

Challenges, Opportunities and Future Perspectives in Including Children with Disabilities in the Design of Interactive Technology

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ABSTRACT

In this paper we discuss participatory approaches to designing interactive technologies for children with disabilities. While participatory design (PD) has been increasingly influential in the field of Human-Computer Interaction as a whole, applying its methods and theories to children with disabilities raises challenges specific to this target group and poses more fundamental questions about the limits of PD. We will first build the underlying argument of why we believe PD is particularly important when designing for children with disabilities, before discussing the challenges and opportunities that come with implementing PD in this context. We ground this discussion in our own experiences with developing a learning environment for children with autism spectrum conditions (ASC). We then consider future perspectives and develop research questions by reflecting on our experiences.

Keywords

design research; participatory design; children; disabilities

Categories and Subject Descriptors

H.5.2 [Information Interfaces and Presentation]: User Interfaces—*User-centered design*

1. INTRODUCTION

Participatory Design (PD) originated in the Scandinavian labour movement, which advocated the involvement of people who are affected by technological change in its design [6]. It has since gained a significant influence in mainstream Human-Computer Interaction, as it complements the field's move towards human-centred and situated interaction design [13]. PD is commonly defined as a collection of theories, practices and methods that facilitate end-users' or other

stakeholders' participation in the design process of technological artefacts or services [20].

Adopting a participatory approach is commonly considered to have three main benefits: 1) better understanding of requirements, 2) building realistic expectations in target groups and 3) empowerment of marginalised groups [6]. In the context of designing technology for children with disabilities, all three benefits take on increased significance. Firstly, designing technology for groups of people with profiles other than one's own is always challenging. The life worlds and lived experiences of children with disabilities, however, are particularly far removed from the experiences of typical designers or researchers, which makes it particularly challenging to create technology from a position of empathy and deep understanding of their needs and requirements. Secondly, building up realistic expectations of what technologies can and cannot do has a positive effect on its uptake and use. And finally and most importantly, giving children with disabilities a stake in the design of technology gives them a sense of ownership and empowerment. In skewed power relationships such as those between adults and children or people with disabilities and their care-givers, being in control and shaping one's own environment can be extremely satisfying and liberating and hence a major contribution to the individual's wellbeing.

Such inclusion of children with disabilities in the design process of interactive technologies, however, does not come without its risks and challenges. For the remainder of this paper we will discuss some of these, grounding the discussion in our experience with our work in ECHOES. ECHOES¹ is a technologically enhanced learning environment (TEL) for typically developing children and children with autism spectrum conditions (ASC), designed to scaffold the development of their social skills [23]. This means that while the following section on related work focuses on autism, and the challenges and opportunities we identified are similarly written from the perspective of our work in autism, we believe that there is an opportunity to develop generic themes that are valid across disabilities, and will help to shape future research directions in this field.

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¹<http://echoes2.org>

2. RELATED WORK

The following is not intended to be an exhaustive review of participatory work, but aims to highlight the different styles of participation found in design work with children with disabilities. To this end we adapt the Ladder of Citizen Participation by Arnstein, which ranges from non-participation over degrees of tokenism to degrees of citizen power [1] and is similar to Druin's roles of children in the design process [5].

Non-participatory approaches are the in the majority when technology is designed for children with disabilities. System designs are typically informed by theories, best practices or prior experiences that revolve around the features of the disability. An example would be *The Transporters*, a system that uses multi-media content to improve emotion recognition in children with autism [11]. Its design has been based on autism theory and prior experiences with a similar prototype, but no children with autism were directly involved in the process.

We call the second category *participation via proxy*. This is when the needs of children with disabilities are represented by people with intimate knowledge of the children, such as their parents or teachers, or by educational experts. A typical example is the design of vSked, a visual support for children with autism [15]. The vSked authors make a point about the usefulness of participation via proxy by stating that "*The burden of involvement was deemed too high for these children by the researchers, teachers, and IRB to include them directly*".

Finally, *full participation* is the most demanding style, both for researchers and children. We define this as any form of involvement that allows children with disabilities to have direct impact on the outcome. Examples include our own work in ECHOES in which we conducted a range of sensory workshops, digital prototype activities and a design critique [9, 7] or the work in the COSPATIAL project [19] and work on developing multi-touch applications for children with autism [16].

As most of this work is very specific to a certain context, fewer *design frameworks* have been developed. Guha et al, have developed an inclusive model of Druin's Co-operative Inquiry [12, 4]. IDEAS (Interface Design Experience for the Autistic Spectrum) is a participatory design process that particularly addresses some of the issues children with autism experience during design activities [2] and Keay-Bright proposed a *Research - Inspire - Listen - Evaluate* cycle for her work on ReacTickles [17].

3. CHALLENGES & OPPORTUNITIES

The implementation of a participatory approach in ECHOES revealed a number of challenges that we have reflected upon from an autism perspective [9]. However, we believe these issues could act as the starting point for the development of generic themes that are valid across different disabilities.

3.1 Relationships

Strong and lasting relationships with participants are the foundation that participatory work requires to flourish. Mutual trust between all stakeholders is vital in order to con-

duct design activities which are fruitful and in which children enjoy participating. In this particular context, the relationships extend to parents, teachers and other care-givers, and are often a complex and sensitive web of connections. We found that building these relationships requires time and empathy. It is particularly important to understand that while we, as designers and researchers, want to elicit information for our work, the children need to equally benefit from the process. This extends to the design as a *process*, and the need to ensure that sessions are enjoyable for children and that they feel valued. It also includes the design as a *product*, and ensuring that children have tangible outputs from their participation in the design sessions, such as copies of their own creations, or small tokens of gratitude such as certificates, or videos showing some of the highlights of the sessions that they can share with their parents or carers.

