

Negotiating Gender and Disability Identities in Participatory Design

Emeline Brulé*
University of Sussex
Falmer, UK
e.t.brule@sussex.ac.uk

Katta Spiel*
TU Wien (Vienna University of Technology)
Vienna, Austria
katta@igw.tuwien.ac.at

ABSTRACT

Standpoint theory draws our attention toward how researchers' identities shape the production of knowledge. Their standpoint depends on previous experiences and their sense of identity, as well as on their social position relative to research participants and their communities. This is particularly the case in Participatory Design (PD), which entices researchers to develop personal relationships with participants through design. However, the way identities affect Participatory Design with children has so far been neglected in research, even though previous works focus on children's and researchers' roles in the design process or encourages auto-ethnography. In this paper, we build on case studies of how identities as they relate to gender and disability shape relationships between researchers and marginalised children through Participatory Design. We show how these identities are continuously negotiated throughout the design process, and how they shape outcomes. We close by proposing an approach to systematic reflexivity on identity in participatory design.

CCS CONCEPTS

• **Social and professional topics** → **Computing profession; User characteristics; People with disabilities; Gender;**

KEYWORDS

Identity, Participants, Participatory Design, Queer, Disability, Intersectionality, Design, Researchers

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*Both authors contributed equally to this research.

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1 INTRODUCTION

Participatory Design (PD) researchers adopt a critical stance towards including individuals with specified characteristics or experiences in design work [36]. PD methodologies were born out of a concern for including non-designers in decisions, as well as to build on existing communities in the broad sense of the term – initially trade unions [25]. Subsequently, PD researchers have a good understanding of how we *identify* suitable participants for a given project. What is less clear though, is how their personal identities, and the communities they are associated to, play into participatory design processes.

Standpoint theory invites attention to researchers' perspectives in the production of knowledge [28]. Researchers' as well as participants' experiences and their sense of identity shape their mutual relationships and, subsequently, data, analysis and outcomes. This is a widely adopted understanding within ethnography, which demands particularly intense social and emotional involvement from researchers [46]. Ethnographers are required to negotiate their position in the field and the community studied as consistent with their research topic [10, 30]. This might, for instance, involve insisting on one identity marker or developing a narrative about the self that might be more acceptable in that context. In defining their position in PD, researchers often reflect on the impacts of broader power dynamics between themselves and participants [3]. For instance, researchers often have a more privileged socio-economic background, which might be challenging when working with marginalised youth and communities [30].

Participatory Design research requires a similar kind of intensive commitment [56]. The practice comes with its own challenges: in particular, participatory design requires understanding how researchers' and participants' identities and values are reflected and supported not just in the write-up of research, but also in the prototypes developed [63]. However, scholarship on relationships during participatory design focuses either on roles in design or on providing advice to working with marginalised communities (i.e. [19, 56]). This hints at several gaps in the literature: on the one hand, the ways researchers' identity shape participatory design processes and outcomes are rarely discussed, even less so when they come from a privileged position; on the other, identities are often framed as fixed, externally assigned attributes, whereas they are continuously renegotiated in participatory design processes. It also hides conflicts arising from differential community affiliations between researchers and participants.

In this paper, we explore *how identities are negotiated in participatory design*. To do so, we present five case studies from three participatory design projects with disabled children. We show how different identities are negotiated both through personal interactions and in the materials used and objects created during the participatory design processes. We analyse in particular how queer and disability identities play into Participatory Design with disabled children; before turning to the notion of communities and standpoints in Participatory Design processes. We close by outlining a methodological approach that explicitly includes identity construction as a part of Participatory Design, which decidedly requires researchers' attention.

2 BACKGROUND

We outline definitions of identity, gender identity and disability, before discussing identity and standpoint theory as they relate to research relationships. We then focus more specifically on identity in participatory design.

2.1 Definitions

2.1.1 Identity as Process. We understand identity as a process — instead of a fixed categorical conceptualisations [26]. Identity then becomes a narration of the self and guides our gaze at the roles individuals can take up. In this framework, the sense of personal identity is relational, and research inquiries can focus on how narratives on identity are constructed and shared or, at the contrary, why proposed narratives are rejected. They can also inquire into how roles are negotiated in a given situation based on individuals' current as well as desired identity narrative and social positions.

We further understand identity as fundamentally co-constructed [26]. This means that while people often conceptualise identity for themselves, they re-conceptualise and shift identities along how they are identified from an outside world. Within this dialogue between identifying self and being identified as other, identity is continually re-evaluated and negotiated [ibid]. We use identities in the plural to acknowledge that multiple facets playing into the identity of an individual and how different shades performed in different contexts [66].

