

# Children with ADHD and their Care Ecosystem: Designing Beyond Symptoms

Evropi Stefanidi  
University of Bremen  
Bremen, Germany  
evropi@uni-bremen.de

Johannes Schöning  
University of St. Gallen  
St. Gallen, Switzerland  
johannes.schoening@unisg.ch

Yvonne Rogers  
University College London  
London, United Kingdom  
y.rogers@ucl.ac.uk

Jasmin Niess  
University of St. Gallen  
St. Gallen, Switzerland  
University of Oslo  
Oslo, Norway  
jasmin.niess@unisg.ch



**Figure 1:** (Left) Example of the material used in a co-design session taking place in the therapy centre. (Middle) Design of one participant (AC5). (Right) Designs of two participants (AC3 and AC4) including the materials they used.

## ABSTRACT

Designing for children with ADHD has been of increasing interest to the HCI community. However, current approaches do not adequately involve all relevant stakeholders, and primarily focus on addressing symptoms, following a medical model of disability that is extrinsic to neurodivergent interests. To address this, we employed a multi-step, multi-stakeholder approach (N=31). First, we conducted 1) interviews with children with ADHD and their care ecosystem followed by 2) a co-design pilot with one child with ADHD and his therapists and an interview with a UX designer and an occupational therapist. We then employed 3) co-design sessions with neurotypical children and children with ADHD, and 4) a focus group with their therapists. We identified communication and reflection as key concepts for empowering and promoting the well-being of children with ADHD and their care ecosystem. We contribute design implications for future systems aiming to promote the overall well-being of this population.

## CCS CONCEPTS

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

## KEYWORDS

ADHD, neurodiversity, neurodivergent, children, interviews, assistive technologies, co-design, participatory design, reflection, empowerment, well-being

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## 1 INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) [46] is the prevailing mental health diagnosis in children [57, 80]. In particular, approximately 5% of children worldwide are diagnosed with ADHD [50]. ADHD is categorised into three types: predominantly inattentive, hyperactive-impulsive, or combined presentation [2, 30], depending on which of these characteristics is prevalent. ADHD has been associated with academic underachievement, bedtime resistance, disruptive behaviours, poor self-regulation of emotions, and social difficulties, such as issues in interacting with peers [27, 71, 77]. This can lead to negative outcomes for both individuals

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with ADHD as well as their care ecosystems (i.e. actors who play a role in their lives, e.g. parents, teachers, therapists [74]) and society.

Over the years, the HCI community has shown an increasing interest in designing and developing technologies for neurodivergent populations [74], with autism spectrum disorder (ASD) being one of the most frequently addressed conditions (e.g. [6, 26, 32]). In recent years, a newly increased interest in the HCI community can be observed in supporting children with ADHD [74]. Research has demonstrated how technologies can support well-being, for example via fostering empowerment [15, 76, 79] or reflection [65]. The majority of existing approaches focus on empowering children with ADHD and supporting their well-being by addressing specific symptoms, driven by the medical model of disability [72–74]. For instance, HCI researchers have developed interactive technologies that aim to train executive functions [78, 81], or self-regulation of their behaviour and emotions [22, 23, 43], or establishing effective morning and bedtime routines for increased child independence and lowered parental frustration [70].

However, there is a need to also design technologies that are driven by the interests, needs, and desires of neurodivergent individuals [72–74], without only focusing on addressing specific symptoms, but rather "establishing their agency" [72]. For instance, Spiel et al. [72] emphasised the need to acknowledge neurodivergent children's agency in defining technologies that are appropriate for them. Hereinafter, we employ the definition of agency by the Cambridge Dictionary as "the ability to take action or to choose what action to take". Therefore, there is a need for future systems that strive to empower children with ADHD and their care ecosystem without (solely) focusing on addressing ADHD-related symptoms [74]. This is in line with Spiel et al. [73] who argued that current HCI research, in particular regarding games, "fails" neurodivergent populations in that it tends to focus on educational and medical settings. It is thus driven by factors that are extrinsic to neurodivergent interests [73]. At the same time, there is a need to actively involve both children with ADHD and the various care ecosystem stakeholders in the design, development, and evaluation of technologies that are intended for use by them, a practice which has not sufficiently been followed so far [74]. Actively involving the care ecosystem of children with ADHD includes engagement of stakeholders such as family and teachers, but also of ADHD professionals, such as therapists and special educators. All these stakeholders play an active part in the everyday lives of children with ADHD, influencing not only their medical health, but also their overall well-being. Therefore, including them is important to collaboratively explore how to design for well-being and empowerment beyond symptoms. The importance of actively involving the care ecosystem stakeholders has already been emphasised by specific guidelines for design sessions with developmentally diverse children [14]. Therefore, we set out to explore how we can design "beyond symptoms", for the overall well-being of both children with ADHD and their care ecosystem. In this work, we seek to address the following research question:

**(RQ):** How can we design technologies that foster the overall well-being of children with ADHD and their care ecosystem, by actively involving them in the process?

To that end, we adopted a multi-step, multi-stakeholder approach that actively engaged both children with ADHD and the following stakeholder groups of their care ecosystem: parents, therapists, and teachers. We first conducted an interview study with six children with ADHD, six ADHD professionals, five teachers, and four parents of children with ADHD. Our aim was to draw insights from their lived experiences, relationships, and the role of technologies in their lives. Based on the interview findings, we came up with key concepts that technologies aiming to improve the overall well-being of this population should foster. These concepts were iteratively refined and enhanced by the subsequent steps of our approach.

As a next step, we conducted a pilot co-design activity including one boy with ADHD and two of his therapists, followed by an interview with an occupational therapist and a UX designer. This further refined the key concepts we had previously identified, and informed the structure and content of a co-design activity that we conducted with both children with and without an ADHD diagnosis. In particular, we performed co-design sessions with five children with ADHD as well as six neurotypical children, leading to an initial set of design considerations. Finally, a focus group with three therapists of children with ADHD led to enhanced and refined design implications.

This paper derives design implications for technologies that aim to foster the overall well-being of children with ADHD and their care ecosystem. We present our method and findings from each step of our process, informing future research in the domain of (collaborative) reflection for empowering children and their care ecosystem and fostering their well-being. Therefore, this paper contributes the following: i) a multi-step, multi-stakeholder approach for designing beyond symptoms for and with children with ADHD and their care ecosystem, ii) identification of key concepts that technologies could target to foster the well-being of children with ADHD and their care ecosystem through empowering them: communication for collaboration, and free expression and reflection on experiences and emotions, and iii) design implications for technologies that aim to foster the overall well-being of children with ADHD and their care ecosystem, without focusing (only) on diagnosing or addressing symptoms.

## 2 BACKGROUND & RELATED WORK

This section presents relevant background, knowledge, and previous work on technologies designed for children with ADHD and their care ecosystem. We then engage with literature on reflection and empowerment, focusing on works published within HCI, to contextualise our use of the terms within this work as key concepts for well-being. Finally, we present other approaches that have included multiple stakeholders in their methods, demonstrating that previous work in the domain has not actively involved both children, therapists, teachers, and parents throughout their design approaches.

### 2.1 Attention Deficit Hyperactivity Disorder (ADHD)

The HCI community has exhibited increasing interest in research for children with ADHD. Various interactive systems and assistive technologies have been developed in recent years, aiming to assist

either children with ADHD or members of their care ecosystem. For instance, Sonne et al. [68] developed a tangible respiration game for children with ADHD, aiming to help them stay focused during breathing exercises by combining them with a video game. Pina et al. [49] developed a system that monitors the stress of parents of children with ADHD, in order to deliver reminders of behavioural strategies to follow. In particular, it includes both "heat of the moment" strategies, for moments of duress, as well as reflective strategies, which can be practised at any time. Sonne et al. [70] developed a smartphone-based system that aims to support families in establishing healthy morning and bedtime routines, with the goal to assist children with ADHD in becoming independent and lowering the parents' frustration levels.