3.2 Communication

All design activities involve some form of communication between facilitators and children. As many adults without disabilities struggle to express their ideas in such situations, this suggests that facilitating communication for children with disabilities may be correspondingly more difficult and also more vital for their design participation to be successful. Participating children with different disabilities will each pose their own set of challenges and will require communicative aids tailored for their particular abilities and needs. Two examples of communication facilitation in the area of autism work include our own research on an annotation tool for design critique [7] and the work by van Rijn et al, who advocate the use of toys in play sessions to foster empathy and facilitate communication through interaction [26].

3.3 Creativity

Participatory design provides a tremendous opportunity to tap into children's creative potential. In order to harness this potential, methods have been developed to put children into situations where their natural, playful attitude towards their surrounding environment is channelled into producing creative triggers for design. One example includes Fictional Inquiry which uses imaginative play around a narrative [3]. Working with children with disabilities requires careful balancing of opportunities for creativity with support and structure. In ECHOES, for example, we have seen children with autism struggle with open ended questions or creative tasks that provided too little structure.

3.4 Translation

Children with disabilities, just as other groups of stakeholders in participatory processes, cannot directly take on the role of designers and should not be expected to do so. This means that much of the input generated by children will require interpretation and translation to become viable design. This interpretation and translation process may be particularly challenging because input from children with disabilities can often appear fuzzy and seemingly irrational to adult designers. We approached this task by building on Keay-Bright's notion of *mindful interpretation* and conducted a design workshop in which we have used designerly methods to develop outcomes while staying true to the input from our children [10]. In the course of this process, we also

used existential phenomenology as an analytical framework to interpret input from children with the aim of separating literal expressions from underlying experiences [8].

3.5 Evaluation & Epistemology

Arriving at implementable designs based on children's input is a wicked problem, affording many different and equally desirable solutions [24], and also making evaluation of the process and outcomes particularly challenging. Design Research could provide a framework that allows a structured approach [27], as well as Action Research [14]. Both perspectives hold promise in allowing researchers to systematically generate knowledge from "messy", qualitative research such as this, but its acceptance in relation to designing technology is still low in the mainstream scientific community.

4. FUTURE PERSPECTIVES

The above challenges already point to many research questions that clearly require attention in the future. However, upon deeper reflection, we believe that two further concerns emerge that derive less obviously from the practical work.

4.1 Digital Inclusion in Education

With technologies playing an ever increasing role in our daily lives, digital inclusion has become linked to social inclusion. For children with disabilities, educational settings are where most of this digital inclusion or exclusion happens, which is demonstrated by considering the proportion of related research that is conducted against an educational backdrop. Schools and care-giving facilities therefore provide a prime access point to facilitate participation of children with disabilities in co-designing technology.

The research brief for the Digital Inclusion theme of the Technologically Enhanced Learning (TEL) programme² in the UK provides an in-depth discussion of the role of technology for children with special needs in educational settings [25]. On the basis of this review it offers a number of avenues for future research in digital inclusion which are prime candidates for being approached through participatory design research. For example, the brief calls for strengthening the conceptualisation of digital inclusion or expanding ways of generating knowledge about technology in inclusive education. It also calls for more qualitative research to bridge the gap between objective learning successes to overall experience, motivation and usage. Requirements for this research agenda resonate with the methods and values of participatory design, and a closer alignment could bring about new knowledge in both areas.

4.2 Designing the Unknown

When designing technologies for children with disabilities, the focus is to alleviate the burden of the disability and either provide access or enable children with disabilities to learn or perform actions that would not be possible without the technology. This preoccupation with "repairing" has brought about a problematic underlying stance towards designing technology for people with disabilities, ignoring the rich and complex web of contextual and individual perspectives that are vital for construing roles for technology

²<http://tel.ioe.ac.uk>

that are meaningful in their lives. Mankoff et al, who have used the field of Disability Studies for a critical inquiry into the field of Assistive Technology (AT) attribute this to the prevalence of the medical model of disability which defines disability through its medical features [18]. Other models, such as the socio-cultural or post-modern model of disability, challenge this view and advocate a shift towards lived experiences, personal wellbeing and disability as a social construct, not to be confused with the impairment [21]. Consequently, this leads to a stance that challenges the notion of normality and the goal of "enabling" the disabled [22].

When applying this perspective to the process of designing technologies for children with disabilities, we arrive at a position that calls for a shift in focus towards a more holistic, situated type of design. Instead of primarily concerning itself with the functional deficits of a disability, a holistic and situated design would emphasise positive experiences and the individual potential of children. For participatory design in this context, this means that we need novel methods which allows us to innovate technology that we, as abled adult designers, *could not imagine* because they can only be imagined from within the life-worlds of children with disabilities. In essence, this implies that children with disabilities should be considered children first. Their life-worlds give rise to an application space for technology that is yet unknown to us, and the key to exploring this space is developing methods that allow children to show us its possibilities.

5. CONCLUSION

In this paper we have discussed challenges, opportunities and future perspectives of participatory approaches for designing interactive technologies for children with disabilities. Our motivation to participate in this workshop is grounded in the belief that this paper will spark discussion amongst researchers and designers and could be a starting point for developing a research agenda that allows us to better understand how to facilitate meaningful participation of children with disabilities in the design process and how to capitalise on the benefits while mitigating the risks.

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