In this context, we understand community as the groups in which an individual evolve, sharing spatial resources for instance, as well as groups an individual chooses to join, based on interests or characteristics. Communities provide a sense of membership, an emotional connection, they serve to fulfil members' needs — and members should feel they have an influence on the group as it does on its members [43]. Different communities, then, afford different roles and support the development of varying identity traits. The following sections highlight how identity can be shaped by associating oneself with a community with a shared political purpose and sense of identity. Research activities themselves provide one such context in which we can research how identities are negotiated.

2.1.2 Identifying as Disabled. A person may identify as disabled before or after being medically identified as such, particularly when it comes to invisible disabilities. Identifying as disabled might but does not always coincide with engaging in disability activism [20, 65]. Reclaiming a label of disability can provide a sense of agency, and belonging [45], or of feeling represented [21]. However, in many

cases, disabled individuals do not see an advantage in identifying as such and even reject an identity of being disabled to foreground other aspects of themselves [65]. An identity marked by disability thereby refers to a self-described personal sense of disability status, which can be positive, negative, or non-existent. It often is co-produced between internal and external attributions of disability as a core characteristic, which means that people who do not self-identify as disabled might still be identified as disabled by others. Further, as the identity is related to access to resources as well as stigma, disclosure or foregrounding of such an identity can be highly contextually dependent [ibid].

2.1.3 Identifying as Gendered. By gender identity, we refer to one's personal perception and description of one's gender [66]. This is constructed in relation to other persons and gender norms of a given society. In Western cultures, a binary gender structure (distinguishing only between woman and man) is predominantly constructed on perceptions of genitalia and deeply embedded in social structures in which men generally hold control over women. In this context, binary trans identities refer for instance to a gender identity opposed to the gender assigned at birth within that binary; whereas trans non-binary identities refuse this dual categorisation [48, 59]. Queer identity then tends to follow similar motions of first identifying the self as queer (though by ascribing to an external group) and then performing to be recognised as queer [12].

2.2 Standpoint theory and identity in research relationships

Standpoint theory engages with the epistemological consequences of Marxist theory in feminist studies. It is built on the premise that “the position of women is structurally different from that of men, and that the lived realities of women's lives are profoundly different from those of men.” Belonging to a structurally dominating class, “sets limits on the understanding of social relations,” providing an understanding “both partial and perverse.” From there, Hartsock argues the production of knowledge by structurally oppressed researcher (including queer or disabled people) is necessary to develop a different knowledge on social phenomena and ultimately support emancipation of the oppressed class [28].

If standpoint theory is originally a feminist theory, arguing women as a class and feminist communities had an epistemic privilege when it comes to studying social phenomena, it more largely entails that researchers' identities shape the research conducted. This has also become the basis of identity politics: identifying with (an) oppressed group(s) and asserting different views given this position that potentially leads to positive change [52]. The negotiation of the researcher's identities during research processes is a widely discussed topic in ethnography, in which researchers embody multiple aspects of their identities [33]. When working closely with a group of research participants, researchers need to find a suitable position and presentation of self in the community to be accepted and conduct their work, that might differ from other displays of self, e.g. due to safety concerns for themselves or participants. In turn, this position needs to be taken into account in analysis: it shapes the generation of data, as both parties adapt to the relationship¹

¹Other types of inquiries, such as structured interviews or questionnaires, are not exempt from this negotiation. Research participants gauge the interviewer or the tone

[27, 30]. When they cannot adapt, they may also object or reframe the inquiry [31], which potentially results in valuable insights for research.

One particular focus in this area is the power differential between researchers and participant. In the case of research with children, adult researchers hold a dominant position towards children [34]: most adults in children’s lives control their movements, schedule, studies and legal representation. If a researcher is not mindful of this power differential, they risk reproducing it. Childhood scholars, hence, propose that adult researchers actively change their attitude to become the *least adult* [42] or *another kind of adult* [49]. Taking this position can change other adults’ perceptions of the researcher, perceived as youthful, or not-quite-adults [4]. This might especially be the case for queer and/or disabled individuals, who often do not have access to traditional characteristics of adulthood [18]. Hence, we constantly need to take multiple facets of identity and the effects of their intersections [15] into account.

2.3 Identity as a Challenge for Participatory Design

Participatory design is framed as a process that can reshape our environment and make it fairer or that participating can provide a sense of agency [62]. While design participates in shaping identity [53]: owning or using specifically and carefully chosen artefacts assert our belonging to gender, disability and other categories and in turn enable us to be recognised by those similar to ourselves. It also bears the possibility of ‘tyranny’, as participation can also be a way to silence diverging voices within a community [13]. Calls for more reflexivity on the impact of researchers on designs often lack engagement with researchers’ identities, engaging instead with character using auto-ethnography [41], practitioner’s knowledge and self-perception [51] or with respective roles within the research process [49]. This is especially highlighted in participatory design with children, or disabled people, who are perceived as participants with abilities and modes of engagements that differ from what is commonly expected [35].

