News and Notes
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Family Center on Technology and Disability

Emerging Technology for Autism Research and Treatment : Life on Mars

In this Issue...

Television news viewers watch as a Mars rover rumbles across the red, rock-strewn surface of the Red Planet before halting and extending a shovel to scoop Martian dirt from the planet's surface for research. A science editor then informs viewers that the handful of dirt may reveal the history of Mars, a planet which, like all planets, is in a state of constant evolution. Viewers ask themselves, "How can so much be learned from so little evidence?"

In the world of lab- and clinic-based autism research and treatment, similar questions may be asked. A traditional autism lab-centered research scenario is summed up thusly by a clinician: "It's where a child is assessed by an unfamiliar person performing unfamiliar tasks in unfamiliar surroundings using unfamiliar medical technology." In such a scenario information may be gathered from the child in a clinic or lab via electrodes placed on the body or wires taped to their skin. The child's personal information flows through wires to a computer where the data are accessed by researchers, averaged over 12 or more other children with autism who are participants in the same assessment, compared to a control group, and then published in a research article months or years later. These findings, how-

ever, may not apply to any single child in the study group. Scientists, of course, understand the statistical limitations of such an approach in which they trade conclusions about the individual for those of the group.

In addition, and importantly, according to some researchers, the unfamiliar nature of a traditional assessment scenario means that only a small sample of a participant's behavioral repertoire is used to characterize him or her. One researcher likens this process to "someone listening to a dozen bars randomly played from the middle of Beethoven's Ninth, averaging them and offering the result as a description of the symphony. The result can be rather inaccurate and, when used to target treatment, it misses the mark."

Autism research and treatment methodologies may become enhanced, however, thanks to the emergence of innovative, personalized technologies that are wearable by children with autism, and capable of transmitting usable, real-world assessment information unobtrusively on a continuous basis.

This issue of FCTD News and Notes focuses on those emerging personalized technologies and their potential benefits to children with autism, their families, teachers, and those who conduct research and develop treatments.

Matthew Goodwin, Ph.D., Speaks

An Experimental Psychologist at the Massachusetts Institute of Technology Media Laboratory, Matthew Goodwin has extensive experience using innovative technologies for behavioral assessment, including telemetric physiological monitors, accelerometry sensors, and digital video/facial recognition systems. Although he is a staunch advocate of these technologies, he sees utility in traditional approaches as well. "I don't mean to say that lab-based data and traditional survey measures are not useful. It's just that we have to be very honest about what we can and cannot conclude when using these assessment strategies. We know autism is a very heterogeneous population with much variability across people who carry the same diagnosis. Temperament is different. Personality is different. Cognitive ability is different. Sensory issues are different. Verbal ability is different. Medical issues are different. We always have to ask ourselves, how much of this uniqueness is captured and preserved when using traditional measures."

"We need to be very mindful that traditional assessment strategies are limiting, and that caution should be taken when interpreting data that arise from them. The onus is on us as researchers to devise better assessment technologies that enable us to more directly and unobtrusively gather a range of longitudinal data from individuals outside of the lab, and in the real world."

When talking about direct observational strategies, he cites the Heisenberg Principle, which states that certain pairs of physical properties, like position and momentum, are affected by virtue of observing them. In other words, he explains, "when you try to study a molecule you are in fact altering the properties of that molecule. We must be mindful that when we collect data from people in obtrusive ways we are likely influencing their behavior."

Emerging "24/7" wearable technology, he says, can help researchers unobtrusively observe children with autism intensely over time in non-lab, real-world environments. He also argues that "getting out of the lab and into the real world will enable researchers to observe behavior, and many of the factors that drive it, where it naturally occurs which should increase the ecologically validity of our findings."

Director of Clinical Research at MIT's Media Lab, Dr. Goodwin is also the Associate Director of Research at the Groden Center, a school for Autism Spectrum Disorders in Providence, Rhode Island. He serves on the Executive Board of the International Society for Autism Research, is Vice-Chairman of the Autism Speaks – Innovative Technology for Autism Research Initiative, and is an Adjunct Research Scientist at Brown University.

His interest in autism was piqued, he says, during his freshman year of college. "I met a treatment teacher in a unit for autism. She explained to me some of the strengths and weaknesses of the children she was serving. I was intrigued and went to observe. I was always interested in psychology and human development. In this group there was an unusually high percentage of children with savant-like abilities. I was fascinated by the fact that a child could have such severe disabilities in terms of social communication and restrictive, repetitive behavior on the one hand, and on the other hand possess very exceptional abilities in memory, artistic skills, and visual/spatial capabilities. These kids were not spending much time or effort on social skills. All of that brain power appeared to be channeled elsewhere. I found that to be very, very compelling."

He found himself spending more and more time with these children and immersed in reading about autism. "What I read was that these kids were consumed with themselves, that they had no sense of others, that they lack a theory of mind, and have executive dysfunction that inhibited forward planning. However, this did not jibe with my experience. I was establishing relationships with children who were very aware of who I was, who anticipated me, and – though idiosyncratic –had ways to communicate with me."

