



AUTISM SPEAKS | CORE77
DESIGN COMPETITION

AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder (ASD) is a lifelong developmental disability, which according to recent reports affects 1 in 110 people and costs more than \$3.2 million in care during an individual's lifetime due to their special needs. Individuals with ASD may have a diagnosis of autism, Asperger Syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). The word “spectrum” is used because ASD can vary enormously in how it presents itself. Some individuals may have significant learning difficulties, no speech, and many challenging behaviors. Others, however, may be able to hold jobs, make friends, and start a family, but still have difficulties understanding the nuances and complexities of the social world.

Despite the breadth of the autism spectrum, there are three domains that define ASD. The first is difficulties in **social behavior** and comprehending the social world. Some individuals with ASD may be very isolated from others around them, even their parents and siblings, and prefer to keep their own company or engage in non-social activities. Other individuals with ASD may actually desire social contact but have difficulties understanding the rules for forming and maintaining close relationships. The second domain is **communication**. The amount and means of communication varies enormously across the autism spectrum with some individuals never gaining verbal (e.g. speech) or non-verbal (e.g. gesturing; facial expression) communication, whereas others may be extremely advanced in their communication skills (e.g. writing books or making excellent public speakers). The third domain is a tendency toward **repetitive and restricted behaviors**. Some individuals with ASD may prefer a rigid or routine way of living and will avoid new activities. Others may have interests in specific or repetitive activities, such as a fascination with a specific period of ancient history or spending long periods of time lining objects up in a row. Despite these commonalities and difficulties, each person on the autism spectrum is an individual with unique personalities, interests, and skill sets.

The complex mixture of genetic and environmental factors that put one at risk for developing ASD has not been determined, but it is likely that these factors affect how the brain develops. More males than females are affected by ASD, and the reason for this is unknown. ASD affects all classes, races, and cultures. Along with the many challenges in social and communication skills, individuals on the autism spectrum also have higher rates of medical complications such as epilepsy, sleep difficulties, eating problems, anxiety, sensory processing disorders, and additional learning problems.

Individuals on the autism spectrum often face many challenges to becoming fully included and accepted into society, which can make it difficult to access meaningful education and employment, limit options for independent living, and impede social and community connectedness. There is much to learn about what ASD is and is not, and how society in

general can be more accepting, understanding, and supportive of this unique and growing population.

For more information on autism spectrum disorders visit these sites:

- <http://www.autismspeaks.org/whatisit/index.php>
- <http://www.autism.org.uk/en-gb/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx>

THE PROMISE OF INNOVATIVE TECHNOLOGY FOR PERSONS WITH AUTISM SPECTRUM DISORDER

Increased awareness of Autism Spectrum Disorders (ASD) in diverse fields of design, art, and technology can speed the development of tools to help manage the everyday challenges faced by those living with ASD. Here we sketch some of the many ways innovative technologies are currently being designed in academic circles to benefit individuals with ASD, their families, and the professionals who support them.

Technology may be used to **promote interventions** specifically designed for ASD. For instance, because many individuals with ASD have difficulty recognizing facial expressions, DVD-based programs and educational computer games are being developed to teach how to look at faces and identify emotions ([Transporters](#); [Face Say](#); [FaceLand](#); [Let's Face it](#)). Robots and dolls that can track faces, expressions, and direction of eye-gaze are being designed to teach basic social interaction skills, such as turn-taking and imitation, in a way that is more engaging and less stressful for individuals with ASD than face-to-face human interaction ([The AuRoRA Project](#); [Other Social Robots](#) <http://bit.ly/bNy3uh>). Virtual reality technology is being explored as a way to provide a relatively low-cost and easy means for individuals with ASD to practice skills in a variety of reproducible environments ([SIMmersion](#)). Safe Internet social networking sites are being designed to improve social skills in this population ([iSocial](#)), and interactive virtual peers are emerging to help children with ASD practice social communication ([virtual buddy SAM](#)). Other VR and gaming technology is being designed to teach making choices, resolving conflict, collaboration, and even road safety ([Collaborative Puzzle Game](#)). The hope is that using these technologies will help individuals with ASD generalize the skills they've learned in the virtual world to their everyday lives ([do2Learn](#); [Affective Robotics](#); [Secret Agent Society Game](#)). For individuals on the autism spectrum who are minimally verbal, a variety of speech technologies are also being designed. These include low-tech picture cards (<http://pecs.com>), digital speech output devices, voice transformation technology ([Center for Spoken Language Understanding](#)), technology for encouraging vocalization through graphics (<http://social.cs.uiuc.edu/projects/spokenImpact.html>), and mobile applications ([Proloquo2go](#); [Voice4u](#); [Look2learn](#); [Autoverbal](#)). Finally, because individuals with ASD often suffer from anxiety, wearable sensors are being developed to record heart rate or sweat responses to help them understand and communicate their arousal levels during social interactions.