3 RESEARCH APPROACH

With this paper, we address the following question: How may we understand how identities are negotiated during and through participatory design? To do so, we draw on three participatory design research projects conducted with disabled children. Each had different goals of aims. The data generated through this research was analysed qualitatively (see below for details on each project). After discussing this ongoing research, we identified this common research question and conducted a secondary analysis to identify relevant case studies.

3.1 Selection of case studies

To select these case studies, we turned to the research literature on methodological approaches to study identities in context. Adams[1] argues there are three ways of understanding how identities are constructed, by examining: 1) Boundaries, such as who is welcome to

of the survey and adapt their answers based on their interpretation of the situation. This is more likely to be the case when the research topic is more personal and subjective [17].

participate in certain activity and structures; 2) Temporal and spatial changes of those boundaries; 3) Reflexive discourses on identities, such as mapping consensus and dissensus between different individuals within a group claiming the same or associated identities. In other words, to study identity as it is constructed in social contexts, we can study their ‘frontiers,’ which are more or less porous: the negotiations, changes and reactions, and (dis)agreements around the topic of identity.

Following this approach, we reviewed videos, photos, audio and written material we had generated while conducting participatory design sessions, and searched for examples of *changes in relationships during design and through time* as well as *moments where our own or the participating children’s identities were explicitly discussed*.

3.2 Analysis of case studies

After selection, case studies were written-up following a three-fold structure: setting; an element suggesting an identity boundary as outlined above, changing the participatory design process; and short discussion using the research literature. The structure of the case studies exemplify how identities are both constructed internally and externally: the fluidity of identities was expressed through presenting the self, having others interpret and react to these representations and adjusting them according to these reactions. Hence, identities are created in tensions and frictions between identifying and being identified. We then conducted a thematic analysis of these case-studies, searching for recurrent themes that would answer our research question. Gender, disability, community, and standpoints were themes we could trace across our research projects, which became the framing of the article. From this, we suggest a more formal approach to reflecting on identity within participatory design.

3.3 Standpoint

Both authors identify as queer, one as disabled. Research participants were recruited because they were identified as either autistic, neurodivergent, or visually impaired children. Some of them self-identify as disabled, others do not.

3.4 About the case studies

We provide two sets of case studies illustrating how the construction of identities of children and researchers might play out in participatory design research. We acknowledge that the negotiation of identities is intertwined even though we artificially distinguish between those perspectives. Here, we introduce the contexts from which we report. In all cases, we drew from elements of participatory design to engage disabled children directly in the design and development of technologies that are supposed to be meaningful to them.

3.4.1 OutsideTheBox. Within the OutsideTheBox² project, a team of three researchers co-designed technologies with eight individual six to eight-year-old autistic children³ with a range of abilities and interests. Through the continued engagement, each lasting more than a year, we developed prototypes addressing the holistic well-being according to the interests of each child. For this, we met,

²<http://www.outsidethebox.at>

³We adopt identity-first language to refer to disabilities in this paper, as it is the political choice and preference for most activists, particularly autistic activists [38, 54].

usually in their school environment for up to 20 times. However, we adhered to a notion for the technology to be meaningful beyond being a toy. The children were included in Contextual Inquiry [32], ideation, conceptualisation, prototyping and evaluation. We have presented insights around the process [22, 40], outcomes [23, 60] and evaluation [57, 58, 61] elsewhere. We have also focused on discourse and attitude changes before and after using the prototypes developed, to understand how identity affects adoption. Finally, we also performed some object speculation [29] to investigate into how the resulting objects position themselves in connection to the identities in play during its design and creation.

3.4.2 Social Play Technologies. In the Social Play Technologies⁴ project, a group of three to six researchers co-design technologies facilitating social play with groups consisting of four to six autistic and allistic⁵ children. The project is ongoing and so far we are working with three groups creating individually suitable technologies that aid the children in realising their visions for play. Previously, we reported on insights into the agonistic qualities of design processes with neurodiverse groups of children [?].

3.4.3 Accessimap. Within the Accessimap research project, one author conducted an 18 months long ethnographic study on visually impaired children’s experiences of schooling and learning technologies. The field-researcher chose ethnography because it enables to build rapport with participants on a long-term basis, providing insights on experiences of schooling through time difficult to acquire otherwise. During that time, the field-researcher co-designed learning technologies with five primary school visually impaired pupils between 8 and 11 years old and a special education teacher. The focus was on developing technologies supporting the development and value of a non-visual culture in school. Children were mainly involved in ideation and evaluation. The full methodology and process [4, 8, 9], prototyped technologies [5–7] and design insights [5] were described elsewhere.

