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Micro-Ethics for Participatory Design with Marginalised Children

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ABSTRACT

Marginalised children are uniquely vulnerable within western societies. Conducting participatory design research with them comes with particular ethical challenges, some of which we illustrate in this paper. Through several examples across two different participatory design projects (one with autistic children, another with visually impaired children), we reflect on the often overlooked tensions on the level of micro-ethics. We argue we are often required to rely on multiple moral frames of references. We discuss issues that the immediate interaction between researchers and marginalised children in participatory projects can bring and offer an understanding of how micro-ethics manifest in these collaborations. We contribute to a theoretical exploration of ethical encounters based on empirical grounds, which can guide other researchers in their participatory endeavours.

CCS CONCEPTS

• **Human-centered computing** → **Participatory design**; Accessibility theory, concepts and paradigms; • **Social and professional topics** → *Codes of ethics*;

KEYWORDS

Children; Marginalisation; Participatory Research; Ethics

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1 INTRODUCTION

Involving children in research, particularly in participatory research, comes with specific ethical challenges [30]. Children belonging to marginalised groups, such as disabled children, are particularly vulnerable. Their social context challenges the assumptions of researchers about ethical conduct in unexpected ways [4, 62]. However, there is broad consensus that involving such groups is essential, both regarding processes and outcomes [42]. It avoids

basing the design of technologies on the assumptions of developers and designers about the lived experience of their target group, which, in turn, would further contribute to their overall marginalisation [50]. Consequently, it is critical to establish ethical frameworks and guidelines for such research collaborations, as well as foster a culture of continuous discussion and reflection to improve practices [25].

The majority of guidelines tend to focus on deontology, i.e. anticipatory ethical principles, expressed as preparatory checklists to go through. They may also underline the importance of the researcher's virtue and caring skills (e.g., [25]). However, while conducting activities with marginalised children, researchers are required to make judgements on the spot, which either may have been unforeseeable or may create a contradiction to over-arching ethical principles.

The general approach of ethics guidelines systematically overlooks a multitude of situated judgements. We argue that these judgements, which often remain tacit and implicit, need to be transparently examined. With this paper, we contribute to existing research on the ethics of researchers-participants collaboration in participatory design [50], which so far has rarely focused on marginalised children. First, we illustrate a range of ethical dilemmas we encountered during two different participatory design research projects. We argue that in many occasions ethical guidelines provide inadequate guidance for researchers to act ethically during the actions in-situ. To address this issue, we delineate a space for discussing tacit, situated ethical judgements, both for research and training purposes. In doing so, we expand existing micro-ethical approaches [34] to the area of participatory design with marginalised children.

After reviewing fundamental concepts in ethics and related work in participatory design (PD) with marginalised children, we examine nine examples which illustrate micro-ethics through our case studies, drawn from two different participatory design projects with disabled children. We unpack their motivations, impacts, and weigh alternative decisions we could have taken. We discuss these examples to flesh out a research agenda on micro-ethics for PD with marginalised children and identify central themes of concern. Finally, we articulate an understanding of micro-ethics in the context of PD with the view to speak to practitioners more generally.

2 BACKGROUND

To contextualise our research, we first present key theoretical considerations regarding ethics in research. We then discuss care ethics, the ethical framework used in both research projects. Subsequently, we outline critical aspects of research ethics in participatory design before we go into more detail for the specifics of participatory research with marginalised children.

2.1 Research Ethics

2.1.1 Theory: On normative and applied ethics. Ethics, or moral philosophy, is concerned with the study of what constitutes a good life and, consequently, how we should live [13]. Within this field, *normative research ethics* focus on determining what general laws should be followed in conducting research activities, and *applied ethics* look into how we can think ethically about specific issues. Our research projects combined a set of standard deontological guidelines (e.g., informed consent) with a strong focus on researchers' virtue, and more specifically their ability to *care*. *Care ethics*, which stems from feminist studies, postulate that all beings are interdependent. This approach aims at highlighting the often hidden or under-valued relations of care. It emphasises the inter-relationships that constitute society. Care supposes: (1) being attentive to others' needs, (2) taking responsibility for responding to them, (3) being skilled in providing care, while (4) being mindful of the potential abuses of care and the subjective perspectives of others on the care received [63]. In care ethics, individuals are inclined to care for others.

The balance between interdependence and agency, however, is fragile. Care can pave the way for abuse, both for the care-giver and the care-receiver [7]. If we were to focus only on the needs for care, we might miss occasions to let someone learn to care for oneself. A care-based approach cannot be separated from more general objectives—such as, in the case of participatory design, the aim to support democracy and individual's empowerment [46].

To sum up, diverse moral frameworks are used in research. For the cases presented in this paper, we adopted a mix of deontological and virtue ethics, which is consistent with recommendations for research with children [2, 25] and with the roots of virtue ethics in participatory design [61]. However, institutionalised ethics focus primarily on deontology and our research leads to challenges that we argue should be examined at a micro-level.

2.1.2 Application: Institutional ethical approval. Institutional ethical approval of research, such as by the Internal Review Boards in the United States of America, often focuses on ensuring that deontological rules are respected (autonomy, beneficence, nonmaleficence, and justice). However, these boards are not standardised and come with different requirements at each institution [35]. In both our case studies, there was no institutional ethics approval process which required us to go through a formalised review, leaving the ethically sound conduct of said research in our own hands¹. On the one hand, this can be a risk. On the other, it provides an opportunity for researchers to more carefully reflect on their practices.

¹This remains relatively common in some European contexts to this day, notably France and Austria, where our research was conducted.

2.1.3 Micro-ethics. Our paper belongs to the domain of applied ethics. More specifically, we focus on *micro-ethics*, i.e. the ethics of “what happens in every interaction” between individuals[34]. Initially developed for health care contexts, it puts the focus on seemingly mundane, yet ethically charged matters: the presentation of food in hospitals, the language used by doctors etc. It is also dialectic: decisions made by the patient also have ethical significance. For Komesaroff Komesaroff, prescriptive ethical principles are ineffective, as they are subject to change in situations they could be applied to: there can only be themes and practical cases. In the field of engineering and computing (or in professional ethics in general), “microethics’ can be seen to include concern with individuals and the internal relations of the engineering profession” [29]. The concept focuses on professional codes of conduct and responsibilities in technical choices, such as being attentive to the risks embedded in a system's design [8], and contrasts this with taking responsibilities for the impact of a technology on society.

PD research is historically concerned with building systems with and for people, towards a fairer society [18]. This is consistent with micro-ethics in engineering. PD researchers also care for providing participants with opportunities to develop their creativity, for encountering others or for developing joint inquiry [61]. Those are forms of professional micro-ethics. A PD researcher would be careful about turn-taking in discussion, for instance, because of these guidelines. We want to propose a micro-ethical approach closer to that of Komesaroff [34]. With this article we focus on *relationships between researchers and marginalised children* as they unfold and create a context for participatory design. We further argue ethics are produced through ‘doing ethics’ or rather making situated judgements that feed back into a larger understanding of what ethical conduct means for a society [38] and for the research community. Focusing on cases of micro-ethical decisions requires researchers to explicitly reflect the values underlying their actions, how they understand participants' values, and the dialectic production of their relationship.

2.2 Ethics in Participatory Design with Marginalised Children

2.2.1 Ethical Principles and Approaches. Historically, participatory design aimed at reinforcing democracy by acknowledging and supporting a diversity of voices [27]. It is often framed as inherently attentive to ethics and caring relationships [61]. Research on ethics in this body of literature take different perspectives around four central questions [50]: Who do we engage as participants? How do we engage with them? How do we represent them²? What can we offer in return? To answer these questions, many approaches co-exist, each at different levels of generality. Some scholars apply ethical theories to participatory design [26]. Others propose frameworks, either anticipatory or updated along the research process [49, 65]. A few have investigated the often implied beneficial effects of participatory design outside of the research project itself (and found them limited) [18]. Further work discusses the researchers themselves, and how their assumptions shape the research process and its outcomes [41].

