



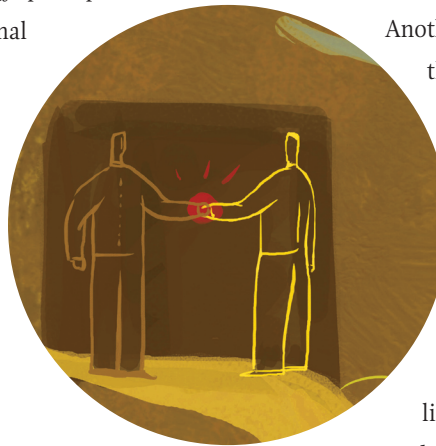
# Innovative Technology

## *The Future of Personalized Autism Research and Treatment*

BY ROSALIND W. PICARD, PH.D., AND MATTHEW S. GOODWIN, ABD

**R**apid developments in technology can be shaped to create a new future for people on the autism spectrum. Before we illustrate that future, consider a common, modern-day scenario: A person goes to an unfamiliar clinic or laboratory and is asked to perform a new task with someone they don't know while wearing possibly uncomfortable medical technology (perhaps electrodes placed on the body or wires taped to the skin). Their personal information streams down wires to a computer where the data are read by researchers, averaged over a dozen or more people who participated in the same assessment, compared to a control group, and then published in a research article months or perhaps years later. The participant (and/or family) may later read the article and learn, for example, that "the autism group has a higher average heart rate" or that "the autism group has more of a specific kind of brain activity," or something else that supposedly holds for that study group. However, these findings may not actually apply to any one individual who was in the group: Their data may appear in significant clusters not numerically in the center, or represent statistical outliers on one or

more scales. Scientists know these statistical limitations and are aware that they are trading off conclusions about the individual for conclusions about the group<sup>1</sup>; however, this represents only one concern with today's approach.



Another enormous problem is that the very nature of going into an unfamiliar clinic or lab for assessment means that only a tiny sample of the participant's behavioral repertoire is used to characterize him or her. This methodology can be likened to someone listening to a dozen bars randomly played from the middle of

Beethoven's Ninth, averaging them and offering the result as a description of the symphony. The result can be rather inaccurate and, when used to target treatment, it misses the mark.

<sup>1</sup>Study of the individual is referred to as *idiographic*, while study of group data, which has become dominant in psychology in the last century, is referred to as *nomothetic*. *Nomothetic* comes from the Greek *nomos*, meaning "custom" or "law," while *idiographic* comes from the Greek *idios*, meaning "proper to one." Allport (1937) introduced these terms to American psychologists and argued that psychology had been defining itself exclusively as a *nomothetic* discipline, and that while both *nomothetic* and *idiographic* approaches are needed, a greater emphasis upon individuality was needed to redress the current imbalance. Several arguments have been put forth for bringing back *idiographic* methods (Molenaar 2004); new technologies and analysis techniques, such as described here, make this approach increasingly favorable.

Measurement and treatment for people on the autism spectrum does not have to be limited by these classic ways of conducting research: it can be dramatically improved with new and forthcoming technologies, if researchers shape them for such improvements. In this article, we present a small set of scenarios from a large space of possibilities, and discuss opportunities that arise in moving toward a future of effective technology-mediated personalized treatment and treatment-guided research.

## FUTURE SCENARIOS

Consider Michael, a primarily non-verbal adolescent boy participating in a lesson. He appears calm and attentive during instruction. When it is time for him to respond, the teacher encourages him to try a little harder as he does not appear to be doing what she is asking. All of a sudden, Michael has a “meltdown.” He engages in injurious behavior, perhaps to himself or to another, frightening the teacher into getting help to restrain Michael. What was intended to be a positive, helpful learning episode turns into a harmful one, with discouragement and possibly even despair ensuing. While there are many variations on this story, with equally many possible explanations, consider for a moment this one possibility: Michael was previously measured as having a heart rate of 120 beats per minute, even while he sat still looking completely calm and attentive on the outside.<sup>2</sup> In such a state he may be experiencing huge internal turmoil, belying his external appearance. How is the teacher to know when all she can see is that he looks calm and ready to learn? There is a chasm separating what he experiences on the inside and what is communicated on the outside.