4 CASES – CHILDREN’S IDENTITIES

As researchers, we identify participant populations that are relevant to our questions. In Participatory Design, this is all the more so the case. However, this comes with the additional complication that while we identified the children we collaborated with through a particular marginalisation, the children themselves might not consider this an essential aspect of their self-conceptualisation of their own identity.

4.1 Identified as Autistic, Identifying as Inventor

When we first met Quentin⁶ as part of the OutsideTheBox project, he was nine years old and went to a mainstream school. He was diagnosed with Aspergers while in pre-school. Tinkering and crafting were well-loved activities, but only to create a finished object that had an obvious immediate use to him (even if that was not necessarily evident to outsiders). For our collaboration, we met

⁴<http://www.socialplay.at>

⁵Meaning non-autistic in the spirit of [39]. Being allistic can and does include other neurodivergent conditions, such as Attention Deficit Hyperactivity Disorder (ADHD) or Trisomy 23.

⁶All names have been anonymised to protect the privacy of the children.

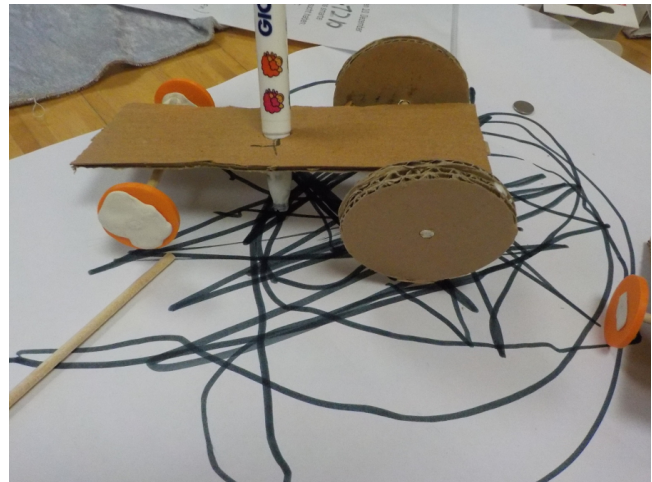


Figure 1: Quentin’s quick invention of a drawing care inspired by the material at hand

in an empty room in his school around the corner from his classroom. We conducted 13 sessions at the school and two additional ones at the digital fabrication lab within the university. *While our project and the associated funding was putting the focus on Quentin as an autistic child, he identified predominantly with the persona of an inventor.* This became apparent not only in his preference for science clubs and crafting activities but also the verbal affirmation of such identity through exclamations such as ‘Can we invent a money making machine?’⁷ or, even literally, ‘I am an inventor.’ Autism was only a reference frame to explain certain actions. ‘I do [this] because I’m autistic’ (see also [47] for a discussion of how children use disability language to negotiate their identity and the perceptions adults hold).

He was full of ideas and impatient to realise them. For example, he creatively used low-tech material to quickly craft functioning prototypes of what he had in mind (see also Figure 1). In speculating on the object, it shows how Quentin quickly assembled things although they might not be able to sustain his attention for a long time *as they are* as he might always switch up and alter aspects of the material and reconfigure certain parts. The objects as presented offers such flexibility by being quickly de- and attachable. However, within the scope of the technologies, we were aiming for, we could not fully determine a theme that was meaningful to Quentin beyond a single session. Once we understood this rapid production of ideas as part of Quentin’s core interest, we could focus on creating a more dynamic and open artefact more appropriately in our final prototype. Through continuously inventing and creating new objects, Quentin actively established himself as a curious builder and crafter. We co-constructed a set of sound-cubes which allowed him to experiment with sending sound but were also accessible enough for him to change and re-invent them continually.

⁷We really could not.



Figure 2: Different materials inviting participants to express their identity subtly through the different qualities these materials bring to the design.

4.2 Identified as Neurodivergent Group, Identifying as Individuals

In one of the groups of the Social Play Technologies project, we collaborated with five children two of which have a diagnosis of autism, one with trisomy 23, one with ADHD and one with generalised learning difficulties. Due to the diversity of the children, different needs and desires had to be continually expressed, identified, assessed and acted upon. The children attended the 2nd year of primary school together but comprised a distinct subgroup within the larger class. Our meetings (fifteen in total) were held in an activity-oriented room next to the traditional classroom.

Within groups, identity construction has different points of contact. It not only occurs between researchers and participants but also between participants. Researchers, hence, encounter a community, as well as the individuals and, similarly, engage with communal as well as individual aspects of identity that might be more or less aligned with each other. Particularly where the group is formed through external factors (in this case, educational needs as identified by adult carers), collective identity is charged with tension holding implications for the design process (see [24]). For example, some children felt excluded from certain activities or topics and had difficulty relating to the actions of the rest of the group. They kept on wailing: “They [points at other children] never, never, never let me play with them.”, even if they had just played together. This indicates that situations and relationships were assessed anew in each moment and overriding previous experiences. In such cases, individual and communal identities had to be renegotiated to create a comfortable environment for all.

