NLM FAMILY FOUNDATION

HARNESSING TECHNOLOGY TO IMPROVE THE LIVES OF PEOPLE WITH AUTISM

July 23, 2014

Welcoming Remarks

Clarence Schutt, PhD
Director, NLM Family Foundation

Susan L. Parish, PhD, MSW
Nancy Lurie Marks Professor of Disability Policy
Director, Lurie Institute for Disability Policy
Brandeis University

Personalizing Autism Technology

Rosalind Picard, ScD, FIEEE
Professor, MIT Media Laboratory
Director of Affective Computing Research
Co-founder Empatica, Inc.
Co-founder Affectiva, Inc.

Transforming Research, Diagnosis, and Treatment Effectiveness in ASD: Towards Better Social Interactions

Elizabeth Torres, PhD
Assistant Professor
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Rutgers, The State University of New Jersey

E*mployment for Adults with Autism*

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Director, Institute for Community Inclusion
University of Massachusetts, Boston

Screening of the documentary, "I Want to Say," produced by Goodby Silverstein & Partners and production company Bodega in partnership with Autism Speaks, that tells the story of how assistive technology can help to unlock the voices of children with autism through technology.

Realizing the Potential of the iPad in Supporting the Communication and Inclusion of People with Autism: Promise, Practice and Pitfalls

Christine Ashby, PhD
Assistant Professor
Teaching and Leadership Department of the School of Education
Syracuse University
Director, Institute on Communication and Inclusion

Developing Innovative Technologies to Enhance Research and Practice with Individuals on the Autism Spectrum: A Computational Behavioral Science Approach

Matt Goodwin, PhD
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Welcoming Remarks

Clarence Schutt, PhD
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Susan L. Parish, PhD, MSW
Nancy Lurie Marks Professor of Disability Policy
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Brandeis University (Waltham, MA)

Susan Parish, Ph.D., Nancy Lurie Marks Professor of Disability Policy and Director of the Lurie Institute for Disability Policy at Brandeis University, and Clarence Schutt, Ph.D., Director of the NLM Family Foundation, welcomed participants to the 4th annual summer symposium, “Harnessing Technology to Improve the Lives of People with Autism,” co-sponsored on July 23, 2014 by the NLM Family Foundation and the Lurie Institute for Disability Policy at the Heller School for Social Policy and Management at Brandeis University (Waltham, MA).

The purpose of this meeting was to discuss the potential of adaptive technology to open up for persons with autism new avenues for acquiring knowledge, improving social communication, and achieving a greater degree of independence and control over their lives. Topics included an introduction to personal health informatics and personalizing autism technology, examination of the use of avatars to engage individuals in learning how to control intended movements and speech production, employment opportunities and vocational training programs for those with ASD, consideration of the potential of the iPad and other mobile technologies to support communication and inclusion, and a computational behavioral science approach to developing innovative technologies to enhance research and practice with individuals on the spectrum.

Co-chaired by Clarence Schutt, and Susan Parish, Ph.D., the workshop included presentations by Christine Ashby, Ph.D. (Assistant Professor, Education, Director of the Institute on Communication and Inclusion, Syracuse University, Syracuse, NY), Matthew Goodwin, Ph.D. (Assistant Professor, Health Sciences, Northeastern University, Boston, MA), William Kiernan, Ph.D. (Director of the Institute for Community Inclusion; Dean and Research Professor at the School of Global Inclusion and Social Development, UMass Boston, Boston, MA), Rosalind Picard, Sc.D. (Professor of Media Arts and Sciences, MIT Media Lab, Cambridge, MA), and Elizabeth Torres, Ph.D. (Assistant Professor, Cognitive Psychology & Computational Neuroscience, Rutgers University, New Brunswick, NJ).

The presentations all focused around the general theme of harnessing technology to improve the lives of people with autism and related disabilities, particularly those with severe communication problems and challenges accessing emerging technologies. In his welcoming remarks, Dr. Schutt encouraged the group to think critically about some of the subtleties and details of each of the presentation titles.

Dr. Schutt urged the audience to consider whether the latest technologies might be drawing people with autism and related disabilities closer into our so-called ‘normal’, optimally-connected world, or whether it might be pushing them further out. Technology has the potential to make our world more inclusive to those with disabilities, but it also has the potential to create even more barriers for this population.

To organize their thinking, Dr. Schutt asked workshop participants to consider “the fast and the slow” (the fast being machines and the slow being human beings). While the machine has the obvious advantage of being much faster, we have to consider some key questions such as:

Who do you want to care for your family member with autism – a machine or an actual person? What do we lose when we replace humans with machines? What do you lose when you don’t have a person carefully monitoring every facial expression, change in pulse, eye contact, etc.?

As technology advances, the fast (machine) is getting cheaper and cheaper to access, which is a serious consideration for lawmakers and service providers with budgets to adhere to. We must consider the tension between the fast and the slow, the cheap and the expensive, and the automated and the human touch.

Personalizing Autism Technology

Rosalind Picard, ScD, FIEEE
Professor, MIT Media Laboratory (Cambridge, MA)
Director of Affective Computing Research
Co-founder Empatica, Inc.
Co-founder Affectiva, Inc.

Rosalind W. Picard, ScD, FIEEE is the founder and director of the Affective Computing Research Group at the MIT Media Laboratory, co-founder of Affectiva, Inc., which delivers technology to help measure and communicate emotion, and co-founder and Chief Scientist of Empatica, Inc., which improves lives with clinical quality wearable sensors and analytics. Picard is the author of over two hundred peer-reviewed scientific articles in multidimensional signal modeling, computer vision, pattern recognition, machine learning, and human-computer interaction. She is known internationally for her book, Affective Computing, which initiated a field by that name. She is a graduate with highest honors from the Georgia Institute of Technology and holds Masters and Doctorate degrees in Electrical Engineering and Computer Science from MIT. Picard is an active inventor and her group's inventions have been twice named to "top ten" lists, including the New York Times Magazine's Best Ideas of 2006 for their Social Cue Reader, used in autism, and 2011's Popular Science Top Ten Inventions for a Mirror that Monitors Vital Signs.

When Dr. Picard first entered the field of autism, she was challenged to try to improve the lives of non-speaking individuals with autism. She shared a case study of a 26-year-old man with autism who would melt down when somebody coughed near him. What made this case challenging was that the man did not use computers or technology.

Many individuals with disabilities are hesitant to use technology because in previous experiences, technology has been used to judge, measure, or analyze them. This is an important consideration for researchers introducing new technology into the daily lives of those with autism. How can we give people rewarding and positive experiences with technology? In this particular case, Dr. Picard's initial thought was to increase his exposure to coughing sounds through a desensitization process using Scratch tools.

Developed by the MIT Media Lab, and designed for ages 8 to 16, but used by all ages Scratch, is a free, publicly available programming language and online community where users can create interactive stories, games, and animations, and share creations with others worldwide. While designing and programming Scratch projects, people learn to think creatively, reason systematically, and work collaboratively.

In the aforementioned case study, Dr. Picard's team built a Scratch game around the man's special interest which was babies. Whenever he heard a cough sound, he was rewarded with a baby picture. This worked temporarily, but it was not effective enough to sustain his behavior over the long-term. His family later divulged that what he really enjoys is seeing pictures of babies being born. When Dr. Picard's team coupled this fascination with therapy, he engaged with the computer for multiple sessions per week and no longer showed sensitivity to cough sounds. Years later, he maintains the ability to tolerate cough sounds and now enjoys using computers and tablets.

Difficulty with maintaining eye contact is a common social anxiety amongst people with autism. Dr. Picard shared excerpts from Amanda Baggs' blog in which she explains her anxiety over eyeballs. Dr. Picard's group has developed technology to monitor and measure sympathetic fight or flight response, and confirmed Ms. Baggs' anxieties with data collected when they made eye contact with her. Ms. Baggs suggested that they customize a program that would gradually desensitize her to eyeballs, starting with robots, a special interest area, with small eyes and gradually increasing eyeball size.

To desensitize individuals with autism to eyeballs, Micah Eckhardt in Dr. Picard's lab took pictures of eyeballs in the community, particularly eyeballs of friends and family members. These pictures were made into tangible puzzle pieces connected to a computer game so that the activity would be fun and engaging.

In collaboration with Matt Goodwin and the Groden Center (Providence, RI), Dr. Picard did a controlled study of people on the spectrum on pre-test and post-test measures of improvements in gaze fixation and looking at faces after using their tangible puzzle game. Using eye-tracking technology, they saw improvements in subjects' willingness to look at eyes.

