Testimony

Study Resulting from SB 2268

October 25th, 2011

Chairman [redacted] and members of the Interim Committee, good afternoon. My name is Vicki Peterson and I live in Bismarck, ND. I am here today to give testimony on the study of Autism Spectrum Disorders as a parent of a child with autism.

I am a single mother of a beautiful 9yr.old son. My son, Aaron has autism. Autism is a neurobiological developmental disorder that significantly impairs communication, socialization, behavior, and learning styles. The Autism Spectrum Disorders includes a varying degree of impairments. The Autism Spectrum Disorders include at this time; Autistic Disorder (Autism), Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Rett's Syndrome, and Childhood Disintegrative Disorder. My son Aaron received his Autism diagnosis at a very early age of 15 months from the University of Minnesota Autism Clinic. Aaron's diagnosis includes Autism with Intellectual Disability. At the time of his diagnosis I had decided there were not sufficient physicians in the state of ND to give an accurate diagnosis, so with the help of his Early Intervention team and his primary care physician I was able to have Aaron's diagnostic testing for Autism done at a multi-disciplinary clinic. Aaron was already receiving services in the Infant Development program which led me to seek a diagnosis. I realized very early that to receive services to help Aaron communicate, learn, and grow, I would need to get an accurate diagnosis. Once the diagnosis was made, I would return to ND to realize I would need much help in navigating the systems that Aaron would utilize, so I dove right in and became the best advocate I could for my son.

Finding resources, emotional support and learning about autism started with a trusted friend, led me to Family Voices of ND and there to parent leadership roles. I am very certain without that trusted friend my family, my personal self, and most of all Aaron would not be in the same place; the place I consider success. It is not an easy road. The system that families have to navigate is a daunting experience. What direction do you take as parents? What will my child's life be like in the future? What will his education look like? Why must I be teacher, therapist, navigator and try to be mom all at the same time? Questions that I wonder about every day and every minute. Having a child with special healthcare needs for me is a 24-7 responsibility. Aaron has chronic health conditions as well. He suffers from a chronic sinus condition that has required 9 surgeries and every 30 days a visit to an ENT specialist for medication injections, an extreme sleeping condition most likely related to autism though he only sleeps about 4 hrs in a day and not at the most convenient or best time, specialists have not a clue and sleeping medication makes it worse and he has an adverse reaction to anesthesia. He also has a very limited diet in what he eats, we have had to seek specialists in this area outside of the state of ND, with not much success , his diet consists only of chicken nuggets, crackers, water and fruit snacks..You may ask how this is healthy. It's probably not,

his immune system is more than likely weaker because of it. We, therapists and I, have tried many diet programs, nutritionists, OT specialists, autism clinics, with not much success. Still in spite of it all he has gained weight. I introduce new foods quite often, but he will not eat and to force him does not work for me or him. So I am constantly searching for new ideas, new strategies, any help...I am a researcher and therapist and mother at these times. Many children with autism spectrum disorders suffer from related chronic health issues. For this reason the Medicaid system, waiver systems and affordable and accessible health insurance are so important for families with children and youth with Autism Spectrum Disorders.

Aaron had developed early when it came to skills. Even his language seemed to develop early, despite the sensory issues he had since birth, not eating well, many upper respitory infections, not being able to dress him easily, constantly needing sensory input as well as many gastrointestinal issues. At 9 months everything stopped for our family, including Aaron's language. I knew at that moment our family and Aaron would have a different journey in life. Early Intervention was key and our starting point. Today Aaron is mainstreamed and in special education, a 3 rd grader whom now is reading in adaptive books, using technology to communicate and learn, learning skills that I took for granted with my other son. Education is so important for the future of our children with autism. Autism is being diagnosed at alarming rates, the CDC informs us that 1 in every 110 children have autism, more prevalent in males, much controversy over causes, and continuing to grow. In ND the number of children is not clear, what can be reported is this; currently, there is no analysis or classification of these children by disability category (personal communication, Susan Burns, ND DoH, May 2, 2011). However, the National Survey of Children with Special Health Care Needs data shows that 5% of children with CSHS have autism/ASD. Using this percentage we would estimate that about 825 children with a special healthcare need (CSHCN) in ND would have ASD. In 2010, NDDPI reported 554 students with a primary diagnosis of autism; likewise, some ND schools do not count students with various diagnoses (e.g., Asperger's Syndrome, PDD-NOS) under the ASD umbrella. (NDDPI). Training of providers, teachers, aides and medical professionals is greatly needed in the state of ND. Aaron is fortunate to have an exceptional IEP team at school. They attend trainings they can, they think outside the box, embrace technology and most of all the general education teachers are involved, this is key if we are going to be mainstreaming. Styles of teaching children with autism need to be embraced, understanding that behavior may be there only means of communication unless we give them tools to communicate with, with this we know takes funding.