There are many challenges in delivering healthcare to families with ASD, and technology can help families **access clinical resources**. Since there are relatively few autism experts, families can wait many months for an appointment, often being forced to travel great distances. Therefore, telecommunication technology is being developed to support long-distance health care. For instance, a secure online environment has been developed for families with ASD to archive personal health information and allow authorized professionals anywhere in the world to access it ([Personal Health Record](#)). Internet resources are also being designed for caregivers

to record episodes of concern at home or at school and transfer the video directly to health professionals for feedback and advice ([BI Capture](#)).

The rising prevalence of ASD, combined with the high cost of support, has encouraged many designers to focus on technologies that **assist caregivers** and decrease their financial burden. For example, interactive computer simulation software is being designed to teach tutors how to administer behavioral interventions ([DTkid](#)) and to aid the rehearsal of conversation skills. Mobile tools such as personal digital assistants (PDAs) are now coming to market to help individuals with ASD and their caregivers organize materials, establish schedules, and complete day-to-day tasks ([Symtrend](#); [iprompt](#)).

(This summary has been adapted from "[Enhancing and Accelerating the Pace of Autism Research and Treatment: The Promise of Developing Innovative Technology](#)." For more information on additional technologies being conceived for ASD see <http://consumer.healthday.com/Article.asp?AID=640037>.)

ADDITIONAL USEFUL LINKS

MORE INFO ABOUT AUTISM SPECTRUM DISORDERS (ASD)

- Autism Speaks' video glossary lets you sign in to the website and see examples of different behaviors and ways children with autism communicate:
<http://www.autismspeaks.org/video/glossary.php>
- On this website from the United Kingdom, you can see and listen to professionals, parents and adults on the autism spectrum talk about various aspects of the disorder:
<http://www.healthtalkonline.org/disability/LifeontheAutismspectrumAdults>
These may include the characteristics of autism:
<http://www.healthtalkonline.org/disability/LifeontheAutismspectrumAdults/Topic/2251/>
Or everyday life with autism spectrum disorders:
<http://www.healthtalkonline.org/disability/LifeontheAutismspectrumAdults/Topic/2258/>

MORE INFO ABOUT TECHNOLOGY USE IN ASD

- Innovative Technology for Autism (ITA) initiative at Autism Speaks:
http://www.autismspeaks.org/science/research/initiatives/ita_initiative.php
- Article from HealthDay titled "The Fight Against Autism Goes High Tech":
<http://consumer.healthday.com/Article.asp?AID=640037>
- International Meeting for Autism Research 2010 ITA Tech Demo:

<http://www.youtube.com/watch?v=laX-rTYOYoU>

- How children with ASD are benefiting from the iPad:
<http://www.sfweekly.com/2010-08-11/news/ihelp-for-autism/>
- The future of technology for autism:
<http://affect.media.mit.edu/pdfs/08.picard+goodwin-Advocate-printed.pdf>
- Automated technology can capture autism in the home:
http://www.sciencedaily.com/videos/2007/1103-autism_caught_on_tape.htm

MORE INFO ON COMMUNICATION IN PEOPLE WITH ASD

- "The iPad: a Near-Miracle for My Son With Autism":
<http://www.blogher.com/ipad-nearmiracle-my-son-autism>
- Robots and the treatment of autism (NBC morning show clip):
<http://today.msnbc.msn.com/id/26184891/vp/30225368>
- Children with Asperger's syndrome testing a facial recognition tool (Wired Science):
http://www.pbs.org/kcet/wiredscience/story/14-face_reader.html
- The iSet is a device helping people with ASD interpret expressions of emotion (Boston Globe):
http://www.boston.com/news/health/articles/2008/10/27/high_tech_clues_to_facial_cues/
- Inspirational commencement speech made with text-to-speech technology by a student with autism: <http://www.youtube.com/watch?v=O8cEtand01w>

COMMUNICATION IN AUTISM

A special blog for "Autism Connects" by John Elder Robison, author of "Look me in the Eye"
Blog site: <http://johnelderrobison.blogspot.com>

Everyone with autism has some sort of communication impairment. The terms autism, Asperger's Syndrome, Rett's Syndrome, or PDD-NOS describe some of its different flavors. The various conditions that make up what we call the autism spectrum differ greatly in their impact upon us, but the one diagnostic feature they all have in common is communication impairment.