To harness the intrinsic motivations, interests, and needs of individuals in a way that will allow them to succeed with technology, full customization is crucial. Given the success of these custom-built pieces of technology, Dr. Picard's group was approached by others who wanted access to similar technology. It is a significant challenge for academics to figure out a way to scale and distribute their technology. How can the technology be successfully scaled and distributed despite constantly changing technology and astronomical start-up costs?

In attempts to respond to this interest in creating customizable programs that incorporate stories, games, sounds, images, and interactive touch, Dr. Picard's group began brainstorming a program that would be user-friendly and more easily manipulated than Scratch. Her hope was to create a program that would be free for users, easy to edit, share, and modify, and run on iOS or Android.

The resulting program, Storyscape.io, now available in the Google store, was created as a tool to meet the challenging language learning needs of children with autism. It was created to be the first truly open and customizable platform for creating animated, interactive storybooks that can interact with the physical world. With this program, a user can make an account online, create a story, and download it to a phone or tablet for free. It allows users to create stories as easily as they can create PowerPoint presentations. But it does much more than PowerPoint or Keynote: Users can add sounds and voices and make things respond to touch or air being blown on them. The idea was to motivate children with whatever special interests they have and reward them when they produce sounds and type words.

Dr. Picard showed video clips of StoryScape being used in a pilot study in schools to demonstrate the success of using the program with children on the spectrum. In their scientific evaluation of StoryScape sessions, prompts, time on task, laughter, facial expressions, engagement, and number of words typed are examined. The pilot study shows promising results, especially with engagement and increased use of vocalizations, largely because users are able to create stories about things that matter to them. Future studies have been planned to further test StoryScape and story co-creation.

Sensory issues are a major concern for those on the spectrum. The skin conductance (or electrodermal) response is the phenomenon that the skin momentarily becomes a better conductor of electricity in the presence of physiologically-arousing external or internal stimuli. Dr. Picard has developed a small, wireless skin conductance sensor that allows researchers to measure electrodermal activity (EDA) resulting in a better understanding of physiological arousal and individual responses to specific stimuli.

Cognitive, emotional, and physical stressors can make the electrodermal signal rise. Activities or stimuli which might create a calming trend for one person might distress another so it is crucial to customize programs to the specific needs and interests of the individual.

Dr. Picard's work on emotion measurement helps researchers understand what triggers might be causing autonomic stress and helps individuals on the spectrum cope better emotionally. She has focused primarily on measuring the sympathetic nervous system response, or fight-or-flight response, a signal captured by the EDA measure on the surface of the skin. Dr. Picard and colleagues also measure parasympathetic response. The parasympathetic nervous system slows the heart, and they use photoplethysmogram (PPG) to measure heart rate and heart rate variability.

Both the sympathetic nervous system response and parasympathetic response can be measured using the wearable autonomic wristband sensors pioneered by Picard and her Media Lab colleagues. The main pioneering contribution that Dr. Picard has made is to make sensors that were comfortably wearable, yet still able to capture and transmit high quality data, so that their response can be measured in natural environments outside of the laboratory. The first commercial version was known as the Q sensor. A new company that Picard co-founded is making an improved version that also provides PPG, the Empatica E4.

Dr. Picard provided examples of a real-time data plot of EDA. She also showed the sympathetic nervous system response of an MIT student over seven days as he watched TV, slept, worked in the laboratory, and went to class. Surprisingly, the data show a high level of activation and arousal during sleep. In fact, the highest peak activation and arousal periods happened during sleep on most days.

As a result of this fascinating sleep data, Dr. Picard has partnered with Chuck Czeisler and Bob Stickgold, two of the top sleep researchers in Boston. They have conducted and compared measurements of EDA, EEG, concurrent polysomnography, and actigraphy to determine what those peaks in activation and arousal during sleep might mean. The one thing that seems to be significant and predictive is an association between patterns in and timing of those peaks and the architecture of sleep and learning on a task. In fact, the prediction of improvement in learning (post-sleep vs. pre-sleep test performance) is more significant using the skin conductance patterns than using EEG-based and polysomnography features.

In Stickgold's classic paper, he had found that the percent of slow wave in the first quadrant of a good night's (7-8 hours) sleep and the percent of REM in the fourth quadrant of sleep were most predictive of improvement in a learning task. What is exciting is that the wrist sensor is even better than EEG in determining who improved most on a learning task after sleep. This may be because the wrist sensor is measuring EDA, a signal elicited strongly by stimulation of the amygdala and hippocampus, two brain regions that play important roles in emotion, memory, and learning.

A research challenge is to attempt to understand what all this personalized data means. Interestingly, behaviors that are visible externally can send a very different message from personalized responses measured internally. Dr. Picard's group is partnering with physicians with various areas of specialization to try to understand how to accurately interpret this personalized data.

In collaboration with Matt Goodwin, Dr. Picard is involved in another study collecting long-term sensor data of electrodermal activity from five children on the autism spectrum at the Groden School (Providence, RI). This is the first set of long-term sensor data (60 days) from children on the spectrum during normal daily life. Objective data can cluster patients and identify physiological phenotypes.

Dr. Picard's work is also improving classical emotion theory and emotion measurement. Recently, her group found that when you measure the EDA on both the left and right wrists, you sometimes get different information on the two sides that cannot be attributed to more sweat glands or different sensors. More work needs to be done on this, but higher right EDA appears to be related to heightened activation on the right side of the brain that can happen during anxiety or threat. Those interested in measuring EDA in the autism population should review these recent findings to appear in Emotion Review in the paper titled, "Multiple Arousal Theory and Daily-Life Electrodermal Activity Assymetry (Picard, Fedor, and Ayzenberg, 2014)." For a long time, researchers have only measured activity on the non-dominant side (usually the left side) and this paper is expected to have quite an impact in the research community. For the first time, it is being suggested that following the standard of measuring only the non-dominant hand could lead to the wrong conclusions.

Collaborating with researchers at Children's Hospital Boston on an IRB-approved, double blind experiment with 90 patients, Dr. Picard and colleagues, including a trained epileptologist labeling gold standard video-EEG, found that every seizure was accompanied by huge skin conductance responses. The responses were usually happening at the same time as the brain activity begins, but they can happen before the outward signs of the seizure. Dr. Picard built an automated detector of these seizures that is more accurate than anything else on the market. The current false alarm rate is acceptable and continues to improve with more data.

The focus of Empatica is to make a version of this device, titled "Empatica Embrace", available to the public to aid in seizure detection. The same device could also run a personalized detector of other autonomic events. In the future, this device will be able to provide alerts and measure autonomic severity in real time. The hope is that this will enable users to better identify their stressors and better manage their emotions.

At every stage of technological development and implementation, human beings are important. Technology alone cannot be expected to provide the whole answer.

Dr. Picard reviewed several other MIT Media Lab projects focused on helping people diagnosed with ASD including Affdex, MACH (My Automated Conversation coacH), Panop.ly (online support cognitive reframing /reduce depression), and online sentiment analysis to reduce bullying.

MACH was developed in an attempt to help people who have difficulty with face-to-face social interaction. It enables users to practice their interpersonal interview skills with an automated system through a personal computer. MACH consists of a 3D character on a computer screen that can see, hear, and make its own decisions based on its interactions with a person. Using a webcam, the system can analyze facial expressions and user's voice. It not only understands what you say, but how you say it. Using real-time speech recognition and prosody analysis, it can capture the non-verbal nuances of conversations and display it in an intuitive format. At the conclusion of a session, the program provides the user with a summary of the information and it can show how these measures change over multiple sessions. It even allows users to watch a video of their interactions with various measures of behavior displayed alongside the video.

Using MIT students as subjects, they set up a randomized control trial, which showed that MIT MACH feedback helps people improve face-to-face interaction in an interview. More information about MACH can be found online at: http://web.media.mit.edu/~mehoque/MACH.htm

As we think together about harnessing technology to improve the lives of people with autism, Dr. Picard urged the audience to remember that each person is an individual and technology does now have the power to help us better understand, serve, and honor that individuality in everybody.

In the group discussion, the audience asked Dr. Picard to comment on the possibility of using big data to help us understand autism better. More specifically, can the sensors that she has developed be used remotely to bring thousands of autistic subjects together? The Epilepsy Society has indicated that they would help support an IndieGoGo campaign for the Embrace sensor, enabling a large-scale study offering the opportunity for anyone who is interested to contribute their physiological data and get personalized feedback. The intention will be to get this technology out to as many people as possible and automate the clustering of the data into unique subsets. Then people will be able to see where they fall in those subsets and will be able to access objective data regarding features of those within their subset.

