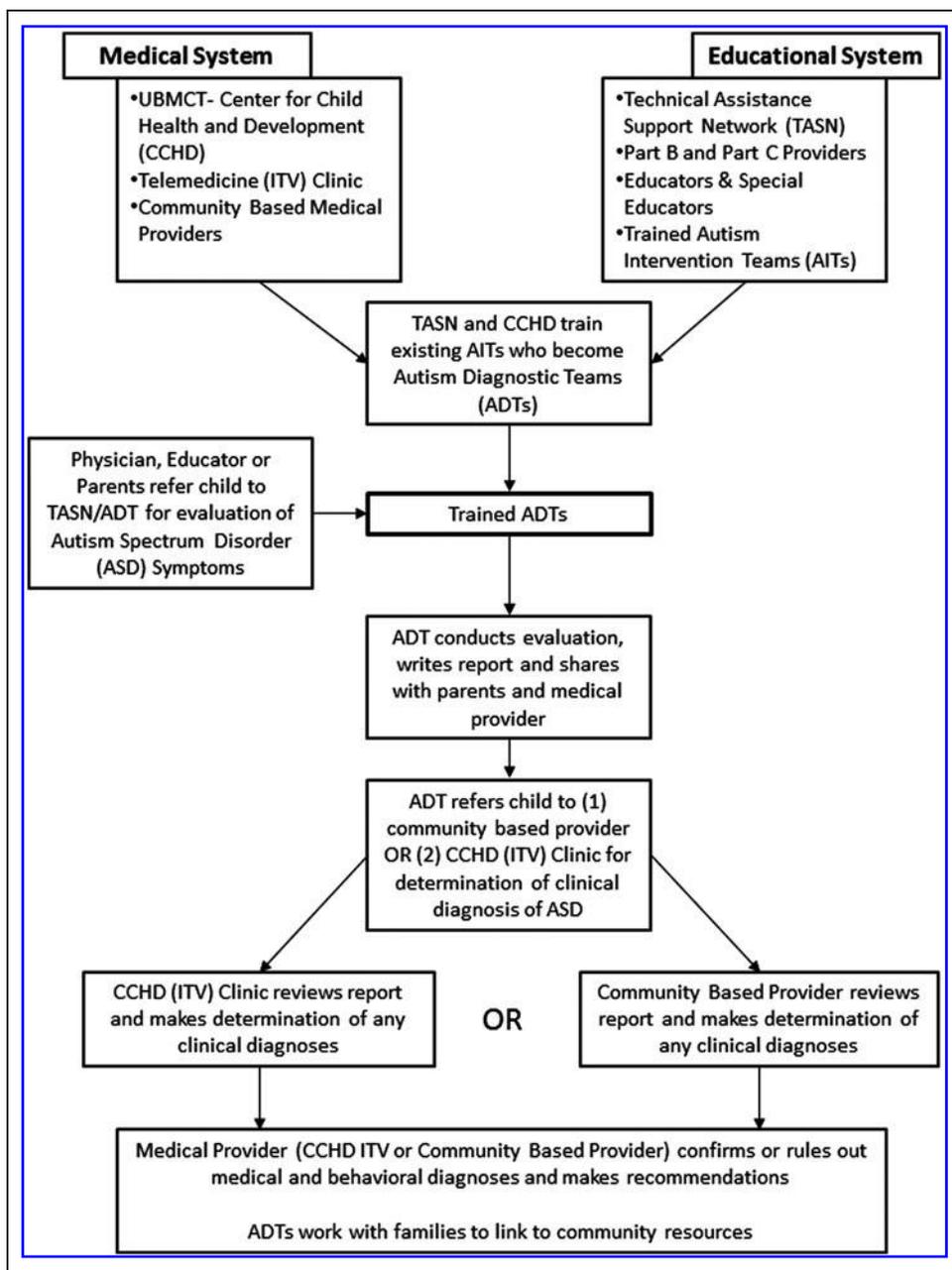
Fig. 1. The Integrated Systems Using Telemedicine Model. ITV, interactive televideo; UBMCT, university-based medical center team.

