In this forum we celebrate research that helps to successfully bring the benefits of computing technologies to children, older adults, people with disabilities, and other populations that are often ignored in the design of mass-marketed products.
— **Juan Pablo Hourcade, Editor**

# Rethinking Autism and Technology

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A common adage in autism research goes, "If you have seen one child with autism, you have seen one child with autism." Autism is a neuro-developmental disorder that is extraordinarily diverse in its manifestations. What defines the scope of Autism Spectrum Disorders (ASDs) are impaired social and communication skills and tendencies toward repetitive behaviors and narrow interests. However, the ways in which these features play out in individuals are unpredictable and make for an extremely heterogeneous group of people. What most people with autism [1] appreciate, though, is structure in their environment, their daily routines, and their social interactions. Which explains why many have an affinity with technology, as its behavior is predictable, governed by rules that might be complex, yet stable. Furthermore, technology offers a tolerance for repetition that few human peers can match.

Consequently, digital technologies are seen as a promising route for engaging autistic people and delivering therapeutic intervention or supporting them pragmatically with everyday issues. Many such interactive systems have been developed, ranging from visual scheduling aids to social-skills training. A consensus is emerging that technology really can effectively support people with autism in various ways. However, many challenges remain largely unsolved, for example, how to measure learning gains as a result of a technology intervention or how to facilitate the effective transfer of learned skills from the therapy room to the playground.

## ECHOES

As I started as a post-doctoral researcher on the ECHOES project, we aimed to make our contribution against this backdrop. Building on a well-known intervention program, we developed a system that allowed children with autism to interact with a virtual character on a big touchscreen to learn specific social skills. A complex evaluation study was devised to investigate the learning effects, and indeed, promising interventional successes started to emerge. For me, however, looking at the countless hours of video we captured from children interacting with the system, the most interesting things were happening off the screen. There was something about the way in which many children interacted with other people in the room while interacting with the system— through small gestures, often in between tasks or in reaction to the system doing what it evidently shouldn't do [2]

In parallel to the formal evaluation study, the design team organized design critique sessions with autistic children. We provided them with a simple digital annotation tool to show us what they liked or disliked in the virtual environment and what could be added. After a pilot was run, the power of the annotation tool quickly became apparent, but not quite in the way we expected: Much more than fulfilling its intended purpose as an annotation tool, it supported children with autism in communicating with us. It acted as a catalyst that scaffolded the human interaction off the screen by taking away many of the perceived social pressures that autistic children feel anxious about. The children happily responded to our questions and interacted with us while drawing and putting smiley faces on the screen. Take the technology away and the conversation became a lot harder [3].

As we saw in the study, interactive technologies can have other roles than the ones on which we had been focusing thus far. They can scaffold interactions; they can mediate and empower. Children with autism seemed to readily appropriate our technology for their communication styles and make it part of the conversation. The learning of social skills became implicit and meaningfully situated rather than instructional. Has our focus on delivering interventions obstructed our view on what could be the real power of interactive technology in the lives of autistic people?

## RETHINKING OUR APPROACH

If we want to create technology that affords these kinds of roles, we need to critically reflect on our drivers and consequently rethink our approach to

**Insights**

→ Interactive technologies can have empowering roles in the lives of people with autism.
→ To design for these roles, we need to shift our attention from mitigating deficits to scaffolding positive experiences.
→ Consequently, we require a more participatory and designerly approach.

designing interactive technologies for people with autism. If we want to be able to respond to needs and desires that go beyond mitigating deficits, we need to shift our attention toward a more holistic notion of well-being, empowerment, and the scaffolding of positive experiences. Doing this, however, turns a relatively well-defined problem into a *wicked* problem, a problem that has neither one best solution nor a straightforward problem statement. While deficits provide clear targets for technology to address, designing more holistically requires us to explore what is meaningful in the lives of autistic people and develop solutions that are firmly situated in their life-worlds. And the only way to do this is to involve people with autism in the design process and let them guide us into the corners of the design space we have not before considered exploring.