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Transforming Research, Diagnosis, and Treatment Effectiveness in ASD: Towards Better Social Interactions

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Elizabeth B. Torres, PhD is a cognitive neuroscientist who has been working on computational aspects of sensory motor integration since the late 90's. She studied mathematics and computer science as an undergraduate and spent a year at the NIH as a Pre-IRTA fellow, working on various computational models of cognition. While obtaining her PhD, she developed a new theoretical framework for the study of sensory motor integration using differential geometry and in particular elements of Riemannian geometry and tensor calculus used in contemporary mechanics and dynamics. Torres provided a model for movement in closed loop with cognition, targeting intentional behaviors of the nervous system. She went on to Caltech to receive postdoctoral training in electrophysiology and computational neural systems. She was a Sloan-Swartz Fellow, a Della Martin Fellow and a Neuroscience Scholar during those years. In parallel, she worked on translational applications of her models to address issues in patients with Parkinson's disease, stroke, neuropathy and upon joining Rutgers University in 2008, she applied a stochastic extension of such models to autism spectrum disorders with a focus on spontaneous and autonomic behaviors. The new extension characterizes a read out of somatosensation in millisecond range fluctuations of physiological motions. These fluctuations enable the sub-typing of severity and the tracking of performance in non-verbal individuals. Under an NSF Cyber Enabled Discovery Award, she developed this new technology and under the NSF I-Corps program is translating it to commercialize it and disseminate it. This framework deals well with the heterogeneity of disorders on a spectrum in general. It allows the design of personalized treatments. The outcome of this work has resulted in multiple ongoing collaborative efforts across various institutions that use the metrics developed in her laboratory to assess natural behaviors in Parkinson's disease, autism, and mental illnesses such as schizophrenia and bipolar.

Neurological disorders, both neurodevelopmental and neurodegenerative, are presently diagnosed using inventories and scales that rely on observation of external behavior. Dr. Torres' work examines a deeper level of activity whereby researchers monitor the kinematics of human movement with wearable sensors that allow an objective, real-time tracking of the physiological system underlying movement. This opens up an opportunity to reshape behavior via feedback in a well-informed manner. This approach relies on observations on the microdynamics of the system, including the interpretation of fluctuations in the system that had previously been considered simply as noise. This information provides physiologically-relevant times scales on the millisecond scale that can be paired with on-going output of human neuromuscular activity. The goal of Dr. Torres' work is to get spontaneous, self-emerging corrective responses in the system that do not require prompting and explicit instructions.

Behavior can be analyzed in terms of movements with inherently different levels of intent controlled by the Central Nervous Systems (CNS). However, Dr. Torres emphasized that the peripheral nervous system is equally as important in the study of behavior, as evidenced by the rich literature on the experiences of amputees, the disturbances in proprioception suffered by some individuals, and the targeted reinnervation that can be stimulated in some victims of accidents and stroke. The peripheral system develops so quickly in infants that one can monitor what is going on moment by moment, offering the opportunity to act on the central nervous system via specific programmed activation of the peripheral nervous system, resulting in more volitional control over actions, and enhanced autonomy. The relevance to autism is that the ability to teach the nervous system to achieve autonomy spontaneously opens up a new window on therapeutic approaches to improved communication and independence.

From instant to instant, all movements are variable, but with the passage of time patterns with a well-defined expectation emerge having statistical significance. These statistical signatures enable the prediction of sensory consequences of impending actions with such high certainty that levels of intent in an ongoing continuous behavior can be separated in its component motor actions. The structure of the noise-to-signal embedded in motor output during these continuous motions is a form of kinesthetic reafference; instruction of the CNS by the PNS. The modulation of central control from one moment to the next depends on the continuous returning afferent stream which the motions themselves cause. The statistical information inherent in the evolution of continuous patterns of movement output depends on the level of intent carried by the motion; some motions in the peripheral nervous system (PNS) are performed with deliberate intent, directed to a goal and executed with precise volitional control, while others occur spontaneously, pursue no specific goal and remain largely beneath awareness.

In autism, the peripheral motions that appear to be occurring with deliberate intent have, in fact, exponential stochastic signatures of motor output variability, meaning that the returning afferent stream reporting on these continuous motions is random and noisy. In consequence, they do not provide a way for the CNS to anticipate cause and effect, or to give system confirmation of statistical guesses over time (a form of learning). Past events contribute no more to future events than present events do. The affected individual must be living in the “here and now”, coping with a system that cannot properly integrate other forms of sensory guidance with the continuous kinesthetic re-afferent flow, which is statistically highly uncertain. Furthermore, if the cycle is corrupted and is carrying a narrow bandwidth signal with noise, the CNS cannot utilize that signal efficiently to predict and will tend to overcompensate for sensory transduction delays and transmission delays of the signal.

To achieve these goals Dr. Torres’ lab will be embedding analytic tools and algorithms into wearable, smart-sensing, technology with controlled feedback, setting the stage for large scale collaboration with other researchers using these wearables to gather data on thousands of participants. The technical challenge is to determine how best to compress this data into meaningful scalars that can serve as a metric for what is going on from moment to moment To measure upper body motions, Dr. Torres’ group uses Polhemus, an electromagnetic sensor technology system that samples at 240 Hz. They developed a simple match-to-sample task in which the subject is presented with two objects and later is shown a third object that matches one of the original two. The subject’s task is to indicate which of the original two objects the third object matches, requiring decision-making between two choices. The intent is to evoke self-regulation and self-control of the upper body motor system. At first, the motored-impaired (autistic) child may require physical prompting to complete the matching task, but with time subjects begin to solve the task on their own

What can be learned from the statistics of low-level physical movements? Dr. Torres' lab has found that the trajectories from natural hand motions while making a decision and pointing are not smooth. They have discovered a scalar quantity that accurately describes how these trajectories change over time. This provides them a means to study the continuous flow of motion and a way to detect intentional, deliberate movement epochs. These signatures can be used to automatically separate intended from spontaneously produced movements along a gradient of observed behaviors.

Dr. Torres' group retained temporal dynamics, often discarded as noise, and collapsed those into a type of signal that resembles peripheral spikes (p-Spikes) in neurons. P-Spikes can differentiate amongst subtype severities in autism spectrum disorders. Spikes from the ASD system, across ages, verbal capabilities, and sex, have the signature of an exponential (random) distribution, indicating that information is not being accumulated in a way that will be statistically informative. However, the stochastic patterns of spontaneous peripheral motions are not as corrupted as the deliberate ones. Dr. Torres' group found that the spontaneous movements of those with ASD look more like the signatures of the typically developing population which fall in the lognormal distribution. They have used spontaneous variability as a proxy to evoke and sustain volitional control without prompting or instructing the person. The gains in predictability and reliability of these stochastic movements were retained over weeks in 25 non-verbal individuals, despite no practice. These gains further transferred across different sensory modalities.

Dr. Torres has worked with Ian Waterman, a patient who lost his proprioception due to a viral infection that damaged the fibers that conduct movement information, pressure, and touch. She found that he has the same kind of exponential distribution in the motor output variability as seen in autism.

Using a general scale metric, Dr. Torres' lab measured every patient and control against the distance in the gamma plane in relation to the patient without proprioception. They plotted that as a function of the noise-to-signal ratio that can be computed using the estimated parameters of the gamma distribution. They computed the mean and variance of the gamma distribution and obtained the final factor. The resulting plot depicts how far each subject is from deafferentation. This can be done for subgroups of autism of known etiology.

Utilizing information parametrized in terms the scalar metric discovered by Dr. Torres, they explored the notion that peripheral feedback might be parameterized and controlled. They devised an experiment in which subjects sit at a computer, wearing wearable sensors, and explore a graphics window to learn what triggers a particular response in the media program. During the task, researchers measure the movement patterns with millisecond time precision and ask what happens to subjects' systems in terms of stochastic signatures and the rate of change of the co-adaptive process. They can determine in real-time the predispositions and preferences and steer the fluctuation patterns toward typical signatures. The subjects are discovering cause and effect and systematically anticipating the graphics response while researchers are measuring and extracting information on the types of media and stimuli subjects prefer. Researchers iterate this process with different media and build a map of preferences to determine a readiness level for behavioral interventions utilizing a scalar quantity which provides a rich condensate of information about the noise in the system and how it is being dampened by a particular task or intervention. These patterns had not been previously studied because in motor control studies that involve kinematics, such movement segments are often thrown away as noise. They also tend to escape visual awareness, so observation alone misses them. Remarkably, these spontaneous motions can be captured with wearable sensors and automatically extracted by Dr. Torres' new technology. Their stochastic patterns and their rates of change will provide us with a lens into the plasticity of the peripheral limb signal in each individual with ASD along with a measure of the adaptive capacity unique to each person.