ITV resources are located in a particular community. A secure two-way ITV connection is made between the sites, with the UBMCT at one site and the families and their ADT providers at the other site. The ITV equipment includes high-definition cameras and monitors to provide the highest quality experience.

This interdisciplinary interaction over telemedicine also provides an opportunity for the family, educational team, ADT, and medical center faculty to discuss strengths, needs, and prospective solutions while relieving the family of the burden of conveying information to

each of the various providers across multiple locations. Of the 290 school districts in our state, 287 have trained autism intervention teams, and 175 of those also have an ADT who can provide services through the ISUT model.

MEASURING THE PRELIMINARY IMPACT OF THE ISUT MODEL

After obtaining approval from the Human Subjects Committee/Institutional Review Board of the University of Kansas, we completed an analysis of existing data to measure the preliminary impact of the ISUT Model on improving access to diagnostic services in our state, potential cost savings, and parent satisfaction with the ISUT Model compared with more traditional UBMCTs. We will present data on the increase in number of families who accessed services through the ISUT Model since its initial implementation in 2008 through 2013. Cost comparisons outline potential costs associated with travel for families who received services through the ISUT Model compared with costs if traveling to the university-based clinic.

Finally, we gathered satisfaction data from a subsample of families who participated in the ISUT Model and families who participated in the more traditional UBMCT. Families received paper-based satisfaction surveys (with return envelopes) sent with the final clinical reports 2–4 weeks after the visit. A clinical services administrative committee at the university-based medical center developed the satisfaction survey based on goals set forth by the university's mission and vision.

SAMPLE

We extracted existing data on the families in our study from our Comprehensive Research Information System. This Comprehensive Research Information System database contains information about every patient seen both through our UBMCT Model and through the ISUT Model. Our university-based clinic provides a variety of services and has several autism diagnostic teams. For this study, we focused on families who participated in the ISUT Model ($n = 370$) and families who participated in "in-person" UBMCT clinics of similar provider make-up (e.g., teams that included the same university-based providers as in the ISUT Model; $n = 405$).

Table 1. Demographic Information			
	UNIVERSITY–BASED MEDICAL CENTER TEAM MODEL (*N*=405)	INTEGRATED SYSTEMS USING TELEMEDICINE MODEL (*N*=370)	*P*
Gender (%)			
Male	80%	81%	0.719
Female	20%	19%	0.719
Mean age (years) at time of diagnosis	9.75	6.72	<0.010
Diagnoses (%)			
Autistic disorder	16%	31%	<0.010
PDD-NOS	24%	37%	<0.010
Asperger's disorder	16%	5%	<0.010
ADHD	18%	11%	<0.010
Other	26%	16%	<0.010
ADHD, attention-deficit hyperactivity disorder; PDD-NOS, pervasive developmental disorder, not otherwise specified.			

Table 1 provides demographic information about the children and families in this analysis. We completed a comparison of proportions using a two-sample *t* test to examine potential differences in demographic data between our groups (ISUT and UBMCT). Groups did not differ on gender make-up ($p=0.72$ for both male and female) but did differ on average age at diagnosis ($p<0.01$) and type of diagnosis (see *Table 1*). Children evaluated through the ISUT Model were on average about 3 years younger than children evaluated in the UBMCT clinic and more often received a diagnosis of autistic disorder or pervasive developmental disorder, not otherwise specified (see *Table 1*).

We examined satisfaction data within a subsample of this total group of participants. Each family received a satisfaction survey with their final report. We had a 16% return rate that formed the subsample ($n=126$; 62 in-person and 64 ISUT) of the total group of participants.

Preliminary Results

IMPROVED ACCESS

We examined the number of families served both in the UBMCT Model and through the ISUT Model to determine the impact of the ISUT Model on access to services. As a result of the ISUT Model, we saw an increase in diagnostic services for families living in rural and underserved areas in our state. *Figure 2* represents the number of families who accessed "in-person" services using the UBMCT from 2008 through 2012 and the number of families who accessed services using the ISUT Model from 2008 through 2012. *Figure 2* illustrates how the implementation of the ISUT Model greatly improved access to services for families living in rural parts of the state. Families from 35 counties participated in the "in-person" UBMCT clinic, and families from 74 counties participated in the "ITV"-based ISUT Model. In addition to more families accessing services, we also found that

children who participated in the ISUT Model received a diagnosis nearly 3 years earlier (see *Table 1*) than those children who participated in the "in-person" evaluation through the UBMCT. We also found that through the ISUT Model, we were able to identify older children who had never received a diagnosis previously. Therefore, our mean age of diagnosis may be somewhat inflated.