Future technology can bridge this communication chasm. Tomorrow, Michael may choose to wear a small comfortable wristband, perhaps with his favorite Red Sox logo on it. This wristband contains miniature electronics, sensors, a radio and a coin-sized battery mounted in a flexible package, which can sense and wirelessly communicate selected internal physiological state information to his teacher. The teacher might see, despite his outward appearance of being calm, that he is in an unusually aroused state, perhaps due to pain he is experiencing, or because of background noise to which he is extraordinarily sensitive. With

this information, she could work with him to figure out what is causing this unusual activation instead of pushing the lesson. Thus, the device can help alert a teacher or caregiver to a problem of which they have no inkling, an important step toward making progress together. At another time the teacher might see that Michael’s internal state has significantly lower activation than normal for him, which is, incidentally, quite different from the average value reported from the group laboratory study he may have participated in. The teacher may determine that some kind of stimulation is needed to help Michael move into a state that enables him to better focus his attention for learning.

Consider also the possibility that the technology is sufficiently comfortable that Michael chooses to wear it around the clock. He shows interest in looking at his data patterns and seems to be gaining better self-understanding as well as new communication abilities. He notices patterns in his activation levels that he brings to his parents’ attention. His parents choose to upload the data via the Internet, with personal identifiers removed, to a worldwide exploratory research site where they compare Michael’s patterns to those from other individuals and groups, seeing how his data cluster with those of other participants. The family compares interventions and outcomes that people in this cluster have tried, finding several promising treatments to explore. Over time, the family makes adjustments to the treatment plan, finding that Michael benefits from having new ways to communicate what he is experiencing with those he trusts and understand various complexities going on within his own body.

Michael’s use of personalized communication technology, and the understanding it helps him and his family achieve, results in almost completely preventing his meltdowns. Simultaneously, the long-term, ultra-dense data sets voluntarily contributed by Michael and other autistic<sup>3</sup> participants and their families provide the research community with objective detailed measures. These data can be collected and compared across individuals with similar features, producing a variety of new insights into fundamental aspects of autism as well as into the efficacy of various individualized treatment plans.

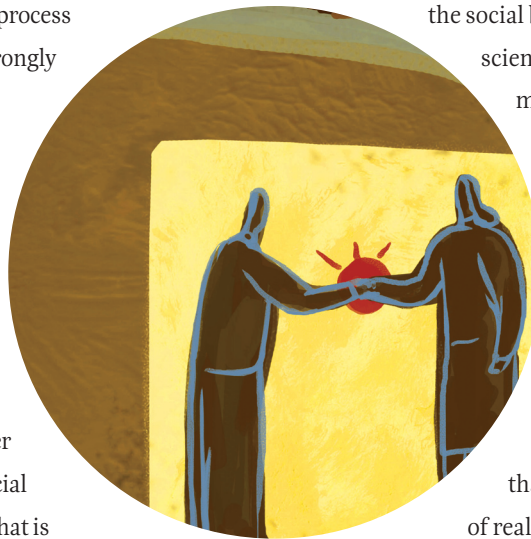
Here is a different future scenario: Sarah is a young teen who has a hard time carrying on a conversation in a face-to-face social

<sup>2</sup> While the name has been changed in this scenario, this situation of having a 120 bpm heart rate, while appearing attentive and calm on the outside, was found in a recent study using a wireless heart rate monitor to record sympathetic arousal while individuals with autism engaged in potentially stressful situations (Goodwin et al. 2006).

