

Exploring the Role of Adults in Participatory Design for Children on the Autism Spectrum

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Abstract. The use of participatory design for the development of technology for children with Autism Spectrum Disorder is highlighted for its importance in ensuring a successful outcome and empowering participating children and their families. To date, research has focused on the role the child with autism can play within the design process. This qualitative study examines the contribution adult stakeholders can bring to such participatory design processes.

Our results suggest that parents and professionals have contributions to make in terms of: (1.) supporting the participation of children; (2.) bringing their own experience to bear on the process. Nonetheless, their inclusion requires a more supportive infrastructure that encourages and assists their participation. Overcoming the reluctance of parents and professionals to partake in research and development processes could be facilitated by the provision of awareness, training and education activities that would allow them to contribute more and better prepare their children to engage in the process.

Keywords: Autism spectrum disorder · Participatory design

1 Introduction

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. It is considered a lifelong, neuro developmental disability and it's characterized by the presence of persistent deficits in two core areas of functioning. Namely, social interaction and communication skills and the presence of fixed or repetitive behaviours [1]. As interventions increasingly look to technology to provide novel and innovative approaches to support education and treatment of children with ASD, there is a need to ensure best practice in research and development is used to underpin future developments [2].

This paper explores challenges to employing participatory design (PD) methodologies to the process of designing technology for children with ASD, who present with significant cognitive, behavioural and communication difficulties. First recognising the reluctance of many adults to partipate in design processes that are of direct relevance to their children, a discussion of the role of the adult within PD projects is presented. Second the proactive inclusion of adults in terms of their unique contribution and their role as proxy participants, ensuring the meaningful inclusion of the children with ASD, is explored. Third the design of a study examining the self-perceptions of

adults and their roles within a technology design process and its findings are described. The paper concludes presenting a set of contributions defined by participant adults in the study which could form the basis for providing more effective structure for collaborative PD workshops with children on the ASP and adult stakeholders.

1.1 Participatory Design (PD)

PD is a design approach that actively involves multiple stakeholders (children, parents, teachers, therapists and others) as participants throughout the design process. It differs from traditional user centred approaches to design insofar as the user is not only a source of information or evaluator but, also plays a decision making role acting as a “co-designer” [3]. To this end the levels of engagement with users which characterizes a PD process is not only more appropriate for groups of people that are marginalized, such as those with ASD [4, 5], but in fact yields higher quality outcome [6]. Notwithstanding the previous, there are significant challenges for designers with ambitions to engage children with ASD in a PD process. This paper explores the benefits for designers, people with a disability and other stakeholders when PD is implemented within the context of a technology design process. In particular, it examines the contribution adult stakeholders can bring to it.

1.2 Challenges of Designing for Children with Autism

Autism is referred to as a “spectrum disorder”, reflecting the high degree of variability of presentation between those diagnosed, with symptoms displayed across a broad range of severity. This heterogeneity of presentation complicates the study of its diagnosis, prognosis and treatment interventions [7] and, it challenges technology designers to create solutions that can match a diverse range of needs and preferences. As many as 50–70 % of children with ASD also have intellectual disabilities, compromising their social, cognitive, and adaptive skills [8] and impacting upon their abilities to participate in collaborative design [9]. Furthermore, one of the core features of ASD: impairment of communication; has a significant effect on a child’s ability to partake in activities requiring face-to-face collaboration with others. Although deficits in language skills are by no means universal in autism, they are found in the majority of children with the disorder [10]. Nonetheless, there are benefits to placing the child with ASD at the centre of the design process. For instance, the children’s perspective of the world can differ significantly from that of adults [11] and hence, their perceptions of the outcome of the design process may be at odds. Against this background, the question remains how can we best facilitate the inclusion of children with ASD in PD processes.

1.3 Inclusion in Design: The Role of the Adult as Inclusion Partnerß

As the complexity of the disability increases so do the requirements for support to ensure that the inclusion of children with ASD in PD is meaningful and adds value. Children with more significant disabilities often require prompting, encouragement and support

from adults and peers to effectively use technology. To date, research has focused on the role of the child within the design process rather than that of the adult. However identifying more explicitly the role of the adult within a PD process, translates into a tangible framework to maximise their own participation and the participation of the children they represent or support. Thus the responsibilities of adults in technology PD projects for children with special needs, extend beyond contributing to the design process and the designed artefact. They provide support and encouragement for the child and create an environment that supports the child's active participation [12]. Given that many designers and researchers may have limited experience of working with children with disabilities, the role of the adult also extends to acting as a communication partner for the child; assisting in the interpretation of language between the designer and the user in the conveyance of meaningful responses [13]. The current study explores the role adults can play within a PD process, in terms of: 1. bringing to bear their own experience and skills; and 2. ensuring the participation of children with more significant cognitive, social and language disabilities is maximised.

