

Technology's Growing Impact on Autism

The Role of Novel Research Technologies in Autism Spectrum Disorders

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Mobile devices are woven into the fabric of our typical day. Portable technologies such as the iPhone, iPad and wearable activity trackers like Fitbit have significantly transformed not only how we communicate but also enable us to collect an enormous amount of health relevant data and information (Kumar et al., 2013). The majority of parents and clinical caregivers who interact with children with Autism Spectrum Disorder (ASD) have mobile devices and children with ASD find smartphone technologies particularly engaging (Mazurek & Wenstrup, 2013; Shane & Albert, 2008). Thus, there seems to be a clear opportunity to harness the flexibility and convenience of portable technologies to conduct research in ASD



(Shic & Goodwin, 2015) and provide meaningful feedback to families and clinicians that may expand treatment options for the ASD population.

In this article, I will discuss some of the most exciting mobile and wearable technologies that are being used in research settings, which aspects of ASD research

these technologies are well suited to target, and future directions for the potential of wearable devices in ASD. It is exciting to consider how both mainstream commercially available devices as well as the development of new devices may change how we study ASD and ultimately help those with ASD and their families.

Since the introduction of the iPhone in 2007, iPad in 2011 and Fitbit Flex (wrist wearable device) in 2013 there has been an explosion in demand for mobile devices. At the end of 2013, 1 in 10 Americans over the age of 18 owned an activity tracker ([Endeavor report](#)). These devices are accessible and affordable to the public and there is acceptance for using them regularly in practically all settings. Thus it is part of our common landscape to see children and adults engaging with some type of portable technology on a regular basis. As long as there is demand, there will be motivation to keep updating and refining these technologies to be applicable to a broad population of users, including those who are on

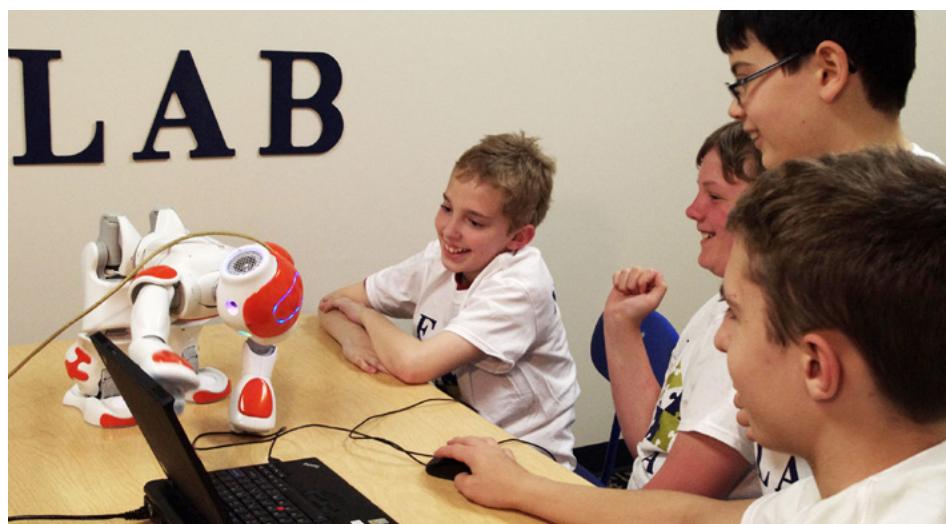
see Novel Research on page 23

Using Technology to Foster Social Interaction

By Juhi Kaboski, PhD
Director, Laboratory for
Understanding Neurodevelopment
University of Notre Dame

As parents watch today's children play mindless and solitary video games for hours at a time, they may worry that digital devices are luring children away from social interactions with real life peers. This concern is more intense for parents of a child with autism spectrum disorder (ASD) as there appears to be a profound mismatch between their child's (often obsessive) desires to engage in technology and the child's need to socially engage with other human beings in order to overcome challenges in social skills.

As a parent of two children on the autism spectrum, I often find myself in the unsavory position of having to wrestle a laptop away from my video-game-drunk child or threaten to delete an iPad app if he does not behave. Sometimes I feel as though I am losing the battle against tech-



An evidence-based summer camp offers a group of technology-oriented adolescents with ASD an opportunity to improve social and vocational skills while decreasing social anxiety

nology in a competition for my child's attention and affection.

Despite these potential drawbacks, technology is not an evil force from which we

should try to shield our children. Technology is only a tool. As such, its utility or harm is determined by how we wield it. Today's technology potentially presents an exciting

new world of learning opportunities that did not exist a decade or two ago. However, we need to strategically ensure that it is used for the benefit, and not detriment, of our children's development. Moreover, it is of utmost importance that these novel learning opportunities are appropriately evaluated for their effectiveness.

Commonly Employed Use of Technology in School, Home, and Therapy Settings

There are at least two ways in which computer and digital devices are incorporated into therapeutic interventions for children with ASD. First, electronic devices and tablets can be used as an alternative/augmentative communication device. Second, a favorite electronic game or device is frequently used as a reward for cooperating in behavioral programs. Electronic devices are commonly used with children with ASD in the home, school, and therapeutic setting to encourage or facilitate targeted behaviors.

see Interaction on page 21

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“CRISPR” Way to Cut Genes Speeds Advances in Autism

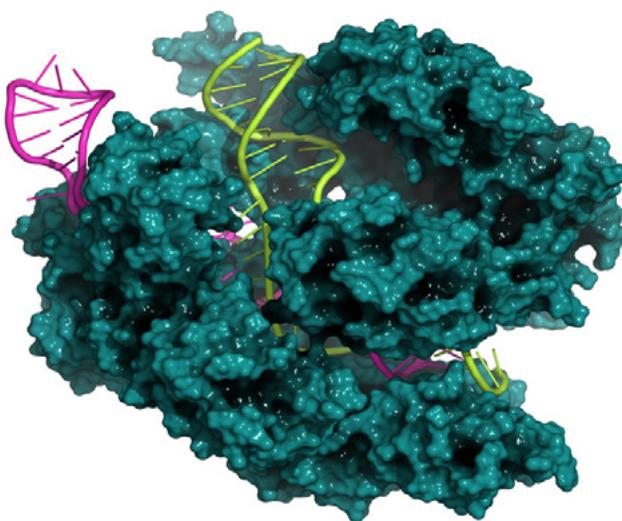
By Jessica Wright, PhD
Spectrum

Less than three years ago, two landmark publications in *Science* gave researchers a quick and easy recipe for tinkering with genes.^{1,2} The papers described a new tool — a modified enzyme called CRISPR-CAS9 — that allows researchers to reach into the genome and snip, or substitute, DNA sequences with unprecedented precision and efficiency.

In cells, researchers have used this new system to disarm the culprit in single-gene disorders ranging from Huntington’s disease to cystic fibrosis.^{3,4} And in one study published last year, researchers inserted a mutation into human stem cells that could prevent HIV from sneaking into the cells.⁵

In the case of complex genetic disorders such as autism, the tool hews the way toward clarifying the subtle effects of thousands of autism-linked mutations. Using the method, researchers can create animal models endowed with these genetic quirks much faster and more efficiently. Tweaking the genes of monkeys, something that was challenging with conventional techniques, is also now a real option.

“It’s a breakthrough technology, that’s for sure,” says [Guoping Feng](#), professor of brain and cognitive sciences at the Mas-



A CRISPR-CAS9 gene editing complex example. The CAS9 nuclease protein uses a guide RNA sequence to cut DNA at a complementary site.

sachusetts Institute of Technology. Feng is using the method to engineer marmosets that lack the autism candidate gene [SHANK3](#).

In one example of its potential for autism research, in October researchers used CRISPR to examine the effect of mutations in *MeCP2*, a candidate gene, on circadian rhythms.⁶ Some teams are trying to recreate autism-linked mutations in mice and in stem cells, and to mutate combinations of genes in fish.

Making Mice

Since the 1990s, researchers have been able to edit genes by fusing enzymes that cut DNA with those that bind to specific sequences. The first of these tools, zinc-finger nucleases, relied on enzymes that each bind to preset sequences of three DNA base pairs. In 2011, two independent teams described a DNA-binding protein from bacteria that infect plants as the basis for a more precise gene-editing system, called

[TALENs](#). Still, each of these methods requires researchers to first create a protein that specifically binds their target sequence.

CRISPR, by contrast, is fused to a protein called CAS9, which binds to DNA. Strands of RNA that can be designed for any desired DNA sequence guide CAS9 to its target. Designing a precise RNA to match a DNA sequence is considerably easier than creating the equivalent protein match.

Last year, one of CRISPR’s inventors, [Feng Zhang](#) at the Massachusetts Institute of Technology, engineered a mouse that already expresses CAS9 in all of its cells.⁷ Use of this mouse eliminates having to introduce CAS9 into the cells of interest, allowing researchers to add only the guide RNAs needed.

One big advantage of CRISPR for creating mouse models is that it allows researchers to closely mimic the autism-linked mutations seen in people. Traditional methods crudely knock out both copies of a relevant gene, a distant simulation of mutations that might affect only one copy of a gene, for example. What’s more, a CRISPR mouse model can be up and running — literally — in three months as opposed to the typical six months or more.

Another significant edge is that the method makes it possible to easily insert multiple mutations into a single animal, unlike the traditional method of painstakingly

see [CRISPR on page 28](#)



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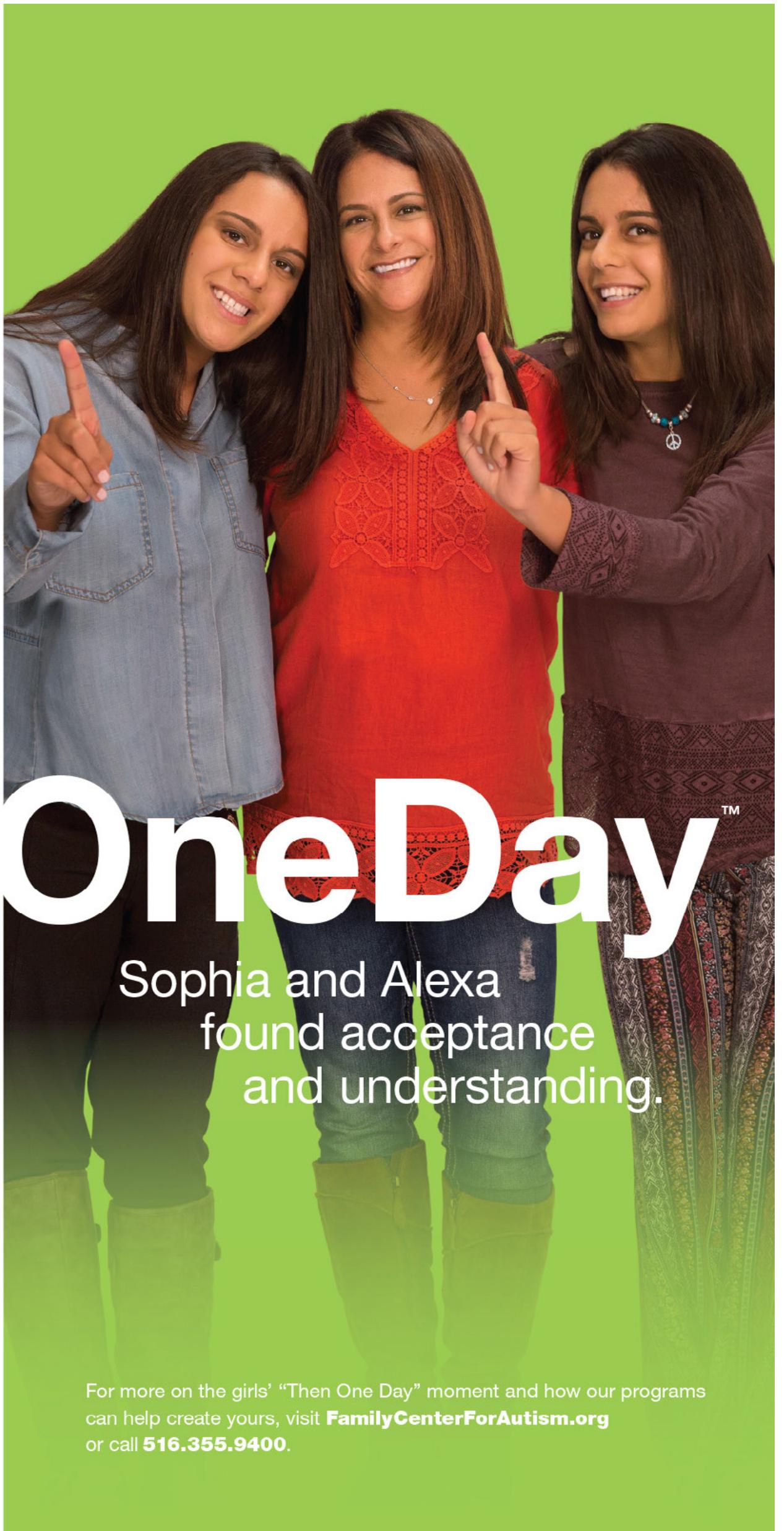
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The Dangers of Social Media for Individuals with Autism

By Nora Baladerian, PhD
Executive Director
The Disability and Abuse Project

The Disability and Abuse Project publishes a weekly news feed of all articles that have been published in the past week on abuse of people with disabilities. These focus on intellectual and developmental disabilities. Recently there has been an increase of articles describing solicitation by perpetrators of abuse to people with autism and other developmental disabilities. All news feeds are on the homepage of disabilityandabuse.org where articles are listed alphabetically by state.

A recent article posted on 8/24/15 described how a teen with autism was asked by a man to send nude photos of herself and to meet him for sex:

“EUGENE, Ore. - A 57-year-old man faces accusations he solicited nude photos from a 15-year-old girl with developmental disabilities and attempted to meet with her for sex, Eugene Police said.” He was arrested on charges of Online Sexual Corruption of a Child in the First Degree and Online Sexual Corruption of a Child in the Second Degree. “Police allege that Calvert communicated with the teen via text message and Facebook....sought nude photos from the girl and tried repeatedly to meet with her for sex.” The National



Nora Baladerian, PhD

Crime Prevention Council has a variety of tips, including some on Internet Safety and Social Media safety. Writer: Matt Spillane, mspillane@lohud.com.”

This report illuminates the dangers of perpetrators, whose purpose is to trick, ensnare and violate. They have a plan. Hapless social media users, however, do not “have a plan.” It is my strong opinion and recommendation, that everyone have a plan, including their parents, friends or caregivers...and use it. Plan elements include a “before-during-after” strategy. The

plan (1) details what one should know prior to using social media, (2) details strategies to assess the conversation, and (3) lists what to do after receiving invitations or requests that do not fall into a category of “things you would normally do with family and friends around.”

Here it is in the words of a man with autism...his message is clear. There should be a plan for every social media user including awareness that there are people who will make requests that should not be honored, they are bad and they do not mean well (posted 6/8/15):

In the article, “Hate crimes aren’t taken seriously enough” (RichardAult, 6/8/15), Author Kevin Healey wrote that he was “...was too frightened to leave his home for three weeks” after internet ‘trolls’ found his address and threatened to chop off his legs. With 118,000 Twitter followers and 14 years of campaigning for the rights of people with autism to his credit, Kevin has become a public figure and an easy target for online bullies. The vile abuse he has received by anonymous trolls mocking his condition (both Kevin and his twin brother Shaun are on the autistic spectrum) have hardened him over the years. Kevin said, “Someone got hold of my e-mail address and managed to find out what street I lived on. I got an e-mail from this person saying, ‘I know where you live, be careful, I’m going to come and sever your legs.’” He says, “People with autism are very lit-

eral. For three weeks I couldn’t leave the house. I thought if I did I would get my legs chopped off. That was horrific.”

Kevin’s experiences of online bullying also included “...people setting up Twitter accounts impersonating me.

One person was even pretending to be me and asking for money.” Although bullied as a school student, he says, “...I think cyber-bullying is more horrific than physical bullying. If someone hits you, you might get hurt, but you can walk away. Cyber-bullying stays with you, you can’t get away from it.” In response to this bullying, Kevin notes that he “came off Twitter for a time, but I felt like I had lost my voice. It is how I communicate with the world.”