²We address this specifically for our context in Section 3.1.

More generally, the field of human-computer interaction (HCI) has recognised the limitations of exclusively anticipatory ethics. In a series of workshops at HCI venues, key researchers have argued that the increasingly explorative, contextual and value-driven nature of HCI work requires a more nuanced approach, which they call “situational ethics” [47, 69, 70]. A similar argument is made by Frauenberger et al. who argue the need to complement anticipatory ethics approaches by a reflective design practice that is guided by an individual or collectively negotiated ethos [22]. With reference to Schön’s reflective practitioner [54], they call this “in-action ethics”.

Our work builds on this strand of research, but does so by focusing on situated moral *judgements* made by researchers when working with marginalised children, and on how these influence the research partnership rather than the research outcomes per se. The originality of this paper resides in the micro-scale we use to look at ethics, and the groups we worked with.

2.2.2 The Case of Marginalised Children. Marginalised children come with specific individual circumstances that require careful considerations which become mostly relevant in-situ. Marginalisations can be vastly different. Examples of marginalisations for children include the experience of seeking asylum, being disabled, living in a low-income household, growing up with adoptive or foster parents, being fat or a person of colour. While not an exhaustive list, it illustrates the diversity through which marginalisation can occur – often in more than one aspect [53].

The experiences of marginalised children (or communities in a broader sense) are often overlooked in research and policies. We decided to focus on marginalised children as a way to counterbalance this under-representation [68], which is consistent with the aims of participatory design. However, some scholars have argued that focusing on marginalisation may backfire and essentialise inequalities and that marginalised group may oppose such categorisation [44, 48, 67]. Potentially, it can enable resistance—or reinforce biases against marginalised groups. However, this decision required us to explicitly engage with the specific power differences posed by the research [3].

Even when researchers are trying to establish a relationship with the children that aims at minimising the power differences between them, multiple aspects play into any participatory research which inherently leads to ethical complications. Researchers are older than the children and their statements are given more validity within society. Marginalised children are often not directly heard, and their accounts are continuously interpreted and re-framed. As researchers, we need to be aware of these experienced power differences and how they actively shape our collaboration. Further, we need to be especially careful to monitor who is making which decisions [10].

Especially in longer-term collaborations, the children build up trust towards the researchers. It may result in researchers becoming aware of private and confidential information, which is of less concern the other way around. Hence, careful management of hierarchies and how they might be subverted in the interest of the children becomes paramount (see also, [1]). In particular, we want to emphasise that “children may exploit, appropriate, redirect, contest or refuse participatory techniques” [24]. Such subversive strategies of the children can be identified and then encouraged – especially

with marginalised children as they are often limited in the resistance they can exercise in their daily life.

We now illustrate how we encountered these aspects in two different participatory design research projects with marginalised children.

3 CASE STUDIES

These case studies demonstrate the setting from which our analytic work stems and provide useful examples which illustrate the messy context in which ethical judgements are continuously necessary on multiple levels.

Both participatory design projects were conducted with disabled children. In OutsideTheBox, we co-designed technologies with autistic children, whereas, in MapSense, we collaborated with visually impaired children. The projects were conducted by two different research groups without any cross-collaboration before the writing of this article. While these can be seen as two specific contexts, the discrimination faced by the children were often similar: Both groups of children were met with adversarial attitudes by their peers due to their occasionally quirky behaviour and communication modes. In our work with disabled children, we initially did not put the focus on other forms of marginalisation, such as race³ or gender identity. Through understanding the children as marginalised, we frame disability as a physical difference as well as a social exclusion [45], hence creating a lens through which we position the children together with the agency over their own life. As an essential aspect of both projects, we focused on the enablement [15] of children, through a participatory design process.

3.1 A Note on Language and Representation

How we represent participants in our research is one key question in participatory design ethics [50] and comprises a case of necessary continuous ethical judgement and reflection. One aspect of this question is how we name and categorise them [37]. When talking about marginalised individuals, there are three main ways in which to formulate a reference:

- *identity-first*, also called label-first language, in which the descriptor comes before the larger group, e.g., autistic people
- *person-first*, where the larger group comes before the descriptor, e.g., people with visual impairments
- a *mix of both*, which occurs when a text mixes both forms to acknowledge both versions

Person-first language had been established within a social model of disability to counteract label-first language which was then deemed to be rooted in a medical model [43]. The argument is that by referencing the person before their disability-related descriptor, the person would come into the foreground and the disability would become secondary [9]. Louis [36] showed that this hope for a positive change about perspectives on disabilities appears to be unfounded. According to their research, “person-first terminology d[oes] little to lessen negative beliefs and attitudes”. Sinclair [55], an autistic self-advocate, goes even further and ridicules person-first language. Their three arguments against using person-first language come down to these:

³Just to be entirely clear: We adhere to a concept of race as a powerful *social* construct [72].

- the language detaches the person from their condition as if it would be an additional part and not essential to their identity and being;
- it furthermore plays down the pervasive effects of the condition
- and, lastly, by separating the condition from the person, it becomes something negative, seeing that positive labels such as 'beautiful' or 'smart' are not phrased in a way that detaches them from the person they describe

Additionally, Kenny et al. [33] established that identity-first language is endorsed more by autistic individuals and their social environment (albeit not in a majority) whereas professionals prefer to use person-first language. Similarly, there is an active discussion within the field of Psychology on which type of language is deemed more appropriate to use, with strong proponents for identity-first language [16]. However, when talking about a specific child we collaborated with, we acknowledge the preferences that were given to us by the child or their social environment to honour their agency on the matter.

In a similar notion, we use 'allistic person' to refer to a non-autistic person. This term, as coined by Main [39], stems from the greek *άλλος* meaning 'other' and, hence, references the opposite of *αυτός* meaning 'self'. Similarly, we use the adjective 'sighted' for people who are not visually impaired.

3.2 OutsideTheBox

In OutsideTheBox, we co-designed technologies with autistic children. Each design process was conducted with an individual child to create a unique object which would support the well-being of that particular child instead of trying to make wider claims on intervention across the population of autistic children. In total, we had eight case studies over the span of three years. In each case, two adult researchers met with one (or, as partly in one case, two) children every other week resulting in a total of ten to 20 different meetings with each child. We discuss unique issues we encountered that allow us to illustrate a range of ethical judgements we had to make during the participatory design processes. We are deliberately not reporting on the design processes [21, 40], the outcomes of the process [23, 59] or our reflection and evaluation within the project [20, 57, 58, 60], but rather concentrate on the situated ethical constraints of each collaboration.

Autism is diagnosed along a triad of characteristics [6]. Autistic people experience difficulties with neurotypical modes of communication, interaction and imagination. Their behaviour is often classified as restricted, repetitive or stereotyped. We follow an understanding of autism as a variation of a neurodiverse spectrum [56].

While the institution in which OutsideTheBox was carried out, does not require any formal ethics approval, we were guided by a collective ethos that was partly articulated, partly implied in our working culture. We recorded this in an extensive document which acknowledged potential issues and benefits for parents, teachers, children and researchers as well as strategies to resolve tensions between stakeholders. The formalised ethics in these documents framed the research activities, but there was also a necessity for ethical judgements emerging in-situ and for which the consequences

were not always clear. These are the types of ethical encounters, we describe.

3.2.1 Enabling Experiences. During our first meeting with one of the children, he was eight years old. His use of language was somewhat idiosyncratic and required knowledge of context and interpretation which meant that we as outside researchers had to tread carefully to not override his goals and agency. The child was initially a little reluctant to work with us, but warmed up when we explained that our activities would revolve around drawing and playing. He seemed to enjoy these activities and indicated looking forward to our next meeting.