Aaron is 9, the time is fleeting by me, and my worries are not the same for Aaron as they are for my other son, though I worry about both. If something happened to me, would someone be taking care of Aaron with the same family-centered care I ensure now? Will they help in a manner so Aaron will have the independence he can handle? Will Aaron make friends? Will healthcare be there for Aaron when he needs it? Not my worry, Aaron has brought so much joy to my life and others, he is a wonder of happiness and has taught more to me than I can ever imagine.

I ask of you when you're discussing policy-making for children and youth with autism, to remember that this is across the lifespan of our children, whom will become adults in our society, productive citizens of our state. To look at education, job coaching, independency and much more for our growing population of adults with Autism Spectrum Disorders. Remember to hold family stakeholder meetings and receive input from the families, living and breathing autism every day, from the self-advocates of autism whom we give us more insight to what it is like living with autism.

I have attached a picture of my son, Aaron.

I have attached testimony and data about Tele-therapy, therapy method that I hope you look at for the future of ND. The rural families in ND have much harder access to therapy. Working with families in rural ND, this is what I hear the most. If you had any questions regarding this method of therapy delivery, their contact information is available on testimony.

I want to thank you for your time, and I would be happy to answer any questions you may have.

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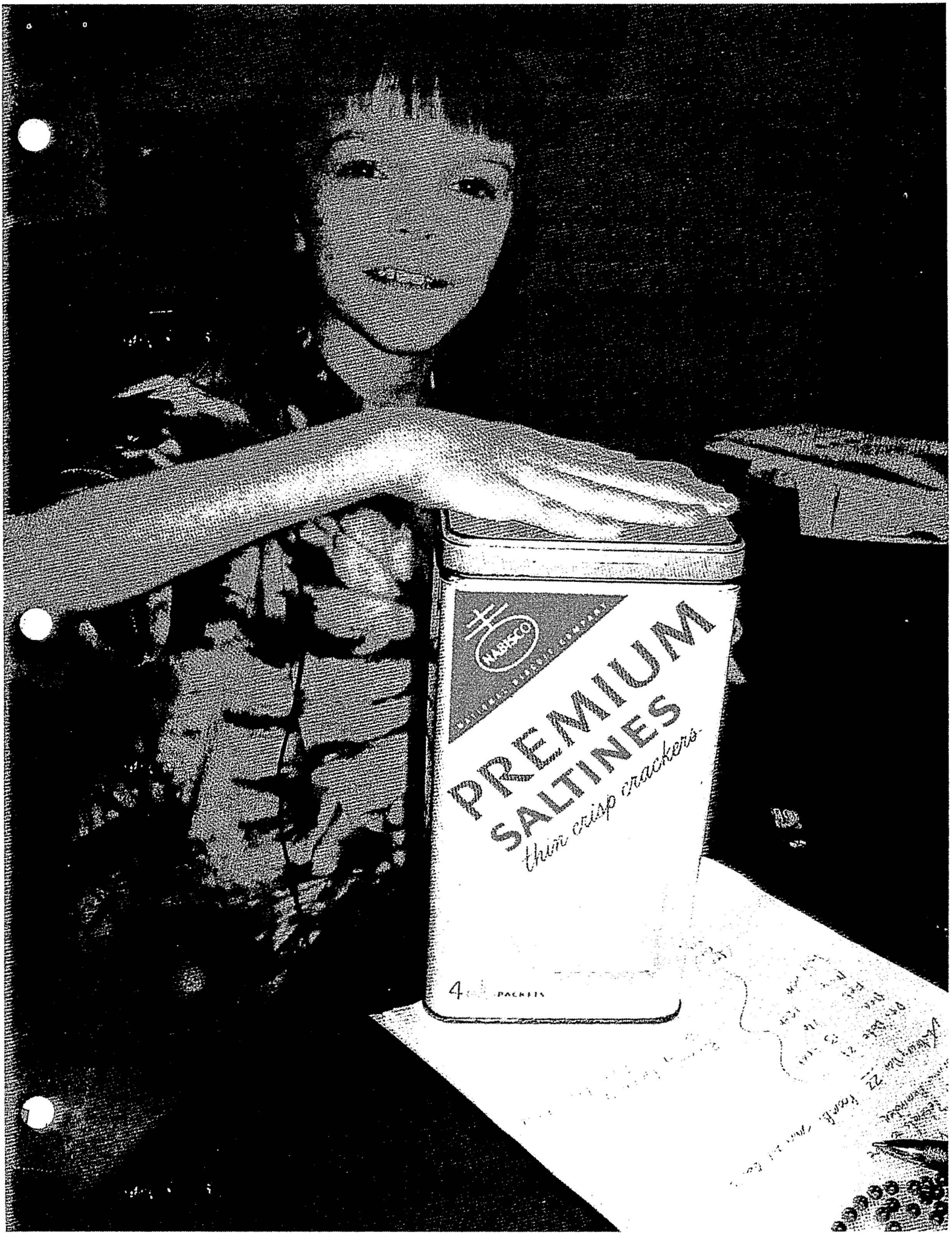
Parent