Dr. Torres would next like to explore the following question: How much of the stochasticity is due to poor integration of arm and torso? This can be done by doing a two-point discrimination throughout the body and measuring which parts are sensing best. Ultimately, this information could provide the theoretical basis for automatically classifying subtypes in the spectrum of autism disorders and, more importantly, on a case-by-case basis, lead to the development of strategies for modifying behavior through engagement of the peripheral nervous system. .

In the group discussion, the audience questioned whether Dr. Torres could use her wearable sensors to track other kinds of behavioral interventions in real-time. Dr. Torres indicated an interest in tracking Floortime, ABA, and Early Start Denver Model. At present her lab is pursuing three additional lines of research in autism. One line of research uses the statistical metrics as outcome measure of efficacy in a clinical trial with very promising results in 9 children with ASD that finished phase I of the trial. Another line of research uses the statistical metrics as outcome measures in occupational and physical therapy, objectively characterizing dyadic interactions between the therapist and the child. The third has been a very successful adaptation of these statistical metrics to EEG-data analyses during the acquisition of volitional control of ones' thoughts to direct a cursor on a computer screen by mere thought. The Torres lab is now in a unique position to automatically assess -using the same statistical platform- the central and the peripheral signals as they change in tandem over time.

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Technology: A Tool, A Pathway, A Future

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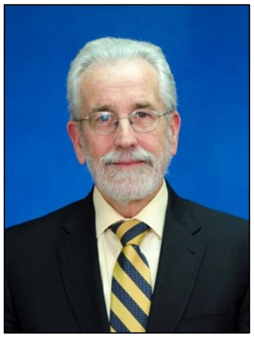

William E. Kiernan, PhD is the Dean and a professor in the School of Global Inclusion and Social Development and Director of the Institute for Community Inclusion, a University Center on Excellence in Disabilities (UCED). The Institute is a joint program of the U. Mass Boston and Boston Children's Hospital. Dr. Kiernan has served as a content expert for state, federal and international governments in the areas of employment policy and practice for persons with disabilities. He has over 130 publications in employment, school inclusion and transition from school to adult life for persons with disabilities and been the Director on over $100M in grants addressing research in employment policies, procedures and practices, training in rehabilitation counseling and vision rehabilitation. He has served on numerous national and international panels addressing systemic change in the employment of persons with disabilities. Dr. Kiernan has been a member of several national boards serving as President of the American Association on Intellectual and Developmental Disabilities (AAIDD) as well as President of the Association of University Centers on Disabilities (AUCD). In addition to holding a PhD in Rehabilitation and Special Education from Boston College and Masters in Rehabilitation Counseling from Boston University, he holds a second Masters in Business Administration with a concentration in Health Care Management from Boston University.

Dr. Kiernan began by emphasizing that while technology can create a pathway to a better future for individuals with disabilities and can have a profound impact on quality of life, it is simply only a tool. He stressed the importance of maintaining the assumption that every child can learn and it is the educational curricula that we must fix to enable this to happen. Dr. Kiernan's work at University of Massachusetts, Boston (UMB) focuses primarily on modifying the educational setting as opposed to increasing the skills of the individual, although both are important.

Dr. Kiernan's presentation focused on several key areas related to achieving inclusion of individuals with disabilities including universal design, the IBM/UMB Campus Access Project, and the wealth of new applications available for use on mobile devices.

Through the IBM/UMB Campus Access Project, IBM and UMB opened a Collaborative Innovation Center that builds on the research that both UMass and IBM have been doing for decades to increase accessibility in the workplace and on campus for people who have developmental disabilities, and vision, hearing, and other impairments. Much of the center's focus has been on developing new technology, but it also works to create new policies for government agencies, schools, and businesses to reduce the barriers to using computer technology. While IBM and UMB focus on building new technologies from scratch, some of the work hones existing projects already underway at IBM. One of its first endeavors was to further develop a prototype app for students with disabilities to find their way around campus by locating ramps and buildings with elevators, or where a visually-impaired student might find audio guides and other services.

Through this partnership, IBM and UMB hope that about ten universities from around the country will gather together to examine issues related to how technology can improve experiences for students with disabilities and how improved accessibility can help to ensure that everybody is engaged in the community and that no one is left out of the communication mode.

Using UMass Boston as an example, Dr. Kiernan and colleagues tested out the ease with which UMB students with disabilities might be able to find a ride, a career, a friend, and an answer. With regard to finding a ride, they focused on an application which tells students when the campus bus is coming and could help track the buses as they moved along their routes. With regard to finding a career, Dr. Kiernan and colleagues focused on an application that helps provide information about each major field and offers guidance about pursuing a career in those fields. With regard to finding a friend, researchers focused on helping individuals with disabilities create opportunities for building a community and connecting with others in the environment, despite the lack of dormitories on campus. With regard to finding an answer, IBM/UMB focused on allowing anyone who visited the UMB campus to have access to simple campus information that was accessible to everybody including students with disabilities, visual impairment, motor impairment, etc.

The researchers looked at applications and how they could work in typical settings. There are many tools and resources available including Dragon Dictation Software, VoCal, Facebook, and Twitter, and there are more being developed daily.

As an example of how technology is opening up opportunities for individuals with disabilities in campus settings and increasing independence, IBM/UMB researchers took pictures around the entire UMB campus which were used to provide students with intellectual disabilities with familiar landmarks. This enabled these students to navigate the campus without having to rely on reading or writing skills.

The labor force participation rate for students with disabilities is low (around 18%). Not many students with disabilities who go through college settings get into the labor market. For all types of disabilities, the labor force participation rate is around 32%, but it is still not anywhere near the 74% that exists for the typical labor force.

Poverty for adults with disabilities is extremely high. Jobs are difficult for this population to find. Employers often state that they can't find the right person, and potential employees often state that they can't find the right jobs. There needs to be a way to use real-time labor market information to match people up with the 3.5 million jobs that are available every day in the US.

Think College (www.thinkcollege.net) is an option that may enable us to change these trends and expectations. It is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability. With a commitment to equity and excellence, Think College supports evidence-based and student-centered research and practice by generating and sharing knowledge, guiding institutional change, informing public policy, and engaging with students, professionals and families. Rather than equipping just the individual, Think College is concentrating its efforts on changing the institutional setting to allow it to be more friendly and supportive.

Think College is about creating opportunities to interact and learn with peers, creating opportunities for the individuals with disabilities to be in charge and make choices on their own, focusing on issues of independence and autonomy, and not building special places for individuals with disabilities. Although well-intentioned, these special places often separate out the individuals with disabilities and limit their learning opportunities.

UMB received a grant from the Tower Foundation to study an innovative approach to improving academic achievement and career outcomes for people with intellectual disabilities and autism. The grant allows researchers to test a new model designed by Think College. The pioneering Think College Transition Model places Boston Public Schools students ages 18-22 in inclusive college classes at UMB and Roxbury Community College. The model calls for students to participate in internships and employment as they finish high school. Think College was also awarded an Investing in Innovation Fund grant from the U.S. Department of Education, one of only 18 in the nation. The Tower Foundation award provides matching funds for this federal grant. The study helps researchers measure the impact of the Think College model on students' academic achievement, employment outcomes, and self-determination skills.

The Think College team at the Institute for Community Inclusion at UMB is led by Debra Hart, M.S., as Principal Investigator and Meg Grigal, Ph.D., Co-Principal Investigator. In October 2010, Think College was selected as the National Coordinating Center by the Office of Postsecondary Education, US Department of Education to provide support, coordination, training and evaluation services for 27 Transition and Postsecondary Education Program (TPSID) grantees as well as other programs for students with intellectual disabilities around the country. Currently, the 27 funded projects offer a TPSID program on 44 college or university campuses.

Findings from the Think College National Coordinating Center on Transition and Postsecondary Education Programs for Students with Intellectual Disabilities (TPSID) indicated that over the last nine years, there has been an increasing effort towards increasing the number of postsecondary education initiatives, and much of this work has been done in Massachusetts, thanks to the efforts of advocacy groups such as the Massachusetts Advocates for Children.

The Think College website provides a searchable database of the two- and four-year institutions of higher education that provide services and supports for students with intellectual disabilities.
There are 233 programs listed on the Think College website including 30 comprehensive transition programs. There are 27 Transition and Postsecondary Education Programs for Students with Intellectual Disabilities (TPSID) programs.

In conducting this research, Think College researchers looked for several different types of higher education programs including dual enrollment programs (referred to in Massachusetts as inclusive concurrent enrollment programs) for students still in high school, programs for adults only 18+ who have exited high school, both dual enrollment programs for students still in high school and adults only 18+ who have exited high school, and individual students.

With regard to levels of college course access offered, ideally the Think College program would like to see full access to course catalog, but many of the programs currently offer partial or limited access or only specially designed courses for students with intellectual disability.