2 Method

A qualitative study, within the context of an on-going PD project to develop a collaborative game to facilitate the development of social interaction skills for children with ASD, was conducted with a group of 27 adult stakeholders. The study employed an interpretive phenomenological analysis approach, previously used to underpin similar research [14], within which the participant is considered an expert of their own experience [15].

2.1 Objectives of the Research

The study aimed to increase understanding of:

1. The contribution adults can make within the process of designing technology for children on the autism spectrum.
2. The challenges and barriers to ensuring the active engagement of adults within a technology development process.

2.2 Description of the Study Process

A workshop, part of an elective session in a national conference on autism and technology in the state of Qatar, was conducted. Potential participants were asked to attend if they had direct experience of working with or caring for a person with autism and if they had an interest in critiquing an educational game developed for children with autism. The workshop comprised two parts: (1) a demonstration of a design workshop providing participants with experience of a simulated design workshop involving an educational game for children on the autism spectrum; (2) a reflective exercise involving participation in a facilitated focus group and a face-to-face interview with a researcher.

2.3 Data Collection and Analysis

Data was collected via two interconnected mechanisms: focus groups and individual questionnaires. Firstly, participants were organized into 5 focus groups comprising 5-6 participants each. Every group was facilitated by a member of the research team and was given a list of specific tasks to complete during the assigned timeframe. Each group had an appointed, non-participant researcher to record the discussions and interactions of group members and to transcribe these afterwards. Data gathered was analysed using procedures guided by constant-comparative methods. This method compares and contrasts data gathered during interviews or other qualitative methods, forming data categories, assigning content to categories, seeking negative evidence so as to identify conceptual similarities in gathered data and to discover patterns [16].

Focus Group Task Assignment: The focus groups provided a platform to discuss the roles and responsibilities for the participation of adults in design projects. They were structured to discuss and report on the following discussion tasks:

- Please identify and provide a brief description of the contributions adult stakeholders can make within the process of design of technology for children with autism.
- Identify challenges to adult participation in design projects.
- In what ways are children on the autism spectrum best utilized within a typical technology design process?

Facilitators ensured discussions stayed on topic, answered specific questions and queries about the tasks and monitored the progress of each group.

Questionnaire: Further data was gathered using a face-to-face interview with each participant.

The principal data gathering tool for this interview was a three part questionnaire focussed on: 1. the participants' experience of children with ASD; 2. their experience of using technology; and 3. their perception of themselves as contributors to technology design projects. The interview aimed to obtain the views of participants regarding the role they felt that they could play within the context of the design of educational games for children with autism and to gain a measure of their perceived confidence in their role. Responses were recorded by the researcher and transcribed alongside each participant's completed questionnaire.

2.4 Participants

Participants fell into two categories: (1) those describing themselves as Health, Education or Social Care professionals (n = 12); (2) those describing themselves as parents of children with autism (n = 15). The majority of participants were female and collectively represented a broad range of nationalities (Table 1).

Table 1. Participant's (n = 27) description

Gender:	Age:	Role:		
Male: 8	18 – 25 years:	3	Parent (Male)	2
Female: 19	25 – 35 years	16	Parent (Female)	13
	36 – 45 years	7	Professional (Male)	6
	>45 years	1	Professional (Female)	6

3 Findings

This section presents findings in relation to the five roles: *Advocate*, *Teacher*, *Technology Enabler*, *Autism Expert* and *Communication Parter*; adults perceive they can play as active contributors to the design of technology for children with ASD. The perspective of *Parents* and *Professionals*, in terms of how their skills and experiences contribute to their abilities as co-designers, are also provided. While the roles emerged from the analysis of the focus group discussions, the.

3.1 Perceived Adult Contribution

The From the facilitated focus group discussion emerged a total of five specific contributions adults of children with ASD could make in a design project. During follow up interview, each participant was asked to identify the areas that best described their own contribution to a design process. The roles and the discussions regarding their contribution to a design process are elaborated upon and discussed below.

1. Advocate

Parents in particular as a group suggested that the primary responsibility for adults in a technology design process was to advocate for the needs of their own child. Ensuring the function of new technology matches the perceived needs of the children they represented is the primary purpose of their involvement in design. Thus, the design processes and technology should reflect the interests, needs and abilities of each child. The *Advocate* role also highlights the importance of the adult, and in particular the *Parent*, in ensuring the safety and well-being of children when they participate in design projects.

