



To Empower or Provoke? Exploring approaches for participatory design at schools for neurodiverse individuals in India

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ABSTRACT

As we push the boundaries of participatory design (PD) to empower children across the world, barriers to participation for those currently underserved require further attention. This includes neurodiverse individuals at special schools in India, whose day-to-day experiences are heavily influenced by the larger socio-cultural context of the schools comprising diverse stakeholders with diverse agendas and motivations. In this paper, we consider *how-to PD* at special schools in India. Employing the lenses of genuine participation and cultural translation, we critically examine two design projects with neurodiverse individuals: a gesture-based application to promote joint attention and using a mobile app to promote composting and entrepreneurial skills. We identified several challenges for adapting PD to the context of special schools in India. Reflecting on our experiences and coupled with previous literature on PD with similar contexts, we suggest potential solutions for these challenges. This includes *how-to* negotiate roles and responsibilities among stakeholders, handle conflicts among stakeholders' socio-technical aspirations, balance power differentials and censorship, and identify possibilities for long-term real-world impact. Our work paves the way to adapt PD, from a provocation or privilege to a possibility, to empower neurodiverse individuals in all corners of the world.

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1. Introduction

Participatory Design (PD) approach has been used widely in the Child-Computer Interaction (CCI) field, already since the 1990s (see e.g., [Druin, 2002](#)), to give children a voice in technology design. We acknowledge that PD has its roots in various research and design disciplines and practices originating from different European countries and the United States, with differing ideological underpinnings and practical implementations, while them all sharing a strong value orientation to human or user-centeredness (see e.g., [Asaro, 2000](#); [Iivari & Iivari, 2011](#); [Spinuzzi, 2002](#)). In this study, we are particularly inspired by the Scandinavian approach to PD ([Bjerknes, Ehn, Kyng, & Nygaard, 1987](#); [Greenbaum & Kyng, 1991](#), [Simonsen & Robertson, 2012](#), [Luck, 2018](#)), which is rooted in trade union struggles to get more power to workers, when new technologies entered the workplace and users had very little say on whether and how they used these technologies in their work. Today, PD practices have an established position in the fields of technology design

and community development and the guiding principles of PD remain valid (see [Bødker, Kensing, & Simonsen, 2009](#); [Luck, 2018](#); [Østergaard, Simonsen, & Karasti, 2018](#); [Simonsen & Robertson, 2012](#)). In CCI, researchers advocate technology design by children, and not just passive consumption of it, some of them calling for following more clearly the Scandinavian approach to PD (e.g., [Dindler, Smith, & Iversen, 2020](#), [Iivari & Kinnula, 2018](#), [Iversen, Smith, & Dindler, 2017](#)).

However, it is not always straightforward to apply PD principles and practices with children despite decades of valuable CCI research on the topic, particularly when taking PD out of settings where we work with Western, neurotypical children. PD research more generally has been criticized for neglecting many cultural and power related issues. For instance, [Smith, Winschiers-Theophilus, Paula Kambunga, and Krishnamurthy \(2020\)](#) look at PD through the lens of decolonization and assert that PD researchers must consider local contextualized political and cultural practices and epistemologies. We argue that this calls for “cultural translation” of PD (see e.g., [Merry, 2006](#)): we see that PD can be seen at the same time as an idea, a practice, and a transnational set of norms, and the underlying philosophy may need to be “translated” differently than the practical aspects,

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while remembering that ideas and practices that resonate with local implementers are more likely to be adopted (see Gardinier, 2012a, 2012b; Merry, 2006). When working with children in PD projects around the globe, we maintain there remains important cultural and power laden issues to be examined. Depending on the context and participants, a PD project can be an intimidating, disturbing, or a scary experience, instead of an empowering one. The literature indicates that involving children who are underserved by current technologies in PD projects does not inherently provide them the experience, vocabulary, or tools to contribute to the PD process (Itenge-Wheeler, Kuure, Brereton, & Winschiers-Theophilus, 2016; Kam, Ramachandran, Raghavan, Chiu, Sahni, & Canny, 2006; Liaqat, Axtell, & Munteanu, 2021; Liu & Roto, 2017; Moraveji, Li, Ding, O'Kelley, & Woolf, 2007). Several barriers must be crossed to enable meaningful and impactful participation (Brotto Furtado et al., 2008; Eduardo Nieto, Tobón Giraldo, & Torres Parra, 2020; Itenge-Wheeler et al., 2016; Kalunda, 2014; Schwartz, Kaplan, Lajoie, Terrell, & Ajambo, 2015; Tushar, Antara, Das, Chandra, Soron, Haque ..., & Ahmed, 2020). The power dynamics and socio-cultural issues are even more exacerbated when employing PD with neurodiverse populations (Frauenberger, Good, Fitzpatrick, & Iversen, 2015; Spiel, Brulé, Frauenberger, Bailly, & Fitzpatrick, 2018; Spiel, Frauenberger, Keyes, & Fitzpatrick, 2019), for instance, due to varying levels of comfort in communicating verbally and non-verbally, in social interactions, and in cognitive activities. Leveraging PD with neurodiverse participants calls for critical examination of how to accentuate participants' voices, increase their autonomy and agency, and empower them in their everyday lives and technology interactions (Benton, Johnson, Brosnan, Ashwin, & Grawemeyer, 2011; Benton, Vasalou, Khaled, Johnson, & Gooch, 2014; Frauenberger, Good, Alcorn and Pain, 2012; Frauenberger, Good, Keay-Bright and Pain, 2012; Frauenberger, Makhaeva, & Spiel, 2017; Mora-Guiard, Crowell, Pares, & Heaton, 2017; Pihlainen, Montero, & Kärnä, 2017; Vasalou, Ibrahim, Clarke, & Grifiths, 2021). Further, while PD is seldom studied across diverse cultures in the Global South,¹ the intersectionality of PD with neurodiverse children and in the Global South is under explored.

Along these lines, we critically examine in this paper two design projects with neurodiverse participants at special schools in New Delhi, India: using gesture-based interaction to promote joint attention and using a mobile app to promote composting and entrepreneurial skills. Our work is situated within the context of a special school where all students are treated equally regardless of age. Students are assigned classes, groups, interventions, tasks, etc., based on their social and cognitive skills, which are evaluated by trained experts every year, and not based on chronological age. In our research, we ask *how to adapt PD to the particular needs of neurodiverse individuals in a special school in India?* By critically scrutinizing projects at two special schools in New Delhi, we uncover several challenges. We employ the lenses of genuine participation manifesto, based on research on PD with children in the Global North (Kinnula & Iivari, 2021), and cultural translation (Gardinier, 2012a, 2012b; Merry, 2006; Merry & Wood, 2015), and reflect on these challenges. We contrast our findings with known challenges in PD with neurodiverse participants and suggest approaches for cultural adaptation of PD for neurodiverse participants in the context of special schools in India, and more broadly in the Global South with similar challenges. This paper paves the way for leveraging PD from a provocation to a possibility, to empower individuals in underexplored contexts through sensitive cultural adaptations; a first step towards CCI's ambitious goal of globally inclusive PD.

¹ We use the term Global South conceptually rather than geographically, to represent an environment that might be underserved, under-resourced, and/or includes vulnerable and marginalized communities.

This paper is organized as follows: Section 2 presents related research, Section 3 the research design and Section 4 our findings. We discuss the implications of our findings in Section 5 and conclude the paper in Section 6.

2. Related research

In this section, we first present our theoretical lens on genuine participation of children, to give the reader a perspective to what we see as an idealistic goal for PD with children, both neurotypical and neurodiverse, in the Global North and anywhere and elsewhere in the world. Then, we present an overview of research on PD with neurodiverse children in the Global North, and PD with children in the Global South, which frame the context of our work and make visible challenges in making the genuine participation ideals to come true in these contexts. Finally, we discuss the process of cultural adaptation, as a potential approach for translating PD to the Global South context.

2.1. Children's genuine participation

As mentioned, CCI research has championed PD with children for decades. Drawing on this vast body of knowledge as well as on the developments within the field of PD and in the literature on genuine participation of children within a multidisciplinary literature base, Kinnula and Iivari (2021) propose a manifesto for children's participation in the context of technology design, in which they aim to articulate what participation means at its best. The manifesto posits that such genuine participation entails five dimensions: meaningful, effective, contextual, political, and educational. Participation must be **meaningful** to the children, i.e., it must be engaging and address relevant and interesting issues from their perspective. Further, their participation should be **effective**: it should empower them to make informed decisions concerning their lives and this should translate into an actual, tangible impact. In terms of **context**, participation always occurs at a particular time and place by particular people. Context-sensitivity thus demands consideration of, e.g., cultural issues and participants' background, skills, knowledge, and interests. There are also **political**, ethical, and power issues to consider: these issues are inextricably intertwined with participation, and it is important to acknowledge them explicitly and initiate debate, reflection, and negotiation about them. Finally, in addition to involving children in the project and encouraging them to have a voice, **educational aspect** needs to be considered, taking into account children's competence development in a longer timeline and future projects as well. Careful adult contemplation is required for this dimension of genuine participation of children. Through the manifesto, it is possible to critically examine how well 'participation at its best' is realized. Against this backdrop, we next discuss previous research on PD with neurodiverse children and PD with children in the Global South, and the identified challenges.

