

# Telemedicine and Autism: Researchers and Clinicians Are Just Starting to Consider Telemedicine Applications for the Diagnosis and Treatment of Autism

## Introduction

**B**ecause autism is largely diagnosed through observation of behavior and treated with behavioral therapy, a number of researchers and clinicians believe that telemedicine applications might be particularly beneficial. Despite that, there has not been extensive work in the area, although a number of researchers and vendors are exploring technology applications.

## Autism and the Autistic Spectrum

Autism spectrum disorders (ASDs) are developmental disorders, of which autism is the most common. ASDs include Asperger syndrome, Rett syndrome, pervasive developmental disorder not otherwise specified, and childhood disintegrative disorder. Typical symptoms are impaired social interaction; difficulties with verbal and non-verbal communication; and unusual, repetitive, or limited activities and interests. The National Institute of Neurological Disorders and Stroke (NINDS) indicates that 3 to 6 children of every 1,000 will have autism, and males are four times more likely to have autism than females. The Centers for Disease Control and Prevention (CDC) cites 1 of every 166 children has an autism spectrum disorder.

According to NINDS, diagnosis is focused on identification of seven core behaviors:

- Difficulty making friends with peers.
- Impaired ability to initiate or sustain a conversation with others.
- Difficulty or absence of imaginative and social play.
- Stereotyped, repetitive, or unusual use of language.
- Restricted patterns of interest that are abnormal in intensity or focus.
- Preoccupation with specific objects or subjects.
- Inflexible attention to specific routines or rituals.

Peter Yellowlees, M.D., Professor-in-Residence at the University of California–Davis Department of Psychiatry and Behavioral Sciences (Sacramento, CA), says, “I think autism is a good illness in some respects to use telemedicine for. The kids actually interact well with technology and more naturally than they do if you’re in the room. They’re not good with social relationships and they may find it easier to find someone talking to them from a television than they do face-to-face, which might make them more anxious.”

Yellowlees notes that the gold standard for an autism diagnosis utilizes the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), “using the diagnostic criteria and also a very long structured work-up using ADOS. But people have to be trained for it—usually child psychiatrists and social workers—and it takes a couple of hours to give.” ADOS is the Autism Diagnostic Observation Schedule.

Treatment for autistic patients is typically behavioral treatment. This involves working on social skills, preferably beginning at an early age by trained people, and is best taught face-to-face. Yellowlees says, “What we could do is use telemedicine to train parents to help with that treatment, and instead of having aides come in, have them supervised by more expert therapists from afar. And obviously we can see telemedicine diagnosis for medication treatment.” Yellowlees notes that about 50% of children with autism end up on some sort of psychiatric medication.

## Autism Specialist Shortage

Yellowlees says that “most people would hope to have a child psychiatrist work with their autistic kid, at least initially for a diagnostic work-up. There’s a significant shortage of child psychiatrists around the country, but particularly in rural areas there’s almost none.”

Yellowlees notes that he's an adult psychiatrist primarily, but when he works with telemedicine he's often asked to consult because of the shortage of experts in the area.

The primary treatment of autism is applied behavior analysis (ABA). ABA is basically a systematic analysis of behavior that is then used to change socially important behaviors. In good ABA programs, the behavior change procedures are specifically laid out and also require parents to undergo training. At its best, ABA training is overseen by professionals with a minimum of a Master's degree, who have met the educational, experiential, and examination performance standards of the Behavior Analysts Certification Board and are Board Certified Behavior Analysts ([www.bacb.com](http://www.bacb.com)), or have equivalent training. It is also recommended that parents be involved in the training for 30 to 40 hours per week.

With those kinds of stringent requirements, it's not surprising that professionals in the field are looking at telemedicine applications for providing more care to more people efficiently. Matthew Goodwin, Ph.D., director of clinical research at the MIT Media Laboratory and associate director of the Groden Center, a school for autism spectrum disorders in Providence, Rhode Island, says, "Many of the professional sites are university-based or in urban settings, so the time it takes for professionals to travel to an individual's home and back is time that could be spent seeing these patients from a distance."

