Involvement of Autistic Adults in the Participatory Design of Technology: A Scoping Review

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Abstract

Research in HCI and autism has become more focused on involving autistic adults in technological design. In this paper, we present the results of a scoping review analysis of 11 projects across 18 papers that focused on including autistic adults in the design of technology that impacts their lives. This paper contributes a deeper understanding of how autistic adults were involved in participatory design processes. Our findings reveal mixed positions on how the lived autistic perspective was harnessed to direct the application of topics and technologies chosen. Most projects employed infrastructures to enhance participation (e.g., providing multiple modes to participate or employing a tailored methodology). We pose future opportunities for autistic involvement, for example, in topics and technologies where autistic research is employed (e.g., autism diagnosis and machine learning), reviewing the importance of formal diagnosis for inclusion, and harnessing the multiple expertise of autistic adults.

CCS Concepts

• **Human-centered computing** → **Participatory design**; *Interaction design process and methods.*

Keywords

scoping review, autistic adults, participatory design

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1 Introduction

In this scoping review, we investigate the involvement of autistic adults[1] in technology design. There has been increasing interest in supporting autistic adults with technology (for example, at home [68, 87] or at work [35, 82]). However, a growing concern relates to the voice autistic people have in designing such technologies [62]. Autistic people are often excluded from research that directly impacts their lives. As advocated by many grassroots autistic groups and researchers [4, 55, 57, 67], embracing the lived experience of autistic people is vital for balanced research, especially where the result directly affects their routine. A 2017 survey revealed that autistics were more likely than non-autistics to describe their social, communication, and empathy styles as differences rather than deficits [37]. This suggests that involving autistics can yield multiple perspectives that could enrich autism research, shifting the imbalances resulting from those led solely by non-autistic people.

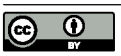
In HCI, the use of Participatory Design (PD) for designing with autistic people has increased in the last ten years [10, 12, 33]. In particular, a strong focus has been on involving autistic children in technology design and evaluation (e.g. [32, 33, 50, 78]). While commendable, as autistic adults require different tools to harness their strengths, analysing their involvement in the design of technologies is also important.

Some review articles explore the application of particular technology for autistic adults. Almurashi et al. [1] propose a taxonomy of VR systems that support social, life, and safety training for autistic people. Wang and Jeon [83] surveyed assistive technologies for autistic adults. Such studies provide valuable insight into how specific technologies are designed and evaluated. However, they do not focus on involving autistic adults in design; this argument is also raised in a recent but limited review of involving autistic adults in co-design [72]. Further work would be valuable to support the participation of autistic adults in designing meaningful technology.

We identified some limited reviews. Çorlu et al. [88] investigate how autistic individuals are involved in UX HCI research. Their review looked at a broader range of autistic users (e.g., children) and not exclusively on adults. They are also not limited to participatory design, focusing on usability and UX. Maun et al. [51] (and later in [52]) review participatory design activities with autistic adults. They identified patterns in how activities could be configured to complement the needs of autistic adults, including sensory considerations, communication, and individual differences. We follow these views; however, we extend them by drawing on PD research that highlights a problem in researchers focusing on singular design activities [41] and a lack of focus on the impact of participatory design processes [11, 42].

There remains a need to understand holistically how autistic adults were involved in design processes, from decision-making in the topic generation to the end of the project. We argue that analysing research projects as a whole aids in understanding how

[1]In this article, we use identity-first language (i.e. autistic adult) rather than person-first language (i.e. person with autism), as this has been the preference of the autistic community [84]. Nonetheless, we understand this is not a one-size-fits-all solution and that participatory design ought to value the preferences of each stakeholder.



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participatory processes unfolded and were facilitated. This understanding would allow researchers to learn from existing projects and identify potential gaps.

To extend this knowledge, this scoping review reflects on the involvement of autistic adults throughout the design process, as opposed to how singular activities were configured. We strive to discover the mechanisms put in place from the beginning (and how these dynamically changed over time) and the medium- to long-term effects they intended to achieve. The research questions we employed were:

- How are autistic adults involved in the participatory design process of technology that impacts their daily lives?
- What opportunities are there for the future involvement of autistic adults in the participatory design of technology?