Apart from designing assistive technologies, the research interest in designing for individuals with ADHD can be observed in various reviews published on the subject. Sonne et al. [69] mapped the design space of assistive technologies for children with ADHD in 2016 and proposed a framework including two dimensions: technology and ADHD symptom, as well as a set of design strategies. They thus pinpointed unexplored opportunities in the domain. In 2020, Cibrian et al. [20]'s book reviewed available technologies for individuals with ADHD, focusing on the technological advancements in the domain and classifying existing technology in seven domains, including diagnosis and assessment, social and emotional skills, and supporting behaviour management and self-regulation among others. Moreover, Cibrian et al. [21] recently reviewed technological interventions that specifically regard the self-regulation of behaviours and emotions of children with ADHD. Their findings included the contexts within which such technologies are deployed (home, school, clinic, lab-based). They highlighted how these interventions can offer a "safe space" for children with ADHD to practice behaviour and receive feedback. In 2021, Stefanidi et al. [74] performed a review of HCI papers focusing on children with ADHD, identifying current trends, opportunities, as well as gaps. Their main findings included a lack of technologies that focus on empowerment and ludic play for children with ADHD, as well as shortcomings with respect to the engagement of both children with ADHD and their care ecosystem throughout the design, development and evaluation phases of current technologies.

As Stefanidi et al. [74] outlined, current approaches mainly focus on addressing ADHD-related symptoms. There is therefore a lack of technologies that focus on improving the overall well-being of children with ADHD without focusing on symptoms or treatment, but rather with the goal of empowering them. Hence, the question arises as to what extent it is necessary to consider aspects that go beyond specific artefacts designed for children with ADHD or their parents. In particular, exploring the lived experiences of children with ADHD and the different stakeholders involved in them could provide a broader perspective on the role technology can play.

## 2.2 Empowerment

Various calls have been made in the HCI community for technology that empowers people [5, 39, 56, 64]. The term empowerment, which has been interwoven with well-being since its introduction in the 1960s and 1970s [17], originally aimed to ensure the well-being of marginalised groups by enabling them to take part

in decision-making processes that affected them [79]. Since then, its meaning has evolved and multiple articulations have emerged, which previous work have tried to clarify by finding an understanding via creating conceptual frameworks to categorise it [35, 60, 76]. Schneider et al. [60] reviewed how empowerment has been used within CHI papers, and derived a framework to analyse notions of empowerment in HCI research. They found that the lines of research on empowerment within HCI can be categorised as follows: i) empowering experiences, ii) skills and education, iii) self-enhancement, iv) holistic approaches, v) empowerment through the design process, vi) technology for development, and vii) protective technology. To illustrate, in the context of empowering children with ADHD, assistive technologies that train executive functioning or attention time on learning tasks could empower them by developing their skills and education. Kinnula et al. [35] focused on children's empowerment, and proposed a framework outlining functional, educational, democratic, mainstream, and critical empowerment. In the context of this work, we adopt the notion of empowerment by providing "empowering experiences", based on the categorisation by Schneider et al. [60]. According to this notion, empowerment refers to users' autonomy or self-esteem. Moreover, our work can also be categorised in the notion of "empowerment through design process", wherein "users are empowered by having their voice heard and being put into the centre of the design process" [60]. Based on this, employing participatory design methods and placing the user in the centre of the design process can lead to empowerment in itself [7]. With respect to the framework discussed by Kinnula et al. [35] et al., our work addresses the following views of empowerment: mainstream, as children take part in design actions initiated by others, democratic, as children's decision power in technology design is increased, and functional, as we aim to contribute to the life conditions of children with ADHD.

## 2.3 Reflection

Reflection has been increasingly associated with well-being [11]; it has important benefits for psychological well-being and personal growth [16, 38] and it has been shown to improve self-awareness and self-esteem [62], concepts that are linked to empowerment. Positive reflection improves mood and ability to enjoy life, helps people maintain relationships, work through past events, and develop self-identity [38]. Even reflecting on negative experiences can have health benefits [48]. Still, a distinction must be made between positive reflection on negative experiences and "rumination", introduced by Niess et al. [45] in the context of fitness-tracking and subsequently discussed by Eikey et al. [25]. Rumination describes the negative thought and emotion cycles that can result from reflective thoughts.

Moreover, research has already demonstrated that technology-mediated reflection can improve well-being [33]. However, there is a lack of conceptual agreement within the HCI field regarding reflection, with a variety of definitions currently in use [11], for instance "reflection-in-action" and "reflection-on-action" by Schön [61] or transformative reflection in the context of social-emotional learning which cannot be simply triggered by data and requires careful scaffolding [65]. Bentvelzen et al. [11] explored constructs associated with reflection and found that the concepts of awareness,

engagement, learning, behaviour change, and empowerment, are related to reflection within HCI literature. Further, they introduced the Technology-Supported Reflection Inventory (TSRI) [10], which is a scale that evaluates how effectively a system supports reflection. In collaborative settings, Marcu et al. [40, 41] explored "collaborative reflection" in the informal processes of documentation and communication in health teams of children with behavioural needs. They suggested that care teams could improve their efficiency and effectiveness by supporting the process of collaborative reflection. Their use of the term reflection refers to interpreting behaviour based on collected data. In the context of this work, we employ Schön [61]'s notion of reflection-on-action and reflection-in-action, as well as the aspects of reflection on past events and reminiscing with the goal of well-being discussed by Isaacs et al. [33]. We also build on Marcu et al. [41]'s work, exploring collaborative reflection in the context of collaborative collection and sharing of data in the form of logging and sharing posts about experiences.

An increasing number of systems designed by HCI researchers aim to support reflection, e.g. for symptom tracking for multiple sclerosis [4], stress management [59], and reflection on everyday experiences [33]. The concept of reflection for children has also been explored within HCI research in varying contexts. Ataguba [3] explored life logs as a form of personal reflection in the context of long-distance parent-child relationships. Torsi et al. [75] engaged 9-11 year-olds in reflection-in-action in the context of promoting their reflection on environmental sustainability by using recycled materials to create computational tools. Chu et al. [19] designed a smartwatch application that allowed elementary school students to record reflections related to specific science topics throughout the course of their everyday lives. However, research on technological artefacts that enable reflection for children remains limited.

Regarding neurodivergent children, the majority of research relating to reflection has addressed symptom-related challenges, and in particular the self-regulation of behaviour or emotions. Self-regulation as a skill involves self-monitoring, goal setting, reflective thinking, decision making, self-evaluation, and management of emotions arising as a result of behaviour change [44, 52]. As such, self-regulation is an important aspect for children with ADHD. Loke et al. [37] identified the lack of digital tools that support learning on how to improve emotional self-regulation, which involves reflection and behaviour change for children with serious emotional behaviour problems. They conducted co-design sessions of a reflective storytelling activity with therapists and developed a framework containing key elements for a reflective experience. Doan et al. [23] developed CoolCraig, a mobile application supporting the co-regulation of behaviours and emotions of children with ADHD. Its interface included a smartwatch for the children and a smartphone application for their caregivers. However, we can observe a lack of technological artefacts that use reflection as a means to improve the overall well-being of children with ADHD and their care ecosystem, without primarily focusing on addressing symptoms. Previously, Spiel et al. [73] had discussed the need for future systems that do not focus on addressing symptoms of neurodivergent populations, such as people with ASD, but rather enable them to feel included, accepted, and promote their independence and self-sufficiency.

## 2.4 Engaging Multiple Stakeholders

HCI research has outlined the importance of considering the "use ecology" in which technologies are used [67], meaning the social and spatial aspects of the environment in which technologies are deployed [67]. Forlizzi [28] argued for a shift from user-centred to stakeholder-centred design, pointing out the need to consider all stakeholders rather than a single user. Particularly with regard to neurodivergent children, guidelines exist that point to the need to actively involve caregivers, teachers and therapists in the design of technologies [14]. Moreover, Benton et al. [9] presented a participatory design framework for involving neurodivergent children in the design process, and highlighted the need to engage both children with ADHD and "the adults that work with them". However, recent research [74] uncovered shortcomings in the engagement of both children with ADHD and their care ecosystem in the design, development, and studies of current technologies.

