
Participation OutsideTheBox

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Abstract**Author Keywords**

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ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous; See [<http://acm.org/about/class/1998/>]: for full list of ACM classifiers. This section is required.

Introduction

Participation of stakeholders in the design of technology has evolved into the state-of-the-art approach, both for ideological and pragmatic reasons [8]. While on the ideological end of the spectrum, fundamental values such as empowerment and democratisation are emphasised, the pragmatic interpretation focuses on efficiently matching user needs with affordances of technology. One area in which participatory design is seen as particularly valuable, is creating technology for vulnerable people or people with special needs (see also [13]). Again, this shift is driven for both, ideological and pragmatic reasons: empowerment is particularly relevant with target groups that are typically marginalised and participatory design is seen as giving these groups "a voice"¹. Pragmatically, it is argued that PD is essential

¹While a commonly used phrase, we would argue their voices have always existed, but were often ignored.

when the lived experience of future users is particularly detached from designers, a gap which is particularly wide in the case of people with special needs. PD emphasises the notion of users being experts in their lives who make it possible for designers to consider design spaces that they could not explore, because their lived experience is so different.

With this position paper, we would like to reflect on the participatory design work conducted in the OutsideTheBox project in which we co-designed ubiquitous computing technology with children with autism. We highlight some of the challenges that we have encountered and thereby point to themes through which we believe PD needs to evolve in the future. While we ground this discussion in a very specific PD experience, we hope to contribute to the discussions at the workshop by arguing that the themes we develop through critical reflection have wider significance and will be drivers in shaping participation in future practices of designing technology.

The subsequent section first introduces the project providing the necessary context for the discussion that follows. In the critical reflection we focus on five themes that we hope to bring to the workshop for discussion: participation over time, mindful interpretation, measures of success, scaling and knowing.

OutsideTheBox

“OutsideTheBox – Rethinking Assistive Technologies with Children with Autism” is a three-year research project that aims to involve children with autism to develop technology that is not exclusively focused on the functional limitations of their disability, as much assistive technology traditionally is. Instead, OutsideTheBox sees autistic children holistically within their life-worlds and explores new meanings and

roles of technology. Consequently, the project takes a radically participatory approach and involves them in an open and child-led design process. The only two requirements we defined as starting points are: a) the technology designed affords positive experiences, i.e., it needs to be fun and meaningful in the lives of the children and b) it supports the children to share those positive experiences with their social environment.

With these requirements, we engage four to six children with autism each year in a co-design process to develop their own smart object. The children are between 6 and 10 years old and we meet them on average every second week for a one hour workshop at school in one-to-one sessions. The collaboration typically involves 10 to 15 meetings over 5 to 8 months, i.e. the best part of a school year. We start with a contextual enquiry phase, getting to know the child, the parents and the life-worlds through open play, interviews and observations. Then, we re-interpret different PD approaches, ranging from Co-operative Inquiry, Future Workshops, Fictional Inquiry, Drama Workshops etc., and adapt them to the context and the child. A common strategy is to start with the “special interest”² and lead the child out into a creative exploration phase—something that autistic children often find very difficult. While in the beginning this involves a lot of concept work, towards the end prototyping and making becomes more central to the work. The design process ends when the child receives their smart object.

While the case studies and prototypes developed in the project constitute the bulk of the tangible outcomes, we also use them to develop a conceptual map of PD methods with the aim to provide others with tested knowledge about how to engage and design with children with autism. The project

²Special interests are a hallmark feature of autism, often very narrow and pursued with compulsory passion (cf. [15]).

wants to demonstrate that such radically open and child-led design processes are possible with a hard-to-reach target group such as this. Our approach can also be interpreted as a critical design intervention [1] in that we challenge the traditional role of assistive technologies by trying to demonstrate that technology can be much richer and meaningfully embedded into the life-worlds of people with disabilities. As such the project also makes a point about the societal conceptualisation of disability (compare [9, 3, 14]).