NABISCO
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October, 17, 2011

Topic: Tele-practice Therapy in North Dakota, Legislative Interim Committee
Date: October 25, 2011
Statement By: Kelli Ellenbaum, MS CCC-SLP Red Door Pediatric Therapy

I am a speech language pathologist who serves the pediatric population at Red Door Pediatric Therapy (a private practice) in Bismarck, ND. I have special training from the University of North Dakota in the area of Autism Spectrum Disorders. I also have 10 years of experience working with this population.

This past summer we trialed tele-practice therapy (speech/language/communication therapy and occupational therapy) with a family who spent most of their summer out of the Bismarck area. We trialed this type of therapy due significant behavioral adjustments* that occurred the prior year while the family was gone for an extended vacation (adjustment period of approximately 1 month or 8 sessions). Sessions were conducted for 2 children diagnosed on the autism spectrum. The participants included one child with high functioning and one child with a more classic form of autism, both school-aged. I will describe these scenarios separately, as they were conducted differently.

The child who was diagnosed with the more classic form of autism was seen for consecutive speech and occupational therapy sessions. The duration of sessions lasted from 45 minutes to 60 minutes one time per week. This child's parent was a participant in both sessions for the purpose of prompting and reinforcement. The parent participated in 2-30 minute training sessions. Materials were provided through the US Postal Service. Ongoing educational instruction was provided to the parent during the sessions and also via email. The participant was able to consistently maintain attention to tasks, complete appropriate number of trials in given sessions, and require less intense redirection. In other words, this participant was able to demonstrate consistent behaviors in tele-practice sessions as he was during actual 1:1 sessions within the clinic setting. Overall, the service delivery model was a positive experience in terms of data and progress. It is significant to note the importance of an adult/aid/parent/caregiver presence in the tele-practice service delivery model.

In the second scenario, speech/language/communication tele-practice was used with a child presenting with a higher functioning form of autism. This patient was

evaluated in the clinical setting and attended 4 1:1 sessions before tele-practice was initiated. Summer sessions focused primarily on teaching the concepts of social communication, abstract reasoning, perspective taking, body language/gesture, facial expression and social inferences. These sessions were 30 minutes in length and did not require the presence of an adult/aid/parent/caregiver. Again, the parent was provided with 30 minutes of training (completed via tele-practice) along with emails describing that week's activities and home programming objectives.

Both children returned to the area in the fall for 1:1 sessions with their therapists. It was noted that there was no adjustment period this time around. We attribute this to consistency in both 'seeing their therapists' and 'continuing the plan of care' with no lapse in treatment. Other options were considered (such as having the child receive services in the same area as the family's vacation home), however it was determined by both the serving facility (Red Door Pediatric Therapy) and the child's parents that familiarity with the therapist was a priority (also the least costly option).

At Red Door Pediatric Therapy, we have determined that this method of therapy would be very useful in rural areas since it provides professional support for families who do not have access to services. This type of service delivery would require a 1:1 in person evaluation along with adult/parent/aid/caregiver training. Tele-practice also addresses the difficulty North Dakota has with staffing professionals in its rural areas.

I thank you for the opportunity to share this information with you. Our state excels in so many ways, it would be wonderful to include tele-practice to rural North Dakota residents (not just those diagnosed on the autism spectrum).

Sincerely,

Kelli Ellenbaum, MS CCC-SLP
Autism Certified

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*These behaviors include decreased attention, decreased participation in therapy driven tasks, decreased trials with defined time limits and increased redirection to specified tasks.

November 18, 2003 Feature

Meeting The Challenge of Rural Service Delivery

by Bobbie Houn & Kolette Trottier

Last month clinicians in North Dakota won a major reimbursement victory when Blue Cross and Blue Shield agreed to cover telepractice speech-language pathology services. This is the story of their pilot project and their successful advocacy with a major health insurer.