Below we present examples of approaches within HCI literature that engage at least some care ecosystem stakeholders and/or children with ADHD, highlighting the phases (design and development, user study or evaluation) in which each stakeholder group (children, family, teachers, therapists) was involved. Cibrian et al. [22] engaged children with ADHD, parents, and teachers in the design phase, conducting participatory design workshops with them towards considerations for designing wearable applications supporting the self-regulation of children with ADHD. Loke et al. [37] also followed a multi-stakeholder approach in their co-design of a reflective storytelling activity for children with serious emotional behaviour issues. In particular, they included both therapists, as well as a single child-parent pair in their design process, in which the child was diagnosed with ASD, ADHD, and anxiety. Weisberg et al. [78] followed a user-centred design process for designing an assistive technology with the goal to improve the executive functioning of children with ADHD. They involved educational psychologists and a psychiatrist, as well as six child-parent pairs, conducting interviews with them. For their user study of a paper prototype, they included three child-parent pairs. Sonne et al.'s [70] work on an assistive technology aimed at improving morning and bedtime routines for families of children with ADHD involved parents of children with ADHD and eight ADHD domain professionals in their design process. In their user study, they involved 11 families, including 13 children with ADHD. Richards et al. [53] did not engage with children with ADHD, but with clinicians, educators, and home caregivers of children with behavioural needs in general. They described how the ability to develop a shared understanding of care goals and progress influences care coordination, which in turn affects the ability of the caregivers to support the health and well-being of a child.

The above examples show that even though some approaches have engaged different stakeholders, as Stefanidi et al. [74] highlighted, current works within HCI literature for technologies for ADHD do not sufficiently involve neither children with ADHD nor their care ecosystem stakeholders throughout their approaches. For instance, none of the above examples include both children and their therapists in both the design & development and the user study phases. In our approach, we actively include both children with ADHD and the key care ecosystem stakeholder categories in

a multi-step design process. Moreover, we make not only design decisions, but also methodological decisions based on iterative discussions and feedback from relevant stakeholders. For instance, our co-design activity for eliciting design implications was not only informed by existing literature but was structured based on discussions and feedback from a co-design pilot session with a boy with ADHD, his two therapists, as well as the interview with an occupational therapist and a UX designer. Therefore, we deliver a holistic approach that considers both children with ADHD and their care ecosystem at every step of the process.

### 3 METHOD

In order to answer our RQ of how we can design for the overall well-being of children with ADHD and their care ecosystem by actively involving them, we followed a multi-step process. The following sections describe each step of this process in detail, including: step 1) the interview study with children with ADHD and the key stakeholder groups of their care ecosystem, step 2) the co-design pilot with a child with ADHD and his therapists and the experts interview with a therapist and a UX designer, step 3) the co-design sessions with children with ADHD as well as neurotypical children, and step 4) the focus group with therapists. This multi-step process continuously informed and refined the final design implications, and each step of the process served as a basis for the ones that followed. This process is visualised in Figure 2, including each of the four steps, the participants involved, and the outcomes of the step.

Ethics approval was obtained by the Ethics Committee of the University of St. Gallen (HSG-EC-20220302), and all adult participants provided written informed consent. Children's parents provided written consent for the participation of their children and children were also verbally asked to provide their assent that they wanted to participate before each session. Consent and participant information forms were tailored separately to ADHD therapists, teachers, parents and children (with or without an ADHD diagnosis). Participants were recruited by contacting ADHD professionals and treatment centres and through snowball sampling. The participants took part on a voluntary basis. All children participants received a board game as a token of appreciation for attendance. Information about the participants who took part in the four steps described in this work is presented in Table 1. Hereinafter, we will refer to the participants as follows: to the children with ADHD as AC1-AC6, to the children without an ADHD diagnosis as NC1-NC6, to the therapists (experts) as E1-E9, to the teachers as T1-T5, and to the parents as P1-P4. It should be noted that E7 is the therapist of AC1, AC3, AC4, and AC5, E8 of AC2, and E9 of AC6. Also, P4 is the parent of AC1, and AC3 and AC4 are siblings. The following sections describe our multi-step process in detail (Figure 2).

### 4 STEP 1: INTERVIEW STUDY

Given the inherent complexity of designing for this population, the need arises for a deeper understanding of their lived experiences. Therefore, in order to explore how to design for their overall well-being, we conducted semi-structured interviews with children with ADHD and key stakeholder groups of their care ecosystem. We strove to explore relationships, roles, challenges between the

different stakeholders of the care ecosystem, what they enjoy, their environment, and technologies.

#### 4.1 Participants

We recruited  $N = 21$  interview participants. In particular, we interviewed six children with ADHD aged 7-10 ( $M = 9$ ,  $SD = 1.4$ ), and fifteen adults aged 29-62 ( $M = 38$ ,  $SD = 9.8$ ), consisting of six ADHD professionals (three occupational therapists, one psychologist, one psychotherapist, and one speech pathologist), five teachers of children with ADHD, and four parents of children with ADHD. More information about the interview participants is visible on Table 1 (see participants marked in column Step 1). Since many participants were involved in multiple steps of our approach, in each of the following sections we only briefly mention the participants who took part and refer to this Table 1, where it is visible who participated in each step.

#### 4.2 Interview Protocol & Analysis

For the adult participants, the semi-structured interviews were conducted via video conferencing software, and lasted between 31 minutes and 1 hour and 5 minutes each (11 hours and 49 minutes total time of recordings,  $M = 49$  minutes,  $SD = 10.7$  minutes). For the children participants, the interviews were conducted in person, at the therapy centre where they attended sessions with their therapists. Each child interview lasted between 7 and 15 minutes (54 minutes total time of recordings,  $M = 8$  minutes,  $SD = 3$  minutes). At each session, the attending therapist was present, along with the researcher conducting the interview. While the interviews with adult participants provided us with rich information regarding relationships, challenges, and the role of the environment and technologies, the interviews with children participants, albeit significantly shorter, served as additional insights. In particular, they verified certain aspects that were already brought up in the adult interviews, e.g. about activities they enjoyed as well as those they did not. For both adults and children, at the beginning of each interview, the interviewer welcomed the participants, and informed them about the structure of the interview and the context of the study. Participants had the opportunity to ask any questions they had and were provided with consent forms to sign. In the case of children participants, both the legal guardian and the child were informed of the process and had to give their written consent and verbal assent respectively. For all participants, the interviewer collected demographic data and then proceeded with some introductory questions, followed by questions on participants' daily routines and challenges, the role of the environment on children's behaviour, the role of their care ecosystem, playful activities and what they enjoy, and their experience with technologies. These questions were used as prompts rather than as solid questions to be asked in a specific order or manner. Furthermore, as this is a sensitive topic, we had taken precautions to phrase our questions openly to ensure that participants can guide the conversation in a direction that is comfortable for them. All interviews were audio recorded for later transcription and analysis, with the consent of the participants.

All 21 interviews were transcribed verbatim, 16 of them were translated from Greek to English. Two researchers analysed the



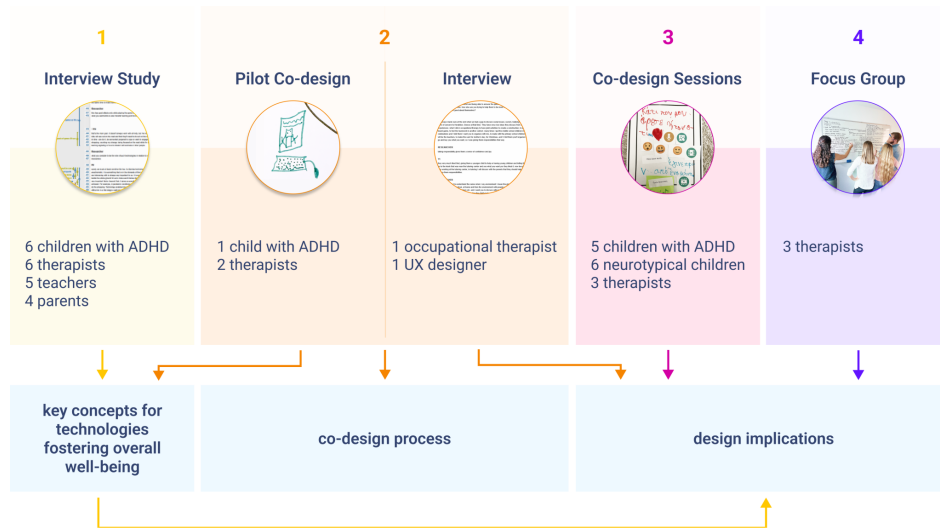


Figure 2: Overview of the process we followed, structured in four steps, and the resulting outcomes of each step.

interviews by performing open coding in an iterative process, using the MaxQDA software. After an initial round of open-coding, two authors applied thematic analysis by using affinity diagramming in line with Blandford et al. [12] to uncover emerging themes. We identified three themes from the data: *Care Ecosystem and Environment*, *Balancing Perceptions of Technology*, and *Paths and Obstacles to Empowerment*.