I think the words of Kevin are powerful. I believe that by listening to someone like Kevin, many will become aware not only of the pain that can be suffered, but how the risk of it can be significantly reduced by following the rules of safety while enjoying social media.

An article posted on 8/24/15 clarifies the dangers (Staff, 2015):

A Somers couple is demanding \$10 million in a lawsuit against a former college professor who was convicted of forcibly raping their autistic son. Paul S. Hines, 74, was convicted of third-degree criminal sexual act, a felony, is now a registered sex offender, and was sentenced to 10 years’

see Social Media on page 30

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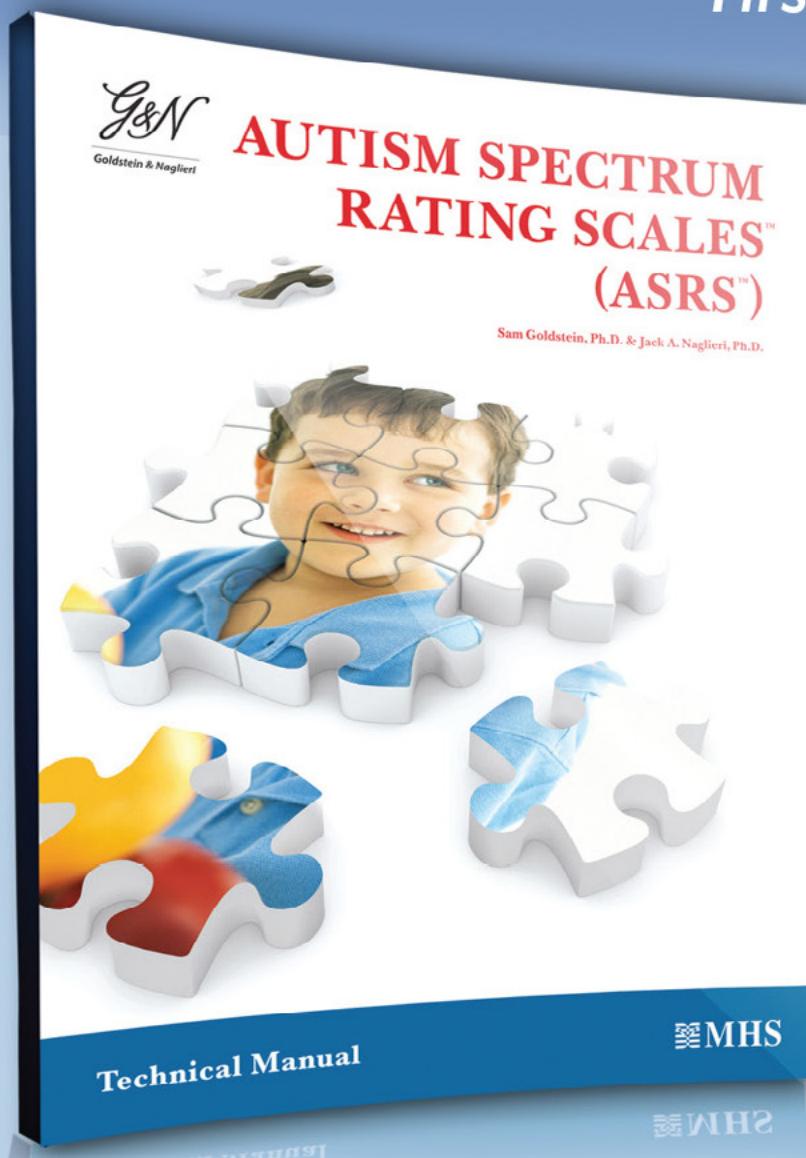
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-Kirsh, Aimee A. Assessment With Aimee, The Ohio
School Psychologist, Volume 55, Number 2.

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Advancing Care for the Developmentally Disabled with Population Health Management

By Adam Sabloff
CEO
Virtual Health

In the wake of the Affordable Care Act, the pace of technological transformation on the patient management side of the healthcare industry has evolved rapidly, reflecting both regulatory shifts and technological advances. Population health management (PHM) represents one potent example. A few years ago the term was barely in use. Today, however, PHM is one of the most actively used terms in the industry vernacular. With the shifting regulatory landscape, healthcare as a whole is realizing greater patient engagement, collaboration and coordinated interventions. A number of specialized service coordination platforms have appeared to address this need. While such platforms are rapidly securing a stronger foothold, many of them are either rigidly specific to the environment in which they operate, or too expensive, especially for the organizations with the greatest need (e.g., the nonprofit and service-oriented sectors). Thankfully, innovations in PHM are offering valuable solutions to improve quality of care for developmentally disabled patients, as well as increasing operational efficiency and lowering costs.



Adam Sabloff

As a category, developmentally disabled populations are complex by nature and require highly trained behavioral health experts who are equipped with specialized skill sets and hands-on experience. These populations also require high volume usage of specialized residential facilities. The combination of both these elements presents a unique challenge in the world of healthcare. Much of the existing technol-

ogy available today focuses on the management of traditional health problems, meaning acute and chronic illnesses, and is therefore largely ineffective in assisting with the care management of developmentally disabled populations. These systems lack the ability to classify challenging behaviors, track behavior frequency and intensity, manage medications and conditions specific to developmentally disabled individuals, and monitor residential and community progress, all of which are crucial to providing holistic care and services.

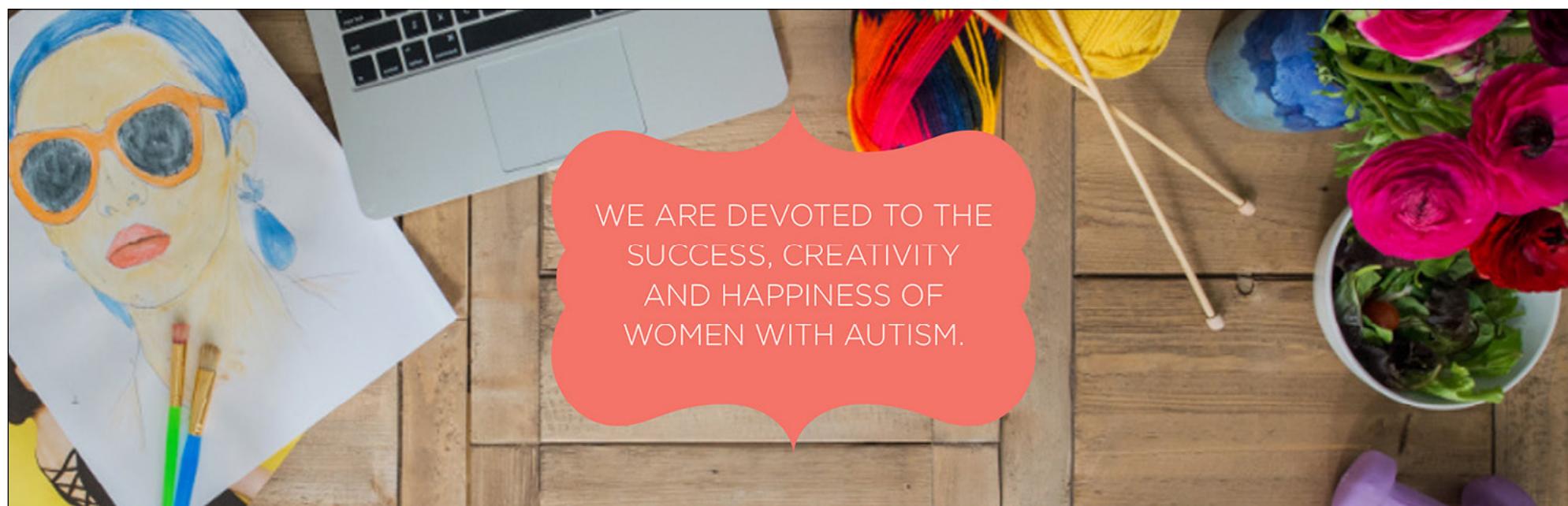
In providing care to developmentally disabled individuals, it is common for multiple caregivers and staff members to support a single consumer, often entering assessments in pen-and-paper formats. The unfortunate end result is error-prone paper records incorporating different terms and descriptive language that require a laborious and manual process to properly collate, input into an electronic system, cleanse for data analysis and assess on an apples-to-apples basis. As a result, it has been challenging to identify care gaps and determine optimal treatment protocols for such complex, specialized populations. Thus, any tool that can address the underlying challenge of providing better quality, cost-effective care to these populations will have significant social and financial valuation.

To solve these unique challenges, the

industry is seeing an emergence of innovative, comprehensive and—perhaps most importantly—customized platforms. One example is [Virtual Health](#), the pioneering provider of next generation health care technology. Virtual Health has partnered with leading human services agencies such as [Services for the UnderServed \(SUS\)](#) to provide a set of transformational tools specifically supporting developmentally disabled populations. With the help of SUS, Virtual Health has been able to do significant research and development in the area of workflow and pathways that support optimal management of developmentally disabled populations, identifying the unique needs of behavioral health specialists and other experts in the field, and delivering a highly specialized software solution. By grafting a purpose-built set of mental health tracking tools into its medical management and population health backbone, Virtual Health has been able to provide a holistic, consistent, and technology-driven process for the management of developmentally disabled individuals not previously possible.

A key benefit of this framework is the ability to layer analytics for the purpose of conducting both retroactive and predictive research and analysis, allowing program

see [Advancing Care on page 22](#)



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The Changing Times and Tools of Assistive Technology: One Man's Story of College Success

By Dena Gassner, MSW
Director
Center for Understanding

Patrick Kelty is a 27-year-old adult with an autism spectrum disorder whose life was changed by multiple forms of assistive technology. From that first elementary school reading tool, his life has immensely improved.

Elementary School

In his elementary years, PK (as we call him) benefited from the symbolic reading intervention I mentioned, but we also noticed that anytime we reduced auditory input and used symbols or visual instructions, he was more settled and more able to perform. He loved playing games on the house computer. And we learned that if he spoke what he knew, he was more able to demonstrate his competency. His language was not well developed, but with interrogatory prompts, he could, with patience, communicate much more than people presumed he could possibly know. Visual schedules and reminder prompt strategies helped him have a more predictable work at school and home. He was also diagnosed with low muscle tone that could be seen in flat, non-muscular hands that tired and fa-



Dena with her son Patrick Kelty

tigued quickly. His torso struggled to support him in a strong seating posture, which is necessary for writing tasks. All of this increased his frustration so dictation was used in greater intensity and his legibility remained far below grade level.

Also, he developed seizures in the 3rd grade from the open classroom setting that he was in. These are classrooms with no walls and up to 100 students in a very large, acoustically challenging room. We learned of Irlen Lenses that are colored lenses that

filter out lighting that makes visual distortions disappear. This was a transformational intervention. This assistive technology prevented him from needing medication, the seizures stopped immediately, and he no longer required pull out for sensory work. This allowed for more time on task in class, and a more focused effort from him.

Middle School

Upon starting middle school, the class settings were too toxic for him to remain. Bullying and constant struggles to get what he needed became too burdensome so he was placed in a private school with small classes and a focus on assistive technology. There he learned to keyboard/touch type with high accuracy and ultimately, higher and higher speed with games designed to reward him for these skills. But due to the unreasonable delays he had endured in trialing assistive technology, the fluency he needed to transition from simple keyboarding tasks to fluid, effortless transfer of knowledge to the keyboard was still lagging. He continued to use pencil to paper for simple, one-work tasks, circling responses and math tasks. There, the school introduced reading software, but it wasn't Kurzweil yet

see *College Success* on page 24

This is what success looks like...



This is what an adult living with autism looks like!

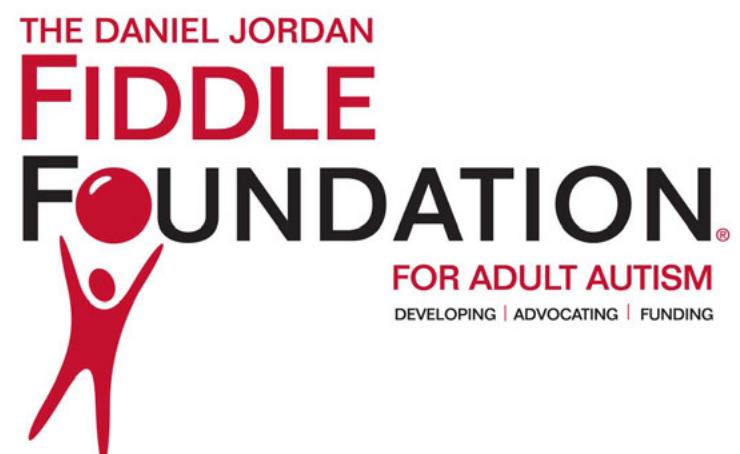
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Applied Behavior Analysis as an Intervention for Individuals with Autism: Reflections on 35 Years of Evolution

By Rita Gardner, MPH, LABA, BCBA
Mary Jane Weiss, PhD, BCBA-D
and Frank Bird, MEd, BCBA
Melmark

It is difficult to find the words that best describe the evolution of autism treatment over the past 35 years. The science of applied behavior analysis (ABA) has changed substantially over the last 35 years. In 1980, autism was considered to be a low incidence disorder that was not as well understood as it is in 2015. In 1980, individuals with autism were routinely diagnosed after the age of six. Specialized programs were few and far between. Effective treatments were in the infant stages of their development. Applied behavior analysis itself was a young science, and the application of it to autism was even younger. Lovaas' revolutionary study demonstrating the power of ABA in changing the behaviors of individuals with autism was still seven years from publication (Lovaas, 1987). Early intervention was not yet a reality for this population of learners, given the late initial diagnosis. Behavioral intervention was available in some specialized settings, though few people with ASD had access to them. In some ways, behavioral interventions lacked nuance. While behaviors could be changed,



Rita Gardner, MPH, LABA, BCBA

they were not yet interpreted, analyzed, and treated with function in mind. Treatment still relied on the use of aversive procedures to a much greater extent than they do in 2015. The assessment of generality, maintenance, and social validity were in their earliest stages.

Looking at the evolution of the field through the lens of time's passage, it may be helpful to see it as a function of the impact of technology on assessment, treatment, and the evaluation of outcomes. We



Mary Jane Weiss, PhD, BCBA-D

are broadly defining technology to include the identification of new ways to understand and treat autism spectrum disorder. New technology has influenced intervention dramatically in diagnosis, the assessment and treatment of challenging behaviors, skill acquisition, and data collection.

As mentioned above, diagnosis in 1980 occurred most often at the end of preschool or in the early elementary years. Diagnosis was generally done through informal assessment and parental interview. Many



Frank L. Bird, MEd, BCBA

individuals who were not "classically" autistic were not understood to be on the spectrum. Furthermore, intervention was a formidable task when individuals were not diagnosed as toddlers. The majority of learners were non-vocal, lacked learning readiness skills that had failed to develop in the preschool years, and had well-established repertoires of automatically reinforced (self-stimulatory) behaviors.

see Reflections on page 22

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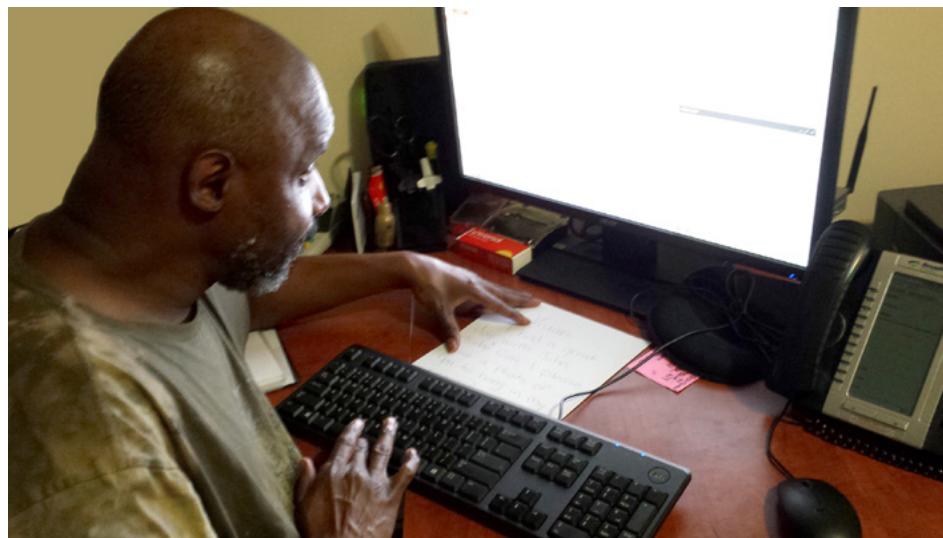
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Internet and Social Media Skills Empower Individuals with DD to Increase Social Interactions and Improve Quality of Life

By John Lampen, RBT
and Vivian Attanasio, BCBA
Services for the UnderServed

Many of us remember a time when paper and pencil were the only way of recording information and encyclopedias and journals were located in a library for research and review. Once the internet was invented our lives changed in many ways. We had access to an infinite amount of information across a never ending variety of topics. We were soon able to send a note through email in real time and look up old friends using social media.