To do so, we identified topics and technologies used in papers about autistic adults from our scoping search. We compared these with the 11 selected projects to understand where autistic voices were included. We utilised Program Theory to analyse the projects, providing a framework to discuss different factors in the design process [27]. This approach visualises participant involvement, activities, driving principles, and the short- to long-term process effects. Our analysis takes a strengths-based perspective, which we outline in the next section.

2 Background

This section introduces the strengths-based perspective of autism research, participatory design, Program Theory, and the considerations for supporting autistic and non-autistic interactions in design.

2.1 Perspectives for Autism Research

Autism research has been framed in three ways. One perspective views the autistic person as having problems that need to be fixed. Infamously, the medical model positions autism as a "deficit" with traits that need to be cured [3]. For instance, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is often referred to when diagnosing autism [5]; the diagnostic criteria positions autistic traits as impairments, notably in social relationships, motor movements, and executive functioning. Moreover, the *theory of mind* positions autistic people as unable to understand the mental states of themselves and others [7]. Autistic people have been characterised as having difficulties seeing the "bigger picture" due to their tendencies to focus on details [34].

While many autistic people need support in daily life, framing the problem from within the autistic person has been seen as harmful; it promotes a perception that autistic people must change their behaviour and adapt to the context [16, 54, 80]. Thus, they have been contested by autistic advocates because they assume that there is an ideal mind to be attained [43, 45, 80]. Many autistic people engage in self-stimulatory movements, such as hand rocking and fidgeting, that help regulate emotions [46]. Autistic people have sensory preferences and aversions, which impact how they respond in certain contexts [13, 49]. From the medical model, these patterns have been viewed as behaviours that need to be fixed [80]. However, when considered effectively, self-stimulatory movement and sensory information can be stimulating for an autistic individual [80]. In contrast, the social model of disability considers the environment to be the barrier that inhibits autistic people from flourishing [43, 45]. This perspective aims to design environments that are inclusive, balanced, and adaptable to the needs of autistic people.

Lastly, it is recognised that autism should be considered from a strengths-based perspective. Murray [58] posits that autistic people's ability to delve into the details enables them to engage in tasks that those who focus on the bigger picture cannot. This demonstrates how attention to detail can be perceived as a strength rather than a deficit. From a strength-based perspective, the preferred outlook for autism is from the lens of *neurodiversity*. Judy Singer [77] popularised this term to describe that all human minds differ. Those who adopt a strength-based perspective advocate harnessing the strengths of neurodivergent minds (for example, autism, ADHD, dyslexia, etc.) [43, 80]. We refer to the strength-based perspective as *neurodiversity-affirmative* [43]. This perspective has increased in popularity in HCI in the last ten years [19]. There has been a strong emphasis towards embracing the strengths of autistic children in design by adapting participatory approaches [33, 53, 78].

We position our analysis of the participatory activities from the neurodiversity-affirmative perspective. We stress the importance of considering the strengths that autistic adults have in participatory design processes. The following section presents how autistic and non-autistic interactions are considered from this perspective.

2.2 Autistic and non-autistic interactions

Participatory design requires relationship building to sustain efforts within and between stakeholder groups. In the case of autism research, it is critical to consider how interactions may evolve between autistic and non-autistic stakeholders.

On these interactions, Milton posits that breakdowns in understanding can occur between autistic and non-autistic individuals due to differing world views [57]. These breakdowns result in a "double empathy problem" [57]. Nonetheless, assumptions regarding how social interactions ought to occur tend to ostracise behaviours that fall outside the perceived norm [57]. Thus, there are often misconceptions that autistic people should make changes to their behaviours and communication styles, resulting in a one-sided effort. This may lead to breakdowns in trust, relationships, power, and, ultimately, participation. Similarly, de Jaegher [20, 21] suggests that autistic and non-autistic interactions in participatory processes ought to value the multiple perspectives of stakeholders. The goal is not to assume there is one way of knowing and experiencing the world and to ensure that a singular perspective does not dominate interactions [21]. The principle lies with stakeholders respecting the autistic experience as a valid way to experience the world. The participatory design process is a sustained engagement within and between autistic and non-autistic people. Therefore, ensuring the multiple lived experiences of all autistic stakeholders are central to the design process is critical.