These children, he decided, "seemed to possess more potential than we gave them credit for. That sparked a philosophical and psychological fascination on my part: If we give them the opportunity to demonstrate that they are capable of more than we give them credit for, it opens up an opportunity for them to progress. That clinical component became very interesting to me."

His exposure to and interest in innovative technologies evolved, he recalls, "because I was intrigued by the effect of stress and anxiety on this population. Clinically, I saw that this was an issue for a lot of our kids who in a calm state could perform very well but in an aroused state could not."

Usually, he notes, "when determining a child's abilities we rarely consider how aroused a child is and whether their performance in the lab during that assessment period is indicative of their real-world behavior. Bringing children into a strange place, with a stranger who uses strange equipment, and who asks them to

perform novel tasks can be stressful." His self-assigned mission, he says, "was to find ways to observe children out of the lab under less stressful conditions. "I asked myself, 'How can we get a child to provide us with accurate data of their abilities without stressing them out? That took me down the technology road."

The Family Center on Technology and Disability
invites you to join our
September Online Forum
on
Inclusion and Assistive Technology

Moderated by
Dr. Christi Kasa-Hendrickson
College of Education
University of Colorado, Colorado Springs
and
Dr. Julie Causton-Theoharis
Inclusive and Special Education Program
Dept. of Teaching and Leadership
Syracuse University

September 7 – 25, 2009
http://www.fctd.info/webboard/index.php

See you online!

Personalized Assessment Technology for Autism Research and Treatment: A Non-Stop Data Flow That Could Break New Ground

An Interview with Matthew Goodwin, Ph.D., Experimental Psychologist and Director of Clinical Research, MIT Media Lab, Associate Director of Research, Groden Center.

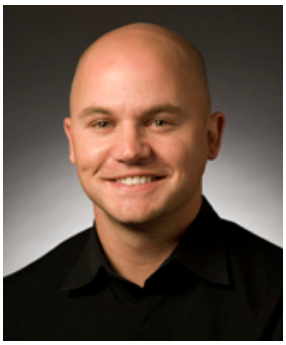
Title: *Sam: Appearances Are Deceiving*
Scene: *A classroom*
Time: *The present.*
Actors: *Sam, a non-verbal child on the autism spectrum; Sam's teacher.*
Action: *Sitting at his desk during instruction, Sam appears calm and attentive while participating in a lesson. Now it's time for him to respond but he appears reluctant. His teacher attempts gentle persuasion. Sam fails to perform the assigned task. The teacher prompts for a response. He erupts. A meltdown ensues. His teacher is frightened and seeks help restraining him.*

Not included in the script is Sam's pre-meltdown heart rate: 120 beats per minute. Despite his serene external appearance Sam has been experiencing intense internal turmoil.

Title: *Sam: The Sequel*
Scene: *A classroom.*
Time: *The near future.*
Actors: *Sam, a non-verbal child on the autism spectrum; his teacher.*
Action: *During instruction Sam appears calm. He wears a small and comfortable wristband*

fitted with miniature electronics, sensors, a radio and a coin-sized battery mounted in a flexible package. The device senses and wirelessly communicates selected internal physiological state information to Sam's teacher. Thanks to the information transmitted by the device Sam's teacher is alerted to the child's actual state: agitation, which may be caused by pain or by background noise to which he is sensitive. With the information provided by the small device Sam's teacher can work with him to determine the source of his agitation instead of persisting with the lesson.

The Technologies: Wearable Sensors



Matthew Goodwin, Ph.D.

These and other technologies are now under development. Eventually, they will benefit researchers, families, children, and teachers and will consist mainly of systems utilizing sensors that can be sewed into articles of clothing, embedded in wearable accessories, or unobtrusively mounted in the environment.

Some wearable sensors, he explains, focus on the Autonomic Nervous System and wirelessly record indices of autonomic arousal, including heart rate, heart rate variability, respiration rate, electrodermal activity, and motor movements.

"These are passive systems in the sense that an individual wearing the technology does not have to consciously provide any data; their physiological reactivity is recorded automatically in a passive way." Sensors measuring autonomic arousal, he explains, are becoming smaller and wireless and can either log the data they collect locally to a chip and/or transmit the data wirelessly to a computer, PDA, or telephone.

"We are currently integrating these sensors into common form factors like bracelets, watches, wrist bands, shirts, and other articles of clothing." Absent, he says, is the stigma of a medical-looking device where clunky electrocardiogram (ECG) electrodes hang out of a box the user wears on a hip. "The new technologies integrate with clothes and accessories the user is already wearing and phones that the user already carries."

The Technologies: Acquiring Arousal Level Data

"We can acquire useful data on the arousal level of individuals with autism who lack the ability to self-report their arousal states and whose behavior may be difficult to interpret by observers who are not well-acquainted with a specific child with autism," Dr. Goodwin declares. "We can now collect data that indicates when people are in hyper-sensitive or hypo-sensitive states, which might help us determine optimal learning opportunities for children, teachers, and parents."