2.2. PD with neurodiverse children

Technology-mediated interventions offer several advantages and opportunities for neurodiverse individuals such as providing a multisensory, structured, predictable, and safe learning environments with possibilities for customization for individualized self-paced learning goals with increasing levels of difficulties (Bartoli, Corradi, Garzotto, & Valoriani, 2013; Frauenberger, Good, Alcorn et al., 2012; Frauenberger, Good, Alcorn, & Pain, 2013; Frauenberger, Good, Keay-Bright et al., 2012; Mora-Guiard et al., 2017). To design and develop such interventions, PD inspired methodology has been widely utilized, mostly in Europe and North America. More specifically, this includes children with autism spectrum

disorders (see e.g., De Leo & Leroy, 2008; Frauenberger, Good, Alcorn et al., 2012; Frauenberger et al., 2013; Frauenberger, Good, Keay-Bright et al., 2012; Grierson & Kiefer, 2013; Malinverni et al., 2014; Mora-Guiard et al., 2017; van Rijn & Stappers, 2008), ADHD (Cibrian et al., 2020; Frauenberger, Spiel, Scheepmaker, & Posch, 2019), and other learning difficulties such as dyslexia (Holone & Herstad, 2013; Kender, Frauenberger, Pichlbauer, & Werner, 2020; Robb, Leahy, Sung, & Goodman, 2017; Vasalou et al., 2021). In some studies, neurotypical children are also involved as participants (Mora-Guiard et al., 2017; Parsons, 2015). Typically, PD sessions are conducted within schools in these studies (e.g., Fage, Pommereau, Consel, Balland, & Sauzéon, 2014; Frauenberger et al., 2013; Frauenberger, Makhaeva, & Spiel, 2016; Mora-Guiard et al., 2017; Parsons, 2015; Spiel, Malinverni, Good, & Frauenberger, 2017; Vasalou et al., 2021) but also at homes (Hamidi, Baljko, & Gómez, 2017; Spiel et al., 2017) and for instance in relation to after school activities in the same premises (Pihlainen et al., 2017). Other stakeholders can also be present or involved in these studies, such as parents (Abdullah & Brereton, 2015; Frauenberger et al., 2013; Vasalou et al., 2021), teachers including special education teachers (Fage et al., 2014; Frauenberger et al., 2013; Vasalou et al., 2021), other school personnel, e.g., coordinators (Vasalou et al., 2021) and ChSL interpreters (Véliz, Espinoza, Sauvalle, Arroyo, Pizarro, & Garolera, 2017), and medical professionals such as therapists (Hirano et al., 2010; van Rijn & Stappers, 2008) and psychologists (Mora-Guiard et al., 2017). When working with neurodiverse children, adult participants can enrich and build understanding on children's contributions (Vasalou et al., 2021), act as design (critique) participants (Frauenberger et al., 2013; Pihlainen et al., 2017), or as proxies or informants through interviews (De Leo & Leroy, 2008; Pihlainen et al., 2017; Vasalou et al., 2021). In Pihlainen et al. (2017), parents' participation was emphasized for three reasons: building parents' expertise and understanding about their own child, providing an opportunity for the parent to see their child working with new inspiring technology and giving a possibility to the child to teach their parents, and providing a possibility for the parents to transfer child's new skills and tools to everyday life (ibid). However, in many cases, it becomes difficult to identify the role and responsibilities of these other stakeholders: are they communication proxies, co-participants, or caregivers watching on as "an audience". This ambiguity leads to more pronounced power differentials between participants and other stakeholders, including the researchers (see e.g., Guha, Druin, & Fails, 2008; Vasalou et al., 2021).

The ethics of participation with neurodiverse children has been contemplated upon (Spiel, Brulé, Frauenberger, Bailley, & Fitzpatrick, 2020; Spiel et al., 2018), pointing out issues around negotiating multiple agendas, being at risk, caring for children, and balancing between personal and professional roles. Participation challenges are exacerbated when children face issues towards communication and self-expression, for instance, due to being non-verbal, shy, anxious around unfamiliar people, and/or learning emotional regulation (Benton et al., 2011; Brown, Silvera-Tawil, Gemeinboeck, & McGhee, 2016; Frauenberger, Good, Keay-Bright et al., 2012; Frauenberger et al., 2016, 2017; Hamidi et al., 2017). In case of children who are non-verbal and have low motivation for social interactions, there is an increased dependency on adults to interpret behavioral expressions, yet these interpretations are individualist and can be prone to misrepresentations (Cibrian et al., 2020; Holone & Herstad, 2013; Robb et al., 2017). Overall, parents and caregivers play an important role in the daily life of neurodiverse individuals as proxies, interpreters, caregivers, and decision-makers, which can create tensions between participants and parents, and increase the burden of participation on parents (Cibrian et al., 2020).

Further, the "situated context" (Frauenberger, Good, & Keay-Bright, 2010) of a classroom or special session, creates barriers to participation, contribution, exploration, and meaningful experience, where children are expected to follow instructions and adult-authority is desirable and enforced (Brulé & Spiel, 2019; Frauenberger et al., 2019). The context may also suffer from a goal-rewards mindset, where divergence of ideas or processes are difficult to support (Kender et al., 2020; Malinverni et al., 2014). Within this complex system, the role of researchers is precarious; Vasalou et al. (2021) identified problematic power dynamics such as children not replying truthfully to researchers' questions and researchers exerting tight control over the direction of the session. Several studies have explored various design techniques and strategies, centering on participants' diverse abilities, for them to flourish in their participation (Benton et al., 2014; Frauenberger, Good, Keay-Bright et al., 2012; Frauenberger et al., 2017; Malinverni et al., 2014; Spiel et al., 2017). For instance, the OutsideTheBox project has a repertoire of tools and techniques for designing, including those for "contextualization, ideation & inspiration, conceptualization, prototyping, refining & testing, and evaluation" (Frauenberger et al., 2017). Further, there is interest in balancing stakeholder and participant voices through long term engagement and designing for school, home, and other contexts (Alper, Hourcade, & Gilutz, 2012).

The challenges mentioned above have been identified in the context of the Global North. There are several socio-cultural, informational, and economic issues affecting neurodiverse children and their families in the Global South (Boujarwah, Hong, Abowd, & Arriaga, 2011; Daley, 2004; Desai Miraj, Divan, Wertz, & Patel, 2012; Sharma, 2018): from lack of culturally adapted screening tools, considerable delays in diagnosis, limited access to health-care interventions and special schools, to lack of information and awareness, and prevailing social taboos against neurodiversity. A recent study across five regions in India reports 1 in 100 children to be on the spectrum (Arora, Nair, Gulati, Deshmukh, Mohapatra, Mishra ..., & Murthy, 2018), thus, it is crucial to explore and develop interventions supporting neurodiversity. Through our work, we highlight an underexplored context of special schools in the Global South and discuss culturally sensitive issues, including stakeholder influence, roles, and responsibilities, and the added burden of social stigmatization and its repercussions to the home and school context (see also Tushar et al., 2020).

2.3. PD in the Global South

PD tradition has also permeated into the Global South, with a handful of studies being conducted with children (Brotto Furtado et al., 2008; Eduardo Nieto et al., 2020; Itenge-Wheeler et al., 2016; Kalunda, 2014; Kam et al., 2006; Liaqat et al., 2021; Liu & Roto, 2017; Moraveji et al., 2007; Scheepmaker, 2018; Schwartz et al., 2015; Tushar et al., 2020). While empowerment of participants through PD is at the heart of CCI research, there are several challenges in introducing and employing PD with children in an underserved context, including unequal power structures or complex social hierarchies (Brotto Furtado et al., 2008; Itenge-Wheeler et al., 2016; Kalunda, 2014; Kam et al., 2006; Liu & Roto, 2017; Pal, Lakshmanan, & Toyama, 2007; Sharma, Achary, Kaur, Linna, Turunen, Varkey ..., & Daeeyya, 2018), a complex social-ecosystem consisting of several influential stakeholders (Brotto Furtado et al., 2008; Eduardo Nieto et al., 2020; Itenge-Wheeler et al., 2016; Kalunda, 2014; Schwartz et al., 2015; Tushar et al., 2020), strict or strong gender roles (Kam et al., 2006), and a lack of experience or familiarity with the technology being designed or with the processes of designing and brainstorming for meaningful contribution and participation (Itenge-Wheeler et al., 2016; Kam et al., 2006; Liaqat et al., 2021; Liu & Roto, 2017;

Moraveji et al., 2007). Further, the educational context can favor rote-learning affecting creativity and self-expression or focus on competition rather than collaboration (Liu & Roto, 2017). It can also be multilingual, e.g., with the native language spoken at home and English at school, adding another layer of complexity to the design process and participation (Boujarwah et al., 2011; Kam et al., 2006; Liaqat et al., 2021; Pal et al., 2007).

Within this complex social ecosystems, adult stakeholders bring in their own agendas and aspirations, which can drive and determine what technology is adopted and desirable, thus, technology design is influenced by the different stakeholders' socio-technical aspirations (Boujarwah et al., 2011; Brotto Furtado et al., 2008; Kumar et al., 2019; Sharma et al., 2018; Toyama, 2018). For instance, technology use is encouraged only when it achieves an educational goal (Brotto Furtado et al., 2008; Eduardo Nieto et al., 2020) or displays (high) social status (Sharma et al., 2018). In this work, we scrutinize this complex social ecosystem, especially considering its influence on neurodiverse students at schools. While adult involvement may or may not be desirable in all PD contexts (Brotto Furtado et al., 2008; Kalunda, 2014; Liaqat et al., 2021; Tushar et al., 2020), within a special school it can be difficult to involve young children, who have communication challenges (Tushar et al., 2020). This increased dependency on adults brings its own set of challenges and opportunities, as presented in the findings of the current study. Previous work also suggests several ways to mitigate the power imbalance between child and adult participants: by enlisting local adults and children as facilitators and politely requesting the teachers to not participate (Kam et al., 2006), understanding the local educational context of teachers, parents, students, and their expectations before introducing PD (Brotto Furtado et al., 2008; Itenge-Wheeler et al., 2016; Liu & Roto, 2017), being cognizant of the different stakeholders involved (Brotto Furtado et al., 2008).

2.4. Translating PD from Scandinavia to the Global South

When reflecting on the PD principles and the genuine participation ideals in relation to the previous research on PD with neurodiverse children in the Global South, it is clear that there are challenges. Though PD is rooted in transnational ideals of democracy and equality, it originated in the Global North and is based on Western epistemologies (Smith et al., 2020), and the Global South can have cultural and epistemological differences that need to be noted in PD practices (Serpa, Portela, Costard, & Silva, 2020; Smith et al., 2020). For this, we take our inspiration from translation of transnational ideals in the field of anthropology, which state that when bringing transnational norms (e.g., equality, inalienable rights, autonomy) into local environments it is important to take the local culture into account, as cultural differences can affect how these concepts are implemented in practice (Gardinier, 2012a, 2012b; Merry, 2006; Merry & Wood, 2015).