COST IMPLICATIONS

In order to evaluate potential cost implications of the ISUT Model, we computed travel costs based on the 2014 state mileage reimbursement rate and the roundtrip mileage between the university clinic and participants' zip codes. As this is a retrospective review, we are limited to data available from our clinical database (i.e., zip code) and not privy to additional travel costs families did experience or would have experienced. *Table 2* illustrates potential travel costs for families evaluated through the ISUT Model had they traveled to the "in-person" UBMCT clinic compared with those families who actually traveled to the university clinic. Families evaluated through the UBMCT traveled an average of 63 miles (range, 1–395 miles), demonstrating average travel costs of $35.28. Families evaluated through the ISUT Model were, on average, 180 miles (range, 1–472 miles) from the UBMCT, estimating potential travel costs of $100.80. Even with the large ranges of mileage for each group, distances traveled for each group were evenly distributed. These results illustrate the potential cost burden for families living in rural and underserved areas who are required to travel long distances to access needed healthcare services. Results also demonstrate the capacity for a model such as ISUT to provide families alternatives in accessing the quality healthcare services they need. Although we were not able to identify socioeconomic status (SES) differences for the families served through the two models, there appeared to be no difference in the percentage of families insured by Medicaid (32% of families in the ISUT Model versus 38% of families in the UBMCT Model).

PARENT SATISFACTION

We examined parent satisfaction data from a subsample of our total group to determine if families who participated in the ISUT model were as satisfied with their experience as those who participated in the "in-person" UBMCT model. *Figure 3* represents a comparison of satisfaction data between the two models. Our pilot data suggest that parents are as satisfied with the telemedicine-based ISUT Model as they are with coming to the UBMCT with respect to feeling they have a relationship with medical providers. Parents were equally
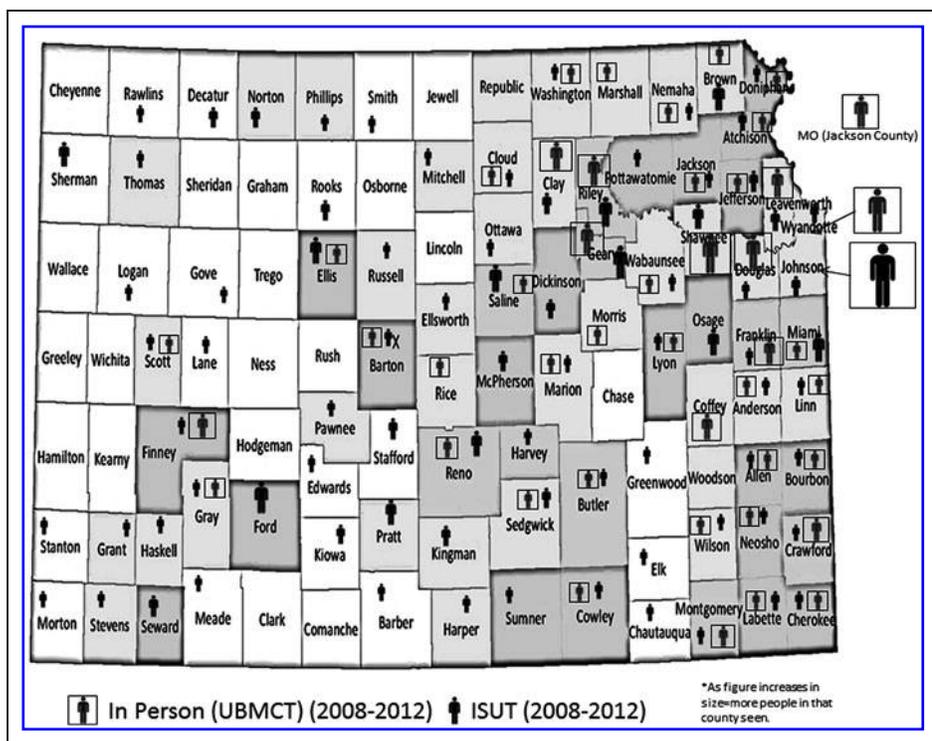
Fig. 2. Number of families from 2008 through 2012 who accessed "in-person" services using the university-based medical center team (UBMCT) approach and who accessed services using the Integrated Systems Using Telemedicine (ISUT) Model.