If an autistic child is in a hyper-aroused state, he notes, she may be defensive to her environment. "If she is overly aroused, chances are she's shutting out sensory information. If we know this, we can help to reduce her sensory load so she can calm down, reorganize, and attend and process information better." In a hypo-aroused state a child is simi-

larly disengaged with her environment. She is lethargic and does not attend very well.

Wearable physiological sensors, Goodwin says, can be used to communicate this internal information and help others to adjust their interaction style depending on a child's arousal state. "For example, if a child is hyper-aroused, I might suggest a deep breathing exercise before proceeding with a lesson. If she's hypo-aroused, I might suggest we take a walk before proceeding with a lesson."

Interestingly, Dr. Goodwin says he has witnessed children who while wearing autonomic sensors appear behaviorally to be in a calm state. The sensors, however, tell another story. "The sensors reveal that instead of a calm state these children are in a shut-down state. Their arousal level is almost through the roof. It's not reflected in their behavior but it is reflected in their autonomic arousal."

According to Dr. Goodwin, there is little autism research that analyzes arousal, regulation, and dysregulation. "Often what you see in the research literature is that kids with ASD are either hyper-aroused or hypo-aroused, and nothing in between. It's likely because we're taking kids and averaging their responses across a group." "What is more likely, and we won't know it until we have intensive, longitudinal measurement, is that these kids are probably oscillating between hyper and hypo aroused states throughout the day. We need to understand when they're up and when they're down and try to teach them when they are in an optimal mid level where there's enough arousal to be engaged, but not so much as to be disengaged. Sensor technology could help with all of this."

Reducing the Cost of Autism via New Technologies

Emerging technologies may also reduce the overall costs associated with supporting those with autism, Dr. Goodwin says. And those costs, he points out, are high.

"Parents who have concerns about their young children often seek medical or psychological attention for help. Unfortunately, there are always going to be more people with autism than there are clinicians or diagnosticians to work with them. So resources are limited, and experts rarely make house calls. This is further compounded for families who are separated geographically from a treatment center. The travel costs are absorbed by the family."

However, he says, " we may be able to reduce this with technology in the home that enables families to share high-quality data of relevant behaviors that a clinician or diagnostician will want to access. This technology could include discrete cameras and microphones that transmit video and audio information securely over the web. With this technology, clinicians could assess and support many more families much more quickly without having to ask them to travel to the clinic."

Two-way audio and video data-capture technology, he notes, would enable clinicians to obtain situated behavioral data from children in their natural environments. "Families could share video via the web and a clinician or di-

agnostician could interact with the parents via phone and/or a web cam, creating a teleconsultation situation where experts can interact with parents at home and coach them on ways they can better support their kids."
Such equipment carries significant initial costs, he admits, "but, once the equipment is widely used, fewer clinicians would be able to service more families, which would ultimately reduce the cost of treatment and increase much needed access to care."

"Right now we bus our kids to schools and special centers. The children, however, often don't perform as well at home as at school. Cost is not the only issue. Generalizing skills that kids with autism are learning is an issue as well. Perhaps with telesupport we can transfer therapists' skills in working with the children to the parents." If parents can then employ some of the effective strategies teachers are using in a school setting, then children may become less reliant on specialized interventions.

An Intense Look at Individuals Over Time

The emerging technologies, he explains, will also enable researchers to look at children with autism as individuals, intensely over time.

Because autism is for the most part an idiopathic disorder with unknown causes, its various manifestations among individual children should not be washed away in the assessment process by taking group averages. Instead, he emphasizes, those individual differences ought to be studied and preserved, especially when a child is moving into treatment. Therefore, he adds, "what is generally good for a large group of people based on an average is not necessarily good for one given individual who does not fit the normal curve. If a major research goal is to understand and help any one given individual then we should study that one given individual. The new technologies will help us achieve that goal."

He argues for an inductive approach in which a single-case design analysis closely examines individuals over prolonged periods of time. "We then work inductively by doing direct replication across multiple individuals to determine if individual findings generalize across a larger group of people. This is in stark contrast to the group-level analysis so prevalent in behavioral and medical sciences that derive generalizable findings from average responses."

He cautions that he considers neither the group-level nor the individual-level design superior, "but in a behavior science they should be equally represented. The reality is that this 50-50 balance does not yet exist. We have an overwhelming majority of group-level approaches." The emerging technologies would likely change that balance, he insists.

Life on Mars: When Will the Measurement Balance Change?

When will researchers and clinicians begin to move away from attempting to glean useful results from their profession's equivalent of a shovelful of Martian dirt and move toward the more precise assessment available from emerging technologies? "Methodologists are debating this issue now, along with statisti-

cians and clinicians. Many are insisting that we can be doing much more with innovative technologies sooner rather than later."