2.3 Participation in design processes

Participatory Design (PD) is concerned with empowering people through design processes [41]. We draw on a growing body of research that uses Program Theory to analyse the activities and outcomes of participatory efforts ([11, 42]). Recently, this approach has been further developed by Falk et al. [27] who, in a CHI2021 paper, employed Program Theory as a structured analytical framework to examine and compare various hackathon formats systematically. This approach allowed the authors to explicate underlying assumptions, evaluate effectiveness, and conduct cross-case analysis of different hackathon designs.

Program Theory is a good fit for our agenda for several reasons. While tensions in interactions are always present in any engagement, they manifest differently in autistic and non-autistic interactions [21, 57]. Participatory design takes as the point of departure that: a) it is impossible to understand someone well enough to replace their participation in the design process [41]; b) learning from each other is key to the PD design process [76]; c) users influencing the design process is not just a pragmatic matter: it is an ethical obligation of any designer participating [41]; and d) for participatory design to have a long-lasting effort, it is vital that we focus on *infrastructuring* efforts, that is, embedding our work into the existing lives, communities, and materialities that autistic users live in [23].

This means that, while all PD would emphasise user involvement, when viewed from a neurodiversity-affirmative lens, it becomes urgent to discuss how and why participation in designing technology with autistic users might matter. Furthermore, it draws our attention to the work done to involve users, allowing us, like Falk et al. [27], to compare and contrast approaches aiming to achieve this goal.

Program Theory provides a lens for reviewing how participatory processes unfold in projects. It is not a theory, but rather is used to identify how programs (such as participatory design) operate more holistically [42]. Through Program Theory, clear relationships between the different stages in design processes can be identified by mapping how projects run across their:

- *Inputs*: tangible or intangible resources available, such as stakeholders and funding;
- *Processes*: including the activities that take place to respond to specific mechanisms. Mechanisms are principles that the project aims to follow, such as mutual learning, relationship building, and power balance between stakeholders.
- *Effects*: which could be immediate, but also medium- to long-term goals of the project.

By employing Program Theory, we can visualise how design processes are considered across projects involving autistic adults. In the next section, we will present the lessons learned from other researchers regarding participatory design activities. We view these lessons through the lens of Program Theory, which aided in understanding considerations for facilitating autistic involvement.

2.4 Lessons from Participatory Research with Autistic Adults

While little work reviews the involvement of autistic adults in design, there are accounts of first-hand experiences and responses from relevant stakeholders on their perspectives of participatory research with autistic people and how these could be facilitated. In this section, we will visualise these recommendations using Program Theory, which guided our analysis.

2.4.1 Inputs. One key input in participatory research with autistic adults is including a diverse range of stakeholders with lived experience, including autistic adults, caregivers, and other relevant stakeholders. Nicoladis et al. [59] recommended considering the multiple expertise of autistics (i.e., as engineers, programmers, designers, and researchers) when formulating research plans. Multiple reflections underscore the value of having autistic researchers on the team, particularly in building trust in the process [22, 31].

Topics and technological applications should be aligned with the needs of autistic individuals to demonstrate respect for the autistic lived experience [30]. Pellicano et al. [64] revealed how autistic adults in the Australian context felt more connected with participatory projects when their lived experience was valued when shaping the project trajectory.

Ensuring everyone involved knows what participation means in the project context is critical. Den Houting [22] warned that misalignments in expectations could lead to participants sitting on the lower end of participation. For researchers, it is crucial to shift participation beyond tokenism toward having opportunities to take ownership of projects that align with their lived experiences [18]. Nonetheless, impediments remain when conducting meaningful participatory research due to resource constraints, such as limited support from senior academics, project timelines, and funding [66]. Including autistic community members in the research and shaping the project idea before funding is sought could help promote more meaningful participation [66].

2.4.2 Process. Facilitating relationships and trust-building is considered critical in PD. With autistic and non-autistic interactions, it is important to re-emphasise that conflicting world views could create tension [57]. Balancing power dynamics within and between autistic and non-autistic stakeholders is crucial to support relationships. Fletcher-Watson et al. [30] have stressed the importance of involving autistic people in developing policies that determine how power permeates within participatory projects. The methods employed should be aligned to support participation [30].