Gina Green, Ph.D., executive director of the Association of Professional Behavior Analysts (San Diego, CA), says, "Yes, there is definitely a shortage of qualified ABA practitioners in general, and specifically in autism. I don't know that anyone has run the numbers, but you can get the picture from the following: At present there are 7,000 Board Certified Behavior Analysts (BCBAs) and Board Certified Assistant Behavior Analysts (BCaBAs, who must be supervised by BCBAs) 'worldwide,' of whom about 70% work in autism and other developmental disabilities."

The states with the largest number of certified behavior analysts—Florida, California, Massachusetts, and New York—each have about 200 to 350 certified individuals, and not all of them specialize in autism. Some states may have fewer than 10 certified individuals. With approximately 1 in 166 children diagnosed as being on the autism spectrum, the shortage becomes obvious.

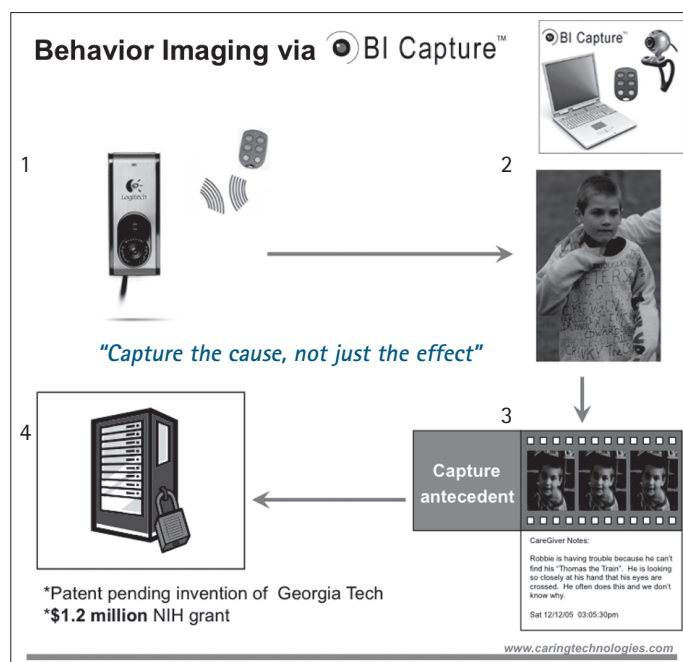
Green doesn't see telemedicine applications as supplanting in-person interactions with autistic children, but thinks there are definite applications. "From where I sit, teleconferencing and other telemedicine applications certainly have a role to play in delivering some of the training that is required to practice ABA competently and ethically, but they are not a complete solution. There are already a number of universities that offer online courses that meet the

coursework requirements to sit for certification as a BCBA or BCaBA, for example."

## BI Capture

BI Capture is a behavior imaging application invented by researchers at the Georgia Institute of Technology and licensed by Caring Technologies, Inc. (Boise, ID) (*Fig. 1*). One of the problems for diagnosing autism is that because autistic children have a difficult time with new environments, moving them to a physician's office may exacerbate or change typical behavior.

Goodwin says, "A lot of these kids have a hard time with a change in the environment, have a hard time with new people, and have a hard time with novel situations. The whole clinical picture the doctor is going to get is based on those 30 to 60 minutes, with some parental report. How a parent reports that child's behavior is not always accurate. How the child performs in that 30 to 60 minute session is not necessarily indicative, so you're making a pretty big lifelong label you're going to associate with the child based on a very small window of behavior. I think it would be interesting if we have enabling



**Fig. 1.** Caring Technologies' BI Capture utilizes a digital camera that automatically buffers content to a computer hard drive. When a remote control is keyed, the camera automatically begins to record, but also captures the buffered content, so that behavior preceding the keying of the remote is also recorded.

technologies where you can actually see the child in their natural setting that they can bring or share with their clinician to develop a fuller picture of their presentation.”