Nowadays our personal lives are very public and employers use social media to determine a possible employee's character by the information that is contained on his/her Facebook page. For some individuals with disabilities, the technological revolution passed them by. Many of our individuals were dependent on staff making telephone calls for them or communicating information about them to their family members on their behalf. Individuals with developmental disabilities were not exposed to the world of technology, possibly because professionals did not believe these were functional skills for them to learn.



Lonzo is working on sending an email to his behavior intervention specialist to ask when she will be visiting him next.

At Services for the UnderServed, individuals are learning to access information on the internet based on their interests, write emails as a way to stay in touch with friends, family and professionals as well as developing a Facebook page to share important events in their lives with friends and family. They are also learning to take pictures with their cell phones and send text messages. This has opened up so many opportunities for them and they are

so excited to be using technology like their contemporaries.

Services for the UnderServed was awarded a Transition to Independence BIP grant by the Department of Health in August 2014. As a part of that initiative, objectives were developed to teach individuals how to operate laptops, desktop computers and/or tablets. This included turning it on, entering a password and manipulating a mouse or mouse pad. Once the individual mas-

tered these steps independently, they were instructed on the purposes for the icons located on the opening page.

Many of the individuals were confused by the idea of the internet, specifically Google search. They were fascinated by the implication that all of the answers to their questions could be answered by the "click of a mouse." Board Certified Behavior Analysts (BCBAs), developed task analyses (small steps of a larger task) for the registered behavior technicians to teach the individuals how to access Google search, create an email and design a Facebook page. Data were collected to determine mastery for each step in the process and additional prompts were added to ensure skill acquisition when needed.

The individuals are now able to take a picture with their cell phones, text it to a friend and upload it to their Facebook page. They are able to advocate for themselves and ask questions to their service providers through email without having to wait for their next visit to the residence. They are able to surf the net to learn more about their areas of interests, get the bus or train schedule or the address for a new restaurant that they want to try out. They are also able to purchase items from stores and concert tickets using the internet.

see Empower on page 18

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Community Partnership and Technological Innovation

By Jordan Jankus
Technologist, Arc of Westchester
and Technology Navigator Fellow,
The Arc of The US

As a great example of community partnership and technological innovation, Jordan Jankus, Technologist at Arc of Westchester, shares some background about Arc of Westchester's partnership with Mercy College in Dobbs Ferry, NY.

Since 2014, faculty and student interns from Mercy College, led by Joan Togli, Dean of Mercy's School of Health and Natural Sciences, have been visiting the agency's residences and other day program sites where Arc of Westchester serves 2,000 people with autism and other developmental disabilities each day. The Mercy College team has been working with Arc of Westchester staff to develop solutions; often involving technology resources, such as tablets and applications (apps), to address some of the daily needs of the people they serve, with the goal being to increase their functional independence and inclusion in community life.

eDocNY, a technology-based social benefit enterprise created under the umbrella of Arc of Westchester, is an electronic document management business that helps its clients transition to paperless workplaces. At eDocNY, Mercy College faculty is



Students from Mercy College demonstrate some of the latest apps to parents and professionals at a recent Arc of Westchester's conference focusing on technology

helping develop touch screen interfaces for the imaging equipment so that it will be more accessible to individuals with cognitive challenges. This new technology will open up employment opportunities for individuals with autism and other intellectual and developmental disabilities.

In one of Arc of Westchester's residenc-

es, an individual had difficulty preparing for his day on a timely basis. Mercy College staff and the direct support professionals analyzed the tasks that the person needed to accomplish and they developed a scheduling program to help him complete those tasks in a timely manner and get out into the community more efficiently. In an-

other residential setting, an individual had medical complications dealing with renal difficulties. With the use of apps and other technologies, including a digital medication reminder device, the nursing faculty and student interns from Mercy successfully taught her to better monitor her medications and dietary requirements resulting in a higher quality of life.

Arc of Westchester and Mercy College have also partnered on several well-attended public events which showcased tablet and app technology for families and professionals in the community. The most recent conference, *Transitioning with Technology*, was held in November and illustrated how technology, both low and high tech, might serve as a valuable resource to help high-school students with autism and other developmental disabilities make a more successful transition to the adult world. Mr. Jankus stated, "Technology holds such potential for people with disabilities, especially those with cognitive challenges and our partnership with Mercy College provides a great vehicle for exploring those possibilities." He also emphasized the importance of first focusing on the person and their immediate need and not just technology. He went on to say, "If technology can provide a solution, that's great, but it's not always the case. The solution might be something as simple as a poster-based

see Partnership on page 18



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Autism and Technology: A Great Benefit and a Double-Edged Sword

By Karl Wittig, PE
Advisory Board Member
GRASP

Individuals with autism have long had great affinity for and been involved with technology, so it is only fitting that modern technology is becoming of greater value and significance to the autism community. I am able to appreciate this both as an adult on the autism spectrum and as a long-time electronics engineer in research and development. I also belong to the generation of engineers that created many of the technologies that we all use today, and which have had such transformational effects on our society and on the way that many of us live our lives. Personally, I was involved in the design of early prototypes for the digital high-definition television and broadcasting systems that are in use today.

Technology has been a very important part of my life since early infancy, when I became "obsessed" with anything mechanical or electrical and with taking apart and assembling anything that I could get my hands on. Although undiagnosed at the time (the broader autism spectrum would not even be known for many years), this is now recognized as a classic autistic special interest, and a fairly common one at that. I had a number of special interests while growing up, but this was both the strongest



Karl Wittig, PE

and the one which I maintained for the longest time. I figured out how things worked by taking them apart and re-assembling them, eventually learning how to repair them. I especially enjoyed finding old radios, televisions, and other electronic devices, taking them home, and getting them to work. This led to my studying physics and electrical engineering in college, and to a career as an electronics engineer.

Years later, when I was finally diagnosed

with Asperger syndrome, I learned that one of the few statistical correlations among people with autism is that they are much more likely to have a close family member in certain occupations, of which engineering is especially common, than are the majority of people. In fact, my father had a degree in electrical engineering. Because my parents divorced very early, though, I barely even knew him and he had no influence on me in this regard. Unlike most people, I did not develop these interests through a role model, as nobody else in my family or environment had even the slightest technical inclination. Instead, I gravitated towards them with no external influence whatsoever. When I informed a half-sister (from my father's subsequent marriage) of my diagnosis, she told me of her suspicion that he might have been on the spectrum as well. With the new expanded definition of autism, I found that individuals on the spectrum were themselves more likely to be in one of these occupations than was the average person. In other words, I was far from being the only autistic engineer around; there certainly were many others. I even remembered some former co-workers and classmates who, in retrospect, had likely been on the spectrum as well.

During the time since my diagnosis in August of 2000, I have learned about the many ways in which assistive technologies are used to help people with autism. Probably the first of these was the computer

keyboard (especially portable and laptop computers), which was of great help to nonverbal individuals with autism, not to mention those with poor coordination or difficulties with handwriting. Along with the proliferation of educational uses for computers, a variety of assistive applications were developed to help children on the spectrum with their challenges, particularly those involving social learning. With the development of even more portable devices like smartphones and tablets, the number of assistive technologies for individuals with autism has exploded. These serve the breadth of the autism spectrum, from severe to mild, as well as the age range from children to adults. In particular, those for organizing time and other resources are of great help to anyone with executive functioning deficits, which many on the autism spectrum have.

Probably the most notable application of technology to help children with autism, however, has been the use of small (under two-foot) human-like robots that I saw exhibited at recent autism conferences. These robots, currently offered as products by such companies as RoboKind and Aldebaran Robotics, are specifically designed to teach social skills to young children on the spectrum, and are very impressive in both their technological capabilities and the receptiveness of children with autism to

see *Benefit on page 25*

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Benefits of Video Consultation for Individuals with Autism Spectrum Disorders

By: Elena Zaklis MA, BCBA, and Glenn M. Sloman, PhD, BCBA-D, NCSP Behavior Therapy Associates

Individuals with an Autism Spectrum Disorder and those supporting them are utilizing technological innovations more than ever before through the use of portable electronic devices in the form of tablets, smart phones, and laptops. These devices are used to assist communication needs as well as to serve as reinforcers to access preferred stimuli (videos and music). The growing use of technology has been used by educators and parents to help generalize skills taught in classroom academic settings/day programs to various community settings.

Professionals may use these same devices to help deliver reinforcement in addition to collecting data on acquisition programs, recording observational data to assess function, and monitoring the effectiveness of problem behavior reduction/replacement programs. The beauty of many of these devices is the inclusion of video cameras. One area that this type of technology may help to better their lives is in the use of video consultation for professional services.

For children with an Autism Spectrum Disorder, caregivers often find that their children require additional services and therapies than those provided during a typical school day. Those additional therapies



Elena Zaklis MA, BCBA

may include speech therapy, social skills groups and sometimes feeding therapy. Navigating to after school therapies and activities may cause stress for any parent, and considering parents whose children have difficulties with transitions, the additional stress of possibly being late or sitting in traffic prior to an appointment. Furthermore, individuals diagnosed with an ASD may have difficulties shifting routines and may engage in problematic behavioral ep-



Glenn Sloman, PhD, BCBA-D, NCSP

isodes (i.e., tantrums, self-injury) when routines are disrupted. These factors to access services, and their cascading effects, can cause unnecessary hardships for all parties involved.

Video consultation helps to circumvent the issues surrounding transportation and transition difficulties for those in need. Although our home state of New Jersey is relatively small, we have the highest density of individuals per square mile in

the US. This density leads to more traffic, which results in lengthy car rides for relatively short distances. By allowing caregivers and professionals an opportunity to consult with those knowledgeable about issues faced by those with an ASD remotely, quality services may not have to be compromised for a lack of psychologists or local board certified behavior analysts (BCBAs). Psychologists, psychiatrists and BCBAs have begun to expand their services by using a video consultation model. Using a secure and HIPAA compliant technology, video consultation has provided families and professionals access to a number of behavior analytic services and trainings. Recently researchers have provided evidence on the benefits of how behavior parent training (Fisher et al., 2014.), treatment of pediatric feeding problems, brief problem behavior assessments, and intervention consultation can occur remotely (Wacker et al., 2013). Results show training sessions that used video consultation have led to significant improvement in the target behavior. By providing video consultation, caregivers and professionals may collaborate at the same time from remote locations. This service may help to ensure that therapeutic services are provided as intended and without disruption. For example, some therapies are provided initially at a clinic setting (e.g., feeding) with the goal

see Video on page 23

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Technology: The Silver Bullet in Education for Individuals with Autism

By Gloria Satriale, JD, MEd, BSL and Thomas L. Zane, PhD, BCBA-D
Preparing Adolescents and Adults for Life (PAAL)

The advent of the iPad and iPhone and a host of other hand-held devices have transformed the way the world gathers, manages and organizes information. One device now encompasses just about everything we need to efficiently execute our lives on professional and personal levels. The same advantages and applications of these devices that we enjoy as typically developing individuals apply to individuals with developmental disabilities including individuals on the autism spectrum. The access to information, music, video and a variety of applications that assist with communication and executive function are both important supports and key reinforcers to individuals with autism and function to enhance quality of life on almost every level. Parents and clinicians regularly report that children with autism are drawn to technological devices and researchers have noted the importance of devising treatments that take advantage of this fascination (Colby, 1973).

Technology today holds great promise for helping students with disabilities learn, communicate, and function effectively in the modern world. Historically, the use of technology was limited to devices special-



Gloria Satriale, JD, MEd, BSL

ly devised for special education purposes exclusively. These assistive technology¹ devices are expensive, complicated to use (in terms of requiring sophisticated training in order to operate them) and are most often bulky and stigmatizing. Today, readily available technology is transforming the way we approach education.² These “retail” devices are easy to use, universally understood, portable and typical in society. These advances in technology are reinventing typical uses of devices creating



Thomas L. Zane, PhD, BCBA-D

new “adaptive” uses that are decreasing stigma and increasing generalized use of technology across environments. Portable devices, such as iPads, iPods, iPhones, or PDAs have the potential of taking teachers out of the equation³ in the instructional interaction and providing widespread opportunity for community immersion and acceptance. Additionally, new research examines how mobile applications such as Smartphones, Skype and Texting Technologies can increase student engagement and

retention and increase learner engagement in an epoch of increasing globalization and diversity. Furthermore, increasingly available technology provides more opportunities for electronic data collection with real-time data graphing, analysis, and archiving. These enabling technologies⁴ are reshaping and reframing the practice of teaching and learning in education.

But remember, when addressing technological applications in education, it is important to understand exactly what the use of the word “technology” is referring to:

Tech·nol·o·gy [tek-nol-uh-jee] *noun*

1. The branch of knowledge that deals with the creation and use of technical means and their interrelation with life, society, and the environment, drawing upon such subjects as industrial arts, engineering, *applied science*, and pure science. (emphasis added)
2. The terminology of an art, science, etc.; technical nomenclature.
3. A *technological process*, invention, method. (emphasis added) (Merriam-Webster, 1994)

Technology does not, therefore, refer exclusively to devices (iPads, etc.) even

see Silver Bullet on page 27

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Becoming the Techie of Tomorrow: Students with ASD Learn Technology

By Beth Rosenberg, MA, MSEd
 Founder and Director
 TechKidsUnlimited.org

There's a lot of talk about why teaching kids technology, in particular programming, in today's educational landscape is good for students. Nearly every other week there seems to be some major news announcement around STEM (science, technology, engineering, math), STEAM (science, technology, engineering, art and math), CS (computer science) and even IT (information technology) education. There's also a current rush for computer science to be taught in all NYC public schools within the next ten years by Mayor De Blasio in a recent New York Times announcement. There are tons of technology camps and workshops for kids, apps to help students with the pre-cursors to learning programming, pre-college programs for gifted high school students and a bunch of start-up organizations who are putting out online programming curriculum step-by-step for the novice coders in the making. However, the question remains, can learning the tools of technology also be beneficial for youth on the autism spectrum?

According to Autism Speaks, advocates for those with autism estimate that up to nine out of ten adults with autism over age 21 are unemployed or underemployed. In



Beth Rosenberg, Founder and Director of TechKidsUnlimited.org and her son.

today's society, students with ASD are still confronted with biases, prejudice, and lack of opportunities. Less than half of students with disabilities graduate from high school and even fewer are privy to meaningful jobs. Unemployment rates are extraordinarily high for adults with autism and yet there are few training programs for young students geared to this population.

According to a November 2015 article from *The Hechinger Report*, "a growing group of educators sees technology work as an ideal field for some adults with au-

tism and hope that tech can provide a career path and a means to financial security. At the same time, employers are beginning to see advantages to hiring people with autism, many of whom have strengths that lend themselves to working well with technology, such as being able to stay focused for long periods of time and to perform repetitive tasks with accuracy."

Many children on the spectrum intuitively understand technology for these reasons and more. Computer code is predictable, rote and follows a set of finite rules - which

makes it comfortable for many of these youth to work with. Individuals with ASD may be the best suited to code but students with disabilities who are school age have been consistently left out of this conversation. In addition, we know that students with ASD are big consumers of technology - how do we make them into producers of digital culture?