All autistic communication problems stem from brain dysfunction. Autistic people can see and hear just like anyone else, but our brains may not make sense of those inputs in the conventional way. The same is true for speaking or moving our bodies to convey messages. The physical parts are all there and working normally, but we have trouble using them in the expected way due to our neurological differences.

The most obvious autistic impairment is the inability to understand or deliver speech. In our society, if you can't understand what others are saying, you are going to be disabled. If you can't speak for yourself – whether through speech or writing – you are going to be disabled. If you can't do either, you are doubly disabled.

If you can't make sense of a phrase like "Bob will pick you up at five," how will you ever get home? The short answer is, you won't. An autistic person who cannot understand speech might be likened to someone who speaks English in a town filled with Chinese speakers, none of whom speak a single word of English.

However, there is an important difference between a native English speaker in China and an autistic person. The English speaker has all the wiring in his brain to converse. In a matter of days, he will be working out the meaning of simple Chinese phrases. The autistic person does not have a system for learning language. So he can't adapt. For autistic people with language trouble, understanding speech can take years. For some, it never happens.

Speech and language impairments are what we might call left-brain afflictions of autism. What about the people with right-brain issues? Those folks may understand the logical meaning of words just fine, but they cannot grasp the emotional undertone. That's always been my problem. I have no problem with logical meanings, but the unspoken subtext – so vital in expressing emotions – goes right over my head.

For example, when I hear, "That's just great!" I cannot tell if I'm hearing praise or sarcastic criticism. With no clue how to answer, I respond incorrectly much of the time. That's the silent communication disability in autism. People who can't speak are obviously disabled, and cry out for compassion. People with good command of language, but no sense of the unspoken

undercurrents, are often perceived as obnoxious, arrogant, or disrespectful. Those negative reactions lead to depression, anxiety, and in extreme cases, suicide or violence.

Some people on the spectrum have a hard time expressing themselves because they are, for lack of a better word, clumsy. That may sound strange, but issues with coordination and fine motor skills can make it hard to form facial expressions or make gestures to convey a message. If you are really ungainly, your meaning may be lost in a dance of strange-looking movements, or rendered invisible with no movement at all.

Where's Bob? He's over there. Most of us take for granted the ability to swivel and point so that you are sure to recognize Bob. A person who can't do that effectively is handicapped just as surely as someone who cannot utter the words. Unfortunately, many individuals who have problems controlling their bodies also have trouble forming the spoken responses, so they are doubly impaired. Physical responses are an expected part of ordinary interchange; people who cannot do that tend to be ostracized, ignored, or subjected to ridicule.

People with traditional autism – also called Kanner's Autism – tend to have both verbal and physical challenges of varying severity. People with Asperger's Syndrome (like me) are more likely to have impairment in reading or conveying unspoken communications. Some of us have challenges in both areas.

We now recognize that early and aggressive intervention results in far better adult language skills. That's why we feel it's so important to identify and address autistic communication problems as early as possible. Technology plays a key role in both the identification and resolution of childhood communication issues.

For most young people, autism therapy ends when they leave high school. One-on-one therapy is costly; few people can afford it on their own. Adult health insurance is often limited in coverage. That's why we look to technology to help adults with communication issues. I hope to see the development of devices that assist adults with communication issues at all levels, from helping severely impaired people with basic communication to helping less impaired people interpret the subtlety of facial expressions or nuances of spoken meaning.

“AUTISM CONNECTS” Q&A

**A conversation with Sophia Colamarino,
Katharina Boser and Matthew Goodwin**

There has been enormous interest around the Autism Connects Technology & Design Competition, so Core77's Allan Chochinov sat down with Innovative Technology for Autism (ITA) members Sophia Colamarino, Katharina Boser and Matthew Goodwin to talk about the motivations behind opening up to the student design community, about their hopes and dreams for the competition outcomes, and to get some advice for designers who want to contribute to this growing, exciting field.

Allan Chochinov: Welcome Katharina, Matthew, and Sophia! I guess my first question has to do with the genesis of this international student design competition. What were some of the motivations of ITA in engaging the greater design community?

Sophia Colamarino: The goal of the ITA initiative is to encourage effective and inspired technology that enhances the pace of autism research and treatment. We've always promoted collaboration among technologists, designers, engineers, and various stakeholders in the autism community, but we realized we've primarily gone about this by working through the academic community.