The process of adapting and reconstituting transnational norms to fit the local framework of norms and practices is called localization (Acharya, 2004). Acharya (2004) proposes a four-stage trajectory of localization: (1) Pre-localization, (2) local initiative, (3) adaptation, and (4) amplification and universalization. In our work, we focus on stage 3 (adaptation), during which both foreign norms may be reconstructed to fit the pre-existing local culture, and local beliefs and practices may be adapted to fit the foreign norms (ibid). To be adopted, transnational ideas must be framed: That is, re-presented in a form that is understandable within the local context (Gardinier, 2012b; Levitt & Merry, 2009; Merry, 2006). If the goal is a concrete change, it is important to strike a balance between challenging prevalent modes of thinking and concealing radical ideas with a culturally acceptable frame (Merry, 2006), which can be very difficult for actors who are not intensely familiar with the local culture and its complexities.

When foreign actors attempt to situate external norms into the local environment, it is called "grafting" (Gardinier, 2012a, 2012b). The process of local actors adapting these grafted foreign norms and practices to their culture and environment is called "vernacularization" (Merry, 2006). The actors who facilitate the localization process, both local and international, are called "norm entrepreneurs" (Acharya, 2004). Indigenization, the symbolic dimension of vernacularization, refers to the shifts in meaning that may result from framing new ideas to fit the existing cultural values, norms, and practices (Merry, 2006). Local norm entrepreneurs also act as cultural "translators" (Merry, 2006; Merry & Wood, 2015), where such "translation" means both the literal act of translating guidelines and terminology from one language to another as well as the concrete act of adjusting foreign norms and practices to be implemented into local environments (Merry & Wood, 2015).

The translators and implementers are not necessarily the one and the same. Implementers (e.g., teachers) can get their guidelines from higher up translators (e.g., local government officials). The implementer can further translate the idea by changing its content and/or practice to fit the local set of norms (Gardinier, 2012a:218). Being up to implementers, they can be unexpected to foreign norm entrepreneurs and even to higher up translators who are not familiar with the field (Gardinier, 2012a:218). Some of the unintended consequences, however, can be avoided if the implementers use their intuition and experience (Gardinier, 2012a). Translators who are committed to the target (e.g., local implementers) produce more hybridized translations than those closer to the source (e.g., local academics) (Merry, 2006). Ideas are more likely to be adopted in the long term if the local implementers are pleased with the outcomes (Gardinier, 2012a).

Coming back to transferring the PD ideals into a new context, even if the local norm entrepreneurs were interested in the idea of PD, this does not intrinsically translate into understanding and acceptance of the set of norms PD is built on. A transnational view of PD must be framed, and concrete practices adjusted to fit local conditions if one wishes to challenge the local norms. For this framing of transnational ideas to be effective, it is imperative to understand the local culture and to recognize the importance of local "translators" (Gardinier, 2012a, 2012b; Merry, 2006; Merry & Wood, 2015; Serpa et al., 2020; please refer to Appendix Table A.1 for terminologies).

Thus, for cultural translation of PD (or any other transnational ideal) to be relevant, the following steps are considered important, particularly if one wishes to challenge and change the local set of norms:

1. Understanding the local culture; recognizing the importance of local translators
2. Framing the transnational ideas and norms so that they are understandable within the local context
3. Adjusting the concrete practices to fit the local context, adapting the ideas to local customs and culture to varying degree
4. Considering whether the goal is a short-term intervention or a long-term reform; how it affects the effort
5. Understanding that interest does not intrinsically translate into understanding and acceptance of the set of the transnational norms

In our work, we approach the cultural translation of PD to the Global South through adaptation with a local implementer and a local norm translator, both of whom are Indian.

3. Research design

To explore adaptation of PD with neurodiverse participants in India, we examine two of our previous user-centered design projects. Neither of these projects were conducted as PD projects, but the general PD ideal of developing technology for the users, with the users, was at the heart of both projects. We argue that the projects open the window for us to reflect on the translation of PD ideals to this very challenging context. Next, we present a brief overview of those projects, *Balloons* and *Compost* and the participant demographics, data collection and analysis process, and author positionality to foreground our findings.

3.1. Case study overview - *Balloons* and *compost*

In the ***Balloons*** project, we created an application that focuses on promoting joint attention between medium–low functioning autistic children and neurotypical individuals through gesture-based interaction using the Microsoft Kinect device (Sharma et al., 2016). Its users have the task of collaboratively selecting one of three balloons by standing in front of the system and pointing, necessitating the need for social interaction between the teammates and capitalizing on the benefits of gesture- and full-body-interaction for neurodiverse participants (Bartoli et al., 2013; Mora-Guiard et al., 2017).

Balloons was designed through a user-centered design approach involving 23 participants: nineteen school specialists, three parents and two high functioning autistic children, where two researchers spent a week at the school becoming familiar with the ongoing interventions and therapies, and then devised the application from insights from group discussions with various stakeholders on how to incorporate an intervention to promote joint attention at the school (Sharma et al., 2016).

The final solution was evaluated with 10 participants with autism over three weeks, with two to four sessions per participant per week. The application was installed in one of the school's classrooms, which is commonly used by the participants to provide a familiar environment. The evaluation was conducted in three phases; phases I and III were carried out with actual balloons for a pre- and post- analysis of joint attention, and phase II included sessions with application. This was required to understand whether learning from a virtual application was translated to the physical world.

In the ***Compost*** project, a student-intern developed a mobile game in the context of compost-making, to support the project's aim to inculcate entrepreneurial skills and financial independence (Sharma et al., 2020a). To practice how to sort kitchen waste, the concept of biodegradable and non-biodegradable materials was first introduced through the game (see Fig. 1). The 67 participants had severe developmental disabilities. None of them had any prior experience with composting. Compost-making was specifically selected as it is understood to be more forgiving in its process, for instance, when compared with other projects such as making personalized notebooks. Further, while actual composting requires several weeks or months of decomposing of organic waste, there are commercially available single-day compost makers that cut and dry the waste within 8 h to be usable for certain domestic use.

Using the mobile game as well as practicing in groups, participants were taught the concept of organic vs. inorganic waste, how to collect and sort common kitchen waste, how to use compost makers, and how to brand and sell the end-product within their local neighborhoods. Compost makers were deployed in the school premises, outside the building, and participants were provided with waste from the school's kitchen, which they had to sort. The main outcomes include several participants learning

the composting process, while those with profound disabilities required supervision. While the main goal was for participants to practice the skills required to self-initiate small-scale startups within their own household, composting was not met with much fanfare by the participants' parents as it involved collecting and sorting waste and required physical activity and maintaining continuous hygiene.

After the project ended, the activity was discontinued. The technologies were not exciting for the stakeholders; the special educators also had no interest in the study and deemed composting a low skill, thus low social status activity, similarly to many of the parents.

Participants for both projects were recruited from two special schools in New Delhi, please refer to the section on selection of participants for more details. The classes at the schools are grouped on the basis of the individuals' social age, as evaluated by experts at the school (using CARS/IQ/SQ tools). Thus, the study participants worked with their peers and classmates, and we did not exclude participants from the interventions on the basis of age. Based on the chronological age, the participants included both children (under the age of 18 years) and adults (over 18 years of age).

Balloons application was evaluated with ten medium–low functioning individuals with autism (6 boys/men, 4 girls/women, ages between 10 and 23, with 6 under 18 years of age) diagnosed by the Autism Diagnostic Observation Schedule (ADOS) (Gotham, Pickles, & Lord, 2009) with Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, 2010) scores ($M = 34$, $SD = 3$) and Social Communication Scores (SCQ) (Malin, 1969) ($M = 48$, $SD = 13$).

In *Compost*, a total of 68 participants ($M = 45$, $F23$), aged between 17–46 years ($M = 31.5$, $SD = 6.3$) with severe or profound challenges ($SQ = 37.9$, $SD = 12.6$; $IQ = 39.4$, $SD = 12.5$) took part in the study. 75% of the participants could communicate verbally and 22% had difficulties in communicating. Based on their social age, all participants can be considered teenagers.

The effect of the participants' age on our findings is limited. Moreover, our focus is on the special school context in India, where students are treated equally regardless of age, and decisions (e.g., related to participation) are based on other cognitive and social parameters, not chronological age. Their interpersonal interactions were dependent on their cognitive and social communication skills as well, rather than their chronological age. The only impact of the chronological age with regards to the context of our work is how participants were addressed in the Indian cultural context; for example, all participants were addressed by their first name, with those who were older having the suffix **ji** (Hindi) added to show respect for age. We did not therefore limit inclusion in projects based on chronological age.

3.2. Data collection and analysis, author positionality

The data collected in both case studies included (1) quantitative data from both applications regarding application use; (2) pre- and post- skill tests devised by the researchers to measure learning; (3) researchers' field notes that include their observations during the studies and comments and interactions from/with/among participants; (4) photos of the sessions; and (5) documentation related to the user study plans and their outcomes (Sharma et al., 2020a, 2016).

From the cultural translation perspective, the two Indian authors of this paper worked as a local implementer and a local norm translator. The local implementer conducted both *Balloons* and *Compost* study. During that time, the local implementer was working with a non-government organization that caters to individuals with special needs in India and has three special schools.



Fig. 1. (left) A child interacting with Balloons, (center) groups sorting trash for composting, (right) mobile app for compost with green tray for biodegradable materials and blue for non-biodegradable. . (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)

The norm translator is native to New Delhi but moved to Northern Europe in 2011. She has experience working with children with special needs in India and EU, and she designed, developed, and co-evaluated the Balloons project. She has been working in collaboration with the local implementer since 2013. These two researchers' doctoral research included empirical work on neurodiversity in India. The other co-authors have over two decades of cumulative experiences with PD with typically developed school children in the EU.

Findings from both case studies from the perspective of the success of the projects have been previously published (Sharma et al., 2020a, 2016). For the purposes of this study, the Indian researchers conducted online data analysis workshops using the theoretical lenses providing prompts and discussion points. In the first phase, they utilized the dimensions of genuine participation (Kinnula & Iivari, 2021) to critically examine both projects. They analyzed the goals, processes, and outcomes, as well as challenges they encountered when starting, conducting, and ending the projects, focusing on the reasons for the challenges, always focusing on the genuine participation of the study participants. In the second phase, they, acting as cultural translators, examined the previously published findings on the success of the projects as well as the genuine participation related findings, and discussed potential solutions to those challenges through the lens of cultural translation (understanding, framing, adjusting). The workshops were audio recorded and transcribed. The findings from this analysis are presented in this paper. They are not differentiated based on the age of participants as that was not a meaningful analysis in the context of this study.