Gary Moore and Dan Selic from the *nonPareil Institute* in Plano, Texas, started a combination-training program and software company for individuals on the spectrum. According to *The Verge*, "Non-Pareil is just one of a handful of US organizations that are dedicated to training and employing autistic young adults — which are estimated to comprise 1 to 1.5 million Americans — who demonstrate valuable talents in technological realms." The same with *UltraTesting*, a headhunter-type program for young adults with ASD in NYC. In San Francisco, *Specialists Guild* trains autistic interns as software testers and then works to place them in full-time jobs. Other organizations like *AspiraTech* in Chicago and *Specialisterne*, a Denmark tech organization that recently opened its doors in the US, is also helping to train young adults ages 18 and above with ASD in the tech industry.

Dr. Patricia Evans, a neurologist at Children's Medical Center in Dallas, says

see *Techie* on page 30

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The Lighter Side of the Spectrum ~ A Mom's View

By Carrie Cariello

Dear World, From Someone with Autism

Editor's Note: I wrote this from my son Jack's perspective, based on conversations and observations of him in Disney and in life.

Dear World,

Last week my family went to Disney. We went to the one in Florida, not California. The one in California is called Disney Land and it opened on July 17th, 1955. Disney World opened in 1971.

Anyway, my mom and dad picked us all up from school at 12:14 on Tuesday afternoon. I was in science and I was very surprised when I heard my name on the loud-speaker. When I got in the car they told my three brothers and my sister and me that we were going for a flu shot. We were all very mad about that.

Then they pulled the car over and said, "Why don't we go to Disney instead?"

I didn't know what to think about it. I was happy, but I also like to know about things a long time before they happen so I can think and talk and plan for them.

But this time my mom was all sneaky about it, because she hates when I know



This is me and my family right before we went on a water ride. That's why we're wearing those weird bag things called ponchos.

about trips. I always want to pack my own suitcase full of the things that make me feel calm inside, like my special bunny and my Chapsticks.

One time we argued for two hours because I tried to pack my humidifier for our skiing trip. I kept showing her how it would fit into the suitcase fine as long as it

didn't have any water in it but after a while she shouted, "We are not taking that humidifier, Jack! Stop driving me so crazy!"

We got to Disney around 6:00 at night, and the first thing I did as soon as we got to our hotel was unwrap everyone's soap in the bathroom. I do this every time we go to a hotel. While everyone else is bounc-

ing on the beds and wheeling the suitcases around, I go quietly into each bathroom and find the soap.

We had dinner in a crowded restaurant. I could tell everyone around me was happy-happy-happy, but I could not stop worrying about school. I was worried about missing something fun like a movie during class, and I kept asking my mother over and over to e-mail my teacher.

There was a man sitting right behind me and he was laughing so hard and weird it sounded like a donkey who had just heard the funniest joke ever.

Then my father ordered something pink and spiny called crab legs, and I could smell their fishy smell and it bothered me.

And there was a woman at the table next to us who was wearing a string of Christmas lights around her neck, and they were blinking on and off and on and off over and over again.

All of a sudden my brain could barely breathe. It was already 9:23 PM and I really like to be in bed by 8:30 PM and because of this laughing and the blinking and the smelling I felt like my skin was trying to come off of my face.

I tried doing my newest trick, which is making my fingers dance and twitch in

see Dear World on page 25

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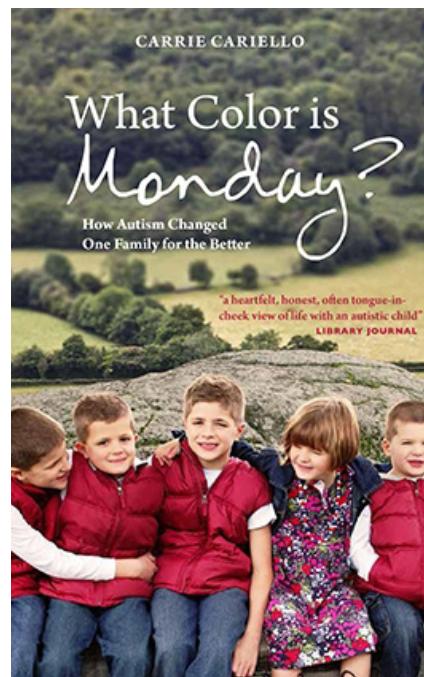
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Different, Not Worse

**By Matthew Ratz, MEd, CESP
Training Program Developer and
Advocate for Adults with Autism & IDD**

What would you say are qualities that make someone a good friend? What are the qualities that make someone a great date? What qualities should a professional look for in a new colleague? When I draw up a list of the qualities my peers and I look for in others, here are some answers: a sense of humor, self-control, empathy or emotional awareness, effective listening, and being comfortable around others. Many people rank these qualities above any technical abilities for the people we want to spend time with.

The list above, though, are soft skills; these are not things people overtly try to learn, but are skills practiced in a variety of settings and on which people rarely receive formal feedback. We may be told what technical skills we perform well on the job, but bosses and managers will rarely tell us that our greetings each morning make colleagues feel special. People spend thousands of hours and millions of dollars trying to improve their soft skills because they know that socially adept people are more successful, more adaptable, and more well-liked.

But what if a person's soft skills could not easily improve? What if that individ-



Matthew Ratz, MEd, CESP

ual's brain chemistry stalled his or her ability to exhibit self-control, understand a joke, or feel comfortable in crowds? These are the experiences of people on the autism spectrum. These are the fundamental, neurological differences that make success in the "neuro-typical world" so challenging for those of us who have autism or for those who love, support, and advocate for people with autism.

My role as a training program coordinator and case manager involves my developing training activities for people with autism; I build tools and exercises through which individuals can learn technical job skills. With the tools I have designed, individuals practice the hard skills for hundreds of different jobs. However, autism affects these individuals' abilities to practice, gain, and exercise the soft skills essential for advancement in the world of work. Similarly, autism affects these individuals' abilities to exercise the soft skills necessary to maintain meaningful reciprocal friendships with non-impaired peers. Because of their autism, these adults may never be fully integrated into the fabric of their communities because they lack the very skills others seek out in their friends, partners, and colleagues. And that is a trend I work to counter, even when I am "off the clock."

Dr. Stephen Shore, a professor of Education at Adelphi University (who has Asperger's syndrome) famously says, "When you've met one person with autism, you've met one person with autism." Autism is a developmental disability that affects people's brain and nervous system development along a wide spectrum and with unpredictable results. The causes of autism have not yet been discovered. Because there are so many variations to its manifestations, some people argue that there may not be a single "autism" but a wide range of different "autisms."

With the ever-rising incidence rates of autism, the latest CDC rates stating 1 in 45 people are diagnosed with an autism spectrum disorder, it has become increasingly important for society to examine its values that contribute to the alienation of those who are different. We humans have evolved the desire to exclude those who are different and avoid the out-of-the-ordinary. For millennia, human beings have traveled in tight-knit groups of familiarity, relying on others' soft skills to determine with whom they would like to spend their time.

But this reliance on soft skills is the very crutch that is kicked out from under the legs of those with autism who are labeled "disabled." As an advocate for adults with autism, I argue that each of us needs to reexamine the qualities we seek out in those with whom we spend our time. Friends and loved-ones need to support our own growth, but our colleagues need not be people whose company we seek, but whose professional skills we value and whose talents advance our collective goals in professional settings.

Through working side-by-side with adults with autism, I have found that it sometimes helps to step outside myself to understand how vastly different people can be from one another. My regular interaction with hundreds of adults with autism has afforded me the opportunity to reflect

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Providing exposure and instruction for technology to our individuals with developmental disabilities has opened up many social opportunities and motivated them to reach beyond their comfort zone to connect with old friends while maintaining relationships with new friends. All professionals should consider adding technology

objectives to ISPs for individuals to learn how to stay virtually connected to others while benefiting from the speed and ease of the internet in their daily lives.

John Lampen is a Registered Behavior Technician and Vivian Attanasio, BCBA, is Director of BIP, at Services for the Under-Served Inc. For more information, contact Vivian Attanasio at vattanasio@sus.org or visit www.sus.org.

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visual schedule or as sophisticated as a calendar app with audible timers. The important thing is that we need to understand the person and their needs first."

On March 31, 2016, Arc of Westchester and Mercy College will be co-hosting *Tech Supports for Cognition & Learning: Everyday Applications & Emerging Trends* on the campus of Mercy College in Dobbs Ferry, NY. Technology experts



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Creating an Online College Degree Program for Students with ASDs

By **Chelsea Donlin, MS, BCBA**
 Behavior Analyst and Adjunct Professor
 Center for Spectrum Services
 and Sage College

Since the early 1990's, a surge in autism spectrum disorder (ASD) diagnoses has occurred (e.g., Robertson & Ne'eman, 2008; Taylor, 2005). The reasons for this marked increase in ASD diagnoses remains controversial, but the reality of this increase has resulted in greater attention to effective educational interventions, early provision of interventions, and in turn the recent increase in individuals with ASDs pursuing postsecondary education (e.g., Robertson & Ne'eman, 2008; Taylor, 2005). Online education offers flexibility and accessibility to those students who may lack important skills for successful participation in traditional on-site courses.

Unlike the typical accommodations and supports designed for students with learning disabilities that are generally commonplace within university settings, students with ASDs may require additional supports above and beyond what the school is familiar with (e.g., Smith, 2007; Taylor, 2005). For many students with ASDs in the college setting, additional prompting may be required to promote adherence to assignment deadlines and course attendance, concrete and specific instructions on as-



Chelsea Donlin, MS, BCBA

signments, adjustment to or alternatives for group based assignments, course lectures available in written form prior to lectures, and computer access for exam completion or note taking (Taylor, 2005; VanBergeijk, Klin, & Volkmar, 2008; Webb, Patterson, Syverud, & Seabrooks-Blackmore, 2008). Additionally, a review of the literature regarding the supports needed for students with ASDs suggest that a major barrier to pursuing and completing a program of

study within a typical university setting revolves around the social interaction deficits of the disorder (e.g., Glennon, 2001). The use of computer-assisted accommodations and supports are commonly suggested in the research as mechanisms to allow students to access academic material if and when the social pressures of the typical environment prove to be untenable (i.e., online access to course materials; email and text chat options for participation; online options for courses [Taylor, 2005]). Taking these technology based accommodations one step further, it may be possible to open up postsecondary educational options for those students for whom the cognitive and social pressures of the typical college experience pose too great a barrier by creating a fully online, distance education bachelor degree program.

The use of computer-based instruction for individuals with autism has been well established as an effective tool in teaching a variety of skills (e.g., communication—Bosseler & Massaro, 2003; writing—Delano, 2007; social skills—Bernard-Opitz, Sriram, & Nakhoda-Sapuan, 2001). The success of computer mediated educational formats with individuals on the autism spectrum could be attributed to the consistency within programs that leads to greater predictability, as well as the ability of the student to learn at their own pace (e.g., Parsons et al., 2000; Swettenham, 1996). While college level courses offered

through online formats would still necessitate the adherence to assignment deadlines, the student is able to repeatedly access and review learning materials such as video lectures or PowerPoint presentations that may have only been available once within traditional college classrooms (e.g., Meyen, Lian, & Tangen, 1998).

A fully online bachelor degree program specifically designed for students with ASDs would, by its very nature, address most of the specific concerns voiced in the literature regarding the strengths and needs of this target student population (see Andreon & Durocher, 2007; Smith, 2007; VanBergeijk et al., 2008). Difficulties in handwriting for students with ASDs are generally addressed by implementing supports such as note takers, laptops, or printed lecture notes (Broun, 2009; VanBergeijk et al., 2008). The online college program would be fully completed through the use of standard computer-based word-processing programs, alleviating any barriers to learning involved in manual handwriting tasks (e.g., Broun, 2009; Myhill, Samant, Klein, Kaplan, Reina, & Blanck, 2007). The need for physical environment accommodations in the classroom would also be ameliorated within the online program. Since the student would be capable of working from home, the accommodations for preferential seating, lighting

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One Father's Experience Developing Apps to Motivate Son with Autism to Learn

By Andre Spivey, BA
 Founder and CEO
 Live 2 Learn Differently, Inc

Much has been said over the years concerning technology and education; there has been and still is an ongoing debate about how we can best implement technology into schools to the benefit of children. Our adult life on a day-to-day basis is filled with technology, from touch screens for ordering plane tickets to self-checkout at the grocery store, so it is pertinent that our children are well-versed with using technology. The popularity of tablets and smart phones has made its way into the education world in the form of educational software and apps. Even textbooks are becoming digital – replacing paperbacks and hard copies. There are a plethora of apps on the market for Android phones, iPhones and even Windows phones. In fact, Google has created an entire section of their app store, called Google Play for Education, that is dedicated to advancing technology in education. As the parent of an autistic son, I've spent lots of time finding ways to make educating my son easier on a daily basis; I've used everything from pictures to PECs, flashcards, boards and more. Currently there are many studies and a major debate surrounding the issue of implementing tablets, smart phones and other technol-



Andre Spivey, BA

ogies into the school curriculum across the US and other countries. Many believe that access to technology increases access to information. However, many also believe that these devices will act as a distraction from a traditional education. The debate differs as countries in the developing world adapt and adopt these technologies, while many undeveloped countries fall behind. It is currently estimated that in the UK 70% of schools have implemented tablets into their education. Meanwhile in the US, only

about 1/3 of schools had done so as of the end of 2014. When focusing on children with autism, the numbers of kids using technology in the classroom decreases, but this of course depends on the type of technology being used. It is most common to see autistic children using primarily "low-tech" devices at school, and a mixture of low- and "mid-tech" at home, due to more devices being available (Coughlan, 2014).

The Impact of Technology on the Autistic Brain

Devices such as tablets and apps have had an interesting impact on children with autism. This impact overall has been positive for reasons that aren't as simple and standard as many would expect. Communication skills has been one of the main challenges among children and adults with autism. Children that don't have the ability to communicate wants and needs often lash out through tantrums, meltdowns or destructive behavior. This behavior is often a result of the frustration from not being able to have your needs or wants met, due to inability to communicate with others. This is often more enhanced among non-verbal children with autism. Often times, improvements in communication result in parents reporting a decrease in the severity of tantrums and meltdowns and a reduction in the frequency of this type of behavior (Heasley, 2013). When we give

the children a device or tool that is more visual than verbal and assist them in communications, we discover more cooperation, patience and more input from the children. It has been discovered that many children with autism are more visual than verbal. This is not out of the norm, because when children are born, during their formative years they learn and take information in a more visual manner. This is normal activity when it comes to processing sensory information, which is typically initiated in the DLPFC (Dorsal Lateral Pre-frontal Cortex). The brain has sensors that intake the information, judge the information, then begin to interpret the data and make a decision. Most of this is perceptual, as children and adults make decisions, learn and act based on what they perceive. The brain is typically great at deciphering information, separating the noisy information from the pertinent (Carey, n.d.).

Why This Matters to an Autism Father and Software Developer

The autistic brain is different than that of a neurotypical individual in unique ways. When using mobile apps and games, children with are able to visually see the actions, communications and messages and also create their own messages to send to others. We are using technology more and

see Motivate on page 27

Examining the Impact of H.R. 3054: The Global Autism Assistance Act of 2013

By Albert Yi, BA
 MSW/MPH Graduate Student 2016
 University of Southern California

The Global Autism Assistance Act of 2013, known as H.R. 3054, is designed to provide training and education to teachers in developing countries with intervention and prevention treatment plans for children diagnosed with an autism spectrum disorder (GovTrack, 2014). It was introduced by Republican Representative Chris Smith of New Jersey and co-sponsored by Democratic Representative Mike Doyle of Pennsylvania on August 2, 2013, because of an increasing prevalence rate of the autism disorder throughout the world (GovTrack, 2014). Autism is an important issue based on the Center for Disease Control and Prevention research data from the year 2000 when the prevalence rate of autism had been 1 in 200 in U.S. children. Since then, the prevalence rate has climbed to 1 in 68 in U.S. children who are diagnosed with the autism spectrum disorder (Center for Disease Control and Prevention [CDC], 2014). This is important because the causes of the autism spectrum are unknown, and there is currently no cure for the developmental disorder (Autism Speaks, 2012). The autism disorder affects all people regardless of race, ethnicity, and social economic status as represented in the CDC data (CDC, 2014). Although the prevalence rate of



Albert Yi, BA

the autism disorder is rising in developed countries, such as the United States, there seems to be a lower prevalence rate in developing countries, such as China, Nigeria, and other developing countries.