In January 2002, the Speech Therapy Department at St. Alexius Medical Center, Bismarck began exploring the possibility of providing services through the Tele-Care Network after receiving several requests to provide direct services to various communities within the state of North Dakota. These rural communities lacked access to local speech-language pathology services. We were unable to provide these services directly due to staffing, reimbursement, and travel constraints.

Five months later, we began providing speech services using telepractice, and launched a pilot project in collaboration with Ashley Medical Center in Ashley, ND, which is 120 miles from Bismarck. The project started with only one patient, but quickly grew to serve four patients.

A woman who suffered a stroke while visiting her daughter in California became the first patient to use telemedicine for speech-language pathology services. After returning to North Dakota, her need for services continued. Because she could not drive, she needed her family to take her to Bismarck twice weekly, and told us that she "would not have attended therapy if it meant driving several times a week." She was very pleased with the services she received and "graduated" from speech services after three months.

The second patient, from Gackle, ND, also received speech services

after suffering a stroke. She received speech services three times weekly for six weeks. She also said that she would not have traveled the 96 miles to Bismarck for therapy, and was pleased that services could be provided through the Tele-Care Network.

The process of delivering speech-language pathology services using telepractice is quite simple. The equipment installed at each facility allows for full-motion video consultation with spontaneous audio and video interaction, much like the interaction that takes place with two people talking in the same room. Prior to conducting a session, we fax and/or mail written material to the rural tele-health coordinator. During the session, we use an Elmo overhead-projector stand, located in the consultation room, to display the materials over the television monitor. If additional materials are required, the rural tele-health coordinator provides them upon request. A facilitator is always present with the patient to assist throughout the session.

According to Ashley Medical Center's Tele-Health coordinator, this service saved the Ashley residents 56 trips to Bismarck, which is equivalent to 13,440 miles. Using a cost of 31 cents per mile, the cost savings to the patients and their families was $4,766.40. This did not include the lost wages of the family members transporting the patients.

We continue to provide speech services over the Tele-Care Network and over the past year have expanded our service to include seven medical centers and one school. We have treated approximately 20 patients. This has been a very positive experience and appears to be beneficial for everyone involved. We feel telepractice provides an opportunity for St. Alexius Medical Center as well as other telehealth providers to reach patients that would otherwise not receive speech-language pathology services.

Next Step: Reimbursement

After seeing patients and realizing how successful the pilot program was, we decided to approach Blue Cross and Blue Shield of North Dakota, Medicaid, and Medicare about adding speech-language pathology to their list of covered services offered through telepractice. We wrote letters and provided examples to each third-party payer. In April 2002, we met with Medicaid staff at the state capitol to discuss

the proposal. They informed us that telehealth speech services would be approved if prior approval requests were made. In July and again in November of last year, BC/BS of ND notified us that services would not be covered until ASHA set specific standards.

At this point we turned for support to ASHA staff, who wrote a letter to the North Dakota State Insurance Commission endorsing our position with citations from various state regulations, national accreditation, training requirements, and supporting outcomes data. In May 2003, we again received notification from BC/BS of ND that services would not be covered. At this point we felt discouraged, but were determined to succeed.

With continued successful outcomes using telehealth, we knew our sevices clearly benefited our patients. Richard Tschider, chief executive officer of St. Alexius Medical Center, also believed our services were beneficial and supported us by repeatedly taking our request to the BC/BS of ND board of directors. Finally, last month, a BC/BS of ND committee added telehealth speech services to their list of covered services. We are very excited about this reimbursement victory and wanted to share our excitement with all ASHA members.

Bobbie Houn, is a senior speech-language pathologist at St. Alexius Medical Center in Bismarck, ND. Contact her atbhoun@primecare.org.

Kolette Trottier, is a telehealth nurse coordinator at St. Alexius Medical Center.

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November 28, 2006 Feature

Telepractice Brings Treatment to Rural North Dakota

by Bobbie Houn & Kolette Trottier

Fourth in an occcasional series of articles highlighting telepractice programs or services provided by speech-language pathologists

In the past four years, a successful pilot project has linked the St. Alexius TeleCare Network with patients in need of speech-language services at the Ashley Medical Center in Ashley, ND.

The project, which started in May 2002, grew quickly with the assistance of a grant awarded to the TeleCare Network by the federal Office for the Advancement of Telehealth (OAT). The OAT grant ended in August 2004, but during that time tremendous strides were made: 49 patients from western and central North Dakota received either evaluation or treatment.