"We're on the envelope. We may not witness a major change for another decade but that does not mean that these new technologies are not worth aggressively pursuing. Social scientists and behavioral scientists are going to have to start collaborating in earnest with engineers and computer scientists who can help us telemetrically measure the phenomena we're interested in."

He hopes that accelerating advances in technology will also result in better data storage, improved wireless communication, and longer battery life, and that the Internet continues to be explored as a vehicle for uploading, sharing, and accessing information.

He cites another factor to using this technology: price. When new technology is first rolled out, he says, scarcity makes it expensive. "One issue we'll have, and one that we will have to consider more closely, is finding industry partners who are willing to produce these technologies in very high volume so we can drive the cost down."

At MIT, he notes, "we can create all sorts of devices that we hope will enrich the research process and improve quality of life for persons with autism. The reality, however, is that we don't have time to fully customize these devices, to market them, or to support them once they are deployed. What's needed is a commercial entity or non-profit organization to do that."

Admittedly, he concedes, this is a difficult era for forging such partnerships, but opportunity exists. "There are a growing number of commercial entities who have more capital than academic and government organizations to fund public health efforts." He uses Microsoft and Intel as examples, "Traditionally these companies were only interested in selling electronic components or software. Major resources in these companies are now devoted to promoting health, education, and accessibility to technology."

The Technologies: From Customized to Universal and Back

According to Dr. Goodwin, autism-specific applications could eventually be used more universally. Autism, he contends, "is our impetus for development because there is a great public health need. But these technologies could become ubiquitous and employed by individuals for whom they were not initially designed and developed. The most famous examples are the telephone and typewriter, which were initially developed for the deaf and the blind. These are ubiquitous technologies that we all use every day."

Dr. Goodwin continues, "We're aiming to help vulnerable populations first because we can make the argument that those populations need these technologies the most, but we won't be myopic to the point where we can't see that many others who the technology was not developed for could benefit from its use."
Barriers: the Onus Is on the Technologies

Cost aside, according to Dr. Goodwin, the

major barrier to technology use is proof of the new technologies' utility. "The onus should be on researchers and clinicians to demonstrate utility, not just technologists."

From a design standpoint, he notes, many products with commercial potential end with a proof of concept. "For us, proof of concept is our starting point. We need to develop a technology in the lab, deploy it in the real-world, evaluate it, and reiterate until we get it right. We need to learn what works and doesn't work. He also adds, "As with any scientific process we need to conduct due diligence by systematically comparing the technology to a placebo or other control. Because it's technology there is a novelty factor, and everyone wants it to work. We nevertheless need data to prove that what we've developed is an improvement over no technology or sham technology. It's vital that there is reliability and validity associated with our technological approach."

"Once we've demonstrated the new technology's effectiveness – and it ought to be equivalent to or improve upon a gold-standard measure – we have to determine who will pay for it. Will the family pay for it, will the school district pay, will insurance pay? Another question is can enough units of the technology be produced to drive the per-unit cost down?

Future Scenarios: Links to Centralized Web-Based Databases

Dr. Goodwin provides a snapshot of the future for innovative personalized autism technologies. "It may be a utopian notion but I'd hope that the technologies would be sufficiently low-cost that universal ownership could be achieved in the autism community."

The technologies, he continues, would be linked to centralized web-based databases where individuals can upload their information and interact with others who are uploading their information. "The technologies would build a community of users who are interested in sharing with and learning from others. This could connect those who would not normally be connected, to great effect."

The community-user concept, he adds, would also enhance scientific progress "in the sense that it increases the number of people who are submitting data."

Dr. Goodwin further explains, "if individuals opt to share de-identified data about their response to various treatments, the issues they identify with, health characteristics, diet, etc., they will have created a powerful centralized database for researchers to explore."

Systems integration, he says, is another possibility as these technologies evolve. "For example, video capture in the home – augmented by autonomic and movement sensors embedded in clothing and toys – can help researchers and clinicians track a child's relevant behaviors and physiology via a constant transmission of real-time, real-world information."

Such systems integration is especially valuable, he explains, "because much of the video we receive from parents consists of selective archives, such as birthdays or when the child is doing well. Rarely do parents record their child having a tantrum or a breakdown. Even more rare do their videos reveal what led

up to a breakdown."

He adds: "With technology currently available, we could semi-automate that process to produce a video that was automatically annotated when a clinically relevant movement, physiological response, or object manipulation was detected by the sensors." This capability could help many parents and clinicians who lack the time, expertise, or resources to capture and review detailed information on events leading up to a given behavior and the consequences of that behavior." A plus, he notes, is that semi-automated annotation could make searching records for relevant information much faster."

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User-Designed Collaborative Research

Dr. Goodwin claims that autistic children and their families have significant insight to contribute to research and ought to be a reliable source of information to the technological, medical, and scientific communities. New technologies, he asserts, may enable them to more easily contribute that insight. "Parents interact with their kids more than any professional does. They view their children in a wider range of environments. They are better at predicting how their children will respond. I think that the parents and the children themselves, if they are capable of reporting, are a much better source of information for us about what is actually occurring in the real world, and what can help them."