Providing tailored approaches and methods is critical for encouraging the involvement of autistic people [30]. Nicoladis et al. [59] have also suggested including autistic people in customising the consent process, which could be challenging for many autistic people.

2.4.3 Effects. Medium to long-term effects can emerge where inputs and mechanisms are supported and harnessed. Fletcher-Watson et al. [30] argued that providing infrastructures for autistic adults to continually share ideas can be useful for developing further meaningful projects. Pellicano et al. [64] highlighted how participatory projects resulted in increased confidence in autistic people to advocate for and value their lived experience.

Table 1 visualises these recommendations across their inputs, mechanisms, and effects. We can see the importance of meaningfully aligning the topic and technology role with the autistic lived

Table 1: A summary of lessons learned from participatory design processes involving autistic adults. These are categorised according to their inputs, mechanisms and effects, in line with the Program Theory framework.

Input	Process		Effects		
	Mechanism	Activity	Output	Outcome	Impact
Topics and technologies aligned with autistic peoples' goals/needs [30, 63, 64] Diverse stakeholders aligning with relevant expertise (autistics, caregivers, etc.) [22, 30, 31, 59, 64, 66] Negotiations on level of stakeholder participation [18, 22, 30, 63, 66] Funding and resources support effective participation [18, 22, 30, 66]	Building relationships, trust and mutual learning [59, 62] Balancing power dynamics [30, 59] Infrastructure to support participation [30, 59] Harnessing communication (including tensions) within and between autistic and non-autistics [30, 66]	Relationship building exercises [59, 63] Reflexive feedback/design activities [59] Activities around consent [59]	Co-distributing of research findings [59] A product that meets autistic goals [62, 63]	Co-learning [31, 59] Capacity and skillbuilding [59]	Improving lives of autistic people [30, 62, 63] Building self-confidence and acceptance [63] Infrastructures for advocating autistic knowledge [30, 59]

experience. Sustaining autistic voices in the process involves employing mechanisms for infrastructuring involvement and managing power imbalances. If performed positively, these can result in lasting effects, including increased confidence in autistic people and infrastructures that support sustained autistic participation. In the next section, we detail the scoping approach employed to select the papers.

3 Methods

In this section, we outline our scoping review approach and methodological reflections on why and how we searched. We also discuss our supporting keyword analysis, which was used to identify topics and technologies represented in the papers we later analysed.

3.1 The Scoping Approach

We employed the Joanna Briggs approach [65] as our search strategy, driven by our goal to include a wide range of case studies involving autistic adults in designing technology. Systematic reviews follow a structured search and pre-defined process; the search concludes when papers are selected by inclusion/exclusion criteria. While valuable, we sought additional insights to strengthen our review. The Joanna Briggs Scoping approach allowed us to scan reference lists of included papers for other relevant sources. This enabled us to add an additional phase to obtain more contextual information on the projects identified.

The inclusion criteria for this scoping review were:

- `Research completed between 2010-2023`: Our justification for choosing this period is to focus on the most recent work toward supporting the involvement of autistic adults in design.
- `Autistic adults over the age of 18`: Our goal was to focus on adult involvement. While children's involvement is imperative in design, a growing focus is on understanding how design activities can be set up for autistic adults.
- `Studies geared toward the needs of autistic adults exclusively`: While the needs of other related groups (such as ADHD and dyslexia) are important, these are not directly comparable to designing for and with autistic adults.
- `Focus on Technology Design`: We focus on technology because creating shared understanding presents unique challenges. With novel technologies, those with limited technical knowledge may struggle to envision how it could support their needs. This requires explorative design interactions between diverse participants.
- `Clear and analysable case`: While lots of valuable research does not describe cases in detail, we need process details to analyse and answer our research questions. This also means that we do not include review articles, pure usability, or evaluation studies as they do not contain information on the mechanisms of how autistic adults were involved.

Our pilot search included Scopus, Pubmed, and Web of Science. However, we found that the search generated a large number of

Table 2: Summary of Database Searches. The search count for 2010-2022 and 2022-2023 are all unique results.