What BI Capture does is run digital video cameras, which can be used in the home or school or institutional setting. The cameras run all the time, but dump their video content into a buffering system rather than actually record. A parent or teacher or social worker has a simple remote control. With a single push of a button, the camera will not only begin to record, but the 5 or 10 or 30 minutes of preceding video in the computer buffer is recorded, depending on how it's programmed. This allows a parent or teacher, when observing unusual or idiosyncratic behavior, to not only record the behavior, but to record any antecedent that may have caused that behavior.

Gregory D. Abowd, Ph.D., interim director of the Health Systems Institute, a joint venture between Georgia Institute of Technology (GIT) and Emory University and director of the GIT Ubiquitous Computing Research Group, says, “It's not for diagnosis. It's being used for a particular kind of behavior intervention in a school system and in a variety of settings like schools and homes where you want to be able to record things. Stop-start is the typical type of recording where you know something is going to start and end, but you also have this other mode that lets you just have the camera up and you

aren't sure when something is going to happen, but you have the ability after-the-fact to record.”

Ron Oberleitner, CEO of Caring Technologies, Inc., says, “The norm is to figure out what the enabling aspects are for these kids. The psychologists will sometimes go into a home or classroom and sit there for hours trying to take data on this child and what aspects of the child are peculiar. With this technology the doctor can now say, “Yes, I have the data that preceded that incident and I'm able to make a determination about what's causing that aberrant behavior.” Now they don't have to be in that room for hours.”

Caring Technologies has taken the video capture technology one step further and created B.I. Care (Consultation and Records Enviro videos and other images and documentation to be shared via a secure network with teachers, healthcare providers, patients, and caregivers.

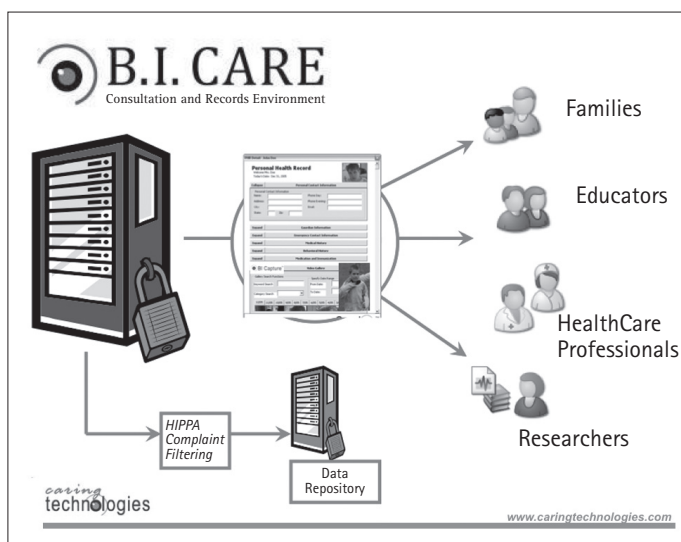
Abowd notes that at the core of B.I. Care is the need for secure transmission of data and compliance with the two relevant regulatory rules: the Health Insurance Portability and Accountability Act and the Family Educational Rights and Privacy Act. “They are compliant with those two regulatory rules in terms of protecting unauthorized access.

### OBAMA STIMULUS PLAN BOOSTS AUTISM RESEARCH

As part of the American Recovery and Reinvestment Act, better known as the Stimulus Package, approximately \$60 million was set aside to support autism research through the National Institutes of Health. Details can be found at the National Institute of Mental Health (NIMH) Web site (<http://www.nimh.nih.gov/recovery/index.shtml#autism-spectrum-disorders>). These funds are not, however, completely typical. According to the NIMH site, “These funds are not 'business as usual.' The Recovery Act stipulates that all stimulus funds must be obligated by Sept 30, 2010.”