4. Findings

Considering the challenges towards genuine participation of neurodiverse individuals in India, in this section we present how PD can be adapted through cultural translation. We highlight what we already observed in the projects, what we think could be done, and who should be involved and how: *to enable genuine participation the best way possible.*

4.1. Meaningful

Meaningful participation is motivating, addresses relevant issues, and generates value for all participants.

Meaningful participation of participants: It was difficult to gauge how meaningful the participation was because of participants' varying levels of communication and social interactions. Participation varied in the projects between those: (a) who found the activity fun and exciting e.g., enjoyed looking at and interacting with virtual balloons; (b) who did not find the activity interesting or were unsure of how to react to the activity; and (c) whose behavior was difficult to interpret. From the participants' perspective, participating in the projects was a part of their regular ICT lessons and they had little say on the technology mediated intervention being designed. Further, considering

the actual activities, familiar or soothing micro actions, such as singing in compost, made the project more relatable and enjoyable for participants, which we suppose enhanced their experience of participation. However, compost included physically stressful work, which required adult supervision, thus, it was relegated as a part-time hobby and not a true entrepreneurial setup neither at school nor at home. These observations are common when working with neurodiverse participants in any cultural context. Specific to the Indian context, we noticed that participants who familiarized themselves with certain technology at school were provided more freedom to use that technology at home, and parents' attitude towards technology can be socio-culturally motivated.

Cultural translation of meaningful participation of participants: Our findings indicate that all forms of participation bring something new – even if it is difficult to gauge reactions and experiences of participants, especially in the short-term. Considering the Indian context, including neurodiverse participants in projects at school exposes them to various technologies creating opportunities to interact with technology also outside of the school. Participation in projects also brings special attention and recognition in the school, which then translates to the home context where being tech savvy brings respect. Thus, the meaningfulness of an intervention, technology, or participation in school should be framed with its translation to both the school and home contexts and adapted to cater to also other stakeholders' reaction/reception to participation.

Meaningful participation considering other stakeholders: In our project, different stakeholders reacted differently to the projects. While the goal of Balloons, of promoting joint attention, was derived from discussions with schools' educators, therapists, and other staff; the application was not adopted in the long-term. This is because educators' expected focus and outcomes in the school did not align well with uncertain outcomes of experimental interventions with the increased overheads. We found that it was important for the educators to have improved educational outcomes from all interventions, as educators themselves were evaluated on their students' performance in school or through standardized tests. In Balloons, the aim was to pair participants with a neurotypical peer, but as participants preferred to work with adults they were familiar with, the burden of interaction increased for the educators. In contrast, parents' motivation towards their wards' participation in projects varied based on the value they perceived e.g., of certain technologies and methods. For instance, in Compost, the meaning and implication of sorting trash (considered low skill work that would not be taught to their neurotypical wards in school) were problematic for the parents. Plus, the nature of the project required almost constant adult supervision. Thus, there was resistance from adults towards participation of neurodiverse individuals in the project. This high involvement of adult stakeholders such as parents in day-to-day activities is particularly noticeable in the Indian special school context.

Cultural translation of meaningful participation considering other stakeholders: We suggest that the value generated from

participation needs to be examined in light of the agendas and objectives of different stakeholders in the special school context regarding the design, process, and outcomes of the interventions, especially in a collectivist cultural context where community ties are strong and social norms are somewhat rigid. Thus, researchers should present short and long-term potentials of the intervention to all stakeholders and participants and then together outline the challenges and opportunities and agree on a roadmap for achieving those potentials. Further, we scrutinized meaningful participation from the perspective of expectations, where there can be conflicts. For instance, our projects aligned with participants seeking acceptance, recognition, and inclusion in society; to share spaces and gain affection. However, realization of these is dependent on society's expectations from the participants as individuals. Within the Indian cultural context, the concept of *being settled* is considered the ultimate goal for adults, as also shared by several parents during our projects. "Being settled" means to have a job and a family and contribute to society. Parents and participants expected schools to support these aspirations of having a job and getting married, which require self-management, emotional-regulation, and responsibility for one's own safety (physical, emotional). At a school, the staff assists with these but at a job and home environment, they are the individual's responsibility. Thus, while all stakeholders value independent dignified living, its definition and approaches vary. Therefore, for PD projects to ensure meaningful participation, it is important to examine, discuss, and agree on the goals and potential outcomes from participation with the different stakeholders and participants.

4.2. Effective

Effectiveness underscores decision-making of participants with regards to their participation, its impact on them and their lives, and to make a change.

Effective participation of participants: Working with neurodiverse individuals poses its own challenges with regards to effectiveness of participation as individuals face challenges in communication and social interactions to impact decision-making, as also observed in our projects. For *Balloons*, one of the main challenges faced was low acceptance of neurotypical peers as interaction partners and ensuring participant-reactions were towards the application and not to people or spaces. This was achieved by removing unfamiliar people from the evaluation environment. For *compost*, participants were gradually introduced to the project and its goals starting from a higher level of considering an environmentally friendly activity and then going into details of why and how to make organic compost. Compost activities were scaffolded through researchers' instructions till participants were able to perform individually. Further, participants were free to decide how to participate; by standing or sitting down, cutting, or sorting waste, and/or singing songs. While the strategies devised by the researchers were contextual, the challenges they addressed are common in the context of technology-mediated interventions for neurodiverse individuals.

Cultural translation of effective participation of participants: We suggest that researchers (or practitioners) act as mediators for participants' effective participation by rooting new activities in familiar ones and balancing study structure with participants' needs, requests, demands, and overall comfort. For instance, researchers and practitioners can incorporate micro activities considering individual preferences and changes to routines should be gradual. Further, these micro-activities can be initiated or suggested by participants, for instance, how participants enjoyed signing while sorting waste in *Compost*. While researchers are inclined to understand the challenges in implementing new

technologies and interventions and to adopt strategies for their acceptance, they should also be mindful of ensuring effective participation of neurodiverse individuals.

Effective participation considering other stakeholders: Given the lukewarm welcome the *Compost* project received from other stakeholders (parents, educators, school staff), there was little room to advocate for making organic compost as a small entrepreneurial venture; even though participants wore gloves, lab coats, and protective glasses to convert the activity from sorting trash to a science experiment to appease the adult-stakeholders. For *Balloons*, while the novelty of the technology (gesture-based interactions) was appreciated, the overheads and demands were too high for long-term adoption — some had to set up the Kinect, run the application, and check the environment (e.g., enough space for interaction via pointing gestures). Further, this operational overhead was increased if there were technical issues to debug, which required university researchers to intervene. There was also a lack of clarity on whose responsibility it was to continue long-term interventions with *Balloons*. This lack of long-term adoption was surprising to us given how *Balloons* was devised to fulfill the school's requirement for joint-attention intervention. However, this is not surprising in the context of technology-mediated interventions for neurodiverse individuals, or in any school context, where adopting new technology long-term has associated costs and burdens, adding to already stretched human resources.

Cultural translation of effective participation for other stakeholders: We find that introduction and use of technology for interventions is influenced by other stakeholders (researchers, educators, administrators) rather than the participants. Short-term experimental processes and outcomes are hard to assess in terms of long-term impacts when considering the added overheads and burden of responsibility. Thus, we suggest that special-school stakeholders need to be considered for effective participation: researchers should negotiate both short- and long-term roles and responsibilities of other stakeholders. This starts by identifying all other stakeholders within the special school context, who may or may not be directly involved in the projects. Negotiation of support and expectations from and of parents and caregivers is also required to ensure participants do not face resistance at home, and to limit self and adult censorship.

4.3. Contextual

Contextual aspects of genuine participation highlight both participants' individuality (their experiences, preferences, background, and histories) and social dynamics (cultural contexts, interactions, and relationships).

Context of participation for participants: Participants had limited voice in terms of the contextual nature of their participation, which was hijacked by all other stakeholders in our projects. As expected in the context of neurodiverse individuals, participants' experiences differ based on their ability to communicate and negotiate with adults. Thus, they relied on researchers to advocate for them.

Cultural translation of context of participation for participants: We find that in this context of technology-mediated interventions with neurodiverse individuals in an cultural context, researchers act as advocates, balancing skill-based learning (for within the school context) with real world scenarios (for outside the school context) and providing hands-on experiences for learning and practice; given participants' varying levels of comfort in verbal and non-verbal communication and social interactions.

Context of participation considering other stakeholders: For *compost*, sorting kitchen waste was considered low-skill and the

project received lukewarm responses. In balloons, several design decisions were based on the cultural context: selecting balloons as the virtual object given the costs and cultural acceptability of physical balloons, e.g., celebratory, acceptable to play and pop; and selecting a simple pointing gesture over punching or jumping to deter such gestures outside of the study context. Further, the costs and responsibility of the technology introduces additional overheads and burdens. This technology can be something novel like the Microsoft Kinect device or even tablets and smart phones used with participants. In our projects, questions arose such as who buys the device (parents, teachers, the school), should the devices be shared and how, and who bears the costs and time to maintain the devices? If personal devices are allowed, then applications must be downloaded and installed by educators or researchers (or other adult stakeholders) and setup for use – adding additional requirements of tech-know-how. The answers to these questions are complex and should be sought (and clearly outlined) before the start of a project. Devising socio-culturally suitable interventions is relevant to neurodiverse participants in any cultural context.

Cultural translation of context of participation for other stakeholders: Participation of neurodiverse individuals, as somewhat expected, was influenced by stakeholders inside, and outside, the special school. As organizations, the special schools placed great importance on the cognitive development of students but at the same time, they also required measurable and visible outcomes. For instance, with tablet-based interventions sitting and attention spans are visibly increased over time regardless of the cognitive development progress. School admins and educators are sensitized to favor interventions with visible and measurable progress. Considering parents, they seek approval from and inclusion in society and thus are keen to support their ward without differentiating between neurodiverse and neurotypical siblings/cousins. Further, context of the technology had its own challenges: its costs, know-how, maintenance, ownership, and responsibilities. While these burdens of technology are also experienced in other cultural contexts, in the Indian context they can be exacerbated in low resource environments. In essence, this is contextual to special schools in an Indian context, and given the array of stakeholders and technologies, contextual factors have a strong influence on participation and participants.