In aiming at catering to different desires and preferences, we used mixed materials through which the children could express themselves in the participatory design process (see also, Figure 2). Some children were more interested in investigating different technologies, others role-played with the tactile sensations of the materials

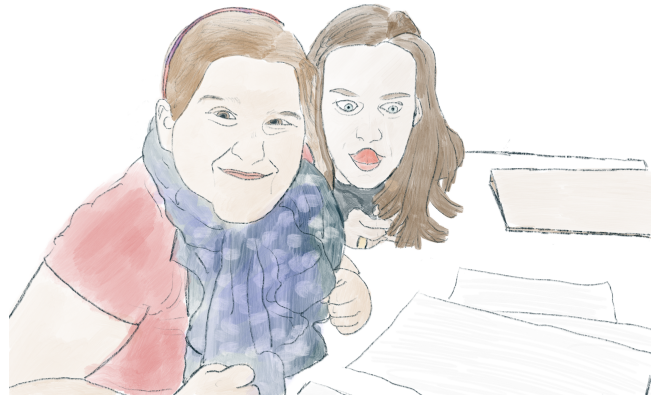


Figure 3: Grimaces as part of a ritualistic practice of expressing the self as part of a design team.

while others again tried to find out ways in which they could combine them. Through the material, they can explore different ways to express various aspects of their identities, and through negotiating limited resources, they also negotiate their identity within the group of peers and the present adult researchers. For example, one of the children took up different roles using different textile accessories as signifiers. The other children included or excluded him in their play according to how they saw the role he embodied as fitting to the group activities in a given moment. They were also inspired to respond to his roles by identifying as counter-characters or comrades. In one case, the child determined one piece of clothing to be a knight’s armour to which one of the other children decided also to take up a knightly identity whereas another became the king and yet another transformed into a dragon.

4.3 Identified as Girl, Identifying as Child

Sasha was one of the participants in OutsideTheBox. We worked with them⁸ in an empty classroom adjacent to their core classroom. They loved video games and drawing. The diagnosis of the then 8-year old was comparatively recent, but they actively engaged with the meaning of being autistic for their life and continuously reflected on their experiences.

Sasha was assigned female at birth. However, they expressed on multiple occasions to us and their environment that they feel stifled by gendered expectations on their behaviour and mannerisms. In one session, they frustratedly reported from an encounter earlier in the day: “And then [my classmate] told me that I cannot like soccer, because video games are just for boys. But then I’m just like boys!” For example, being interested in video games was something they experienced as an interest strictly associated with boys. In that context, it should be noted that gender variance appears to be more prevalent among autistic people [37], which means Sasha’s experiences are comparatively common.

⁸We use they/them pronouns in this case, as we are not entirely sure which pronouns Sasha would choose in English.

Even within the research team, we initially also, without knowing Sasha personally yet, were excited to have a non-male participant as diagnostic procedures are highly gendered [16]. While in a different case the social environment was more conservative requiring us to tread carefully, Sasha’s parent actively sought out the queer-presenting researcher to inquire about the genderqueer attitudes of their child. As this was not at the core of our intended research, it required us to act as embodied researchers; we decided to provide information on where to seek external guidance around gender non-conforming identity development in children. Within the project, we were careful not to bring up gender issues to allow Sasha to take the lead on them if they wanted to. At a later point, Sasha brought up the topic themselves and stated that they were ‘a different type of girl’ – at least for the time being.

5 CASES – RESEARCHERS’ IDENTITIES

Similarly to the participants, researchers’ identities are continuously re-negotiated and re-affirmed through PD, even if that is often less explicitly obvious or reflected upon. The way we present ourselves, the choices we make in that and how we are interpreted in our roles and activities play into the process and the designs stemming from it. We present two personal vignettes that describe how we negotiated gender and disability for ourselves.

5.1 Female and Carer for Adults, Non-Binary for Children

As a queer individual, I am used to answering questions about my ‘real’ gender, especially in public settings. For years, children have pointed at me in the streets to ask their parents ‘what I am.’ Parents’ answers are rarely positive towards queer individuals, answers ranging from ‘we do not discuss this’ to ‘this is a monster.’ However, I also have been working with children for more than ten years, as a private tutor, art teacher and babysitter. I am thus a skilled professional when it comes to care and interact with children. In these more private professional settings, children are still inquisitive, wondering why a ‘girl’ does not wear jewellery or makeup, or alternatively how I can be a ‘boy’ and have breasts. But looking queer is not as much of an issue, as in care roles I practice female respectability [55], with my queer appearance being attributed to being humble or poor.