At the start of the second meeting, we set up the session in the design room, when suddenly the classroom door opened and the child stood there. When he saw us, he yelled: "NO!" and slammed the door shut. His teacher came back and informed us that it might be difficult to conduct a session with him as he had indicated all day that he was not looking forward to the meeting. Five minutes later, she pushed him into the design room. He sat down, but covered his eyes and refused to interact with us. However, the teacher urged us to start the session regardless. Here, we trusted the teacher's judgement to engage with the child against his stated desires.

What made him eventually warm up to us, was a video camera we had installed in a corner of the room. Once he investigated it, he happily collaborated in all other tasks for this session. We finished by giving him a single-use photo camera with which he could capture things he found interesting until our next meeting. He was quite excited about the flash functionality and indicated pride when his classmates admired him for having it.

At the start of every further meeting, he played hiding games and initially refused to work with us. It became part of a ritual where we had to rebuild the trust to work with us anew every single time. To some extent, this behaviour bothered us, but since he enthusiastically reported to his teacher after every session how fantastic it was to design with us, we continued our work with him.

In this collaboration, we had to actively and consciously override the child's expressed desires at the start of almost every session. While we did so in agreement with his carers, we also went against one of our core ethical guidelines, which dictated that our processes were supposed to be child-led and that the collaboration could be ended at any point by any involved parties. We did so because we weighed the initial refusal against the positive experiences the participatory design processes could offer and which he continued to praise after the fact. However, it could have been, that at some point he would not have regarded a session as a positive experience in which case, our judgement may have caused more harm than good. Trusting the teacher's judgement and overriding our own virtue ethics eventually led to a positive outcome for the child, the researchers and the participatory design process more generally. However, at each point of engagement, we could not have foreseen the consequences, which shows how risky these necessary judgements can be.

3.2.2 Child Context. While in all other cases, the collaboration between researchers and children was initiated by schools or mentors, in one particular instance, a parent had heard of the project and wanted their eight-year-old son to participate. In this case, we

had closer parental involvement than in others. In the first meeting with said parent, they informed us about the preferences and dislikes of their son and also mentioned that they were not only seeing themselves as a parent but also as an Applied Behavioural Analysis (ABA) therapist for their child. They also implied that they expected us to follow the structural approach of ABA. However, after close inspection of the principles of this kind of therapy, we felt uncomfortable adhering to it. Seeing that ABA requires the child, to be under a near-constant therapeutic setting ('intense' treatments expect 36 hours of therapy per week [19]), we wondered when the children were allowed to follow their interests and be self-guided. We do not intend to go into the details of the controversies surrounding the approach [14] but want to illustrate our critical stance towards it. Still, we continued our collaboration with the child as we saw an opportunity to create spaces for self-guided interests through participatory design.

Especially at the beginning of our collaboration, we noticed that the child was quite shy and more trying to find a 'correct' answer to a task than expressing himself through it. This behaviour is of limited usefulness when engaging with children in design. It took us four sessions until he started opening up to play activities through which he was able to express ideas and concepts.

When we enquired about the frequency of use of the final object he created, the parent informed us that they used it during ABA and that the child was not playing with the artefact in a self-driven fashion. By connecting the technology to therapeutic activities within the home environment, the child refrained from using it in the playful modes of interaction we had established between us during the design sessions. However, when he was with us, he happily shared his experiences and wanted to engage with us over and with the object. Unfortunately, the object use eventually remained solely within a therapeutic context.

Through our rejection of the dominant therapeutic model, we ended up ignoring a core part of the child's context and what it meant for the further use of an object once the participatory design cooperation ended. We were not well prepared for a shift in use that would be initiated by his parent and failed to negotiate our values with those coming from the child's context in a productive way. Hence, we might have missed an opportunity for empowerment.

3.2.3 Bodies in Research. In several of our collaborations, the physicality of our bodies mattered. Children sat in our laps or climbed on us during design workshops, disregarding whether researchers felt comfortable with this interaction or not. However, as long as bodies were used playfully, we were able to establish and negotiate boundaries through play. In one case, though, our physical bodies mattered as signifiers of hierarchy and dominance.

When working with two brothers (five and seven years old), we did not meet them in an established school environment, but rather in a section of their parents' workplace. Hence, the physical space was much more known to the two of them than to us, and that power structures were challenged more strongly than when we had worked with the older one alone at his school. While we encourage these subversive strategies on most occasions, the exploration of social boundaries led to situations in which the researchers could not foresee potential consequences and occasionally even had to fear for the children's physical safety, for example, when they started

throwing objects in a room with cardboard boxes full of glasses. However, intervening meant here – due to the architecture of the space –, using the larger, stronger body of the researcher to pick up the child and physically move them out of the zone of potential danger.

Ultimately, both children seemed to appreciate us as design partners and liked engaging with us, even though we had to assert a more hierarchical position and sometimes manifest it through bodily interactions to keep them safe. Using our bodies to assert dominance in situations where children could be harmed or cause damage to their surroundings was uncomfortable. Our general ethical framing had the value that the children should not be exposed to harm, but using one's body as a tool for setting the children out of potentially dangerous situations also meant counteracting against a child-led process and making power dynamics we tried to tear down in our interactions all the more visible. We deem our judgement of the situation appropriate, but it led to broader ethical implications about the nature of our collaboration with the children than apparent in the moment of execution.

3.2.4 Leaving the Field. Another nine-year-old child we started working with had just recently been diagnosed. She and her parent were still figuring out what the diagnosis meant to them and others. Since one of the researchers had an autistic family member, the parent bonded quickly with them and asked for support and strategies she could try out with her daughter. They also sought out advice when the family experienced hardships that were unrelated to our collaboration with the child.

Due to this closeness we were even invited into the family home. Although we realised that this was different from most other collaborations, we judged this as appropriate within the relationship we had established with the child. Within the home environment, we witnessed complex family dynamics with other members. Afterwards, we decided to more actively push an agenda of empowerment not only with the child but also with her parent. Including the child's social environment made the relationship even more personal than in other collaborations.

We understood the process of ending our relationships as 'transitional', in which the needs of multiple stakeholders (parents, children, researchers) are negotiated [11]. We had been such an essential part of their lives that we felt an abrupt ending would be uncalled for. Our strategy was then to phase out the contact slowly by having longer intervals between meetings after our primary design and evaluation processes had ended. In those meetings, we discussed aspects of the child's life, designed little tokens or reviewed our work – with longer and longer time spans in between.

When designing for the life worlds of marginalised children, researchers cannot avoid becoming part of that life world. We had to negotiate our professionalism with how close we grew with this family. It then became a question not only of which roles we can expect to fill ourselves but also on how we could end our collaboration with the child respectful of everyone's needs. We had to act carefully and deliberately not to abuse the trust that was put in us as researchers and designers, but also as individuals.

3.2.5 Intersections. Within OutsideTheBox, the child participants were often marginalised in more than one aspect of their lives. For example, several children were not raised by parents of

the same nationality of the country they resided in, and two children expressed complex issues around their gender identities. For one of the children, the family context had stringent boundaries and expectations when it came to gender preferences and behaviour. In this context, we had to mindfully weigh acknowledging a child's desires with the consequences they might face in their immediate environment for expressing them.

In the other case, the child's parents actively sought our advice on how to identify and handle trans identities. Since one of the researchers in the project is non-binary themselves, they had to pay close attention to not bring their agenda into the research, effectively over-interpreting the child's stated desires. Hence, they consciously did not address any related topics themselves and only reacted to the child if they brought something up (such as the fixation on pink and purple colours in the case of one child which has been assigned male at birth). Even though these marginalisations were not in the focus of our research with the children, it was important to be aware of them and acknowledge them as relevant for productive design partnerships.

Being aware of further aspects of marginalisation in a child's life could allow co-designers to develop more relevant technology for the children. However, if researchers share a marginalisation, they might be putting too much focus on it. To counter this risk, we shied away from discussing overlapping marginalisations with the children without their explicit input. However, without positive (or in some cases even just any) role models, children might not find ways to express themselves productively in their identity (as has been shown, for example, for boys in primary schools with predominantly female-presenting teaching staff [5]). In choosing to refrain from not bringing up specific topics, we reduced the children again to the marginalisation focused on by the research context (in this case the disabilities) even though we aimed at designing for their holistic life worlds.