Treating autism spectrum disorder is costly, which can create a financial burden to the families of the autism disorder and the United States as a nation, with average costs in the U.S. to be estimated at \$137 billion for services to treat the developmental disability (Diament, 2012). Researchers at the University of Pennsylvania and the London School of Economics found that a child who

has autism with an intellectual disability would cost, on average, \$2.3 million dollars in the United States for lifetime care, whereas a child with autism without an intellectual disability would cost, on average, \$1.4 million dollars in the United States for lifetime care (Diament, 2012). The rising concern of the autism spectrum has a greater impact on families financially and emotionally because of the expenses to receive services for their children of the autism disorder (Autism Speaks, 2012). Past President Mark Roithmayr of Autism Speaks emphasized the need for the health insurance companies to cover services for the autism spectrum, because many families are denied coverage which can force families to pay out of pocket expenses regardless of their economic status (Autism Speaks, 2012). Research has shown that the autism spectrum treatment is expensive for both direct medical care and non-medical care, and the non-medical care accounts for a larger proportion of the costs to care for individuals with the autism disorder (Autism Speaks, 2012).

Nongovernmental organizations, such as Autism Speaks and The Autism Society of America (ASA), believe that early intervention and prevention planning can help offset costs in the long term (ASA, 2014). Research shows that early diagnosis of autism reduces lifetime costs by two-thirds with access to effective treatment plans for the autism spectrum disorder (ASA, 2014). When access to treatment plans are limited or minimized, it can be overwhelmingly

difficult on the families as many have to adjust their work schedules to accommodate services financially (Autism Speaks, 2012). An article in CNN money explained the harsh realities of life with autism when health insurance companies do not provide accurate information on what services are covered and the fees associated with treating the autism disorder (Dickler, 2012). Families tend to take out loans, find a second job, or ask for donations because of the costs of treatments that are not covered by their health insurance, even after President Obama had signed into law the Affordable Care Act of 2011 (Dickler, 2012). Although treatment plans can be expensive, most of the costs tend to go into adult care for mental illnesses. Autism Speaks and the Autism Society of America elaborate how many children end up in adult day care centers because they were not able to receive treatment plans at an early age or that their families were unable to afford coverage of the autism disorder (Autism Speaks, 2012).

Todd Datz (2006) stresses the need to allocate resources towards intervention and prevention options. Michael Ganz, who is the assistant professor at the Harvard School of Public Health, believed that the current data of how much autism care would cost can vary between direct medical and non-medical care (as cited in Datz, 2006). Ganz believes that the reason for high costs is because of a wide range of

see Autism Act on page 24

Interaction from page 1

For example, Kyle, a 10-year-old boy with ASD, got into trouble at school on a daily basis for inappropriately screaming or hitting others when he was frustrated. One goal for his parents and teachers was to teach Kyle effective ways to appropriately express himself when frustrated. At school, his resource teacher implemented the following behavior program: when faced with a situation that Kyle could not handle in the classroom, he was taught to calmly state, "I'm frustrated because _____. Can you help me?" rather than becoming loud, destructive, or violent. Due to Kyle's limited expressive language skills, he relied on an iPad app to serve as his augmentative communication device. He would tap his finger on pictures that would produce preset vocalizations. According to his behavioral program, if he was successful in expressing his frustration without the use of undesirable behaviors, he was rewarded with three minutes to play his favorite iPad game.

**Finding a New Way to Take
Advantage of Technology for the
Benefit of the Individual with ASD**

In addition to it being used as an alternative/augmentative communication device or as a reward for a desired behavior, technology is emerging as a means to enhance natural social interaction among children with ASD and their peers. Research repeatedly has demonstrated that a cognitive understanding of social skills is useless without opportunities to practice them outside of the clinical setting and in more naturalistic settings with age peers. Given that social demands become increasingly complex with age, and adolescents with ASD are vulnerable to developing social anxiety as they become painfully aware of their own social limitations, it is imperative that we develop targeted interventions to improve social and vocational development in adolescents with ASD.

Since many children with ASD already are attracted to technology, it can be used as a motivator to draw children into natural social interactions. One such effort is ongoing at the University of Notre Dame's F.U.N. Lab (Laboratory For Understanding Neurodevelopment). My colleagues and I at the F.U.N. Lab have developed an evidence-based summer camp for adolescents with ASD. Children who express an



Juhi Kaboski, PhD

interest in technology are invited to participate. We try to keep the composition of the group to roughly 50% ASD and 50% typically developing children. The participants are first taught basic technical skills necessary to program a robot or develop a computer game. Then they are given collaborative group projects in which they have to share robots and computers, negotiate group project ideas, resolve any conflicts, make small talk during breaks, and present their final projects together on the last day of camp to an audience of family and friends.

All these skills are taught directly and indirectly while children are having fun together in a supportive and nonjudgmental environment. We find that regardless of their pre-existing technical or communication skills, children of all abilities are motivated by their shared interest in technology to engage in reciprocal social conversations. Because they are doing something they enjoy and at which they feel proficient, their motivation to learn is high, pressure to engage in contrived social interactions is low, and their confidence grows.

This approach is different from other more traditional peer-mediated interventions where typically developing children are given special training to work with children with ASD. Of course peer-mediated interventions can be highly effective at including children with autism who would otherwise not be able to engage with their peers. They also have the benefit of bringing much needed awareness

and acceptance of autism into inclusive classrooms. However, for high-functioning adolescents, such contrived situations may not be appropriate due to the unavoidable imbalance of power and the lack of motivation to engage in reciprocal conversations. An adolescent with ASD once told me that he feels uncomfortable, and even ridiculous, participating in these relationships set up by his well-meaning teachers. He explained, "These kids don't even like me. They're just being nice to me because they think I'm 'special needs.' They treat me like a baby." On the other hand, when he participates in our summer camps, his proclivity and aptitude for computers seems to level the playing field. He feels he is just one of them, a rare experience indeed for a child who always feels he is different.

Our preliminary research results show that adolescents with ASD who participate in these summer camps exhibit significant increase in social skills and vocational skills, and decrease in social anxiety (Kaboski et al., 2014). In addition to scientific evidence of effectiveness, anecdotal success stories shared by participants and their parents offer much encouragement. One mother sent an email message about her son's involvement in the Computer Game Design Camp: "My heart is absolutely soaring for Nate*! He has come home both days so excited. Although the details are few, which is normal for him, his first words to me (both days) have been: 'I'm so excited. I love it. Finally, something that I understand and don't feel stupid doing. And, I am meeting new friends.'" (*Pseudonym used to protect privacy.)

**Increasing Interest in Utilizing
Technology in Social Skills Intervention**

There are a number of other notable recent efforts to use technology for the purpose of increasing social skills. For example, Dr. Christina Noel at the School of Teacher Education, developed the Minecraft Club for individuals with ASD and neurotypical peers who share the common specialized interest in the video game, Minecraft. The club allows adolescents to work on the virtual Minecraft "worlds" they jointly created while simultaneously learning and practicing how to interact and work with others. Another example is the Secret Agent Society (SAS) developed by Dr. Renae Beaumont at the University of Queensland (Beumont, 2008). SAS is an interactive

spy game where children with ASD learn about relationships and emotions. SAS offers small group sessions for children to discuss the social skills learned in the game and also sessions for parents to support their child's burgeoning social skills development.

I hope to see more such interventions that capitalize on children's shared interest in technology to increase social skills. At the same time, more research to scientifically validate the effectiveness of such programs is needed.

As I type this, I glance at the Christmas presents wrapped under the tree. One of the gifts is for Andy, my 8th grader with ASD. He wants to be a computer programmer or video game developer when he grows up. For Christmas, I bought him a Raspberry Pi starter kit and a programming book for children called *Adventures in Minecraft*. I am giving him something that I know he will enjoy. But more importantly, I am giving him an opportunity to naturally venture into conversations about these things with his cousins and neighborhood children who will find his new toy "cool" and will want to talk about their common interest in technology. Instead of fretting that he is playing too many video games by himself, I will be able to sit back and watch him develop his own video games – with other children.

Juhi Kaboski, PhD, is a Research Assistant Professor of Psychology and Director of the F.U.N. Lab (Laboratory For Understanding Neurodevelopment) at the University of Notre Dame. If you have any questions, please feel free to contact Dr. Kaboski at fun.lab@nd.edu or 574-631-2814. To learn more about her research, please visit www.funlab.nd.edu.

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Reflections from page 10

Over the last 20 years, there has been a radical change in our ability to detect autism in young children. Diagnostic procedures have evolved to include direct observational methods of assessment, enabling diagnosis to be considerably more objective. The ADOS (Lord, Lisi, Lambrecht et al., 2000) is the gold standard measure, and it brilliantly includes the assessment of pivotal deficits that are notable at young ages, including joint attention. Furthermore, outreach to the pediatrician community has resulted in routine screenings of autism red flags at most well-baby visits. Many doctors now administer tools such as the M-CHAT (Robins, 2008) at the 18 month visit, screening for early signs of autism, including the absence of pointing, joint attention, responsiveness to name, and babbling. Parents also have instantaneous access to information on the web about warning signs, leading more parents to identify those signs in their children.

In addition, the Center for Disease Control has altered the prevalence rates, and it is now clear that this is not a low incidence disorder. As a result of all of these changes, and with the increase in information available on the web, awareness of autism is exceptionally high. The media routinely covers autism stories, and autism interventions are frequently cropping up and being touted as effective. This can be a challenge for parents seeking information on effective treatment, but it is much easier to access information about autism in 2015 than it was in 1980.

For diagnosed children who are receiving services, the greatest changes may have occurred in the realm of the assessment and treatment of challenging behaviors. In 1980, there was still a focus on behavior modification in the absence of behavioral assessment. The technology of functional analysis, first outlined in the seminal article published in 1982, was revolutionary (Iwata, Dorsey, et al., 1982). Challenging behaviors are now evaluated in terms of the functions they serve for the learners. Is this individual garnering attention, effectively escaping from tasks, successfully obtaining desired items? In other words, how is this (aberrant) behavior working for the individual; what maintains it in their behavioral repertoire? The assessment of function enables treatment to focus on preventing the occurrence of the behavior through a variety of antecedent strategies and replacing the aberrant behavior with appropriate replacement behaviors.

There has also been a tremendous change in the array of skill acquisition approaches.

In 1980, most individuals with ASD were taught using discrete trial instruction (DTI; e.g., Lovaas, 1981). This sequenced form of instruction enabled individuals with autism to learn concrete skills in an effective way. DTI remains an essential component of educational interventions for autism, and is still heavily relied on to efficiently teach many skills. However, the field has also developed many additional procedures to target initiation skills, including incidental teaching, pivotal response training, and natural environment training (e.g., Fenske, Krantz, & McClannahan, 1991; Hart & Risley, 1982; Koegel & Koegel, 2012; Koegel, O'Dell, & Koegel, 1987; Sundberg & Partington, 1998, 1999). All of these methods teach in more informal and more naturalistic contexts. The addition of naturalistic teaching procedures has expanded the focus of intervention and the identified goals for individual learners, and has resulted in improved generalization of skills. In addition, there has been an increased value placed on the development of functional skills (e.g., Cooper, Heron, & Heward, 2000). Behavior analysts focus on the development of skills that will increase the individual's access to reinforcers, community integration, and quality of life. In 1980, training was fairly simple and straight forward, as competent staff had only a few skills to master in order to effectively teach. Today, the training of staff is a complex endeavor, and it is a moving target. As the field improves and identifies new effective techniques, staff must be trained in these state-of-the-art interventions.

One excellent development over the last 20 years has been the credentialing of behavior analysts. The Behavior Analyst Certification Board (bacb.com) certifies individuals at the paraprofessional level (Registered Behavior Technician or RBT), the assistant level (Board Certified Assistant Behavior Analyst or BCABA), and behavior analyst level, including BCBA (master's level) and BCBA-D (doctoral level). There have been steady increases in the rigorous standards set for certification, and the credentials have become fully recognized as the designation associated with competence.

Data collection has also been revolutionized with new technological options. Hand held data devices and a multitude of apps allow for instantaneous data collection during instruction. The IPAD has been used in novel ways to present instructional material, track progress, and fill the communicative needs of individuals with ASD.

The evolution has been astonishing. With the advent of new diagnostic methods and early detection, individuals are able to

begin effective treatment as toddlers. This has dramatically altered the course of the disorder for many individuals with ASD. Furthermore, individuals receive more diverse and effective instruction, as the number of evidence-based procedures has grown. Challenging behaviors are now routinely addressed through function-based assessments and interventions tailored to those functions. Functional assessment has become individualized in the same ways that treatment has been tailored to individual service recipients. This has led to the development of more effective behavior intervention plans and a far reduced need for interventions relying on aversive procedures. Finally, data collection strategies have been tremendously expanded with the development of new devices and new apps.

As we look to the future, it is with great anticipation and optimism. Autism is routinely detected at young ages. Increasingly, effective treatment is available to individuals diagnosed with ASD. Nuanced applications of the science of ABA have led to assessment and intervention procedures that are more individualized and more effective. The science continues to evolve more precise methods and more precise data collection strategies to track progress and outcomes. The credentialing of behavior analysts continues to become more rigorous, and the BCBA credential is being recognized not only as useful, but also as essential. The field as a whole continues to add to the literature in crucially important areas including the assessment of generalization, social validity, and quality of life. It is impossible to know just what will define the field 35 years from now, but the momentum is high and the future is very bright.

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managers to visualize, trend, tabulate, report and quantify results from selected interventions and regimens. In turn, this provides direct, quantifiable linkages between therapy adjustments and individual outcomes. The attendant ability to visualize patterns and trends in real time stands in stark contrast to traditional practices comprised of recording paper observations, collecting forms, translating diverse documentation into spreadsheet form by hand, hunting for trends or patterns, and ultimately trying to extract useful conclusions from inconsistent datasets.

The advantages of employing the newest developments in population health management for the developmentally disabled are significant and, in many cases, the use of such technologies would not be possible without the financial backing of state health agencies. For example, the vitally important efforts of SUS are supported by New York State's Office for People with Developmental Disabilities (OPWDD), an agency responsible for coordinating services to more than 126,000 individuals with intellectual and developmental disabilities. For states like New York that offer monetary support, the significant expense of providing care for

specialized populations—like those with developmental disabilities—presents a built-in incentive to identify new ways of providing higher quality, cost-effective care.

It appears likely that the next wave of progress in caring for complex populations will come from innovative health-care organizations working with government agencies and leveraging pioneering technologies—like those provided by Virtual Health—to better manage, understand, coordinate and ultimately care for patients. By using this technology to create a comprehensive approach, record a consistent and accessible set of data

points, and collaborate with interdisciplinary care teams, caregivers are able to optimize treatments at the point of care. Already the use of such technologies has been shown to reduce the costs of care for certain individuals by 50 percent or more. Although PHM solutions have primarily focused on acute and chronic patients, the work done by SUS shows that the potential impact for highly complex, specialized populations may prove even greater.

For more information, please visit www.VirtualHealth.com or email adam@virtualhealth.com.

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the spectrum and their caregivers.

There are countless applications for these devices for the health sector, and there is a growing response from the scientific and medical communities about what data to collect and how it should be processed and interpreted. The introduction of ResearchKit, Apple's new Health application in 2015, made it clear that research with mobile devices is going mainstream. A recent collaboration between researchers at Duke University and the developers at ResearchKit, called "Autism and Beyond", is designed to study facial emotion abnormalities associated with ASD using the outward facing camera of a smartphone. The collaboration suggests that there is going to be an increasing crosstalk between both academic researchers and commercial entities.

One significant area for portable devices in ASD research is a wearable wrist sensor that can typically track arousal through a sweat response (electrodermal activity – EDA) as well as movement (acceleration). Newer models also include the ability to track heart rate and temperature. While classic studies of arousal and sweat response have been in a laboratory setting, what is appealing about these wrist sensors is that they are mobile and can be worn during daily activities. Some children and adults with ASD have tantrums or disruptive behavior and it is the hope that these sensors will be able to identify these events in their early stages or before they begin. In other words, if these devices can detect precipitous changes in arousal that foreshadow a tantrum, perhaps caregivers or clinicians could be alerted in advance to these events through mobile technology connected to the wrist sensor in order to minimize the behavior. This area of research is interesting but in nascent stages. What is most exciting is being able to understand how to use the various readouts from these wrist sensors as a way to better understand the internal state of an individual with ASD who may not be able to communicate as well about how they are feeling (either in a positive or negative manner). If we can continue to study how physiological measurements correspond to different moods, emotions, attitudes and health conditions, we will be better equipped to understand



Rebecca M. Jones, PhD, MPhil

individuals who have difficulty expressing how they are feeling.