### 4.3 Interview Findings

In this section, we present the three themes we constructed based on the analysis of the interviews with children with ADHD and their care ecosystem: *Care Ecosystem and Environment*, *Balancing Perceptions of Technology*, and *Paths and Obstacles to Empowerment*. We provide a detailed description of the themes and illustrate them with excerpts of the interview data.

**Care Ecosystem and Environment:** The interviews allowed us to build an understanding of the roles and interconnections between the different members of the care ecosystem of children with ADHD. We place the child in the middle, and "paint" the surrounding layers of the care ecosystem and how the connections between them relate to their and the child's well-being. Our interviews demonstrated the important role that each layer plays in defining the child's experience, and additionally how the environment in which the child finds itself in can have a direct influence on its behaviour. "It is of infinite importance how [the actors of the care ecosystem] actually interact and what relationships exist within that environment" (E2). Our interviews also demonstrated a strong relationship between the environment and the behaviour of a child with ADHD, showing how the first affected the second. In particular, the environment plays a crucial role "in terms of semantics", for instance "what the school environment means for a child, what their home means" (E1), and also because of "the different stimuli that the child receives in different environments" (E2). The analysis of the interviews also showed that the roles of the care ecosystem members can span multiple layers. For instance, parents often take

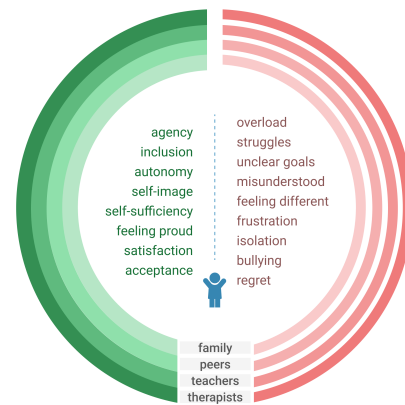


Figure 3: A visualisation of our findings regarding the layers of the care ecosystem of children with ADHD. The left part of the figure demonstrates the positive outcomes when the care ecosystem layers come together, communicate and efficiently collaborate, which can lead to empowerment. On the other hand, the right part of the figure shows the negative outcomes of poor communication and unclear goals. Gaps in communication, translating to barriers in collaboration, are visualised by the white gaps between the ecosystem layers on the right part. For instance, communication without barriers (visualised by the connected green stripes on the left semicircle) between the family and the therapists can lead to clear goals and shared understanding between them, which in turn can help the child feel proud when completing the goals and accepted by both the family and the therapists. On the other hand, the reverse situation (red separated stripes showing the gaps in communication) can lead to overload, unclear goals, and frustration for the child.

**Table 1: Demographics of participants (total N = 31) and the steps where they were involved. Step 1: Interview study. Step 2: Co-design pilot and interview. Step 3: Co-design sessions. Step 4: Focus group. AC1-AC6: children with ADHD, NC1-NC6: neurotypical children, E1-E9: therapists (experts), T1-T5: teachers, P1-P4: parents.**

Participant	Step 1	Step 2	Step 3	Step 4	Description	Gender	Age	Country of residence
E1	■				occupational therapist	male	36	Greece
E2	■				occupational therapist	female	31	Greece
E3	■	■			occupational therapist	female	57	Greece
E4	■				psychologist	male	38	UK
E5	■				psychotherapist	female	56	UK
E6	■				speech pathologist	male	38	Greece
E7		■	■	■	child & family psychologist	female	26	Greece
E8			■	■	psychologist	female	28	Greece
E9		■	■	■	psychotherapist	male	33	Greece
T1	■				special educator	female	37	Greece
T2	■				special educator	female	30	Greece
T3	■				special educator	female	47	Germany
T4	■				special educator	male	34	UK
T5	■				private tutor	female	29	Greece
P1	■				mother of boy with ADHD-HI and boy with ADHD-I	female	41	Greece
P2	■				mother of girl with ADHD-I	female	44	Greece
P3	■				mother of boy with ADHD-C	female	62	The Netherlands
P4	■				mother of boy with ADHD-C	female	40	Greece
U1		■			UX designer	female	43	Greece
AC1	■	■			ADHD-C, no medication	male	7	Greece
AC2	■		■		ADHD-C and Asperger, no medication	male	8	Greece
AC3	■		■		ADHD-C and HFA, no medication	female	10	Greece
AC4	■		■		ADHD-C and HFA, no medication	male	7	Greece
AC5	■		■		ADHD-I, no medication	female	10	Greece
AC6	■		■		ADHD-C, medication	male	10	Greece
NC1			■		neurotypical child	female	10	Greece
NC2			■		neurotypical child	male	13	Greece
NC3			■		neurotypical child	female	10	Greece
NC4			■		neurotypical child	male	11	Greece
NC5			■		neurotypical child	male	7	Greece
NC6			■		neurotypical child	female	8	Greece

on multiple roles, including those of the teacher or "therapist". This often resulted in parents having limited time to engage in playful interactions with their children, which some children recognised; for instance *"Mum doesn't want to play something with me, [she] doesn't have time"* (AC2). Instead, we observed mothers taking on the role of a "private tutor", actively assisting children with tasks such as homework or getting them to calm down in stressful situations, acting as a support system in different contexts. However, the support system of families can be wider than the parents, including

siblings and grandparents, who need to have a *"shared vision and deal with things the same way (P1)."*

Our analysis particularly highlighted the importance of communication for effective collaboration between the different layers of the ecosystem, and how it can have a crucial effect on their and the child's well-being and everyday experiences: *"When there's a good partnership of family, child and therapist, miracles happen there"* (T1). We found that aligned goals across all contexts are crucial, not only for goal achievement, but also as a way to avoid negative

experiences and feelings. This is evident by the side effects of poor cooperation between parents and therapists, which result in the child exhibiting "a complete different behaviour in therapy than they have at home" (E2). The following participant quote describes this aspect:

*"The child is sort of like, do you know pinball machines, so that child is ricocheting around basically, in different environments. And it gets a different experience every time it lands from one side to another. So home, school, extracurricular activities, that child doesn't get a joined up, equal experience of how they're treated. So everywhere they go, they're treated differently. And so it's like this constant need to be understood and being misunderstood, being missed, basically" (E5).*

This is in line with previous work that emphasised the need for creating a shared understanding in care coordination for children with "behavioural needs" [53]. Our findings shed light on which implications this has for children with ADHD and their care ecosystem, and extends previous knowledge by outlining the multi-faceted roles of caregivers and the role of the environment within the picture.

**Balancing Perceptions of Technology:** Another theme that we identified focuses on the different perceptions of technology. In particular, caregivers regarded technology as a means of potentially "addictive" entertainment for children, e.g. in the form of social media or video games, or as a successful and useful intervention media; a "very big ally" (E2). Positive perceptions regarding technology included evident improvement in ADHD-related symptoms and enhanced motivation by the child to participate. "I saw that the attention span was much better, but also there was motivation to try even harder than other methods" (E1). "There was a very big difference in [the child's] concentration and his hyperactivity [after the neurofeedback treatment]" (P1). This disagreement amongst parents, children, and research on the extent to which children should engage with technology has been established in general [13, 51] and with respect to neurodivergent children, e.g. with ASD [36]. For example, some parents think their children's technology use is positive since it supports child development [24, 54], while others suggest it has negative implications for their physical activity [54]. Building on this, our interviews also uncovered a different dimension of these mixed perceptions for children with ADHD: the possibility that games utilised in the context of therapy could lose their appeal on children. In particular, despite the importance and usefulness of using technologies in interventions to address ADHD-related symptoms, analysis of the interviews demonstrated that children often felt like activities and games played in therapy, even digital ones, became "more like a chore at one point" (P1). This further underlines the need for technologies that on the one hand do not fall into the "addictive video game" category, but on the other support children's well-being without solely focusing on addressing symptoms or solely being used within the context of therapy. This is tied to the third theme we identified, that focuses on empowerment.