4.4. Political

Political aspects include ethical and power issues that are inextricably intertwined with participation and other stakeholders, which are crucial to acknowledge and negotiate.

Politics of participation for participants: We found that neurodiverse individuals have the least decision-making power – individuals older than 18 and/or physically bigger than many adults they encounter are still seen as students at the school and expected to follow the student-adult socio-cultural dynamics. Further, individuals can sometimes say NO to things they like doing or YES to something they do not like, if they do not understand what is being asked, muddling further the gaps in communication and challenges in social interactions. Challenges in communication and social interactions faced by neurodiverse individuals unfortunately occur in all cultural contexts, and these challenges inadvertently off load decision-making to other stakeholders, maintaining the status quo.

Cultural translation of politics of participation for participants: While adults, in all socio-cultural contexts, act with the best intentions; we find that conflicts can still arise when considering typical student/learner mold vs. being able to break away from typical school demands and studies for neurodiverse individuals in a special school context. Thus, the onus of sharing

decision-making and ethical conduct relies heavily on the adult stakeholders surrounding neurodiverse individuals.

Politics of participation considering other stakeholders: The socio-political spectrum surrounding neurodiverse individuals is complex and diverse. Adults' stakeholders include the school educators, admin, therapists, and other staff, and parents and caregivers (or domestic helpers) who accompany many of the students to school. Culturally, we observed a layered social hierarchy not only within this group of adults with the schoolhead having the most decision-making power within the school, but also outside of it depending on the parents' socio-economic or educational status. We found that the school admins had power over the educators, therapists, and other staff. We suppose this is because admins evaluate performances, in addition to the schoolhead, and approve project budgets, funding, and plans in discussion with the schoolhead. The admins are also responsible for managing and measuring the school's goals and vision. As is typical everywhere, schools are designed to discipline students to follow rules and instructions and excel in the study material as measured through (standardized) tests and other performance metrics.

From the educators' perspective, their own performance is linked to how well their class performs. For instance, we found that if a student tends to run out of the classroom during sessions for various reasons (such as boredom, following a classmate, or curiosity), locking the classroom door to restrict such outbursts was suggested as a solution. While this may not be optimal; for educators to monitor and cater to each student means neglecting others and losing teaching time. Further, linking educator's performance to student's performance on various skills inadvertently incentivizes them to focus on those specific skills.

We found that parents expect schools to inculcate discipline to follow instructions and respect elders. When it comes to other staff (such as day-care workers and custodians who are primarily from low socio-economic classes): they have the least decision-making power in the adult-groups and sometimes also with neurotypical children, yet with neurodiverse individuals the equation changes. Worryingly, we also noticed that neurotypical peers/siblings, regardless of age, also exert power over neurodiverse individuals.

Cultural translation of politics of participation considering other stakeholders: This complex socio-cultural ecosystem introduces several challenges due to varying stakeholder expectations, agendas, and aspirations. Difficult questions arose: what is the role of a special school and its stakeholders? Is a special school a gateway to being settled in life? What does it mean to be settled? Researchers should question and challenge existing societal expectations by openly discussing them with different stakeholders and share their vision for participants and a future outside of schools where assistance is limited. At the macro-level, we should consider what is the aim of parents and school admin – is it preparing the neurodiverse individual for employment, enrolling them to university/vocational colleges, or enabling them to complete their studies. At a micro-level, we should consider how are these achieved through everyday goals and activities. To answer these, both top-down and bottom-up approaches are required. For instance, from a school's perspective, the focus of interventions can be on daily living skills, spending time positively, being less destructive, ensuring no self-injury or harm to others, providing appropriate guidelines of self-stimulation, etc. Through these, participants can expect inclusion in society at various levels. Further, schools follow RCI guidelines, which in recent years has introduced several policy level changes including how intellectual disabilities are categorized (which has implications on job quotas) and a technology-driven educational model. As the definitions and understanding of disabilities is improving

both through media discourse and policy frameworks, the day-to-day experiences of neurodiverse individuals in terms inclusion and acceptance still vary and are influenced by a complex social ecosystem surrounding them.

4.5. Educational

Within a school context, the aim is to develop competence and learning for life within and outside of school. We discuss the educational aspects of participation for participants and other stakeholders from the context of a special school.

Educational aspects of participation: We found that all stakeholders had varying agendas and expectations from a school context. While some agendas were shared, such as the parents' desire to have technology on par with the west and the school's desires to be technically savvy and outgoing to set the path for other organizations in the country, stakeholder also had various expectation from schools, such as parents expected schools to enable their ward to participate in society, and gain qualifications and employment. However, due to the complex socio-political spectrum of stakeholders, these agendas are realized differently in practice. For instance, learning and empowerment are supported as long as students adhere as well as they can to expected social norms at school and at home. With compost, learning to differentiate between biodegradable and non-biodegradable materials through a mobile application was not as controversial as sorting actual kitchen waste. However, for researchers, translating game-based learning to real-world contexts was important (to make learning more generalizable) while for parents and schools, a mobile app and an actual waste were two different concepts. Further, as expected everywhere, schools prefer measurable and visible outcomes from interventions, as they are answerable to participants' parents who spend money on fees and supplies. Overall, an educational context is lathered with expectations.

Cultural translation of educational aspects of participation: While it is easy scrutinize the agendas and goals of a school in imparting education, we hypothesized that their incentives are defined by local socio-political entities through policy frameworks and media discourses. As mentioned earlier, RCI is actively making changes to its handling of resources, policies, and opportunities for people with disabilities in India. As these changes permeate into the system and psyche of the special school context and stakeholders, we expect educational reforms hopefully to also follow suit. Thus, to enable genuine participation in PD projects, researchers should align their interventions with educational goals and motivations and discuss measurable outcomes and their implications. Within the Indian context, this can include outlining how to scale the interventions to many students in a low resource environment, agreeing on the responsibilities of the educators and other stakeholders given the complex social ecosystem, and pushing towards incorporating new educational reforms for long-term lasting impact.

5. Discussion

This study was set to explore how the ideals of genuine participation from research on PD with children in the Global North can be culturally translated in the context of Global South and special needs education. Critically reflecting on the two projects revealed several challenges for PD with neurodiverse participants in the context of a special school in India. Further, we identified strategies for researchers to negotiate the challenges. While several of our findings resonate with previous research on PD with neurodiverse individuals, which has been conducted mainly in the Global North, and PD with neurotypical participants in the Global South, the strategies we recommend are devised from our

cultural context. Table 1 summarizes our findings and translation of *how-to PD* from the viewpoint of genuine participation, when taking PD into the realm of neurodiverse children in India.

Genuine participation is in the heart of Participatory Design, tied deep in its paradigmatic thinking. It calls for open and democratic ways of working, aiming for reducing power differences between participants, mutual learning, and real impact, among others (Kinnula & Iivari, 2021). Reaching this kind of ideal is not easy even in the Global North, at the roots of PD: it requires self-study from the researchers and designers, who need to consider their own values, motivations, and ideals for the work, and acknowledge that these do not necessarily meet with the ones of other stakeholders. Further, understanding of the context, negotiations between different actors, and adjustment of work practices are needed, to create *participation at its best*, as Kinnula and Iivari (2021) aim for with their genuine participation dimensions. When taking PD to other contexts, new considerations arise, related to whether researchers and designers are able to step out of their familiar ways of thinking and working, and see *how-to PD* in these new contexts. We argue that this situation calls for cultural translation.

Previous PD research has accumulated valuable understanding on *how-to PD* with neurodiverse children, and many of those findings are relevant when entering a special school in India. However, several differences still exist (Boujarwah et al., 2011), as also seen in our findings. Previous studies have largely focused on the design process (Benton et al., 2014; Frauenberger et al., 2016, 2017; Malinverni et al., 2014), and in very few cases the evaluation of the process, with neurodiverse individuals (Spiel et al., 2017), however, the pre-PD negotiations and agreements with adult (and child) stakeholders are seldom discussed. Our study indicates that in the Indian special school context, educator performance and incentives are set by the school admin and schoolhead, which can sometimes conflict with what researchers expect. As many stakeholders are already present at a special school, before the researchers arrive and projects begin, there can be "preexisting conflicts and hierarchies already established" (Frauenberger et al., 2019). Such conflicts are bound to resurface during the project and can be fostered into "constructive disagreements" (Frauenberger et al., 2019). When framing the genuine participation ideal as a transnational value to be aimed for, it is not enough that we familiarize ourselves with the existing research on the topic, conducted in other contexts; instead, we argue that local implementers and norm translators are needed (Merry, 2006). In many cases this happens naturally through local partners or collaborators in e.g., a special school. However, it is also possible to still design projects and experiments without deeper discussions with the local parties, and end up making mistakes that then annoy, alienate, or even frighten the study participants, when the aim has been to empower. Not understanding e.g., the various layers of social stigma attached with neurodiverse individuals and families (Tushar et al., 2020) in the local context, for example, can lead to unwelcome situations.

In this complex social ecosystem surrounding neurodiverse individuals, we also show the significance of the various stakeholders, mostly adults, shaping PD with children in special schools in India. This study contributes by showing that the adults can have conflicting views on children's participation, as was the case in Compost, when researchers and others were not on the same page, giving conflicting messages to the participants. PD literature has recognized that the roles and responsibilities of adults can vary greatly in both frontstage and backstage PD activities (Dreessen & Schepers, 2018). Adults may act as facilitators, mediators, motivators, caregivers, proxies, co-designers, play mates, and friends, and their influence on the participants may vary with their familiarity with the participants and their

Table 1
Strategies for genuine participation.