Non-Office of Postsecondary Education (OPE) funding for the Transition to Postsecondary Programs for Students with Intellectual Disabilities (TPSIDs) (45 sites) came from a variety of funding sources. Developing a TPSID program is complicated and there are several different funding streams that can be pursued such as the institute of higher education's own resources, local school districts, state vocational rehabilitation agency funds, state intellectual/developmental agency funds, individual and/or corporate donors, private foundation grants, Medicaid, other government funded grants, funding from state budget, Veterans Affairs funds, and other funding sources.

The primary aim of these programs is to blend these students with ID into the postsecondary settings as much as possible. Dr. Kiernan and colleagues collected data on student use of resources across the 45 sites to ascertain where on campus the students with intellectual disability (ID) were going, what services they used, and whether they were attending separate programs. They found that these students were very integrated into the campus community and generally access the same academic, administrative, and generic community resources used by the general student body. Specific campus resources used by students enrolled in 2012-13 included student center or dining hall, bookstores, library, computer lab/student IT services, sports and recreational facilities or arts, registrar, bursar, or financial aid office, health center/counseling services, career services, and tutoring services.

Dr. Kiernan briefly discussed typical partners in these TPSID programs. The most common funding sources and partnerships were with the local education agencies (LEAs), Vocational Rehabilitation agencies, and Developmental Disabilities agencies. The most common partner roles were project advisory committee, student recruitment, and service provision to students.

Dr. Kiernan discussed Think College research on course access in 2012-13. In 2012-2013, there were 733 students enrolled in a total of 5,584 courses across the US. On average, eight courses per student were accessed. 58% of these students were enrolled in specialized courses that are more customized for students with disabilities. 42% of these students were enrolled in inclusive course environments. 53% of students were enrolled in inclusive courses for standard institute of higher education credit. This is an indication that students with intellectual disabilities are really being integrated throughout the postsecondary setting.

64% of the courses offered are for-credit courses attended by TPSID and non-TPSID students. There is a wide range of courses taken by the TPSID students including Microcomputer Applications for Business, Principles of Advertising, Introduction to Psychology, Advanced Microcomputer Applications, Criminal Procedure, Vocal Performance Workshop, Hospitality Seminar, Principles of Management, Introduction to Mass Media, Child Development, Web Page Development I & II, and Intermediate Photoshop. Each year, the range of courses offered is expected to become more diverse.

With regard to student employment, Of the 838 students who attended TPSID programs in 2012-2013, over 70% of the students participated in career development activities including paid employment, other career development, or both. 36% of students held a total of 424 paid jobs. 62% of students participated in other career development activities. 89% of jobs were paid minimum wage or higher.

TPSID students were employed in the following settings: Art studios, YMCAs, elementary schools, hospitals, retail stores, neighborhood markets, fitness centers, restaurants, colleges, libraries, bakeries, and nursing homes.

45% of the jobs held by TPSID students were individual paid jobs. 20% were paid, non-credit internships. 15% were individual work training site paid by stipend (below minimum wage). Other types of student jobs held were group paid work, sheltered workshop, federal work-study, paid (for-credit) internships, and group work training site paid by stipend. One of every five paid jobs held by students (20%) were paid internships. This is a pathway to career employment that might be unavailable to youth with intellectual disability who do not attend TPSID programs.

The hope is that students who complete the programs in institutions of higher education will eventually become employed. The longer the students remain in the program, the better their career development opportunities become. If a person in a three-year program has been in the program for more than a year, it is much more likely that the person has gained requisite skills and experience to move on to a career development setting. There is a shift in focus to paid employment as student gets further along in their programs. This may be due to a greater focus on academics and other career activities than during the earlier years of attendance.

For the most part, these students are working toward certificates as opposed to degrees. In 2012-13, 40% of the TPSID students earned a certificate specifically for TPSID students; 10% earned a certificate or exit document granted by the TPSID program (not the institute for higher education); 9% earned a certificate available to both TPSID and non-TPSID students; 2% earned an associate degree available to both TPSID and non-TPSID students; 0% earned a bachelor’s degree available to TPSID and non-TPSID students.

Of the 297 students exiting the programs in 2012-13, 66% of the students earned a credential of some sort, mostly certificates; 16 students transferred to traditional (inclusive) postsecondary programs; 57% were in a paid job, other career development activities, or both.

None of these initiatives are without their policy implications. There are generally poor transition outcomes and poor adult outcomes for individuals with intellectual disabilities (ID). In 2011, employment rates for transition-aged individuals (ages 16-21) were 18% or less than half the employment rate for people without disabilities (Butterworth et al., 2013). This gap becomes worse as people with ID age with only 32% of adults ages 20-30 being employed as compared to 74% of people without disabilities (Sulewski, Zalewska, Butterworth, & Migliore, 2013).

What is being done to prepare students with IDD for work and college in K-12? How are our expectations limiting the opportunities students get? How can we achieve the goal of college access and real employment as a realistic option for long-term planning?

What are the predictors of employment? Dr. Kiernan emphasized the power of expectations. The only post-high school transition goal that was a predictor of employment for students with intellectual disabilities (ID) was having the goal of attending college. 11% of students with ID had this goal (Grigal, Hart, & Migliore, 2011).

Completing a college program is associated with higher employment rates for students with any disability including ID (Grigal et al., ACS 2013; NLTS-2, Migliore et al., 2009; Newman et al., 2011). Other studies also found individuals who take college courses, but do not graduate from college have better employment outcomes than those without any college (Carnevale & Desrochers, 2003; Marcotte, Bailey, Borkoski, & Kienzl, 2005).

Students need academic and foundational skills. Students will benefit from being academically prepared, having confidence, self-reflection skills, problem solving skills, self-determination, a clear understanding of accommodation needs, and concrete career goals.

Can we figure out different ways of funding and financing postsecondary education opportunities for those with intellectual disabilities? Can we apply some of the emerging technologies into the classroom to help better support individuals with ID and help them better manage their own spaces in the postsecondary setting?

Group discussion focused on how to engage university professors in modifying their traditional classroom approaches to accommodate the learning styles of those with autism and developmental disabilities. Often the Office of Student Disabilities Services will become involved in the early stages. At UMB, they run a series of training sessions with faculty focused on optimal ways to present to diverse student populations. The professors must feel that the adaptations that they make will benefit a much wider audience, beyond just those with intellectual disabilities. It is crucial when approaching faculty to encourage them to modify their delivery style, as opposed to change their entire curriculum, and this often results in higher rates of cooperation.

To what degree are students with autism coming to these programs prepared or unprepared in terms of access to personal technology that typical students and faculty are using? Many existing programs, particularly those in Hawaii, are focusing on the use of technology applications and design as an avenue to level the playing field. The success of this program in the long-term depends on its intimate relationship with the use of personal devices and technology. Often adults are least comfortable accessing the technology and the younger generation leads the way with advantage of the universal design nature of mobile computing. Peer-to-peer support is a model that has proven useful in these programs.

The Threshold Program at Lesley University is a campus-based, two-year program for young adults with special needs. Threshold gives adults the opportunity to experience college life in an atmosphere in which they can be successful, achieve, and gain confidence. Threshold students study for careers in Business and Support Services or Early Childhood Studies, are motivated to become independent, may have received special services in school, would probably struggle in a traditional college degree program, score below average on tests of intellectual ability, and may have difficulty with reading, writing and math skills. Threshold graduates receive a certificate of completion and six college credits.

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Realizing the Potential of the iPad in Supporting the Communication and Inclusion of People with Autism: Possibilities, Practice and Pitfalls

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Christine Ashby, PhD is an assistant professor in the Teaching and Leadership Department of the School of Education at Syracuse University and the Director of the Institute on Communication and Inclusion, where she oversees research, training and dissemination of information on communication strategies for individuals with disabilities who are non-speaking or who have limited speech. Her teaching and research focuses on inclusive education broadly, with specific emphasis on supports for students with labels of autism and other developmental disabilities, facilitated communication, disability studies, and inclusive school reform. A consistent theme throughout her research and writing is the challenging of the construct of intellectual disability and a consideration of the social construction of competence. Her work seeks to disrupt dominant notions of disability as deficiency and underscores the importance of considering the lived experiences of individuals considered to have significant disabilities. Dr. Ashby's research has been published in journals including the International Journal of Inclusive Education, Disability and Society, Teacher Education and Special Education, Research and Practice for Persons with Significant Disabilities, Equity and Excellence in Education and Intellectual and Developmental Disability.

Dr. Ashby's presentation focused on the potential of the iPad to support communication and inclusion of people with autism with particular attention paid to the pitfalls which might arise if users neglect to access technology in a way that helps them move forward. She echoed Dr. Kiernan's sentiment that technology by itself is just a tool.

