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Experiences of autistic children with technologies

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ABSTRACT

Experiences of autistic children with technology are often assessed by neurotypical researchers, although their perceptual and sense-making processes differ fundamentally. Empathy, as the underlying mechanism to infer another person's experience, is of limited use in cases where life-worlds radically diverge. The same holds true for indirect assessments, e.g., through contextual information, observations, or parent or carer interviews. It is poorly defined what constitutes a positive experience for autistic children and how an allistic society can meet them halfway in establishing one. Using Actor-Network-Theory and Critical Discourse Analysis we present our methodological concept of experience, which emphasises relational as well as interactional aspects in constructing experience, while staying open for multiple interpretations and remaining critical towards its assessments. We apply our framework in a case study within OutsideTheBox, sampling multiple data sources from multiple viewpoints, and demonstrate how it can yield insightful results about the experiences that autistic children have with technologies, going beyond what can be inferred via proxy or empathy.

1. Introduction

Where technologies were formerly almost exclusively tied to a workplace environment, they are now ubiquitous in everyday lives. This results in the same technology being used and appropriated in different contexts, such as a mobile phone used for finding a restaurant when travelling, facilitating meetings between friends or searching for animated figures on an augmented reality screen. With this diversification of use contexts, we now require evaluation strategies for interactive technologies that go beyond narrowly conceived notions of task-performance. Consequently, user experience has become the dominant term used in designing and evaluating interactive technologies. However, conceptions of experience vary widely. While some aim to quantify experience as an outcome measure (e.g., [1]), others rely on shared life-worlds that enable researchers to infer experience via an empathic understanding of others [2].

Regardless of perspective, when experience is turned into a design goal or evaluation criterion, researchers often make assumptions about people's life-worlds in order to quantify or qualify outcomes. These assumptions can include the goals users might have with a device or application (such as: gaming, finding food, etc. including the assumption that there is a goal), actions they might perform to achieve this goal (e.g., pressing certain buttons) and a range of experiences they might have doing so (for example enjoyment and frustration). While they are helpful to understand use contexts researchers are familiar with and encounter in a similar fashion, such assumptions increasingly break down when working with people whose experiential world is constructed differently. A prime example of such a user group is autistic children.[1] Kirby et al. [4] have shown that sensory processing in autistic children is markedly different, leading to hyper-sensitivities in certain modalities for some. Beyond perceptual differences, we also know that many autistic children have unique cognitive styles that can manifest in narrow interests and repetitive behaviours or thought patterns. Thus, if allistic researchers[2] want to enquire into the experience of autistic children with technology, they cannot rely on the assumptions of a shared life-world.

We present a novel approach to conceptualise experience, developed to capture the experiences of autistic children with technology in a holistic and nuanced way. Theoretically, we base this

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[1] We are fully aware about the complex discussions surrounding person-first vs. label-first language; we opt for the latter, due to it being the predominantly self-chosen form (as per Kenny et al. [3]).

[2] We use the term neurotypical to refer to the dominant cognitive style in western societies and the term allistic to mean not autistic as coined by Main [5].

framework on ideas drawn from Actor-Network Theory (ANT) and Critical Discourse Analysis (CDA), with the aim of bringing together multiple perspectives and layers that contribute to autistic children's experiences. While we developed and exemplified our understanding of experience within the specific context of autistic children, our aim is to build our argument in a way that more generally leads to an increasingly diverse understanding of experience and yields novel insights that are not mainly guided by researchers' expectations of a technology.

The following section provides the background for our line of argument. We begin by discussing concepts of disability in Human–Computer Interaction (HCI) and different understandings of experience and their limitations. In the subsequent section, we review relevant work around technology for autistic children and existing attempts to assess these. Having laid out the foundations, we develop our understanding of experience in Section 3 conceptually, theoretically and methodologically. We then provide a case study in which we apply the framework within OutsideTheBox, in which we design technologies with autistic children that target their holistic well-being. We close by critically reflecting on the progress we made towards a holistic understanding of the experience of autistic children with technology.

2. Background

Assessing the experiences of autistic children requires combined knowledge from different scientific areas. Next to how neurodiversity has been discussed in HCI, it is important to understand how experience is constructed in autism and which experience concepts are used in technology evaluation. This lets us illustrate how problematic it would be to solely rely on researchers' empathy when users' life worlds are experienced radically differently. To motivate the need for our concept we also show the dominant aim of technology for autistic children together with commonly used assessment strategies.

