

Designing for Inclusion with Children with ADHD and their Care Ecosystem

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ADHD is the most prevalent mental health diagnosis in children. However, little is understood about how the increasing number of technologies developed actually support them. Coupled with the inherent complexities related to designing for children with mixed abilities, and the number of stakeholders involved in their everyday experiences, the need arises for a deeper understanding of how to design for inclusion for this population. In order to build an understanding of the design space of technologies for children with ADHD, and explore the barriers and opportunities when (co-)designing for and with children with ADHD and their care ecosystem, we conducted a literature review focusing on technologies for children with ADHD, as well as interviews with members of their care ecosystem (ADHD professionals, teachers, parents). In this position paper, we briefly outline our findings from these studies, and sketch out our future plans. Our goal is to support and promote the well-being of children with ADHD and their care ecosystem.

CCS Concepts: • **Human-centered computing** → **Interactive systems and tools; HCI theory, concepts and models; Human computer interaction (HCI).**

Additional Key Words and Phrases: ADHD, co-design, participatory design, literature review, interviews, children, digital well-being

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1 INTRODUCTION

Over the last decades, children have increasingly taken the role of the target users of technologies [2]. This has led to an increased need to understand how to design technologies for and with them. The rise of the Child-Computer Interaction (CCI) research field has contributed to that endeavour [2]. Especially with regards to neurodivergent children, there has been a growing interest by the Human Computer Interaction (HCI) and CCI community in building a systematic understanding of technologies for neurodivergent populations, e.g. evident in literature reviews on neurodiversity within HCI [2, 4, 14]. However, there remain many unanswered questions about how to design inclusive technologies and services for children with mixed abilities.

Children with attention deficit hyperactivity disorder (ADHD) [11] constitute such a population, with ADHD being the most prevalent mental health diagnosis in children [13, 16]. Children with ADHD exhibit symptoms across two broad areas: inattention and hyperactivity/impulsivity [1]. Despite the prevalence of ADHD, little is understood about how the increasing number of technologies developed by HCI researchers for children with ADHD actually support them. Building a comprehensive understanding about how to design technologies for this population is an inherently complex process, due to their increased needs (e.g. assistance and monitoring), and to the number of stakeholders, comprising their care ecosystem, involved in their everyday experiences. From parents, siblings and extended family, to

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peers, teachers, therapists, and the wider ecosystem, i.e. community and society, the care ecosystem of children with ADHD plays a crucial role in their everyday life [5, 8, 12]. It can offer support, motivational and emotional scaffolding [5], and it strongly influences quality of life, social activity, and success in school [8, 12]. Therefore, it is vital to consider these stakeholders when designing technologies for children with ADHD [5]. Forlizzi [6] already argued for a shift from user-centred design to a stakeholder-centred one. In line with that, we strive to build an understanding of how to design inclusive technologies for neurodivergent children, such as children with ADHD, which can benefit and be used in collaboration with the whole spectrum of children's caregivers.

With the aim to design for inclusion of children with ADHD and their care ecosystem, we first conducted a literature review of HCI papers with a focus on children with ADHD [15], examining the identified literature under the lens of the care ecosystem. Then, we conducted interviews with core members of their care ecosystem (ADHD professionals, teachers, parents). Based on our literature review and the interviews, we are currently exploring how we can build inclusive technologies by using approaches that could contribute to children's collaboration and inclusion, while at the same time considering their care ecosystem. Our next steps include interviews with children with ADHD to build an understanding about their everyday life and investigate their experience with technology use. Our plan is to use the acquired knowledge towards designing technologies that successfully support and promote the well-being of children with ADHD and of their care ecosystem.

2 LITERATURE REVIEW OF HCI PAPERS ON CHILDREN WITH ADHD

We performed a systematic literature review of 27 out of 377 initially identified HCI papers focusing on children with ADHD, with the aim to understand how HCI research has supported children with ADHD to-date, and explore how HCI researchers have approached the subject of designing with and for them. Our review positions the child in the centre while considering the role and involvement of the care ecosystem. The role of the care ecosystem has not been addressed by previous work, despite its defining role [5, 8, 12]. Our coding of the full corpus of papers led to findings in the following categories: i) the target user group(s), ii) the involvement of care ecosystem stakeholders in the design, development and user study phases of systems, iii) the methods employed, iv) the context of use of the proposed technologies, v) the papers' contribution, the technology type when applicable, and their objective, and vi) the evaluated measures. One of the main themes we identified was limited involvement of the various care ecosystem stakeholders by current approaches. Additionally, we found a lack in technologies where the target user group spans multiple levels of the care ecosystem, i.e. where the target user group consists of multiple stakeholders. Another interesting finding was the gap between what technologies "promised" to deliver and what measures were actually used and evaluated during the user studies reported in our corpus.

