

Designing for "Positive" Technology Removal? Ethical Considerations for Participatory Approaches with Children and their Care Ecosystem

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Employing participatory approaches with children and their care ecosystem for the design, development, and evaluation of technologies that are meant to be used by them could help mitigate ethical considerations and support their agency by actively involving them. However, beyond ensuring comfort and well-being during participatory sessions, it is crucial to consider the transition phase after prototypes are removed. This position statement reflects on the need for a discussion on how we can design for positive transitions, thus facilitating the removal of a prototype from participants lives. This becomes particularly relevant when conducting longitudinal studies with vulnerable populations, where a technology might be embedded in participants' daily lives for extended periods of time.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI); Participatory design; HCI design and evaluation methods.**

Additional Key Words and Phrases: ethics, participatory design, children, design, neurodivergent, vulnerable, ADHD

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1 INTRODUCTION

Participatory design (PD) is a well-established method to include users and stakeholders in the design process. PD has a long history of involving vulnerable, disadvantaged or marginalised groups in the design processes of technologies. The benefits of PD are well-established, and researchers have successfully involved both neurotypical and neurodivergent children towards meaningful design processes [12]. Previous research has discussed methods to achieve that and to mitigate potential challenges of actively involving (neurodivergent) children in the design process [3, 15]; for instance, involving as many as possible members of a child's care ecosystem (i.e. the people involved in their everyday experiences such as family, peers, teachers, and therapists) [15, 16]. The importance of supporting children's agency in designing future technologies was also highlighted by Sharma et al. [14], who argued for the need for children to become active designers and makers of digital technologies, rather than passive consumers. PD approaches have also been connected to the empowerment of children, with pertinent research in the CCI field highlighting democracy, agency, power, and choice around digital technology in the lives of children [5, 9–11, 13].

Nevertheless, ethical considerations arise when children assume this role of technology designers and makers. In particular, when designing for and with vulnerable populations, the focus of current (ethical) guidelines and considerations usually lies in making them comfortable in the moment, e.g. by offering additional support during the PD [3]. However, the topic of how to ensure long-term comfort and the well-being of study participants, especially children, after the end of a (longitudinal) study when the technology is removed, still requires research. It may even

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53 seem counter-intuitive to, on the one hand, aim to foster children's agency by supporting them becoming technology
54 designers, and on the other hand, to take *their* designs away at the end of a project. Therefore, it seems crucial to discuss
55 and research how to design for a positive technology removal, a positive transition or end process of studies, and how
56 to make sure that the well-being of study participants is considered. In the context of my research work on designing
57 technologies for and with (neurodivergent and neurotypical) children and their care ecosystem that empower them and
58 foster their well-being, this is a particularly crucial aspect that arises. Therefore, this position statement outlines my
59 interest to participate in the workshop "Participatory Approaches to the Ethics of Emerging Technologies for Children"
60 at IDC'23. In the following sections, I elaborate further on my motivation to participate, my previous experience and
61 envisioned contribution, as well as the expected outcomes of participating in this workshop.
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65 2 MOTIVATION TO PARTICIPATE

66 My motivation to participate in this workshop stems from my interest to explore the ethical considerations that arise
67 in relation my PhD research on designing technologies that support both neurotypical and neurodivergent children
68 and their care ecosystem, and in particular engaging in a discussion about potential methods for designing a positive
69 transition phase at the end of user studies, when the technological prototypes have to be removed. In the context
70 of my research, I employ participatory approaches for the design, development, and evaluation of technologies, and
71 am currently implementing a technological prototype based on already conducted co-design sessions. The plan is to
72 evaluate this prototype both in one-day evaluation sessions, as well as to conduct a longitudinal user study to explore
73 the effect of the developed prototype on the well-being of children and their care ecosystem. However, considerations
74 of how to address the end of the longitudinal study, and in particular the end of the technology use, arise. I would
75 therefore be interested to discuss how to design for a transition period, when we "take the technology away" after
76 the end of the study, how this might impact participants, and what we can do to make this transition as smooth as
77 possible, minimising any negative effects that removing the technology might procure. The workshop organisers have
78 conducted significant research within the CCI field and beyond, including research on the concepts of participatory
79 approaches with children (e.g. [4, 6, 7, 17]) and designing for and with neurodivergent children (e.g. [1, 2, 8]), making
80 this workshop an ideal hub to discuss and explore the aforementioned aspects.
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86 3 PREVIOUS EXPERIENCE & ENVISIONED CONTRIBUTION

87 My previous experience includes employment of participatory approaches for the design, development and evaluation
88 of technologies that aim to foster the well-being of children [16]. As part of my PhD research, I have also conducted
89 a systematic literature review of technologies for children with ADHD, proposing that challenges associated with
90 PD could be mitigated by including as many members of the child's care ecosystem as possible, as they could offer
91 additional support [3]. Subsequently, I conducted co-design sessions with neurotypical and neurodivergent children and
92 their therapists, to design together a technology that could promote their well-being and empower them, which was
93 engaging and fun for participants [16]. I envision contributing to the workshop discussions by sharing my experiences
94 on the above topics, as well as raising awareness and suggesting deeper discussions on the topic of how to design for a
95 positive removal of technology when employing participatory approaches with these populations.
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100 4 EXPECTED OUTCOMES

101 Expected outcomes by participating in this workshop include taking part in fruitful discussions about the topics of
102 employing participatory approaches for the design, development, and evaluation of technologies with both neurotypical
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and neurodivergent children and their care ecosystem, and of potential methods for designing a transition phase that would facilitate the removal of a technology from their lives, particularly when conducting longitudinal studies with these vulnerable populations. I also look forward to exciting collaboration opportunities with researchers in the field of CCI and beyond who will be part of the workshop, and to acquiring new perspectives from them. Finally, I expect fruitful discussions on the topic of how to ethically involve children and their care ecosystem in the design of technologies that are meant to be used by them within the community of the workshop.