2.1. Neurodiversity in HCI

Coined by autistic self advocate Singer [6] the concept of *neurodiversity* refers to neurological conditions that are commonly identified by the process of medical diagnosis and afford unique requirements within a *neurotypical* society. The neurodiversity movement celebrates different *cognitive styles*. It is tied into the idea of a *third model of disability* that unifies a purely medical (a.k.a. first model) and a purely environmental (a.k.a. second model) of disability by conceptualising it as a combination of experienced peculiarities within the functioning of the human body (including neurological differences) combined with societal unpreparedness to accommodate these peculiarities (see, with a focus on children, Watson [7]). Doing so, some advocates reject the disability label completely and focus instead on the unique strengths of individual people. In the past few years, neurodiversity has been linked more broadly with research on quality of life [8].

Within HCI, Mankoff et al. [9] argue for a change in approaching assistive technologies, which are often developed *for* disabled people instead of *with* them and assessed solely by functional parameters that determine a disability. Similarly, Frauenberger [10] shows how the focus on perceived functional deficits is reductionist in that disabled experiences are more complex than can be captured by a purely functional perspective.

Dalton [11] introduced neurodiversity to HCI and argues for including this perspective in research interests. Neurodiversity as a means for more inclusive research has also been used as a motivation for Benton et al. [12]. They developed a design framework that aims at including neurodiverse children in Participatory Design (PD). What is lacking, however, is a theoretically and methodologically inclusive concept that is informative about the experiences not only of autistic children, but users with different cognitive styles in general.

2.2. Experience in autism

Autism is an umbrella diagnosis that covers a variety of characteristics. Core traits are difficulties with (neurotypically defined) reciprocal socio-communicative interaction — often combined with repetitive interests and behaviours. It is estimated that about 1% of the world's population and about one in 68 children in the United States of America have this condition [13], although the recently reported increase might at least partly result from the change in diagnostic criteria [14].

Diagnoses are given within a broad spectrum. Some autistic people can live independently within society, others might require constant attention and assistance, because of e.g., harming or self-harming behaviour. Each individual faces different challenges, exhibits different behaviours and is interested in different things; they have a unique character. Using cognitive style [15] as a concept allows us to acknowledge each autistic person as unique and to not over-generalise individual aspects.

According to De Jaegher [16] different processing of sensory input leads to different sense-making which influences the assignment of meaning. For example, a preference for listening to the same set of music in only one order, while potentially tedious to allistic people, can be very important for autistic people. Repetitive behaviour, a preference for sameness and a focus on detail help structure the environment and create a feeling of safety. Sharing experiences in a mode De Jaegher calls *participatory sense making* becomes challenging when meaning is assigned differently between participants.

Autistic children are of special interest to researchers, because early intervention and acquiring coping strategies can help establish positive ways of emotional regulation.[3] However, interacting with autistic children can be challenging. Many researchers tend to avoid gathering self-reported data directly from autistic children due to the lack of shared modes of communication. Instead, assessments are most often via proxy, e.g. through parents and caretakers (for example, [17]), who are limited to giving their interpretations of the children's experiences. We define this as an *indirect* perspective. Alternatively, researchers also conduct interviews with autistic adults (e.g., in [18,19]), who can provide a hindsight view on their experiences as a child; we define this as a *reflective* perspective. It is only recently that the experiences of autistic children have been more directly assessed: Kirby et al. [4], for example, talked with autistic children about their everyday experiences and gathered previously unconsidered perspectives, which showed, e.g. how autistic children acquire coping strategies to deal with situations that are overwhelming to them. We define this as a *direct* perspective. Kirby's findings support De Jaegher's theory about sense-making of autistic individuals and are relevant to describing a *felt* experience.

While each individual perspective – indirect, reflective and direct – is limited in a different way, through combining the three ways of reporting, we can arrive at a more holistic view about the everyday experiences of autistic children than any one of them individually. However, to date there is no concept available that methodologically combines these perspectives when assessing experience in an HCI context.

[3] We want to point out that we do not see the onus simply on the side of the autistic individual, but also on a society that should learn accepting harmless, albeit unusual ways of emotional regulation, such as stimming (self-stimulatory behaviours).