3.3 MapSense

In MapSense, we co-designed technologies with visually impaired children (some of them living with additional impairments) and their teachers or therapists (e.g., orientation and mobility therapists). The purpose was to explore how to design technologies for more enjoyable experiences in the classroom for children in primary and secondary school while supporting adults' educational goals. Often, these youngsters had framed the classroom as an adversarial space in initial interviews. Rather than aiming at validating the usability or educational gains of the prototypes, we aimed at studying how a design process might modify the relationships between children and teachers, and provide design inspiration to others. During this two-year ethnographic study conducted in an organisation providing all required services to this population (educational support, rehabilitation etc.), we designed more than ten different probes and prototypes, used by 15 children.

As with OutsideTheBox, we focus here on specific ethical issues that arose during that process. At the time we began MapSense, our institution did not have an ethics committee or formalised procedures for participatory research projects. We thus developed our own approach, building on the UNICEF's guidelines for ethics in research with children [25], and the literature on care ethics in action

research [71]. Furthermore, we kept a detailed auto-ethnographic diary to reflect continuously on our difficulties (similarly to [41]). While we had conducted a substantial literature review for structural, ethical issues (e.g., how to handle differentials of power between adults and children participants), there were situations that required rapid ethical decisions with unclear consequences at the time.

3.3.1 Preserving the relationship with adult gatekeepers. Though we were very engaged in trying not to constrain the children, this was not the case for the established adults taking care of them (hereby named "carers"). For instance, a carer wanted to observe a child manipulating a probe (a 3D printed tactile globe). While the researcher was interested in the child's comments and critiques, asking only questions for clarification, the carer wanted to transform this activity into a formal learning task. She started asking more restrictive questions or making comments such as "no, you're wrong". To not compromise our collaboration with the carers, which was fundamental for collaborating with the children, we retreated from the interaction by slightly moving away and remaining silent. After a few minutes, the child stopped answering and turned away. Such withdrawal from interaction happened at other times as well: when we tried to help a child regulating their emotions, his teacher intervened and told the child to cry somewhere else. In another case, a carer wanted a teenager to demonstrate how to use newly adapted computer software but the teenager refused.

In other words, there were apparent differences between our approach and that of the carers. In these interactions, we had to balance two issues of trust: maintaining the trust of the child, which had taken time to build *and* maintaining the trust of the carers to be able to work further with children (which in the carers' views includes "*enforcing discipline*", and "*making children do what they're supposed to do*"). Additionally, we had to preserve the conditions for the participatory design research. For instance, we did not want to give a child the impression that there were right or wrong answers in the design process.

However, withdrawing from interaction also meant that we did not directly engage carers on the subject of educational norms, even though this might have been beneficial for the children as well as the carers. Furthermore, we let children go through an apparently distressing experience without intervention from our side, which affects the level of trust in the researcher.

3.3.2 Demonstrations of affection. Similar to OutsideTheBox, one issue, arising mainly when working with younger children, or children with multiple impairments, was the physical contact initiated by them. Such interactions involved hugging, haptically exploring the body of the researcher (which can be part of how visually impaired children get to know and engage with people), and activities such as dancing. We did not refuse any of the contacts initiated by the children, as we considered this a form of relationship building. We also found that these activities were an essential part of the development of trust. However, we sometimes felt uncomfortable, were unsure of how children understood our relationship, and how we could manage it. To protect both, children and researchers, there were always at least two or three adult researchers present.

At stake was the interchange of care: whereas it is accepted for researchers to care for children, it feels somewhat dangerous to

take care of children given the fact that researchers' presence is very temporary. Furthermore, discussing their expectations was difficult, as this was not something they were used to do. Additionally, children would sometimes forget about previous meetings, while at other times they would not. Judging the appropriateness of this form of engagement and its consequences was thus difficult to foresee, which also raises the question of how we develop rapport with participants, who do not have a shared mode in which to manage and reflect on social relationships as we do as adults, trained to interact with children.

Our strategy was to adopt a transparent mode of communication, based on the acknowledgement of the exchanges with them and the duration of the study. We informed them every time when we would come back and when we would ultimately leave and re-assured them that the probes and prototypes would stay with them. Indeed, these were framed as gifts, or proofs of interest and affection by the children. However, the adequate distance in our research relationships with the children remains an open question. Additionally, it is unclear to what extent we can ask researchers to actively become comfortable with physical interactions with children.

3.3.3 Confidentiality. In a different instance, during a research interview, a 17-year-old male-presenting teenager asked questions about the romantic life of the (25-year-old) field researcher. When she indicated that such questions were inappropriate, he propositioned her using further inappropriate language. This particular teenager had been described to us as "deviant" by the organisation staff.

Following this, the researcher reminded him that he was a minor and that she was acting in a formalised working setting, which made this interaction inappropriate on two grounds. She also explained that declining to answer his first questions marked the refusal of such interactions, a refusal that should be respected in this and other contexts. She encouraged him to ask questions about romantic relationships to an adult he knew and trusted and informed him of an official website, which provides sex education resources and contacts with educators and social workers to teenagers. He replied that this was just something he often attempted with young (female) adults he met. The researcher immediately stopped the interview after this. She then purposefully decreased the frequency of interactions with this teenager. The incident remained isolated.

In our opinion, there are three ethical issues at stake here. First, the field researcher was not formally trained or authorised to discuss these topics with a teenager. A professional carer could have had a better strategy to handle this situation. Second, not every family agrees with teenagers receiving sex education. Even though the resources provided were designed by a governmental agency, making this call can be opposed by other carers. Third, we found this behaviour worrisome: the reasons behind it were unclear, and if repeated, the student would have gotten into trouble, especially as he would soon after legally be considered an adult. But we also guaranteed him that everything he said during the research process was confidential. Because this did not happen again, we provided him with resources he could consult and, not wishing to fuel discourses labeling him as deviant; we did not report the incident. We

judged this to not fall into the "minor in danger" category, which we would have a legal obligation to report.

3.3.4 Being "other-gendered". In research with marginalised children, how researchers present themselves and their research to the social environment of the children becomes a concern. An example from MapSense is about the physicality of the field researcher's body. Because the field researcher did not fit gender norms (traditionally female first-name, short hair, traditionally male clothing, deep voice, taller than most women etc.), children would use one or the other pronoun during the interaction. They also sometimes asked why the researcher was different, to which we answered that everyone could wear any clothes and have any haircut. We note that the pronouns used depended on the context, and in particular, on the on-going activity. Reading was associated with 'she', while cycling was associated with 'he'. In design activities, the children used both pronouns. In some occasions, children were told by their carers that they were wrong to use 'he' to identify the researcher. Teenagers, on the other hand, insisted on knowing which gender to attribute. As the researchers were often ascribed to different genders (e.g., male, female, non-binary) across multiple contexts, they did not take issue with this.

However, this still posed several problems. The first was that we were unsure about parents' reactions if they were to learn about this. Indeed, there has been a renewed anti-LGBT movement in France during the last few years⁴, which opposed discussing, or even mentioning gender issues in schools. Would they have agreed to their children participating in the research if they had known the researcher was gender nonconforming from the start? The second is that no one should be discriminated against based on their gender expression and, thus, be barred from conducting participatory research with children. On the other hand, parents are entitled to protect their children from whatever they see as a danger. Third, if children were to ask questions to their parents about gender expression because of this, it could have negative effects for them.

Yet, providing a positive identification model to children seems in line with our stance on care ethics. We decided not to discuss gender explicitly with the children, even when they actively enquired. This also means that those who may have needed someone to talk to were not encouraged to do so. Not engaging in such discussion was the most straightforward choice for the research itself, and we hoped that this approach would reduce the perceived importance of gender in social interactions.