In addition to Dr. Ashby, also present at the workshop were several members of the Institute on Communication and Inclusion (ICI) Research Team including Eunyoung Jung, Doctoral Student/Research Assistant, Casey Woodfield, Doctoral Student/Research Assistant, Katherine Vroman, Doctoral Student/Research Assistant, and Marilyn Chadwick, Consulting Trainer.

Dr. Ashby shared a quote from Amy Sequenzia, a blogger who types to communicate and is gradually developing greater independence. When asked what communication inclusion means to her, Ms. Sequenzia responded with the following: "*Finding a voice through typing is no simple task. It does not mean just typing words. It takes courage to face skeptical eyes; it takes time to become independent-a long time in some cases. It does not mean that our voices can't be powerful and a change in the world. Only we can relate how we think. We can be empowered through our thoughts, our fingers, our voices. We don't need to* *yell to tell people how think. Our voices come through typing, but they are OUR VOICES and they tell the world who we are*."

iPads and other mobile technology can be effective tools for helping people develop greater communicative independence; however, communication alone isn't enough. It needs to be deeply embedded in context.

How and why might mobile technology be helpful in supporting communication and inclusion for people with autism? iPads pair visual and auditory content and enable multimodal learning. Children and adults absorb more information when receiving it from multiple modalities. Additionally, iPads can serve as data collection tools and data trackers. They enable parents and students to connect with schools around common goals. They also link users to a phenomenal amount of outside resources. iPads allow immediate access to information related to the oftentimes unusual interests of those on the spectrum. Many apps help tie into the sensorimotor needs and preferences of individuals on the spectrum. iPads also appeal to the unique learning styles of those with autism in that they offers consistent, reliable responses and variety can be built in later.

Other potential benefits of the iPad for an individual from an education standpoint include portability, size, price, visual-based, multi-use technology, flexibility, "cool factor" and the fact that new applications are constantly being developed.

Proprioception is one of the systems most dysregulated in individuals with autism. Interacting with the iPad can help to calibrate one's proprioceptive system. User contact with the iPad screen helps to improve eye-hand coordination. Proprioceptive systems need to be recalibrated on an ongoing basis, and part of that calibration is through direct finger contact with the environment. Simply touching a surface with one's finger creates a reaction vector that points toward the shoulder and is present for only about 30 milliseconds. That force tells an individual where their finger is relative to their body.

iPads also present an opportunity for individuals with autism to move more towards inclusion and normalization and farther away from stigma. Often when you see someone using a DynaVox or similar device, you may make one set of assumptions, but when you see a person using an iPad, there seems to be more presumed competence.

The goal of the Institute on Communication and Inclusion is to help individuals with autism to gain more independent access and control over their communication. How can iPads be used to support more independent communication for people with autism who do not rely on verbal speech? In other words, how can the iPad connect to supported typing? These questions reside in this highly contested, controversial field of supported typing or facilitated communication.

Facilitated Communication (FC) or Supported Typing is a strategy which supports the physical, communicative, and emotional needs of a person with a communication disability to move more purposefully to express themselves through an alternate mode of communication. It is a method of training a person to access an augmentative and alternative communication (AAC) device or low-tech display to communicate. FC or supported typing is a method of teaching someone to use their body more reliably, to be able to point more consistently, volitionally, and intentionally in order to communicate.

This method is often referred to as Facilitated Communication Training to emphasize that this is a skill that can be learned, with the goal of physically independent typing with minimal physical support (i.e., a facilitator's hand on the shoulder) or a combination of speaking and typing.

We know that more communication yields more communication. Individuals with autism often start to use verbal speech because of all of these different modalities. The idea is to help people become more effective in their movement patterns. We are seeing the iPad as a tremendous support in that direction.

Dr. Ashby's presentation focused primarily on her study which researches the use of iPad apps that help people meet goals they have established to move them towards more independent communication. In her study, the iPad is the communication aid (object or device which transmits or receives messages), and the symbol system (methods used to represent concepts and ideas) is a combination of pointing at pictures, dots, and typing. The piece that Dr. Ashby's group is focusing on is the pointing technique (method used to send or convey a message) used to access the device. The teaching strategy (way of learning to use an aid to improve communication skills) relates to how one thinks about assistive technology and communication.

Dr. Ashby urged the group to consider any potential pitfalls of the iPad as a communication device. What role is the iPad playing? What is the potential danger? There is a distinct difference between simply being simply looking engaged and being distracted by the iPad and actually using the iPad for communication and/or academic access. The iPad is only a tool. You have to know how to use it for academic gain and as a pathway towards greater communicative independence.

Dr. Ashby's research questions include the following: How can the iPad be used to help individuals who type to communicate develop greater communicative independence? What apps and strategies are most useful for developing and practicing communication skills? How can we help people apply the skills they develop in non-communicative apps to open-ended communication? What can we learn from apps that do not seem communicative in nature that help somebody scaffold toward communication?

Dr. Ashby and colleagues set up a program with nine participants, ranging from young children to adults in their 40s. They videotaped bi-weekly training sessions with a Master Trainer, Marilyn Chadwick, and conducted pre- and post-interviews. Each of the individuals established their own goals and selected the apps that they wanted to use. They introduced and practiced using these apps in between the sessions to work toward established goals and they set practice goals for the days between sessions.

Some of the apps used helped the participants work on goals such as initiation, focus, developing rhythm in typing, sensory regulation, eye gaze and tracking, spelling discrete words, completing sentences, and sequencing events. All of these are prerequisite or co-requisite skills to communication and typing with the ultimate goal of increasing open-ended, spontaneous communication.

Marilyn Chadwick commented on the care taken to select the most appropriate apps to use with the research subjects based on each individual's background and skill level. There was a great deal of variety in how the apps engage the brain. Some apps are word-based and the user has to concentrate to develop the word. Other apps focus more on letter sequencing and require more of a surface level of working with words. Other apps are more appropriate for a person solely working on developing motor planning skills.

Ms. Chadwick commented on one app that they have had some success with in terms of encouraging the participants to make speech sequence sounds. Using a split screen, the apps provides users with a diagram of how a model appears when making a particular sound and displays a mirror on the other side of the screen. Users can simultaneously watch the model and watch themselves making the same sound.

Dr. Ashby spoke briefly about the role of facilitators and support people. One of the greatest challenges for facilitators and support people is to remember to focus on the process of providing support and not on the outcome of the message.

Three of Dr. Ashby's doctoral students, Eunyoung Jung, Casey Woodfield, and Katherine Vroman, who were responsible for data collection for this project each took turns presenting one participant, one clip, and one example of how participants can isolate a skill, practice it, and connect that to open-ended communication.

On the Institute on Communication and Inclusion's website (ici.syr.edu), there is a new updated list of apps useful for people who type. The apps are organized by category (sensory, educational, advocacy, communication, etc.) and they are not all typing apps. The ICI selected the top ten apps in each category and organized them by cost, app features, and the application that it might have for someone who types beyond its stated purpose.

In closing, Dr. Ashby reiterated Dr. Picard's earlier statement that for a lot of people with autism technology has been used to assess their competence level, knowledge, and capabilities and this can often lead to discomfort with and distrust of technology. Given this, Dr. Ashby's group is careful when designing app-based activities that they are not creating a situation that could be intuited as a test of one's knowledge or abilities. Dr. Ashby's group intentionally makes it clear that the focus of their work is on practicing motor planning.

In the discussion that ensued, the audience discussed several relevant applications, including a new app developed by Technology for Autism Now called AutiKnow. AutiKnow is a mobile education, learning, organization and task sequencing app designed to help teach individuals on the spectrum practical skills, while also teaching them how to learn. In addition, AutiKnow collects behavioral information on how these individuals learn, and uses this data to better understand autism, and potential ways to more effectively treat individuals on the spectrum.

A comment from the audience was that adults with autism themselves have often indicated that they resent the fact that people frequently question their intelligence. Researchers really have to be careful about the content they present to individuals with autism, particularly adults.

Given that the younger generation is increasingly relying on mobile technology in their daily lives, will it be easier for this generation to transition to independence? Dr. Ashby agreed that we are a culture that is so much more reliant on typed technology (pointing, apps) so children in the upcoming generation are much more comfortable and fluent with this pointing movement. One potential risk is that we may not be engaging and interacting with these children enough. Engagement with a device should not replace engagement with a caring adult or peer. There needs to be an appropriate balance.

Since friendships are important, is there a way to engage peers to work together using the iPad? Dr. Ashby has been working in the Montgomery County Schools piloting a project with children who type to communicate. One of the research questions which has arisen in this work is: How do you take this device as a form of communication and bring in peers? The iPad lends itself well to peer interaction through playing a two-person game, reading a story together, and having one-word conversations (one person types in a word and the other person responds to that by typing in another single word). One important consideration is that this peer interaction based around the iPad must be scaffolded appropriately by adults so it does not become a non-communicative, non-academic distraction.