3 INTERVIEWS WITH CARE ECOSYSTEM MEMBERS

Following the literature review, we conducted an interview study with core members of the care ecosystem of children with ADHD (six ADHD professionals, five teachers, three parents). The purpose of this study was to further our understanding of the interconnections between designing technology for children with ADHD and considering their care ecosystem, due to the complexity and multidimensional nature of the subject. We explored requirements, barriers and relationships between the different stakeholders of the care ecosystem. We inquired how the environment is perceived and the role it plays. Additionally, we explored the everyday experiences of children with ADHD and their care ecosystem and engaged with the role of games and play in their lives. We wanted to shed light on how the different stakeholders and the approaches they employ empower or cause disturbances for both the child and the care ecosystem.

Our goal is to use the knowledge acquired from the interviews to map the constraints and opportunities for designing technologies that promote the well-being and empower both children with ADHD and their care ecosystem. Our current findings span in the following areas: i) the roles and relationships of the different actors of the care ecosystem, ii) the effect of the environment, iii) societal embedding, which affects the experiences of both the care ecosystem and the child, e.g. therapy being a "taboo" subject, especially in smaller provinces, and iv) empowering children with ADHD, and specifically ways and obstacles to empowerment. Based on these findings, we draw insights for the design of future technologies. For instance our findings concerning the role of the environment point towards a need for future systems that facilitate a balance between i) making changes to the environment to accommodate the child's needs, and ii) the child learning to adapt to the existing environment. We are currently in the process of conducting additional interviews with more parents of children with ADHD, as well as with children with ADHD themselves, to solidify as well as expand our findings.

4 DESIGNING FOR INCLUSION WITH THE CARE ECOSYSTEM

Based on our findings from the literature review, we discovered that despite the defining role of the care ecosystem [5, 8, 12] and the known importance of involving relevant stakeholders in IDC research (e.g. parents [10]), current approaches entail limited engagement of both children with ADHD and their care ecosystems. Additionally, based on our current findings from the interviews, we identified issues and tensions with respect to communication and collaboration across the various care ecosystem layers. For instance, poor cooperation between parents and therapists can lead to the child having *"a different picture in therapy than they have at home"*, which we found can impede goal achievement and lead to negative experiences and feelings. Therefore, there is a need for technologies that facilitate and foster communication and collaboration, both between children with ADHD and their care ecosystem, and among the care ecosystem members. Furthermore, there is a need for active involvement of both children with ADHD and their care ecosystem in (co-)designing technologies that are intended for use by them. One way towards achieving inclusive design approaches could be to actively employ Participatory Design (PD) when designing for and with this population. Researchers have often employed PD approaches and involved vulnerable, disadvantaged or marginalised groups in the design processes of technologies. Involving neurodiverse children in design, such as children with ADHD, can lead to particular challenges that require adaptations to participatory methods [7]. For example, the amount of required time can increase, as participants might need longer than usual to get to know each other, both with respect to trust establishment as well as (body) language and communication [9]. Nevertheless, the benefits of PD are well-established, and researchers have effectively involved both neurotypical and neurodiverse children towards meaningful design processes [10]. For instance, Benton et al. [3] developed a framework for designing with neurodiverse children, focusing on empowering them by structuring the environment and offering additional support. Involving (more) members of a child's care ecosystem in a PD process could also help with mitigating some of the challenges of actively involving children with ADHD in the design process; for example, including their siblings or best friend could offer additional support.