Database	Searches 2010-2022	Searches 2022-2023	Keywords
International Journal of Human-Computer Interaction	12 (26 August 2022)	4 (26 May 2023)	autism OR autistic OR ASD OR Asperger OR Aspergers OR Asperger's
International Journal of Human-Computer Studies	14 (26 August 2022)	2 (26 May 2023)	
ACM	626 (26 August 2022)	130 (26 August 2022)	autis* OR ASD OR asperg*
IEEE	2409 (26 August 2022)	2 (26 May 2023)	autis* OR ASD OR asperger*
Assistive Technologies	18 (24 August 2022)	1 (26 May 2023)	
Disability and Rehabilitation: Assistive Technology	21 (24 August 2022)	5 (26 May 2023)	
Journal of Applied Research in Intellectual Disabilities	87 (24 August 2022)	7 (26 May 2023)	
Journal of Intellectual & Developmental Disability	88 (24 August 2022)	4 (26 May 2023)	
Developmental Disabilities Research Reviews	6 (25 August 2022)	0 (26 May 2023)	
Advances in Autism	13 (26 August 2022)	1 (26 May 2023)	participation OR participatory OR co-design OR co-development OR co-creation OR collaborative OR collaboration OR "experience-centred design"
Autism Research Journal	395 (29 August 2022)	49 (26 May 2023)	
Good Autism Practice	30 (26 August 2022)	0 (26 May 2023)	
Journal of Autism and Developmental Disorders	450 (29 August 2022)	42 (26 May 2023)	
Research in Autism Spectrum Disorders	50 (26 August 2022)	10 (26 May 2023)	

false positives. Therefore, we narrowed the search to specific peer-reviewed journals and venues within and outside the scope of HCI (Table 2).

The generation of keywords for our search involved careful discussion between the two authors and an independent reviewer (recommended by the Joanna Briggs approach [65]). We considered what keywords could be used to retrieve research on autistic adults, participatory design (and design in general), and technology. The independent reviewer is an expert in participatory design and has experience conducting systematic reviews.

We considered whether we should include technology-specific keywords (e.g. *technology*, *web*, *app*, *virtual reality*). In their review on the agency of autistic children in technology design, Spiel et al. [78] included the inclusive search term (*technolog**). Domínguez-Lucio et al. [24] also included a range of technology-related keywords in their search (such as *apps*, *technology*, and *internet*). We were careful not to restrict our search to specific technologies; therefore, we did not include these keywords.

We adapted keywords based on venue themes. For instance, as ACM and IEEE were technology-focused venues, technology-related keywords were unnecessary. Similarly, autism-specific venues did not require autism-related keywords. So, in technology development venues, we used only autism-specific keywords (with wildcards (*) where appropriate). In the venues dedicated to autism research, our keyword searches focused on participation in the design process (Table 2). We considered keywords such as *human-centred* and *user-centred*. However, collective discussions between the authors and the independent reviewer resulted in a focus on participatory approaches, as they invite stakeholders as partners throughout the design process, potentially leading to a sustained impact [42]. This was important for us when employing analysis using Program Theory. Since the goal was to focus on the design process rather than evaluation, keywords such as *user study* and *evaluation* were not included. We also chose not to focus on specific methods (e.g. *interviews* or *workshops*), because they are not specific to design and can be conducted during evaluation stages.

Our search includes 01/01/2010-26/05/2023. The initial corpus of papers was 4499, and our search and filtering strategy unfolded in four phases:

Phase 1 - screening: We manually screened through titles and abstracts to remove false positives and irrelevant articles. False positives included articles where the search term ASD returned papers on, for instance, *Adjustable Speed Drives*, *Approximate Simultaneous Diagonalization*, etc. Subsequently, we examined each dataset to exclude papers focusing on children, adolescents, other neurodivergent populations, and papers that did not focus on technology, according to our criteria above. This search resulted in 484 papers. The significant reduction in papers could be explained by the strong emphasis on children in autism research [72], the large amount of non-technical papers returned from Autism research venues, and false positives.

Phase 2 - abstract search: We reviewed article abstracts to decide whether Program Theory analysis was feasible in the remaining papers. This search resulted in 52 papers. This included the criteria in phase 1, as well as papers that a) do not describe the design process; b) only describe a usability study; and c) experiments that are performed using datasets collected from autistic people, such as the Autism Brain Imaging Data Exchange (ABIDE) [25].