Another significant area of expansion is developing novel applications for smartphones that better track an individual's daily behavior, particularly tailored for those who are on the spectrum or a caregiver of someone on the spectrum. Traditionally, information about behavior such as language, social skills, restricted interests or tantrums are collected via paper and pencil. When there is an interest from either a clinician, school and/or research study to measure changes in behavior over time, these paper and pencil questionnaires are administered repeatedly. Collecting data in this fashion is tedious and redundant both for those completing the forms as well as those who are interpreting the data. They are also potentially more prone to human error. Methods that rely on electronic entering and storage of data facilitate all aspects of the data process and have the potential to be less time intensive.

Smartphones also offer flexibility and immediacy in data collection since caregivers can answer various questions about their child, student or patient in real-time. This means not only ease but also speed in general data collection and the ability to provide real-time reports about a child's behavior. Research questions can focus on 'what is happening right now' or 'what

happened today', versus static questions that target a general trend about behavior. Mobile devices may be able to provide a more complete picture of how behavior changes across time and also how it may vary in different contexts. Lastly, caregivers may be more motivated to complete data collection on a mobile device because of its constant availability. The ability to offer an adaptable time window is especially important and appealing to those who are taking care of children with ASD. Lastly, in cases where individuals with ASD provide self-report, they may be more motivated to do so on a mobile device versus the traditional paper and pencil methods.

Quick automated analysis algorithms are tackling the high volumes of data that are generated by portable technologies. For example, recent work that has designed automated tools to measure eye contact from video cameras embedded into commercially available eye-glasses (Pivothead glasses) (Ye et al., 2012). In order to generate information on the frequency and duration of eye contact from videos, a researcher typically needs to manually code the video frame by frame. This process is time consuming and prone to human error. The automated algorithms are more efficient and are equipped to handle the large amounts of data that are generated by the video camera. These algorithms developed for wearable eye glasses is just one example of the many different computer algorithms that are being developed to process data generated from wearable devices including wrist sensors, devices that record spoken language and information from smartphones. This is an exciting area where research and the technology industry intersect and it is clearly mutually beneficial.

The types of devices as well as the capacity of existing devices to collect real-time information is growing and I expect that we will continue to see innovative tools that are adapted specifically to the needs of individuals with ASD. For example, there are wearable vests that measure electrodermal activity (EDA), acceleration electrocardiography (ECG) and temperature (Fletcher, Amemori, Goodwin, & Graybiel, 2012) and these might become tools that are particularly helpful when an individual with ASD has sensory sensitivities and will not tolerate a wrist sensor.

It is likely that wearable technologies will become more commonplace for individuals with ASD and that, increasingly, families and schools will want the data from these devices to be processed in a way that provides them with real-time feedback that they can use to change how they engage with the child or adult with ASD. While there are many privacy concerns that are beyond the scope of this article, the more data that is generated about the child or adult with ASD, when used in conjunction with clinical observations and recommendations, the more we can optimize treatment for those with ASD. Ultimately, portable devices may help us to understand the everyday fabric of living with ASD.

For more information, please visit www.nyp.org/autism.

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to have the individual demonstrate the skill independently in the home, school and community setting. Scheduling these observations for the entire team (child study team members, parents and other professionals) to attend the clinic and problem solve may be possible with the use of video consultation.

With video consultation, parents and caregivers can be supported while providing interventions for the components that have been determined to maintain the problem behavior. They may be taught to provide both intervention and prevention strategies in the comfort of their homes. In some cases, families may struggle to have all caregivers attend trainings at the same place (e.g., traveling to the appointment from a work destination); with video consultation parents can attend from two different remote locations and participate at the same time. An additional benefit is that extended family members (e.g., grandparents, older siblings) can participate in the training, which is helpful to ensuring

consistency among all family members. Alternatively, those seeking video consultation services need not be caregivers. Group homes and school districts may find that travel may make accessing BCBA services cost prohibitive. BCBAs may find themselves providing initial on-site consultations with follow-up consultations given remotely. There are clear advantages with video consultation over that of a telephone-consultation model behavior, antecedents and consequences can be observed directly rather than described, making the consultation more effective and efficient. With the portability of electronic devices, behavior can be seen where it happens, in the community or at school as long as the minimum bandwidth is secured.

Other types of video consultation services may be useful. In the area of case management, parents may desire a second opinion from an outside professional. For example, parents may seek advice about their child's educational program and prefer to have a 1:1 consultation with a professional that they can see rather than a voice

over the phone. Additionally, parents may require on-going assistance in securing services from a state's Division of Developmental Disabilities. A knowledgeable professional may help navigate the state's system to obtain entitled services. Another aspect where video consultation may prove useful is assisting individuals with more severe disabilities with the transition to adult services/group home settings. Sheltered workshops may not have access to professionals trained in behavior analysis. Travel time and access to the new location may become cost prohibitive and cause difficulties when ensuring services. By using a common professional, continuity of services is ensured and is beneficial to the individual.

Overall, professional services may be able to be provided via video consultation. Psychiatrists, psychologists, and BCBAs may work with families and educators that are encumbered with distance to make the trip to multiple offices impractical. The saying "it takes a village" is truly the norm when we examine the community efforts necessary to provide quality care and services for

those with Autism Spectrum Disorder.

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(www.kurzweilededu.com). Soon, he was performing at grade level.

It's also important that I mention the use of video games. PK used simple games like Lego Star Wars to learn persistence, patience, determination and to pace himself between pleasure-seeking activities and prioritizing academics. Also, the Wilson tutor, Miss Tiffany, used learning games during break times in his remediation so every moment of the remediation protocol included the opportunity to read and learn.

High School

After a difficult battle, he was provided strong supports in high school. He received Wilson Reading program that allowed him to learn the decoding and phonetic foundation that he had been denied during early elementary, due to his autism, sensory assault and simply put, the darkness surrounding the early days of understanding autism in the early 90's. He used Wilson intervention for two years and finally learned to decode the symbols he loved so well.

The high school used Kurzweil more often, but still, the temptation to read aloud to him was so much easier, the teachers found the Kurzweil to be a bit annoying. So while he was getting the work read aloud, he was still person dependent for most things. One regret I do have is that we never wrote goals to learn to *read* cursive. His signature is still printed and this is not a problem, but not being able to read cursive continues to be a bit of a barrier.

But the use of a note taker, 1 hour a day of 1-2-1 support, dictation to scribe for written work and the strong commitment of his teachers and PK's own work ethic resulted in an excellent outcome. He was so academically successful, he got to manage the ice hockey team and enjoy many of the same extracurricular joys as other students.

College

PK is now at Marshall. He tried another learning disability specific program in Florida, but they were overwhelmed with managing entire classes of students with disabilities, and did not find in their hearts to invest in PK's success. But Marshall's program was quite individualized, invested, committed, and flexible about working collaboratively with us to provide his assistive technology needs and the other supports to help him achieve.

Vocational Rehabilitation has provided PK with two different computers over his post-secondary career, his Irlen lenses and the cost of a private tutor. He's received two Kurzweil systems (one and then an update). They also provide his tuition costs and fees for the Marshall College Autism Program.

At Marshall, because of the College Program, his Kurzweil has been provided with 100% consistency, resulting in constant and stable access to the written curriculum, with complete independence. His tests are provided partially with Kurzweil reading and sometimes, depending on content, with read aloud. To facilitate needed movement, he dictates his test answers utilizing separate testing accommodations. He uses a color-coded visual schedule that is provided every Monday. While many interventions have come and gone, the Irlen Lenses are his one constant. They allow access to all learning environments, ease of learning and sensory regulation. I also believe they have diminished the need for prescribed medications. Of course, each person's benefit is unique and not everyone will enjoy such an outcome, but this has been our experience.

Independent Living

Assistive technology has helped PK live more independently, too. After two years in the dorm, he now lives in his own off-campus apartment. He has important details posted on a whiteboard (emergency/family contacts, the code for the laundry room,

police, and fire). He has an old-fashioned calendar that I fill in with all of the important dates for his term. We write out his rent checks and he uses the ATM to report his balance, to know when to sign them and drop them by the rental office. This is all "assistive technology" that even non-disabled persons use!

Very low-tech support happens with kitchen equipment, the shower and the water emergency shut off valve—red nail polish marks the settings so he is protected from burning himself or being unable to respond in a crisis. He uses his cell phone to check the weather to know what to wear, to text clarifying questions for independent living (how do I put a Band-Aid on my toe?), and in September, to address a lock out (only his second in three years!).

The greatest accomplishment for me is that now, because of the consistency of the access to Kurzweil, PK is reading independently. They are high interest, low reader books (chapter books) but he reads from the time he wakes until he retires and this was on my "mommy wish list" for as long as I could remember. I live to read, and I so wanted him to have that love of reading. And now he does!

As you can see, the use of assistive technology has been ongoing and of greater and greater value over his life. Going forward, I believe technology will allow him to be employed and to work in the community. His mastery of technology and the ability to read maps and bus schedules will lead to more independence and community navigation. Every moment of his life benefits from the use of both use of both simply and complex assistive technologies help with school and home. He has achieved the level of independence we had most envisioned in our dreams for him, not by outgrowing technology, but by maximizing technology.

That is the most important message I can convey. Maximizing assistive technology options reduces physical and cognitive fatigue, so a paradigm shift needs to happen for students requiring these supports.

Assistive technology needs to be provided earlier, with more consistency from teachers who are highly skilled at training students to take the greatest advantage of these benefits. I am deeply saddened to think about all of the very capable students who are held back or completely denied the ability to show their intelligence because of the lack of assistive technology. And deeply grateful that some angels did see his intellect and his dedication to learning, and were willing to put forth the effort to see him succeed.

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She is a national board member for GRASP and the Arc US and an advisory board member for the Autism Society. In 2014, she spoke on issues related to autistic girls/women at the UN in Geneva and recently consulted to the autism researchers at Cambridge University for Dr. Simon Baron-Cohen's team. She seeks to live a fully authentic life not by overcoming autism but by wholly embracing and maximizing her abilities including her autism. For more information, visit www.denagassner.com or email c4ucontact@gmail.com.

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services; however, with further research to utilize what treatment plans are the most effective forms of treating the disorder, it could create less of a financial challenge for the family (Datz, 2006). There is currently no known cure for autism, and it tends to be more common in boys than in girls (Datz, 2006).

There is a concern about the differences in prevalence rates between developing and developed countries in an article of the Harvard College Global Health Review (Maguire, 2013). In many post-industrial, developed countries, many are experiencing an increase autism spectrum prevalence rate; however, in a developing country such as China, it is estimated that 1.1 in 1,000 children are diagnosed with an autism spectrum disorder. This brings to question: why there is a difference in prevalence between developed and developing countries (Maguire, 2013)? Maguire believed that the reason for the differences is because many developed countries have better autism spectrum detection and services that provide intervention and prevention treatment plans. In many developed countries, doctors have more experience and are familiar with autism spectrum dis-

orders, health services provide early detection and intervention plans, and many families are becoming increasingly aware of the pervasive disorder (Maguire, 2013). Developing countries do not have health-care professionals, who are trained and experienced in the field of the autism disorder. Many of them do not have the necessary medical capabilities to diagnose a child with autism, which could be a factor as to why the prevalence rates are low in the developing countries (Maguire, 2013).

Maguire believed that differences in culture may play a factor into why the prevalence rates are low in developing countries compared with developed countries. An example is in South Korea, where having a child diagnosed with an autism spectrum disorder is a stigma that forces families to avoid having treatment or early detection of the developmental disorder (Maguire, 2013). Other countries, such as India, believed that it was natural for males to speak later on in life; however, evidence may show that they suffer from a language impairment which is associated with the autism disorder (Maguire, 2013). With cultural differences in their perspective of autism, there needs to be more educated and trained professional to help utilize treatment plans with cultural awareness, and reduce costs of the disorder

at the global level (Datz, 2006).

The current status of the Global Autism Assistance Act of 2013 (H.R. 3054) includes the prevalence rates are for children of autism, how autism is defined by Congress, and the effectiveness of early detection, intervention, and prevention treatment plans (CongressGov, 2014). The legislation allows large nongovernmental organizations, such as Autism Speaks and the ASA to lead autism cause and provide funding to medical clinics with experience in diagnosing autism spectrum disorders (CongressGov, 2014). Since the H.R. 3054 is designed to provide education and training to health-care professionals in developing countries, it allows for professionals to share information on how to best utilize the intervention and prevention treatment plans, and create a team to address the growing autism spectrum prevalence rates (CongressGov, 2014).

The growing prevalence rate of autism is a big concern leaving many families to worry and doubt as to when and how to treat the disorder. The importance of the H.R. 3054 helps to provide many developing countries techniques, education, and training to help combat autism. The medical clinics in the developing countries would be better equipped to detect and diagnose autism spectrum disorders at an early age. With

training and education for professionals who specialize in autism spectrum disorders in the developing countries, families will be able to receive intervention and prevention plans for their children.

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Dear World from page 17

front of me. It makes me feel good but I can tell it does not make my mom feel good because she leaned over and asked me to stop. She said we should have brought my stress ball, and if I had known about the trip, I would have reminded her a lot of times to pack it.

So I tried to keep my hands very still but I felt like a balloon that was going to pop. I had to do something, so I shouted "What the F*&%!"

I know these words are bad, but sometimes they feel so good to say. They feel hot and salty on my tongue and when I shout them, it's like letting a little bit of air out of the balloon.

Words are very weird for me. If they sound even a little bit different I have to double-check in my brain before I recognize them.

Like the way my bus driver likes to say, *this is the route home*, and she says it like the root on a tree. When I hear her say this, I think of tall, straight trees with soft leaves.

Then one day we had a substitute bus driver and he said *we're going to take the same route home*, except he didn't say it like the tree root, he said it like *rowt*, so then I had to do my double-checking and figure out what he was trying to say.

We went to visit places called *parks* every day, except they look nothing like regular parks that have slides and stuff. These places are huge and crowded and they have music and food and people called characters wandering around in their big silly costumes.

The minute we stepped into the park everyone—especially my brothers and sister—started to be so bossy about me. It was making me really mad.

"Jack! Over here!"

"Where's Jack?"

"Jack, stay with us!"

Finally I screamed, "Everyone stop BOSSING me!"

Mom took me aside and told me our family just wants to make sure I am safe and that I don't wander off, but it still didn't feel very good. I am eleven, not a baby.

The ride called Space Mountain was so fun. My dad took me and my brother Charlie back to the park until late one night and we rode it all together and it made me so happy. I could not stop talking about it.

Sometimes I can't stop thinking or talking about things, like that night at dinner I kept asking and talking about the death penalty because I saw something about it on the television at the airport. Whatever I am thinking about gets big and huge in my mind and it pushes everything else to the side, like an elephant in a crowded elevator.

My mom got a little mad and said, "Jack! We are in Disney! Please stop talking about the death penalty."

The next day we went to a place called Epcot, which was totally boring and not as fun as the park called the *Magic Kingdom* because it was all about learning.

We were on line to go on a ride inside of this big ball that looks just like one of the golf balls my dad keeps in the garage but he tells us not to fool with, and I turned to my mom and asked when it was going to snow at home.

The lady in line behind us heard me, and she said, "Oh, you said it! You said that nasty word, *snow*!"

I had to do my double-checking because I didn't think snow was a nasty word. Snow is nice. It is cold and pretty and sometimes we don't have to go to school if we get a lot of it.

"Snow is not NASTY. You are freaking WRONG."

When I said this to her, the smile disappeared from her face like someone had wiped it away with a sponge. My mom put her arms around my shoulders and turned me away, and then she turned back to the lady and said a few things quietly. I think she was telling them about my autism.

