

Critical Experience – Evaluating (with) Autistic Children and Technologies

Katharina Spiel

Vienna University of Technology
Vienna, Austria
katharina.spiel@tuwien.ac.at

Abstract

Technologies for autistic children dominantly focus on diagnostic procedures, interventionist approaches or therapeutic support. The space of technologies for positive experiences for autistic children has only recently been explored. My research is situated in the OutsideTheBox project where we co-design such technologies with autistic children. Concretely, my PhD tackles the questions of how to assess the experiences autistic children have with the resulting technologies and how these technologies are meaningful to them. To this effect, I conceptually broaden a critical understanding of experience within HCI and develop an approach for participatory evaluation with autistic children.

Author Keywords

Experience; Autism; Children; Participatory Evaluation

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous

Context, Motivation and Background

Many technologies for autistic¹ children have been developed with a focus on diagnosis, therapy and intervention (see for an overview [5]). However, autistic children – just

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¹There is a lively debate about person-first vs. identity-first labelling in the disability community and especially their autistic self-advocates, who

Autism

The condition is diagnosed along differences in reciprocal socio-communicative interaction (compared to allistic people) and repetitive interests and behaviours. These symptoms appear to be a manifestation of a different mode of perception and, hence, making sense of the world [2].

like allistic² children – enjoy engaging with their environment, want to have fun and explore topics of interest. To design for such activities, we need to include the children directly in the design of technologies in their lives. Hence, several recent research projects conduct participatory design activities with autistic children and focus on positive experiences made with those technologies (e.g., [8, 12]). With such a turn in focus for the design, there also comes a turn in focus for the assessment and evaluation of such technologies: Not diagnostic precision or therapeutic success are important, but rather the experiences the children make.

Within HCI, the dominant concept of a constructive approach to understanding experience has been developed by McCarthy & Wright [7]. It relies heavily on researchers' empathetic interpretation of the users' interaction with a given technology in order to establish what the experience encompasses [14]. While it is essential for researchers to be empathic when working with autistic children, it is also extremely limited as a single approach, since the sensory perception of autistic children is fundamentally different from that of allistic researchers [2]. If the very basics of how we make sense of the world differ between researcher and user, another approach to capturing experience is required; one that goes beyond empathy and considers multiple perspectives of different stakeholders such as researchers, parents, teachers and – most importantly – the autistic child themselves.

Assessing the first-person perspective of autistic children poses a unique challenge as communication between allistic and autistic individuals always has to be interpreted

appear to prefer identity-first (e.g., [9]). In order to acknowledge their political agenda as a non-autistic researcher, I opted for identity-first language throughout.

²Meaning non-autistic as defined in [6].

carefully from both sides. For researchers, this has to be done in a rigorous and transparent way, to find out what makes sense to the child and whether a technology is meaningful to them. I ground my methodological approach in previous work detailing best practises regarding the structures of joint research endeavours [1] and for the interpretation of feedback from autistic children [3]. This work builds the foundation of my work on participatory methods in evaluation so that I can establish what is important to a given child, how the technology makes sense to them and acknowledge their own agency in the assessment of the technology.

Goals and Methods

My research addresses two gaps: The lack of a constructive notion of experience that goes beyond empathy as well as the lack of methods to allocate data from the first-person perspective of autistic children.

Consequently, my work is also twofold: Conceptually, I broaden established notions of experiences with technologies through my work on 'Critical Experience'. Methodologically, I developed PEACE, a framework for participatory evaluation with autistic children. To this end, I identified four research objectives:

RO1: *Mapping out the current status of participation and attributed agency of autistic children in research processes*
Through a critical analysis of available publications, I provide a succinct overview over trends and opportunities in the field and reflect on dominant power dynamics in research concerning autistic children.

RO2: *Conceptualise a notion of experience that goes beyond empathy and considers multiple perspectives and data sources.*

Personal Motivation

I have a personal investment in the research I am conducting. I deeply care for an empowering research agenda when it comes to work with marginalised user groups – and especially autistic children.

I combine Actor-Network Theory (ANT) and Critical Discourse Analysis (CDA) into a framework of 'Critical Experience'. A five step process allows me to establish potential perspectives and relationships between human and non-human actors, gather data for each of those deemed relevant, put the data results (after analysis) into comparable statements and analyse those critically along context, content, discursive position and so on (see [4] for the methodological background) [11, 10].

RO3: *Develop methods for meaningful participatory evaluation with autistic children.*

I provide a systematic and rigorous approach for participatory evaluation with autistic children called PEACE. That way, researchers will be able to include autistic children in dedicated evaluation phases of PD through the co-definition of goals and methods, joint processes of data gathering and the co-interpretation of results. Additionally, the perspective of autistic children on the process and their technologies can be assessed directly [13].

RO4: *Validate both, 'Critical Experience' and PEACE, beyond the contextual grounding they have been developed in.*

Within the OutsideTheBox³ project we work with individual autistic children in a tight collaborative process. I want to make my conceptual work truly accessible for researchers working with marginalised user groups. For this I explore options to collaborate with different researchers and projects.

Contributions

My PhD offers two main contributions: First, there is the concept of *Critical Experience*, which offers a novel way with which to evaluate the experiences autistic children

have with technologies that are designed for their holistic well-being and enjoyment. Second, I make a methodological contribution by showing how *PEACE* enables researchers to evaluate these technologies together with autistic children.

Smaller contribution are made through the work in the case studies, which show *how autistic children experience these technologies* and *what about the technologies matters to them*. Additionally, I provide a *critical overview over current technologies available to autistic children* and how they are evaluated, which could be helpful for other researchers to understand the design and research space better.

The work presented in my PhD then promises to be useful not only to researchers working with users with very different life worlds, but also to a community of developers and designers of assistive technologies in general.

It argues the case for a considerate and critically informed approach when evaluating technology with marginalised user groups and shows how this can be done successfully.

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³<http://www.outsidethebox.at>

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