<sup>3</sup> Many people diagnosed as being on the autism spectrum wish to avoid “person with” language in favor of being called “autistic” (see Sinclair 1999, [http://web.syr.edu/~jisincla/person\\_first.htm](http://web.syr.edu/~jisincla/person_first.htm), for this respectful use). Others prefer phrases such as “classified autistic” (Biklen 2005). There is currently no overall agreement on language.

situation, especially when she attempts to process facial expressions at the same time. She strongly desires to improve her social interaction skills and make friends. Alas, her attempts at school have met with taunting, bullying and such painful rejection that she has retreated into an online world. While online she gets to practice social language and conversation, and making friends, but she still craves (and dreads) real-time face-to-face interaction with her peers. In the near future, Sarah gets a “Social Learning Companion,” a new technology that is best described as a mixture of a virtual avatar (a computer character that represents the person in an online world, such as SecondLife) and an embodied socially intelligent humanoid robot (which still only fully exists in the movies).

With this learning companion, Sarah has conversations where the amount of facial expression and head gesture activity is controlled in real-time. She plays games that challenge her to not only recognize, but also to engage in socially appropriate turn taking, eye contact and joint-attention. She gains rewards as she achieves behaviors that are



the social behaviors, but it can be a lot of fun. To the scientific community, it is something much more. This technology provides fine-grained continuous measurement and assessment. The technology-mediated interaction is capable of recording actions, timing and various expressive parameters. These measures show that Sarah performs fine with one style of responding in a conversation, and is achieving spoken language together with eye contact, but that she needs to work on some other skills of real-time interaction, perhaps detecting fake smiles or knowing when to nod. Sarah can record, replay

and view the interactive social behaviors where she has trouble, something that is hard to do in a nonmediated human-human interaction. She can upload this information and share it with teachers and caregivers who support her and help her focus on the elements that challenge her most. She can also voluntarily upload her performance on the Web and share it with researchers and others like her to learn more about the specific nonverbal and social communication abilities of people on the spectrum. These tools,

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within the typical social range and timing. She practices looking at expressive faces while listening to expressive speech, adjusting the speed and playing back the interaction until she is comfortable with listening while maintaining a socially natural pattern of eye contact. After getting comfortable performing “socially typical” behaviors with an introductory machine-like version of the companion, she adjusts its appearance, making its eyes increasingly human-like (which scares her and makes it harder for her to perform) and adding other features that ever so gradually increase its human verisimilitude. All of this practice happens in an environment that is free from peer teasing, and that allows her to safely try out and perfect new behaviors without fear of failure or ridicule.

To Sarah, this new social-emotional technology is a challenging game: She has to work hard to produce and respond to

while no substitute for real human interaction, nonetheless give her a way to expand her repertoire and comfort level, connect her to others who are working on the same skills, and develop abilities and confidence for engaging in the real high-speed social world. However, her favorite aspect of the tool is that it is always available to her.

The scenarios above illustrate two possibilities that researchers could bring to fruition by shaping new and forthcoming technologies. These examples emphasize new physiological communication and social-emotional skill development technologies, areas where there is a lot of potential for autism treatments. The reader can find more descriptions of affective technologies for autism by el Kaliouby, Picard, & Baron-Cohen (2006). For a review of many additional ways for current and future technologies to be harnessed to enhance and accelerate the pace of autism research



and treatment, see Goodwin (2008) and the Autism Speaks—Innovative Technology for Autism (ITA) initiative ([www.autism-speaks.org/science/research/initiatives/ita\\_initiative.php](http://www.autism-speaks.org/science/research/initiatives/ita_initiative.php)). These sources highlight how technology can be further used to foster research recruitment and implementation, promote access to specialized resources, reduce the cost of treatments, enhance real-world skills learned in therapeutic sessions and evaluate the efficacy of technological innovation.

Below we raise a few key issues that are distinctive about future personalized treatment technologies, highlighting new opportunities that arise for the whole autism community, together with potential concerns of technology placebo effects and flim-flam treatments, and how these might be avoided.