"We should include their information as an added data stream with which we can try to understand the strengths and weaknesses of these kids. If we are going to be creating personalized technology we should invite our end-users into the research and development process."

Dr. Goodwin regards the children's insight as an aspect of user-designed collaborative research. "We'll create something we believe will be useful and we'll give it to a child or his parents to use. We'll ask them how they think the device is working, what they like and dislike and how the device can be improved. Based on their feedback we can reiterate and change the device accordingly. Their feedback as end-users is much more effective than if we tried to imagine what might work." Such arrangements, he remarks, serve the same purpose as focus groups in the business world, an unusual approach in academia, he says. "In academia we often think we know better than consumers about what they need and want. We could be a little more humble."

The user-designed approach, he believes, will result in significantly compressed time frames, and higher success rates, for new technologies. "If we get enough participants in a focus group or get the technology in the hands of enough users, we'll see that there are commonalities across users. As a result we may devise new general features or functions that perhaps had not been considered which might be very useful to the autism community." At the same time, he notes, "We're also trying to make the hardware and software customizable and open source so that users can customize it themselves or suggest a dif-

ferent customized iteration to us. We don't assume by default that one size will fit all."

This approach, he notes, is far superior to the way traditional research is conducted and communicated. "The new approach says that you who have this condition or you who live with someone who has this condition can be empowered to become part of this process."

He predicts that "by enabling this two-way communication between technology developers and families we will see much more willingness among the user community to participate in the process, which could result in faster progress. Those individuals talk to others who have similar issues, which could also facilitate information dissemination through distribution channels that are more efficient than professional conferences and journal articles that few have access to."

"I'm an Experimental Psychologist"

Dr. Goodwin emphasizes, "I'm an Experimental Psychologist with clinical interests. Therefore, I'm always very interested in assuring that our tools are as good if not better than those that currently exist. I would never ask that technology supplant a well-intentioned parent or teacher, educator, or clinician. What we create are but added tools, not replacements for the crucial human element. Furthermore, we're often interacting with parents who are desperate for help, who have limited resources, time, and emotional reserves. I don't want to flash a new fad device that has not yet been shown to be efficacious and have parents use it at the expense of other useful supports and proven educational strategies."

Ideally, he regards the new technologies as temporary. "From a clinical standpoint, the optimal outcome for a child is to use technology for a limited time until he or she achieves a learning goal and then phase the technology out. We don't want to make anyone dependent on yet another device." However, he adds, "there may be some individuals who are always going to require that extra aid. In that case we'd see this as assistive technology."

Decentralizing Research via Community Involvement

After a study, Dr. Goodwin says, researchers rarely contact a child's parents to share the results. That should change, he declares. Parents should remain in and contribute to the information loop; the Internet could help with that.

Using the web, "parents could access their child's data and write in to contribute their insights and their own interpretation of the findings. Traditionally, we keep all this data locked up and assume that the academics know how to deal with it best. I'm not saying that every parent possesses the requisite skills to interpret the data the same way a researcher might, but they may have alternative interpretations or other ideas that we failed to consider that are data-based."

The ultimate goal, he emphasizes, "is to decentralize research, to make the process more utilitarian and more transparent."

Caveat: "This Is Exploratory"

Dr. Goodwin emphasizes two caveats he associates with the development of personalized autism technologies: 1) All development efforts are exploratory until proven; 2) Future use of these technologies will likely require new legal and moral discussions in terms of ethics, privacy, and security.

"All our development activities so far have been exploratory," he points out. "Before making any claims about their efficacy we need to subject them to rigorous scientific evaluation methods widely used in the behavioral and medical sciences. We think we have good ideas that are worth pursuing, but it will require time and study before we can say confidentially that our technology can do what we think it can do."

About his second concern, he comments, "With the emergence of these technologies we are entering areas of ethics, privacy, and security that may be unprecedented. We don't have law yet for this. We have laws about closed-circuit television. Every state has a law about one-party or two-party consent for audio recording. Soon parents of autistic children may be taking video of their kids in their homes and physiological and other highly sensitive medical information may be transmitted. How is that information protected so an individual identity is not revealed, so, for example, an insurance company does not learn that a child who participated in the study has an arrhythmia and refuses to provide insurance, or that information is taken out of context and is erroneously interpreted as an abusive situation?

"This is a challenge to all of us. We need to think carefully about what data is being collected, who has access, and define how it will be used. We need to use secure systems that are HIPPA (Health Insurance Portability and Accountability Act) and FERPA (Family Education Rights and Privacy Act) compliant when we send information over the web. Despite evidence to the contrary, many people assume that the Internet and email are secure, but they are not.

"We also need to accurately communicate how these technologies can threaten privacy. I would never propose the use of these technologies in a Big Brother sense. Users ought to always be afforded the opportunity to opt in or opt out, with no penalties associated with their decision."