4 DISCUSSION

Across the individual case studies, we identified several reoccurring challenges, but our judgements differed according to context and needs. In our discussion, we highlight the consequences of these different judgements which builds the starting point for an understanding of micro-ethics in participatory design with marginalised children.

4.1 Negotiating Multiple Agendas

While carers play a role in any work with children, in research with marginalised children the carers' presence is even more prominent.

⁴hrw.org/news/2017/05/17/struggle-lgbt-rights-france

As social workers, medical personnel, specialised teachers, therapists or family members, they set the frame and structure of the children's life. In our case studies, carers framed the research in unexpected ways. Our strategies in negotiating with carers were manifold, all of them with unforeseeable consequences at the point where they had to be enacted.

- We withdrew ourselves when a co-researcher or other adult acted contrary to our judgement and only discussed our concerns afterwards. While this meant that children were potentially exposed to negative experiences, this approach seemed more effective in a setting where we would not threaten a carer's authority as a by-product. As the carers were gatekeepers to the participatory research, we had to partly adhere to their desires as well. This aspect of participatory research with marginalised children inherently complicates virtue ethics proclaiming child-led processes.
- We established alternative approaches to working with the children. In part, this meant excluding or ignoring parts of their context during the design process for the benefit of opening up new spaces in which empowerment and design activities were possible. Together with the withdrawing strategy, however, this potential space becomes fleeting and insecure as it can only happen through precariously balancing the values of carers and researchers alike.
- We carefully navigated the influence of different carers and mediated on topics where there were already existing tensions between carers and children. This strategy had several sub-strategies where we would either not bring up a controversial issue (or change the topic with reference to external sources) or talk about it in a normalising way to everyone involved. Which one of these sub-strategies was adequate changed according to the context of the situation in which it occurred, as can be seen in how they were differently applied within and between the projects.

These strategies show that even in participatory design research in which we attempt child-led processes, carers play a relevant role in creating the circumstances for our research. As such, their tangential role in participatory processes might be under-conceptualised. In our cases, their presence made us carefully prioritise certain topics over others, which meant they had circumstantial influence on the participatory design work and its outcomes. Hence, an analysis of Carer-Children-Researcher relationships through an ethical lens can increase an understanding of how our processes are shaped and which strategies exist in including carers more transparently. That way, caring strategies in research can be negotiated explicitly – appropriate to the level of involvement in the research activities –, which might resolve potential tensions beforehand.

4.2 Being at Risk

When working with marginalised children, risks become at the same time more explicit *and* more implicit. We have to take care of the marginalised children and ensure that we are not exposing them to harm, but we are also vulnerable ourselves. Our comfort zones are continuously challenged. When children are invited to long-term research collaborations needed for participatory design with disabled children, they are also enabled to build complex personal

relationships with researchers (including, for instance, demonstrations of affection). On the one hand, this might allow them to make new experiences and widen their horizons, on the other, the more personal relationships get, the more vulnerable the children and the researchers themselves become.

How to appropriately balance professional conduct and personal relationships is a matter that can only be practically engaged with during the research activities; anticipatory deliberations remain theoretical and speculative (see also [38]). In the case where a participant displayed inappropriate conduct during a research activity, we had to weigh the risk of the child being impacted disproportionately in the future, the risk of the researcher who was unsure how to appropriately handle the situation and who was in a position of liability, and the adherence to the confidentiality of the meeting which has been ensured to participants before they engaged in the research.

Hence, participatory design projects not only pose potential risks to children but also to researchers. These risks are not always physical, but might also affect mental health, the career of people involved, or the development of the children. While researchers might not ever be able to eliminate or foresee all risks, it helps to be aware of them and consider which choices might lead to which potential outcomes and the attached risks for researchers and children or other stakeholders in the participatory processes alike. As a core point of care ethics, all participants in the research – researchers as well as marginalised children – are vulnerable and 'at-risk' when they cooperate [63]. It is, ultimately, a matter of our own judgement to limit the risks for people, in a context where the most appropriate procedure is not necessarily clear-cut.

4.3 On being Care-ful

In both our projects, we envisioned the processes as child-led. We understood the children as design partners with equal rights who were not only shaping but leading the design. In practice, however, we had to carefully negotiate with the children about their level of participation. In the most extreme case (see Section 3.2.1), we were initially timid and unsure about how to proceed but over time became more confident in our judgement. We convinced the child to engage with us since they continuously expressed positive experiences after sessions with us. We negotiated different needs: the desire of the child for sameness (which is not fulfilled in progressive participatory design sessions) and the opportunity to make new experiences, expand knowledge and find new ways for self-expression.

Another aspect of caring for the children required us to be mindful of the responsibility put on us as researchers not only by the adult environment of marginalised children but ultimately also by the children themselves. They trusted us to keep them safe. Such trust is fundamental for a productive participatory research relationship. At the same time, we created a space in which they should also feel free to express themselves in creative ways and explore the boundaries of what they know – which includes rules. As researchers, we tried to engage with the children at eye-level in a relationship of equal partners. However, situations can occur (like the one where children were about to smash glass) where

researchers need to assert authority to keep everyone safe. In negotiating different needs of marginalised children, the design process and the researchers themselves, we need to find a balance between rejecting and embracing responsibility, between equal partnership and care.

4.4 Acknowledging Personal Context

Our work with marginalised children gave us additional insights into the importance of positioning ourselves transparently as researchers towards the children and their social environment. Professional and personal aspects of ourselves played into the participatory design research. For example, in both case studies, a queer researcher was involved, which led them to be wary of over-interpreting any related issues regarding gender identity or expression – even though there is tentative evidence for this being more prevalent at least with autistic people [32, 51]. However, researchers’ gender expressions (be they traditionally binary or nonconforming) shape participatory research in often unforeseen ways [66]. We judged that it was best to shy away from discussing these issues pro-actively with the children despite the fact they inquired in different ways about them, given the risks we would face if we were identified as activists. Through that, we implicitly adopted a (hetero-)normative discourse, despite personally experiencing it as repressive. This normative discourse builds upon a strictly binary concept of gender and does not enable alternative gender expressions (especially not in French or German).

Another personal aspect we encountered across both case studies was how it mattered who embodied the research. Different bodies invite different modes of interaction. Children engaged with the uncommon bodies of both researchers (other-gendered, fat or with an unconventional hairstyle) in curious, playful and exploratory ways. Through the comparatively long collaborations, the engagement with the children built closer relationships. However, researchers were also forced to use their bodies to exert dominance in situations of potential harm. Hence, researchers’ bodies can play ambivalent roles in participatory research with marginalised children: friendly and engaging, but yet with the potential to set firm boundaries.

5 MICRO-ETHICS FOR PARTICIPATORY DESIGN WITH MARGINALISED CHILDREN

While checklists [49] and rolling ethics approaches [22] have discussed the ethical framing of research more generally, little attention has been paid to the concrete situations in which ethical choices arise and researchers have to make in-the-moment judgements, nor to how it affects the relationships between all research participants. We argued it is necessary to reflect on *micro-ethics* and their interaction with other ethical principles (e.g., pre-established research conditions or guidelines). These micro-ethical judgements cannot always be foreseen. They may not seem immediately relevant but offer rich insights into the participatory design process – as illustrated by our case studies. Hence, it becomes all the more important to be reflective practitioners [54] during [38] participatory research engagements. The themes above provide starting points for reflection. We now propose an understanding of micro-ethics for participatory design research with marginalised children and offer a few suggestions on how to actualise them in-situ.

5.1 Micro-Ethics as a Lens

While virtue and care ethics provided an overall frame to our research that helped orient our actions, actualising them in research relationships is not always straightforward. Micro-ethics provide a lens to look into the seemingly mundane everyday activities that contribute to ethical conduct on a larger scale [34]. When interacting with marginalised children in participatory design research, the necessary in-situ judgements might appear contradictory to the broader ethical goals and create tensions with these in their actualisation.