5 CONCLUSION

In this position paper, we presented our past and on-going work on designing for inclusion in the case of children with ADHD, considering their care ecosystem. To create a deeper understanding about barriers and possibilities when designing for this complex care ecosystem, we first performed a systematic literature review of 27 HCI papers focusing on children with ADHD. Among other relevant findings, we found a shortage in the presence of care ecosystem

members as co-designers as well as end users in current approaches. This undermines their known importance and crucial role [5, 8, 12]. We also outlined our findings from 14 semi-structured interviews with core members of the care ecosystem of children with ADHD (ADHD professionals, teachers, parents). The interviews helped us draw insights concerning the roles and relationships of the various care ecosystem stakeholders, and emphasised the importance of collaboration and communication without barriers across care ecosystem levels. In particular, effective collaboration can lead to positive outcomes, such as feelings of inclusion, satisfaction, and independence, thus fostering empowerment. Our current work focuses on conducting additional interviews with parents as well as with children with ADHD. In this position paper we discussed barriers and possibilities for inclusive design for and with children with ADHD and their care ecosystem. Our overarching goal is to empower and enhance the overall well-being of children with ADHD and their care ecosystem by building more effective and engaging technologies supporting their everyday life.

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REFERENCES

- [1] American Psychiatric Association et al. 2013. *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- [2] Gökçe Elif Baykal, Maarten Van Mechelen, and Eva Eriksson. 2020. Collaborative technologies for children with special needs: A systematic literature review. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–13.
- [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] Peter Börjesson, Wolmet Barendregt, Eva Eriksson, and Olof Torgersson. 2015. Designing technology for and with developmentally diverse children: a systematic literature review. In *Proceedings of the 14th international conference on interaction design and children*. 79–88.
- [5] Franceli L Cibrian, Kimberley D Lakes, Sabrina Schuck, Arya Tavakoulia, Kayla Guzman, and Gillian Hayes. 2019. Balancing caregivers and children interaction to support the development of self-regulation skills using a smartwatch application. In *Adjunct Proceedings of the 2019 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2019 ACM International Symposium on Wearable Computers*. 459–460.
- [6] Jodi Forlizzi. 2018. Moving beyond user-centered design. *interactions* 25, 5 (2018), 22–23.
- [7] Christopher Frauenberger, Kay Kender, Laura Scheepmaker, Katharina Werner, and Katta Spiel. 2020. Designing social play things. In *Proceedings of the 11th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society*. 1–12.
- [8] Alexandra Harborne, Miranda Wolpert, and Linda Clare. 2004. Making sense of ADHD: a battle for understanding? Parents' views of their children being diagnosed with ADHD. *Clinical Child Psychology and Psychiatry* 9, 3 (2004), 327–339.
- [9] Harald Holone and Jo Herstad. 2013. Three tensions in participatory design for inclusion. In *Proceedings of the sigchi conference on human factors in computing systems*. 2903–2906.
- [10] 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>
- [11] World Health Organization. 2018. *ICD-11: International Classification of Diseases 11th Revision*. Retrieved July 4, 2021 from <https://icd.who.int/en>
- [12] Maria João Pimentel, Salomé Vieira-Santos, Vanessa Santos, and Maria Carmo Vale. 2011. Mothers of children with attention deficit/hyperactivity disorder: relationship among parenting stress, parental practices and child behaviour. *ADHD Attention Deficit and Hyperactivity Disorders* 3, 1 (2011), 61–68.
- [13] Perou Ruth, Bitsko H Rebecca, Blumberg J Stephen, Pastor Patricia, Ghandour M Reem, Gfroerer C Joseph, Hedden L Sarra, Crosby E Alex, Visser N Susanna, Schieve A Laura, Parks E Sharyn, Hall E Jeffery, Brody Debra, Simile M Catherine, Thompson W William, Baio Jon, Avenevoli Shelli, Kogan D Michael, Huang N Larke, Centers for Disease Control, and Prevention (CDC). 2013. Mental health surveillance among children—United States, 2005–2011. *MMWR Surveill Summ* 62 Suppl 2: 1–35 (2013).
- [14] Katta Spiel, Christopher Frauenberger, Os Keyes, and Geraldine Fitzpatrick. 2019. Agency of autistic children in technology research—A critical literature review. *ACM Transactions on Computer-Human Interaction (TOCHI)* 26, 6 (2019), 1–40.
- [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 *Proceedings of the 2022 Conference on Interaction Design and Children*. (to appear).
- [16] Nathan D Zasler, Michael F Martelli, and Harvey E Jacobs. 2013. Neurobehavioral disorders. *Handbook of clinical neurology* 110 (2013), 377–388.