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REFERENCES

- [1] Meryl Alper. 2013. Making space in the makerspace: Building a mixed-ability maker culture. *Proceedings of the Interaction Design and Children (IDC-13), New York, NY, USA (2013)*, 24–27.
- [2] Meryl Alper, Juan Pablo Hourcade, and Shuli Gilutz. 2012. Interactive technologies for children with special needs. In *Proceedings of the 11th International Conference on Interaction Design and Children*. 363–366.
- [3] Laura Benton, Asimina Vasalou, Rilla Khaled, Hilary Johnson, and Daniel Gooch. 2014. Diversity for design: a framework for involving neurodiverse children in the technology design process. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. 3747–3756.
- [4] Elizabeth Bonsignore, June Ahn, Tamara Clegg, Mona Leigh Guha, Juan Pablo Hourcade, Jason C Yip, and Allison Druin. 2013. Embedding participatory design into designs for learning: An untapped interdisciplinary resource? (2013).
- [5] Christian Dindler, Rachel Smith, and Ole Sejer Iversen. 2020. Computational empowerment: participatory design in education. *CoDesign* 16, 1 (2020), 66–80.
- [6] Betsy DiSalvo, Jason Yip, Elizabeth Bonsignore, and DiSalvo Carl. 2017. Participatory design for learning. In *Participatory design for learning*. Routledge, 3–6.
- [7] Jerry Alan Fails, Mona Leigh Guha, Allison Druin, et al. 2013. Methods and techniques for involving children in the design of new technology for children. *Foundations and Trends® in Human-Computer Interaction* 6, 2 (2013), 85–166.
- [8] Juan Pablo Hourcade, Stacy R Williams, Ellen A Miller, Kelsey E Huebner, and Lucas J Liang. 2013. Evaluation of tablet apps to encourage social interaction in children with autism spectrum disorders. In *Proceedings of the SIGCHI conference on human factors in computing systems*. 3197–3206.
- [9] Netta Iivari and Marianne Kinnula. 2018. Empowering children through design and making: towards protagonist role adoption. In *Proceedings of the 15th Participatory Design Conference: Full Papers-Volume 1*. 1–12.
- [10] Ole Sejer Iversen and Rachel Charlotte Smith. 2012. Scandinavian participatory design: dialogic curation with teenagers. In *Proceedings of the 11th International Conference on Interaction Design and Children*. 106–115.
- [11] Ole Sejer Iversen, Rachel Charlotte Smith, and Christian Dindler. 2017. Child as protagonist: Expanding the role of children in participatory design. In *Proceedings of the 2017 conference on interaction design and children*. 27–37.
- [12] Florence Kristin Lehnert, Jasmin Niess, Carine Lallemand, Panos Markopoulos, Antoine Fischbach, and Vincent Koenig. 2021. Child-computer interaction: From A systematic review towards an integrated understanding of interaction design methods for children. *International Journal of Child-Computer Interaction* (2021), 100398. <https://doi.org/10.1016/j.ijcci.2021.100398>
- [13] Sumita Sharma, Krishnaveni Achary, Marianne Kinnula, Netta Iivari, and Blessin Varkey. 2020. Gathering garbage or going green? shifting social perspectives to empower individuals with special needs. In *Proceedings of the Interaction Design and Children Conference*. 311–322.
- [14] Sumita Sharma, Leena Ventä-Olkkonen, Netta Iivari, Tonja Molin-Juustila, Heidi Hartikainen, Jenni Holappa, and Essi Kinnunen. 2022. Madness to the methods: Speculating approaches to study and nurture children's designer and Maker identities. In *6th FabLearn Europe/MakeEd Conference 2022*. 1–9.
- [15] Evropi Stefanidi, Johannes Schöning, Sebastian S Feger, Paul Marshall, Yvonne Rogers, and Jasmin Niess. 2022. Designing for Care Ecosystems: a Literature Review of Technologies for Children with ADHD. In *Interaction Design and Children*. 13–25.
- [16] Evropi Stefanidi, Johannes Schöning, Yvonne, and Jasmin Niess. 2023. Children with ADHD and their Care Ecosystem: Designing Beyond Symptoms. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (CHI '23)*. <https://doi.org/10.1145/3544548.3581216>
- [17] Svetlana Yarosh and Stephen Matthew Schueller. 2017. "Happiness inventors": informing positive computing technologies through participatory design with children. *Journal of medical Internet research* 19, 1 (2017), e14.