Importantly, he adds, "I'd never espouse the use of any of this technology to an unwilling participant. This is about empowering people, not spying."

RESOURCES

Articles

Innovative Technology: The Future of Personalized Autism Research and Treatment
By Matthew S. Goodwin, ABD, Rosalind W. Picard, Ph.D.
Autism Advocate (2008)
Accelerating developments in technology can be shaped to create a better future for children on the autism spectrum, predicts the author, a director of clinical research at MIT's Media Lab. Wearable technology now emerging, he notes, will provide more assistance to children while also producing more accurate readings for researchers to whom information generated by the technology flows.

Mr. Goodwin points out that until now children undergoing assessment in a lab environment, due to technology limitations, have been evaluated based only on a tiny sample of their behavioral repertoire. This methodology, he points out, can be likened to someone listening to a few bars randomly played from the middle of Beethoven's Ninth Symphony, averaging them and offering the result as a description of the symphony. This approach, he adds, can produce inaccurate results which can result in mistargeted treatment.

Goodwin adds: "At MIT we say, 'If you've met one person with autism, then you've met one person with autism.' While we teach standard diagnostic criteria and know many of the difficulties that are commonly shared across the spectrum, we also recognize that two people with the same age, gender, IQ, medication use and diagnosis may respond differently to treatment. In this day when the computational power of the lunar mission can fit neatly into your pocket, when wireless technology is pervasive, and when individuals can easily upload the videos of their life for the pleasure of people around the globe, there is no reason to restrict research to the old paradigm of lab observations that use snapshot measurement technology and average the findings across a group." Increasingly, he concludes, technology can help address these measurement problems and advance personalized treatment, enabling the collection of unprecedented ultra-dense long-term data.
http://affect.media.mit.edu/pdfs/08.picard+goodwin-Advocate-printed.pdf

The Truth about Autism: Scientists Reconsider What They THINK They Know
By David Wolman
Wired Magazine (2008)
This online article describes a video posted on YouTube by a young autistic woman. The video is embedded in the article. The young woman is part of a movement among individuals with autism and some scientists who believe autism is the result of a brain that develops and functions differently. Via an interview with the young woman, the author asserts that those who are autistic are not mentally retarded and that assistive technology, especially text-to-speech software in the case of the woman interviewed, provide a truer gauge of their real abilities.
http://www.wired.com/medtech/health/magazine/16-03/ff_autism/?currentPage=1

"Kaspar" the Robot Helps Autistic Kids Play
By John Blau
Computerworld, Inc. (2007)
The article features a $4.3 million robot designed to help children on the autism spectrum develop stronger play skills. Children with autism spectrum disorders have difficulty recognizing gestures, facial movement and other social nuances and interpreting them while playing or socializing. Funded by the European Union and housed at the University of Herefordshire in the UK, the project investigates how robotic toys can become social mediators for human contact, aiding autistic children in their interactions with other children and adults. Kaspar, an acronym for Kinesics and Synchronization in Personal Assistant Robotics, performs basic functions such as smiling or waving, which appeal to autistic children because the actions are simple and predictable. Research continues until October 2009.
http://www.computerworld.com/s/article/9025258/_Kaspar_the_robot_helps_autistic_kids_play

Enhancing and Accelerating the Pace of Autism Research and Treatment: the Promise of Developing Innovative Technology
By Matthew S. Goodwin
Focus on Autism and Other Developmental Disabilities, Hammill Institute on Disabilities (June 2008)
The author highlights emerging autism-related technologies, detailing the ways these technologies can be employed to enhance and accelerate the pace of research and treatment. He cites Internet, audio and video recorders, electronic sensing technology, computer architecture and software, virtual reality and robotics as beneficial to children with autism, their families and the professional who support them.
http://www.autismspeaks.org/docs/sciencedocs/ita/In_Focus_Innovative_Technology_for_Autism_Goodwin_2008.pdf

Assistive Technology for Children with Autism
By Susan Stokes
CESA 7 (2004)
This brief article discusses how various modes of technology (including augmentative communication systems), can be used for children with autism to increase or improve their:
- Overall understanding of their environment;
- Expressive communication skills;
- Social interaction skills;
- Attention skills;
- Motivation skills;
- Organization skills;
- Academic skills;
- Self help skills;
- Overall independent daily functioning skills.