velopmental delays.[1–3] In its nature, our model challenges existing, more traditional clinical practices that evaluate children with ASD. Positive outcomes from the ISUT Model challenge existing systems that promote inequity for families living in rural or underserved areas and provide a model for replication. The ISUT Model is unique in that it braids the family, educational system, and medical system while using an innovative, yet accessible and cost-effective method appropriate to collaborate through telemedicine. Although we describe similar models that aim to increase capacity for screening and diagnosis of ASD in underserved communities, our model demonstrates at least two additional advantages over these models: (1) the unique collaboration among the family, educational system, autism experts in the community, and university medical center autism teams and (2) the use of telemedicine technology provides a cost-effective means to access specialty care while promoting coordination of care within the community.

Additionally, preliminary findings suggest that families were equally satisfied with the ISUT Model compared with families who participated in the more traditional UBMCT Model. Providing services through the ISUT Model relieves families of the stress of traveling long distances to receive care and of the burden of having to share information across providers from multiple institutions. Families may be more satisfied with the telemedicine visit because the local teams (ADTs) support parents throughout the diagnostic process and are able to link families with local resources for health and mental health services. It is interesting (although not necessarily significant) that the largest discrepancy between the two groups (ISUT versus UBMCT) on the satisfaction data was with respect to the team's ability to provide resources in the family's community. The ISUT Model addresses this parent concern directly by involving actual members of the community who will naturally be more familiar with available resources in the community.

Preliminary data for our ISUT Model provide support for a change in the clinical practice of evaluating children at risk for ASD, promoting access to quality healthcare services and significant cost savings for individuals in rural and underserved areas. We demonstrated a significant increase in the number of families accessing ASD diagnostic services through telemedicine across our state following implementation of the ISUT Model. We noted potential travel cost savings of $35.28 for families evaluated through the ISUT Model without considering additional cost burdens
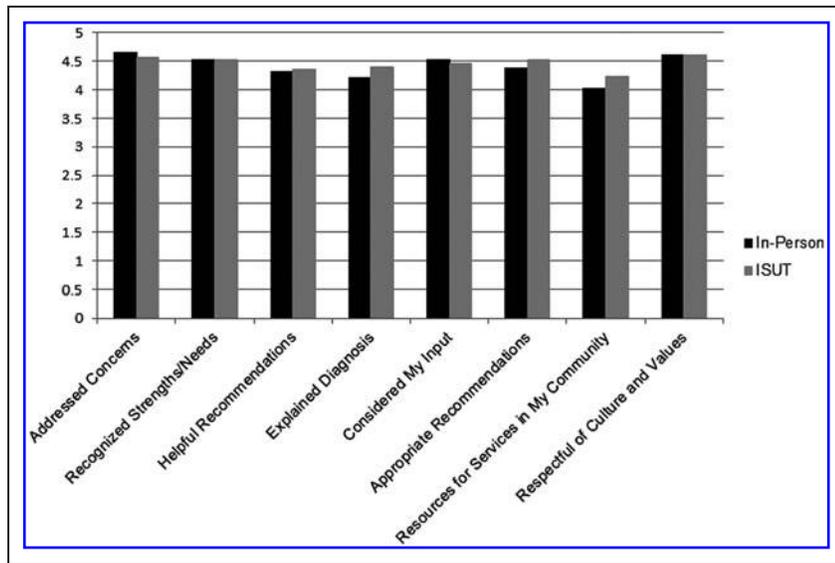
satisfied with the manner in which each team addressed family concerns, recognized strengths and weaknesses, provided helpful recommendations, explained the diagnosis, considered family input, appropriateness of the recommendations, the team's provision of resources within the family's community, and the team's respectfulness of the family's culture and values.