2. Teacher

The role of *Teacher* involves identifying and articulating how the technology can best contribute to each child reaching his/her educational potential. Therapists and specialist teachers of children with autism emphasize their personal responsibility to ensure the design of new technology reflects this and has authentic educational value. All the *Professionals* participating in this study felt that this role was critical in terms of defining the success of the process and identified it as their primary role within a design process. For *Professionals* the value of new technology resides squarely with its overall impact on either educational provision or learning outcomes for children on the spectrum.

3. Technology Enabler

The role *Parents* and *Professionals* play as enablers of technology use for children with ASD was highlighted in discussions. Several parents mentioned that children on the autism spectrum will often not seek out new technology to use and may not have the initiative or motivation to explore new technology alone. As such, the role of the parent becomes that of introducing the technology, creating the context for its use and encouraging and motivating the child. This role is often overlooked in many design processes or is relegated to the margins of the development cycle. *Parents* and *Professionals* have a unique insight of the additional human supports required to enable children with disabilities to use technology.

4. Autism Expert

A common theme emerging from the focus group discussion was the need for domain expertise to influence the direction of design processes. The consensus amongst study participants was that everyone brought a degree of this expertise based on their own experience, but in general, *Professionals* felt that they were in a better position to bring this particular quality to bear on the design process.

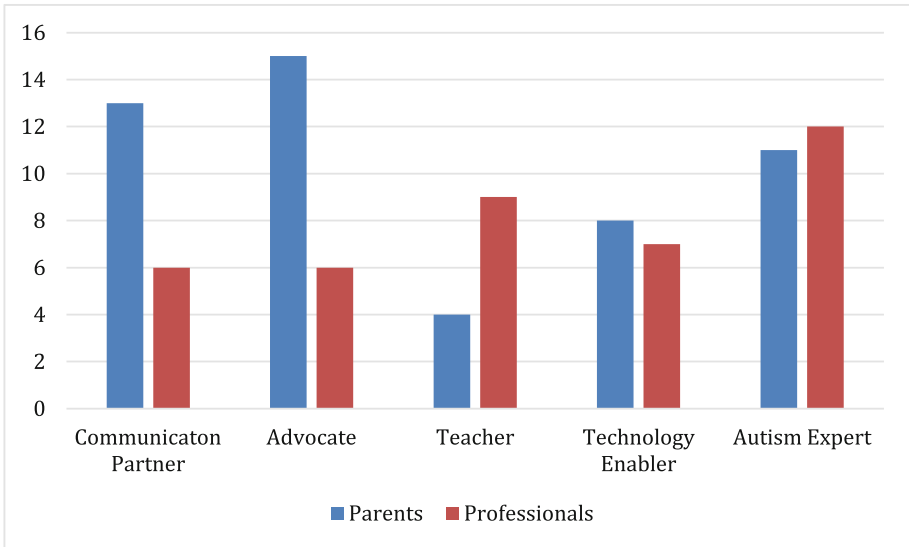
5. Communication Partner

Parents in particular struggled during the focus group to find a short description of what they felt was a very important role they could potentially play. Supporting a child's ability to communicate and represent themselves in a collaborative workshop with other adults was highlighted as a potentially stressful situation for many children on the spectrum. Parents spoke about the need to prepare children for participation well ahead, through mechanisms such as Social Stories [17] or other cognitive behavioural interventions. For children that are non-verbal, the parent's role as communication proxy is a determining factor in their inclusion in design. An additional factor emerging from discussions, particularly for parents of older children or those with more significant presentations of their disability was of motivating the children. Firstly to participate and secondly to maintain their participation throughout what is often a time consuming process.

The lack of distinction and the blurring and overlapping of the above roles and contributions was a theme that extended through the discussions on this task. This possibly reflected the breadth of contributions that adult stakeholders could in fact present if included more comprehensively in PD processes. When asked to choose one or more role that described their potential contribution to a design project the entire sample of *Professionals* ($n = 12$) and the majority of the *Parents* ($n = 13$) chose two or more roles (Table 2).

3.2 Perceived Challenges to Active Adult Inclusion in Design

Overwhelmingly both *Parents* and *Professionals* pointed to several issues they consider impair the participation of adults in design processes. The more salient ones were the lack of previous experience, skills or knowledge of what constitutes a "design process", as articulated in a statement by the mother of a 14 year-old boy with autism:

Table 2. Parents & Professionals views of their contributions to a technology design process

"I would think it natural that those who design the technology know best, better that I let them get on with their job"

Another, impairment for their participation was the lack of clarity regarding the expectations of them and their contributions to a design process. In particular statements by the parents within the group suggested that their experience as parents of children with disabilities was such that their general engagement with service providers was fraught with a lack of clarity of purpose. *Parents* reported that as their children grew older engaging with services or supports for their children required a clear and tangible benefit for their children and their families in the short-term, due to demands on their time.