Ms. Stokes describes research-based low-, mid- and high-tech strategies.
http://www.specialed.us/autism/assist/asst10.htm

Using Video Skills to Teach Social Skills to Secondary Students with Autism
By Lynn D. Parsons
Teaching Exceptional Children; Council for Exceptional Children (2006)
After considering the literature on the use of video to model behavior for young children with autism, Ms. Parsons, a teacher, created

a social skills program for secondary students by incorporating parent observations, peer to peer surveys, and students' self-reflective surveys with videotaped social skills role-play. Ms. Parsons presents the results of her research and discusses the steps necessary to build and implement a similar program. Sample permission and survey forms are included. Ms. Parsons cautions readers to become familiar with video technology before using it with students. She outlines the methodology, data collection and three-phase case studies that underpin this model program.
http://www.cec.sped.org/AM/Template.cfm?Section=Home&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=7743

Virtual World Teaches Real World Skills
By Tom Loftus
MSNBC (2005)
Mr. Loftus explains virtual technology's potential to teach social skills to individuals with neurological disorders, including autism and Asperger's syndrome. This virtual world, an island called Brigadoon, is a 3D virtual environment created by gaming technology. Users create their own avatars, build digital houses and seek out friends in this virtual community. They are free to create an interactive life through technology that may otherwise have been difficult to achieve.
http://www.msnbc.msn.com/id/7012645/

Education and Learning Aids
Exceptional Parent (2007)
Part of the Exceptional Parent 2007 Guide to Assistive Technology, this article describes software designed to enable children with cognitive impairments become more independent learners. The DTTrainer was developed by the father of a child with autism to help the child comprehend concepts such as categorization, matching, reasoning, decision-making, problem-solving, memory skills and word prediction. The trainer is appropriate for children whose developmental age range is 2-9 years. The software serves as a virtual one-to-one tutor and can be adjusted to meet a child's unique needs.
http://www.dttrainer.com/files/docs/exceptionalparentDTTArticle.pdf

The Future Is Now: Where Today's Assistive Technologies Will Take Learners Tomorrow
By Pamela Wheaton Shorr
Cable in the Classroom (2005)
Ms. Shorr examines the innovative use by classroom teachers of existing AT in three areas: wearable technology; the use of brain waves to reprogram behavior; virtual reality. In the first example, a child with autism gains the ability to communicate by wearing a device designed for telephone-line technicians and other field workers. In the second example, a plan for reprogramming behavior grows out of a technique used by NASA to help pilots maintain their concentration during long flights. This method evolved into the development of Play Attention by Peter Freer, in which is a modified bicycle helmet tracks brain waves in children with attention disorders. The third area, virtual reality, provides children with limited mobility a feeling of freedom previously been denied to them.
http://www.ciconline.org/c/document_library/get_file?folderId=30&name=T-Win05-FutureIsNow.pdf

Websites

RERC on Communication Enhancement
Rehabilitation Engineering Research Center
This RERC website assists users of AAC technologies. The RERC conducts research, sponsors/conducts conferences, develops technology, provides technical assistance, conducts training seminars, facilitates technology transfer and evaluates technology.
http://www.aac-rerc.com

The Autism Acceptance Project
Estee Klar-Woolfond
The Autism Acceptance Project works to promote acceptance of and accommodations for autistic people in society. The website celebrates rather than medicalizes or stigmatizes those who have autism. The focus is on artistic production that is viewable via the site's online gallery.
http://www.taaproject.com/

ChildNet.TV
Dan Marino Foundation
Created in 2003, ChildNet.tv is a 24/7, interactive, Internet channel focusing on autism and neurological disorders and specializing in on-demand video that includes new releases, lectures, family stories and therapy presentations.
http://www.childnett.tv/

Educational Programs

Max and Friends
Launch into Learning (2007)
Max and Friends is a multimedia educational program designed for young children with autism, but is also useful with children and adults experiencing developmental delays. The website claims that its content is particularly useful for autistic children because content is based on Applied Behavioral Analysis (ABA), a methodology that has been successfully utilized to produce educational programming. The site's books and DVDs incorporate ABA training methods with television-type viewing, breaking down each task to be learned into components that are then practiced in various applications. To order this program, contact:
Launch into Learning
P.O. Box 669
Greenlawn, NY 11740
http://www.launchintolearning.org/index.php?focus=max

KNOWLEDGE NETWORK MEMBERS

Autism Speaks – Innovative Technology for Autism Initiative (ITA)

ITA aims to accelerate the pace of autism research and treatment by promoting collaboration among technologists, designers, engineers, researchers, clinicians, educators, individuals with autism and their families. Via an interdisciplinary approach the organization adapts and encourages the use of available technologies and spurs the development of new technologies to facilitate applied autism research. For more information, contact:

Autism Speaks/ITA
2 Park Avenue, 11th floor
New York, NY 10016
Phone: (212) 252-8584
Fax: (212) 252-8676
http://www.autismspeaks.org/science/research/initiatives/ita_initiative.php

MIT Media Lab

Affiliated with the Massachusetts Institute of Technology (MIT), the lab applies an unorthodox research approach to envision the impact of transformative emerging technologies on daily life. Unconstrained by traditional disciplines, lab designers, engineers, artists and scientists collaborate via 30 research groups conducting more than 400 projects, ranging from neuroengineering to children's learning styles. Now in its 25th year, the lab focuses on human adaptability projects that include finding ways to treat conditions such as autism, Alzheimer's disease and depression plus the development of social robots capable of monitoring the health of children and the elderly. Also in the development stage are smart prostheses that can mimic, or exceed, the capabilities of biological limbs. For additional information, contact:

The Media Laboratory
Massachusetts Institute of Technology
Building E15
77 Massachusetts Avenue
Cambridge, MA 02139-4307
Phone: (617) 253-5960
Fax: (617) 258-6264 .
http://www.media.mit.edu/

Animated Speech Corporation (ASC)

ASC is a private company whose software is designed to give speech pathologists, educators and parents who work with autistic children and children experiencing developmental delays a tool to build comprehension and vocabulary skills. The company's software is a computer program that converts typewritten words into a computer-generated talking head whose facial muscles, jaw, and tongue move with unprecedented accuracy. For further information, contact:

Animated Speech Corporation
2261 Market Street #293
San Francisco, CA 94114
Phone: (800) 701-9025 (toll free)
Contact: Dan Feshbach
Email: info@animatedSpeech.com
http://www.animatedspeech.com/

Autism Program at Yale: Yale Developmental Disabilities Clinic

Staffed by clinicians and scholars and housed in Yale's Child Study Center, this interdisciplinary program provides comprehensive clinical services to children with autism and their families. The program involves infants, toddlers, pre-school and school-age children and young adults age 18-21. It integrates professionals from clinical psychology, neuropsychology and neuroimaging, child psychiatry, speech-language pathology, social work, genetics and biological sciences as well as psychopharmacology and psychiatric nursing. The program was recently recognized as an Autism Center of Excellence by the National Institutes of Health. Autism and development research studies include:

- The Simons Simplex Collection
- The Simons Baby-Sibs Project of Social Neuroscience in Infancy
- Mechanisms of Social Engagement in Autism Spectrum Disorders
- The Yale Sibling Project
- Studies of Prosody in Individuals with Autism Spectrum Disorders
- Study of Speech Treatment for Young Children with Autism Spectrum Disorders Who Do Not Talk Yet

For additional information, contact:
The Autism Program at Yale
Child Study Center
230 South Frontage Road
New Haven, CT 06520-7900
Phone: (203) 785-2540
http://childstudycenter.yale.edu/autism/

Organization for Autism Research (OAR)

OAR employs science-based research to provide answers, practical alternatives and solutions to parents, families, individuals with autism, teachers and caregivers. The organization has established a Scientific Council comprised of leading authorities in applied autism research and builds alliances with professional associations of clinicians, educators, special educators, and pediatricians, in order to disseminate as much information as possible. OAR awareness efforts include business partnerships with corporations. For more information, contact:
Organization for Autism Research
2000 North 14th Street, Suite 480
Arlington, VA 22201
Phone: (703) 243-9710
Contact: Michael Maloney, Executive Director
Email: OAR@researchautism.org
http://www.researchautism.org/

Autism Research Institute (ARI)

ARI conducts and fosters autism research and disseminates research findings to parents and others worldwide. The organization's data bank contains more than 40,000 detailed case histories of autistic children from over 60 nations. ARI publishes the Autism Research Review International, a quarterly newsletter covering biomedical and educational advances in autism research. Since 1995 ARI has convened recurring meetings for selected physicians, researchers

and scientists. ARI-funded research topics include the possible links between autism and environmental toxins and thimerosal in vaccines. For further information, contact:
Autism Research Institute
4182 Adams Avenue
San Diego, CA 92116
Phone: (866) 366-3361 (toll free)
Fax: (619) 563-6840
http://www.autism.com/index.asp

Center for the Study of Autism

The center provides information about autism to parents and professionals, and conducts research on the efficacy of therapeutic interventions. Much of the organization's research is conducted in collaboration with the Autism Research Institute in San Diego, California. For more information, contact:
Center for the Study of Autism
P.O. Box 4538
Salem, OR 97302
Phone: (503) 363-9110
Email: sait@teleport.com
http://www.autism.org

Southwest Autism Research and Resource Center (SARRC)

A community-based organization, SARRC undertakes self-directed autism research, serves as a satellite site for national and international projects and provides timely information, training and assistance to families and professionals regarding autism and related disorders. Through integrative research, educational outreach, model programs and collaborative initiatives, the center facilitates best practices for early intervention and long-term care. SAARC's research team is led by Christopher Smith, Ph.D., an experimental psychologist with expertise in the diagnosis of autism for genetic research. Dr. Smith is developing a large-scale autism family study to aid in the identification of genes that are associated with autism. For additional information, contact:
Southwest Autism Research and Resource Center
300 North 18th Street
Phoenix, AZ 85006
Phone: (602) 340-8717
Fax: (602) 340-8720
Contact: Emily Chappell, Executive Director
Email: sarrc@autismcenter.org
http://www.autismcenter.org/

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Newslettter Editor: Thomas H. Allen
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Family Center on Technology and Disability
1825 Connecticut Avenue, NW
Washington, DC 20009
Phone 202-884-8068 Fax (202) 884-8441
fctd@aed.org www.fctd.info