

Mr. Josh Cobbs,
Chairperson of the Iowa Autism Council,
Parent Board Member of the Iowa Association for Behavior Analysis,
Autism Speaks Chapter Advocacy Chair for Iowa,
Co-Chair of Marketing and Fundraising for the Siouxland Autism
Support Group, a Chapter of the Autism Society of America
Parent Advisor to Cnow

Testimony to the
Labor, Health and Human Services, Education and Related
Agencies
Subcommittee of the US Senate Appropriations Committee:
Hearing on Combating Autism, August 5th, 2009

“Seeking Standards in Telehealth Technology and Service
Delivery to Qualify for Autism Services Reimbursement”

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“Seeking Standards in Telehealth Videoconferencing Technology and
Service Delivery to Qualify for Autism Services Reimbursement”

Good morning, Mr. Chairman and members of this distinguished Committee. My name is Josh Cobbs. I am the Chairperson of the Iowa Autism Council, a Parent Board member of the Iowa Association for Behavior Analysis, the Autism Speaks Chapter Advocacy Chair for Iowa, the Co-Chair of Marketing and Fundraising for the Siouxland Autism Support Group, a Chapter of the Autism Society of America, a Parent Advisor to Cnow and most importantly, the parent of a child with autism. I have spent over seven years trying to better the lives of individuals and families affected by autism by working on education and insurance reforms.

When I was last in front of this distinguished Committee I spoke of the successful and cost-efficient services my son and family received using telehealth technology. These services were provided in my home in Iowa from qualified professionals in Florida through the Celeste Foundation's federally funded national research project. We were one of 15 families that participated in this demonstration across the nation. In this model, after a brief phase of on-site face-to-face training (which is crucial to build a therapeutic relationship), we were linked to professionals by an interactive video system that enabled live training, consultation and support directly into our home when and where it was needed. Through this telehealth model, we received professional support in teaching our son language, life skills, and overall improving his quality of life. One of the main components of participating in this study was the reduction in our family stress through empowering us as frontline teachers and therapists. Additionally, through training and education in this project we had a better understanding of our child's condition and those things we could bring to bare to improve his life. Not only did it improve my son's quality of life, but it had an impact on my family as well. Also, as a family we showed a dramatic reduction in stress, anxiety and became more focused as a family unit.

I will never forget the call from my wife saying, "You'll never guess what our son did, he went potty on the big boy potty!" This was a monumental moment for the entire family. While many consider toilet training a milestone, it becomes a super-milestone when your child is five years old with autism and has the additional burden of societal rejection. Through our telehealth connections and access to certified professionals, we were given the right teaching skills and able to achieve what previously was unobtainable. Our experience was chronicled in a two part series filmed by the CBS affiliate in Sioux City, Iowa and aired during recognition of Autism Awareness Month. We have copies of this footage that we would like to share with the Committee and it can also be viewed at www.celestefoundation.org.

I can not stress enough that the needs of persons with autism do not conveniently conform to clinic hours or professional appointments. We were able to access these professional's help when we needed it and it made all the difference. Also, just having the support in my home allowed natural interaction for my son and allowed the professionals to see the behaviors as they really occur.

As chairperson of the Iowa Autism Council, I have the opportunity to speak with many family members and stake holders within the autism community to learn their needs. From my perspective and my experience, these families are desperately in need of services. Today, as parents search online for appropriate telehealth services for their children, they are confronted with an array of un-validated technologies and various individuals claiming expertise in treatment. Unfortunately, there are no safeguards in place to protect vulnerable parents and children. For example, from anywhere in the world anyone with a personal computer, a webcam and internet access can offer video services termed as "advice". Under these circumstances, any individual or group can claim qualifications in helping parents and children with autism. Not only are families experiencing the emotional burden of treating a child with a disability, but they also have the financial burden of paying for this treatment with no assurance as to the quality of care provided. When individuals or organizations that are collecting fees for services can distance themselves into the "cloud" that is the internet, what can families expect for recourse to failed expectations?

The reality of standard setting is evident because without standards there can be no reimbursements. While the method and systems are cost-effective, without a proper reimbursement model they still remain unobtainable for most parents who, similar to the rest of the nation, are struggling financially to find care for their children. There are millions of dollars being placed into rural telehealth networks. However, there are few, if any, methodologies for reimbursement for autism telehealth treatments. Additionally, the current wave of state-wide health insurance requirements aimed to provide reimbursements for individuals with autism do not have well-defined standards for telehealth reimbursements. In the absence of consistent reimbursement policies and

standards, families and children are not granted access to proven and effective care.

I know this committee through report language has recognized the need to assess “best practices and professional criteria standards and to make recommendations to the Committee concerning national standards for telehealth reimbursement which advances and encourages this technology.” I commend the Committee’s foresight in doing so and simply urge that this momentum continues.

In closing, you may be wondering how my son is doing today. He is now nine years old and my family is still utilizing telehealth technology. We are currently addressing such behaviors as: food selectivity, expressive language, academic skills, etc. It is important to note that as he grows, my son’s treatment program continues to address his ever evolving needs. We continue to use telehealth treatment because it has been an effective delivery system for our family. In fact, it has been so effective that now my eight year old daughter has become a mini-therapist using teaching strategies learned in the telehealth program with my son. At this point in my son’s life he continues in the role of student and teacher to us all. His future is bright. Thank you.