Dimension (<i>genuine participation</i>)	Strategies for genuine participation
Contextual	<p>Plan, design, and implement the projects with local implementers and norm translators to ensure fit with the context</p> <p>Work directly with the individuals even when it is challenging; aim for finding ways for the participants to have a say</p> <p>Work directly with representatives of individuals and other central stakeholders, including school heads, teachers, therapists, etc., to be able to link the work with the actual settings</p> <p>Have open and explicit discussions of values and collective reflections of imagined futures for all stakeholders, to understand, frame, and accordingly adjust the work; make it visible that choices are always value-laden; it is important to openly and collectively discuss the norms, values, and motivations behind choices and thoughts of imagined futures that concern not only individuals but the community surrounding them as well</p> <p>Consider additional costs and responsibilities introduced with the technology; especially in a low resource environment as additional costs can be a burden</p>
Meaningful	<p>Link the participation as part of the individuals' existing everyday practices and enjoyable activities</p> <p>Link and frame the individuals' participation with the existing goals, norms, and expectations for the individual and their community, to find support for the participation</p> <p>Consider what kind of value the individual's participation brings to both the individuals and the community around them</p>
Effective	<p>Root new activities in familiar ones and balance study structure with participant needs/requests/demands/comfort</p> <p>Whenever possible, aim for making the researchers'/designers' choices open and transparent to all participants and stakeholders and link them with the local norms</p> <p>Negotiate both short- and long-term roles and responsibilities of other stakeholders, including who is responsible for the new technologies in the future and how are cost and resources handled?</p>
Political	<p>Identify the local stakeholders both during project and in-project collaborations utilizing stakeholder frameworks, such as dominant, affected and dormant stakeholders (Mitchell, Agle, & Wood, 1997), to form a legitimate base for the work</p> <p>Work on different levels of stakeholders – individuals and their homes, schools, structures guiding the schools – to shape the work from different perspectives; the complex social hierarchy within the school context can create a layered process of decision-making, making it even harder to penetrate for neurodiverse individuals</p> <p>Aim for equalizing power relations, even though it can be challenging; note that the onus of ethical and responsible conduct is heavily geared towards other stakeholders, who may or may not choose to share decision-making powers with neurotypical individuals</p> <p>Make challenges visible and discuss them openly</p> <p>Acknowledge that conflicting and contradicting views offer a possibility to see the world in a new light</p> <p>Times are changing slowly – it is not always possible to hasten the process: definitions and understanding of disabilities is improving both through media discourse and policy frameworks, but the day-to-day experiences of neurodiverse individuals in terms of inclusion and acceptance still vary and are influenced by the complex social-ecosystem surrounding them.</p>
Educational	<p>Aim for the increased competence of all participants and mutual learning between them by finding common ground and ways of working, not only researchers getting data for their research</p> <p>To enable genuine participation in PD projects, researchers should align their interventions with educational goals and motivations and discuss measurable outcomes and their implications; within the Indian context, this can include outlining how to scale the interventions, agreeing on the responsibilities, and pushing towards incorporating new educational reforms</p>

position within the social ecosystem. Adults can be responsible for complementing and encouraging participants, for example, teachers can scaffold learning with suggestions (Fage et al., 2014), researchers can assist in staying on track (Rubegni, Landoni, & Jaccheri, 2020), parents can encourage the child (Frauenberger et al., 2016), and even grandparents can take on both leadership and supportive roles for designing and ideating (Liaqat et al., 2021). Teachers and therapists in special schools have their own roles, too. Thus, we maintain that the stakeholder roles and responsibilities should be broadly considered, defined and agreed upon before the start of the project at a special school, asking what is expected from educators, parents, school staff and admin, participants, and anyone else that directly affects the PD process, once again setting these roles and responsibilities in the wider context of a special school in India, working with local implementers and norm translators.

From a technology design standpoint, we need to consider how educational technology is introduced, used, and maintained. It is mostly introduced at the special schools by researchers and school staff, which is also an expectation by parents who look to the school staff to guide them for technology interventions at home (Boujarwah et al., 2011; Sharma et al., 2018, 2020b). However, teachers' technical knowledge and skills can vary greatly (e.g., RCI's degree programs for special educators in

India). Thus, it also becomes important to understand the context of the educational field, "identify teachers' and students' needs related to literacy and detect opportunities for technology to be used for their benefit" (Brotto Furtado et al., 2008). This study forefronts that the burden of technology innovation, introduction, adoption, and sustenance lies within the school and its staff, while in some cases on the researchers who must convince all other adult stakeholders. Regarding technology, questions and conflicts arise: who pays for, repairs, and maintains it? Who is responsible for the technology before, during, and after PD? Further, the value of the intended technology to be developed together with children should be made explicit (Read, Horton, Sim, Gregory, Fitton, & Cassidy, 2013) and the real-world impact of children's ideas to improve their used technologies should be explained to them (McNally, Guha, Mauriello, & Druin, 2016). It is important to also consider the emotional state and socialization opportunities that the technology fosters (Knowles, Beck, Finney, Devine, & Lindley, 2019). Further, it should be shown to children how their contributions impacted the project/design outcomes (Read, Fitton, & Horton, 2014) and their contributions should be summarized for them and their families (Lindberg, Thomsen, & Åkesson, 2014). Lastly, exploration of collaborations or links "with other social organizations... [which] share objectives and needs"

Table A.1

Summary of terminology in 'cultural translation', i.e., in adapting and reconstituting transnational norms to fit the local framework of norms and practices.

Term	Explanation
localization, focusing on adaptation	Adapting and reconstructing foreign norms to fit pre-existing local culture (Acharya, 2004) Adapting local beliefs and practices to fit the foreign norms (Acharya, 2004)
grafting	Attempting to situate external norms into the local environment (Gardinier, 2012a, 26)
norm entrepreneurs	Actors who facilitate the localization process, both local and international (Acharya, 2004)
transnational norm entrepreneurs	Actors doing the localization in transnational, higher level (Gardinier, 2012a:229)
framing	Re-presenting transnational ideas in a form that is understandable within the local context (Merry, 2006:4; Gardinier, 2012a)
vernacularization	Local actors adapting the grafted foreign norms and practices to their culture and environment (Merry, 2006)
indigenization	The symbolic dimension of vernacularization referring to the shifts in meaning that may result from framing new ideas to fit the existing cultural values, norms, and practices (Merry, 2006:3)
cultural translation	The literal act of translating guidelines and terminology from one language to another but also the concrete act of adjusting foreign norms and practices to be implemented into local environments (Merry, 2006:2; Merry & Wood, 2015:39)
cultural translators, local experts	Local norm entrepreneurs, the people, organizations, and other actors who translate and implement transnational norms into their communities (Merry & Wood, 2015:39; Gardinier, 2012a:229) Local norm entrepreneurs – the people, organizations, and other actors who translate and implement transnational norms into their communities – are very important to the process of vernacularization, because they act as cultural “translators” (Merry, 2006:2; Merry & Wood, 2015:39).
implementers, local implementers	The cultural translators and implementers are not necessarily the one and the same, as the implementer can further translate the idea of a norm entrepreneur/cultural translator by changing its content and/or practice to fit the local set of norms (Gardinier, 2012a:218–220)

is required for long-term sustainable impact (Eduardo Nieto et al., 2020).

Studies with intergenerational PD teams have explored equal partnership in PD between adults and children (Lee, Roldan, Zhu, Kaur Saluja, Na, Chin ..., & Yip, 2021; Liaqat et al., 2021; Rubegni et al., 2020; Yip et al., 2017). However, in the context of neurodiverse individuals, the adult-participants relationship is rather complex. Understanding what constitutes equitable practices to support equality is the first step to remove adults as gatekeepers to participation (Lindberg et al., 2014), such as carers' inappropriate level of involvement and consequently their conflicting roles and demands with the researchers' wishes and plans (Spiel et al., 2018). An analysis of carer-child-researcher relationships through an ethical lens could help in realizing how to include carers more transparently. Sometimes physical contact with the children with special needs is required, e.g., researchers using their bodies to assert dominance in dangerous situations with autistic children, hugging, or children haptically exploring the body of the researcher (Spiel et al., 2018). At the other extreme, participation can sometimes be only of the adult stakeholders for several reasons: participants could have communication issues, be too young (e.g., 5 years of age), or “feel stressed when faced with unusual routine or unknown people” (Tushar et al., 2020). Thus, adult stakeholders can decide to not put any additional burden on the neurodiverse individual. We need to negotiate then what is in which situation participation at its best. When considering the question of how-to ensure all stakeholders have an equal voice; the situation is even more challenging in the Indian context where the hierarchical difference between children and adults is relatively high. It requires deep understanding of local cultural values and histories behind them, to be able to operate with small nuances. Once again, this calls for cultural translation.

6. Conclusions

We see that although our findings are related to the specific cultural context, many of the strategies we propose can be useful in other contexts as well. We call for other researchers and designers to take the cultural translation lens into use consciously, when taking PD out of its traditional arenas. We argue that the concept of cultural translation is an interesting one to consider whenever entering a different realm – also when adults enter

the neurotypical children's realm in the Global North, as that lens reminds us that we are stepping into the world where we are not 'natives' and we need to advance carefully, minding our steps, and that cultural translation can open our eyes to new nuances in participation (see e.g., Cumbo, Eriksson, & Iversen, 2019).

This study is limited with the fact that the two projects examined in the current paper were not PD projects. We argue however, that the projects still opened a window into the challenges and nuances of the realm where these projects were conducted: the world of a neurodiverse child in an Indian special school. Further, we argue that using cultural translators in the data analysis particularly shows the local perspective on the challenges in *how-to PD* in this context. Another limitation is that the chronological age of most of the participants is over 18 years. However, participants' social ages, as evaluated by experts at the school, is considered to be closer to teenagers or younger. Nevertheless, further research is required to ensure that our findings are generalizable to younger children.

Selection of participants

Participants for both projects were recruited from two special schools in New Delhi: one catering to individuals with autism (for the Balloons project), and the other one for individuals with special needs other than autism or ADHD (for the Compost project). The studies were run at different times. Permission to conduct the projects was taken from the schools' heads. Parents or legal guardians provided consent for participation for all the individuals involved in our studies. Further, consent and assent to participate was verbally obtained from the participants regularly during the projects, since project goals and outcomes were introduced gradually. Participant inclusion (and exclusion) was determined based on who had permission from their parents and were willing to participate in the sessions (participants could decide to skip sessions). In the case of the Compost project, a few parents did not consent to their ward's participation in the project altogether, and those participants were excluded (even if they did express an intention to join a session with their friends). This was not common but did occur a few times (no data recorded).

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix

See Table A.1 for summary of terminology in 'cultural translation'.