For instance, we've funded some great ITA classes at several universities around the country (see http://www.autismspeaks.org/science/research/initiatives/ita_funded_courses.php) as well as many academic research grants. This time we wanted to do something different, so we specifically chose to run this competition through a design community site to engage an entirely new community of talent that has not previously been working on autism. We're basically crowdsourcing to students, although we very purposely kept the “charge” of the competition open-ended to enable them to run with whatever kernel of an idea popped into their minds. Communication challenges can mean different things to different individuals on the spectrum, and we wanted to be as inclusive as possible. My goal is to entice as many bright minds as possible to start thinking about autism-related issues, which is why Autism Speaks is extremely excited about the opportunities this competition will provide.

Katharina Boser: We are very excited to be considering the student input in technology applications for people with autism. Our Innovative Technology for Autism initiative has been around for at least ten years, as a part of both the science program of Autism Speaks and its precursor organization, Cure Autism Now.

Most of our committee members and network consist of either psychologists and clinicians with an expertise in autism (its therapy and diagnosis) or computer scientists and human computer interaction experts. We have never had any input from designers regarding how

therapies can strive for better “design” whether or not high or low technology is engaged. I see the idea of design factors as crucial to opening up the world for a person with autism.

Autism has two specific underlying impairments that I believe designers are particularly good at thinking about. One is that people with Autism Spectrum Disorder are not motivated by the same things that motivate the rest of us (such as social factors), and the second is that people with ASD have incredible sensory sensitivities to touch, taste, smell, audition and vision that can be so extreme as to severely impair daily life and experience. Both of these factors influence the ability to engage and connect or communicate with the rest of us. I see the design world contributing something very important in finding new ways to motivate communication and addressing a range of different sensory sensitivities through the consideration of the physical experience which designers undertake.

Matthew Goodwin: I wanted to add that we’re seeking to encourage out-of-the-box thinking by inviting fresh perspectives from a community with different backgrounds, methods, and styles of solving a problem. The complexity of autism is overwhelming scientifically. Designers are comfortable with complexity, and often produce elegantly simple solutions to hard problems. ITA is obviously also interested in capitalizing on technology as a way to better study, understand, and support those affected by autism. A design competition that takes place over the Internet is exactly the kind of technology use we applaud. The Internet becomes a tool to connect diverse thinkers around a common problem. The openness of the competition is also appealing as it invites transparency, collaborative thinking, and opportunities for flexibility and enhancement of an idea. Many of us working in the field are also entrenched in our own paradigms; what we think is impossible might actually be attainable through a fresh and different perspective.

AC: Talk to us about the level of “completeness” of the entries. A lot of the videos we link to in the brief are finished working products or prototypes, but this competition also invites design “concepts.” How would you characterize what that means in terms of design deliverables?

MG: Every product begins with an idea and undergoes many changes. Nearly all the technology examples we’ve provided started with a sketch on a napkin, underwent numerous revisions after talking with others, and were built in a variety of ways before settling on a finished product. We invite entries at all levels of the design process. Concepts are especially welcome, and designers should not feel confined to actually producing a prototype or tangible product. We can’t build what we can’t imagine.

KB: We also hope to foster collaboration on design projects by getting different experts to contribute their knowledge to the entrants’ concepts through the platform of the open design competition. We certainly welcome ideas that come in at all levels.

AC: So you don't need to be on a team of grad students working on a project that is already funded to enter a design!?

KB: Absolutely not. We want fresh ideas, not necessarily the ones that have all the background knowledge in this area. A “blank slate” or “tabula rasa” with respect to background of autism technology is not a bad thing to bring to the table here; we believe a new perspective is what’s needed to drive the field forward in terms of what is missing with current products. We would love for our designers to be thinking not only of the cost and feasibility of their design but also of ease of use for both the child and the parent or therapist. We included a number of videos that demonstrate the child who clearly is frustrated at a lack of ability to express themselves. And in that frustration, they lash out or have a tantrum (even at age 14!). Many of us have a hard time empathizing with someone who cannot speak or understand language as we are rarely, if ever, in that position. However, it is empathy for the larger-than-life emotions that accompany this disorder, both due to the circumstances of lack of language and because of the impairment, that may just drive the next great design idea in this area.

AG: What are some of the iconic examples you've seen over the years having to do with technology and autism, both and low- and high-tech?

MG: Some of the high-tech examples include virtual reality, social robots, automated facial recognition detection, and wearable sensors that record physiological functions. Low-tech examples include picture-exchange systems, social stories, and sequencing of events on a calendar. Something I hope designers who participate in this competition come to understand is that autism is an incredibly diverse population, so many tools, high and low, will be applicable. There is also likely a “sweet spot” along the low-to-high tech continuum when it comes to accessibility, price, and usability.