I used to hate when she did this because it made me feel bad. But my mom tells me a lot that autism is not a secret - it is not something to feel embarrassed or ashamed of, because it is as much a part of me as the freckle on my left leg.

World, all day long you flash and dance around me being your funny, stinky, noisy, happy, scary self. You confuse me.

See, I am like a fish inside an aquarium. I want to watch you from behind the glass. I want to stay in my school and eat my regular food and listen to my favorite radio station and go to bed at my normal time. I do not like surprise trips.

I am safe here, in my bubble. Your sounds are muted and hushed, and I can tell the difference between a nasty word and a nice word. I don't have to listen to your big loud donkey laughs or shut my eyes against your blinking lights.

At Disney we took something called a shuttle a lot. My dad was always shouting, "Come on! We're going to miss the shuttle!" and then when we got to the pick-up place it would have just left like a second ago so we'd stand around and wait another twenty minutes.

One night we were riding the shuttle very late. It was very dark inside, and I was sitting next to my mom and thinking about snow and nice words and nasty words, and then I remembered another word I didn't know.

"Mom. What does *loner* mean?"

"Well, it means, like, to be alone. A person who is alone. Why are you asking? Do you think you're a loner?"

"Without you. For yes."

"Oh, Jack."

I could not see her face, but I could feel her wearing her sadness on her body like an itchy sweater, the kind she makes us wear for our Christmas picture. I put my head on her shoulder and then she put her head on my head, and we stayed that way until the shuttle stopped, even though I don't usually like to touch people for that long.

On our second to last day in Disney, we had lunch in an African restaurant called Sanaa, where we could look out the window while we ate and watch giraffes and ostriches strolling around. Our server was a nice smiley man named Boylson. His nametag said he came from Botswana, which is in Africa, and he didn't get mad when I shouted, "This food. Makes no SENSE TO ME."

After we were done eating this funny bread called naan and my brothers and sister wandered away from the table to look at the animals, I heard my mother ask Boyl-

son if they had autism in Botswana.

She is not shy, my mom.

"Oh yes," he smiled at her. It was not a real smile that made his face look happy, but more like he stretched the corners of his mouth. "It is everywhere."

Then she asked about services, and evaluations, and doctors, and he just looked at her and smiled once more, gentle-like this time.

"You know, there was a boy in our village who could not hear a single sound. Nothing at all. But still, we found a way to talk to him. We loved him."

I was thinking hard about a boy who could not hear a single sound, because I think that would be weird and also maybe kind of nice not to have to hear loud donkey laughs, but when I looked at my mother I could tell she wasn't thinking about that boy at all. I could tell she was thinking about me.

She was thinking about always trying to find new ways to talk to me, and to hear me, and to love me—to nudge me out of my fish tank and into the wide, open world. She knows I don't want to be a *loner*.

I think I know the answer, world.

You and I, we can't be something or someone we're not. We can't change all the way for each other. But this does not mean we won't be friends.

So I think you should keep being your stinky, funny, loud, busy self. Tell your jokes and laugh your laughs and smell your smells.

And I will continue to be myself. I will do my double-checking and try to understand your words and shrink the elephant in my brain so he's smaller, more like a turtle.

In the meantime, if you happen to notice a boy standing in the airport and his fingers are dancing in front of his eyes, be kind.

Be tender.

I am trying.

From,
Jack

"*What Color Is Monday?*" is available on Amazon.com and BarnesandNoble.com. You can also follow Carrie on her weekly blog: www.CarrieCariello.com and Facebook.com/WhatColorIsMonday.

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them. Their various mechanisms are very sophisticated (having many "degrees of freedom" as referred to by engineers) and can emulate a wide range of body movements and facial expressions. As such, they can display a broad repertoire of amazingly human-like behaviors. Most interesting to me, however, was that they were originally developed to train technologists in the field of robotics, until someone brought his small daughter with autism to see the robot and saw that she related to it immediately. This was a significant breakthrough because, up to that time, she had never been able to relate to another human. The robot designs were then adapted for working with children with autism, who generally respond to them much better than they do to humans. Their appeal could even be seen in the response of neurotypical adults, who related to these little robots much as they might to a puppy or a kitten or even a small child.

As significant as the practical uses of modern technologies might be to the autism community, the prospects of learning about, working, and eventually finding

employment in technology-related fields is of even greater significance to a substantial part of the autistic population. Most notably, a number of firms have committed themselves to train and employ adults on the autism spectrum in the field of software testing. This area is particularly suitable for individuals with autism, as it involves very repetitive, systematic, highly-focused work to detect subtle coding errors in computer software, and this population is known to often be exceptionally good at finding a variety of mistakes and pointing them out.

Praiseworthy and commendable as such initiatives are, however, I am strongly of the opinion that there is nothing new about individuals with autism working with and even developing technologies - in fact, I believe that this has probably been the case for much if not all of human technological history. I am also convinced that there are a number of occupations that have capitalized on the strengths and talents of many on the spectrum throughout history and up to recent times. The ability to spot errors and correct them is essential for proof-reading and the ability to do repetitive and

systematic mental work is needed in such occupations as bookkeeping. I am certain that numerous individuals with autism have been employed in these and other related fields. Also, the mechanical talents of many individuals with autism are of great value in the repair, maintenance, and even design of such devices. Consequently, I am once again certain that many individuals on the spectrum have been involved in these areas, both as repairpersons (which I no doubt would have been had I not had the opportunities I did) and as engineers.

Unfortunately, while many technologies have provided great benefits for humanity, some have resulted in great harm as well. The modern age is largely defined by transportation, communication, automation, information, and other technologies that liberated man from the hardships of physical labor, allowed him to travel anywhere in the world and communicate with just about everyone, provided nearly unlimited access to many forms of human knowledge and expression, and generally brought about a quality of life that our ancestors could not even have imagined. Nevertheless, it has also resulted in the most destructive of

weapons, ranging from firearms to nuclear weapons, and brought about considerable damage to our environment. What I am proposing here is that modern technology has had both kinds of effects on the autism community as well.

One adverse result of technology has been (especially since the industrial revolution) the disappearance of jobs which had been performed by human workers but were now done by machines, and the very need for which was sometimes eliminated. Most recently, this happened because of dramatic increases in the capabilities of electronic and especially computing and communication technologies (the power of which have grown exponentially over time). These have greatly reduced the need for human labor in a number of areas, particularly those involving repetitive or systematic tasks. While such developments have certainly affected everyone in our society, I strongly believe that individuals with autism, who tend to be especially adept at such tasks, are affected by this in much greater proportion than the general

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adjustments, and the reduction of distractions during test taking could be controlled by the student to meet their particular needs at any particular time (Myhill et al., 2007; Oravec, 2003). Difficulties with time-management and organizational skills that are often addressed in the typical college classroom through adult prompting or relying on the course instructor's ability to provide clear instructions and timelines, can be supported in the online classroom through platform design while simultaneously promoting independent functioning through the use of non-socially mediated stimuli (i.e., topic and assignment areas presented one at a time where assignments are visually broken down into smaller components; visual reminders on the screen for due dates [Klemes, Epstein, Zuker, Grinberg, & Illovitch, 2006; Stromer, Kimball, Kinney, & Taylor, 2006]).

The literature on successful college transition and retention for students with ASDs emphasizes the need for intensive supports and accommodations related to the social environment of the college campus (Taylor, 2005; VanBergeijk et al., 2008). A great deal of the resources needed to support the successful completion of a college degree is related to this core deficit of ASDs (e.g., Collins, Hedrick, & Stumbo, 2007). Offering a fully online degree program would immediately tear down this very real barrier to the student's realization of a college education. No longer would supports be necessary in the dorm, in the dining hall, at extracurricular activities, or in the lecture hall. The student would be free to access college-level courses without the social pressures of the typical college campus, much like the use of computers for writing tasks has eliminated the pressure of graphomotor difficulties in attending to the content of academic materials (Broun, 2009; Richardson, 2010).

A college or university program seeking to develop an online degree program for individuals with ASD must not only rely on the inherent characteristics of online learning and the general benefits provided

by well-designed e-learning environments. Early and ongoing assessment of individual learning styles and learning needs at the onset of the program ensure that the necessity for individualization in instruction is not forgotten. This could be realized through a systematic learning strategy intervention program that assesses needs at the onset, designs personalized interventions and directly instructs the skill using behaviorally sound instructional techniques, evaluation of the learned techniques within course-specific contexts, and ongoing support and practice of the techniques until independent performance is observed (Allsopp, Minskoff, & Bolt, 2005). Training in evidence-based learning practices for individuals with ASD for faculty or the provision of highly skilled support staff to act as "mentors" for students will be needed and a systematic plan to fade these outside supports. It is feasible to utilize individuals with such expertise in applied behavior analysis (ABA) and ASDs as individual mentors as well as instructors for those courses or support programs that directly address the core deficits found in the disorder. The role of these mentor-instructors should include assessment of student strengths, needs, and learning styles as well as to act as a liaison between student and academic content course instructors (Carroll, Blumberg, & Petroff, 2008; Taylor, 2005). As the mentor's role fades from direct support and instruction to evaluator and facilitator, the student should be able to demonstrate the self-advocacy and self-management skills necessary to seek out assistance when needed from these services (e.g., Wehmeyer, 1999).

As in any evidence-based intervention, ongoing assessment throughout the program is necessary to evaluate the effectiveness of the supports and accommodations that were put in place to address these needs. This can be realized through the use of the wealth of permanent product samples inherent in online learning environments (e.g., discussion forums, assignments, exam results). One promising mechanism to gather all of these course-work products would be the use of

an electronic portfolio (e.g., Mason, Pegler, & Weller, 2004). The electronic portfolio (e-portfolio) requires that the student (or instructor) select samples from coursework throughout the semester. These work samples could be evaluated not only in terms of a summative assessment tool for each course, but as a means to evaluate the effectiveness of the individual supports and accommodations in place. Finally, attention must be given to assure the generalization of skills to real-world applications. Research has demonstrated that skills learned to mastery within virtual environments can generalize to real-world settings (e.g., Herrera, Jordan, & Vera, 2006; Hetzroni & Tannous, 2004). Providing intensive training based on real-world job or volunteer site contexts through virtual reality simulations could prepare the student for the expectations within their selected site.

By offering a fully online undergraduate program for students with ASDs, the social barrier to obtaining a college degree can be circumvented. While it is necessary that the program addresses the social needs of this student population, it can do so through carefully planned and proactive interventions designed for the individual student rather than reactive strategies implemented within the often chaotic social realm of the typical college campus. The technology is available. Effective computer-mediated interventions have been identified. Online education can create an academic environment that is at once stimulating and rigorous, but also individualized and supportive to the specific needs of the ASD population.

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upon the qualities I seek for self-improvement. Because of my work, I have added "advancing opportunities for others less fortunate than I" to the list of traits (a sense of humor, self-control, empathy or emo-

tional awareness, effective listening, and being comfortable around others, from above) I seek out in colleagues and friends.

I believe we in the autism advocacy community must continue to speak out so that our friends, siblings, and loved-ones with autism are given opportunities to

share their considerable technical skills in spite of their perceived impairments with soft skills. What I long for is a time when society can look past labels; instead of dismissing people for their weaknesses, we must value people for their strengths.

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population. In particular, occupations such as proofreading and bookkeeping which require these abilities have been decimated, because the tasks are now performed by computer software such as word processors and spreadsheets. Also, those involving repair and maintenance of mechanical, electrical, and electronic devices are much less needed because these have become so

inexpensive that their repair is economically impractical. The result is that many individuals with autism who in the past might have found employment in these areas are no longer able to do so. Unfortunately, the relatively few software testing jobs, beneficial though they certainly are, cannot make up for these huge losses. The result is that unemployment among individuals with autism, who have well-known challenges in finding employment, has greatly

increased; it may very well be that many more were employed in the past than is the case today.

If there is any lesson to be learned from the history of technological advances, it is that it is very difficult, if not impossible, to predict what technologies will be developed in even the near future. It is still more difficult to foretell what they will be used for, let alone how they will be used; only the future itself will tell us. Where the au-

tism community is concerned, we can only be certain that, as new technologies continue to come about, they will significantly affect us. The best that we can do is try to understand their effects so that the community can benefit from them as much as possible, but is also able to address any adverse consequences that they might bring.

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though it is these devices that most immediately come to mind today when using the term technology. Technology equally refers to the process and framework⁵ within which the devices need to be used – one such important technology is Applied Behavior Analysis (ABA). Behavior analysis is a field of inquiry dedicated to investigating and modifying behavior in a systematic way. ABA is: Data-based, Analytical, Able to be replicated, Socially important, Contextual, and Accountable (Mayer, Sulzer-Azaroff, & Wallace, 2012). In combination, we use these technologies to allow us to improvise, adapt and overcome any challenge the environment or function presents as a barrier to improving ability.

Not only is technology innovative and additional research into the use of technology to teach is occurring at a rapid rate (necessary, because much clinical use of technology remains unsupported as evidenced-based practices), but the students and their needs are continuously evolving. These needs must be constantly evaluated.⁶ Vocabulary must be kept functional and current and reflect the relevant environments, age appropriate terminology in order to increase the child's capability for communication need to be considered and, most importantly, behavioral technologies such as data collection to ensure that the use of the technological devices contribute to appropriate progress toward goals must always be used in conjunction with any hardware and software. The handheld devices or applications that run them alone are not the silver bullet to educational innovation some may think. So remember, a comprehensive approach utilizing all available technology is the proper path to integrating technology into your intervention strategies.

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Footnotes

1. Any item, piece of equipment, or prod-

uct system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve the functional capacities of a child with a disability (Individuals with Disabilities Education Act, 2004)

2. Individuals with autism often need external stimulus prompts to initiate or maintain behavior (McDuff, Krantz, & McClannahan, 2001). Technological advancements in the last decade have created cost effective automated prompting devices with the ability to deliver the same levels of prompting with less human interaction and obtrusiveness and often less human effort in managing prompt delivery (e.g. Tabor, Seltzer, Heflin, & Alberto, 1999).

3. An influx of epic proportions is expected with the numbers of children identified with ASD entering the adult system within the next 10-15 years (Advancing Futures with Autism, 2015) at a cost of \$137 billion per year (Cidav, Marcus, & Mandell, 2013) in an environment where there are fewer and fewer services available for adults and less and less professional support for the development of instructional plans (Gerhart & Lainer, 2011) elevating the need to use technology to ease this burden to the highest priority.

4. The IDEA requires an IEP team to consider the need for the use of (assistive) technology and while IDEA does not specifically define what "consideration" by the IEP team means, the case law generally regards "consideration" to mean "careful and deliberate thought" and the generally accepted practice suggests that the IEP team needs information about:

- The student, environment, including general education curriculum access needs
- IEP goals, benchmarks, objectives
- The full range of Assistive Technology possibilities

There are established tools to assist in the "consideration" process such as the SETT Framework, found at www.joyzabala.com. Districts have been required to pay for typical devices (iPad, etc.), software and data plans and the use of this technology can appear in the SDI section of the IEP as well

as have individually stated and measurable goals. Independent evaluation rules apply to decisions regarding technology. Don't forget to include within the IEP the requirement for training or additional supports and services for school district personnel to become fluent in the use of this technology and to provide that the technology will follow the student across environments including home and community. Regarding repairs, according to an OSEP Policy Letter (1994), a school has only two options: repair the family's device, or purchase its "own," in order to assure access to working equipment as per the IEP.

5. For example, the application of stimulus control is technology to a behavioral clinician.

6. Assessment Considerations for the Use of Technology in Education:

Level of Development: At what level is the student's fine motor skills (for assessment of the ability to navigate hardware devices: buttons; swipe screens); Tracking skills; problem solving skills; ability to chain tasks.

Level of Communication: What is the student's current primary modality of communication; can the methodology be effectively digitized (most often can); will the device be necessary for voice output (is the volume sufficient)?

Environmental Factors: Will the device be used across environments (it should). What are the considerations for security (insurance, tracking ability – for student and device); Considerations for stigma (use of earbuds vs. bulky headphones).

Cost: Is Wi-Fi sufficient or is a data plan required? Is a phone necessary or can an iPad meet needs? Is a computer or tablet with the capability to make calls and texts a better solution?