Thus, I argue we need a more designerly and participatory approach to get to those alternative roles of technology and the ways in which they can contribute to the well-being of autistic people. And this has consequences for our methodologies, our epistemology, our theoretical underpinnings, as well as the philosophy we build on.

*Participation.* The field of participatory design (PD) has gained traction over the years, and more and more practice and research involves users and other stakeholders in the design process. While PD historically had strong ideological connotations, its widespread use has led to more pragmatic interpretations, so that today we see a wide spectrum of approaches. Accordingly, many different methods have been developed to enable people to meaningfully contribute to design processes.

When involving people with autism in the design process, participatory methods need careful reinterpretation. Some of the challenges include managing anxiety in social group settings, scaffolding communication during PD activities, and inspiring autistic people to think beyond their narrow interests without taking away the security these provide for them. Furthermore, collaborative decision making in design is ruled by power structures between participants, stakeholders, and designers, which



A child sharing his ideas on what his future smart object should be like in a participatory design workshop using low-fi craft materials.

are particularly complex when people with disabilities are involved. Another key challenge is that of interpreting collaborative work. In many cases, people with autism cannot be expected to create or articulate design inputs, but they can contribute by providing inspirations and ideas that need mindful interpretation by expert designers.

For all these reasons, levels of participation have varied considerably in related work, ranging from using proxies instead of the user group itself to attempts at making them full design partners and including their support network. However, to go beyond token participation it is also important to look at the scope for change participants are given. And this starts with the design brief, which very often is not within the reach of participants. In ECHOES, for example, autistic children have been involved in every phase of the project, but the given intervention

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goals have restricted the scope for their contributions significantly.

So, exploring new meanings for technology requires us to think about participation more radically and make design briefs accessible to participants. However, such open and exploratory processes are even more messy and uncontrollable than traditional PD approaches.

*Disability and technology.* This refocusing is part of another broader argument. It concerns the way we as a society see people with disabilities and what our efforts in designing technology to lighten their burden tells us about our attitudes. The field of disability studies has researched the concept of disability in our society and has developed a number of theories and models that describe our understanding of being disabled. For a long time, the medical model dominated our views, defining being disabled by people's physical or cognitive differences and the resulting functional limitations. In the early 1980s, the disability rights movement caused a rethinking of the concept, and the social model of disability gained traction. The terms *impairment* and *disability* were separated to convey different meanings. While the impairment defined the physical or cognitive difference, the disability was seen as a social construct that resulted in impaired people being disadvantaged
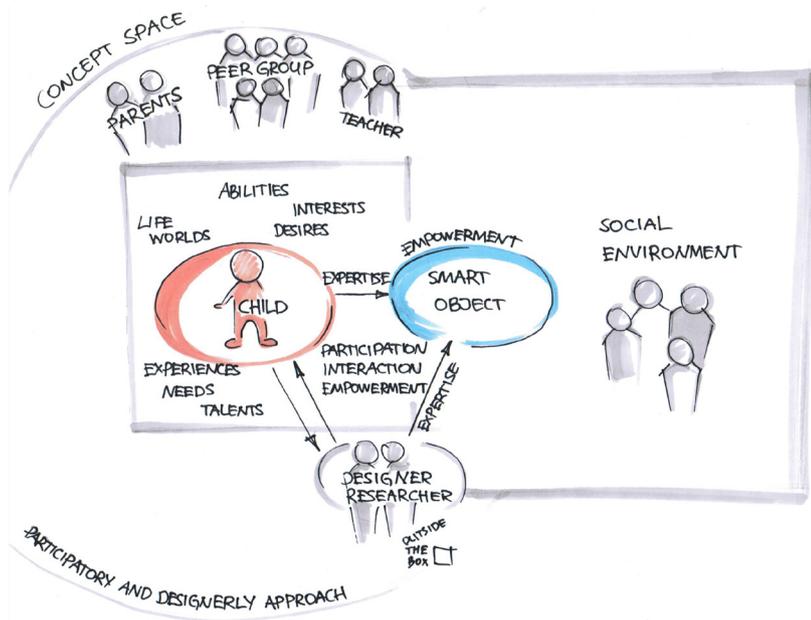
**Autistic children co-design smart objects in OutsideTheBox that are meaningful and empower them to share their experiences with their social environment.**