**Paths and Obstacles to Empowerment:** The term empowerment was often mentioned in the interviews, especially by the therapists and educators. Our interviews highlighted the importance of empowerment and showed ways that it manifests in the case of children with ADHD. We identified manifestations of empowerment

in the interviews in the following forms: i) having fun, receiving satisfaction and feeling happy, ii) self-image (self-confidence, self-esteem), iii) self-sufficiency, agency, autonomy, independence, iv) feeling safe, accepted, included, and v) feeling proud. The interviews helped us identify both paths and obstacles to empowerment, visualised in Figure 3, which connects this aspect to the other two identified themes. In particular, efficient communication among the various care ecosystem layers and with the child leading to collaboration and shared, clear goals, can be a path to empowerment (left side of Figure 3), including positive outcomes such as satisfaction, inclusion and increased self-esteem. For instance, "setting common goals together [...] helps [both children and the parents] have a better picture and a satisfaction in seeing that they achieve them" (T2). On the other hand, gaps and issues in communication create collaboration barriers and constitute obstacles to empowerment. Therefore, Figure 3 provides an overview of possible ways to empowerment and of obstacles to empowerment and their negative outcomes, thus helping to better conceptualise the term within the context of this population. Participants described multiple situations of negative experiences and feelings connected to undesirable outcomes. These negative experiences are often coupled with a "stream of interventions", so that the child "always feels as being in emergency mode", and often "gets tired of the overloaded schedule" (T4). This focus on interventions and symptoms, following the medical model of disability, is discussed in Spiel et al.'s work [73], who argue that current HCI work is driven by factors extrinsic to neurodivergent interests. Nevertheless, technologies have great potential to empower children with ADHD, as "it is something that they like, it gives them satisfaction and builds the whole ground for us to make each child feel good in each intervention. That alone makes it a very important factor. Beyond that, it gives us possibilities that in other circumstances could not be achieved" (T2).

Having identified these themes, it becomes clear that a **key concept for fostering the overall well-being of children with ADHD and their care ecosystem is to empower them by facilitating and supporting efficient communication and collaboration among them.**

## 5 STEP 2: CO-DESIGN PILOT & EXPERT INTERVIEWS

The next step in our method was employing co-design, with the ultimate aim to foster the children's agency and allow them to draw a technology that they would like to have in their lives. Co-design refers to proactively involving non-designers in the design process, in this case including end-users and stakeholders affected by the design [42]. Before conducting a series of co-design sessions, and in line with our vision of involving children with ADHD and their care ecosystem in every step of the process, we wanted to explore how the co-design sessions should look like. We therefore conducted a co-design pilot with a seven-year-old boy and his two therapists at the therapy centre. We drew from previous work that employed co-design processes with children of similar ages, such as drawing and using collages similar to Aarts et al. [1]. Many of the children we interviewed had also stated that "drawing is [their] favourite activity" (AC5). We decided to employ storytelling as a means of expression, since research shows it is an appropriate design method



for children [66]. This was followed by a semi-structured group interview involving an occupational therapist and a UX designer. This process refined the content and structure of the co-design activity and resulted in further design implications. Participants AC1, E7 and E9 took part in the pilot co-design session, and E3 and U1 participated in the group interview (see participants marked in column Step 2 in Table 1).

## 5.1 Process & Analysis

After following the same process regarding greeting and consent forms described in Step 1 (see section 4), the researcher engaged in a short, casual conversation with AC1, so as to re-establish rapport, and help the child feel more comfortable. The researcher and the child then engaged in a short discussion about the child's likes and dislikes, and the child was asked to "draw the story" about the activities he did the previous day and illustrate them on a DIN A2 piece of paper. He could draw, paint, and collage various paper snippets, including cartoon-like sketches of different activities, objects, and smileys. This session was subsequently discussed in a semi-structured group interview with E3 and U1. The two-hour interview took place online via video conferencing software, where findings of the interview study and the pilot co-design were discussed. Both the pilot co-design session and the interview were audio recorded with the participants' consent, were transcribed verbatim, and translated from Greek to English for analysis. Two authors analysed the interviews by performing open coding, using the MaxQDA software. The findings from Step 2 are presented below.

## 5.2 Findings

Here, we describe the main implications that resulted from the pilot co-design session with AC1, followed by the interview with E3 and U1. They span two dimensions: i) implications that regard the content and structure of the co-design activity, and ii) general design implications for technologies that foster well-being.

Firstly, AC1 enjoyed the activity, and particularly explaining and illustrating his daily activities as a story. He described what he liked and did not like in his day, and used appropriate smileys "to make [his] story whole" (AC1). The importance of giving children the means to express themselves in this way was highlighted by E3:

*"Every child does things in their everyday lives that gives them meaning. It is important for a child to be able to define what has meaning for them, to reflect, to declare it, to keep it."*

E3 proceeded to link the act of reflecting with empowering children to express themselves in this way via technology, emphasising how "[a technology for] enabling a child to depict their thoughts while reflecting on an event would be "wow"" (E3). **Therefore, we identified reflection as a possible vehicle towards empowerment in this context.** However, "the way children are asked to describe their "story" of events that happened matters. If you ask a child why they did not sleep well the previous night, and they try to justify it with other actions or events of the day, that could be forcing them to make connections, and is not necessarily leading to reflection" (E3). Therefore, to explore how reflection could be used as a means to

well-being, we decided to integrate it within the co-design activity. The activity was designed to include stages from Gibb's [29] reflective cycle, and in particular to guide the child to answer the questions: what happened, when it occurred, who was there, what was the outcome, and to additionally describe their feelings about it. Specifically regarding feelings, E3 suggested that "the co-design activity should be less activity-driven and more feeling-driven. For instance, instead of asking the children to describe what activities they did recently, they could be asked to tell the story about something that recently happened which they enjoyed. They can then elaborate on it, and articulate the exact feelings they had about it, for instance happiness or surprise." Further insights for the content of the co-design activity from U1 included that it should allow children to "draw" the technological artefact on a "paper-based tablet". This would "allow them to quickly get into the concept that it's a technology and make them excited given the appeal of playing on a tablet for children" (U1). Finally, both U1 and E3 suggested that the co-design be conducted with both children with and without an ADHD diagnosis, as this would "solidify the findings".

Based on the findings of our interview study (Step 1 - section 4), and the pilot co-design and interview with experts (Step 2 - section 5), we formulated a co-design activity, to conduct with both children with and without an ADHD diagnosis. The key concepts for technologies fostering the overall well-being of children with ADHD and their care ecosystem were also refined to include the aspect of expressing experiences and feelings and reflecting upon them as a vehicle towards empowerment and well-being.

## 6 STEP 3: CO-DESIGN SESSIONS

The formulated co-design activity was conducted with five children with ADHD as well as six children without an ADHD diagnosis, following the suggestion of U1 and E3 to additionally recruit neurotypical children. Including neurotypical children in the design process was also in line with our vision to include as many stakeholder groups of the care ecosystem of a child with ADHD as possible, which can include neurotypical children. Our goal was to explore how children would envision and interact with a technology that allows them to tell a story about a recent past event and their perceived emotions about it (reflection aspect) and share it with other members of the care ecosystem (communication aspect). Before conducting the first co-design session, we consulted with therapists E7-E9. We presented the final structure of the co-design activity to them for any additional feedback. Having the detailed description of the co-design activity at hand, the therapists made an informed selection of children they were treating who they deemed appropriate to contact for participating in the study. Originally, eight families were contacted, of which five responded positively and participated in the co-design sessions.

In particular, children AC2-AC6 participated in the co-design sessions, along with E7-E9, who were present during the co-design activity. It should be noted that AC3 and AC4 who are siblings participated in the co-design session together, each making their own "design". Moreover, the co-design activity was carried out with six neurotypical children, NC1-NC6. The neurotypical children participants were recruited using the extended network of the authors and snowball sampling strategy. More information is presented in

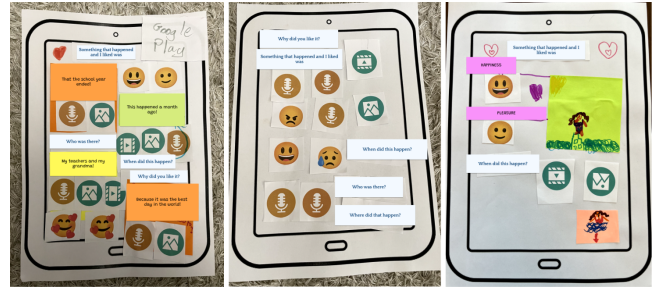
Table 1 (see participants marked in column Step 3). The co-design activity with AC2-AC6 took place at the therapy centre, while the sessions with NC1-NC6 were conducted at a location that was convenient to the participants, either their own homes or the house of a contact person of the authors.