### GROWING THE RESEARCH COMMUNITY

There is a tendency in some scientific and medical circles to assume that a patient should not become a significant source of information—that this source is not objective and can lead to erroneous conclusions. While that can happen, and scientists should not ignore that possibility, there is growing awareness that autistic people and their families have enormous insights to contribute. On top of their valuable first-hand experience, and the general usefulness of bringing a different perspective, the nature of autistic intelligence may be such that many autistic people are especially adept at identifying and characterizing patterns. This ability is supported by autistic participants' performance on the Ravens Progressive Matrices test of fluid intelligence, where scores for autism groups were significantly higher than on the Wechsler IQ test (WISC-III Full-Scale for Children and WAIS-III Full-Scale for Adults), while the non-autism groups scored statistically the same on the Ravens as they did on the Wechsler. These findings suggest a way in which autistic intelligence may have been significantly underestimated<sup>4</sup> (Dawson, Soulieres, Gernsbacher, & Mottron 2007).

Baron-Cohen (2006) has been emphasizing the ability of autistic people to be strong systemizers, where systemizing involves law detection via observation of input-output relationships, and facilitates a search for structure such as patterns, rules, regularities and periodicity in data. Recognizing the power of coupling pattern understanding and systemizing talents with

access to unprecedented sets of data online, we may expect valuable contributions from some individuals with first-hand experience of autism, who find the data sets interesting and have the time and desire to support research efforts. While no such Web site currently exists for inviting participation at a grassroots data pattern analysis level, information system technology is starting to be used for improving community involvement in research, such as the Interactive Autism Network (IAN) (<http://www.IANproject.org>). IAN promotes data collection and research recruitment by enabling parents of individuals with autism to participate in research studies by sharing genealogical, environmental and treatment data from remote locations (e.g., home or office) using the Internet. IAN is only a tiny step toward what could be accomplished with networking technology and shared online data.

### OUT OF THE LAB AND INTO DAILY LIFE

Today, it is well known that you can go online in a coffee-shop, airport, office and many other places that have network access; however, it is much less well known that clothing, jewelry and body-worn technologies can be continuously online through miniaturized wireless technologies that sense and transmit information according to the wearer's preferences. Steve Mann, an inventor and pioneer in wearable computers and personal imaging, started sending continuous streams of his daily life to the Web in 1994; this movement has since grown into a community of over 20,000 "gloggers" (<http://glogger.mobi>), where you can see what another person observes from their body-worn camera's perspective. While video may be too personal and full of identifying information for some people to put online (although the success of YouTube shows that many people like to participate in this), technologies can be used to contribute depersonalized data, where personally identifying information is removed or obscured, yet rich streams of behavioral data remain. For example, with the wrist-worn sensor described in the opening example, one person might wish to contribute raw data (such as heart rate, arm-flapping movements and skin conductance), together with high-level annotations (such as "stomach pains tonight" and "Day 1 of new treatment routine"), in an anonymous way that builds up a log of their daily life online, without associating it with their personal identity.

<sup>4</sup> These are group (nomothetic) results, so this conclusion may apply to some members of the group and not others.

Data shared from daily life have the advantage of representing real-world continuous experiences in familiar and unfamiliar environments, under naturally varying conditions (after a good night sleep vs. a bad night sleep), and in encounters that really matter to people (as opposed to most lab encounters, where some test or otherwise atypical activity is requested, which a person may or may not feel motivated to perform). Data measured during lab visits can also be tainted by “new environment overload,” where an autistic person may find it hard to perform because of the workload of trying to process a huge amount of detail that is novel to them in that environment. While the lab environment can provide significant control over several potentially confounding variables,

technology would have helped; and (2) placebo effects have been shown to be modulated by expectation—the product appears to be made by a reputable company so people expect it will be helpful, it is expensive so people think it will work well, or it is approved by some authority so people assume it must have passed some tests. Note that all of these expectations can be influenced simply by the packaging of the placebo. Since all of these expectation effects can apply to technology, they could influence belief that technology would help, and such a belief might lead to benefit even when the technology is effectively inert.

What is wrong with benefiting from an inert intervention? Perhaps nothing, as long as it costs as little as a sugar pill and

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and can validate a participant’s compliance with a task, it may also produce results that do not reflect behavior in real life. If treatments are to work in daily life, it is important that daily life data be represented in the scientific data collection process. New technology, if properly developed, can make this advancement both possible and practical.