There are basically four grant announcements, all of which fall under the title, “Research to Address the Heterogeneity in Autism Spectrum Disorders.” The four categories are:

- Research Project Grants (R01), which support large-scale studies with already existing preliminary data
- Collaborative Research Project Grants (R01), which support larger-scale collaborative studies with previously existing preliminary data
- Exploratory/Developmental Research Grants (R21), which support research in the exploratory or preliminary phase. There is a limit on direct costs, not to exceed \$175,000 per year for 2 years
- Clinical Exploratory/Developmental Research Grants (R34/Collaborative R34), which support early-phase treatment development studies. There is a limit on direct costs, not to exceed \$225,000 per year for 2 years



**Fig. 2.** Caring Technologies extended their digital imaging capture technology to electronic health records, B.I. Care. Captured images and video are uploaded to a data repository and made accessible to families, educators, healthcare professionals or researchers, but are controlled by the patients or families.

The way the B.I. Care environment works is you explicitly cite which specific people are authorized members of the B.I. Care environment, so you can control what level of viewing or hearing anyone has for any video you've created and decided to share with other people." This is partially done by allowing viewers to see annotated tags and allow them to add their own tags to the videos. The patient or guardians can also decide whether or not to provide viewers with their own copies of the video.

### Reimbursement and Validation

Although reimbursement for many areas of telemedicine is still in flux, in areas of psychiatric counseling it is fairly well established. Yellowlees says, "The reimbursement issues for telemedicine consults are the same as any other consult. Psychiatry in most states is paid the same as you would get for any normal face-to-face consults. It's not the same with store-and-forward technology consults. I'm doing some store-and-forward with psychiatry, but there's really not much reimbursement."

If reimbursement is not a major hindrance, clinical validation is. Yellowlees specifically notes he thinks more research studies are needed "where we demonstrate seeing autistic kids in the homes."

Fred R. Volkmar, M.D., director of the Child Study Center at the Yale University School of Medicine, says, "Because of emotional troubles, autistic children are much better able to deal with the computer. But there's probably very little evidence for dealing with computer programs, and I'm not sure anybody is trying to do treatment online with that kind of thing. I would be a little nervous about it."

Oberleitner suggests that more evidence-based research to show how telemedicine has efficacy in treating autistic children is needed. Oberleitner has published a number of technical articles on the subject in health and engineering journals. He has done extensive work in the area of telemedicine and autism and is poised for definitive program development and larger scale investigation. Oberleitner says, "The areas we're dealing with, mental and social disorders, don't really have the backing to say it really makes sense."

### CAN AUTISTIC KIDS LEARN SOCIAL SKILLS IN A VIRTUAL WORLD?

Second Life is an online "virtual world." That is to say, it is an online computer program that allows viewers to create avatars, or three-dimensional alter egos, and live in the "virtual world" of Second Life. A few researchers and autism support groups have set up virtual environments on Second Life where autistic individuals can interact with each other via their avatars.

In a talk that Milton Brignelle, a Lecturer in Psychology at the University of Derby in the U.K., gave in Second Life in June 2008, he noted that one of the unique properties of Second Life was that "it provides high levels of social interactivity but without complex linguistic and social-behavioral processing necessary for face-to-face conversations."

Brignelle notes in the same talk, "People with autism can have considerable communication difficulties in social situations and higher level language skills, such as inferring intentions or mental states from others."

Yellowlees says, "They are starting to look at whether they can teach the avatar you have in Second Life social skills, and then taking that foundation back to the real world. Autistic children like computers, they like the nonthreatening virtual environment. It's got an endless list of possibilities to basically teach social skills almost by proxy."

### Conclusion

Utilizing telemedicine applications and technology for the diagnosis and treatment of autism spectrum disorders is clearly in its infancy. In particular, the use of technology to help train individuals to treat autism spectrum patients is needed. Green says, "In my professional opinion, if it's done properly and frequently enough, supervision of ABA intervention by teleconference can increase the efficiency of service delivery and help keep the costs of treatment down, but it should be seen as an adjunct to in-person training and supervision, which needs to be provided as frequently as possible."

—Mark Terry