## 6.1 Process & Analysis

The same process regarding welcoming participants and consent forms described in Step 1 (see section 4) was followed, after which the researcher engaged in a short, casual conversation with each child to re-establish rapport and help the child feel more comfortable. The researcher explained once again the process they would follow, and that *"they needed the help of the child to design a cool technology for them"* that the child itself could make it *"in any way they wanted"*. The researcher and the child then engaged in a short discussion about what the child enjoys doing. Following this, the researcher instructed the child to imagine an application where they could input what they like and what they do not like about things or events that have happened. This would allow them to be able to "keep" all those things and be able to look at them later. The researcher then asked the children if they would like to help with making this application and drawing what it would look like.

The children were provided with a variety of materials in order to equip the application with "something that recently happened and they liked". The materials that children had at their disposal for the activity was the following (see Figure 1): paper "tablets", different coloured crayons, pens, pencils and markers, post-it notes, and glue. They were also provided with paper icons which they could glue upon their designs. The icons represented various type of media: videos, images, and recordings, as well as smileys portraying different feelings: happiness, sadness, surprise, anger, disgust and love. The smileys were pre-selected based on a discussion with E7, E8 and E9 about which feelings should be included in the activity. Finally, participants were also provided with paper snippets baring the following prompts: "Something that happened and I liked was", "When did this happen", "Who was there", "Where did this happen", "Why did you like it". All children could read the prompts by themselves, without external help from the researcher or their therapist. We used these scaffolding questions to facilitate storytelling as suggested by Loke et al. [37].

Participants made designs using the materials described above, in which they told a story about "something that happened that they liked", explained their feelings about it, and answered the reflective questions described above. At each stage, children could use any of the available icons described above. During the sessions, the researcher was not taking any notes but was fully present and engaging with the children [37]. After the design activity, children were asked questions to infer their opinions and experience. In particular, they were asked if they would use this application, what kind of things they would like to input in such an application, if they would share those things with others, if they would change or add something, and what they liked and disliked about the application. The sessions were audio recorded with the participants' consent, transcribed non-verbatim, and translated from Greek to English for analysis. Two researchers analysed the interviews by performing



**Figure 4: Example designs from the co-design sessions (with handwritten texts translated from Greek to English). From left to right: AC3, AC2, NC6. Variations in the use of text, recordings, images, and videos can be observed, additionally including drawings to depict the events children were describing.**

open coding, using the MaxQDA software. The findings from Step 3 are presented below.

## 6.2 Co-design Session Findings

Here, we summarise our findings from the co-design sessions. As an example of the children's designs, Figure 4 shows the designs of AC3, AC2, and NC6 (translations in English of the children's handwritten text superimposed). The supplementary material includes all eleven designs of children participants crafted in this step.

Overall, the process and the technology concept appealed to all participants, and they were very engaged with it. For instance, the majority of the children, both with and without an ADHD diagnosis, got so immersed in the application concept, that they would pretend to tap on the recording button once they glued it on the paper tablet, and say out loud what they would like the application to record. This is also reflected in the comment of one of the therapists, who voiced positive surprise about the behaviour of a usually particularly active child who participated in the co-design activities without any issues: *"I think I have never seen you so calm and focused!" (E9 to AC6)*. For AC2-AC6, the previously conducted interviews with the same researcher present seemed to have acted as a warm up activity, making them feel more comfortable and potentially acting as a scaffold to the co-design activity, as they had already discussed with the researcher activities they enjoy doing.

Both groups of children (with and without an ADHD diagnosis) liked the idea of being able to log and *"keep the things that happened"* (NC1). They would *"use the app to see what [they] did and liked, in order to do it again"* (NC1, NC3). Regarding when they would use such a technology, they *"would use it when [they] had something important to log. [They] would have [their] memories in it so that [they] could go back to it afterwards"* (NC3). Others said they would use it *"at least a couple of times a week"*, when something important happens (NC1, NC4, AC3, AC4, AC6), while others *"sometimes"* (NC3, AC5). All participants also said that they would not need any specific incentive to use it, but would like to use it anyway.

*"I would not have it as a game. I would have it as a means, I would use it to be able to express myself more freely." (AC6)*

This further underlined the value that the children found in a technology that would allow them to express what they liked and be able to reflect upon it. With respect to the way that they could "tell their story", all children found the guiding questions helpful, as "it helps [them] keep the basic important content" (NC1). They also enjoyed the ability to be able to express themselves with multiple media types (text, recording, image, video), with each child using a variety of the media they preferred. AC5 and NC6 additionally drew pictures about the experience they were describing. All children stated they would like to share the "posts" they would make in such an application, e.g. with their parents, teachers or therapists. In more detail, AC2 mentioned he would like to share his post with his mother, AC3 to her friends, cousins, and "actually all the people [I] know!", AC5 "to [her] teacher, to [her] mum, to [her] dad, and to [name of E7]" and AC6 to everyone, but "mostly [his] friends". AC4 however specified he would "only want to show it to [his] sister". From the six neurotypical children, NC1, NC2, and NC3 specified they would share their posts with friends, parents, and teachers. On the other hand, NC4 would prefer to share his posts with his cousins, friends, and siblings, but "maybe not with teachers". Participants did not mention specific types of posts they would or would not want to share, rather focusing on the types of posts they would like to create in general, as described above.

Participants particularly liked the ability to "add the feelings that belonged to the experience with the icons" (NC6). We observed that the only feeling that was not used from the available icons was disgust, while AC6 said he would have liked to be able to add the feeling of pride, which was currently missing. Another finding regarding the feelings that children expressed can be observed in the design of AC2 (see Figure 4). In particular, he associated both positive and negative feelings with a positive experience (playing a video game), namely happiness, anger and sadness.

Another interesting finding regarded the nature of things that children would like to log in such a technology. In more detail, when asked whether they would like to input the things that happened and they liked, those they did not like, or both, eight out of eleven children responded that they would only like to log the positive experiences. The explanations for that included that they "don't want to remember the negative things" (AC3, AC4), because that would make them "sad" (NC1) or "upset and angry" (NC4), or because they "simply don't want to" (AC2). The exceptions were NC2, who would "like to be able to also log the negative experiences to look at them afterwards and maybe improve them in the future", AC5, who would "like to log both the positive and negative experiences, but be able to see only the positive afterwards", and AC6, who said that he'd "like to log if [he] had a fight with [his] friends, to also be able to input the next day that they made up and played together". Finally, it should be noted that we found no notable differences to report between the co-design with children with ADHD and neurotypical children who participated in the co-design. This applied both to the process of the co-design, as well as the findings we derived from the co-design sessions.

The findings from the eleven co-design sessions further underlined the importance of free expression and reflection as vehicles to well-being, additionally linking them to aspects of empowerment such as satisfaction and agency, since the activity appealed to all children and they enjoyed "being able to freely express themselves".

## 7 STEP 4: FOCUS GROUP

As a next step, in order to get valuable input from the children's therapists and inform them of the progress, as well as further refine the design implications, we conducted a focus group with three psychologists specialising in children and family therapy. The session, which lasted two hours, took place at the therapy centre. Participants for the focus group were E7, E8, and E9, namely the therapists of AC1-AC6 (see participants marked in column Step 4 in Table 1).

### 7.1 Process & Analysis

The focus group took place in person at the therapy centre where E7-E9 work. The participants engaged in a conversation with the researcher concerning the findings of the co-design sessions. The focus group was audio recorded with the participants' consent, transcribed verbatim, and translated from Greek to English for analysis. Two authors analysed the transcripts by performing open coding, using the MaxQDA software. After an initial round of open coding, two authors applied thematic analysis by using affinity diagramming. We identified two emerging themes from the data: *Communication for Collaboration* and *Enabling Expression and Reflection*. These themes correspond to the perceived benefits of such a technology. The findings from Step 4 are presented below.

### 7.2 Focus Group Findings

Here, we discuss the main findings from the focus group conducted with E7-E9. Based on our analysis, we identified two themes: *Communication for Collaboration* and *Enabling Expression and Reflection*.

**Communication for Collaboration:** Overall, the therapists were excited about the idea of a technology that would allow children to log their experiences, reflecting upon them and noting their feelings. In particular, "this kind of externalisation and visualisation is important, as it can significantly decrease the noise in the communication" (E9). It also enables both therapists and other care ecosystem members to "assess and evaluate the child's feelings easier" (E7, E8). The idea of such an application additionally providing similar functionality for the adult members of the care ecosystem was also discussed. Having access to such "posts" from children but also from other members of the care ecosystem, e.g. their parents or teachers, would enable therapists to "complete the picture, to have a more holistic view" (E9) from the various care ecosystem layers. The therapists were particularly excited about the possible benefits of such an application on their communication and collaboration with other care ecosystem members, as it would "allow for coordination and getting insights you would not otherwise have" (E7). "This coordination could lead to common standards and goals" (E9).