I had not envisioned however how it would impact my ethnographic and participatory design work. More specifically, disability specialists and teachers, I was working with identified me primarily as a carer and a female. These workers were almost all women, as professions in close contact with children and care work generally are [44]. The children participants, however, alternatively used both grammatical genders⁹ and pronouns to refer to me. It depended on the activity undertaken and the gender they associated with it. Adults often tried to ‘rectify’ the pronouns to use.

Being a queer researcher, hence, placed me in a precarious situation, showing two different identities over the ethnography and design process. It creates challenges in the rapports one can build: the literature suggests it is sometimes better for researchers to be

of the same gender of research participants [30]. Being queer creates unexpected opportunities in design: they start discussions on gender identity, troubling children’s representations of what ‘girls’ or ‘boys’ can do. The researcher truly becomes ‘another kind of adult.’ These opportunities, however, are uncharted, as cisgender researchers¹⁰ predominantly fail to discuss how their gender identity affect the roles they have with children and how other adults that come to be involved in PD research perceive them.

5.2 Pride in Disability vs Disability as External Marker

As a disabled researcher, I take pride in my disability as a radical act of defiance to those who understand disabled as being less than. “We can celebrate, and take pride in, our physical and intellectual differences, asserting the value of our lives. And while confronting the genuine difficulties that physical and intellectual differences involve, we can fight against discrimination and insist that the needs created by those differences are met in a way which enhances the quality, and our control, of our lives.” [45] Additionally, I aim to take this stubbornness about my own identity to make it productive. After all, “[i]dentity politics is both about achieving a better deal for people, but also about establishing the stories people tell about themselves, and having them listened to” [52]. Fueled from the community I created with other disabled researchers, I try to be a vocal scholar who makes a (hopefully convincing) case about the relevance of equity initiatives for disabled people in academia.

However, in interacting with the children and their caretakers, I dial back this pride and often foreground other aspects of my identity and work. Hence, I am usually not considered as ‘disabled’, but instead seen within the researcher role I represent. In doing so, I share an experience with our participants many of which, as we saw above, identify themselves through alternative avenues and experience disability mostly as an externally assigned identity (similar to participants in Watson’s study [65]); an aspect we further through selecting them on a basis of clinically established categories of disability. While this separation of identities on my side is, to some extent, explicit as to not endanger access to participants or make sure the children are centred, it also breaks apart in the active engagement with participants. Implicitly, my lived experience, as disabled and neurodivergent allows me to understand some issues the children might articulate with their environment from a place of similarity instead of a place of difference. This does not necessarily entail that my interpretation is in any way more appropriate than others’, but it does come from a different place. For example, in one case a child seemed overwhelmed by the level of background noise that had been increasing throughout our interaction up to a point where they were not able to finish a task they were able to do previously. While parent and teacher tried pushing the child towards completing the task, as they knew that he was able to do the activity, I started supporting the child quietly in constructing the artefact. That way, we converted a potentially frustrating feeling of failure due to background distractions into a collective experience of success.

⁹French, the language in which this research was conducted in, heavily relies on binary gender structures.

¹⁰A person is cisgender, if their gender identity coincides with the sex they were assigned with at birth.

6 DISCUSSION

Within our PD processes, identity was continuously negotiated and subsequently co-constructed between participants and researchers. This is often an ambient process that is not necessarily addressed explicitly but shapes processes and designs. Through our accounts, we aim at encouraging researchers to further reflect on identity in their own participatory design processes. We now discuss our findings on identities in participatory design. From our case-studies, we develop three inter-related themes. We discuss gender and disability in PD, particularly salient in our projects. We then look more broadly at how communities and standpoints are evoked in various aspects of PD. From there, we note that, although the role of design in shaping identity has been extensively discussed, the tangible ways in which it does so have been left out. Finally, we broaden the analysis and suggesting a more formal approach to reflecting on identity within PD.

6.1 Gender and Disability in PD

Especially salient in our case-studies, disability and gender shape Participatory Design. Gender fundamentally affects relationships: with children participants and their communities, and with adults involved in the same project. Disability identity, on the other hand, appears in the case studies as being mediated through artefacts, materials, and values in design. We suggest this could be explained by the difference in visibility: not only queer identities are more present in media and public discussions, but they are also associated with visible traits — whereas disability can be invisible.

6.1.1 Gender. We first reflect on how gender plays into participatory design. Working with children is a highly gendered line of work [11]: throughout the Global North, women provide the bulk of the care and teaching work, especially before teenage years. This is clearly affecting interactions in the case studies above. As Section 5.1 exemplifies, being first perceived as a woman means being perceived as competent for caring for children in design. Other adults went to great length to re-assert researchers' gender according to their own assumptions when children perceived it differently.

Both researchers and children have tactics to contest the gender assigned to them in interactions. Children do express discomfort or resistance towards expected gendered roles and traits. Researchers use gendered clues to adapt to the situation. Both participants and researchers share a collective experience of contextual disclosure according to safety in the process and around other people. The difference lies in residing in self-identification, as both researchers reclaim queer as a label and as a community.