Remember, device and software trials can be an empirical way to determine appropriate technology. Adapted from Dell, Newton, & Petroff (2008).

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more (mainly mobile apps) to add new information into our memory - memory is one of the most important functions of the brain especially when it comes to learning.

Studies have shown that in the "normal" brain, there are differences in gene expression in the temporal lobe and frontal lobe, while in the autistic brain there is very little difference between the two. This in particular affects the synaptic function, which directly relates to how neurons in the brains share information. As a software developer and a father of a son with autism, I take into account how my son will process information while learning and what will motivate, inspire and leave a lasting memory. While taking this into account as a developer, I build and develop apps based on his individual education plan (IEP). This enables me to measure his improvements year to year to determine how well integrating technology and mobile apps are helping him improve in communications,

language, following directions and social skills. What I have discovered is that integrating or "gamifying" his education has increased his motivation and his ability to retain the information, steps and processes. This same effect is true for the large percentage of those who learn through gaming; this is also why early education heavily involves songs and games to teach simple language and number skills. Even the adult workplace is increasingly implementing competition and gaming to motivate its workers (McGonigal, 2011). Children with autism that become accustomed to using technology early will be able to order food, purchase plane tickets, communicate, connect socially and use grocery self-checkout lines among other skills, which will give them more independence and experiences that can improve their life and livelihood as adults. All of us are becoming more and more visual in processing information, so why not take advantage of these technologies in order to teach and improve the lives of children with autism (Seth, 2014).

Andre Spivey is the founder and CEO of Live 2 Learn Differently, Inc. He comes with a wealth and diversity of IT experience spending over 8 years in the US Air Force. During my time in the Air Force, my son was diagnosed with autism. As he began school I became inspired to find a way that I could use my experience to help him learn. We built the start-up Live 2 Learn Differently to have a huge impact on the technology used to teach children with autism and other special needs. Through this he developed the mobile apps "HearMePlease" and "GoToZoo" and many more these educational apps for children with autism. Some of these apps used currently by schools in the United States and South Africa. Andre, has a B.A. in Organizational Management and Leadership Skills from Morris Brown College, and Graduate Certificates in Financial Management, Business Leadership Skills and Executive Leadership Skills from Cornell University. He is also Business Communications major at Harvard Extension School. For more information, please

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creating sets of mice for each animal and then interbreeding them over years.

Autism is thought to stem from the additive effect of multiple mutations, so this advantage is a particularly powerful one for research on the condition.

Flips and Swaps

Michael Talkowski and his team at Harvard University are exploring how mutations in CHD8, a leading autism candidate, influence gene expression.

Some people with autism carry one mutated copy of CHD8. Last year, in a bid to study [how CHD8 might lead to autism](#), Talkowski's team used the traditional method of RNA interference, in which a string of RNA binds and blocks expression of a gene — in this case, CHD8 — and tracked the effects. This method is not ideal because researchers are guessing at the level of expression when one copy of the gene is mutated. CRISPR, by contrast, allows researchers to reproduce those effects directly.

“CRISPR has enabled a way to very accurately, repeatedly and robustly model genome mutation in ways that mimic what we see in actual [people],” says Talkowski, assistant professor of neurology at Harvard University.

His team has now switched to using CRISPR. Another team has used CRISPR to generate stem cells that lack one copy of CHD8.⁸ The mutation is stable over generations, providing a ready and renewable source for future experiments.

CRISPR can also recreate deletions or duplications of long stretches of DNA that occur in people with autism. In October, Talkowski's team reported at a conference that they have been able to engineer [duplications or deletions of the 16p11.2](#) chromosomal region, both of which are associated with autism. They have since also recreated duplications and deletions of 15q13.3, another candidate region.

“Microduplications, especially, is something we're able to do now that I never could have imagined being able to do before,” says Talkowski. He says he plans to reconstruct [even more complex rearrangements in DNA](#), such as DNA inversions that flank duplications or deletions. “Everybody's working on different things to do here, and I think it's really exciting,” he says.

Autism Zoo

To make these intricate manipulations, Talkowski is banking on the continued sharpening of the tool, in ways that enable even greater precision.

In January, Zhang and his colleagues reported that CRISPR can not only block but [boost the expression of target genes](#). This tweak opens up therapeutic avenues — by, say, compensating for the mutant copy of a gene by enhancing expression from the unaffected copy. In another study published this month, Zhang tinkered with CAS9 to minimize its binding to unintended target regions.⁹

Even before these tweaks, CRISPR held the promise of opening up autism research to more sophisticated animal models than mice. “One of the reasons why we have very little progress [in autism research] is probably that we don't have adequate animal models for it,” says Feng.

The rat genome is more complex than the mouse, and not as responsive to traditional genetic engineering methods. Using CRISPR will make engineering rats easier, says [Rodney Samaco](#), assistant professor of molecular and human genetics at Baylor College of Medicine in Houston. [Comparing the rat and mouse model](#) of the same mutation may enhance our understanding of the mutation's effects better than studying it in one type of animal, he says.

Primates are even more difficult to manipulate than rats, says Feng, who has tried many approaches. To create mouse models, researchers typically engineer mutations in embryonic stem cells so they can easily se-

lect for those that carry the mutation. They then inject these mutant cells into mouse embryos, transforming some small proportion of germ, or reproductive, cells. (Once in a germ cell, a mutation is retained across generations.) This implantation technique has never worked in primates.

CRISPR instead allows researchers to tweak DNA directly in a single-cell embryo, so that it is present in every resulting cell in the body of primates, including humans. Feng and his colleagues are using CRISPR to generate a breeding colony of marmoset monkeys with autism mutations. Their [first planned model](#) is a monkey lacking SHANK3.

Tricky Treatments

Because CRISPR makes it easy to create changes that can remain stable over generations, it offers promise as a gene therapy. Its application in people still seems far off, however.

In April, Chinese researchers used the method to modify the gene involved in a sometimes-fatal blood disorder, called beta thalassemia, in fertilized embryos.¹⁰ To circumvent ethical concerns, the researchers [used embryos from a local fertility clinic](#) that were not viable. They reported that the method replaced the gene with low efficiency and may have unintended consequences.

The study reignited a long-held debate about how far researchers should go to make genetic fixes in people. Early this month, a group of nearly 500 scientists and ethicists concluded that the scientific community needs to [address potential misuses](#) of the technology before allowing any more experiments on human embryos.

Still, the idea that CRISPR may have a therapeutic use is exciting, says Feng.

“This is really opening the doors for many things we could potentially do,” he says. “[CRISPR] changed our ways of thinking and approaching autism research. Instead of focusing on research, maybe we should also think about therapeutic approaches.”

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Free Support Group For Families of Adults with Asperger's Syndrome and High Functioning Autism

The focus of the support group is to assist families in understanding the complex issues related to their adult child impaired with Asperger's Syndrome or High Functioning Autism. At many of our meetings, we have speakers address various topics of importance related to these syndromes.

For more information, visit our website www.FAAHFA.com or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group For Asperger's Syndrome and High Functioning Autistic Adults

Focused on: Employment and Vocational Issues, College Coaching and Supports, Socialization, Self-Advocacy, Dating, and Relationships

For further information contact the facilitators:

Patricia Rowan, LMSW - (914) 736-7898 - Patrowan@bestweb.net | Susan Cortilet, MS, LMHC - (845) 406-8730 - Susan.cortilet@gmail.com

Upcoming Meeting Dates: 2016 - 1/24, 2/28, 3/20, 4/17, 5/22, 6/12

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BEHAVIORAL HEALTH NEWS

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“Advocacy Award”



Linda Rosenberg, MSW

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“Leadership Award”



Ann Marie T. Sullivan, MD

Commissioner
New York State
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“Public Service Award”

Tuesday, June 21, 2016

5:00 PM - 8:00 PM

**NYU Kimmel Center - Rosenthal Pavilion, 10th floor
60 Washington Square South, New York, NY 10012**

Online Registration: www.mhnews.org/AwardsReception.htm

5:00 PM Networking Reception - 6:00 PM Awards Presentation

Final Registration Deadline - May 30, 2016

Proceeds from this event will go towards enhancing behavioral health education and awareness by expanding the free print distribution of Behavioral Health News and providing free access to the Behavioral Health News online library of science-based behavioral health information, education, advocacy and vital resources in the community.

Contact Ira Minot with any questions at: iramino@mhnews.org or (570) 629-5960

Social Media from page 6

probation. Their son invited Paul Hines, who had impersonated a much younger person, to their house through a social media website.

How to Stay Safe

I recommend that individuals with Autism and Asperger's (actually all teens) design a Risk Reduction Plan to be able to safely use the internet and social media. I recommend that their parents and other caregivers including teachers and consultants, therapists, and others in their lives assist in the development of the plan as well as a monthly practice and review of the plan, making changes as appropriate to the individual's increasing skills in discerning safe and unsafe practices. This approach mirrors the Individual Response Plans used for physical and sexual abuse (Baladerian, 2014).

It is essential to keep in mind that the rules for safety in internet and social media use are not unique to those on the spectrum, but apply to everyone using the internet. And the phone. And email. There is likely only a tiny number of folks who have never been deceived and lost money, safety or something else by trusting another person whose plan was to deceive. Let's not fool ourselves into thinking that this is a special problem for those on the spectrum. It is a problem for everyone.

Do's and Don'ts for Improving Social Media Safety

1. Know that predators seek victims on social media sites.
2. Know that you cannot trust someone you meet online to be who he says he or she is.
3. Consider how what you are about to do feels. Does it feel a bit scary, risky, or adventurous? Does it make you uncomfortable? Who could you easily tell that you are about to do this or have done it?
4. When you are thinking of how sharing

information feels, consider if there is any risk to you. For example, if someone has asked for your address, phone number, credit card information, social security number, date of birth, etc., keep in mind that with this information you can be found, stolen from, or hurt; Not only you, but also those with whom you live.

5. Keep in mind that just because someone asks for information, this does not mean you have to give it. In fact, think about the request. Why in the world would they want that information? What should you do? You can decline. You can provide fake information.
6. If someone asks you to do something risqué, for example to send pictures of yourself naked or specific body part naked, do not do so. Why not? Most likely the person asking for you to do this is a predator. They do not like you. They want to exploit you. They want to satisfy their own selves. They can later use the photo to blackmail you, to threaten you into doing things you do not want to do but are feeling scared not to do because they said they'd show your photos to others and identify what you have done.
7. If you post pictures of yourself naked or just certain body parts, or in a sexual act, those pictures cannot be "taken back." They will be on the internet forever. If later in your life you want to get a job, you may not get the job as they might see these pictures and tell you "you showed poor judgment, so we cannot expect you to be responsible."
8. Do not post information that tells people you will be gone for a few weeks on vacation. Why not? Think about it. If someone online knows your address and is a robber, they might take advantage of your absence.
9. Think about your feelings when online. If you feel something is creepy or weird or uncomfortable, get out of that site. Do not respond to others from that site. And do not revisit it. You may have

positive or negative feelings while online or when a question is asked. Assess your feeling before answering. Do you feel happy, scared, excited, intrigued, regret, confident, a sense of adventure or a sense of danger?

10. In our culture, we are taught that it is polite (nice) to answer questions strangers and others ask. Yet, some are inappropriate. They make us feel very queasy and uncomfortable. This is the body helping alert us to danger. It is essential to pay attention and get out of that conversation and away from communication with that person. This is our intuition that some are now calling our internal GPS system. Listen to the warnings. Declining to answer personal questions or providing personal information is a smart skill that we are taught as adults. How do you decline the request? You can either say no, just get offline and out of that conversation or provide fake information if you feel you cannot decline. Do not give the numbers of your friends. You can also say that you have a personal rule not to provide any important information to anyone whom you have not "vetted." That means, someone with whom you have had enough time *in person* to believe that they mean well. There is never any reason to give a friend or acquaintance your social security number or banking information. If that is asked, that is a danger sign. Stop communication with that person.
11. Another way to check how something feels is to ask yourself, how would you feel if your parent or sibling or other loved one found out what had been happening in your social media communications? Would they be proud of you? Would they approve? Ask them! They will be happy to provide guidance for you.
12. Always decline requests for photos, phone numbers, addresses or places that you go. Check such request out with parents, or put them on a list of things to not share on social media.

Do not give out your social security numbers, Medicare card numbers. When you give out any of these three sets of six digits, one becomes vulnerable to identity theft: phone number, date of birth, and social security number.

13. Finally, remember that in our culture we are taught that it is "nice" to answer questions and respond to requests made of us. People with autism who have been trained in compliance training formats with rewards and consequences for behaving in a particular way may have a harder time breaking those rules and finding a personally empowered way to manage the rules of safety while enjoying the social benefits of social media. Better to be safe.

You can go online to search "safety rules for social media use" and find many more recommendations. As things change quickly online, check again every three months.

To contact the author send an email to nora@disability-abuse.com or visit www.disabilityandabuse.org.

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Techie from page 16

people on the high-functioning end of the autism spectrum often have an amazing ability to hyper-focus on a task. "They may really flourish at engineering-type tasks or computer design, where their interaction with people is somewhat limited," Evans says.

At TechKidsUnlimited.org, a NYC-based tech educational not-for-profit started by a parent educator and her son who learns differently, technology classes are given to students in weekend and week-long workshops to students on the spectrum as young as 7 up to age 19. Students who have been diagnosed with Autism Spectrum Disorder, that have learning and emotional disabilities, can become technologists early on by learning alongside peers in supported workshops with a 3:1 student ratio and a social worker in every program. By creating, developing and sharing the tools of technology in a supportive and nurturing individualized environment, TechKidsUnlimited.org is

working to change the paradigm for education and employment for young people with disabilities.

At TechKidsUnlimited.org youth learn open-source or free software in workshops and often continue experimenting with the program at home. For example, high support student J.L. learned the complex 3D game development software Unity in a recent TKU workshop where students were learning Unity to make a game which was then deployed to a 3D Oculus Rift headset. Staff noticed that by the second day of the workshop, he had gone way ahead of the other students who were still trying to master this complex and industry-standard software. When asked, he mentioned that he went home and downloaded the free software program onto his own computer (which took an hour!) he then opened his account and continued working on his project throughout the evening. This inspiring anecdote made it clear that students with ASD really have an innate ability and talent to learn and create with today's tools

of technology.

Media experts and educational technologists akin learning to program with learning to read way back in the Renaissance. They argued, should only the few - the monks and clergy - know how to read and henceforth, control the knowledge of the world? To rephrase: should only the smartest math students and most gifted science students hold the secret to programming? With the advent of the Gutenberg Press literacy rates soared just by placing the Bible into the hands of the masses. The same can be said for introducing students of the 21st century to programming where they then can become producers and makers. Getting students to "geek out" by teaching them to learn how to make games, apps, websites and more using step-by-step coding curriculum and intuitive software is gaining momentum. Students with autism spectrum disorder should not be ignored and left out of this conversation.

The hope is that in the next ten years, we're going to have a lot more jobs in the

tech sector to fill and students with ASD will become tomorrow's gainfully employed if they are given the opportunity to explore tech as youth. By working with students on the spectrum ages seven and up to learn and use state of the art software and hardware, students with ASD can become the techies of tomorrow.

For more information, please visit TechKidsUnlimited.org, [@techkidsu](https://www.facebook.com/techkidsunlimited), [facebook.com/techkidsunlimited](https://www.facebook.com/techkidsunlimited), and www.lolaapp.com.

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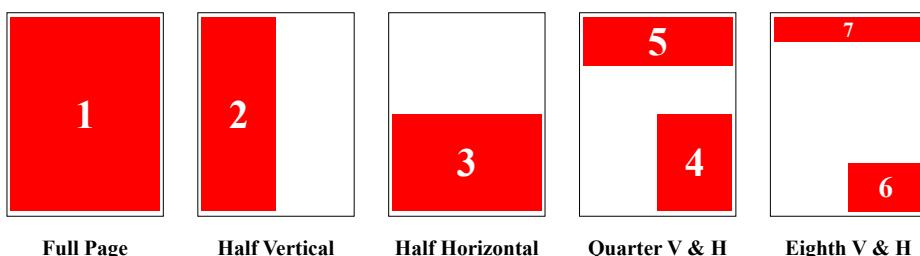
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