**Enabling Expression and Reflection:** The second identified theme regards how such an application would enable free expression and could foster reflection. When asked about their opinion on showing children positive past events and discussing their feelings about them, all three therapists agreed on the usefulness of such a feedback, associating it with free expression, satisfaction, and the possibility for reflection:

*"Children can see and review their development and can be reminded that they are having fun in life. The app itself is a tool, "I have something where I can express myself". Even in its simplest form this is useful.*

*Some children don't even enter the process of expressing themselves, just being able to do so is evolutionary" (E9).*

This echoes the answer of AC6 about the use of such a technology to *freely express* himself. Other benefits of expressing oneself in this way were emphasised by E8:

*"Such an application can be used as a means of expression, as a soothing and relieving medium, for instance instead of having a stress ball, the child could channel their energy into the application and also get feedback from the app. Sometimes we forget what makes us happy if we don't pay attention to it at that moment" (E8).*

However, the therapists noted that although reflecting on negative experiences could be beneficial, this should only be considered after a discussion with a particular child's therapist, or for older children. The ability to "share posts" of these expressions made in such an application among the care ecosystem stakeholders and the child could also *"help children with empathising by seeing others' posts" (E7)*. Additionally, it *"would also be helpful for emotion regulation and for achieving feelings of togetherness" (E8)*. The two concepts of empathy and emotion regulation were highlighted as particularly important possible outcomes of such technologies by the therapists. Empathy refers to *"the ability to share someone else's feelings or experiences by imagining what it would be like to be in that person's situation"* (Cambridge Dictionary). Emotion regulation refers to *"attempts to influence which emotions one has, when one has them, and how one experiences or expresses these emotions"* [31], and it is common for individuals with ADHD to struggle with controlling their emotional responses, or even struggle due to emotion dysregulation [8, 63]. The therapists particularly underlined that the above are not simple tasks and that children with ADHD can face challenges in that respect.

The two identified themes (*Communication for Collaboration* and *Enabling Expression and Reflection*) reflect the key concepts we had identified in Step 1 and Step 2. Step 4 additionally demonstrated how the terms "empathy" and "emotion regulation" relate to these concepts and are possible and desired outcomes.

## 8 DISCUSSION

Designing technologies for children with ADHD and their care ecosystem is complex given the vulnerability of the population and the interrelations that exist within the care ecosystem. In order to explore how to design for this population's overall well-being, without a primary focus on addressing ADHD-related symptoms, and thus answer our RQ, we employed a multi-step approach, consisting of four steps, actively involving both children with ADHD and key stakeholder groups of their care ecosystem. Based on our findings, we identified key concepts that future technologies should consider in order to foster their overall well-being: empowerment through facilitating i) communication and collaboration, and ii) free expression and reflection on experiences and emotions. Notably, our analysis did not show any particular differences between neurotypical children participants and children with ADHD in that context, neither in the co-design sessions process nor in our findings. Perhaps this was due to the fact that, in the case of participants with ADHD, their therapists were present for the duration of the co-design process, providing them with support and nudging them to continue

even when they got a bit distracted or "off-task". This potentially mitigated challenges that could have arose, coupled with the fact that all children enjoyed the activity, even children with ADHD who according to their therapists usually had a more active behaviour and sometimes struggled with staying focused. The above further supports that involving stakeholders of the care ecosystem in participatory design activities could help mitigate challenges associated with the participation of children with ADHD [74], by offering additional support [9].

In the following sections, we reflect on our findings and envision how they can inspire the design of future systems that empower children with ADHD and their care ecosystems, aiming to promote their well-being.

### 8.1 Recording, Sharing, and (Collaboratively) Reflecting on Data & Emotions

Our work showed that a technological artefact allowing both children and members of their care ecosystem to log posts *-recording aspect-*, share them among each other *-sharing aspect-*, and reflect upon their experiences and emotions *-(collaborative) reflection aspect-* could empower them and would be beneficial for their well-being. This reflection process can happen both on an individual level, i.e. when the child (or adult) records and reviews their logged data and emotions, as well as on a collaborative level.

We identify two distinct ways in which technologies could offer collaborative reflection support in this context. One, technologies could prompt and scaffold further communication of users with other care ecosystem members regarding a specific logged experience, allowing one user to share their own perspective and feelings about the data of another, thus collaboratively reflecting on the logged data and emotions while using the technology. An example of this would be a parent viewing the logged data of their child about a recent experience and logging their own emotions regarding the specific post as well as adding a conversation-triggering comment within the application. Two, such technologies could foster collaborative reflection that takes place outside of the technology use scenario, by sparking further discussions to take place in person, based on the new information or perspectives acquired while using the technology. For example, the therapist could observe specific emotions that a child expresses regarding an activity and prompt the child to engage in a discussion about it during their sessions, encouraging the child to reflect on the experience and associated emotion (i.e. collaborative reflection).

A technological artefact facilitating collaborative reflection could support children's agency, which is directly in line with the manifestations of empowerment for this population (Step 1 of our approach). In particular, such technologies could enable children to have their voice heard, as they are expressing themselves and their emotions. Children's agency is also supported by allowing them to choose whether and which posts they share and with which members of their care ecosystem. We found that such an artefact would be desired by both the caregivers and, importantly, the children themselves, relating to the aspect of satisfaction that we identified as another possible path to empowerment for children with ADHD.

Below, we discuss how the aspects of recording, sharing, and (collaboratively) reflecting on data and emotions relate to and are

supported by previous work. In particular, our findings regarding the usefulness of these capabilities echo those of Marcu et al. [41], in that electronic collection of patient-related information could increase its availability, meaningfulness, granularity and reliability during reflection [41]. To elaborate, a technological artefact following the principles derived from our studies, would i) make data available for stakeholders in real-time across contexts, ii) provide stakeholders with useful data as well as information on emotions, while *"decreasing noise in the communication"* (E9), iii) increase granularity of data that would be relevant to caregivers, e.g. via the posts themselves, as well as statistics the technology could provide based on the logged data, and iv) increase reliability, as information about the same event could be collected from more than one source, e.g. both child and teacher. Saario et al. [58] also noted how collaborating stakeholders in the health-care sector, do not usually have access to the systems being used for data collection, limiting their ability to develop a shared understanding. We recommend addressing this issue by including both children and their care ecosystem as target users, and giving them access to the system (both for viewing and for recording data). Furthermore, a technology that employs the concepts we identified based on our analysis would be in line with the recommendation by Marcu et al. [41] that data collection tools could be designed to facilitate reflection of children themselves, in addition to their various caregivers. This is also in line with the implications derived from Stefanidi et al.'s literature review of technologies for children with ADHD [74], who called for future systems where the target user group includes both children and various care ecosystem stakeholders.

Moreover, our findings extend previous knowledge on technology-mediated reflection, and particularly on aspects of previous models that encompass reflection. In particular, the concept of (collaborative) reflection on data and emotions that we constructed based on our findings considers both children and their caregivers in contrast to related work [37, 40]. Marcu et al.'s [40] "collaborative reflection process" and the "safety, connection and reflection" framework by Loke et al. [37] both document reflection processes in therapy and intervention-related contexts. The first regards the decisions that treatment teams have to make for children with behavioural needs and targets interventions. In more detail, Marcu et al.'s [40] model consists of a short-term inner loop and a long-term outer loop, and describes how treatment teams reflect on data and corroborate interpretations of the data with others. While this model focuses only on patient-related data, aiming to improve the efficiency and effectiveness of treatment teams, Loke et al. [37] emphasised that caregivers must also be aware of their own emotions to scaffold the reflective experience of children [37]. Their framework illustrates how therapists can scaffold reflective experiences in the case of children with trauma, with the goal of social emotional learning, based on their needs: safety, relatedness, empathy, and social resilience. Our work adds to HCI researchers' and designers' understanding of how the collaborative reflection process can look like when designing "beyond symptoms" for children with ADHD and their care ecosystem. We explore how children themselves can engage in reflection along with other members of their care ecosystem, who are actively taking part in the reflection process, including both professional and informal caregivers. Our findings contribute to the understanding of how reflecting on experiences and emotions can

lead to empowerment in the context of fostering children's overall well-being, without a specific focus on therapy or social emotional learning.