Binary and non-binary trans researchers are under heightened observation in a society and communities structured on binary genders, which expects them to explain their actions and perspectives [2]. This includes the pressure to reflect on how their own convictions impact participatory processes. However, cisgender people bring their individual normative identities and shape the process alongside [64] without being expected to reflect much on their own perspectives, such as assuming participants to be hetero and cis.

Hence, reflecting on gender in PD cannot only be required from researchers (or participants) with marginalised gender identities or transgressing gender expression. In other words, identities that

are particularly *visible*. Actively seeking to understand how participatory design and its practitioners may reinforce both compliance and resistance to gender roles is a relevant lens to reflective practitioners.

6.1.2 Disability. All children were identified as potential research partners through medical diagnoses. While disability could be a potential marker of identity, children did not necessarily adopt this for themselves [65] — and, in fact, in the case of the Accesimap project, actively resisted it. The children we cooperated with had diverse interests and enjoyed participating in our projects as scientists, tinkers, game developers, movie enthusiasts, drawers, explorers, adventurers and so on. If they acknowledged their own disability at all, this was more done as an afterthought or as the reason behind individual choices and actions (see Section 4).

A pronounced, recurring conflict in several of the case studies is that the external assessment of disability does not necessarily match children's self-identity. This is further complicated when researchers and designers claim disability as an identity for themselves. Participants' and researchers' relationship to disability as an identity rendering an individual as part of a community should thus ideally be discussed and negotiated transparently and honestly and appropriately towards the form of communications participants might prefer. In cases where this is less possible, design can be a way of introducing these ideas and trying to open a different perspective on identities. Design, after-all, materialises values and participates in the shaping of identity [53]. There is, thus, a case for designers to propose artefacts supporting disability identity, regardless of whether they identify as disabled or not and irrespective of whether participants might take them up on that option or not.

Another issue raised by the case study in Section 5.2 is that the disability status of a researcher involved in participatory design might be invisible and undisclosed. Queer identities are sometimes hidden (hence the metaphor of getting out of the closet), but the visibility of a disability status is more often bound to vary. Not only it can be invisible, but as disability emerge when the environment is not adapted to a specific body, there are many contexts in which even visible disabilities may not be understood as such. Participatory design, then, can make disability identities a focus — although it may also ignore it.

6.2 Identity as a Lens for Design

This connects to the second theme we develop from these case studies. Although design and artefacts have long been discussed as part of identity work, there is little focus on the ways through which this identity work unfolds in PD. It might be argued that all activities of the children's lives participate to identity work, especially considering that they are more actively trying out new identities to shape their own [14]. PD offers an opportunity to do so through artefacts, design activities and materials. In other words, Participatory Design can not only serve as a platform where negotiations of identity can occur but also as a means to explicitly mediate identities and their constructions.

For example, the car depicted in Figure 1 embodies an interest in movement (wheels), creativity (appropriation of a pen) and resourcefulness (mix and match of different materials) coming from the child. It also illustrates practicality (offering certain materials),

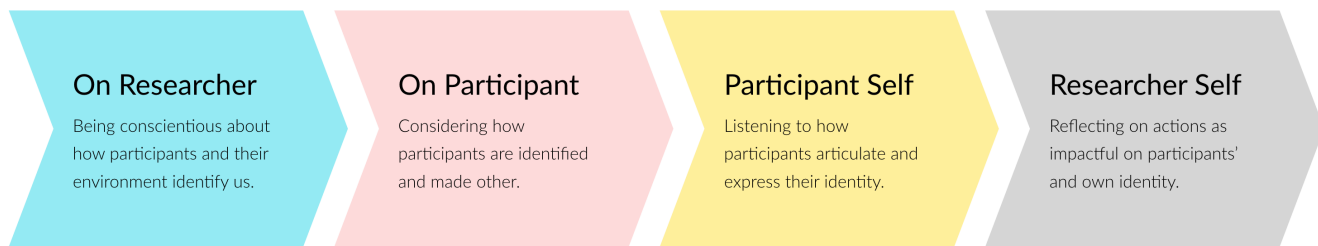


Figure 4: Proposed Reflection Process for Identity in Participatory Design

transition (bringing prototypical material that is more impermanent) and attention to children’s needs (a type of pen is particularly suitable to the age group). These characteristics are part of a more substantial, more coherent identity of the child, which had been identified as autistic, identifies himself as an inventor and interacts with a researcher who self-identifies as a careful, reflective practitioner [50]. Similarly, in the Accessimap project, focusing on audio experiences was crucial to suggest other ways of social sharing of personal representations. Further research would be needed on this topic. We recommend that first steps in that direction could further investigate the roles of materials used and artefacts co-constructed in PD particularly with a focus to their contribution to identity construction for all participants. Such a process require reflexivity from all parties involved and ways to support it.