Ethical Principles	Strategies in Micro-Ethics
full context of children	navigation of carers priorisation of topics
do no harm	complex risk assessment making judgements
child-led PD	negotiation of needs being responsible
professional conduct	personal relationships commitment to participants embodied research

Table 1: Tensions between ethical principles stemming from virtue ethics and strategies used in micro-ethics

In Table 1 we list the four ethical areas discussed in the previous section, together with the micro-ethical strategies we employed encountering similar situations. It illustrates the space of negotiations between different stakeholders. Taking into account the full context required making contestable prioritisations. Doing no harm can only be evaluated as a dynamic in which potentials and risks have to be carefully considered. Child-led PD requires researchers to negotiate between all participants. Finally, codes of professional conduct – that are considered as micro-ethics in engineering[8, 31] – sometimes prevent forms of commitment beneficial to the researcher and to the children, whereas the personal position researchers bring into the collaboration remains present and influential to the processes and outcomes—which coincides with the micro-ethics considerations in health care[34, 64].

In other words, micro-ethics is an invitation to focus on relationships surrounding PD processes. It requires careful navigation of values that were not initially in focus. For instance, emphasising *child-led* PD might obfuscate our responsibilities as adults to both protect from harm and encourage the kind of risk-taking that offers positive experiences. Or the values we hold and embody, that shape our professional conduct, sometimes need to be revisited or toned down. This is especially relevant in participatory research where close relationships with participants are crucial for the success of the endeavour.

While these tensions are ever-present in participatory design, they often remain under-reported. Within large parts of the literature, they appear to have no impact the outcome. Yet, reporting on the micro-ethical level of research not only aids researchers in reflecting about their work but also provides an opportunity to discuss ethical conduct in participatory design with marginalised children more generally. Instead of ignoring these tensions, we

suggest critically engaging with them to better understand how ethical principles are enacted micro-ethically and in-situ and how they affect participatory design as a discipline and practice.

5.2 Practical suggestions

For future work, we suggest actively identifying ethically charged situations after each encounter with participants, determining the choices and the judgements made and then reflecting on them with others. Regarding who these 'others' are, we further recommend that it might be useful to discuss them with people who are not directly involved in the research since shared assumptions within a group might hinder the identification and explicit discussion of some of these choices.

It is also essential to negotiate between what the children can do and the desires they have. With marginalised children, researchers have to pay close attention to the children's abilities and preferences concerning the high cognitive and sometimes even physical demands that participatory design can require. For example, to avoid overwhelming some children, it might be appropriate to partly include additional children with different characteristics. For example, Ruland et al. conducted participatory design with children with cancer and used groups of children without cancer at some points in the design process to not demand too much from the first group [52]. While this might leave marginalised children out of parts of the design process, which consequently leads to them not having direct influence over those parts, such a procedure might be the appropriate approach in some cases. Agency, participation and what is possible to ask for without 'tyrannising' [12] the children has to be continually conceptualised anew for each research collaboration and, ultimately, each encounter with marginalised children. While this is true for all PD collaborations, we argue that researchers have to be especially careful when aiming for child-led processes with marginalised children as, for example, younger children might not have the same vocabulary or skills to express their ideas and desires as the researchers. This means researchers have to be especially attuned to explicitly making space for the participation of the children on their own terms [60].

The physical presence of all participants – researchers and children alike – additionally play a role in shaping the power distribution in research contexts. Researchers tend to be taller and larger than the children who are participating. They take up more space, even when they lower themselves to the eye-level of the children. Hence, explicitly reflecting on how researchers' bodies shape the interaction with the children can provide a useful lens into how power dynamics play out on a more mundane level.

Researchers could also benefit from adopting a growth mindset attuned to kindness and learning [17]. In the situations in which researchers have to make ethical judgements, they often cannot know or assess beforehand whether a decision was right, correct or even just the best available, particularly given the intricacy of multiple ethical strands in the research. Often, it is our task to *judge when different choices are available*. Without making excuses, we then need to be kind towards ourselves and others, reflect on those choices and discuss them, learn from them and improve our capabilities to make ethically sound judgements in the moment.

6 CONCLUSION

We aimed at shedding light on micro-ethical decisions, how and when they are made, and their potentially far-reaching implications for the research relationships in participatory design. We argue that as a community, we should be aware that such decisions are omnipresent. Though we focus here on participatory design with marginalised children, which comes with specific challenges, we emphasise that most of the examples presented could have occurred with a group of children not belonging to a particularly marginalised group – and, more broadly, in any participatory research. One limitation of this work is that it is based on personal experiences of the key researchers only, instead of emerging from a shared account between researchers, research teams, children participants and their adult gatekeepers.

Future work in this area would benefit from an even deeper theoretical integration to the field of ethics. In particular, we envision exciting parallels with Haraway's recent work on ethics in which she advocates for "*staying with the trouble*", by which she refers to unresolvable ethical concerns [28]. Our work can also be expanded in the field of design education and training, as this for now, and in our own experience, is something that each new researcher needs to figure out along the way, rather than an established topic of interest or training.

We make two main contributions: the first is pragmatic and resides in the empirical grounding of complex judgements during interactions with marginalised children in participatory research as provided by our detailed examples. The second is the articulation of an approach to ethics which combines normative ethics frameworks and situated moral judgements made over the course of the research through the analytic lens of micro-ethics.

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REFERENCES

- [1] Tatek Abebe. 2009. Multiple methods, complex dilemmas: negotiating socio-ethical spaces in participatory research with disadvantaged children. *Children's Geographies* 7, 4 (2009), 451–465. <https://doi.org/10.1080/14733280903234519>
- [2] Priscilla Alderson and Virginia Morrow. 2011. *The ethics of research with children and young people: A practical handbook*. Sage Publications Ltd, Thousand Oaks, CA, USA.
- [3] Alissa Antle. 2017. Crazy Like Us: Design for Vulnerable Populations. In *Proceedings of the 2017 Conference on Interaction Design and Children (IDC '17)*. ACM, New York, NY, USA, 3–4. <https://doi.org/10.1145/3078072.3078074>
- [4] Alissa N. Antle. 2017. The Ethics of Doing Research with Vulnerable Populations. *interactions* 24, 6 (Oct. 2017), 74–77. <https://doi.org/10.1145/3137107>