References

- Abdullah, M. H. L., & Brereton, M. (2015). MyCalendar: fostering communication for children with autism spectrum disorder through photos and videos. In *Proceedings of the annual meeting of the Australian special interest group for computer human interaction* (pp. 1–9).
- Acharya, A. (2004). How ideas spread: Whose norms matter? Norm localization and institutional change in Asian regionalism. *International Organization*, 58(2), 239–275.
- Alper, M., Hourcade, J. P., & Gilutz, S. (2012). Interactive technologies for children with special needs. In *Proceedings of the 11th international conference on interaction design and children* (pp. 363–366).
- Arora, N. K., Nair, M. K. C., Gulati, S., Deshmukh, V., Mohapatra, A., Mishra ..., D., et al. (2018). Neurodevelopmental disorders in children aged 2–9 years: Population-based burden estimates across five regions in India. *PLoS Medicine*, 15(7), Article e1002615.
- Asaro, P. M. (2000). Transforming society by transforming technology: the science and politics of participatory design. *Accounting, Management and Information Technologies*, 10(4), 257–290.
- Bartoli, L., Corradi, C., Garzotto, F., & Valoriani, M. (2013). Exploring motion-based touchless games for autistic children's learning. In *Proceedings of the 12th international conference on interaction design and children* (pp. 102–111).
- Benton, L., Johnson, H., Brosnan, M., Ashwin, E., & Grawemeyer, B. (2011). IDEAS: an interface design experience for the autistic spectrum. In *CHI'11 extended abstracts on human factors in computing systems* (pp. 1759–1764).
- Benton, L., Vasalou, A., Khaled, R., Johnson, H., & Gooch, D. (2014). Diversity for design: a framework for involving neurodiverse children in the technology design process. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 3747–3756).
- Bjerknes, G., Ehn, P., Kyng, M., & Nygaard, K. (1987). *Computers and democracy: A scandinavian challenge*. Farnham: Gower Publishing.
- Bødker, K., Kensing, F., & Simonsen, J. (2009). *Participatory IT design: Designing for business and workplace realities*. MIT Press.
- Boujarwah, F. A., Hong, H., Abowd, G. D., & Arriaga, R. I. (2011). Towards a framework to situate assistive technology design in the context of culture. In *The proceedings of the 13th international ACM SIGACCESS conference on computers and accessibility* (pp. 19–26).
- Brotto Furtado, A. W., Falcão, T. P., Gomes, A. S., Eduardo, C., Rodrigues, M., & Sonnino, R. (2008). E-du box: Educational multimedia with tangible-enhanced interaction. In *Proceedings of the 7th ACM conference on designing interactive systems* (pp. 139–146).
- Brown, S. A., Silvera-Tawil, D., Gemeinboeck, P., & McGhee, J. (2016). The case for conversation: A design research framework for participatory feedback from autistic children. In *Proceedings of the 28th Australian conference on computer-human interaction* (pp. 605–613).
- Brulé, E., & Spiel, K. (2019). Negotiating gender and disability identities in participatory design. In *Proceedings of the 9th international conference on communities & technologies-transforming communities* (pp. 218–227).
- Cibrian, F. L., Lakes, K. D., Tavakoulnia, A., Guzman, K., Schuck, S., & Hayes, G. R. (2020). Supporting self-regulation of children with ADHD using wearables: tensions and design challenges. In *Proceedings of the 2020 CHI conference on human factors in computing systems* (pp. 1–13).
- Cumbo, B. J., Eriksson, E., & Iversen, O. S. (2019). The least-adult role in participatory design with children. In *Proceedings of the 31st Australian conference on human-computer-interaction* (pp. 73–84).
- Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social Science & Medicine*, 58(7), 1323–1335.
- De Leo, G., & Leroy, G. (2008). Smartphones to facilitate communication and improve social skills of children with severe autism spectrum disorder: special education teachers as proxies. In *Proceedings of the 7th international conference on interaction design and children* (pp. 45–48).
- Desai Miraj, U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, 49(3–4), 613–637.
- Dindler, C., Smith, R., & Iversen, O. S. (2020). Computational empowerment: participatory design in education. *CoDesign*, 16(1), 66–80.
- Dreessen, K., & Schepers, S. (2018). The roles of adult-participants in the back-and frontstage work of participatory design processes involving children. In *Proceedings of the 15th participatory design conference: Full papers-Volume 1* (pp. 1–12).
- Druin, A. (2002). The role of children in the design of new technology. *Behaviour and Information Technology*, 21(1), 1–25.
- Eduardo Nieto, A., Tobón Giraldo, I. C., & Torres Parra, C. (2020). Mi Fink app, a participative research-creation experience for afro-caucan territory protection in Colombia. In *Proceedings of the 16th participatory design conference 2020-participation (s) otherwise-Volume 2* (pp. 1–4).
- Fage, C., Pommereau, L., Consel, C., Balland, E., & Sauzéon, H. (2014). Tablet-based activity schedule for children with autism in mainstream environment. In *Proceedings of the 16th international ACM SIGACCESS conference on Computers & accessibility* (pp. 145–152).
- Frauenberger, C., Good, J., Alcorn, A., & Pain, H. (2012). Supporting the design contributions of children with autism spectrum conditions. In *Proceedings of the 11th international conference on interaction design and children* (pp. 134–143).
- Frauenberger, C., Good, J., Alcorn, A., & Pain, H. (2013). Conversing through and about technologies: Design critique as an opportunity to engage children with autism and broaden research (er) perspectives. *International Journal of Child-Computer Interaction*, 1(2), 38–49.
- Frauenberger, C., Good, J., Fitzpatrick, G., & Iversen, O. S. (2015). In pursuit of rigour and accountability in participatory design. *International Journal of Human-Computer Studies*, 74, 93–106.
- Frauenberger, C., Good, J., & Keay-Bright, W. (2010). Phenomenology, a framework for participatory design. In *Proceedings of the 11th biennial participatory design conference* (pp. 187–190).
- Frauenberger, C., Good, J., Keay-Bright, W., & Pain, H. (2012). Interpreting input from children: a designerly approach. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 2377–2386).
- Frauenberger, C., Makhaeva, J., & Spiel, K. (2016). Designing smart objects with autistic children: Four design exposés. In *Proceedings of the 2016 CHI conference on human factors in computing systems* (pp. 130–139).
- Frauenberger, C., Makhaeva, J., & Spiel, K. (2017). Blending methods: Developing participatory design sessions for autistic children. In *Proceedings of the 2017 conference on interaction design and children* (pp. 39–49).
- Frauenberger, C., Spiel, K., Scheepmaker, L., & Posch, I. (2019). Nurturing constructive disagreement-Agonistic design with neurodiverse children. In *Proceedings of the 2019 chi conference on human factors in computing systems* (pp. 1–11).
- Gardinier, M. P. (2012a). *From global projects to classroom practice: The localization of democratic citizenship education in post-communist Albania*. Cornell University.
- Gardinier, M. P. (2012b). Agents of change and continuity: The pivotal role of teachers in albanian educational reform and democratization. *Comparative Education Review*, 56(4), 659–683.
- Gotham, K., Pickles, A., & Lord, C. (2009). Standardizing ADOS scores for a measure of severity in autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(5), 693–705.
- Greenbaum, J., & Kyng, M. (Eds.). (1991). *Design at work: Cooperative design of computer systems*. Hillsdale NJ, L: Erlbaum Associates.
- Grierson, M., & Kiefer, C. (2013). NoiseBear: a wireless malleable multiparametric controller for use in assistive technology contexts. In *CHI'13 extended abstracts on human factors in computing systems* (pp. 2923–2926).
- Guha, M. L., Druin, A., & Fails, J. A. (2008). Designing with and for children with special needs: An inclusionary model. In *Proceedings of the 7th international conference on interaction design and children* (pp. 61–64).
- Hamidi, F., Baljko, M., & Gómez, I. (2017). Using participatory design with proxies with children with limited communication. In *Proceedings of the 19th international ACM SIGACCESS conference on computers and accessibility* (pp. 250–259).
- Hirano, S. H., Yeganyan, M. T., Marcu, G., Nguyen, D. H., Boyd, L. A., & Hayes, G. R. (2010). vSked: evaluation of a system to support classroom activities for children with autism. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 1633–1642).