6.3 Communities and Standpoints

A difficulty encountered in all case studies is how the identity work enable by PD, especially with children, requires careful considerations of entities external to the design process itself. Broadening the perspective, from queerness and disability to communities in general, the case studies illustrate the diversity of community affiliations to take into account and the conflicts arising between them.

Our case studies confirmed the definition of communities we had started from while researching this topic: the groups in which an individual evolve, either by choice or because of spatial arrangements [43]. Due to their material dependence on their parents and kin, children share their community, but may belong to others (e.g., school, clubs). It also includes the researcher’s personal and professional affiliations. In the case studies, communities children’s family belong to, and researchers’ chosen communities play a large role.

Case-study 4.3 shows that researchers might come to embody a queer way of doing gender and be explicitly sought out because of that. More broadly, researchers can represent communities, and ways of being and doing children find desirable. They can, however, find themselves in a situation where this puts a child in a potentially problematic position in their other communities. This clearly questions the extent to which participatory design can be transformative for individual minors.

It further confirms the methodological approach proposed to understand identities in Participatory Design. We examined the ascription of communities to participants in the framing of the

research and complemented this by a study of barriers, frictions, or discursive differences. It revealed conflicts between the framing and the participants’ self-identity, as well as between identity possibilities of researchers and those of the children at the time of the research. Moreover, tying identities to communities enables to consider identities as not only individual but also social and relational, from the start.

6.4 Structure for Reflecting on Identity

In our analysis, we had already divided the perspectives of cases so that we distinguished between participants’ and researchers’ positions. Given the interwoven construction of identity as simultaneously individual and in connection to others, participants and researchers both shape their identities themselves and are identified externally by others and each other. Hence, we then further distinguish between an inside and an outside perspective when it comes to reflecting on identity in participatory design.

We suggest that researchers and practitioners could more systematically reflect on four standpoints relevant to identity in participatory design processes. Our suggestion is to follow four different steps to somewhat disentangling these dimensions while acknowledging that any separation between these perspectives is necessarily artificial and leads to an incomplete picture. The order of the steps is chosen to switch between different viewpoints finishing with a self-reflection on researchers’ identity as this comprises an on-going process researchers cannot take themselves out of.

- (1) *On Researcher* – Requires us to deliberately distance us from ourselves and let participants speak about how they identify us. This can be facilitated explicitly or implicitly but requires attuning to the participant and the attempt to not try and challenge their position. Researchers can use the opportunity to learn about how others identify them, which can guide future interactions. For example, in settings where researchers are assumed to have authority, they might implement playful parts into the design sessions to mitigate this effect. Researchers with marginalised identities already do this implicitly to figure out how open they can be with disclosing these aspects of their identity, as we illustrated for gender and disability above.
- (2) *On Participant* – Requires us to explicitly point out how we identified participants and which aspects of their identity we might have ignored through that. Journaling can offer a useful outlet to reflect on this axis of identity. As a practice, it

allows us to make explicit our assumptions and then enables us to test them against our observation through other forms of data. It also provides a basis from which to enter the next step without conflating the two too much.

- (3) *Participant Self* – Requires us to be humble about our assumptions and attuning ourselves to how participants articulate their own identity. We suggest to make this explicit, but again, this might also be the result of a post-hoc data analysis through an identity lens as we have done here. Having the presumptions of researchers as articulated through their perspective made explicit beforehand allows (at least potentially) the disentanglement of these positions.
- (4) *Researcher Self* – Requires us to revisit our actions within the process and how they tie into our own understanding of ourselves. This can be seen as a continuous process that is constantly acted out in-situ and, hence, constantly subject to reflection-in-action. However, by revisiting the construction of identity on-action and understanding how this might influence the other dimension might aid researchers in further developing how to express themselves in future projects.

Reflecting from these four standpoints in participatory research allows us to ask questions of ourselves and as researchers more explicitly. Understanding identity as a lens means we provide opportunities for ongoing negotiation and bring it into design processes. It also helps us understand why some designs might work better than others. It requires us to relinquish some of the power researchers have by identifying participants and instead be humble about how others conceptualise themselves and active listening towards how participants identify, what is important to them.

7 CONCLUSION

In this paper, we explore how researchers and participants negotiate aspects of their identities during participatory design processes. Our case studies illustrate how identities are brought to the research site, and then tied to activities and materials, revisited, challenged and articulated through active social and material engagement or disengagement. We discuss in particular queer and disabled identities and standpoints in Participatory Design. These are our own, and they are salient, forcing us to be especially reflexive on our impact on design. From there, we propose a broader approach for reflecting on identities in participatory design and call for a larger community effort towards researching and accounting for them.

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