What percentage of people who are nonverbal ultimately become verbal through supported typing? Dr. Ashby indicated that some individuals do become verbal through supported typing, but the majority will start saying individual letters or individual sounds as they are typing. Individuals who do become verbal through supported typing often read what they are typing and it appears as though they may still require that motor movement to initiate speech. It is far less common for individuals to become spontaneously verbal although that certainly is possible.

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Developing Innovative Technologies to Enhance Research and Practice with Individuals on the Autism Spectrum: A Computational Behavioral Science Approach

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The National Science Foundation (NSF) has invested heavily in technology for autism. “Computational Behavioral Science: Modeling, Analysis and Visualization of Social and Communicative Behavior” is a five year, $10 million NSF grant. Experts in computer vision, audio-speech analysis, wearable physiology, machine learning, pattern recognition, and data visualization from MIT, Northeastern, Georgia Tech, Carnegie Mellon, University of Southern California, University of Illinois at Urbana-Champaign, and Emory University, are collaborating to better quantitatively define the diagnostic phenotype of autism and evaluate response to interventions. NSF hopes that the grant will result in disruptive technologies and new fields emerging.

Dr. Goodwin and colleagues have proposed a new field called Computational Behavioral Science. The field of behavioral science is skilled in asking real world questions, generating hypotheses to test elegant theories, and employing systemic research designs; however, its measures (surveys, interviews, behavioral observations) are not always sufficient. The field of computer and electrical engineering sciences has exquisite methods with which to collect, store, manage, and analyze data. Merging the fields enables us to use the measurement capabilities from computer science to explore behavioral/psychological science questions for public health purposes.

Founded three years ago, the doctoral program in Personal Health Informatics at Northeastern University is the only interdisciplinary, PhD-conferring degree program in the US that combines behavior science with computer science.

The overwhelming majority of US autism research grants from 1997 to 2006 can be categorized as basic (as opposed to clinical or translational) research grants focused on brain and behavior, epidemiology, neuroscience, and genetics. These are critically important areas to help us better understand autism. Unfortunately, these research findings rarely translate into actionable services or technologies for people currently living with the disorder. What is being done in the funding emphasis within autism to help people currently living with the disorder?

Individuals on the more severely affected end of the spectrum often cannot comply with the methodology of modern psychological science, resulting in their absence from many autism research studies. The majority of autism studies involve subjects with normal IQ and verbal fluency and findings from such a demographic cannot be generalized to the autism population. These circumstances motivated Dr. Goodwin to essentially bring the laboratory into the world and naturalistic settings.

Telemetric monitoring is technology-enabled (video, audio, physiological) behavioral assessment that is unobtrusive, longitudinal, and carried out in naturalistic settings. Telemetrics can reduce reactive arrangements and increase compliance, increase ecological validity, model change over time at the individual level, enable multimodal data analysis and visualization, and provide just-in-time feedback.

Dr. Goodwin discussed different areas in which his group has made innovations in these technologies. The first is around stereotypical motor movements, repetitive motor sequences (hand flapping, body rocking, finger flicking) that appear to the observer to be invariant in form and without any obvious eliciting stimulus or adaptive function.

Given that there is no published data which suggests that these movements are having a self-stimulatory function, he cautioned against referring to these as ‘stims’ which suggests that these are bad, non-functional behaviors which should be eliminated. These behaviors may have several different kinds of functions for a particular individual that should either be preserved or replaced with a more socially acceptable way of achieving that function.

Dr. Goodwin then discussed the impact and significance of stereotyped and repetitive motor movements. Preventing or stopping these movements is often problematic as individuals with ASD may become anxious, agitated, or aggressive if they are interrupted. These stereotypical motor movements can become the dominant behavior in an individual's repertoire and interfere with the acquisition of new skills and performance of established skills. Engagement in this behavior is socially inappropriate and can complicate social integration in school. Stereotypical motor movements are thought to lead to self-injurious behavior under certain circumstances.

There is empirical literature that supports a multiplicity of hypothesized functions of stereotyped and repetitive motor movements. The predominant theory is biological. Most in the field think these movements are behavioral outputs of dysregulated neuronal systems including the basal ganglia and dopaminergic pathways in the brain.

Current methods for researching these motor movements are not sufficient. Surveys regarding presence, absence, and intensity do not give much information on intra-individual variation over time. Real-time observation documenting topography, onset, and offset resulted in low inter-rater reliability. Behavioral observation and coding of videotaped footage can be time-consuming and cost prohibitive.

Given these challenges, Dr. Goodwin wanted to use telemetric assessment methods to explore sensor-enabled, automated pattern recognition of stereotypies. The goal is to use sensory technology to provide a measure of behavior that may be more objective, detailed, and precise than survey scales and direct observation and more efficient than video-based methods. Could wireless 3-axis accelerometers be placed on the limbs of individuals in the primary areas where they engage in their behavior to get training examples and then train classifiers to automatically detect them?

Dr. Goodwin shared examples of research that his group has conducted at the Groden Center Day and Residential Programs (Providence, RI). Video footage of a student wearing sensors on both wrists and torso was displayed alongside the corresponding physiological and behavioral data.

Dr. Goodwin's group found that if they can get 50 training examples while somebody is observing a child engaging in these stereotypical motor behaviors, they have 90% automated accuracy in detecting future behaviors of that individual for up to two years. Once those 50 examples have been obtained, a classifier can be built, and a computer or phone can continuously measure the topography of the behavior, onset, offset and intensity.

With telemetric assessment measures, one can quantify kinematics and examine the kinematic parameters of a behavior to determine whether there is within-bout, across-bout, or between-bout variability. This addresses important questions regarding biological versus operant mechanisms. Goodwin challenged the hypothesis that these are invariant behaviors, which has implications with regard to neural networks that might be involved in these behaviors.

Determining response topography and dynamics across settings and activities can indicate function and have important implications for treatment. Additionally, telemetric assessment methods can provide a wealth of data regarding response to a behavioral or pharmacological intervention such as which behaviors were affected at what intensity and at what rate over what period of time.

Dr. Goodwin's group is now using the autonomic measures to test in natural environments. They are measuring autonomic response (heart rate/heart rate variability, respiration, electrodermal activity, and temperature) in seven individuals at the Groden Center who were recorded over a 6-month period wearing accelerometers. For some individuals, there appears to be a context-by-physiology interaction which will predict whether an individual is going to engage in a behavior. This indicated that there is coupling between the brain and peripheral autonomic nervous system interacting with the environment that gives rise to these behaviors, which suggests that these behaviors may be functional for many of these individuals.

With computer science and experimental psychology doctoral students, Dr. Goodwin has developed a phone system which can receive accelerometry data. They wanted to explore whether an individual who had never worked with the student before could come up with the 50 training examples using that accelerometry data and they were able to obtain 87% accuracy using this technique. This mobile logging and annotation system involves real-time data logging and pattern-recognition using mobile devices and enable teachers, therapists, and caregivers to monitor movement behavior and gather data that can assist with intervention decisions.

Electrodermal activity, associated with cognition, emotion, stress, anxiety, and novelty, is sweat secretion from eccrine sweat glands that are innervated purely by the sympathetic nervous system. The regions that govern this response are amygdala, premotor cortex, prefrontal cortex, hypothalamus, hippocampus, and reticular activating system.   To demonstrate telemetric assessment of the autonomic nervous system, Dr. Goodwin wore a wrist sensor device, developed by Dr. Goodwin in collaboration with Rosalind Picard at MIT Media Lab, which stores all autonomic nervous system data locally and if in proximity to a Bluetooth receiver, electrodermal activity can be displayed in real-time. The sensors respond to a stimulus quickly, within 1-5 seconds of latency.

This telemetric assessment technology is being used to look at challenging behaviors (aggression towards others, property destruction, self-injury, elopement and tantrums). Once you rule out sensory, social and access to tangibles, 30% of functional analysis of challenging behaviors are inconclusive (Carr et al., 2007). This means that it is entirely unclear to us why the individual is engaging in the behavior for 30% of functional analyses being conducted.

Most people who study challenging behaviors tend to look at the consequents, but there is another train of thought that focuses on antecedents. What contexts that might be producing these behaviors? To change the behavior, it's crucial to focus on what you do before the behavior to mitigate the chance of these behaviors occurring.

Dr. Goodwin urged the audience to think about the relationship between arousal and performance. The Yerkes-Dodson Curve indicates that there is an optimal level of arousal. We all have a unique homeostatic set point. If we have too little arousal (lethargy), we have a response decrement, and if we have too much arousal, we have a response decrement.