Reflection

The project has now neared the end of the first cycle and below we offer a first reflection on the participatory process. In year one we have worked with four children and have succeeded with each of them to develop their individual smart object. We have had 13 meetings with each of the children and have freely interpreted and adapted Co-operative Inquiry and Future workshops in our work. Details on the process and the outcomes will be published elsewhere. In the following, we want to pick up some challenges that we encountered in this work and that we would like to bring to this workshop.

Participation over Time

While the core practices of participatory design are well researched and many PD methods are available for designers to draw on, these are often not where the most significant decisions are being made and when the success of a project is evaluated. We are particularly interested in the very beginnings of PD work when projects are scoped and goals are defined. This is a very important, but challenging phase in the process to involve stakeholders. PD projects so far are almost exclusively designed by researchers or practitioners and participation is only initiated after the project starts. Forming relationships to participants is seen as the initial part of the design work, but we argue it should

be part of the planning before. Vines et al. have touched on a similar challenge in their editorial to a special issue on PD, but rightly say that comparatively little is published on the very beginnings of PD [12].

Mindful Interpretation

The interpretation of our co-design experiences with autistic children is one of the fundamental struggles that stays with us during all of our work. Because we interpret our approach as reflective design [11] and are mindful of our skills, values and contributions, we are acutely aware that the power relation between us and the children is skewed in many ways (compare [2]). Not only the age gap and our status as researchers have an impact on the work but also the diagnosis the child received and the fact that much of their lives is decided for them.

We ask ourselves, what is “child-led”? How can we assess the impact the children have? How can we make interpretation mindful and transparent (also compare [5])? The involvement of stakeholders has brought responsibilities to PD, which we argue are often neglected or forgotten.

Measures of Success

The success of a PD effort can be assessed in different ways, depending on the perspective one takes [4]. While in our context parents might deem the involvement of their child in OutsideTheBox a success when they learn new things. Children might define success entirely through the fun they had or the gadget they get, but researchers by what they learn about the process and how many publications they get out of it. Garde and van der Voort have recently demonstrated how different the perception of success in PD work can be [6]. Does PD need a multi-faceted, multi-layered concept of success in which these different perspectives are integrated or is success “sold” independently to different audiences?

Scaling

The way OutsideTheBox interprets participation results in deep participation with low numbers. While there is value in this from a research perspective, as we learn about processes and concepts, it is an unsolved challenge in PD how it could scale while maintaining its core qualities. There seems to be a trade-off between the level of engagement and the number of or the distance between participants. While research is being conducted into finding ways to facilitate large scale participation (e.g. [10], or identifying representatives for large stakeholder groups, both approaches are not satisfactory as they water down empowerment. What could future PD methods look like that can engage and empower large participant groups? Or, to frame the question in the context of OutsideTheBox: how can we reach ~1% of the population who is believed to be on the autistic spectrum with technology that fits into their very diverse life-worlds and that they feel is theirs?

Knowing

In the meanwhile, PD shares large parts of its epistemological foundation with mainstream HCI [7, 4]. With it also comes the concern about transferability of knowledge from one context into another. Large parts of the academic research into PD is devoted to the process and its methods. However, the question arises, whether the situatedness of the knowledge PD generates allows for progress in the field. For such progress it would be necessary to say that we have gained “more” understanding about something, or that something works “better” than something else. But what “more” and “better” means is not trivial. For example, in the context of OutsideTheBox, a central challenge is to re-frame the experiences that we make with our children as valuable knowledge contribution that others can build on. Consequently, we argue PD needs to critically reflect on its philosophical foundations in order to find its place as a

(non- / trans- / intra-)discipline and argue its contributions.

Conclusion

We hope to contribute to the workshop through the critical reflection of our own PD practice. While the above list of challenges is far from exhaustive, we believe they can provide a good starting point for a discussion that aims to unfold aspects of PD within the context of OutsideTheBox and beyond.

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