- Holone, H., & Herstad, J. (2013). Three tensions in participatory design for inclusion. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 2903–2906).
- Iivari, J., & Iivari, N. (2011). Varieties of user-centredness: An analysis of four systems development methods. *Information Systems Journal*, 21(2), 125–153.
- Iivari, N., & Kinnula, M. (2018). Empowering children through design and making: towards protagonist role adoption. In *Proceedings of the 15th Participatory Design Conference: Full Papers-Volume 1* (pp. 1–12).
- Itenge-Wheeler, H., Kuure, E., Brereton, M., & Winschiers-Theophilus, H. (2016). Co-creating an enabling reading environment for and with Namibian children. In *Proceedings of the 14th participatory design conference: Full papers-Volume 1* (pp. 131–140).
- Iversen, O. S., Smith, R. C., & Dindler, C. (2017). Child as protagonist: Expanding the role of children in participatory design. In *Proceedings of the 2017 conference on interaction design and children* (pp. 27–37).
- Kalunda, J. M. (2014). Participatory mural at Pashukeni pre-primary school. In *Proceedings of the 13th participatory design conference: Short papers, industry cases, workshop descriptions, doctoral consortium papers, and keynote abstracts-Volume 2* (pp. 157–158).
- Kam, M., Ramachandran, D., Raghavan, A., Chiu, J., Sahni, U., & Canny, J. (2006). Practical considerations for participatory design with rural school children in underdeveloped regions: Early reflections from the field. In *Proceedings of the 2006 conference on interaction design and children* (pp. 25–32).
- Kender, K., Frauenberger, C., Pichlbauer, J., & Werner, K. (2020). Children as Designers-Recognising divergent creative modes in Participatory Design. In *Proceedings of the 11th nordic conference on human-computer interaction: Shaping experiences, shaping society* (pp. 1–11).
- Kinnula, M., & Iivari, N. (2021). Manifesto for children's genuine participation in digital technology design and making. *International Journal of Child-Computer Interaction*, 28, Article 100244.
- Knowles, B., Beck, S., Finney, J., Devine, J., & Lindley, J. (2019). A scenario-based methodology for exploring risks: children and programmable IoT. In *Proceedings of the 2019 on designing interactive systems conference* (pp. 751–761).
- Kumar, N., Wong-Villacres, M., Karusala, N., Vishwanath, A., Kumar, A., & Ismail, A. (2019). Aspirations-based design. In *Proceedings of the tenth international conference on information and communication technologies and development* (pp. 1–11).
- Lee, K. J., Roldan, W., Zhu, T. Q., Kaur Saluja, H., Na, S., Chin ..., B., et al. (2021). The show must go on: A conceptual model of conducting synchronous participatory design with children online. In *Proceedings of the 2021 CHI conference on human factors in computing systems* (pp. 1–16).
- Levitt, P., & Merry, S. (2009). Vernacularization on the ground: local uses of global women's rights in peru, China, India and the United States. *Global Networks*, 9(4), 441–461.
- Liaqat, A., Axtell, B., & Munteanu, C. (2021). Participatory design for intergenerational culture exchange in immigrant families: How collaborative narration and creation fosters democratic engagement. *Proceedings of the ACM on Human-Computer Interaction*, 5(CSCW1), 1–40.
- Lindberg, S., Thomsen, M., & Åkesson, M. (2014). Ethics in health promoting PD: designing digital peer support with children cured from cancer. In *Proceedings of the 13th participatory design conference: Research papers-Volume 1* (pp. 91–100).
- Liu, J., & Roto, V. (2017). Chinese preschoolers as design partners—lessons learned. In *Proceedings of the 2017 CHI conference extended abstracts on human factors in computing systems* (pp. 951–958).
- Luck, R. (2018). What is it that makes participation in design participatory design? *Design Studies*, 59, 1–8.
- Malin, A. J. (1969). *Manual for Malin's intelligence scale for Indian children (MISIC)*. Lucknow: Indian Psychological Corporation.
- Malinverni, L., Mora-Guiard, J., Padillo, V., Mairena, M., Hervás, A., & Pares, N. (2014). Participatory design strategies to enhance the creative contribution of children with special needs. In *Proceedings of the 2014 conference on Interaction design and children* (pp. 85–94).
- McNally, B., Guha, M. L., Mauriello, M. L., & Druin, A. (2016). Children's perspectives on ethical issues surrounding their past involvement on a participatory design team. In *Proceedings of the 2016 CHI conference on human factors in computing systems* (pp. 3595–3606).
- Merry, S. E. (2006). Transnational human rights and local activism: Mapping the middle. *American Anthropologist*, 108(1), 38–51.
- Merry, S. E., & Wood, S. (2015). Quantification and the paradox of measurement: Translating children's rights in tanzania. *Current Anthropology*, 56(2), 205–229.
- Mitchell, R. K., Agle, B. R., & Wood, D. J. (1997). Toward a theory of stakeholder identification and salience: Defining the principle of who and what really counts. *Academy of Management Review*, 22(4), 853–886.
- Mora-Guiard, J., Crowell, C., Pares, N., & Heaton, P. (2017). Sparking social initiation behaviors in children with autism through full-body interaction. *International Journal of Child-Computer Interaction*, 11, 62–71.
- Moraveji, N., Li, J., Ding, J., O'Kelley, P., & Woolf, S. (2007). Comicboarding: using comics as proxies for participatory design with children. In *Proceedings of the SIGCHI conference on Human factors in computing systems* (pp. 1371–1374).
- Østergaard, K. L., Simonsen, J., & Karasti, H. (2018). Examining situated design practices: Nurses' transformations towards genuine participation. *Design Studies*, 59, 37–57.
- Pal, J., Lakshmanan, M., & Toyama, K. (2007). My child will be respected: Parental perspectives on computers in rural India. In *2007 international conference on information and communication technologies and development* (pp. 1–9). IEEE.
- Parsons, S. (2015). Learning to work together: Designing a multi-user virtual reality game for social collaboration and perspective-taking for children with autism. *International Journal of Child-Computer Interaction*, 6, 28–38.
- Pihlainen, K., Montero, C. S., & Kärnä, E. (2017). Fostering parental co-development of technology for children with special needs informal learning activities. *International Journal of Child-Computer Interaction*, 11, 19–27.
- Read, J. C., Fitton, D., & Horton, M. (2014). Giving ideas an equal chance: inclusion and representation in participatory design with children. In *Proceedings of the 2014 conference on Interaction design and children* (pp. 105–114).
- Read, J. C., Horton, M., Sim, G., Gregory, P., Fitton, D., & Cassidy, B. (2013). CHECK: a tool to inform and encourage ethical practice in participatory design with children. In *CHI'13 Extended Abstracts on Human Factors in Computing Systems* (pp. 187–192).
- Robb, N., Leahy, M., Sung, C., & Goodman, L. (2017). Multisensory participatory design for children with special educational needs and disabilities. In *Proceedings of the 2017 conference on interaction design and children* (pp. 490–496).
- Rubegni, E., Landoni, M., & Jaccheri, L. (2020). Design for change with and for children: how to design digital storytelling tool to raise stereotypes awareness. In *Proceedings of the 2020 ACM designing interactive systems conference* (pp. 505–518).
- Scheepmaker, L. (2018). Exploring opportunities for scalable outcomes of co-design activities with marginalised groups of children. In *Proceedings of the 2018 annual symposium on computer-human interaction in play companion extended abstracts* (pp. 77–83).
- Schopler, E., Reichler, R. J., & Renner, B. R. (2010). *The childhood autism rating scale (CARS)*. Los Angeles, CA, USA: WPS.
- Schwartz, A., Kaplan, E., Lajoie, E. W., Terrell, T., & Ajambo, E. (2015). Using a principal agent model to explain user-centered design challenges for mother tongue reading in Kenya. In *Proceedings of the seventh international conference on information and communication technologies and development* (pp. 1–8).
- Serpa, B., Portela, I., Costard, M., & Silva, S. M. (2020). Political-pedagogical contributions to participatory design from Paulo Freire. In *Proceedings of the 16th participatory design conference 2020-participation (s) otherwise-Volume 2* (pp. 170–174).
- Sharma, S. (2018). *Collaborative educational applications for underserved children: Experiences from india* (PhD Dissertation), Finland: Tampere University, <https://urn.fi/URN:ISBN:978-952-03-0807-0>.
- Sharma, S., Achary, K., Kaur, H., Linna, J., Turunen, M., Varkey ..., B., et al. (2018). 'Wow! You're Wearing a Fitbit, You're a young boy now! socio-technical aspirations for children with autism in India. In *Proceedings of the 20th international ACM SIGACCESS conference on computers and accessibility* (pp. 174–184).
- Sharma, S., Achary, K., Kinnula, M., Iivari, N., & Varkey, B. (2020a). Gathering garbage or going green? shifting social perspectives to empower individuals with special needs. In *Proceedings of the Interaction Design and Children Conference* (pp. 311–322).
- Sharma, S., Avellan, T., Linna, J., Achary, K., Turunen, M., Hakulinen, J., et al. (2020b). Socio-technical aspirations for children with special needs: A study in two locations—India and Finland. *ACM Transactions on Accessible Computing (TACCESS)*, 13(3), 1–27.
- Sharma, S., Srivastava, S., Achary, K., Varkey, B., Heimonen, T., Hakulinen, J. S., et al. (2016). Promoting joint attention with computer supported collaboration in children with autism. In *Proceedings of the 19th ACM conference on computer-supported cooperative work & social computing* (pp. 1560–1571).
- Simonsen, J., & Robertson, T. (Eds.). (2012). *Routledge international handbook of participatory design*. Routledge.
- Smith, R., Winschiers-Theophilus, H., Paula Kambunga, A., & Krishnamurthy, S. (2020). Decolonizing participatory design: Memory making in Namibia. In *Proceedings of the 16th participatory design conference 2020-participation (s) otherwise-Volume 1* (pp. 96–106).
- Spiel, K., Brulé, E., Frauenberger, C., Bailley, G., & Fitzpatrick, G. (2020). In the details: the micro-ethics of negotiations and in-situ judgements in participatory design with marginalised children. *CoDesign*, 16(1), 45–65.
- Spiel, K., Brulé, E., Frauenberger, C., Bailly, G., & Fitzpatrick, G. (2018). Micro-ethics for participatory design with marginalised children. In *Proceedings of the 15th participatory design conference: Full papers-Volume 1* (pp. 1–12).
- Spiel, K., Frauenberger, C., Keyes, O., & Fitzpatrick, G. (2019). Agency of autistic children in technology research—A critical literature review. *ACM Transactions on Computer-Human Interaction*, 26(6), 1–40.

- Spiel, K., Malinverni, L., Good, J., & Frauenberger, C. (2017). Participatory evaluation with autistic children. In *Proceedings of the 2017 CHI conference on human factors in computing systems* (pp. 5755–5766).
- Spinuzzi, C. (2002). A Scandinavian challenge, a US response: methodological assumptions in Scandinavian and US prototyping approaches. In *Proceedings of the 20th annual international conference on computer documentation* (pp. 208–215).
- Toyama, K. (2018). From needs to aspirations in information technology for development. *Information Technology for Development*, 24(1), 15–36.
- Tushar, A. K., Antara, I. J., Das, D., Chandra, P., Soron, T. R., Haque ..., M. M., et al. (2020). We need more power to stand up: Designing to combat stigmatization of the caregivers of children with autism in Urban Bangladesh. In *Proceedings of the 2020 international conference on information and communication technologies and development* (pp. 1–12).
- van Rijn, H., & Stappers, P. J. (2008). Expressions of ownership: motivating users in a co-design process. In *PDC, Vol. 8* (pp. 178–181).
- Vasalou, A., Ibrahim, S., Clarke, M., & Griffiths, Y. (2021). On power and participation: Reflections from design with developmentally diverse children. *International Journal of Child-Computer Interaction*, 27, Article 100241.
- Véliz, S., Espinoza, V., Sauvalle, I., Arroyo, R., Pizarro, M., & Garolera, M. (2017). Towards a participative approach for adapting multimodal digital books for deaf and hard of hearing people. *International Journal of Child-Computer Interaction*, 11, 90–98.
- Yip, J. C., Sobel, K., Pitt, C., Lee, K. J., Chen, S., Nasu, K., et al. (2017). Examining adult-child interactions in intergenerational participatory design. In *Proceedings of the 2017 CHI conference on human factors in computing systems* (pp. 5742–5754).