### AVOIDING FLIM-FLAM TECHNOLOGY AND TECHNOLOGY PLACEBO EFFECTS

Like a pill, technology, can bring about sudden and strong changes in a person’s behavior, which might include placebo effects. The placebo effect occurs when a person’s condition improves after taking an inert substance (such as a “sugar pill”) in conjunction with suggestions that lead the person to believe that the pill will aid in healing. This effect has been known for years in medicine, and accounting for it is part of gold-standard medical practice. While we do not know of rigorously conducted studies characterizing the power of technology placebo effects,<sup>5</sup> there is good reason to consider that technology placebos exist and can have significant impact: (1) There are uncontrolled studies where a new technology has been introduced and people claimed it helped them, even when there is no clear reason why that

you don’t consume so much of it that you put on 30 pounds. A technology placebo may also appear to be harmless; however, technology is often expensive and it too can have side-effects (e.g., computer users sometimes develop wrist injuries). To be ethical, it really should work and do what it claims.

How do you evaluate a new therapeutic technology in a controlled way to verify its efficacy? The problem is especially challenging in light of the discussion above: It needs to be tested by individuals, over possibly long periods of time, in natural environments. It will probably need some kind of technology control comparison to see if it really provides an improvement over some other “sham technology.” Thus, in the technology equivalent of the classic therapeutic treatment experiment, there may need to be three groups: (1) a no-technology group; (2) a “sham”-technology<sup>6</sup> group; and (3) the group using the technology of interest. Or if individualized longitudinal research is conducted, each person could use “technology one” and “technology two” in counter-balanced order (where one of these is the technology really being evaluated) to compare benefits within a person across the two technology conditions. As in medical double-blind studies, the persons showing participants how to use the new technologies also

<sup>5</sup>There is interesting but inconclusive evidence for the existence of an enhanced placebo effect for devices and procedures over that of traditional orally administered placebo pills (Katzchuk et al. 2000).

<sup>6</sup>The technology may not have to be inert—it could simply be another state-of-the-art technology that, to the participant, appears equally novel to the technology that is being genuinely evaluated.

should be blind to the hypothesis and condition of technology one and technology two. Ideally, objective behavioral measurements will be made both before and after adopting each technology to check for therapeutic benefit, as well as during use, to validate how the technology was actually used. We have evidence from one exercise-support technology study where a participant said, “I loved the technology,” and “It really helped me,” but when we opened it up to see the usage pattern, it was clear they never actually turned it on.

Since new technologies are usually expensive, it can be very costly to build enough units to test the technology with even a few

This is not a new problem, and as the numbers increase, one can expect the effect to be reduced. Also, there is little incentive for independent buyers who aren't invested in the company to inflate efficacy measures, unless perhaps someone paid a huge amount for one product, and feels the need to justify that expense. In such a case, one may include in the evaluation some sort of price/performance curve, which may help normalize some of these potential biases or at least allow for them to be considered. Other ways can also be devised to give incentives to companies to promote honest evaluation of their products.

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dozen participants. Given the tendency of good-hearted families in the autism community to work hard and try almost anything that might help their loved ones (provided there is no apparent risk of harm), there is huge incentive for entrepreneurs to build lots of quantity (thus lowering unit cost) and take products to market even when they have questionable or unproven efficacy. The autism community needs to be aware of this likelihood and may wish to take collective measures to address it.

There are several ways the community can respond to minimize potentially negative side-effects of unproven, false or flim-flam technology treatments. One way to respond, using the Internet, is to set up a community site allowing independent experts to comment on the possibility that the technology might actually be able to do what is claimed, and allowing others to provide evidence if those experts are receiving kickbacks from the company. An online community could also form ad hoc study groups of voluntary buyers of these technologies who agree to take measures on themselves before and after, contribute their data on the efficacy of each of the products, and perhaps share other features that they as autistic individuals have (again, de-identifying their data for privacy). While there is potential for over-inflation and dishonesty in reporting, we expect that these problems may tend to be less in the autism community than in other communities. Furthermore, false self-reports from participants can even happen in studies run by respected scientists and academics.