KB: Actually, I have a wonderful low-tech design idea that was submitted to me by a parent of a child with autism. She purposefully made it without batteries or electricity because she worried about this device losing charge. Her name is Amy Miller, and she is still looking for a partner to take this idea further, so perhaps someone who reads this interview might want to look her up on the competition site. Here’s her description of the device:

“The concept of the device is a low-tech, interactive way for kids without the needed language or communication skills to be able to indicate what they want. The prototype is a Plexiglas unit with plastic disks that you insert. The disks have a number of pictures on them that when turned move the appropriate picture so it faces out the window. Different disks can have different groupings of items – foods, movies, places, toys, actions (bathroom, etc). The child holds the unit and simply turns the disk so that the picture of what they want is showing. The nice thing is that there’s no electricity, no batteries, etc. So in the car, on a plane, trip, etc. it always works.”

Of course some of the best high-tech ideas involve mobile devices. One design developed by Gillian Hayes at UCSD and LouAnne Hunt was shown at the 2010 IMFAR conference and involved a social compass for kids with ASD. This mobile application would use GPS to recognize social “partners” and then cue the user regarding potential conversation topics, closeness of stance, as well as the necessity to “close” the conversation appropriately. For further information you can see the *Healthday* article included in the briefing packet. There are

so many great new technologies that were displayed at the conference, but they can benefit from further work on user design. We hope some designers consider contacting Dr. Hayes with their ideas, as she will be a member of the competition 'expert mentor' team.

AG: There seems to be a steep learning curve in understanding around autism as a prerequisite to submitting a well-informed, appropriate design solution. How can designers quickly get up to speed to the point where they can contribute valuable design research, insights, products or services?

KB: We hope that we have provided enough materials in the briefing packet for Autism Connects to inform designers of the main areas of impairment and provide examples of types of people with autism. What's very important to remember is that it is a very broad spectrum, and, as has been said many times, "If you've met one person with autism, you've met one person." We encourage designers to spend some time getting to know someone with autism, joining in discussion boards or blogs that have been generated by someone with autism, and watch the video links we provided that show several examples of the range of communication and connection issues that are shared by people with ASD. Linked in, Twitter and Facebook all have autism communities that are easy to find, and designers might consider starting discussions about their topic there. We provided URLs to web pages that give research information regarding autism and technology, and we hope designers explore the expert web pages of those people associated with Autism Speaks' ITA steering committee and the important work currently funded by Autism Speaks and others in the area of communication and technology for those on the spectrum. Our packet includes a description of much of the current technology that has been or is being developed, with links to either YouTube video of its use or websites for further information.

Be careful not to pre-judge from popular movies or books about people with autism, such as "Rain Man" with Dustin Hoffman, as they may often misrepresent. Some excellent novels with characters who have some form of autism or autistic features include Mark Haddon's "The Curious Incident of the Dog in the Night-Time" or "Rules" by Cynthia Lord and my personal favorite is "Marcelo in the Real World" by Francisco X. Stark. Although these are all excellent books, they are often more about the realities of Asperger's Syndrome than autism, and it is important to keep in mind how different these two forms of autism are. Some firsthand accounts to read include Temple Grandin's book "Thinking in Pictures," John Elder Robison's "Look Me in the Eye," Dawn Prince-Hughes's "Songs of the Gorilla Nation" or Tim Page's "Parallel Play." There is an Amazon list of books with ASD characters at <http://amzn.to/bK1HDF>.

SC: There are also two fabulous short documentaries called "Autism Is a World" and "Autism: The Musical." (The first was nominated for an Academy Award and the second for an Emmy.) I always highly recommend these to people who want a quick, easy and very engaging immersion into the world of ASD. Both highlight the special – and very different – communication challenges poised by ASD.

MG: In addition to these materials, there is no substitute for interacting with persons on the autism spectrum. We hope to enable this through the web-based design process (for example,

individuals on the spectrum have agreed to provide input along the way), and also encourage designers to reach out to local service providers. Much of scientific understanding begins with an unbiased observation.

AG: Tell us a little bit more about Autism Speaks, its overall mission and its sponsored programs (such as the ITA). Where do you see it going in the coming years?

SC: Autism Speaks is the nation's largest autism science and advocacy organization. Our mission is to improve the future for all who struggle with autism spectrum disorders, and we are dedicated to funding global biomedical research into the causes, prevention, and treatments for autism. We are also dedicated to raising awareness of the spectrum of autism disorders, and crucially, to advocating for the needs of individuals with autism and their families. We know that everyone has different needs, but the goal of all of our science program activities, including the ITA initiative, is to translate discoveries into opportunities that have a real and *tangible* impact on the lives of individuals with autism and their families. That's the only place for us to head.