- [5] Martin Ashley. 2003. Primary School Boys' Identity Formation and the Male Role Model: An exploration of sexual identity and gender identity in the UK through attachment theory. *Sex Education* 3, 3 (2003), 257–270. <https://doi.org/10.1080/1468181032000119131> arXiv:<https://doi.org/10.1080/1468181032000119131>
- [6] American Psychiatric Association. 2000. *DSM-IV-TR*. APA, 1000 Wilson Boulevard, Arlington, VA 22209. <https://doi.org/10.1176/appi.books.9780890420249.dsm-iv-tr> arXiv:<https://doi.org/10.1176/appi.books.9780890420249.dsm-iv-tr>
- [7] Marian Barnes, Tula Brannelly, Lizzie Ward, and Nicki Ward. 2015. *Ethics of care: critical advances in international perspective*. Policy Press, Bristol, UK.
- [8] Peter Bittner and Eva Hornecker. 2005. A Micro-ethical View on Computing Practice. In *Proceedings of the 4th Decennial Conference on Critical Computing: Between Sense and Sensibility (CC '05)*. ACM, New York, NY, USA, 69–78. <https://doi.org/10.1145/1094562.1094571>
- [9] Joan Blaska. 1993. The power of language: Speak and write using "person first." *Perspectives on Disability* (1993), 25–32.
- [10] Tone Bratteteig and Ina Wagner. 2012. Disentangling Power and Decision-making in Participatory Design. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1 (PDC '12)*. ACM, New York, NY, USA, 41–50. <https://doi.org/10.1145/2347635.2347642>
- [11] Jane Coad, Faith Gibson, Maire Horstman, Linda Milnes, Duncan Randall, and Bernie Carter. 2015. Be my guest! Challenges and practical solutions of undertaking interviews with children in the home setting. *Journal of Child Health Care* 19, 4 (2015), 432–443. <https://doi.org/10.1177/1367493514527653> arXiv:<https://doi.org/10.1177/1367493514527653> PMID: 24812062.
- [12] Bill Cooke and Uma Kothari. 2001. *Participation: The new Tyranny?* Zed Books, London, UK.
- [13] John Deigh. 2010. *An Introduction to Ethics*. Cambridge University Press, Cambridge, UK.
- [14] Elizabeth devita raeburn. 2016. Is the Most Common Therapy for Autism Cruel? (2016). <https://www.theatlantic.com/health/archive/2016/08/aba-autism-controversy/495272/?045hpbeaqd3k>
- [15] Lynn Dombrowski, Ellie Harmon, and Sarah Fox. 2016. Social Justice-Oriented Interaction Design: Outlining Key Design Strategies and Commitments. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems (DIS '16)*. ACM, New York, NY, USA, 656–671. <https://doi.org/10.1145/2901790.2901861>
- [16] Dana S Dunn and Erin E Andrews. 2015. Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist* 70, 3 (2015), 255.
- [17] Carol Dweck. 2017. *Mindset: changing the way you think to fulfil your potential*. Hachette UK.
- [18] Pelle Ehn and Richard Badham. 2002. Participatory design and the collective designer. In *Proceedings of the 2002 Participatory Design Conference*. ACM, New York, NY, USA, 1–10.
- [19] Sigmund Eldevik, Richard P. Hastings, J. Carl Hughes, Erik Jahr, Svein Eikeseth, and Scott Cross. 2010. Using Participant Data to Extend the Evidence Base for Intensive Behavioral Intervention for Children With Autism. *American Journal on Intellectual and Developmental Disabilities* 115, 5 (2010), 381–405. <https://doi.org/10.1352/1944-7558-115.5.381> arXiv:<https://doi.org/10.1352/1944-7558-115.5.381> PMID: 20687823.
- [20] Christopher Frauenberger, Julia Makhaeva, and Katharina Spiel. 2016. Designing Smart Objects with Autistic Children: Four Design Exposés. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 130–139. <https://doi.org/10.1145/2858036.2858050>
- [21] Christopher Frauenberger, Julia Makhaeva, and Katharina Spiel. 2017. Blending Methods: Developing Participatory Design Sessions for Autistic Children. In *Proceedings of the 2017 Conference on Interaction Design and Children (IDC '17)*. ACM, New York, NY, USA, 39–49. <https://doi.org/10.1145/3078072.3079727>
- [22] Christopher Frauenberger, Marjo Rauhala, and Geraldine Fitzpatrick. 2016. In-Action Ethics. *Interacting with Computers* 28 (2016), published online first. Issue 6. <https://doi.org/10.1093/iwc/iww024> arXiv:<http://iwc.oxfordjournals.org/content/early/2016/06/20/iwc.iww024.full.pdf+html>
- [23] Christopher Frauenberger, Katharina Spiel, and Julia Makhaeva. 2018. Thinking OutsideTheBox – Designing Smart Things with Autistic Children. *International Journal of Human-Computer Interaction* (2018). Issue accepted for publication.
- [24] Michael Gallagher. 2008. 'Power is not an evil': rethinking power in participatory methods. *Children's Geographies* 6, 2 (2008), 137–150. <https://doi.org/10.1080/14733280801963045>
- [25] Anne Graham, Mary Powell, Nicola Taylor, Donnah Anderson, and Robyn Fitzgerald. 2013. Ethical research involving children – Florence: UNICEF Office of Research–Innocenti. (2013).
- [26] Sandra Burri Gram-Hansen and Thomas Ryberg. 2016. From Participatory Design and Ontological Ethics, Towards an Approach to Constructive Ethics. *SIGCAS Comput. Soc.* 45, 3 (Jan. 2016), 147–153. <https://doi.org/10.1145/2874239.2874260>
- [27] Kim Halskov and Nicolai Brodersen Hansen. 2015. The diversity of participatory design research practice at PDC 2002–2012. *International Journal of Human-Computer Studies* 74 (Feb. 2015), 81–92. <https://doi.org/10.1016/j.ijhcs.2014.09.003>
- [28] Dona J. Haraway. 2016. *Staying with the Trouble: Making Kin in the Chthulucene*. Duke University Press, Durham, NC, USA.
- [29] Joseph R. Herkert. 2005. Ways of thinking about and teaching ethical problem solving: microethics and macroethics in engineering. *Sci Eng Ethics* 11, 3 (July 2005), 373–385.
- [30] Sally Holland, Emma Renold, Nicola J. Ross, and Alexandra Hillman. 2010. Power, agency and participatory agendas: A critical exploration of young people's engagement in participative qualitative research. *Childhood* 17, 3 (2010), 360–375. <https://doi.org/10.1177/0907568210369310>
- [31] Eva Hornecker and Jacob Buur. 2006. Getting a Grip on Tangible Interaction: A Framework on Physical Space and Social Interaction. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06)*. ACM, 437–446. <https://doi.org/10.1145/1124772.1124838>
- [32] Aron Janssen, Howard Huang, and Christina Duncan. 2016. Gender Variance Among Youth with Autism Spectrum Disorders: A Retrospective Chart Review. *Transgender Health* 1, 1 (2016), 63–68. <https://doi.org/10.1089/trgh.2015.0007>
- [33] Lorcan Kenny, Caroline Hattersley, Bonnie Molins, Carole Buckley, Carol Povey, and Elizabeth Pellicano. 2015. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20, 4 (July 2015), 1362361315588200. <https://doi.org/10.1177/1362361315588200>
- [34] Paul A. Komesaroff. 1995. From Bioethics to Microethics: Ethical Debate and Clinical Medicine. In *Troubled Bodies: Critical Perspectives on Postmodernism, Medical Ethics and the Body*, Paul A. Komesaroff (Ed.). Duke University Press, Durham, NC, USA, 62–86.
- [35] Elaine Larson, Tiffany Bratts, Jack Zwanziger, and Patricia Stone. 2004. A Survey of IRB Process in 68 U.S. Hospitals. *Journal of Nursing Scholarship* 36, 3 (2004), 260–264. <https://doi.org/10.1111/j.1547-5069.2004.04047.x>
- [36] Kenneth O. St. Louis. 1999. Person-first labeling and stuttering. *Journal of Fluency Disorders* 24, 1 (1999), 1–24. [https://doi.org/10.1016/S0094-730X\(98\)00024-2](https://doi.org/10.1016/S0094-730X(98)00024-2)
- [37] Scott Lunsford. 2005. Seeking a Rhetoric of the Rhetoric of Dis/Abilities. *Rhetoric Review* 24, 3 (2005), 330–333. <http://www.jstor.org/stable/20176665>
- [38] Richard A Lynch. 2016. *Foucault's critical ethics*. Oxford University Press.
- [39] Andrew Main. 2003. allism: an introduction to a little-known condition. (2003). http://www.fysh.org/~zefram/allism/allism_intro.txt
- [40] Julia Makhaeva, Christopher Frauenberger, and Katharina Spiel. 2016. Creating Creative Spaces for Co-designing with Autistic Children: The Concept of a "Handlungsspielraum". In *Proceedings of the 14th Participatory Design Conference: Full Papers - Volume 1 (PDC '16)*. ACM, New York, NY, USA, 51–60. <https://doi.org/10.1145/2940299.2940306>
- [41] Laura Malinverni and Narcis Pares. 2017. An Autoethnographic Approach to Guide Situated Ethical Decisions in Participatory Design with Teenagers. *Interacting with Computers* 29, 3 (2017), 403–415. <https://doi.org/10.1093/iwc/iww031>
- [42] Jennifer Mankoff, Gillian R. Hayes, and Devva Kasnitz. 2010. Disability studies as a source of critical inquiry for the field of assistive technology. In *Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility (ASSETS '10)*. ACM, Orlando, Florida, USA, 3–10. <https://doi.org/10.1145/1878803.1878807>
- [43] Deborah Marks. 1997. Models of disability. *Disability and Rehabilitation* 19, 3 (1997), 85–91. <https://doi.org/10.3109/09638289709166831> arXiv:<http://dx.doi.org/10.3109/09638289709166831> PMID: 9134350.
- [44] Edward W. Morris. 2016. 'Let Me Know When You Figure Everyone Around Here Out': Placing Gender in the Ethnographic Process. In *Gender Identity and Research Relationships*. Studies in Qualitative Methodology, Vol. 14. Emerald Group Publishing Limited, Bingley, UK, 125–144. <https://doi.org/10.1108/S1042-31922016000014019> DOI: 10.1108/S1042-31922016000014019.
- [45] Jenny Morris. 1991. *Pride against prejudice: transforming attitudes to disability*. New Society Publishers, Gabriola Island, BC, CA.
- [46] Jenny Morris. 2001. Impairment and disability: constructing an ethics of care that promotes human rights. *Hypatia* 16, 4 (2001), 1–16.
- [47] Cosmin Munteanu, Heather Molyneux, Wendy Moncur, Mario Romero, Susan O'Donnell, and John Vines. 2015. Situational Ethics: Re-thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 105–114. <https://doi.org/10.1145/2702123.2702481>
- [48] Kysa Nygren. 2006. Reproducing or challenging power in the questions we ask and the methods we use: A framework for activist research in urban education. *The Urban Review* 38, 1 (2006), 1–26.
- [49] Janet C. Read, Matthew Horton, Gavin Sim, Peggy Gregory, Daniel Fitton, and Brendan Cassidy. 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 (CHI EA '13)*. ACM, New York, NY, USA, 187–192. <https://doi.org/10.1145/2468356.2468391>
- [50] Toni Robertson and Ina Wagner. 2012. Engagement, representation and politics-in-action. In *The Handbook of Participatory Design*. Routledge, London, UK, 64–85.
- [51] Christiane E. S. Rudolph, Andreas Lundin, Jill W. Åhs, Christina Dalman, and Kyriaki Kositidou. 2017. Brief Report: Sexual Orientation in Individuals with Autistic Traits: Population Based Study of 47,000 Adults in Stockholm County.