In the past four years, major changes have taken place in areas of reimbursement and research. At the time the project was initiated, no reimbursement was available for speech treatment delivered by telepractice. Of the 49 patients treated, 86% were covered with funds from the OAT grant. As the end of the grant period approached, St. Alexius began requesting coverage from Medicaid, Medicare, and Blue Cross/Blue Shield. Medicaid began coverage, with prior approval, in the summer of 2002. Blue Cross/Blue Shield began coverage in October 2003, also with prior approval. Medicare continues to deny reimbursement of telepractice speech services.

The TeleCare Network utilizes real-time, two-way, interactive teleconferencing equipment over dedicated T-1 phone lines. A document camera, called an "ELMO," is used to view evaluation and treatment materials to facilitate patient learning. Although an evaluation may take one hour to complete, individual treatment sessions are typically 30-45 minutes and most often are scheduled two to three times a week for three to six months.

Clinicians from St. Alexius Medical Center treat pediatric through geriatric patients, with diagnoses that include global developmental delays, speech and language deficits, autism, voice disorders, cognitive deficits, aphasia, apraxia, dysarthria, dyslexia, and

dysphagia.

At the time the pilot project was initiated, the Speech-Language Pathology Department at St. Alexius consisted of three full-time employees. These three speech-language pathologists (SLPs) were responsible for inpatients, transitional care, rehabilitation, outpatients, home health care, and outside contracts. To meet the increasing demands and the addition of telepractice patients, the department hired an additional full-time employee and two on-call staff. A telepractice specialist, the SLP, and the rural telepractice coordinator at St. Alexius—and a nurse, physician's assistant, physician or interpreter at the rural site—were all needed to ensure the telepractice session worked effectively.

Documentation for telepractice speech treatment follows the same requirements as outpatient visits. Initially a physician order is required from the referring provider for an evaluation and/or outpatient treatment. A telepractice request form is also needed from the rural health care facility. An evaluation is done by the SLP and is faxed to the referring physician. Initial certification is obtained before the first treatment session and then renewed every 30 days.

The SLP completes a daily flow sheet and charge ticket for each session. Upon discharge, a final report is faxed to the referring physician. Although there are no changes in the requirements for documentation, there are changes in the CPT codes. Telepractice charge tickets continue to have the same CPT codes for evaluation and treatment, but the modifier changed from GN to GT, indicating that the encounter was through telepractice rather than face-to-face.

Patient Response

Patients have responded positively to receiving treatment by means of telepractice. Speech treatment is not available in many rural health care facilities in North Dakota; telepractice allows rural patients the convenience and efficiency of staying in their own community for services. One of the first stroke patients in the pilot project stated, "I would not have traveled the 96 miles to Bismarck and was very pleased that services were provided using telepractice."

Patients appreciate receiving services two to three times a week

without the expense of fuel, meals, and time off from work for the patient and/or family members. The wife of a recent telepractice patient with Blue Cross coverage said, "I wasn't sure how I would be able to maintain my health benefits if I had to stop working to drive my husband to Bismarck two or three times a week for treatment." In addition to reducing expenses, telepractice also eliminates the hazards of driving on winter roads in North Dakota.

St. Alexius SLP Kathie Beneke said, "Due to staffing and time limitations, we were not able to treat patients in their rural communities. With telepractice these patients now have access to speech-language services."

A school-based SLP treating a young patient with a brain tumor said, "Education-based speech treatment follows a specific curriculum to help the student participate in the classroom. I felt the telepractice services provided additional hours and focused on the dysarthria and aphasia, helping her to excel."

The future of the delivery of speech-language pathology services by telepractice looks promising. The willingness of the SLPs and the patients' continuing satisfaction indicate that telepractice has a definite future and value in rural communities. The Telemedicine and Speech Language Pathology departments at St. Alexius, along with ASHA, continue to advocate-with support from OAT and the Center for Telemedicine Law-for Medicare reimbursement for telepractice speech treatment. In addition, the SLPs at St. Alexius are working in conjunction with ASHA to study the effectiveness and benefits of telepractice speech services through the use of the National Outcomes Measurement System.

Patients in many rural settings have benefited from speech treatment delivered through telepractice. The success of this project over the last four years can be partially attributed to the willingness of skilled SLPs to reach out to those in underserved areas of central and western North Dakota by integrating telepractice into their schedules.

cite as: Houn, B. & Trottier, K. (2006, November 28). Telepractice Brings Treatment to Rural North Dakota. The ASHA Leader.