At the same time, our findings indicate that providing users with the ability to share their posts, could not only support reflection [18], but also actively help with communication and crossing the barriers that impede achieving a shared understanding. To illustrate, Richards et al. [53] identified the following barriers to the development of shared understanding in care teams of children with behavioural needs: differences in approaches and motivations, inability to rely on documentation, and information loss during transfer across the care team. They also proposed a framework for mitigating these barriers, in which sharing descriptive information (contextual or holistic knowledge) is a key mechanism. Based on the concepts we derived from our studies, we could enable both children and their care ecosystem to share their experiences across different contexts, facilitating the sharing of descriptive information. Traditionally, this requires intentional effort and one-on-one and group communication, as well as moving across contexts for observation and learning [53]. By rendering information available "on-demand" through a technology that allows viewing this information and collaboratively reflecting on it, the aforementioned effort and movement can be significantly reduced. This in turn would facilitate a more seamless integration of perspectives on experiences and emotions. We thus argue that technologies that follow the principles derived from our multi-step, multi-stakeholder approach can help mitigate these barriers. Moreover, our findings showed that communication across barriers, which can lead to shared understanding and uniform goals, constitutes a path to empowerment. On the other hand, communication barriers connect to negative consequences for children, creating obstacles to empowerment, as visualised in Figure 3.

**Therefore, we extend previous work by proposing that enabling both children with ADHD and their care ecosystem to record and reflect on their experiences and emotions, and share these among them can be a way towards crossing communication barriers, serving as a vehicle towards their empowerment and overall well-being.**

## 8.2 Empowering Children with ADHD and their Care Ecosystem via Non-Complex, Multi-Context Technologies

Our findings demonstrated the potential of technologies that "break" the barriers in communication and collaboration, and facilitate free expression and reflection on events and emotions for empowerment. One notable aspect, which is particularly evident from Step 3 and Step 4, is the possible simplicity of such a technology. In particular, for the implementation of a technological artefact following the principles and design implications that our approach identified, even simple mobile or tablet-based solutions, without specialised equipment, hardware, or technical expertise from users could work. This is further motivated by the evident excitement for such a technological artefact by both children and therapists in our study.

**Therefore, designing technologies that are relatively simple, such as mobile applications, could be a way to address**

**the current literature gap that notes a "great divide" in translation from design to adoption of technological artefacts designed for children with ADHD and their care ecosystem [20], thus supporting their empowerment.** This is not to say that employing more complex approaches, e.g. AI, or sophisticated hardware, could not present fruitful ways forward. Rather, we point out the possibility of empowering this population towards enhancing their overall well-being utilising technologies that they are already familiar with and are easy to adopt in real life. This also connects to the interview findings regarding the mixed perceptions of technology. In particular, a system enabling logging, sharing, and reflecting on experiences and emotions could be a simple yet fun way to motivate children to use it without perceiving it as therapy or a "chore", which caregivers would also approve and use. At the same time, it could be perceived as a collaborative technology, with which children and their care ecosystem interact together.

Another aspect to consider is the use of technologies by children with ADHD and their care ecosystem, depending on the context. In particular, given the important role that the environment plays for children with ADHD, it could be important to consider the interplay between human and technology mediation within the care ecosystem. In more detail, some contexts could provide ample scope for different types of technological artefacts to facilitate communication and reflection, while in other contexts it might be best for interactions between the child and the care ecosystem to take place without the use of technology. **Future work should further explore this aspect by investigating the contexts in which technology-mediated approaches should be used, and how to design different kinds of technology mediations that fit together; some to be used in the moment by the child as interactive expressive tools, others as aggregate tools to be looked at later with their caregivers, while others as explicit shared tools to be used with other children.** This echoes the findings of Kawas et al. [34] who reviewed the values that informed the work of authors in the Interaction Design & Children community that seek to empower children and foster their agency. In particular, they identified the need to reflect on the role of technologies in addressing children's needs, and to build awareness of technology serving to augment children's experiences and not replace them. Exploring the use of a reflection tool such as the one derived from our multi-step approach, which can be used in different contexts and by different stakeholder groups, could be a step in that direction.

### 8.3 Designing Beyond Symptoms as a Potential "Best of Both Worlds" Scenario

In this work, we started with the aspiration to design "beyond symptoms", for the overall well-being of children with ADHD and their care ecosystem. This was based on previous work outlining the need for future systems that would do that, by designing for empowerment instead of specific symptoms, thus establishing children's agency [72] and self-determination, which is related to concepts such as competence and autonomy [73]. For instance, Stefanidi et al. [74] proposed designing for empowerment of children with ADHD could be achieved by e.g. designing for ludic play. Interestingly, our findings showed that, while "designing beyond symptoms", our approach could lead to positive outcomes

for children with ADHD such as emotion regulation, which is a symptom-related aspect and a goal that intervention-driven technologies might have (e.g. [22]). Therefore, our findings demonstrate how "designing beyond symptoms" has the potential to not only lead to different forms of empowerment through technology, e.g. delivering empowering experiences that are driven by neurodivergent interests, but also to support children with ADHD with symptom management. This presents a new argument for future research to make the design decision of not (only) targeting specific symptoms when seeking to empower children with ADHD through technology. **Therefore, we extend previous knowledge on "designing beyond symptoms" and inform future research by both presenting a new argument towards the importance and need for such a design approach, and by demonstrating how it can be beneficial. In particular, we argue that designing beyond symptoms can potentially deliver a "best of both worlds" approach, both catering to neurodivergent interests and supporting ADHD-related challenges.**

### 8.4 Limitations

We recognise that our work is subject to certain limitations. In particular, we originally planned to involve both more parent participants, as well as more children with ADHD in our interviews. Acquiring access to vulnerable populations, such as children with ADHD and their families is challenging, and requires particular considerations to not place an additional burden on them. Additionally, recruiting participants in parts of the world where COVID-19 related restrictions were still on-going within the past year made the process even more challenging. Pecor et al. [47] already found that caregivers of children with ADHD and/or autism were disproportionately affected by the pandemic. However, research has demonstrated not only how important it is to involve neurodivergent populations in the design of technologies, but also how one might approach the topic and the benefits it can procure [9, 55, 74]. We also wanted to include parents of children with ADHD in the co-design process, as well as their friends, but we only involved their therapists due to time constraints and to not place an additional burden on them. Nevertheless, including their therapists in the co-design sessions already seemed to provide children participants with ADHD with enough additional support [9] during the co-design activity. Future work includes conducting co-design sessions with both parents and peers of children with ADHD. Throughout our approach, we were still able to involve an overall considerable number of participants (N=31). The interviews and co-design sessions we conducted were very rich in content, allowing us to derive key concepts and design implications for technologies that aim to foster the overall well-being of children with ADHD and their care ecosystem. Finally, it is worth noting that therapy is not always a comfortable scenario, and the presence of therapists during the co-design sessions could have impacted how children engaged with the activity. Future work should investigate how children with ADHD use technologies that realise the concepts we constructed based on our findings in multiple settings and contexts. This could help in exploring the use of such systems to address the issue identified in the interviews that therapy activities and games might eventually feel like a chore. In any case, the importance of the context of use



of technologies for children with ADHD is evident from the crucial role the environment plays on their behaviour [2], underlined by the fact that a list of symptoms must impair daily functioning in *two or more settings* to merit an ADHD diagnosis [2].

## 9 CONCLUSION

In this paper, we conducted a multi-step, multi-stakeholder approach (N=31). We identified design implications for technologies fostering the overall well-being of children with ADHD and their care ecosystem while "designing beyond symptoms". Our work revealed how empowerment via facilitating communication and collaboration, and free expression and reflection are key aspects for technologies that aim to foster the overall well-being of children with ADHD and their care ecosystems. In particular, our findings show how technologies allowing collaborative reflection on experiences and emotions can help with overcoming communication barriers and achieving collaboration. Our findings also indicate that designing rather simple technologies can lead to empowering experiences that could mitigate use and adoption issues. Such technologies can be used by multiple stakeholders and in different contexts, and allow recording, sharing, and both individually and collaboratively reflecting on experiences and emotions. Finally, we showed that designing beyond symptoms can potentially both cater to the interests and desires of neurodivergent children, while also supporting them with symptom-related challenges. We hope that our research inspires further work in the domain of designing beyond symptoms for children with ADHD and their care ecosystems that is driven by neurodivergent interests and seeks to empower them.

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