- Journal of Autism and Developmental Disorders* (30 Oct 2017). <https://doi.org/10.1007/s10803-017-3369-9>
- [52] Cornelia M. Ruland, Justin Starren, and Torun M. Vatne. 2008. Participatory design with children in the development of a support system for patient-centered care in pediatric oncology. *Journal of Biomedical Informatics* 41, 4 (2008), 624–635. <https://doi.org/10.1016/j.jbi.2007.10.004>
- [53] Ari Schlesinger, W. Keith Edwards, and Rebecca E. Grinter. 2017. Intersectional HCI: Engaging Identity Through Gender, Race, and Class. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 5412–5427. <https://doi.org/10.1145/3025453.3025766>
- [54] Donald A Schön. 1987. *Educating the reflective practitioner: Toward a new design for teaching and learning in the professions*. Jossey-Bass, Hoboken, NJ, USA.
- [55] Jim Sinclair. 2013. Why I dislike “person first” Language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* 1, 2 (2013). <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1>
- [56] Judy Singer. 1999. Why can’t you be normal for once in your life? From a problem with no name to the emergence of a new category of difference. *Disability discourse* (1999), 59–70.
- [57] Katharina Spiel, Christopher Frauenberger, and Geraldine Fitzpatrick. 2017. Experiences of autistic children with technologies. *International Journal of Child-Computer Interaction* 11 (2017), 50 – 61. <https://doi.org/10.1016/j.ijcci.2016.10.007> Designing with and for Children with Special Needs.
- [58] Katharina Spiel, Christopher Frauenberger, Eva Hornecker, and Geraldine Fitzpatrick. 2017. When Empathy Is Not Enough: Assessing the Experiences of Autistic Children with Technologies. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 2853–2864. <https://doi.org/10.1145/3025453.3025785>
- [59] Katharina Spiel, Julia Makhaeva, and Christopher Frauenberger. 2016. Embodied Companion Technologies for Autistic Children. In *Proceedings of the TEI '16: Tenth International Conference on Tangible, Embedded, and Embodied Interaction (TEI '16)*. ACM, New York, NY, USA, 245–252. <https://doi.org/10.1145/2839462.2839495>
- [60] Katharina Spiel, Laura Malinverni, Judith Good, and Christopher Frauenberger. 2017. Participatory Evaluation with Autistic Children. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 5755–5766. <https://doi.org/10.1145/3025453.3025851>
- [61] Marc Steen. 2011. Upon opening the black box of participatory design and finding it filled with ethics. In *Proceedings of the Nordic design research conference no 4: Nordes 2011: Making design matter*. 29–31.
- [62] E. Kay M. Tisdall and S Punch. 2012. ‘Not So ‘New’?: Looking Critically at Childhood Studies. *Children’s Geographies* 10, 3 (2012), 249–264. http://www.research.ed.ac.uk/portal/files/5457511/Tisdall_and_Punch_2012_Not_so_new_Children_s_Geographies_10_3_pdf
- [63] Joan C Tronto. 2001. An ethic of care. In *Ethics in community-based elder care*. Springer Publishing Company, New York, NY, USA, 60–8.
- [64] Robert D Truog, Stephen D Brown, David Browning, Edward M Hundert, Elizabeth A Rider, Sigall K Bell, and Elaine C Meyer. 2015. Microethics: the ethics of everyday clinical practice. *Hastings Center Report* 45, 1 (2015), 11–17.
- [65] Maarten Van Mechelen, Gavin Sim, Bieke Zaman, Peggy Gregory, Karin Slegers, and Matthew Horton. 2014. Applying the CHECK Tool to Participatory Design Sessions with Children. In *Proceedings of the 2014 Conference on Interaction Design and Children (IDC '14)*. ACM, New York, NY, USA, 253–256. <https://doi.org/10.1145/2593968.2610465>
- [66] Michael R. Ward (Ed.). 2016. *Gender Identity and Research Relationships*. Studies in Qualitative Methodology, Vol. 14. Emerald Group Publishing Limited, Bingley, UK.
- [67] Nick Watson. 2002. Well, I Know this is Going to Sound Very Strange to You, but I Don’t See Myself as a Disabled Person: Identity and disability. *Disability & Society* 17, 5 (2002), 509–527. <https://doi.org/10.1080/09687590220148496> arXiv:<http://dx.doi.org/10.1080/09687590220148496>
- [68] Nick Watson. 2012. Theorising the Lives of Disabled Children: How Can Disability Theory Help? *Children & Society* 26, 3 (May 2012), 192–202. <https://doi.org/10.1111/j.1099-0860.2012.00432.x>
- [69] Jenny Waycott, Hilary Davis, Anja Thieme, Stacy Branham, John Vines, and Cosmin Munteanu. 2015. Ethical Encounters in HCI: Research in Sensitive Settings. In *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '15)*. ACM, New York, NY, USA, 2369–2372. <https://doi.org/10.1145/2702613.2702655>
- [70] Jenny Waycott, Cosmin Munteanu, Hilary Davis, Anja Thieme, Wendy Moncur, Roisin McNaney, John Vines, and Stacy Branham. 2016. Ethical Encounters in Human-Computer Interaction. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '16)*. ACM, New York, NY, USA, 3387–3394. <https://doi.org/10.1145/2851581.2856498>
- [71] Graham R. Williamson and Sue Prosser. 2002. Action research: politics, ethics and participation. *Journal of Advanced Nursing* 40, 5 (Dec. 2002), 587–593. <https://doi.org/10.1046/j.1365-2648.2002.02416.x>
- [72] George Yancy. 2016. *Black Bodies, White Gazes: The Continuing Significance of Race in America*. Rowman & Littlefield, Lanham, ML, USA.