The idea is that through using technology to share data and experiences in a networked community, individualized benefits can be brought to light where they may genuinely occur, and effects that are not above baseline “sham technology use” can also be identified.

Funding organizations can and do help prevent sham technology treatments by funding carefully controlled studies, and by funding costly but justified technology development in quantities that support proper evaluation. They may also wish to provide incentives for people to participate at a grassroots level in pooling and comparing their experiences with new technologies. However, the wealth of new technology possibilities is likely to swamp even the best-endowed efforts of these organizations, and it will be prudent for the autism community to develop its own mechanisms for detecting new flim-flam treatments and helping get the word out so that individuals testing the efficacy of individualized treatments do not forsake objective evaluation measures.

### SUMMARY

We teach a course on autism theory and technology at MIT, and on the first day of class one of the messages we present is: “If you’ve met one person with autism, then you’ve met one person with autism.” While we teach the standard diagnostic criteria and we know many of the difficulties that are commonly shared across the spectrum, we also recognize that two people with the

same age, gender, IQ, medication use and diagnosis may respond very differently to the same treatment. In this day when all the computational power of the lunar mission can fit neatly into your pocket, when wireless technology is pervasive, and when individuals can easily upload the videos of their life for the pleasure of people around the globe, there is no reason to restrict research to the old paradigm of laboratory observations that use snapshot measurement technology and average the findings across a group. While there are important conclusions to make about groups, the technology is ripe to address the rich understanding of individuals. While difficult challenges bedevil the researcher who wishes to conduct rigorous science in this topsy-turvy, uncontrolled real-world measurement environment, the difficulties are well worth tackling. Increasingly, technology can help address these measurement problems and advance personalized treatment, enabling the collection of unprecedented ultra-dense long-term data that can drive science to new places.

## References

Allport, G.W. (1937). *Personality, a psychological interpretation*. New York: Henry Holt.

Baron-Cohen, S. (2006). The hyper-systemizing, assortative mating theory of autism. *Progress in Neuro-Psychopharmacology & Biological Psychiatry*, 30, 865–872.

## About the Authors

**ROSALIND PICARD, PH.D.**, is the founder and director of the Affective Computing Research Group at the Massachusetts Institute of Technology Media Laboratory and co-director of the Things That Think Consortium, the largest industrial sponsorship organization at the lab.

**MATTHEW GOODWIN, ABD**, has over a decade of experience working with individuals with ASD, their teachers and parents at the Groden Center, a non-profit educational and treatment center for persons with ASD and other developmental disabilities located in Providence, R.I.

Biklen, D. (2005). *Autism and the myth of the person alone (quantitative studies in psychology)*. New York: NYU Press.

Dawson, M., Soulières, I., Gernsbacher, M.A., & Mottron, L. (2007). The level and nature of autistic intelligence. *Psychological Science*, 18, 657–662.

el Kaliouby, R., Picard, R.W., & Baron-Cohen, S. (2006). Affective computing and autism: Progress in convergence. In W.S. Bainbridge and M.C. Roco (Eds.), *Annals of the New York Academy of Sciences*, 1093, 228–248.

Goodwin, M.S. (2008). Enhancing and accelerating the pace of autism research and treatment: The promise of developing innovative technology. *Focus on Autism and Other Developmental Disabilities*, 23, (awaiting page numbers from publisher).

Goodwin, M.S., Groden, J., Velicer, W.F., Lipsitt, L.P., Baron, M.G., Hofmann, S.G., & Groden, G. (2006). Cardiovascular arousal in individuals with autism. *Focus on Autism and Other Developmental Disabilities*, 21, 100–123.

Kaptchuk, T.J., Goldman, P., Stone, D.A., & Stason, W.B. (2000). Do medical devices have enhanced placebo effects? *Journal of Clinical Epidemiology*, 53, 786–792.

Molenaar, P.C.M. (2004). A manifesto on psychology as idiographic science: Bringing the person back into scientific psychology, this time forever. *Measurement*, 2, 201–218.