Discussion

Early identification and intervention as well as identification of anyone with autism even when the child is older are crucial in promoting improved outcomes for children with autism and other de-

Table 2. Potential Cost Savings for Roundtrip Travel to the University–Based Medical Center Team			
SETTING	NUMBER	AVERAGE ROUNDTRIP MILEAGE FOR FAMILIES TO COME TO THE UBMCT	AVERAGE ROUNDTRIP COST FOR TRAVEL TO THE UBMCT[a]
UBMCT	370	180 miles	$100.80
ISUT	405	63 miles	$35.28

[a]Cost calculated using 2014 state mileage reimbursement for travel (56 cents/mile).[18]

ISUT, Integrated Systems Using Telemedicine; UBMCT, University-Based Medical Center Team.

Fig. 3. Mean item satisfaction scores compared between the university-based medical center team approach (In-Person) and the Integrated Systems Using Telemedicine (ISUT) Model groups.

related to meals, hotels, childcare, or lost wages. These same data demonstrate the capacity of the ISUT Model to reach families at long distances from university medical centers and that we can provide an equitable service to families who may not have the means to travel long distances to access such services.

LIMITATIONS AND FUTURE DIRECTIONS

We acknowledge several limitations in our study. First, we only had a 16% return rate on satisfaction survey data. More recent mail-in satisfaction data have not yielded a higher return rate. We consider our satisfaction data preliminary in nature, yet promising given the fact that most participants were satisfied with the services they received. Next, the finding that children who participated in the ISUT Model received a diagnosis an average of nearly 3 years earlier than those who participated in the UBMCT requires caution in interpretation. Our center has several diagnostic clinics, including birth to 5 autism diagnostic clinics, staffed by providers from a range of disciplines (e.g., occupational therapy, speech therapy, physical therapy, psychology, and medicine). Because ISUT clinics are staffed only by a medical provider and a psychologist, we considered only UBMCT clinics with similar providers involved (e.g., psychologist and medical provider) for a comparison of satisfaction data. Although other data were available, we believe their inclusion would introduce too many potentially confounding variables to provide an accurate depiction of family satisfaction between models. Our findings also indicate significant differences across the various diagnoses between the two groups. It is not clear what specific factors influence these differences as these initial data are based on a convenience sample. Potential factors may include lack of random assignment, variables related to age of diagnosis, and differences in sensitivity and specificity of the ISUT model.

Finally, we completed a retrospective study using existing data from our clinical database, resulting in a convenience sample without randomization or other controls that decrease Type I or Type II errors. We interpret these results within the framework of these limitations while recognizing the strength and clinical utility in such community-based research.

Future investigation should consider a larger, more formal evaluation of the ISUT Model. We are planning a larger, more controlled study evaluating the impact of the ISUT Model on access to autism services as well as services for coexisting conditions. Because the ISUT Model involves local educational teams, these individuals may be more familiar with local resources than the UBMCTs and may be more equipped to help link families to these services. Additionally, a larger study might consider better methods for gathering demographic and satisfaction data as well as a process for measuring satisfaction several years after receiving treatment. Given the potential cost savings for families participating in the ISUT Model, a larger study should also look at SES of families who participate in both the ISUT Model and the UBMCT Model. Although we had percentages of families receiving Medicaid, this proxy measure was not sufficient. Having SES data would help to determine if the ISUT Model is helping to provide families who come from lower SES backgrounds greater access to services who might not have the means to travel to larger UBMCTs.

In conclusion, changes in clinical practice are necessary if we are to address the inequality of access to services and promote earlier detection and intervention for individuals in rural and underserved areas. The model we described in this article is a first step in improving access to services for families in rural and underserved areas. Examining existing data provides preliminary evidence for the utility of models such as ISUT to reach underserved families and provides implications for evaluating current clinical practices. Results provide justification for continued collaboration between our partners and to pursue further evaluation of our model.

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Disclosure Statement

No competing financial interests exist.

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