Dr. Goodwin's clinical partner, the Center for Discovery in Upstate New York, a 2,000 acre biodynamic farm 90 miles outside of Manhattan, serves 150 medically-fragile children including many with autism. This Center works with the most severely affected segment of the autistic population that is not institutionalized and these kids appear to be getting better but have not had the means to conduct research demonstrating efficacy.

Recognizing that the Center for Discovery Lab School was a good technology candidate, Dr. Goodwin and colleagues installed 10 cameras and two microphones in one of their classrooms and outfitted every student and staff member with a wrist sensor and cardiovascular monitor. Over two years, they have 1,056 examples of problem behaviors operationally defined for twelve individuals. Using video footage, coded behavior data, and accompanying physiological data for before, during, and after the behavior, Dr. Goodwin's group aims to develop person-dependent algorithms which calculate the probability that a problem behavior will arise given an internal state change in the individual.

Dr. Goodwin showed an example of a video of a problem behavior being exhibited by a student alongside the student's electrodermal activity, highlighting the specific periods of time when the student engaged in the challenging behavior. Analyzing the video alongside the corresponding electrodermal data can provide detailed insight into the individual's internal state.

Dr. Goodwin's group is interested in developing ways to do person-dependent tracking and automatic labeling of individuals and behaviors based on training examples. The technology would be able to identify each individual and their operationally-defined behaviors such that one could pass a two-year video record through this algorithm, and retrieve data regarding when each individual engaged in the challenging behavior, the type of behavior it was, and when the behavior started/ended. This type of tool could have real research and clinical utility.

Dr. Goodwin's group is now working on visualizing this data in real time and creating a wearable device which displays one's internal state by color. For example, a person at their optimal level of arousal might be glowing green. A person at 2 to 3 standard deviations below their homeostatic set point might be glowing blue. A person at 2 to 3 standard deviations above their homeostatic set point might be glowing red. This method of self-monitoring could be useful for an ASD population and their staff.

With regard to interpersonal physiology/child-therapist co-regulation, physiological data from the teachers can enable researchers to examine whether there is coupling or decoupling happening between a student and a teacher before/during/after challenging behaviors and when a student is performing well or not on an academic task.

Dr. Goodwin went on to discuss monitoring in the home environment. He discussed his work with colleagues at Georgia Tech (Jim Rehg, Gregory Abowd, Ivan Riobo, Chan Ho Kim, Akshay Gupta) and MIT (Deb Roy, Soroush Vosoughi, Bill Washabaugh). Deb Roy's TED talk titled, "Birth of a Word" provides a detailed description of his Speechome Project. Deb, who runs the Cognitive Machines group at MIT Media Lab, is interested in artificial intelligence, machine learning, and pattern recognition. His wife, Rupal Patel, is a speech-language pathologist/audiologist at Northeastern University. They put a camera and microphone in every room of their house and recorded every minute of the first three years of their son's life in an attempt to better understanding language acquisition and large dataset management.

Dr. Goodwin showed video highlights to demonstrate the capabilities of the technology used in the Speechome Project. They can fit 3D models to heads and assuming the head is a proxy for the eyes, they can estimate where a person is looking. This is a way to study joint attention in naturalistic settings.

Using raw wave forms of the audio, they can separate out words from non-words using machine learning, resulting in an automatically-populated complete record (closed captioning) of everything that was said.

To demonstrate the power of data visualization, Dr. Goodwin displayed person-tracking data, which shows the paths each individual took over a given time period. Users can draw a perimeter around the area that they are interested in to get an automatic, full transcript of all the words that were said in that time period in that setting. It is interesting to consider what kind of language is being produced in which setting as potential environmental input to help people acquire language skills.

Big data typically takes a nomothetic approach and examines one million people at a single data point. Conversely, one might examine a single individual with one million data points. As a powerful demonstration of this concept, Dr. Goodwin showed a child producing one word ("water") over a 6- month period with data being tracked automatically. The topographical maps displayed indicate where and when the child said the word "water". Use of these methods can result in a detailed developmental history in a sequence of images that provide insight into a basic language learning process.

Recognizing that many of the things that the Speechome system can automatically measure and record relate to the early signs of autism, Dr. Goodwin challenged Dr. Roy to make a portable version of his system. In 4 months, Drs. Roy and Patel had built a portable version of the Speechome recorder that could be wheeled into someone's home, record data for months, and share data collected with researchers at a distance. Telecommunication or telemonitoring were also possible.

Dr. Goodwin used this portable Speechome recorder in his own home to record the first two years of his daughter's life. Using something called optical flow, one can visually plot accelerometers around angles of people's bodies. He was able to predict his daughter's word acquisition with about 80% accuracy just using data regarding where two people oriented in time and space over successive frames.

In his current Bio-behavior Capture System (BBCS) project, Dr. Goodwin and colleagues are developing a system similar to the Speechome, but that is less expensive, easier to use, and can be deployed in homes of caregivers of individuals with autism. BBCS will provide video, audio, physiological, and sleep records as well as mobile annotation with a phone or platform to turn parents into citizen scientists to gather information about their children that can be shared with clinicians and researchers. The result would be a well-documented record of how individuals are performing and behaving over time.

In Dr. Goodwin's lab, they are using technology such as cameras, microphones, electrodermal, cardiovascular, physical activity sensors, cameras that you can wear as glasses to gather data on point of view, and a Live Scribe pen to provide detailed data related to clinician-child-parent interaction. In live test administration situations involving clinician and child, Dr. Goodwin's lab is trying to work out computationally how technology might automatically detect therapist and child, identify objects versus people, and identify a person-object interaction.

To achieve noninvasive detection of eye contact, they use special eye tracking glasses that the user can see out of. Using these eye tracking glasses and facial detection technology, the software can identify instances in which there is mutual gaze present between clinician and child and the video then slows down to enable researchers to study joint attention.

In addition to the gaze tracking, they can also plot facial action units on different parts of the face to quantify the range of emotional expressivity on the face, enabling researchers to study affective, attentional engagement.

The overarching idea is that if we can get this quantitative information in a standardized setting, we have potentially better ways to discriminate autism from non-autism.

The following are all behaviors/states that can be measured telemetrically in natural settings: Sleep, seizure activity, general physical activity/tone, challenging behaviors, repetitive behaviors, affect, stress/anxiety, body temperature, social proximity, language, non-specific, general state changes.

In the discussion that ensued, the audience inquired about whether Dr. Goodwin has considered using this technology to develop biomarkers for autism and better outcome measures for pharmaceutical trials. Dr. Goodwin is working with pharmaceutical companies interested in obtaining better quantitative data in field trials to distinguish responders from non-responders. In randomized clinical control trials involving thousands of subjects, half get the active agent and half get a placebo. In both groups, there are usually some who claim that they improved and some who claim they have declined. It's difficult to ascertain real effects from placebo effects, and unless there is significant change in one group versus the other, these become inconclusive studies. Dr. Goodwin is working with these companies to collect detailed information from subjects through continuous, unobtrusive monitoring, which can result in greater power and accuracy.

The discussion then focused on Dr. Goodwin's work at the Discovery Center, and the potential of this technology to improve staff's ability to predict when problem behaviors might arise and help people with autism with self-regulation. Regarding scaling up his technology, Dr. Goodwin works with clinical service providers in attempts to get his technology to the real world, but otherwise he has no formal means of moving it beyond the research setting. While it is feasible to get his technology to the real world within one year with ample research support, it is a longer process when progressing grant by grant. Dr. Goodwin's group is currently working on demonstrating how this technology can be used, and the next step would be to make it simpler, more robust, and easier to use. To manufacture, market, distribute and support the product would require industry involvement as this is not an area of strength of universities.

With regard to ethical issues in the use of this technology, all of the work is IRB-approved with informed consent from the guardian and assent from the child when possible. Subjects and guardians are informed of why data is being collected and who has access to it, and they have a right to see the data before it gets released. They are aware of when data is recording, they can opt in/out at any time, and they have the right to delete any undesirable footage. Anytime their data is to be published in a manuscript or shown in a scientific presentation, guardians have a chance to review it and explicit consent is obtained.

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ADDITIONAL RESOURCES

The additional resources listed below represent a selection of articles about some emerging and evolving tools and technologies which might be used to improve the lives of those with autism including telemedicine, distance learning, remote monitoring systems, brain-wave-reading technology, virtual communities, human-computer interfaces, gaming technology, vocational programs, and employment in the high-tech sector. Article links are provided for your reference only. The NLM Family Foundation does not control such websites and is not responsible for their content. The Foundation's inclusion of these articles on this list does not necessarily imply any association with or endorsement of the material.

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