3.3 Determining Objectives for Technology Design

Determining the objective of a new technology, whether from a therapeutic or a learning perspective, is often the first step within the design process. Inclusion in design from the earliest stage emerged as an important consideration for adults. In particular, the participation of children at the outset of a design process is crucial for adults in order to establish technology that is meaningful for children, and ensuring that the outcome can provide some degree of intrinsic motivation for use by its intended audience.

Collectively, *Parents* and *Professionals* expressed the belief that PD practices should focus on collaboratively defining the objectives of the proposed technology. *Parents* in particular, expressed the view that they are not often aware what the purpose of using specific technology is and hence are not in a position to attribute value to its use. Furthermore, *Parents* suggested that the emphasis on learning and therapeutic

objectives for technology often disenfranchises them as parents. Parental feedback was that they do not have the skills required to evaluate the learning or therapeutic progress a child may experience when using a specific piece of technology. The lack of technology designed for leisure and fun was highlighted alongside the unique role parents have determining the value of technology for their children's pleasure. These findings echo those of Frauenberger and his colleagues where the focus on design for people with disabilities tends to follow a deficit model focused on "repairing" rather than on a holistic perspective of the experience of disability [18].

3.4 Recommendations for Future Design Workshops

Our study indicates benefits from the active inclusion of adult stakeholders in the design of technology for children with ASD. However, challenges remain in order to identify, exactly what contribution individual parents and/or professionals can make and, how best to facilitate their articulation of these contributions. Contrary to the suggestion that PD processes should be entirely self-managing [19], it appears the inclusion of adults requires a degree of scaffolding in terms of the preparation for participation and tools to be used during the project. Increasing awareness and knowledge of the anticipated design process amongst participants and a clear articulation of the expectations of those about to engage in collaborative PD are desirable. In preparation for this study an effort was made to identify relevant and appropriate training packages for parents and professionals who are recruited in participatory design processes. It would appear however, that there is a need for those involved technology design to pro-actively seek to develop training and support packages to support the inclusion of not only potential end-users of technology but other stakeholders. The effective use of structured training for participants could ensure that research and design endeavours are truly collaborative and more reflective of participatory processes rather than user-centred design processes.

Utilising the experience and expertise of parents in particular to structure the timing, duration and demands of children's inclusion in the process are practical suggestion to incorporate in PD projects.

Moving forward, the five contribution roles identified here can form the basis for the development of a range of tools for PD workshops. The development and field testing of a range of supports, including training and information packages, role guidance for participants and decision making would appear to be the next step necessary in creating a structure of support for designers that ensure that they can maximise the participation of parents and professional stakeholders.

4 Conclusion

Adults participating in the design of technology tend to be employed to support the inclusion of their children or those they work with [12]. This would appear to be a missed opportunity for designers, considering that there are unique contributions they can offer based on their experience with children and technology. The focus of this

study was to begin to investigate the contribution adults can make through their participatory engagement in technology design for children with ASD. Their unique role reflects not just that they are supporters, enablers and facilitators of their children as technology users, but that they have the additional responsibility of representing and articulating the beliefs and experiences of their children or those they work with.

One of the defining differences between user-centred design and PD is in relation to how decision-making is devolved from designers to participants. For truly PD there is a need for designers to not just gather data that will inform the design process, but to create the conditions necessary and the tools required to proffer upon participants the opportunity to be articulate and creative. Designers must also be cognisant of the need to facilitate adult participants both in terms of determining their own values and opinions but also, their responsibilities to represent children who do not have the skills to fully articulate their own experiences and beliefs. In fact, there is an expectation upon designers to ensure that they as a community create the tools and infrastructure required to support and facilitate continued resonance with user experiences [20].

The final arbiter of the success or otherwise of PD must be the eventual outcome of the process. For technology designers the additional burden involved in creating a participatory process is of value only if the final product is enriched and improved by the participation of other stakeholders. To justify the on-going efforts to promote PD processes it is imperative that a body of evidence emerges articulating the value to be accrued through inclusive, participatory design practices. Echoing the recent work by Benton and Johnson [12] determining the impact of the inclusion of adults in the design process should lead to a better understanding of the value of their contribution to the outcomes of design.

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