ILLUSTRATION BY JULIA MAKHAEVA

(disabled) by their environment. This shift had far-reaching consequences in policymaking, science, and the public discourse, since it called on the environment to change. In recent years, the social model too was criticized for being one-sided and ignoring the experiential perspective. Both the medical and the social model had little to say about what experiences individuals had with being disabled or living with an impairment. While there are fundamental differences, feminist and queer studies address some similar questions, and the field is in the process of incorporating postmodern and critical realist thinking in order to make progress in analyzing our understanding of the relationship between disability, impairment, culture, and society [4].

The relationship between technology and people with disabilities is still widely dominated by the medical model, because it has proven to be pragmatically useful in providing requirements for design. Technology is designed to assist people in overcoming their functional limitations, and as Mankoff, Hayes, and Kasnitz have written in a recent paper [5], these efforts are to be applauded. But they also rightly say that disability studies can help us develop a more nuanced understanding of these efforts and guide us to critically reflect on our attempts at "doing good."

## OUTSIDETHEBOX

With OutsideTheBox, my first project as principal investigator, we take up this line of argument and implement a research agenda that aims to explore how we can find new, meaningful roles for technologies in the lives of children with autism. We adopted a designerly and participatory approach and chose ubiquitous computing as a technological opportunity space. The only requirements we defined in the design brief are that the technology affords positive experiences within the life-worlds of children with autism, and that it supports the children in sharing those experiences within their social environment.

In a series of case studies, OutsideTheBox reinterprets a range of PD methods in which we work with autistic children to co-design their very own smart objects. The design processes are evaluated to assess how well they enable children with autism in leading the exploration and expressing their ideas. Mapping out various methods, we aim to provide designers with a concept space offering methodological guidance that is firmly grounded in the case studies.

The project is less than a year old, but we are starting to see how powerful our approach is in unlocking design spaces. We are also confronted by many challenges—in practical and theoretical terms—but we believe our work demonstrates how we could start redefining the relationship between people with autism and technology.

## ACKNOWLEDGMENTS

### ENDNOTES

1. There are different views on the use of "people-first" language in reference to people with autism/autistic people. Good arguments have been made on both sides and many say it is a matter of personal preference. This article uses both terms interchangeably as a way to acknowledge this.

2. Alyssa Alcorn, another former member of ECHOES, further investigated the effects of these unintentional slips and argues to use them as an opportunity for design in her Ph.D. work. See: Alcorn, A.M., Pain, H., and Good, J. Motivating children's initiations with novelty and surprise: Initial design recommendations for autism. *Proc. of the 2014 Conference on Interaction Design and Children.* ACM, 2014, 225–228. DOI:10.1145/2593968.2610458

3. Frauenberger, C., Good, J., Alcorn, A., and Pain, H. Conversing through and about technologies: Design critique as an opportunity to engage children with autism and broaden research(er) perspectives. *International Journal of Child-Computer Interaction 1*, 2 (2013), 38–49. DOI:10.1016/j.ijcci.2013.02.001

4. Shakespeare, T. *Disability Rights and Wrongs Revisited, Second Edition.* Routledge, Oxon, U.K., 2014.

5. Mankoff, J., Hayes, G.R., and Kasnitz, D. Disability studies as a source of critical inquiry for the field of assistive technology. *Proc. of the 12th International ACM SIGACCESS Conference on Computers and Accessibility.* ACM, New York, 2010, 3–10. DOI:10.1145/1878803.1878807

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